Rehabilitation for chronic neurological disorders including acquired brain injury

Consultation on draft guideline - Stakeholder comments table
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NHS England	Committee Member List	002 - 005	002 - 005	The office of the Chief Allied Health Professions Office note that's a wide range of professionals who provide rehabilitation for chronic neurological disorders including traumatic brain injury are part of the committee list. However, in page 5, it is acknowledged that the committee recognises that it may need further expertise from special educational needs advisors and vocational rehabilitation advisors. Has their input been received?	Thank you for your comment. The committee agreed that no further committee appointments or expert input was required. The committee were mindful that the NICE guideline "Disabled children and young people up to 25 with severe complex needs" already covered much of what would be relevant with regards integrated service delivery with schools and so recommended practitioners should also follow recommendations in this guideline. There were a number of people on the committee who were very familiar with and involved in vocational rehabilitation.
NHS England	Committee Member List	General	General	Looking at pathways for this cohort from a system perspective, adult social care plays an important role at different points of the journey. The committee membership does not seem to have someone from Adult social care. While Dr. Mark Holloway is a Social worker, his expertise is in case management and expert witness.	Thank you for your comment. Whilst the guideline acknowledges the interaction between NHS funded and local authority funded social care in supporting effective rehabilitation the guideline was primarily from a health, mainly primary and community health care perspective. It was focusing on rehabilitation interventions for people with chronic, usually life-long neurological disorders rather than long term social care interventions. The committee felt that existing committee members had enough expertise to consider this overlap and reflect it in the recommendations.
Anglia Ruskin University	Committee Member List	General	General	The list of committee members did not include any music therapists or other arts therapists. We are concerned that this lack of representation on the committee may have introduced bias reducing the committee's ability to consider music therapy as a rehabilitation intervention for meeting the functional goals and emotional and psychological needs of this population.	Thank you for your comment. The constituency of the committee was agreed by a NICE senior team ensuring it adequately represented the range of expertise needed to deliver the agreed scope of the guideline which set out explicitly the key areas and key questions for the guideline to cover. Given the size and scope of the population and size and scope of the interventions explored, music therapy was not explicitly written into the scope but creative therapies (including art therapy) was included in the protocol for the question about emotional health and wellbeing and some evidence was indeed found about music therapy for this review. Neither the committee nor the NICE team ever felt the committee lacked the ability to make decisions about creative therapies, based on their understanding of the evidence available and their own knowledge and experience of working with or alongside these interventions.
MS Society	EHIA	003	N/A	Section 1.3.6 highlights important considerations around access to specialist neurorehabilitation, especially for people in rural areas or those with rare conditions. The suggestion to improve collaboration within and between integrated care systems to enable access and share expertise is welcome. This echoes findings from the Cheshire and Mersey neurorehabilitation review, which also emphasises the value of linking specialist services closely with community rehabilitation.	Thank you for your comment and for supporting the recommendation to strengthen collaboration within and between integrated care systems. The committee acknowledged service gaps as a key challenge and developed the recommendations aimed at mitigating them. However, as this specific topic was outside the scope of the guideline, no evidence was reviewed in relation to it.

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				However, there remains a broader question about how well the full scale of service gaps is understood across the country. We know from our work with people affected by neurological conditions that many face challenges accessing timely, appropriate rehabilitation. Yet, the evidence base in this area often remains limited by small sample sizes and less robust study designs. This partly reflects a wider issue in neurorehabilitation research, where funding constraints make it difficult to deliver the kind of rigorous trials that the medical model typically requires to demonstrate treatment effectiveness.	
The Neurological Alliance	EHIA	003	N/A	We welcome the acknowledgement that people affected by neurological conditions may face barriers in travelling to appropriate rehabilitation, particularly given the significant unwarranted variation in spread of specialist expertise across the country. 21% of England adult respondents to My Neuro Survey disagreed that they have access to reliable transportation or assistance to attend appointments.	Thank you for your comment, for sharing additional data, and for supporting the committee's recommendations.
MS Society	EHIA	004	N/A	The document notes that "The committee also discussed that chronic neurological conditions often require ongoing treatments, therapies, and medications, which can be costly." This is an understandable concern, but there are examples that demonstrate the value of investing in certain specialist treatments. Regarding costly equipment and technology, the existing evidence pack on functional electrical stimulation (FES) for foot drop shows how investment in specialist equipment can lead to meaningful improvements in patient outcomes and quality of life. (https://www.mssociety.org.uk/sites/default/files/2022-05/FES%20Evidence%20Pack%20V3.pdf) The Purchasing and Supply Agency found FES to be cost-effective, with an incremental cost-effectiveness ratio (ICER) of £19,238 per quality adjusted life year (QALY) gained. Since then, several other cost-effectiveness studies have supported these findings using different data and methods, reporting ICERs between £6,137 and £15,406 per QALY. Even though FES has been NICE approved for over 13 years, many people with MS still struggle to access it. Treatment clinics offering FES are limited and often not geographically accessible. Funding for FES is fragmented across the UK, and most healthcare professionals are unclear on how to refer patients for FES elsewhere.	Thank you for your comment. The EHIA outlines how individuals from lower socioeconomic backgrounds may face financial challenges that could hinder timely access to essential services, potentially affecting equality and health outcomes.

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MS Society	EHIA	008	N/A	Section 7 highlights the importance of collaboration between specialist and non-specialist rehabilitation services to meet the needs of people with chronic neurological conditions from diverse ethnic backgrounds. Data in Liverpool reveals significant disparities in fibromyalgia diagnosis rates across ethnic groups. For example, only about 37 per cent of the expected cases among the Asian population (509 recorded out of 1,388 estimated) are documented in GP records. Among Black populations, around 50 per cent of expected cases are recorded (424 out of 848). For those of Mixed/multiple ethnicity, approximately 48 per cent of expected cases are recorded (408 out of 844), and for the 'Any other' ethnic group, just under 50 per cent (395 out of 801). These figures suggest substantial barriers in diagnosis and access to specialist rehabilitation services for ethnic minority groups. The findings support the committee's recommendation that rehabilitation services need to adapt and build culturally competent local workforces to ensure equitable access and better meet the needs of diverse communities.	Thank you for your comment, for sharing additional data, and for supporting the committee's recommendations.
MS Society	EHIA	008	N/A	As referenced in section 1.3.2, the establishment of separate local service level agreements for mental health support tailored to adults, and to children and young people with chronic neurological disorders, is essential. However, in practice, many areas have yet to implement such agreements, resulting in inconsistent access to appropriate mental health services. A positive example is seen in the Cheshire and Mersey region, where neurological conditions have recently been added to the list of long-term conditions that Talking Therapies services are required to support. This development highlights the importance of explicitly including neurological conditions within mental health service frameworks. To ensure equitable provision across all areas, it would be beneficial for the protocol to require all Talking Therapies services to formally incorporate neurological conditions into their service remit. Doing so would support a more consistent and accessible offer of mental health care for people with chronic neurological disorders, aligning with the intentions set out in section 1.3.2.	Thank you for your comment. This recommendation (1.3.2) aims to strengthen local service agreements to enhance workforce skills and communication between neurorehabilitation specialists and mental health practitioners. As evidence on Talking Therapies services formally including neurological conditions in their remit was not reviewed, the recommendation cannot be amended.
Chiltern Music Therapy	EHIA	010	N/A	We suggest acknowledging the role of music therapy in addressing health inequalities. Music therapy can be particularly beneficial for	Thank you for your comment. We have included how the role of music therapy can reduce health inequalities in the EHIA document.

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				individuals with communication difficulties or cognitive impairments, offering an accessible and engaging form of rehabilitation. References: Tamplin et al. (2014), Bradt & Dileo (2014).	
Inflammatory Neuropathies UK	EHIA	011	N/A	Section 10 is focussed on multiple needs, but seems to only highlight TBI. All people with multiple needs, or in specific groups (i.e. homeless or at risk of homelessness, or prisoners) may be diagnosed with a neurological condition and a s a result may need longer term rehabilitation. We need to ensure that these subgroups of people have equal access (or at least access) to the assessments and interventions as outlined in the guideline. We are not sure that this section of the Equality and Health Inequalities Assessment highlights this sufficiently and as a result, this is not met within the guideline itself.	Thank you for your comment. Section 10 of the document addresses subgroups with notably high rates of traumatic brain injury. While the committee acknowledged that these subgroups may have multiple needs, the section was not intended to focus exclusively on this aspect.
Inflammatory Neuropathies UK	EHIA	10	N/A	Section 9 is focused on digital literacy, and while it does highlight socioeconomic issues, we feel that the focus is on the fact that people cannot use systems, rather than being able to access them. A focus on digital inclusion may have been better that looks at all issues (including digital literacy) but also highlights to a greater excess the availability of data and devices, and the issues faced accessing digital resources for many people. Looking at issues in this way would lead to the need for actions around seeking appropriate support to access digitally, which could be linked to the community sector or social care personal budgets (for instance).	Thank you for your comment. We have added a bit more information to the EHIA to better explain what digital inclusion means, covering both digital literacy and access to technology.
Anglia Ruskin University	EHIA	General	N/A	There is no central database that captures accurately the numbers of children and adults with chronic neurological disorders and categorises them according to disorders and needs. Having this information would then allow Local Authorities and professional bodies to address health inequalities across the UK.	Thank you for your comment. Establishing a database to track the number of individuals with chronic neurological disorders was beyond the scope of this guideline, and as a result, we were unable to create this database.
Brain Injury Social Work Group	EHIA	General	N/A	• Equality and health inequalities assessment I am just wondering why there is no mention of Mental Capacity Assessments in this document. **1. Geography: access to in-patient, out-patient and community rehabilitation** 1.8.8 *environmental and wider social factors that might encourage or prevent them from taking part in rehabilitation (for example, access to community resources and, equipment for rehabilitation and housing) EHIA TEMPLATE V8.0 4 1.16.5 Discuss any barriers preventing the person from achieving their physical activity goals and work together to*	Thank you for your comment. The EHIA documents the potential impact on equality and health inequalities. which have been considered throughout

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				overcome these. Barriers could relate to: • availability of suitable facilities to undertake physical activity. 1.25.7 Consider online options for social activities if in-person activities are scarce, for example, in rural areas, or travel is challenging Is there considering for the person has mental capacity and who would carry out mental capacity assessments if needed? https://www.scie.org.uk/mca/practice/assessing-capacity/ 2. Have due consideration been given to instances where there might be executive dysfunction or where there is lack of insight due to the brain injury? George, M.S., & Gilbert, S. (2018). *Mental Capacity Act (2005) Assessments: Why Everyone Needs to Know about the Frontal Lobe Paradox*. The Neuropsychologist 5, 59-66 https://www.researchgate.net/publication/324899681_Mental_Capacity_Act_2005_assessments_why_everyone_needs_to_know_about_the_frontal_lobe_paradox 3. Would triangulation be beneficial – where someone, a carer, family member, professional might support with this? 4. The role of the social worker – the only mention of 'social worker' is the section of 'Looked after children' there is no mention of social worker in relation to adults. The nearest professionals named are 'Key workers and 'Complex Case Managers'. The title 'social worker' is a legally protected title, a social worker may be a key worker but a key worker might not necessarily be a social worker. 1.11.5 *Consider assigning a key worker if the person has: • impaired cognitive or executive function that impacts on their ability to selfmanage their condition or navigate rehabilitation services • an unpredictable or rapidly changing neurological condition* Would that key worker be able/trained to carry out mental capacity assessments? *1.13.2 Explain what financial support is available to assist with rehabilitation…* *1.22.8 Give the person advice and support to access, or to access funding for equipment, assistive technology …* The presupposition is that the person might the ability to understand and retain the information. There should be provision for supporting people to have an understanding of the information being relayed and their meaning for the messages being conveyed.	the guidance development according to the principles of the NICE equality policy and those outlined in Developing NICE guidelines: the manual. 1. At the start of each section, the guideline cross-refers to the NICE guideline on decision-making and mental capacity (NG108), which covers assessment of mental capacity and how to conduct the assessment. Thank you for the reference (https://www.scie.org.uk/mca/practice/assessing-capacity/), which we have checked against our review protocols and is not eligible for inclusion. 2. The guideline document highlights the importance of factoring in impaired cognition or executive function, specifically in recommendations 1.11.5, 1.11.6, 1.15.1, 1.18.3, and 1.18.11. Thank you for the reference (George, M.S., & Gilbert, S. (2018). Mental Capacity Act (2005) Assessments: Why Everyone Needs to Know about the Frontal Lobe Paradox. The Neuropsychologist 5, 59-66 https://www.researchgate.net/publication/324899681_Mental_Capacity_Act_2005_assessments_why_everyone_needs_to_know_about_the_frontal_lobe_paradox), which we have checked against our review protocols and is not eligible for inclusion. 3. The committee developed numerous recommendations to foster collaboration among healthcare and social care professionals, families, carers, and others engaged in supporting individuals with chronic neurological disorders. 4. The guideline document includes references to social workers where relevant. The glossary provides additional details on the committee's intended message regarding social workers. Additionally, NICE's guideline on social work with adults experiencing complex needs (NG216) is cross-referenced. The committee defined the term key worker in the glossary, and the guideline cross-refers to the NICE guideline on decision-making and mental

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				3. Access to services: people with pre-existing physical and/or mental health and behavioural conditions, communication impairment, physical and learning disabilities, or frailty *1.8.10 Encourage the person to talk freely about how their life has been impacted by their neurological condition.* Again, the presupposition that the person may have the ability to communicate verbally, what about people with speech impairments? Teater (2014) finds, that less verbal service users may find it difficult to articulate or express other factors that may contribute to their impairment. **4. Approaches to engagement with rehabilitation that are sensitive to cultural differences** It might be beneficial to speak to other family members not just the person. Family transcends geographical boundaries but includes circles of influence such as the church, mosque or community groups. It would have been beneficial to consider these in relation to children too. **7. Race and ethnicity: access to specialist rehabilitation services** There is no indication or evidence that this was written in relation to race and ethnicity. Terms used were ' many people with chronic neurological disorders in the community' , 'specialist and generalists' services to work together to build more expert capacity within the local area workforce', *1.3.2 'mental health services for adults, and for children and young people, with a chronic neurological disorder',* *1.3.3 'build capacity for mental health services for people with a chronic neurological disorder'* *1.3.4 'rehabilitation needs because of an existing chronic neurological disorder, and know when and how to refer people to rehabilitation specialists'* *1.3.6 'in some areas or for some people (including for people living in rural areas or with rare conditions)'* **9. 9. Delivery of interventions: remotely, via video or tele link (digital literacy)** *1.13.3 Advise people (and advocate for them as necessary) that their local authority has a statutory requirement, under the Care Act 2014 and Children and Families Act 2014, to assess their care and support needs, when requested.* And Section 117 (Mental Health Act 1983) Aftercare rights where there has been an admission under the Mental Health Act 1983?	capacity (NG108), which covers assessment of mental capacity and how to conduct the assessment. The committee formulated recommendations with speech, language, and communication needs in mind, specifically addressing complex communication needs in recommendation 1.8.1. 5. The committee developed recommendations to involve family members and other people involved in care, with specific recommendations for children. The guideline did not specifically seek evidence on interventions aimed at improving access to specialist services for certain groups. However, all recommendations were drafted to ensure equitable access to high-quality neurorehabilitation care.

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Success – Life After Cure Ltd	Evidence Review A	024	017	A 1.5 Telehealth/remote delivery; we would like to add our small pilot study of 6 children with brain tumours or cancer receiving 3 weeks tailored digital therapy was well received and showed improvement in at least 2 of 3 goal-based outcomes in 2019. However, there were concerns with engagement of socially disadvantaged groups. Our charity is now launching a wider evaluation roll-out of the updated digital platform to children under 19y with brain tumours from August 2025	Thank you for your comment. Unfortunately, without publication in a peer-reviewed journal, we are unable to include your pilot study in our evidence review. However, it is reassuring to hear that your conclusions support the inclusion of digitally delivered therapy. We agree that there are areas of concern surrounding engagement of socially disadvantaged groups when delivering healthcare remotely (for example, technological poverty), which has been highlighted in our EHIA document. The committee were conscious of mitigating these barriers when drafting their recommendations. If possible, we recommend that you aim to publish the results of your wider roll-out trial. Future updates of this guideline may then be able to consider your valuable research contributions.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review A	032	001 - 006	Consider sustainability impacts on settings where rehabilitation is delivered now to future proof service provision.	Thank you for your comment. The text that you have highlighted in your comment is regarding the committee's discussion and interpretation of the evidence and needs to stay as an accurate record of committee conversation. Therefore, no change has been made here. However, the guideline does contain sections on commissioning rehabilitation services, building capacity within services, and providing responsive services, which we hope speaks to your concerns about sustainability.
Brain Injury Social Work Group	Evidence Review A	032	General	I have comments for Page 32: **Hospital discharge** - which highlighted the need for equipment and adaptations to be addressed timely to prevent delay discharges. However there is no mention of housing as a key challenge for delay transfer of care. People often have to face lengthy stay in inpatient rehab/hospital due to housing delays. There is mention of housing adaptations within the whole document but for some cohort of patients, this does not meet their needs and they need a completely different set up i.e. wheelchair accessible property. I wonder if there is limited study in this area as its a huge issue in inpatient rehabilitation settings which means others that need rehab are having to wait a longer time before they can be brought in. This could be a potential area for further research. Also Page 32: **Single point of contact**- Really good acknowledgement for the need of this as there is often no continuity of care for some patients. It a postcode lottery for some, some areas have great Neuronavigator who stay involved from their hospital admission and follows them up on discharge. And some local authorities have adopted a system of a dedicated Neuro-social worker who is involved within the inpatient setting and remains involved post discharge at least 6 weeks- In an ideal world if this model is adopted by all L.A's it would be a positive way forward to ensure continuity of care.	Thank you for your comment. The section of evidence review A that you have highlighted (Committee's discussion of the evidence) is meant to be an account of the committee's interpretation of the evidence and how this informed any resulting recommendation. Housing as a barrier to discharge was not a theme that was identified in the evidence, so it was not discussed by the guideline committee. Therefore, no change has been made. It would also be difficult for us to issue a research recommendation in this area as we have to stick closely to the parameters that were used to search for evidence. Evidence review A is a qualitative review, and the themes reported in the review cannot be stipulated up front; the review is led by the data. However, housing is included as a consideration within the holistic needs assessment that might impact participation in rehabilitation. There is also mention of ensuring people have access to information on housing advice within the section on information, advice and learning as part of rehabilitation. We hope that these 2 recommendations help to address your concerns over the impact of the availability of suitable housing for people with chronic neurological disorders. Thank you for your support for the single point of contact section, as well as holistic assessment, early intervention, and tailoring of services to individual needs.

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				The need for holistic assessments, early intervention and tailoring services to individual needs was well evidenced by the studies and acknowledged by the committee.	
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review A	033	047 - 050	Consider including the term "Poverty Proofing" services to make accessible to all as this does have an impact on engagement of individuals and continuation of engagement.	Thank you for your comment. We agree that this is important but have not included it as a term in this section as it was not explicitly identified in the qualitative review. However, the guideline makes many recommendations to improve service accessibility and promote engagement, including a single point of contact, delivery of rehabilitation in settings appropriate to the person's goals and preferences (home, school, work, community, or remotely), and simple referral and re-referral processes (including self-referral).
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review A	036	016 - 018	Consider adding about challenges with recruitment.	Thank you for your suggestion. We clarified in the discussion that services currently face recruitment challenges.
Chiltern Music Therapy	Evidence review A	045	012	The current evidence review lacks consideration of music-based interventions, particularly Neurologic Music Therapy® (NMT™) which has shown positive outcomes in neurorehabilitation. Including studies on NMT™ could provide a more comprehensive understanding of effective rehabilitation strategies. Patient feedback from services have demonstrated that the inclusion of Neurologic Music Therapy® alongside standard care has increased motivation, helped achieve functional goals across multiple domains, supported early discharge from services, and supported an overall improvement in their quality of life. For example, patient discharge questionnaires from the pilot phase of an NMT™ project run by Chiltern Music Therapy at the Regional Neuro Rehab Unit at Homerton Hospital for 2 days/week for 12-months in 2021-2022 evidenced that all patients agreed or strongly agreed that NMT™ had helped to reduce stress/anxiety, increase their engagement with rehab, as well as improve speech, cognitive skills and physical function. Another example is from Chroma's 3-day/week 3-year NMT™ service on an in-patient neurorehabilitation unit at Charing Cross Hospital. Standard rehab care plus NMT™ created a "casual relationship" of patients being discharged 5.5 days prior to their original discharge date. This resulted in a cost saving of an approximate average of £10k per patient.	Thank you for your comment. This evidence review was designed to identify qualitative research on what works well and what can be improved in the delivery of rehabilitation. No specific area of rehabilitation was excluded in the search strategy, and several citations including music in the title were identified by our database searches. Unfortunately, they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made. For completeness, please see below for reasons why your suggested papers would not be considered for this review. - Magee (2017) - excluded on population (systematic review with 25/29 papers only including adults with stroke [out of protocol] and 4/29 including people with mixed aetiologies). - Gong (2024) - excluded on population (systematic review with all papers including adults with stroke [out of protocol]). - Siponkoski (2020) - excluded on study design (quantitative data only presented). - Siponkoski (2021) - excluded on study design (quantitative data only presented, included in review H). - Siponkoski (2020) - same citation as above. - Thaut (2025) - excluded on format (book). - Thaut (2009) - excluded on study date (pre-2010).

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				The Cochrane Review for Music Interventions in Acquired Brain Injury highlighted that provision provided by Music Therapists increased efficacy of treatment and that music interventions positively impacted on functional goals (Magee et al 2017). **The following literature also demonstrates how music supports neuroplasticity and recovery for those in neurorehabilitation:** Gong, D. and Ye, F. (2024). Effects of Music Therapy on Aphasia and Cognition of Patients with Post-stroke: A Systematic Review and Meta-analysis. Noise and Health, 26(121), pp.136–141. doi:https://doi.org/10.4103/nah.nah_24_24. Siponkoski, S.-T., Martínez-Molina, N., Kuusela, L., Laitinen, S., Holma, M., Ahlfors, M., Jordan-Kilkki, P., Ala-Kauhaluoma, K., Melkas, S., Pekkola, J., Rodriguez-Fornells, A., Laine, M., Ylinen, A., Rantanen, P., Koskinen, S., Lipsanen, J. and Särkämö, T. (2020). Music Therapy Enhances Executive Functions and Prefrontal Structural Neuroplasticity after Traumatic Brain Injury: Evidence from a Randomized Controlled Trial. Journal of Neurotrauma, 37(4), pp.618–634. doi:https://doi.org/10.1089/neu.2019.6413. Siponkoski, S.-T., Koskinen, S., Laitinen, S., Holma, M., Ahlfors, M., Jordan-Kilkki, P., Ala-Kauhaluoma, K., Martínez-Molina, N., Melkas, S., Laine, M., Ylinen, A., Zasler, N., Rantanen, P., Lipsanen, J. and Särkämö, T. (2021). Effects of neurological music therapy on behavioural and emotional recovery after traumatic brain injury: A randomized controlled cross-over trial. Neuropsychological Rehabilitation, 32(7), pp.1–33. doi:https://doi.org/10.1080/09602011.2021.1890138. Siponkoski, S.-T., Martinez-Molina, N., Kuusela, L., Laitinen, Sari, Holma, Milla, Ahlfors, Mirja, Jordan-Kilkki, Päivi, Ala-Kauhaluoma, Katja, Melkas, Susanna, Pekkola, Johanna, Rodriguez-Fornells, Antoni, Laine, Matti, Ylinen, Aarne, Rantanen, Pekka, Koskinen, Sanna, Lipsanen, Jari, & Särkämö, T. (2020). Music therapy enhances executive functions and prefrontal structural neuroplasticity after traumatic brain injury: Evidence from a randomized controlled trial. Journal of Neurotrauma, 37(4), 618–634. https://doi.org/10.1089/neu.2019.6413 Thaut, M. and Volker Hoemberg (2025). Handbook of neurologic music therapy, second edition. New York, Ny: Oxford University Press.	- Thaut (2005) - excluded on study date (pre-2010). - Twyford (2024) - excluded on study design (scoping review).

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				Thaut, M.H., Gardiner, J.C., Holmberg, D., Horwitz, J., Kent, L., Andrews, G., Donelan, B. and McIntosh, G.R. (2009). Neurologic music therapy improves executive function and emotional adjustment in traumatic brain injury rehabilitation. Annals of the New York Academy of Sciences, [online] 1169(1), pp.406–16. doi:https://doi.org/10.1111/j.1749-6632.2009.04585.x. Thuat, M.H. (2005). Temporal Entrainment of Cognitive Functions: Musical Mnemonics Induce Brain Plasticity and Oscillatory Synchrony in Neural Networks Underlying Memory. Annals of the New York Academy of Sciences, 1060(1), pp.243–254. doi:https://doi.org/10.1196/annals.1360.017. Twyford, K., Taylor, S., Valentine, J., Pool, J., Baron, A. and Thornton, A. (2024). Functional outcomes in children and adolescents with neurodisability accessing music therapy: A scoping review. Developmental Medicine & Child Neurology, 67(4), pp.428–442. doi:https://doi.org/10.1111/dmcn.16135.	
The Royal Hospital for Neuro-disability	Evidence Review A	General	General	We are concerned that the exclusion of terms such as 'Music Therapy', 'Neurologic Music Therapy', 'music', 'singing', and 'rhythm' overlooks a well-established evidence base and the documented benefits these approaches offer to patients.	Thank you for your comment. This evidence review was designed to identify qualitative research on what works well and what can be improved in the delivery of rehabilitation. No specific area of rehabilitation was excluded in the search strategy, and several citations including music in the title were identified during our database searches. Unfortunately, they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made.
The Royal Hospital for Neuro-disability	Evidence Review A	General	General	Neurologic Music Therapy, a recognised specialist area within Music Therapy, is well-established in neurorehabilitation across NHS, private, and community services, with referrals from a range of healthcare professionals. It is concerning that this field's evidence base has been excluded from the protocol, despite its proven impact on cognitive, physical, and communication outcomes, along with psychological support. Previous omission from NICE guidelines has already created barriers to access, as noted by some commissioners.	Thank you for your comment. This evidence review was designed to identify qualitative research on what works well and what can be improved in the delivery of rehabilitation. No specific area of rehabilitation was excluded in the search strategy. Similarly, the review covered all inpatient, outpatient and community settings in which either fully or partially publicly funded rehabilitation interventions for chronic neurological disorders are provided. The only settings that were excluded were accident and emergency departments, critical care units, and prisons. Several citations including music in the title were identified during our database searches but they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made.

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British Association for Music Therapy	Evidence Review A	General	General	The British Association for Music Therapy is concerned that there is no inclusion of 'Music Therapy' or 'Neurologic Music Therapy™' or musical terms such as 'music', 'singing', 'rhythm' in any of the search criteria or protocol for this evidence base. This completely disregards and excludes the entirety of the research and evidence base for the Music Therapy profession and the successful care and treatment patients have benefitted from.	Thank you for your comment. This evidence review was designed to identify qualitative research on what works well and what can be improved in the delivery of rehabilitation. No specific area of rehabilitation was excluded in the protocol or the search strategy, and several citations including music in the title were identified during our database searches. Unfortunately, they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made.
British Association for Music Therapy	Evidence Review A	General	General	Music Therapy includes a specialist field, Neurologic Music Therapy™. This is an established intervention within neurorehabilitation services across the UK, including in the NHS, Private Healthcare and Community Neurorehabilitation Units as well as referrals from Case Managers and other community-based clinicians for patients who live at home. It is highly concerning that the evidence base for the profession has been excluded from the protocol, as Music Therapy organisations have demonstrated that the inclusion of Neurologic Music Therapy™ directly supports improving cognitive, physical, communicative functioning as well as providing holistic psychological support and this has been recognised and valued by other clinicians. There is a challenge to accessing this provision as some commissioners have noted the lack of inclusion of the Music Therapy profession in previous NICE guidelines, despite the evidence base. The Cochrane Review for Music Interventions in Acquired Brain Injury highlighted that provision provided by Music Therapists increased efficacy of treatment and that music interventions positively impacted on functional goals (https://www.cochrane.org/CD006787/STROKE_music-interventions-acquired-brain-injury#:~:text=We%20found%20no%20strong%20evidence,of%20the%20evidence%20is%20low.) The following literature also demonstrates how music supports neuroplasticity and recovery for those in neurorehabilitation: THAUT, M.H. (2005). Temporal Entrainment of Cognitive Functions: Musical Mnemonics Induce Brain Plasticity and Oscillatory Synchrony in Neural Networks Underlying Memory. Annals of the New York Academy of Sciences, 1060(1), pp.243–254. doi:https://doi.org/10.1196/annals.1360.017.	Thank you for your comment. This evidence review was designed to identify qualitative research on what works well and what can be improved in the delivery of rehabilitation for chronic neurological disorders. Studies on specific therapies and interventions would likely not provide findings that were generalisable to the overall delivery of rehabilitation and therefore would not be considered for inclusion in this review. Despite this, no specific area of rehabilitation was excluded in the search strategy. Several citations including music in the title were identified through our database searches but they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made. For completeness, please see below for reasons your suggested papers do not meet the inclusion criteria for this systematic review: - Magee (2017) - Excluded on study design (systematic review reporting quantitative outcomes). - Thaut (2005) - Excluded on study date (published pre-2010). - Thaut (2009) - Excluded on study date (published pre-2010). - Siponkoski (2020) - Excluded on study design (quantitative study). - Siponkoski (2021) - Excluded on study design (quantitative study). Has been included in evidence review H. - Siponkoski (2020) - Duplicate reference to Siponski (2020) noted above. - Twyford (2024) - Excluded on study design (scoping review). - Thaut (2025) - Excluded on format (book). - Gong (2024) - Excluded on population (systematic review including adults with stroke).

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				Thaut, M.H., Gardiner, J.C., Holmberg, D., Horwitz, J., Kent, L., Andrews, G., Donelan, B. and McIntosh, G.R. (2009). Neurologic music therapy improves executive function and emotional adjustment in traumatic brain injury rehabilitation. Annals of the New York Academy of Sciences, [online] 1169(1), pp.406–16. doi:https://doi.org/10.1111/j.1749-6632.2009.04585.x. Siponkoski, S.-T., Martínez-Molina, N., Kuusela, L., Laitinen, S., Holma, M., Ahlfors, M., Jordan-Kilkki, P., Ala-Kauhaluoma, K., Melkas, S., Pekkola, J., Rodriguez-Fornells, A., Laine, M., Ylinen, A., Rantanen, P., Koskinen, S., Lipsanen, J. and Särkämö, T. (2020). Music Therapy Enhances Executive Functions and Prefrontal Structural Neuroplasticity after Traumatic Brain Injury: Evidence from a Randomized Controlled Trial. Journal of Neurotrauma, 37(4), pp.618–634. doi:https://doi.org/10.1089/neu.2019.6413. Siponkoski, S.-T., Koskinen, S., Laitinen, S., Holma, M., Ahlfors, M., Jordan-Kilkki, P., Ala-Kauhaluoma, K., Martínez-Molina, N., Melkas, S., Laine, M., Ylinen, A., Zasler, N., Rantanen, P., Lipsanen, J. and Särkämö, T. (2021). Effects of neurological music therapy on behavioural and emotional recovery after traumatic brain injury: A randomized controlled cross-over trial. Neuropsychological Rehabilitation, 32(7), pp.1–33. doi:https://doi.org/10.1080/09602011.2021.1890138. Siponkoski, S.-T., Martinez-Molina, N., Kuusela, L., Laitinen, Sari, Holma, Milla, Ahlfors, Mirja, Jordan-Kilkki, Päivi, Ala-Kauhaluoma, Katja, Melkas, Susanna, Pekkola, Johanna, Rodriguez-Fornells, Antoni, Laine, Matti, Ylinen, Aarne, Rantanen, Pekka, Koskinen, Sanna, Lipsanen, Jari, & Särkämö, T. (2020). Music therapy enhances executive functions and prefrontal structural neuroplasticity after traumatic brain injury: Evidence from a randomized controlled trial. Journal of Neurotrauma, 37(4), 618–634. https://doi.org/10.1089/neu.2019.6413 Twyford, K., Taylor, S., Valentine, J., Pool, J., Baron, A. and Thornton, A. (2024). Functional outcomes in children and adolescents with neurodisability accessing music therapy: A scoping review. Developmental Medicine & Child Neurology, 67(4), pp.428–442. doi:https://doi.org/10.1111/dmcn.16135.	

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				Thaut, M. and Volker Hoemberg (2025). Handbook of neurologic music therapy, second edition. New York, Ny: Oxford University Press. Gong, D. and Ye, F. (2024). Effects of Music Therapy on Aphasia and Cognition of Patients with Post-stroke: A Systematic Review and Meta-analysis. Noise and Health, 26(121), pp.136–141. doi:https://doi.org/10.4103/nah.nah_24_24. Patient feedback from services have demonstrated that the inclusion of Neurologic Music Therapy™ alongside standard care has increased motivation, helped achieve functional goals across multiple domains, and supported early discharge from services, and with an overall improvement in their quality of life. For example, patient discharge questionnaires from the pilot phase of an Neurologic Music Therapy™ project run by Chiltern Music Therapy at the Regional Neuro Rehab Unit at Homerton Hospital for 2 days/week for 12-months in 2021-2022 evidenced that all patients agreed or strongly agreed that Neurologic Music Therapy™ had helped to reduce stress/anxiety, increase their engagement with rehab, as well as improve speech, cognitive skills and physical function. Another example is from Chroma's 3-day/week 3-year Neurologic Music Therapy™ service on an in-patient neurorehabilitation unit at Charing Cross Hospital. Standard rehab care plus Neurologic Music Therapy™ created a "casual relationship" of patients being discharged 5.5 days prior to their original discharge date. This resulted in a cost saving of an approximate average of £10k per patient.	
MS Society	Evidence Review B	006	019	Pertaining to: "Views may be expressed about the availability of services including inpatient rehabilitation, community outpatient, third sector services, residential options, specialist care and personalised care such as named contacts or key workers" The MS Society has been providing webinars and regional forums have been hosted (https://www.mssociety.org.uk/supporting-someone-with-ms/for-professionals/events-professionals). These have highlighted a clear mismatch between what is recommended in terms of provision and workforce, and what is currently available in practice. We're also seeing evidence of significant variation in access, even within the same ICB areas.	Thank you for your comment. The line that you have referenced is from the protocol, describing a potential theme from the literature about the availability of rehabilitation services for chronic neurological disorders. In the evidence review, 5 sub-themes were identified under this theme, and at least 3 of these seem to support the experiences you describe. The committee have used these themes, along with considerations highlighted in our EHIA document, to inform several recommendations throughout the guideline (especially in the commissioning sections) to try and reduce the health inequalities that you have described.

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				As part of this, we've heard examples from across the country, including within Cheshire and Merseyside. In Halton and Warrington, there is a commissioned community neurorehabilitation service with a dedicated staff team. No other area within the same ICB appears to have an equivalent offer, which illustrates the postcode lottery people face depending on where they live. The Halton Community Therapy Team, for instance, supports adults registered with a Halton GP who need therapy in the community. This includes people with long-term neurological conditions, those recently discharged from hospital, and individuals needing support to manage mobility or functional impairments. The team provides personalised rehabilitation plans, therapeutic assessments, equipment and adaptations, and works closely with other local services to support hospital discharge and reduce the risk of admission.	
MS Society	Evidence Review B	006	019	Pertaining to: "The role of information and awareness surrounding chronic neurological disorders is expected to influence the identification of rehabilitation needs and referral to services (whether self-referrals or referrals from primary care or intermediary organisations). This may apply to people with chronic neurological disorders, their families or practitioners" We note that the panel includes only two lay members, with the remaining representatives coming from clinical backgrounds. It may be helpful to draw attention to the engagement work already taking place with local groups to understand need from the perspective of people living with neurological conditions. For example, the St Helens MS Group recently conducted a survey which found that 61% of respondents had never heard of neurophysiotherapy until the group raised awareness locally. This points to both a lack of public understanding and an opportunity to improve how information about services and their value is communicated. The voluntary sector also plays an important role in responding to unmet needs. At the MS Society, we are aware that local groups and neurotherapy centres are often providing additional support where statutory services are limited. This includes funding private physiotherapy sessions, counselling and other forms of rehabilitation.	Thank you for your comment. You are correct that only 2 members of the guideline committee are lay members. However, a strength of this guideline was the inclusion of 4 qualitative reviews (of which evidence review B is one) that cover the whole rehabilitation pathway. This qualitative evidence was used to inform many guideline sections, including recommendations on information for people with chronic neurological disorders and increasing knowledge and awareness of primary care providers (2 areas that you specifically highlight in your comment). Unfortunately, we are unable to include evidence that has not been published in peer-reviewed journals, but it is reassuring that your case studies support the evidence identified in our evidence reviews, and the resulting recommendations.

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				These services are not consistently available across all areas and often rely on local fundraising. It is also important that people with neurological conditions are identified and referred into appropriate rehabilitation services, including secondary care physiotherapy, regardless of the reason for their hospital attendance or contact with health services. Without this, individuals may be at risk of deterioration or deconditioning, which can have a lasting impact on quality of life. Reports from people with MS suggest that the quality of neurorehabilitation support, including clinical understanding of their condition, can vary. We would be happy to share case studies to help illustrate the impact this has on people's experiences.	
Success – Life After Cure Ltd	Evidence Review B	014	Table	Study Treadgold et al 2019; we note this is the only study reviewed in children; but in fact it relates to children with brain tumours and the availability of neurorehabilitation services we refer to in [2] above. Clarification of whether this guideline pertains to that group would be helpful	Thank you for your comment. The guideline does cover the rehabilitation needs of children with brain tumours.
Success – Life After Cure Ltd	Evidence Review B	020	038	We agree with the committee's interpretation that increasing specialist knowledge, interdisciplinary collaboration, integrated care and unlocking capacity within existing services would improve identification of need and access. However, some resource is likely to be needed in the short term for children with brain tumours now that 80% survive, as part of the promised cure, if the aim is to improve long term quality of life, independence and employment. But early interventions with reassessments across key maturational stages are cost-efficient and highly likely to reduce the secondary health care burden and long term public costs. Such longitudinal assessments from baseline are also key to unlocking the dilemma between tumour- and treatment – aetiologies of the acquired brain injury. This therefore may need consideration under a specific childhood brain tumour neurorehabilitation guideline within neuroncology service provision.	Thank you for your comment. While our recommendations are not specific to your issue, we do provide guidance on follow-up. Although we have not detailed what should occur at these appointments, they should involve practitioners suited to the individual's care. If longitudinal assessments are beneficial, practitioners can agree on their inclusion. Given our recommendations cover a broad population, it would be inappropriate to include such specific statements in this guidance. However, practitioners are free to determine the specifics of follow-up care. Also, there is a supporting resource use and cost-effectiveness section which discusses the impact of assessment, planning and review recommendations.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review B	024	001 - 002	Agree with the sentence "*Consent will also have to be obtained from those people nominated in this process."* However, I would like to suggest an additional sentence to cover capacity where a person lacks capacity best interest decisions should be sought and appropriate person appointed.	Thank you for your comment. The paragraph that you have referenced is explaining the committee's discussion behind the recommendation on identify and involving people who are important to the individual with a chronic neurological disorder within their rehabilitation. This was drafted using qualitative evidence which showed that people surrounding someone with the chronic neurological disorder can often provide rehabilitation professional with additional information on symptoms and impairments that

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					would be helpful when discussing rehabilitation goals and developing a rehabilitation programme. This is different to conversations about mental capacity and best interest. The principles of assessing capacity and maintaining best interest apply throughout this guideline, not simply this recommendation. NICE already has guidance on these topics, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws), NG108 Decision-making and mental capacity, NG227 Advocacy services for adults with health and social care needs, and NG204 Babies, children and young people's experience of healthcare. References to these documents have been made at the beginning of the main guideline section on assessing rehabilitation needs, and separate references to NG108, NG227 and NG204 have been included at the beginning of this section on conducting a holistic rehabilitation needs assessment. Therefore, no change has been made.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review B	028	003	Consider adding in what format/media information could be presented in for the patient to access e.g. on a website, easy read paper leaflets, SMS messages.	Thank you for your comment. It is unclear what patient information you are referring to, as the paragraph you have referenced is discussing the potential resource impacts of holistic rehabilitation assessments (specifically coordination, scheduling and communication across health and social care). Therefore, no changes have been made. However, format of information for patients is already covered in existing NICE guidelines on CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS services and NG204 Babies, children and young people's experience of healthcare, which are referenced throughout this guideline, and therefore are not overlooked.
Chiltern Music Therapy	Evidence Review B	060	015	The review discusses interventions for improving communication post-stroke but does not mention Melodic Intonation Therapy (MIT)™, a music-based intervention and NMT™ speech & language technique with evidence supporting its efficacy in aphasia rehabilitation (Zumbansen et al. 2014, Van der Meulen et al. 2014).	Thank you for your comment. The review does not discuss interventions for improving communication after stroke. It is a qualitative review investigating the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services. Indeed, adults stroke survivors are excluded from this protocol (and guideline scope) as NICE already has published guidance on it. Although 1 study (Norman 2020) did include a proportion of adults with stroke within its population, no themes relating to interventions were extracted. The evidence identified was relating to knowledge of professionals, scheduling, signposting, empathy, hidden disability, and safeguarding. Therefore, no change has been made.
The Royal Hospital for Neuro-disability	Evidence Review B	General	General	We are concerned that the exclusion of terms such as 'Music Therapy', 'Neurologic Music Therapy', 'music', 'singing', and 'rhythm' overlooks a well-established evidence base and the documented benefits these approaches offer to patients.	Thank you for your comment. This evidence review was designed to identify qualitative research on barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services. No specific area of rehabilitation was excluded in the search strategy, and several citations including music in the

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					title were identified during our database searches. Unfortunately, they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made.
British Association for Music Therapy	Evidence Review B	General	General	The British Association for Music Therapy is concerned that there is no inclusion of 'Music Therapy' or 'Neurologic Music Therapy™ or musical terms such as 'music', 'singing', 'rhythm' in any of the search criteria or protocol for this evidence base. This completely disregards and excludes the entirety of the research and evidence base for the Music Therapy profession and the successful care and treatment patients have benefitted from.	Thank you for your comment. This evidence review was designed to identify qualitative research on barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services. No specific area of rehabilitation was excluded in the search strategy, and several citations including music in the title were identified during our database searches. Unfortunately, they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review C	021	018 - 021	This section would benefit from an additional sentence about if an inpatient that flow and discharge planning will account for this. The pressure of beds and waiting lists is heavier than ever, I regularly see the negative impact flow and wait list targets has on those with neurological conditions.	Thank you for you comment. We are unsure as to what section this comment is referring to. The page and line numbers align with a paragraph on setting and reviewing rehabilitation goals, which doesn't make sense in the context of your comment. There is also not enough information in your comment for us to locate what section it might instead refer to. Therefore, no change has been made. However please also note that there is a section of the guideline focussing on discharge from hospital, which also signposts to the NICE guideline on transitions from inpatient hospital settings to community or care home settings.
The Royal Hospital for Neuro-disability	Evidence Review C	General	General	We are concerned that the exclusion of terms such as 'Music Therapy', 'Neurologic Music Therapy', 'music', 'singing', and 'rhythm' overlooks a well-established evidence base and the documented benefits these approaches offer to patients.	Thank you for your comment. This evidence review was designed to identify qualitative research on what works well and what could be improved in assessment, planning and review of rehabilitation needs for people with chronic neurological disorders. No specific area of rehabilitation was excluded in the search strategy, and several citations including music in the title were identified during our database searches. Unfortunately, they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made.
The Royal Hospital for Neuro-disability	Evidence Review C	General	General	Neurologic Music Therapy, a specialist area within Music Therapy, offers tailored sessions that can complement or stand alone alongside Physiotherapy, Occupational Therapy, and Speech and Language Therapy to help patients meet functional goals. Its exclusion from the evidence review means the guideline fails to reflect the full range of effective services available for individuals with chronic neurological conditions.	Thank you for your comment. This evidence review was designed to identify qualitative research on what works well and what could be improved in assessment, planning and review of rehabilitation needs for people with chronic neurological disorders. Studies on specific therapies and interventions would likely not provide findings that were generalisable to the overall assessment and planning of rehabilitation and therefore would not be considered for inclusion in this review. Despite this, no specific area of rehabilitation was excluded in the search strategy, and several citations including music in the title were identified during our database searches. Unfortunately, they were all excluded at the title and abstract stage as they

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					were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made.
British Association for Music Therapy	Evidence Review C	General	General	The British Association for Music Therapy is concerned that there is no inclusion of 'Music Therapy' or 'Neurologic Music Therapy™ or musical terms such as 'music', 'singing', 'rhythm' in any of the search criteria or protocol for this evidence base. This completely disregards and excludes the entirety of the research and evidence base for the Music Therapy profession and the successful care and treatment patients have benefitted from.	Thank you for your comment. This evidence review was designed to identify qualitative research on what works well and what could be improved in assessment, planning and review of rehabilitation needs for people with chronic neurological disorders. No specific area of rehabilitation was excluded in the search strategy, and several citations including music in the title were identified during our database searches. Unfortunately, they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made.
British Association for Music Therapy	Evidence Review C	General	General	Neurologic Music Therapy™ (a specialist field of Music Therapy) involves the assessment and delivery of bespoke sessions which support and can be offered independently or alongside Physiotherapy, Occupational Therapy and Speech and Language Therapy to support patients to achieve their functional goals. The profession of Music Therapy has been completely excluded from this evidence review and so the guideline does not accurately portray the services available which can positively support those with chronic neurological conditions.	Thank you for your comment. This evidence review was designed to identify qualitative research on what works well and what could be improved in assessment, planning and review of rehabilitation needs for people with chronic neurological disorders. Studies on specific therapies and interventions would likely not provide findings that were generalisable to the overall assessment and planning of rehabilitation and therefore would not be considered for inclusion in this review. Despite this, no specific area of rehabilitation was excluded in the search strategy, and several citations including music in the title were identified during our database searches. Unfortunately, they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. Therefore, no change has been made.
Anglia Ruskin University	Evidence Review C	General	General	The search strategy did not appear to include "music therapy". I would suggest including search terms involving "music therapy" and "music intervention", when considering approaches to assessment and treatment for this population. There are two music-based measures that are used for assessing disorders of consciousness. They are both designed to have diagnostic and treatment planning capabilities. Here are two references for these tools: Magee WL, Siegert RJ, Taylor SM, Daveson BA, Lenton-Smith G. Music Therapy Assessment Tool for Awareness in Disorders of Consciousness (MATADOC): Reliability and Validity of a Measure to Assess Awareness in Patients with Disorders of Consciousness. J Music Ther. 2016 Spring;53(1):1-26. doi: 10.1093/jmt/thv017. Epub 2015 Dec 7. PMID: 26647402.	Thank you for your comment. This evidence review was designed to identify qualitative research on what works well and what could be improved in assessment, planning and review of rehabilitation needs for people with chronic neurological disorders. Studies on specific music-based measures would likely not provide findings that were generalisable to the overall assessment and planning of rehabilitation, and therefore would not be considered for inclusion in this review. Despite this, no specific area of rehabilitation was excluded in the search strategy, and several citations including music in the title were identified during our database searches. Unfortunately, they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review

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				Pool, J. W., Magee, W. L., Siegert, R. J., & Wood, C. L. (2025). The development and face validity of the music therapy sensory instrument for cognition, consciousness, and awareness (MuSICCA). *Frontiers in Psychology*, *16*, 1441178.	has not overlooked the area of music therapy. Therefore, no change has been made. For completeness, please see below for reasons your suggested papers do not meet the inclusion criteria for this systematic review: Magee (2016) – excluded on study design (no qualitative synthesis reported). Pool (2025) – excluded on study design (no qualitative synthesis reported).
MYoroface AB	Evidence Review D	006	017	The report lists the possible alternatives as, "Interventions for sustaining or improving capability in eating, drinking and swallowing: o Diet and fluid modification: thickeners o Swallowing exercises, manoeuvres and programmes and swallow re- training by Speech and Language Therapists o Neuromuscular electrical stimulation or pharyngeal stimulation, transcranial direct current or magnetic stimulation o Enteral tube feeding." We feel that Neuromuscular training should be included here, it is a widely-used in the UK and across Europe as a treatment for people with swallowing difficulties after events including traumatic brain injury. It is a simple-to-administer and inexpensive treatment that is more accessible and much less expensive than the interventions listed in the third category above. The device is being used to some extent (some only small) in more than 100 NHS hospitals and institutions and is available on prescription in all four countries of the UK.	Thank you for your comment. Although not specifically named in the list, neuromuscular training would fall under the bullet point 'swallowing exercises, manoeuvres and programmes and swallow re-training by Speech and Language Therapists'. Therefore, no change has been made. A reference to neuromuscular retraining has been added to the recommendations.
MYoroface AB	Evidence Review D	009	003	We feel that your 'Table 2: Summary of included studies' should include the SOFIA study which provides relevant input to the conditions in question and the IQoro treatment. In the event that you now choose to include this your evidence summary, I have tried to be helpful by presenting it here in PICO format. **Study**:	Thank you for your comment. We have looked at the paper that you referenced and, unfortunately, it would be excluded on the basis that the population is unclear. The paper details that the study population included older (above 65) adults admitted to intermediate care. We cannot find the full list of disabilities that you have mentioned in your comment, only a footnote that frequent diagnoses were stroke, musculoskeletal disorders, neurological disorders, cardiovascular diseases, traumatic brain injury. There is no information provided on the proportion of these disorders, and 3 of them are out of scope for this guideline (adults with stroke,

				Effects of oral neuromuscular training on swallowing dysfunction among older people in intermediate care — a cluster randomised, controlled trial.
				(A part of the SOFIA study)
				
				Authors:
				Patricia Hägglund, Mary Hägg, Per Wester, Eva Levring Jäghagen
				
				Publication
				Age and Ageing, Volume 48, Issue 4, July 2019, Pages 533 - 540, https://doi.org/10.1093/ageing/afz042. Published: 07 May 2019
				
				Population
				385 participants who had been in one of 36 intermediate care units for at least 3 days were screened, and 116 participants were randomly assigned to IQoro neuromuscular training or usual care. No other selection criteria were applied. The cohort included residents with neurological disabilities, Parkinsons, stroke, Acquired Brain Injury (ABI), Traumatic Brain Injury (TBI), dementia, Chronic Obstructive Pulmonary Disease (COPD), cardiovascular diseases, musculoskeletal disorders, more. All recruited residents had diagnosed conditions affecting at least three different organs / organ systems.
				
				• intervention group
				  ○ (*n* = 49, F = 22, M = 27)
				  ○ median age 83 (range 72 – 87)
				
				• control group
				  ○ (*n* = 67, F = 38, M = 29)
				  ○ median age 85 (range 80 – 89)
				
				The two groups were matched for gender, age, functional ability, BMI, comorbidities, dysphagia related illness, cognitive ability, and educational level.
				
				Intervention
				Older people with swallowing dysfunction were cluster randomised according to care units for either:
				
				• intervention group: IQoro neuromuscular training 3 x 10 seconds, three times per day for 5 weeks,
				• control group: traditional and compensatory care.
					musculoskeletal disorders, cardiovascular diseases). Therefore, no changes have been made.

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				Residents were measured at three time points: before training, at end of training and at late follow up (6 months post-treatment). **Comparison** • At end of treatment, the geometric mean of the swallowing rate in the intervention group had significantly improved 60% more than that of controls (p = 0.007). • Signs of aspiration significantly reduced in the intervention group compared with controls (p = 0.01). • At 6 months post-treatment, the swallowing rate of the intervention group remained significantly better (p = 0.031). • No significant between-group differences were found for swallowing-related QOL. Statistical significance of result (p < 0.007) improved swallowing rate in intervention compared with control group. (p < 0.01) reduced signs of aspiration in intervention compared with control group. (p < 0.031) swallowing rate in intervention compared with control group at 6 months after end of treatment. (p < 0.46) signs of aspiration were similar in both groups at 6 months after end of training. **Outcomes** Residents were tested at each time point for: • Primary endpoint: swallowing rate assessed by Timed Water Swallow Test (TWST) – lower normal value for swallowing rate ≥ 10 ml / sec • The secondary endpoints were changes in signs of aspiration during the TWST and swallowing-related quality of life (QOL).	
Royal College of Speech and Language Therapists	Evidence Review D	030	029	Although this evidence review refers specifically to "swallow retraining" in the PICO formulation and to "improving capability in eating, drinking and swallowing" (p30, line 30), the discussion on page 31 lines 11-24 indicates a lack of consideration for interventions focussed aimed at **rehabilitation** of swallowing ability, as opposed to compensatory manoeuvres and strategies. This has resulted in these approaches being omitted from recommendation 1.21.4. See:	Thank you for your comment. We have amended the referenced recommendation to include rehabilitation techniques to regain swallow function. Examples given include the Shaker exercise, the Masako

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				• Eskildsen SJ, Poulsen I, Jakobsen D*, et al* (2021) Scoping review to identify and map non-pharmacological, non-surgical treatments for dysphagia following moderate-to-severe acquired brain injury *BMJ Open*;11**:**e053244. doi: 10.1136/bmjopen-2021-053244 • Félix-Lusterman, C. C., Joseph, M. E., & Daniels, S. K. (2021). Update on Exercise-Based Rehabilitation Approaches for Neurogenic Dysphagia. *Current Physical Medicine and Rehabilitation Reports*, *9*(4), 252-266. https://doi.org/10.1007/s40141-021-00333-4 • Malandraki, G. A. (2016) The Intensive Dysphagia Rehabilitation Approach Applied to Patients With Neurogenic Dysphagia: A Case Series Design Study, *Archives of Physical Medicine and Rehabilitation*, Volume 97, Issue 4, Pages 567-574, https://doi.org/10.1016/j.apmr.2015.11.019 • Hansen, T. S., & Jakobsen, D. (2010). A decision-algorithm defining the rehabilitation approach: 'Facial oral tract therapy'. *Disabil Rehabil*, *32*(17), 1447-1460. https://doi.org/10.3109/09638280903556482 • Huckabee, M.-L., Flynn, R., & Mills, M. (2023). Expanding Rehabilitation Options for Dysphagia: Skill-Based Swallowing Training. *Dysphagia*, *38*(3), 756-767. https://doi.org/10.1007/s00455-022-10516-3 • McCurtin, A., Lindsey, C., Lizzie, K., Tracy, L.-P., Dominika, L., Paula, L., Michelle, M., Aoife, M., Shaun, O. K., & and Smith, A. (2024). Beyond thickened liquids: for your consideration. *Journal of Clinical Practice in Speech-Language Pathology*, *26*(2), 128-166. https://doi.org/10.1080/22000259.2024.2359368 • Sasegbon, A., Cheng, I., Labeit, B., Lapa, S., Rommel, N., & Hamdy, S. (2024). New and Evolving Treatments for Neurologic Dysphagia. *Drugs*, *84*(8), 909-932. https://doi.org/10.1007/s40265-024-02064-x • World Health Organisation. (2023). *Package of interventions for rehabilitation. Module 3. Neurological conditions*. World Health Organisation. Retrieved 20 May 2025 from https://www.who.int/publications/i/item/9789240071131	manoeuvre, expiratory muscle strength training and neuromuscular re-training. After reviewing the list of references you attached to your comment, we are unfortunately unable to include them in our evidence review. Please see below for a list of reasoning: - Eskildsen 2021 – excluded on study design (scoping review). - Félix-Lusterman 2021 – excluded on study design (non-systematic literature review). - Malandraki 2016 – excluded on study design (case series). - Hansen 2010 – excluded on publication date (pre-2013). - Huckabee 2023 – excluded on study design (opinion piece). - McCurtin 2024 – excluded on study design (non-systematic literature review). - Sasegbon 2024 – excluded on study design (non-systematic literature review). - WHO 2023 – excluded on publication type (online textbook). - Zupo 2025 – excluded on study design (systematic review with only 3/43 randomised controlled trials included).

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				Zupo R, et al. (2025) Methods of diagnosis and rehabilitation of dysphagia in patients with spinal cord injury: a systematic review. Eur J Phys Rehabil Med. 61(1):41-51. doi: 10.23736/S1973-9087.24.08614-3	
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review D	031	014 - 015	Agree with "*Proper posture and positioning are important to reduce the risk of coughing and choking*" however please consider rewording to: *Proper posture and positioning are important optimise a safe swallow and to reduce the risk of coughing and choking.*	Thank you for your comment. We have made the addition as suggested, although we have slightly amended your wording to 'Proper posture and positioning are important to optimise a safe swallow and to reduce the risk of coughing and choking'.
British Association for Music Therapy	Evidence Review D	267	General	The following study has been excluded from being considered: Gatti, Roberto, Tettamanti, Andrea, Lambiase, Simone et al. (2015) Improving hand functional use in subjects with Multiple Sclerosis using a musical keyboard: a randomized controlled trial. Physiotherapy research international : the journal for researchers and clinicians in physical therapy 20(2): 100-7. The reason given for this is: 'No relevant outcomes reported. Reports measures of hand function, dexterity and strength.', yet in Table 1 of page 6, the protocol clearly states that this evidence review seeks to report on 'Interventions, equipment, and devices to support functioning and modify the environment', with the 5th bullet point under this heading states that it includes 'Interventions for upper limb function'. This study clearly includes an intervention which reports improved upper limb functions, therefore the rationale provided for excluding the study directly contradicts the protocol. This is concerning and we would recommend that this study is re-considered for inclusion.	Thank you for your comment. The study has not been excluded because the intervention is ineligible. It has been excluded because it did not report any of the outcomes that the guideline committee prioritised during protocol development (functional independence, quality of life, personal goal attainment, swallowing related quality of life, pain, and carer quality of life). A study has to meet all protocol criteria to be included in the systematic review. Therefore, no changes have been made in light of your comment. For more detail about the protocol outcomes and why the guideline committee felt they were the most relevant to the review question, please see the section of the report headed 'The outcomes that matter most'.
The Royal Hospital for Neuro-disability	Evidence Review D	General	General	The following study has been excluded from being considered: Gatti, Roberto, Tettamanti, Andrea, Lambiase, Simone et al. (2015) Improving hand functional use in subjects with Multiple Sclerosis using a musical keyboard: a randomized controlled trial. Physiotherapy research international : the journal for researchers and clinicians in physical therapy 20(2): 100-7. The reason given for this is: 'No relevant outcomes reported. Reports measures of hand function, dexterity and strength.', yet in Table 1 of page 6, the protocol clearly states that this evidence review seeks to report on 'Interventions, equipment, and devices to support functioning and modify the environment', with the 5th bullet point under this heading states that it includes 'Interventions for upper limb function'. This study clearly includes an intervention which reports improved upper limb functions, therefore the rationale provided for excluding the study	Thank you for your comment. The study has not been excluded because the intervention is ineligible. It has been excluded because it did not report any of the measures that the guideline committee prioritised during protocol development (functional independence, quality of life, personal goal attainment, swallowing related quality of life, pain, and carer quality of life). A study has to meet all protocol criteria to be included in the systematic review. Therefore, no changes have been made. For more detail about the protocol outcomes and why the guideline committee felt they were the most relevant to the review question, please see the section of the report headed 'The outcomes that matter most'.

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				directly contradicts the protocol. This is concerning and we would recommend that this study is re-considered for inclusion.	
The UK FND Network	Evidence Review E	006	019	Evidence review for stability, mobility and upper limb function. The framing of the search strategy set out in the PICO table is not well-suited to FND, focussing as it does on specific localisation-related dysfunction, whereas FND is a central biopsychosocial condition with multiple and diverse symptom manifestations. Perhaps for these reasons key high quality papers in the physiotherapeutic treatment of FND have not been found in the search (although one is from this year and may have been too recent): Jordbru et al., 2014 https://doi.org/10.2340/16501977-1246, Nielsen et al., 2017 https://doi.org/10.1136/jnnp-2016-314408, Nielsen et al., 2024 https://doi.org/10.1016/s1474-4422(24)00135-2, Hunter et al., 2025 https://doi.org/10.1212/CPJ.0000000000200465	Thank you for your comment. All the papers listed were picked up in our population search. Due to the number of conditions covered in the population, it was necessary to restrict the interventions to those named in the protocol. Studies such as Neilson and Jordbru were not picked up as the indexing terms for these studies did not include terms related to the interventions, or terms they did include were broader than it was possible to use for a search with a population of this size (for example, physiotherapy). For completeness, please see below for reasons your suggested papers do not meet the inclusion criteria for this systematic review: Jordbru (2014) - Excluded on intervention (psychological intervention involving symptom explanation, positively reinforcing normal function and not positively reinforcing dysfunction. Does not fit into any of our protocol groups). Nielsen (2017) - Excluded on intervention (protocolised programme involving education, movement retraining, and development of management plan. Does not fit into any of our protocol groups). Nielsen (2024) - As above. However, note that in view of other stakeholder comments, this paper has now been added to review O about the effectiveness of rehabilitation interventions to support access to physical activity, exercise or sport, for people with chronic neurological disorders. Hunter (2025) - Economic analysis of the above intervention.
Association of Chartered Physiotherapists in Neurology	Evidence Review E	006	019	[E] Evidence review for stability, mobility and upper limb function The PICO table for evidence search does not map well to FND pathology or rehabilitation approaches. In particular the breakdown of interventions do not map well to the pathophysiology or rehab approach to FND. This may account for why the search appeared to miss some published randomised studies that appear to meet the eligibility criteria. • Jordbru AA, Smedstad LM, Klungsøyr O, Martinsen EW. Psychogenic gait disorder: A randomized controlled trial of physical rehabilitation with one-year follow-up. J Rehabil Med. 2014;46(2):181–7. • Nielsen G, Buszewicz M, Stevenson F, Hunter R, Holt K, Dudziec M, et al. Randomised feasibility study of physiotherapy for patients with functional motor symptoms. J	Thank you for your comment. All the papers listed were picked up in our population search. Due to the number of conditions covered in the population, it was necessary to restrict the interventions to those named in the protocol. Studies such as Neilson and Jordbru were not picked up as the indexing terms for these studies did not include terms related to the interventions, or terms they did include were broader than it was possible to use for a search with a population of this size (for example, physiotherapy). For completeness, please see below for reasons your suggested papers do not meet the inclusion criteria for this systematic review: Jordbru (2014) - Excluded on intervention (psychological intervention involving symptom explanation, positively reinforcing normal function and not positively reinforcing dysfunction. Does not fit into any of our protocol groups). Nielsen (2017) - Excluded on intervention (protocolised programme involving education, movement retraining, and development of management plan. Does not fit into any of our protocol groups). Nielsen (2024) - As above. However, note that in view of other stakeholder

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				Neurol Neurosurg Psychiatry. 2017;88:484–90. http://www.ncbi.nlm.nih.gov/pubmed/27694498 • Nielsen G, Stone J, Lee TC, Goldstein LH, Marston L, Hunter RM, et al. Specialist physiotherapy for functional motor disorder in England and Scotland (Physio4FMD): a pragmatic, multicentre, phase 3 randomised controlled trial. Lancet Neurol. 2024. • Hunter RM, Nielsen G, Le Novere M, Marston L, Lee TC, Stone J, et al. Cost Utility of Specialist Physiotherapy for Functional Motor Disorder (Physio4FMD). Neurol Clin Pract [Internet]. 2025 Jun;15(3). https://www.neurology.org/doi/pdf/10.1212/CPJ.0000000000200465 Some of these studies may have been published after the search was conducted.	comments, this paper has now been added to review O about the effectiveness of rehabilitation interventions to support access to physical activity, exercise or sport, for people with chronic neurological disorders. Hunter (2025) - Economic analysis of the above intervention.
The International FES Society (IFESS) UK and Ireland chapter.	Evidence Review E	078 539		When reporting outcomes from users of FES devices, it is very important to distinguish between outcome measures recorded while using a device to assist function and outcome measures taken when not using device, used to determine the training effect from using the device. The difference between walking speed measured while walking with a device and without a device is often referred to as an orthotic effect and reflects the effect of using a device as an assistive device. This is important because use of FES can often have two connected but separate goals, the first to provide immediate assistance while using the device and the second longer term goal to improve walking without the device. For people with MS, it is generally recognised that FES is and effective means of assisting walking (orthotic effect) but less effective at training unassisted walking. (Street 2015) In Parkinson's, the emerging evidence it is the opposite, with FES leading to a training effect, but being less effective as an assistive device. In the study by Taylor et at 2021 (Page 539), the therapeutic effect on walking speed was recorded as 0.14m/s (confidence interval 0.03 to 0.26) after 18 weeks of FES use. This exceeds the limit for a substantial effect of 0.1m/s so should be considered a significant result. For and elderly population, the minimum clinical important difference is 0.05m/s, (Perera 2006). Street TD, Taylor PN, Swain ID. The Effectiveness of Functional Electrical Stimulation on Walking Speed, Functional Walking Category	Thank you for your comment. We have now been through evidence review E and where outcomes from functional electrical stimulation interventions are reported, have added whether these were measured using devices, not using devices, or if device use was not reported. Regarding your second point about the 0.14 m/s between group difference in 10MWT outcome at post-intervention in Taylor 2021, unfortunately this does not meet our definition of clinically important. NICE use a formula to calculate minimum important differences for continuous outcomes (0.5 x standard deviation of control group baseline scores), which equates to 0.165 m/s in this instance. As the point estimate of 0.14 falls below that, we concluded that there is no evidence of important difference. While we appreciate that this sets a higher target than the 0.05 m/s calculated by Perera 2006, it is in line with the methods (described in the guideline methods supplement) and has been consistently applied throughout the evidence reviews for this guideline. Furthermore, the population included in Perera 2006 is not the same as our guideline population (they list included participants as community-dwelling older adults and, the only neurological condition they mention in the abstract is stroke, which is outside of the guideline scope), they measured gait speed during a 6-minute walk test rather than the 10 metre-walk test reported by Taylor 2021, and it is published before our protocol cut-off of 2013.

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				and Clinically Meaningful Changes for People with Multiple Sclerosis. Archives of Physical Medicine. Volume 96, Issue 4, April 2015, Pages 667–672 Perera S, Mody SH, Woodman RC, Studenski SA. Meaningful change and responsiveness in common physical performance measures in older adults: meaningful change and performance. J Am Geriatr Soc 2006;54:743-9.	
The International FES Society (IFESS) UK and Ireland chapter.	Evidence Review E	078	006	The requirement for an effect to exceed twice the minimum stated important clinical difference appears harsh. It is not necessarily the case that the stated minimum important difference is of little consequence to the individual and the degree of perceived benefit is likely to vary between outcome measures. It also assumes the perceived benefit is linear in effect, which cannot be assumed across all outcome measures.	Thank you for your comment. The sentence that you have referenced is not saying that that the point estimate needs to exceed twice the minimum important difference to be considered a significant difference. The point estimate only needs to exceed the value of the minimum important difference to be considered significant, so long as the 95% confidence interval does not cross the line of no effect. If the point estimate lies between the minimum important differences (for example, less than that to confer an important benefit and higher than that to confer an important harm), then we have interpreted it as 'no important difference'. We apologise for the misunderstanding and hope that this explanation answers your concerns.
The International FES Society (IFESS) UK and Ireland chapter.	Evidence Review E	088	001 - 034	We would like to bring to the committee's attention the extensive review and guideline development that has been done by ACPIN. This is of particular relevance to the use of FES to support walking in MS as well as all upper motor neurone conditions. While the committee's comments recommending the use of FES and NMES are welcome, we feel the report would be strengthened by referencing the much more detailed work done by ACPIN around the application of and evidence for the technique. Andreopoulou G, Busselli G, Street T, Bulley C, Safari R, van der Linden ML, et al. Is functional electrical stimulation effective in improving walking in adults with lower limb impairment due to an upper motor neuron lesion? An umbrella review. Artif. Organs. 2024;48:210–231. https://doi.org/10.1111/aor.14563. The Association of Chartered Physiotherapists Involved in Neurology (ACPIN) Clinical Practice Guidelines for FES to assist walking. Queen Margaret University and ACPIN 29 September 2022 https://www.acpin.net/pdfs/2210%20QMU%20Report.pdf	Thank you for your comment. NICE can only cross-refer to other guidance in 2 cases. Firstly, if there are already published NICE recommendations on a subject. Secondly, by stating, a priori, that guidelines would be an accepted evidence source in a systematic review. In this case, relevant guidelines would be included and subject to critical appraisal and then considered by the committee as a basis for recommendations. They could also cross refer to the included guideline. As the ACPIN guidelines did not meet our review protocols ('guidelines' were not an accepted evidence type), they cannot be used to inform recommendations, nor referenced in the guideline. It is also worth highlighting that in the ACPIN report, the majority of included papers come from adults with stroke, which is outside the scope for this guideline. Therefore, no change has been made in light of your comment.

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				Bulley C, Meagher C, Street T, Adonis A, Peace C, Singleton C, Burridge J. Development of clinical guidelines for service provision of functional electrical stimulation to support walking: mixed method exploration of stakeholder views. BMC Neurol. 2021 Jul 5;21(1):263. Doi: 10.1186/s12883-021-02299-1. PMID: 34225695; PMCID: PMC8256555. Bulley C, Burridge J, Adonis A, Joiner S, Curnow E, van der Linden ML, Street T. Delphi consensus study and clinical practice guideline development for functional electrical stimulation to support upright mobility in people with an upper motor neuron lesion. 2024 Artif Organs Mar;48(3):285-296. doi: 10.1111/aor.14611. Epub 2023 Aug 7.	
The International FES Society (IFESS) UK and Ireland chapter.	Evidence Review E	088	020	The reports conclusions on electrical stimulation based on the discussions of the committee are potentially concerning. It states on page 88 line 20 "Functional electrical stimulation is common practice for both people with upper and lower motor neurone lesions leading to muscle weakness or an inability to adequately dorsiflex the ankle for foot clearance in gait." It is important to distinguish between upper and lower motor neuron lesions. Functional Electrical Stimulation FES) is almost always only used in upper motor neurone patients. FES uses short duration pulses, typically of less than 1ms duration and achieves a muscle contraction by exciting the motor nerve connected to that muscle. For this to be successful, the motor nerve must be intact. FES is therefore typically used in conditions such as MS, stroke, SCI, TBI, CP, HSP, PD where the lesion is in the brain or spinal cord above T12. It is less often used in lower motor neurone patients and only when there is a mix of intact and affected peripheral nerves, with the aim of activating or strengthening the muscle supplied by the intact nerves. It is possible to stimulate denervated muscles directly where the nerve is absent, but this requires stimulators that provide significantly more charge, as much as one hundred times more. These device while available are much less often used. Typically, they are used for training only and not for function. The committee should be aware that the term FES relates to electrical stimulation used to assist or create function at the time it is used. Electrical stimulation intended to produce a therapeutic effect but does not assist function at the time it is used is referred to as Neuro-Muscular Electrical Stimulation (NMES).	Thank you for your comment. We have now amended the recommendation to reflect that functional electrical stimulation is useful for people with muscle weakness of the lower limbs from an upper motor neurone lesion. The 'Benefits and harms' section has also been updated to reflect this. However, the committee's expertise suggested that this intervention in helpful in people with lesions above T10, rather than T12 as stated in your comment. This has not been changed in the committee's discussion of the evidence in evidence review E.

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Consultation on draft guideline - Stakeholder comments table
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The International FES Society (IFESS) UK and Ireland chapter.	Evidence Review E	088	028	The report states on page 88 line 28 "However, the committee caveated that it should be used as an adjunct to gait training, rather than an intervention by itself, to ensure it is as effective as possible." The Clinical practice guidelines produced by ACPIN do recommend that FES should be applied as part of gait training, but this is not to say it should not be used as a long-term mobility aid, once gait training has been completed. Long term clinical audit of FES use (Taylor 2013) shows that people with MS can benefit from FES for in excess of 10 years. If it is the intention of the report to say that FES should not be used as a long-term mobility aid, then we strongly disagree with this conclusion. The Association of Chartered Physiotherapists Involved in Neurology (ACPIN) Clinical Practice Guidelines for FES to assist walking. Queen Margaret University and ACPIN 29 September 2022 https://www.acpin.net/pdfs/2210%20QMU%20Report.pdf Taylor P, Humphreys L, and Swain I, The long-term cost-effectiveness of the use of functional Electrical stimulation for the correction of dropped foot Due to upper motor neuron lesion. J Rehabil Med 2013; 45: 154–160	Thank you for your comment. That was not the intention of the report. The committee discussed that functional electrical stimulation devices should not be provided purely for the immediate therapeutic effect and forgotten about. While the committee were aware of the benefits of electrical stimulation, they were concerned that sometimes this intervention is given without any consideration about other rehabilitation techniques that could be implemented alongside. We have amended the referenced wording in the 'Benefits and harms' section to better convey this.
The International FES Society (IFESS) UK and Ireland chapter.	Evidence Review E	088	031	On page 88 line 31 the report states "Finally, the committee discussed that electrical stimulation devices are not tolerated by everyone, with some people reporting uncomfortable sensations during use. They recommended that these devices are always trialled before they are incorporated into a rehabilitation programme, ensuring maximum adherence." While it is the case that ES is not tolerated by all, this is common to many interventions. To single out ES for this caveat is disproportional to the difficulty of applying it. The recorded rejection rate of FES in the Renfrew study was just under half that of AFOs, which indicates this recommendation should be extended to those devices. Other studies have also found that the rejection rate of FES is low, both in research studies and clinical practice.	Thank you for your comment. The committee's point was that time is needed when providing electrical stimulation equipment, to support people to adjust to using the device, as well as to problem-solve potential issues. We have amended the wording of this section to better reflect the nuance of the discussion.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review E	088	031 - 032	Please consider adding a sentence here to state - *electrical stimulation devices are contraindicated for certain populations.*	Thank you for your comment. The committee focused on highlighting the populations that would benefit from electrical stimulation, rather than those that do not respond well to the intervention. Therefore, no change has been made.

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The International FES Society (IFESS) UK and Ireland chapter.	Evidence Review E	089	029	The report states that no economic evaluations were found for this categories of intervention. However, Renfrew 2019 includes such an evaluation. If the reviewers may have excluded this, it should be stated that it has been excluded and the reasons given for its exclusions. There are an additional two published reports of economic evaluation of FES in the review period, Taylor 2013 and Jukes 2019. While the reviewers may consider these studies to be of low quality, they do exist and the reason for their rejection should be stated. Taylor P, Humphreys L, and Swain I, The long-term cost-effectiveness of the use of functional Electrical stimulation for the correction of dropped foot due to upper motor neuron lesion. J Rehabil Med 2013; 45: 154–160 Juckes FM, Marceniuk G, Seary C, Stevenson VL A cohort study of functional electrical stimulation in people with multiple sclerosis demonstrating improvements in quality of life and cost-effectiveness. Clin Rehabil. 2019 Apr 10:269215519837326.	Thank you for your comment. Listed below are the explanations for why each of your suggested papers were excluded: Taylor 2013 - economic studies older than 10 years were excluded due to costings not being relevant to the current NHS context. Also, this study included only intervention costs, whereas we are interested in assessing the impact of intervention on wider NHS and Personal Social Services costs. Renfrew 2019 - adopted a very narrow perspective, including only intervention costs, and therefore did not meet our inclusion criteria for economic studies. Jukes 2019 - same as Renfrew.
The International FES Society (IFESS) UK and Ireland chapter.	Evidence review E	101	Table 3	The exclusion of evidence from before 2013 appears arbitrary and is likely to bias the outcome of the review to interventions developed more recently.	Thank you for your comment. The 2013 date cut-off specified in the quantitative protocols is not arbitrary - it corresponds to a decade from when the protocols were drafted (2023). The aim of these reviews is to provide evidence to support recommendations on current practice, on emerging fields, or on controversial areas. The committee can use their experience and expertise to recommend standard practice that was developed over a decade ago if they feel it is an important area to address (for example, if at risk of being defunded or if there is inequality with access). The guideline committee were confident that limiting the date of published articles would not mean that they would risk missing valuable evidence or being unable to make recommendations on certain interventions.
The International FES Society (IFESS) UK and Ireland chapter.	Evidence review E	101	Table 3	The exclusion of case series data from the review is a serious omission. Case series data provides ecologically valid evidence for interventions used in clinical practice and hence are valuable to validate the results of RCTs.	Thank you for your comment. As a general rule, NICE guidelines do not consider case series data as it does not meet the methodological rigour of randomised controlled trials or controlled studies. They also do not allow for comparative analysis, which means they are not suited for effectiveness reviews. However, the guideline committee are always encouraged to take account of evidence from their own experience and expert knowledge, which can then be used to inform recommendations.
The International FES Society (IFESS) UK and Ireland chapter.	Evidence Review E	462	025	In Renfrew et (2019) (page 462 25FWT) the data selected for presentation is misleading because the orthotic effect is not given. The paper reports that participants consistently walked faster with FES than	Thank you for your comment. We have not presented the othotic effect, but we have clearly presented and labelled walking speed both with the orthotic and without the orthotic. Changes from baseline were only compared within

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				without FES, equalling or exceeding the minimum important clinical difference at each post baseline time point. For the AFO group the minimum important difference was not achieved at any time point and at 6 months was negative. It is a significant finding that the abandonment rate for AFOs was nearly twice that of FES devices and it is likely this may have biased the results.	these groupings, and neither met the NICE default minimum important difference of 0.5 standardised mean difference. Regarding your concern about dropouts due to assignment to group being significantly higher in the group receiving ankle-foot orthoses this has been noted in the risk of bias for this study, resulting in a high bias rating which informs the GRADE confidence rating of results. In light of your comment, we have added some further detail to the corresponding domain rating text to clarify how the reasons for exclusion between groups differ.
The Royal Hospital for Neuro-disability	Evidence Review E	744	General	The study by De Luca et al. (2020), which explored the impact of music-assisted therapy combined with treadmill training for Parkinson's patients, was excluded due to the use of an intervention "outside of protocol." However, the entire evidence base for Music Therapy and Neurologic Music Therapy was not included in the literature search. Notably, two included studies also combined musical elements with protocol-approved interventions, highlighting an inconsistency in selection criteria. These were: Hoang, Phu; Schoene, Daniel; Gandevia, Simon; Smith, Stuart; Lord, Stephen R; Effects of a home-based step training programme on balance, stepping, cognition and functional performance in people with multiple sclerosis--a randomized controlled trial.; Multiple sclerosis (Houndmills, Basingstoke, England); 2016; vol. 22 (no. 1); 94-103 and Song, Jooeun; Paul, Serene S; Caetano, Maria Joana D; Smith, Stuart; Dibble, Leland E; Love, Rachelle; Schoene, Daniel; Menant, Jasmine C; Sherrington, Cathie; Lord, Stephen R; Canning, Colleen G; Allen, Natalie E; Home-based step training using videogame technology in people with Parkinson's disease: a single-blinded randomised controlled trial.; Clinical rehabilitation; 2018; vol. 32 (no. 3); 299-311 This selective exclusion is concerning, and we strongly urge that research from the field of Music Therapy be reviewed and incorporated into the evidence base.	Thank you for your comment. We reviewed the exclusion and inclusion of the selected studies, and our decisions remain the same. De Luca was a mixed intervention, including treadmill gait training [in protocol] and rhythmic auditory stimulation [cueing is outside of protocol]. You are correct in that the other 2 papers included music, but the main reason it was included was that both games required accurate stepping movements, which mapped to our step training intervention group. The music aspect was a by-product of the videogame format of the intervention, and to increase engagement, rather than part of the intervention. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review H, about interventions to improve emotional health and wellbeing. On the basis of the evidence located in the review and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no changes have been made in light of your comment.
British Association for Music Therapy	Evidence Review E	744	General	The following study has been excluded from being considered: De Luca, Rosaria, Latella, Desiree, Maggio, Maria Grazia et al. (2020) Do patients with PD benefit from music assisted therapy plus treadmill-based gait training? An exploratory study focused on behavioural outcomes. The International journal of neuroscience 130(9): 933-940.	Thank you for your comment. We have reviewed the exclusion and inclusion of the selected studies, and our decisions remain the same. De Luca was a mixed intervention, including treadmill gait training [in protocol] and rhythmic auditory stimulation [cueing is outside of protocol]. You are correct in that the other 2 papers included music, but the main reason it was included was that both games required accurate stepping movements, which mapped to our step training intervention group. The music aspect

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				The reason given for this is: 'Intervention - Mixed intervention including components in protocol (treadmill-based gait training) and out of protocol (music assisted therapy).' However, the **entire** evidence base for Music Therapy and Neurologic Music Therapy™ was **not** included in the searches in the literature review. Two other studies which were included in this evidence review utilised a musical intervention alongside interventions stated in the protocol. These were: *Hoang, Phu; Schoene, Daniel; Gandevia, Simon; Smith, Stuart; Lord, Stephen R; Effects of a home-based step training programme on balance, stepping, cognition and functional performance in people with multiple sclerosis--a randomized controlled trial.; Multiple sclerosis (Houndmills, Basingstoke, England); 2016; vol. 22 (no. 1); 94-103* and *Song, Jooeun; Paul, Serene S; Caetano, Maria Joana D; Smith, Stuart; Dibble, Leland E; Love, Rachelle; Schoene, Daniel; Menant, Jasmine C; Sherrington, Cathie; Lord, Stephen R; Canning, Colleen G; Allen, Natalie E; Home-based step training using videogame technology in people with Parkinson's disease: a single-blinded randomised controlled trial.; Clinical rehabilitation; 2018; vol. 32 (no. 3); 299-311* It is highly concerning that not only was the evidence base for Music Therapy excluded, but that there is a discrepancy between studies being rejected for utilising a musical intervention where others have included music. We strongly urge that the inclusion of the research from the field of Music Therapy be considered and included in this evidence review.	was a by-product of the videogame format of the intervention, and to increase engagement, rather than part of the intervention. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review H, about interventions to improve emotional health and wellbeing. On the basis of the evidence located in the review and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no changes have been made in light of your comment.
The International FES Society (IFESS) UK and Ireland chapter.	Evidence Review E	General	General	The estimates of potential bias appear harsh. In rehabilitation, it is often not possible to blind the patient or the care provider to the intervention. Where possible blinded assessors should be used. However, this review rates such single blinded studies as at great risk of bias, which is surly over cautious. In clinical practice patients and providers are not blinded so it can be reasonably be argued that single blinded studies are likely to be more representative of clinical practice.	Thank you for your comments. We do agree that it can often be difficult for rehabilitation trials to blind participants, due to the nature of the interventions. We agreed that, in cases where patients or care providers were unblinded, but it was not possible to blind them, the domain would have been rated as 'some concerns'. However, this is only true if it is the only area of potential bias identified. If a paper has been rated as a high risk of bias in that domain, then there were additional considerations that resulted in the harsher rating. Any ratings were done in accordance with the Cochrane RoB2 (or CASP checklist for qualitative reviews) and were checked for consistency between reviewers.
Chiltern Music Therapy	Evidence Review E	General	General	There is no inclusion of 'Music Therapy', 'Neurologic Music Therapy®' or musical terms such as 'music', 'singing', 'rhythm' or Neurologic Music Therapy® techniques such as Rhythmic Auditory Stimulation® in any of	Thank you for your comment and your suggested music therapy studies, which were not located by this evidence review because music or creative therapies were not included in the protocol. The evidence reviews

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				the search criteria or protocol for this evidence base. This completely disregards and excludes the entirety of the research and evidence base for the Music Therapy profession and the successful care and treatment patients have received from this intervention. We recommend that the Music Therapy literature is included in the searches for this evidence review. **The following studies demonstrate positive outcomes in stability, mobility and upper limb function for patients with Spinal Injury and Acquired Brain Injury:** de l'Etoile, S.K. (2008). The effect of rhythmic auditory stimulation on the gait parameters of patients with incomplete spinal cord injury: an exploratory pilot study. International Journal of Rehabilitation Research, 31(2), pp.155–157. doi:https://doi.org/10.1097/mrr.0b013e3282fc0f44. Kim, S.J., Shin, Y.-K., Yoo, G.E., Chong, H.J. and Cho, S.-R. (2016). Changes in gait patterns induced by rhythmic auditory stimulation for adolescents with acquired brain injury. Annals of the New York Academy of Sciences, [online] 1385(1), pp.53–62. doi:https://doi.org/10.1111/nyas.13294. **The following studies demonstrate positive outcomes in stability, mobility and upper limb function for patients with Parkinson's Disease:** Capato, T.T.C., de Vries, N.M., IntHout, J., Barbosa, E.R., Nonnekes, J. and Bloem, B.R. (2020). Multimodal Balance Training Supported by Rhythmical Auditory Stimuli in Parkinson's Disease: A Randomized Clinical Trial. Journal of Parkinson's Disease, 10(1), pp.333–346. doi:https://doi.org/10.3233/jpd-191752. Chang, H.-Y., Lee, Y.-Y., Wu, R.-M., Yang, Y.-R. and Luh, J.-J. (2019). Effects of rhythmic auditory cueing on stepping in place in patients with Parkinson's disease. Medicine, [online] 98(45). doi:https://doi.org/10.1097/MD.0000000000017874. Cochen De Cock, V., Dotov, D., Damm, L., Lacombe, S., Ihalainen, P., Picot, M.C., Galtier, F., Lebrun, C., Giordano, A., Driss, V., Geny, C.,	underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review H, about interventions to improve emotional health and wellbeing. Therefore, the literature search designed for review E would not have picked up the studies you suggest. However, on the basis of the evidence located in review H and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no change has been made to evidence review E or to the recommendations on the basis of your comment.

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				Garzo, A., Hernandez, E., Van Dyck, E., Leman, M., Villing, R., Bardy, B.G. and Dalla Bella, S. (2021). BeatWalk: Personalized Music-Based Gait Rehabilitation in Parkinson's Disease. Frontiers in Psychology, 12. doi:https://doi.org/10.3389/fpsyg.2021.655121. de Dreu, M.J., van der Wilk, A.S.D., Poppe, E., Kwakkel, G. and van Wegen, E.E.H. (2012). Rehabilitation, exercise therapy and music in patients with Parkinson's disease: a meta-analysis of the effects of music-based movement therapy on walking ability, balance and quality of life. Parkinsonism & Related Disorders, 18(1), pp.S114–S119. doi:https://doi.org/10.1016/s1353-8020(11)70036-0. Freeman, J.S., Cody, F.W. and Schady, W. (1993). The influence of external timing cues upon the rhythm of voluntary movements in Parkinson's disease. Journal of Neurology, Neurosurgery & Psychiatry, 56(10), pp.1078–1084. doi:https://doi.org/10.1136/jnnp.56.10.1078. Kadivar, Z., Corcos, D.M., Foto, J. and Hondzinski, J.M. (2011). Effect of Step Training and Rhythmic Auditory Stimulation on Functional Performance in Parkinson Patients. Neurorehabilitation and Neural Repair, [online] 25(7), pp.626–635. doi:https://doi.org/10.1177/1545968311401627. Thaut, M.H., Rice, R.R., Braun Janzen, T., Hurt-Thaut, C.P. and McIntosh, G.C. (2018). Rhythmic auditory stimulation for reduction of falls in Parkinson's disease: a randomized controlled study. Clinical Rehabilitation, [online] 33(1), pp.34–43. doi:https://doi.org/10.1177/0269215518788615. Zhou, Z., Zhou, R., Wei, W., Luan, R. and Li, K. (2021). Effects of music-based movement therapy on motor function, balance, gait, mental health, and quality of life for patients with Parkinson's disease: A systematic review and meta-analysis. Clinical Rehabilitation, 35(7), p.026921552199052. doi:https://doi.org/10.1177/0269215521990526. **The following studies demonstrate positive outcomes in stability, mobility and upper limb function for patients with <u>Multiple Sclerosis</u>:**	

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The Royal Hospital for Neuro-disability	Evidence Review E	General	General	We are concerned that the exclusion of terms such as 'Music Therapy', 'Neurologic Music Therapy', 'music', 'singing', and 'rhythm' overlooks a well-established evidence base and the documented benefits these approaches offer to patients. We recommend that the Music Therapy literature is included in the searches for this evidence review. The following studies demonstrate positive outcomes in stability, mobility and upper limb function for patients with Parkinson's Disease: Freeman, J.S., Cody, F.W. and Schady, W. (1993). The influence of external timing cues upon the rhythm of voluntary movements in Parkinson's disease. Journal of Neurology, Neurosurgery & Psychiatry, 56(10), pp.1078–1084. doi:https://doi.org/10.1136/jnnp.56.10.1078. de Dreu, M.J., van der Wilk, A.S.D., Poppe, E., Kwakkel, G. and van Wegen, E.E.H. (2012). Rehabilitation, exercise therapy and music in patients with Parkinson's disease: a meta-analysis of the effects of music-based movement therapy on walking ability, balance and quality of life. Parkinsonism & Related Disorders, 18(1), pp.S114–S119. doi:https://doi.org/10.1016/s1353-8020(11)70036-0. Capato, T.T.C., de Vries, N.M., IntHout, J., Barbosa, E.R., Nonnekes, J. and Bloem, B.R. (2020). Multimodal Balance Training Supported by Rhythmical Auditory Stimuli in Parkinson's Disease: A Randomized Clinical Trial. Journal of Parkinson's Disease, 10(1), pp.333–346. doi:https://doi.org/10.3233/jpd-191752.	Thank you for your comment and your suggested music therapy studies, which were not located by this evidence review because music or creative therapies were not included in the protocol. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review H, about interventions to improve emotional health and wellbeing. Therefore, the literature search designed for review E would not have picked up the studies you suggest. However, on the basis of the evidence located in review H and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no change has been made to evidence review E or to the recommendations on the basis of your comment.

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Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

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British Association for Music Therapy	Evidence Review E	General	General	The British Association for Music Therapy is concerned that there is no inclusion of 'Music Therapy' or 'Neurologic Music Therapy™ or musical terms such as 'music', 'singing', 'rhythm' or Neurologic Music Therapy™ Techniques such as 'Rhythmic Auditory Stimulation' in any of the search	Thank you for your comment and your suggested music therapy studies, which were not located by this evidence review because music or creative therapies were not included in the protocol. The evidence reviews underpinning the guideline were designed to cover the broad population of

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British Association for Music Therapy	Evidence Review E	General	General	The British Association for Music Therapy is concerned that there is no inclusion of 'Music Therapy' or 'Neurologic Music Therapy™' or musical terms such as 'music', 'singing', 'rhythm' or Neurologic Music Therapy™ Techniques such as 'Rhythmic Auditory Stimulation' in any of the search criteria or protocol for this evidence base. This completely disregards and excludes the entirety of the research and evidence base for the Music Therapy profession and the successful care and treatment patients have benefitted from. The British Association for Music Therapy recommends that the Music Therapy literature is included in the searches for this evidence review. The following studies demonstrate positive outcomes in stability, mobility and upper limb function for patients with Multiple Sclerosis: Ghai, S. and Ghai, I. (2018). Effects of Rhythmic Auditory Cueing in Gait Rehabilitation for Multiple Sclerosis: A Mini Systematic Review and Meta-Analysis. *Frontiers in Neurology*, 9. doi:https://doi.org/10.3389/fneur.2018.00386. Conklyn, D., Stough, D., Novak, E., Paczak, S., Chemali, K. and Bethoux, F. (2010). A Home-Based Walking Program Using Rhythmic Auditory Stimulation Improves Gait Performance in Patients with Multiple Sclerosis: A Pilot Study. *Neurorehabilitation and Neural Repair*, 24(9), pp.835–842. doi:https://doi.org/10.1177/1545968310372139. M Shahraki, Sohrabi, M., Torbati, H.T., K Nikkhah and M NaeimiKia (2017). Effect of rhythmic auditory stimulation on gait kinematic parameters of patients with multiple sclerosis. *Journal of Medicine and Life*, [online] 10(1), p.33. Available at: https://pmc.ncbi.nlm.nih.gov/articles/PMC5304368/.	Thank you for your comment and your suggested music therapy studies, which were not located by this evidence review because music or creative therapies were not included in the protocol. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review H, about interventions to improve emotional health and wellbeing. Therefore, the literature search designed for review E would not have picked up the studies you suggest. However, on the basis of the evidence located in review H and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no change has been made to evidence review E or to the recommendations on the basis of your comment.
Chroma	Evidence Review E	General	General	The NICE review for mobility and upper-limb function focused on technologies and conventional physiotherapy methods (e.g. robotics, wearables, balance exercises, gait training) and did not consider music-based motor interventions. As a result, the evidence reviewed, though extensive, overlooks the contributions of rhythmic auditory stimulation and similar creative interventions. The external evidence strongly indicates that music and rhythm can enhance motor rehabilitation	Thank you for your comment and your suggested music therapy studies, which were not located by this evidence review because music or creative therapies were not included in the protocol. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The

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				outcomes. Rhythmic Auditory Stimulation (RAS), a core NMT technique, has been confirmed in multiple RCTs and meta-analyses to improve gait in neurological populations. For example, a meta-analysis by Spaulding et al. (2013) found that RAS significantly increased gait velocity and stride length in Parkinson's disease patients. Likewise, Ghai et al. (2018) reviewed gait training studies and reported that rhythmic cueing with music led to clinically meaningful improvements in walking speed, cadence, and balance across various conditions. In stroke rehabilitation, music-supported training for the upper limb has shown superior results: Schneider et al. (2010) demonstrated that stroke survivors who practiced simple melodies on instruments regained fine motor skills faster and more fully than those undergoing equivalent conventional motor training. These high-quality studies illustrate that Neurologic Music Therapy® techniques can yield significant improvements in mobility and limb function – outcomes that translate to greater safety (e.g. reduced fall risk) and independence. By facilitating better walking and arm use, music-based therapy contributes to functional goals in a way that is both clinically effective and potentially cost-effective (improved rehabilitation efficiency and long-term reductions in care needs). Integrating such evidence-backed creative therapies into practice would address gaps in the current guideline and align with NICE's emphasis on interventions that improve quality of life and functional ability in a measurable, sustainable manner.	committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review H, about interventions to improve emotional health and wellbeing. Therefore, the literature search designed for review E would not have picked up the studies you suggest. However, on the basis of the evidence located in review H and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no change has been made to evidence review E or to the recommendations on the basis of your comment.
Aquatic Therapy Association of Chartered Physiotherapists	Evidence Review E	General	General	Thank you for including the Aquatic Therapy Association of Chartered Physiotherapists (ATACP) as a stake holder for these Nice Guidelines. We as a professional network group would like to express the importance of aquatic therapy in rehabilitation for this patient group. Aquatic therapy is mentioned under Evidence Review E of the original document; there are many more recent articles that could be included in the new guidelines. We would appreciate the continued inclusion of aquatic therapy, expressing its importance in rehabilitation.	Thank you for your comment. Although you have mentioned there are many more recent articles that could be included in the guidelines, there are no references provided so we are unable to check them for eligibility. The committee were aware of the potential benefits of hydrotherapy but also noted that there is a significant cost to providing it as a rehabilitation intervention (for example, availability of pools, maintenance of pools, and recruitment of trained professionals). In the absence of strong effectiveness evidence identified by the review, the guideline committee were unable to issue a general recommendation on its use. However, they were aware that not issuing a recommendation could risk decommissioning of these valuable services. Therefore, they recommended that hydrotherapy be considered for inclusion in rehabilitation programmes where it is available. This recommendation is in the section on stability, mobility and limb function.

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Chiltern Music Therapy	Evidence Review F	General	General	There is no inclusion of 'Music Therapy' or 'Neurologic Music Therapy®' in any of the search criteria for this evidence base. This completely disregards and excludes the entirety of the research and evidence base for the Music Therapy profession and the successful care and treatment patients have benefitted from, including from specific NMT™ speech & language techniques (e.g. Rhythmic Speech Cueing®, Therapeutic Singing™ and Oral and Motor Respiratory Exercises®) which have demonstrated positive outcomes in speech, language and communication for patients who require respiratory support as well as those with Aphasia, Dysarthria, Respiratory Support (required for speech production) or Apraxia of Speech. **Supporting research:** Azekawa, M. and Lagasse, A.B. (2017). Singing Exercises for Speech and Vocal Abilities in Individuals with Hypokinetic Dysarthria: A Feasibility Study. Music Therapy Perspectives, 36(1), pp.40–49. doi:https://doi.org/10.1093/mtp/miw042. Ang, K., Maddocks, M., Xu, H. and Higginson, I.J. (2017). The Effectiveness of Singing or Playing a Wind Instrument in Improving Respiratory Function in Patients with Long-Term Neurological Conditions: A Systematic Review. Journal of Music Therapy, 54(1), pp.108–131. doi:https://doi.org/10.1093/jmt/thx001. Brendel, B. and Ziegler, W. (2008). Effectiveness of metrical pacing in the treatment of apraxia of speech. Aphasiology, 22(1), pp.77–102. doi:https://doi.org/10.1080/02687030600965464. Marchina, S., Norton, A. and Schlaug, G. (2022). Effects of melodic intonation therapy in patients with chronic nonfluent aphasia. Annals of the New York Academy of Sciences, 1519(1). doi:https://doi.org/10.1111/nyas.14927. Racette, A. (2006). Making non-fluent aphasics speak sing along! Brain, 129(10), pp.2571–2584. doi:https://doi.org/10.1093/brain/awl250. Schlaug, G., Marchina, S. and Norton, A. (2009). Evidence for Plasticity in White-Matter Tracts of Patients with Chronic Broca's Aphasia Undergoing Intense Intonation-based Speech Therapy. Annals of the	Thank you for your comment and your suggested music therapy studies, which were not located by this evidence review because music or creative therapies were not included in the protocol. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review H, about interventions to improve emotional health and wellbeing. Therefore, the literature search designed for review F would not have picked up the studies you suggest. However, on the basis of the evidence located in review H and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no change has been made to evidence review F or to the recommendations on the basis of your comment.

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The Royal Hospital for Neuro-disability	Evidence Review F	General	General	We are concerned that the exclusion of terms such as 'Music Therapy', 'Neurologic Music Therapy', 'music', 'singing', and 'rhythm' and specific techniques used in the Neurologic Music Therapy such as 'Rhythmic Speech Cueing', 'Therapeutic Singing' and 'Oral and Motor Respiratory Exercises'. This overlooks a well-established evidence base and the documented benefits these approaches offer to patients. We recommend that the Music Therapy literature is included in the searches for this evidence review. The following studies, for example, demonstrate positive outcomes in speech, language and communication for patients who require respiratory support as well as those with Aphasia, Dysarthria, Respiratory Support (required for speech production) or Apraxia of Speech: Brendel, B. and Ziegler, W. (2008). Effectiveness of metrical pacing in the treatment of apraxia of speech. Aphasiology, 22(1), pp.77–102. doi:https://doi.org/10.1080/02687030600965464. Schlaug, G., Marchina, S. and Norton, A. (2009). Evidence for Plasticity in White-Matter Tracts of Patients with Chronic Broca's Aphasia Undergoing Intense Intonation-based Speech Therapy. Annals of the New York Academy of Sciences, 1169(1), pp.385–394. doi:https://doi.org/10.1111/j.1749-6632.2009.04587.x. Marchina, S., Norton, A. and Schlaug, G. (2022). Effects of melodic intonation therapy in patients with chronic nonfluent aphasia. Annals of the New York Academy of Sciences, 1519(1). doi:https://doi.org/10.1111/nyas.14927.	Thank you for your comment and your suggested music therapy studies, which were not included in this evidence review as they didn't meet the inclusion criteria of the protocol: Azekawa et al 2017 - not a RCT and therefore didn't meet the study design inclusion criteria for adults in the protocol. Ang et al 2017, Schlaug et al 2009 - outcomes not of interest for protocol - improvement in respiratory function. Brendel et al 2008, Racette et al 2006 - published prior to 2013 and excluded from the protocol. Marchina et al 2022 and Van der Meulen et al 2014 - population was post-stroke aphasia in adults and this population was excluded from the protocol. However, please note that creative therapies (which would encompass music therapy) were included as an intervention category in review H, about interventions to improve emotional health and wellbeing. On the basis of the evidence located in review H and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no change has been made to evidence review F or to the recommendations on the basis of your comment.

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British Association for Music Therapy	Evidence Review F	General	General	The British Association for Music Therapy is concerned that there is no inclusion of 'Music Therapy' or 'Neurologic Music Therapy™' or musical terms such as 'music', 'singing', 'rhythm' in any of the search criteria for this evidence base. Specific techniques used in the Neurologic Music Therapy™ was also excluded, and could have used 'Rhythmic Speech Cueing', 'Therapeutic Singing' and 'Oral and Motor Respiratory Exercises' to name a few. This completely disregards and excludes the entirety of the research and evidence base for the Music Therapy profession and the successful care and treatment patients have benefitted from. Music Therapy includes the specialist field of Neurologic Music Therapy™. This is an established intervention within neurorehabilitation services across the UK, including in the NHS, Private Healthcare and Community Healthcare Neurorehabilitation. The British Association for Music Therapy recommends that the Music Therapy literature is included in the searches for this evidence review. The following studies, for example, demonstrate positive outcomes in speech, language and communication for patients who require respiratory support as well as those with Aphasia, Dysarthria, Respiratory Support (required for speech production) or Apraxia of Speech:	Thank you for your comment and your suggested music therapy studies, which were not included in this evidence review as they didn't meet the inclusion criteria of the protocol: Azekawa et al 2017 - not a RCT and therefore didn't meet the study design inclusion criteria for adults in the protocol. Ang et al 2017, Schlaug et al 2009 - outcomes not of interest for protocol - improvement in respiratory function. Brendel et al 2008, Racette et al 2006 - published prior to 2013 (protocol cut-off date). Marchina et al 2022 - population was post-stroke aphasia in adults and this population was excluded from the protocol. However, please note that creative therapies (which would encompass music therapy) were included as an intervention category in review H, about interventions to improve emotional health and wellbeing. On the basis of the evidence located in review H and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no change has been made to evidence review F or to the recommendations on the basis of your comment.

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Chroma	Evidence Review F	General	General	The NICE review acknowledges that "little is known about which interventions may best help" people with communication difficulties in chronic neurological conditions, reflecting a lack of clear guidance or comparative evidence in this area (NICE 2025). Indeed, traditional speech and language therapy approaches have varying success, and the evidence base in the review was limited. In contrast, there is significant evidence that music therapy can effectively improve communication outcomes – especially in cases where conventional therapies struggle. One high-quality example is in post-stroke aphasia: a Cochrane review (Magee et al., 2017) found that music-based interventions (such as melodic intonation therapy and therapeutic singing) led to better communication ability for people with aphasia compared to standard care. Clinical studies also support music therapy for speech: Baker et al. (2005) reported that a song-singing program improved the affective intonation of speech and elevated mood in people with TBI, indicating gains in both communication prosody and psychological state. For motor speech disorders, a pilot RCT by Tamplin (2008) showed significant improvements in speech intelligibility and naturalness in neurological patients with dysarthria after a singing-based intervention, whereas no such gains were seen in the control condition. Additionally, a narrative review by Leonardi et al. (2018) highlights that music therapy can facilitate language recovery by engaging neural mechanisms of language through melody and rhythm. Together, this body of evidence demonstrates that creative arts therapies like music therapy directly address speech and communication goals with proven efficacy. These interventions fulfil NICE's effectiveness criteria, using evidence-based techniques to achieve meaningful improvements in communication skills, and they can be integrated into rehabilitation at relatively low cost (for example, group music therapy for communication can complement standard speech therapy, extending reach to those who cannot engage in purely verbal therapy).	Thank you for your comment and your suggested music therapy studies, which were not included in this evidence review as they didn't meet the inclusion criteria of the protocol: Magee et al 2017 - 25 studies had a population of stroke in adults and this population was excluded from the protocol; 4 studies had a population of ABI and were excluded (Baker 2001 - pre-2013 publication; Fernandes 2014, O'Kelly 2014 - outcomes not relevant to any protocols as covered vital signs, facial expressions and neurophysiological outcomes; Mueller 2013 - conducted in the USA) Baker et al 2005 and Tamplin et al 2008 - published prior to 2013 and were excluded from the protocol. Leonardi et al 2018 - not a RCT and therefore didn't meet the study design inclusion criteria for adults in the protocol. However, please note that creative therapies (which would encompass music therapy) were included as an intervention category in review H, about interventions to improve emotional health and wellbeing. On the basis of the evidence located in review H and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no change has been made to evidence review F or to the recommendations on the basis of your comment.
Recolo UK	Evidence Review G	047	020 - 022	From our knowledge and experience, the importance of emphasis on integrating assessment, planned intervention and strategies with real-world context, adaptive life skill development and within person-centred goals, to support engagement.	Unfortunately, we are unable to tell from your comment exactly what it is you are hoping we can change. Our best guess is that you are emphasising the importance of integrated assessments conducted in the context of the person's life, goals and aspirations. The committee are aware of the importance of taking this approach and made a number of

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					recommendations including to ensure that rehabilitation services are designed and developed in partnership with the people who use them and their families and carers, and health and mental health and social care practitioners. There is also a recommendation that highlights designing rehabilitation services for people with CND that operate across hospital and community settings, including people's homes and where they work, learn and undertake daily activities. Furthermore, we have recommendations specifically regarding assessment to offer the person and their family and carers a discussion soon after injury or diagnosis about their prognosis and rehabilitation needs as well as if the person does not want to discuss their prognosis to offer and initiate further opportunities for discussions. There is also a section in the guideline which focuses on holistic rehabilitation needs assessment which includes 26 further recommendations to ensure that assessments are integrated and person-centred.
Recolo UK	Evidence Review G	049	023	Just to emphasise that from our knowledge and experience working in paediatric rehabilitation, the family's role is **vital** in the rehabilitation process.	Thank you for your comment and you support for the importance of family in the rehabilitation process. We have evidence and the committees' knowledge and experience also supporting this.
Chiltern Music Therapy	Evidence Review G	General	General	There is no inclusion of 'Music Therapy' or 'Neurologic Music Therapy®' in any of the search criteria for this evidence base. Specific NMT™ cognitive techniques were also excluded, such as 'Musical Attention Control Training®, Musical Mnemonics Training®, Musical Executive Functioning Training® and Musical Neglect Training®. The following studies demonstrate positive outcomes in cognitive function such as attention, memory, neglect and executive function: Impellizzeri, F., Leonardi, S., Latella, D., Maggio, M.G., Foti Cuzzola, M., Russo, M., Sessa, E., Bramanti, P., De Luca, R. and Calabrò, R.S. (2020). An integrative cognitive rehabilitation using neurologic music therapy in multiple sclerosis. Medicine, 99(4), p.e18866. doi:https://doi.org/10.1097/md.0000000000018866. Knox, R., Yokota-Adachi, H., Kershner, J. and Jutai, J. (2003). Musical Attention Training Program and Alternating Attention in Brain Injury: An Initial Report. Music Therapy Perspectives, 21(2), pp.99–104. doi:https://doi.org/10.1093/mtp/21.2.99. Làdavas, E., Tosatto, L. and Bertini, C. (2020). Behavioural and functional changes in neglect after multisensory stimulation. Neuropsychological Rehabilitation, pp.1–28. doi:https://doi.org/10.1080/09602011.2020.1786411.	Thank you for your comment. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review, H about interventions to improve emotional health and wellbeing. On the basis of the evidence located in the review and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. For completeness, here are the reasons the suggested references did not meet the inclusion criteria of the protocol: Impellizzeria et al. 2020 does not include an intervention that fits one of the 7 protocol intervention groups (intervention is broadly aimed at cognition but further specifics provided), Ladavas et 2020 does not contain an intervention specifically aimed at improving cognitive function, Thaut et al. 2014 was conducted in the US and Knox et al. 2014 does not report any relevant outcomes.

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				Thaut, M.H., Peterson, D.A., McIntosh, G.C. and Hoemberg, V. (2014). Music mnemonics aid Verbal Memory and Induce Learning â€“ Related Brain Plasticity in Multiple Sclerosis. Frontiers in Human Neuroscience, 8. doi:https://doi.org/10.3389/fnhum.2014.00395.	
The Royal Hospital for Neuro-disability	Evidence Review G	General	General	We are concerned that the exclusion of terms such as 'Music Therapy', 'Neurologic Music Therapy', 'music', 'singing', and 'rhythm' and specific techniques used in the Neurologic Music Therapy such Musical Attention Control Training', 'Musical Mnemonics Training', 'Musical Executive Functioning Training' or 'Musical Neglect Training'. This overlooks a well-established evidence base and the documented benefits these approaches offer to patients. We recommend that the Music Therapy literature is included in the searches for this evidence review. The following studies, for example, demonstrate positive outcomes in cognitive function such as attention, memory, neglect and executive function: Knox, R., Yokota-Adachi, H., Kershner, J. and Jutai, J. (2003). Musical Attention Training Program and Alternating Attention in Brain Injury: An Initial Report. Music Therapy Perspectives, 21(2), pp.99–104. doi:https://doi.org/10.1093/mtp/21.2.99. Thaut, M.H., Peterson, D.A., McIntosh, G.C. and Hoemberg, V. (2014). Music mnemonics aid Verbal Memory and Induce Learning â€“ Related Brain Plasticity in Multiple Sclerosis. Frontiers in Human Neuroscience, 8. doi:https://doi.org/10.3389/fnhum.2014.00395. Làdavas, E., Tosatto, L. and Bertini, C. (2020). Behavioural and functional changes in neglect after multisensory stimulation. Neuropsychological Rehabilitation, pp.1–28. doi:https://doi.org/10.1080/09602011.2020.1786411. Impellizzeri, F., Leonardi, S., Latella, D., Maggio, M.G., Foti Cuzzola, M., Russo, M., Sessa, E., Bramanti, P., De Luca, R. and Calabrò, R.S. (2020). An integrative cognitive rehabilitation using neurologic music	Thank you for your comment. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review H, about interventions to improve emotional health and wellbeing. On the basis of the evidence located in the review and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. For completeness, here are the reasons the suggested references did not meet the inclusion criteria of the protocol: Impellizzeria et al. 2020 does not include an intervention that fits one of the 7 protocol intervention groups (intervention is broadly aimed at cognition but further specifics provided), Ladavas et 2020 does not contain an intervention specifically aimed at improving cognitive function, Thaut et al. 2014 was conducted in the US and Knox et al. 2014 does not report any relevant outcomes.

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				therapy in multiple sclerosis. Medicine, 99(4), p.e18866. doi:https://doi.org/10.1097/md.0000000000018866.	
Recolo UK	Evidence Review G	General	General	Albeit that this is data from the US, we really wanted to showcase TOPS as an example of international research that could inform guidelines and clinical practice: About TOPS – TOPS 4 All Kurowski BG, Wade SL, Kirkwood MW, Brown TM, Stancin T, Taylor HG. Online problem-solving therapy for executive dysfunction after child traumatic brain injury. Pediatrics. 2013;132(1):e158–e166. doi: 10.1542/peds.2012-4040. Wade SL, Walz NC, Carey J, Williams KM, Cass J, Herren L, Yeates KO. A randomized trial of teen online problem solving for improving executive function deficits following pediatric traumatic brain injury. The Journal of Head Trauma Rehabilitation. 2010;25:409–415. doi: 10.1097/HTR.0b013e3181fb900d. Wade SL, Walz NC, Carey JC, Williams KM. Preliminary efficacy of a Web-based family problem-solving treatment program for adolescents with traumatic brain injury. The Journal of Head Trauma Rehabilitation. 2008;23:369–377. doi: 10.1097/01.HTR.0000341432.67251.48. A key set of evidence from the US (Shari Wade's group) on the effectiveness of working with EF, using a family-approach TOPS-Fwhich although as a package is not yet available here, we can apply much of the 'problem solving' toolbox for teens (and their families). There are in our view links between cognitive interventions and educational interventions, which did not seem to be included or	Thank you for your comment and highlighting this evidence. Although these are interesting and valuable studies, we are unable to include these US studies as they do not meet protocol inclusion criteria. The GC designed the review protocol limiting studies to those conducted in similar healthcare contexts so that the evidence would be relevant to the UK context and a sound basis for making recommendations.

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				cross-referenced as a key environment for learning cognitive (and academic) skills for CYP. Nothing on children whose learning is still developing and are being educated and where there is evidence around approaches such as errorless learning and many other educational-focussed interventions.	
Chroma	Evidence Review G	General	General	The NICE evidence review on cognitive rehabilitation found no clear benefits of the interventions studied, with many comparisons showing "no important differences between groups" and overall evidence judged to be very low quality (often single, underpowered studies). In fact, for several cognitive domains (such as social cognition and orientation) the review identified no evidence at all, highlighting a considerable gap in high-quality research. By contrast, there is growing robust evidence that music therapy – particularly Neurologic Music Therapy® techniques – can significantly improve cognitive outcomes in neurological conditions. A landmark RCT by Särkämö et al. (2008) demonstrated that stroke patients receiving daily music exposure achieved greater improvements in cognitive function (notably verbal memory and focused attention) compared to standard care. In traumatic brain injury, a recent controlled trial (reported in Siponkoski, 2022) showed that Neurologic Music Therapy® led to significant gains in executive functions (like cognitive flexibility and attentional control) alongside measurable neural network changes, whereas those without music intervention showed far less improvement. These results align with broader reviews of the literature (e.g. Sihvonen et al., 2017 in *Lancet Neurology*), which conclude that music-based interventions engage attention and memory circuits to enhance cognitive rehabilitation. The strong outcomes from these studies meet NICE's clinical-effectiveness criteria by providing evidence from RCTs and systematic reviews, and suggest that incorporating music therapy could address the evidence gap in cognitive rehabilitation – potentially offering a cost-effective option given its ability to improve cognitive engagement and functional independence in the long term.	Thank you for your comment. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review, H about interventions to improve emotional health and wellbeing. On the basis of the evidence located in the review and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation.
The British Psychological Society	Evidence Review G	General	General	This review seems to mix interventions specifically directed at improving cognitive ability such as computerised cognitive training (practice of cognitive tasks) and rehabilitation interventions aimed at improving functioning in areas affected by cognitive disability, such as activities of	Thank you for your comment. This review addressed a large, complex area of rehabilitation including a broad population and wide range of interventions. The committee had to agree a way in which to describe and group interventions for analysis and chose to do so in the following way:

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				daily living or everyday activities. These two types of approach should be considered separately.	Interventions to improve and maintain executive function, Interventions to improve processing speed, Interventions to improve memory and learning, Interventions to improve social cognition, Interventions to improve visual, spatial and perceptual functions, Interventions to support orientation, and Interventions to improve attention. They grouped interventions this way as this is the way in which they hoped to make recommendations. They were possibly other ways in which intervention could have been grouped; however this approach suited the committee's purpose most.
The UK FND Network	Evidence Review H	006	018	Evidence review for emotional health and wellbeing. Search strategy Although emotional health and wellbeing is as relevant in FND as in other neurological conditions, the sole focus on this aspect of psychological/psychiatric care results in the omission of the (in FND much more important) field of psychological/psychiatric therapy as a disease-modifying treatment. This point could be expanded to emphasise that the biopsychosocial nature of the condition in FND often requires a coordinated multi-disciplinary approach to disease-modifying therapies more so than in other conditions i.e. multidisciplinary psychological/psychiatric, physiotherapeutic, occupational therapy, speech and language therapy, and medical treatments. So that the division of the evidence reviews into separate disciplines/areas does not capture this aspect of FND, and consideration might have been given about how to remedy this with review of multi-disciplinary approaches.	Thank you for your comment. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. However, the committee were acutely aware of the importance of multi-disciplinary rehabilitation for people with chronic neurological disorders and although there was not a specific review on multi-disciplinary approaches (considered to be unmanageable for such a broad population), the committee placed great emphasis in the recommendations on holistic approaches to assessment and rehabilitation. The committee were confident that the guideline as a whole would ensure the involvement of all relevant professionals as well as coordination and communication between services, organised around individual need.
EMDR UK	Evidence Review H	008	003	There is an "Error! Reference source not found." Message where the summary of included studies should be linked to.	Thank you for your comment. There isn't usually a link to table 2 in the included studies of the effectiveness evidence, it is a reference to look in the table. We have removed the error message.
The UK FND Network	Evidence Review H	009	007	The Goldstein et al., 2021 study is mischaracterised as an 'intervention for adjustment and engagement', and selected secondary outcomes are listed as though they were primary outcomes. This was not an adjustment study but a treatment study of functional seizures with primary outcome of seizure frequency. This is perhaps an artefact of the search strategy which focussed on adjustment and engagement and did not consider treatment studies.	Thank you for your comment. We agree that occasionally the studies don't fit perfectly into the pre-specified categories in the protocol, however we took the pragmatic approach to include Goldstein et al 2021 under interventions for adjustment and engagement rather than excluding the study from the evidence review and guideline altogether.
Brain Injury Social Work Group	Evidence Review H	024	019	I thought it's an excellent document. I haven't added points to the form as there isn't really a specific point I wanted to comment on, but two general comments. page 24, line 19 talks about the person's ability to get in contact. I wonder if there also needs to be a point on the organisations ability to respond positively to that initial contact? The other point is that they clearly conducted a detailed systematic review,	Thank you for your comment. We have amended the intervention category from mindfulness to CBT throughout the evidence report. In terms of some inaccuracy in the summary of the study "showed no important difference compared with control in terms of physical and mental health related quality of life and distress", we agree that there is a statistical

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				which is very impressive, but then many of the recommendations were made based on the expertise of the committee, as the findings from the literature review were not strong enough. It seemed incongruous to go from meta-analysis of the literature to expert opinion.	significance in favour of active treatment on the measure of distress (CORE-10), however as referenced in the guideline methods supplement an important benefit is characterised as a standard mean difference of ≥0.5, whereas the difference for CORE-10 was 0.25 in favour of active treatment, thus was categorised as no important difference in line with NICE methods. With respect to other relevant measures showing a significant difference but not being reported and potential selective reporting, outcomes were only reported if they were prioritised as critical and important by the guideline committee, which is described in the protocol, which was drafted before conducting the systematic review. Reporting outcomes in the systematic review which were not included in the protocol would be deemed selective reporting i.e. seizure frequency. We understand your concerns regarding only reporting the study's secondary outcomes, therefore have added further details to the committee's discussion of the evidence to highlight that some study outcomes including primary outcomes may have shown a benefit for CBT, however, were not extracted for our review as they did not meet our protocol criteria. Finally, in terms of the control arm having active components, which may result in the intervention and control having effects, this was seen in a number or trials and not just pertinent to Goldstein 2021. This is already highlighted in the committee's discussion of the quality of the evidence, where heterogeneity may be due to differences in standard care in the control arm.
The UK FND Network	Evidence Review H	024	025 - 027	"A mindfulness intervention for adults with functional neurological disorders showed no important difference compared with control in terms of physical and mental health related quality of life and distress" There are some errors and omissions in this statement: • It is initially confusing as there is no mindfulness intervention for adults with FND in the listed studies. This must be referring to the only FND-specific study, the Goldstein et al., 2021 study, which used a CBT intervention. • There is some inaccuracy in the summary of the study: "showed no important difference compared with control in terms of physical and mental health related quality of life and distress". First, there was in fact a significant difference in	Thank you for your comment. We have amended the intervention category from mindfulness to CBT throughout the evidence report. In terms of some inaccuracy in the summary of the study "showed no important difference compared with control in terms of physical and mental health related quality of life and distress", we agree that there is a statistical significance in favour of active treatment on the measure of distress (CORE-10), however as referenced in the guideline methods supplement an important benefit is characterised as a standard mean difference of ≥0.5, whereas the difference for CORE-10 was 0.25 in favour of active treatment, thus was categorised as no important difference in line with NICE methods. With respect to other relevant measures showing a significant difference but not being reported and potential selective reporting, outcomes were

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				favour of the active treatment on the measure of distress (CORE-10), although perhaps here the intention may have been in relation to the measures of anxiety and depression, the confidence intervals of which cross the zero-effect mark. Second, it is true that there was no significant difference on the SF12 Physical and Mental component scores, but other relevant measures did show a significant difference in favour of the active treatment. There appears to be some selective reporting of outcomes in this summary. • The primary outcome was seizure frequency at 12 months and this is not reported. Here there was no statistically significant difference between treatment and control. But the key point is that both arms showed improvement, and the control arm (treatment as usual) was not typical in that it provided substantially better treatment than usually available in most services, so this needs further research. Also, seizure frequency at 6 months showed a statistically significant difference in favour of the active condition. A more nuanced summary would reflect the fact that the active treatment was superior to control on a number of secondary outcomes, including measures of wellbeing, and seizure frequency at six months but not 12, that the control arm may have had active components, and that seizure frequency reduced in both arms of the study at 12 months.	only reported if they were prioritised as critical and important by the guideline committee, which is described in the protocol, which was drafted before conducting the systematic review. Reporting outcomes in the systematic review which were not included in the protocol would be deemed selective reporting i.e. seizure frequency. We understand your concerns regarding only reporting the study's secondary outcomes, therefore have added further details to the committee's discussion of the evidence to highlight that some study outcomes including primary outcomes may have shown a benefit for CBT, however, were not extracted for our review as they did not meet our protocol criteria. Finally, in terms of the control arm having active components, which may result in the intervention and control having effects, this was seen in a number or trials and not just pertinent to Goldstein 2021. This is already highlighted in the committee's discussion of the quality of the evidence, where heterogeneity may be due to differences in standard care in the control arm.
South London and Maudsley NHS Foundation Trust	Evidence Review H	024	025 - 027	This refers to a study in mindfulness for adults with functional neurological disorder. The only study included relating to FND was Goldstein et al, 2021. The intervention here was CBT, not mindfulness.	Thank you for your comment. We have amended the intervention category from mindfulness to CBT throughout the evidence report.
Recolo UK	Evidence Review H	032	009 - 013	In total agreement with this statement and a vital part of rehabilitation. *"Considering that rehabilitation for a person with CND is an iterative process that requires a feedback loop to develop and progress, family are a key part of that. Therefore, the committee recommended family, carers and other social networks be involved and integrated when agreeing the most appropriate interventions for emotional health and wellbeing interventions".*	Thank you for your support for this recommendation.
Chiltern Music Therapy	Evidence Review H	035	007	This concern pertains to lines 7–32. In lines 7–10, the document states: *"the committee noted music therapy was the only area of creative therapies that evidence was identified in the review. For these reasons,*	Thank you for your comment. We have amended the wording in the committee's discussion of evidence to better reflect the discussion - "The committee discussed the evidence identified for creative therapies on

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				the committee decided not to use the evidence and instead use their collective experience and expertise when making their recommendations on creative therapies." This is highly troubling. It reflects a lack of understanding of Music Therapy as a distinct HCPC-registered profession, which is formally recognised as both an Allied Health Profession and a Psychological Profession. It also highlights a concerning subjectivity in the committee's decision to dismiss evidence that had already been submitted and accepted as part of the review process. The term 'Creative Therapist' is not a protected or regulated title in the UK. Similarly, 'creative therapies' is not a formally recognised professional category. It is a service-level descriptor used to group professions such as Music, Art, Drama, and Dance & Movement Therapy. There is no overarching professional body governing 'creative therapies' as a whole, and neither the British Association for Music Therapy nor the HCPC use this terminology. The evidence reviewed and accepted in this process pertained specifically to Music Therapy, not to a broader collection of professions. Between lines 11–32, the language alternates inconsistently between 'Music Therapy' and 'creative therapies. Yet, the literature reviewed does not represent a collection of therapies—it pertains exclusively to Music Therapy. This inconsistency is particularly concerning in lines 20–22, where it states: *"the committee recommended the use of creative therapies for people who have difficulty engaging in talking therapies due to cognitive or communication difficulties, or for those where speaking is not their preferred way of communicating."* We would strongly urge that future guidelines make this distinction clearer and more accurate. On what basis is this recommendation for 'creative therapies' made? And why is Music Therapy not explicitly named, given that it was the sole contributor to the evidence base supporting improved emotional wellbeing in individuals with chronic neurological conditions, such as acquired brain injury? Referring to an undefined and unregulated	emotional health and wellbeing in CND. The committee emphasised that music therapy was the only area of creative therapies that evidence was identified in the review, however the music therapy in the studies were not interventions that were usually used in clinical practice to enhance emotional health and wellbeing, as their primary aim was to improve cognition. For these reasons, the committee decided not to use the evidence and instead use their collective experience and expertise when making their recommendations on creative therapies, described below". We understand your concerns about evidence being dismissed and subjectively excluded, however given the primary aim of the studies was to improve cognition rather than emotional health and wellbeing, the committee agreed that the evidence wasn't strong enough to make specific recommendations pertaining to music therapy. Occasionally studies don't fit perfectly into the pre-specified categories in the protocol, however we took the pragmatic approach to include the studies on music therapy in the review on emotional health and wellbeing rather than excluding the studies from the evidence review and guideline altogether. In relation to Music therapy being a distinct health and care professionals (HCPC) registered profession, we have added music, art and drama as examples of creative therapies in the recommendations and have added music therapists, art therapists and drama therapists to the glossary (all registered HCPC professions).

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				category such as 'creative therapies' risks promoting interventions that do not meet NICE evidence standards. This misrepresentation is disappointing, and we strongly urge the committee to reconsider and revise the language used in this recommendation to accurately reflect the evidence and professional scope of Music Therapy.	
The Royal Hospital for Neuro-disability	Evidence Review H	035	007	It is stated that although Music Therapy was the only creative therapy with evidence identified the committee chose to disregard it in favour of their own expertise. This is highly troubling and suggests a lack of understanding of Music Therapy as a regulated, HCPC-registered Allied Health and Psychological Profession. The term 'creative therapies' is not a protected or formally recognised professional category in the UK. It is not used by the British Association for Music Therapy or the HCPC and has no regulatory body. The evidence reviewed related solely to Music Therapy, not to other modalities grouped under this broad term. The document inconsistently switches between 'Music Therapy' and 'creative therapies', despite only Music Therapy contributing evidence. This is especially problematic in lines 20–22, where a recommendation is made for 'creative therapies' without clarifying that the evidence basis applies only to Music Therapy. Why is Music Therapy not specifically named in the recommendation when it is the sole source of evidence? Using a vague and unregulated term risks endorsing interventions that have not met NICE standards. We strongly recommend that this recommendation be revised to accurately reflect the profession and evidence presented.	Thank you for your comment. We have amended the wording in the committee's discussion of evidence to better reflect the discussion - "The committee discussed the evidence identified for creative therapies on emotional health and wellbeing in CND. The committee emphasised that music therapy was the only area of creative therapies that evidence was identified in the review, however the music therapy in the studies were not interventions that were usually used in clinical practice to enhance emotional health and wellbeing, as their primary aim was to improve cognition. For these reasons, the committee decided not to use the evidence and instead use their collective experience and expertise when making their recommendations on creative therapies, described below". We understand your concerns about evidence being dismissed and subjectively excluded, however given the primary aim of the studies was to improve cognition rather than emotional health and wellbeing, the committee agreed that the evidence wasn't strong enough to make specific recommendations pertaining to music therapy. Occasionally studies don't fit perfectly into the pre-specified categories in the protocol, however we took the pragmatic approach to include the studies on music therapy in the review on emotional health and wellbeing rather than excluding the studies from the evidence review and guideline altogether. In relation to Music therapy being a distinct health and care professionals (HCPC) registered profession, we have added music, art and drama as examples of creative therapies in the recommendations and have added music therapists, art therapists and drama therapists to the glossary (all registered HCPC professions).
EMDR UK	Evidence Review H	043 - 053	General	Caregivers are not mentioned in the population inclusion/exclusion criteria. However, a search terms related to this population are included in the search strategies. Some studies included this population, so it is unclear how studies about caregivers were handled – whether solely this population or a mixed population with adults/children with rehabilitation needs due to chronic neurological disorders.	Thank you for your comment. Alongside critical and important outcomes for people with CND, the committee also prioritised caregiver quality of life as an important outcome for this evidence review. Studies reporting quality of life for caregivers (using a validated, global measure) of people with CND were searched for and included in the evidence review. Studies reporting outcome's other than quality of life for caregivers of people with CND were not included in the evidence review.

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EMDR UK	Evidence Review H	053 - 070	General	Search filters used should be cited in accordance with PRISMA-S guidance: *"Indicate whether published search filters were used (as originally designed or modified), and if so, cite the filter(s) used."*	Thank you for your comment. This information has been added to the methods supplement.
EMDR UK	Evidence Review H	053 - 070	General	All databases should state the platform used to search them in accordance with PRISMA-S guidance: *"Name each individual database searched, stating the platform for each."* Without this information the search is neither transparent nor fully reproducible.	Thank you for your comment. This information has been added to the methods supplement.
EMDR UK	Evidence Review H	053 - 070	General	Eye Movement Desensitisation and Reprocessing/EMDR was not included in the intervention search terms, therefore there is a risk that potential studies to include have not been retrieved. For example, the MODIFI trial protocol may not have been retrieved: Cope et al. (2023). MODIFI: protocol for randomised feasibility study of eye-movement desensitisation and reprocessing therapy (EMDR) for functional neurological disorder (FND). *BMJ open*, *13*(6), e073727. Although an ongoing study and therefore may not be included (although this is not totally clear from the eligibility criteria), it suggests the search is not as comprehensive as it could be.	Thank you for your comment. The list of interventions under adjustment and engagement in the protocol wasn't an exhaustive list, although EMDR wasn't listed as an intervention to improve adjustment and engagement, if it was designed to improve adjustment and engagement the study would have been captured in the search strategy and included in the review. In relation to Cope et al 2023, as this is an ongoing study it would have not been included in our current evidence review, however given the current research on the use of EMDR in FND this is something that would be taken into consideration in any future updates of this guideline.
EMDR UK	Evidence Review H	053 - 070	General	Carletto et al (2016). Treating post-traumatic stress disorder in patients with multiple sclerosis: A randomized controlled trial comparing the efficacy of eye movement desensitization and reprocessing and relaxation therapy. *Frontiers in psychology*, *7*, 526. This study may not have been identified by the database searches due to not including search terms for EMDR. Although this study would not meet the eligibility criteria due to co-morbidity (PTSD), its potential absence suggests the search strategy is not as comprehensive as it could be.	Thank you for your comment. Carletto et al (2016) was identified in the database search, however the study was excluded at title and abstract stage as EMDR was treating PTSD, which is a condition outside the scope of the guideline.
EMDR UK	Evidence Review H	053 - 070	General	English language limits were applied. The Cochrane Handbook for Systematic Reviews of Interventions recommends making decisions about inclusion/exclusion based on the publication language at the screening stage rather than the searching/retrieval stage (https://training.cochrane.org/handbook/current, section 4.4.5). Also see: Pieper, D., & Puljak, L. (2021). Language restrictions in systematic reviews should not be imposed in the search strategy but in the eligibility criteria if necessary. *Journal of Clinical Epidemiology*, *132*, 146-147.	Thank you for your comment. We apply English language limits routinely when developing NICE guidance, as indicated in chapter 5 of Developing NICE guidelines: the manual: Section 5.3 "Typically, English language limits, date limits, and the exclusion of conference abstracts and animal studies are usually done as a matter of routine"
EMDR UK	Evidence Review H	242	General	Passoni, S., Curinga, T., Toraldo, A., Berlingeri, M., Fernandez, I., & Bottini, G. (2018). Eye movement desensitization and reprocessing integrative group treatment protocol (EMDR-IGTP) applied to caregivers of patients with dementia. *Frontiers in Psychology*, *9*, 967.	Thank you for your comment. The list of interventions under adjustment and engagement in the protocol wasn't an exhaustive list, although EMDR wasn't listed as an intervention to improve adjustment and engagement, if it was designed to improve adjustment and engagement the study would

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				This study does not appear to have been retrieved by the database searches. Although dementia is not an included population, it was included as a search term, and therefore it would be expected to be retrieved.	have been captured in the search strategy and included in the review. In relation to Passoni et al 2018, as this is a study on "caregiver syndrome" in dementia it would not have met the protocol criteria in our current evidence review.
Chiltern Music Therapy	Evidence Review H	General	General	Patient feedback from services have demonstrated that the inclusion of Neurologic Music Therapy® alongside standard care has increased motivation, helped achieve functional goals across multiple domains, supported early discharge from services, and supported an overall improvement in their quality of life. For example, patient data from the pilot phase of an NMT™ project run by Chiltern Music Therapy at the Regional Neuro Rehab Unit at Homerton Hospital for 2 days/week for 12-months in 2021-2022 evidenced that 75% of patients accessing NMT™ improved in mood following this intervention. This was based on use of a 5-point Likert mood rating scale patients completed at the beginning and end of sessions. No negative impact on mood was evidenced. In patient discharge questionnaires, all patients agreed or strongly agreed that NMT had also helped to reduce stress/anxiety and increase engagement with rehab.	Thank you for your comment. Unfortunately, without publication in a peer-reviewed journal with full reporting of methods and data, we are unable to include your pilot study in our evidence review.
The Association of British Neurologists	Evidence Review H	General	General	"Emotional health and mental wellbeing in adults with a functional neurological disorder - What is the effectiveness and cost effectiveness of interventions and approaches for improving and sustaining emotional health and mental wellbeing for adults with a functional neurological disorder?" This is one of your recommendations for further research needed. Please see our points above – addressing mental/emotional wellbeing is not separable from other interventions in the assessment and management of functional neurological disorder; it is an integral part of it. The evidence base for treatment in functional neurological disorder incorporates this. For example the CODES trial (www.sciencedirect.com/science/article/pii/S2215036620301280) examined psychological treatment of functional seizures, the physio4FMD trial (www.physio4fmd.org/publications) examined physiotherapy treatment of functional movement disorders, using psychologically relevant techniques including attentional management.	Thank you for your comment. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. This review focused on interventions to support emotional health and wellbeing and due to the paucity of evidence for FND, the committee agreed to prioritise this for future research. They are somewhat restricted in drafting NICE research recommendations, to ensure they map closely with the original review question, which explains the wording of the research recommendation. In terms of the evidence you mention, the physio4FMD trial (Nielsen 2024) has now been included in the guideline, in evidence review O. However, note that of the outcomes listed in the protocol, only anxiety and depression were extracted. Although health-related quality of life was included in the protocol, SF-36 was not extracted as no overall score was provided, only sub-domain categories. The CODES trial (Goldstein 2021) was included in evidence review H and all outcomes that were listed in the protocol were extracted.

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Recolo UK	Evidence Review H	General	General	Intra-personal in focus, with no recognition that family adjustment especially when there is a child/young person with ABI needs work with the family. From our knowledge and experience ... Positive inclusion with regards to trauma-focussed work and ways to approach this and integrate with rehab and not deliver in isolation.	Thank you for your comment. The committee agree and in the holistic rehabilitation needs assessment section of the guideline, recommendations referring to family life and integration with rehab are made, to avoid siloed working. A recommendation was made to identify the rehabilitation interventions that may help the person, and their family or carers, if appropriate, to prepare psychologically and physically for future changes to impairment and functioning. This is especially important if the person has a rapidly progressing condition. Furthermore, there are recommendations in the goal planning section of the guideline, which states to allow sufficient time during consultations with the person, and their family or carers, if appropriate, for goal setting, and later for rehabilitation planning. In terms of trauma-focused work, the committee agree with your comment and a new recommendation has been drafted in the holistic rehabilitation needs assessment section of the guideline, which states to be aware that people who have experienced trauma as a direct result of their injury or condition, or prior life experiences, or both, may need adaptions to assessment, rehabilitation and support plans.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review I	010	034 - 037	Agree with statement "*The committee also discussed the need of a complex case manager for people with particularly complex and long-term rehabilitation needs. These people are more likely to need care that not only crosses rehabilitation services, but also straddles health and social care services*." However, would benefit from adding in these people also cross geographical and ICB boundaries in services.	Thank you for your comment. The committee agreed with your point, and it has therefore been added to the benefits and harms section of the evidence review.
Midlands and South Essex ICB	Evidence Review I	011	020	Whilst CCM can be, and is already, delivered by people already in services, it is unlikely to be a single point of contact which is what is stated within the guideline. A single point of contact for all of those with CND is unattainable within current service budgets.	Thank you for your comment. The single point of contact will vary based on the complexity of needs and the ability to self-manage rehabilitation. For those with severe, complex and long-term needs, the assigned complex case manager may be best suited to undertake this role. We acknowledge the potential resource impact, but NICE is not involved in funding decisions. The committee hopes the recommendations will be adopted and funded accordingly. They also suggest reconfiguring services to create efficiencies, and which may free up resources and funds for other uses which might include provision of single point of contact roles. NICE is also planning to develop an implementation tool on complex case managers to support commissioners
Midlands and South Essex ICB	Evidence Review I	011	025	The evidence from private practice cannot be extrapolated into an NHS system as it is often supported by a high amount of funds to commission specialist services not available to those within the NHS.	Thank you for your comment. We completely agree that private practice cannot be extrapolated into an NHS system. However, this paragraph outlines what is the current practice, i.e., that clinical case management is currently mainly available only in the private sector and litigation. We do not

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					extrapolate, and we go on to acknowledge that there is not much provision within the NHS and discuss resource use implications, providing some examples as to how this could be offset.
Head First	Evidence Review I	011	039	We are concerned that this may imply that those with FND should not receive a clinical case manager because there are limited resources available. The clinical case manager role is not based on the services available and signposting an individual to those services but rather developing a bespoke approach, determining an individual's need and seeking the services that are available. FND should be included precisely because there are limited services, it is increasing the rationale and need for a clinical case manager to support and navigate in seeking what resources can be utilised for an individual.	Thank you for your comment. We have removed this sentence.
British Association for Music Therapy	Evidence Review I	General	General	The British Association for Music Therapy is concerned that there is no inclusion of 'Music Therapy' or 'Neurologic Music Therapy™' or musical terms such as 'music', 'singing', 'rhythm' in any of the search criteria for this evidence base. Specific techniques used in the Neurologic Music Therapy™ was also excluded, and could have used 'Rhythmic Speech Cueing', 'Therapeutic Singing' and 'Oral and Motor Respiratory Exercises' to name a few. This completely disregards and excludes the entirety of the research and evidence base for the Music Therapy profession and the successful care and treatment patients have benefitted from. The lack of inclusion in the search criteria highlights a concerning lack of awareness of the current practice of Neurologic Music Therapy™ and Music Therapy services within the community. Working with case managers and providing holistic interventions in the community for children and adults with chronic neurological conditions is a well-established field and we urgently request that the exclusion of Music Therapy within this evidence base is re-considered.	Thank you for your comment. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review, H about interventions to improve emotional health and wellbeing. On the basis of the evidence located in the review and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation.
Recolo UK	Evidence Review J	017	006 - 011	A comment here about the possible impact of neurological conditions on sleep-wake cycle and that it might be more helpful to name the difficulties around sleep as *possible sleep-wake disruption* rather than "difficulty sleeping" (line 8).	Thank you for your comment. We have amended the wording to "possible sleep-wake disruption" as suggested.
Chiltern Music Therapy	Evidence Review J	General	General	This review on fatigue management does not include any reference to music-based interventions despite the established evidence that Neurologic Music Therapy® (NMT™) can address fatigue-related	Thank you for your comment. The evidence review on fatigue management focused on multimodal (combined physical and psychological) interventions rather than unimodal interventions. Given that neurologic music therapy is a

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				symptoms through Rhythmic Auditory Stimulation (RAS)® and cognitive-motor entrainment. NMT™ may improve engagement, mood regulation, and perceived effort in physical activity through structured music-based strategies. References: Thaut & Abiru (2010); Särkämö et al. (2014).	unimodal intervention we were unable to include the studies referenced in your comment.
Brain Injury Social Work Group	Evidence Review J	General	General	My interest in "Fatigue" had been piqued by spotting reference to the trial of graduated intense exercise with people with ME. I know of people who suffered serious consequences including hospitalization due to that approach. I was relieved to see the NICE guidelines reflect the outcomes and strongly advise against enforced exercise with that cohort. The document is considered and comprehensive and acknowledges the cliff edge of understanding and support as people venture from health to local authority social care. I hope BISWG can participate in the roll out (if NICE do such a thing) when it is finally published.	Thank you for your support of the evidence review and the draft guideline.
Brain Injury Social Work Group	Evidence Review K	021 - 052	General	I have had a look at this (Section K) – I've been trying on & off the last few days and will say I've found it really challenging/ overwhelming due to the sheer amount of words and trying to process/ retain the info… So my comments are really limited as I tried to just pick up some key points around the summaries of the evidence? Access to support for education – picks up on the key points, particularly around difficulties with information sharing, lack of knowledge around other professional roles & lack of confidence (from schools) about support and resources. From what I can see earlier, the economic impacts of issues identified in the evidence is not addressed – but this is a significant factor. Access to support for employment – positive that the evidence is included which notes that earlier vocational rehab begins leads to improved outcomes. Again, cost implications do have an impact on services/support. K10 integration – interesting to note that employers "need" a health/rehab professional involved to take reasonable adjustment requests seriously… Also positive that it identifies the concerns individuals have about involving employers and worries about ongoing working relationships. *I couldn't see any evidence (but it may have been elsewhere) about the impact of dealing with the DWP/government organisations and policies that are focused on "getting people back to work"….*	Thank you for your comment. This was a challenging area to review. We conducted 3 related systematic reviews to assess quantitative evidence, including economic studies, about interventions to support access to education, employment and social support. Due to a lack of quantitative and economic evidence, the committee-based recommendations on related qualitative evidence (reported in review K) and their expert opinion. We agree that the lack of high-quality evidence in this area is a concern, and have made a research recommendation on support to access employment in people with a chronic neurological disorder. Despite the lack of economic evidence identified, the committee adequately considered the potential resource implications and cost effectiveness of their recommendations on education, workplace, and social participation. Full details of this discussion, including potentially offsetting downstream outcomes, can be found in the 'Cost effectiveness and resource use' section of evidence review K. The committee hopes their recommendations will be adopted and funded as necessary. The committee did agree with qualitative evidence showing that there was a lack of appropriate leisure activities available. However, they did not discuss possible reasons for this. In response, they made several recommendations focusing on promoting participation and adapting existing social and leisure activities. No evidence was identified on the impact of taking part in government policies, including ones that are focused on people rejoining the workforce.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

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				Access to support for social participation – the evidence picks up the lack of availability of community activities and groups; although it does not explicitly note as a result of the cost of living crisis/austerity *(aware that this is probably because it was not mentioned in the research?)* P30 – line 21-37 picking up concerns around resource implications. P30 Line 50-52 & P31 lines 1-10 – also positive the committee are identifying concerns about bias and discrimination that may be experienced by individuals. Further picked up on p35 lines 42-49 about disclosure which is a barrier. Positive that the discussion around the need for advocacy is a very clear recommendation many times. Also pleased to see that the committee did not make recommendations around individuals needing to depend on informal support networks / unpaid carers as this should not be an expectation (p39 34-41). I note the phrase "low quality evidence" many times – which in itself is a concern!.	We are assuming that your belief is that some policies are too focused on returning to employment as an outcome, even when this is not the most appropriate course of action for the individual with a chronic neurological disorder. The committee were aware of this, and have made recommendations to also support an individual in leaving or changing employment. However, the committee were also aware that governmental schemes can also be very helpful to people who are able to return to work. Therefore, they have included a link to the current Access to Work scheme at the end of this section. Additionally, they have highlighted the WorkWell programme within the resource impact section of evidence review K, a government initiative designed to help disabled people and those with health conditions start, stay, and succeed in work. This may also support implementation.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review K	037	043	I'm not sure if this is a typo for the word identify in this line: "*characteristics such as a person's gender identify, sexual orientation, religion, and cultural*" Is it meant to read identity instead of identify?	Thank you for your comment. We have amended the typo in the text.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Evidence Review K	39	006 - 007	Referring to this sentence: "*This would make forming 7 appropriate groups difficult, if not impossible, for most services to implement*." May I suggest that there may be a place for certain generic key messages including the Equality Act about returning to work could be delivered in a group setting for some adults with a CND. A more personalised 1:1 approach could follow on from this?	Thank you for your comment. This part of the committee discussion section provides a transparent account of why the committee did not feel able to use themes identified in the qualitative evidence. Having considered your suggestion, they agreed to stay with their original interpretation of the evidence and therefore, no change has been made.
Chiltern Music Therapy	Evidence review K	General	General	Music therapy is absent in this qualitative synthesis of barriers and facilitators to social participation, employment, and education. Given the well-documented use of group-based music interventions to support social reconnection and emotional expression in individuals with acquired brain injury and other neurological disorders, we recommend inclusion of this approach in future iterations. References: Tamplin et al. (2014); Bradt et al. (2010); Gibbs (2022).	Thank you for your comment. This qualitative review was designed to answer the question ' Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment, and social participation?'. It was not designed to report the barriers and facilitators of individual therapies that may be used to promote social participation. Despite this, no specific area of rehabilitation was excluded in the search strategy. Several citations including music in the title were identified but they were all excluded at the title and abstract stage as they were not relevant to the review question. We are confident that this review has not overlooked the area of music therapy. For completeness, please see below for reasons your suggested papers do

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					not meet the inclusion criteria for this systematic review. As you did not provide full references, these are a best guess at the publications you're referring to: - Tamplin (2014) Thematic analysis of the experience of group music therapy for people with chronic quadriplegia. doi: 10.1310/sci2003-236 - Excluded on phenomena of interest (about the experience of group music therapy, and not the access to support for social participation). - Bradt (2010) Music therapy for acquired brain injury. doi: 10.1002/14651858.CD006787.pub2 - Excluded on study design (systematic review of quantitative studies). Note that this is also not appropriate for evidence review N (Interventions to support social participation) as that has a date cut-off of 2013. - Gibbs (2022) - we are unable to identify and locate this paper.
MS Society	Evidence Review K	General	General	It would be useful to reference the Exercise for Long-Term Neurological Conditions qualification (https://www.wrightfoundation.com/course/exercise-for-long-term-neurological-conditions-24-06-25/) developed by the WRIGHT Foundation CIC in partnership with Keele University, a leader in Rehabilitation Science. This five-day course endorsed by CIMPSA, delivered across the UK by experienced university lecturers, combines theoretical knowledge and practical skill development to equip exercise and health professionals with the confidence and expertise to support people living with long-term neurological conditions. The syllabus covers key areas such as an overview of the nervous system, common neurological conditions, neurological exercise principles and prescription, posture and balance, mental health considerations, and behaviour change. We also recommend referencing the resource Exercise: the Unsung Disease Modifying Therapy, which treats exercise as a disease-modifying therapy, exploring how it works, potential barriers to uptake, and side effects. This resource highlights the important role physical activity plays in managing long-term neurological conditions. (https://www.youtube.com/watch?v=Xa1lab_Y-d8)	Thank you for your comment. Unfortunately, it is beyond NICE's remit to issue recommendation on specific training or qualifications for professionals. Therefore, no change has been made. However, the committee were aware of the many beneficial effects that exercise can provide for people with chronic neurological disorders and that this is often overlooked during rehabilitation. They have drafted a section on physical activity and exercise, which includes several recommendations aimed at developing programmes, decreasing barriers to, and increasing engagement in physical activity and exercise programmes. In relation to your suggested reference, we are unable to make this link in the guideline because it was not included as an evidence source in the review (because this would not fit the protocol) and nor is it published by NICE.
Recolo UK	Evidence Review K	General	General	Our main concern is that the evidence reviewed is very narrow for such a broad field. They only used 25 studies altogether, only 3 of which were about children. Their recommendations are based on "low" or "very low" quality evidence.	Thank you for your comment. With respect to the 3 studies highlighted: - Linden: this was picked up in the population set of the search but was not retrieved when combined with the intervention set as the indexing and the abstract for this study contains very broad terms. Additionally, only

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				We would suggest that the panel open the search parameters. Currently they restrict evidence to UK only, with a publication date of 2010 or later. The explanation at the beginning says that they would consider data from NZ, Aus and Canada if not enough was available from the UK and we would argue that this needs to be implemented here. We'd still miss all the US data, but there is quite a bit from Australia that would be helpful. Even within the current search parameters, studies have been missed e.g. Linden, M. A., Braiden, H. J., & Miller, S. (2012). Educational professionals' understanding of childhood traumatic brain injury. Brain Injury, 27(1), 92–102. https://doi.org/10.3109/02699052.2012.722262 Keetley, R., Manning, J. C., Kettlewell, J., Williams, J., Bennett, E., Lyon, V., & Radford, K. (2024). Enabling participation in community-dwelling children and young people with acquired brain injuries and their families: a theory-based, evidence-based and person-based approach to intervention development. *BMJ open*, *14*(12), e088516. Bate, C., Turner, K., & Fricke, S. (2021). Return to school after acquired brain injury in the UK–the educators' perspectives. *Journal of Research in Special Educational Needs*, *21*(3), 242-253. With respect to the conclusions, we had the following thoughts based on our knowledge and experience delivering paediatric neuropsychological rehabilitation: Participating in social and leisure activities – nowhere does it talk about the impact of the child's condition on the family. Even where there are activities specifically suitable for the child's needs, the siblings may not be able to access the same activities, the specific activities are unlikely to be as convenient as mainstream activities in terms of time and	quantitative analysis results were presented for this survey, which would not be included for a qualitative meta-synthesis. - Keetley: this would have been retrieved by our MEDLINE search, but it was indexed and added to MEDLINE in May 2025, after the search was run. - Bate: this was picked up in the population set of our PsycINFO search. It was not retrieved when combined with the intervention set. The subject headings for this reference focus on the teacher and teacher attitudes. This is not the focus of this review question and therefore not how we designed the search. However, we have looked at the studies and are confident that all the themes identified in the research have been covered by the current review, and including them would not make any differences to the recommendations. Regarding your request to expand the search countries, the wording of the protocol is that study countries will be expanded if the findings were insufficient to inform the committee's decision-making process. The committee were happy with the amount of themes and data presented in the evidence review, and decided not to expand the search parameters. With respect to your thoughts on delivering paediatric neuropsychological rehabilitation: - Participating in social and leisure activities and Family life and friendships: We have now highlighted that school and home relationships need to be discussed with children and young people, as well as considering additional barriers that these environments might add. We have also updated the relevant sections of the 'Benefits and harms' in evidence review K to consider siblings, and included the example you mention in your comment within the barriers for social participation. - Intimate and sexual relationships and sex: This section intentionally does not include age-specific recommendations, and has been designed to cover all of our guideline population. The committee acknowledge that there is an intrinsic link between intimate and sexual relationships and emotional health, and has now included a cross-refence to emotional health and mental wellbeing section of the guideline, which includes recommendations on impulsivity and disinhibition. Finally, while the committee acknowledge the importance of safeguarding within this area of rehabilitation, it is beyond the scope of this guideline to cover all the safeguarding and consent scenarios and legislation that we would need to in order to adequately address this issue. However, we have included a recommendation to seek

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				location, and parents will have to get them there. Online is not a viable alternative for children's social activities. Family life and friendships – apparently no specific themes were identified for this area which surprises me. The entire section is focused on adults with conditions and how it may affect their marital or parenting relationships, there is nothing at all about children, managing in families where there may be multiple siblings, and increasingly important peer relationships. Sex and intimacy – again this section is all about adults. Thought needs to be given to sex & relationships education for children too, especially where their condition may mean that they are impulsive, lacking in social understanding or disinhibited. And noting here the importance of developing safe and caring intimate relationships or about safeguarding with respect to risk-taking / developing Designing and commissioning rehabilitation services for complex and long-term needs – the committee discussed only social and leisure groups. It seems important to consider ongoing therapeutic services as well. Rehabilitation and education for children and young people – the recommendations cover only communication, as if health sector professionals have no further role than to tell education professionals what they know. There should be mention of the EHCP (Statement in Wales) processes, given that this is a UK-specific guideline, and information for health professionals about their role in assessment, treatment and being part of the EHCP co-ordinated process.	specialist advice if potential issues are raised. - Designing and commissioning rehabilitation services: A life-long approach to rehabilitation services (including access to therapeutic services) has been stressed throughout the guideline. Therefore, no changes have been made. - Rehabilitation to support education for children and young people: NICE already has published guidance on the use of EHCP's within NG213 Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education, meaning it is out of scope for this guideline. We have included a direct cross-reference to this guidance at the start of the section on education for children and young people, with a note that these recommendations will also need to be followed. Therefore, no changes have been made.
Chroma	Evidence Review M and N	General	General	The NICE evidence review acknowledges outcomes such as social participation, return to work, and meaningful activity as important but underexplored, and no interventions were identified that consistently demonstrated effectiveness in supporting these domains. In contrast, there is real-world and research-based evidence that Creative Arts Therapies, particularly Neurologic Music Therapy®, can meaningfully	Thank you for your comment and your suggested music therapy studies, which were not located by this evidence review because music or creative therapies were not included in the protocol. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The

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				support clients in rebuilding cognitive, communicative and emotional capacities critical for return to work and independent participation. These therapies directly impact executive function, motivation, self-regulation and social confidence—all foundational for re-entry into employment, education or voluntary activity. The economic benefits of this are well documented. Bungay & Clift (2010) and Spandler et al. (2007) report that engagement in creative arts interventions leads to reduced support needs and increased readiness for employment. TBR (2018) and Daykin et al. (2012) found that arts-based interventions not only improve wellbeing but yield cost savings by reducing reliance on statutory services and increasing productivity via return to work. This reflects our own clinical experience, where music, art and drama therapy often form part of a successful vocational rehabilitation pathway for clients recovering from acquired brain injury. Given that even modest increases in employment reduce welfare dependence and generate tax contributions, these interventions offer significant cost-effectiveness relative to their delivery cost. We therefore recommend that Creative Arts Therapies be included in this review as evidence-based interventions with both clinical and economic value.	committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review H, about interventions to improve emotional health and wellbeing. Therefore, the literature search designed for review M and N would not have picked up the studies you suggest. However, on the basis of the evidence located in review H and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. Therefore, no change has been made to evidence review M and N, nor to the recommendations on the basis of your comment.
Chroma	Evidence Reviews	General	General	Chroma is the UK's largest provider of neurorehabilitation-focused Creative Arts Therapies, employing over 120 HCPC-registered art, drama, and music therapists working across NHS, independent hospital, and community settings These include HCA Healthcare UK (a 10-year partnership) and The Cleveland Clinic London among others. In 2024 alone, Chroma received over 400 individual referrals from brain injury case managers, representing approximately 280 unique clients, including re-instructions. We are routinely commissioned by some of the UK's most established case management organisations, including Active Care Group, HeadFirst, and Bush & Co, as well as leading medico-legal firms such as Fieldfisher, Irwin Mitchell, and Stewarts Law. Most of our work with these partners/settings is via Music Therapy or Neurologic Music Therapy® although art and drama therapy are starting to be commissioned especially for psychological recovery and support. These instructions are made within a highly scrutinised medico-legal framework and reflect a consistent, real-world judgement by referrers	Thank you for your comment. The evidence reviews underpinning the guideline were designed to cover the broad population of people with chronic neurological disorders and a wide range of interventions contributing to rehabilitation, in the holistic sense, with the evidence reviews each focussing on a specific aspect of rehabilitation. The committee recognised the important contribution of creative therapies for a range of domains, but they chose to cover it as an intervention category in review, H about interventions to improve emotional health and wellbeing. On the basis of the evidence located in the review and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation. We have also included creative art therapists in our definition of rehabilitation practitioners in the glossary, as well as how the role of music therapy can reduce health inequalities in the EHIA document. Due to the scope of the guideline and the amount of published studies in the area, we have limited our effectiveness evidence to RCTs. However, we have also included 4 qualitative evidence reviews throughout this guideline

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				that Creative Arts Therapies provide measurable psychological and functional benefits to clients following traumatic and acquired brain injury. The continuation and expansion of these services, year-on-year, evidence both clinical relevance and tangible impact in supporting recovery and rehabilitation goals. While the NICE guideline methodology rightly prioritises high-quality evidence such as randomised controlled trials, it is also important to consider the weight of real-world clinical commissioning. In neurorehabilitation, particularly within the medico-legal and case management sectors, therapies are only commissioned when there is clear and demonstrable clinical utility. Case managers and solicitors operate in a highly outcomes-focused environment, often requiring therapies to show measurable progress in function, mood, communication, or participation in daily life. While we acknowledge the value of randomised controlled trials within NICE's framework, we also urge consideration of the broader spectrum of high-quality evidence and real-world clinical outcomes—particularly in complex, relational and neurorehabilitation contexts where standardisation may diminish therapeutic integrity. As part of Document C's review question, you use the following descriptor: "When done well, a rehabilitation programme is a bespoke intervention designed to meet the needs of the person and their family, formulated and updated through regular assessment and goal planning". The broader spectrum of high-quality evidence and real-world clinical outcomes—particularly in complex, relational and neurorehabilitation contexts meets the descriptor you use. The consistent, repeated instruction of Chroma's Creative Arts Therapies by these professionals, across hundreds of cases annually, provides strong real-world evidence of effectiveness. In many respects, this pattern of clinical commissioning offers a pragmatic validation of therapeutic value—often reflecting more immediate and meaningful outcomes than what may be captured within the narrow parameters of academic trials. While formal research is essential, real-world use and reinstruction over time serve as powerful indicators of both efficacy and clinical relevance.	that focus on service user and professional lived experiences. These were not limited to interventions and have consistently reported on the benefits of a holistic approach throughout rehabilitation. The committee agreed and have made several recommendations to highlight the importance of considering all aspects of a person's wellbeing and life during rehabilitation planning and delivery. Finally, the committee were disappointed with the paucity of evidence identified in evidence review H, and have already prioritised 2 research recommendations in this area (1 regarding emotional health and wellbeing interventions in children and young people with chronic neurological disorders and another to cover emotional health and wellbeing interventions in adults with functional neurological disorder). As per our protocols, creative therapies are listed as an intervention area to be considered. The committee believe that they have covered creative arts therapies as much as the evidence and scope of the guideline allows. Therefore, no changes have been made.

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				The exclusion of Creative Arts Therapies—particularly evidence-based modalities such as Neurologic Music Therapy® from this guideline risks overlooking interventions that are already widely embedded within neurorehabilitation practice across both NHS and independent sectors. These therapies are not peripheral or experimental; they are commissioned routinely by experienced clinicians, case managers, and legal teams on the basis of observed functional, cognitive, emotional, and communicative improvements in patients with acquired brain injury and other neurological conditions. Failure to reflect this reality within NICE guidance may lead to a disconnect between evidence-based policy and clinical commissioning practice, potentially undermining access to interventions that demonstrably improve quality of life, engagement in therapy, and rehabilitation outcomes. Inadvertently, this may also constrain the ability of commissioners and clinicians to justify continued funding for therapies that have proven benefit in real-world contexts but do not yet conform to narrowly defined evidence hierarchies. Should the current evidence base be deemed insufficient for full inclusion, we would strongly support the addition of specific research recommendations to evaluate the clinical and cost-effectiveness of Creative Arts Therapies, including Neurologic Music Therapy®, in neurological rehabilitation contexts. Finally, Creative Arts Therapies, including Neurologic Music Therapy®, art therapy and dramatherapy, play a vital role in supporting individuals with neurological conditions to re-engage with meaningful roles in their communities, including employment. Social participation and vocational rehabilitation are often underexplored within research hierarchies, yet they are among the most important long-term outcomes in terms of quality of life and economic value. Evidence from practice shows that Creative Arts Therapies can help individuals reconstruct identity, develop confidence, improve executive function and communication, and manage emotional distress—each of which directly supports the capacity to return to work or voluntary roles. From a cost-benefit perspective, the impact is significant: even a modest increase in the number of individuals able to return to employment or education results in reduced care dependency, lower welfare expenditure, and increased tax contributions.	

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				This represents a tangible economic return on relatively low-cost therapeutic input. Failure to include these therapies in NICE guidance risks undervaluing interventions that improve long-term social integration and economic productivity—core outcomes for both patients and public services. We recommend that the potential contribution of Creative Arts Therapies to social and occupational reintegration be recognised within the guideline's assessment of both clinical and cost-effectiveness.	
Rotherham, Doncaster and South Humber NHS Foundation Trust	General	General	General	The Health Inequalities Assessment and papers mentions the term "Lower socio-economic groups" and referred to the patients, however, may I suggest the whole document reflects the national cost of living wage crisis and the challenge this has on staff providing this service too. I experience staff in my team unable to afford to run cars to provide community services for example.	Thank you for your comment. The committee was aware of the national cost of living crisis and the challenges this presents for services and staff, including those in community settings. In response, they made recommendations for commissioners on service design and specification, aimed at ensuring more efficient and effective services. These improvements may help release resources and funding for other uses, including improved community provision, which would also align with the priorities outlined in the newly published NHS 10-Year Plan. The committee also acknowledged the challenges currently faced by services, in their supporting discussions within the rationale and impact sections, as well as in the full evidence reviews. They also hope that their recommendations will be adopted and funded accordingly.
Kent and Medway NHS and Social Care Partnership Trust	General	General	General	There could be more emphasis on empowering the person to have destiny of their rehab needs including move towards optimising self-management and maintenance.	Thank you for your comment. All in the interventions set out within the guideline were included by the committee with optimising independence as a goal. It is also intrinsic to the included approaches around holistic needs assessment, goal setting and approaches to delivery and coordination, especially the needs-based approach to assigning a single point of contact depending on the person's ability to coordinate their own care and requests for intervention when needed. We have included a definition of rehabilitation in the terms used in this guideline to emphasise this also. We have added "other interventions to enable supported self -management' explicitly into the designing and commissioning rehabilitation services.
Brainkind	Guideline	001	001 - 008	The wording 'It does not cover chronic neurological disorders covered in NICE's guidelines on (…) stroke rehabilitation in adults' gives the impression that this guideline is not applicable to people living with the long-term effects of stroke. However, stroke is a type of acquired brain injury and people with stroke may develop rehabilitation needs in the long-term, as their functioning and level of disability could be affected by changes to their general health or life circumstances. While it is noted that the current NICE Guideline for Stroke Rehabilitation in Adults	Thank you for your comment. We have added clearer information to the overview section about the conditions, diseases, disorders and injuries covered and non-covered by this guideline. This guideline does NOT cover people living with the long-term effects of stroke because a specific rehabilitation guideline already existed for this population. However, it does cover the effects of stroke in under 16s as

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				considers long-term health and social support, and enables patients to self-refer, the recommendations of the present guideline (NH 10181) may still be relevant for that patient group. We suggest that there is cross-reference to the two guidelines, rather than implied 'exclusion', (i.e. similar to the recommendation for progressive neurological disease), or that the present guideline provides an operational definition or acquired brain injury, specifying all the conditions covered under the term and / or when an acquired brain injury would be considered to become chronic.	children were not covered by the stroke guideline. there will be a cross reference between the two guidelines for this reason.
Success – Life After Cure Ltd	Guideline	001	General	We are concerned that the guideline states it covers neurological impairment from acquired brain injury and chronic neurological disorders but seems to imply apparent exclusion of neurorehabilitation needs of children with brain injury due to brain tumours, by referring to NICE guidance on brain tumours in over 16s. We would like to point out that there is no reference to specific NICE guidance on neurorehabilitation for children under 16 with brain tumours . This leads to inequity and the reported inaccessibility of neurorehabilitation for this now high survival [80%] group. Clarification of where these children's needs are considered would be helpful. Is it the intention to exclude them from this guideline? Would it not be appropriate to make specific reference to them? Is a dedicated brain tumour under 16s neurorehabilitation NICE guideline needed to support the oncology cure and improve outcomes for the 800-1000 young people accruing every year and living near-normal life spans?	Thank you for your comment. We apologise for the confusion. This guideline covers rehabilitation for ALL people (adults , children and young people) who have experienced brain injury due to brain tumours. We have amended the overview/introductory information about the guideline to make this clearer. We have also now added a full list of all conditions, diseases, disorders and injuries covered and non-covered by this guideline. The reference to the NICE guideline brain tumours (primary) and brain metastases in over 16s is simply to say that this new guideline should be followed together with the recommendations about rehabilitation already contained within the existing guideline about brain tumours.
Success – Life After Cure Ltd	Guideline	001	General	There is evidence of lack of access to neurorehabilitation for children with brain tumours from a 2019 survey of children's neuroncology centres [Treadgold et al; https://bmjpaedsopen.bmj.com/content/3/1/e000567 . More recently our unpublished 2024 'gap-analysis' study /[https://youtu.be/4hHeS7FCz20] at the largest UK paediatric neuroncology treatment centre [Great Ormond Street] showed lack of awareness and expertise on accessing neurorehabilitation referral pathways amongst professionals and families, and low provision of physiotherapy [20- 40% over two consecutive 5-year periods] with just 7% referred for streamlined neurorehabilitation.	Thank you for your comment and for sharing this information. We apologise for the confusion. This guideline covers rehabilitation for ALL people (adults , children and young people) who have experienced brain injury due to brain tumours. We have amended the overview/introductory information about the guideline to make this clearer. We have also now added a full list of all conditions, diseases, disorders and injuries covered and non-covered by this guideline. The reference to the NICE guideline brain tumours (primary) and brain metastases in over 16s is simply to say that this new guideline should be followed together with the recommendations about rehabilitation already contained within the existing guideline about brain tumours.
Success – Life After Cure Ltd	Guideline	002	General	Our charity repeatedly hears from families unable to access neurorehabilitation, despite the recommendation from NICE 2005 children and young people's cancer guidance that for children with CNS tumours, neurorehabilitation "*should continue for as long as it is needed and can make a difference" (p68)* re-iterated in a 2014 update. https://www.nice.org.uk/guidance/qs55/chapter/Quality-statement-5-	Thank you for your comment and for sharing this information. We apologise for the confusion. This guideline covers rehabilitation for ALL people (adults , children and young people) who have experienced brain injury due to brain tumours. We have amended the overview/introductory information about the guideline to make this clearer. We have also now added a full list of all conditions, diseases, disorders and injuries covered and non-covered

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				Neuro-rehabilitation . We are aware of models of rehabilitative care in Cambridge [Brainbow] at a cost of some £2000 p.a. per child, https://www.cuh.nhs.uk/our-services/childrens-services-paediatrics/brainbow/ and Nottingham [BRILL] which support children with brain tumours specifically, or amongst others with acquired brain injury. However, there is general acknowledgement of significant funding barriers and challenges to access, as well as a lack of understanding that such effects are indeed neurological consequences of an acquired brain injury, not just irremediable 'late effects' of treatment'. This lack of recognition impacts on transitions between hospital and community settings 'post-cure', and on childhood to adult transition services. Their neurorehabilitation needs are inadequately met in cancer late effects [long term follow up] services; these were modelled 20 years ago for childhood cancer survivors without acquired brain injury. There is a need for a NICE management guideline which addresses the modern neurorehabilitation reality for this growing cohort of childhood brain tumour survivors, and this is most especially needed if they are not referenced in this guideline.	by this guideline. The reference to the NICE guideline brain tumours (primary) and brain metastases in over 16s is simply to say that this new guideline should be followed together with the recommendations about rehabilitation already contained within the existing guideline about brain tumours.
University College London Hospital	Guideline	004	007	Where will this "single point of contact sit – i.e. medical or social? When will they be appointed and by whom?	Thank you for your comment. The guideline recommends that the single point of contact is not appointed until a holistic needs assessment has been completed and that decisions about the level of support the person will need are made as part of agreeing the rehabilitation plan. Decisions about who that person or service is and whether it is appropriate for them to be more medical or social will depend on the nature of the rehabilitation plan and the criteria regarding the person's ability to self-manage their rehabilitation as set out in the section 'Assigning a single point of contact and assessing the person's ability to coordinate their own care'. Before a single point of contact (key contact or key worker or complex case manager) is appointed the person will have an initial contact for rehabilitation and then an agreed Lead practitioner who will oversee the completion of a holistic needs assessment. Again, due to breadth of this population and the fact that the person could be either hospital or community based, at the point of a needs assessment, it is not possible to say whether either the Lead practitioner or the Single point of contact should be based in primary, secondary or social care.
The Royal Hospital for Neuro-disability	Guideline	006	001 - 023	The service design should be evidence-based. Whilst acknowledging the heterogeneity of evidence for the effectiveness of specific services, this is fundamentally important in providing clinical and cost-effective care.	Thank you for your comment. Due to the nature of the 'intervention', there is a lack of published effectiveness evidence on service design within rehabilitation services for chronic neurological disorders. Developing and carrying out a quantitative evidence review was thought unlikely to return high-quality evidence, or evidence homogeneous enough to pool, that could be used to inform recommendations on the topic. However, there is a lot of

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					qualitative evidence of service delivery and what service users and professionals would like to see implemented. Therefore, it was decided to conduct a qualitative review to inform recommendations, strengthened and supported by the expertise and experience of the guideline committee. One of our committee members is particularly qualified to advice on service design recommendations, due to their commissioning role.
Parkinson's UK	Guideline	006	001 - 023	We welcome the approach to service design as outlined here. However, we believe it would benefit from greater clarity on whose responsibility it is to bring these different groups and stakeholders together to initiate this collaborative response. There is also no mention of the sports and leisure sector, who deliver much of the exercise activity.	Thank you for your comment. The responsibility is on the commissioners, as highlighted in the title of this section ('Designing and commissioning rehabilitation services'). Furthermore, there is a recommendation stating that someone needs to have overall designated responsibility for implementing clinical pathways. Therefore, no change has been made for this request. However, we have added included that sports and leisure providers should be considered when designing rehabilitation services.
The British Psychological Society	Guideline	006	001 - 023	The service design proposed in this guideline is equally appropriate for people diagnosed with dementia and it is therefore disappointing that the guidance does not include people with dementia. Understanding of the relevance and benefits of rehabilitation for people with dementia is growing; for example, rehabilitation will be the topic of the World Alzheimer Report 2025.	Thank you for your comment. We do agree that there is a need to better understand the potential benefits of rehabilitation for people with dementia. However, this is already covered under the scope of NG97 Dementia: assessment, management and support for people living with dementia and their carers. We note that you are currently listed as a stakeholder for that guideline, and suggest you raise the need for further and more detailed guidance in the area of rehabilitation during the next update cycle.
Parkinson's UK	Guideline	006	002 - 004	We welcome the recommendation to involve people with lived experience in the design and development of care pathways. We would recommend extending this to include voluntary, community and social enterprise (VCSE) organisations that represent people with chronic neurological conditions.	Thank you for your comment. We have added voluntary, community, and social enterprise organisations to this recommendation as requested.
The Wolfson Neurorehabilitation Service	Guideline	006	002 - 020	**Service Design (Recommendations 1.1.1 - 1.1.4)** We recommend strengthening the language in recommendations 1.1.1 and 1.1.2 to more explicitly underscore the vital role of family members' views and feedback in the design and development of rehabilitation services. For recommendation 1.1.3, whilst acknowledging the long-term need for care, we suggest balancing this with clearer guidance on the provision of both time-limited, focussed rehabilitation and lower-intensity, long-term maintenance. The inclusion of self-management tools and strategies should also be emphasised. Regarding recommendation 1.1.4, we encourage further exploration of strategies to ensure that integrated clinical pathways are genuinely effective in preventing duplication and ensuring comprehensive patient support.	Thank you for your comment. We have now included that families and carers should also be included when designing and developing rehabilitation services and care pathways. Regarding your second request, this is more detail than we would include in any 1 recommendation. However, the committee were very aware of these competing interests that are often present in rehabilitation services for chronic neurological disorders. They have drafted many recommendations, woven throughout the guideline, that address both these concerns (for example, providing responsive services). Self-management also is mentioned in the section on assessing a person's ability to coordinate their own care. Therefore, no change has been made. Finally, it is beyond the scope of this guideline to comment on the implementation of these guidelines, including how commissioners and local

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					authorities choose to monitor and procure feedback on care pathways. Therefore, no change has been made.
Headway – The Brain Injury Association	Guideline	006	004	We suggest that this line explicitly states, *including third sector providers* after *healthcare and social care practitioners who deliver them.*	Thank you for your comment. We have expanded the referenced recommendation to include voluntary, community and social enterprise organisations.
Success – Life After Cure Ltd	Guideline	006	010	Rec 1.1.3 We endorse this early assessment of rehabilitation needs from diagnosis and symptom presentation, and our charity is advocating for a parallel recovery pathway alongside that of the cure from diagnosis in children with brain tumours. We are concerned there is general lack of recognition that the symptoms of the brain tumour itself are often those of a potentially emerging chronic neurological disorder which has been overlooked in the pathway to cure, and which neurosurgery, cancer therapy and the lack of timely rehabilitation, aggravate. Now that 80% diagnosed under 25y survive and live long lives, promoting functional independence and quality of life by early intervention, in the accruing 800 - 1,000 added each year to a pool of 30,000-40,000, is a priority whose costs are very likely to be offset by reduced long term public health costs, and increased employment.	Thank you for your comment. We also hope that our recommendations can enable earlier access to rehabilitation services for those that need them, regardless of symptom aetiology or diagnosis.
British Society of Physical and Rehabilitation Medicine	Guideline	006	010 - 017	Seamless care across the tiers of healthcare system (tertiary, secondary, community, and primary care)	Thank you for your comment. We are assuming that your comment is either asking for a reword of the current bullet point that specifies to design rehabilitation services that operate across all health and care settings, or adding it as a separate consideration. Either way, the wording does not cover the whole rehabilitation for chronic neurological disorder pathway (which would include those outside healthcare-only settings). Furthermore, while we hope that this guideline will help services to deliver coordinated and continuous care, it is not realistic to recommend that services deliver seamless care. Therefore, no change has been made.
University College London Hospital	Guideline	006	012	Lifelong access to rehabilitation is a good idea (included in stroke guidelines also), but no resources to deliver this.	Thank you for your comment. We acknowledged potential resource implications in supporting discussions. The committee also discussed the current siloed and disjointed services, poor communication leading to duplication, delays in assessments and care, and reliance on costly inpatient and crisis care. They made recommendations on service design and specification to improve efficiency, potentially free up resources and overall savings to the NHS, which may be used to e.g., facilitate lifelong access to those who need it. The committee also hopes their recommendations will be adopted and any additional funding provided to ensure best outcomes for people with chronic neurological disorders.
Guy's and St Thomas' NHS Foundation Trust	Guideline	006	012	Rec 1.1.3 - We are pleased to note that "lifelong support" has been stated from the outset in this new guideline and would support this key inclusion. Chronic neurological disorders are lifelong conditions that require a whole lifespan approach to their care and management. We	Thank you for your comment. We hope that our commissioning recommendations focusing on continued access to and life-long support with rehabilitation for people with chronic neurological disorders help to bridge the gaps in services that your trust is experiencing.

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				currently have significant gaps in services, including in our own, where we are unable due to commissioning structures to offer neurorehabilitation to young people who are 17-years of age, and struggle to find adult services who will accept young people under the age of 18. Increasingly, the evidence base is demonstrating that brain development extends well into the 20s (Uda et al., 2015; Bourke et al., 2022), and therefore we welcome services being designed with "lifelong support and care in mind".	
Shaftesbury Icanho	Guideline	006	018	1.1.4 - We agree establishing Integrated , collaborative and flexible clinical pathways is a must. Implementing truly integrated working can be a challenge and often third sector contribution or potential contribution is overlooked. Inclusion of some best practice examples, e.g. ensuring inclusion in pathway mapping work and establishing integrated MDTS involving third sector and patient voice.	Thank you for your comment. We have now given greater emphasis to the role of voluntary, community and social enterprise organisations (VCSE) in the designing and commissioning rehabilitation services section and in building local capacity. We have also added some further detail to the section about agreeing, delivering and reviewing a coordinated rehabilitation plan emphasising the importance of interdisciplinary working and timely and joined-up delivery and the role of VCSEs in ongoing support and care.
Success – Life After Cure Ltd	Guideline	006	018	Rec 1.1.4 We endorse this view but see challenges in commissioning and delivering these services where the acute aetiology of injury - in our case a childhood brain tumour which requires repeated experimental treatments and may never be resectable - is separated in distance and time from the inpatient neurorehabilitation assessments, though the neurological disorder becomes the lifelong priority. In essence, the oncology need for tumour surveillance competes with the awareness of, and need for, neurorehabilitation during the vital developmental years and across the lifespan.	Thank you for your comment. The committee acknowledge that there may be other continuing medical needs of people with chronic neurological disorders, which can impact on their rehabilitation needs and planning. They have recommended a flexible criteria to start a rehabilitation needs assessment, including as soon as a diagnosis is established. This would cover your scenario where neurorehabilitation may end up occurring later than the initial cancer treatment and oncology surveillance. Similarly, they have highlighted the important of considering comorbidities during assessment and when designing rehabilitation plans. However, it is beyond the scope of this guideline to cover all scenarios where this may be the case. Instead, we hope that the recommendations in this guideline encourage commissioners provide adaptable pathways that prioritise collaboration and communication between services, which can help prevent the competition of interests you note. Therefore, no change has been made.
Headway – The Brain Injury Association	Guideline	006	018	In 2024, the National Neurosciences Advisory (NNAG) published an Optimum Clinical Pathway for adults with neurological conditions. We suggest that explicit reference is made here to this pathway and its recommendations.	Thank you for your comment. In order for us to explicitly reference external guidance, we have to have enough detail provided covering the development of recommendations to complete a quality appraisal checklist. This is the same criteria as any evidence that we include in out evidence reviews, and allows the guideline committee to fully consider the strengths and weaknesses of any recommendations they are linking to. There is not enough information published on the development of this pathway for us to do this. For example, the website simply says that the pathway for traumatic brain injury developed by a working group of specialists in

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					consultation with relevant stakeholders with no further information provided. Therefore, no change has been made.
South London and Maudsley NHS Foundation Trust	Guideline	006	018	Rec 1.1.4 - We agree with the benefit of integrated clinical pathways. We would suggest that it is made explicit that care is best delivered in an integrated fashion across physical and mental health services, ideally with clinicians embedded in the same services	Thank you for your comment. We have amended the wording of this recommendation to reflect that integration should span physical and mental health services.
United Kingdom Acquired Brain Injury Forum	Guideline	006	018	Relates to the proposal for lifelong care something which in terms of ongoing access to specialist neuro rehab is often denied. We would support this recommendation. This is much needed to reduce the use of IFR etc to restrict demand for people seeking support more than a year post injury or diagnosis	Thank you for your comment. We hope that our commissioning recommendations focusing on continued access to and life-long support with rehabilitation for people with chronic neurological disorders help to address the access inequalities that you note in your comment.
Heads Together	Guideline	006	021	It is important to have an understanding of who is responsible for implementing clinical pathways. Our experience has shown poor communication across organisations that hinder this process	Thank you for your comment. Due to the wide range of services and local needs that will need to be addressed, the committee decided that the professional role best placed to fulfil this position will likely vary between regions. The most important aspect was to have a single person take responsibility, in part to reduce the historically poor communication that you note in your comment. Therefore, they did not wish to nominate a specific professional and left it up to individual Integrated Care Boards to decide the most appropriate person to appoint.
Success – Life After Cure Ltd	Guideline	006	021	Rec 1.1.5 We welcome the designation of a nominated individual responsible for implementation of clinical neurorehabilitation pathways but see this might prove challenging where complex needs care involves a child also receiving intensive, experimental repeated cycles of treatment and surveillance for a brain tumour, which may be inoperable but nevertheless low grade and of high survival. Is there a need for specific guidance on neurorehabilitation for those with brain tumours under 16 as in over 16s?	Thank you for your comment. This overlap of commissioning responsibilities for treatment and rehabilitation clinical pathways will be the same for many of our included conditions (for example, multiple sclerosis and Parkinson's disease). However, agreeing the person with overall responsibility for implementation of neurorehabilitation pathways within a region should help to simplify this area of potential confusion, as it will mean people are aware of who to coordinate with when designing any complementary pathways. This guideline is designed to cover the rehabilitation needs of children under 16s with brain tumours, but if you have identified areas where you feel more specific guidance is needed, please complete the online form at https://www.nice.org.uk/forms/topic-suggestion.
Headway – The Brain Injury Association	Guideline	006	021	Responsibility for the implementation of this guideline is key. Headway has previously called for each ICB to have a named neurorehabilitation lead. We suggest that this recommendation could be included within this guideline, to ensure its successful implementation.	Thank you for your comment. Due to the wide range of services and local needs that well need to be addressed, the committee acknowledged that the professional role best placed to fulfil this position will likely vary between regions. The most important aspect was to have a single person take responsibility. Therefore, no change has been made.
United Kingdom Acquired Brain Injury Forum	Guideline	006	021	We agree that it is important that there is clarity and leadership over responsibility for implementing clinical pathways. We have suggested in other forums that each ICB should have Director of Rehabilitation.	Thank you for your comment. We hope that this recommendation, along with others from the sections on commissioning, building local capacity, and providing responsive services, will help to encourage coordination across

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				Furthermore, if all ICBs had a programme board for neurological conditions including stroke / ABI/ FND / progressive neurological conditions etc then this would encourage more coordinated strategies for the development of a neuro specialist workforce which is badly needed, a cohesive approach to single point of access models and an overall approach to training and support for primary care.	pathways and more efficient delivery of rehabilitation for people with chronic neurological disorders.
Royal College of Speech and Language Therapists	Guideline	006	021 - 023	In addition to recommendation 1.1.5, the importance of well-supported transitions from child to adult services should also be included. We appreciate that NICE guidance regarding transition is referenced, but a specific recommendation would highlight the importance of this for young people with chronic neurological disorders.	Thank you for your comment. As you mentioned, transition between child and adult services is already covered by NG42 (Transition from children's to adults' services for young people using health or social care services), which has been referenced at the beginning of this guideline section. Therefore, recommendations on this topic are out of scope for this guideline and no change has been made.
Midlands and South Essex ICB	Guideline	006	023	Provide a mechanism whereby case managers can provide feedback to commissioners regarding the effectiveness of the nationally commissioned pathways (e.g. specialised commissioned services) where there are gaps in provision.	Thank you for your comment. Specifying how commissioners decide to implement these recommendations, including any feedback mechanisms, is beyond the remit of this guideline. Therefore, no changes have been made.
Cambridge University Hospital NHS Foundation Trust	Guideline	006	General	Rec 1.1.3 needs to include – "that monitors the impact of their neurological condition on their developmental trajectory"	Thank you for your comment. We have reworded the referenced recommendation to highlight that rehabilitation services need to be designed with lifelong support and monitoring in mind.
The Wolfson Neurorehabilitation Service	Guideline	007	001 - 025	**Commissioning Rehabilitation Services and Service Specifications (Recommendation 1.2)** The commitment to a single point of contact (key contact, key worker, or complex case manager) is strongly supported. We urge the committee to consider recommending that these roles be formally designated and sustainably funded, rather than additional responsibilities for existing therapists, acknowledging current challenges with the continuity of such positions. Furthermore, we suggest that the guideline emphasises the necessity of robust data collection from the outset to capture and demonstrate the long-term benefits of these initiatives. We also recommend expanding the list of interventions within the service specifications to explicitly include behavioural interventions and those focussed on social activity and health.	Thank you for your comment. The committee acknowledged potential resource implications. However, they noted that key contact and key worker roles are already undertaken by existing staff, so it is mainly about ensuring these roles are nominated and communicated to people with chronic neurological disorders. The committee also discussed the current siloed and disjointed services, which lead to reliance on costly crisis and inpatient care. Their proposed recommendations on service design aim to improve efficiency, potentially freeing up resources and funds for other uses. The committee hopes their recommendations will be adopted and appropriately funded. We will also pass your comment to the implementation team. Regarding your comment about expanding the interventions to specifically include behavioural interventions, and social activity and health, this recommendation is drafted as a high-level list of minimum service specifications. It also serves to link different sections of the guideline. The detail that you have requested is covered in the subsequent section on emotional health and mental wellbeing, and participating in social and leisure activities.

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Rehabilitation for chronic neurological disorders including acquired brain injury

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Heads Together	Guideline	007	003	Having a single point of contact is vital. Our research has shown how a lack of this allows people to fall through the gaps in services: Holloway, M., & Norman, A. (2022). Just a Little Bit of History Repeating: The recurring and fatal consequences of lacking professional knowledge of acquired brain injury. Journal of adult Protection.	Thank you for your comment. We hope that our recommendations on assigning a single point of contact are helpful in increasing continuity of care across different rehabilitation services, as well as the social and voluntary sectors.
First Community Health and Care	Guideline	007	003	Rec 1.2.1 - The role of a key worker/ Case manager/ SPC (single point of contact) varies in the context of the patient's situation and need for therapy intervention. The use of the word 'Rehabilitation' throughout this document implies patients will receive therapies to optimise or improve function in a timely and coordinated way. Often patients are on long wating lists and input may be fragmented e.g. seeing a physio weeks before seeing a speech therapist, therefore the need for key working becomes more vague. When working in a rehab setting, e.g. inpatient rehab ward or Early Supported Discharge (ESD) services, the role of a Keyworker is more defined. For others, services are quite separate and therefore the role of a keyworker would be huge and very time consuming. The role of a case manager stretches beyond rehabilitation and may incorporate longer periods of intervention. This may need to be delivered by someone working in a specific role, who can work across multiple services. Patients with chronic or progressive neurological conditions may not have 'rehabilitation needs' They require support with managing their disability. It may be useful to consider rehabilitation pathways i.e. Intermediate Care Team (ICT), ESD separately from 'disability management' pathways, as these will look very different in terms of case management, staffing and service delivery.	Thank you for your comment. The committee agrees and distinguished between initial contact and single point of contact for rehabilitation. Initial contact is a named healthcare practitioner following diagnosis or initial treatment for a chronic neurological disorder. This role, often hospital-based, is generally temporary until a single point of contact is agreed, unless the initial contact practitioner is deemed most appropriate for this role. The committee also emphasised the need for a timely and coordinated approach. And agreed that this could be effectively achieved through a single point of contact, which could be a key contact, key worker or complex case manager, depending on the person's needs. They acknowledged potential resource implications but noted that key contact and key worker responsibilities are already undertaken by existing staff. The main impact is to ensure these roles are nominated and communicated to those with chronic neurological disorders. There is flexibility in who can fulfil this role as per the included definitions. The committee recognised that complex case managers are sparse within the NHS, which may present resource challenges. They discussed the many benefits of this approach, outlined in the supporting discussions, and made recommendations on service design to improve efficiency, potentially freeing up resources and any additional funds for single point of contact roles. The committee hopes their recommendations will be adopted and appropriately funded. We will also pass your comment to the implementation team. NICE is also planning to develop an implementation tool on complex case managers to support commissioners.
Success – Life After Cure Ltd	Guideline	007	003	Rec 1.2.1 Our charity has, over the last 2 years, garnered significant patient and professional support for such a nominated key contact / worker /complex case manager, responsible for implementing neurorehabilitation pathways to children with brain tumours. This pathway should function separately, but in parallel, with the well-established clinical cure pathway in children with brain tumours	Thank you for your comment. We are glad that your charity's experience with key contacts, key workers, and complex case managers supports the recommendations in this guideline.

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MS Society	Guideline	007	003	Key Worker Role The requirement for a single point of contact is important. This was extensively explored in Greater Manchester during the development of the longer-term neuro support model. It is something that many people with neurological conditions say they would value, and we recognise the positive difference it could make to their care and experience. However, given current workforce pressures and the capacity challenges faced by already overstretched teams, introducing a dedicated care coordinator role is difficult in practice. In the model currently being piloted, we have instead identified a set of 'key functions' which could be shared across several members of the Community Neurological Rehabilitation Teams (CNRTs). While this is not an ideal solution, it was important to avoid designing a model that would immediately face implementation barriers and deter services from adopting it.	Thank you for your comment. The committee acknowledged potential resource implications. However, they noted that key contact and key worker roles are already undertaken by existing staff, so it is mainly about ensuring these roles are nominated and communicated to people with chronic neurological disorders. The committee discussed the current siloed and disjointed services, which lead to reliance on costly crisis and inpatient care. They believe this model would present overall cost savings to the NHS. Many recommendations on service design were made to improve efficiency, potentially freeing up resources and resulting in cost savings. The committee hopes their recommendations will be adopted and appropriately funded. We will also pass your comment to the implementation team.
University College London Hospital	Guideline	007	003	Needs to say it is the ICB's responsibility to resource and identify point of contacts/ key workers- see above.	Thank you for your comment. This recommendation is aimed at commissioners to ensure it is commissioned, resourced and funded. To future-proof the guideline, the committee did not think it necessary to refer to ICBs specifically. Additionally, the committee did not believe it was the ICB's role to identify single points of contact. There is a section on how to agree and assign the most appropriate single point of contact based on the rehabilitation needs assessment.
South London and Maudsley NHS Foundation Trust	Guideline	007	003	Rec 1.2.1 – We agree with the benefit of a key contact for all patients with rehabilitation needs in a chronic neurological disorder. In practice this will be challenging to implement particularly within FND care due to current provision of services.	Thank you for your comment. The committee made several recommendations on service design which may improve efficiency, releasing resources and funds for other uses, including facilitating a single point of contact role. They noted that key contact and key worker responsibilities are already undertaken by existing staff, and their recommendation is mainly about ensuring clarity on who this person is and communicating this to people with chronic neurological disorders. The committee acknowledged the current lack of services for people with FND but suggested that having at least a key contact could be beneficial if their needs change. They hope that service provision will improve as a result of this guidance, increasing the need for a single point of contact role in this population. We will also pass your comment to our implementation team.

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United Kingdom Acquired Brain Injury Forum	Guideline	007	003	Having a single point of contact is vital and we welcome this suggestion. We are concerned that the decision-making process around which level of input a patient receives relies upon the knowledge and experience of NHS staff who may lack knowledge of the impact of • Patients' executive impairment • lack of patient's insight into their own condition, and lack experience of integrating social care, rehabilitation and community services NHS staff are often used to working with boundaried budgets (health separated from social care) excluded. It is this matter, this decision about what level of support people get, that will be the most important. The case management industry is able to demonstrate the cost efficiency of this role however, more research is needed to strengthen the evidence base.	Thank you for your comment. The committee highlighted the need to build local capacity and expertise throughout the guidance. Depending on the setting, there are options to seek expertise from specialist neurorehabilitation services. The guidance also recommends holistic needs assessments, involving multiple practitioners and including someone with specialist clinical knowledge as needed. For example, this may be someone who understands the impact of patients' executive impairment. Recommendations were also made on integrated service design across all healthcare settings, and ensuring collaboration between commissioning bodies from healthcare, social care and other relevant community providers which may help to overcome budgetary barriers that you mention. The committee agreed and made a research recommendation for clinical case management, which was included in the supporting evidence review but omitted in the main guideline document. This was rectified.
Central London and Community Healthcare Trust	Guideline	007	003	1.2.1 Answer to question 2) Single point of contact throughout lifetime even when not receiving active care has significant cost implications: For in reach funding for community rehab to rehab/hospital, staffing to enable key worker capacity, additional administration to re-allocate staff when required.	Thank you for your comment. Depending on the complexity of needs, a single point of contact may involve signposting and providing information for some people, while others may require more intensive support to navigate services, coordinate rehabilitation, access services, and refer to other services as needed. The committee recognised that many staff already undertake key contact and key worker responsibilities. Their recommendation involves ensuring a nominated practitioner is communicated to individuals with chronic neurological disorders. While there may be resource implications, particularly for the complex case manager role, the committee outlined many benefits, including reduced reliance on expensive inpatient and crisis care. Please see supporting evidence review I for a full discussion of potential benefits and cost effectiveness. The committee also made several recommendations on service design to improve efficiency, potentially releasing resources and funds for other uses, including staff capacity building. We will also pass your comment to our implementation team and NICE is planning to develop an implementation tool on complex case managers to support commissioners

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Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	007	003	We agree this is essential for co-ordination of rehab for patients but commissioning pathways need to be considered as currently inequitable geographically and adult vs paediatrics (currently very limited in paediatric services).	Thank you for your comment. The guideline includes recommendations on service design, promoting integrated, collaborative and flexible pathways across hospital and community rehabilitation. The guideline aims to reduce unwarranted geographical variation in access to rehabilitation services through included service specification. This guideline also applies to children and young people, aiming to improve access to paediatric services. The committee hopes their recommendations on service design will create efficiencies, potentially releasing resources and funds for other uses, such as expanding paediatric services. We hope the recommendations will be implemented and any additional funding provided. We will also pass your comment to our implementation team.
Community Case Management Ltd.	Guideline	007	003 - 006	**Access to a Case Manager as a Single Point of Contact** We strongly support the inclusion of "complex case manager" as a potential single point of contact. From our experience managing long-term, multidisciplinary rehabilitation for clients with complex needs, this role is often essential for ensuring continuity, communication across services, and patient advocacy. **Recommendation:** We encourage NICE to expand this section to: • Define the qualifications and scope of a complex case manager. • Clarify how the case manager integrates into the multidisciplinary team and rehabilitation planning process.	Thank you for your comment and support for our recommendation on a single point of access. It is beyond the scope of this guidance to specify the qualifications required for this role. However, the section on "Terms used in this guideline" defines the complex case manager and lists their responsibilities. The qualifications and NHS AfC band for this role would be agreed by commissioners and service providers. A complex case manager would be assigned (following holistic rehabilitation needs assessment) to individuals with severe, complex, and long-term rehabilitation needs, meeting specific criteria outlined in the related recommendation. These cases are very complex and the approach would vary. It is challenging to provide useful guidance on exact arrangements that would apply across all individuals needing complex case managers, only that their involvement is essential to ensure integrated care, timely access to appropriate care for optimal outcomes and experience of care. NICE is also planning to develop an implementation tool on complex case managers to support commissioners
Kent and Medway NHS and Social Care Partnership Trust	Guideline	007	003 - 006	1.2.1 - A good goal, but to have single point of contact for the person with a chronic neuro condition over their lifetime when needs will change is unrealistic. Good to have a contact to navigate from i.e. GP / neuro navigator.	Thank you for your comment. The single point of contact does not have to be the same professional throughout a person's lifetime. If rehabilitation or other needs (for example, social care) change and another professional is more suited to these new needs then it can change. Limiting the amount of transfers would be preferable for continuity of care, but it is not a fixed position. Both GPs and neuro navigators are listed as examples of this single point of contact in the glossary. Therefore, no change has been made.
Parkinson's UK	Guideline	007	003 - 006	The guideline is clear about the NHS roles involved in this collaborative approach to rehabilitation. The guideline should include how the NHS	Thank you for your comment. Implementation of these recommendations is beyond the scope of this guideline, and will be decided by local authorities

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				staff involved can find out about and keep up-to-date with relevant non-NHS services (e.g. those provided by the voluntary, community and social enterprise (VCSE) sector).	when they come to action the guideline. However, we have amended several recommendations in the sections on service design, building local capacity and expertise, and providing responsive services to highlight collaboration of services should extend over the third sector. We hope that strengthening the collaboration and communication between these different services will also increase the knowledge of NHS staff regarding relevant non-NHS services.
Parkinson's UK	Guideline	007	003 - 006	We welcome the guidance that people with a chronic neurological disorder have access to a single point of contact, as this will help ensure better communication and coordination of care. We recommend more details on the responsibilities of the staff member acting as the single point of contact.	Thank you for your comment. More details are in the 'Terms used in this guideline' section. Please see definitions for single point of contact, key contact, key worker and complex case manager.
Headway – The Brain Injury Association	Guideline	007	004	We agree with the recommendation of a single point of contact for rehabilitation for all people with a chronic neurological disorder and consider that this would be beneficial for all brain injury survivors. From our experience of supporting people with acquired brain injury, this should be a skilled professional working in neurorehabilitation, with a detailed understanding of the effects of acquired brain injury. However, we think it is likely that the neurorehabilitation workforce across England and Wales is currently not sufficient to provide for this and would need to increase in line with standards across comparable countries.	Thank you for your comment. The committee was aware of current resource constraints and made recommendations on building expertise and capacity within services. A single point of contact could be a key contact, key worker or complex case manager. Some people may only need signposting and information, while others may require more intensive help to navigate rehabilitation services, coordinate care, support access to services, and make referrals as needed. The type of single point of contact will depend on the complexity of needs. The committee recognised that many responsibilities associated with key contact and key worker roles are already undertaken by existing staff. Their recommendation requires a nominated practitioner to be communicated to individuals with chronic neurological disorders. The committee also made several recommendations on service design to improve efficiency, potentially releasing resources and funding for other uses, such as capacity building. The committee discussed many other benefits associated with a single point of contact, including potential cost savings, detailed in supporting discussions within the full evidence review I. The committee hopes their recommendations will be implemented and appropriately funded. We will also pass your comment to our implementation team.
The Spinal Injuries Association	Guideline	007	007	Incorporated should be specific guidance on bowel, bladder and sexual dysfunction treatment although mainly bowel and bladder within the patient group relating to spinal injuries alongside other neurological conditions such as MS. Readmission rates for such conditions relating to poorly managed or lack of incorporated training for individuals to self-manage their neurogenic problems is widely documented.	Thank you for your comment. This recommendation is meant to be a high-level list of what should be included in service specifications for integrated rehabilitation care. Although not specifically named, rehabilitation for sexual function is included in the bullet point on to support engagement in intimate relationships. Regarding rehabilitation for bladder and bowel function, these areas are out of scope for this guideline as there is already NICE guidance on these topics (CG49 Faecal incontinence in adults: management and

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					CG148 Urinary incontinence in neurological disease: assessment and management). However, the guideline committee agree that bladder and bowel management is important in this population and have included signposting to CG49 and CG148 at the beginning of the section on independent living, equipment and environmental adaptations. This is covered in the list by the bullet point on occupational health. Therefore, no changes have been made.
Success – Life After Cure Ltd	Guideline	007	007	Rec 1.2.2 It seems to us that this integrated rehabilitation care is vital for children with chronic neurological needs emerging from a brain tumour diagnosis; early commissioning of such services may require some investment - perhaps 20% of the cancer spend per child, given 80% are now cured - but will be offset by both later cost-efficiencies arising from reduced secondary neurological and mental health disorders and hospitalisations which burden the NHS [Chung et al 2022 ; https://www.thelancet.com/journals/lanepe/article/PIIS2666-7762(22)00127-2/fulltext, and improved independence and employment outcomes. Some clear steer to address this apparent 'gap' in commissioning neurorehabilitation for this group would be welcome .	Thank you for your comment. This guidance covers children and young people with chronic neurological needs including those resulting from brain tumours. The committee acknowledged limited services and integrated pathways for children and young people but felt it inappropriate to single out this group. They hope their recommendations will be adopted and funded accordingly. The committee has also made several recommendations on service design to improve efficiency, potentially freeing resources and funds, which may be used to support services for children and young people with chronic neurological needs.
University College London Hospital	Guideline	007	007	It doesn't actually say who is responsible for producing these. Needs to be much more direct- each ICB is responsible for commissioning of services. These must include community teams specialist in adult neurological conditions, learning disability, and children's health.	Thank you for your comment. This section is aimed at commissioners, so it is implicit the recommendations are directed at ICBs. To future-proof the guideline, the committee did not consider it necessary to refer to ICBs specifically. Therefore, no change has been made.
The Royal Hospital for Neuro-disability	Guideline	007	007- 025	Services need to be able to demonstrate outcomes and should have outcome recording and monitoring embedded within their processes.	Thank you for your comment. Unfortunately, it is beyond the remit of this guideline to comment on the implementation of these recommendations, and specifying how local authorities monitor their rehabilitation services. However, the committee believe that your concerns are adequately covered by the first 2 recommendations in this guideline. The first states that rehabilitation services and care pathways should be delivered with a variety of stakeholders (including people that use them, their families and carers, third sector organisations, and practitioners. Implicit within this wording is that qualitative, lived experience will be fed-back to commissioners and incorporated in future planning. To strengthen this, the second recommendation is to seek feedback from people with a chronic neurological disorders, and use this to inform service design. Therefore, no changes have been made.
Defence Medical Rehabilitation Centre	Guideline	007	009	No mention is made of "Consultant Physician in Rehabilitation Medicine" this role is recognised as a key practitioner who should lead and coordinate rehabilitation services. Cite recommendations made by the British Society of Physical and Rehabilitation Medicine (BSPRM)	Thank you for your comment. We have now added 'consultant physician in rehabilitation medicine' to the list of examples given for guideline definition of rehabilitation practitioners. This can be found in the section titled 'Terms used in this guideline'.

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Royal College of Speech and Language Therapists	Guideline	007	012	Due to the high prevalence of communication difficulties in this group of patients, recommendation 1.2.2 should specifically say "**personalised and accessible** information, advice…"	Thank you for your comment. This recommendation is drafted as a high-level list of minimum service specifications, as well as serving to link different sections of the guideline. The detail that you have requested is covered in the subsequent section on information, advice and learning. Therefore, no change has been made.
Anglia Ruskin University	Guideline	007	014	Rec 1.2.2 - This recommendation states that service specifications should include "play therapies that facilitate the delivery of rehabilitation interventions for children". We are concerned that music therapy is not named specifically in this recommendation. There is evidence, including a Cochrane Review, that recommends the use of music therapy to deliver rehabilitation outcomes and interventions. We feel that music therapy is essential to holistic rehabilitation and to addressing functional gains and emotional and psychological needs for many children, young people and adults with chronic neurological disorders.	Thank you for your comment. This recommendation is meant to be a high-level list of what should be included in service specifications for integrated rehabilitation care. Play therapies has been specifically highlighted as a form of delivery because this guideline covers all age groups. As it is a mode of delivery that is specific to the paediatric population, to not include it would be an oversight as it is does not appear in any other specification. Conversely, although not specifically highlighted, music therapy is included the 'interventions for' bulletpoint (as part of our list of creative therapies). Therefore, no change has been made.
Oxford University Hospitals - Paediatric Neuropsychology Department	Guideline	007	014	It would be helpful to clarify whether this refers to play specialists or play therapists. Play therapy is not a major aspect of neurorehabilitation in our service and to our knowledge, is not something which is provided by the NHS in the community.	Thank you for your comment. We have now amended the wording to reference play interventions to facilitate rehabilitation for children. This broadens the recommendation to encompass both play therapists and play specialists, as well as other professionals that may use play within their sessions (for example, physiotherapists).
Central London and Community Healthcare Trust	Guideline	007	016	1.2.2 *environmental adaptations*- Answer to question 2) significant cost implications as Disabled Facilities Grants a)- not available to all adults as means tested and b)- capping/inadequately funded to meet all needs	Thank you for your response. We agree and acknowledge in the "How recommendations may affect practice" section (related to the recommendations on independent living, equipment and environmental adaptations) that access to equipment, environmental adaptations, and funding currently varies and may require additional resources to implement. We added a bit more detail to the rationale and impact section and will also pass your comment to our implementation team.
Central London and Community Healthcare Trust	Guideline	007	017	1.2.2 *equipment, assistive devices and compensatory aid* Answer to question 2) significant cost implications as gaps in funding. As well as long waits for provision.	Thank you for your response. Equipment, assistive devices, and compensatory aids are integral to rehabilitation, and NHS England already provides pathways and funding. We acknowledged delays in accessing these. The committee also discussed the importance of reusing and repurposing equipment in relation to this. We added a bit more detail to the rationale and impact section and will also pass your comment to our implementation team.
Inflammatory Neuropathies UK	Guideline	007	019	This should be both specialist (i.e. Neurological Physiotherapy) and generic, and be available in both inpatient settings and in the community	Thank you for your comment. This recommendation is drafted as a high-level list of minimum service specifications, as well as serving to link different sections of the guideline. We have additional recommendations on appropriate settings to deliver rehabilitation within the section on agreeing and delivering a coordinated rehabilitation plan. Similarly, guidance on the content of exercise and physical activity programmes can be found in the corresponding guideline section, along with who should develop and oversee an exercise programme. Therefore, no change has been made.

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British Association of Prosthetists and Orthotists	Guideline	007	022	We feel that it may be beneficial to directly mention orthoses here as an example of equipment, both to aid mobility/gait, but also (for example) where there is upper limb involvement. To add some context to our views across the board in this consultation: prosthetics and orthotic services are the smallest of the AHPs and are generally poorly understood, resourced or referenced. They do however have a hugely important role to play in management of Chronic Neurological conditions. In practice, they can minimise contracture and secondary complications, manage pain and optimise mobility and independence. This is highlighted and referenced in The Walton report on Neuro muscular disease. Whilst now an older report is still representative of the services today which have progressed little since its publication. I am linking the report here so it can be reviewed: https://www.musculardystrophyuk.org/app/uploads/2024/05/PDF-MDUK-APPG-Walton-Report-Access-to-specialist-care-2009.pdf	Thank you for your comment. This recommendation is drafted as a high-level list of minimum service specifications, as well as serving to link different sections of the guideline. The detail that you have requested is covered in the subsequent sections on stability, mobility and limb function. Therefore, no change has been made.
Heads Together	Guideline	007	024	Emotional and mental wellbeing must form an integral part of neurorehabilitation rather than viewed as an optional extra.	Thank you for your comment. We believe that it has been highlighted throughout this guideline that rehabilitation for chronic neurological disorders should be approached holistically, with psychological and cognitive symptoms receiving the same weight as physical disabilities. The recommendation that you are referencing is about a minimum service specification commissioners need to consider in order to deliver integrated rehabilitation. Including interventions for emotional health and mental wellbeing in this list as saying it is a necessary component of rehabilitation, not an optional extra. Therefore, no change has been made.
The Chartered Society of Physiotherapy	Guideline	007	024	We agree with the interventions and would also like to add 'interventions to enable supported self-management'	Thank you for your comment. We have added the bullet point as requested.
Oxford University Hospitals - Paediatric Neuropsychology Department	Guideline	007	024	It would be helpful to include behavioural interventions on this list in its own right (rather than being subsumed under emotional health and wellbeing).	Thank you for your comment. This recommendation is drafted as a high-level list of minimum service specifications, as well as serving to link different sections of the guideline. The detail that you have requested is covered in the subsequent section on emotional health and mental wellbeing. Therefore, no change has been made.
United Kingdom Acquired Brain Injury Forum	Guideline	007	024	Emotional and mental wellbeing must form an integral part of neurorehabilitation rather than viewed as an optional extra.	Thank you for your comment. We believe that it has been highlighted throughout this guideline that rehabilitation for chronic neurological disorders should be approached holistically, with psychological and cognitive symptoms receiving the same weight as physical disabilities. The recommendation that you are referencing is about a minimum service specification commissioners need to consider in order to deliver integrated rehabilitation. Including interventions for emotional health and mental

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					wellbeing in this list as saying it is a necessary component of rehabilitation, not an optional extra. Therefore, no change has been made.
Headway – The Brain Injury Association	Guideline	007	025	We suggest that particular reference is made here to the importance of neuropsychologists in supporting people with ABI and other chronic neurological conditions to have better mental health.	Thank you for your comment. This recommendation is drafted as a high-level list of minimum service specifications, as well as serving to link different sections of the guideline. We have highlighted the importance of maintaining or supporting emotional health and mental wellbeing in the corresponding section of the guideline. The guideline committee did not specifically mention neuropsychologists in this section due to the resource implications of such a recommendation but did ensure to stress that rehabilitation plans in this area should developed and overseen by people with psychological expertise and an understanding of the effects of their condition or injury. Therefore, no change has been made.
Parkinson's UK	Guideline	007 – 008	007 - 025 001 - 007	Health professionals we spoke to have recommended that interventions for balance and transfers be added to the list of what should constitute a service specification for integrated rehabilitation care for people with a chronic neurological condition.	Thank you for your comment. This recommendation is drafted as a high-level list of minimum service specifications, and linking to different sections of the guideline. The detail that you have requested is covered in the subsequent sections on 'Stability, mobility and limb function' and 'Independent living, equipment and environmental adaptations'. Therefore, no change has been made.
British Association for Music Therapy	Guideline	007	General	Throughout this guideline, there is a repeated reference to services which provide 'holistic' care. Yet on page 7, there is no mention of Music Therapy or Neurologic Music Therapy. The evidence base for Music Therapy demonstrates clearly that it offers holistic support for functional physical, cognitive, communication and psychological needs. The exclusion of Music Therapy within this guidance document undermines not just the profession but impacts upon service delivery for child and adult patients who could directly benefit and be supported by a Music Therapy intervention.	Thank you for your comment. This recommendation is drafted as a high-level list of minimum service specifications, as well as serving to link different sections of the guideline. Music therapy would be classed as a creative therapy, which are covered under interventions for emotional health and mental wellbeing. Therefore, no change has been made.
Headway – The Brain Injury Association	Guideline	008	004	Given the government's current focus on supporting people with disabilities into work, we suggest that more attention could be paid in this section to the importance of vocational rehabilitation.	Thank you for your comment. This recommendation is drafted as a high-level list of minimum service specifications, and linking to different sections of the guideline. The detail that you have requested is covered in the subsequent sections on goal setting for work and rehabilitation for work. Therefore, no change has been made.
Central London and Community Healthcare Trust	Guideline	008	004	1.2.2 *occupational therapy and skills-based learning*- Answer to question 2) significant cost implications, due to longer term needs to ensure effective skill acquisition and ability to implement strategies to other functional tasks to achieve self-management.	Thank you for your comment. This reflects current practice and is likely to be cost-neutral. It involves acquiring skills in the workplace, where for example, junior staff are mentored by more experienced colleagues.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	008	007	The guideline may benefit from listing an intervention specifically for partners, families or carers of the individual with brain injury. Research has shown that the symptoms often seen in brain injury such as personality changes, increased aggression and disinhibition can be	Thank you for comment. This recommendation is drafted as a high-level list of minimum service specifications, and linking to different sections of the guideline. While we note the importance of helping families, partners, and carers adjust to new symptoms and engage in rehabilitation, this guideline

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				difficult to navigate for families, partners and carers and can lead to relationships breaking down and increased distress of the individual and the people closest to them https://doi.org/10.1017/BrImp.2015.22 https://doi.org/10.1097/HTR.0b013e3182068588	is not designed to cover interventions to facilitate this. It would be inappropriate to include it in this list as it is out of scope. Therefore, no change has been made. However, despite interventions for family members and carers being out of scope, the importance of these support units is highlighted throughout the guideline. There are several recommendations on including them in rehabilitation planning, as well as ensuring they are including in training for rehabilitation interventions for the person with a chronic neurological disorder.
The Association of Clinical Psychologists UK	Guideline	008	007	ACP-UK feels that the guideline may benefit from listing an intervention specifically for partners, families or carers of the individual with brain injury. Research has shown that the symptoms often seen in brain injury such as personality changes, increased aggression and disinhibition can be difficult to navigate for families, partners and carers and can lead to relationship break downs and increased distress of the individual and the people closest to them https://doi.org/10.1017/BrImp.2015.22 https://doi.org/10.1097/HTR.0b013e3182068588	Thank you for comment. This recommendation is drafted as a high-level list of minimum service specifications, and links to different sections of the guideline. While we note the importance of helping families, partners, and carers adjust to new symptoms and engage in rehabilitation, this guideline is not designed to cover interventions to facilitate this. It would be inappropriate to include it in this list as it is out of scope. Therefore, no change has been made. However, the importance of these support units is highlighted throughout the guideline. There are several recommendations on including them in rehabilitation planning, as well as ensuring they are including in training for rehabilitation interventions for the person with a chronic neurological disorder.
MS Society	Guideline	008	008	If people with neurological conditions are to receive joined-up care, commissioning cannot happen in silos. Collaboration between NHS commissioners, local authorities and wider services such as education and housing is essential. Without it, people are left navigating gaps between services, with care that too often feels disjointed or inconsistent. In Greater Manchester, a review of the MS pathway has shown how important this coordination is. While the work is being led by the Neuro Rehab Network, with strong clinical input, many of the challenges uncovered, especially around outpatient and hospital care, sit across different commissioning bodies and fall outside the remit of any one team. This kind of system-level misalignment is not unique to Greater Manchester. If this guideline is to drive real change, it must set clear expectations for joint commissioning across health, social care and other relevant services. Otherwise, even well-designed pathways risk failing in practice	Thank you for your comment. We acknowledge the challenge of commissioning truly holistic rehabilitation care for people with chronic neurological disorders, and appreciate the difficulties of ensuring continuity of care across different teams, services and commissioning bodies. We hope that the recommendations contained in this guideline, especially those regarding service design, commissioning rehabilitation services, and building local capacity and expertise sections, will form a strong blueprint to guide the co-production of rehabilitation pathways moving forward.

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				because the structures around them do not support shared planning or accountability.	
MS Society	Guideline	008	008	Neuro rehabilitation networks have an important role in shaping, improving and supporting services, particularly community neuro rehabilitation teams. They provide essential opportunities for clinical leadership, shared learning and coordination across different parts of the system. Despite their clear value, these networks are increasingly under threat. The most recent round of ICB budget cuts led to the closure of several neuro rehabilitation networks, and further reductions may result in more being lost. In Greater Manchester, the Neuro Rehab Network has been able to deliver meaningful improvements in service design and coordination, but this success has depended on a strong local commitment to maintaining the network. In other areas, similar networks became inactive over ten years ago and have only recently begun to re-establish themselves in new forms. Funding arrangements add to the uncertainty. The Greater Manchester network previously received part of its funding from NHS England, but responsibility has now passed to the Integrated Care Board, and there is no guarantee that this support will continue. The network has warned of a possible funding shortfall in 2026 to 2027, which would directly impact staffing levels and its ability to deliver improvement projects. For these reasons, it is essential that NICE guidance recognises the critical role neuro rehabilitation networks play within the wider system. Without clear emphasis on the need for sustainable commissioning and funding structures, progress in improving neuro rehabilitation services will remain uneven and vulnerable to ongoing pressures. Ensuring these networks are supported is key to delivering more consistent, coordinated and effective care for people with neurological conditions.	Thank you for your comment. The committee were very aware of the funding constraints and resource challenges that are neurorehabilitation services are experiencing. There have been many long discussions on how best to support organisations and local authorities to implement these guidelines, with many committee members highlighting the constant risk to funding hanging over services. Therefore, the committee have included a whole section on designing and commissioning rehabilitation services. This area of the guideline tackles important issues within service delivery such as service design, commissioning rehabilitation, service specification, building local capacity, and providing responsive services. The term neurorehabilitation network has not specifically been used. In order to maintain the applicability of this guideline for future readers, NICE guidance tries to limit specific organisational terms because these are likely to change with time. However, the recommendations in this section do centre around building sustainable and comprehensive commissioning models, which we hope will translate into stable funding structures that are appropriate to support rehabilitation services for people with chronic neurological disorders. Therefore, no change has been made.
The Stroke Association	Guideline	008	008 - 024	It is vital that relevant charities and community organisations are engaged in efforts to build local capacity and expertise. The guideline mentions relevant community service providers. This could explicitly include charities and community groups. The third sector is mentioned in the following section in relation to responding to peoples' needs, but many also deliver support services and are a key part of local capacity. For example, the Stroke Association has been commissioned by many	Thank you for your comment. We have now included third sector providers, charities, and community groups as examples of community service providers.

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				local systems to deliver life after stroke support, which can complement NHS provided-rehabilitation services. The voluntary sector can be commissioned to provide services including providing information and support provision by a stroke coordinator/stroke key worker, psychological and emotional support, peer support, post-stroke reviews, "Return to work" support as part of NHS vocational rehabilitation services, support for carers and communication support.	
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	008	009	Points 1.3.1 – there is a need for improved communication as this is essential across services. There is insufficient shared understanding of what rehabilitation entails, especially among commissioners, which creates barriers to implementation. Therefore, 'ensuring collaboration' appears vague and it is not clear how this would be done or implemented.	Thank you for your comment. This is the first recommendation in this section. We believe that the subsequent recommendations provide clear examples of how collaboration can be achieved. There is guidance covering local service agreements for mental health services, building capacity within services, increasing knowledge of primary care practitioners, increasing access to specialist neurorehabilitation services, and increasing support for rehabilitation groups in the community. Therefore, no change has been made.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	008	009	Point 1.3.2 - Proposing separate psychological services often results in rejection by commissioners and local services. Many services refuse to work with individuals who had neurological disorders with comorbid mental health. These patients are not seen by general mental health services and referrals are rejected. The guideline should promote integration of psychological input within core rehabilitation pathways to avoid fragmentation and improve uptake	Thank you for your comment. The guideline committee were aware that some mental health services have admittance criteria that specifically exclude people with a diagnosis of a chronic neurological disorder, which was supported by qualitative evidence. This recommendation was designed to specifically reduce this barrier to access, stating that there needs to be local service agreements for the provision of mental health services for people with chronic neurological disorders. However, after discussing several comments on the wording, the committee agreed that using the 'separate' may accidentally encourage this division between mental health and rehabilitation services. We have re-phrased the recommendation to read that there should be clear local service level agreements for providing mental health services. The subsequent recommendation on building capacity for mental health services for people with chronic neurological disorders then acts to support delivery of these clear local service level agreements.
Shaftesbury Icanho	Guideline	008	010	1.3.1 - To support with engagement from social care consider need for education in neuro rehab and its value for social care commissioners and social workers to support collaboration and effective commissioning. Evidence to consider? • Linden, M.A., Holloway M., Cooper, C., Amadiegwu, A., Bald, C., Clark, M., Mantell, A., Norman, A., Bateman, A. (2023) Social workers and acquired brain injury: A systematic review of the current evidence -	Thank you for your comment. Unfortunately, we are unable to include the systematic review that you have references as it is a mixed-methods review (that is, contains both qualitative and quantitative data) that presented the results together in a narrative synthesis. This means it does not fit either our qualitative or quantitative review questions. The recommendation is regarding collaboration between commissioning bodies for healthcare, social care, and community service providers. It is beyond the remit of this guideline to specify how these recommendations

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				base. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0292128 Icanho have recently hosted a workshop for social work staff and launched social worker ABI champion scheme.	should be implemented by commissioners. However, it is assumed that involving social care in the commissioning process for rehabilitation for chronic neurological disorder services will involve a level of education and engagement on behalf of every professional involved. Therefore, no change has been made.
Headway – The Brain Injury Association	Guideline	008	010	We suggest that specific reference is made here to third sector providers.	Thank you for your comment. We have expanded the list of examples of relevant service providers to include third sector providers.
United Kingdom Acquired Brain Injury Forum	Guideline	008	011	We welcome this recommendation as currently the links between health and education for children with brain injuries is very hit and miss	Thank you for your comment. We hope that this recommendation can increase collaboration between commissioning bodies for healthcare and education for children with brain injuries.
Huntington's Disease Association	Guideline	008	012	Rec 1.3.2 - We agree that there should be separate local service level agreements in place for the provision of mental health services for adults, and for children and young people, with a chronic neurological disorder. We suggest the guideline makes clear in this section that, as stated in the Department of Health and Social Care's Rare Disease Action Plan 2025, 'Mental health services should be offered based on need and should not exclude anyone because of a particular physical health or neurological diagnosis'. People with neurological conditions often face additional barriers to accessing general mental health services and can be denied support because they have an organic brain condition (see the Huntington's Disease Association's mental health report (2024) and the Neurological Alliance's response (2022) to the call for evidence on an NHS 10 year mental health plan).	Thank you for your comment. The guideline already contains recommendations saying that rehabilitation for chronic neurological disorders should be offered to people based on identified needs, rather than diagnosis. Adding it to this section as well would be duplication of guidance, which we have tried to avoid as often as possible to prevent confusion. Therefore, no change has been made.
South London and Maudsley NHS Foundation Trust	Guideline	008	012	Rec 1.3.2 – Whilst service level agreements would be essential, we would instead advocate for integrated psychological medicine input into rehabilitation services, the manner of which would be dependent on needs of the population served.	Thank you for your comment. It is beyond the remit of this guideline to advise how these service level agreements should be delivered. As you mention in your comment, this will vary with the needs of the local population. It will be up to the commissioning bodies to decide what model will be best suited to their regional needs. Therefore, no changes have been made.
Brainkind	Guideline	008	012 - 014	There may be challenges with implementing the recommendation of establishing service level agreements for provision of mental health services for adults given how 'stretched' some services are. In addition, mental health and rehabilitation needs interact. In many cases, mental health needs could and should be addressed within neurorehabilitation services. In its current form, this recommendation could be read to imply	Thank you for your comment. The guideline committee agree that additional resources that may be needed in some regions to deliver mental health services for people with chronic neurological disorders (including funding for staff training or additional staff). However, they also noted several benefits from the recommendation (including reducing inefficiencies, and ensuring timely access to mental health services) that could ultimately

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				that neurorehabilitation services will provide neurorehabilitation and mental health services will provide care for mental health, when in reality a two-way service level agreement that promotes easy access between services may be more effective (i.e. including referral to neurorehabilitation services when a neurological condition may be affecting engagement with mental health services).	improve overall rehabilitation outcomes. Additionally, they drafted a subsequent recommendation focusing on building capacity within these mental health services in order to address the increased demand, in order to try mitigating the identified barriers to implementation. After discussing several comments on the wording of this recommendation, the committee agreed that using the 'separate' may accidentally encourage a division between mental health and rehabilitation services, rather than ensuring mental health services adequately cover and provide for people with chronic neurological disorders as was the intention. Therefore, we have re-phrased the recommendation to read that there should be clear local service level agreements for providing mental health services. However, it is not in the remit of this guideline to specify how these services are delivered (that is, addressing mental health concerns within neurorehabilitation services). This will be at the discretion of the Integrated Care Boards in response to the needs and organisational structure of the region.
First Community Health and Care	Guideline	008	012 - 018	Rec 1.3.2 and rec 1.3.3 - This recommendation will be a challenging change in practice because there is currently no provision for mental health/psychologist support for those with long term neurological conditions aside from mainstream services which are only accessible to those with the most severe of need, limited to crisis management or establish diagnosis rather than proactive support for long-term conditions. Currently refer to counselling services as able.	Thank you for your comment. The guideline committee were aware that some mental health services have admittance criteria that specifically exclude people with a diagnosis of a chronic neurological disorder, which was supported by qualitative evidence. As you mention in your comment, this then means access is limited to those with immediate and very severe needs, rather than long-term mental health support for this population. This recommendation was designed to specifically reduce this barrier to access, stating that there needs to be local service agreements covering the provision of mental health services for people with chronic neurological disorders. The guideline committee acknowledged that there are challenges to implementing this recommendation, and agree that additional resources may be needed in some regions to deliver mental health services for people with chronic neurological disorders (including funding for staff training or additional staff). However, they also noted several benefits from the recommendation (including reducing inefficiencies, and ensuring timely access to mental health services) that could ultimately improve overall rehabilitation outcomes. In order to try mitigating the identified barriers to implementation, the committee drafted a companion recommendation focusing on building capacity within these mental health services in order to address the increased demand.
Central London and Community Healthcare Trust	Guideline	008	012 - 018	1.3.2 and 1.3.3 Build capacity for mental health services for people with a chronic neurological disorder through local workforce skills development and communication protocols between different services involved in rehabilitation. Whilst we fully support this recommendation,	Thank you for your comment. We do include more detail of how the recommendations may impact practice (which covers workforce development and use of referrals to mitigate increased resource demand) can be found in the committee's discussion of the evidence section in

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				would the committee consider provision of examples in recommendations from evidence of best practice in this area as part of guidelines and recommendations in the guidelines? There are many barriers that exist to ensure this can happen (e.g. are there the local service level agreements?), how do we support training needs across different trust aiming to work in partnership? These have implications including funding costs to support and embed better pathways, but evidence for models of good practice in partnership pathway working would support services to build better capacity and provision in mental health for people with chronic neurological disorders.	evidence review H. Unfortunately, due to the breadth of conditions, rehabilitation needs, and settings covered in this guideline, it is not possible to cover specific examples of implementation of these recommendations. These would still need to be generalisable to the whole guideline population, which is not feasible. The delivery of this guideline will be at the discretion of individual Integrated Care Boards, who will be better able to tailor services to the needs and organisational structure of the region. Therefore, no changes have been made.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	008	015	Encourages expansion of mental health services to be able to meet the needs of people with neurological conditions and brain injury. It should also make reference to a level of training in order to understand and meet the needs of these peoples.	Thank you for your comment. We believe that training in mental health services to understand and meet the needs of people with chronic neurological disorders is adequately covered by developing local workforce skills. This has also been further explained in the corresponding rationale section of the guideline, as well as the 'Benefits and harms' section of evidence review H. Therefore, no change has been made.
Headway – The Brain Injury Association	Guideline	008	015	Again, we suggest that specific reference is made here to the recruitment and development of neuropsychologists.	Thank you for your comment. This recommendation is designed to be broader than the recruitment and development of 1 profession. While adequate staffing is a way of building capacity within mental health services, it is not the only way of doing so. Therefore, no change has been made.
Headway – The Brain Injury Association	Guideline	008	015	We think it would be helpful to see here some specific examples of how ICBs could ensure that GPs and other primary care practitioners are trained in recognising rehabilitation needs for chronic neurological disorders.	Thank you for your comment. It is beyond NICE's remit to issue recommendations on specific training requirements for professionals. Therefore, no change has been made.
Oxford University Hospitals - Paediatric Neuropsychology Department	Guideline	008	015	We agree that this would be brilliant in an idea world but are concerned that many of our patients do not meet criteria for local mental health services and this is unlikely to be a training priority for their very busy and stretched services.	Thank you for your comment. The committee acknowledge that there is competing interest for funding from local authorities, which can ultimately lead to mental health services having to implement strict access criteria for service users in order to keep costs within budget. In order to tackle this initial barrier of exclusion, the committee have made an earlier recommendation ensuring there are clear local service level agreements in place providing mental health services for a people with a chronic neurological disorder. This recommendation will mean that people with chronic neurological disorders will meet criteria for local mental health services. We hope that the provision of these services agreements, along with this recommendation that specifies building capacity for mental health services through local workforce skills development and communication protocols between different services, will result in prioritising training for healthcare professionals.

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South London and Maudsley NHS Foundation Trust	Guideline	008	015	Rec 1.3.3 – We agree with the need for workforce development but would recommend a specific recommendation to how this may be delivered.	Thank you for your comment. Specific examples of how to build local workforce skills are given throughout the rest of this guideline section. Examples include recommendations on ensuring primary care practitioners are trained in recognising emerging rehabilitation needs because of an existing chronic neurological disorder, collaborating within and between integrated care systems to increase access to specialist care and advice, and funding social and leisure groups to support community rehabilitation. Therefore, no change has been made.
Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Guideline	008	015 - 018	Expertise for pain management in this complex population from the very beginning is essential. This will not only aid rehabilitation but improve function as well. The guideline explicitly quote build capacity for mental health services (1.3.3). A similar strategy of either building capacity or service level agreement with local pain service should be considered.	Thank you for your comment. The committee agree that the recommendation on building capacity should not only apply to mental health services, and have re-worded to incorporate building workforce skills in rehabilitation and mental health services. The committee did not feel pain clinics should be specifically referenced over other services in this aspect of service delivery and have not named them specifically. However, the committee do agree with your concern that pain management is especially important in the population and requires specialist knowledge and expertise. Therefore, we have added a new recommendation into the pain management section on referral to pain specialists where there is a diagnostic difficulty or further advice is needed.
The Royal Hospital for Neuro-disability	Guideline	008	015 – 018	This statement is not sufficiently robust to derive any meaningful recommendation from.	Thank you for your comment. We are sorry to hear that you believe that this recommendation lacks an action. Due to the scope of this guideline, there is a limit to the amount of detail we can include in recommendations before it starts to impact generalisability across neurorehabilitation services and different commissioning bodies. We have made a few minor changes to the recommendations in this section which we hope make the action and message clearer.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	008	015 – 018	1.3.3 - Need to build services that do not exclude people because of a primary diagnosis i.e. people with brain injury may also have mental health issues and needs ton access both services.	Thank you for your comment. The committee agree that mental health services should not exclude people due to a primary diagnosis of a chronic neurological disorder. The recommendation prior to the one referenced is about first ensuring there are local service level agreements agreed for the provision of mental health services as part of rehabilitation for chronic neurological disorders. Therefore, no change has been made here. However in section 1.8 we have included a recommendation to not exclude someone from any aspect of holistic needs assessment based on their communication, memory, learning or other cognitive difficulties.
Shaftesbury Icanho	Guideline	008	017	1.3.3 - Agree capacity needs to be built for mental health services for people with chronic neurological disorder and improved joint working with rehabilitation services. Establishing an integrated MDT could be one example of improved communication.	Thank you for your comment. The committee agreed that the use of integrated multi-disciplinary teams were a good example of improving communication protocols. We have added this extra detail to the 'Benefits and harms' section of evidence review H.

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The Association of Clinical Psychologists UK	Guideline	008	018	ACP-UK comments that this encourages the expansion of mental health services to be able to meet the needs of people with neurological conditions and brain injury. However, it should also make reference to a level of training in order to understand and meet the needs of these peoples.	Thank you for your comment. It is beyond NICE's remit to make recommendations on training of professionals. However, we do include a reference that building capacity should include local workforce skills development, which could include training in identifying the mental health needs of people with chronic neurological disorders. Therefore, no change has been made.
Inflammatory Neuropathies UK	Guideline	008	019	We welcome this, but it may be difficult to ensure it happens without incentives for GPs etc. It would be good to know how this will be delivered	Thank you for your comment. Unfortunately, it is beyond NICE's remit to advise on the implementation of these recommendations. This will need to be decided by the relevant commissioning bodies and local authorities. Therefore, no change has been made.
The Spinal Injuries Association	Guideline	008	019	Add The priority on freeing up staff through tech, by recommending national SCI alerts in digital records and investment in shared data infrastructure. This would allow all HCPs especially in primary care be alerted to those living with SCI in their regions and allow for their rehabilitative and chronic needs to be effectively monitored and managed. The addition of SCI condition alerts in electronic records would not only allow for enhanced identification of patient needs but allow for HCPs to be instantly notified of the onward steps necessary, i.e. linking to local / national charities, referrals to bladder and bowel services or regional SCIC services.	Thank you for your comment. The guideline committee agree that your suggestion about national spinal cord injury alert system could help to improve continuity of care for people with spinal cord injury. However, they noted that system is not currently in place, meaning any recommendations would have a large resource impact which would not be supported by effectiveness or cost-effectiveness evidence. Additionally, the system that you have proposed is only for a proportion of people covered in the guideline. Any system would have to be applicable to the whole guideline population, which would increase the resource impact and logistical concerns of this intervention. They also noted that providing a universal system capable of communicating with different IT systems in different trusts is not feasible at this time. Therefore, no change has been made.
University College London Hospital	Guideline	008	019	Who is being asked to 'Ensure that GPs and other primary care practitioners know how…'? Who is this directed to? Should the responsibility be put on primary care to ensure they are trained and skilled. So perhaps; 'Primary care practitioners should ensure they are skilled in…..'	Thank you for your comment. This recommendation sits under the guideline section on commissioning, with the responsibility of implementing this falling to the commissioning bodies themselves. There is no expectation for primary car to ensure they are appropriately skilled and trained. Therefore, no change has been made.
The Stroke Association	Guideline	008	019 - 024	We welcome the inclusion of the link to the stroke specific rehabilitation guidance, which covers returning to work. One in four strokes occurs in people of working age, and the incidence of stroke for people under 55 is rising[1]. People without access to rehabilitation services are less likely to be in employment[2]. 700 of the 6616 respondents to the Stroke Patient Reported Experiences Measures Survey indicated they would have liked more support in returning to work but were not offered it[3].	Thank you for your comment. We hope that inclusion of this recommendation will assist other people with chronic neurological disorders in returning to work.

[1] 10-Year-Health-Plan
[2] Easing the pain report second edition_web version.pdf
[3] Patient Reported Experience Measures Survey (PREMS) 2022/3 | Stroke Association

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Parkinson's UK	Guideline	008	019 - 024	The guideline could be more explicit here about what is meant by "local rehabilitation services" and be clear that this can include non-NHS providers that do not necessarily use the term "rehabilitation service" (such as voluntary, community and social enterprise (VCSE) sector organisations) but do provide an essential service.	Thank you for your comment. The committee did not want to define local rehabilitation services because they will vary hugely between geographical areas. However, they have amended the first recommendation in this section to highlight that community service providers can include third sector providers, charities, and community groups.
United Kingdom Acquired Brain Injury Forum	Guideline	008	023	We agree with this recommendation A national analysis/review/audit of rehabilitation services providers will be required.	Thank you for your comment. The recommendation that you are referring to only specifies that primary health practitioners maintain up-to-date information on local rehabilitation options, not national options. Additionally, this is only given as an example of how services may increase knowledge of how to refer people to rehabilitation specialists. During implementation, services may find other ways that are more suitable to their specific settings.
Independent Neurorehabilitation Providers Alliance	Guideline	008	023	We agree with this recommendation but a piece of work will need to be completed to identify all local rehabilitation services provided by all sectors to create a database as this is not currently available locally or nationally. This will also need to be maintained.	Thank you for your comment. Maintaining up-to-date information on local rehabilitation options is only given as an example of how primary health practitioners may increase knowledge on how to refer people to rehabilitation specialists. During implementation, services may find other ways that are more suitable to their specific settings. However, if a service decides to collate and maintain a directory of local rehabilitation options, this will require time and resources to carry out. As discussed in the corresponding rationale and impact section, the guideline committee were aware of this but noted that it will also allow to share expertise without requiring formal training. Additionally, this approach is already in place in some areas. Therefore, significant additional resource to implement this recommendation is not expected.
The Wolfson Neurorehabilitation Service	Guideline	008 – 009	008 - 024 001 - 013	**Building Local Capacity and Expertise (Recommendations 1.3 & 1.3.7** Concerning mental health services (Recommendation 1.3), we advise specifying that service level agreements must ensure mental health clinicians possess expertise in neurological conditions, ideally through dedicated training and supervision arrangements with Neuropsychologists and Neuropsychiatrists. This is crucial to address the unique presentation of mental health issues in neurological populations and to overcome current service refusal due to perceived organic components. For recommendation 1.3.7, we recommend including more practical guidance or examples on how the suggested considerations for funding social and leisure group activities can be effectively implemented within diverse community settings.	Thank you for your comment. We have not specified what expertise mental health clinicians possess in the recommendation you have referenced, as this is designed to ensure that these service level agreements are commissioned in the first place, and prevent people being refused entry to mental health services due to their chronic neurological disorder (as you have noted in your comment). However, we do have a new recommendation in the emotional health and mental wellbeing section that states that a mental health practitioners with an understanding of a person's disorder or injury should be the practitioner to develop and oversee the emotional health and mental wellbeing component of a rehabilitation. This will cover your concern of addressing unique presentations of mental health issues in neurological populations. Therefore, no changes have been made. Regarding your comment about implementation of social and leisure group activities in diverse community settings, unfortunately this is beyond the remit of this guideline. However, we have added cultural factors as an

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					example to consider when funding social and leisure groups. We hope that this highlights to commissioners that diverse community settings may face additional barriers to group participation.
Inflammatory Neuropathies UK	Guideline	009	001	Could be difficult to achieve with pressures on budgets meaning even with commissioning knowledge this may not be affordable	Thank you for your comment. This recommendation was made in response to evidence showing that affordability of interventions can be a barrier to accessing rehabilitation services. The committee agreed with this, further noting that the commissioning pathways for these are not always publicised or widely known about. We appreciate that there are budgeting pressures within the NHS that will impact commissioning decisions, but this recommendation is aiming to reduce one of the barriers to access by increasing knowledge.
University College London Hospital	Guideline	009	001	Key contact information after discharge, how long will they provide support for and remain the key contact? Who will do this in the community? Ensure that healthcare and social care practitioners know how to commission high-cost specialist equipment: are there sufficient splinting resources locally to meet the requirement after discharge?	Thank you for your comment. Due to the wide population covered in this guideline (which includes a variety of disorders, reason for admittance to hospital, and rehabilitation needs), the committee were not able to specify how long this key contact for medical information will be needed for . Similarly, they did not specify who would fulfil this role as it will be different for each individual. Therefore, no changes have been made.
First Community Health and Care	Guideline	009	001 - 002	Rec 1.3.5 - This recommendation will be a challenging change in practice because of issues accessing Continuing Health Care Occupational Therapist for specialist equipment – vacant posts long standing	Thank you for your comment. This recommendation aims to raise awareness and ensure practitioners understand the commissioning process for high-cost specialist equipment and services, and have the necessary skills and knowledge to support people with chronic neurological disorders. Referrals may increase, but these services are already funded. Thank you for highlighting issues with accessing Continuing Healthcare occupational therapists and recruitment challenges. We will share your comment with the NICE implementation team. The committee also made recommendations on service design and commissioning, which may help release resources and funding for other uses, for example, to build occupational therapist specialist capacity.
Heads Together	Guideline	009	003	This is an important idea. There are many areas where there is limited service. It is vital that ICBs work more closely to share services across regions. This is particularly true in relation to neuropsychology provision	Thank you for your comment. We hope that this recommendation can help to address limited access to specialist equipment and services that you note.
British Association of Brain Injury and Complex Case Management	Guideline	009	003	1.3.6 In relation to the comment about rural locations, it is concerning to see that there is suggestion that specialist services be provided according to geographic location, as opposed to clinical needs. It is quite possible to commission services, for example CCMs, to work in all geographic locations and then commission other services identified as necessary. That would provide equity of rehabilitation, rather than support an approach where provision is dependent on geographic location. By way of example, our members - who are CCMs – regularly source rehabilitation options across the UK to fill gaps in services.	Thank you for your comment. This recommendation is not saying that specialist services be provided according to geographic location. It is acknowledging that rural locations may have a reduced availability of specialist services, which was informed by qualitative evidence and committee experience. In order to ensure that people in these areas do not experience inequalities in provision, integrated care systems should collaborate in their provision of rehabilitation. This supports your model rather than opposes it. Therefore, no change has been made.

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Headway – The Brain Injury Association	Guideline	009	003	We know, from the experience of many brain injury survivors, that access to specialist neurorehabilitation is often a postcode lottery. This should not be the case. All brain injury survivors should have access to specialist neurorehabilitation, regardless of where they live or the rarity of their condition. This section implies that a 'patchwork' approach may be suitable for people living in rural areas – this is not the case.	Thank you for your comment. We agree that people living in remote or rural areas should not face reduced access to specialist rehabilitation for chronic neurological disorders. This recommendation is not saying that specialist services be provided in a 'patchwork' manner, but it is acknowledging that rural locations may have a decreased availability of specialist services, which was informed by qualitative evidence and committee experience. In order to ensure that people in these areas do not experience inequalities in provision, integrated care systems should collaborate in their provision of rehabilitation. Therefore, no change has been made.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	009	003	Point 1.3.6 - The term 'specialist services' is vague and how is a local team supposed to access a team that is not present? Who would fund this coworking?	Thank you for your comment. The guideline use of the term 'specialist neurorehabilitation services' is included in the glossary/terms used in this guideline section. The funding of increased collaborative working will come from integrated care systems and primarily from ICBs. The guideline makes recommendations about redesigning care pathways with a focus on building local area capacity and improving communication and skills sharing. However, NICE is not involved in funding decisions. The committee made recommendations on commissioning rehabilitation services and service specifications, and they hope these will be implemented and funded accordingly. We recognise the implementation of this guideline will take time.
United Kingdom Acquired Brain Injury Forum	Guideline	009	003	This is an important idea. There are many areas where there is limited service. It is vital that ICBs work more closely to share services across regions. This is particularly true in relation to neuropsychology provision	Thank you for your comment. We hope that this recommendation can help to address limited access to specialist equipment and services that you note.
The Royal Hospital for Neuro-disability	Guideline	009	003 - 006	This is an opportunity to suggest that rehabilitation services should be delivered according to need rather than diagnosis as is currently the case.	Thank you for your comment. We already have recommendations in subsequent guideline sections on ensuring that rehabilitation needs are identified as early as possible, and beginning the process for a holistic rehabilitation needs assessment based on symptoms or impairment rather than diagnosis of a chronic neurological disorder. Therefore, no change has been made.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	009	003 - 006	Where specialist neurorehab is lacking in some areas, who is it proposed that supports the 'general rehab' services?	Thank you for your comment. The funding of increased collaborative working between specialist and non-specialist rehabilitation services will come from integrated care systems and primarily from ICBs. The guideline makes recommendations about redesigning care pathways with a focus on building local area capacity and skills sharing. We recognise the implementation of this guideline will take time. However, NICE is not involved in funding decisions. The committee made recommendations on commissioning rehabilitation services and service specifications, and they hope these will be implemented and funded accordingly. We recognise the implementation of this guideline will take time.

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Inflammatory Neuropathies UK	Guideline	009	007	Where possible is not acceptable, this should be available to everyone, no matter geographical location. We need to make sure there is access to all	Thank you for your comment. The committee recognised that whilst some people with chronic neurological disorders receive specialist rehabilitation due to pathways of care for people with Parkinsons disease or multiple sclerosis for example, there are many other people, with chronic neurological disorders who currently receive a very fragmented rehabilitation service or no service at all. In order for the guideline to be implementable for all, the committee agreed that it would be important to build more flexible specialist expertise in generalist services as well as to improve access to specialist services for a wider group of people (based primarily on neurorehabilitation need, within the context of their specific disease or injury). This recommendation reflects the reality that specialist neurorehabilitation will not always be available for all and that in order to create sustainable and effective services for all, specialist neurorehabilitation and general community rehabilitation services will need to work more closely together in future.
Guy's and St Thomas' NHS Foundation Trust	Guideline	009	009	Rec 1.3.6 We recognise the need for far more widespread community services for young people with chronic neurological disorders and support commissioning community rehabilitation services for their needs supported by specialist services.	Thank you for your comment. We hope that this recommendation, along with others in the guideline, will help to address the unequal access to community rehabilitation services for young people with chronic neurological disorders that you note in your comment.
Royal College of Speech and Language Therapists	Guideline	009	010	Could a recommendation to consider delivery via telehealth be added here? There has been an increase in evidence for efficacy in speech and language therapy, which suggest it could be a viable alternative to increase accessibility, provided that limitations, barriers and patient choice are fully considered.	Thank you for your comment. The committee agree that telehealth can be a good way of increasing accessibility to certain interventions. They have added it as an example of how to enable access to specialist care where possible.
Inflammatory Neuropathies UK	Guideline	009	011	We welcome the inclusion of this and the breadth of the advice attached. However, just stating 'consideration of funding' will mean that it won't happen. Maybe need to look at funding, contributing to funding, or supporting social and leisure groups	Thank you for your comment. We understand your concern but this recommendation was drafted using qualitative evidence and the committee's expertise and opinion. The qualitative evidence showed mixed experiences with group settings, with some people finding them beneficial while others reported that they were not suitable. Additionally, there was no cost-effectiveness evidence identified for social and leisure group activities. Given the resource implications of recommending funding social and leisure group activities, and the mixed qualitative evidence supporting the recommendation, the committee did not want to issue strong guidance in this area and instead used the word consider. Therefore, no change has been made.
Headway – The Brain Injury Association	Guideline	009	011	We know, from our extensive work supporting brain injury survivors in the community, that funding for ongoing community rehabilitation and	Thank you for your comment. We hope that this recommendation , and others within the guideline, will help safeguard ongoing funding for

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				reablement for brain injury survivors is essential. Local Headway charities across the UK offer a wide range of services, including brain injury rehabilitation programmes, carer support, social re-integration, community outreach and respite care. However, these services are under threat, due to a perfect storm of local authority and ICB funding cuts, far greater running costs for charities, fewer donations from members of the public and a much tougher grant funding environment. We suggest that the wording here is stronger, to reflect the essential need for ongoing community rehabilitation and for government funding to be provided locally to enable this. E.g. *Provide urgent and essential funding to support ongoing rehabilitation in the community*	community rehabilitation services (including social and leisure group activities).
University College London Hospital	Guideline	009	011	It is not clear who is being asked to fund, if it's the ICB then say so. Or is it primary care? Also this is very vague, it would be much better to specify social prescribing. This would be best as; 'Consider including a Social Prescriber within the primary care network to support rehabilitation in the community through accessing social and leisure group opportunities according to the individual's needs'.	Thank you for your comment. Due to the chronic nature of the rehabilitation needs of people covered by this guideline, the committee note that funding could come from a variety of sources. If the social and leisure group activities are part of a goal-driven, time-limited therapeutic neuro rehabilitation programme, they would usually be funded by ICBs. However, if the social and leisure group activities are part of a longer-term approach (for example, maintaining function, preventing deterioration, and/or preventing secondary complications), then it is likely that they would be funded by charities or even local authorities. The committee also discussed that there are significant national commissioning changes currently underway, with full details not currently being known. As such, the committee did not want to specify who should fund social and leisure group activities.
First Community Health and Care	Guideline	009	011 - 024	Rec 1.3.7 - This recommendation will be a challenging change in practice because not consistent across different neurological conditions	Thank you for your comment. The committee were aware of the different needs of such a breadth of chronic neurological disorders. However, this recommendation is simply stating a list of things commissioners should think about when considering funding of community social and leisure group activities. It is not a prescriptive list but it is highlighting that one size will not fit all.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	009	011 - 024	The reference to group therapy being potentially unhelpful for people with FND lacks clear supporting evidence. The bullet points included in this section feel overly generalised and do not adequately reflect the complexity of FND presentations or other groups. This should be removed, or the full spectrum of individual difference should be represented (e.g., neurodiversity, individuals with differing religious beliefs) The section on groups is contradictory in that it recommends but then seems to dissuade from use of groups.	Thank you for your comment. This bullet point has now been removed from the recommendation.

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Rehabilitation for chronic neurological disorders including acquired brain injury

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Sheffield Teaching Hospital NHS Foundation Trust	Guideline	009	011 - 024	Participation of People from ethnic and linguistic minorities in social and leisure groups is poor. The guideline need to include culturally appropriate social and leisure groups.	Thank you for your comment. The committee agree that a shared culture can be an important factor in getting people with a chronic neurological disorder to engage in social and leisure groups. Therefore, they have added this to the list of considerations when funding these activities in the community.
The Neurological Alliance	Guideline	009	011 - 024	Participation of people from ethnic and linguistic minorities in social and leisure groups is poor. The guideline needs to include culturally appropriate social and leisure groups.	Thank you for your comment. The committee agree that a shared culture can be an important factor in getting people with a chronic neurological disorder to engage in social and leisure groups. Therefore, they have added this to the list of considerations when funding these activities in the community.
British Society of Physical and Rehabilitation Medicine	Guideline	009	011 – 024	Participation of People from ethnic and linguistic minorities in social and leisure groups is poor. The guideline needs to include culturally appropriate social and leisure groups.	Thank you for your comment. The committee agree that a shared culture can be an important factor in getting people with a chronic neurological disorder to engage in social and leisure groups. Therefore, they have added this to the list of considerations when funding these activities in the community.
Parkinson's UK	Guideline	009	019 - 024	We welcome the inclusion of this guidance to collaborate with other Integrated Care Systems in the circumstances where the availability of specialist neurorehabilitation services is restricted, to enable access to specialist care or share specialist expertise.	Thank you for your comment. We appreciate your support of the recommendation.
The UK FND Network	Guideline	009	020	In the context of a recommendation to consider funding social and leisure group activities in the community the following recommendation is made regarding people with FND: "people with a functional neurological disorder may not find a group approach helpful". • The evidence for this statement is not clear, and expert opinion and opinion in the charitable sector on the preferences of people with FND is that it is incorrect. • This potentially wrongly excludes people with FND from this sort of support. This is the only FND specific recommendation in the guideline. It is on a very minor point, but there is the impression that there may be incorrect assumptions at work here about people with FND. This impression is not counterbalanced by any other evidence in the document of a correct understanding of FND and people with FND.	Thank you for your comment. This bullet point has now been removed from the recommendation.
South London and Maudsley NHS Foundation Trust	Guideline	009	020	It is unclear to us where the specific recommendation to single out that some individuals with FND may not find groups helpful has come from in the evidence reviewed. This appears stigmatising and we would not want this to potential restrict individuals with FND who did want to access group interventions. We would suggest either removing or rewriting to acknowledge that some individuals do not find group interventions helpful.	Thank you for your comment. This bullet point has now been removed from the recommendation.

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Association of Chartered Physiotherapists in Neurology	Guideline	009	020	On what grounds is the statement "people with FND may not find a group approach helpful" made? I am not aware of any evidence to support this statement but I am aware of several studies showing promising outcomes for group interventions for people with FND. One wonders if this statement is based on an unfounded assumption that all people with FND have disordered personality traits that prevents social interaction. This statement should be removed or the evidence to support this statement must be cited.	Thank you for your comment. The recommendation was not made on the basis of disordered personality traits, but a concern that group settings may contribute to a continued focus on physical symptoms. However, based on yours and other stakeholder comments, this bullet point has now been removed from the recommendation.
British Society of Physical and Rehabilitation Medicine	Guideline	009	020 – 021	We are unsure regarding the evidence base for the statement that FND disorder patients do not find group approach helpful. There is evidence to support group approach in many conditions that overlap/ are similar to FND such as chronic pain, long COVID	Thank you for your comment. This bullet point has now been removed from the recommendation.
Shaftesbury Icanho	Guideline	009	022	1.3.7 - Agree there are lots of potential opportunities for people in universal social and leisure groups in community. Rehabilitation providers can play a part in developing connections and educating interested organisations and groups to enable these to be more accessible to people with chronic neurological disorders. Shaftesbury Icanho has been involved in a Community Opportunities project to this aim in order for people to continue to access support following their discharge from specialist rehabilitation.	Thank you for your comment. We hope that this recommendation will encourage other services to explore different ways of funding appropriate and accessible social and leisure activity groups within the community for people with chronic neurological disorders, similar to the Community Opportunities project.
British Association of Prosthetists and Orthotists	Guideline	009	022	It may be beneficial to further define accessibility here; for example, specifying an intersectional approach where not only physical limitations are considered, but also cognitive, social, and emotional limitations. (For example – offering email over telephone as an accessible communication method). This ensures that accessibility and inclusion is considered for co occurring conditions such as autism, mental illnesses, and learning difficulties; and not just the physical limitations e.g. wheelchair use that are often associated with accessibility measures.	Thank you for your comment. This is drafted as a high-level recommendation to ensure commissioners consider funding a flexible range of local social and leisure groups that are not dictated by common assumptions on which sorts of groups people with chronic neurological disorders would like to attend. The explanation that you have requested is too detailed to fit in with this objective. Furthermore, we do have recommendations on discussing wider barriers to social participation and using these to inform goals and identify appropriate social club and activities in the subsequent section on 'Participating in social and leisure activities'. Therefore, no change has been made to the recommendation wording but we have added the requested clarification of 'accessible' in the benefits and harms section of the corresponding evidence review (K).
Inflammatory Neuropathies UK	Guideline	010	002	Avoid using 'should' and use 'must' otherwise it won't happen or always happen	Thank you for your comment. While we understand your concern, NICE does not use the phrase 'must' in their recommendations unless it references a legal requirement. Therefore, no change has been made.
British Association of Brain Injury and	Guideline	010	002	1.4.1 some specific guidance on management of equipment between different commissioning bodies, for example hospital beds/wheelchairs and the practical difficulties meeting needs when budgetary	Thank you for your comment. The examples that you have requested are more detail than NICE provides in it's recommendations. The commissioning landscape changes quite regularly within the NHS, and

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Complex Case Management				responsibility and service contracts change would be helpful as delays can impact significantly on rehabilitation and maintain functional gains.	there is a danger of recommendations quickly becoming obsolete if they are too specific. However, there are several recommendations throughout the guideline on ensuring communication between services and working collaboratively to ensure timely delivery of equipment and environmental adaptations.
Brainkind	Guideline	010	002 - 005	The recommendation 'service providers should communicate and collaborate, including across specialties, and with the third sector and private sector' could lead to confusion, as service providers can be part of the third sector and private sector. Consider rephrasing this recommendation to read: 'Service providers from all sectors (including third section and private sector) and across specialities, should communicate and collaborate...'.	Thank you for your comment. We have re-worded the recommendation as suggested.
Heads Together	Guideline	010	006	Setting up simple referral systems including self-referral is vital. The lack of understanding about brain injury among GPs makes it essential that they do not act as gatekeepers for healthcare services after brain injury.	Thank you for comment. We hope that this recommendation can help to decrease barriers to accessing rehabilitation services for chronic neurological disorders, including primary care gatekeepers as you have noted.
Inflammatory Neuropathies UK	Guideline	010	006	This section should also include how people access, i.e. to achieve this a contact number or email address must be provided	Thank you for your comment. The committee did not want to specify how referral and re-referral mechanisms should be provided. Not only will these differ between commissioning bodies and services, but potentially even individuals depending on the level of support they may need. A contact telephone number or email may be suitable for some populations, but not others. Therefore, no change has been made.
University College London Hospital	Guideline	010	006	*Set up simple referral and re-referral (including self-referral) mechanisms that allow people with a chronic neurological disorder to access rehabilitation needs assessments*: If the resources don't exist where will they refer to? Who is responsible for funding and setting these systems up. Is this a recommendation for ICB's?	Thank you for your comment. The committee were aware that there is an inequality of provision of rehabilitation services for chronic neurological disorders across the NHS, and this was a significant barrier to access. They have made a number of recommendations in the beginning of the guideline, in the section titled 'Designing and commissioning rehabilitation services'. Guidance focuses on favourable aspects of service design, minimum service specifications, building local capacity and expertise, an providing responsive services. It is hoped that implementing these recommendations can start to tackle the poor access to specialist rehabilitation services that are experienced by many people with chronic neurological disorders, by increasing the number of services and the knowledge of health and social care professionals working in them. As the title of the section suggests, the responsibility for setting up these referral pathways lies with commissioners. In the current landscape, that would be ICBs. However, in order to future-proof this guideline in future systems, we have not named them specifically.
United Kingdom Acquired Brain Injury Forum	Guideline	010	006	This is a great recommendation - especially the re referral as it allows access to support as needed. But there is lack of understanding about brain injury among GPs which must be addressed.	Thank you for your comment. The committee agree that a lack of knowledge of non-specialist healthcare professionals can often act as a barrier to identification and referral for people with chronic neurological

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					disorders. This was also identified as a theme in evidence review B, a qualitative review covering the barriers and facilitators to identification and referral. As a result, the committee made a recommendation in the previous guideline section on building local capacity and expertise, on ensuring that primary care practitioners know how to identify emerging rehabilitation needs for people with a chronic neurological disorder and referral processes to appropriate services.
The Wolfson Neurorehabilitation Service	Guideline	010	006 - 017	**Providing Responsive Services (Recommendations 1.4, 1.4.2, 1.4.4)** We strongly advocate for a recommendation that addresses the need for integrated and interoperable IT systems across health and social care to facilitate seamless communication and information sharing, which is currently a significant barrier. In relation to referral mechanisms (Recommendation 1.4.2), we suggest acknowledging situations where individuals may lack insight or cognitive capacity for self-referral, and recommend proactive strategies involving healthcare professionals and family members to ensure ongoing access to rehabilitation. For recommendation 1.4.4, whilst endorsing a tailored approach to changing needs, we suggest the guideline acknowledges the current infrastructure limitations and encourages innovative resourcing to meet the demand for responsive services.	Thank you for your comment. The committee acknowledge that an integrated and interoperable IT system would assist with increased information sharing, communication and collaboration between specialities and services. However, we did not look for any effectiveness evidence on interventions to improve service delivery and this section was drafted using qualitative evidence. Any guidance recommending implementing an integrated IT system would have a large resource impact, which we cannot do without appropriate cost-effectiveness data and economic modelling. Therefore, no changes have been made. The committee agree that individual referral mechanisms should be accessible to people who lack insight of cognitive capacity, and have made several recommendations on assessing a person's ability to self-manage and assigning a single point of contact to assist with referral to services. Additionally, we have recommended agreeing whether follow-up appointments should be practitioner or patient initiated. However, this does not mean that services should not ensure that these referral and re-referral pathways are designed to be as simple as possible, or that a self-referral option should not be offered if suitable. Therefore, no changes have been made. The committee has extensively discussed the impact of the recommendations within this section of the guideline, and are aware that more resources will be needed to implement them. However, they noted that better integration, clear clinical pathways, and reconfiguration of existing services and funding may help mitigate these resource implications. For full details of the committee's resource use discussion, please see the corresponding section in evidence review A.
Shaftesbury Icanho	Guideline	010	009	1.4.2 Should it be made explicit in the guidelines that commissioned services should not have a time boundary? Provider contract specifications vary on this point and often rehabilitation services for people with TBI .may limit access dependant on when they had their injury.	Thank you for your comment. The guideline has multiple recommendations that state rehabilitation for chronic neurological disorders should be commissioned and provided with life-long approach in mind. The committee did not believe it needs to be re-stated in the referenced recommendation. Therefore, no change has been made.

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Inflammatory Neuropathies UK	Guideline	010	011	We would like to see trusted assessors a key part rather than a consideration	Thank you for your comment. This recommendation was drafted using qualitative evidence, supported by committee experience and expertise. No evidence was specifically identified on trusted assessors, and the committee discussed that the most important aspect of this recommendation was the efficient sharing of rehabilitation needs assessments. While trusted assessors are a way of doing this, they are not the only way. Therefore, no change has been made.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	010	011	The term 'trusted assessor' requires clearer definition. Some services do not accept clinical specialists in the rehab team to be trusted assessors, which delays equipment provision and delays discharge to other specialist services. This should be standardised in order to maximise patient care and reduce confusion with the term.	Thank you for your comment. We have added a definition of 'trusted assessment' to the glossary, which includes trusted assessors.
Inflammatory Neuropathies UK	Guideline	010	015	Need to define 'timely and proportionate way'	Thank you for your comment. Due to the wide population that this guideline covers (including different ages, different disorders, and different rehabilitation needs), the committee did not believe it appropriate to be more specific in the timing of service response. Therefore, no change has been made.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	011 - 012	002 - 004 001 - 009	We agree with the recommendation of the need for early discussion about prognosis and rehabilitation needs with patient and family in section 1.5, however, it would be helpful to give guidance on how this should be documented. For instance, should the patient be given written and/or verbal information	Thank you for your comment. There is already NICE guidance on the format of information. These recommendations can be found in CG138 (Patient experience in adult NHS services) and NG204 (Babies, children and young people's experience of healthcare), and are clearly referred to at the start of this guideline section. Therefore, no change has been made.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	011 - 012	002 - 004 001 - 009	In addition to more clarity in the guidelines on how prognosis conversations (section 1.5), it would be good to have guidance on how the rest of the MDT/IDT are informed of what has been shared e.g. details should be included in the patients medical records of the conversation to enable all health practitioner to be fully aware around sensitive issues around prognosis to avoid mixed messages to the patient	Thank you for your comment. There is already NICE guidance on communication between healthcare professionals. These recommendations can be found in CG138 (Patient experience in adult NHS services) and NG204 (Babies, children and young people's experience of healthcare), and are clearly referred to at the start of this guideline section. Therefore, no change has been made.
The Wolfson Neurorehabilitation Service	Guideline	011 - 018	002 - 004 001 - 009 006 - 021 001 - 016 001 - 018 023 - 026 005 - 020	**Assessing Rehabilitation Needs and Goal Setting (Recommendations 1.5, 1.7, 1.8, 1.8.4, 1.8.5, 1.8.8, 1.8.20, 1.9)** We recommend explicitly stating the benefits of early identification and intervention for rehabilitation needs across all chronic neurological conditions, including for preventive purposes and to optimise function from initial diagnosis. We suggest clarifying the relationship between "Assessment" and "Holistic Assessment" to ensure the guideline consistently promotes a comprehensive, person-centred approach as the default. For holistic assessments (Recommendation 1.8.4), we encourage the inclusion of skilled interviewing techniques, such as those rooted in motivational interviewing, particularly for individuals where insight or acceptance may be a challenge. We also	Thank you for your comment. The committee agree with you on the importance of early identification of rehabilitation needs for people with chronic neurological disorders, and have made a recommendation stating this in the section on early discussion about prognosis and rehabilitation. Although anticipated benefits are more than we would usually include in recommendation wording, the committee did discuss them and a write up of this conversation can be found in the 'Benefits and harms' section of evidence review B. Regarding the ambiguity between the terms assessment and holistic assessment, we have now re-drafted the section so we are consistent with

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				recommend emphasising the crucial role of family and advocates in the assessment process, drawing lessons from established practices in learning disability services, especially for individuals with impaired capacity. The scope of holistic assessment (Recommendations 1.8.8, 1.8.20) should explicitly cover significant life events, anticipated barriers to engagement, a full range of cognitive and communication difficulties, transport needs, and access to interpreters to ensure true inclusivity. For goal setting (Recommendation 1.9), we suggest that the guideline addresses situations where patient insight may be limited, stressing the importance of collaboratively agreed goals that are realistic and supported by the individual's network, ensuring their relevance to everyday function and vocational outcomes.	our language. We are unable to add any guidance on skilled interview techniques to inform a holistic needs assessment as we did not look for evidence in this area and the committee believe the other recommendations on how assessment should be carried out give more than enough guidance for practitioners. However, we have amended the recommendation on completing a holistic rehabilitation needs assessment for people with 'invisible' or less easily recognisable symptoms or impairments, lacks awareness and insight to note that multiple methods (including observation) should be used to help determine their rehabilitation needs. The committee have acknowledged the very important role family and advocates play throughout rehabilitation for chronic neurological disorders. We have highlighted their role in helping a person make decisions about their health and social care in the very first recommendation in this section. Similarly, we have guidance covering both identifying important people to the person with a chronic neurological disorder, and including them in the rehabilitation needs assessment. Again, the reasoning behind this is more than we would usually include in recommendation wording, but a full write up of this conversation can be found in the 'Benefits and harms' section of evidence reviews A and B. The committee have discussed your suggested additions to the scope of the holistic assessment recommendations, but believe that they are all covered in the existing draft even if they have not been specifically named: significant life events are covered in background, relationships, work, education, meaningful activities, spiritual and religious practices, and hobbies and interests; anticipated barriers to engagement will be identified by all areas specifically detailed in this recommendation; cognitive and communication difficulties is covered in a later recommendation on assessing the person's functioning; and transport needs would be covered in environmental and wider social factors that might encourage or prevent them from taking part in rehabilitation. Finally, access to interpreters is covered in NG108 'Decision-making and mental capacity', CG138 'Patient experience in adult NHS services: improving the experience of care for people using adult NHS services' and NG204 'Babies, children and young people's experience of healthcare'. All 3 guidelines have been highlighted at the beginning of the section on assessing rehabilitation needs and goal setting, and have been specifically re-iterated at the start of this section on the holistic rehabilitation needs assessment to remind health and social care practitioners that they should also be following foundational guidance.

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					Regarding your suggested amendments to the goal setting section we believe that your concerns have been addressed in the current wording. We have already addressed people with limited insight in the previous section on conducting a holistic rehabilitation needs assessment, and it is anticipated that any adjustments identified will be carried throughout a person's rehabilitation plan, including goal setting. The committee agree that collaboration is important in goal setting, and have recommended working collaboratively with the person to agree goals that focus on what is most important to the person. The committee discussed the important balance of keeping rehabilitation realistic but encouraging. They have included a recommendation on making short-term realistic goals that can be built into longer-term motivational goals. Vocational goals are covered in the next section titled 'For education, training and work'.
Heads Together	Guideline	011	003	While rehabilitation many years down the line can be effective, the most cost-effective method is early rehab. Getting this right would reduce long term costs and improve outcomes for individuals and their families.	Thank you for your comment. The committee agreed with your belief that earlier access to rehabilitation can lead to decreased downstream costs (including a potential decrease in crisis care costs). This is covered in the corresponding 'How the recommendations might affect practice' section, and in further detail within the 'Benefits and harms' section in evidence reviews A and B.
Success – Life After Cure Ltd	Guideline	011	003	Rec 1.5.1 We believe this is important for children with brain tumours, with some evidence to suggest the chronicity and degree of lifelong postcure neurological disorder is predictable from location of the tumour rather than its grade. This needs differentiating from imposed treatment toxicity by longitudinal assessments from the beginning in each child. It would be helpful to ensure this group are included in those with chronic neurological disorders given their long life span and very high survival rates, unlike in adults with brain tumours.	Thank you for your comment. The guideline does cover rehabilitation needs in children with brain tumours. However, the level of detail you have requested in your comment is beyond the scope of this guideline as we did not look for evidence specifically on what information should be covered in prognosis discussions, or how topics such as imposed treatment toxicity should be addressed. Therefore, no change has been made.
United Kingdom Acquired Brain Injury Forum	Guideline	011	003	While rehabilitation many years down the line can be effective, the most cost-effective method is early rehab. Getting this right would reduce long term costs and improve outcomes for individuals and their families. In some ICBs access to rehab specialist neuro rehab services for people with ABI or FND who are more than one year post injury / diagnosis is controlled using the IFR process – this is clearly not acceptable	Thank you for your comment. Although we did not identify any effectiveness or cost-effectiveness evidence on early rehabilitation, the committee agreed with your belief that earlier access to rehabilitation can lead to decreased downstream costs (including a potential decrease in crisis care costs). This is covered in the corresponding 'How the recommendations might affect practice' section, and in further detail within the 'Benefits and harms' section in evidence reviews A and B. We hope that this recommendation on identifying rehabilitation needs as early as possible can help to address some of the access concerns noted in your comment, particularly for people with acquired brain injury or functional neurological disorder.

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British Society of Physical and Rehabilitation Medicine	Guideline	011	003 – 004	For ABI, add specific guidance about discussing potential recovery trajectories and late-onset symptoms during early prognosis conversations.	Thank you for your comment. This suggested inclusion is more detail than we have been giving throughout the recommendations, and only covers a specific sub-population of the guideline. Therefore, no change has been made. However, in the 'Benefits and harms' section of the corresponding evidence review (B), we have highlighted that late-onset symptoms for people with acquired brain injury should be discussed in order to appropriately monitor emerging rehabilitation needs. We hope that this compromise appropriately addresses your concerns.
British Association of Brain Injury and Complex Case Management	Guideline	012	001	1.5.2 with reference to the offer of discussion early discussion and later follow up offers; for some people, following ABI or other traumatic event in particular, there is significant risk they will slip the net at this stage or that they will not be able to retain the information discussed or the offer of a later conversation. We suggest that this needs to be proactively followed up by the professional, not rely on individual to initiate contact.	Thank you for your comment. We have amended the wording of this recommendation to stress that practitioners will need to initiate further opportunities to discuss their prognosis and rehabilitation needs. The 'Benefits and harms' section in evidence review B has also been update to reflect the example you have provided.
University College London Hospital	Guideline	012	001	Time Frame about prognosis and when this discussion should happen? patient may be changing as they emerging. Consider reviewing of goals ~ Rehabilitation needs in acute versus long-term goals. Idea about coaching techniques; does this exist and who would fund it? We are very concerned about the lack of integration of services from different areas – postcode lottery, ICB funding varies, how will this guideline help solve these issues?	Thank you for your comment. We have taken your points one by one below: - Time frame about prognosis and when this discussion should happen: Due to the wide population that this guideline covers (including age, disorders and setting), the committee did not believe it was appropriate to provide a specific time frame for these discussions. Additionally, as other recommendations in the section reference, some people may not want to discuss their prognosis while they are still processing a lot of information. What is important is that people are given the opportunity to discuss their prognosis and potential rehabilitation needs soon after their injury or diagnosis if they wish. - Consider reviewing of goals~ Rehabilitation needs in acute versus long-term goals: The committee discussed that goals will invariably change throughout rehabilitation including the transition from acute needs to long-term needs. They have recommended agreeing long-term rehabilitation goals with the person, but for these to be broken down into shorter-term steps that will be easier to achieve. They have also recommended frequently adjusting rehabilitation goals and plans. Additionally, they have recommended tailoring review time frames of to a person's circumstances. This will allow a greater number of short- or medium-term goals to be made during acute stages, and fewer long-term goals during periods of remittance or stability. - Idea about coaching techniques; does this exist and who would fund it?: The section on goal setting was informed by qualitative evidence, and no themes pertaining to specific coaching techniques were identified. Therefore, no recommendations have been made. - The committee recognised the lack of service integration, postcode lottery and variation in ICB funding. A key aim of NICE guidance is to reduce such

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					unwarranted variation in practice. In response, the committee made several recommendations for commissioners (ICBs) to support more joined-up and collaborative working, including integrated clinical pathways across hospital and community rehabilitation services, interdisciplinary input into rehabilitation plans, a single point of access etc. Service specifications were also included to promote more equitable provision and access. While the committee acknowledged that additional funding may be needed, they also noted that their recommendations would lead to more efficient and effective services, timely and appropriate care, improved outcomes, and associated cost savings for the NHS. Although NICE is not directly involved in funding decisions, the committee hopes their recommendations will be adopted and funded accordingly. We will also share your comment with the team supporting implementation of this guidance.
The Association of Clinical Psychologists UK	Guideline	012 014 023 050	001 006 007 005	ACP-UK comments that the guideline makes no reference to domestic violence or abuse. There is international evidence that domestic violence is a risk factor for acquired brain injury (e.g., https://pmc.ncbi.nlm.nih.gov/articles/PMC8773525/; https://www.tandfonline.com/doi/full/10.1080/10926771.2019.1602089?casa_token=tBFHpJ7PamYAAAAA%3Ap2Z4jW9KdZ0v_SpPdBLAof7rwMRuufu5XP_ic8JQKUyMzGCG6vbTJI_fpuxmYIlFvgZoSPbruLc; https://doi.org/10.1177/1524838018821951; https://link.springer.com/article/10.1007/s10896-021-00278-1). It is important for clinicians to consider the possibility of domestic abuse and / or coercive control when involving family members.	Thank you for your comment. We agree that domestic violence and abuse are serious risk factors for acquired brain injury. Although not specifically mentioned in the guidance, the committee were aware of several scenarios where people may not want their family involved in rehabilitation. Throughout the recommendations, we have been very careful to caveat involving friends and family with 'where appropriate', in order to prevent family members being incorporated as a default. Additionally, we have a specific recommendation in the section on the holistic rehabilitation needs assessment, which recommends discussing who is important to an individual and how they would like them to be involved in rehabilitation. The committee made this recommendation specifically to address their concern that the people an individual most trusts will not always be what we traditionally consider family. Therefore, no change has been made.
University College London Hospital	Guideline	012	003	Re prognosis: Encouraging health care professionals to have early discussions about prognosis requires that we have good prognostic models. Unless these are available, better to say outcomes are variable and prognosis is unclear at the moment.	Thank you for your comment. The committee were aware that it would not be easy to provide an accurate prognosis for many of the conditions covered in this guideline. They discussed that the unpredictable nature of chronic neurological disorders should be stressed to people. The actual recommendation itself does not specify what this prognosis discussion should entail, or that a specific prognosis should be given. However, the committee did want to show the importance of early information, in order to equip people with the knowledge needed to appropriately monitor rehabilitation needs and start to plan for future needs. This discussion has been recorded in the 'Benefits and harms' section of the contributing evidence review (B). Therefore, no change has been made.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Guideline	012	005 - 006	1.5.3 Early discussion about prognosis and rehabilitation Agree with "*If the person does not wish to discuss their prognosis, offer further opportunities at a later date for this discussion*." However, may I suggest a timeframe is added here? For example, if an inpatient,	Thank you for your comment. The committee did not wish to add a timeframe to this recommendation because they did not want to suggest that an individual would have a limit on their period of adjustment to a diagnosis. While some people may accept their diagnosis and prognosis

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				discuss importance of having this discussion to aid discharge planning. Or for community interventions, need to discuss so can offer appropriate and suitable interventions for their diagnosis.	relatively quickly, some others may need a much longer time before they are able to have these potentially upsetting conversations about symptom progression and developing rehabilitation needs. Additionally, as you highlight in your comment, this timeframe will also be context dependent. Therefore, no change has been made. However, we believe that the scenarios you mentioned about having prognosis conversations in order to ensure future rehabilitation delivery are covered in the sections on developing and reviewing a rehabilitation plan.
University College London Hospital	Guideline	012	007	'Following diagnosis or initial treatment for a chronic neurological disorder, the responsible clinician should give the person a contact for rehabilitation, and inform their GP of this contact'. Could this be more specific- We would suggest this is details of their community neuro team.	Thank you for your comment. Due to the wide population that this guideline covers (including different ages, different disorders, and different rehabilitation needs), the committee wanted to keep this recommendation as broad as possible and did not believe it appropriate to be more specific in who would fulfil the contact for rehabilitation role. Therefore, no change has been made to the recommendation. However, we have added community neuro team as an example in the 'Benefits and harms' section of the corresponding evidence reviews [A and B].
Midlands and South Essex ICB	Guideline	012	007	Whilst we agree with a named contact for rehabilitation it will be challenging to implement over a multi-stage pathway (e.g. in acute hospital, specialist rehabilitation and then into community services), involving multiple agencies (i.e. health and social care) Each of these stages can contain a key contact with oversight from a complex case manager/neuro navigator in the responsible ICB, who may not have direct contact with the individual but can support the rehabilitation pathway	Thank you for your comment. The named contact for rehabilitation referenced in this recommendation is an initial contact for rehabilitation assigned by the responsible clinician following diagnosis or initial treatment for a chronic neurological disorder where potential rehabilitation needs are identified. They may be a temporary contact until a lead practitioner is nominated for the holistic rehabilitation needs assessment. It is a distinct role from the single point of contact recommended in subsequent guideline sections, which seems to be what you are talking about in your comment. We have re-drafted this recommendation, as well as the accompanying glossary definitions, in order to make the boundaries of this role clearer and when other roles will take over. The single point of contact recommendations have also been extensive re-drafted in order to help clarify what this practitioner is meant to do to help a person with chronic neurological disorder navigate the health and social care system.
First Community Health and Care	Guideline	012	007 - 009	Rec 1.5.4 - Ambiguous comment re: contact details for rehab at point of diagnosis or initial treatment. This will depend on service needed, appropriateness of referral etc.	Thank you for your comment. The named contact for rehabilitation referenced in this recommendation is an initial contact for rehabilitation assigned by the responsible clinician following diagnosis or initial treatment for a chronic neurological disorder where potential rehabilitation needs are identified. They may be a temporary contact until a lead practitioner is nominated for the holistic rehabilitation needs assessment. As you mention, this contact for rehabilitation will be different depending on considerations such as services needed, and referral needs. As recommendations need to be generalisable to the whole guideline

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					population wherever possible, the committee did not feel as though they could be too specific when drafting this recommendation. It will be at the discretion of the responsible clinician to appoint an appropriate initial contact. However, the committee wanted to highlight the importance of a single point of contact to ensure consistency of information and help coordination during the early stages of rehabilitation.
Headway – The Brain Injury Association	Guideline	012	010 - 019	Within section 1.6, hospital discharge, we suggest that a recommendation could be added that a rehabilitation assessment is undertaken prior to discharge from hospital. This would help to enable a smoother transition from hospital care to community care. A further assessment could be undertaken at a later date if an individual's needs change.	Thank you for your comment. There is another recommendation in the rehabilitation needs assessment section that recommends undertaking a needs assessment as soon as a diagnosis is made, or if suggested by certain symptoms or impairments. This would cover the scenario that you mention in your comment. Similarly, there is a recommendation advising for the provision of any equipment or environmental adaptations be made for a person's home prior to discharge. This would also be carried out as part of the holistic needs assessment. The guideline is set as linearly as possible, reflecting probable navigations through rehabilitation services, but it does mean that sometimes you read setting-specific sections before generic sections. However, in order to minimise confusion, we have tried not to duplicate recommendations where possible. Therefore, no change has been made.
Brain Injury Social Work Group	Guideline	012 - 013	010 - 019 001 - 005	Transitions and Continuity of Care (pp. 12–13, Section 1.6) We were pleased to see the recognition of social workers' involvement at the point of hospital discharge. Social work input is crucial to preventing delays and avoiding readmission, especially where home adaptations, care packages, or safeguarding plans are required. It would be helpful to strengthen expectations around joint discharge planning involving both health and social care practitioners. We therefore recommend that admission become the trigger for discharge planning as much can be achieved at the point of admission (home, family) which will enable better planned discharge. Note could also be made re transition into health settings can also be planned and as such there is space for social care to aid transition. For example a recent situation meant a family member completed the "about me' document post surgery for it to be then used as baseline information rather than families or social care professionals being able to handover into the hospital care with discharge in mind, maintaining a continuity of health and social care. Supporting Participation and Inclusion (pp. 46–50, Sections 1.24–1.25) Social workers often support people to access education, employment and community life by coordinating support and advocating for reasonable adjustments. Their role in enabling access to personal budgets, support workers or transport assistance could be more	Thank you for your comment. The committee agree that effective joint discharge planning is central to ensure a smooth transition from hospital, and that social care practitioners can help with this process. However, NICE already have published guidance on this in NG27 'Transition between inpatient hospital settings and community or care home settings for adults with social care needs', which has been referenced at the beginning of the section on assessing rehabilitation needs and goal setting, and re-iterated at the start of this section with a note that these recommendations should also be followed. The committee acknowledge the important role that social care professionals play in supporting access to education, employment and community life. They made sure to reference social care and social care professionals throughout the guideline where appropriate, as well as including social workers as an example in our definition of rehabilitation practitioner. They are also listed as an example for lead practitioners and key workers. Specifically within the guideline section on rehabilitation to support education, work, social and leisure activities, and relationships and sex, we have included them in the practitioners that may be carrying out the recommendations when we list supplementary guidance to be followed.

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				explicitly referenced. This is especially important in supporting individuals whose impairments are less visible or fluctuating such as in the case of ABI. Carer Support and Family Networks While carers are acknowledged throughout the document, social workers have a statutory duty to assess carers' needs and ensure appropriate support is provided. This could be more clearly reflected, particularly where carers are key partners in discharge, rehabilitation or at risk of burnout. Involving People with Lived Experience in Service Design (p. 6, Section 1.1) We support the guidance's emphasis on full co-production with experts by experience. Social workers, especially those embedded in community statutory teams, can play a role in facilitating the involvement of people with lived experience in service design and evaluation. We would encourage further emphasis on inclusive methods that enable participation from people with communication or cognitive difficulties.	As you note, we have acknowledged the role of carers throughout the recommendations. However, it is beyond the scope of this guideline to make recommendations for people other than those with a chronic neurological disorder. However, carer needs assessment is covered in NG150 Supporting adult carers, which is clearly cross-referenced at the beginning of each guideline section. Finally, we welcome your support for our recommendation on including people with lived experience within service design. We already have stated that feedback methods be inclusive, and including additional guidance on engaging people with communication or cognitive difficulties would be more detail than we would usually include in service design recommendations. Additionally, we have stated throughout the guideline that rehabilitation services should be mindful of 'invisible' symptoms, due to their prevalence in this population. We hope that commissioners would carry this awareness through to their service design. However, we have given cognitive and communication difficulties as an example of when inclusive strategies may be needed.
Heads Together	Guideline	012	011	It is not acceptable for someone with a brain injury to leave hospital without a key clinical contact	Thank you for your comment. The committee agree and made this recommendation to ensure that assigning a key clinical contact is not overlooked.
Headway – The Brain Injury Association	Guideline	012	011	We suggest this could be strengthened to include a recommendation that these key contacts are provided to the individual's GP, as well as to the individual. This would help to ensure that people with memory problems (which many brain injury survivors experience) are able to access their key contacts after leaving hospital.	Thank you for your comment. We have expanded the recommendation to say that a person's GP should be given the details of their key clinical contact for medical advice and their initial contact for rehabilitation.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	012	011	Within paediatric services this contact would not always be available for rehabilitation as many services are inpatient only	Thank you for your comment. The named contact for rehabilitation referenced in this recommendation is an initial contact for rehabilitation assigned by the responsible clinician following diagnosis or initial treatment for a chronic neurological disorder where potential rehabilitation needs are identified. They may be a temporary contact until a lead practitioner is nominated for the holistic rehabilitation needs assessment. Due to the wide scope of this guideline (including ages and conditions) the committee did not believe it appropriate to be more specific on who will fulfil this role. It will be at the discretion of the responsible clinician to appoint an appropriate initial contact. However, in the scenario that you have mentioned, we anticipate that the most probable contact for rehabilitation would either be the key clinical contact or GP.
Midlands and South Essex ICB	Guideline	012	011	As above a key contact for rehabilitation at hospital discharge is likely to not yet be known, the GP will need to hold some ongoing management	We have added some new recommendations throughout the section 'rehabilitation to maintain, improve and support function' to ensure that

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				of the need until the individual is at the point of accessing a community based service at which point a key contact can be given.	registered practitioners with expertise in that particular professional discipline, and with an understanding of the effects of the persons particular condition or injury should always oversee assessments and that particular element of the persons rehabilitation plan.
United Kingdom Acquired Brain Injury Forum	Guideline	012	011 - 012	Vital for people with a brain injury to leave hospital with a key clinical contact	Thank you for your comment. The recommendation that you have referenced is part of the section on early discussions about rehabilitation and it applies to all settings where diagnoses or initial treatment may be provided, not just hospital inpatients. Therefore, no change has been made. However, there is another recommendation specifically on discharge from hospital in a subsequent section, which states people should be given a key clinical contact for medical advice.
Guy's and St Thomas' NHS Foundation Trust	Guideline	012	013	Rec 1.6.2 – We welcome the recommendation of having a key contact for neurorehabilitation following hospital discharge, however we would advocate for psychologists to be included in this list of professionals that can contribute to this role. Psychologists are not classes as an allied health professional group and are therefore not currently represented in this list.	Thank you for your comment. We have made particular reference to clinical psychologists and neuropsychologists in relation to the cognitive functioning element of the person's rehabilitation plan and to the role of initial contact and single point of contact
British Association of Brain Injury and Complex Case Management	Guideline	012	016	1.6.2 We strongly suggest that this recommendation be phrased 'must' agree, rather than 'should' agree to the allocation of a key worker or CCM prior to discharge, because after discharge it is usually very difficult to rectify for an individual.	Thank you for your comment. NICE does not use the phrase 'must' in their recommendations unless it references a legal requirement. Therefore, no change has been made.
Community Case Management Ltd.	Guideline	012	016 - 019	**Contact for Rehabilitation at Hospital Discharge** This section correctly lists a case manager as one of the options for post-discharge rehabilitation coordination. However, this reference would benefit from clearer criteria to guide when a case manager should be appointed over another professional. **Recommendation:** We suggest specifying that case managers are particularly appropriate when: • The person has multiple, interacting needs across health, social care, education/vocation and legal domains. • There are significant risks of care breakdown or safeguarding concerns.	Thank you for your comment. We have now re-drafted this section along with the accompanying glossary definitions to better clarify the difference between an initial contact for rehabilitation and a single point of contact for rehabilitation, and what the responsibilities of each role would be. We have also now included a link to the section on assigning a single point of contact and assessing the person's ability to coordinate their own care, where we have recommendations that will detail the criteria of when to consider appointing a key worker or complex case manager. Within these, we have already noted people with needs across multiple areas of care, people with potential to develop new needs around accessing care and there are associated family support needs, and people with an inability to advocate for themselves. Although not specifically mentioned, we believe that the last 2 cover your concern about the risk of care breakdown and safeguarding concerns.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	012	017	Single point of contact should be specialist in the area with a defined role – GP does not have the time or the specialist knowledge to signpost and support in this way. The GP's role is already broad enough.	Thank you for your comment. We have re-worded this recommendation so it now references only an initial contact for rehabilitation or a single point of contact. A GP is still listed as an example of a practitioner who can perform the initial contact for rehabilitation role. However, the definition shows that this

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					is not expected to be an in-depth role, so no specialist knowledge should be required. The initial contact for rehabilitation is simply a named practitioner assigned by the responsible clinician following diagnosis or initial treatment for a chronic neurological disorder where potential rehabilitation needs are identified, in order to provide consistency of information and help coordinate initial assessments for individuals. The single point of contact is only appointed following a holistic rehabilitation needs assessment and encompasses 3 potential roles - key contact, key worker, or complex case manager. The type of single point of contact will depend on the complexity of needs and the person's or their family's ability to self-manage rehabilitation. A key contact will provide the least intensive support (with key workers and complex case managers representing a higher intensity), not necessarily offering direct advice but seeking information from others. Furthermore, a single point of contact must remain even when the person is not receiving rehabilitation, to ensure access to services as needs may emerge. The committee have kept a GP as an example for this definition because they believe that they could be a suitable professional to carry out the lower intensity key contact role.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	012	019	The guideline may benefit from including clinical psychologists as a professional that could be listed as a contact for rehabilitation.	Thank you for your comment. This recommendation has been extensively re-drafted and an example list of professionals who can fulfil the role no longer appears in the text. We have moved the list to sit under the definition of initial contact for rehabilitation and the lead practitioner for holistic assessment in the 'Terms used in this guideline' section. Psychologists have been added as requested.
The Association of Clinical Psychologists UK	Guideline	012	019	ACP-UK comments that the guideline would benefit from including clinical psychologists as a profession that could be listed as a contact for rehabilitation.	Thank you for your comment. This recommendation has been extensively re-drafted and an example list of professionals who can fulfil the role no longer appears in the text. We have moved the list to sit under the definition of initial contact for rehabilitation and the lead practitioner for holistic assessment in the 'Terms used in this guideline' section. Psychologists have been added as requested.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	012	General	Discharge – basic information for the person including understandable information about diagnosis and condition that is a handover of information relevant for the person and other services they may have contact with. Clarity of expectation too.	Thank you for your comment. Much of the guidance which relates to discharge from hospital is contained within the NICE guideline on transitions between inpatient hospital settings and community or care home settings for adults with social care needs, which we have linked to here. See also the section about Information, advice and learning (section 1.12)
Central London and Community Healthcare Trust	Guideline	012	General	1.6. This section makes reference to a single point of contact in the rehabilitation community such as a neuro-navigator. We agree with this recommendation for a single point of contact and strongly support it. However, consideration needs to be given to capacity within local services to be able to do this where demand already outstrips capacity,	Thank you for your comment. The committee have extensively discussed the potential resource impact of these recommendations on assigning a single point of contact for people with chronic neurological disorders. They noted that not everyone will be eligible for the highest intensity single point of contact, a complex case manager. Most people will only need a key

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				therefore there are implications for question 2) i.e. funding and commissioning of this essential role for all people with chronic neurological disorders.	contact or key worker. These could be undertaken by existing practitioners, therefore avoiding the need to create new roles. They acknowledged that there is a lack of complex case managers and providing these roles, even for the minority of people with the most complex needs, will require significant resources. However, the committee argue that implementing the recommendations may enable timelier access to assessment and care, which may reduce reliance on crisis care,. This could potentially offset additional costs. It may also reduce the number of people contacting their GPs in order to access care. Finally, if needed, assigning a complex case manager may provide other benefits such as reducing prolonged stays in inpatient neurobehavioural units or residential care. For a more detailed account of their discussion regarding the resource impact of this guideline section, please see 'The committee's discussion of the evidence section' in evidence reviews A, B and I.
Midlands and South Essex ICB	Guideline	013	002	The role of 'Neuro-navigator' is not universal across systems. E.g. in some areas this is a clinical case manager that continues to hold responsibility for an individuals pathway, and in others it is a pathway and commissioning role.	Thank you for your comment. We have moved the list of examples to the glossary under the definition of 'initial contact for rehabilitation and lead practitioner for holistic assessment', and specified that neuro-navigator is an example of a specialty-specific coordinator to remove ambiguity.
Inflammatory Neuropathies UK	Guideline	013	003	Whilst we welcome 'at the earliest opportunity' this should be caveated with a maximum timeframe	Thank you for your comment. Due to the breadth of disorders, symptoms, and potential equipment and/or environmental adaptations, the committee did not feel as though they could specify a maximum timeframe. What might be unrealistic for one adaptation could be unacceptable for another. Therefore, no change has been made.
British Association of Brain Injury and Complex Case Management	Guideline	013	003	1.6.3 in practice there are usually protracted waiting lists for equipment and adaptations , it would therefore be beneficial for the guidance to state that there must be an allocation to a local authority occupational therapist within a specific timescale.	Thank you for your comment. The committee believe that the language used in the recommendation conveys the importance of putting equipment and adaptions in place when planning an efficient discharge, and that this should not be left until last. However, due to the wide range of disorders covered by this guideline, and therefore equipment and adaptations including in this recommendation, they were not able to specify a timeframe. Therefore, no change has been made.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	013	003	Requires buy in from local authority teams for environmental adaptations to support rehab and prevent delayed discharge. This is inequitable dependent on geographic location.	Thank you for your comment. We acknowledge that there may be regional variation in provision of equipment and environmental adaptations. However, this reflects best practice and a recommendation in this area will begin to address the highlighted inequalities. We hope that local authorities will adopt these recommendations and fund provision of equipment and environmental adaptations as appropriate.
Independent Neurorehabilitation Providers Alliance	Guideline	013	003	We agree but processes need to be improved so that equipment is provided in a timely manner. Also the time to provide equipment should not be determined by where the referral has come from e.g. NHS healthcare vs private provider. Provision should still be provided even if	Thank you for your comment. The committee were aware that inefficient provision of equipment and environmental adaptations was often a barrier to continuity of care. However, due to the wide population that this guideline covers (including different ages, different disorders, and different rehabilitation needs), the committee were not able to be more specific on

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				the person is at end of life and requires equipment to enable them to be safe, comfortable and maintain their dignity.	timely provision. Regarding your point about improving processes and ensuring that all referrals are treated equally (regardless of where they originate), implementation of these guidelines are beyond NICE's remit. This will be up to local authorities and commissioning bodies to review and improve if necessary. Finally, while this guideline specifically does not cover end of life care, the committee discussed that some healthcare professionals were less inclined to provide rehabilitation if they had preconceived ideas of its effectiveness (for example, for people with time-limited diagnoses). Therefore, they have made a recommendation in the section on coordinating the rehabilitation plan to address this internal bias.
Corporé	Guideline	013	003 - 004	'At the earliest opportunity….' Can you include 'Assistive Technology' alongside 'environmental adaptations' and 'equipment'?	Thank you for your comment. We have added the requested example.
The Royal Hospital for Neuro-disability	Guideline	013	003 - 005	This could be reworded to ensure that an individual's local service would take on provision of equipment and seating in conjunction with a referring service, reducing the need for repeated assessments.	Thank you for your comment. The committee acknowledge that an individual's local service is one way of providing equipment and environmental adaptations, it is not the only way. Exact implementation of this recommendation will need to be decided at a local level. Therefore, no change has been made. However, in response to your concern about repeated assessments, we do have an earlier recommendation in the section on 'Providing responsive services' that advocates for sharing rehabilitation needs assessments to improve service provision.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	013	006 - 021	We recommend that doing holistic rehabilitation needs assessments are appropriate for referrals to community services. However, we do not believe that referrals to inpatient specialist units are required as the needs of the patient are likely to change from acute phase(acute hospital stay) to rehabilitation phase (rehabilitation specialist units).	Thank you for your comment. The recommendation that you have referenced does not say that a holistic rehabilitation needs assessment has to be performed with every new diagnosis, or if symptoms or impairments suggest. It is recommending to consider making a referral or undertaking one. Clinical judgement and experience can still be used to delay the needs assessment. As you say, there may be very specific situations where this is not an appropriate initial step (for example, an acute setting with rapidly evolving needs). However, even in this very specific situation, the need for a holistic rehabilitation needs assessment will still need to be considered at some point during their inpatient stay (for example, prior to discharge). Therefore, no change has been made.
British Association of Brain Injury and Complex Case Management	Guideline	013	008	1.7.1 ref an assessment when there is a suspected neurological condition. This would be a positive move, but will have significant implications for services where a confirmed diagnosis is often a requirement for a referral being accepted.	Thank you for your comment. The committee acknowledged in the accompanying rationale and impact section that beginning rehabilitation assessments before a diagnosis in confirmed may increase demand for initial assessments and put pressure on existing services. However, the committee were also aware that, for some conditions, it takes time for the full clinical picture to emerge. These people may already be experiencing significant problems before diagnosis is confirmed, and delaying care may significantly exacerbate problems requiring costly emergency, crisis-related

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					care. Therefore, such approach is likely to represent value for money for the NHS.
Success – Life After Cure Ltd	Guideline	013	008	Rec 1.7.1 We endorse this holistic needs assessment from diagnosis for children presenting with brain tumours and believe it is a currently missing, key opportunity for cost-efficiency and patient benefit . We would welcome cross-referencing to children's brain tumour guidelines, as well as including this group here.	Thank you for your comment. This guideline does cover the rehabilitation needs of children with brain tumours, so the recommendation already includes this group. Regarding the requested cross-references, there is no additional NICE guidance that would be applicable in this scenario. Additionally, we do not cross-link to external guidance unless it has been included in an evidence review and therefore subjected to quality appraisal. Therefore, no change has been made.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	013	008	Access to holistic rehabilitation needs assessment is currently inequitable in paediatrics	Thank you for your comment. We hope that the recommendations in this guideline help to address the access inequalities to holistic rehabilitation needs assessment that you have noted.
University College London Hospital	Guideline	013	010	As soon as diagnosis is established- this has significant cost implications as this is not currently done routinely. Currently, a referral could be made however, community rehab services have significant waiting lists- more resources in community would be required.	Thank you for your comment. The committee agreed and acknowledged that implementing this recommendation may put pressure on existing services, including community rehabilitation services. They made recommendations on service design, where community rehabilitation is an essential component, and hope these will be adopted and funded accordingly to meet any increased demand. They also proposed reorganising existing services to improve efficiency, potentially freeing resources and funds which may be used, for example, to build capacity within community services. This also aligns with the new NHS community rehabilitation and reablement model, and also NHS 10 year plan which may support implementation of this recommendation.
Brainkind	Guideline	013	011 - 012	For clarity, consider revising this recommendation to read 'based on symptoms, or impairment (even if a chronic neurological disorder is suspected but not yet confirmed), or impact on activities and participation'.	Thank you for your comment. The committee believe that considering how symptoms and impairment would impact activity and participation is the next logical step in this process, and it what healthcare professionals are trained to do after collecting data on an individual. Their conclusion is what would decide whether to make a referral for or begin a holistic rehabilitation needs assessment. Therefore, no change has been made.
Inflammatory Neuropathies UK	Guideline	013	013	This section should also mention environment as well as circles of support if it is really holistic	Thank you for your comment. This recommendation is not referring to domains that should be addressed by a holistic rehabilitation needs assessment. It is regarding a brief assessment professionals may undertake in order to help them make the decision whether a referral for a complete holistic rehabilitation needs assessment is needed or not. Therefore, no change has been made.
The Royal Hospital for Neuro-disability	Guideline	013	013	What would this "brief assessment" be? Who would be doing it? What would the threshold be for deciding that someone does need a subsequent holistic assessment?	Thank you for your comment. Due to the broad population that this guideline covers (including ages, disorders, and rehabilitation needs) the committee were not able to issue more specific guidance on what this brief assessment should be. Furthermore, the professional carrying it out will depend on where an individual is presenting in the rehabilitation service

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					pathway. Therefore, no changes have been made. However, the committee envision this being an initial informal conversation with an individual, getting to know them and how their condition is impacting them. The domains listed are a reminder that a condition can affect multiple areas of a person's functioning, and practitioners should not only focus on the physical aspect.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	013	013	If assessing these needs, this is a holistic needs assessment (unfamiliar terminology in paediatrics)	Thank you for your comment. The brief assessment referenced here is not a holistic rehabilitation needs assessment, it is a much less comprehensive evaluation to determine if a full holistic rehabilitation needs assessment is needed. The committee envision that this is likely to be an initial informal conversation with an individual, getting to know them and how their condition is impacting them. The domains listed are a reminder that a condition can affect multiple areas of a person's functioning, and practitioners should not only focus on the physical aspect.
Brainkind	Guideline	013	014 - 015	For clarity, consider revising this recommendation to read '…physical health, level of impairment and impact on activities and participation'.	Thank you for your comment. These additions have been made.
British Association of Brain Injury and Complex Case Management	Guideline	013	017	1.7.3 In practice this is likely to need proactive follow up, especially for anyone with potential EF difficulties as poor insight and initiation may prevent them seeking support and rehab. Frequently EF difficulties do not emerge until post acute discharge home - when they may not be noticed or understood. Return to previous roles, work, education (and changes in settings/development) are all trigger points when EF difficulties frequently emerge.	Thank you for your comment. The committee agree that certain sub-populations of the guideline will need a proactive follow-up approach for reviewing their need for a holistic rehabilitation needs assessment. We have added a new recommendation to the end of this section to cover this.
Headway – The Brain Injury Association	Guideline	013	017	Again, this information on future assessment if needed should also be provided to the individual's GP, in case the individual experiences memory issues.	Thank you for your comment. This recommendation is specifically about self-referral for a holistic rehabilitation needs assessment, if a person feels their needs or impairment levels change in the future. There is a recommendation already in the guideline section on building capacity that focuses on primary care practitioners ability to identify emerging rehabilitation needs and how to refer people to rehabilitation specialists if needed. Therefore, no change has been made.
The Association of Clinical Psychologists UK	Guideline	014	001	ACP-UK comments that the guideline as it stands makes no reference to inclusion health populations, approaches or the NHS Inclusion Health Framework. As a specific example, the guideline makes no reference to people experiencing homelessness, despite their increased risk of acquired brain injury as evidenced by multiple studies (e.g., https://doi.org/10.1016/S2468-2667(19)30188-4) and a recent scoping review highlighting the potential to adapt existing rehabilitation for individuals who are experiencing homelessness and the need for	Thank you for your comment. The committee have developed recommendations to tackle health inequalities present in the NHS. They agree that people experiencing homelessness have a greater risk of developing certain chronic neurological disorders, as well as facing different challenges to accessing rehabilitation services and receiving care once they are referred. Therefore, they have added a cross-reference to NG214 Integrated health and social care for people experiencing homelessness at the beginning of each section of the guideline

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				research that considers the needs of diverse individuals experiencing homelessness and TBI (https://www.frontiersin.org/journals/medicine/articles/10.3389/fmed.2022.916602/full). The guideline could draw on the limited evidence on inclusion health approaches to brain injury and rehabilitation for people experiencing homelessness (e.g. https://pmc.ncbi.nlm.nih.gov/articles/PMC11203637/) ACP-UK points out that cross referencing with NICE Guidelines for Integrated Health and Social Care for People Experiencing Homelessness may be helpful alongside the other cited guidelines that need consideration when making a holistic rehabilitation needs assessment.	
Kent and Medway NHS and Social Care Partnership Trust	Guideline	014	001	The guideline as it stands makes no reference to inclusion health populations, approaches or the NHS Inclusion Health Framework. As a specific example, the guideline makes no reference to people experiencing homelessness, despite their increased risk of acquired brain injury as evidenced by multiple studies (e.g. https://doi.org/10.1016/S2468-2667(19)30188-4) and a recent scoping review highlighting the potential to adapt existing rehabilitation for individuals who are experiencing homelessness and the need for research that considers the needs of diverse individuals experiencing homelessness and TBI (https://www.frontiersin.org/journals/medicine/articles/10.3389/fmed.2022.916602/full). The guideline could draw on the limited evidence on inclusion health approaches to brain injury and rehabilitation for people experiencing homelessness (e.g. https://pmc.ncbi.nlm.nih.gov/articles/PMC11203637/) Cross referencing with NICE Guidelines for Integrated Health and Social Care for People Experiencing Homelessness may be helpful alongside the other cited guidelines that need consideration when making a holistic rehabilitation needs assessment.	Thank you for your comment. The foundational guidelines referenced at the beginning of the section on carrying out a holistic rehabilitation needs assessment contain recommendations for health and social care practitioners specifically about supporting people to make decisions about their healthcare. These need to be followed in addition to any of our recommendations. A cross-reference to NG214 would be inappropriate to add here as those recommendations do not address this area of practice. Therefore, no change has been made. However, the committee have developed recommendations to try tackle health inequalities present in the NHS. They agree that people experiencing homelessness have a greater risk of developing certain chronic neurological disorders, as well as facing different challenges to accessing rehabilitation services and receiving care once they are referred. Therefore, they have added a cross-reference to NG214 Integrated health and social care for people experiencing homelessness at the beginning of each section of the guideline
Headway – The Brain Injury Association	Guideline	014	001	Given that an individual's needs are likely to change over time, would it be sensible for this section to include a recommendation regarding provision for follow up and future holistic rehabilitation needs assessments?	Thank you for your comment. The recommendation for initiating a holistic rehabilitation needs assessment is designed to be repeatable if needed, referring to symptoms and impairments rather than simply diagnoses. Additionally, there is a further recommendation to offer a full holistic rehabilitation needs assessment when a specific functional needs assessment is received. Finally, there is a commissioning recommendation included in the guidance regarding simple re-referral (including self-referral)

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					procedures for people with chronic neurological disorders to access rehabilitation needs assessments. We believe that these 3 recommendations adequately cover follow-up and future holistic rehabilitation needs assessment. Therefore, no change has been made.
Heads Together	Guideline	014	003	Advocacy must be provided by people who are trained in understanding issues of executive impairment and insight, and how these may impact people's abilities to make decisions.	Thank you for your comment. There is already NICE guidance on advocacy, meaning that the abilities and knowledge of advocates are out of scope for this guideline. These recommendations can be found in NG227 (Advocacy services for adults with health and social care needs) and NG204 (Babies, children and young people's experience of healthcare), and are clearly referred to at the start of this guideline section. Therefore, no change has been made.
United Kingdom Acquired Brain Injury Forum	Guideline	014	003	Advocacy must be provided by people who are trained in understanding issues of executive impairment and insight, and how these may impact people's abilities to make decisions.	Thank you for your comment. There is already NICE guidance on advocacy, meaning that the abilities and knowledge of advocates are out of scope for this guideline. These recommendations can be found in NG227 (Advocacy services for adults with health and social care needs) and NG204 (Babies, children and young people's experience of healthcare), and are clearly referred to at the start of this guideline section. Therefore, no change has been made.
Royal College of Speech and Language Therapists	Guideline	014	007	The RCSLT welcomes the acknowledgement in recommendation 1.8.1 of the need to consider complex communication and/or cognitive needs. This recommendation would be strengthened by explicitly stating that it is necessary to involve a speech and language therapist. This would ensure that information is adapted for the person to understand, and strategies are put in place for them to make their wishes known (for example if they are not able to use verbal communication).	Thank you for your comment. We agree that information should be adapted for individuals, which has been covered by recommendations in the 'Information, advice and learning as part of rehabilitation and strategies' section of the guideline. However, the recommendation referenced is about supporting a person to make decisions about their health and social care, the need for which will be greater in a person with complex communication or cognitive needs, rather than identifying what aids and adaptations they may need for communication. While we understand a speech and language therapist may need to be involved in identification, they will not need to be involved in every subsequent discussion. Therefore, no change has been made. Further guidance on communication aids and strategies are covered in NICE's foundation guidelines on service user experience (CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS services and NG204 Babies, children and young people's experience of healthcare), which have been clearly referenced at the beginning of this guideline section.
Brainkind	Guideline	014	011 - 013	Consider including the label 'criteria for when a holistic assessment is not needed' within this recommendation.	Thank you for your comment. The committee believe that their current wording ('unless') and your suggested re-wording are synonymous, with their draft being easier to understand. Therefore, no change has been made.

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University College London Hospital	Guideline	014	General	Could not see any support for carer's, educating them about rehabilitation pathway following a chronic neurological disorder (what questions to ask- expert by experience). This would be really useful to consider.	Thank you for your comment. Information and education for families and carers (where appropriate) is included in the guideline section on information, advice and learning. Any other sort of supportive interventions for carers and families is outside of the scope of this guideline, unless it also includes the individual with a chronic neurological disorder.
Brain Injury Social Work Group	Guideline	014 - 018	General	Holistic Rehabilitation Needs Assessment (pp. 14–18, Section 1.8) This section rightly emphasises the need to assess a wide range of factors affecting a person's functioning. Social workers routinely assess social, emotional, and environmental needs and are well placed to lead or contribute to holistic assessments, particularly where there are overlapping care and support needs. It may be helpful to clarify expectations around when and how local authority social workers should be involved, and to reference statutory duties under the Care Act 2014 (England) and equivalent frameworks in devolved nations. This too would apply to those social workers assessing the needs of prisoners.	Thank you for your comment. The committee acknowledge the important role social workers play in assessing rehabilitation for chronic neurological, and the fact that they are well placed to co-ordinate multiple professionals and services throughout needed to complete a holistic rehabilitation needs assessment. Therefore, they have included them as an example of a practitioner who could act as the lead practitioner for holistic assessment. Guidance on how local authority social workers should be involved is not covered in this guideline, as it will vary between regions. However, the committee did want to highlight to readers the statutory requirement of local authorities to assess care and support needs. They have included reference to the Care Act 2014 and Children and Families Act 2014 (covering both paediatric and adult populations) in the 'Committee discussion of the evidence' section of evidence review B.
The Association of Clinical Psychologists UK	Guideline	015	002	ACP-UK points out that cultural factors are only mentioned in relation to barriers to physical activity goals, employment, and discussion of sex and sexuality. There is international evidence of cultural differences in relation to the understanding of brain injury (e.g., https://doi.org/10.1080/09602011.2018.1453367; https://doi.org/10.1080/09602011.2018.1453367) and the need for rehabilitation services to be culturally competent (e.g. https://pubmed.ncbi.nlm.nih.gov/36594860/ Arguably these should be considered under section 1.5, Early discussion about prognosis and rehabilitation.	Thank you for your comment. The committee agree that cultural factors are an important consideration in maximising understanding and engagement in rehabilitation for chronic neurological disorders, not only for the individual but also their extended support network. They have already included it as an area to discuss during the holistic rehabilitation needs assessment, where they recommend asking about a person's background, relationships, meaningful activities, and spiritual and religious practices. The information gathered during the rehabilitation needs assessment will be used to inform the rehabilitation plan. However, the committee do not agree that this should also be address in the section on early discussions about prognosis and rehabilitation. The focus of these recommendations is about providing early opportunities to inform people about their prognosis and potential rehabilitation needs to facilitate access to rehabilitation services, rather than how to tailor their rehabilitation plan and delivery to individual circumstances. Therefore, no changes have been made.
University College London Hospital	Guideline	015	005	This assumes that these services will be available. There are whole areas in the UK without adequate services- it is a post code lottery and this will require significant resource to address.	Thank you for your comment. The guideline committee were aware of the potential inequalities in accessing rehabilitation services throughout the UK. In order to try to address this, the committee have drafted an entire section of the guideline focusing on building local capacity and expertise. The resource impact that you have noted has been considered at every stage of guideline development, with details being located in the 'Resource and impact' section of the guideline document.

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Inflammatory Neuropathies UK	Guideline	015	008	It would be useful to include community sector professionals here (if they are involved)	Thank you for your comment. The list given is an example list and not meant to be exhaustive. As community sector professionals would be included under the 'other practitioners', no change has been made.
British Association of Brain Injury and Complex Case Management	Guideline	015	008	1.8 – We recommend that the assessor or lead be experienced and a qualified health professional or social worker for certain conditions in particular. For example ABI and Functional Neurological Disorder (FND) which are easily misinterpreted by individuals not experienced - sometimes with far reaching negative consequences for the person being assessed.	Thank you for your comment. The committee agree that knowledge and experience of certain conditions, and the impact that they can have on assessments, is necessary for certain rehabilitation domains covered by this guideline. In these cases, they have stated what expertise the professional performing the assessment or overseeing the development of the rehabilitation plan (for example, cognitive functioning or emotional health and wellbeing). These recommendations can be found in the section on rehabilitation to maintain, improve or support function. The lead practitioner for the holistic rehabilitation needs assessment is a coordination role. They identify and seek input from health, mental health and social care practitioners and other practitioners to inform the assessment, and make onward referrals if other needs not linked to rehabilitation are identified. They may not be the professional performing the individual assessments that will form the larger holistic needs assessment. However, while the committee do not agree that it is mandatory for this managerial role, they did agree that it could be beneficial when collating all the different streams of information, and designing an overall rehabilitation plan for an individual. Therefore, they have amended the definition of lead practitioner to state that they should ideally have some knowledge or experience of people with that chronic neurological disorder.
Headway – The Brain Injury Association	Guideline	015	008	We suggest that this section contain specific reference to third sector providers, such as local Headway charities, who are often key enablers of rehabilitation in the community.	Thank you for your comment. The list given is an example list and not meant to be exhaustive. As third sector providers would be included under the 'other practitioners', no change has been made.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	015	012	We were concerned that those with insight and awareness problems may not see the need for important people/family members to be involved in their rehabilitation -both in providing crucial assessment information that might be omitted and in them needing to play a vital role in supporting their rehabilitation. We thought the following should be added to line 13 'Where insight and awareness problems are likely e.g. after injuries associated with frontal impairment, consider inviting a family member or friend to accompany the patient to the initial assessment as accurate information may be omitted by the patient and the early engagement of those important to the patient may be important as they may, ultimately have a significant rehabilitative role to play.'	Thank you for your comment. This is more detail than we usually add to recommendations, and the committee believe that your specific concern is covered in the current wording. Discussing who is important to a person, and how they would like to involve them in their rehabilitation, would involve consideration of the benefits you mention. However, even if people have insight and awareness issues, they may not want family members involved. This choice should be respected. Also, family members may not wish to be involved. Therefore, no change has been made. However, we have added your scenario to the 'Benefits and harms' section of evidence reviews A and B.
PTSD UK	Guideline	015	013 - 016	1.7.2 - We recommend explicitly including trauma history or signs of PTSD in the brief assessment of psychological needs. This would help	Thank you for your comment. The recommendation you have referenced is describing a brief assessment to help decide whether people will need to

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				ensure that mental health impacts from trauma are not overlooked during early rehabilitation assessments, particularly in cases where the person may not immediately disclose trauma. Suggested amendment to 1.7.2: "Make a brief assessment of the person's social, psychological (including history or signs of trauma or PTSD), emotional, cognitive and communication needs..."	undergo a full holistic rehabilitation needs assessment. It is not designed to form part of a formal assessment. However, the committee agree that this is an important factor to keep in mind during rehabilitation. Therefore, they have included a new recommendation in the related assessments section which reminds professionals that trauma may require adaptations to assessment, rehabilitation and support plans.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	015	017	We agree that the holistic rehabilitation assessment should not delay the commencement of rehabilitation. One reason for the delay is duplication of assessments by different teams. An explicit recommendation not to duplicate the assessments and make use of assessments already done by the team looking after the patient will help in reducing the time to start rehabilitation.	Thank you for your comment. This recommendation has been made in the previous section on providing responsive services. Therefore, no change has been made.
The Neurological Alliance	Guideline	015	017	An explicit recommendation not to duplicate the assessments and make use of assessments already completed will help in reducing the time to start rehabilitation. This could also improve experience of care - in My Neuro Survey, 47% of adults disagreed that they have a consistent healthcare professional so do not have to explain their condition(s) repeatedly to different people.	Thank you for your comment. This recommendation has been made in the previous section on providing responsive services. Therefore, no change has been made.
British Society of Physical and Rehabilitation Medicine	Guideline	015	017	We agree that the holistic rehabilitation assessment should not delay the commencement of rehabilitation. One reason for the delay is duplication of assessments by different teams. An explicit recommendation not to duplicate the assessments and make use of assessments already done by the team looking after the patient will help in reducing the time to start rehabilitation.	Thank you for your comment. This recommendation has been made in the previous section on providing responsive services. Therefore, no change has been made.
First Community Health and Care	Guideline	015	017 - 018	Rec 1.8.7 - Holistic needs assessment form the basis of assessment. They should be completed prior to rehab starting to ensure safety, appropriateness of intervention, goals and planning.	Thank you for your comment. We understand your concern that starting rehabilitation interventions before an assessment has been completed could lead to inappropriate interventions. However, the committee were concerned that waiting for a comprehensive rehabilitation needs assessment to be completed could cause an unacceptable delay for people receiving treatment for clearly identified and more urgent needs. However, this recommendation does only cover interventions. Goal setting and rehabilitation planning are not included and should take place after a more complete picture of rehabilitation needs is ascertained.

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Sheffield Teaching Hospital NHS Foundation Trust	Guideline	015	020	Other factors like attitude of friends and family to the rehabilitation, access to benefits, care and social support may also encourage or discourage patients form taking part in rehabilitation.	Thank you for your comment. This recommendation is meant to act as a guide for areas to discuss with the individual with chronic neurological disorders, in order to form a more complete picture of their individual circumstances, motivations and barriers regarding rehabilitation. It is not meant to be an exhaustive list. As such, we believe that all the areas you have highlighted are covered by asking people about their relationships and environmental and wider social factors encouraging or preventing participation. Therefore, no change has been made.
The Neurological Alliance	Guideline	015	020	Other factors like attitude of friends and family to the rehabilitation, access to benefits, care and social support may also encourage or discourage people from taking part in rehabilitation.	Thank you for your comment. This recommendation is meant to act as a guide for areas to discuss with the individual with chronic neurological disorders, in order to form a more complete picture of their individual circumstances, motivations and barriers regarding rehabilitation. It is not meant to be an exhaustive list. As such, we believe that all the areas you have highlighted are covered by asking people about their relationships and environmental and wider social factors encouraging or preventing participation. Therefore, no change has been made.
British Society of Physical and Rehabilitation Medicine	Guideline	015	020	Other factors like attitude of friends and family to the rehabilitation, access to benefits, care and social support may also encourage or discourage patients form taking part in rehabilitation.	Thank you for your comment. This recommendation is meant to act as a guide for areas to discuss with the individual with chronic neurological disorders, in order to form a more complete picture of their individual circumstances, motivations and barriers regarding rehabilitation. It is not meant to be an exhaustive list. As such, we believe that all the areas you have highlighted are covered by asking people about their relationships and environmental and wider social factors encouraging or preventing participation. Therefore, no change has been made.
Independent Neurorehabilitation Providers Alliance	Guideline	015	022	Cultural needs should also be included and cultural attitudes to rehabilitation should be considered.	Thank you for your comment. This recommendation is meant to act as a guide for areas to discuss with the individual with chronic neurological disorders, in order to form a more complete picture of their individual circumstances, motivations and barriers regarding rehabilitation. It is not meant to be an exhaustive list. As such, we believe that all the areas you have highlighted are covered by asking people about their background, spiritual or religious practices, and environmental and wider social factors encouraging or preventing participation. Therefore, no change has been made.
Royal College of Speech and Language Therapists	Guideline	015	025	It may also be important in adults to establish previous skills and levels of functioning.	Thank you for your comment. While previous skills and levels of functioning are important to assess in rehabilitation, it is more important to focus on current skills and levels of functioning for safe rehabilitation planning and delivery. Previous abilities could be raised in goal setting, as motivational milestones for individuals to try achieving. However, the committee note that focusing on what someone used to be able to do might be demotivating and demoralising for an individual. If it was a clinical necessity, it would be

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					covered under the subsequent recommendation on assessing functioning, symptoms and impairment. Therefore, no changes have been made.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	016	003	It may be helpful to include substance misuse issues as a health condition that may affect rehabilitation given the bidirectional relationship between brain injury and substance use.	Thank you for your comment. While the committee acknowledge the increased prevalence of substance abuse in people with brain injury, this recommendation has been written as a universal recommendation to ensure rehabilitation professionals adequately consider the impact co-morbidities may have when planning rehabilitation. Mental health is specifically mentioned because the guideline committee's experience is that professionals have a bias towards physical impairments and they did not want invisible symptoms to be overlooked. However, in order to maintain the generalisability of the recommendation, we have not included any specific examples. Therefore, it would not be appropriate to only name substance misuse and no change has been made.
The Association of Clinical Psychologists UK	Guideline	016	003	ACP-UK comments that it may be helpful to include substance misuse issues as a health condition that may affect rehabilitation given the bidirectional relationship between brain injury and substance use.	Thank you for your comment. While the committee acknowledge the increased prevalence of substance abuse in people with brain injury, this recommendation has been written as a universal recommendation to ensure rehabilitation professionals adequately consider the impact co-morbidities may have when planning rehabilitation. Mental health is specifically mentioned because the guideline committee's experience is that professionals have a bias towards physical impairments and they did not want invisible symptoms to be overlooked. However, in order to maintain the generalisability of the recommendation, we have not included any specific examples. Therefore, it would not be appropriate to only name substance misuse and no change has been made.
North Cumbria Integrated Care NHS Foundation Trust	Guideline	016	003 - 005	We would like the committee to consider including forensic, drug and alcohol factors along with other factors listed.	Thank you for your comment. While the committee acknowledge the increased risk of these factors in people with brain injury, this recommendation has been written as a universal recommendation to ensure rehabilitation professionals adequately consider the impact co-morbidities may have when planning rehabilitation. Mental health is specifically mentioned because the guideline committee's experience is that professionals have a bias towards physical impairments and they did not want invisible symptoms to be overlooked. However, in order to maintain the generalisability of the recommendation, we have not included any specific examples. Therefore, it would not be appropriate to name forensic, drug and alcohol factors, and no change has been made.
Heads Together	Guideline	016	008	Or may be unable to state their needs due to lack of insight.	Thank you for your comment. Although insight is not specifically mentioned in the recommendation, the committee believe that this is covered in the current wording. Therefore, no change has been made.
Inflammatory Neuropathies UK	Guideline	016	008	It may be prudent to talk about 'professional curiosity' in this section as a way of seeking hidden needs, and to alleviate the 'I'm ok' issue	Thank you for your comment. Your suggestion would result in more detail than we typically add to recommendations. However, the committee were aware that hidden needs are often discovered unintentionally when

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					individuals are talking about other areas of concern. More detail on their discussion, including how healthcare professionals can hold conversations to better identify hidden disabilities, can be found in the 'Benefits and harms' section of evidence review B. It is also briefly mentioned in the linked rationale and impact section. Therefore, no change has been made.
Headway – The Brain Injury Association	Guideline	016	008	Many brain injury survivors lack insight into the effects of their injury. We suggest that this section could be strengthened to make recommendations as to how the person undertaking the assessment should gain more information about the effects of the individual's condition where this is the case.	Thank you for your comment. The committee agree that people who lack insight into their condition will need additional methods of assessment beyond discussion. To make sure that all pertinent information is captured, rather than simply what an individual has noticed, the committee have already made a recommendation on completing the holistic rehabilitation needs assessment in partnership with people important to the individual. After discussing your comment, the committee agreed that this will not always be sufficient. They have now also recommended that multiple methods of assessment (including observation) be used to assess rehabilitation needs in people lacking awareness or insight into their condition.
United Kingdom Acquired Brain Injury Forum	Guideline	016	008	People with ABI often lack of insight into their own condition.	Thank you for your comment. Although insight is not specifically mentioned in the recommendation, the committee believe that this is covered in the current wording. Therefore, no change has been made.
Brainkind	Guideline	016	008 - 009	We welcome the reminder of the impact that hidden disabilities or lack of awareness could have on the results of a holistic assessment. However, we suggest that another sentence is added to this recommendation, to briefly outline the best course of action in these cases / highlight that obtaining information from multiple sources, including direct observation, would be essential.	Thank you for your comment. The committee agree that people who lack awareness into their condition will need additional methods of assessment beyond discussion. To make sure that all pertinent information is captured, rather than simply what an individual has noticed, the committee have already made a recommendation on completing the holistic rehabilitation needs assessment in partnership with people important to the individual. After discussing your comment, the committee agreed that this will not always be sufficient. While we have not added in your suggested sentence, we have now also recommended that multiple methods of assessment (including observation) be used to assess rehabilitation needs in people lacking awareness or insight into their condition.
Royal College of Speech and Language Therapists	Guideline	016	011	Due to the high prevalence of communication difficulties in this group of patients, recommendation 1.8.12 should specifically say "**personalised and accessible** information, advice…"	Thank you for your comment. While the committee acknowledge that there is an increased prevalence of communication difficulties in people with chronic neurological disorders, there is already NICE guidance on the format of information. These recommendations can be found in CG138 (Patient experience in adult NHS services) and NG204 (Babies, children and young people's experience of healthcare), and are clearly referred to at the start of this guideline section. Therefore, no change has been made.
Head First	Guideline	016	013	1.11 Regarding the single point of contact for rehabilitation, we feel that further definition is required to determine when a keyworker, neuro-navigator or complex case manager is required. We recommend discrimination within the terminology in the guidelines regarding the	Thank you for your comment. The committee believe that they have made adequate recommendations throughout the guideline to guide the decision on which form of single point of contact would be most appropriate for an individual. As this guideline covers such a wide population (including age,

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				clinical expertise required to make this judgement as to the appropriate level of input required and recognition of the nuances of executive dysfunction and frontal lobe paradox and the challenges of determining an individual's capacity and therefore most appropriate single point of contact for ongoing rehabilitation. With consideration to lifelong rehabilitation, it is difficult to implement unless there is joint up working across all sectors, social care, primary healthcare, healthcare, private and charity. Whilst a framework for lifelong rehabilitation is essential, we would like to highlight that current health and social care systems appear to work under a reactive framework and not a proactive framework. We recognise that there is a lack of clinical case management within the NHS and that the role of a neuro-navigator can be limited to signposting services available beyond discharge. The cost of this role within the NHS would need clarification, would this be costed by the ICB rather than hospital trusts. In terms of lack of research around the case manager role, consideration could be given to evidence gathered in other specialist roles such as MND practitioners and MS specialist nurses and the justification for this role.	disorders and impairments, and rehabilitation needs), it is not possible to identify every scenario where a key worker or complex case manager would be appropriate. However, we have compiled criteria to consider when making the decision which is fairly detailed. We have noted people with cognitive difficulties impacting their ability to self-manage their condition or navigate rehabilitation services as 1 sub-population that might benefit from being assigned a higher-intensity single point of contact. While we do not specify the expertise required to make this decision in this section, this information will be obtained during an individual's cognitive assessment, which we have stated should be performed as part of the holistic rehabilitation needs assessment. The guidance in the corresponding guideline section does state that it should be carried out by a registered practitioner with expertise in neuropsychology. We anticipate they will have the experience to recognise the nuances you note in your comment. The committee are aware of the challenges to providing life-long rehabilitation, and have extensively discussed the lack of collaboration and communication between different rehabilitation sectors and providers. They note that this currently results in care often being silos and segmented. However, they have made multiple recommendation within the section on designing and commissioning rehabilitation services to try to address this issue. These focus on building flexible and responsive rehabilitation services across all sectors (including private and third sectors), highlighting the need for increased collaboration and communication. Similarly, the committee have stressed the need for proactive services by recommending that rehabilitation assessments begin as soon as symptoms or impairments manifest, rather than having to wait for an official diagnosis. This will allow for rehabilitation needs to be anticipated, and planning for these to being as early as possible. The committee have extensively discussed the resource impact of assigning a complex case manager. They have provided a list of criteria where this is appropriate, which ensures that this highest-intensity of case management will be reserved for the people who need it. Even so, they acknowledge that there is a lack of complex case managers and providing these roles, even for the minority of people with the most complex needs, will require significant resources. However, the committee argue that implementing the recommendations may enable timelier access to assessment and care, which may reduce reliance on crisis care,. This could potentially offset additional costs. It may also reduce the number of people contacting their GPs in order to access care. Finally, if needed, assigning a

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					complex case manager may provide other benefits such as reducing prolonged stays in inpatient neurobehavioural units or residential care. For a more detailed account of their discussion regarding the resource impact of these recommendations, please see 'The committee's discussion of the evidence section' in evidence reviews A, B and I. Evidence review protocols are designed to directly answer research questions the committee have developed to inform guideline recommendations. We would not look for evidence on other specialist roles as this would provide indirect evidence at best, which is too weak to inform recommendations. We hope that, by prioritising complex case management as a research recommendation, the next update of this guideline will be able to make stronger evidence-based recommendations in this area.
University College London Hospital	Guideline	016	014	Rehab interventions are not always available in local areas.	Thank you for your comment. The committee acknowledged throughout drafting this guidance that there is unequal access to rehabilitation for chronic neurological disorders throughout the NHS. They noted a variety of reasons, with access to specialist services being one. In order to combat this, and to aid implementation of the recommendations, the committee have made a number of recommendations at the beginning of the guideline on designing and commissioning rehabilitation services. These cover service design, commissioning rehabilitation services, building local capacity and expertise, and providing responsive services. It is hoped that implementing these recommendations, including those on collaborating between integrated 5 care systems to share specialist advice and enable access to care, will help to decrease these geographical heal inequalities.
Inflammatory Neuropathies UK	Guideline	016	017	Or if the condition involves relapse or fluctuating residuals	Thank you for your comment. While the committee do understand that relapse or fluctuating residuals will need planning for, they will be temporary adaptations. This recommendation is aimed at helping people, and their family or carers, to adequately prepare for permanent changes in impairment or functioning. for example, beginning wheelchair skills training while people are still ambulatory to help ease the transition when they need to start to use wheelchairs. Rapidly progressing conditions are highlighted because this preparation will need to be expedited. Therefore, no changes have been made.
British Association of Brain Injury and Complex Case Management	Guideline	016	018	1.8.14 We suggest that it will be important to include consideration around any decisions where the individual may lack mental capacity (as defined in the Mental Capacity Act 2005) as this is not covered in the explanation for 'cognition'. Mental capacity assessment in complex cases of ABI in particular needs specific assessment by an experienced/qualified person.	Thank you for your comment. The principles of capacity apply throughout this guideline, not simply this recommendation. NICE already has guidance on this topic, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws) and NG108 Decision-making and mental capacity. Additional guidance can be located in CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS

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					services and NG204 Babies, children and young people's experience of healthcare. These have been referenced at the beginning of this section. Therefore, no change has been made.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	016	018	We would also include social skills and competence here as this is a significant area of need, particularly for children/YP with neurological conditions.	Thank you for your comment. Rehabilitation for social participation is included in the subsequent recommendation on assessing rehabilitation needs to allow an individual to participate in every aspect of their daily life. Therefore, no changes have been made.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	016	018	Thank you for including these invisible symptoms. Issues related to bowel and bladder continence and sexual dysfunction are common in people with chronic neurological disorders. They are often under reported and under recognised. Please include them in this list.	Thank you for your comment. Although not specifically named, assessment for sexual dysfunction is included in the subsequent recommendation advising assessment of domains impacting a person's ability to participate in everyday activities. The internal cross reference links to the section on intimate and sexual relationships. Regarding rehabilitation for bladder and bowel function, these areas are out of scope for this guideline as there is already NICE guidance on these topics (CG49 Faecal incontinence in adults: management and CG148 Urinary incontinence in neurological disease: assessment and management). Therefore, they have included a new recommendation highlighting a cross-reference to these guidelines in the related assessments section to ensure that these areas are not overlooked when identifying rehabilitation needs.
The Neurological Alliance	Guideline	016	018	Further issues should be included in this list. For example: - 23% of adult respondents to My Neuro Survey said sexual function was impacted by their neurological condition. - 39% said maintaining romantic relationships were impacted by living with a neurological condition. - 29% of adult respondents to My Neuro Survey said their bladder and bowel were impacted by their neurological condition.	Thank you for your comment. Although not specifically named, assessment for sexual dysfunction is included in the subsequent recommendation advising assessment of domains impacting a person's ability to participate in everyday activities. The internal cross reference links to the section on intimate and sexual relationships. Regarding rehabilitation for bladder and bowel function, these areas are out of scope for this guideline as there is already NICE guidance on these topics (CG49 Faecal incontinence in adults: management and CG148 Urinary incontinence in neurological disease: assessment and management). Therefore, they have included a new recommendation highlighting a cross-reference to these guidelines in the related assessments section to ensure that these areas are not overlooked when identifying rehabilitation needs.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	016	018	Consider including social skills and competence, participation (community integration) in this list as very important for children and young people	Thank you for your comment. Rehabilitation for social participation is included in the subsequent recommendation on assessing rehabilitation needs to allow an individual to participate in every aspect of their daily life. Therefore, no changes have been made.
British Society of Physical and Rehabilitation Medicine	Guideline	016	018	Thank you for including these invisible symptoms. Issues related to bowel and bladder continence and sexual dysfunction are common in people with chronic neurological disorders. They are often under reported and under recognised. Please include them in this list. Also	Thank you for your comment. Although not specifically named, assessment for sexual dysfunction is included in the subsequent recommendation advising assessment of domains impacting a person's ability to participate in everyday activities. The internal cross reference links to the section on intimate and sexual relationships. Regarding rehabilitation for bladder and

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				include multimorbidity (other medical conditions) that impact functioning in the individual.	bowel function, these areas are out of scope for this guideline as there is already NICE guidance on these topics (CG49 Faecal incontinence in adults: management and CG148 Urinary incontinence in neurological disease: assessment and management). Therefore, they have included a new recommendation highlighting a cross-reference to these guidelines in the related assessments section to ensure that these areas are not overlooked when identifying rehabilitation needs.
The Royal College of Ophthalmologists	Guideline	016	019 - 029	Section 1.8.14 – should add assessment of vision as a potential area of impairment. This could use tools such as VISA (Visual Impairment Screening Assessment)	Thank you for your comment. The scope of the guideline did not cover interventions to support visual impairment, and therefore does not contain recommendation on this area. However, the guideline committee did agree that a holistic rehabilitation assessment should cover visual problems, not least because they can highlight potential vestibular problems which are covered by this guideline. They have made a new recommendation to cover this, although it does not contain the requested reference to VISA as this was not an area that we looked for evidence on.
The Chartered Society of Physiotherapy	Guideline	016	026	We agree with the assessments and would also like to add 'ability to engage in supported self-management'	Thank you for your comment. Recommendations covering assessment and review of a person's ability to self-manage are covered in a subsequent section on assessing the person's ability to coordinate their own care. Therefore, no change has been made.
The British Psychological Society	Guideline	016 - 017	General	The following needs to be added to the list of areas to assess (1.8.14): • Risks to self or others related to the neurological condition • Behaviour that challenges • Social and relationship function Levels of family distress	Thank you for your comment. Although not specifically named, the committee believe that all the areas you have mentioned are covered by the current recommendations. Risks to self or others related to the neurological condition is covered by the criteria for assigning a complex case manager, so would be assessed during this decision stage. Behaviour that challenges are mentioned in the emotional health and mental wellbeing section, which is cross-referenced in this recommendation. Finally, social and relationship function, and levels of family distress are covered in the section on rehabilitation to support education, work, social and leisure activities, relationships and sex. A cross-reference to this section appears in a subsequent recommendation on assessing rehabilitation needs to enable an individual to participate in every aspect of their daily life. Therefore, no change has been made.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	017	005	It may be helpful to include substance misuse issues as an area to assess given the relationship between the two.	Thank you for your comment. This recommendation lists the areas function, symptoms and impairment as mentioned in the subsequent guideline sections, as this is how we have organised the recommendations. Assessment for substance misuse would be covered in a previous recommendation on considering any environmental or wider social factors that might impact engagement in rehabilitation. Therefore, no change has been made.

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The Association of Clinical Psychologists UK	Guideline	017	005	ACP-UK comments that it may be helpful to include substance misuse issues as an area to assess, given the relationship between the two.	Thank you for your comment. This recommendation lists the areas function, symptoms and impairment as mentioned in the subsequent guideline sections, as this is how we have organised the recommendations. Assessment for substance misuse would be covered in a previous recommendation on considering any environmental or wider social factors that might impact engagement in rehabilitation. Therefore, no change has been made.
Inflammatory Neuropathies UK	Guideline	017	006	It would be good to add other impacting variables to this section such as 'under different influences such as stress or illness'	Thank you for your comment. The committee discussed the need for rehabilitation professionals realise that peoples rehabilitation needs will not always be the same as when they are assessed, and the need to capture this in conversations during the holistic rehabilitation needs assessment. Settings, periods of day and time living with a condition are all things that are highly likely to affect an individual's rehabilitation plan, and need to be considered for everyone. While stress of illness will also be experienced people with chronic neurological diseases, it is not possible to guess what illness people will experience (for example, severity) or reliably predict how these factors would affect someone's rehabilitation plan. At one extreme, it may be that an acute, severe illness will mean rehabilitation ceases for a period of time while a person received treatment. Therefore, no change has been made. However, rehabilitation needs assessments are not a single occurrence. Recommendations in this guideline promote multiple assessments if needed. Similarly, there is guidance on self-referral mechanisms for people. These would cover people who were facing worsening symptoms or impairments due to the stress of illness.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	017	006	The symptoms in chronic neurological conditions also vary with pregnancy, physical and mental health conditions like infections, injuries, anxiety, stress etc. Please mention this in this section. A new neurological condition could be the cause of worsening symptom. This is often missed. For example, a person with cerebral palsy may develop Alzheimer's disease or Parkinson's disease.	Thank you for your comment. The committee discussed the need for rehabilitation professionals realise that peoples rehabilitation needs will not always be the same as when they are assessed, and the need to capture this in conversations during the holistic rehabilitation needs assessment. Settings, periods of day and time living with a condition are all things that are highly likely to affect an individual's rehabilitation plan, and need to be considered for everyone. While the examples that you have given may be experienced by people with chronic neurological diseases, they will happen to far fewer people. Additionally, there would be no way to reliably predict how these factors would affect someone's rehabilitation plan. Therefore, no change has been made. However, rehabilitation needs assessments are not a single occurrence. Recommendations in this guideline promote multiple assessments if needed. Similarly, there is guidance on self-referral mechanisms for people.

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					These would cover people who were facing worsening symptoms or impairments due to pregnancy, or physical and mental health conditions.
The Neurological Alliance	Guideline	017	006	29% of adult respondents to My Neuro Survey in England reported living with more than one condition. A new neurological condition could be the cause of worsening symptom. For example, a person with cerebral palsy may develop Alzheimer's disease or Parkinson's.	Thank you for your comment. The committee discussed how co-morbidities, including living with multiple chronic neurological disorders, can impact an individual's rehabilitation planning. As such, they made a recommendation to ask rehabilitation professionals to consider how other health conditions can affect rehabilitation earlier in this section. Therefore, no change has been made.
British Society of Physical and Rehabilitation Medicine	Guideline	017	006	The symptoms in chronic neurological conditions also vary with pregnancy, physical and mental health conditions like infections, injuries, anxiety, stress etc. Please mention this in this section. A new neurological condition could be the cause of worsening symptom. This is often missed. For example, a person with cerebral palsy may develop Alzheimer's disease or Parkinson's disease.	Thank you for your comment. The committee discussed the need for rehabilitation professionals realise that peoples rehabilitation needs will not always be the same as when they are assessed, and the need to capture this in conversations during the holistic rehabilitation needs assessment. Settings, periods of day and time living with a condition are all things that are highly likely to affect an individual's rehabilitation plan, and need to be considered for everyone. While the examples that you have given may be experienced by people with chronic neurological diseases, they will happen to far fewer people. Additionally, there would be no way to reliably predict how these factors would affect someone's rehabilitation plan. Therefore, no change has been made. However, rehabilitation needs assessments are not a single occurrence. Recommendations in this guideline promotes multiple assessments if needed. Similarly, there is guidance on self-referral mechanisms for people. These would cover people who were facing worsening symptoms or impairments due to pregnancy, or physical and mental health conditions.
University College London Hospital	Guideline	017	008	As part of the holistic needs assessment: impacts that different people would have on the individual, consider the impact person's pet may have on the assessment.	Thank you for your comment. While pets are not specifically mentioned in the guideline, your suggestion is already covered under 2 other recommendations in this section. The first is one on assessing rehabilitation needs to allow a person to participate in every aspect of their daily life. The second is asking an individual about their activities of daily living and how this has changed or is changing. Therefore, no change has been made.
Inflammatory Neuropathies UK	Guideline	017	016	Also include 'due to their cognitive functioning'	Thank you for your comment. We have now expanded the referenced recommendation to state that people should not be excluded from a holistic needs assessment due to communication, memory, learning, or cognitive difficulties.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	017	016	Given the research showing a high prevalence of brain injury within individuals who are homeless https://doi.org/10.1016/S2468-2667(19)30188-4) and using substances https://doi.org/10.1097/HTR.0000000000000249 it may be helpful to list these as reasons not to exclude somebody from having an holistic assessment. Additionally, it may be useful to mention disinhibited	Thank you for your comment. The committee acknowledge that there are many more groups beside the ones named here that do not receive equal access to rehabilitation services. However, they wanted to highlight these specifically within the guidance because their experience shows that rehabilitation services (mental health in particular) commonly use these factors as reasons to exclude people from receiving treatment. They are

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				behaviour as many people with brain injury experience issues with disinhibition which may lead to them being excluded from accessing support, due to shouting or swearing in reception areas or appointments.	either considered unsuitable for assessment, or unlikely to adequately engage in rehabilitation. Expanding this list with environmental circumstances, substance misuse and disinhibited behaviour will may confuse this message. Additionally, it is not possible to compile an exhaustive list of why people may be refused access to rehabilitation for chronic neurological disorders but expanding the recommendation means it starts to look like one. This in turn increases the risk of services thinking is it fine to exclude groups of people who are not mentioned. Therefore, no changes have been made. However, although we have not amended this recommendation, we do believe that the concerns you have listed are covered elsewhere in this guideline. Homelessness was listed as a sub-group with particularly high levels of traumatic brain injury within the Equality and Health Inequalities Assessment (EHIA). This form contains a full description of how recommendations have been drafted to increase access to rehabilitation services for this portion of the population. We have also included a cross-reference to NG214 (Integrated health and social care for people experiencing homelessness) at the beginning of every guideline section to remind practitioners to also follow the recommendations in that guideline. Misuse of drugs and alcohol has been included in the criteria of when to consider assigning a complex case manager. One of the responsibilities of this role is to coordinate rehabilitation across multiple services, which would include challenging services refusing treatment. Finally, disinhibited behaviour is covered in the emotional health and mental wellbeing section.
The Association of Clinical Psychologists UK	Guideline	017	016	Given the research showing a high prevalence of brain injury within individuals who are homeless https://doi.org/10.1016/S2468-2667(19)30188-4) and using substances https://doi.org/10.1097/HTR.0000000000000249, ACP-UK feels that it may be helpful to list these as reasons not to exclude somebody from having a holistic assessment. Additionally, it may be useful to mention disinhibited behaviour as many people with brain injury experience issues with disinhibition, which may lead to them being excluded from accessing support, due to shouting or swearing in reception areas or appointments.	Thank you for your comment. The committee acknowledge that there are many more groups beside the ones named here that do not receive equal access to rehabilitation services. However, they wanted to highlight these specifically within the guidance because their experience shows that rehabilitation services (mental health in particular) commonly use these factors as reasons to exclude people from receiving treatment. They are either considered unsuitable for assessment, or unlikely to adequately engage in rehabilitation. Expanding this list with environmental circumstances, substance misuse and disinhibited behaviour may confuse this message. Additionally, it is not possible to compile an exhaustive list of why people may be refused access to rehabilitation for chronic neurological disorders but expanding the recommendation means it starts to look like one. This in turn increases the risk of services thinking is it fine to exclude groups of people who are not mentioned. Therefore, no changes have been made.

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					However, although we have not amended this recommendation, we do believe that the concerns you have listed are covered elsewhere in this guideline. Homelessness was listed as a sub-group with particularly high levels of traumatic brain injury within the Equality and Health Inequalities Assessment (EHIA). This form contains a full description of how recommendations have been drafted to increase access to rehabilitation services for this portion of the population. We have also included a cross-reference to NG214 (Integrated health and social care for people experiencing homelessness) at the beginning of every guideline section to remind practitioners to also follow the recommendations in that guideline. Misuse of drugs and alcohol has been included in the criteria of when to consider assigning a complex case manager. One of the responsibilities of this role is to coordinate rehabilitation across multiple services, which would include challenging services refusing treatment. Finally, disinhibited behaviour is covered in the emotional health and mental wellbeing section, which also includes a recommendation on behaviours that challenge.
Brainkind	Guideline	017	016 - 017	Consider referring to other frequent barriers to access, such as poor awareness, avolition, behaviours of distress / behaviours that challenge.	Thank you for your comment. The committee acknowledge that there are many more groups beside the ones named here that do not receive equal access to rehabilitation services. However, they wanted to highlight these specifically within the guidance because their experience shows that rehabilitation services (mental health in particular) commonly use these factors as reasons to exclude people from receiving treatment. They are either considered unsuitable for assessment, or unlikely to adequately engage in rehabilitation. Expanding this list to poor awareness, avolition and behaviours that challenge may confuse this message. Additionally, it is not possible to compile an exhaustive list of why people may be refused access to rehabilitation for chronic neurological disorders but expanding the recommendation means it starts to look like one. This in turn increases the risk of services thinking is it fine to exclude groups of people who are not mentioned. Therefore, no changes have been made. However, although we have not amended this recommendation, we do believe that the concerns you have listed are covered elsewhere in this guideline. There are multiple recommendations on considering if a person lacks insight or awareness into their condition, and how to adapt rehabilitation assessment and delivery if they do. Similarly, we have many recommendations on identify what goals are important to a person and their motivational factors, so they can be used to design a rehabilitation plan that maximises engagement. Finally, behaviours that challenge is covered in the emotional health and mental wellbeing section.

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Rehabilitation for chronic neurological disorders including acquired brain injury

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Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	017	016 - 019	We were concerned 'memory and learning difficulties' was somewhat narrow and should read 'memory, learning or other cognitive difficulties' in lines 17 and 19	Thank you for your comment. We have now expanded the referenced recommendation to state that people should not be excluded from a holistic needs assessment due to communication, memory, learning, or cognitive difficulties.
The British Psychological Society	Guideline	017	016 - 019	The statements 'Do not exclude someone…learning difficulties' (1.8.17) and 'make reasonable adjustments…engage in rehabilitation' (1.8.18) seem oddly placed here in the context of a guideline that covers conditions usually or frequently involving cognitive disability and delivery of rehabilitation for the impact of cognitive disability (termed cognitive rehabilitation). It is rightly important to convey the message that no-one should be excluded from physical rehabilitation on the grounds of cognitive disability and this message could be stated up front and woven throughout the guideline, for example by drawing on relevant evidence. However, providing physical rehabilitation for people who also have cognitive disability is not necessarily only a matter of making adjustments. Where cognitive or learning difficulties are present, rehabilitation needs to be tailored to take account of these and may require different strategies and additional skills on the part of the workforce.	Thank you for your comment. The committee agreed that in their experience, rehabilitation is often precluded in people with memory and learning difficulties. They noted that this was not appropriate, and made a strong recommendation that this was not a valid reason to exclude someone. Therefore, no change has been made. We would argue that ensuring rehabilitation for chronic neurological disorders accessible for everyone is already woven through the guideline, with many recommendations on identifying barriers to participation and tailoring rehabilitation interventions to a person's strengths and weaknesses. Similarly, as this is a section on a holistic rehabilitation needs assessment, it is not only pertaining to physical rehabilitation, and should be considered throughout.
Royal College of Speech and Language Therapists	Guideline	017	017	Recommendation 1.8.17 needs to be strengthened to include other "'invisible' or less easily recognisable symptoms or impairments" as referenced in other parts of the guideline. i.e. "Do not exclude someone from any aspect of holistic needs assessment based on their **communication, memory, learning, or other cognitive difficulties**."	Thank you for your comment. We have now expanded the referenced recommendation to state that people should not be excluded from a holistic needs assessment due to communication, memory, learning, or cognitive difficulties.
Inflammatory Neuropathies UK	Guideline	017	018	Also include 'due to their cognitive functioning'	Thank you for your comment. We have now expanded the referenced recommendation to state that people should not be excluded from a holistic needs assessment due to communication, memory, learning, or cognitive difficulties.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	017	018	People with neurodiversity and those with childhood onset disabilities are often excluded from rehabilitation. Please include them in this statement	Thank you for your comment. The committee acknowledge that there are many more groups beside the ones named here that do not receive equal access to rehabilitation services. However, they wanted to highlight these specifically within the guidance because their experience shows that rehabilitation services (mental health in particular) commonly use these factors as reasons to exclude people from receiving treatment. They are either considered unsuitable for assessment, or unlikely to adequately engage in rehabilitation. Expanding this list with neurodiversity or childhood onset disabilities may confuse this message. Additionally, it is not possible to compile an exhaustive list of why people may be refused access to rehabilitation for chronic neurological disorders but expanding the recommendation means it starts to look like one. This in turn increases the

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					risk of services thinking is it fine to exclude groups of people who are not mentioned. Therefore, no changes have been made.
The Neurological Alliance	Guideline	017	018	People with neurodiversity and those with childhood onset disabilities are often excluded from rehabilitation. Please include them in this statement.	Thank you for your comment. The committee acknowledge that there are many more groups beside the ones named here that do not receive equal access to rehabilitation services. However, they wanted to highlight these specifically within the guidance because their experience shows that rehabilitation services (mental health in particular) commonly use these factors as reasons to exclude people from receiving treatment. They are either considered unsuitable for assessment, or unlikely to adequately engage in rehabilitation. Expanding this list with neurodiversity or childhood onset disabilities may confuse this message. Additionally, it is not possible to compile an exhaustive list of why people may be refused access to rehabilitation for chronic neurological disorders but expanding the recommendation means it starts to look like one. This in turn increases the risk of services thinking is it fine to exclude groups of people who are not mentioned. Therefore, no changes have been made.
British Society of Physical and Rehabilitation Medicine	Guideline	017	018	People with neurodiversity and those with childhood onset disabilities are often excluded from rehabilitation. Please include them in this statement	Thank you for your comment. The committee acknowledge that there are many more groups beside the ones named here that do not receive equal access to rehabilitation services. However, they wanted to highlight these specifically within the guidance because their experience shows that rehabilitation services (mental health in particular) commonly use these factors as reasons to exclude people from receiving treatment. They are either considered unsuitable for assessment, or unlikely to adequately engage in rehabilitation. Expanding this list with neurodiversity or childhood onset disabilities may confuse this message. Additionally, it is not possible to compile an exhaustive list of why people may be refused access to rehabilitation for chronic neurological disorders but expanding the recommendation means it starts to look like one. This in turn increases the risk of services thinking is it fine to exclude groups of people who are not mentioned. Therefore, no changes have been made.
Royal College of Speech and Language Therapists	Guideline	017	019	Recommendation 1.8.18 needs to be strengthened to include other "'invisible' or less easily recognisable symptoms or impairments" as referenced in other parts of the guideline. i.e. "Make reasonable adjustments and adaptations to enable a person with **communication, memory, learning, or other cognitive difficulties** to engage in rehabilitation"	Thank you for your comment. We have now expanded the referenced recommendation to state that adjustments should be made to engage people with communication, memory, learning, or cognitive difficulties in rehabilitation.
The Spinal Injuries Association	Guideline	017	021	CHC funding and D2A process needs to happen internally in the rehabilitation setting as early as possible to ensure no delays happen for the patient or healthcare provider.	Thank you for your comment. Due to the wide scope of this guideline (including settings, disorders and rehabilitation needs), it is not possible to issue any more specific guidance on when to use the NHS continuing healthcare decisions tools. Therefore, no changes have been made.

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				The patient having specialist representation will aid a more thorough and clinically competent CHC assessment of their needs – this does not always happen especially in spinal injury units. This leads to inappropriate and inadequate discharges, unsafe and not meeting the individual's needs. Patients often suffer due to having to have to do without specialist representation, leading to lengthy stays that are inappropriate and often challenge and appeals which are lengthy and ultimately more expensive.	However, we do recommend that people with complex rehabilitation needs that impact their ability to navigate rehabilitation services be considered for a key worker or a complex case manager. Practitioners performing these roles could also act as specialist representation during continuing healthcare discussions.
British Association of Brain Injury and Complex Case Management	Guideline	017	021	1.8.19 We highlight a slight inaccuracy. The document refers to the NHS Continuing Healthcare checklist determining CHC eligibility. In practice, the checklist indicates the need for a full assessment using the Decision Support Tool (DST) and is therefore more of a screening tool. The DST is used to determine eligibility.	Thank you for your comment. We have amended the wording to reference NHS continuing healthcare guidance, which encompasses both the screening checklist and the decision tool.
The Royal Hospital for Neuro-disability	Guideline	017	021	When and by whom would the continuing care checklist be used?	Thank you for your comment. There is already guidance on when to use the Continuing Healthcare checklist decision tools, and who can use these, which is published on the NHS website. A hyperlink to this resource is included within this recommendation. Therefore, no change has been made.
Midlands and South Essex ICB	Guideline	017	021	This is challenging in the context of discussing ongoing rehabilitation. CHC pathways will not accept patients until they are 'at their optimum' and this is often interpreted as excluding those who have ongoing rehabilitation needs. There needs to be specific guidance that these individuals with chronic neurological conditions can make functional change which may not impact their overall care needs and as such they should not be excluded from accessing CHC pathways concurrently with ongoing rehabilitation.	Thank you for your comment. Unfortunately, it is beyond the remit of this guideline to issue recommendations on Continuing Healthcare criteria. Therefore, no change has been made. However, we do have a recommendation that highlights the importance of providing rehabilitation even if the potential for improvement appears to be limited, that could be used to support access to CNC pathways in the situation you describe.
Inflammatory Neuropathies UK	Guideline	017	026	This should include a carers assessment	Thank you for your comment. Although the committee recognise the invaluable role carers play in supporting rehabilitation, issuing recommendations for people other than those with chronic neurological disorders is beyond the scope of this guideline. NICE already has published guidance on assessing carers needs, in NG150 Supporting adult carers. This is clearly linked at the beginning of the section on assessing rehabilitation needs and goal setting. Therefore, no changes have been made.
The Stroke Association	Guideline	017	027	We welcome the inclusion of a reference to the Education, Health and Care Plan (EHCP) for children and young people with Special Educational Needs and Disabilities (SEND). As this guidance will apply to Wales it would be positive for the Welsh equivalent to also be referenced, the Individual Development Plan.	Thank you for your comment. As stated in the scope of this guideline, NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive. As such, we have made no changes but hope the Welsh Government enact these recommendations with the Welsh equivalent.

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Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	017	027	Not all children will be eligible for EHCP – geographical dependent – but may still have rehab needs. Use of IEP and other structured support systems in education should acknowledge and include rehab needs.	Thank you for your comment. The recommendation that you have referenced already acknowledges that not every child with a chronic neurological disorder will be eligible for an EHCP. It states within the wording that this is for children and young people with severe complex needs. Guidance for children and young people outside of an EHCP is covered in the subsequent guideline section on rehabilitation to support education. Therefore, no changes have been made.
Royal College of Speech and Language Therapists	Guideline	017	028	This reference to the education, health and care plan (EHCP) is welcome, but it should be acknowledged that the Welsh equivalent is an 'individual development plan'.	Thank you for your comment. As stated in the scope of this guideline, NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive. As such, we have made no changes but hope the Welsh Government enact these recommendations with the Welsh equivalent.
Success – Life After Cure Ltd	Guideline	018	001	Rec 1.8.21 The most frequent helpline calls to our charity and the most frequently asked questions at our twice-yearly conferences, are from parents requiring support to access EHCP's for their children. This is at the stage after brain tumour 'cure' or remission, and where scheduled follow-up cognitive assessments have demonstrated specific learning needs, often alongside secondary endocrine and/or complex behavioural needs. It would be helpful to cross-reference relevant guidance [if/when it exists] for this group of children and/or include them within this guidance as a named, specific group with complex needs and disability.	Thank you for your comment. While the committee acknowledges that the sub-population of children your charity represents do have specific and complex needs, they argue that there will be many children will similar levels of complexity also covered by this guideline. As we would be unable to compile an exhaustive list, the committee do not believe it appropriate to provide examples. NICE already has guidance to support access EHCP's for children with complex needs, which has been directly cross-referenced in the current draft recommendation (NG213 Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education). The guideline has a broad population, defined as disabled children and young people from birth to 25 years who need coordinated education, health and social care support because of their severe and complex needs, and are eligible for an education, health and care plan, in line with the Children and Families Act 2014. The group of children noted in your comment would be covered by this guideline. Therefore, no change has been made.
Oxford University Hospitals - Paediatric Neuropsychology Department	Guideline	018	006	While it is often appropriate to explain the process of goal setting to the person, when working with young children or children with significant cognitive impairment we would often be setting goals with parents, rather than the young person themselves. Also in the acute stages, goals may be less collaborative (i.e. more therapist directed) due to rapidly changing abilities.	Thank you for your comment. The committee agree and were aware when drafting recommendations in this guideline that they need to appropriately reflect all ages of our population, including children and young people. They noted during their discussions that any recommendations for children and young people would automatically include their parents, carers or legal guardians. It was overlooked in the initial draft, but we have added a section to the context section of the guideline to explain this clearly.

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					Regarding your comment about goals being less collaborative in the early stages of rehabilitation, the committee do agree that this may be true for people after injury. However, that does not mean that the recommendations in this section are void. Practitioners should still explain the process of goal setting, work collaboratively, and tailor timeframes of review to an individual's circumstances.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	018	007 - 009	We thought this should be added at 1.9.2 to help those with insight and awareness difficulties optimise the goals that are set with them - 'Where insight and awareness problems are likely e.g. after injuries associated with frontal impairment, these goals may need to co-constructed with the patient and people important to them e.g. family members.'	Thank you for your comment. This has been covered in the previous section on support and advocacy, which says that people should be supported to make decisions about their health and social care if they have 'invisible' symptoms and impairments. This would extend to goal setting if needed. Therefore, no changes have been made.
Oxford University Hospitals - Paediatric Neuropsychology Department	Guideline	018	010	We feel that 'developmentally appropriate approaches' would be more helpful terminology than 'age-specific approaches', in line with the needs of this patient group.	Thank you for your comment. This recommendation is made directly from qualitative evidence showing that children and young people often dis-engaged from goal setting discussions when rehabilitation practitioners did not make an effort to tailor their conversation to their age. The recommendation wording directly reflects this. Therefore, no changes have been made.
University College London Hospital	Guideline	018	012	The list presented as potential "rehabilitation contacts" is long and covers a variety of skills and knowledge bases. Whilst this is admirable, and patient specific/orientated, it risks undermining the idea of a trained single point of contact which is set out as a key aim above. Again, it is not clear who would be responsible for assigning this, what say the "contact" gets or what support they should be offered by the commissioning ICB.	Thank you for your comment. We are assuming that the reference provided alongside this comment is reverse, as it currently directs to the goal setting section. The named contact for rehabilitation referenced in this recommendation is an initial contact for rehabilitation assigned by the responsible clinician following diagnosis or initial treatment for a chronic neurological disorder where potential rehabilitation needs are identified. They may be a temporary contact until a lead practitioner is nominated for the holistic rehabilitation needs assessment. It is a distinct role from the single point of contact recommended in subsequent guideline sections, which is a more involved and permanent role that will be agreed after a person's circumstances and ability to self-manage their rehabilitation has been assessed. We have re-drafted this recommendation, as well as the accompanying glossary definitions, in order to make the boundaries of this role clearer and when other roles will take over. The single point of contact recommendations have also been extensive re-drafted in order to help clarify what this practitioner is meant to do to help a person with chronic neurological disorder navigate the health and social care system.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	018	012	More and more people are living with chronic neurological conditions and aging with it. Aging has an impact on the neurological disabilities. Please consider including changes due to aging	Thank you for your comment. The committee were aware of the increasing number of people who are living longer with a chronic neurological disorder, and the changes that they will experience as they age. They believe that

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					they have already this aspect under the bullet point on aiming to improve deterioration over time. The subsequent recommendation also speaks to future changes, asking rehabilitation professionals to discuss the impact future changes may have on a person's functioning. Therefore, no change has been made.
British Society of Physical and Rehabilitation Medicine	Guideline	018	012	More and more people are living with chronic neurological conditions and aging with it. Aging has an impact on the neurological disabilities. Please consider including changes due to aging	Thank you for your comment. The committee were aware of the increasing number of people who are living longer with a chronic neurological disorder, and the changes that they will experience as they age. They believe that they have already this aspect under the bullet point on aiming to improve deterioration over time. The subsequent recommendation also speaks to future changes, asking rehabilitation professionals to discuss the impact future changes may have on a person's functioning. Therefore, no change has been made.
Kent and Medway NHS and Social Care Partnership Trust	Evidence Review B	018	040	Need to highlight that it is not just the location of the service which makes it difficult to access but also the proximity of patients to the service.	Thank you for your comment. The sentence highlighted relates to the 'Outcomes that matter most' section of evidence review B, which directly correlate to the already published qualitative protocol. As such, it cannot be changed or amended. As part of the protocol process, the guideline committee describe potential themes that may be found in the evidence, based on their experience and expertise. However, these phenomena of interest are not finalised, and review findings will ultimately be driven by data in the included studies. If proximity of patients to the service was reported as a barrier in the literature, we would have extracted and reported it.
The Association of Clinical Psychologists UK	Evidence Review B	018	040	ACP-UK comments that the guideline should highlight that it is not just the location of the service that makes it difficult to access but also the proximity of patients to the service.	Thank you for your comment. The sentence highlighted relates to the 'Outcomes that matter most' section of evidence review B, which directly correlate to the already published qualitative protocol. As such, it cannot be changed or amended. As part of the protocol process, the guideline committee describe potential themes that may be found in the evidence, based on their experience and expertise. However, these phenomena of interest are not finalised, and review findings will ultimately be driven by data in the included studies. If proximity of patients to the service was reported as a barrier in the literature, we would have extracted and reported it.
Kent and Medway NHS and Social Care Partnership Trust	Evidence Review B	018	041	Talks about a lack of transport for children and young people but this is the case for all people with neurological conditions not specific to age, due to many people being unable to drive due to their condition.	Thank you for your comment. The sentence highlighted relates to the 'Outcomes that matter most' section of evidence review B, which directly correlate to the already published qualitative protocol. As such, it cannot be changed or amended. As part of the protocol process, the guideline committee describe potential themes that may be found in the evidence, based on their experience and expertise. However, these phenomena of interest are not finalised, and review findings will ultimately be driven by

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					data in the included studies. If lack of transport for adults was reported as a barrier in the literature, we would have extracted and reported it.
The Association of Clinical Psychologists UK	Evidence Review B	018	041	ACP-UK comments that this talks about a lack of transport for children and young people but this is the case for all people with neurological conditions not specific to age, since many are unable to drive due to their condition. We would therefore suggest it would be helpful to identify those adults also requiring transport.	Thank you for your comment. The sentence highlighted relates to the 'Outcomes that matter most' section of evidence review B, which directly correlate to the already published qualitative protocol. As such, it cannot be changed or amended. As part of the protocol process, the guideline committee describe potential themes that may be found in the evidence, based on their experience and expertise. However, these phenomena of interest are not finalised, and review findings will ultimately be driven by data in the included studies. If lack of transport for adults was reported as a barrier in the literature, we would have extracted and reported it.
United Kingdom Acquired Brain Injury Forum	Guideline	018	General	Optimum Clinical Pathway https://static1.squarespace.com/static/5f1021faf6248b39f4c64f5d/t/64fe266fa42f975f1623d5c2/1694377587517/02+NNAG+Traumatic+Brain+Injury+Pathway+Final+03.pdf	Thank you for your comment. In order for us to explicitly reference external guidance, we have to have enough detail provided covering the development of recommendations to complete a quality appraisal checklist. This is the same criteria as any evidence that we include in out evidence reviews, and allows the guideline committee to fully consider the strengths and weaknesses of any recommendations they are linking to. There is not enough information published on the development of this pathway for us to do this. For example, the website simply says that the pathway for traumatic brain injury developed by a working group of specialists in consultation with relevant stakeholders with no further information provided. Therefore, no change has been made.
Cambridge University Hospital NHS Foundation Trust	Guideline	018	General	Rec 1.9 Goal Setting needs to include "when goal setting, consider the needs of those who will be supporting the child with this from the young person's family, school and community." A parent with PTSD may not be able to get their child to appointments. Parent delivered rehab is more effective: Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: A randomized controlled trial. Many of our parents have PTSD: Systematic Review and Meta-analysis: Prevalence of Posttraumatic Stress Disorder in Trauma-Exposed Preschool-Aged Children - PubMed Predicting Parental Post-Traumatic Stress Symptoms Following their Child's Stay in a Pediatric Intensive Care Unit, Prior to Discharge - Mekela M. Whyte-Nesfield, Eduardo A. Trujillo Rivera, Daniel Kaplan, Simon Li, Pamela S. Hinds, Murray M. Pollack, 2025	Thank you for your comment. Your comment seems to be more concerned with planning and delivery of rehabilitation, rather than the rehabilitation goals themselves. The committee discussed a variety of factors that need to be considered when assessing rehabilitation needs, in order to appropriately inform the resulting rehabilitation plan. Two of these would prompt conversations that would help identify parental needs that might impact participation in rehabilitation: asking a person about their relationships; and environmental and wider social factors that might prevent them from taking part in rehabilitation. Therefore, no change has been made.

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Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	018 - 019	General	We believe that a nationally agreed measurement tool for goal setting should be recommended	Thank you for your comment. We did not look for evidence on measurement tools for goal setting and cannot issue a recommendation in this area. Therefore, no change has been made.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	018 - 019	General	We believe there needs to be consideration for how best to engage patients within the goal setting process, particularly for those who lack insight.	Thank you for your comment. The committee agree that people need to be engaged in their goal setting process in order for it to be worthwhile and effective. However, they disagree that this has not already been considered in these recommendations. The whole section is designed around engagement, with recommendations covering collaborative working, age-specific approaches, taking into account a person's wishes and aspirations, and allowing specific time. Therefore, no change has been made.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	018 - 021	General	1.9.3, 1.9.8 and 1.10.3 - Doesn't need to include the child statement - Setting goals with someone should always be using accessible language, setting/ adjustments; its not just for young people. Ie appropriate to stage/ ability as well as culture etc.	Thank you for your comment. While we agree that goal setting should always include accessible language, this recommendation is made directly from qualitative evidence showing that children and young people often dis-engaged from goal setting discussions when rehabilitation practitioners did not make an effort to tailor their conversation to their developmental age. The committee's experiences supported this evidence, and so they wished to highlight the identified issue within the guideline. The 1.10.3 recommendation you referenced is about focusing interventions on optimising functioning and does not include any mention of children or young people. However, we have amended the review of goals to include all ages of people with chronic neurological disorders. Best practice recommendations for conversations between healthcare professionals and patients of all ages are covered in NICE foundational guidelines CG138 (Patient experience in adult NHS services: improving the experience of care for people using adult NHS services) and NG204 (Babies, children and young people's experience of healthcare). Both of these have been referenced at the beginning of each of the main guideline sections, including this one on assessing rehabilitation needs and goal setting.
Brainkind	Guideline	019	010	'Frequently' is vague. Consider instead ''adjust rehabilitation goals and plans at a frequency appropriate to respond to children's and young people's growth or developmental stage'.	Thank you for your comment. The committee do not see a material difference in the wording that they have drafted and the one you propose. Appropriate frequency is already implied by saying this adjustment should be carried out in response to growth and developmental stage. Therefore, no change has been made.
University College London Hospital	Guideline	019	012	Vocational and educational financial resources and rehabilitation services are lacking throughout the UK. This will need significant funding uplift to achieve	Thank you for your comment. This section is specifically about setting rehabilitation goals connected to education, training and work. There is a separate guideline section on delivering rehabilitation to support education and work. The committee has considered the resource impact of all the

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					recommendations in this section and do not anticipate a significant resource impact. This is explained in the accompanying 'How the recommendations might affect practice' paragraphs, linked at the bottom of each sub-section. Full details of the committee's discussion of the resource impact can be found in 'The committee's discussion and interpretation of the evidence' section of evidence review K.
Brainkind	Guideline	019	015 - 016	Consider adding 'or health trajectory in adults'.	Thank you for your comment. We have already recommended goal setting should include consideration of future changes in functioning in the main goal setting section. Please note that the recommendations in the 'For education, training and work' sub-section should be followed in addition the general goal setting guidance. Therefore, no changes have been made.
The Neurological Alliance	Guideline	020	General	We welcome reference to the NICE guideline on Transition from children to adults' services for young people using health or social care services (NG43). My Neuro Survey highlights significant challenges in providing smooth transition from paediatric to adult services in particular. Notably, aspects of NG43 are not consistently applied in practice. 23% of young people aged 14-17 who responded to My Neuro Survey said they had not received any information about transition to adult services but would like this. 27% of the same group said they did not have information and did not know where to access it from. Just 8% of those who had received information have a named worker – itself a key recommendation of NG43.	Thank you for your support. We hope this reference helps to highlight the importance of this aspect of care and will help reduce variation in practice when transitioning from children's to adult services.
The Royal Hospital for Neuro-disability	Guideline	021	001 - 008	Is it realistic to develop a long-term rehabilitation plan for everyone with a chronic neurological disorder?	Thank you for your comment. Generic rehabilitation plans are already often provided, so the committee asserted that they could easily be tailored to an individual through holistic assessments. They acknowledged that this may require more resources. However, effective plans can support independence, reduce reliance on paid carers, improve outcomes and lower overall NHS costs. Therefore, no change has been made.
The Wolfson Neurorehabilitation Service	Guideline	021	001 - 016	Rehabilitation Planning and Delivery (Recommendations 1.10, 1.10.2) We recommend that the guideline further emphasises the importance of timely rehabilitation planning and delivery, particularly concerning its impact on vocational goals. The principle of tailoring the timing and intensity of interventions to prevent patient overwhelm and improve engagement should be clearly articulated.	Thank you for your comment. Due to the wide population that this guideline covers (including different ages, different disorders, and different rehabilitation needs), the committee did not believe it appropriate to be specific in the timing of rehabilitation as it would not always apply to the whole population. However, we disagree that the importance of timely rehabilitation planning and delivery has been understated in the current draft recommendations. There are several recommendations that state rehabilitation should commence from symptom manifestation, or from when there is resulting impairment in functional domains, rather than having to

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					wait for an official diagnosis. Similarly, we have recommended early provision of equipment or environmental adaptations. Collaboration between services has been stressed multiple times, with the rationale of improving coordination and timeliness of provision. Specifically, in the section on workplace rehabilitation, we have recommended that discussions on returning or remaining in work take place as early as possible. Regarding your point about explaining that tailoring timing and intensity of interventions will help to improve engagement, this is more detail than we usually put into recommendations. However, this did form part of the committee discussion of the evidence and has been appropriately noted in evidence review A. Therefore, no change has been made.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	021	002	Holistic rehab needs assessments are currently not conducted in many paediatric settings. They would be a very helpful addition to provision but it is important who would lead on completing these assessments and individual plans. This again highlights the need for specialist teams, ideally with a Case Manager role which can work alongside neuropsychology and MDT therapists. Once again this might need some form of competency framework for neurological conditions to ensure effective and informed interventions.	Thank you for your comment. This guidance includes children and young people with chronic neurological needs, so the recommendation on holistic rehabilitation assessment applies. It outlines when to initiate it, who to involve and who should lead. As you suggest, the guideline already recommends a single point of contact—this could be a key contact, key worker, or complex case manager, depending on needs. The nominated person would have the clinical expertise to coordinate and navigate to ensure effective rehabilitation. The committee considered resource implications but highlighted benefits such as timely care, better outcomes, reduced duplication, and less reliance on inpatient or crisis care, potentially leading to overall cost savings to the NHS.
Brainkind	Guideline	021	009 - 010	Clarity is needed on who should agree / how should timing, intensity and frequency be determined (e.g. who: a healthcare practitioner qualified to deliver the interventions in question / how: determined by clinical need).	Thank you for your comment. Due to the wide population that this guideline covers (including all age ranges, with different symptoms and rehabilitation needs), the committee did not feel able to specify who should agree interventions and approaches or how timing, intensity and frequency should be determined. This would be different for each individual. However, the section on holistic rehabilitation assessment, and planning and delivery explains who should be involved and the most appropriate practitioner to lead. It is implicit that those convened to deliver different components of rehabilitation will have the required expertise. The subsequent section on maintaining, improving or supporting function covers rehabilitation for various needs, which may also help to guide decisions on timing, intensity and frequency. Therefore, no change has been made.
Parkinson's UK	Guideline	021	009 - 016	We believe an additional point should be added here that condition-specific, evidence-based outcome measures to assess the baseline,	Thank you for your comment. Unfortunately, we did not look for evidence on specific outcome measurement tools and cannot make a

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				determine the rehabilitation plan, and assess the efficacy of the intervention should be used.	recommendation on their use. However, we do have a recommendation the prior section on what to cover in the holistic rehabilitation needs assessment, which advises assessing multiple areas of function, symptoms and impairment. Similarly, there are assessment recommendations or sections in each of the sub-sections covering rehabilitation to maintain, improve or support function. It is implicit that this will be done by a trained professional who will be aware of which measures are most appropriate for their population and the domain being assessed. The rehabilitation assessment will then go on to inform the rehabilitation plan. Therefore, no change has been made.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	021	013	Fatigue will also be a crucial factor to consider, particularly for young people who are returning to education	Thank you for your comment. While the committee agree that fatigue might be a factor to consider when modifying interventions when designing a rehabilitation plan, they are not compiling an exhaustive list in this recommendation. The 2 listed currently are purely examples. Therefore, no changes have been made. The committee appreciate the impact fatigue can have on people with chronic neurological disorders, and have included a whole section on how best to believe to assess and manage fatigue within rehabilitation. They note that your concerns are already covered by a recommendation in this section that specifies asking about fatigue as part of the holistic rehabilitation needs assessment, and whenever rehabilitation is being discussed.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	021	013	Needs addition of "fatigue"	Thank you for your comment. While the committee agree that fatigue might be a factor to consider when modifying interventions when designing a rehabilitation plan, they are not compiling an exhaustive list in this recommendation. The 2 listed currently are purely examples. Therefore, no changes have been made. The committee appreciate the impact fatigue can have on people with chronic neurological disorders, and have included a whole section on how best to believe to assess and manage fatigue within rehabilitation. They note that your concerns are already covered by a recommendation in this section that specifies asking about fatigue as part of the holistic rehabilitation needs assessment, and whenever rehabilitation is being discussed.
British Association of Prosthetists and Orthotists	Guideline	021	015	There is a typo here – should be "rehabilitation goals" rather than "rehabilitations goals"	Thank you for your comment. The typo has been amended.

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British Association of Brain Injury and Complex Case Management	Guideline	021	017	1.10 In practice some guidance on how to assess consistently against agreed benchmarks would be helpful so that people are not denied rehabilitation due to a perceived or inaccurate assessment of their rehabilitation potential. Clarity on whether every person with a CND should have an opportunity for rehabilitation before their potential is suggested. CCMs and key workers will be key in this process as they may be the professionals with experience of the potential for progress to be made given the opportunity for slow stream and bespoke rehabilitation services.	Thank you for your comment. Since consultation, we have significantly amended this section to cover agreeing, delivering and reviewing a rehabilitation plan. We hope that including all 3 aspects together within this section will highlight that reviewing should form part of the normal rehabilitation pathway. Unfortunately, we are unable to issue more specific guidance on agreed benchmarks due to the wide scope of this guideline (including age, disorders, and rehabilitation needs) and we did not search for evidence in this area. Therefore, no changes have been made. However, the committee believe that the concerns you have noted are covered by the existing draft recommendations. We have stressed the important of rehabilitation practitioners sharing assessments, which would require an agreement between services of how to perform and score these assessments. Additionally, we have a specific recommendation on focusing rehabilitation on optimising or maintaining a person's functions even if their potential for improvement seems limited.
Independent Neurorehabilitation Providers Alliance	Guideline	021	020	We agree but it should be noted that this could require additional resources as travelling to different locations reduces the number of patients that could be seen compared to seeing them in a clinic setting.	Thank you for your comment. The committee was aware that many services have already adopted hybrid models, delivering interventions in homes, community settings or remotely. Therefore, they did not anticipate significant additional resources would be needed.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	021	020	It is essential children are able to rehabilitate within school and teacher / SENCo understanding of neurological conditions will be essential to support this. Links to specialist teams who can provide training and support will also be crucial. It would be helpful if NICE guidance extended to education as well as health and care professionals, or that parallel guidance is developed for schools/colleges.	Thank you for your comment. The guidance recommends for commissioner to collaborate with other sectors, including local authorities, voluntary organisations and education. It also states the guidance is for practitioners in related services, including education. The committee recognised the vital role of education and referenced it throughout, including in the holistic needs assessment and the dedicated rehabilitation section supporting children and young people. They hope practices to support implementation will be put in place and education practitioners equipped to support children with neurological conditions. To facilitate this, the committee recommended a named healthcare contact for education practitioners and emphasised two-way communication and information sharing. Unfortunately, making recommendations for education professionals is beyond NICE's remit but the committee hope commissioners will adopt these recommendations and support education and other sectors as needed.
Oxford University Hospitals - Paediatric Neuropsychology Department	Guideline	021	020	We feel it may be difficult to achieve this level of flexibility within NHS services.	Thank you for your comment. The committee was aware that many services have already adopted hybrid models, delivering interventions in homes, community settings, or remotely, potentially mitigating some resource impact. This aligns with NHS England's community rehabilitation model, where some provision could be diverted from inpatient care to local, community-based support, making it more accessible for people with chronic neurological disorders requiring ongoing rehabilitation. This also

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					aligns with the new NHS 10 year plan. The committee also made recommendations on service delivery to make services more efficient, potentially releasing resources and funds for alternative use, such as building flexibility within services.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	021	023	It may be helpful to include hostels and supported living accommodation as an area that interventions could be delivered in given the high rates of homelessness in people who have brain injury.	Thank you for your comment. The committee acknowledge that it is important for these recommendations to be equally applicable to all people covered by the guideline. However, the settings listed in the recommendation are only given as examples to consider and do not exclude hostels or supported living accommodations. These could fall under home or community settings. Therefore no change has been made.
The Association of Clinical Psychologists UK	Guideline	021	023	ACP-UK comments that it may be helpful to include hostels and supported living accommodation as an area that interventions could be delivered in, given the high rates of homelessness in people who have brain injury.	Thank you for your comment. The committee acknowledge that it is important for these recommendations to be equally applicable to all people covered by the guideline. However, the settings listed in the recommendation are only given as examples to consider and do not exclude hostels or supported living accommodations. These could fall under home or community settings. Therefore no change has been made.
Heads Together	Guideline	021	024	There needs to be collaboration with schools, employers etc to ensure appropriate transitions are managed.	Thank you for your comment. The committee agreed and has already recommended that if the person is in work, education, or training, collaboration with their employer, education setting, or adult learning support centre should be undertaken to agree on and deliver rehabilitation interventions relevant to the tasks and activities the person will be undertaking.
Success – Life After Cure Ltd	Guideline	021	024	1.10.5 Many young people at our charity are keen to work but report feeling abandoned as young adults, once cured of their brain tumour, and needing support to have dialogue with employers, find and maintain work. We welcome this recommendation for continued dialogue and review	Thank you for your comment. We hope that our recommendations can help to address continuity of support for young adults.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	021	024	This is essential and needs to be an ongoing process, particularly for CYP whose needs may evolve across development. However, it's not clear who would be doing this liaison. In many areas there would be no provision within paediatric services, and schools would struggle to recognise need and deliver effective rehab interventions without specialist support. Indeed the level of training and awareness to support those with neurological conditions within community services might be an area to consider in terms of core competencies for all professional groups.	Thank you for your comment. The section o who to involved in 'Initiating holistic rehabilitation needs assessment' outlines who is best placed to lead, coordinate and liaise to inform the plan and its delivery.
United Kingdom Acquired Brain Injury Forum	Guideline	021	024	There needs to be collaboration with schools, employers etc to ensure appropriate transitions are managed.	Thank you for your comment. The committee agreed and has already recommended that if the person is in work, education, or training, collaboration with their employer, education setting, or adult learning support centre should be undertaken. This will allow time to agree on and

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					deliver rehabilitation interventions relevant to the tasks and activities the person will be undertaking.
Brainkind	Guideline	021	024	We are concerned that the wording 'if the person is in work, education or training' may exclude those who may not be in work at the time of rehabilitation or may not be able to work towards returning to the role they used to have. Consider rephrasing to integrate these possibilities: 'when possible and in line with the person's preferences and abilities, collaborate with their current employer (…) or explore options for future roles'.	Thank you for your comment. This recommendation is simply about identifying aspects of rehabilitation that might be delivered in work, so this can then be incorporated into the rehabilitation plan. If a person is not in employment, then it would not be applicable. Therefore, no change has been made. However, the committee were aware of the possibility of individuals not currently being in employment, or considering changing roles. There is further, more detailed guidance incorporating these options in the rehabilitation and the workplace section of the guideline.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	021	024	For CYP it is particularly important this is an ongoing process as needs may evolve and change across their development.	Thank you for your comment. Children and young people are covered in their own section titled 'Rehabilitation to support education for children and young people'. In this section, the committee recommends regular reviews of education, health and care plans if they include rehabilitation provision, especially if the person has a chronic neurological disorder that is progressive or fluctuating.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	021	025	We thought line 25 should read *'…learning support centre (with their consent) to agree.'* and thought 'Occupational Health, Human Resources and Disability Employment Advisor' should also be added to this line.	Thank you for your comment. The principles of consent apply throughout this guideline, not simply this recommendation. NICE already has guidance on this topic, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws) and NG108 Decision-making and mental capacity. These have been referenced at the beginning of this section. Regarding your request for adding professionals to the list of collaborators, this recommendation is simply about identifying aspects of the rehabilitation that can be delivered in a workplace, education or training setting. These can then be incorporated into a comprehensive rehabilitation plan. There are more detailed recommendations on who to involve in discussions on specific rehabilitation needs and interventions within the sections of rehabilitation to support education and work. Occupational health and human resources have been given as examples. Therefore, no change has been made.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	022	001	Should this not include children and young people too? It is essential they are reviewed, as brain injuries in CYP look different at different points in development as new skills come on line (or do not because of the brain injury / neurological condition). Could this also include reference to fatigue, which has a significant impact on an individual's support and rehab needs.	Thank you for your comment. However, children and young people are covered in their own section titled 'Rehabilitation to support education for children and young people'. In this section, the committee recommends regular reviews of education, health and care plans if they include rehabilitation provision, especially if the person has a chronic neurological disorder that is progressive or fluctuating.
Nottingham University Hospitals Department	Guideline	022	001	Needs to include Children and young people	Thank you for your comment. However, children and young people are covered in their own section titled 'Rehabilitation to support education for

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of Clinical Psychology and Neuropsychology					children and young people'. In this section, the committee recommends regular reviews of education, health, and care plans if they include rehabilitation provision, especially if the person has a chronic neurological disorder that is progressive or fluctuating.
Anglia Ruskin University	Guideline	022	007	Rec 1.10.7 – While we agree that 'Practitioners involved in delivering the rehabilitation plan should work together to ensure timely and joined-up delivery of the interventions and approaches', we think that it might be important to state that there should be provision for regular MDT meetings to ensure that communication and discussion as a team are facilitated. This will help the team remain aware of changes to the patient's needs and abilities, and to respond to these changes in a timely manner,	Thank you for your comment. There was limited qualitative evidence showing that people with chronic neurological disorders, their family members, and rehabilitation practitioners reported that collaboration between clinicians facilitated holistic assessments. Multidisciplinary teams were seen as effective for increasing communication within rehabilitation, ensuring realistic plans and goals, and conveying clear and consistent messages to people with chronic neurological disorders. The committee agreed with this but noted that multidisciplinary teams are not feasible in every setting and recommending them would represent too much of a change in practice and have a significant resource impact. Instead, the committee recommended producing and agreeing on a personalised rehabilitation plan with people with chronic neurological disorders, their families, and the healthcare and social care practitioners involved in their care. Although formal multidisciplinary teams were not recommended, the committee emphasised that rehabilitation for chronic neurological disorders requires collaboration and integration of various disciplines. To facilitate such working, committee also made a single point of contact recommendation. The committee hopes this approach addresses your concern.
Chiltern Music Therapy	Guideline	022	008	The guideline emphasises multidisciplinary approaches but omits music therapy as one of the listed Allied Health Professions. Including music therapy and particularly Neurologic Music Therapy®, aligns with holistic rehabilitation practices that can enhance patient outcomes. References: Thaut & Abiru (2010), Särkämö et al. (2014). Services may encounter difficulties in implementation if they are unaware of available NMT™ practitioners or established clinical pathways. To address this, it is important to refer to international training bodies like the Academy of Neurologic Music Therapy®, national HCPC registries that list qualified music therapists, and make reference to examples where NMT™ has been successfully implemented within a range of NHS Trusts (e.g. Chiltern Music Therapy has services set up currently at the RNRU at Homerton Hospital, the Complex Rehabilitation Unit at Chapel Allerton Hospital and the stroke unit at Wycombe Hospital. The Royal Hospital for Neurodisability also has its own team of qualified neurologic music therapists).	Thank you for your comment. We are aware of the important role music therapy can play in rehabilitation for people with chronic neurological disorders. As such, we have included creative arts therapists (which encompass music therapists) as an example of a rehabilitation practitioner. this can be found in the 'Terms used in this guideline' section of the guideline document. Therefore, no change has been made.

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Success – Life After Cure Ltd	Guideline	022	013	Rec 1.11 We endorse the single point of contact for care co-ordination which we as a charity are also advocating. However we are disappointed not to see any reference to children with brain tumours, although specific guidelines for adults with brain tumours and brain metastases in over 16s, is referenced specifically. The implication therefore, throughout the guideline, is that children with brain tumours have been omitted. Yet we are unaware of any other defined management guideline and service specification for them, other than a general recommendation in the 2005 children's and young peoples NICE cancer guidance, that rehabilitation for those with CNS tumours should be commissioned and available. Despite its re-iteration in 2014 update, this remains largely inaccessible and seems inequitable and unintended. Could it also reflect challenges in co-ordinating neurorehabilitative speciality care alongside an acute neuroncology pathway in a complex and vulnerable group of patients, whose long term survival has been standing at close to 80% for the last two decades? Might the duality of the diagnostic need also be part of the proposed solution and a specific dual pathway of care considered in a dedicated childhood brain tumour neurorehabilitation guideline?	Thank you for your comment. We appreciate your support of our guidance on a single point of contact. We can reassure you that this guideline does cover the lifelong rehabilitation needs resulting from central nervous system tumours in children and young people. The box at the beginning of the section is merely highlighting to healthcare and social care practitioners that there is additional NICE guidance on single points of contact in several sub-populations covered by this guideline, which they should also follow. Referencing brain tumours and brain metastases in over 16s is the full name of the guideline, as is NICE style - it does not mean these recommendations do not apply to children and young people under 16 with rehabilitation needs resulting from brain tumours. However, if you have identified areas where you feel more specific guidance is needed, please complete the online form at https://www.nice.org.uk/forms/topic-suggestion.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	022	General	Single point of contact/case manager is rare in paediatric service but an essential component of rehabilitation. Commissioning is required to create posts that are able to deliver these recommendations as current team structures within paediatrics do not have capacity.	Thank you for your comment. The committee agreed that a single point of contact is an essential component of rehabilitation. They noted that some key contact or key worker responsibilities are already undertaken by existing staff. Their recommendation involves officially nominating this practitioner and communicating this to individuals with chronic neurological disorders and/or their carers. The committee acknowledged potential resource implications, particularly regarding the complex case manager role. They outlined many benefits, including reduced reliance on expensive inpatient and crisis care. Please see supporting evidence review I for a full discussion of potential benefits and cost effectiveness. The committee also made several recommendations on service design to improve efficiency, potentially releasing resources and funds for other uses, including additional funds for single point of contact roles. We will also pass your comment to our implementation team.
Corporé	Guideline	022	General	In relation to the role of the single point of contact, there is no protocol stipulated with regards to communication or coordination between the single point of contact and with wider team. Would it be helpful to include guidance on this?	hank you for your comment. Information on follow-up arrangements (including who to involve) can be found in the next guideline section. Therefore, no change has been made.

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Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	022 - 024	General	Assigning a single point of contact across geography and diagnosis might be difficult to achieve practically. We recommend further consideration around this.	Thank you for your comment. The committee noted that the single point of contact role, such as key contacts or key workers, is already fulfilled by existing practitioners in most services and did not anticipate major implementation challenges. The recommendation aims to ensure that the individuals are nominated for these roles and this is clearly communicated to people with chronic neurological disorders. They also made recommendations on how to agree who is the best practitioner to fulfil this role within the constraints that you mention in section on 'Assigning a single point of contact'. The committee also acknowledged a shortage of complex case managers, which may require additional resources. In addition, they made recommendations on service design to improve efficiency, potentially freeing up resources and funds to support these roles where they do not currently exist. We hope this addresses your concerns.
The Neurological Alliance	Guideline	022 - 024	General	We welcome the recommendation to assign a care coordinator. 42% of adult respondents to My Neuro Survey disagreed that they knew who to contact if they need support about their neurological condition in between appointments. 47% disagreed that they have a consistent healthcare professional so do not have to explain their condition(s) repeatedly to different people. Assigning an appropriate care coordinator will help address this unmet need and improve experience of care. However, it is clear that community neuro rehab teams may not have the resources required in order to implement this recommendation consistently. Investment and support to appropriately plan this implementation is required.	Thank you for your comment. We appreciate your support of this recommendation. The committee acknowledged that there will be a resource impact associate with assigning a single point of contact. This might be more true in certain services or settings (for example community neurorehabilitation teams as you mention). However, the committee discussed how current services are often siloed and disjointed, leading to communication gaps, duplication, delays in assessments and care, and reliance on costly inpatient and crisis care. They have also proposed several recommendations for service redesign to improve efficiency and potentially free up funds for other uses, including any additional funding that may be needed to facilitate a single point of contact. The committee hopes their recommendations will be adopted and appropriately funded. We will also pass your comment to our team supporting implementation of this guideline.
Huntington's Disease Association	Guideline	023	001	Rec 1.11.1 – We strongly support the recommendation to assign a person a single point of contact as part of their rehabilitation plan. The complex nature of Huntington's disease means there are frequently multiple professionals involved in a person's care, often with little knowledge of the disease. People affected by Huntington's tell us how draining it can be to coordinate care across a number of health and social care services, and to have to keep explaining Huntington's disease. Having a single point of contact to help people understand and navigate rehabilitation services and coordinate their rehabilitation plan could have a significant positive impact. This is support that people living with Huntington's disease want. A 2023 study of people affected by Huntington's disease highlighted how	Thank you for your comment. We appreciate your support of this recommendation, and hope that implementation of this guidance will help to address the challenges many people with chronic neurological disorders face trying to coordinate their rehabilitation care.

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				important it is to have the support of a professional to coordinate care. Although 90% (112) of people said it was very important or extremely important to have a care coordinator, less than one in five (19%) had one. Among those with a care coordinator, 81% reported being somewhat or extremely satisfied with their services.	
First Community Health and Care	Guideline	023	001	Rec 1.11.1 - To resource keyworker for all patients is very unrealistic. Different therapists may be involved at different times. The role of the keyworker may be limited and unnecessary in most cases causing unnecessary work for staff and increased confusion for patients. It can work in Early Supported Discharge (ESD) and inpatient services.	Thank you for your comment. The guidance recommends a single point of contact, which could be a key contact, key worker, or complex case manager. The 'Terms used in guideline' section provides further details on these roles and their responsibilities. Depending on the complexity of needs, the single point of contact may only involve signposting and providing information for some people, while others may require more intensive support to navigate services, coordinate rehabilitation, access services, and make referrals. The type of single point of contact will depend on the complexity of needs and the person's or their family's ability to manage rehabilitation, with a key contact providing the least intensive support and a complex case manager providing the most. Not all people will need a key worker. The committee noted that many staff already undertake the roles of key contact and key worker. Their recommendation implies officially nominating a practitioner and communicate this to the person with a chronic neurological disorder. The committee discussed the need for a timely and coordinated approach to rehabilitation and agreed that the most practical way to achieve this is through a single point of contact. This role is distinct from initial contact, in settings such as in Early Supported Discharge (ESD) and inpatient services.
Headway – The Brain Injury Association	Guideline	023	001	As previously stated, it would be helpful for brain injury survivors if details of their single point of contact were also communicated to their GP. This is particularly important for those with memory issues.	Thank you for your comment. The single point of contact noted in this recommendation is likely to be different from the initial contact for rehabilitation specified in previous recommendations. We have included that information on the initial contact for rehabilitation should be given to a person's GP. Additionally, we have re-drafted these sections to highlight the differences in the roles being described in recommendations.
Midlands and South Essex ICB	Guideline	023	001	As above, a single point of contact is likely to be difficult to implement when rehabilitation takes place across multiple services, agencies and providers. If this guideline is to be implemented with a single point of access across a system or ICB area then there will need to be substantial investment in a case management team in many areas.	Thank you for your comment. The committee acknowledged potential resource implications but noted that key contact and key worker responsibilities are already undertaken by existing staff. The main impact would be to ensure people are officially nominated and this is communicated to those with chronic neurological disorders. There is flexibility in who can fulfil this role as per the included definitions. However, the committee was aware of the shortage of complex case managers and

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					the associated resource implications. The committee discussed many benefits of having a single point of contact, outlined in the related discussions and supporting evidence review I. They also made several recommendations on service design to improve efficiency, potentially releasing resources and funds for other uses within rehabilitation services, including investment in case management services.
Parkinson's UK	Guideline	023	001 - 013	Recognition of the importance of self-management is positive. The terminology 'self-management' may not fully encompass the significant role of family members and friends in supporting individuals with long-term neurological conditions. Therefore, we suggest considering the term 'shared management' to better reflect the collaborative nature of care and support systems. The impact of non-motor symptoms in Parkinson's, particularly cognitive decline, on family members and informal caregivers is substantial. These support systems are increasingly integral to enabling individuals with this condition to maintain their well-being.	Thank you for your comment. The committee acknowledge that self-management is often not a solitary effort and may involve family, carers and friends. They have already included a recommendation in this section to assess family and carer ability to self-manage rehabilitation before assigning a single point of contact. Similarly, there is a recommendation in the holistic rehabilitation needs assessment section that describes identifying important people to a person with chronic neurological disorders and how they should be involved in delivering rehabilitation. There is additional guidance in this section that details how to help family and carers prepare psychologically for future changes to impairment and functioning. We believe that these recommendations cover your concerns on including support networks in self-management. Regarding your request for a terminology change, the committee believe that self-management is the most common phrase for what is being recommended. Shared management is less common terminology, and could introduce confusion for people reading the guideline. Therefore, no change has been made.
The Wolfson Neurorehabilitation Service	Guideline	023	001 - 029	Single Point of Contact and Assessing the Person's Ability to Coordinate Their Own Care (Recommendations 1.11.1/1.11.2, 1.11.5/1.11.6) We suggest clarifying that a designated individual or service is responsible for monitoring and oversight of the single point of contact. For complex case managers (Recommendations 1.11.5/1.11.6), we recommend that the guideline acknowledges the potential for lifelong support as patient complexity may increase over time, and clarifies that impairments can be cognitive or communication-related, not solely executive function. We also propose that the guideline's accompanying rationale consider the benefits of dedicated external roles, such as neuro-navigators, who can provide specialist local knowledge and consistent patient pathways, alleviating the burden on direct therapy time.	Thank you for your comment. The committee discussed your suggestion on designating an individual or service for monitoring and overseeing the single point of contacts. They noted that it would be very difficult to do this, as each commissioning body could implement these guidelines in different ways as informed by their local needs and current service set up. Therefore, any recommendation in this area would be overly prescriptive. However, we do have a recommendation on commissioning services to ensure access to a single point of contact. As commissioning will also include contract management aspects, the committee believe that this will be covered even if not explicitly mentioned in a recommendation. The committee also believe that the potential for a life-long access to a complex case manager is implicit in the current section on assigning a single point of contact. We have designed recommendations to focus on the complexities and impairments that would benefit from a complex case manager approach. There is no mention that this appointment should be

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					time-restricted. Although we do note that this might be the case for people experiencing temporary changes of circumstances, which is accurate, we also say that people's ability to self-manage should be reviewed if significant difficulties are observed or reported and potentially re-consider their current single point of contact. Finally, a neuro navigator has already been listed as an example of a practitioner who could fulfil the role of a single point of contact. This can be found in the 'Terms used in this guideline' section. The committee have expanded the criteria list of when to consider appointing a key worker or complex case manager to include people with communication or cognitive difficulties affecting their ability to self-manage their condition or navigate rehabilitation.
Inflammatory Neuropathies UK	Guideline	023	011	When will this happen and how often	Thank you for your comment. The recommendation already states that the most appropriate single point of contact should be reviewed when significant difficulties are observed or reported.
University College London Hospital	guideline	023	014	Case management would be a good model however, this is rarely available in statutory services in the UK	Thank you for your comment. The committee acknowledged the potential lack of complex case managers within the NHS and the need for workforce expansion. They also recommended designing and commissioning rehabilitation services that facilitate access to a single point of contact, including complex case managers. The committee hopes the recommendations will be adopted and appropriate funding provided.
Headway – The Brain Injury Association	Guideline	023	016	As so many effects of brain injury are hidden or invisible, and it can be difficult for survivors to communicate this due to lack of insight, awareness or communication difficulties, we would suggest that for all brain injury survivors, their single point of contact has specialist clinical knowledge of brain injury and of local services for brain injury survivors.	Thank you for your comment. There is a related recommendation to consider whether specialist knowledge is necessary when deciding on the most appropriate single point of contact. Therefore, no change has been made.
Inflammatory Neuropathies UK	Guideline	023	019	May be worth adding if the person has very complex needs, has a complex family life, has environmental considerations, has multiple needs, or if there are additional considerations	Thank you for your comment. Please see our responses to each suggestion below: Person has very complex needs: The committee discussed that people with very complex needs would benefit from the highest-intensity single point of contact and has listed this as a criteria for a complex case manager. Person has a complex family life: This is covered in the bullet point on associated family support needs. Environmental considerations: The committee agree that environmental considerations are important, but that including the term 'environmental factors' would not be useful without listing examples. They have purposefully kept these factors generalisable due to the wide population this guideline convers. However, they believe that environmental factors that would suggest the need for a case worker would be covered under the bullet point on multiple rehabilitation needs that require rehabilitation across

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					multiple services and areas of care. Person has multiple needs: This is covered in the bullet point on multiple rehabilitation needs. Additional considerations: This wording is too vague and could be interpreted in multiple ways, making it unsuitable for national recommendations. Therefore, no changes have been made.
British Association of Brain Injury and Complex Case Management	Guideline	023	019	1.11.5 For those with potential for future EF difficulties (for example children) indicating the need for a CCM rather than a key worker is suggested - as key worker may not be specialist and this cohort of people are at significant risk of being misunderstood, having 'hidden disabilities' and being poor at self-identification of and advocacy for their own needs.	Thank you for your comment. Impaired executive function is also covered in the criteria for complex case manager. The different between the 2 models is how much this impacts their ability to self-manage their condition or navigate rehabilitation services. This would need to be assessed at the time of appointment. Additionally, the single point of contact is not a concrete decision. If a person is originally assigned a key worker and their needs become more severe (either short- or long-term), then a complex case manager can be provided. Therefore, no changes have been made.
Cambridge University Hospital NHS Foundation Trust	Guideline	023	019 - 027	Needs to include: "Consider a key worker if the person has Mental health needs that prevent them from being able to meet their own needs or the parent of the child has mental health needs that prevent them from being able to meet their child's needs"	Thank you for your comment. The committee agree that mental health is an important area to consider when determining what level of single point of contact to assign a person. However, they argue that both the examples that you have provided would be better served by a complex case manager rather than a key worker (which is the recommendation you have referenced). We have now added complex mental health issues to the list of considerations. Parents being unable to meet their child's needs would be covered under the bullet point on people having no-one to advocate for them.
The British Psychological Society	Guideline	023	020	The phrase 'cognitive or executive function' (1.11.5) is confusing/ incorrect. Executive function is an aspect of cognitive functioning.	Thank you for your comment. We have amended the wording of the recommendation to say cognitive function (including executive function).
Royal College of Speech and Language Therapists	Guideline	023	022	RCSLT proposes the following addition to recommendation 1.11.5 "• **impaired communication that impacts on their ability to navigate rehabilitation service**"	Thank you for your comment. We have added communication difficulties as a criteria for considering assigning a key worker or complex case manager, if it impacts their ability to self-manage their condition or navigate rehabilitation services.
Success – Life After Cure Ltd	Guideline	023	025	Rec 1.11.5 Specific Impairments of cognitive or executive function along with multiple health needs and sensory or physical disability affects most [70%] childhood brain tumour survivors and we welcome the recommendation for a keyworker from neurorehabilitation [as opposed to cancer services] should help them navigate this aspect during and beyond the cure itself.	Thank you for your comment. The committee agrees and made recommendations on this.
United Kingdom Acquired Brain Injury Forum	Guideline	023	028	Complex case management provides a tried and tested model which has the potential for use in public health to ensure rehabilitation is bespoke and managed.	Thank you for your comment. The committee agrees and made recommendations on this.

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The Royal Hospital for Neuro-disability	Guideline	023 - 024	001 - 009	Which professional would be the point of contact be and where and who would the complex case manager be? These roles do not really exist at present and there is little capacity in the system for people to adopt them as additional roles.	Thank you for your comment. The definition of a single point of contact is provided in the guideline. The committee acknowledged the potential lack of complex case managers within the NHS and the need for workforce expansion. They also recommended designing and commissioning rehabilitation services that facilitate access to a single point of contact, including complex case managers. The committee hopes the recommendations will be adopted and appropriate funding provided.
Community Case Management Ltd.	Guideline	023 - 024	001 - 009 001	**Assigning a Complex Case Manager** We commend NICE for recognising the role of complex case managers and for identifying clear criteria where their involvement is appropriate. This represents a major step forward for improving the quality and consistency of care for individuals with the most complex neurorehabilitation profiles. **Recommendation:** We recommend: • Including specific references to the role of independent case managers, particularly those working in medico-legal or privately commissioned contexts, where NHS pathways may be limited or fragmented. • Encouraging early referral to case management services during acute care or inpatient rehabilitation, to ensure seamless transition into the community.	Thank you for your comment. We hope that our recommendations on complex case managers can improve the quality and consistency of rehabilitation for chronic neurological disorders as you describe. The committee did not want to list multiple examples of practitioners who could deliver the complex case manager, as this can imply that the list provided is exhaustive. However, they have made several recommendations within the guideline section on designing and commissioning rehabilitation that highlight the need to include the private sector in rehabilitation care pathways in order to best serve people with chronic neurological disorders. The current guidance recommends assigning a single point of contact as part of a person's rehabilitation plan, meaning after a holistic rehabilitation needs assessment has been conducted and their ability to self-manage their care has been ascertained. This may be during inpatient rehabilitation, but not always as people will be presenting to different services and settings within the pathway. However, we do stress throughout the guideline that rehabilitation should be based on symptoms and impairments, rather than diagnosis. This will increase the likelihood of an earlier assessment for the most appropriate single point of contact. Therefore, no changes have been made.
Heads Together	Guideline	024	001	Complex case management provides a model that can be emulated within statutory health and social care settings to ensure rehabilitation is holistic and bespoke and appropriately managed.	Thank you for your comment. The committee agrees and made recommendations on this.

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Royal College of Speech and Language Therapists	Guideline	024	001 - 004	RCSLT proposes that recommendation 1.11.6 explicitly recognises that impaired communication may impact a person's ability to navigate rehabilitation services and ability to advocate for themself.	Thank you for your comment. We have added communication difficulties to the list of characteristics provided to guide the appointment of a key worker or complex case manager.
North Cumbria Integrated Care NHS Foundation Trust	Guideline	024	001 - 009	We would like the committee to consider including complex case manager / Key worker role to be extended supporting family members of the brain injured patient.	Thank you for your comment. The scope of this guideline only covers the rehabilitation needs of people with chronic neurological disorders. While we recognise the significant impact family members of these individuals may face due care needs, it is not possible to make recommendations for this population. Therefore, no change has been made.
Inflammatory Neuropathies UK	Guideline	024	006	Covers some of the above, but could add environment in here, i.e. prison, homelessness, etc	Thank you for your comment. The committee agree that environmental considerations are important when deciding what level of single point of contact a person needs. However, due to the wide population this guideline convers, they have purposefully kept these factors as generalisable as possible. They note that both examples you have provided would be covered under the bullet point on multiple rehabilitation needs that require rehabilitation across multiple services and areas of care. Therefore, no changes have been made.
Success – Life After Cure Ltd	Guideline	024	006	Rec 1.11.6 Serious and multiple comorbidities affect a proportion of childhood brain tumour survivors and we welcome the recommendation to assign complex case managers to those who are now adult with long term rehabilitation needs, as they report to us difficulties in navigating their adult lives long term.	Thank you for your support for this recommendation.
Brainkind	Guideline	024	006 - 009	To facilitate recognition of when a complex case manager would be recommended, consider including a definition of 'neurobehavioural symptoms' in the glossary and explicitly mentioning mental health conditions, psychosis, depression and elevated suicide risk as examples of comorbidities within the recommendation.	Thank you for your comment. NICE will only define terms in the glossary if they are being used in a unique way or if there are a multiple definitions. Neurobehavioural symptoms does not meet either requirement in this guideline, and therefore no change has been made. However, we have amended the criteria of when to consider assigning a complex case manager to include complex mental health needs.
Headway – The Brain Injury Association	Guideline	024	010	It may be helpful to include a recommendation here acknowledging the ongoing rehabilitation needs of many individuals, including brain injury survivors. Rehabilitation is often approached as a process that will have an end point. However, we know that many brain injury survivors, particularly those who attend Headway rehabilitation services in the community, are able to maintain their level of function because they attend Headway services on an ongoing basis. If they do not attend (often due to delays in assessments and/or lack of funding at local level), their level of function and ability can rapidly deteriorate and require much higher level interventions and support. This is particularly relevant to the more 'hidden' impacts of brain injury, such as social skills, emotional wellbeing, memory, behavioural difficulties etc.	Thank you for your comment. The recommendation already considers anticipated rehabilitation needs. The committee believes that practitioners deciding on follow-up will have the necessary expertise to manage specific chronic neurological conditions, including brain injury, and make optimal decision regarding their follow-up.

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University College London Hospital	Guideline	024	011	Without significant resource uplift, GP services will be responsible for all single point contacts and they are already over stretched	Thank you for your comment. The committee recommended commissioning rehabilitation services and service specifications, including access to a single point of contact. The definition of this role is provided and includes various roles. The committee hopes the recommendations will be implemented and appropriately funded to ensure responsibilities are shared.
The Royal Hospital for Neuro-disability	Guideline	024	011	"After the rehabilitation has ended" – there needs to be a clearer description of the start and endpoint (?goal attainment) prior to this statement as the proceeding sections read as if everyone with a chronic condition should have rehabilitation all the time.	Thank you for your comment. This section has been re-drafted following stakeholder comments and no longer includes reference to rehabilitation ending.
Community Case Management Ltd.	Guideline	024	011 - 013	**Continuity After Rehabilitation** We support the recommendation to inform patients of changes to their key contact. However, this section could be strengthened by explicitly noting that case managers often provide long-term continuity across multiple phases of care, including vocational and social reintegration. **Recommendation:** We suggest NICE consider: • Highlighting the importance of not discontinuing case management support prematurely, particularly in cases of cognitive impairment or behavioural risk. • Reinforcing the value of case managers in reducing readmissions and service duplication.	Thank you for your comment. It would be inappropriate to include this information in recommendation. There is additional detail in the guideline's definition to of a complex case manager role that highlights their importance in working across multiple services. Our rationale and supporting discussion in the full evidence review [I] includes the point you make about reducing readmissions and service duplication.
First Community Health and Care	Guideline	024	011 - 014	Rec 1.12.1 - Changing keyworker contradicts the reason keyworkers are put in place. Unless there is some consistency, the role is less effective, more time consuming and reduces continuity of care. Discharging a patient is inevitable and needs to be discussed clearly with the patient. Agree, informing them of who to contact when their condition changes is useful but this may be their GP.	Thank you for your comment. We agree that the single point of contact could be their GP, as defined. However, the committee believes that in some cases, this role could be more effectively fulfilled by a key worker who is familiar with individual needs and best placed to help navigate rehabilitation services.
Heads Together	Guideline	024	015	We would argue that all individuals should receive a follow-up appointment.	Thank you for your comment. The committee agreed that follow-up needs vary by individual, disorder, and rehabilitation needs. Some may not need follow-up until symptoms or impairment levels change. This should be decided individually, with the option to initiate follow-up through their single point of contact.
United Kingdom Acquired Brain Injury Forum	Guideline	024	015	All individuals should receive a follow-up appointment.	Thank you for your comment. The committee agreed that follow-up needs vary by individual, disorder, and rehabilitation needs. Some may not need follow-up until symptoms or impairment levels change. This should be decided individually, with the option to initiate follow-up through their single point of contact.

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University College London Hospital	Guideline	024	016	Treatment escalation plan needs to be discussed early along with consideration about involving palliative care teams.	Thank you for your comment. This recommendation is only concerned with scheduling follow-up appointments. Anticipated rehabilitation needs surrounding deterioration or end-of-life care are mentioned because these are times where more frequent follow-ups may need be needed. Discussions about treatment escalation and palliative care would occur when undertaking a rehabilitation needs assessment and compiling the rehabilitation plan. We already have a recommendation saying that this assessment should be initiated early (as soon as a diagnosis is made or if symptoms dictate). Therefore, no change has been made.
British Association of Prosthetists and Orthotists	Guideline	025	003	Consider inclusion of Allied Health Professional in this list of examples.	Thank you for your comment. Key therapists are already named in this list, which would be an example of an allied health professional. Therefore, no change has been made.
Success – Life After Cure Ltd	Guideline	025	006	Rec 1.12.4 We welcome the follow-up assessments recommended at key neurodevelopmental stages in children, but see challenges in implementing these in children receiving repeated years of cancer chemotherapy for brain tumours, unless there is provision for a parallel recovery pathway in place from brain tumour diagnosis to protect their maturation whilst undergoing prolonged or repeated experimental treatment. As the vast majority [80%] will survive and the intention is to cure, even those 20% with poorer prognoses deserve a quality of life. There is guidance on neurorehabilitation for adults with less curable brain tumours and brain metastases and would ask for equity for the under 16s.	Thank you for your comment. This guideline is designed to cover the lifelong rehabilitation needs of children and adults with brain tumours, and the committee have designed their recommendations to be generalisable across the wide population of people with chronic neurological disorders. However, if you have identified areas where you feel more specific guidance is needed, please complete the online form at https://www.nice.org.uk/forms/topic-suggestion.
Royal College of Speech and Language Therapists	Guideline	025	006	Recommendation 1.12.4 should also include follow-up at key transition points (e.g. moving from primary to secondary school), as referenced in recommendations 1.11.5 and 1.23.24	Thank you for your comment. This recommendation is specifically about how to plan follow-up if aspects of a rehabilitation plan are coming to an end. In this case, the committee feel that neurodevelopmental is the most appropriate consideration, as it will be broader and more inclusive than key transition stages. Therefore, no changes have been made.
University College London Hospital	Guideline	025	009	Funding provision of equipment such as wheelchairs rarely coincides with rehabilitation stays due to lengthy waiting lists in wheelchair services. Financial uplift would be required to meet this aim	Thank you for your comment. The referenced recommendation is referring to what should happen before rehabilitation ends, not necessarily before a hospital discharge. The committee do have a similar recommendation in the hospital discharge section, but were aware that it may not be possible to provide equipment, technology and environmental adaptations before discharge (for example, due to the long wait times you have noted in your comment). Therefore, this recommendation states they should be provided at the earliest opportunity.
The Wolfson Neurorehabilitation Service	Guideline	025	009 - 011	**After the Rehabilitation Plan (Recommendation 1.12.5)** We recommend that this section emphasises the proactive provision of information, equipment, and advice during the active rehabilitation phase, rather than solely at its conclusion. This ensures individuals are better prepared for future changes and can retain essential equipment.	Thank you for your comment. This section was originally about putting plans in place for future needs when an element of the rehabilitation plan comes to an end, which is why it is written as taking place at a conclusion. However, based on stakeholder feedback, we have extensively re-drafted this section to better illustrate the cyclical nature of rehabilitation and

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					reviewing needs. Additionally, we cover proactive provision of information and advice in another guideline section on information, advice and learning as part of rehabilitation. Similarly, proactive provision of equipment is covered throughout the main section on rehabilitation to maintain, improve or support function, depending on what domain of rehabilitation needs addressing.
British Association of Brain Injury and Complex Case Management	Guideline	026	001	1.13 there is no reference to ceasing rehab or guidance on this. Specific identification of those with lifelong needs and how that will be followed up- in particular for those people whose needs are barriers to them initiating further support/assessment/rehab – or these people are at risk of falling fall through service gaps. Serious case reviews in safeguarding identify unmet needs, particularly for ABI when EF/insight/capacity assessment inaccuracies have been factors in avoidable deaths, so rehabilitation – and the cessation of rehab- is an opportunity to highlight needs and make recommendations for how they are to be followed up and supported in the longer term.	Thank you for your comment. The committee have taken the default view that rehabilitation for chronic neurological disorders should be life-long, and kept this in mind when drafting their recommendations. However, they were aware that certain aspects of rehabilitation will inevitably end during this time, and have included guidance on this process within the re-drafted section on agreeing, and delivering and reviewing a coordinated rehabilitation plan. The committee did note that certain populations of people with chronic neurological disorders (including some people with acquired brain injury as you note in your comment) will have trouble re-accessing services due to issues with executive function, insight and capacity. They have included guidance stating that plans for follow-up need to include consideration of who will be initiating follow-up (that is, people with cognitive difficulties would be better placed to have it be practitioner initiated). Additionally, the subsequent section details assigning a single point of contact for people with chronic neurological disorders, where we have recommended considering key workers for people with impaired cognitive or executive function affecting their ability to self-manage. This provision will act as a safety net for the people you are concerns about falling through gaps in services.
The Association of British Neurologists	Guideline	026	001	1.13 - Information, advice and learning. We recommend that clinicians treating patients with functional neurological disorders ensure information provided about the person's condition is diagnosis-affirming and avoids language that might perpetuate symptom-related anxieties or promote disability-related identity.	Thank you for your comment. We have included a recommendation in the information, advice and learning as part of rehabilitation section that details how information and psychoeducation should be tailored for people with functional neurological disorders. Diagnosis acceptance and using language that redirects attention away from symptoms are both covered in this.
Royal College of Speech and Language Therapists	Guideline	026	002	Due to the high prevalence of communication difficulties in this group of patients, recommendation 1.13.1 should specifically say "personalised **and accessible** information"	Thank you for your comment. While the committee acknowledge that there is an increased prevalence of communication difficulties in people with chronic neurological disorders, there is already NICE guidance on the format of information. These recommendations can be found in CG138 (Patient experience in adult NHS services) and NG204 (Babies, children and young people's experience of healthcare), and are clearly referred to at the start of this guideline section. Therefore, no change has been made.
Heads Together	Guideline	026	004	There needs to be greater recognition given to the role of unpaid cares (family members) in supporting needs and ensuring they are included in	Thank you for your comment. The committee were aware of the significant role that unpaid carers play in supporting the rehabilitation needs of people with chronic neurological disorders, which is why the stem of this

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				conversations and planning from an early stage and given appropriate information about rehabilitation.	recommendation includes family and carers alongside the individual. We have also included family and carers as options in recommendations on developing rehabilitation plans and delivering rehabilitation interventions. As we have already appropriately covered the areas of concern you have noted in your comment, no change has been made.
University College London Hospital	Guideline	026	007	Very few areas have work resources from a rehabilitation perspective and long waiting lists often make the services available unresponsive and unhelpful. This would require significant financial uplift to achieve.	Thank you for your comment. This section is specifically about providing information about how to get advice for work. There is a separate guideline section on delivering rehabilitation to support work. The committee has considered the resource impact of all the recommendations in this section and do not anticipate a significant resource impact. This is explained in the accompanying 'How the recommendations might affect practice' paragraphs, linked at the bottom of each sub-section. Full details of the committee's discussion of the resource impact can be found in 'The committee's discussion and interpretation of the evidence' section of evidence review K.
Independent Neurorehabilitation Providers Alliance	Guideline	026	009	We agree but there is currently limited knowledge within areas of what is available locally or nationally. We would suggest building a database but creating and maintaining it will require some resources in terms of workforce.	Thank you for your comment. It is beyond the scope of this guideline to comment on the implementation of these recommendations, as it will need to be tailored to the needs of a local population and rehabilitation service structure. However, the committee did not envision the need for a national database and believe this can be achieved at a local level. They also argue that recommending provision of tailored information simply reinforces good practice, as most services already offer such information tailored to individual needs. Additional resources (for example, staff time to develop or collate relevant resources) will only be needed where this is not currently done.
University College London Hospital	Guideline	026	014	1.13.1 Give personalised information to people with a chronic neurological disorder, and their family or carers, if appropriate, about: please consider including lasting power of attorney or guardianship discussions.	Thank you for your comment. Lasting power of attorney or guardianship is already covered in the bullet point on advice about legal support. Therefore, no change has been made.
The Wolfson Neurorehabilitation Service	Guideline	026 - 027	General	Information, Advice and Learning as Part of Rehabilitation (Recommendations 1.13.1 - 1.13.6) Whilst not explicitly commented upon by the team, we suggest reinforcing this section to highlight the critical importance of providing comprehensive, personalised, and accessible information throughout the rehabilitation journey. This should encompass financial support, navigation of services, and advocacy, recognising these as fundamental to patient empowerment and engagement.	Thank you for your comment. The committee believe that this section already covers the area you have highlighted. We have recommended giving personalised advice on a wide variety of topics, including how to access rehabilitation services and social care, and financial support. Acknowledgement of voluntary and community organisations that can provide further support and information is also made. Finally, we have recommended that this is an ongoing process to cover when rehabilitation needs or circumstances change. While your final point about these being fundamental to patient empowerment and engagement is more detail than we add to recommendations, the committee continually stressed the importance of personalised information during their discussion of the

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					evidence, an account of which can be found in evidence review B. Therefore, no change has been made.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	026 - 027	General	We believe that a national resource needs to be developed to enable this to happen across country, particularly in relation to how often there are changes and updates to the services provided within the voluntary and community organisations.	Thank you for your comment. It is beyond the scope of this guideline to comment on the implementation of these recommendations, as it will need to be tailored to the needs of a local population and rehabilitation service structure. However, the committee did not envision the need for a national database and believe this can be achieved at a local level. They also argue that recommending provision of tailored information simply reinforces good practice, as most services already offer such information tailored to individual needs. Additional resources (for example, staff time to develop or collate relevant resources) will only be needed where this is not currently done.
Brain Injury Social Work Group	Guideline	026 - 027	General	Information, Advice and Advocacy (pp. 26–27, Section 1.13) We support the emphasis on personalised information and advice, particularly in relation to education, housing, benefits and legal rights. Social workers often act as the bridge between clinical services and wider social care or community supports. The guidance could usefully signpost to statutory advocacy rights under the Care Act and Mental Capacity Act, and encourage local authorities to ensure that advocacy is sufficiently available to support people through rehabilitation and care planning processes including POA.	Thank you for your comment. We have made a recommendation in the previous section on the holistic rehabilitation needs assessment that states people with chronic neurological disorders should be supported to make health and social care decisions, and this may include formally appointed advocates. Additional NICE guidance on advocacy has already been published, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws), NG108 Decision-making and mental capacity, NG227 Advocacy services for adults with health and social care needs, and NG204 Babies, children and young people's experience of healthcare. References to these documents have been made at the beginning of the guideline. Therefore, no change has been made.
Inflammatory Neuropathies UK	Guideline	027	001	As can a carer through a carers assessment	Thank you for your comment. Unfortunately, recommendations for carers of people with chronic neurological disorders are out of scope for this guideline. However, carers assessments are covered in NG150 Supporting adult carers, which has been clearly referenced at the beginning of this section. Therefore, no change has been made in light of your comment.
The Royal Hospital for Neuro-disability	Guideline	027	014	What is a "disability passport"?	Thank you for your comment. A disability passport allows individuals with long term health conditions and disabilities to record their health conditions and the support they need, to that this can be shared with others. It is carried by the person and can be used in the workplace, education settings and when accessing any other service. It helps to explain the necessary adjustments and accommodations required by the person in order to access or participate. We have added 'health or' to the recommendation as these are sometimes called 'health passports'

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Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	027	017	Consider adding as a fourth bullet point after line 17 'Information to share with their workplace or educational establishment'	Thank you for your comment. This has been covered in subsequent sections on rehabilitation to support education for children and young people and rehabilitation and the workplace. Therefore, no change has been made.
University College London Hospital	Guideline	028	003	The guideline should add that pain assessment should consider if any pain is driven by the primary progressive neurological condition or secondary complications. MSK complications are common in this group and should not be excluded from normal MSK pain pathways as frequently happens.	Thank you for your comment. We recognise that the cause of pain is important and there may be different aetiologies, therefore we have added that the cause of pain is important to consider to the pain management section where the rehabilitation goals and plans are being discussed.
The Royal Hospital for Neuro-disability	Guideline	028	General	For all of these individual dimensions, there is a need to quantify the issue that is being treated / addressed in order to establish and monitor response. It would require the use of some sort of repeatable scale / measure appropriate to the individual.	Thank you for your comment. We agree with your comment and it is implicit that interventions are delivered in this way. However, pain assessment is beyond the scope of the guideline so without having conducted any systematic reviews of the evidence in this area, it is not possible to make recommendations about the use of scales. However, we would expect that an evaluation of baseline and future pain would be an implied element of the kinds of discussions described in the pain management section. Therefore, no change has been made.
The Wolfson Neurorehabilitation Service	Guideline	028 - 029	General	**Pain Management (1.14.1)** We recommend explicitly addressing the impact of pain on parenting capabilities and the needs of children whose caregivers have neurological conditions, including safeguarding aspects.	Thank you for your comment. We agree that it's important to address the impact of the various impairments (including pain) in chronic neurological disorders on parenting capabilities. In the family life and friendship section of the guideline, there is a recommendation to provide targeted rehabilitation interventions, for example, to address specific impairments that impact on how they can, or whether they can, care for another person. Therefore, no changes have been made.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	028 - 029	General	We would recommend greater clarity about pharmacological and non-pharmacological options for management of pain, linking with and consistent with other pain clinical guidelines (e.g. the NICE's guideline on chronic pain (primary and secondary) in over 16s: 14 assessment of all chronic pain and management of chronic primary pain). This guidance mentions some but not all e.g. pain education, acupuncture are missing from this guideline as it stands	Thank you for your comment. We have cross-referred to the NICE guideline on chronic pain in over 16's: assessment of all chronic pain and management of chronic primary pain and the NICE guideline on neuropathic pain in adults: pharmacological management in non-specialist settings. Pain education and acupuncture are both covered in the NICE guideline on chronic pain in over 16's: assessment of all chronic pain and management of chronic primary pain which we cross refer to.
Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Guideline	028 – 029	General	On pages 28-29 it refers to NICE Guideline NG 193 and NICE Neuropathic guidelines in non-specialist setting CG173. Overall there is little mention of pain clinic input for complex pain issues in this patient population. They may have post stroke pain or post traumatic pain issues in spine of skull. A wide range of complex pain issues may (will) be present. FPM would recommend these guidelines draw attention to utility of specialist or local pain clinic input for such wide-ranging pain issues and	Thank you for your comment. The committee agreed with your comment and have added a new recommendation in the pain management section of the guideline to consider referral to a pain specialist where there is difficulty in identifying the causes of pain or for advice on a biopsychosocial approach to pain management.

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				sign posting as appropriate or at least initially make a proper pain diagnosis. The holistic pain management (as mentioned in the very beginning in pain section) is great but should include significant biological element in our view. It depends how much this section can be expanded, but FPM prefer this to be significantly expanded to cover the points highlighted.	
The Association of British Neurologists	Guideline	029	001	1.14.2 "Proactively support people in managing their pain and ensure that they have adequate analgesia to facilitate rehabilitation" Medication/analgesic overuse/polypharmacy is a common and problematic complication for many patients with chronic pain and functional neurological disorder – we therefore recommend you insert "where appropriate" before recommending analgesia (pain management techniques are often more appropriate), and state the potential iatrogenic harm of polypharmacy.	Thank you for your comment. We have added "if appropriate" to the recommendation. We have also added details about the potential iatrogenic harm of polypharmacy to the committees' discussion of evidence in evidence review J.
Parkinson's UK	Guideline	029	001 - 013	There is an assumption here that pain is of a secondary nature (e.g. post injury or due to rigidity as associated with Parkinson's), so it can therefore be alleviated by analgesia. People with Parkinson's have complex pain issues because of altered sensory integration and often have poorly explained pain of central origin (e.g. akathisia, restless leg syndrome, dystonic pain). Additional advice needs to be added to 1.14.3 about the variability of the needs of different conditions, such as Parkinson's.	Thank you for your comment. The committee recognise that pain can be complex and have various aetiologies, in view of this a new recommendation was made to consider referral to a pain specialist where there is difficulty in identifying the causes of pain or for advice on a biopsychosocial approach to pain management.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	029	003	Interventions for spasticity may reduce pain. Please include spasticity management approaches to the list.	Thank you for your comment. The committee agreed that spasticity can cause pain and included interventions for stability, mobility and limb function (including muscle tone and postural management strategies) as interventions to reduce pain or improve pain management. Furthermore, the committee agreed to make a new recommendation to consider referral to a pain specialist where there is difficulty in identifying the causes of pain or for advice on a biopsychosocial approach to pain management
South London and Maudsley NHS Foundation Trust	Guideline	029	003	Rec – 1.14.3 – Alongside psychological interventions for low mood and anxiety in the context of chronic pain we would suggest a recommendation for pharmacological intervention for depression and anxiety in the context of pain where appropriate.	Thank you for your comment. Pharmacological interventions for depression and anxiety are outside the scope of the guideline. Pharmacological interventions for depression and anxiety are covered in other NICE guidelines and are cross-referenced.
British Society of Physical and Rehabilitation Medicine	Guideline	029	003	Interventions for spasticity may reduce pain. Please include spasticity management approaches to the list. Also add pharmacological agents and injection techniques such as nerve blocks to reduce pain in these patients.	Thank you for your comment. The committee agreed that spasticity can cause pain and included interventions for stability, mobility and limb function (including muscle tone and postural management strategies) as interventions to reduce pain or improve pain management. Furthermore, the committee agreed to make a new recommendation to consider referral to a pain specialist where there is difficulty in identifying the causes of pain

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					or for advice on a biopsychosocial approach to pain management. Pharmacological agents are outside the scope of the guideline, therefore no recommendations were made on these.
British Association of Prosthetists and Orthotists	Guideline	029	008	We feel that it is important to mention orthoses here, as a key interventional choice for stability/mobility/limb function.	Thank you for your comment. As you mention, orthoses are a standard intervention for stability, mobility and limb rehabilitation. Therefore, the committee believe it is implicit in the current wording and no change has been made.
Inflammatory Neuropathies UK	Guideline	030	002	Need to add to this section to consider how fatigue can fluctuate due to a range of variables dependent on the condition and other factors	Thank you for your comment. In the committee's discussion of evidence section in evidence review J on fatigue management, the committee emphasised that fatigue is not static and can fluctuate for a person with CND. The recommendations also makes reference to fluctuation in 'when the person is feeling at both their best and worst'.
Shaftesbury Icanho	Guideline	030	005	1.15.2 – Consider whether use of a recognised fatigue scale, such as Fatigue Severity Scale or Modified Fatigue Impact Scale, may assist clinicians to find out the impact of specific activities on fatigue in daily living?	Thank you for your comment. In the committee's discussion of evidence section in evidence review J on fatigue management, the committee highlighted that scales to measure fatigue do not always reflect the lived experience, often underestimating the impact of fatigue in people with CND. In view of this, the committee preferred not to name a specific fatigue scale when assessing the impact of specific activities on fatigue in daily living.
Defence Medical Rehabilitation Centre	Guideline	030	005	We recommend this specifically references Occupational Therapy involvement.	Thank you for your comment in light of which we have added to the recommendation on checking for treatable factors for fatigue, which now also states 'seek specialist advice if needed'.
The Wolfson Neurorehabilitation Service	Guideline	030	010 - 011	Fatigue (1.15.4): We suggest revising the recommendation to explicitly state that fatigue can affect mood, and that basic education on the causes of fatigue should be provided.	Thank you for your comment. We have added a new recommendation at the start of the intervention section to address your comment - "Explain to the person how and why their condition or injury may cause fatigue, the factors that can influence fatigue and how fatigue can fluctuate and impact their daily life, including their mood."
North Cumbria Integrated Care NHS Foundation Trust	Guideline	030	010 - 011	There is much more a wider group of people to whom education need to be provide to raise awareness on impact of fatigue; example employer, student support services, etc.	Thank you for your comment. We agree with the importance of sharing and raising awareness of the impact of the different impairments, including fatigue in chronic neurological disorders on the person's day to day activities. In the agreeing and delivering a coordinated rehabilitation plan section of the guideline, there is a recommendation stating that based on the person's holistic rehabilitation needs assessment and their goals, agree a personalised rehabilitation plan (based on interventions in sections on rehabilitation to maintain, improve or support function and support education, work, social and leisure activities, and relationships) with the person, those people important to their rehabilitation and the health and mental health care and social care practitioners involved in their assessment or care. Furthermore, another recommendation in the agreeing and delivering a coordinated rehabilitation plan section states that if the person is in work, education or training, collaborate with their employer, education setting or adult learning support centre to agree and deliver

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					rehabilitation interventions that are relevant to the tasks and activities the person will be undertaking. Therefore, no changes were made.
University College London Hospital	Guideline	030	012	1.15.5 Check for treatable factors: include assessing for hearing problems.	Thank you for your comment. We recognise that there are additional treatable factors for fatigue such as hearing problems. Therefore we have added "vestibular and sensory symptoms" to the recommendation to cover the wide range of impairments.
Success – Life After Cure Ltd	Guideline	030	013	Rec 1.15.5 We welcome the recommendation to check for treatable factors that may be causing fatigue including under-recognised sleep disorders. However we foresee a challenge in implementing the necessary cross-referral pathways for treatment if awareness of such disorders and the physicians [neuropsychiatrists and neurorehabilitation specialists] who might prescribe such medication are only in highly specialist centres and difficult to access if patients are deemed not to meet criteria for referral in interdisciplinary care that is not streamlined.	Thank you for your comment. We understand your concerns and have added "seek specialist advice, if needed" to the recommendation if the necessary specialism isn't available at the centre where the person with CND is being treated.
Recolo UK	Guideline	030	013	In the context of the possible impact of neurological conditions on sleep-wake cycle / disruption, a general comment about fatigue management is that from our knowledge and experience it is helpful to include a good assessment of sleep and rest as part of the fatigue management assessment and to support and inform the fatigue management guidelines. We think it could be helpful to emphasise the value of an assessment of sleep to inform sleep hygiene / management as part of fatigue management.	Thank you for your comment. The committee recognise that sleep-wake disruption may affect fatigue and therefore had made a recommendation about checking for treatable factors for fatigue using sleep problems as an example and to seek specialist advice if needed. Furthermore, there is reference to sleep-wake disruption in the committee's discussion of the evidence in evidence review J. Nothing further was added in light of your comment.
Central London and Community Healthcare Trust	Guideline	030	013 - 014	1.15.5 A concern here is that non-medical community rehabilitation professionals would be unable to check for abnormal endocrine function and may not be able to explain what would need to be tested and why for people with fatigue, therefore it may be important to include recommendations on how best to manage this. An implication of guidance on these biological factors is that this may be a training gap that needs to be considered for non-medical rehabilitation professionals and will as a result have a funding implication for staff training.	Thank you for your comment. We understand your concerns and have added "seek specialist advice, if needed" to the recommendation if the necessary specialism isn't available at the centre where the person with CND is being treated.
Central London and Community Healthcare Trust	Guideline	030	015	*1.15.5* Consideration should be given to the ability to assess vestibular symptoms and would vary amongst professional groups and between non-specialist and specialist rehabilitation services. Consideration should also be given to the fact that referral pathways for vestibular symptoms will significantly vary area to area.	Thank you for your comment. The scope of the guideline did not cover interventions to support visual or hearing impairment, but we have included in the guideline that the impact of these on rehabilitation would still need to be covered in assessment.

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Consultation on draft guideline - Stakeholder comments table
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Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	030	017	Interventions should be offered in context for the CYP e.g. in school/nursery/college environment and may need to be structured and implemented by the education support staff	Thank you for your comment. The environment for the delivery of fatigue management interventions was out of scope of evidence review J. No evidence was identified for interventions to treat fatigue in CYP in evidence review J, therefore a research recommendation was made. In relation to the delivery of interventions for CYP, recommendations in the section on rehabilitation to support education for children and young people already address your concerns across all interventions not only fatigue.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	030	019	For CYP, it would be important to include practical interventions such as adjustments to school timetables / length of school day, and curriculum planning here. It would also be helpful to note that interventions should be delivered in a person's context – i.e. home and work/school as evidence supports ecological / context-sensitive rehabilitation (e.g. Braga, 2005; Ylvisaker, 2003)	Thank you for your comment. The environment for the delivery of fatigue management interventions was not included within the protocol of evidence review J. No evidence was identified for interventions to treat fatigue in CYP in evidence review J, therefore a research recommendation was made. In relation to the delivery of interventions for CYP, recommendations under the section about rehabilitation to support education for children and young people address your concerns across all interventions, not only fatigue.
Defence Medical Rehabilitation Centre	Guideline	030	020	We recommend firstly providing education on why the diagnosis could cause fatigue and interacting factors that can influence fatigue; and subsequently how fatigue can impact on daily life.	Thank you for your comment. We have added a new recommendation at the start of the intervention section to address your comment - "Explain to the person how and why their condition or injury may cause fatigue, the factors that can influence fatigue and how fatigue can fluctuate and impact their daily life, including their mood."
Shaftesbury Icanho	Guideline	030	021	1.15.6 – Agree that Cognitive Behavioural Therapy is a recognised modality that very much can be included as part of a rehabilitation approach; however, at the same time recognising that this resource may be limited within teams as delivery requires a suitably qualified clinician to design or deliver treatment.	Thank you for your comment. The committee was aware of this and made recommendations to build local capacity and expertise, particularly in mental health services. They also suggested a range of interventions to support fatigue management, with CBT being just one option. The committee hopes their recommendations will be adopted and appropriately funded. We will also share your comment with our implementation team.
Defence Medical Rehabilitation Centre	Guideline	030	021	CBT – other psychological approaches should be referenced e.g. ACT.	Thank you for your comment. The psychological approaches listed in the recommendations were included as they were identified by evidence review J. No evidence on ACT was identified for fatigue in evidence review J, however the committee agreed that it is widely used in practice. We recognise that there may be other techniques and the stem of the recommendation accounts for this by using "could" meaning this is not a definitive list of techniques for fatigue management.
Central London and Community Healthcare Trust	Guideline	030	021	1.16.5. It could be useful here to provide clarification in this section as to whether it is CBT specific to fatigue, or CBT for other conditions e.g. depression, low mood. As we know the latter contribute to the individual experience of fatigue for a person living with a neurological condition. It is positive that the evidence review indicates that CBT based approaches for fatigue are being included and recommended. An additional benefit to this is that such interventions can be delivered by a range of health professionals, however it is important to note that again	Thank you for your comment. The reference to CBT in the recommendation was pertaining to encouraging lifelong behaviour change around physical activity, as indicated in the stem of the recommendation. The CBT element of the recommendation is based on evidence supporting CBT techniques incorporated into exercise programmes to encourage physical activity in evidence review O. We appreciate that that there be fewer professionals to deliver CBT in non-specialist settings compared to specialist settings, publication of the guideline should ensure that people with CND can still

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				across services there may be fewer professionals in non-specialist rehabilitation services confident to deliver CBT based approaches than there would be in specialist services. Research relevant to the developing evidence base to consider include an RCT running funded via NIHR which has implications for roll out in NHS services for MS Fatigue specifically (combination of behavioural approaches to MS fatigue including CBT and exercise delivered digitally), but not due to complete until 2028. National Institute of Health Research (NIHR) 2022 Developing, optimising and implementing a blended digital self-management treatment for fatigue in multiple sclerosis (REFUEL-MS). NIHR funding award ID NIHR203290 available at: https://fundingawards.nihr.ac.uk	access CBT in different settings. We look forward to the publication of the REFUEL-MS study.
Defence Medical Rehabilitation Centre	Guideline	030	024	Consider including an additional point: Consider implementation of fatigue strategies and evaluate their effectiveness with the patient to grade and refine as needed.	Thank you for your comment. The point that you highlighted in your comment was already captured in the draft recommendations on fatigue and these still stand in the final guideline.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	030 - 031	General	These sections refer to CBT and behaviour change strategies in the context of fatigue management and physical activity promotion, respectively. These sections risk blurring the lines between psychological and physical health professionals, as they do not clearly specify who should be delivering CBT. Examples of this: • "Offer a fatigue management approach… This could include: … cognitive behavioural therapy…" [Page 31, Section 1.15.6] • "Consider the following approaches to encourage lifelong behaviour change around physical activity: • cognitive behavioural therapy…" [Page 32, Section 1.16.4] The guideline should clarify that CBT, mindfulness-based talking therapies, and other psychotherapeutic interventions should only be delivered by trained psychological professionals. This is essential to maintain safety, treatment fidelity, and professional boundaries. This still prompted IDT working, while ensuring that each professions contribution is maximised.	Thank you for your comment. We agree that the person delivering CBT and behaviour change strategies should have the necessary training and expertise to deliver those strategies. In response to your comment, we have made edits to existing recommendations and added in recommendations to emphasise the skillset and expertise the people delivering the interventions should have. In the emotional health and wellbeing section of the guideline we have edited a recommendation emphasising that a registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse), and an understanding of the person and the effects of their condition or injury, should develop and oversee the emotional health and wellbeing element of the person's rehabilitation plan. Furthermore, in the physical activity and exercise section of the guideline, we have added a recommendation stating that a registered practitioner with expertise in exercise programmes and physical health (for example, a physiotherapist or occupational therapist), and an understanding of the person and the effects of their condition or injury, should develop and oversee the exercise and physical activity programme.
EMDR UK	Guideline	030 - 32	General	We would recommend that Eye Movement Desensitisation and Reprocessing (EMDR) be added to the list to enable lifelong behaviour change around physical activity as there is research evidence to support behaviour change post trauma recovery.	Thank you for your comment. No evidence was identified for EMDR in evidence review O, therefore EMDR was not included in the recommendations referenced in the comment. The interventions included in the recommendation on life long behaviour change around physical activity are included as evidence was identified in evidence review O to support their use.
The Association of British Neurologists	Guideline	031	001	1.16 - Where symptoms are functional in origin, consider a graded approach to exercise, using principles from functional neurological	Thank you for your comment. The committee agree and have added a new recommendation in the physical activity and exercise section of the

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				disorders-focused physiotherapy such as redirecting attention, goal-oriented movement, and avoiding reinforcement of symptoms	guideline, stating for people with a functional neurological disorder use activities that encourage and enable recovery of movement and function. These should: • focus on planned and purposeful movement to achieve a specific outcome (goal-oriented movement) • acknowledge the presence and impact of symptoms whilst redirecting attention away from them • focus on the potential for recovery.
Cumbria Northumberland Tyne and Wear NHS Trust	Guideline	031	001	In section 1.16 Physical activity and exercise reference is made to guidelines for MND, Parkinson's disease and MS. Could the: Rehabilitation after traumatic injury, NICE guideline, Reference number:NG211, Published: 18 January 2022 https://www.nice.org.uk/guidance/ng211/chapter/recommendations#physical-rehabilitation also be referenced	Thank you for your comment. We have referenced the NICE guideline on rehabilitation after traumatic injury in the section at the start of physical activity and exercise.
University College London Hospital	Guideline	031	002	'Develop an exercise and physical activity programme with the person to optimise their muscle strength and physical functioning' Again it would be better to be more specific to be useful- mention Exercise on prescription and Social prescribing for classes in their area.	Thank you for your comment. While the committee acknowledge that exercise on prescription and social prescribing are valuable ways of increasing exercise and physical activity, they are not the only way to deliver this recommendation. Therefore, no change has been made.
University College London Hospital	Guideline	031	002	Should this specifically say "developed by a physiotherapist or exercise prescriber"	Thank you for your comment. We have added a new recommendation to this section to specify that a person's exercise and physical activity programme should be overseen by a registered practitioner. This professional should have exercise and physical health expertise, as well knowledge of the effects of the relevant chronic neurological disorder.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	031	002 - 009	We recommend including cardio-respiratory/ cardio-metabolic health and WHO exercise guidelines	Thank you for your comment. NICE can only cross-refer to other guidance in 2 cases. Firstly, if there are already published NICE recommendations on a subject. Secondly, by stating, a priori, that guidelines would be an accepted evidence source in a systematic review. In this case, relevant guidelines would be included and subject to critical appraisal and then considered by the committee as a basis for recommendations. They could also cross refer to the included guideline. As the cardio-respiratory/ cardio-metabolic health and WHO exercise guidelines did not meet our review protocol criteria (because guidelines were not stated as a type of study to be included), they cannot be referenced in the guideline.
University College London Hospital	Guideline	031	007	Suggest include online resources e.g. short exercise clips to get people more physically active.	Thank you for your comment. We have added online resources as an example of an unsupervised exercise programme in the referenced recommendation.

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Midlands and South Essex ICB	Guideline	031	007	Consider addition of recommendation to access local authority subsidised exercise programmes (e.g. sports for confidence).	Thank you for your comment. We have added local subsidised programmes as an example of an exercise programme in the referenced recommendation.
Inflammatory Neuropathies UK	Guideline	031	008	Highlighting this as an excellent point that is really important to individuals	Thank you for your support for this recommendation.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	031	Exercise	There is a scarcity of community therapy to support patients to exercise while they are being seen by the service but unless patients have supportive families it is incredibly difficult to find sustainable exercise solutions for those needing supervision, prompts or physical assistance to participate in the long-term. Barriers tend to be resource and finance based.	Thank you for your comment. The committee agreed and noted potential resource implications. They made several recommendations on service design to improve efficiency and free up resources and funds, which could be used, for example, to support better access to behaviour change interventions. The committee discussed that these often involve simple activities like walking, yoga or using existing self-help resources. The committee also believed any additional costs would likely be offset by improved health outcomes, such as reduced fatigue and better cardiovascular, physical and mental health due to increased physical activity. They hope their recommendations will be adopted and funded accordingly. We will also pass your comment to our implementation team.
The Royal Hospital for Neuro-disability	Guideline	031	General	The domains of "physical activity and exercise" is not consistent with the previous impairments/conditions (pain/fatigue) – does this chapter need to be organised differently as these are completely different dimensions	Thank you for your comment. The committee are happy that this section is organised logically and therefore made no changes.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	031 - 032	General	There is a lack of representation for facial weakness that requires rehabilitation which should be included	Thank you for your comment. We have now amended recommendations in the eating, drinking and swallowing section. The committee are happy that these changes adequately cover your concern.
Parkinson's UK	Guideline	031 - 032	General	It is not clear whose role it is to develop a programme of physical activity and exercise with the person. Usually, a Consultant or Nurse Specialist will refer people with long-term neurological conditions to exercise professionals, who rarely have the expertise of the dosage of exercise necessary, as they have their own knowledge base and expertise. We recommend that NICE specify which professionals they recommend to develop a programme of physical activity and exercise with the person, and that those professionals should have condition-specific expertise.	Thank you for your comment, in response to which we have added a recommendation. The recommendation is for a registered practitioner with expertise in exercise programmes and physical health (for example, a physiotherapist or occupational therapist), and an understanding of the person and the effects of their condition or injury, should develop and oversee the exercise and physical activity programme.
The Royal Hospital for Neuro-disability	Guideline	032	001 - 004	It's very difficult for a generalist (or a non-psychologist) to understand how these 4 approaches would or could be used in the real world.	Thank you for your comment. We understand your concern and in response to your comment we have made edits to existing recommendations and added in recommendations to emphasise the skillset and expertise the people delivering the interventions should have. In the emotional health and wellbeing section of the guideline we have edited a recommendation emphasising that a registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse), and an understanding of the person and the effects of their condition or injury, should develop and oversee the emotional health and wellbeing element of the person's

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					rehabilitation plan. Furthermore, in the physical activity and exercise section of the guideline, we have added a recommendation stating that a registered practitioner with expertise in exercise programmes and physical health (for example, a physiotherapist or occupational therapist), and an understanding of the person and the effects of their condition or injury, should develop and oversee the exercise and physical activity programme.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	032	005	Our PPIE meetings on exercise revealed that lack of knowledge about neurological conditions among physical trainers\exercises trainers is a barrier. Please include this. The rehabilitation team should offer to discuss with the providers of physical activity about the neurological condition and safety of the exercises.	Thank you for your comment. We have not added lack of knowledge of neurological conditions among physical and exercise trainers. Instead, we have added a new recommendation to this section to specify that a person's exercise and physical activity programme should be overseen by a registered practitioner. This professional should have exercise and physical health expertise, as well knowledge of the effects of the relevant chronic neurological disorder.
British Society of Physical and Rehabilitation Medicine	Guideline	032	005	Our PPIE meetings on exercise revealed that lack of knowledge about neurological conditions among physical trainers\exercises trainers is a barrier. Please include this. The rehabilitation team should offer to discuss with the providers of physical activity about the neurological condition and safety of the exercises.	Thank you for your comment. We have not added lack of knowledge of neurological conditions among physical and exercise trainers. Instead, we have added a new recommendation to this section to specify that a person's exercise and physical activity programme should be overseen by a registered practitioner. This professional should have exercise and physical health expertise, as well knowledge of the effects of the relevant chronic neurological disorder.
Inflammatory Neuropathies UK	Guideline	032	008	Or social	Thank you for your comment. We have added social factors alongside cultural and socioeconomic factors to the recommendation.
The Association of British Neurologists	Guideline	032	011	1.17 "Stability, mobility and limb function" - this section is very physio-focused but doesn't acknowledge the evidence-based approaches used for functional neurological disorders-focused physio, which are different to those used in other conditions. For example, in people with functional motor disorders, physiotherapy should focus on movement retraining using principles of automaticity, redirection of attention, and positively framed explanations of reversibility, rather than impairment-based protocols. We recommend that (a) functional neurological disorders-specific techniques are specified as being needed, and (b) that the recommendations in the international consensus guidelines for physiotherapy in functional neurological disorders are cited (functional neurological disordershope.org/functional neurological disorders-guide/treatment/physiophysical-therapy/). Please consider also: 1.Gelauff JM, Dreissen YE, Tijssen MA, Stone J. Treatment of Functional Motor Disorders. Current treatment options in neurology 2014b; 16: 1-15. 2. Nielsen G, Stone J, Edwards MJ. Physiotherapy for functional (psychogenic) motor symptoms: A systematic review. Journal of psychosomatic research 2013; 75: 93-102.	Thank you for your comment. The committee agree and have added a new recommendation in the physical activity and exercise section of the guideline, stating for people with a functional neurological disorder use activities that encourage and enable recovery of movement and function. These should: • focus on planned and purposeful movement to achieve a specific outcome (goal-oriented movement) • acknowledge the presence and impact of symptoms whilst redirecting attention away from them • focus on the potential for recovery. In terms of the evidence you mention, the physio4FMD trial (Nielsen 2024) has now been included in the guideline, in evidence review O. However note that outcomes on anxiety and depression that were listed in the protocol, measured using SF-36 were not extracted as no overall score was provided, only sub-domain categories. The other references mentioned in the comment didn't meet the inclusion criteria for the guideline: Czarnecki et al (2011) and Edwards et al (2012) were both published prior to 2013

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				3. Czarnecki K, et al., Functional movement disorders: Successful treatment with a physical therapy rehabilitation protocol, Parkinsonism and Related Disorders (2011), doi:10.1016/j.parkreldis.2011.10.011 4. Edwards MJ, Stone J, Nielsen G. J Neurol Neurosurg Psychiatry (2012). doi:10.1136/jnnp-2011-302147 5. The main results of Physio4FMD (clinical outcomes) Specialist physiotherapy for functional motor disorder in England and Scotland (Physio4FMD): a pragmatic, multicentre, phase 3 randomised controlled trial. Lancet Neurology, 2024 https://www.sciencedirect.com/science/article/pii/S1474442224001352	Gelauff et al (2014) was a narrative review, not a systematic review Nielsen et al (2013) included studies published prior to 2013.
British Society of Physical and Rehabilitation Medicine	Guideline	032	011	Topics/ sections (and evidence summary) to be added in this section on following crucial topics • Management of neurogenic bladder • Management of neurogenic bowel Medical and surgical interventions such as botulinum toxin injections, medical management of spasticity, pain, depression and contracture surgery.	Thank you for your comment. As there is already NICE guidance on bladder and bowel management (CG49 Faecal incontinence in adults: management and CG148 Urinary incontinence in neurological disease: assessment and management), these areas are out of scope for this guideline. However, the guideline committee agree that bladder and bowel function is important in this population and have now included a cross-reference to CG49 and CG148 at the beginning of the section on independent living, equipment and environmental adaptations for further NICE recommendations on management of bladder and bowel dysfunction. Medical management of any condition or symptom is similarly out of scope, although we have made several non-pharmacological recommendations covering pain and emotional health in people with chronic neurological disorders. Therefore, no changes have been made in light of your suggestion.
Anglia Ruskin University	Guideline	032	017	A Cochrane Review recommended Rhythmic Auditory Stimulation (a Neurologic Music Therapy Technique) for gait training in acquired brain injury. This suggests that music therapy should be recommended for gait training here. Here is the Cochrane Review: Bradt J, Dileo C, Myers-Coffman K, Biondo J. Music interventions for improving psychological and physical outcomes in people with cancer. Cochrane Database of Systematic Reviews 2021, Issue 10. Art. No.: CD006911. DOI: 10.1002/14651858.CD006911.pub4. Accessed 24 April 2025.	Thank you for your comment. The paper you have cited is not applicable to this guideline population as it describes participants as people diagnosed with any type of cancer, with only 2 of the included studies involving people with brain tumours (and even then, as part of a mixed population). In addition, the paper is focussed on music therapy, which was not included as an intervention for the evidence review underpinning this recommendation (review E). Music therapy was however included as an intervention category in review H, about interventions to improve emotional health and wellbeing. On the basis of the evidence located in the review and informed by their own experiential knowledge, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult and they reflected this in a recommendation.

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Sheffield Teaching Hospital NHS Foundation Trust	Guideline	032	General	Medical and surgical interventions will help with these issues. We need to include medical and surgical interventions such as botulinum toxin injections, medical management of spasticity, pain, depression and contracture surgery.	Thank you for your comment. This guideline did not cover surgical and medical interventions. Therefore, no changes have been made.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	032	General	Resources such as robotics, body-weight support treadmill training, hydrotherapy are almost exclusively available only for patients in the private sector. This should be the gold standard of rehab but it significant investment in NHS rehab services would be required to support this.	Thank you for your comment. The committee have already acknowledged that robotics, body-weight supported treadmill training, and hydrotherapy are not universally available and would require considerable funding for every service to implement. In order to mitigate this, robotics and hydrotherapy are caveated with 'where available'. Similarly, body-weight supported treadmill training is given as an example for gait training instead of specifying it alone. Finally, the stem of this recommendation begins 'consider', meaning that services do not have to offer every intervention on this list if there is a reason not to. Therefore, no change has been made. For further details on the committee's discussion of the resource impact of this recommendation, please see the 'The committee's discussion of the evidence' in evidence review E.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	032 - 033	General	This section frequently mentions appendicular (limb) rehab but little about axial (spinal/core) rehabilitation which we believe should be addressed.	Thank you for your comment. The guideline section you are referring to makes continued reference to rehabilitation exercises for stability, and includes specific recommendations on rehabilitation for balance. The guideline committee also highlighted that, even if not their primary function, most of the interventions named in this section will still impact spinal and core muscles. For example, treadmill gait training will be prescribed for mobility rehabilitation, but does require core activation as well. Therefore, no changes have been made.
Neater Solutions Ltd.	Guideline	032 - 033	General	**2. Upper Limb Rehabilitation** We broadly support the guidance in sections 1.17.1–1.17.7. We suggest an enhancement to **section 1.17.7**, recommending the inclusion of **arm supports** as part of **24-hour postural management strategies**.	Thank you for your comment. We have now included arm supports as an example into the recommendation on 24-hour postural management strategies.
Parkinson's UK	Guideline	032 - 034	General	People with Parkinson's are affected by managing transfers in different ways from people with other neurological conditions; cues and other strategies are taught to help them overcome these difficulties. Interventions should be offered for these specifically in people with Parkinson's, but these do not currently feature in this guidance. We recommend that interventions for managing transfers, such as rolling over in bed/getting in and out of bed, getting off the floor, and getting in and out of chairs, should be added here.	Thank you for your comment. You mention that recommendations on managing transfers for people with Parkinson's disease would not be generalisable to people with other chronic neurological disorders, or even people with other progressive neurological disorders. As a general rule, all recommendations in this guideline have been carefully drafted to apply to our whole population. There are a few exceptions, but these are still generalisable to one of our 5 disorder categories. Writing recommendations for 1 specific disorder would not be fair to other conditions covered by this guidance. Therefore, no changes have been made.

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					On reflection, it seems that your concerns would be better addressed in future updates of NG71 Parkinson's disease in adults. As a stakeholder of the guideline, you will be informed about any future work on it and can raise this as an area to be investigated.
First Community Health and Care	Guideline	033	001 - 003	Rec 1.17.1 - This recommendation will be a challenging change in practice because in our area there are no accessible NHS services to provide: hydrotherapy, robotics. Use of robotics and funding for this is very limited. Unrealistic to assume that even some services have this available to them. Only specialist services or those in research settings will likely include this as part of a patient treatment.	Thank you for your comment. The committee have already acknowledged that robotics and hydrotherapy are not universally available and would require considerable funding for every service to implement. In order to mitigate this, these options are caveated with 'where available'. Additionally, the stem of this recommendation begins 'consider', meaning that services do not have to offer every intervention on this list if there is a reason not to. Therefore, no change has been made. For further details on the committee's discussion of the resource impact of this recommendation, please see the 'The committee's discussion of the evidence' in evidence review E.
British Association of Brain Injury and Complex Case Management	Guideline	033	002 - 003	1.17.1 we are concerned that the guidance suggests service led recommendations, rather then being needs-led, by suggesting that hydrotherapy and robotics is only accessed where available.	Thank you for your comment. The committee acknowledge your concern but agreed not to make revisions in light of your comment. The clinical- and cost-effectiveness evidence for both hydrotherapy and robotics was mixed for the guideline population of people with chronic neurological disorders. Using their expertise and experience, the committee discussed that they have had some positive experiences with both interventions. However, they could not ignore the large resource impact on rehabilitation services that would result from making a strong recommendation about either. When combined with the poor clinical evidence, the committee decided to include a caveat of 'where available'. This would mean that already existing services would not be at a risk of being de-commissioned, but also would not place undue pressure on those services which did not have these facilities. For further details of the conversation behind these recommendation, please see 'The committee's discussion of the evidence' section in evidence review E.
Shaftesbury Icanho	Guideline	033	005	1.17.2 Generally agree with this guidance, however equipment to support movement such as FES for the lower limb, to support people with foot-drop is not readily funded in our county and can be difficult and expensive to obtain. FES for the lower limb is often used for its orthotic effect rather than a restorative strategy (although this can be the case), so could be funded as such and would likely be more widely adopted if funding were more available.	Thank you for your comment. The committee agree that functional electrical stimulation can be especially effective in people with foot drop. NICE already has guidance on this topic, IPG278 Functional electrical stimulation for drop foot of central neurological origin, so a link to this has now been added into the section on electrical stimulation interventions. We hope that this addition helps to ease funding and access to these devices for people with foot drop due to a chronic neurological disorder.
British Association of Brain Injury and Complex Case Management	Guideline	033	005	1.17.3 We are concerned that in practice delays in orthotic provision impact negatively on contractures and long term outcomes for individuals - it would therefore be helpful for the guidance to include specific timeframes.	Thank you for your comment. Due to the wide population that this guideline covers (including different ages, different disorders, and different rehabilitation needs), the committee did not believe it appropriate to be more specific in the timing of orthotic provision, not least because there was

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					no evidence to support this. Therefore, no change has been made. However, we do have a recommendation in the later section on independent living, equipment and environmental adaptations, that recommends early access to occupational therapy. It is anticipated that this will facilitate timely access to interventions such as orthoses.
University College London Hospital	Guideline	033	005	Orthotics and their role in providing stretch for spasticity and prevention of contracture is not mentioned.	Thank you for your comment. The committee believe that both of these concerns are adequately covered in the current wording of providing orthoses to support movement, and protect against injury and secondary impairment. Therefore, no changes have been made.
The UK FND Network	Guideline	033	005	Orthotics and splints may be unhelpful and can be harmful in FND.	Thank you for your comment. We have now included extra wording in the referenced recommendation that highlights the harms of inappropriate prescription of compensatory or adaptive interventions where they may limit scope for recovery.
British Association of Prosthetists and Orthotists	Guideline	033	005	We feel it is important to highlight the wider MDT involvement and engagement that is necessary for successful use of an orthosis. For example – highlighting that providing an orthosis in conjunction with ongoing physiotherapy to support the use of it, or occupational therapy to improve skills in the case of an upper limb orthosis. This goes beyond simple provision of the device; there must be a holistic approach to managing it beyond provision, if the user is to get the full benefit of the device.	Thank you for your comment. The committee believe that involving the wider healthcare and social care team to successfully implement interventions during rehabilitation for chronic neurological disorders applies to all recommendations in this guideline, not just this one on orthosis provision. They have taken great care to draft guidance that accurately reflects that holistic rehabilitation planning and delivery involved every member of the team (including the individual themselves, as well as their family members, carers, and friends). There are several recommendations on collaboration and communication between healthcare, social care, and other relevant professionals when designing and implementing a holistic rehabilitation plan. Therefore, no changes have been made.
Association of Chartered Physiotherapists in Neurology	Guideline	033	005	Orthotics and splits are documented to be harmful in FND. They are linked to worsening and in some cases the onset of fixed dystonia and symptoms at the intersection between FND and complex regional pain syndrome (Schrag 2004, https://pubmed.ncbi.nlm.nih.gov/15342362/) Additionally expert consensus papers on rehabilitation for FND advise against using splints and orthotics due to potential for harm (Nielsen 2015, https://pubmed.ncbi.nlm.nih.gov/25433033/; Nicholson 2020, https://pubmed.ncbi.nlm.nih.gov/32732388/) A very clear statement that orthotics and splints may be unhelpful and in some cases harmful for FND must be made to prevent this guideline causing harm.	Thank you for your comment and the information provided. We have now included extra wording in the referenced recommendation that highlights the harms of inappropriate prescription of compensatory or adaptive interventions where they may limit scope for recovery.

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Central London and Community Healthcare Trust	Guideline	033	005 - 006	*1.17.2 Provide equipment, including orthoses and splinting, to support movement and protect against injury and secondary impairment.*- More specific wording required to include provision of appropriate mobility for all including in and outdoor self-propel or powered mobility with adapted access methods such as head switches where required.	Thank you for your comment. Although we looked for studies on indoor and outdoor functional mobility, we did not identify any effectiveness or cost-effectiveness evidence. As guidance in this area would incur a significant resource cost, we are limited to what we can recommend without supporting evidence. However, although self-propelled and powered mobility are not specifically mentioned in this wording, they are not excluded from it. Similarly, the committee have made recommendations that specifically name wheelchairs as examples, notably to optimise independence and aid participation in daily life, and as a 24-hour postural management strategy. Therefore, no changes have been made.
University College London Hospital	Guideline	033	007	Given this statement starts with "Think about" it should either be re-written to be more inclusive, or it should be de-prioritised in this list when considering the impact of gaming on stability/mobility and limb function.	Thank you for your comment. There is no hierarchy to the guideline recommendations. As such, they are ordered in the way the committee and our editorial team believed would flow the best, for example in terms of a rehabilitation pathway. Although the committee considered your comment, they agreed not to make the changes you suggest.
First Community Health and Care	Guideline	033	007 - 009	Rec 1.17.3 - This recommendation will be a challenging change in practice because in our area there are no accessible NHS services to provide: gaming. Virtual reality and gaming also very unrealistic to provide in community settings due to resources, funding or support and expertise.	Thank you for your comment. The committee acknowledged variation in practice and availability. Given the lack of convincing evidence on effectiveness and cost-effectiveness in most cases, the committee have recommended a range of interventions, but have not prioritised any. As the recommendation on gaming and virtual reality mentions, the committee felt as though one of the main benefits of these formats is the engagement aspect. Therefore, they decided to make it a consider recommendation rather than an offer. Additionally, they felt that these modalities will become more popular as time passes, so they wanted to make a recommendation in this area to future-proof the guideline and incorporate guidance that future updates could build upon as effectiveness and cost-effectiveness evidence emerges. Regarding your concerns on implementation, the committee have also made recommendations on collaboration and integrated pathways which may improve access to interventions such as gaming and virtual reality. Based on experience, the committee noted these interventions may be cost effective and reduce pressure on NHS resources, including staffing. Some modalities may also be more accessible due to delivery in varied settings. We also recommend improving access to rehabilitation in community settings, aligning with the new NHS plan, which may support implementation of this recommendation.
The Association of British Neurologists	Guideline	033	015	1.17.6 "As part of rehabilitation to restore or maintain limb structure and function, provide serial or removable casting." Serial casting is not recommended for functional neurological disorders; on the contrary, it can be actively harmful. In addition to the direct physical effects	Thank you for your comment. We have added a new recommendation following on from the one referenced, which asks rehabilitation professionals to take into account the potential harms of inappropriate use of serial casting. Within this, we have highlighted people with functional

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				including altered gait, passive interventions like casting can reinforce abnormal illness beliefs or perceived paralysis for patients with functional neurological disorders.	neurological disorders as a specific group where use of serial casting may limit recovery.
The UK FND Network	Guideline	033	015	Serial casting can be harmful in FND.	Thank you for your comment. We have added a new recommendation following on from the one referenced, which asks rehabilitation professionals to take into account the potential harms of inappropriate use of serial casting. Within this, we have highlighted people with functional neurological disorders as a specific group where use of serial casting may limit recovery.
Association of Chartered Physiotherapists in Neurology	Guideline	033	015	Serial casting is documented to be harmful in FND. It is associated with worsening and in some cases the onset of fixed dystonia and symptoms at the intersection between FND and complex regional pain syndrome (Schrag 2004, https://pubmed.ncbi.nlm.nih.gov/15342362/). In clinical practice, specialist FND services often encounter patients whose symptoms have been made substantially worse by casting delivered by expert neurology services who have no experience in FND. Expert consensus papers on rehabilitation for FND advise against using splints and orthotics due to potential for harm (Nielsen 2015, https://pubmed.ncbi.nlm.nih.gov/25433033/; Nicholson 2020, https://pubmed.ncbi.nlm.nih.gov/32732388/) A very clear statement that serial casting can be harmful in FND must be made to prevent this guideline causing harm.	Thank you for your comment and the additional information provided. We have added a new recommendation following on from the one referenced, which asks rehabilitation professionals to take into account the potential harms of inappropriate use of serial casting. Within this, we have highlighted people with functional neurological disorders as a specific group where use of serial casting may limit recovery.
British Association of Brain Injury and Complex Case Management	Guideline	033	017	1.17.7 We note the positive impact of the consideration for 24 hour postural management, we would also like to add the importance of standing for maintenance of bone health and digestive function and suggest the addition of sleep systems and Mollii Suits to the list of potential options.	Thank you for your comment. The interventions listed in the referenced recommendation are only examples for consideration. It is not an exhaustive list of options. Therefore, no change as been made.
British Association of Prosthetists and Orthotists	Guideline	033	023	This section does not mention any other health care professionals that may be involved in the delivery of gait training; a more holistic approach may be achieved by highlighting that (for example) an orthotist may be helpful in assessing gait, and identifying where additional assistive devices such as orthoses may be indicated.	Thank you for your comment. In order to be generalisable across the whole guideline population (including a wide range of disorders and rehabilitation settings), and to minimise the resource impact, recommendations in this section do not include the mention of any specific rehabilitation professional. Therefore, no change has been made.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	033	General	This section feels very much like a prescription for physios to do their job. It mentions serial or removable casting which are used in some inpatient rehab settings but are difficult to oversee in community. It is unclear in the guideline whether inpatient/outpatient is recommended.	Thank you for your comment. The guideline committee agree that serial or removable casting is not always available. However, this is a local implementation issue as the service should be available for inpatient, outpatient and community settings. Therefore, no change has been made.

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Kent and Medway NHS and Social Care Partnership Trust	Guideline	033 - 034	General	1.17.8 - Disparity over what facilities are available and suitable and necessary. The aspiration is good but needs to be realistic or people expect inappropriate things. so maybe start with consideration of ….	Thank you for your comment. The recommendation that you have referenced is preceded by the first recommendation in this section that specifically frames treadmill gait training as an optional intervention when designing a rehabilitation programme for stability, mobility and limb function, among many others. They have not prioritised one over another. The section on treadmill gait training should only be followed in the event that treadmill gait training is selected as an appropriate component for an individual. Therefore, no changes have been made.
University College London Hospital	Guideline	034	006	NMES – should specify this is for UL (if this is what is meant – LL usually refs to FES, UL to NMES	Thank you for your comment. According to the committee's experience and expertise, FES and NMES can be used for both upper and lower limb function. While they do acknowledge that FES is more well known in lower limb and NMES in lower, they are not restricted to these domains. The reason the FES recommendation is lower limb specific is because that is where the evidence was identified. Additional considerations are that lower limb FES have greater availability and are more affordable that upper limb FES. The committee made their NMES recommendation based on their own experience, which includes all limbs. The fact that it is for both upper and lower limb use is also reflected in the rational and impact section for that section. Therefore, no changes have been made in light of your suggestion.
The International FES Society (IFESS) UK and Ireland chapter.	Guideline	034	006 - 009	We are broadly in agreement with the guideline relating to electrical stimulation	Thank you for your comment. We hope that these recommendations covering electrical stimulation will help to increase access to this intervention for people with chronic neurological disorders.
First Community Health and Care	Guideline	034	006 - 007	Rec 1.17.12 - This recommendation will be a challenging change in practice because very limited access to electrical stimulation for patients, can be referred but due to device availability and staff training, robust local pathways do not exist.	Thank you for your comment. The committee discussed that electrical stimulation combined with task-based activity is widely used by current services, although they did acknowledge the potential cost implications of recommending neuromuscular electrical stimulation for services where devices are not available. However, they have only recommended that services consider providing this intervention, rather than to offer it, which will mitigate the amount that services will need to invest. Additionally, the committee noted that not all devices are funded by the NHS. Some people purchase stimulators themselves or use Personal Independence Payment funding. Therefore, no changes have been made in light of your comment.
University College London Hospital	Guideline	034	008	There is NICE guidance on FES- this should be referenced here. It is also too vague to fit with previous NICE guidance and clinical practices. If the person has upper motor neurone muscle weakness of the lower limbs causing foot drop, consider functional electrical stimulation in addition to gait training. Overview | Functional electrical stimulation for drop foot of central neurological origin | Guidance | NICE	Thank you for your comment. This recommendation now includes a cross-reference to the NICE interventional procedures guidance on functional electrical stimulation for drop foot of central neurological origin (IPG278). Unfortunately, we are unable to make this recommendation more precise in response to your comment about vagueness. This is due to both the broad nature of this guideline's population and the poor quality of the evidence identified in evidence review E for electrical stimulation as an intervention.

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Association of Chartered Physiotherapists in Neurology	Guideline	034	011	Early Neurorehab need to consider how patients access this and pathways within acute and community services to refer into rehab services. Signposting and pathways need to be explicit	Thank you for your comment. Early assessment of vestibular problems is covered in the section assessing stability, mobility and limb function within the section on what to cover in the holistic rehabilitation needs assessment. Additional specialist assessment is covered in this recommendation, as well as provision of interventions for identified vestibular issues. The committee hope that making a specific recommendation on assessment, along with several recommendations throughout the guideline on information for people with chronic neurological disorders and increasing knowledge of healthcare professionals on appropriate referrals, will increase access to the appropriate services.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	034	011	The identification of vestibular difficulties, and therefore referral to services who can treat are often lacking. Dizziness screening tools with a referral pathway would be useful as issues are quite often passed off as medication, stress, anxiety and therefore incorrectly treated.	Thank you for your comment. Early assessment of vestibular problems is covered in the section assessing stability, mobility and limb function within the section on what to cover in the holistic rehabilitation needs assessment. Additional specialist assessment is covered in this recommendation, as well as provision of interventions for identified vestibular issues. Given the wide population this guideline covers and the fact we did not search for evidence in this area, we cannot recommend specific dizziness assessment tools.
The Royal College of Ophthalmologists	Guideline	034	011 - 013	This section states, "If vestibular problems are suspected, provide central and peripheral vestibular assessment, and, if needed, exercises or procedures such as gaze stability exercises…" and the linked definition defines "vestibular problems" as, "Dizziness or problems with balance caused by damage to parts of… the brain that process the sensory information involved with controlling… eye movements." This definition and recommendation fails to mention that damage to parts of the brain controlling eye movements may cause problems that could be described as vestibular, but may also cause ocular misalignment and non-vestibular nystagmus. Gaze stability (or any other form of) exercises are not an effective treatment for most ocular motility disorders, which may benefit from orthoptic and ophthalmologic assessment and treatment. I recommend that after acquired brain injury, a VISA screen be conducted, which would detect ocular misalignment as a potential visual impairment and allow appropriate onward referral and treatment.	Thank you for your comment. We have included a new recommendation on the assessment of visual and hearing issues within the section on what to cover in the holistic rehabilitation needs assessment. From this, we have linked to subsequent recommendations on interventions for vestibular problems. We have also amended the guideline definition of vestibular problems. Unfortunately, the scope of this guideline does not cover interventions to support visual impairment, so further recommendations covering the later stages of these rehabilitation pathways cannot be included. However, we hope that making a specific recommendation on assessment, along with several recommendations throughout the guideline on information for people with chronic neurological disorders and increasing knowledge of healthcare professionals on appropriate referrals, will increase access to the appropriate services. Similarly, given the wide population this guideline covers and the fact we did not search for evidence in this area, we cannot recommend specific visual assessment tools.
Association of Chartered Physiotherapists in Neurology	Guideline	034	013	Need to consider training within AHP services to support the development of clinicians who have the skills to identify and address impairments to optimise function and outcomes. Training needs to be embedded into this area.	Thank you for your comment. It is beyond NICE's remit to comment on specific training for allied health professions. Therefore, no change has been made.

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British Association of Brain Injury and Complex Case Management	Guideline	034	014	1.18.7 We agree the services that can assist with mental health and wellbeing, in addition we would like neuropsychology listed, as these professionals are specialists in assessment and treatment of cognitive disorders, especially following ABI and with many other CNDs.	Thank you for your comment. Neuropsychologists have been listed in the glossary alongside other registered professions by the health and care professions council as rehabilitation practitioners. We have also added a new recommendation to assess emotional health and wellbeing, cognitive function and behaviour, when completing a neuropsychological assessment (see also the section on cognitive function).
The Association of British Neurologists	Guideline	034	014	1.18 "Emotional health and mental wellbeing" The whole guideline, and this section in particular, frames e.g. physiotherapy as a physical process with holistic assessment of emotional health/mental wellbeing sitting alongside that, albeit with a recommendation that it is well-integrated. This does not work for functional neurological disorders, however: for functional neurological disorders, emotional health and physical rehabilitation are not parallel streams but deeply intertwined. Optimal outcomes require integrated treatment models where psychological formulation informs physical rehabilitation and involvement of psychologist would be encouraged with the PT/OT/rest of the multidisciplinary team. Assessment by a psychiatrist is also often recommended. We recommend the guidelines in general and this section in particular are adjusted to reflect this.	Thank you for your comment, with which the committee agree. The assessment section in emotional health and wellbeing has now been extensively edited and a more collaborative approach with the cognitive section is adopted. Furthermore, there are new recommendations focusing on functional neurological disorders in the intervention sections of the guideline and how delivery may differ, for example in the physical activity and exercise section of the guideline a new recommendation has been added that states: For people with a functional neurological disorder use activities that encourage and enable recovery of movement and function. These should: • focus on planned and purposeful movement to achieve a specific outcome (goal-oriented movement) • acknowledge the presence and impact of symptoms whilst redirecting attention away from them • focus on the potential for recovery. A further recommendation in the information and advice section of the guideline also highlights the above as well as the importance of reinforcing a biopsychosocial approach. In the rehabilitation planning and delivery section of the guideline, there is a recommendation stating that practitioners involved in delivering the rehabilitation plan should work together to ensure timely and joined-up delivery of the interventions and approaches. The committee agrees that a registered mental health practitioner should be an integral part of the rehabilitation team and a new recommendation in the emotional health and wellbeing section of the guideline states that a registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse), and an understanding of the person and the effects of their condition or injury, should develop and oversee the emotional health and wellbeing element of the person's rehabilitation plan.
Central London and Community Healthcare Trust	Guideline	034	014	1.18 We agree with these recommendations, however it should be considered adding in the holistic assessment, that possible biological influence mental health and wellbeing specific to neurological conditions	Thank you for your comment. The committee agree and there is a recommendation in the section about 'what to cover' in the holistic rehabilitation needs assessment that states that in addition to their

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				and this should be reviewed and where appropriate referrals onwards for investigations to the appropriate pathway (e.g. endocrinology imbalances are not uncommon in some conditions such as traumatic brain injury and can have a detrimental effect on mental health e.g. cortisol imbalances)	neurological condition or injury, think about how other health conditions, including mental health conditions, may affect someone's rehabilitation. Therefore, no change has been made in light of your comment.
Central London and Community Healthcare Trust	Guideline	034	014	1.18 We agree with these recommendations but think consideration should be given to include the acknowledgement on the impact of culture on identity and mental health with neurological conditions, that is that the impact of the neurological condition may result in changes to identity, family systems and mental wellbeing within different cultures.	Thank you for your comment. We agree that it is important to assess the impact of culture in the rehabilitation plan. There is already a recommendation to ask the person about their background, relationships, work, education, meaningful activities, spiritual and religious practices, and hobbies and to review these as part of the rehabilitation plan. This is in the section about holistic needs assessment. Therefore no change was made in response to your comment.
Inflammatory Neuropathies UK	Guideline	034	015	Within this section we would like to see issues around fear of a condition returning, relapsing, or progressing highlighted, and how this should be part of assessment, referral, and intervention selection	Thank you for your comment. We have added fear of a condition, returning, relapsing, or progressing to the committee's discussion of the evidence pertaining to the recommendation on acceptance and adjustment alongside their condition in evidence review H.
Cambridge University Hospital NHS Foundation Trust	Guideline	034	015 - 021	Needs to include "Consider the impact of the neurological condition on the health and wellbeing of the whole family (parents and siblings). Make local referrals for support as early as possible."	Thank you for your comment. We have cross-referenced to the NICE guideline on supporting adult carers in the sections on designing and commissioning rehabilitation services and assessing rehabilitation needs and goal setting , which covers the needs of the family and carers across a range of interventions and conditions.
Shaftesbury Icanho	Guideline	034	016	1.18.1 – Agree that the person's mental and emotional health needs to be considered, on par with other aspects of rehabilitation. Do you need to include outcome measures as part of the assessment to look at severity and manage changes over time? E.g. PHQ9 / GAD7 or HADS?	Thank you for your comment. The assessment of a person's emotional health and wellbeing is outside of the scope for evidence review H. In view of this, specific assessment tools for assessing a person's emotional health and wellbeing were not listed in the recommendation.
British Society of Physical and Rehabilitation Medicine	Guideline	034	016 - 017	The emotional issues will also increase the neurological disabilities and make symptoms worse. The treating teams should be aware of this.	Thank you for your comment. We agree with your comment, however the recommendation pertains to developing the emotional health and wellbeing element of a rehabilitation plan, highlighting issues to consider. Although we haven't added to the recommendation that emotional issues can increase neurological disabilities and make symptoms worse, we have included it in the committee's discussion of evidence.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	034	018	We agreed that the mention of, and cross referencing to, emotional lability was very helpful. We recommend that this introductory section needs expanding to include other related considerations. For instance, emotions and behaviour can be neurologically dysregulated, such as apathy, lability, disinhibition, perseveration etc. Also that strong emotional reactions can be caused primarily by cognitive impairments that hinder: emotional recognition, theory of mind, problem solving, ruminative thinking. These problems are common in neurological conditions and need to be identified and distinguished from a	Thank you for your comment. The committee agree with your comment that additional factors need to be taken into consideration around neurological injury and behaviour. They therefore edited the recommendation to account for this and now recommend to be aware that neurological injuries and conditions can result in: • neurobehavioural disturbance • neurobehavioural changes such as apathy, disinhibition and perseveration • difficulties with emotion regulation • abrupt fluctuations in a person's emotional state, known as emotional lability

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				psychological reaction to their circumstances, i.e. depression or adjustment and acceptance.	
Association of Chartered Physiotherapists in Neurology	Guideline	034	023	Consider involving A/E, private neuro practices and community services to identify mild/moderate conditions with associated pathways to access specialist screening rehabilitation services	Thank you for your comment. The guideline recommends designing services across all health and care settings, including hospital, community, primary care, home care, third sector and private providers, and establishing integrated, flexible pathways. It also recommends responsive services requiring collaboration across specialties and sectors, including mental health services. Specific recommendations cover mental health assessment and interventions, which acknowledge the role of the third sector providers. Service configuration will vary depending on local needs but should follow the principles outlined above, involving hospital, third sector, private and community services.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	034	General	The emotional issues will also increase the neurological disabilities and make symptoms worse. The treating teams should be aware of this.	Thank you for your comment. We agree with your comment, however the recommendation pertains to developing the emotional health and wellbeing element of a rehabilitation plan, highlighting issues to consider. Although we haven't added to the recommendation that emotional issues can increase neurological disabilities and make symptoms worse, we have included it in the committee's discussion of evidence.
The Wolfson Neurorehabilitation Service	Guideline	034	General	Emotional Health and Mental Wellbeing (Recommendation 1.18) Given the high prevalence of mental illness in neurological populations, we strongly recommend making it explicit that all neurological patients should be routinely screened for mood disorders as an integral part of their holistic rehabilitation needs assessment.	Thank you for your comment. Routine screening for mood is already included under the section on holistic rehabilitation needs, therefore the committee agreed that a separate recommendation was not required.
The Neurological Alliance	Guideline	034	General	Neurological conditions can be worsened due to changes in mood, mental wellbeing and stress. This should be referenced here.	Thank you for your comment. We agree with your comment, however the recommendation pertains to developing the emotional health and wellbeing element of a rehabilitation plan, highlighting issues to consider. Although we haven't added to the recommendation that emotional issues can increase neurological disabilities and make symptoms worse, we have included it in the committee's discussion of evidence.
Central London and Community Healthcare Trust	Guideline (In relation to Evidence H)	034	General	1.18 Throughout this section there is limited focus on the systems and systemic approaches – we wondered if the committee had considered reviewing the evidence base for systemic approaches in people with chronic neurological disorders as part of the evidence review? We cannot see this is the case in Evidence H, and we wonder if the committee would consider re-visiting and reviewing this?	Thank you for your comment. Evidence review H focused on interventions for emotional health and wellbeing and did not include systems and systemic approaches. To ensure that our evidence reviews are systematic, protocols are designed apriori and to avoid introducing bias, they cannot be changed after conducting the review.
Nottingham University Hospitals Department	Guideline	034	General	As in other sections, reference to the role of clinical psychology is absent. We agreed that the guidance recommend that problems with mood and behaviour are routinely screened and evaluated. And that if	Thank you for your comment. In order to be generalisable across the whole guideline population (including a wide range of disorders and rehabilitation settings), and to minimise the resource impact, recommendations in this

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of Clinical Psychology and Neuropsychology				primary cognitive, emotional or behavioural disturbance is suspected, then the patient is referred for specialist assessment, by clinical psychology or neuropsychology.	section do not mention any specific rehabilitation professional. However neuropsychologists and clinical psychologists have been listed in the glossary alongside other professions registered by the health and care professions council as rehabilitation practitioners. Significant changes have also been made to the emotional health and wellbeing assessment and cognitive assessment sections of the guideline, which do broadly address your point. For example, in the emotional health and wellbeing section we have edited a recommendation emphasising that a registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse), with an understanding of the person and the effects of their condition or injury, should develop and oversee the emotional health and wellbeing element of the person's rehabilitation plan. Furthermore, the committee agreed a new recommendation to assess emotional health and wellbeing, behaviour and cognitive function (see the section on cognitive function), when completing a neuropsychological assessment. In the cognitive section of the guideline, we have recommended that a registered practitioner with expertise in neuropsychology (for example, a clinical psychologist, counselling psychologist or neuropsychologist), and an understanding of the person and the effects of their condition or injury, should oversee and interpret cognitive assessments and oversee the cognitive functioning element of the person's rehabilitation plan.
Parkinson's UK	Guideline	034 - 037	General	There does not appear to be a reference to the fact that the person's family and community might need to be helped to adjust to the diagnosis, as well as the person with the condition. For example, in some communities, the person with a long-term neurological condition may be treated differently after diagnosis by their family and community. It is beneficial to the person mentally and emotionally if their family and community are supportive.	Thank you for your comment. The committee agree that this is important and had addressed it in the draft guideline, with a recommendation in the section on early discussion about prognosis and rehabilitation. The recommendation stated to offer the person, and their family or carers, if appropriate, a discussion soon after injury or diagnosis (before symptoms or impairments may have emerged) about their prognosis and how their rehabilitation needs may emerge or change over time.
Defence Medical Rehabilitation Centre	Guideline	035	001	Give examples of 'appropriate management interventions' for emotional lability	Thank you for your comment. The committee agreed to add to the principles of assessment section, highlighting that neurological injuries can result in neurobehavioural changes. The management of emotional lability is outside the scope of evidence review H, therefore examples of 'appropriate management interventions' are not provided, however the committee were aware of the management of emotional lability in the NICE MS guideline and have cross-referred to this guideline if treatment a person with MS.
Defence Medical Rehabilitation Centre	Guideline	035	001	Move entire paragraph on emotional lability down to 1.18.5	Thank you for your comment. Although they discussed your suggestion, the committee all agreed to keep the recommendations in their current order.

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Rehabilitation for chronic neurological disorders including acquired brain injury

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Defence Medical Rehabilitation Centre	Guideline	035	001	Add in a paragraph on depression, anxiety and post traumatic symptoms	Thank you for your comment. Depression, anxiety and post traumatic-stress disorder are included in the final recommendation on emotional health and wellbeing, which also refers to the appropriate NICE guidelines for further management of those conditions.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	035	002	We thought adding the following to line 2 '..appropriate *pharmacological and psychological interventions*…' would specify the types of intervention to consider.	Thank you for your comment. Evidence review H only examined psychological interventions for emotional health and wellbeing. Given that pharmacological interventions were outside of the scope of this review question there would be no basis on which to make the suggested additions.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	035	006 - 008	1.18.3 - To be able to access psychology for support with adjustment not just mental health services. benefit of being able to access at different times of their journey. This is often not available or delayed and hard to access. Another education needs for clinicians as well as patients	Thank you for your comment. The section on interventions for emotional health and wellbeing recommends individual or group interventions for low mood and anxiety, including adjustment difficulties. The committee acknowledged that needs fluctuate and recommended allowing people to opt in and out of emotional and mental wellbeing services as needed, coordinated either by the service or a single point of contact. They shared your concerns about service availability and further recommended building capacity within mental health services. The committee also noted in the supporting rationale and impact section that general mental health staff may need additional training to understand the challenges faced by people with chronic neurological conditions and to deliver appropriate interventions. Further detail is provided in the related evidence review H: emotional health and mental wellbeing.
Huntington's Disease Association	Guideline	035	009	The psychiatric and cognitive symptoms of Huntington's disease are well-documented. A 2021 review of the most frequent psychiatric disorders in patients with HD states: "*In symptomatic HD patients, it is estimated that up to 73–98% of patients will have a major psychiatric disorder or psychiatric symptoms. Psychiatric manifestations in HD include depression, irritability, apathy, anxiety, mania, perseverations, obsessions and psychosis.* *Cognitive changes include progressive deficits in attention, learning, executive and sensory functions, resulting in dementia. Depression, diagnosed in half of patients with HD, is the most common and earliest symptoms prior to the motor onset. There are likely multiple causes of the psychiatric symptoms, with underlying factors including a*	Thank you for your comment. The guideline scope covers the broad range of chronic neurological disorders (with exceptions). The evidence reviews were therefore not designed to locate evidence pertaining to individual conditions or to inform condition specific recommendations. It is therefore not possible to add in the level of detail about people with Huntington's disease that you suggest so no changes have been made in light of your comment.

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				combination of neurobiological, cognitive, psychological, social and environmental factors". It is important that rehabilitation practitioners are aware of these psychiatric and cognitive symptoms. After recommendation 1.18.3 we suggest that the following text is added, which covers the common range of problems experienced by people with Huntington's disease: *Be aware that mental illness and significant behavioural changes are common features of some neurological conditions (such as Huntington's disease).* *These changes and symptoms can include:* • *psychiatric problems – some people develop obsessive behaviours, delusional thoughts or behaviours, stubbornness, lack of self-awareness, or suicidal thoughts* • *a lack of emotion and not recognising the needs of others* • *periods of aggression, excitement, depression, antisocial behaviour and anger* • *apathy – causing a person to appear lazy or have a lack of interest in hygiene and self care* • *difficulty concentrating on more than one task and handling complex situations* • *irritability and impulsiveness*	
Inflammatory Neuropathies UK	Guideline	035	009	Within this section we would like to see issues around fear of a condition returning, relapsing, or progressing highlighted, and appropriate interventions outlined	Thank you for your comment. We have added fear of a condition, returning, relapsing, or progressing to the committee's discussion of the evidence pertaining to the recommendation on acceptance and adjustment alongside their condition in evidence review H.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	035	009	There are unmet needs in housing, social care, lack of community therapy, or vastly delayed and time-limited rehab, equipment provision, mental health services. How as clinicians with limited resources ourselves can we even start to tackle these unmet needs when services simply don't exist or are vastly understaffed. This statement is too broad.	Thank you for your comment. The committee highlighted the impact of care delivery on the emotional wellbeing of people with CND, noting that fragmented services often cause distress due to miscommunication, repeated history taking and poor understanding of the condition. They agreed that unmet needs in other areas of rehabilitation can negatively affect emotional wellbeing, and that implementing recommendations on service delivery, planning and coordination would likely improve outcomes. The committee acknowledged variation in practice and made

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					recommendations on service design and commissioning, including service specifications aimed at improving equity. These could also create efficiencies and free up resources, for example, for service expansion and staffing. They also recommended increasing capacity, particularly in mental health services. We hope that this explanation goes some way to addressing your concerns. Recommendations support more integrated working, such as personalised rehabilitation plans involving multiple practitioners as needed and a single point of contact. This should facilitate collaboration with, for example, housing, social care and other services, and also help to ensure that broader needs are considered when assessing emotional health and wellbeing.
Heads Together	Guideline	035	014	It is important to treat family members as individuals and not just care accessories for patients.	Thank you very much for your comment. We agree that family members are important, and their needs also need to be addressed, we have stated "family and carers" in recommendations to avoid focusing only on carers, who won't always be family members.
Central London and Community Healthcare Trust	Guideline	035	014	1.18.5 Perhaps here rather than 'take account of' it should be considered to including 'work with' and make this more explicit as we should be working within the social systems that support the client, not just 'taking account of' them.	Thank you for your comment. We have changed the wording in the recommendation to 'work with'.
University College London Hospital	Guideline	035	017	As well as emotional needs, some mention of spiritual/religious needs is required in relation to goal achievement.	Thank you for your comment. We agree that it is important to consider culture in the rehabilitation plan. There was already a recommendation in the draft guideline (holistic rehabilitation needs assessment) to ask the person about their background, relationships, work, education, meaningful activities, spiritual and religious practices, and hobbies and review these as part of the rehabilitation plan. Furthermore, under the goal setting section, a recommendation was made to focus on optimising participation in the most important aspects of the person's life, which could entail the person's spiritual/religious beliefs if the person highlighted it as an important part of their life. No further changes were made in light of your comment.
Brainkind	Guideline	035	017 - 019	Consider adding 'and consider the impact of emotional health and wellbeing on the progress of other rehabilitation goals'.	Thank you for your comment. We have added your suggestion into the recommendation.
Headway – The Brain Injury Association	Guideline	035	020	We suggest that explicit reference is made here to the importance of neuropsychologists in assessing and treating people with chronic neurological conditions, including brain injury survivors, and for the need for neuropsychology to be a key aspect of rehabilitation.	Thank you for your comment. Neuropsychologists have been listed in the glossary alongside other professions registered by the health and care professions council as rehabilitation practitioners. Significant changes have also been made to the emotional health and wellbeing assessment and cognitive assessment sections of the guideline, which do broadly address your point. For example, in the emotional health and wellbeing section we have edited a recommendation emphasising that

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					a registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse), with an understanding of the person and the effects of their condition or injury, should develop and oversee the emotional health and wellbeing element of the person's rehabilitation plan. Furthermore, the committee agreed a new recommendation to assess emotional health and wellbeing, behaviour and cognitive function (see the section on cognitive function), when completing a neuropsychological assessment. In the cognitive section of the guideline, we have recommended that a registered practitioner with expertise in neuropsychology (for example, a clinical psychologist, counselling psychologist or neuropsychologist), and an understanding of the person and the effects of their condition or injury, should oversee and interpret cognitive assessments and oversee the cognitive functioning element of the person's rehabilitation plan.
The British Psychological Society	Guideline	035	020	Mental health issues (1.18.7) are a very significant element in the experiences of people with the conditions covered by this guideline. Making referrals to mental health services is difficult because these services may decline referrals for people with neurological conditions as they are already working at capacity, and/ or may feel they do not have sufficient knowledge of these conditions. Further still, the mental health challenges experienced in these conditions both have distinct features and are more complex than those found in the general, otherwise healthy population, and it is not appropriate to leave them to GPs or NHS Talking Therapies Practitioners without specialist knowledge of neurological conditions – this benefits neither the person concerned nor the NHS. People with these conditions need access to skilled practitioners who understand their condition and can address their mental health needs accordingly.	Thank you for your comment. The committee recognised that services differ in their capacity and expertise and in view of this they wrote recommendations on building local capacity and expertise. Specifically, the committee recommended to build capacity for mental health services for people with a chronic neurological disorder through local workforce skills development and communication protocols between different services involved in rehabilitation. Furthermore, the committee recognised that GPs or other primary care practitioners may not be equipped to treat people with chronic neurological disorders and recommended that GPs and other primary care practitioners know how to recognise emerging rehabilitation needs because of an existing chronic neurological disorder, and know when and how to refer people to rehabilitation specialists. For example, using expertise from specialist neurorehabilitation services and maintaining up-to-date information on options for local rehabilitation services.
South London and Maudsley NHS Foundation Trust	Guideline	035	020	We would recommend that emotional health and wellbeing services are integrated within neurorehabilitative services where possible	Thank you for your comment. The committee agreed and to support this integrated approach have added a new recommendation in the section on emotional health and wellbeing. The recommendations is to assess emotional health and wellbeing, behaviour and cognitive function (see the section on cognitive function), when completing a neuropsychological assessment. The committee agree that an integrated service between mental health and neurorehabilitation services is optimal. Consequently, a new recommendation has been added to the building local capacity and expertise section of the guideline to develop protocols to improve

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					communication between neurorehabilitation, mental health and other services involved in delivering and supporting rehabilitation.
Defence Medical Rehabilitation Centre	Guideline	035	023	Assessments or interventions may be provided by neurorehabilitation services – we are concerned that the inequity in neurorehabilitation services across the UK will not be addressed through this recommendation as it suggests that neurorehabilitation teams all have capacity to provide assessment and intervention for emotional wellbeing. Instead, we wonder if the recommendation should be 'neurorehabilitation services, which include team members who specialise in this domain e.g., Clinical Psychologists, Neuropsychologists and Psychiatrists'	Thank you for your comment. The committee recognised that some neurorehabilitation services will have more capacity than others and recognise that there are inequalities within neurorehabilitation and mental health services. In view of this, the committee agreed to write recommendations on building local capacity and expertise. Specifically, the committee recommended to build capacity for mental health services for people with a chronic neurological disorder through local workforce skills development and communication protocols between different services involved in rehabilitation. Furthermore, the recommendations on building local capacity and expertise is part of the planned implementation of the guideline over the coming years.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	035	024	Referral to CAMHS is often very appropriate, but frequently referrals for children are rejected with services saying they present with a 'physical health condition' so do not meet criteria, or they do not meet current thresholds of overstretched services. This leaves huge gaps for CYP in terms of mental health provision.	Thank you for your comment. The guideline committee were aware that some mental health services have admittance criteria that specifically exclude people with a diagnosis of a chronic neurological disorder, which was supported by qualitative evidence. In view of this, the guideline executive document will highlight to NHS England the inequality in accessing mental health services for people with chronic neurological disorders to review.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	035	024	CAMHS as a service is difficult to access for CYP with neurological conditions as often don't meet threshold – geographical variation noted, leaving big gaps in mental health provision.	Thank you for your comment. The guideline committee were aware that some mental health services have admittance criteria that specifically exclude people with a diagnosis of a chronic neurological disorder, which was supported by qualitative evidence. In view of this, the guideline executive document will highlight to NHS England the inequality in accessing mental health services for people with chronic neurological disorders to review.
Headway – The Brain Injury Association	Guideline	035	025	We note that Headway is explicitly referred to here as a provider, and we are proud to provide rehabilitation services in the community for brain injury survivors. However, it should be acknowledged that, like many third sector providers and through no fault of their own, some local Headway charities are struggling to continue to provide services, and indeed, 10% of local Headway charities have had to close in the last two years. Please see our points above regarding third sector funding. If this trend continues, without urgent funding support from government, more community rehabilitation services will be lost to brain injury survivors.	Thank you for your comment. We agree that third sector providers are imperative to rehabilitation services. The recommendations on designing and commissioning rehabilitation have third sector providers in mind. The committee clarified this by editing recommendations under the building capacity and expertise section of the guideline. They now recommend collaboration between commissioning bodies from healthcare, social care and other relevant community service providers, for example education services for children, third sector providers, charities and community groups. Furthermore, in the providing responsive services section of the guideline, the recommendation has been edited to recommend that service providers from all sectors (including third sector and private sector), across specialities, should communicate and collaborate, to ensure care pathways are responsive to people's needs, including when people are moving between services.

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National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	035	027	Educational Psychologists	Thank you for your comment. We unable to respond as we are unsure what your query or question is.
PTSD UK	Guideline	035 - 037	General	1.18.1 – 1.18.6 - We strongly support the inclusion of emotional health in the rehabilitation pathway. However, we recommend that screening for trauma and post-traumatic stress disorder (PTSD), including Complex PTSD (C-PTSD), is explicitly referenced. There is a significant and growing body of evidence showing the link between traumatic brain injuries and PTSD. Given the symptom overlap and potential for misdiagnosis, screening for PTSD should be routine in people presenting with acquired brain injuries and emotional health difficulties. In particular, we suggest amending 1.18.1 to read: "Think about the person's emotional health and mental wellbeing throughout rehabilitation, paying particular attention to key life stages and the potential impact of past or recent trauma. Where relevant, consider screening for PTSD or C-PTSD to ensure appropriate treatment."	Thank you for your comment. Given the symptom overlap between mental health conditions and chronic neurological disorders, we agree that screening for mental health conditions is important in chronic neurological disorders. The committee therefore added "screen for" to the recommendation on treating diagnosed post-traumatic stress disorder, anxiety and depression in adults with chronic neurological disorders, and depression in children and young people with a chronic neurological disorder, as part of their rehabilitation.
Defence Medical Rehabilitation Centre	Guideline	036	001	Although a necessary statement, we are concerned that 'ensuring two-way communication and coordination' will be unachievable in practice because of the current pressures on both neurorehabilitation teams and mental health services. In addition, where neurorehabilitation services do not include mental health professionals, a conduit for this interaction is often lacking.	Thank you for your comment. The committee recognised that some neurorehabilitation services will have more capacity than others and recognise that there are inequalities within neurorehabilitation and mental health services. In view of this, the committee wrote recommendations on building local capacity and expertise in the guideline. Specifically, the committee recommended to build capacity for mental health services for people with a chronic neurological disorder through local workforce skills development and communication protocols between different services involved in rehabilitation. Furthermore, the recommendations on building local capacity and expertise are part of implementation of the guideline over the coming years.
PTSD UK	Guideline	036	001 - 008	1.18.8 - We support the inclusion of two-way communication between services and recommend an explicit reference to trauma-informed care pathways here. Coordination with specialist trauma services or charities (such as PTSD UK) may provide vital support where PTSD or C-PTSD co-exists with neurological disorders.	Thank you for your comment. Treatment of specific mental health conditions are outside of the scope of evidence review H, therefore reference to PTSD or C-PTSD within the recommendation can't be made. However, at the end of the recommendations on emotional health and wellbeing, we recognise that it's important to treat diagnosed post-traumatic stress disorder and a cross-reference is made to the relevant NICE guideline.

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Defence Medical Rehabilitation Centre	Guideline	036	005	We advocate for an individuals' choice in opting in and out of emotional health and mental wellbeing services, however we are concerned this statement does not capture complexity of neurological patients, for example, those who have executive function changes impacting initiation and/or those who lack capacity to make decisions about emotional health care.	Thank you for your comment. We agree some people with CND have executive function changes impacting initiation, or they lack capacity or both are true. Therefore, in the recommendation we have stated that "opting in and out" may be direct with the service or via a single point of contact to account for the varying levels of autonomy people with CND may be. Additionally, there are multiple links to advocacy guidelines throughout the guideline, including sections on assessing rehabilitation needs and goal setting, holistic rehabilitation needs assessment, rehabilitation planning and delivery and information, advice and learning as part of rehabilitation.
Brainkind	Guideline	036	005	We are concerned that the recommendation to 'enable the person to opt in and opt out of services for emotional health' may not be appropriate for people with limited self-awareness into their own emotional states. Consider rewording to 'enable flexible access to services, as needed'.	Thank you for your comment. We agree some people with CND have limited self-awareness into their own emotional states. Therefore, in the recommendation we have stated that "opting in and out" may be direct with the service or via a single point of contact to account for the varying levels of autonomy people with CND may be. Additionally, there are multiple links to advocacy guidelines throughout the guideline, including sections on assessing rehabilitation needs and goal setting, holistic rehabilitation needs assessment, rehabilitation planning and delivery and information, advice and learning as part of rehabilitation.
EMDR UK	Guideline	036	009 - 013	We would recommend that EMDR is added to the list of therapies to use if the person is having difficulties adjusting to a neurological condition or if they have low mood. Additionally at point 1.18.13 we would recommend that on the spot EMDR be offered as an intervention to help manage behaviours that challenge as there is some evidence to suggest that this has been effective with people with dementia and behaviours that challenge. Point 1.18.14. We would add EMDR based group interventions such as the G-TEP protocol. Point 1.18.15 we would add that the types of intervention considered for this client group includes EMDR with CBT or mindfulness.	Thank you for your comment. No evidence was identified for EMDR in evidence review H, therefore EMDR was not included in the recommendations referenced in the comment. Moreover, dementia is out of scope for the guideline. Also, when talking about individual or group based interventions, we haven't listed any specific interventions but rather focused on the delivery of the intervention. Finally, the interventions included in the recommendation on adjustments to delivering talking therapies are included as examples and evidence was identified in evidence review H to support their use.
Shaftesbury Icanho	Guideline	036	010	1.18.10 – is there any evidence for compassion focussed therapy (CFT) to consider? • Ashworth, F., & Murray, C. (2020). Compassion focused therapy for neurological conditions. • Campbell, I. N., Gallagher, M., McLeod, H. J., O'Neill, B., & McMillan, T. M. (2019). Brief compassion focused imagery for treatment of severe head injury. *Neuropsychological rehabilitation*, *29*(6), 917-927. • Smith, S. (2019). Testing the effectiveness and acceptability of a digitally distributed Compassion Focused Therapy intervention for acquired brain injury using single case experimental design.	Thank you for your comment. No evidence on compassion focussed therapy was identified in evidence review H. The references included in your comment weren't included for the following reasons: • Ashworth, F., & Murray, C. (2020). Compassion focused therapy for neurological conditions - study design doesn't meet protocol criteria (not a randomised controlled trial in adults) • Campbell, I. N., Gallagher, M., McLeod, H. J., O'Neill, B., & McMillan, T. M. (2019). Brief compassion focused imagery for treatment of severe head injury. Neuropsychological rehabilitation, 29(6), 917-927 - Of the outcomes of interest in the protocol only pre- and post- data reported (STAI and PANAS). Comparative data available in supplementary material (file 2) for heart rate, empathy and compassion, however these are not outcomes of interest in the protocol.

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				• Ashworth, F., Clarke, A., Jones, L., Jennings, C., & Longworth, C. (2015). An exploration of compassion focused therapy following acquired brain injury. *Psychology and Psychotherapy: Theory, Research and Practice*, *88*(2), 143–162. https://doi.org/10.1111/PAPT.12037 • Ashworth, F., Gracey, F., & Gilbert, P. (2011). Compassion Focused Therapy After Traumatic Brain Injury: Theoretical Foundations and a Case Illustration. *Brain Impairment*, *12*(2), 128–139. https://doi.org/10.1375/BRIM.12.2.128 • Peoples, L & Crawley, L (2022). Evaluating a Compassion Focused Group for Adults with Acquired Brain Injury. Clinical Psychology Today.	• Smith, S. (2019). Testing the effectiveness and acceptability of a digitally distributed Compassion Focused Therapy intervention for acquired brain injury using single case experimental design - study design doesn't meet protocol criteria (not a randomised controlled trial) • Ashworth, F., Clarke, A., Jones, L., Jennings, C., & Longworth, C. (2015). An exploration of compassion focused therapy following acquired brain injury. Psychology and Psychotherapy: Theory, Research and Practice, 88(2), 143–162. https://doi.org/10.1111/PAPT.12037 - study design doesn't meet protocol criteria (not a randomised controlled trial in adults) • Ashworth, F., Gracey, F., & Gilbert, P. (2011). Compassion Focused Therapy After Traumatic Brain Injury: Theoretical Foundations and a Case Illustration. Brain Impairment, 12(2), 128–139. https://doi.org/10.1375/BRIM.12.2.128 - Publication date pre-2013 • Peoples, L & Crawley, L (2022). Evaluating a Compassion Focused Group for Adults with Acquired Brain Injury. Clinical Psychology Today - couldn't find the reference (no doi provided), it looks like it is an ongoing study and not published in a peer reviewed journal yet.
Shaftesbury Icanho	Guideline	036	010	1.18.10 – not all services have access to clinical psychology or psychotherapists who can implement these therapies. I agree it vital that people have access to these, but there are difficulties/ barriers for implementation by services with current resources.	Thank you for your comment. The committee recognised that some neurorehabilitation services will have more capacity than others and recognise that there are inequalities within neurorehabilitation and mental health services. In view of this, the committee wrote recommendations on building local capacity and expertise. Specifically, the committee recommended to build capacity for mental health services for people with a chronic neurological disorder through local workforce skills development and communication protocols between different services involved in rehabilitation. Furthermore, the recommendations on building local capacity and expertise are part of the implementation of the guideline planned for the coming years.
University College London Hospital	Guideline	036	010	CBT services are overstretched- This would require significant financial uplift to achieve.	Thank you for your comment. The committee recognised that some neurorehabilitation services will have more capacity than others and recognise that there are inequalities within neurorehabilitation and mental health services. In view of this, the committee wrote recommendations on building local capacity and expertise. Specifically, the committee recommended to build capacity for mental health services for people with a chronic neurological disorder through local workforce skills development and communication protocols between different services involved in rehabilitation. Furthermore, the recommendations on building local capacity and expertise are part of the implementation of the guideline planned for the coming years.
Nottingham University Hospitals Department	Guideline	036	010	We would like the committee to consider stating that the interventions mentioned should be delivered, or supervised, by appropriately trained	Thank you for your comment. The committee agreed and have added a new recommendation in the section on emotional health and wellbeing that

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of Clinical Psychology and Neuropsychology				professionals. This will help to ensure that evidence based treatments are delivered, rather than derivatives or single techniques that are not evidenced on their own.	states a registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse), with an understanding of the person and the effects of their condition or injury, should develop and oversee the emotional health and wellbeing element of the person's rehabilitation plan.
The British Psychological Society	Guideline	036	010 - 017	• People with neurological conditions often experience a combination of emotional, cognitive and behavioural consequences. Practitioners need to be able to understand these difficulties to adapt mental health support to account for them. Cognitive changes need to be assessed, and support offered to patients to understand and cope with these. Changes in cognitive function can also be accompanied by a lack of awareness of such changes in the individual. Family members need to be included in the support. All of this means that an individual psychotherapy model of care is often not appropriate for the needs of this population. • A matched care model, where those with the most complex problems related to their neurological condition receive the most specialist support, would be favourable. This would depend on skilled triage in the neuroscience centre. • There should be adequate training and supervision for all mental health therapy staff working with those with neurological conditions, to help them develop the essential skills required to adapt therapy to working with people with neurological conditions. Supervision arrangements need to be in place between the mental health staff and the tertiary neuroscience service, with opportunities for patient transfer if the individual patient needs cannot me met by the mental health service. • Clinical neuropsychologists should be involved in the assessment and delivery of interventions for those with the most complex cognitive, behavioural and emotional problems linked to their neurological condition, and in the supervision and training of staff delivering mental health interventions for people with neurological conditions. This is because of the need to tailor mental health interventions to the cognitive, behavioural and emotional consequences of the neurological condition. Mental health/ cognitive/ behavioural interventions for people with complex problems related to neurological conditions are often not effective if they are only carried out by one discipline in isolation, and if	Thank you for your comment. The committee agree with the comment, the assessment section in emotional health and wellbeing has been extensively edited and a more collaborative approach with the cognitive section is adopted. A new recommendation has been made in the emotional health and wellbeing section of the guideline that states a registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse), and an understanding of the person and the effects of their condition or injury, should develop and oversee the emotional health and wellbeing element of the person's rehabilitation plan. Furthermore, a recommendation was made to assess emotional health and wellbeing, behaviour and cognitive function (see the section on cognitive function), when completing a neuropsychological assessment, indicating a collaborative approach. Throughout the guideline, there is reference to the integration of family members and carers in the planning, assessment and management, there is a recommendation in the emotional health and wellbeing section of the guideline to work with family, carers, people important to the person and the person's social networks when agreeing the most appropriate interventions to improve or sustain emotional health and mental wellbeing. The committee agree that there should be adequate training and supervision for all mental health therapy staff working with those with neurological conditions, to help them develop the essential skills required to adapt therapy to working with people with neurological conditions. There is a new recommendation in the building local capacity and expertise section of the guideline to develop local workforce skills to build capacity for neurorehabilitation and mental health services for people with a chronic neurological disorder. Furthermore, a new recommendation was made in the cognitive section of the guideline states that a registered practitioner with expertise in neuropsychology (for example, a clinical psychologist, counselling psychologist or neuropsychologist), and an understanding of the person and the effects of their condition or injury, should oversee and interpret cognitive assessments and oversee the cognitive functioning element of the person's rehabilitation plan. Additionally, neuropsychologists have been listed in the glossary alongside other registered professions by the health and care professions council as rehabilitation practitioners.

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				they are carried out only with the individual, without family involvement. The mental health care of people with complex cognitive, emotional or behavioural difficulties linked to neurological conditions should be addressed by a multidisciplinary team approach that supports the person with the neurological condition and their family. This could be incorporated within the interventions offered by a community brain injury team, if clinical neuropsychology were appropriately funded to be a core member of a community team.	
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	036	010 - 028	These recommendations around talking therapies are phrased as optional rather than directive, e.g. "consider CBT or mindfulness". This weakens their implementation potential. Without clear minimum standards or session frequency, psychological support risks being overlooked or de-prioritised.	Thank you for your comment. The committee's discussion of evidence in evidence review H highlighted that the evidence to support interventions for adjustment and engagement were different in their duration, intensity, and delivery, therefore it was difficult to recommend a specific type of CBT or mindfulness intervention other than talking therapy for adjustment and engagement in people with CND. In view of this, the committee agreed to a "consider" recommendation for CBT or mindfulness and agreed that there wasn't sufficient evidence to recommend a stronger recommendation about the specific session duration, intervention, or delivery.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	036	014	We considered that low mood, anxiety & distress all very probably present a barrier to daily activity. Although it is addressed in line 10, if recommendations in 11 were implemented without appropriate assessment and treatment, then the recommendations could be harmful. In other words, MI and psychoeducation should not be a first or automatic treatment before assessment of the root cause.	Thank you for your comment. The committee agree that a comprehensive assessment by health care professionals with expertise is critical for the emotional health and wellbeing of a person with CND to guide appropriate treatment. There have been significant changes to the recommendations in 'principles of assessment, referral and intervention selection' under 'emotional health and wellbeing' to reflect this, and these now also link with the cognitive section of the guideline. A recommendation emphasising the importance of expertise when conducting assessment states that a registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse) with an understanding of the person and the effects of their condition or injury should develop and oversee the emotional health and wellbeing element of their rehabilitation plan. Furthermore, there is a new recommendation to assess emotional health and wellbeing, cognitive function and behaviour, when completing a neuropsychological assessment (see also the section on cognitive function). These recommendations aim to ensure comprehensive assessment before the selection of treatment.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	036	016	Consider adding to line 16 *'…psychoeducation, cognitive behavioural therapy (CBT) and motivational'*	Thank you for your comment. We have added your suggestion into the recommendation.
Oxford University Hospitals - Paediatric Neuropsychology Department	Guideline	036	018	We agree that this is important and feel that needs to be expanded on significantly as this can be a major need in this population which does not seem to be addressed in full within the guidance.	Thank you for your comment. Evidence review H identified 2 studies on interventions for adaptive dysfunction and behaviours that challenge others. Based on the evidence identified, the committee agreed that no further recommendations could be made.

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Rehabilitation for chronic neurological disorders including acquired brain injury

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Central London and Community Healthcare Trust	Guideline	036	020	1.18.13 To add to this point, it may be helpful to signpost to the use of adapted outcome measures or those validated for people with communication/cognitive difficulties	Thank you for your comment. The committee agree with you and they felt it is implicit that adapted outcome measures or those validated for people with communication or cognitive difficulties are used. However, it is beyond the scope of the emotional health and wellbeing question to go into details about which adapted outcome measures should be used. Furthermore, the committee agree that the breadth of conditions and complexities within those would make it very difficult to account for every circumstance, which is why it is not possible to individualise the recommendations. Therefore, no change has been made in light of your comment.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	036	020	We would like to see involvement of speech and language therapist as the first and preferred option, to enable equitable access to the most evidenced psychological therapies, before considering creative therapies.	Thank you for your comment. We agree with your comment and have re-ordered the recommendations on interventions in emotional health and wellbeing to reflect this. The recommendation about taking into account the person's cognitive and communication needs when delivering talking therapies and making adjustments is now before the recommendation on creative therapies. This now reflects equitable access to the most evidenced psychological therapies, before considering creative therapies.
Defence Medical Rehabilitation Centre	Guideline	036	020	We are concerned that this recommendation misses the option of referring to neuropsychology for neuropsychological psychotherapy, or interdisciplinary working (e.g. between SLT, OT, neuropsychology and creative therapies) which would/could be adapted for cognitive and/or communication needs	Thank you for your comment. The committee agreed and have added in a new recommendation in the emotional health and wellbeing section of the guideline to make referrals to emotional health and mental wellbeing services with the most appropriate expertise, based on the person's needs and circumstances. Assessments or interventions may be provided by: • neurorehabilitation services • mental health services • voluntary, community and social enterprise (VCSE) organisations • education services (for children and young people, those delivered by a special educational needs coordinator or through an emotional literacy support assistant programme, for example).
Royal College of Speech and Language Therapists	Guideline	036	022	The acknowledgement that cognitive and/or communication problems can impact on access to talking therapies is welcome. However, there is a risk of inequity by only suggesting alternative provision. It is possible to adapt talking therapies to allow access for people with communication difficulties. A speech and language therapist can support mental health professionals to do this, for example where a person is using augmentative or alternative communication (AAC). People with functional neurological disorders, in particular, often experience issues accessing appropriate support because they are referred to psychological therapies which they are unable to access, due to significant communication symptoms. This highlights the need for appropriately commissioned interdisciplinary services, including speech and language therapy, to ensure equitable access to care.	Thank you for your comment. We agree with your comment and have re-ordered the recommendations on interventions in emotional health and wellbeing to reflect this. The recommendation on taking into account the person's cognitive and communication needs when delivering talking therapies and making adjustments is now before the recommendation on creative therapies. This now reflects equitable access to the most evidenced psychological therapies, before considering creative therapies. Furthermore, there is a recommendation stating that when assessing a person's emotional health and mental wellbeing, recognise that emotional health and mental wellbeing may be adversely impacted by unmet needs in other areas of rehabilitation. If this is the case, follow other recommendations in this guideline to meet those unmet needs. For example, if a person has speech, language, or communication difficulties

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				See: Barnett, C., Davis, R., Mitchell, C., & Tyson, S. (2020). The vicious cycle of functional neurological disorders: a synthesis of healthcare professionals' views on working with patients with functional neurological disorder. *Disability and Rehabilitation*, *44*(10), 1802–1811. https://doi.org/10.1080/09638288.2020.1822935	they would follow recommendations in the speech. language, and communication section of the guideline where recommendations on assessment by a speech and language therapist sit alongside referral for interventions e.g. augmentative and alternative communication aids.
Shaftesbury Icanho	Guideline	036	023	1.18.14 – same as above – hard for services to implement these guidelines with current resources.	Thank you for your comment. The committee acknowledged the current lack of mental health services and considered resource implications and cost effectiveness in supporting discussions, including about evidence review H. They discussed potential benefits such as timely, appropriate care; reduced distress for people with CND; improved emotional wellbeing; greater engagement with rehabilitation; better outcomes; and possible overall NHS cost savings. They also made recommendations on service design to improve efficiency, potentially freeing resources and funds for other uses, including for emotional health and wellbeing services. The committee also made recommendations on capacity building. The committee hopes their recommendations will be adopted and appropriately funded.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	036	023 - 025	We thought the additional benefits of group interventions for emotional health and wellbeing should be included in this section. We recommend an additional sentence after line 25 'Group interventions can afford additional therapeutic advantages by providing peer support, enabling patients to learn directly from other peers' experiences and facilitating insight, awareness and acceptance of disabilities, and should be considered accordingly.'	Thank you for your comment. We didn't identify evidence that group interventions were superior to individual sessions, therefore rather than add an additional sentence to the recommendation we have included it in the committee's discussion of evidence in evidence report H.
South London and Maudsley NHS Foundation Trust	Guideline	036	026	Rec 1.18.15 - The reasonable adjustments required for delivering psychological therapy in these circumstances require expertise. This could be delivered by therapists with experience in the field, ideally with supervision by neuropsychologists, or neuropsychologists themselves.	Thank you for highlighting this. We have added your suggestion into the committee's discussion of evidence in evidence review H.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	036	General	People with Chronic neurological disorders may also develop functional neurological symptoms resulting in worsening of the symptoms. Identification and Interventions for functional neurological symptoms is often required.	Thank you for your comment, with which the committee agree. They added a new recommendation to the sections on initiating holistic rehabilitation needs assessment and who to involve. The recommendation states to be aware that a person may have multiple chronic neurological disorders, including a functional neurological disorder alongside another neurological disorder. If this is the case, undertake holistic rehabilitation needs assessment based on the impact of all disorders and agree a single rehabilitation plan.
Nottingham University Hospitals Department	Guideline	036 - 037	026	We agreed that this was helpful guidance	Thank you for your support of the guideline.

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of Clinical Psychology and Neuropsychology					
Inflammatory Neuropathies UK	Guideline	037	006	Within this section (or in a separate additional section) we would like to see trauma highlighted (as a result of diagnosis of a life altering condition, or after significant trauma at point of onset – such as through ICU) along with access to trauma informed therapy and practise	Thank you for your comment, with which the committee agree. They have added a new recommendation in the section on holistic rehabilitation needs stating to be aware that people who have experienced trauma as a direct result of their injury or condition, or prior life experiences, or both, may need adaptions to assessment, rehabilitation and support plans.
Success – Life After Cure Ltd	Guideline	037	006	Rec 1.18.16 We feel survivors of childhood brain tumours meet the criteria for a chronic neurological disorder with mental health disorders being an important area of under-recognised need we hear about at the charity. We also hear major challenges in accessing any support, particularly during childhood due to the overstretched CAMHS services and the complexity of their neurobehavioural disorders, particularly when the tumour affects the deep midbrain.	Thank you for your comment. The guideline committee were aware that some mental health services have admittance criteria that specifically exclude people with a diagnosis of a chronic neurological disorder, which was supported by qualitative evidence. In view of this, the guideline executive document will highlight to NHS England the inequality in accessing mental health services for people with chronic neurological disorders.
Defence Medical Rehabilitation Centre	Guideline	037	006	Although a recommendation to treat diagnosed post-traumatic stress disorder, anxiety, and depression we are concerned that neurological rehabilitation teams without embedded mental health professionals (e.g., Clinical Psychologists, Psychiatrists) will not understand or recognise signs and symptoms of these emotional wellbeing presentations without further training.	Thank you for your comment. The committee recognised that services differ in their capacity and expertise, and in view of this they wrote recommendations on building local capacity and expertise. Specifically, the committee recommended to build capacity for mental health services for people with a chronic neurological disorder through local workforce skills development and communication protocols between different services involved in rehabilitation. Furthermore, the committee recognised that GPs or other primary care practitioners may not be equipped to treat people with chronic neurological disorders and recommended that GPs and other primary care practitioners know how to recognise emerging rehabilitation needs because of an existing chronic neurological disorder, and know when and how to refer people to rehabilitation specialists. For example, using expertise from specialist neurorehabilitation services and maintaining up-to-date information on options for local rehabilitation services.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	037	006 - 015	We were concerned that the optimal benefits of treating emotional sequelae as part of a single-service interdisciplinary team were not part of this section and wondered if a sentence could be added after line 15: 'Such treatment is optimally delivered as part of a single interdisciplinary neurorehabilitation service. Where it is not, close liaison and goal reviews between the services providing rehabilitation for the patient should be included in the treatment planning.'	Thank you for your comment. The committee agree and have edited a recommendation in the section on 'agreeing, delivering and reviewing a coordinated rehabilitation plan'. They added that when agreeing the interventions and approaches that will constitute the rehabilitation plan, consideration should be given to how practitioners will liaise and work jointly with one another.
PTSD UK	Guideline	037	006 – 015|	1.18.16 - We welcome the recommendation to treat diagnosed PTSD as part of rehabilitation. However, PTSD is often under-recognised following acquired brain injury, particularly mild TBIs. We recommend that this section encourages assessment for PTSD where symptoms such as avoidance, hyperarousal, or intrusive thoughts are present –	Thank you for your comment. Given the symptom overlap between mental health conditions and chronic neurological disorders, we agree that screening for mental health conditions is important in chronic neurological disorders. The committee therefore added "screen for" to the recommendation on treating diagnosed post-traumatic stress disorder, anxiety and depression in adults with chronic neurological disorders, and

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				especially as they may be mistakenly attributed solely to cognitive or behavioural consequences of brain injury.	depression in children and young people with a chronic neurological disorder, as part of their rehabilitation.
Central London and Community Healthcare Trust	Guideline	037	012 - 014	1.19.4 and 1.19.5 There is a need to include taking into account cultural factors/issues and use of cultural appropriate tests if possible, where appropriate.	Thank you for your comment. We agree that it is important to assess the impact of culture in the rehabilitation plan. There was already a recommendation in the draft guideline under holistic rehabilitation needs assessment to ask the person about their background, relationships, work, education, meaningful activities, spiritual and religious practices, and hobbies and review as part of the rehabilitation plan. Furthermore, under the goal setting section, a recommendation was made to focus on optimising participation in the most important aspects of the person's life, which could entail the person's spiritual/religious beliefs if the person highlighted it as an important part of their life.
The Stroke Association	Guideline	037	016	We welcome that the guidance makes reference to assessment of visual function. The British and Irish Orthoptic Society and the Vision group at Liverpool University have identified that the guidance could be strengthened by adding further detail on screening and interventions for visual issues. The Stroke Association fully supports the 2023 NICE guidance for rehabilitation for adults who have had a stroke which includes recommendations and additional detail – we were involved in the development of this guideline and its implementation[4]. This guidance includes offering people a specialist orthoptist assessment as soon as possible, and offering eye movement therapy for people who have persisting hemianopia and consulting with Driver and Vehicle Licensing Agency regulations where the person drives. Many people who have a stroke and those with chronic neurological conditions will experience problems with their vision. Without a specialist orthoptist, there are risks that some people will not have their vision problems identified, and ongoing issues can worsen if problems are not identified early[5].	Thank you for your comment. We have included a new recommendation on the assessment of visual, hearing, and balance issues within the section on what to cover in the holistic rehabilitation needs assessment. From this, we have linked to subsequent recommendations on interventions for vestibular problems. The scope of this guideline does not cover interventions to support visual or hearing impairment, so further recommendations covering the later stages of these rehabilitation pathways cannot be included. However, we hope that making a specific recommendation on assessment, along with several recommendations throughout the guideline on information for people with chronic neurological disorders and increasing knowledge of healthcare professionals on appropriate referrals, will increase access to the appropriate services (including specialist orthoptist assessment if needed).
The British Psychological Society	Guideline	037 - 038	General	The cognitive functions interventions are not detailed enough. Sources for evidence/ guidelines include: • SIGN 130 - Brain injury rehabilitation in adults – this guidance provides a lot more detail on appropriate interventions for people with cognitive difficulties.	Thank you for your comment. The committee discussed your responses but agreed that they are unsure what detail is missing. Nonetheless, in light of other stakeholder comments and further discussions some details were added for the cognitive function interventions, for example to not only explain compensatory strategies to a person's family and carers but also to

[4] Recommendations | Stroke rehabilitation in adults | Guidance | NICE
[5] Recommendations | Stroke rehabilitation in adults | Guidance | NICE

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				• INCOG 2.0 Guidelines for Cognitive Rehabilitation Following Traumatic Brain Injury: What's Changed From 2014 to Now? • National Clinical Guideline for Stroke	other people who are important to that person. In terms of the guidelines you mention, unfortunately NICE can only cross-refer to other guidance in 2 cases. Firstly, if there are already published NICE recommendations on a subject. Secondly, by stating, a priori, that guidelines would be an accepted evidence source in a systematic review. In this case, relevant guidelines would be included and subject to critical appraisal and then considered by the committee as a basis for recommendations. They could also cross refer to the included guideline. None of the 3 guidelines you list meet our review protocol criteria (because guidelines were not stated as a type of study to be included), so they cannot be referenced in the guideline.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	037 - 038	General	We recognise that various professions make a valuable contribution to assessing cognition; such as screening for dementia or general cognitive impairment, and also how cognitive impairments interfere with everyday activities (functional assessment). We think that it would be helpful if the guidance clarified different types of assessment, and the scope of assessment. For instance, we thought that consideration of social cognition was helpful in the list (line 11). We think that other impairments are also important clinically, such as neurobehavioral disturbance and emotion regulation problems. We recommend that the committee considered clarifying and broadening this section, to include what we would term neuropsychological assessment, perhaps with cognition as a subset.	Thank you for your comment. The committee agreed that issues such as neurobehavioural disturbances and emotion regulation problems are covered in the section for 'Emotional Health'. Furthermore, the issue of neurobehavioural disturbances have been added to some recommendations including that a neuropsychological assessment should be considered, especially if there are neurobehavioural disturbances and changes.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	037 - 038	General	Whether or not the committee decide to include the term 'neuropsychological assessment'; this area represents the core expertise of the profession of neuropsychology, and yet we noted the absence of any specific refence to the role of neuropsychologists. We recognised that there is substantial variation across services in terms of the presence of neuropsychologists, not dissimilar to speech and language therapists. Where present, our role and clinical perspective is highly valued by the team and by patients. This guidance has made a good case for the role of speech and language therapists, and we recommend that neuropsychology is afforded similar in the guidance.	Thank you for your comment. The committee agreed with your comment and have added a definition of neuropsychologists to the glossary section. Furthermore, recommendations have been added to consider a joint neuropsychological assessment for both emotional health and cognitive function as well as that assessments should be developed and undertaken by registered practitioners with expertise in neuropsychology and an understanding of the person's condition or injury.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	037 - 038	General	Further to the question of competencies required to conduct cognitive assessment, the committee may consider the British Psychological Society (Code of Good Practice) and BPS levels of training and competence. Relatedly, the committee may be aware that many cognitive tests are regulated at the point of purchase (e.g. Pearson's 3 level qualification policy) in order ensure competence in their use. These, of course, sit within the context of HCPC requirement to work	Thank you for your comment, with which the committee agree. They therefore added a definition of neuropsychologists to the glossary section. Recommendations have also been added to consider a joint neuropsychological assessment for both emotional health and cognitive function as well as that assessments should be developed and undertaken by health practitioners with expertise in neuropsychology and an understanding of the person's condition or injury.

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				within professional competencies. As a group, we have all seen examples of other professions using cognitive assessments not for the purpose there were designed and validated; and misinterpretation of results obtained. Indeed, this could be described as frequent in services that lack appropriately trained specialists, where staff do the best they can with what they have. With these considerations in mind, our group agreed that this NICE guidance should play an important role in promoting safe and quality clinical practice with regard to cognitive assessment. Acknowledge that there may be gaps in service provision; they should be filled; and reinforce the message that the assessment of many cognitive domains (those listed page 38 lines 5 – 11) require specialist training and qualification.	
The Wolfson Neurorehabilitation Service	Guideline	038	001 - 011	**Cognition (1.19.3)** We recommend adding 'Cognitive Communication Disorder (CCD)' as a domain for assessment and explicitly mentioning the impact of medication on cognitive function.	Thank you for your comment. The committee agreed and have added a couple of recommendations. One to assess and plan a rehabilitation plan with speech and language therapy if a cognitive communication order is suspected. And one to think about the possible impact of any existing medication on impairment (for example, cognitive function) and review medication as part of rehabilitation planning.
The British Psychological Society	Guideline	038	001 - 022	If a patient has complex cognitive problems (not progressing in rehabilitation as they should or are experiencing symptoms that are moderate and impact on their daily life/ ability to work) they should be referred for a cognitive assessment with a clinical neuropsychologist. Clinical neuropsychologists are the only professional group qualified to carry out a detailed assessment of the areas listed in the assessment and take account of cognitive function. Many of the psychometric tools that would be used require a qualification in psychology to be administered. Other professional groups such as speech and language therapists and occupational therapists have been listed as needing to be involved an assessment for their specialist areas. Therefore, the need for a clinical neuropsychologist for complex cognitive assessment and treatment of emotional mental health issues in complex cases should be included.	Thank you for your comment. The committee agreed with your comment and have added a definition of neuropsychologists to the glossary section. Furthermore, recommendations have been added to consider a joint neuropsychological assessment for both emotional health and cognitive function as well as that assessments should be developed and undertaken by health practitioners with expertise in neuropsychology and an understanding of the person's condition or injury.
British Association of Brain Injury and Complex Case Management	Guideline	038	002	1.19.3 In relation to cognitive testing and interventions we agree the importance of the suggestions made and would like to add that cognitive tests must be carried out by suitably qualified and experienced professionals – most often clinical/neuro psychologists, occupational	Thank you for your comment. The committee agreed and have added a recommendation that assessments should be developed and undertaken by registered practitioners with expertise in neuropsychology and an understanding of the person's condition or injury.

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				therapists (OTs), speech therapists (SLTs), doctors and registered nurses Intervention is most often carried out by psychologists, OTs and SLTs	
South London and Maudsley NHS Foundation Trust	Guideline	038	002	Rec 1.19.3 - Particularly in complex cases this level of cognitive assessment will require to be delivered by neuropsychologists or clinical psychologist who specialise in neuropsychology.	Thank you for your comment. The committee agreed and have added a recommendation that assessments should be developed and undertaken by registered practitioners with expertise in neuropsychology and an understanding of the person's condition or injury.
South London and Maudsley NHS Foundation Trust	Guideline	038	002	Rec 1.19.3 – Where relevant performance validity measures should also be used in cognitive assessments.	Thank you for your comment. We believe your concern regarding performance validity measures is addressed in the recommendation about providing in depth detail about how to conduct assessments and how to interpret these results (including considering external factors).
Cambridge University Hospital NHS Foundation Trust	Guideline	038	002 - 011	Cognitive assessment – Needs to include "use repeat cognitive assessments to track the developmental trajectory for children and young people affected by neurological conditions" Triangulate scores on standardised measures with parent report and schools report. Needs to include "track academic attainment to understand the impact of the condition on their developmental trajectory"	Thank you for your comment. The committee agreed and have added a recommendation for repeat cognitive assessments to track the developmental trajectory for children and young people.
Oxford University Hospitals - Paediatric Neuropsychology Department	Guideline	038	004	We feel that 'reasoning abilities' should be included within this list.	Thank you for your comment. The committee discussed your responses but agreed that 'reasoning abilities' is considered under the outcome of 'executive function' and have therefore decided not to add this as a separate outcome.
Guy's and St Thomas' NHS Foundation Trust	Guideline	038	011	Rec 1.19.3 Social cognition is a term describing a variety of disparate cognitive, affective, and behavioural abilities which interact to contribute to our interactions with other people. As such, there are parallels with executive function in the wealth of assessment tools available. However, in our experience these are not yet as well-established in clinical services and clinicians do not have as much experience in assessing social cognition. We would find it beneficial if the section of social cognition is expanded upon to include a definition of social cognition (in Page 53, Terms use in the guideline) which includes reference to the multi-dimensional nature of social cognition, and therefore the multiple types of assessment that can be used (e.g., behavioural assessment tools, functional integration of the young person with their social world). For consideration: Wallis, K., Kelly, M., McRae, S. E., McDonald, S., & Campbell, L. E. (2021). Domains and measures of social cognition in acquired brain injury: A scoping review. *Neuropsychological*	Thank you for your comment. The committee agreed with your comment and have added a definition of social cognition to the glossary. Unfortunately the suggested reference by Wallis et al (2021) does not meet the inclusion criteria for this review as this is a scoping review and not a systematic review.

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				Rehabilitation, 32(*9*), 2429–2463. https://doi.org/10.1080/09602011.2021.1933087	
The Association of British Neurologists	Guideline	038	012	1.19.4 "Use both standard cognitive tests and functional assessments when assessing the person's cognitive strengths and weaknesses". In Functional Cognitive Disorder, functional assessment, observation, and dynamic testing are often more informative than standard psychometric tests. This reflects real-world practice and avoids misdiagnosis or unnecessary escalation (e.g. for dementia). We recommend drawing on Functional Cognitive Disorder consensus statements (e.g. Ball et al., 2020)	Thank you for your comment. The committee agreed and have added a recommendation to be aware that for people with functional neurological disorders functional assessment, observation, and dynamic testing are often more informative than standard cognitive tests
Defence Medical Rehabilitation Centre	Guideline	038	012	Consider adding into this section that the professionals completing the assessments must be appropriately trained and competent at completing assessments and analysing the results.	Thank you for your comment. The committee agreed and have added a recommendation that assessments should be developed and undertaken by registered practitioners with expertise in neuropsychology and an understanding of the person's condition or injury.
Central London and Community Healthcare Trust	Guideline	038	012	1.19.4 To add to these recommendations for cognitive assessment, is it important to include clinical interview with the family/other/collateral information as key part of the holistic assessment process to build a clear rationale for formulation.	Thank you for your comment. Section 1.8 includes 'Initiating holistic rehabilitation needs assessment and who to involve' and covers who to involve in assessments and rehabilitation needs. Furthermore there are recommendations throughout the guideline and the cognitive function section to include family, carers, and/or other people close the person's in the rehabilitation and assessment needs. There is also a recommendation to "plan cognitive rehabilitation based on the results of the cognitive assessment" to which we have added "to take into account the input of family, carers and other people important to the person and involved in their rehabilitation."
Independent Neurorehabilitation Providers Alliance	Guideline	038	012	Full cognitive assessment should be completed by a neuropsychologist but for many patients this is not an option due to the national shortage of neuropsychologists. This needs to be addressed in order to meet the recommendation for cognitive assessment.	Thank you for your comment. The committee agreed and have added a recommendation that assessments should be developed and undertaken by health practitioners with expertise in neuropsychology and an understanding of the person's condition or injury.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	038	012 - 013	Related to the wider issues of model and terminology adopted by the guidance, we recommend that the committee make clear to the reader the distinction between mental functions (aka cognitive processes) and activity (aka everyday functioning). Clarify that cognitive tests are designed to evaluate mental functions whilst activity performance (aka everyday functioning) is evaluated via functional assessments and observations gathered from the patient and their family.	Thank you for your comment. We have added a definition of cognitive tests into the glossary, which addresses your point.
Nottingham University Hospitals NHS Trust -	Guideline	038	012 - 013	Consider acknowledging that assessment of mental functions is highly specialist, and services should refer to a profession like Clinical Neuropsychology if cognitive impairment is having a significant impact	Thank you for your comment, with which the committee agree. They therefore added a recommendation that assessments should be developed

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National Rehabilitation Centre				on the patient's usual day-to-day activities. (This would then be consistent with the guidance regarding speech and language therapy, in section 1.20.3)	and undertaken by registered practitioners with expertise in neuropsychology and an understanding of the person's condition or injury.
Inflammatory Neuropathies UK	Guideline	038	014	Need to add in 'the impact of any additional factors or variables that could impact on an individuals life'	Thank you for your comment. The recommendation already encompasses a large range of variables that should be taken into account when deciding assessment techniques and how to interpret results; therefore no further changes were made.
Central London and Community Healthcare Trust	Guideline	038	014	1.19.5 To add to these recommendations, we believe it is important to consider adding: take into account that language background (e.g. if English is not a first language) and cultural factors when selection assessment techniques and interpretation of the results. With that in mind there are cost implications for ensuring, where appropriate, there are translation services available with staff that are *trained in best practice* in understanding the role of translator in neuropsychological assessment and how to do this appropriately and correctly whilst remaining culturally sensitive.	Thank you for your comment. The committee agreed and have added to the recommendation to also take into account the person's cultural, linguistic and educational background. The NHS is legally required to provide interpreting and translation services to ensure that all people can access healthcare. Therefore, translation services should already be available and no resource impact is anticipated. However, the committee agreed that staff may need additional training in best practices and there may be some resource implications where practices are sub-optimal. We included further detail to acknowledge this in the supporting discussion in evidence review G on rehabilitation for cognitive function.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	038	014 - 022	We recommend clarifying that, when deciding which assessment techniques to use, take account of: the purpose of assessment, for instance evaluation of mental functions or evaluation of everyday functioning. Because of their widespread use, advise that cognitive screening tests can be a helpful first step, but should not be interpreted beyond their intended use.	Thank you for your comment. We have added a definition of 'cognitive tests' to the glossary and believe some of these concerns are also addressed in the definition of 'functional assessments'. In addition, in the assessment section of cognitive function there was already a draft recommendation to take into account a person's cognitive ability before the neurological injury, the demands of the test and functional assessment, how symptoms and fatigue may influence the assessment, and the impact of any other health conditions on the assessment. Furthermore, there was also a draft recommendation to explain the format and purpose of any cognitive test prior to using them. These recommendations were retained for the final guideline as the committee felt they addressed your concerns.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	038	014 - 022	We recommend that 'patient engagement with the assessment' should be added, perhaps alongside fatigue, mood, pain.	Thank you for your comment. The committee discussed and agreed not to add this to this recommendation as the recommendation already covers taking into account the person's cognitive ability prior to the assessment, the demands of the test and the environment in which the tests are being undertaken, how symptoms such as mood may affect testing, and the impact of other health conditions on testing and assessments. Furthermore, there is a also a recommendation to produce service specifications for integrated rehabilitation care for people with a chronic neurological disorder to include other interventions to support engagement in education, employment, social and leisure activities, parenting, family life, friendships and intimate relationships.

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Rehabilitation for chronic neurological disorders including acquired brain injury

Consultation on draft guideline - Stakeholder comments table
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Rotherham, Doncaster and South Humber NHS Foundation Trust	Guideline	038	016	1.19.5 Cognitive function - Assessment May I suggest this is reworded to "*The person's cognitive* and intellectual *ability before neurological injury…"*	Thank you for your comment and suggestion. This has now been added to the recommendation.
Royal College of Speech and Language Therapists	Guideline	038	016	Throughout this guideline there is a separation of cognitive and communication skills, which does not account for the high prevalence of cognitive-communication disorder (CCD) in this group and risks ignoring their complex needs. While it is welcome that assessment of language is mentioned in this section, a speech and language therapist must be involved to ensure a full assessment of all aspects of language and communication, with consideration of interplay with social cognition, memory and other sequelae. See: • Bayley, M. T et al (2023) INCOG 2.0 Guidelines for Cognitive Rehabilitation Following Traumatic Brain Injury: Methods, Overview, and Principles *Journal of Head Trauma Rehabilitation* 38(1):p 7-23 https://doi.org/10.1097/HTR.0000000000000083 • MacDonald, S. (2017). Introducing the model of cognitive-communication competence: A model to guide evidence-based communication interventions after brain injury. *Brain Injury*, *31*(13–14), 1760–1780. https://doi.org/10.1080/02699052.2017.1379613 • Togher, L. et al (2023) INCOG 2.0 Guidelines for Cognitive Rehabilitation Following Traumatic Brain Injury, Part IV: Cognitive-Communication and Social Cognition Disorders. *Journal of Head Trauma Rehabilitation* 38(1):p 65-82 https://doi.org/10.1097/HTR.0000000000000835	Thank you for your comment. The committee agreed and have added a recommendation to assess and plan a rehabilitation plan together with speech and language therapy if a cognitive communication disorder is suspected. Unfortunately the references provided do meet the inclusion criteria for this review. MacDonald (2017) is not a intervention or systematic review. NICE can only cross-refer to other guidance in 2 cases. Firstly, if there are already published NICE recommendations on a subject. Secondly, by stating, a priori, that guidelines would be an accepted evidence source in a systematic review. In this case, relevant guidelines would be included and subject to critical appraisal and then considered by the committee as a basis for recommendations. They could also cross refer to the included guideline. As the Guidelines by Bayley and Togher did not meet our review protocol criteria (because guidelines were not stated as a type of study to be included), they cannot be referenced in the guideline.
PTSD UK	Guideline	038	016 - 027	1.19.1 – 1.19.7 - We recommend that the interaction between cognitive difficulties and trauma-related symptoms be recognised explicitly in this section. PTSD and C-PTSD can impact executive function, memory, and attention – potentially complicating assessment and rehabilitation. A person with both a brain injury and PTSD may require trauma-informed adaptations to cognitive rehabilitation. Suggested addition to 1.19.7: "...and consider whether trauma or PTSD may be contributing to cognitive difficulties. If suspected, involve trauma-informed professionals in rehabilitation planning."	Thank you for your comment. The committee agreed and have added a recommendation to be aware that emotional disturbance (e.g. low mood, anxiety, and psychological trauma) can impact cognitive function. The committee decided to make this recommendation broader than just focusing on PTSD alone, and instead include 'emotional disturbances' as all of these can impact cognitive function. Furthermore, people who are assessed for PTSD may be defined as being just under the threshold for PTSD; however psychological trauma can still impact their cognitive function.

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Defence Medical Rehabilitation Centre	Guideline	038	020	Recommend signposting to 'INCOG 2.0 Guidelines for Cognitive Rehabilitation Following Traumatic Brain Injury, Part II: Attention and Information Processing Speed' for consideration of additional interacting factors.	Thank you for your comment. Unfortunately, NICE can only cross-refer to other guidance in 2 cases. Firstly, if there are already published NICE recommendations on a subject. Secondly, by stating, a priori, that guidelines would be an accepted evidence source in a systematic review. In this case, relevant guidelines would be included and subject to critical appraisal and then considered by the committee as a basis for recommendations. They could also cross refer to the included guideline. As the 'Guidelines for cognitive rehabilitation following traumatic injury, part II' did not meet our review protocol criteria (because guidelines were not stated as a type of study to be included), they cannot be referenced in the guideline.
Shaftesbury Icanho	Guideline	038	023	1.19.6 – do you also need to include NICE guidelines for feeding back the assessment results to clients and/or family members etc in the most appropriate format for them to understand?	Thank you for your comment and concern. The committee agree this is already addressed by the recommendation about helping the person and their family or carers, if appropriate, to understand, build insight and awareness of, and adjust to any difficulties with cognitive function. Therefore no further changes have been made.
Defence Medical Rehabilitation Centre	Guideline	038	025	Cognitive rehab may also include interventions to manage interacting factors such as sleep, fatigue, mood, and pain (as per 'INCOG 2.0 Guidelines for Cognitive Rehabilitation Following Traumatic Brain Injury, Part II: Attention and Information Processing Speed').	Thank you for your comment. The recommendation states to plan cognitive rehabilitation based on the results of the cognitive assessment. An earlier recommendation in the draft guideline also mentioned to take into account symptoms such as fatigue, low mood or pain and how they might affect testing and assessment when deciding on assessment techniques and interpreting results. The committee is happy that between these 2 recommendation, the point is covered that cognitive rehabilitation potentially also includes interventions to manage factors such as sleep, fatigue, mood, an pain.
Central London and Community Healthcare Trust	Guideline	038	025	1.19.7 When considering cognitive rehabilitation, we recommend adding a consideration here for the impact of the assessment results feedback on acceptance and adjustment, its impact on sense of identity and emotional wellbeing, and consideration of whether these may create barriers for engagement and how to consider these within rehabilitation. E.g. difficulties accepting that there are cognitive difficulties or where awareness may impact on insight into difficulties thus affecting engagement.	Thank you for your comment. The guideline does consider acceptance and making adjustments on several occasions. For example, a recommendation in section 1.8 is about making reasonable adjustments and adaptations to enable a person with memory and learning difficulties to engage in rehabilitation. Recommendations in the pain management section also refer to psychological, individual, or group interventions to help with acceptance and adjustments. Therefore no changes were made in light of your comment.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	038	025 - 028	We recommend adding that, once a patient's goals and priorities have been established, then planning their cognitive rehabilitation should be rooted in an understanding a patient's mental functions alongside their everyday problems (aka performance limitations). Also consider moving this paragraph into the next section.	Thank you for your comment. The committee agreed and in response, have broadened the recommendation, which now reads "Plan cognitive rehabilitation based on the results of the cognitive assessment, taking into account • everyday problems with cognitive function • any interaction between the domains listed in recommendation 1.18.9

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					(which include orientation, processing speed, visual, spatial and perceptual cognition, language, attention and working memory, learning and memory, executive function, and social cognition) • the person's preferences • the suitability of group or individual activities • the person's retained and emerging cognitive skills • the input of family, carers and other people important to the person and involved in their rehabilitation."
Central London and Community Healthcare Trust	Guideline	038	General	1.19 In the section on assessment and intervention, it is worth considering placing emphasis on 'collaboration' with the client. Much focus on 'explain' but engagement very much based on a collaborative approach and considering for example the strengths the client already has in cognition and how to use these to support compensating for cognitive challenges elsewhere. In general, is it worth considering bringing in some aspects of positive psychology approach such as resilience and strengths building into the narrative?	Thank you for your comment. The assessment section of the cognitive function recommendations are about collaboration. The recommendation about explaining the format and purpose of any test before using them involves a collaborative approach between practitioners and patients. The general section on pathways, assessments, and planning rehabilitation involves collaboration and puts emphasis on engagement and collaboration being a key to rehabilitation. For these reasons, no changes were made in light of your comment.
South London and Maudsley NHS Foundation Trust	Guideline	039	001	Cognitive interventions does include the main types of intervention, but may benefit from further details regarding these e.g. metacognitive strategies, NHS supported apps etc.	Thank you for your comment. The committee discussed this but decided not to include 'metacognitive strategies' because no relevant, supporting evidence had been identified in the review.
The Wolfson Neurorehabilitation Service	Guideline	039	001 - 004	Cognition Interventions (1.19.8) We advise reviewing the evidence base for brain training exercises to ensure clarity on their context and limitations.	Thank you for your comment. The committee has reviewed yours and other stakeholder comments regarding the reference towards 'brain training' and have agreed to remove this from the guideline.
Defence Medical Rehabilitation Centre	Guideline	039	002	We would recommend the first intervention would be to provide education on their diagnosis / condition and how that influences their cognitive performance; in addition to clear feedback on the assessment outcomes and cognitive formulation (including impact of interacting factors). Recommend provision of cognitive rehab strategies clinically reasoned for a patient based on their individual assessment outcomes, before suggesting the more generic activities listed lines 3 and 4.	Thank you for your comment and suggestion. The committee agree that earlier recommendations in the guideline cover your suggestion. For example the recommendation for people (and their family or carers) to be given personalised advice about their condition and rehabilitation needs, including any anticipated future needs, covers this. The recommendations for assessments in the cognitive function section of the guideline also set out to provide clear feedback and expectations about assessment outcomes. Therefore no further changes were made in response to your comment.
Central London and Community Healthcare Trust	Guideline	039	002	1.19.8. In terms of the evidence for brain training – what is this? It would be helpful to be more explicit.	Thank you for your comment. The committee has reviewed yours and other stakeholder comments regarding the reference to 'brain training' and have agreed to remove this from the guideline, due to there being insufficient supporting evidence.
The Royal Hospital for Neuro-disability	Guideline	039	002 - 004	The evidence to support this statement is lacking and the use of "brain-training" in acquired cognitive impairment can actually be unhelpful in certain contexts	Thank you for your comment. The committee has reviewed yours and other stakeholder comments regarding the reference towards 'brain training' and have agreed to remove this from the guideline, due to there being insufficient supporting evidence.
Nottingham University Hospitals NHS Trust -	Guideline	039	002 - 004	We recommend commenting that, clinicians should identify cognitive treatments based upon the most up-to-date research evidence (there	Thank you for your comment. The committee has reviewed yours and other stakeholder comments regarding the reference towards 'brain training' and

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National Rehabilitation Centre				are plenty of reviews and published recommendations, and these are likely to evolve over the lifetime of the present document e.g. the INCOG series of publications). We suggest removing the illustrative examples given in this and following sections, because they risk confusing the reader (who might take one of those examples on face value, rather than tailoring the treatment choice to clinical need and evidence base).	have agreed to remove this from the guideline, due to there being insufficient supporting evidence. However the committee wished to retain the other illustrative examples to help practitioners better understand the sorts of interventions they should consider. The guideline is unable to be more prescriptive due to the breadth of the population these recommendations are for.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	039	004	We were concerned that 'using brain training exercises' was included in the intervention section when there is very limited evidence their effectiveness. Minimally we would like to see section 1.19.10 as being the first recommendation in this section as compensatory strategies have the best evidence base and that some contextualisation around brain training exercises is added at line 4 '…or using brain training exercises as a means of cognitive stimulation.'	Thank you for your comment. The committee has reviewed yours and other stakeholder comments regarding the reference towards 'brain training' and have agreed to remove this from the guideline, due to there being insufficient supporting evidence.
Success – Life After Cure Ltd	Guideline	039	004	Rec 1.19.9 Many children with brain tumours receive cognitive assessments [with accompanying advice] as is recommended, before and after radiation as part of the research attempts to reduce radiation toxicity to the young brain. However our unpublished recent gap analysis study at Great Ormond Street in 100 children surviving varied brain tumours, showed none received cognitive training exercises for cognitive weakness. Ways to ensure these are implemented in the community and education require thought.	Thank you for your comment. The committee agreed that cognitive rehabilitation is essential and made recommendations on service specifications and needs assessments that include cognitive function and the provision of related interventions. They also recommended designing services that span health and care settings, including community provision. This is in line with NHS reforms and the 10-year plan which should help with the implementation of these recommendations. The guidance applies to practitioners in related services, including education, and recommends collaboration between commissioning bodies across healthcare, social care and community services, and other relevant community service providers, for example education. The committee hopes these recommendations will be implemented, and assessments and interventions delivered in settings best suited to meet people's rehabilitation needs, including cognitive needs.
Defence Medical Rehabilitation Centre	Guideline	039	004	We are concerned that including brain training as 'a way to optimise or maintain cognitive function' implies that this has an evidence base in this regard, which in our opinion it does not	Thank you for your comment. The committee has reviewed yours and other stakeholder comments regarding the reference to 'brain training' and have agreed to remove this from the guideline, due to there being insufficient supporting evidence.
Guy's and St Thomas' NHS Foundation Trust	Guideline	039	004	Rec 1.19.8 – We do not recommend the inclusion of "brain training exercises" in this section. There is limited evidence for the effectiveness of brain training from controlled trials, especially when it comes to young people's generalisation of skills from one brain training tasks to other related activities. Reading the supporting sections for this recommendation (evidence review G), we do not believe there is enough evidence presented that supports this inclusion.	Thank you for your comment. The committee has reviewed yours and other stakeholder comments regarding the reference to 'brain training' and have agreed to remove this from the guideline, due to there being insufficient supporting evidence. We did not review the suggested reference due to it no longer being relevant.

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				For consideration: Rossignoli-Palomeque, T., Perez-Hernandez, E., & Gonzalez-Marques, J. (2018). Brain training in children and adolescents: is it scientifically valid?. *Frontiers in Psychology*, *9*, 565.	
The Wolfson Neurorehabilitation Service	Guideline	039	005 - 008	Cognition Interventions (1.19.9)We recommend clarifying that Allied Health Professionals (AHPs) should refer patients to medical professionals for medical advice, such as blood pressure control, and that their role is focussed on rehabilitation.	Thank you for your comment. The committee agreed and have added to this recommendation to refer people to relevant health professionals as needed.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	039	005 - 008	We recommend that the three approaches cognitive treatment are distinguished for the reader: maintenance (e.g. general cognitive stimulation in the context of a progressive disorder); restoration (e.g. cognitive process training); and compensation (as already well defined in the document).	Thank you for your comment. The committee agreed that this recommendation was slightly confusing and have separated the approaches here to make it clearer. The recommendation now reads "Discuss and agree ways to help the person to manage difficulties with memory and learning in daily life. This may include compensatory aids (for example, paper diaries, electronic calendars or smartphone apps) and activities to restore or maintain memory and learning (for example, virtual reality or computerised cognitive tasks). "
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	039	009	For CYP, it is essential that the system around them is taught about compensatory strategies as they will need significant scaffolding to support cognition, particularly in younger children; this can hopefully be reduced as they grow and develop when they may be able to take more responsibility for strategies themselves.	Thank you for your comment. The committee agreed with your comment but decided not to change the recommendation to specifically mention CYP as this recommendation is relevant for adults as well.
Central London and Community Healthcare Trust	Guideline	039	009	1.19.10. In terms of memory what about evidence for compensatory strategies? See Scotland's SIGN guidelines (2013) which highlights more about this.	Thank you for your comment and suggestion. Unfortunately no evidence was found for compensatory strategies and the ideas for compensatory strategies are based on the committee's knowledge and experience. In terms of the guidelines you suggest, NICE can only cross-refer to other guidance in 2 cases. Firstly, if there are already published NICE recommendations on a subject. Secondly, by stating, a priori, that guidelines would be an accepted evidence source in a systematic review. In this case, relevant guidelines would be included and subject to critical appraisal and then considered by the committee as a basis for recommendations. They could also cross refer to the included guideline. As the SIGN guidelines did not meet our review protocol criteria (because guidelines were not stated as a type of study to be included), they cannot be referenced in the guideline.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	039	009 - 014	We recommend that the three approaches cognitive treatment are distinguished for the reader: maintenance (e.g. general cognitive stimulation in the context of a progressive disorder); restoration (e.g. cognitive process training); and compensation (as already well defined in the document).	Thank you for your comment. The committee agreed that this recommendation was slightly confusing and have separated the approaches here to make it clearer. The recommendation now reads "Discuss and agree ways to help the person to manage difficulties with memory and learning in daily life. This may include compensatory aids (for example, paper diaries, electronic calendars or smartphone apps) and

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					activities to restore or maintain memory and learning (for example, virtual reality or computerised cognitive tasks). "
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	039	009 - 014	As above, the different treatment approaches and example treatments have been mixed up in this paragraph. The prominence of (non-specific) video games, VR and computer-based exercises in the paragraph risks overstating the clinical effectiveness of these activities. Note the definition of compensatory aids on page 53, refers to treatments such as video games, which are not compensatory, (where there is evidence, then they tend to be restorative, or maintaining).	Thank you for your comment. The committee agreed that this recommendation was slightly confusing and have separated the approaches here to make it clearer. The recommendation now reads "Discuss and agree ways to help the person to manage difficulties with memory and learning in daily life. This may include compensatory aids (for example, paper diaries, electronic calendars or smartphone apps) and activities to restore or maintain memory and learning (for example, virtual reality or computerised cognitive tasks). "
North Cumbria Integrated Care NHS Foundation Trust	Guideline	039	009 - 014	There is very little evidence highlighting the benefit of computer based exercise and we are concerned that this is recommended.	Thank you for your comment. The committee agreed and has removed computer based exercises as an example here.
Defence Medical Rehabilitation Centre	Guideline	039	009 - 015	We are concerned recommendations focus on memory and executive functions in isolation. We recommend rehabilitation across all cognitive domains that may be affected by traumatic injury (e.g., for TBI, INCOG guidelines cover post-traumatic amnesia, speed of processing, attention, memory, executive function & cognitive communication impairment).	Thank you for your comment. There are 3 recommendations in the intervention section for cognitive function which encompass all cognitive domains and do not isolate for a single domain. The committee decided to have particular recommendations focussing on memory and learning and executive function as these were the only ones where evidence of effectiveness was found. The committee also agreed that memory and learning and executive function are considered fundamental skills which can be improved specifically by compensatory strategies. Therefore no changes were made in response to your comment.
The British Psychological Society	Guideline	039	009 - 016	The two paragraphs seem muddled. In cognitive rehabilitation, goals can be addressed using enhanced learning strategies (sometimes called restorative strategies) and/ or compensatory strategies, both internal and external. These approaches are used to manage functional difficulties with everyday functioning and activities of daily living that arise from various aspects of cognitive functioning, including memory and executive function. Often, a mixture of strategy types is required; for example, introducing a compensatory aid may only be effective if accompanied by use of enhanced learning strategies to teach and establish use of the aid. Goals are not typically cognitive but are functional or reflect functional cognition. It can therefore be misleading to separate cognition and function as if these are distinct, when they are closely interlinked.	Thank you for your comment. The committee discussed your comment but agreed that function and cognition are not muddled here as this paragraph is talking about compensatory strategies and the review is specifically about cognitive function. Therefore the focus has been on rehabilitation not impairment. Restorative strategies have not been mentioned as no specific evidence was found and in the committees' knowledge and experience there is also no evidence to support this.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	039	010	We were concerned that 'memory and learning in daily life.' was very narrow in terms of the range of cognitive difficulties that might be helped with compensatory strategies. We would like it to read *'… difficulties with, memory, speed of processing, executive, learning and other cognitive difficulties in daily life.'*	Thank you for your comment. The committee discussed this and agreed not to add any other examples in this instance as the evidence in this review did not support this. The committee would like to highlight that although these cognitive difficulties are not listed in this recommendation that does not mean they are excluded.

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Rehabilitation for chronic neurological disorders including acquired brain injury

Consultation on draft guideline - Stakeholder comments table
08/04/2025 – 20/05/2025

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Shaftesbury Icanho	Guideline	039	015	1.19.11 – you have outlined recommendations for new learning, memory and executive function intervention. However, there are no guidelines for other areas you have said are key to assess earlier (1.19.3 – orientation, processing speed, visual, language, attention and social cognition). If there are guidelines for assessment (which I agree important to assess all these cognitive domains), should there then be guidelines for intervention?	Thank you for your comment. There are 3 recommendations in the intervention section for cognitive function which encompass all cognitive domains and do not isolate for a single domain. The committee decided to have a particular recommendations focussing on memory and learning and executive function as these were the only ones where evidence of effectiveness was found. The committee also agreed that memory and learning and executive function are considered fundamental skills which can be improved specifically by compensatory strategies.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Guideline	039	015 - 016	1.19.11 Cognitive function - Interventions "*To improve executive function* (add comma here?) *discuss and agree internal and external 16 compensatory strategies and changes to the person's environment*"	Thank you for your comment. We have edited this accordingly.
The Royal Hospital for Neuro-disability	Guideline	039	015 - 016	This recommendation does not make sense; compensatory strategies are not aimed at "improving executive functioning"	Thank you for your comment. The committee agreed that the recommendation was not clear and have changed the wording, which now reads "To improve executive function, discuss and agree internal and external compensatory strategies and changes to the person's environment. "
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	039	015 - 016	We approved of making this fine distinction between internal and external compensatory strategies, which would fall under a clearer taxonomy of treatment approaches (above).	Thank you for your comment and your support for this recommendation.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	039	016	We thought the additional benefits of group interventions in cognitive rehabilitation should be included in this section with an additional sentence after line 16 ' Group interventions that facilitate the understanding of cognitive difficulties and compensatory strategies can afford additional therapeutic advantages by providing peer support, enabling patients to learn directly from other peers' experiences and facilitating insight, awareness and acceptance of disabilities, and should be considered accordingly.' See for review of effectiveness - Freyr Patterson, Jennifer Fleming & Emmah Doig (2016) Group-based delivery of interventions in traumatic brain injury rehabilitation: a scoping review, Disability and Rehabilitation, 38:20, 1961-1986, DOI: 10.3109/09638288.2015.1111436	Thank you for your comment. The committee discussed that unfortunately there was no evidence to support a strong recommendation for group interventions. In terms of the reference you suggest from Patterson et al (2016), this does not meet the protocol inclusion criteria because it is a scoping review and not a systematic review. However the committee are aware of the importance of group interventions and therefore have added a bullet point to the recommendation about planning cognitive rehabilitation based on the results of cognitive assessments. This now states that group or individual therapies should be considered, taking into account a person's personal preference.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	039	017	It is essential this information is also shared with education settings for CYP who spend large amounts of their time in school.	Thank you for your comment. The committee agreed to make this recommendation more inclusive and have edited to also include the input of people important to them and involved in their rehabilitation, which would address your point..

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Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	039	017	Add in "education support staff"	Thank you for your comment. The committee agreed to make this recommendation more inclusive and have edited to also include the input of people important to them and involved in their rehabilitation, which would address your point.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	039	017 - 018	This is a welcome acknowledgement, and we recommend expanding this section, such that the person's family or carers can offer direct support with maintaining, restorative and compensatory cognitive interventions. They can help by reminding the person about the intervention and provide encouragement.	Thank you for your comment. The committee made some additions to this recommendations to explain compensatory strategies to the person's family or carers and other people who are important to them and involved in their rehabilitation so they can offer support outside of therapy sessions.
British Association of Brain Injury and Complex Case Management	Guideline	039	019	1.20- In addition to the aspects covered we would like to add 'cognitive communication disorder' (CCD) in this section – it is our experience that this is often not identified unless a SLT assessment is carried out	Thank you for your comment, with which the committee agree. They added a recommendation about cognitive communication disorder to the cognitive function section. The recommendation states that if cognitive communication disorder is suspected, assess and plan cognitive rehabilitation at the same time as speech and language therapy (see the section on speech, language and communication).
Royal College of Speech and Language Therapists	Guideline	039	019	This section should include an additional recommendation that speech and language therapists should keep other members of the rehabilitation team informed regarding communication needs, in order to facilitate rehabilitation engagement and consent for certain treatments.	Thank you for your comment, with which the committee agree. They have edited an existing recommendation in the section on agreeing and delivering a coordinated rehabilitation plan. For the recommendation about agreeing the interventions and approaches that will constitute the rehabilitation plan, the committee added that consideration should be given about how practitioners will liaise and work together to enable interdisciplinary working.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	039	General	All needs to acknowledge that for children and young people, training needs to be provided for support systems (e.g. family, school staff, carers etc)	Thank you for your comment. The committee recognised the crucial role played by people around the individual with rehabilitation needs and they had made a number of draft recommendations reflecting this, for example planning all interventions in a way that recognises their contribution to delivering rehabilitation and also specifically in relation to cognitive interventions, taking into account the role of family members when planning cognitive rehabilitation. In relation to children and young people, 'family and people important to them' will most commonly refer to parents and siblings. No further changes have been made in light of your comment.
Defence Medical Rehabilitation Centre	Guideline	040	001	We would suggest the term Cognitive Communication Disorder (CCD) is used explicitly in terms of what we are assessing and treating. There should also be reference to the INCOG guidelines on CCD in the reference pages as there is now a strong body of evidence for treating CCD (Leanne Togher, Sheila Macdonald)	Thank you for your comment, with which the committee agree. They added a recommendation about cognitive communication disorder to the cognitive function section. The recommendation states that if cognitive communication disorder is suspected, assess and plan cognitive rehabilitation at the same time as speech and language therapy (see the section on speech, language and communication). NICE can only cross-refer to other guidance in 2 cases. Firstly, if there are already published NICE recommendations on a subject. Secondly, by stating, a priori, that guidelines would be an accepted evidence source in a

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					systematic review. In this case, relevant guidelines would be included and subject to critical appraisal and then considered by the committee as a basis for recommendations. They could also cross refer to the included guideline. As the INCOG guidelines did not meet our review protocol criteria (because guidelines were not stated as a type of study to be included), they cannot be referenced in the guideline.
The Royal Hospital for Neuro-disability	Guideline	040	003 - 005	An initial SLT assessment will identify areas of impairment but also areas of strength that can be utilised to support communication while further assessment is ongoing.	Thank you for your comment, with which the committee agree. They therefore added "strengths" to the recommendation on asking about difficulties with speech, language and communication as part of holistic rehabilitation needs assessment.
Royal College of Speech and Language Therapists	Guideline	040	004	We recommend that the initial screening is carried out urgently, due to the impact communication difficulties are likely to have on access to and consent for wider rehabilitation, as well as day-to-day activities.	Thank you for your comment. We agree that if a recommendation is made that it should be carried out and not delayed, this point is highlighted in the sections of the guideline on when to undertake, or make a referral for, holistic rehabilitation needs assessment and initiating holistic rehabilitation needs assessment and who to involve. The recommendations highlight early referral and assessments, furthermore they emphasise not delaying the start of rehabilitation interventions while undertaking holistic needs assessment. Therefore, no change has been made in light of your comment.
Royal College of Speech and Language Therapists	Guideline	040	004	The inclusion of the phrase "for impairment" is unnecessary here	Thank you for your comment. We agree and have deleted "for impairment" from the recommendation.
Defence Medical Rehabilitation Centre	Guideline	040	006	Further clarification required on what classifies as 'urgent'. Often conditions such as CCD are not prioritised when they are in fact having a significant impact on a person's life.	Thank you for your comment. The committee recognised that urgent referral should be made based on the level of impact on a person's life. The recommendation already includes an example of severe speech, language or communication impairment having a significant impact on someone's usual day-to-day activities. Therefore, no change has been made.
Royal College of Speech and Language Therapists	Guideline	040	006	Like initial screening (1.20.2), further assessment must be carried out by a speech and language therapist. This is not clear in the current wording of recommendation 1.20.3. The RCSLT recommends that this is reworded.	Thank you for your comment. The committee agree and therefore added that further assessment should be carried out by a speech and language therapist.
The Royal Hospital for Neuro-disability	Guideline	040	006 - 009	Disagree that urgent referral only needed if person's impairment is severe as this disregards the potential impact on an individual. Urgent referral should be made based on level of impact on person's life and wellbeing which would include the level of impairment.	Thank you for your comment. The committee recognised that urgent referral should be made based on the level of impact on a person's life. The recommendation already includes an example of severe speech, language or communication impairment having a significant impact on their usual day-to-day activities. Therefore, no change has been made.
Midlands and South Essex ICB	Guideline	040	010	Offer SLT services with an intensity that supports functional change in communication needs (e.g. ICAP programmes)	Thank you for your comment. We agree and have edited the wording in the recommendation to offer therapy that supports functional change in identified speech, language and communication needs, focusing on the

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					person's rehabilitation goals. We haven't included any examples of programmes to follow as NICE will only cross-refer to other guidance in 2 cases. Firstly, if there are already published NICE recommendations on a subject. Secondly, by stating, a priori, that guidelines would be an accepted evidence source in a systematic review. In this case, relevant guidelines would be included and subject to critical appraisal and then considered by the committee as a basis for recommendations. They could also cross refer to the included guideline. As the ICAP programmes did not meet our review protocol criteria (because guidelines or programmes were not stated as a type of study to be included), they cannot be referenced in the guideline.
The Royal Hospital for Neuro-disability	Guideline	040	010 - 012	Suggest changing wording to 'rehabilitation or maintenance goals' as may be the case for a patient with a progressive condition.	Thank you for your comment. To address this we have added maintenance into the definition of rehabilitation in the glossary.
The Wolfson Neurorehabilitation Service	Guideline	040	010 - 012	**Speech, Language, and Communication (1.20.4)**We suggest revising the recommendation to emphasise working with individuals and their support networks to identify relevant communication goals, especially when patient insight into their impairment may be limited.	Thank you for your comment. The committee agreed that it is important to work with individuals and their support networks to identify goals. This is not only pertinent to speech, language, and communication, but cross-cutting for all rehabilitation areas. In view of this, the committee agreed to address your point in the goal setting section of the guideline where there is a recommendation to work collaboratively with the person to agree long-term rehabilitation goals, broken down into short-term steps, that focus on what is most important to the person. Furthermore, there is another recommendation in the goal setting section of the guideline about allowing sufficient time during consultations with the person, and their family or carers, if appropriate, for goal setting, and later for rehabilitation planning.
Shaftesbury Icanho	Guideline	040	011	1.20.4 – consider rehabilitation *or maintenance* goals (given progressive nature of some conditions). Also should Lee Silvermann Voice Treatment (LSVT) be mentioned here as evidence based in some neurological conditions such as Parkinson's Disease.	Thank you for your comment. TO address this, we have added maintenance into the definition of rehabilitation in the glossary. The evidence pertaining to LSVT LOUD® in Parkinson's disease was discussed by the committee and documented in the committee's discussion of evidence in evidence review F. The committee discussed the meta-analysis of 2 RCTs in this evidence review that showed an important benefit in voice-related quality of life measured using the VHI-summary at 12-months in people with progressive neurological diseases receiving LSVT LOUD® when compared to a speech and language therapist (SLT). However, they also noted that this evidence was low quality and that it was only the outcome at 12 months follow up where there was any important difference. The committee observed that the 2 RCTs on LSVT LOUD® compared to usual care or SLT failed to show any important difference on any other outcome in the long-term, important differences were limited to the post-intervention period. The remaining RCT on interventions for voice,

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					comparing LSVT LOUD® online to LSVT LOUD® face-to-face failed to show any important differences in voice, physical and mental health related quality of life, social care related quality of life, and mood. For these reasons, the committee decided not to use the evidence on interventions to improve voice to make any recommendations and instead used their collective experience and expertise.
First Community Health and Care	Guideline	040	013 - 015	Rec 1.20.5 - This recommendation will be a challenging change in practice because limited access for patients to access alternative and augmentative communication equipment. Have to apply to charities etc. Only Motor Neurone Disease Association (MNDA) will support. Other charities very limited funding for equipment. Teams don't have equipment to demonstrate use of software to support therapy programmes.	Thank you for your comment. The committee agreed it is essential that people with severe communication difficulties and CND have access to alternative and augmentative communication (AAC) equipment to support communication, empowerment, self-identity and participation. They noted that low-tech AAC is typically provided by locally commissioned services, while high-tech AAC is provided by NHS England Specialised AAC Services. Providing AAC is standard practice and a legal requirement under equality legislation. Also, most individuals require only basic, low-cost devices. The committee acknowledged that services are often overstretched but the service design recommendations could release resources, potentially improving AAC access. They agreed that the benefits, such as improved communication, reduced anxiety and isolation, better engagement with rehabilitation, fewer unplanned care visits, greater independence and increased participation in education and employment could potentially outweigh the additional resource needs. While NICE does not make funding decisions, the committee hopes the recommendations will be implemented and funded appropriately. We will also share your comment with the NICE implementation team. Further supporting discussion can be found in the full evidence review F on speech, language and communication.
The Royal Hospital for Neuro-disability	Guideline	040	013 - 015	Person does not need to have a severe impairment to potentially benefit from AAC. Change wording to 'the SLT should establish whether the person may have the prerequisite skills and will benefit from AAC. The SLT will carry out their assessments and consider referring to a specialist AAC team if appropriate.	Thank you for your comment. Severe speech, language or communication impairment is defined in one of the recommendations (in the speech, language and communication section) as having a significant impact on someone's usual day-to-day activities. The committee believe that it is this scenario in which people benefit from AAC. They also believe the term "clinically appropriate" in the recommendation on AAC covers having the prerequisite skills to benefit from AAC. Therefore, no changes were made.
Defence Medical Rehabilitation Centre	Guideline	040	016	IDT working should be encouraged here, e.g. assessing communication in function jointly with OT. The word 'Consider' should be changed to 'Provide' as it's imperative that we are considering speech/language/communication in function.	Thank you for your comment. The committee agree that collaborative working should be encouraged and it is considered throughout the guideline not only in the speech, language and communication section. In the rehabilitation planning and delivery section, there is a recommendation stating that practitioners involved in delivering the rehabilitation plan should work together to ensure timely and joined-up delivery of the interventions and approaches. Furthermore, there is a recommendation in information,

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					advice and learning as part of rehabilitation, to consider joined-up education and training interventions to support the person, and their family or carers, if appropriate, to understand and deliver interlinked elements of the person's rehabilitation plan at the same time, for example, teaching cognitive memory strategies alongside use of memory aids for independent living, both of which might happen in the person's home.
Royal College of Speech and Language Therapists	Guideline	040	016	The use of 'teaching' is not appropriate. We suggest "Consider speech, language and communication goals which focus on functional skills the person can practise and use in real-life environments".	Thank you for your comment. The committee considered your suggestion but agreed that 'teaching' was the most appropriate action here - as these were skills which would be taught.
The Royal Hospital for Neuro-disability	Guideline	040	016 - 017	Replace word 'teaching' which is very didactic and disempowering for patients to 'developing' or 'working on'	Thank you for your comment. The committee considered your suggestion but agreed that 'teaching' was the most appropriate action here - as these were skills which would be taught.
Shaftesbury Icanho	Guideline	040	018	1.20.7 – Should this section also mention importance of referral to/linking with local, often voluntary support groups (e.g. Headway, Parkinson's UK groups) for ongoing support and often communication focussed activities (such as conversation groups or singing groups) to help maintain/practise/improve communication skills.	Thank you for your comment. The delivery of the recommendation on providing a speech and language therapist-led education and training programme in communication skills for family, carers or others close to the person is driven by the local authority and not for NICE to specify. However, the recommendation on ensuring collaboration between commissioning bodies in the building capacity section has been edited to expand the list of providers, which now includes healthcare, social care and other relevant community service providers, for example education services for children, third sector providers, charities and community groups.
Defence Medical Rehabilitation Centre	Guideline	040	018	Consider including wider IDT in list of who to provide training to. Define what is meant by 'therapy-led education'. Could perhaps include how training could also be offered remotely if required- evidence for use of telecommunications in CCD in InCog guidelines.	Thank you for your comment. The recommendation on providing training is directed at family, carers or others close to the person with CND and not healthcare professions. However, there are recommendations in the section on building local capacity and expertise that discuss interdisciplinary team working. Therefore, no change has been made. Thank you for highlighting "therapy-led education" as an ambiguous term, the recommendation has now been edited to "therapist-led education", which should be clearer. In terms of the delivery of training remotely, a recommendation in the building local capacity and expertise section has been edited to state that if availability of specialist neurorehabilitation services is restricted in some areas or for some people (including for people living in rural areas or with rare conditions) there should be collaboration within and between integrated care systems to: • enable access to specialist care where possible (including via tele health). No further changes have been made in light of your comment.

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Royal College of Speech and Language Therapists	Guideline	040	018	The clearest and most rigorous communication skills training provide opportunities for this training to be undertaken jointly with the person, and their partner and include elements of behaviour change theory (see Cruice, M., Blom Johansson, M., Isaksen, J., & Horton, S. (2018). Reporting interventions in communication partner training: a critical review and narrative synthesis of the literature. *Aphasiology*, *32*(10), 1135-1166.)	Thank you for your comment. There are recommendations on producing service specifications for integrated rehabilitation care for people with a chronic neurological disorder to include information, advice, education and training to support all aspects of rehabilitation in the section on commissioning rehabilitation services and service specifications. The critical review by Cruice et al 2018, is based on studies from adults with stroke, which is out of scope for this guideline and would therefore not be included in any of the evidence reviews. Furthermore, the study design is a narrative analysis and not a systematic review. Therefore, no change has been made in light of your comment.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	040	019	Add in "education support staff"	Thank you for your comment. Education support staff has been added to the definition of rehabilitation practitioners in the glossary.
Defence Medical Rehabilitation Centre	Guideline	040	021	Voice banking needs to be done whilst speech is still intelligible. A patient with voice loss already is likely to need other options to augment their communication, rather than voice banking.	Thank you for your comment. The recommendation on referral to voice banking is to highlight the service, the decision as to whether voice banking is clinically appropriate will be made after referral and outside the scope of this review question. Therefore, no changes were made.
Royal College of Speech and Language Therapists	Guideline	040	021	The RCSLT welcomes the inclusion of voice banking in this guideline. However, the current recommendation does not adequately address who may benefit or the practical, emotional and financial considerations involved in voice banking/storage/retrieval processes. The process involves complex and emotionally sensitive discussions about future communication loss and end-of-life planning, also with a need to manage expectations. It would be more appropriate for this recommendation to be for speech and language therapists to initiative sensitive conversations about voice banking, as soon as appropriate, for people who may benefit from high-tech alternative and augmentative communication at that time or in the future. There is currently no coordinated pathway for voice banking and provision varies. To ensure equity for service users, there need to be clear, centralised and funded pathways for voice banking, storage and retrieval.	Thank you for your comment. We are aware that there is no co-ordinated pathway for voice banking and that provision varies. The recommendation on referral to voice banking is intended to highlight the service. The practical, emotional and financial considerations involved in the voice banking/storage/retrieval process will be made after referral and are outside the scope of this review question. Therefore, no changes were made.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	040 - 042	General	We were confused why Speech and Language Therapists were the only professional group specifically highlighted regarding optimal assessment and rehabilitation of key areas of need. Should not occupational therapists for functional rehab, physiotherapists for physical rehab, clinical psychologists/neuropsychologists for cognitive and emotional rehab etc also be specified as the optimal professional groups for such areas also?	Thank you for your comment. After discussing your comment, the committee have reviewed the nomination of specific professionals throughout the guideline. This has resulted in changes in several sections, including physical activity and exercise, emotional health and mental wellbeing, and independent living. However, when making these recommendations, the committee focused on the skills that professionals should have in order to appropriately fulfil them, rather than citing specific

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					job roles. Certain professionals are only named as an example or, if not, if they are only one with training for the task. Continuing this, in the eating, drinking and swallowing section, we do not specify speech and language therapists as the only ones who can deliver interventions. They are named as an appropriate example in the recommendation on dysphagia assessment, and that several interventions be overseen by a speech and language therapist to reduce safety risks.
Defence Medical Rehabilitation Centre	Guideline	041	004	Support to follow an effective mouthcare regime would likely need to be provided by carers/nursing staff – SLT would recommend but not always be present to give support.	Thank you for your comment. In order to be generalisable across the broad guideline population and included settings, the referenced recommendation does not specify which profession would be providing the assessment of support. The guideline committee were cognisant that this might not always be the same person and noted in their discussion of the evidence that, although this process will be overseen by an appropriately trained professional (for example, a dentist or speech and language therapist), the resulting support does not need to be. Full details can be found in evidence report D.
Rotherham, Doncaster and South Humber NHS Foundation Trust	Guideline	041	004 - 005	1.21.1 Eating, drinking and swallowing – Assessment and management Full stop required at end of sentence "*Assess oral hygiene and support the person to follow an effective 5 mouthcare regime, if needed*"	Thank you for your comment. We have added in the suggested full stop.
Royal College of Speech and Language Therapists	Guideline	041	011	This recommendation should specify "healthcare professional trained in dysphagia, **such as a speech and language therapist**." Speech and language therapists have a unique HCPC recognised and registered role in identifying and managing oropharyngeal dysphagia. The key role of the speech and language therapist in the assessment, differential diagnosis and management of dysphagia has been recognised in national and international guidelines of practice e.g. National Clinical Guideline for Stroke. We recommend that the guideline explicitly acknowledges the critical contribution of speech and language therapists to ensure high-quality care for individuals with dysphagia.	Thank you for your comment. We have added speech and language therapist as an example of the healthcare professional trained in dysphagia, as requested.
The Royal Hospital for Neuro-disability	Guideline	041	011 - 015	Reword to specify that dysphagia assessment should be carried out by a qualified speech and language therapist. The population which this guideline refers has a known neurological condition meaning that dysphagia will need specialist, potentially long term management and complex ethical decision making e.g. Eating and Drinking at Risk (EDAR). Due to this assessment or screening by other health professional would not provide sufficient level of assessment. We acknowledge that others carry out screening assessments for dysphagia at other points in the pathway but this is unlikely to be useful for someone with a known chronic condition	Thank you for your comment. We have added speech and language therapist as an example of the healthcare professional trained in dysphagia.

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MYoroface AB	Guideline	041	016	We are concerned that in the Draft Guideline in §1.21.4 there is no mention of neuromuscular training as a treatment option to improve swallowing and other functions. Your stated goal is: "To prevent deterioration in, or sustain or improve, the person's ability to eat, drink and swallow, provide one or more of the following: • advice on the best position and posture for eating and drinking • speech and language therapy-led interventions to improve swallowing safety, including swallowing exercises and manoeuvres (for example, the supraglottic swallow, the effortful swallow and Masako manoeuvres)"	Thank you for your comment. We have amended the referenced recommendation to include rehabilitation techniques to regain swallow function, and named neuromuscular re-training within that category.
Royal College of Speech and Language Therapists	Guideline	042	001	The examples provided in recommendation 1.21.4 are all compensatory strategies. There should be a separate bullet point to cover the consideration of interventions, such as exercises, aimed at **rehabilitation** of swallowing ability. This may be particularly relevant for patients with acquired brain or spinal cord injury or functional neurological disorder. There does not seem to have been adequate consideration of these separately in the evidence review.	Thank you for your comment. We have amended the referenced recommendation to include rehabilitation techniques to regain swallow function. Examples given are the Shaker exercise, the Masako manoeuvre, expiratory muscle strength training and neuromuscular re-training.
Shaftesbury Icanho	Guideline	042	002	1.21.4 - Should EMST be named?– evidence based growing in MND/PD (e.g. Plowman et al, 2018, 2023)	Thank you for your comment, in response to which the committee added expiratory muscle strength training (EMST) as an example to a recommendation on rehabilitation techniques to regain swallow function.
First Community Health and Care	Guideline	042	003 - 004	Rec 1.21.4 - This recommendation will be a challenging change in practice because minimal access to adapted eating and drinking equipment which can be used for demonstration, no resources for a patient to trial a product to see if it is suitable, falls on patients to fund this even if found later to need changing. E.g. Drinking cups £50.	Thank you for your comment. The committee maintain that basic adapted equipment for eating and drinking is an essential intervention for rehabilitation for eating, drinking and swallowing. This is standard practice and should not incur additional costs for services. Therefore, no change has been made.
The Royal Hospital for Neuro-disability	Guideline	042	003 - 004	Adapted equipment should be advised upon by suitably trained professional e.g. SLT, OT, specialist nurse	Thank you for your comment. When drafting recommendations, the committee focused on the skills professionals should have in order to appropriately fulfil them, rather than specific job roles. Certain professionals are only named as an example or, if not, if they are only one with training for the task. As noted in your comment, there are several professional roles that would be able to fulfil this recommendation. Therefore, no change has been made.
The Royal Hospital for Neuro-disability	Guideline	042	005 - 007	All sensory interventions need to be initiated under the direction of a qualified SLT due to associated risks e.g. a increase of saliva/aspiration. Also replace 'not allowed' with if the person is Nil by Mouth	Thank you for your comment. When drafting recommendations, the committee focused on what skills professionals should have in order to appropriately fulfil them, rather than specific job roles. Certain professionals are only named as an example or, if not, if they are only one with training for the task. The committee did not feel that speech and language therapists needed to be nominated for the recommendation on sensory

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					interventions. However, we have amended the wording of the recommendation to read nil by mouth as requested.
The Royal Hospital for Neuro-disability	Guideline	042	008 - 009	Nowhere does it cover that SLT will also provide advice beyond food and fluid consistency to optimise safety and promote enjoyment e.g. level of support and supervision, compensatory strategies such as bolus size/rate control, environmental modifications.	Thank you for your comment. The referenced recommendation is not meant to cover all the advice that a speech and language therapist may give. The guideline committee prioritised several interventions for sustaining or improving capability in eating, drinking and swallowing at the beginning of the guideline, which were then included in the protocols for the evidence reviews underpinning these recommendations. Diet and fluid modification was one of these interventions, which is why it is included here. Therefore, no change has been made.
Shaftesbury Icanho	Guideline	042	010	1.21.5 – Could a reference to the common use of thickening fluids be given – and the growing evidence that thickened fluids do not decrease risk of aspiration pneumonia and for some clients have a detrimental affect on QOL, hydration etc. See RCSLT position paper 2023 for considered (not standard) use of fluid modification. Aware in many care homes etc this thickened fluids are considered standard practice for people who show overt signs of aspiration – would be good to acknowledge the potential risk of thickened fluids if not properly considered/assessed	Thank you for your comment. The committee were aware that there are several important factors that need to be considered when recommending modified food and fluids, including the risks that are attached to such a prescription. As such, the recommendation is drafted to specify that modification should be directed by a speech and language therapist. It is assumed that these professionals will have adequate training and knowledge to evaluate both the safety concerns (for example, the impact of modified food and fluids on quality of life and hydration levels) and potential benefits of thickened fluids. Therefore, no change has been made to the recommendation. However, we have amended the benefits and harms section of evidence review D in order to incorporate this facet of thickened fluids.
Royal College of Speech and Language Therapists	Guideline	042	010	Should this read '**recommended'** rather than 'provided'? Evidence review D (p31, line28) states that these modifications should be overseen **by a speech and language therapist.** This should also be made clear in the recommendation. However, regular review is important in relation to many dysphagia strategies and recommendations, not just when modified foods or fluids.	Thank you for your comment. We have amended the wording in the recommendation as requested. However, we have not reiterated that it should be overseen by a speech and language therapist as it has been noted in the previous recommendation. Finally, the committee agree that regular review is important in all rehabilitation interventions, and have made several recommendations throughout the guideline about reviewing rehabilitation plans. However, they noted that people can easily get stuck with specially modified food and fluids due to the risk averse nature of some healthcare settings. We have amended the Benefits and harms section of evidence review D to better explain this reasoning.
The Royal Hospital for Neuro-disability	Guideline	042	018	Enteral feeding does not automatically restrict choice and autonomy, it can facilitate it in situations where eating a meal becomes risky, time consuming and upsetting for an individual with swallowing problems. People can still continue to have oral intake alongside enteral feeding. The presence of a feeding tube may improve the oral experience as there is no pressure to meet nutrition and hydration needs orally so that what the patient is able to manage supports their quality of life.	Thank you for your comment. We have amended the wording of the recommendation to reflect that feeding mechanisms such as enteral feeding does not always restrict choice and autonomy.

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University College London Hospital	Guideline	042	024	The principle of timely discussions means very little if the service has long waiting lists	Thank you for your comment. We appreciate the challenge of ensuring timely discussions when healthcare services are faced with long waiting lists, as a result of high demand or under resourcing. However, that does not mean we should avoid recommending it as a principle of care. Therefore, no change has been made.
The Royal Hospital for Neuro-disability	Guideline	042	024 - 025	Include comment on discussion may need to be with patient's loved ones if the person lacks capacity to make decisions about oral intake for themselves, to facilitate best interests decision making	Thank you for your comment. Capacity and decision-making apply throughout this guideline, not simply this recommendation. NICE already has guidance on these topics, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws), NG108 Decision-making and mental capacity, NG227 Advocacy services for adults with health and social care needs, and NG204 Babies, children and young people's experience of healthcare. References to these documents have been made at the beginning of the interventions section. Therefore, no change has been made.
Royal College of Speech and Language Therapists	Guideline	042	025	This should read "what, **how** and when", to acknowledge the importance of strategies and adaptations.	Thank you for your comment. We have amended the recommendation as requested.
Royal College of Speech and Language Therapists	Guideline	042	028	Advice and training is not limited to adapted equipment. This recommendation should also include modified food and fluids, manoeuvres and rehabilitation interventions. We recommend that this is added.	Thank you for your comment. The action in this recommendation centres around mitigating the risks and benefits of eating and drinking, with training in adapted equipment an example of how a person can reduce risks. Recommendations on general advice and training to deliver interventions can be found in the sections on the holistic rehabilitation needs assessment and information, advice and learning as part of rehabilitation. Therefore, no change has been made.
Neater Solutions Ltd.	Guideline	042 - 045	General	We welcome the inclusion of assistive eating equipment in the guidance (1.21.4, page 42, line 3), and the recommendation to "support the person to use compensatory aids" (1.22.2, page 44, lines 4–9). Additional relevant sections include 1.22.7 page 44, line 19 to 1.22.9 page 45, line 9. Whilst the guidance is broadly sound, our practical experience highlights several implementation challenges: **Funding barriers across departments:** Access to equipment can be delayed or denied when responsibility is split between bodies or even departments (e.g., NHS Rehabilitation vs Community Occupational Therapy). Early intervention, including within inpatient settings, is often more effective, yet harder to achieve under current funding structures. NHS funding is typically approved only when savings accrue within the same department—a structural barrier that can limit adoption.	Thank you for your comment. The committee appreciate your frustrations regarding poor collaboration between services often being a barrier to accessing assistive eating equipment, despite there being considerable guidance on the matter. Implementation of these guidelines will be the responsibility of commissioners and local authorities and we can only add our recommendations to the case you make. However, the committee were well aware of the considerable challenges in encouraging communication and collaboration between the departments and services involved in rehabilitation for chronic neurological disorders. In addition to the one you highlight in your comment there are several recommendations throughout the guideline that aim to promote partnership, from designing rehabilitation services that operate across all health and care settings, to establishing collaborative pathways across hospital and community rehabilitation services. We also have additional guidance on early provision of equipment prior to discharge, and to help them prepare

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				Recommendation 1.22.9 – "Work collaboratively with required services to ensure timely delivery of equipment and environmental adaptations" – acknowledges this issue. We wish to reinforce, through real-world experience, how vital such collaboration is – and that despite guidance, it often does not happen. Furthermore, historical and contemporary research and guidance consistently demonstrate the value of assistive technology in daily living. The *Fully Equipped Reports* from 1999 and 2002 described it as a "wonder drug" for cost-effectiveness. However, health and social care funding remains siloed, despite the comparative cost-effectiveness of assistive aids relative to drugs, surgeries, or ongoing carer support. This is also in spite of the Guidance in the *Care Act 2014 which requires:* 1. Community equipment to be provided to meet individuals' needs (s.18) 2. Assessment of individuals' needs and information about available equipment (s.9(1) and s.4) 3. Financial support for care and support (Care and Support (Charging and Assessment of Resources) Regulations 2014, s.3) 4. To coordinate with relevant partners including Clinical Commissioning Groups (CCGs) to ensure efficient provision of care and equipment for their clients. (s.6) **References:** 1. UK Government. *Care Act 2014*. Available at: https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted 2. UK Government. *Care and Support (Charging and Assessment of Resources) Regulations 2014*. Available at: https://www.legislation.gov.uk/uksi/2014/2672/contents/made 3. Royal College of Occupational Therapists. *Fully Equipped 2000: The provision of equipment to older or disabled people by the NHS and Social Services in England and Wales*. Available at: https://www.pmguk.co.uk/data/page_files/publications%20and%20reports/2000/R.FullyEquipped2000.pdf 4. Royal College of Occupational Therapists. *Fully Equipped 2002: Assisting Independence*. Available at: https://www.pmguk.co.uk/data/page_files/publications%20and%20reports/2002/R.FullyEquipped2002.pdf	for changes that may happen in future. We hope that these guidelines are appropriately funded and implemented by commissioners, in order to begin to dismantle the barriers to service delivery that poor communication creates.

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Neater Solutions Ltd.	Guideline	042 - 045	General	**Adoption issues:** In our experience, some patients in rehabilitation are initially reluctant to accept assistive technology. Many believe they will recover quickly and therefore feel it is not worth investing in it. However, outcomes are generally positive when equipment is available early and integrated into therapy centres. Equipment reuse and accessibility significantly promote rehabilitation progress.	Thank you for your comment. A recommendation on equipping therapy centres with display or trial equipment would be difficult to make given that we have not looked for any evidence, no themes were identified in our qualitative review on rehabilitation delivery, and considering the likely resource impact. However, we do have a recommendation in this section that advises on early access to occupational therapy for independent living skills. We anticipate that these will include assistive technology where appropriate. Therefore, no changes have been made.
Royal College of Speech and Language Therapists	Guideline	043	001	This recommendation is not sufficient to convey the importance of appropriate discussions and decision-making (as acknowledged in the rationale p97, lines 10-12). There are also legal risks. Clear reference should be made to RCP and RCSLT guidance available at the following links: Supporting people who have eating and drinking difficulties Eating and drinking with acknowledged risks: Multidisciplinary team guidance for the shared decision-making process (adults)	Thank you for your comment. The committee have added more detail to this recommendation to better reflect the complexity of decision making around eating and drinking with acknowledged risks and to include the factors that should always be considered when these decisions are made.
The Royal Hospital for Neuro-disability	Guideline	043	001 - 003	The person may decide to eat and drink with acknowledged risks (EDAR), OR this can be as a result of a best interests decision.	Thank you for your comment. The committee have added more detail to this recommendation to better reflect the complexity of decision making around eating and drinking with acknowledged risks and to include the factors that should always be considered when these decisions are made.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	043	001 - 003	1.21.11 - Statement needs to state capacity not just understanding of risk. Assessed and documented capacity related to decision.	Thank you for your comment. The committee have added more detail to this recommendation to better reflect the complexity of decision making around eating and drinking with acknowledged risks and to include the factors that should always be considered when these decisions are made. Capacity and decision-making apply throughout this guideline, not simply this recommendation. NICE already has guidance on these topics, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws), NG108 Decision-making and mental capacity, NG227 Advocacy services for adults with health and social care needs, and NG204 Babies, children and young people's experience of healthcare. References to these documents have been made at the beginning of the interventions section. Therefore, no change has been made in this regard.
North Cumbria Integrated Care NHS Foundation Trust	Guideline	043	006 - 007	We would like the committee to consider adding a recommendation to complete a positive risk plan to deal with risk arising from eating and drinking.	Thank you for your comment. The committee have discussed your comment and believe that, although not specifically named, a positive risk plan has been adequately covered by the drafted guidance in this section. Therefore, no change has been made.
British Association of Brain Injury and	Guideline	044	002	1.22.1 We support the assessment of Activities of Daily Living (ADL) and would like to see mention these assessments being carried out by,	Thank you for your comment. In response, we have added a new recommendation in this section, saying that a practitioner with appropriate

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Complex Case Management				or under supervision of an occupational therapist in addition to OTs providing interventions.	expertise should assess the person's ability to carry out activities of daily living. Occupational therapists are named as an example.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	044	002 - 003	1.22.1 - Consideration of risk to assess for facilities/ equipment to mitigate risk or enable function and for any plans of action to be 'future proofed' to anticipate long term needs not just immediate needs i.e. development, progress or deteriorating prognosis.	Thank you for your comment. The committee believe that the assessment of risks that you note is implicit within the current wording, and would form part of the recommended assessment by a trained professional. Regarding your other point about anticipating long-term rehabilitation needs, this has been covered in an earlier guideline section on designing a holistic rehabilitation needs assessment. Here, we recommend learning how a person's functioning and needs will vary in different environments, different times of the day, and over the longer term. Therefore, no changes have been made.
Central London and Community Healthcare Trust	Guideline	044	002 – 003	*1.22.1 Assess the person's ability to carry out activities of daily living, including the impact of their condition on this.* Suggested addition: consider, sensory, motor, motor planning, perceptual, cognitive and emotional barriers to function through appropriate assessments.	Thank you for your comment. Although we have given this extra detail in other assessment recommendations, it is not appropriate here. The committee note that the guidance in this section is related to overcoming physical barriers, and this is covered in the current wording. The examples that you list are internal barriers, which would not be addressed by the subsequent recommendations. Therefore, no changes have been made.
The Association of British Neurologists	Guideline	044	004	1.22.2 - "Teach and support the person to use compensatory aids to improve or maintain independence with activities of daily living" Compensatory aids are not routinely recommended for patients with functional gait (or other functional) disorders and including this in the guidance without appropriate caveats is potentially harmful.. We recommend you insert "where appropriate" here at least. Therapists need to retain the ability to be flexible and use their clinical judgement for this group of patients. It is important they are able to encourage patients with e.g. functional gait disorders to try to improve mobility without sticks, wheelchairs or other aids, or at least to explore this.	Thank you for your comment. The committee agree that there may be occasions where compensatory aids can limit the scope for recovery. Therefore, we have added a new recommendation at the end of the section asking Practitioners to consider potential harms of equipment, compensatory aids, assistive devices and adaptive approaches. People with functional neurological disorders are highlighted as a particular population where this could occur.
The British Psychological Society	Guideline	044	004	Maintaining independence with activities of daily living (1.22.2) may require both enhanced learning and compensatory strategies.	Thank you for your comment. While the committee agree that maintaining independence with activities of daily living will use a variety of techniques (including enhanced learning strategies), this recommendation is specifically covering compensatory aids (for example, personal digital assistants) as identified in the evidence. For full details of the committee's discussion of the evidence, please refer to the benefits and harms section of evidence review D. No change has been made in light of your comment.
South London and Maudsley NHS Foundation Trust	Guideline	044	007	Rec 1.22.3 – Within physio management of FND the use of mobility aids is more cautious, avoiding where possible to avoid reinforcement of abnormal movement. Details of this can be found in the following consensus guidelines by Nielsen et al, 2015 (https://jnnp.bmj.com/content/86/10/1113?papetoc=). This view is detailed further in Occupational therapy consensus recommendations by Nicholson et al, 2020 (https://pubmed.ncbi.nlm.nih.gov/32732388/).	Thank you for your comment. We have added a new recommendation following on from the one referenced, which asks rehabilitation professionals to take into account the potential harms of inappropriate prescribing equipment, compensatory aids, assistive devices or adaptive approaches. Within this, we have highlighted people with functional neurological disorders as a specific group where use of serial casting may limit recovery.

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				We believe a specific recommendation regarding this relating to FND should be included in the guidelines.	
British Association of Prosthetists and Orthotists	Guideline	044	007	Consider inclusion of orthoses as another example of assistive devices. Whilst we understand there is a huge range of possible types and categories of assistive devices available, orthotic intervention (especially beyond gait and mobility oriented orthotic intervention) is often overlooked as an option.	Thank you for your comment. As requested, we have added orhoses as an example to this recommendation.
Central London and Community Healthcare Trust	Guideline	044	007 - 009	1.22.3 *Support the person to optimise independence and aid participation in daily life. This may include providing equipment, such as a wheelchair or other assistive devices, for postural support and movement.* Specific wording would support more timely provision as delays over 6 months are impacting rehabilitation outcomes.	Thank you for your comment. The committee acknowledge that there is variation in waiting lists for equipment and assistive devices throughout the NHS for people with chronic neurological disorders. However, this guideline encompasses a broad spectrum of chronic neurological disorders with accompanying symptoms, which translates to a large provision of potential equipment or assistive devices. Due to the number of considerations and potential exemptions, the committee did not feel able to make more specific recommendations or include timeframes. Therefore, no change has been made.
University College London Hospital	Guideline	044	011	Early referral to OT- what does this mean? Currently vague and no way to audit this.	Thank you for your comment. The committee discussed that many people with chronic neurological disorders did not access occupational therapy until their symptoms begin to affect their daily life. They noted that independence in daily living can be prolonged if occupational therapy began before the physical manifestation of disorders. However, as this guideline is covering such a large population (each with a different range of potential symptoms, rehabilitation needs, and prognoses), the committee did not feel able to specify a timeframe within which access to occupational therapy should be provided. Early was chosen to stress the pre-emptive nature of occupational therapy without specifying a timeframe that would not be suitable for everyone. Therefore, no change has been made.
British Association of Prosthetists and Orthotists	Guideline	044	013	This section does not include mention of assistive devices; this may be worth highlighting as an important tool when approaching occupational therapy holistically for this patient group.	Thank you for your comment. We agree that assistive devices are an important tool within holistic physiotherapy. They are covered in the subsequent guideline section on environmental adaptations, assistive technology and equipment. Therefore, no change has been made.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	044	015	We suggest at line 15 '… task-based training, consider using errorless based…' as there will be many situations when this is not the most appropriate approach	Thank you for your comment. The committee agree that errorless based techniques may not always be the most appropriate. In the recommendation, they have also suggested error-based techniques as an alternative. Similarly, they have highlighted that the decision about which approach to use should be determined by the cognitive abilities of the individual, as well as the task or skill being taught. These 2 additional pieces of guidance address the concerns you raise. Therefore, no change has been made.

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The British Psychological Society	Guideline	044	015	Skills-based learning and task-based training (1.22.6) in cognitive rehabilitation are forms of enhanced learning strategies but are not mentioned in previous sections on strategies. Furthermore, the statement about errorless learning methods is too general. Errorless learning methods (1.22.6) are only indicated where evidence shows this approach is more effective than trial-and-error learning; this does not apply to all situations or task types. For example, evidence suggests errorless learning yields no benefits over trial-and-error learning for people with dementia. However, reducing errors during learning may help to maintain motivation by providing an experience of success.	Thank you for your comment. The guideline section on cognitive rehabilitation does not name any specific enhanced learning strategies, so these examples would not sit within previous recommendations. The evidence for skills-based learning and task-based training were specifically identified within the context of improving or maintaining activities of daily living, which is why they are included in this section. Regarding your comment about the general nature of the recommendation on errorless learning methods, we believe that the wording already addresses your concerns. The recommendation caveats itself by saying 'depending on the person's cognitive strengths and weaknesses and the skill or task the training is focusing on'. Furthermore, error-based learning is also included in this statement, acknowledging that errorless learning is not the only approach that can be used. Therefore, no changes have been made.
Central London and Community Healthcare Trust	Guideline	044	015 - 018	*1.22.6 depending on the person's cognitive strengths and weaknesses* suggested rewording: "depending on the persons sensory, perceptual, motor planning and cognitive strengths and weaknesses"	Thank you for your comment. The suggested list that you have provided is more detail than the committee wish to include in this recommendation. They have used the term cognitive strengths and weaknesses to represent a range of impairments, and wanted to avoid listing many different domains as this tends to suggest a complete list, which would be very hard to do for this subject. This is more consistent with several other recommendations throughout the guideline that cover tailoring and adjusting interventions to an individual's rehabilitation needs without listing what they might be. Therefore, no changes have been made.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	045	002	Remove word "bed"	Thank you for your comment. We have amended the wording as suggested.
Corporé	Guideline	045	002	Where you have provided examples of environmental barriers and moving and handling equipment, you have not provided examples of environmental adaptations, which would be beneficial here.	Thank you for highlighting this. We have added an example of using ramps where steps exist to cover potential environmental adaptations. Each category of adjustments now has an example next to it in the referenced recommendation.
Shaftesbury Icanho	Guideline	045	008	1.22.9 - In working collaboratively with required agencies, consideration should be made to the timing of both assessing for and implementing environmental adaptations, depend on the resources of the Local Authority at that time, and may vary between areas.	Thank you for your comment. The committee acknowledge that one of the barriers to accessing environmental adaptations is a lack of continuity of care between services, which would be impacted by the poorly coordinated assessment and implementation that you highlighted. However, this is an example of an area that will naturally improve by implementing the guidance and focusing on collaboration between services, which will in turn

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					lead to better communication between organisations. Therefore, no change has been made.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	045	008	Equipment services and wheelchair services for example, are often run by private companies who have a strict criteria which is about budgets and targets and is inflexible to patient/client need. Complex provision often involves a large amount of form filling on the clinician's part, Independent Funding Requests with often lengthy delays, refusals, resubmissions. This results in discharge delays, rehab delays and reduced quality of life for individuals who cannot move forward. Clinicians may identify and action needs in a timely manner but then hit blocks in provision.	Thank you for your comment. It is unclear what action you would like us to take based on your observation. We agree that there may be certain services that might have criteria and complex application processes, and these may end up affecting the provision of equipment and environmental adaptations. However, the committee discussed that one of the most common causes of discontinuities of care is when services do not coordinate between themselves. Even if it is not possible to collaborate well with private companies, that does not mean that other rehabilitation services should not endeavour to practice it where possible in order to provide as efficient a service as possible.
Central London and Community Healthcare Trust	Guideline	045	008 - 009	1.22.9 *Work collaboratively with required services to ensure timely delivery of equipment and environmental adaptations.* Cost implications as therapy intervention block often completed before provision of equipment or adaptations which can take years. "timely" is helpful but what constitutes a breach of this?	Thank you for your comment. The committee agrees there is currently a problem with timely provision of equipment and environmental adaptations and noted that this may require greater collaboration, communication, and additional resources. The committee also discussed that any additional costs would be offset by preventing prolonged inpatient or residential stays and reducing reliance on costly formal care. Due to the wide range of conditions and disabilities covered by this guideline, they could not be more specific on what timely exactly constitutes.
The Royal Hospital for Neuro-disability	Guideline	046	001	This section should make an explicit recommendation about transition between children's and adult's services – at very least highlighting the need to use existing guideline for transition	Thank you for your comment. As you mention, NICE already has published guidance on the transition between children and adult services, meaning it is out of scope for this guideline. However, we have included a cross-reference to NG43 Transition from children's to adults' services for young people using health or social care services at the beginning on the guideline, and again at the beginning of this section. Therefore, no change has been made.
University College London Hospital	Guideline	046	003	Need to clarify consent and best interest for this action.	Thank you for your comment. The principles of consent and best interest apply throughout this guideline, not simply this recommendation. NICE already has guidance on these topics, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws). This has been referenced at the beginning of the section you refer to. Therefore, no change has been made.
Guy's and St Thomas' NHS Foundation Trust	Guideline	046	003 - 006	Rec 1.23.1 / 1.23.2 – We welcome the inclusion of informing the child or young person's nursery, school or college. These guidelines will be useful in helping organisations think about how to operationalise this consistently and who in their teams might be best placed to do this. From clinical experience as psychologists, we see more positive transitions back to education settings when the educational setting has had early contact with a clinician and the opportunity to ask questions.	Thank you for your comment. We hope that the recommendations included in this guideline help to ease transitions back into education settings for people with chronic neurological disorders, particularly through increasing communication between education providers and rehabilitation practitioners. We have not made the amendment that you have requested for recommendation 1.23.2. The recommendation currently focuses on

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				This reduces the delay in the child returning to school and ensures that their social and emotional wellbeing is being considered. Rec 1.23.2 – we would recommend that the information included includes sign-posting schools to their local authority teams and suggesting they make early contact with local authority to enquire about additional support available. Where we have had delays in children returning to school, the barrier has often been practical (i.e. taxi services to school) with additional delays in the child accessing education from home as local authority has not been notified in a timely manner by the school. This could also be included as a section similar to the one below for "1.24 Rehabilitation in the workplace" where is says "if the person is unable to remain in …". The child section for education recommendations is noticeably shorter than the section on workplace although we know that education plays a protective role in the lives of children who are living with chronic neurological conditions.	healthcare professionals providing medical information to education settings in the early stages of diagnosis, to allow schools adequate time knowledge to consider and anticipate potential support needs. Contacting local authorities would likely form part of this consideration process. However, we have amended the 'Benefits and harms' section in the corresponding evidence review (K) to include that early information on injury and potential prognosis will allow education settings time to contact their local authority teams to identify local support available. We have also not added a recommendation on 'If the person is unable to remain in...' to this section. As you mention in your comment, education has a protective role in the lives of children and young people with chronic neurological conditions. Additionally, there are legal protections to removing children from education, which the scope of this guideline is not nuanced enough to consider.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	046	006	This is crucial but is limited by availability of professionals in some areas due to absence of clear, updated Service Specification for Paediatric Neurorehabilitation, and adequate funding for rehab teams. It is crucial the Service Specifications are updated appropriately and highlight the need for commissioning of specialist teams and roles.	Thank you for your comment. The guideline committee were aware when drafting recommendations that the current availability of rehabilitation professionals and funding for rehabilitation teams may limit the implementation of these recommendations. In order to mitigate these barriers, they have drafted a whole section on service design at the beginning of the guideline. Recommendations are aimed at commissioners, and focus on clinical pathways, minimum service specifications, building local capacity, and providing responsive services. By implementing these recommendations alongside those aimed at professionals, it is hoped that future capacity of rehabilitation practitioners will increase and allow them to action this guidance.
United Kingdom Acquired Brain Injury Forum	Guideline	046	006	This idea is welcomed. However, in this recommendation will be challenging in practice due to • limited availability of professionals • funding for rehab teams is inadequate	Thank you for your comment. The guideline committee were aware when drafting recommendations that the current availability of rehabilitation professionals and funding for paediatric rehabilitation teams may limit the implementation of these recommendations. In order to mitigate these barriers, they have drafted a whole section on service design at the beginning of the guideline. Recommendations are aimed at commissioners, and focus on clinical pathways, minimum service specifications, building local capacity, and providing responsive services. By implementing these recommendations alongside those aimed at professionals, it is hoped that future capacity of rehabilitation practitioners will increase and allow them to action this guidance.
United Kingdom Acquired Brain Injury Forum	Guideline	046	006	This idea is welcomed. However, in this recommendation will be challenging in practice due to • limited availability of professionals	Thank you for your comment. The guideline committee were aware when drafting recommendations that the current availability of rehabilitation professionals and funding for paediatric rehabilitation teams may limit the implementation of these recommendations. In order to mitigate these

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				• funding for rehab teams is inadequate It is crucial the Service Specifications are updated appropriately and highlight the need for commissioning of specialist teams and roles.	barriers, they have drafted a whole section on service design at the beginning of the guideline. Recommendations are aimed at commissioners, and focus on clinical pathways, minimum service specifications, building local capacity, and providing responsive services. By implementing these recommendations alongside those aimed at professionals, it is hoped that future capacity of rehabilitation practitioners will increase and allow them to action this guidance.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	046 - 047	001	1.23 - Remove children and young people – could be any age accessing education	Thank you for your comment. While we agree that people can access education at any age, the majority of these will be children and young adults due to the legal requirements involved. The recommendations in this section are specifically aimed at this age range, due to the unique experiences of this population. The committee did not believe that these could be extrapolated to further education in adults. However, we have made several recommendations on education throughout other sections of the guideline that are not age-restricted. Therefore, no change had been made.
Success – Life After Cure Ltd	Guideline	047	004	Rec 1.23.4 We welcome this recommendation but recognise the difficult dichotomy in prioritising to schools the 'temporary' acute oncology vs the longer term neurorehabilitation needs of children with brain tumours. Two separate named health care professionals across two coordinated pathways of care might be required to avoid neurorehabilitation being forgotten indefinitely and opportunities missed. A specific neurorehabilitation guideline, across age transitions and the lifespan, for these children would be helpful [as in adults with brain tumours and metastases]	Thank you for your comment. The committee acknowledge that there may be very specific examples of overlap between treatment and rehabilitation in people with chronic neurological disorders (for example, multiple sclerosis and Parkinson's disease). However, this guideline is about rehabilitation and that is what our recommendations cover. Implementing this guidance on providing a named healthcare practitioner that education practitioners can contact, and ensuring 2-way communication does not preclude another oncological professional from doing the same in acute treatment phases. Therefore, no change has been made. This guideline is designed to cover the lifelong rehabilitation needs of children and adults with brain tumours, but if you have identified areas where you feel more specific guidance is needed, please complete the online form at https://www.nice.org.uk/forms/topic-suggestion.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	047	005	This is crucial but is limited by availability of professionals in some areas due to absence of clear, updated Service Specification for Paediatric Neurorehabilitation, and adequate funding for rehab teams. There is currently a postcode lottery bringing inequity to the local offers and outcomes achieved following ABI.	Thank you for your comment. The guideline committee were aware when drafting recommendations that the current capacity of paediatric rehabilitation teams may limit the implementation of these recommendations. In order to mitigate these barriers, they have drafted a whole section on service design at the beginning of the guideline. Recommendations are aimed at commissioners, and focus on clinical pathways, minimum service specifications, building local capacity, and providing responsive services. By implementing these recommendations alongside those aimed at professionals, it is hoped that future capacity of rehabilitation practitioners will increase and allow them to action this

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					guidance, reducing the geographical inequalities that you mention in your comment.
United Kingdom Acquired Brain Injury Forum	Guideline	047	005	This idea is welcomed. However, in this recommendation will be challenging in practice due to • limited availability of professionals • funding for rehab teams is inadequate	Thank you for your comment. The guideline committee were aware when drafting recommendations that the current capacity of paediatric rehabilitation teams may limit the implementation of these recommendations. In order to mitigate these barriers, they have drafted a whole section on service design at the beginning of the guideline. Recommendations are aimed at commissioners, and focus on clinical pathways, minimum service specifications, building local capacity, and providing responsive services. Implementing these recommendations alongside those aimed at professionals should also increase future capacity of rehabilitation practitioners.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	047	008	This is a great recommendation, but in the absence of commissioned rehabilitation services, who do the committee envisage will act as Rehabilitation Practitioner. We have concerns over how this might be implemented and who commissioners might deem to be suitable for the role.	Thank you for your comment. The most appropriate named healthcare professional stated in this recommendation will differ depending on the individual child or young person, their chronic neurological disorder, whether they are still in an acute phase, and their rehabilitation needs. It is likely to be their key contact (or key worker or complex case manager if they are assigned one), as they will be best placed to answer concerns about rehabilitation needs for the child or young person. However, for another example of a child undergoing a period of intensive rehabilitation shortly after an acquired brain injury, this role may be better fulfilled by the lead practitioner of the multi-disciplinary team. Due to these changing needs, the professional may need to change over time. We have added information to the 'Benefits and harms' section of evidence review K to explain this.
United Kingdom Acquired Brain Injury Forum	Guideline	047	008	This is a welcome recommendation, but it is unclear who will take on the role of Rehabilitation Practitioner.	Thank you for your comment. The most appropriate named healthcare professional stated in this recommendation will differ depending on the individual child or young person, their chronic neurological disorder, whether they are still in an acute phase, and their rehabilitation needs. It is likely to be their key contact (or key worker or complex case manager if they are assigned one), as they will be best placed to answer concerns about rehabilitation needs for the child or young person. However, for another example of a child undergoing a period of intensive rehabilitation shortly after an acquired brain injury, this role may be better fulfilled by the lead practitioner of the multi-disciplinary team. Due to these changing needs, the professional may need to change over time. We have added information to the 'Benefits and harms' section of evidence review K to explain this.
National Acquired Brain Injury in Learning and	Guideline	047	012	We would agree this is essential in ensuring children are effectively supported and the hidden impact of neurological conditions are monitored over time in education settings. There is currently no data on	Thank you for your comment. Unfortunately, it is beyond the remit of NICE to recommend how education settings collate and utilise data on pupils with a chronic neurological disorder. Therefore, no change has been made.

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Education Syndicate (NABLES)				numbers of children with neurological conditions within schools, and there is also no way to flag them across development when new needs may present as their brain develops. This means schools currently fail to track many pupils and may struggle to review appropriately. Including brain injury in the SEN census and ensuring schools have a way to flag and monitor children would be hugely beneficial to support this recommendation.	However, we do include a recommendation to regularly review education, health and care plans, as well as ensuring there is 2-way communication between education and rehabilitation professionals. NICE also has far more detailed guidance on education, health and care plans, published in 'Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education' (NG213), which is cross-referred to at the beginning of this section. Again, this guideline highlights the importance of regularly reviewing these plans and communicating with education settings.
United Kingdom Acquired Brain Injury Forum	Guideline	047	012	This is a welcome recommendation to ensure children are with neurological conditions are supported and monitored over time in education settings. The SEN census and schools monitoring systems need to be updated appropriately.	Thank you for your comment. Our recommendations also apply to related services, including education. Service design recommendations require collaboration between commissioning bodies, including education services, and there is a dedicated section on rehabilitation to support education for children and young people. The committee therefore hopes any changes to current processes will be undertaken to support implementation of their recommendations.
Inflammatory Neuropathies UK	Guideline	047	019	It would be useful to have reference in this section to potential retraining and also to highlight referrals to external support where appropriate to support return to work, or access to work	Thank you for your comment. We believe that both your concerns are addressed by the existing draft recommendations, although we have made small adjustments to strengthen the coverage. There is a recommendation on retraining, advising and supporting an individual to change work if they are unable to remain in (or return to) work. In light of your comment, we have re-worded this recommendation to include changing job roles, rather than simply careers or organisations. We have also listed examples in the 'Benefits and harms' section of evidence review K to show what support may entail, including ones aimed at retraining. Similarly, signposting to external advice about work is included in the section on information, advice and learning. However, we have now expanded our cross-reference at the end of this section to all sections of NG146 Workplace health: long-term sickness absence and capability to work and included a direct link to the Access to Work scheme. Both of these provide further advice on support available when returning to employment.
MS Society	Guideline	047	019	The guideline makes no mention of FIT notes to support return to work as part of the rehabilitation process. This is a significant omission, particularly for working-age adults whose rehabilitation needs may include help returning to employment. The optimal clinical pathway for adults with neurological conditions: rehabilitation recommends that, where relevant, a FIT note should be completed to advise on return to work. This supports a more holistic	Thank you for your comment. NICE already has published guidance on the use of FIT notes to support returning to work, which can be found in NG146 Workplace health: long-term sickness absence and capability to work. We have a link to this guidance at the end of the section on rehabilitation in the workplace, but only to specific sections on workplace culture and policies. We have now expanded that cross-reference to span the entire guideline, including the benefits of FIT notes in this population.

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				approach to rehabilitation, taking account of the social and vocational aspects of recovery. This is especially important for people with MS, who are often diagnosed in early adulthood and may need to balance ongoing symptoms with employment over many years. Fatigue, cognitive changes, mobility issues and pain can all impact the ability to work, even if a person is otherwise medically stable. Structured advice about adjustments or phased return can make a crucial difference in helping someone remain in or return to employment, and in reducing the risk of long-term worklessness. FIT notes, when used appropriately, offer a valuable opportunity for clinicians to support this process. They can recommend workplace adaptations, reduced hours or modified duties, all of which can help people stay connected to work and avoid unnecessary absence. Yet in the current system, this is rarely integrated into rehabilitation planning. Without clear guidance from NICE, opportunities to use FIT notes proactively are often missed, and vocational rehabilitation remains underused and inconsistently provided. Embedding structured advice about work into rehabilitation reflects the broader purpose of rehabilitation itself: to support people to live as fully and independently as possible.	
North Cumbria Integrated Care NHS Foundation Trust	Guideline	047	019	We would like the committee to extend their recommendations on vocational rehabilitation for patients who are self-employed and run their own business.	Thank you for your comment. We have amended the statement at the beginning of the section of rehabilitation and workplace to state that recommendations cover people who are self-employed.
British Association of Brain Injury and Complex Case Management	Guideline	047	021	1.24.3 We agree the importance of the link between rehabilitation and work and would like to see added reference to the Equality Act 2010, reasonable adjustments, and funding streams, such as Access to Work	Thank you for your comment. Although not explicitly mentioned in this guideline, reasonable adjustments and the Equality Act 2010 are both covered by the specific cross-reference to a recommendation in the adult stroke guideline. Additionally, there are several recommendations focused on workplace adjustments in this section. However, we have now included a link at the end of this section to the Access to Work website.
United Kingdom Acquired Brain Injury Forum	Guideline	047	021	We agree on the importance of assessing the ability to work and facilitation of a return to work wherever possible but feel it should be stipulated that referral to a Vocational Rehabilitation Specialist should be made and especially for more complex cases or at least with their support if not available locally.	Thank you for your comment. The committee recognise the important role that vocational rehabilitation specialists can play in supporting people with chronic neurological disorders with rehabilitation for employment goals. However, as you mention in your comment, this is not a job role that is currently universally available within the NHS. As such, any guidance would likely have a significant resource impact, and we cannot make this kind of recommendation without compelling supporting cost-effectiveness

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					evidence. Unfortunately, although we looked for evidence on interventions or approaches to support access to employment, which would include access to a vocational rehabilitation specialist, we did not identify any strong evidence in the area. Therefore, no change has been made.
Independent Neurorehabilitation Providers Alliance	Guideline	047	021	We agree on the importance of assessing the ability to work and facilitation of a return to work wherever possible but feel it should be stipulated that referral to a Vocational Rehabilitation Specialist should be made and especially for more complex cases or at least with their support if not available locally.	Thank you for your comment. The committee recognise the important role that vocational rehabilitation specialists can play in supporting people with chronic neurological disorders with rehabilitation for employment goals. However, as you mention in your comment, this is not a job role that is currently universally available within the NHS. As such, any guidance would likely have a significant resource impact, and we cannot make this kind of recommendation without compelling supporting cost-effectiveness evidence. Unfortunately, although we looked for effectiveness evidence on interventions or approaches to support access to employment, which would include access to a vocational rehabilitation specialist, we did not identify any strong evidence in the area. Therefore, no change has been made.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	047	General	Lots of mention of roles for specialist healthcare professional to link with education, but in reality services have limited capacity or no capacity at all to deliver this, however it is essential as Education has limited knowledge with regards to ABI.	Thank you for your comment. The committee explained that this could be achieved by assigning an existing healthcare practitioner to liaise with education providers. They noted that any additional costs may be offset by improved retention of children and young people in education, along with improved social participation, health and wellbeing, and wider socio-economic benefits. Also, the committee made recommendations on service design to make service delivery more efficient, potentially freeing resources and funds for other uses, which could be used, for example, to build capacity within rehabilitation services. The committee also hopes their recommendations will be adopted and funded accordingly.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	047 - 048	019 001 - 028	1.24 - Add - People to be empowered to utilise work related strategies to continue to maintain work	Thank you for your comment. The committee agree that empowerment is important to ensure people feel comfortable advocating and using work adjustments for their rehabilitation needs and, although the word is not explicitly stated, recommendations in this section continually stress the importance of a collaborative approach. Guidance focuses on including people and employers in discussions about their workplace adjustments, setting realistic and attainable goals, identifying potential barriers (of which lack of confidence may be one), and how to communicate needs with colleagues. Therefore, no change has been made.
The Royal Hospital for Neuro-disability	Guideline	048	003	Perhaps phrase as "unable to remain in, or return to, a specific work role provide support to enable them to leave or change roles"	Thank you for your comment. We have amended the wording of the recommendation to include that people may wish to change or leave job roles, rather than vocations.
Defence Medical Rehabilitation Centre	Guideline	048	003	Consider bullet points to expand on point - "If the person is unable to remain in, or return to, work, provide support to enable them to leave or change work: • explore areas of interest and values	Thank you for your comment. This is more detail than we provide in recommendations, and some of these examples constitute duplication with already drafted recommendations (for example, providing information on unemployment benefits). Therefore, no change has been made to the

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				• Identify transferable skills • Identify functional abilities, limitations and any strategies/adjustments that may be required. • Empower the person to identify and explain adjustments and adaptations needed with future employers. • consider capacity for new learning/retraining. • facilitate engagement in work experience, volunteering or leisure activities. • Provide education and signposting to information regarding disclosure, reasonable adjustments, support services for finding new employment or educational support, schemes such as Access to Work and condition specific information. • Provide guidance on medical retirement, job seeker or unemployment benefits • discuss alternatives to paid employment such as volunteering, home/family roles or leisure activities.	recommendation. However, we have added some of these examples to the 'Benefits and harms' section of the corresponding evidence review (K).
The Neurological Alliance	Guideline	048	003	49% of adult respondents to My Neuro Survey in England agreed they have stopped working because of my neurological condition(s). The section on vocational rehabilitation should be expanded to include more specific guidance on the needs of those planning to reduce hours, leave work or retire early due to a neurological condition. This group often misses out on tailored support, despite experiencing significant impacts on identity, income and wellbeing.	Thank you for your comment. The committee appreciate the unique challenges that people with chronic neurological disorders face when navigating the area of employment, which is why this was identified in the scope as a key area. Unfortunately, although we looked for effective evidence on interventions or approaches to support access to employment (including leaving employment), we did not identify any strong evidence in the area. Due to this, guidance in this section is drafted based on qualitative evidence (see evidence review K for further details) and committee experience and expertise, which limits how specific they can be. However, we disagree that these recommendations do not support a tailored approach to workplace rehabilitation. Several recommendations in this section stress a collaborative approach. Similarly, there is an entire section earlier in the guideline on setting personalised rehabilitation goals for education, training and work. Therefore, no change has been made.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	048	004	We thought adding the following would be helpful '*…or change work (including finding new career opportunities consistent with their strengths and weaknesses if returning to a previous job role is no longer possible)'*	Thank you for your comment. We feel that exploration of new career opportunities is implied in the current wording of the recommendation about providing support for changing work. Therefore, no change has been made to the recommendation. However, we have added a few examples of what information and support could encompass in the 'Benefits and harms' section of the corresponding evidence review (K).
Defence Medical Rehabilitation Centre	Guideline	048	005	We would recommend the need to seek consent from patients to approach their employer.	Thank you for your comment. The principles of consent apply throughout this guideline, not simply this recommendation. NICE already has guidance on these topics, which can be found in 'Making decisions using NICE

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					guidelines' (including links to the most up-to-date professional guidelines, standards and laws) and NG108 Decision-making and mental capacity. These have been referenced at the beginning of this section. Therefore, no change has been made to the recommendation. However, we have highlighted these discussions should only occur with the consent of the individual with a chronic neurological disorder within the 'Benefits and harms' section of the corresponding evidence review (K).
Defence Medical Rehabilitation Centre	Guideline	048	005	Consider adding additional point: Empower the person to identify and explain adjustments and adaptations needed with their employer.	Thank you for your comment. The committee agree that empowerment is important to ensure people feel comfortable advocating and using work adjustments for their rehabilitation needs and, although the word is not explicitly stated, recommendations in this section continually stress the importance of a collaborative approach. Guidance focuses on including people and employers in discussions about their workplace adjustments, identifying potential barriers (of which lack of confidence may be one), setting realistic and attainable goals, and how to communicate needs with colleagues. Therefore, no change has been made.
Faculty of Occupational Medicine	Guideline	048	005 - 011	1.24.3. We wonder if adding occupational health (OH) professionals (such as OH physiotherapists and psychologists) and Health ad safety advisers might be useful. It may be helpful to suggest a single point of contact to liaise with the line manager about putting in place the needed workplace adjustments or redeployment. This would likely be OH adviser or OH physician. Risk assessment may be useful to consider adding as well to ensure the safety of the patient, colleagues and service users when returning to work is planned.	Thank you for your comment. Occupational health professionals are already mentioned in the recommendation, as part of the example list of people to collaborate with in the workplace. However, this is not meant to be an exhaustive list and so we have not added health and safety advisors. We have not specified a single point of contact throughout these recommendations, because no evidence was identified that this would be helpful specifically in an employment setting. However, the wording of the recommendations does encourage 1 rehabilitation professional to meet with the people with a chronic neurological disorder and their employers, undertaking a work capacity evaluation, and collaborate with other professionals. Due to the wide range of disorders, workplace settings, and rehabilitation needs, the most appropriate person to carry out this recommendation will likely differ from person to person. However, in practice, it is likely to be an occupational health professional as you suggest. Finally, risk assessments are now covered after we have expanded the cross-reference to NG146 Workplace health: long-term sickness absence and capability to work at the bottom of this section, to include the whole of the guideline.
The Chartered Society of Physiotherapy	Guideline	048	008	We agree with the recommendations and would also like to add in 'provide rehabilitation to enable achievement of social participation goals'	Thank you for your comment. The recommendation that you have referenced is specific to rehabilitation in the workplace. Rehabilitation for social participation is covered in the following 3 guideline sections on

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					participating in social and leisure activities, family life and friendships, and intimate relationships and sex. Therefore, no change has been made.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	048	011	We thought that the following should be added after line 11 'Liaise and work with Access to Work and Disability Employment Advisors. Develop phased return-to-work plans, work trials/experience, educational sessions for employers and colleagues, strategies for getting to and from work and reasonable adjustment recommendations.'	Thank you for your comment. The areas that you mention are covered in the subsequent recommendation cross-referencing to the adult stroke guidance. Therefore, no change has been made.
Shaftesbury Icanho	Guideline	048	011	1.24.3 – In discussion with the person and employer, consideration could also be given to the inclusion of the Dept. of Work and Pensions Access to Work Scheme, which is referenced within the supporting documentation.	Thank you for your comment. We have now included a link to the Access to Work scheme at the end of this section on rehabilitation and the workplace.
Central London and Community Healthcare Trust	Guideline	048	012 - 014	*1.24.4 When planning return to work see also recommendation 1.16.4 in NICE's guideline on stroke rehabilitation in adults, which is applicable to people with other forms of chronic neurological disorder.* This will be very helpful could this type of specific recommendation be used for other rehabilitation outcomes?	Thank you for your comment. The committee wished to directly reference this recommendation in the stroke guideline because it did not require any re-wording or extra consideration in order to be directly applicable to this population. They did not think the same was true of other recommendations. Therefore, no change has been made.
Inflammatory Neuropathies UK	Guideline	049	008	It would be useful in this section to highlight the need to consider socioeconomic factors, and where support may be available. Also need to highlight the emotional impact of social activities, both in terms of considering the impact of loss/change and the impact of actually attending or participating and access to support if needed	Thank you for your comment. We have now expanded the recommendation to include examples of barriers to social participation. One of these is socioeconomic factors.
University College London Hospital	Guideline	049	009	Refer to Social prescribing.	Thank you for your comment. The committee recognise that some of these recommendations may be delivered through social prescribing. However, they did not want to limit to this, or inadvertently suggest that this was the preferred method. This is especially true as social prescribing was not identified in the qualitative evidence themes that were used to inform these recommendations. Therefore, no change has been made.
Central London and Community Healthcare Trust	Guideline	049	009 - 011	*1.25.1 Talk to the person about any barriers preventing them from achieving their social participation goals and work together to overcome these barriers* Suggested addition: Talk to the person and assess any barriers, which may include, sensory, perceptual, motor, motor planning, emotional, regulation(fatigue), and or cognitive barriers.	Thank you for your comment. We have now expanded this recommendation to reference potential barriers. These include the need for support, cultural, social or socioeconomic factors, and availability of facilities.
University College London Hospital	Guideline	049	015	Clubs are very infrequently available locally and difficult to access referral to them too.	Thank you for your comment. The referenced recommendation does not state that the clubs need to be specifically for people with chronic neurological disorders, which is what we assume your concern about availability is based on. As long as they are accessible to the individual, then they could be any community group or activity that aligns with their social participation goal. If a person is only comfortable joining groups that are for people with their disorder, then we agree that availability will be more limited. However, in that case, the committee argue that having

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					someone supporting them in identifying these clubs or activities will be very beneficial to them. Indeed, the committee are aware of the poor provision of social and leisure group activities to support rehabilitation in some areas, and have made a recommendation in the commissioning section of this guideline that stresses the importance of providing funding for these enterprises. Therefore, no change has been made.
Shaftesbury Icanho	Guideline	049	019	1.25.5 – Supporting the person to access social and leisure activities – suggest need for a support worker, family member or friend of the person going with the person to new social and leisure activities (at least for the initial sessions). If the person is expected to go to new social and leisure activities on their own this may be difficult for them to action due to cognitive impairments caused by an ABI for example	Thank you for your comment. This is quite a specific example, and more detail than we would usually include. Also, in-person attendance may not be feasible for people who do not have a family member or friend to support them due to many groups taking place out of work hours. Therefore, no change has been made to the recommendation. However, we have included your example in the 'Benefits and harms' section of the corresponding evidence review (K), which gives further information and background on guidance.
Parkinson's UK	Guideline	049	019 - 021	We recommend that this point be extended to include education of people at places of faith, so that the ability of a person with a long-term neurological condition to participate in religious practices is understood, and can be adapted if appropriate (e.g. needing to eat and drink during periods of religious fasting or needing a chair if they cannot kneel for prayer).	Thank you for your comment. We have amended the referenced recommendation to include faith-based activities, and updated the 'Benefits and harms' section of evidence review K to reflect the context of your comment.
Inflammatory Neuropathies UK	Guideline	050	005	This section must highlight the need as part of assessment to focus on impact on relationships and to highlight support that may be needed due to the significant impact on relationships linked to neurological conditions	Thank you for your comment. The person is given the opportunity to highlight important relationships in the context of a rehabilitation assessment in the section about what to cover in a holistic rehabilitation needs assessment. The guideline recommends that people are asked about their relationships, what is most important to them and given the opportunity to talk freely about how their life has been impacted by their neurological condition. These identified issues would then feed into goal setting and consideration of interventions. In addition this section, about family life and friendships focuses on identifying barriers to family life and friendships as part of the rehabilitation assessment so that physical, cognitive, communication and emotional wellbeing interventions can be incorporated into a rehabilitation plan that support people in overcoming barriers where this is possible. The section on intimate and sexual relationships also includes recommendations which require identifying needs and priorities for the person as part of a holistic assessment. We have therefore not made any additions to the guideline in this regard

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					apart from to emphasise the importance of family and friendships for children, adding a reference to school and home life in this section.
Oxford University Hospitals - Paediatric Neuropsychology Department	Guideline	050	005	We feel that this guidance comes very much from an adult perspective e.g. as a parent and feel that there could be recommendations made here for in relation to child's relationships with friends, parents and wider family. For both children and adults, it is important to think about the support for the family/ systems around the young person and this could be emphasised here.	Thank you for your comment. In response to your comment, we have re-drafted this section to explicitly mention children and young people.
Guy's and St Thomas' NHS Foundation Trust	Guideline	050	005	Rec 1.26 – This section reads with a heavy adult focus and we would welcome more inclusion of children and young people's needs. Childhood and adolescence are key developmental periods where the foundation for life-long social relationships are formed and we would welcome an additional section such as "support adolescents to maintain and develop friendships".	Thank you for your comment. In response to your comment, we have re-drafted this section to explicitly mention children and young people.
Brainkind	Guideline	050	005 - 022	Consider adding a recommendation around providing information to the family about the impact that having a family member with brain injury could have on them, including impact on children and young people, in order to enable families to recognise their own needs, be provided with sources of support in the community (e.g. Anchor Point https://ukabif.org.uk/page/anchorpoint, Headway family groups), as well as information on how to access services if needed.	Thank you for your comment. Personalised information for family and carers is covered in the section on information, learning and advice as part of rehabilitation. The recommendations cover education about a person's disorder, their current and anticipated rehabilitation needs, and how to access services (including healthcare, social care, community groups and third sector organisations). Therefore, no change has been made.
Success – Life After Cure Ltd	Guideline	050	006	1.26.1 There is evidence that childhood brain tumour survivors need support once adult to achieve family life and friendships, which our charity aims to facilitate. The services they currently access in adulthood are however general childhood cancer toxicity surveillance, and not geared to identify the needs of those with acquired brain injury from brain tumours. This leads to misassumptions, for example that fertility preservation [before cancer] is the greater priority. The competing complex priorities of the two [childhood cancer and brain tumour neurorehabilitation] pathways would benefit from clarity in a specific neurorehabilitation guideline for childhood brain tumours.	Thank you for your comment. The support that you are mentioning would be covered in the first recommendation in this section, regarding discussing and setting rehabilitation goals surrounding family life and friendships. The committee were unable to make more specific recommendations due to a lack of evidence identified in this area. This guideline is designed to cover the lifelong rehabilitation needs of children and adults with brain tumours. However, this example that you have provided is a very specific sub-population with a complex interplay of disorders, competing interests, and healthcare needs. If you have identified areas where you feel more specific guidance is needed, please complete the online form at https://www.nice.org.uk/forms/topic-suggestion.
Shaftesbury Icanho	Guideline	050	009	1.26.2 – Useful to identify the barriers to family life and friendships, including parenting and caring relationships – the next stage is ensuring there are effective and simple strategies that can be used by professional colleagues to reduce these barriers for the person.	Thank you for your comment. The person is also given the opportunity to highlight important relationships in the context of a rehabilitation assessment in the section about what to cover in a holistic rehabilitation needs assessment. The guideline recommends that people are asked about their relationships, what is most important to them and given the opportunity to talk freely about how their life has been impacted by their neurological condition. These identified issues would then feed into goal

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					setting and consideration of interventions. In addition this section, about family life and friendships focuses on identifying barriers to family life and friendships as part of the rehabilitation assessment so that physical, cognitive, communication and emotional wellbeing interventions can be incorporated into a rehabilitation plan that support people in overcoming barriers where this is possible. We have therefore not made any additions to the guideline in this regard apart from to emphasise the importance of family and friendships for children, adding a reference to school and home life in this section.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	050	022	We thought 'providing educational and emotional support for those close to the patient, including their children (where consent has been given)' should be added after line 22.	Thank you for your comment. Although we appreciate the emotional and mental challenges experienced by family members, making recommendations on support for people who do not have a chronic neurological disorder is beyond the scope for this guideline. Therefore, no change has been made. However, we do have a recommendation in the guideline section on information, advice and learning as part of rehabilitation to provide personalised information for families and carers on a person's disorder, their current and anticipated rehabilitation needs, how to access services, as well as alternative third sector and community organisations that can provide further information and support. Similarly, we have several recommendations throughout the guideline on involving family members and carers in assessment of rehabilitation needs and delivery of rehabilitation, if appropriate. Finally, although we are aware this does not cover children of people with chronic neurological disorders, NICE already has published guidance on supporting adult carers (NG150). This has been highlighted at the beginning of the guideline document, as well as this specific section.
University College London Hospital	Guideline	051	001	Rehabilitation for sexual relationships and sex are one of the areas where staff will need a great deal of upskilling to assess and intervene. This is generally poorly addressed at present and will need significant resource and training to meet this area	Thank you for your comment. The committee acknowledge that implementing these recommendations may be associated with a resource impact. As you mention, there will be an increased need for staff training. However, the lack of support with sexual rehabilitation was a strong theme identified in the qualitative evidence, and was supported by the committee's own experience and expertise. This can have a considerable impact on a person's quality of life. They note that all recommendations represent current best practice, with many of the recommendations in this section focused on creating a trusting and open environment where people feel comfortable in discussing their rehabilitation needs for intimate relationships and sex. Once identified, any simple rehabilitation needs can be addressed

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					by community services (for example, provision of information or training or carers or partners). For more complex rehabilitation needs, the committee has only recommended people be signposted to the appropriate specialist service. Finally, the committee made sure to include interventions to support intimate relationships and sex in a list of minimum service requirements that commissioners should be considering when designing their services. This will ensure that there is adequate funding and resources to continue to provide these services in the future. Therefore, no change has been made.
Shaftesbury Icanho	Guideline	051	006	1.27.2- Agree, sex and intimate relationships is a key area to include, and perhaps one services find difficult to talk about / address. Would it be useful to include guidelines around couple sessions/ having open conversations with clients and spouses where appropriate?	Thank you for your comment. Both the qualitative evidence and the committee experience agree with your comment, that intimate relationships and sex are topics that professionals historically find difficult to talk about. These recommendations are focused on creating a more comfortable and trusting environment during rehabilitation planning, in the hopes of facilitating open conversations about rehabilitation for sexual function.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	051	008	We thought '*and sex and provide couple counselling where appropriate*.' should be added at line 8	Thank you for your comment. The recommendation referenced here is simply about providing opportunities to discuss rehabilitation needs and set rehabilitation goals connected with intimate relationships and sex. It would not be appropriate to add providing couple counselling here. However, we have added is as an example to a later recommendation about signposting to other services for specialist advice and support.
Royal College of Speech and Language Therapists	Guideline	051	011	We suggest adding to recommendation 1.27.3 to state "…and sex, **including any legal issues e.g. giving or obtaining consent**."	Thank you for your comment. Although the committee was aware of the importance of safeguarding in a section discussing sexual rehabilitation needs, they decided that the principles of consent should apply throughout this guideline, rather than specifically this section. NICE already has guidance on these topics, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws) and NG108 Decision-making and mental capacity. This has been referenced at the beginning of this guideline section. Additional detail about why the committee made this recommendation can be found in the corresponding evidence review (K), which already makes explicit reference to consent in this population. We have now slightly re-worded this section to include both giving or obtaining consent. The relevant rationale section has also been up-dated to include consent.
University College London Hospital	Guideline	051	012	Rehabilitation practitioners should know when and how to signpost to other services. Consider changing places spaces – have a link to these in UK Changing Places Toilets	Thank you for your comment. The recommendation that you have referenced is specifically concerned with signposting for specialist advice and support about intimate or sexual relationships and sex. Changing Places Toilets appears to be an initiative to provide larger accessible toilets for severely disabled people. This would be an inappropriate example to

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					add here. However, we do mention toileting needs during travel in the prior section on leisure and social activities. Therefore, we have added a reference to Changing Places Toilets into the 'Benefits and harms' section in the corresponding evidence review (K).
The British Psychological Society	Guideline	051	012 - 015	If required, psychosexual issues could be discussed as part of talking therapies in a community neurorehabilitation, provided by a clinical neuropsychologist where appropriate.	Thank you for your comment. We acknowledge that psychosexual issues could be addressed through community-delivered talking therapies. We have now included an internal cross-reference to the previous section on emotional health and mental well-being, highlighting the overlap in interventions to support intimate or sexual relationships and sex.
Huntington's Disease Association	Guideline	051	016	Rec 1.27.5 – We suggest adding: Rehabilitation practitioners should be aware that people with some neurological disorders, such as Huntington's disease, can experience sexual disinhibition.	Thank you for your comment. There is already a recommendation in the section on emotional health and mental well-being that highlighted the possibility of disinhibition in people with brain injuries. We have expanded this recommendation to include all people with chronic neurological disorders. However, we have not made any new recommendation in the referenced section (intimate and sexual relationships, and sex) in response to your comment.
British Association of Brain Injury and Complex Case Management	Guideline	051	016	1.27.5 We agree the proposals around intimate relationships and sex, We would like to also see reference to mental capacity in this section to highlight the need to identify and address any issues in this regard.	Thank you for your comment. Although the committee was aware of the importance of safeguarding in a section discussing sexual rehabilitation needs, they decided that the principles of consent and mental capacity should apply throughout this guideline, rather than specifically this section. NICE already has guidance on these topics, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws) and NG108 Decision-making and mental capacity. This has been referenced at the beginning of this guideline section. Therefore, no change has been made.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	051	019 - 022	1.27.6 - Statement about gender identify, beliefs etc should cover all sections	Thank you for your comment. The committee agreed that gender identity, sexual identity and cultural beliefs should be considered and respected throughout every interaction with rehabilitation services and professionals. However, they wanted to include it in this section as a distinct recommendation because of its role in creating an open and inclusive environment. Qualitative evidence showed that is it not only healthcare professionals that struggle to address the topic of intimate and sexual relationships, and sex. People with chronic neurological disorders can also feel uncomfortable raising issues in this area. This agreed with the committee's own experience, and they noted that concerns with potential prejudice in the area of gender identity, sexual identity or cultural beliefs will only heighten this barrier. Therefore, no change has been made.
First Community Health and Care	Guideline	051 - 052	General	Rec 1.27 - This recommendation will be a challenging change in practice because although already included in assessment and screened, patients can only be signposted for support. Community	Thank you for your comment. The committee acknowledge that implementing these recommendations may be associated with a resource impact (for example, in staff training). However, the lack of support with sexual rehabilitation was a strong theme identified in the qualitative

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				neuro rehabilitation services are more limited around treatment and interventions and access to specialist training.	evidence, and was supported by the committee's own experience and expertise. This can have a considerable impact on a person's quality of life. They note that all recommendations represent current best practice, with many of the recommendations in this section focused on creating a trusting and open environment where people feel comfortable in discussing their rehabilitation needs for intimate relationships and sex. Once identified, any simple rehabilitation needs can be addressed by community services (for example, provision of information or training or carers or partners). For more complex rehabilitation needs, the committee has only recommended people be signposted to the appropriate specialist service. Finally, the committee made sure to include interventions to support intimate relationships and sex in a list of minimum service requirements that commissioners should be considering when designing their services. This will ensure that there is adequate funding and resources to continue to provide these services in the future. Therefore, no change has been made.
Brainkind	Guideline	052 106	004 001	Minor edit: 'sexual relationships' instead of 'sexual relationship'	Thank you for your comment. We have amended the typos that you identified.
British Association of Brain Injury and Complex Case Management	Guideline	053	020	We would like to add comment on the CCM definition – it would help to include that a CCM will analyse clinical presentation alongside situation and circumstances in order to inform recommendations and decisions. This sets CCM apart from key working and is important to clarify while the title CM/CCM is not protected – so literally anyone can call themselves a CM. reference to BABICM as a professional membership body for brain injury and CCM, a resource for information about brain injury and complex case management would be helpful to guide commissioners and professionals not familiar with CCM, and as this guidance has identified it is not widely available and therefore understood. CCM is already being commissioned by ICBs across the UK, as BABICM members report their services as being commissioned in this way, although BABICM are not able to comment on the frequency of this.	Thank you for your comment. We considered your comments but felt these changes were not needed to the definition as the final paragraph as the definition already captures issues of situation and circumstance to inform recommendations and decisions. However we did add reference to consideration of multiple clinical assessments as part of this paragraph which we hope addresses your first point
Kent and Medway NHS and Social Care Partnership Trust	Guideline	053	028	Substance use is only referenced in relation to the potential for this to require a complex case manager. However, given the bidirectional relationship between substance use and acquired brain injury, greater emphasis could be placed on the need to consider how to engage individuals with ongoing significant drug and alcohol use and / or recommend future research needs.	Thank you for your comment. We have added clearer information to the overview section about the conditions, diseases, disorders and injuries covered and non-covered by this guideline. This includes reference to alcohol or drug induced brain injury and alcohol induced nerve disorders. Rehabilitation needs resulting from these are

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					covered by this guideline. However specific interventions to address substance misuse were not prioritised as a key area in the scope and therefore we did not conduct a systematic review of the effectiveness of these interventions. The committee were therefore unable to make specific recommendations on the topic and nor were they able to recommend future research in this area (because they can only make research recommendations to address evidence gaps identified by systematic reviews conducted for the guideline).
The Association of Clinical Psychologists UK	Guideline	053	028	Substance use is only referenced in relation to the potential for this to require a complex case manager. However, given the bidirectional relationship between substance use and acquired brain injury, greater emphasis could be placed on the need to consider how to engage individuals with ongoing significant drug and alcohol use and / or recommend future research needs.	Thank you for your comment. We have added clearer information to the overview section about the conditions, diseases, disorders and injuries covered and non-covered by this guideline. This includes reference to alcohol or drug induced brain injury and alcohol induced nerve disorders. Rehabilitation needs resulting from these are covered by this guideline. However specific interventions to address substance misuse were not prioritised as a key area in the scope and therefore we did not conduct a systematic review of the effectiveness of these interventions. The committee were therefore unable to make specific recommendations on the topic and nor were they able to recommend future research in this area (because they can only make research recommendations to address evidence gaps identified by systematic reviews conducted for the guideline).
Birmingham Community Healthcare NHS Trust	Guideline	054	001 - 003	A barrier to inclusion to attend rehabilitation services for people with a chronic neurological disorder (including acquired brain injury) is equality of access to transport to attend the rehabilitation. At the Trust where I'm based there is access to 'Non-Emergency Hospital Transport' for a small number of clients that meet the criteria (most clients are unable to access this), there is access to the Healthcare Travel Cost Scheme for clients claiming certain benefits but for the rest of the clients transport is unavailable. This can lead to clients being unable to attend rehabilitation when they are allocated a place to attend. A partial solution is hybrid rehabilitation where some appointments/ groups can be attended remotely. For the appointments that need to be attended in person it would help if an additional task of the complex case manager is to assist the client with accessing transport to attend	Thank you for your comment, which refers to the description of 'complex case manager' in the 'terms used in this guideline'. The committee agree with you about the importance of travel and transport to enable access to rehabilitation and this is why they described the complex case manager as having a role in providing advice, proactive support and signposting, coordinating rehabilitation across multiple services including transport and housing services. Please also note that, in line with your comment, telehealth has now been added to the guideline as a means of supporting hybrid delivery of rehabilitation. The committee also made a recommendation to deliver rehabilitation interventions in settings that are appropriate to the person's rehabilitation goals and meet their preferences.
Brainkind	Guideline	054	002	Minor edit: 'identify' instead of 'identifies'	Thank you for your comment. We have edited the text to "identify" instead of "identifies".

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Rehabilitation for chronic neurological disorders including acquired brain injury

Consultation on draft guideline - Stakeholder comments table
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Kent and Medway NHS and Social Care Partnership Trust	Guideline	054	015 - 018	Executive function should also state about initiation and implementation of plan, social communication and behaviour. Appraisal and judgement of ability.	We have added clearer information to the overview section about the conditions, diseases, disorders and injuries covered and non-covered by this guideline.
British Association of Brain Injury and Complex Case Management	Guideline	054	016	We suggest that the EF definition - should state underlie 'ability' not ' capacity' so as not to conflate capacity with it's meaning under the MCA 2005. Would help to include initiation and insight in the definition of EF as these elements are often misunderstood, not identified and leave people vulnerable with unmet needs. Similarly, an understanding of frontal lobe paradox and it's implications for assessment of an engagement in services could be helpfully included within this definition as it is results in a person being able to describe ability they in fact lack, and is often overlooked in telephonic assessments or by professionals without expertise in ABI and EF difficulties and how they may present.	This includes reference to alcohol or drug induced brain injury and alcohol induced nerve disorders. Rehabilitation needs resulting from these are covered by this guideline.
British Association of Brain Injury and Complex Case Management	Guideline	056	003	Key worker definition – refers to 'healthcare practitioner' (HCP), we suggest that this would benefit from further clarification. For example the CQC definition of HCP refers to Doctors, registered nurses and HCPC registered professionals, but there is room for ambiguity if not clearly defined. For example, could a key worker be a social worker? They are not usually defined as health care practitioners but may be specialists and are registered social care professionals. There is reference to the NHS employing qualified staff as key workers, but not whether those staff should be registered health or social care professionals.	However specific interventions to address substance misuse were not prioritised as a key area in the scope and therefore we did not conduct a systematic review of the effectiveness of these interventions. The committee were therefore unable to make specific recommendations on the topic and nor were they able to recommend future research in this area (because they can only make research recommendations to address evidence gaps identified by systematic reviews conducted for the guideline).
MS Society	Guideline	056	021	Rehabilitation Prescription The draft guideline states that a rehabilitation plan "may be in the form of a rehabilitation prescription". It also "may come in different versions such as the rehabilitation passport, which is a patient-held document, and may be a simplified version of the plan." This document is intended to be carried by the person, shared between teams, and updated to record rehabilitation treatments in an accessible format. However, NICE stops short of requiring a Rehabilitation Prescription for all patients who need one, or of setting out how this information should be used or monitored. In the optimal clinical pathway for adults with neurological conditions: rehabilitation (https://www.nnag.org.uk/optimal-clinical-pathway-adults-neurological-conditions-rehabilitation), every	Thank you for your comment. The guideline uses the term 'rehabilitation plan' but acknowledges in the glossary that this is sometimes called a 'rehabilitation prescription' to be clear that these two phrases mean the same thing. Having a rehabilitation plan is clearly a requirement of this guideline and is set out in the section Agreeing, delivering and reviewing a coordinated rehabilitation plan. This is based on the holistic needs assessment and the setting of goals agreed in the previous sections. A 'menu' of interventions to be included in the plan is included in the second half of the guideline.

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				patient with complex rehabilitation needs should have a Rehabilitation Prescription. This should set out their rehabilitation needs and the plan to meet them. The information should be collated centrally to track whether needs are being met. Patients needing Level 1 or Level 2 rehabilitation should be transferred in a timely way to the appropriate service, in line with national standards. This is important because people with MS often have fluctuating and complex rehabilitation needs that span physical, cognitive and psychological domains. Without a structured, shared Rehabilitation Prescription, there is a real risk that their needs will be missed or poorly coordinated across services. People with MS may move between acute care, neurology, primary care and community rehabilitation, and without a consistent document in place, vital information about their goals and progress may be lost. This can result in delays to treatment, duplication, or fragmented care that fails to support independence and quality of life. A centrally recorded Rehabilitation Prescription would help ensure that everyone with MS receives timely, appropriate rehabilitation, and that their care is responsive to changes in condition or circumstances. It would also allow systems to monitor whether services are meeting need, where delays or gaps exist, and where investment is required. This level of oversight is critical for accountability and for ensuring people with MS do not fall through the cracks in a stretched system. For patients requiring specialist rehabilitation, timely transfer to the right level of care is essential for achieving the best outcomes. The Rehabilitation Prescription plays a central role in making that possible.	
United Kingdom Acquired Brain Injury Forum	Guideline	056	022	Rehabilitation prescription are no longer mandated and in practice rarely used or incompletely filled in.	Thank you for your comment. The guideline uses the term 'rehabilitation plan' but acknowledges that this is sometimes called a 'rehabilitation prescription' to be clear that these two phrases mean the same thing. We recognise the implementation of this guideline will take time.
Independent Neurorehabilitation Providers Alliance	Guideline	056	022	This implies that the rehabilitation prescription is widely used but this is not the case. From our experience with acquired brain injury patients, very few are discharged from hospital with a rehabilitation prescription or rehabilitation passport.	Thank you for your comment. The guideline uses the term 'rehabilitation plan' but acknowledges that this is sometimes called a 'rehabilitation prescription' to be clear that these two phrases mean the same thing. We recognise the implementation of this guideline will take time.
British Association of Brain Injury and Complex Case Management	Guideline	057	001	'Rehabilitation Practitioners' is very broad in definition - it is clear that registered professionals are included, but the document also refers to others. We are concerned that the assessment and decision making by inexperienced/unqualified individuals can result in needs being unmet,	Thank you for your comment. We have added some new recommendations throughout the section 'rehabilitation to maintain, improve and support function' to ensure that registered practitioners with expertise in that particular professional discipline, and with an understanding of the effects

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				misunderstood and people falling through service gaps with negative consequences. We would like to see more clarity, for example reference to 'registered nurse' rather than just 'nurse' as that is the protected title for a qualified nurse. Anyone can use the title 'nurse' i.e. dental nurse, school nurse and these would not necessarily possess the appropriate registration or skills.	of the persons particular condition or injury should always oversee assessments and that particular element of the persons rehabilitation plan. We have also included a definition for the term rehabilitation practitioner within the 'terms used in this guideline' and have amended throughout to be clear and consistent when we are referring to health, mental health and social care practitioners. However it is also acknowledged that some people contributing to rehabilitation may not be registered health, mental health or social care practitioners, for example those working in health or fitness at local sports clubs and teachers.
Head First	Guideline	057	001	The broad definition of the term 'rehabilitation practitioners' and the potential negative impact and ongoing consequences to the individual of a practitioner not having the expertise to recognise some of the 'invisible' deficits associated with CND. We feel that further clarity is required on the experience within CND to determine the needs of an individual. Consideration of registration with specific governing bodies such as BABICM, CMSUK or VRA.	Thank you for your comment. We have added some new recommendations throughout the section 'rehabilitation to maintain, improve and support function' to ensure that registered practitioners with expertise in that particular professional discipline, and with an understanding of the effects of the persons particular condition or injury should always oversee assessments and that particular element of the persons rehabilitation plan. We have also included a definition for the term rehabilitation practitioner within the 'terms used in this guideline' and have amended throughout to be clear and consistent when we are referring to health, mental health and social care practitioners. However it is also acknowledged that some people contributing to rehabilitation may not be registered health, mental health or social care practitioners, for example those working in health or fitness at local sports clubs and teachers.
Brain Injury Social Work Group	Guideline	057	001 - 014	Recognition of Social Work Roles (p. 57, Section 1.10) We welcome the inclusion of social workers among core rehabilitation practitioners and the recognition of the value of a multidisciplinary approach. However, in our view, the guidance could go further in articulating the distinct contributions of social workers to rehabilitation - both as specialist case managers and local authority social workers. These include care coordination, safeguarding, advocacy, and an understanding of the wider social determinants of health such as housing, addiction, mental health, poverty, family dynamics, and community inclusion. We recommend more explicit reference to the specialist skills of social workers in these areas, particularly in complex or high-risk cases.	Thank you for your comment. We have also included a definition for the term rehabilitation practitioner within the 'terms used in this guideline' and have amended throughout to be clear and consistent when we are referring to health, mental health and social care practitioners. So there are now additional references to social care professionals throughout the guideline. However there are so many different professional roles involved with rehabilitation that it was impossible to add how social workers can contribute in every possible scenario. We have made reference in the terms used in this guideline in the context of acting as an 'initial contact for rehabilitation', a 'lead practitioner for holistic assessment' and as a single point of contact for rehabilitation , including complex case management.
Anglia Ruskin University	Guideline	057	005	Music therapy is recognised worldwide as a rehabilitation therapy, and we feel it should be named specifically in the list of rehabilitation practitioners. There is a significant body of evidence describing the use of music therapy as a rehabilitation intervention. Music therapy is a protected title and registered as an allied health profession by the	Thank you for your comment. We have added examples of music, art and drama therapists to the creative arts therapists in the rehabilitation practitioners section in the 'terms used…' section of the guidelines.

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				Health and Care Professions Council. We feel that it should be listed here specifically in the list of rehabilitation practitioners.	
South London and Maudsley NHS Foundation Trust	Guideline	057	005	Rehabilitation practitioners – list should also include neuropsychologists.	Thank you for your comment. We have added these to definitions in the 'terms used…' section of the guidelines.
University College London Hospital	Guideline	057	007	There is no mention of the specialist field of Physical and Rehabilitation Medicine as it is now known in the UK. Suggest this is added.	Thank you for your comment. We have now added the role of consultant physician in rehabilitation medicine to the list of rehabilitation practitioners involved in rehabilitation in the 'terms used in this guideline'
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	057	009	We thought '…*clinical psychologists/neuropsychologists*…' should be added at line 9	Thank you for your comment. Neuropsychologists have been listed in the glossary alongside other registered professions by the health and care professions council as rehabilitation practitioners.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	057	009	Might you consider adding educational psychologists and specialist teachers. The paediatric community NHS neurorehabilitation service and the level 1 unit for children both have educational psychologists within their team. Specialist teachers are also a part of the rehabilitation provision in acute services. An acknowledgement to those established teams and the connection to education would be welcomed. We appreciate the list states its not exhaustive, but they appear to be outstanding roles against all other named professional groups.	Thank you for your comment. Educational psychologists and education support staff have been listed in the glossary alongside other registered professions by the health and care professions council. Although the list doesn't specifically mention specialist teachers, the list is not exhaustive and not restricted to the professionals listed.
Defence Medical Rehabilitation Centre	Guideline	057	009	Rehabilitation practitioner list should include Clinical Psychologists and *Neuropsychologists*	Thank you for your comment. We have added these to definitions in the 'terms used…' section of the guidelines.
Oxford University Hospitals - Paediatric Neuropsychology Department	Guideline	057	011	Neuro navigation roles are not something we have come across in paediatric services, but we feel that this could be very helpful, if integrated in a meaningful way, without duplication of work. We also wondered whether this could overlap with other roles within the document e.g. key workers, case managers, speciality-specific coordinators etc. It may be helpful in the guidance to clearly distinguish between these roles and make recommendations about which roles are essential and should be prioritised.	Thank you for your comment. We have added definitions for all key roles mentioned in the guideline e.g. initial contact for rehabilitation, lead practitioner for rehabilitation assessment, key contact, key worker and complex case manager. We hope the guideline is clearer about the distinctions between these roles now.
Defence Medical Rehabilitation Centre	Guideline	057	012	We would advocate for the use of inter-disciplinary teams, rather than multi-disciplinary teams	Thank you for your comment. We have added that when agreeing the interventions and approaches that will constitute the rehabilitation plan, think about and include in the plan: how practitioners will liaise with one another and work together to enable interdisciplinary working.
National Acquired Brain Injury in Learning and Education Syndicate (NABLES)	Guideline	057	022	The 'single point of contact' whilst this is welcomed how do we ensure they have the relevant knowledge to understand the hidden nature of acquired brain injuries and that young people require monitoring with the potential to 'grown into needs'. The absence of such knowledge will mean that young people continue to remain hidden without the support of the navigator that they require. We wondered if this might link again to the need for core training in acquired brain injury which is often	Thank you for your comment. We would like to highlight that a single point of contact could be a key contact, key worker or complex case manager depending on the person's needs. We ensured that the definition of a complex case manager also covers for complex case managers to have sufficient training and understanding to support children and young people. Furthermore, there are several recommendations in the guideline to ensure that any staff involved in the rehabilitation process have received training

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				misunderstood by many professionals as there is such limited awareness and training.	and have sufficient knowledge to help the person and their potentially unique needs.
Brain Injury Social Work Group	Guideline	057 – 058	General	Assigning a Single Point of Contact (pp. 57–58, Section 1.11) The inclusion of key workers, specialist case managers and social workers as potential points of contact is welcomed. Given their role in managing often complex transitions (such as hospital admission to discharge, changes in care provision, or moving between services), social workers are often well placed to coordinate support. Further guidance on how roles might be assigned or negotiated across disciplines would support implementation in local systems.	Thank you for your comment. Sections 1.10 to 1.12 of the guideline help to set out how roles might be assigned or negotiated across disciplines. We also made an addition to the recommendation about agreeing interventions and approaches that will constitute the rehabilitation plan to include in the plan how practitioners for services will liaise and integrate their input throughout rehabilitation.
University College London Hospital	Guideline	058	006	The guideline must set out direction that the "single point of contact" should be able to access support/training from the ICB (with regards to rehabilitation needs) where this identified.	Thank you for your comment. The committee acknowledged workforce shortages and the lack of skilled staff. As a result, they recommended that commissioners (ICBs) support local workforce development to build neurorehabilitation capacity, which may include training and support opportunities for practitioners undertaking single point of contact roles. Unfortunately, the committee did not feel they could be more prescriptive than this.
Brainkind	Guideline	058	012 - 019	There is little differentiation between specialist and general rehabilitation services. Including *'beyond the scope of their local rehabilitation services*' is not necessarily what makes a rehabilitation service 'specialist'. There may be multiple reasons why local services cannot take an individual, which may or may not relate to the scope or specialism of the service. In addition, there are small specialist services, which primarily operate at the local level, but have expertise that could respond to referrals at the national level. The definition of 'specialist neurorehabilitation services' should focus on the level of complexity of needs these services can respond to, including physical, emotional and behavioural needs, and the level of specialist advice, expertise or care or equipment that they are able to provide, including the availability of a multidisciplinary team.	Thank you for your comment. We have added a little more detail to the definitions e.g. that rehabilitation services based within a neuro science centre are an example of a specialist neurorehabilitation service and added local community, generalist rehabilitation services as the comparator. It is not preferable to add more detail that that considering the breadth of the guideline regarding the conditions it covered and that fact that it covers both adults and children's services.
The Stroke Association	Guideline	059	002	We welcome the recommendations for further research into the effectiveness of interventions for children and young people with a chronic neurological disorder. There is a lack of evidence on the frequency and amount of rehabilitation for children and young people with a chronic neurological condition. It would be valuable for recommendations for future research to include this, to be able to provide more effective and targeted clinical guidance in the future.	Thank you for your comment. The committee agree with your point and this is why the PICO for the research recommendation is designed with one of the comparators being interventions 'varied in terms of frequency, intensity, timing and setting'. They therefore didn't make any subsequent changes to the research recommendation.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	059	004	We thought *'…job roles, retraining or support in leaving a job role well and finding alternative occupations.'* should be added at line 4	Thank you for your comment. We have added this.

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Kent and Medway NHS and Social Care Partnership Trust	Guideline	059	011	Recommendations for research do not currently include recommendations for how to adapt rehabilitation approaches for people experiencing homelessness, despite the above evidence and a lack of evidence for adapted rehabilitative interventions, in line with recommendations of NICE Guidelines for Integrated Health and Social Care for People Experiencing Homelessness	Thank you for your comment. None of the research recommendations specify particular populations within chronic neurological disorders, such as people experiencing homelessness. Equally, those populations are not excluded so commissioners and researchers could potentially formulate study designs where these populations are included. This is not specified in the research recommendations themselves because it was not specified in the protocol for the original systematic reviews underpinning this guideline. Therefore no changes were made in light of your comment.
University College London Hospital	Guideline	059	011	Recommendations for research – any recommendation for a treatment that we are currently unclear about, e.g. VR should be listed as priority for research (either for efficacy or implementation work).	Thank you for your comment. The committee discussed the research recommendations at length and would have favoured making many more than can be included in a NICE guideline. They therefore had to prioritise areas for future research based on the most significant gaps in evidence resulting from the systematic reviews underpinning the guideline and the areas in which new research evidence could most helpfully contribute to any future updates of this guideline. No changes were made in light of your comment.
The Association of Clinical Psychologists UK	Guideline	059	011	ACP-UK comments that the recommendations for research do not currently include recommendations for how to adapt rehabilitation approaches for people experiencing homelessness, despite the evidence mentioned in point 16 and a lack of evidence for adapted rehabilitative interventions, in line with recommendations of NICE Guidelines for Integrated Health and Social Care for People Experiencing Homelessness	Thank you for your comment. None of the research recommendations specify particular populations within chronic neurological disorders, such as people experiencing homelessness. Equally, those populations are not excluded so commissioners and researchers could potentially formulate study designs where these populations are included. This is not specified in the research recommendations themselves because it was not specified in the protocol for the original systematic reviews underpinning this guideline. Therefore no changes were made in light of your comment.
The UK FND Network	Guideline	061	001	Re Key Recommendation for Research, point 5: Emotional health and mental wellbeing in adults with a functional neurological disorder. What is the effectiveness and cost effectiveness of interventions and approaches for improving and sustaining emotional health and mental wellbeing for adults with a functional neurological disorder? Please see next item for comments.	Thank you, please see answer to subsequent comment, reference number 844.
South London and Maudsley NHS Foundation Trust	Guideline	061	001	Whilst we acknowledge the benefit of research focussed on emotional wellbeing in FND, we feel a research recommendation about cost effectiveness of alternative treatments to aim to improve physical and mental health symptoms in FND would be more prudent.	Thank you for your suggestion. The research recommendation for improving physical wellbeing (stability, mobility and upper limb function) includes people with FND, albeit that the focus is specifically on children and young people. The committee made this recommendation because there was a particular paucity of evidence about physical wellbeing (stability, mobility and upper limb function) for children and young people and they agreed that future research for that specific population would benefit subsequent guideline updates. They also recommended future

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					research on mental health (and emotional wellbeing) for adults with functional neurological disorders, which includes the effectiveness and cost-effectiveness of interventions or treatments. Considering the need to prioritise research recommendations in the areas with the most notable gaps, the committee chose not to make changes in light of your comment.
Association of Chartered Physiotherapists in Neurology	Guideline	061	001	It is not clear why the committee chose the recommend further research into emotional health and mental wellbeing in adults with FND. They appear to have made an assumption that wellbeing is more important than any other domains of health. This does not make sense for several reasons. Including that evidence suggests that mental wellbeing in FND is directly associated with the presence and severity of symptoms, and so interventions should address symptoms and their mechanisms (though multidisciplinary interventions). Choosing only to recommend wellbeing might suggest that there is sufficient evidence for the other recommendations in this guideline for FND. This is clearly untrue as the literature review did not identify a single study of rehabilitation for the motor symptoms for FND. Add to this expert consensus recommendations noting that the rehabilitation approach for FND must differ from other neurological disease; it must therefore be recognised that multidisciplinary rehabilitation approaches must also be a very high priority, perhaps greater than wellbeing (Nielsen 2015, https://pubmed.ncbi.nlm.nih.gov/25433033/; Nicholson 2020, https://pubmed.ncbi.nlm.nih.gov/32732388/; Baker 2021 https://jnnp.bmj.com/content/92/10/1112.abstract) The current single recommendation for FND research implies that the best we can hope for people with FND is that they can adjust to living with FND. Current evidence suggests this is untrue. The recommendation for research should reflect all aspects where there are insufficient evidence, i.e. multidisciplinary rehabilitation approaches. It should be acknowledged that none of the recommendations in the guidelines have any evidence base for FND.	Thank you for your suggestion. The committee were tasked with prioritising areas for future research based on the most significant gaps in evidence resulting from the systematic reviews underpinning the guideline. It is not the case that they thought wellbeing was the single most important outcome for adults with FND but that given the evidence gaps in the relevant review, future research in that area would helpfully contribute to any future updates of this guideline. The committee made recommendations for future research in several other areas, namely; improving or maintaining independence in activities of daily living; improving and sustaining stability, mobility and upper limb functioning; the effectiveness of transcranial direct current stimulation (TDCS) and transcranial magnetic stimulation (TMS) for improving and maintaining cognitive function; interventions or approaches for supporting people to enter, remain in, return to or leave employment and volunteering; digital applications to support access to physical activity, exercise or sport, for people with a chronic neurological disorder and the effectiveness of complex case management. They recommended that all people with chronic neurological disorders be included in the population for all those research questions, which therefore covers people with FND. In terms of the evidence base underpinning the guideline recommendations, each evidence review provides an account of the committee's discussion of the evidence - or lack thereof - and how this influenced their decision making. The committee certainly acknowledged the paucity of evidence specifically relating to people with FND and in some cases therefore made recommendations on the basis of their expert knowledge in the area.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	061	015	We thought *'return to, change or leave..'* should be added at line 61	Thank you for your suggestion. The committee are constrained by needing to align the research recommendation with the review question on which it is based so unfortunately the change you suggest cannot be made. However, the committee think that the issue is covered by the focus of the research recommendation including 'leaving' a role or employer and 'entering' a new employer (or role).

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Central London and Community Healthcare Trust	Guideline	061	General	*Emotional health and mental wellbeing in adults with a functional neurological disorder.* It was hard to know where to collate information relevant to people with FND in this guidance document as it was overall exceptionally poorly addressed. Perhaps the committee could look to guidance from other areas in considering the very specific and MDT rehabilitation needs of this group including the following: Executive Summary on FND BPS British Psychological Society (published in 2024) NHS Scotland's Functional Neurological Disorder Pathway (published in May 2024) There are significant funding implications for rehabilitation services for these individuals who make up significant numbers of referrals into community rehabilitation services (=>30% in some cases) In addition, we recommend further data collection is needed on this group in terms of understanding how best to provide rehabilitation to this group, the following papers highlight the need for an MDT approach given the diversity of symptoms and presentations: Bailey, C., Tamasauskas, A., Bradley-Westguard, A., Gilli, P., Poole, N., Edwards, M.J., Agrawal, N. & Nicholson, T. (2025) What are the experiences of people with motor and sensory functional neurological disorder? A systematic review and thematic synthesis of qualitative studies. *Disability and Rehabilitation*. 47[1], 1-15. Nicholson, C., Edwards, M.J., Carson, A., Gardiner, P., Golder, D., Hayward, K., Humblestone, S., Jinadu, H., Lumsden, C., Maclean, J., Maine, L., McGregor, L., Nielsen, G., Oakley, L., Price, J., Ranford, J., Ranu, J., Sum, E., Stone, J. (2020) Occupational Therapy consensus recommendations for functional neurological disorder (Long Version). *Journal Neurology Neurosurgery and Psychiatry*. Supplement. 1-9. Nielson, J.S., Lee, T.C., Goldstein, L.H., Marston, L., Hunter, R.M., Carson, A., Holt, K., Marsden, J., Le-Nouvere, M., Nazareth, I., Noble, H., Reuber, M., Strudwick, A., Santana-Suarez, B. (2024) Specialist physiotherapy for functional motor disorder in England and Scotland (Physio4FMD): a pragmatic, multicentre, phase 3 randomised controlled trial. *Lancet neurology*. 23. 675-686.	Thank you for your comment. The committee agree that there was a paucity of evidence about people with FND and for this reason made several recommendations for future research covering this population (as well as other chronic neurological disorders when the lack of evidence applied more widely - not just to people with FND). Those research recommendations covered a range of areas: activities of daily living; improving and sustaining stability, mobility and upper limb functioning; transcranial direct current stimulation (TDCS) and transcranial magnetic stimulation (TMS) for improving and maintaining cognitive function; supporting people to enter, remain in, return to or leave employment and volunteering; digital applications to support access to physical activity, exercise or sport, and complex case management. In addition, the committee made a recommendation for future research on intervention to improve emotional health and wellbeing, specifically focussed on people with FND. With future research conducted in those areas, it is anticipated that subsequent versions of the guideline would be based on stronger evidence, including in relation to people with FND. In terms of the way the guideline itself is organised, this was intended to cover the general population of people with chronic neurological disorders, rather than exclusively focussing on any one category of disorder and for that reason is structured loosely according to a pathway rather than according to population groups. Thank you for the listed references. For completeness, these have been checked for relevance to the evidence reviews underpinning the guideline and responses for each, provided below: Executive Summary on FND BPS British Psychological Society (published in 2024) NHS Scotland's Functional Neurological Disorder Pathway (published in May 2024); these do not meet the protocol criteria for any of the evidence reviews (qualitative or intervention), due to the publication type. Bailey et al (2025) - this does not fit the protocol for any of the review protocols. The qualitative questions included in the guideline were specifically about the delivery of rehabilitation, access to services and assessment and review. Nicholson et al (2020) - this does meet the protocol criteria for any of the evidence reviews (qualitative or intervention), due to the publication type.

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					Nielson et al (2024) - the searches for the evidence reviews, which are relevant too this paper were conducted before this paper was published, which explains why the paper was not located. However please note that in light of other stakeholder comments, an earlier paper describing the results of this trial has now been added and presented to the committee for their consideration.
United Kingdom Acquired Brain Injury Forum	Guideline	063	023	The shortage of rehabilitation practitioners must be taken into account.	Thank you for your comment. Where appropriate we acknowledged the shortage of practitioners and the need to build capacity to enable services to respond in a timely way. We also recommended making services more efficient, for example, by reducing disjointed and uncoordinated care, which may free up some resources and capacity.
Independent Neurorehabilitation Providers Alliance	Guideline	063	023	We agree that services should be flexible and integrated and agree that resources could be used flexibly but it should be noted that there is a national shortage of rehabilitation practitioners and this needs to be addressed. One of the recent suggestions for using therapists differently has been to place them in an assessment role only and to delegate treatment to non-qualified staff. Whilst this means more people can be assessed it is not what therapists entered their profession to do. They want to treat people and support them. It runs the risk of depleting the numbers of these qualified staff further if they leave the NHS or the profession. It may also deter potential therapists from joining the profession.	Thank you for your comment. We agree and acknowledge throughout the shortage of various practitioners and recommend ensuring responsive and timely services which includes building necessary capacity. The committee also makes recommendations on service design to improve efficiency which may free up some resources and funds, e.g., for any staffing. The committee hopes their recommendations will be adopted and funded accordingly. We will also pass your comment to our implementation team.
University College London Hospital	Guideline	063	024	We do not agree that the need for extra resources can largely be achieved by using existing resources differently. Additional resource will be needed	Thank you for your comment. The committee discussed many problems with existing rehabilitation services and pathways, such as siloed services, duplication, and delays in assessment and care, which incur substantial costs to the NHS and beyond. They believed that recommendations on service design and specification would enable more effective and responsive services. For example, shifting from expensive inpatient/hospital-based services to community-based support, adopting hybrid models, and delivering interventions in various settings such as homes, community locations, or remotely. Having a single point of contact to ensure communication and coordination will avoid duplication and ensure the right care at the right time. Also, the use of digital solutions. The committee discussed that most of this could be achieved by repurposing existing funds or using these more efficiently / effectively. More detailed discussions of potential cost effectiveness and resource use implications are provided in supporting evidence review A.
Brainkind	Guideline	064	010 - 017	Consider including the label 'minimum service specification required' within the recommendations.	Thank you for your comment. As with all NICE guidance, we try to write recommendations in a way that ensures they are still implementable in

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					future healthcare landscapes. Minimum service specifications is a common term now, but may change with time. Therefore, no change has been made.
United Kingdom Acquired Brain Injury Forum	Guideline	064	013	The key worker role must be adequately resourced.	Thank you for your comment. Based on their experience, the committee explained that responsibilities aligned with key contact or key worker roles are already largely undertaken by staff within services. Implementing these recommendations would only require officially nominating this person and communicating this to people with chronic neurological conditions. The committee also made several recommendations on service design and commissioning, which should make services more efficient and potentially release resources and funds. These could fund some of the additional roles that may be needed. The committee also discussed this as essential to enable timelier access to assessment and care, reducing reliance on costly crisis care which incurs substantial costs to the NHS.
Independent Neurorehabilitation Providers Alliance	Guideline	064	013	We are concerned by the assumption that existing staff could assume the role of key worker and avoid creating new roles. Key worker activities can be time consuming which takes the practitioner away from other patients. It should be considered that there may be a need to increase practitioner numbers to compensate for this depending on caseload.	Thank you for your comment. Based on their experience, the committee explained that responsibilities aligned with key contact or key worker roles are already largely undertaken by staff within services. Implementing these recommendations would only require officially nominating this person and communicating this to people with chronic neurological conditions. The committee also made several recommendations on service design and commissioning, which should make services more efficient and potentially release resources and funds. These could fund some of the additional roles that may be needed. The committee also discussed this as essential to enable timelier access to assessment and care, reducing reliance on costly crisis care which incurs substantial costs to the NHS.
United Kingdom Acquired Brain Injury Forum	Guideline	065	010	The shortage of mental health staff should be taken into account.	Thank you for your comment. The supporting discussions in the related section titled 'How the recommendations might affect practice' acknowledge staffing and funding challenges. The committee recommended building local capacity and expertise in mental health services for people with chronic neurological disorders. They also hope their recommendations will be adopted and appropriately funded.
Independent Neurorehabilitation Providers Alliance	Guideline	065	010	We agree that mental health staff should be trained to support those with a chronic neurological condition but it should be noted that there is a shortage of mental health staff nationally and this could require additional resources in terms of actual staff as well as training.	Thank you for your comment. The supporting discussions in the related section titled 'How the recommendations might affect practice' acknowledge staffing and funding challenges. The committee recommended building local capacity and expertise in mental health services for people with chronic neurological disorders through workforce development and communication protocols. They also hope their recommendations will be adopted and appropriately funded.
United Kingdom Acquired Brain Injury Forum	Guideline	066	006	Lack of knowledge about service provision needs to be addressed	Thank you for your comment. The committee acknowledged that rehabilitation services can be challenging to navigate. Therefore, they recommended a model of care where everyone with chronic neurological

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					disorders is assigned a key contact, key worker, or complex case manager, depending on their needs. This person would have the required knowledge about services and their availability. We also recommend maintaining up-to-date information on options for local rehabilitation in the section on building local capacity and expertise.
Independent Neurorehabilitation Providers Alliance	Guideline	066	006	We agree that greater collaboration is needed but in order to share information, commissioning bodies need to know what is available in their area. This requires establishing and maintaining a database of local services provided by all sectors.	Thank you for your comment. There is already a recommendation to maintain up-to-date information on local rehabilitation service options.
Independent Neurorehabilitation Providers Alliance	Guideline	066	020	We agree that awareness needs to be raised but also processes by equipment providers should be reviewed to ensure timely delivery.	Thank you for your comment. We agree, but it was beyond the scope of this guidance to go into such detail. We made several recommendations on designing and commissioning rehabilitation services and service specifications to facilitate access to equipment. We also recommend services work together to ensure timely and coordinated delivery of interventions and approaches. This may require, for example, equipment providers to review their processes to ensure they can achieve this.
University College London Hospital	Guideline	067	003	Referral from one service to another is often problematic. Every service has a different referral form and process. A single point of access form with all services represented on the form would simplify processes and the same form for all areas would make the entire process easier.	Thank you for your comment. The reference that you have provided links to the rationale section for the building responsive services. We assume that you are instead requesting a new recommendation to cover a single point of access form throughout services. While your suggestion may represent a simpler referral process, it also represents a very large change in practice with accompanying implementation costs. As we did not identify any effectiveness or cost-effectiveness evidence in this area, we are unable to recommend changing referral methods where there is a resource impact. Therefore, no change has been made.
Independent Neurorehabilitation Providers Alliance	Guideline	070	005	We agree that pathways exist for funding equipment but delays in assessing need are often the result of a shortage of staff which leads to delays in discharge. Additional resources in terms of staffing is required to speed up assessment of needs but also processes should be reviewed to make the provision more efficient. Improved processes may result in less of a need for additional staffing.	Thank you for your comment. We agree and acknowledge delays in assessing needs. As suggested, we clarified that this is often due to staff shortages. We recommend ensuring services have the necessary capacity to address these issues. The committee also makes recommendations on service design to improve efficiency and free up resources, e.g., for staffing. Additionally, we recommend integrated, responsive and timely rehabilitation care, which may require improved various processes which may include those for providing equipment and adaptations. We added a sentence about potentially reducing the need for additional staffing through improved processes.
South London and Maudsley NHS Foundation Trust	Guideline	072	018 - 025	This view on the evidence does not appear to be reflected in the guidance itself. We would argue that this demonstrates the need for appropriate psychological medicine input integrated in neurorehabilitation services. There is a need for assessment of psychiatric comorbidity within the holistic assessment of individuals with	Thank you for your comment. The committee agrees that the biopsychosocial approach is central to rehabilitation for chronic neurological disorders, and has stressed this throughout the guideline. Emotional health and mental wellbeing is listed as a core domain of rehabilitation, and mentioned throughout the document, beginning with minimum service

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				chronic neurological disorders, in particular, but not limited to, tbi and FND, and this needs to be performed by appropriate professionals, namely (neuro)psychiatrists.	requirements. We have recommended ensuring local service agreements are in place for the provision of mental health services for people with chronic neurological disorders, and issued guidance on how they can build capacity to face the increased demand. The rationale that you have referenced is explaining a recommendation that explicitly states mental health comorbidities can prevent people from engaging in rehabilitation, and to bear this in mind when completing a holistic rehabilitation needs assessment. The committee did agree that it was important to highlight that a registered mental health professional should develop and oversee the emotional health and mental wellbeing element of a person's rehabilitation plan, and have made a new recommendation to state this. A psychiatrist is listed as an example. Similarly, they have now noted that an individual may have multiple neurological disorders, and that this should be considered in the holistic rehabilitation needs assessment before agreeing a single rehabilitation plan that encompasses all disorders.
British Association of Brain Injury and Complex Case Management	Guideline	073	019	We would like to draw attention to an inaccuracy under the Related assessments section – this refers to MDT being required to complete a CHC checklist. This is not correct. The checklist is a screen and can be completed by any Health or social care professional. An MDT is required to complete the decision support tool (DST)	Thank you for your comment. We have amended the recommendation to refer to NHS continuing healthcare guidance.
The British Psychological Society	Guideline	074	014	There is no mention of (a) the use of structured tools to aid in collaboratively identifying appropriate goals; (b) ensuring goals are specific, measurable, achievable, realistic and time-bound (SMART); or (c) rating performance/ attainment in relation to the goal and using follow-up ratings to evaluate progress with the goal. Evaluating progress with personalised goals is an essential component of the rehabilitation process.	Thank you for your comment. The recommendations in this section were informed by a qualitative review investigating experiences with assessing and reviewing rehabilitation needs and plans. Goal setting was a strong theme identified in the literature, with a number of sub-themes identified such as collaborative goal setting and achievable goals. However, no themes were identified on the use of structured tools to aid this process or evaluate progress. Therefore, no changes have been made.
University College London Hospital	Guideline	075	017	Will require specialist services that don't currently exist- not widespread.	Thank you for your comment. This is acknowledged in the 'Rehabilitation and the workplace' section. Links to related recommendations, including rationale and impact sections, are provided at the end of the recommendations covered in this section.
Midlands and South Essex ICB	Guideline	075	025	Addition that appropriate goal setting can help commissioning decisions when there is evidence that it will reduce care needs and increase independence at the point of discharge from rehabilitation services.	Thank you for your comment. These recommendations were based on qualitative evidence, with the appraisal of the potential cost effectiveness based on the committee's expert opinion. Therefore, we wanted to keep this justification generic as there could be many other examples of how outcomes may improve and also cost savings realised. We believe that our generic statement would cover your suggestion.

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Independent Neurorehabilitation Providers Alliance	Guideline	076	013	We agree that this is often the case and frequently is the result of caseload management where staffing resources are limited. Providing longer courses of rehabilitation and earlier on in the condition may well require additional staffing.	Thank you for your comment. We agree and have acknowledged potential resource implications in the related section 'How the recommendations might affect practice' and the full evidence review 'The committee discussion of the evidence' section. We also made recommendations on designing and commissioning rehabilitation services, which may result in efficiencies and release resources and funds for other activities, such as building and developing additional workforce capacity. The committee hopes these recommendations will be adopted and funded accordingly.
Brainkind	Guideline	076	025	Minor edit This should read 'belief that rehabilitation is for treating impairments', not '… disabilities'	Thank you for your comment. We have amended the text as suggested.
University College London Hospital	Guideline	076	028	Community rehab services are grossly underfunded and often just don't exist. There will be a significant financial implication to this	Thank you for your comment. The guideline makes many recommendations on designing and commissioning services to improve efficiency, through better integration, enhanced communication, reduced duplication etc. This may release some resources and allow funding to be reallocated, for example, to community rehabilitation services, aligning with NHS reforms to shift care towards community-based settings. NICE is not involved in funding decisions, but the committee hopes their recommendations will be adopted and funded accordingly.
Independent Neurorehabilitation Providers Alliance	Guideline	076	029	We agree that the person's preferences should be taken into account but in reality the additional time required to travel to other locations puts a strain on already limited resources. It is more efficient to see people in a clinic setting as travel time is unproductive time in terms of patient care. In order to implement this, additional staffing would be required.	Thank you for your comment. The committee noted that many services have already adopted hybrid models, delivering interventions in homes, community settings, or remotely, potentially mitigating some resource impact. This aligns with NHS England's community rehabilitation model, where some provision could be effectively diverted to local, community-based support, making it more accessible for people with chronic neurological disorders requiring ongoing rehabilitation.
The Spinal Injuries Association	Guideline	077	022	A focus on prevention and early intervention, through structured pathways, early access to rehab, and clearly defined admission criteria would also be added	Thank you for your comment. This section focuses on agreeing and delivering a coordinated rehabilitation plan. Other sections of the guideline discuss the impact of your points, mainly within the rationales and impact sections for designing and commissioning rehabilitation services.
Independent Neurorehabilitation Providers Alliance	Guideline	077	023	We agree that effective rehabilitation may reduce overall NHS costs but additional resources will be required initially to address the increased access to interventions. The reduction in overall NHS costs will take some time to become apparent. Systems need to be developed and put in place to measure this.	Thank you for your comment. The committee discussed many problems with existing rehabilitation services and pathways, such as siloed services, duplication, and delays in assessment and care, which incur substantial costs to the NHS and beyond. They believe that recommendations on service design and specification could enable more effective and responsive services. For example, shifting from expensive inpatient/hospital-based services to community-based support, adopting hybrid models, and delivering interventions in various settings such as homes, community locations, or remotely. Having a single point of contact to ensure communication and coordination will avoid duplication and ensure the right care at the right time.

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					The committee discussed that most of this could be achieved by repurposing existing funds. More detailed discussions on potential cost effectiveness and resource use implications are provided in supporting evidence review A. While NICE is not involved in funding decisions, the committee hopes their recommendations will be implemented with appropriate funding as required. We also agree that the effectiveness of rehabilitation services needs to be measured. However, commissioners would be best placed to agree on the best approach. We will also pass your comment to the NICE Quality Standards team responsible for developing quality standards, which set out priority areas for quality improvement and include statements to help improve quality and information on how to measure progress.
The Spinal Injuries Association	Guideline	078	005	Agreed – emphasis on a key worker / care coordinator would prove advantageous to have overall ownership from a HCP perspective for a patients care and help them navigate internally and externally to the NHS	Thank you for your comment.
Independent Neurorehabilitation Providers Alliance	Guideline	078	023	The term "complex case manager" should be defined. What makes it complex?	Thank you for your comment. A definition for complex case manager has already been included in the guideline under the 'terms used in this guideline' section on page 53.
The Spinal Injuries Association	Guideline	078	028	The push to shift care closer to communities, by highlighting the need for minimum community rehab standards and better home-based support can also be highlighted here to prevent the economic burden readmissions have on society.	Thank you for your comment. This is a brief summary of the recommendations' impact on practice. You can find a more extensive discussion, including potential economic benefits, in supporting evidence review I on clinical case management and evidence review A on rehabilitation delivery, summarised in the committee's discussion of the evidence sections.
Huntington's Disease Association	Guideline	079	021	There is a typo in this sentence (see bold text) - If the person's single point of contact is **going changing** once rehabilitation has ended, this should be communicated.	Thank you for your comment. We have now amended the sentence.
South London and Maudsley NHS Foundation Trust	Guideline	079	021	Presumably this sentence should read "If the person's single point of contact is going to change once rehabilitation has ended, this should be communicated."	Thank you for your comment. We have amended the sentence as suggested.
Brainkind	Guideline	079	021	Minor edit: 'going' should be deleted from the following sentence: 'if the person's single point of contact is **going** changing…'. Consider adding to whom this should be communicated at the end of the sentence.	Thank you for your comment. We have now amended the sentence. However, we have not actioned the second part of your comment, as this is specified in the recommendation itself and does not need to be repeated in the rationale section.
British Association of Prosthetists and Orthotists	Guideline	079	021	There is a typo here – "is going changing" should likely be "is going **to be** changing"	Thank you for your comment. We have amended the sentence to read 'going to change'.
University College London Hospital	Guideline	080	008	Each team currently requires a different form to be completed for rehab services. The form has to be gained via a lengthy process of	Thank you for your comment. Your suggestion falls under the recommendation in the section on 'Providing responsive services,' where

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				investigation and several emails to gain the form for completion. Referral forms could be standardised across England to simplify processes.	the committee recommends setting up simple referral and self-referral mechanisms. We have also added this to evidence review A as an example in the committee's discussion.
University College London Hospital	Guideline	082	015	Specialist pain management services are increasingly difficult to access due to lengthy waiting lists. This area needs significant resource uplift	Thank you for your comment. While there may be an increase in referrals to specialist pain management services, routine rehabilitation interventions can also reduce or improve pain management and many people could be successfully managed without referral to specialist services. NICE does not make funding decisions but we will pass your comment to the implementation team.
EMDR UK	Guideline	083	006 - 012	In relation to interventions to manage fatigue we would recommend that EMDR be added, alongside Cognitive Behavioural Therapy (CBT), as a form of intervention that could be offered to manage fatigue as there is an evidence base for using EMDR to address chronic fatigue and EMDR has been adapted to work with clients with severe traumatic brain injury and fatigue.	Thank you for your comment. CBT is in included as an intervention for fatigue as it was identified in evidence review J. No evidence was identified for EMDR in fatigue for evidence review J, therefore is not included in the recommendation.
Association of Chartered Physiotherapists in Neurology	Guideline	085	042	Excellent to have the recognition of requirement for specific rehabilitation programs targeted to individuals and their needs. Need to consider the workforce development required to enhance specialist assessment and clinical reasoning skills in AHPs to deliver bespoke rehabilitation to a complex chronic neurological population.	Thank you for your comment. We acknowledged in the 'How the recommendations might affect practice' section that there is variation in provision and where such interventions are not available, there may be a significant initial resource impact in terms of staff training to deliver these interventions. Any additional costs are likely to be offset by improved health outcomes and related cost savings.
Association of Chartered Physiotherapists in Neurology	Guideline	086	009	The evidence to support upper limb robotics in rehabilitation is limited. Currently it does not support its ability "to create clinically meaningful improvements at level of upper limb capacity". De Iaco I, Kwakkel G. Upper-Limb Robots after stroke: How to Get beyond the Hype? J Exp Neurol 2025;6(11)11-20	Thank you for your comment. We are unsure what recommendation this is referring to, as we do not mention upper limb-specific robotics within the guideline and the reference provided links to a rationale section on gaming modalities and virtual reality. We do recommend that robotics and/or exoskeletons be considered as part of a rehabilitation programme for stability, mobility and upper limb function, where available. However, this also includes lower-body robotics. In support of your point, there was very little evidence of effectiveness identified for upper limb robotics in the contributing evidence review (E), although the committee believed that this could be due to the fact the interventions were standardised across participants and that trials only recruited small numbers of participants. They noted that their experiences with robotics was that they could increase engagement and actually decrease the number of rehabilitation professionals needed to deliver interventions. In deference to the expensive nature of this intervention, they recommended that robotics only be considered if already available. Similarly, the evidence for exergaming and augmented/virtual reality interventions was mixed and the committee was unsure of the long-term

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					benefits due to the lack of follow-up data reported by studies. However, in their experience, exergaming and augmented/virtual reality can also be very useful in increasing engagement in rehabilitation , introducing variety into otherwise repetitive programmes. They also believed that this in an area that will continue to grow and improve with time and our continued investment in technology for healthcare. Therefore, they recommended that these interventions be considered in the context of increasing participation, rather than direct effectiveness. Full details of the committee's discussion of the evidence can be located in evidence review E. The committee acknowledged in both cases that the evidence identified was mixed. Despite this, no evidence of harms was identified and the experience of the committee argued to include both sets of interventions. Therefore, no change has been made.
University College London Hospital	Guideline	087	018	Electrical stimulation and its role in managing spasticity e.g. via stretch or improved joint positioning is not mentioned. NMES is rarely funded in the NHS and this leads to health inequalities for patients.	Thank you for your comment. Unfortunately, we did not identify any evidence on using electrical stimulation in managing spasticity despite including it in our evidence review protocols. Therefore, the committee did not prioritise this as an area for guidance and no changes have been made.
The Royal College of Ophthalmologists	Guideline	087	024 - 027	Interventions for vestibular problems should also consider visual impairment and other disorders of eye movements as potential causes of apparent balance problems	Thank you for your comment. We have included a new recommendation on the assessment of visual, hearing, and balance issues within the section on what to cover in the holistic rehabilitation needs assessment. This then includes a link to the section on interventions for vestibular problems. By recommending these 3 areas be assessed together, we hope that it will prompt clinicians to consider and identify other potential causes of balance problems, instead of simply assuming vestibular issues.
Independent Neurorehabilitation Providers Alliance	Guideline	088	011	We agree that robotics can save professional time but there still needs to be some monitoring and adjusting during a patient's session although often this can be provided by a therapy assistant.	Thank you for your comment. We added this detail to 'The committee's discussion and interpretation of the evidence' section in supporting evidence review E.
The Spinal Injuries Association	Guideline	088	023	Insert specific guidelines, referral criteria, and service requirements for emotional and mental health requirements for referral. This will aid and reduce the ambiguity seen with referral criteria.	Thank you for your comment. Evidence review H which supported recommendations in the emotional health and wellbeing section of the guideline looked at effectiveness of interventions and approaches for improving and sustaining emotional health and mental wellbeing. Referral criteria for emotional health and wellbeing are outside the scope of the review question, therefore, no recommendations were made.
Brainkind	Guideline	089	013 - 015	We are concerned that the wording 'especially relevant for people with spinal cord injuries where wheelchair use affects their interactions with other people and the world' could be interpreted as implying that those with hidden disabilities do not experience such changes, when this is not the case.	Thank you for your comment. In the committee's discussion of evidence we have added that hidden disabilities are also pertinent and may prevent them from living the same independent life they lived before.

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Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	089	015	We thought *'… the world and where executive impairment following brain injury leads to changes in personality and/or problems with insight and awareness.'* Should be added to line 15	Thank you for your comment. The committee agree with your comment and have adjusted the committee's discussion of evidence and the rationale and impact sections to highlight those with reduced cognitive abilities and hidden disabilities - "The committee emphasised that this was particularly pertinent for people with a spinal cord injury, where there are significant physical changes for example using a wheelchair adjusts their height and how they interact with the people and the world around them. However it is equally pertinent for people whose reduced cognitive abilities or hidden disabilities now prevent them from living the same independent life they lived before".
Association of Chartered Physiotherapists in Neurology	Guideline	090	001	While we need to recognise training intensity has a part to play in rehabilitation there needs to be recognition that problem solving drives neuroplasticity and carryover not just repetition of task practice. Robotics are an adjunct to personalised specialist assessment providing opportunities for variability of task practice. This needs to be guided and developed by skilled and specialist AHPs to optimise outcomes Nudo RJ (2013) Recovery after brain injury: mechanisms and principles. Front Hum. Neurosci. 7:887. doi:10.3389/fnhum.2013.00887	Thank you for your comment. The study referenced wasn't included in any of the evidence reviews as the study design was a narrative review and didn't meet the protocol criteria. We aren't really sure how the comment links to the rationale and impact section of the emotional health and wellbeing. Therefore, no changes have been made.
EMDR UK	Guideline	090	003 - 029	We would also recommend that EMDR is added to the list of interventions that can be offered for chronic neurological disorders and challenging behaviour as EMDR does have some evidence base in these client groups to aid in adjustment and acceptance within these conditions.	Thank you for your comment. The list of interventions in the recommendation that can be offered for CND and challenging behaviour were identified in the evidence or through committee consensus for evidence review H. No evidence was identified for EMDR or committee consensus for EMDR in evidence review H, therefore EMDR is not listed under the interventions. We understand that there is current ongoing research on the use of EMDR in FND (Cope et al 2023), this is something that would be taken into consideration if there was an opportunity in the future to update the guideline.
Central London and Community Healthcare Trust	Guideline	090	008 – 010	*There was little evidence on acceptance-based interventions for people with a chronic neurological disorder. However, it is widely used in practice and so the committee agreed it could be another option for treating these symptoms.* Given this point on recommendations based on the evidence, we would argue that this is a similar case for other psychological approaches including compassion focused therapy as well as systemic and narrative approaches.	Thank you very much for your comment. Although only one study on acceptance-based interventions was identified for adjustment and engagement in evidence review H, the study showed important benefits on anxiety and coping and adjustment. The beneficial effects of the acceptance-based intervention in the study included in evidence review H and wide use in practice led to the inclusion of acceptance-based interventions alongside CBT-based interventions and mindfulness in the recommendation by the committee. We recognise that there evidence to support compassion focused therapy and it is used in practice, however no evidence was identified for inclusion in evidence review H and therefore the committee didn't include compassion focused therapy in the recommendation.

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Independent Neurorehabilitation Providers Alliance	Guideline	090	023	We agree that creative therapies are of benefit but access to these services varies considerable throughout the UK. Additional resources may well be needed in terms of staffing and consumable supplies if there is more demand for this type of therapy.	Thank you for your comment. Creative therapies are recommended only for those who struggle with talking therapies due to cognitive or communication issues, or where speaking is not their preferred way of communicating. The committee does not anticipate significant resource impact, as these therapies would be delivered instead of talking therapies and potentially be cost-neutral to the health service.
The UK FND Network	Guideline	091	006 - 011	Rationale for Research Recommendations regarding limited evidence in the field of emotional health and mental wellbeing in people with FND. While it is true that there is limited evidence of the highest RCT quality in this area, we were concerned about this recommendation and the discussion here for a number of reasons: • When seen from the point of view of the emotional/wellbeing impact of symptoms, and disability and adaptive function there is no obvious reason to distinguish FND from other neurological conditions such as MS or to consider that evidence applying in those conditions (and indeed in the wider literature on treatment of depression/anxiety/stress) would not also apply in FND. Indeed in relation to other conditions the committee felt able to make recommendations based on personal experience and common practice in the field. Accordingly there is ample evidence that interventions such as CBT, Mindfulness-based approaches, ACT and others would be helpful for people with FND in areas such as adjustment and treatment of depression, anxiety and health-related stress and quality of life. Certainly this is a potential area for FND-specific research but it is not currently a research priority in the FND field (see the next point). • The priority area for psychological/psychiatric research in FND is in psychological/psychiatric treatment of FND as a biopsychosocially modifiable condition. Such treatment often includes treatment helpful to adjustment/depression/anxiety, but has a primary outcome of symptom modification. There is no mention of this in the guideline. The one study which is referenced in Evidence Review H is a treatment study with the primary outcome of functional seizure frequency, but this is reported in relation to its secondary outcomes, including QoL and mood. There is a lack of the highest quality RCT research in this area, and this would be very suitable to highlight as a research priority.	Thank you for your comment. The committee agreed when making recommendations on interventions in the emotional health and wellbeing section of the guideline that they wouldn't be condition specific, therefore the recommendations on emotional health and wellbeing interventions apply to the whole population of the guideline. Despite being able to make these recommendations, the committee were concerned about the relative lack of evidence that met the protocol for evidence review H, and to address this gap they recommended future research in this area. According to NICE methodology, research recommendations must be the same or very similar to the original review question because they are based on the principle of addressing gaps in our evidence reviews. If the committee made a research recommendation that was not closely connected with one of our evidence reviews, they would actually have no basis on which to argue that an evidence gaps exists (because we would not have searched for it). These principles supersede the concept of priority areas in a given academic or policy area. In terms of outcomes for all review questions, the committee prioritised the outcomes, a priori across the wide range of chronic neurological disorders. Due to the broad population of this guideline, outcomes were not condition specific, however were chosen to capture the effects of the interventions on the emotional health and wellbeing of the individual across all the conditions. With respect to Goldstein 2021, the one study referenced in evidence review H, outcomes were only reported if they were prioritised as critical and important by the guideline committee and stated in the protocol. In the conduct of our evidence reviews, outcomes cannot be extracted if they were not stated upfront in the protocol i.e. seizure frequency. We understand your concerns regarding only reporting the study's secondary outcomes, therefore have added further details to the committee's discussion of the evidence to explain that some study outcomes, including primary outcomes, may have shown a benefit for CBT, however they were not extracted for our review as they did not meet our protocol criteria.

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				• Despite the lack of high quality RCT research in psychological/psychiatric treatment of FND, there is a substantial scientific literature on psychological treatment of FND, and based on the discussion in this section which includes references to the committee's experience and common practice, it is a notable omission that none of this is referenced. Eg for a review Gutkin et al., 2021, https://doi.org/10.1136/jnnp-2019-321926, or more recently BPS, 2024 https://doi.org/10.53841/bpsrep.2024.rep181.a It appears to be an omission to single out recommendations for more research only in the psychological/psychiatric care of people with FND when other areas of care in FND are also in need of research: your search found no evidence for physiotherapy, occupational therapy or speech and language therapy (despite some high quality research existing in physiotherapy which has been missed in the search, see below). Coordinated multidisciplinary treatment is considered key in the treatment of FND, and there is a lack of high quality research in this area. A general call for more research in treatment of FND would be appropriate.	We understand that there may be substantial literature on the psychological treatment of FND but it did not meet our protocol criteria. In terms of referencing to BPS 2024, NICE can only cross-refer to other guidance in 2 cases. Firstly, if there are already published NICE recommendations on a subject. Secondly, by stating, a priori, that guidelines would be an accepted evidence source in a systematic review. In this case, relevant guidelines would be included and subject to critical appraisal and then considered by the committee as a basis for recommendations. They could also cross refer to the included guideline. As the BPS guideline/briefing paper did not meet our review protocol (because guidelines were not stated as a type of study to be included), it cannot be referenced in the guideline. Furthermore, the systematic review for Gutkin et al 2021 wasn't included in evidence review H, because the only study that met our protocol criteria (Goldstein 2021), was included as a primary study and was discussed in the evidence review and considered by the guideline committee. With regards to the high quality research in physiotherapy, The physio4FMD trial (Nielsen 2024) has now been included in the guideline, in evidence review O. However note that of the outcomes listed in the protocol, only anxiety and depression were extracted. Although health-related quality of life was included in the protocol, SF-36 was not extracted as no overall score was provided, only sub-domain categories.
The Spinal Injuries Association	Guideline	091	012	Further consideration in importance of lived experience within the services, via peer support or through clinicians with clinical training and lived experience themselves, such as SIAs specialist SCI clinical counselling service.	Thank you for your comment. Peer support was included in the effectiveness protocol; however, no evidence was found, and no recommendation was made for this. We acknowledged the need for additional training to understand the challenges faced by people with CND who are accessing mental health services.
The Spinal Injuries Association	Guideline	091	012	Every patient requires to have access to mental and emotional health treatment and offer of such services in every rehabilitative setting given the increased mental health needs of conditions such as spinal injuries. The requirement for screening and intervention to cope with emotional tolerance and adjustment is profound and should be a key factor to emphasise a true holistic approach.	Thank you for your comment. We agree, and emotional health and mental wellbeing feature strongly throughout the guidance, including recommendations around principles of assessment, referral and intervention selection. There are also recommendations for commissioners on building local capacity and expertise. We also cross-refer to other related NICE mental health guidelines.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	091	014	We thought *'…services are often provided separately from other rehabilitation services. Whilst neurorehabilitation services with clinical psychology/neuropsychology ensure optimal provision of such, where this is not possible, additional resources may be needed…'* Should be added to lines 14 and 15	Thank you for your comment. As suggested, we have reworded the rationale and impact section slightly.
Nottingham University Hospitals NHS Trust -	Guideline	092	014 - 020	We recommend clarifying the distinctions between standardised cognitive tests (mental functions), other assessments in a controlled environment (e.g. capacity to perform an activity) and assessment in	Thank you for your comment. The committee agreed and have added definitions of 'Cognitive tests' and 'Functional assessment' to the glossary to help define and clarify the distinction between these tests.

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National Rehabilitation Centre				everyday life (i.e. activity performance). The committee might clarify for the reader that each assessment approach has its own purpose and adds its own value to a holistic assessment. The current wording appears to judge standardised tests against daily life, which they were never designed to do. However, we agree with the final statement that both (all) types of assessment are important. Making these issues clear to the reader will assist them to follow the subsequent recommendation (26-29) of explaining the assessments to the patient.	
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	092	017	We thought *'…cognitive impairments, vary in their ability to reflect…'* should be what is said in line 17 as it is inaccurate to state that all neuropsychological tests fail to reflect real world distractions.	Thank you for your comment. The committee agreed and have edited this to say 'do not always reflect the impact of real-world distractions on cognitive function'.
Brainkind	Guideline	092	017	Minor edit: Consider rewording to '…do not **always** reflect the impact…' (The recent systematic review by Suchy and colleagues adds strength to the recommendation of 'using both standardised and functional assessments'.	Thank you for your suggestion. We have edited this section accordingly.
Central London and Community Healthcare Trust	Guideline	092	026 - 029	*Evidence indicated that people with a chronic neurological disorder sometimes found the assessments tools to be patronising. So, the committee recommended that rehabilitation practitioners should explain what the assessments involve and why they are needed to prevent confusion and feelings of humiliation.* The guidance here has the potential to be clearer about what "explain" entails e.g. a leaflet, verbal? Consideration of cognition, communication, culture in this is needed to ensure good practice.	Thank you for your comment. The committee decided to not be too specific here to ensure flexibility in how this is provided as it depended on the person's own needs. The recommendation is clear to explain formats and purpose of tests to the individual. Previous recommendations in the cognitive function section also highlight to take into account the person's cognition and communication (including as person's cultural, linguistic, and educational background) for assessments.
Brainkind	Guideline	093	016 - 017	Minor edit: To reflect that impairments may still be present, even when using effective environmental interventions, consider rewording to read: 'such as reducing background noise, can in turn reduce the impact on daily function of impairments of executive function and memory and learning'	Thank you for your suggestion. We have edited this section accordingly.
Brainkind	Guideline	093	019 - 020	Minor edit: Consider deleting 'cognitive', as executive function deficits can affect self-managing of multiple aspects of function, not just cognitive function.	Thank you for your suggestion. We have edited this section accordingly.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	093	General	The group thought that it would be important to acknowledge gaps across the range of assessments relevant to cognitive function. We welcomed the clinical value placed on daily activity, and recognition of the contribution of the speech and language profession (on page 94). However the clinical importance of assessing mental functions appears absent in these sections, and there is no specific reference to the role of neuropsychologists in treatment (as opposed to diagnosis), which is often a service gap. Our group recommend a more balanced guidance across the different levels of functioning (ref ICF) and the professions who contribute to those levels. We recommend caution against	Thank you for your comment. The committee considered this comment as well as other stakeholder responses and decided to add a few recommendations to ensure neuropsychologists are also referenced. Newly added recommendations include to ensure that a health and mental health practitioner with expertise in neuropsychology should develop and undertake assessments; and to consider a joint neuropsychological assessment for both emotional health and wellbeing and cognitive function, especially if there is neurobehavioral disturbance and neurobehavioral changes.

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				prioritising one level or one profession, because in clinical practice, this risks an incomplete formulation of cognitive functioning and inappropriate treatment choices that would follow.	
Midlands and South Essex ICB	Guideline	093	028	There is a need for additional resource within community based services to support the specialism of functional assessment and increase the ability of services to meet cognitive rehabilitation needs, rather than a focus on OT provision of equipment.	Thank you for your comment. We acknowledge that functional assessment is not standard practice and would require additional resources, including staff training. The need to provide equipment will depend on people's needs and it would be inappropriate not to include this.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	094	012	We thought that an emphasis on communication impairments being overlooked (also P95 line 16) and the potential increased demand for speech and language therapists (p95 line 19) should be balanced by an acknowledgment that insight, awareness and social cognitive impairments are also often overlooked and should be assessed by a clinical psychologist/neuropsychologist.	Thank you for your comment. The committee agree and have added a recommendation to assess emotional health and wellbeing, behaviour and cognitive function (see the section on cognitive function), when completing a neuropsychological assessment. In the cognitive section of the guideline, we have recommended that a registered practitioner with expertise in neuropsychology (for example, a clinical psychologist, counselling psychologist or neuropsychologist), and an understanding of the person and the effects of their condition or injury, should oversee and interpret cognitive assessments and oversee the cognitive functioning element of the person's rehabilitation plan.
University College London Hospital	Guideline	096	001	AAC services mostly do not accept a referral unless the patient has seen Speech therapists first. This can be a real delay for the patient in accessing the technology and a waste of services if SALT is not needed other than to gate keep.	Thank you for your comment. We understand AAC services require referral and are mainly for those with severe and complex speech, language, or communication needs. The committee believes anyone with suspected difficulties should be offered initial screening by a speech and language therapist. Therefore, any further AAC referrals are based on clinical need and not used as a gatekeeping tool. The committee acknowledged the shortage of speech and language therapists and recommended service re-design and capacity building to ensure timely, responsive care. They hope these recommendations will be adopted, resourced and funded accordingly.
United Kingdom Acquired Brain Injury Forum	Guideline	100	023	We agree with regular reviews to address the evolving needs of children but feel that there is an unmet need around the transition between paediatric and adult services and this is where many young adults are lost to the system.	Thank you for your comment. NICE already has published guidance on transitioning from paediatric to adult services, which can be found in NG43 Transition from children's to adults' services for young people using health or social care services. Therefore, this period is out of scope for this guideline and no change has been made.
Independent Neurorehabilitation Providers Alliance	Guideline	100	023	We agree with regular reviews to address the evolving needs of children but feel that there is an unmet need around the transition between paediatric and adult services and this is where many young adults are lost to the system.	Thank you for your comment. NICE already has published guidance on transitioning from paediatric to adult services, which can be found in NG43 Transition from children's to adults' services for young people using health or social care services. Therefore, this period is out of scope for this guideline and no change has been made.
Midlands and South Essex ICB	Guideline	101	006	Provision of specific vocational rehabilitation pathways is likely to require significant additional specialist multi professional and multi agency resource.	Thank you for your comment. The committee acknowledged the importance of vocational rehabilitation and made recommendations for existing services. Due to a lack of evidence on effectiveness, they could not recommend vocational rehabilitation for everyone or the creation of new

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					services. Current recommendations may require reorganising existing services, but there are no implications for new funding.
Independent Neurorehabilitation Providers Alliance	Guideline	102	017	We agree on the importance of assessing the ability to work and facilitation of a return to work wherever possible but feel it should be stipulated that referral to a Vocational Rehabilitation Specialist should be made for more complex cases or at least with their support if not available locally.	Thank you for your suggestion. However, due to a lack of effectiveness and economic evidence on vocational rehabilitation, we are unable to recommend it. The committee has made several best practice recommendations that may support vocational rehabilitation.
Independent Neurorehabilitation Providers Alliance	Guideline	104	003	We agree with the importance of social participation and that lack of awareness of availability is a barrier and would like to suggest that additional training on chronic neurological conditions could be provided to social prescribers so that they can support with this.	Thank you for your suggestion. The introduction section titled 'Who is it for?' states that this guidance is for all healthcare and social care practitioners, which would include social prescribers.
Midlands and South Essex ICB	Guideline	104	012	It should be included that parenting roles form part of care act assessment and as such cross agency support from health and social care should be utilised in the provision of this part of the guideline.	Thank you for your comment. The committee believe that cross agency support has been highlighted throughout every section of the guideline, beginning with the initial designing and commissioning rehabilitation services section. We have several recommendations aimed at improving communication and collaboration between health, mental health, and social care professionals, in order to ensure better delivery of rehabilitation across all domains of a person's rehabilitation plan. Therefore, no changes have been made.
Brainkind	Guideline	106	011	Minor edit: 'preferences' instead of 'preference'	Thank you for your comment. We have amended the typo as suggested.
The UK FND Network	Guideline	106	026	FND is omitted from a listing of common disorders and their prevalence, which is of the same order of magnitude in FND. https://doi.org/10.1136/jnnp-2024-334767	Thank you for your comment. The context section has been rewritten and the prevalence information removed as these were old and do not represent the full population of this guideline.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	106	028	The figure of 1 in 37 people living with Parkinson's disease seemed vey high and we thought this should be double-checked	Thank you for your comment. The context section has been rewritten and the prevalence information removed as these were old and do not represent the full population of this guideline.
Birmingham Community Healthcare NHS Trust	Guideline	107	005	Should the work 'spine' be altered to 'brain' i.e. Injuries to the spine [brain] from whatever cause that result in …	Thank you for your comment. The context section has been rewritten and this error corrected.
South London and Maudsley NHS Foundation Trust	Guideline	107	005	It appears the definition for acquired brain injury is in fact that for acquired spinal injury, and then the definition for acquired peripheral nerve disorder is duplicated for that and acquired spinal injury.	Thank you for your comment. The context section has been rewritten and this error corrected.
Brainkind	Guideline	107	005	Typo: Replace 'spine' with 'brain' after 'Acquired brain injury:'	Thank you for your comment. The context section has been rewritten and this error corrected.
Royal College of Speech and Language Therapists	Guideline	107	005 - 012	There appear to be some errors in these definitions. Line 5 mentions 'spine' rather than 'brain' and the definition for peripheral nerve disorders seems to have been used for spinal cord injury.	Thank you for your comment. The context section has been rewritten and these errors corrected.

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Rehabilitation for chronic neurological disorders including acquired brain injury

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Brainkind	Guideline	107	009	Typo: Replace 'peripheral nervous system' with 'spine' after 'Acquired spinal cord injury'	Thank you for your comment. The context section has been rewritten and this error corrected.
The Royal Hospital for Neuro-disability	Guideline	107	017 - 020	For context can we include Huntington's Disease as an example of a progressive neurological disease? Despite being considered a rare disorder there has been an increase in the number of cases within the UK since 1990; according to the Huntington Study Group there is approximately 6700 cases in the UK (equivalent to 1 in 8,065). Individuals with Huntington's Disease also require changing neurorehabilitation over time, in the community and specialist inpatient settings for symptom management depending on the severity and progression of the disease. Whilst there are no specific NICE guidelines for the management of Huntington's disease, many of the principles within this guideline can be applied to this cohort of patients due to the progressive neurological nature, therefore reference to this will provide clinicians with support/ guidance (since reference in evidence review D; to study in HD population for intervention relating to mobility and ADLs, evidence review K; walking group intervention, evidence review O; physical activity intervention. However, It is a shame that many HD studies did not meet research protocol criteria. Therefore perhaps in a conclusion/ summary section there can be mention that more robust research is required to ensure effective guidance can be provided on HD/ other rare progressive conditions?	Thank you for your comment. We have included a new section at the end of the introductory/overview sections to set out clearly a list of the conditions, diseases, disorders and injuries covered and non-covered by this guideline. Huntington's disease is included in these lists.
The British Psychological Society	Guideline	107	017 - 024	The list of examples of progressive neurological disorders should include Huntington's disease. Huntington's currently lacks a NICE guideline, and people are inappropriately referred to the Parkinson's guideline, which is unhelpful.	Thank you for your comment. We have included a new section at the end of the introductory/overview sections to set out clearly a list of the conditions, diseases, disorders and injuries covered and non-covered by this guideline. Huntington's disease is included in these lists.
Community Head Injury Service, Bucks Healthcare NHS Trust	Guideline	107	021	We thought line 5 should read *'… injuries to the brain from.'* rather than 'spine'.	Thank you for your comment. The context section has been rewritten and this error corrected.
South London and Maudsley NHS Foundation Trust	Guideline	107	025	We believe that in the definition of functional neurological disorder the neurological symptoms caused should specifically include "seizures" and "cognitive dysfunction".	Thank you for your comment. We have included non-epileptic seizures and added cognitive dysfunction to the list.
The Spinal Injuries Association	Guideline	108	028	Ensure localised or condition specific charities are embedded within the service spec and work alongside NHSE / DHSC.	Thank you for your comment. We have made stronger reference to role of voluntary, community and social enterprise (VCSE) organisations in the Designing and commissioning rehabilitation services sections and throughout the guideline.
Brainkind	Guideline	109	001	For clarity, consider referring to 'activity or participation focused functional goals' instead of 'less impairment specific'.	Thank you for your comment. We have added this.

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Kent and Medway NHS and Social Care Partnership Trust	Guideline	109	015	Also does not cover transition to dementia services for people with progressive long term neurological conditions, or neurological vulnerability which requires investigation and potential services for dementia.	Thank you for your comment. The context section has been updated and these sections removed. A more comprehensive list of conditions, diseases, disorders and injuries covered and not-covered by this guideline has been included in the early sections of this guideline. This directs people to NICE guidelines on dementia. However you are right to note that this guideline does not cover transition to dementia services for people with progressive long term neurological conditions, or neurological vulnerability which requires investigation and potential services for dementia.
The Association of Clinical Psychologists UK	Guideline	109	015	ACP-UK comments that the guideline also does not cover the transition to dementia services for people with progressive long-term neurological conditions or neurological vulnerability, and which require investigation and potential services for dementia.	Thank you for your comment. The context section has been updated and these sections removed. A more comprehensive list of conditions, diseases, disorders and injuries covered and not-covered by this guideline has been included in the early sections of this guideline. This directs people to NICE guidelines on dementia. However you are right to note that this guideline does not cover transition to dementia services for people with progressive long term neurological conditions, or neurological vulnerability which requires investigation and potential services for dementia.
NHS England	Guideline	109	015 - 017	While the draft makes it clear that "end of life" care isn't covered, it would be beneficial to mention access to wheelchairs for those who are on palliative care and end of life care. It could be mentioned in page 33 lines 17 to 22	Thank you for your comment. We have made some changes to the context section and removed these paragraphs. A comprehensive list of conditions, diseases, disorders and injuries covered and not-covered by this guideline has been included in the early sections of this guideline. There is also information about areas of care which are not covered by the guideline. end of life care has been included in that list
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	The guidance does not appear to mention driving as part of the holistic assessment. This is often a function that is very important to adults and young adults as a key goal of their rehabilitation. We feel this should be mentioned given the importance of it for patients. Although it is acknowledged that DVLA has specific requirements in relationship to driving – we are requesting the author consider rehabilitation strategies in relation to driving. It would be helpful to have clear guidance considering when further assessment or working with the DVLA is needed for people with progressive conditions.	Thank you for your comment. As the scope of the guideline was so broad, we were unable to include details of all areas of rehabilitation. We did however include the importance of sharing information and advice with the person about financial support that might be available to assist with rehabilitation in relation to travel and travel support, which would include driving.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	We are pleased to see that sex and intimate relationships are part of this guidance.	Thank you for your comment. The committee believed strongly, and were supported by qualitative evidence, that this was an area often overlooked by services (often due to shame or embarrassment surrounding discussions on sexual rehabilitation needs). We hope that the recommendations contained in this guideline can address identified barriers to sexual rehabilitation for people with chronic neurological disorders in the future.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	It should be acknowledged that at each stage of the holistic assessment, the likelihood of negative impacts to the patient and those around them are considered and monitor, with appropriate steps in	Thank you for your comment. The committee agreed with qualitative evidence showing that rehabilitation goals should be realistic for people with chronic neurological disorders, and drafted a recommendation in the

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				place to minimise the severity and likelihood of harm. This is an ongoing section of the assessment involving the whole team, with clear communication to those involved if there are concerns. This should also consider capacity and best interest decision making.	goal setting section about discussing both positive and negative outcomes when considering rehabilitation goals. It is expected that this discussion and resulting rehabilitation plans will include mitigation strategies if applicable. Additional recommendations also state that both assessment and goal setting should be a collaborative process based around what is most important to the individual, and reviewed as appropriate. However, we feel that your suggested amendment of acknowledging potential negative outcomes at every stage of the holistic assessment could be interpreted by individuals undergoing rehabilitation as too pessimistic, which may negatively impact their engagement in the process. The principles of consent and best interest apply throughout this guideline, not simply this recommendation. NICE already has guidance on these topics, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws), NG108 Decision-making and mental capacity, NG227 Advocacy services for adults with health and social care needs, and NG204 Babies, children and young people's experience of healthcare. References to these documents have been made at the beginning of the guideline document, and separate references to NG108, NG227 and NG204 have been included at the beginning of the assessment section. Therefore, no changes have been made.
The Association of Clinical Psychologists UK	Guideline	General	General	ACP-UK is pleased to see that sex and intimate relationships are part of this guidance.	Thank you for your comment. The committee believed strongly, and were supported by qualitative evidence, that this was an area often overlooked by services (often due to shame or embarrassment surrounding discussions on sexual rehabilitation needs). We hope that the recommendations contained in this guideline can address identified barriers to sexual rehabilitation for people with chronic neurological disorders in the future.
The Association of Clinical Psychologists UK	Guideline	General	General	The guidance does not appear to mention driving as part of the holistic assessment. ACP-UK points out that this is often a function that is very important to people of all ages as a key goal of their rehabilitation. ACP-UK feels this should be mentioned given its importance to patients. Although it is acknowledged that DVLA has specific requirements in relation to driving – we are requesting the author consider rehabilitation strategies specifically around driving. It would be helpful to have clear guidance for considering when further assessment or working with the DVLA is needed for people with progressive conditions.	Thank you for your comment. As the scope of the guideline was so broad, we were unable to include details of all areas of rehabilitation. We did however include the importance of sharing information and advice with the person about financial support that might be available to assist with rehabilitation in relation to travel and travel support, which would include driving.

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The Association of Clinical Psychologists UK	Guideline	General	General	ACP-UK comments that it should be acknowledged that at each stage of the holistic assessment, the likelihood of negative impacts to the patient and those around them are considered and monitored, with appropriate steps in place to minimise the severity and likelihood of harm. This is an ongoing section of the assessment involving the whole team, with clear communication to those involved if there are concerns. This should also consider capacity and best interest decision making.	Thank you for your comment. The committee agreed with qualitative evidence showing that rehabilitation goals should be realistic for people with chronic neurological disorders, and drafted a recommendation in the goal setting section about discussing both positive and negative outcomes when considering rehabilitation goals. It is expected that this discussion and resulting rehabilitation plans will include mitigation strategies if applicable. Additional recommendations also state that both assessment and goal setting should be a collaborative process based around what is most important to the individual, and reviewed as appropriate. However, we feel that your suggested amendment of acknowledging potential negative outcomes at every stage of the holistic assessment could be interpreted by individuals undergoing rehabilitation as too pessimistic, which may negatively impact their engagement in the process. The principles of consent and best interest apply throughout this guideline, not simply this recommendation. NICE already has guidance on these topics, which can be found in 'Making decisions using NICE guidelines' (including links to the most up-to-date professional guidelines, standards and laws) and NG108 Decision-making and mental capacity. This has been referenced at the beginning of the main guideline section on assessing rehabilitation needs and NG108 has been included at the beginning of the section on conducting a holistic rehabilitation needs assessment. Therefore, no changes have been made.
Huntington's Disease Association	Guideline	General	General	We suggest that there is more clearly defined criteria to determine whether someone should be assigned a key worker, key contact or complex case manager. For example, it would be useful to have criteria to help services determine whether someone's cognitive impairment 'impacts them' or 'severely impacts them'. Please see these recommendations, which highlight this point (bold text is our emphasis): Rec 1.11.5 - Consider assigning a key worker if the person has: impaired cognitive or executive function that **impacts on their ability** to self-manage their condition or navigate rehabilitation services. Rec 1.11.6 - Consider assigning a complex case manager if the person has severe, complex and long-term rehabilitation needs and: impaired cognitive or executive function that **severely impacts their ability** to self-manage their condition or navigate rehabilitation services.	Thank you for your comment. The committee were unable to agree further criteria that could be applied across all populations of the guideline. As these are new recommendations which will change current practice we believe that additional local area commissioning criteria will emerge over time as the guideline is implemented. It is hoped that as practice evolves in this area future updates of the guideline will be able to include some of this best practice criteria as appropriate. We are also providing a resource impact tool to help commissioners consider the costs and benefits of a complex case manager for those most in need of this intensity of support.
Inflammatory Neuropathies UK	Guideline	General	General	We were surprised to see no reference to sensory needs within the 'rehabilitation to maintain, improve or support function' section. With	Thank you for your comment. When the committee were designing protocols for the evidence reviews that would inform guideline

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				sensory loss being a key issue for some conditions we feel that this should be considered within rehabilitation, particularly around coping mechanisms and specialist input	recommendations, they were asked to prioritise the interventions that they believe most applicable to our whole of our guideline population. Interventions for sensory loss were not suggested. As we did not look for evidence on these interventions, we cannot make any recommendations on their use and no changes have been made.
Inflammatory Neuropathies UK	Guideline	General	General	Whilst the guideline says that it is not meant for prisons, we feel that there should be reference to how people in prison are able to access rehabilitation services (in the same way as the general population can access) as we have experience where people have received no or very limited rehab to the long term detriment of their life chances	Thank you for your comment. Text is included in the overview/introduction to the guideline that says "Although recommendations are not intended to apply in prisons or military hospitals, this guideline may be of interest to professionals working in these settings."
Inflammatory Neuropathies UK	Guideline	General	General	Similarly, it would be useful to indicate in the guideline how support for specialist groups like homeless people or people facing multiple challenges are able to access rehabilitation, and how this is managed within assessment and intervention	Thank you for your comment. We acknowledge that there are currently health inequalities associated with these groups. We have added in links to the NICE guideline: Integrated health and social care for people experiencing homelessness throughout. We have also added additional detail to some of the recommendations to give greater consideration to cultural factors when designing services and building local capacity and given greater emphasis to the role of voluntary, community and social enterprise organisations (VCSE) in this . We have also added a greater emphasis on practitioner proactive follow up and review and navigation support remains central to the recommendations with the role of a single point of contact and various forms that this may take depending on the needs of the individual which would include consideration of potential health inequalities in ability to access services. . We also made some specific additions related to your comments such as in the cognitive function section where we have added the importance of considering the person's cultural, linguistic and educational background when deciding which assessment techniques to use.
Inflammatory Neuropathies UK	Guideline	General	General	We would also like to see reference to how the impact of acute conditions (such as GBS) and the long term rehab needs of people impacted by conditions that they have 'had' rather than 'have' are able to access rehabilitation, especially in the community after they have been discharged from hospital. This cohort report real issues accessing longer term support, especially when they have no key contact from a neurologist, limited condition knowledge with a GP, and where residual symptoms can fluctuate and 'flare' years after discharge, but where long term impact and ongoing rehab is needed. Perhaps this is an area where further research is needed?	Thank you for your comment. Rehabilitation needs as a result of Guillain-Barre syndrome are covered by this guideline. We have now included a list of all conditions, diseases, disorders and injuries covered and not-covered in the early introductory sections . GBS is included in this list. The committee made recommendations about commissioning rehabilitation services and service specifications covering all these conditions for long term, sometimes lifelong rehabilitation , and they hope these will be implemented and funded accordingly.
The Stroke Association	Guideline	General	General	The Stroke Association welcomes this opportunity to comment on the draft NICE guidance on rehabilitation for chronic neurological conditions. Rehabilitation is recognised as a critical component of stroke recovery. While there is separate NICE guidance specifically for	Thank you for your comment. We are pleased that you welcome the recommendations within this guideline. We have added clearer information to the overview section about the conditions, diseases, disorders and injuries covered and non-covered

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				rehabilitation for stroke in adults (October 2023, which we contributed evidence to under consultation), we know that many stroke survivors struggle to access stroke specific rehabilitation as recommended in your guidelines, and as a result may be impacted by any changes to more general rehabilitation guidance. Children and young people who have a stroke will fall under the scope of this guidance. The needs of stroke survivors and their families are often complex and can change during their recovery. Every stroke is unique, and the impacts are wide and varied: from physical disability and issues with mobility, vision, swallowing difficulties; speech and communication difficulties including aphasia; to struggling with everyday tasks[6]. Stroke has many hidden effects too, many stroke survivors experience problems with thinking, fatigue and depression. Nine in ten stroke survivors experience at least one cognitive impact[7]. One in four survivors will have another stroke within five years[8]. Given stroke survivors ongoing individual health needs, it is vital they have regular reviews after their stroke. However, just 39% of eligible stroke survivors received a six-month review in 2023-24, meaning over 42,000 individuals missed out on the support they need to continue their recovery that year[9]. Rehabilitation is crucial for people's recovery from stroke. Four out of five stroke survivors said having more rehabilitation is the most important intervention which would improve recovery after stroke[10]. Not only does good rehabilitation lead to a healthier and a happier population, but it also reduces pressure on the health and social care system and increases the number of working age stroke survivors and their carers who can regain their independence, including where relevant, re-entering meaningful employment[1112].	by this guideline. This guideline does NOT cover people living with the long term effects of stroke because a specific rehabilitation guideline already existed for this population. However it does cover the effects of stroke in under 16s as children were not covered by the stroke guideline. there will be a cross reference between the two guidelines for this reason.

[6] http://stroke.org.uk/lived-experience-of-stroke-report
[7] http://www.stroke.org.uk/lived-experience-of-stroke-report
[8] 10-Year-Health-Plan
[9] http://strokeaudit.org/About/About-SSNAP/Annual-reports.aspx
[10] 10-Year-Health-Plan
[11] Easing the pain report second edition_web version.pdf
[12] http://safestroke.eu/wp-content/uploads/2020/10/03.-At_What_Cost_EIOS_Full_Report.pdf

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				Many stroke survivors are unable to access the rehabilitation they require to support their recovery. Data from the Sentinel Stroke National Audit Programme (SSNAP) shows that stroke survivors are not receiving levels of rehabilitation in line with the national targets. The 2023 NICE guidelines recommend that stroke survivors are offered a minimum of three hours needs based, multi-disciplinary rehabilitation for at least five days a week[13]. The proportion of patients receiving this level of therapy in hospital falls far below the recommended levels, with only 13% of patients receiving recommended levels of speech and language therapy, 25% receiving recommended physiotherapy and 30% receiving recommended occupational therapy[14]. The intensity levels for these therapies has fallen over the past five years. Only 18% of inpatients in stroke units have access to all the core disciplines involved in stroke rehabilitation[15]. Despite the challenges in accessing rehabilitation in acute settings, the distribution of resources is skewed towards acute rehabilitation services, leaving community rehabilitation care under-resourced. There is a desperate need for a greater allocation of resources towards community rehabilitation services, as well as data collection. Only 17% of community-based services have appropriate access to each core therapy: physiotherapy, speech and language therapy and occupational therapy[16]. Only one in five survivors reported having received a six-month review, and some that did reported the process as inadequate[17]. Stroke survivors across England should have equal access to personalised needs-based rehabilitation and life after stroke support with regular reviews built in (including at six months). These services should be fully integrated across the stroke pathway, prioritised and invested in.	

[13] https://www.strokeaudit.org/Results2/Clinical-audit/National-Results.aspx
[14] https://www.strokeaudit.org/Results2/Clinical-audit/National-Results.aspx
[15] https://www.strokeaudit.org/Results2/Clinical-audit/National-Results.aspx
[16] http://strokeaudit.org/Audits/Post-acute-organisational-audit-information/Results-and-reports.aspx
[17] 10-Year-Health-Plan

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				We welcome this guidance and hope that it can improve rehabilitation services for stroke survivors and others.	
The Stroke Association	Guideline	General	General	Would it be challenging to implement of any of the draft recommendations? Please say why and for whom. Please include any suggestions that could help users overcome these challenges (for example, existing practical resources or national initiatives. The recommendations in the guideline are welcome, however the reality of rehabilitation services in the UK may make them challenging to implement. Research shows that frequent and more intense rehabilitation leads to better recovery following a stroke, but many stroke survivors only receive a fraction of what guidelines suggest. National data shows that most stroke survivors are not receiving recommended levels of rehabilitation (the 2023 NICE guidance on stroke rehabilitation in adults recommends that stroke survivors should receive a minimum of three hours a day, five days a week covering a range of multi-disciplinary therapies) when measured against previous guideline levels of 45 minutes per day at least five days a week[18]. Therefore, they are far from achieving the recommended levels of rehabilitation. In practice, services are unable to get close to these targets. The proportion of stroke patients to receive Occupational Therapy, Physiotherapy and Speech and Language Therapy assessments within 24 and 72 hours in all three disciplines, has either decreased or flatlined over the last five years[19]. Oonly 17% of community-based services have appropriate access to all the core disciplines involved in stroke rehabilitation. There are significant shortages in the workforce relating to stroke rehabilitation. Research suggests that 12,000 additional physiotherapists and 6,500 additional rehab assistant posts are needed in the NHS over the next five years to meet demand (and bring into line with international standards)[20]. Less than a third of community-based rehabilitation teams meet recommended staffing levels[21]. Even in areas	Thank you for your response; it is very helpful for context setting. The committee was aware of service shortages and access issues. Several recommendations were made for designing and commissioning rehabilitation services to streamline and improve efficiency, eliminate duplication and improve access. Implementation challenges, including staff shortages, were discussed, and a flexible approach was recommended, incorporating remote access, digital solutions like gaming modalities and virtual reality, and robotics. We reviewed evidence for children and young people and included relevant expertise on the committee, including topic advisors, to ensure recommendations address their needs.

[18] https://www.strokeaudit.org/Results2/Clinical-audit/National-Results.aspx
[19] https://www.strokeaudit.org/Results2/Clinical-audit/National-Results.aspx
[20] CSP workforce review reveals potential across the UK | The Chartered Society of Physiotherapy
[21] 03.-At_What_Cost_EIOS_Full_Report.pdf

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				where the commissioning and funding has been confirmed, there is not the skilled workforce to appoint into these roles. The role of rehabilitation assistants, digital solutions such as Neurorehabilitation on-line (NROL) and patient activation/self-efficacy should also be explored to support implementation of higher intensity evidence based rehabilitation. For children and young people who have had a stroke there are particular challenges. Paediatric rehabilitation is less well developed than adult rehabilitation, and children and young people who have had a stroke have specific needs which may not be well addressed through generic rehabilitation[22].	
The Stroke Association	Guideline	General	General	The guideline will apply to children under 16 who have had a stroke. Each year around 400 children in the UK have a stroke[23]. The needs of children who have a stroke often go unmet, and families often struggle to access the right treatment and support they need to help with their child's recovery[24]. When a child has a stroke, the impact will generally last their whole lifetime and some of the effects, both physical and emotional, may not show until years later as they develop and struggle to acquire new skills. The evidence on the causes and impact of stroke in children, and the effectiveness of rehabilitation interventions is still limited. We recommend that the recommendations in the Royal College of Paediatrics and Child Health (RCPCH) childhood stroke guideline are followed[25]. These, include establishing a multi-disciplinary team as soon after diagnosis as reasonably possible, and ensuring families have a key worker to help them access appropriate rehabilitation[26]. The guideline recommends early, persistent and flexible multidisciplinary rehabilitation. Specific guidance is provided on rehabilitative interventions for: motor function and mobility; sensory functions; dysphagia; communication; speech and language; cognition; mental	Thank you for your comment. We have added clearer information to the overview section about the conditions, diseases, disorders and injuries covered and non-covered by this guideline. This guideline does NOT cover people living with the long term effects of stroke because a specific rehabilitation guideline already existed for this population. However it does cover the effects of stroke in under 16s as children were not covered by the stroke guideline. there will be a cross reference between the two guidelines for this reason.

[22] Factors Influencing Recovery From Pediatric Stroke Based on Discussions From a UK-Based Online Stroke Community: Qualitative Thematic Study - PubMed
[23] 2017_Stroke_in_childhood_guideline_final.pdf.pdf
[24] Stroke in children impact report – resource available on request
[25] Stroke in childhood - clinical guideline for diagnosis, management and rehabilitation | RCPCH
[26] 20170516_stroke_in_childhood_-_full_clinical_guideline_v3.2_final.pdf

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				health; interpersonal relationships; learning and applying knowledge; and self-care and independence.	
British Association of Brain Injury and Complex Case Management	Guideline	General	General	Overall, the document is very positive and advocates the need for rehabilitation, a co-ordinated approach and utilising the skills of Complex Case Managers (CCM) to benefit individuals living with Chronic Neurological Disorders (CND). We recognise the depth and breadth of the work that has taken place to put together these draft guidelines and we thank the group for their effort and commitment. There is a clear move to a consistent approach to rehabilitation of Chronic Neurological Disorders (CND) including Acquired Brain Injury (ABI) specifically There is a clear acknowledgement in the guidance about the complexity and nuances of rehabilitation in CND and how specific needs may be identified and met. It is extremely positive to see that consideration of impaired of executive functions (EF) have been included throughout and explained, as these are so frequently misunderstood by those assessing. It is positive to see that newer technology has been included to meet needs, as well as CCM, and the recognition that there are very few CCMs available within the statutory sector with the relevant skills, as this sets a clear objective for that position to be rectified for the benefit of people with a CND.	Thank you for your comment and positive feedback.
British Association of Brain Injury and Complex Case Management	Guideline	General	General	We highlight that the definition of 'practitioner' is unclear. It includes support workers and HCAs in some sections, qualified professionals in others. Greater clarity for the avoidance of doubt in practice is suggested.	Thank you for your comment. We have included a definition for the term rehabilitation practitioner within the 'terms used in this guideline' and have amended throughout to be clear and consistent when we are referring to health, mental health and social care practitioners. We have added 'registered practitioner' in many of the recommendations across the section "rehabilitation to maintain, improve or support function" to ensure that those developing and overseeing the different elements of the rehabilitation plan set out in this section are always registered practitioners. However it is also acknowledged that some people contributing to rehabilitation may not be registered health, mental health or social care practitioners, for example those working in health or fitness at local sports clubs and teachers. We have also defined more clearly particular roles mentioned in the guideline, such as the Lead practitioner who has a role coordinating the holistic needs assessment before a single point of contact has been appointed.

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British Association of Brain Injury and Complex Case Management	Guideline	General	General	We highlight that there is no mention of bladder and bowel function as a rehabilitation need for someone with a CND, but this will frequently be a presenting need requiring rehabilitation and then ongoing management if required.	Thank you for your comment. Unfortunately, as there is already NICE guidance on these topics (CG49 Faecal incontinence in adults: management and CG148 Urinary incontinence in neurological disease: assessment and management), it is out of scope for this guideline. However, the guideline committee agreed that bladder and bowel function is important in this population, impacting on both rehabilitation planning and goal setting. Therefore, they have included a new recommendation to highlight a cross-reference to these guidelines in the related assessments section to ensure that these areas are not overlooked when identifying rehabilitation needs. Similarly, they have also included signposting to CG49 and CG148 at the beginning of the section on independent living, equipment and environmental adaptations for further recommendations on management of bladder and bowel dysfunction.
First Community Health and Care	Guideline	General	General	The word 'Rehabilitation' is not always helpful as it implies patients will improve or at best, maintain function, where for many neurological patients, their condition will decline over time (at varying speeds). For some patients, we are only managing their disability and supporting them to do so. We can still set 'goals' but the language feels quite different.	Thank you for your comment. We have included the definition of rehabilitation as used in the guideline in the 'terms used in this guideline' section. This includes supporting people to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living. The guideline aims to optimise or maintain function for as long as possible for the people with progressive disorders you refer to here.
Chiltern Music Therapy	Guideline	General	General	We recommend the inclusion of Neurologic Music Therapy® (NMT™) as a recognised intervention within multidisciplinary rehabilitation for chronic neurological disorders. NMT™ has demonstrated efficacy in improving motor function, communication, and emotional well-being in patients with acquired brain injuries and other neurological conditions (Bradt et al. 2010; Magee et al. 2017; Sihvonen et al. 2017; Siponkoski et al. 2020, Thaut et al. 2015; Thaut et al. 2009; Särkämö et al. 2014; Schneider et al. 2010; Altenmüller et al. 2009). Implementation may be challenging if services are unaware of trained NMT™ practitioners or existing clinical pathways. To overcome this, reference should be made to international clinical training frameworks (e.g. the Academy of Neurologic Music Therapy®), national registries of accredited music therapists (HCPC), and existing NHS models using music therapy in neurorehabilitation (e.g. Chiltern Music Therapy, Royal Hospital for Neuro-disability).	Thank you for your comment. Neurological Music Therapy was considered as an intervention in evidence review H on emotional health and wellbeing, however the committee agreed that there wasn't robust evidence to support it's use in emotional health and wellbeing, please see the committee's discussion of the evidence in evidence review H for full rationale. We recognise that there are studies on music therapy that may improve improving motor function, communication, and emotional well-being. Indeed Siponkoski et al 2020 was included in evidence review H. However, the other references sited were not included in the evidence review as they didn't meet the inclusion criteria of the protocol: Magee et al 2017 - 25 studies had a population of stroke in adults and this population was excluded from the protocol; 4 studies had a population of ABI and were excluded (Baker et al 2001 - pre-2013 publication; Fernandes et al 2014, O'Kelly et al 2014 - outcomes not relevant to any protocols as covered vital signs, facial expressions and neurophysiological outcomes; Mueller 2013 - conducted in the USA). Bradt et al 2010, Thaut et al 2009, Schneider et al 2010, Altenmuller et al 2009 - published prior to 2013 and were excluded from the protocol. Shvonen et al 2017 - narrative review and therefore didn't meet the study design inclusion criteria for adults in the protocol. Sarkamo 2014 - dementia is not a population of interest for the whole guideline. We could not check the eligibility of Thamut et al 2015 as we could not locate

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					the full reference. Given there are no recommendations on NMT in the guideline, we have not referenced NMT in the glossary. However, in relation to Music therapy being a distinct health and care professionals (HCPC) registered profession, we have added music, art and drama as examples of creative therapies in the recommendations and have added music therapists, art therapists and drama therapists to the glossary (all registered HCPC professions).
The Royal College of Ophthalmologists	Guideline	General	General	Many people with ABI have visual problems (for instance around half of patients with traumatic brain injury or stroke). The guideline rarely mentions visual impairment and does not recommend any sort of assessment. Whilst this does not need to be specialist assessment, rehabilitation providers should assess and screen for visual problems.	Thank you for your comment. We have included a new recommendation on the assessment of visual, hearing, and balance issues within the section on what to cover in the holistic rehabilitation needs assessment.
The Royal College of Ophthalmologists	Guideline	General	General	The document makes no mention of registration as sight impaired (or severely sight impaired), which should be considered in patients with visual loss.	Thank you for your comment. Unfortunately, the scope of the guideline did not cover interventions to support visual impairment. Therefore, no changes have been made.
Community Case Management Ltd.	Guideline	General	General	While the guideline makes several positive references to case managers, their strategic value and distinct contribution within rehabilitation pathways could be more clearly defined.	Thank you for your comment. Complex case managers are defined in the 'terms used in the guideline' along with other key roles involved in rehabilitation. The case for them has also been made strongly in evidence review I Evidence reviews for clinical case management in particular in relation to the economic arguments and considerations of the committee.
MS Society	Guideline	General	General	Rehabilitation Review NICE does not require regular rehabilitation reviews. The language it uses around follow-up is vague, leaving decisions to clinical teams without setting out expectations. In contrast, the optimal clinical pathway for adults with neurological conditions: rehabilitation is clear that patients with neurological disability should be seen annually for a rehabilitation review. Reviews should also happen if requested by the person or if clinically indicated. Where appropriate, the review should result in a written Rehabilitation Prescription. This distinction matters because many people with long-term neurological conditions, such as MS, experience changes in their symptoms and functioning over time. These changes may be gradual or sudden, and without routine reviews, rehabilitation needs can go unrecognised and unmet. A lack of regular review risks missed opportunities to intervene early, support self-management or refer on for specialist input. It can also contribute to avoidable deterioration, increased reliance on urgent care, and a lower quality of life.	Thank you for your comment. We have made some changes to the section about Agreeing, delivering and reviewing a coordinated rehabilitation plan including more explicit references to reviews within this section. For example, we have recommended that the timing of review appointments for reassessing interventions, approaches, rehabilitation needs and goals should be included as part of the rehabilitation plan. We have not included a requirement for an annual review because the committee felt this was too prescriptive across our population groups and this would not always be the optimum timing as more or less frequent reviews may be required. We have added a recommendation about reviewing goals and interventions when people are moving from more acute rehabilitation needs to longer term goals and interventions. There is also reference to review within many of the separate intervention chapters in the section Rehabilitation to maintain, improve or support function

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				An annual review provides a structured opportunity to assess progress against goals, identify new or emerging needs, and adjust the rehabilitation plan accordingly. It helps ensure that care remains person-centred and responsive, rather than reactive. Importantly, it also creates a formal mechanism for patients to be reconnected with rehabilitation services if they have been discharged or lost to follow-up. For people with MS, who may experience relapses or progression over time, regular reviews are essential to maintaining function, independence and participation in daily life. Reviews should not be limited to physical rehabilitation needs, but should also consider cognitive, psychological, vocational and social factors. Where necessary, a new or updated Rehabilitation Prescription should be issued to reflect the person's current goals and required interventions. By setting out a clear expectation for annual rehabilitation reviews, the optimum pathway recognises the dynamic nature of neurological conditions and the importance of continuity in care. Adopting this approach more widely would support more proactive, equitable and effective rehabilitation services.	
MS Society	Guideline	General	General	Workforce The guideline does not address the workforce required to deliver specialist rehabilitation, including rehabilitation medicine consultants. While this may be outside the technical scope of NICE, the omission makes it harder to link guidance with the service capacity needed to implement it. The 'optimal clinical pathway for adults with neurological conditions: rehabilitation' highlights that there are very low numbers of rehabilitation medicine consultants, and that these numbers have not increased in proportion with the growth in neurologists. This mismatch affects access to specialist care and limits delivery of recommended standards. This is a significant barrier to implementation. Without a workforce capable of delivering specialist rehabilitation, even the most robust guidance cannot be translated into consistent, high-quality care. People with complex neurological conditions such as MS may require input from multidisciplinary teams led by consultants in rehabilitation	Thank you for your comment. You are correct that the workforce required for specialist rehabilitation, including rehabilitation medicine consultants, was outside the scope of this guideline. However, the guidance includes several recommendations on designing and commissioning rehabilitation services, service design, service specification and capacity building which should guide workforce planning. The broad scope of this guideline, covering many service components, makes it challenging to estimate useful benchmark staffing levels, which would largely depend on local needs and services availability. In many areas, we recommended a menu of options based on current best practices due to the lack of effectiveness evidence showing the superiority of one intervention or approach over others. The committee shares your concerns and hopes the recommendations will be implemented, resourced and funded accordingly. We will also pass your comments to our implementation team.

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				medicine, particularly when needs cross multiple domains – physical, cognitive, psychological and vocational. These teams play a critical role in coordinating care, setting goals, overseeing specialist interventions and linking with community-based services. The current shortage of rehabilitation medicine consultants means many areas of the country are unable to offer Level 1 or Level 2 specialist rehabilitation in line with national standards. In some regions, patients with complex needs are managed by generalists or not referred to rehabilitation at all. This leads to unwarranted variation in access, delays in care, and unmet need. It also increases pressure on other parts of the system, such as neurology, general medicine, and primary care, which may not have the training or capacity to deliver complex rehabilitation.	
MS Society	Guideline	General	General	Role of Neuroscience Centres NICE does not mention the role of neuroscience centres within wider rehabilitation networks, nor how they should work with local services to support joined-up care. The 'optimal clinical pathway for adults with neurological conditions: rehabilitation' recommends that neuroscience centres should be part of a local rehabilitation network. These networks should work together to deliver the Community Rehabilitation Alliance Best Practice Standards and ensure that people receive coordinated, high-quality rehabilitation across settings. This is important because people with complex neurological conditions, including MS, often require input from a range of services over time, across both specialist and community settings. Neuroscience centres typically host specialist teams and facilities, including neurology, neurosurgery, and Level 1 rehabilitation services. However, without formal links to local rehabilitation networks, there is a risk that care becomes fragmented once the person is discharged or moves into community settings. When neuroscience centres are integrated into local rehabilitation networks, it becomes easier to coordinate care across the pathway from acute and inpatient rehabilitation through to community and long-term support. These networks provide a framework for shared planning, data collection, workforce coordination and consistent standards. They	Thank you for your comment. The guideline uses of the term 'specialist neurorehabilitation services' and this is defined in the glossary/terms used in this guideline section. We have included neuroscience centres as an example within this definition to make this explicit. The section "Designing and commissioning rehabilitation services" explicitly talks about the need to design services taking account of the mix of specialist and general rehabilitation services required to meet long term progressive or fluctuating rehabilitation needs in the community. It also talks about the importance of collaboration within and between integrated care systems to enable better access to specialist care and building capacity within community rehabilitation services to offer more care supported by specialist services. We would envisage Neuroscience centres would have a role to play here in the implementation of this guideline However neuroscience centres have not be named explicitly beyond this because this guideline does not cover the interface between specific medical treatments for disease and injury and rehabilitation interventions for long term, chronic rehabilitation needs. The condition specific NICE guidance for MS and NICE guidance for other progressive neurological conditions would be the best place to consider this.

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				also help ensure that patients are referred appropriately and that services work together rather than in silos. The optimum pathway recognises that no single service can meet the needs of people with complex rehabilitation needs. Instead, it calls for local rehabilitation networks to deliver care that is person-centred, well-coordinated and consistent with the Community Rehabilitation Alliance Best Practice Standards. These standards include timely access, clearly defined pathways, multidisciplinary input and ongoing review. For people with MS, this approach is particularly valuable. Rehabilitation needs may change over time, and people often move between hospital, specialist clinics and community-based care. Without a joined-up network, transitions between services can lead to delays, lost information, and unmet needs.	
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	It is unclear why the guidelines do not cover congenital neurological conditions that would not be seen in other services for example congenital hydrocephalus, epilepsy from birth, birthing injuries which would not meet criteria for cerebral palsy or learning disability. People with congenital neurological conditions will need holistic assessments throughout their lives and are seen in neuro rehabilitation services. There should be equity of provision for those with congenital as well as acquired conditions.	Thank you for your comment. We have added clearer information to the overview section about the conditions, diseases, disorders and injuries covered and not covered by this guideline. The guideline does cover congenital disorders that result in long term chronic neurological disorders. Epilepsy is not covered because a NICE guideline already exists covering people with this condition.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	Given the paper has been written for a wide audience, it would be beneficial to state that people with neurological conditions and brain injury should be able to access all health and social care services as required. It is good that the guidance highlights they may need adjustments, additional support and collaboration with neuro services in order to access these services, but that their diagnosis is not an exclusion for accessing other services. Referral to a neuro rehabilitation services would be for symptoms related to their neurological condition either maintenance or improvement or compensation. In providing holistic assessments there is a risk that people with neurological conditions and brain injury will only be directed to the neuro rehabilitation service in the first instance because they have this diagnosis and are seen as the service for people with these conditions when they may have other co-morbidities or needs.	Thank you for your comment. We have been explicit in the section about holistic needs assessment that services should not exclude someone from any aspect of a holistic needs assessment or service based on their communication, memory, learning or other cognitive difficulties. We also included a recommendation about developing local workforce skills to build capacity for both neurorehabilitation and mental health services and in relation to general community rehabilitation services supported by specialist services.

Rehabilitation for chronic neurological disorders including acquired brain injury

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Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	Specific staff mix of neuro rehabilitation services are not explicitly set out in the guidance. In the communication section it refers to speech and language therapists completing screens, however much of the document refers to rehabilitation practitioners. Although we recognise that different types of services and patient populations would need different skill mixes, it could be unhelpful for those commissioning services not to understand who are the core members of the multi-disciplinary team in neuro rehabilitation services. We advise that the guidance should state that clinical psychologists and clinical neuropsychologists are an essential member of the multi-disciplinary team providing assessment and intervention in cognition, behaviour and emotional wellbeing as part of the holistic assessment by the neuro rehabilitation team. These are core areas of the assessment and as such clinical psychologist role should be appropriately highlighted. To meet the needs of the people with neurological conditions and brain injury having emotional wellbeing embedded within the neuro rehabilitation team is essential, given the prevalence of cognitive and mood difficulties known in these populations. We are concerned by not highlighting clinical psychology, commissioners may feel this role can be undertaken by other members of the team who do not have the same level of training and experience in assessing and providing interventions in this area. There needs to be recognition that there is a sufficient level of staffing of clinical psychologists to deliver what is recommended per the guideline.	Thank you for your comment. We have added some new recommendations throughout the section 'rehabilitation to maintain, improve and support function' to ensure that registered practitioners with expertise in that particular professional discipline, and with an understanding of the effects of the persons particular condition or injury should always oversee assessments and that particular element of the persons rehabilitation plan. Clinical psychologists have been mentioned explicitly in both the cognitive and emotional health and wellbeing sections. So, for example, we have made particular reference to clinical psychologists and neuropsychologists in relation to the cognitive functioning element of the person's rehabilitation plan. We have also added more detail to the section about agreeing , delivering and reviewing the rehabilitation plan about how practitioner will liaise with one another and work together to enable interdisciplinary working an to ensure timely and joined-up delivery of interventions. The definition for 'rehabilitation practitioners' includes how 'these practitioners may also form hospital or community based multi-disciplinary teams to deliver holistic assessments and rehabilitation plans'.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	The guidelines do not provide bench marking recommendations for staff per population. The guidance is comprehensive in what is expected to be assessed and treated for people with neurological conditions and brain injury. However, in order to deliver this level of service, most neuro rehabilitation services would require additional resources, primarily but not exclusively in staffing. The guidance does not give reference to what staffing is needed to deliver a comprehensive neuro rehabilitation service, with capacity as stated per this guidance. It is therefore hard for existing services to benchmark and make the case for additional resources to improve their delivery of neuro rehabilitation.	Thank you for your comment. However, this was a clinical guideline and it was beyond its scope to provide guidance on service staffing levels. The guideline's broad scope, covering various populations and areas of function, symptom, and impairment, makes it impossible to set a single benchmark for appropriate staffing levels. Commissioners should decide this, considering the service specification components for integrated rehabilitation care outlined in the commissioning rehabilitation recommendations. We acknowledged staffing issues throughout the guidance and made specific recommendations to build local capacity and expertise, and commission services in a way that necessitates appropriate staffing to deliver recommended rehabilitation services.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	It is recognised that rehabilitation can save money on potential social care and further medical costs. This is made reference to in the guidance, however reference is made to a lack of evidence regarding economic modelling. Given the current climate of service delivery it feels essential to be considering the costs and financial benefits of investing in rehabilitation. If the committee feel that there is currently	Thank you for your comment. However, we did not look at the effectiveness of neurorehabilitation per se but rather at different components of rehabilitation and their effectiveness and cost-effectiveness, as per defined scope. There is already evidence on the cost effectiveness of neurorehabilitation, e.g., Turner-Stokes research. Where appropriate, we made research recommendations including cost effectiveness research for

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				insufficient evidence – why is this not recommended as part of the research questions? It would be important in maintaining these services to have longitudinal economic modelling.	particular rehabilitation interventions or approaches, e.g., interventions and approaches for improving and sustaining emotional health and wellbeing, that may be part of a broader neurorehabilitation package.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	At several points in the guidance it makes reference to having a key person identified in order to co-ordinate care. Although in principal having a named individual for communication and co-ordination would be beneficial, in practice this can be hard to deliver. Most services providing a case holding and reviewing role have a team to contact – e.g. specialist nurses thereby there is cover when a member of staff is not available. It would be preferable to be advocating that more than one person is holding the responsibility for communication and care coordination even if there is still a named lead.	Thank you for your comment. The guidance recommends a single point of contact i.e., key contact, key worker or complex case manager, based on the complexity of rehabilitation needs. As noted in 'Terms used in this guideline', and for the reasons you mention, this may be a named unit or team. The committee identified issues with a service configuration that includes multiple contacts, including lack of ownership, duplication and confusion over who to contact leading to delays in care and worse outcomes. They agreed a single point of contact is the most feasible way to support access, re-access and coordinated care across multiple services. Additional benefits including resource implications and cost effectiveness arguments are outlined in the supporting discussions in Evidence Review A (rehabilitation delivery) and Evidence Review I (clinical case management).
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	We are pleased to see the important role that family and friends have within this guidance. However, in some areas it can read as if the needs of the family and friends are almost more important. It should be recognised that there can be disagreements between the person and their family and friends. The role of the professionals is primarily based on the needs and wishes of the patient – and this should be emphasised. It is important that the needs of family and friends are identified and supported but not eclipsing the patient. It is important to emphasis that there can be many reasons as to why it is harder to hear the voice of this patient group.	Thank you for your comment. We disagree that the needs of family and friends are given undue prominence in the guideline. We do not include interventions specifically aimed at family and friends but we do recognise that family and friends often have a role in delivering rehabilitation interventions and in that respect are an important consideration when agreeing a rehabilitation plan. The consideration of family is friends as part of rehabilitation is only included following the express wishes of the person (see the section about Assessing rehabilitation needs and goal setting") or their advocates.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	The guideline emphasises a holistic assessment which is welcomed. However, it should be acknowledged that in providing a holistic service that the person can be re referred back to will enable continuity of care with a care team who is familiar with this patient and network. It would be good to emphasis that any holistic assessment would be building on clinical knowledge obtained from previous assessments and that there is good communication at steps in the pathway to ensure that the patient is not put through any unnecessary assessments. These patients often undergo a lot of previous assessment which should be acknowledged prior to deciding what further assessments are required.	Thank you for your comment. The guideline recognises that people might be accessing rehabilitation services for the first time or might be re-referred for changed rehabilitation needs. The early part of the accessing rehabilitation needs and goal setting section recognises that rehabilitation needs may first be identified when someone is in the community or when they are in an inpatient hospital setting. The section on rehabilitation planning and delivery includes recommendations about review and follow-up.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	Cultural factors are only mentioned in relation to barriers to physical activity goals, employment, and discussion of sex and sexuality. There is international evidence of cultural differences in relation to the	Thank you for your comment. We have added further reference to cultural factors in sections about cognitive function, participating in social and leisure activities and in considerations when fundings social and leisure

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				understanding of brain injury (e.g. https://doi.org/10.1080/09602011.2018.1453367; https://doi.org/10.1080/09602011.2018.1453367) and the need for rehabilitation services to be culturally competent (e.g. https://pubmed.ncbi.nlm.nih.gov/36594860/ Arguably these should be considered under section 1.5 Early discussion about prognosis and rehabilitation.	group activities. In the section about what to cover in a holistic rehabilitation needs assessment there are also questions about what is important to the person, meaningful activities, spiritual and religious practices, hobbies and interests.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	The guideline makes no reference to domestic violence or abuse. There is international evidence that domestic violence is a risk factor for acquired brain injury (e.g. https://pmc.ncbi.nlm.nih.gov/articles/PMC8773525/; https://www.tandfonline.com/doi/full/10.1080/10926771.2019.1602089?casa_token=tBFHpJ7PamYAAAAA%3Ap2Z4jW9KdZ0v_SpPdBLAof7rwMRuufu5XP_ic8JQKUyMzGCG6vbTJI_fpuxmYIlFvgZoSPbruLc; https://doi.org/10.1177/1524838018821951; https://link.springer.com/article/10.1007/s10896-021-00278-1). It is important for clinicians to consider the possibility of domestic abuse and / or coercive control when involving family members.	Thank you for your comment. We have added a new recommendation suggesting that practitioners Be aware that people who have experienced trauma as a direct result of their injury or condition, or, prior life experiences, or both, may need adaptions to assessment, rehabilitation and support plans. Family and friends are only included in the persons rehabilitation plans as the request of the person or their advocate.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	Very broad remit for the guidance – age/ diagnosis / prognosis – there will be different needs and so guidance may be diluted as trying to cover too much. May be better to have different guideline for progressive/ degenerative condition that those expected to be on an improvement trajectory. There is already some guidance for parts of the remit.	Thank you for your comment. We have added clearer information to the overview section about the conditions, diseases, disorders and injuries covered and not covered by this guideline. We have also added information about the areas of care not covered by this guideline and how to use these recommendations together with other guidelines produced by NICE where these cover conditions in scope of this guideline.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	Rehabilitation should not be the only term used. Some of the guidance relates to enablement, maintenance or management. Especially for progressive conditions.	Thank you for your comment. We have added a definition for rehabilitation (as agreed by the committee) into the 'terms used in this guideline'.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	There should be more reference to coordinated care considering social care as well i.e. social services/ care packages and those providers being part of the rehab/ enablement or maintenance programme.	Thank you for your comment. The scope of this guideline was rehabilitation only interventions specifically focused on the aims of rehabilitation. Though the committee recognised that local authority funded social care services often have a part to play in contributing to successful rehabilitation outcomes and social workers can have an important part to play, often acting as key coordinators between services, which is why social care practitioners and services were referenced throughout the guideline. NICE has produced a range of social care guidelines which are more focused on transitional, short term and long term care needs and some of these have also been referenced in this guideline. Non rehabilitation focused social care services were not included. Pharmacological, medical and surgical interventions were also not included

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Rehabilitation for chronic neurological disorders including acquired brain injury

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Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	Greater realistic view what services can provide. The gold standard in guidance is useful but services are not necessarily commissioned to meet this.	Thank you for your comment. NICE is not involved in funding decisions. The committee made recommendations on commissioning rehabilitation services and service specifications, and they hope these will be implemented and funded accordingly.
Kent and Medway NHS and Social Care Partnership Trust	Guideline	General	General	Little mention of social care – they may be well placed to identify and refer back into rehab/ maintenance services , as could GP.	Thank you for your comment. The scope of this guideline was rehabilitation only interventions specifically focused on the aims of rehabilitation. Though the committee recognised that local authority funded social care services often have a part to play in contributing to successful rehabilitation outcomes and social workers can have an important part to play, often acting as key coordinators between services, which is why social care practitioners and services were referenced throughout the guideline. NICE has produced a range of social care guidelines which are more focused on transitional, short term and long term care needs and some of these have also been referenced in this guideline. Non rehabilitation focused social care services were not included. Pharmacological, medical and surgical interventions were also not included
Headway – The Brain Injury Association	Guideline	General	General	Headway welcomes the development of this NICE guideline and the recognition that neurorehabilitation following acquired brain injury is crucial to the wellbeing of all brain injury survivors. We agree that the recommendations contained within the guideline are sensible and likely to result in better outcomes for brain injury survivors. We would like to see greater recognition within these guidelines that currently, access to specialist neurorehabilitation is a postcode lottery. The latest national clinical audit of neurorehabilitation services in 2019 revealed that out of 1,381 individuals assessed in Major Trauma Centres needing specialist rehabilitation, only 40% received it. This glaring disparity is unacceptable, and the postcode lottery must come to an end. We are concerned that currently, it is likely that there are not enough neurorehabilitation professionals in the UK to support these guidelines, and that unless greater efforts are made to train and retain these professionals, these guidelines are unlikely to be consistently followed across England and Wales. The 2018/19 survey of the Association of British Neurologists found that, at the time it was conducted, the UK had 1.1 consultants per 100,000 population. This is significantly low when compared with countries of similar wealth; the average in the EU, is around one consultant neurologist per 12,000 people. Within the UK, London and the South East have the largest proportion of consultant neurologists. (See Roche Economist Impact Report, 2024).	Thank you for your comment. The guidance acknowledges variations in neurorehabilitation practice. NICE guidelines are evidence-based, setting benchmarks for best practice to reduce unjustified variation. The guidance covers service specification, assessment, interventions, and support services with the aim of standardising provision, resource allocation and reducing postcode-based variation. The committee recognised staffing issues and made recommendations to build local capacity and expertise, and commission services to ensure appropriate staffing. Recommendations also aim to streamline and improve efficiency, eliminate duplication, and incorporate remote access, digital solutions like gaming and virtual reality, and robotics to relieve pressure on services while capacity is built. Thank you for highlighting the challenges faced by Headway charities. The guidance and supporting discussions acknowledge the issues you have raised. The committee hopes their recommendations will be implemented, resourced and funded accordingly. However, NICE is not involved in funding decisions.

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				We suggest that the neurorehabilitation workforce will need support to ensure that this guidance is implemented comprehensively. We suggest that it would be helpful to specify which data and metrics will be used in measuring the impact of the guidance, and that the use of patient experience data would be a valuable tool in this. Local Headway rehabilitation services are explicitly referenced in these guidelines. The Headway network operates in communities throughout the UK, offering a range of fundamental rehabilitation and support services for brain injury survivors and caregivers. These services encompass brain injury rehabilitation programs, caregiver support, social reintegration initiatives, vocational rehabilitation, community outreach efforts, and respite care. Each charity offers services tailored to meet the needs of local people, so provision differs across the UK. Local Headway charities are often described as lifelines by those who benefit from them. However, these services are now at risk due to the escalating cost-of-living crisis, dwindling local authority funding, and decreased public donations. In the last two years, 10% of local Headway charities have had to close their doors. Many Headway charities nationwide are being forced to scale back services or are in danger of closure. Without these services, and without ongoing community-based rehabilitation for brain injury survivors, we are likely to see an increase in costly state-funded crisis interventions, which could be prevented if ongoing neurorehabilitation were sufficiently funded across the UK.	
Head First	Guideline	General	General	Congratulations on drafting these much-needed guidelines and we are delighted to be in a position to review them. We feel that the guideline is very positive, particularly in recognising the need for Case Management to benefit those with Chronic Neurological Disorders (CND) including Acquired Brain Injury (ABI), there is recognition of executive functions and frontal lobe paradox as well as the long-term cost effectiveness of Case Management input. The framework for lifelong rehabilitation is groundbreaking. As brain injury specialist case management company with over 30 years' experience in supporting people and their families living with brain injury, we welcome the recognition of clinical case managers within these guidelines for people with complex rehabilitation needs.	Thank you for your comment. We are pleased you are supportive of this important guideline.

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				When reviewing these guidelines, we wish to start our focus on the clinical case manager role. We acknowledge that there is little evidence for Case Management intervention available but that the guidelines have drawn up clinical experience and as an organisation can testify that the 30+ years of experience in the field of brain injury rehabilitation confirms the cost effectiveness to the NHS for complex individuals evidence in reduced hospital admission, longevity of admissions and the facilitation and coordination of care and services in the community. It is positive to read that Functional Neurological Disorder (FND) has been recognised within the guidelines. As an organisation we want to thank the group for the enormous commitment and dedication to bring the draft guidelines to fruition.	
The Association of British Neurologists	Guideline	General	General	We are responding to this guideline as a group of neurologists with expertise in functional neurological disorders. We welcome the inclusion of functional neurological disorders in these guidelines: it is a chronic neurological condition, managed primarily through rehabilitation. However, we are concerned that the guideline does not meaningfully distinguish functional neurological disorders from other neurological conditions: this is problematic because (a) there are differences in treatment between those used in functional neurological disorders and those used in many other neurological conditions, and (b) there appears to be a lack of awareness of the risks of iatrogenic harm caused by inappropriate treatment approaches in patients with functional neurological disorders (e.g. validating maladaptive beliefs, avoidance of splinting etc).	Thank you for your comment. We recognise that the guideline did not offer enough helpful advice for practitioners working with people with FND. We have now added the following recommendations specific to people with FND. New recommendation in the holistic needs assessment section to be aware that FND can exist alongside other neurological disorders and to adjust assessment accordingly. New recommendation in the section about information, advice and learning about information and psychoeducation for people with FND and the importance of validating presence of symptoms whilst avoiding reinforcing beliefs that there is structural damage or disease to the nervous system and emphasising the potential for recover. A similar new recommendation in the Physical activity and exercise section about using activities that encourage and enable recovery of movement (goal-orientated movement) A new recommendation considering the potential harms of inappropriate use of some physical interventions for people with FND (e.g. serial or removal casting) A new recommendation to consider replacing standard cognitive tests with observation and dynamic testing for people with FND A new recommendation considering the potential harms of inappropriate use of compensatory aids, assistive devices and adaptive approaches to support independent living We have also removed the reference to group work and people with FND in recommendation 1.3.8 as the committee agreed this was misleading.
The Association of British Neurologists	Guideline	General	General	Rehabilitation strategies are the mainstay of treatment for patients with functional neurological disorders and offer patients the potential for full	Thank you for your comment. We recognise that the guideline did not offer enough helpful advice for practitioners working with people with FND. We

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				recovery. Consensus guidelines for physiotherapy, occupational therapy, speech and language therapy and psychological therapy in patients with functional neurological disorders are key to informing patients' holistic rehabilitation planning and treatment. We recommend their inclusion in this guideline: • Physio: Neilsen et al: jnnp.bmj.com/content/jnnp/early/2014/11/28/jnnp-2014-309255.full.pdf • OT: Nicholson et al: J Neurol Neurosurg Psychiatry 2020 Oct;91(10):1037-1045. doi: 10.1136/jnnp-2019-322281. Epub 2020 Jul 30 • SALT/Communication: Baker et al (2021) Journal of Neurology Neurosurgery and Psychiatry (JNNP) Doi:10.1136/jnnp-2021-326767 • Neuropsychology: Detert et al https://doi.org/10.53841/bpsrep.2024.rep181 Non specialist testing (e.g. cognitive) and treatment (e.g. splinting) and exclusion of patients with mental ill health, or lack of concomitant mental health care, for patients with functional neurological disorders may result in iatrogenic harm and suboptimal outcomes for patients with this treatable condition.	have now added the following recommendations specific to people with FND. New recommendation in the holistic needs assessment section to be aware that FND can exist alongside other neurological disorders and to adjust assessment accordingly. New recommendation in the section about information, advice and learning about information and psychoeducation for people with FND and the importance of validating presence of symptoms whilst avoiding reinforcing beliefs that there is structural damage or disease to the nervous system and emphasising the potential for recover. A similar new recommendation in the Physical activity and exercise section about using activities that encourage and enable recovery of movement (goal-orientated movement) A new recommendation considering the potential harms of inappropriate use of some physical interventions for people with FND (e.g. serial or removal casting) A new recommendation to consider replacing standard cognitive tests with observation and dynamic testing for people with FND A new recommendation considering the potential harms of inappropriate use of compensatory aids, assistive devices and adaptive approaches to support independent living We have also removed the reference to group work and people with FND in recommendation 1.3.8 as the committee agreed this was misleading. NICE does not usually reference good practice guidelines by other bodies as part of its recommendations.
The Association of British Neurologists	Guideline	General	General	There is no mention of neuropsychologists in the guideline. Neuropsychologists – where available – are central part of the team when assessing and treating patients with functional neurological disorders (and in our experience other neurological conditions too) – we recommend this is commented on in the guidelines.	New recommendation in the section about information, advice and learning about information and psychoeducation for people with FND and the importance of validating presence of symptoms whilst avoiding reinforcing beliefs that there is structural damage or disease to the nervous system and emphasising the potential for recover.
The Association of British Neurologists	Guideline	General	General	Was the NICE committee aware of the well-established consensus guidelines on rehabilitation in functional neurological disorders? We strongly recommend them and would like to see them referenced and cited directly in the guidance. • Physio: Neilsen et al: jnnp.bmj.com/content/jnnp/early/2014/11/28/jnnp-2014-309255.full.pdf • OT: Nicholson et al: J Neurol Neurosurg Psychiatry 2020 Oct;91(10):1037-1045. doi: 10.1136/jnnp-2019-322281. Epub 2020 Jul 30	Thank you for your comment. We recognise that the guideline did not offer enough helpful advice for practitioners working with people with FND. We have now added the following recommendations specific to people with FND. New recommendation in the holistic needs assessment section to be aware that FND can exist alongside other neurological disorders and to adjust assessment accordingly. New recommendation in the section about information, advice and learning about information and psychoeducation for people with FND and the importance of validating presence of symptoms whilst avoiding reinforcing beliefs that there is structural damage or disease to the nervous system

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				• SALT/Communication: Baker et al (2021) Journal of Neurology Neurosurgery and Psychiatry (JNNP) Doi:10.1136/jnnp-2021-326767 • Neuropsychology: Detert et al https://doi.org/10.53841/bpsrep.2024.rep181	and emphasising the potential for recover. A similar new recommendation in the Physical activity and exercise section about using activities that encourage and enable recovery of movement (goal-orientated movement) A new recommendation considering the potential harms of inappropriate use of some physical interventions for people with FND (e.g. serial or removal casting) A new recommendation to consider replacing standard cognitive tests with observation and dynamic testing for people with FND A new recommendation considering the potential harms of inappropriate use of compensatory aids, assistive devices and adaptive approaches to support independent living We have also removed the reference to group work and people with FND in recommendation 1.3.8 as the committee agreed this was misleading. NICE does not usually reference good practice guidelines by other bodies as part of its recommendations.
Recolo UK	Guideline	General	General	A lot of the evidence is adult population. Also note in terms of child evidence base that the evidence was limited to UK only, thus missing all the masses of publications from USA, Australia etc. In our view, there may be enough UK evidence for adults, but certainly not for children. We would suggest that the panel open the search parameters. Currently they restrict evidence to UK only, with a publication date of 2010 or later. The explanation at the beginning says that they would consider data from NZ, Aus and Canada if not enough was available from the UK and we would argue that this needs to be implemented here. We'd still miss all the US data, but there is quite a bit from Australia that would be helpful. Value the integration of evidence base **and** knowledge and experience of the panel to inform draft recommendations.	Thank you for your comment. We appreciate that paucity of paediatric evidence is disappointing to you. The committee agreed with you, and have made several research recommendations specifically in the children and young people population in order to try and increase the wealth of evidence available for future updates of this guideline. However, you are incorrect in saying that evidence for children and young people was limited to the UK. For all of our quantitative evidence reviews, the restriction was studies conducted in the UK, Australia, New Zealand and Canada and high-income European countries (ac-cording to the World Bank) for all age ranges. For our qualitative reviews, we implemented a step-wise approach, stating we would expand to Australia, New Zealand and Canada if there was insufficient UK evidence to support decision-making for people under 18. Indeed, we did end up including evidence from these countries in 3 of our qualitative reviews (A, B and C). The 1 evidence review that was restricted to UK was evidence review K, where the committee believed that they had enough data to inform their recommendations. Therefore, no change has been made.
Recolo UK	Guideline	General	General	Transition is discussed only in the context of referring to NICE guidelines (1) child to adult services and (2) inpatient hospital settings and community or care home. We wonder whether transitions are specifically excluded as there is another NICE guideline on child-adult health services transitions. And	A new recommendation considering the potential harms of inappropriate use of some physical interventions for people with FND (e.g. serial or removal casting)

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				as this is a health document in the main the guidelines won't be considering educational transitions as it is seen outside their remit. However, as psychologists delivering into paediatric rehabilitation, a significant part of our work is supporting children and young people at key transitions in education and supporting the systems around children and young people at these times.	
Recolo UK	Guideline	General	General	We note that across the draft guidelines it recommends involvement of family members to support access to, engagement / participation in rehabilitation. We cannot emphasise strongly enough the absolute importance of family participation in rehabilitation. And also noting the evidence of increasing burden on families after (paediatric) brain injury, and the importance and value of resourcing families by for example, supporting their own mental health, family functioning, and timely psychoeducation. Family involvement and support is **vital** in the rehabilitation process.	Thank you for your comment. We are pleased you are supportive of the inclusion of the consideration of family and friends in the guideline.
University College London Hospital	Guideline	General	General	We welcome this guideline however we are concerned it is too vague and does not specify who the recommendations are for. Without a bit more detail it will simply be ignored as someone else's responsibility. We believe the guideline should hold the ICB ultimately responsible for commissioning services. The single point of contact for those with long term conditions should be specified as a condition specific CNS, community matron, neuronavigator or a member of the community neuro or learning disability team.	Thank you for your comment. There are a lot of different practitioners involved in delivering rehabilitation services. We have defined these in the terms used in the guideline section. We have included a section on Designing and commissioning rehabilitation services that sets out the importance of commissioning bodies working together to design and commission services and build local capacity. We would envisage this would be implemented through ICBs and through Integrated care systems but do not specify this in the recommendations as sometimes policy requires these commissioning bodies change name. However the guideline is very clear that there should be clear overall designated responsibility for implementing clinical pathways for rehabilitation taking into account local and national commissioning responsibilities. The committee did not want to specify who the single point of contact should be, but we have included a set of definitions in the 'terms used in this guideline ' section that cover the various practitioners that could perform the roles of initial contact for rehabilitation, lead practitioner for assessment, key contact, key worker and complex case manager.

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University College London Hospital	Guideline	General	General	We do not feel the recommendations are realistic. There is a huge amount of recommendations here many of which are entirely outside of current NHS resources and not even available in many specialist rehab settings (treadmill training, VR, electrical stimulation, psychological therapies such as for example; cognitive behavioural therapy, self-determination theory, social context theory and motivational interviewing or coaching techniques for establishing lifelong exercise).	New recommendation in the holistic needs assessment section to be aware that FND can exist alongside other neurological disorders and to adjust assessment accordingly.
University College London Hospital	Guideline	General	General	As a general comment, there is a huge amount of inequity of the services currently provided across the UK. So many of the services mentioned are available to some but not all of the patients we see. Some mention of the need for commissioners to be considering how to resolve this inequity would be very welcome.	A new recommendation considering the potential harms of inappropriate use of compensatory aids, assistive devices and adaptive approaches to support independent living
University College London Hospital	Guideline	General	General	As a general comment, there is a section on sexual function but there is no section on bladder and bowel function in this document. A section on bladder / bowel function in the document should be considered or at least NICE guideline CG148 should be referred to.	Thank you for your comment. Unfortunately, as there is already NICE guidance on these topics (CG49 Faecal incontinence in adults: management and CG148 Urinary incontinence in neurological disease: assessment and management), it is out of scope for this guideline. However, the guideline committee agreed that bladder and bowel function is important in this population, impacting on both rehabilitation planning and goal setting. Therefore, they have included a new recommendation to highlight a cross-reference to these guidelines in the related assessments section to ensure that these areas are not overlooked when identifying rehabilitation needs. Similarly, they have also included signposting to CG49 and CG148 at the beginning of the section on independent living, equipment and environmental adaptations for further recommendations on management of bladder and bowel dysfunction.
University College London Hospital	Guideline	General	General	In general we am supportive of this document, but it feels very focussed on what happens at the time of first consultation when the diagnosis is given and patients are early in their journey, particularly chronic progressive disorders, for example there are multiple mentions of MND and PD, but little references to other disorders. It has not highlighted a few domains which would be worth covering in "Rehabilitation to maintain, improve or support function": - Spasticity and contracture management - Skin management I also think a document such as this really needs to consider how patients should be informed about end of life care, advanced care planning and palliative care input even if it is just to highlight the importance of this and refer to separate guidelines which have been drawn up for this.	We have also removed the reference to group work and people with FND in recommendation 1.3.8 as the committee agreed this was misleading.

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University College London Hospital	Guideline	General	General	Did the issue of rehabilitation prescriptions come up – should be revisited and included	Thank you for your comment. The guideline uses the term rehabilitation plan, but this would include rehabilitation prescriptions . See the definition of rehabilitation plan in the 'terms used in this guideline' .
University College London Hospital	Guideline	General	General	In terms of access to splinting or postural management equipment there are some areas where there is no access at all to custom made splints or functional splints, and equipment for postural management equipment is extremely limited. There would need to be a huge uplift to equipment budgets and training in order to allow access to these essential items for all.	A new recommendation to consider replacing standard cognitive tests with observation and dynamic testing for people with FND
The UK FND Network	Guideline	General	General	In this submission we will focus on the treatment of Functional Neurological Disorder (FND) in the draft guideline as this is our area of expertise. We are open to direct engagement with the NICE guideline committee to improve the guideline. • We welcome the inclusion of FND in the scope of the guideline, and recognise that many of the recommendations which apply generally to chronic neurological conditions do indeed apply to FND also, such as recommendations relating to care pathways, key workers etc. • However we have serious concerns that the particular and important ways in which FND differs from other chronic neurological conditions are systematically not acknowledged in the draft guidance and evidence reviews. There appeared to be a lack of understanding of the nature of FND across the guidance. To us it appeared as though when FND was added to the scope retrospectively, it was treated broadly as though it were the same as the other conditions, and made to conform to the structure already set out for those other conditions. • One example of this is a general lack of acknowledgement that treatment targets differ in rehabilitation of FND, as symptom improvement and even remission is a relevant goal. Likewise the biopsychosocial nature of the condition itself and the treatment implications of this are not acknowledged. This leads to advice which is misleading by omission. • In some places generalisation of recommendations appropriate to other neurological conditions includes advice which could be harmful in FND (see below). • The evidence reviews use search strategies which are not well-fitted to FND possibly resulting in skewed search results and omissions of relevant research. The one piece of FND-	Thank you for your comment. We recognise that the guideline did not offer enough helpful advice for practitioners working with people with FND. We have now added the following recommendations specific to people with FND. New recommendation in the holistic needs assessment section to be aware that FND can exist alongside other neurological disorders and to adjust assessment accordingly. New recommendation in the section about information, advice and learning about information and psychoeducation for people with FND and the importance of validating presence of symptoms whilst avoiding reinforcing beliefs that there is structural damage or disease to the nervous system and emphasising the potential for recover. A similar new recommendation in the Physical activity and exercise section about using activities that encourage and enable recovery of movement (goal-orientated movement) A new recommendation considering the potential harms of inappropriate use of some physical interventions for people with FND (e.g. serial or removal casting) A new recommendation to consider replacing standard cognitive tests with observation and dynamic testing for people with FND A new recommendation considering the potential harms of inappropriate use of compensatory aids, assistive devices and adaptive approaches to support independent living We have also removed the reference to group work and people with FND in recommendation 1.3.8 as the committee agreed this was misleading.

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				specific research which is referenced is incorrectly summarised. See below for more details on these points. There are very few references to FND, and only one rather minor FND-specific recommendation in the main guideline, which appeared to be both wrong and unevidenced. There was a call for evidence which appeared tangential to the needs in this area. See below for more detail on these points.	
Montelukast Side Effects (Singulair) Support and Discussion Group	Guideline	General	General	The Montelukast (Singulair) Side Effects Discussion and Support Group welcomes these guidelines as a structured way for getting long term support for those suffering the impact of neuropsychiatric side effects to Montelukast. In April 2024 the Medicines and Healthcare products Regulatory Authority (MHRA) issued a second Drug Safety Update regarding the potential for neuropsychiatric side effects https://www.gov.uk/drug-safety-update/montelukast-reminder-of-the-risk-of-neuropsychiatric-reactions. However, the experience of patients in getting a clear diagnosis of a chronic neurological condition is challenging. This could be due to a number of factors; the sudden onset versus insipid onset of neuropsychiatric symptoms or the evolving nature of symptoms whilst taking and on stopping the medication. For some patients' symptoms resolve on stopping, whereas for others there are reports of worsening and new onset symptoms on stopping, extended recovery times (typically 3 years) and in some cases neuropsychiatric symptoms are reported to persist. This has been acknowledged by the US Food and Drug Administration (FDA) and has been reflected in the US Medication Guide for Montelukast, which states that "mental health problems have happened in people taking Singular (montelukast) even after treatment has stopped." https://www.organon.com/product/usa/pi_circulars/s/singulair/singulair_mg.pdf. Information regarding the patient experience during and on stopping montelukast information has been shared with the MHRA and is also highlighted by patient and carer testimonies (which include some from the UK) attesting to the issues and are publicly recorded by the US FDA: Joint Pediatric Advisory Committee and Drug Safety and Risk Management Advisory Committee; Notice of Meeting; Establishment of a Public Docket; Request for Comments	Thank you for your comment. Unfortunately, as noted in our pre-agreed scope, diagnosis of neurological disorders is not an area covered by this guideline. Additionally, the recommendations in this guideline are designed to be generalisable to the whole population of people with chronic neurological disorders. There are a few exceptions where we have made more specific guidance, but this is still for certain sub-populations (for example, children and young people, or people with functional neurological disorders) rather then specific disease aetiologies. Therefore, no changes have been made. However, rehabilitation for the neurological side effects of medication would be covered in this guideline under the 'acquired' category. As you mention in your comment, the committee has highlighted the importance of early access to rehabilitation services by recommending that an assessment for rehabilitation needs can be based on symptoms and impairments instead of waiting for a diagnosis. While the recommendation you referenced does mention a diagnosis, it also says initial treatment, which would cover people who are presenting with neurological symptoms but do not currently have a diagnosis. Furthermore, the guideline has continually stressed the importance of taking a biopsychosocial approach to rehabilitation, considering all the rehabilitation needs of a person and their disorder. Alongside mental health, the committee has recommended assessing physical, cognitive, vocational, educational and social rehabilitation needs. This should assist with your concern of people being not being referred appropriately to neurological services for rehabilitation. We also have 2 new recommendations that state to assess cognitive function, emotional health and wellbeing, and behaviour together when completing a neuropsychological assessment. Again, this joint assessment should help to provide more accurate evaluations to support person-centred care. The committee were also aware that knowledge of rare conditions may limit availability for rehabilitation. Therefore, they made a recommendations about collaborating within and between integrated care services to try increase access to specialist neurorehabilitation services. We hope that this

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				Posted by the Food and Drug Administration on Aug 21, 2019 Ref: https://www.regulations.gov/document/FDA-2019-N-3611-0001/comment National Center for Toxicological Research (NCTR) Science Advisory Board (SAB) Meeting May 18-19, 2022 Virtual Meeting Ref: https://www.fda.gov/media/158517/download Whilst the Guideline is welcomed as a route to accessing long term care, concerns remain regarding the initial diagnosis of a chronic neurological disorder due to a lack of awareness of the side effects and the potential for long term issues resulting in patients and their carers struggling to be heard, 'getting lost in the system' and not necessarily being referred to neurology. Para 1.5.4 Assumes a clear diagnosis in Secondary or Tertiary Care, potentially with a hospital discharge mentioned in Para 1.6; however, in practice those in our support group find it difficult to get help often directed to overstretched mental health services, rather than the impact on the brain being the primary consideration. It is acknowledged that Pg 13, Para 1.7.1 states a rehabilitation assessment can be undertaken based on symptoms and impairment (even if a chronic neurological disorder is suspected but not confirmed). The same issue may be true for other medications which hold a risk of neuropsychiatric symptoms as detailed in Ref: Parker and Tait, Adverse psychiatric effects of drugs prescribed for physical illness, Treatment strategies and psychopharmacology. Volume 52, Issue 9 p596-602 September 2024. https://www.medicinejournal.co.uk/article/S1357-3039(24)00153-1/abstract **QUESTION**: We would be grateful for consideration as to how those suffering neuropsychiatric side effects from prescription medications are adequately evaluated and diagnosed to enable access to the best pathway for support recovery and rehabilitation?	would extend to increasing knowledge of neuropsychiatric side effects from prescription medications.
Montelukast Side Effects (Singulair) Support and Discussion Group	Guideline	General	General	We remain concerned regarding the impact on Montelukast on the brain (and the developing brain) during treatment and after treatment has stopped and respectfully request that consideration be given to the following research:	Thank you for your comment and concern. Unfortunately, pharmacological treatment is out of scope for this guideline, no evidence was reviewed and therefore no recommendations have been made on this topic.

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				Marques et al Oct 2022 (https://www.sciencedirect.com/science/article/pii/S0024320522007561) . The mechanisms underlying montelukast neuropsychiatric effects – new insights from a combined metabolic and multiomics approach. Life Sciences Vo. 110. Dec 2022, 121056. Key findings: The multi-omics approach employed confirmed that montelukast interferes with the glutathione detoxification system in the brain. Moreover, montelukast is also able to dysregulate various neurostransmitter and neurosteroid pathways, particularly those involved in regulation of the hypothalamic-pituitary-adrenal axis, also interfering with mitochondrial function in neuronal cells. Significance: Results clearly indicate that montelukast therapeutic effects are accompanied by a strong modulation of specific processes in the central nervous system that may explain the observed neuropsychiatric reactions. Moreover, the results also suggest that adverse drug reactions are more likely to occur in children, due to the early maturation stage of their brains. Tseng et.al (https://www.sciencedirect.com/science/article/abs/pii/S0009279720300326?via%3Dihub) In vitro cytotoxicity of montelukast in HAPI and SH-SY5Y cells. Chemico-Biological Interactions, Volume 326, 1 August 2020, 109134 This study "provides the first in vitro evidence on Montelukast toxicity to microglial and neuronal cells. Provides evidence that this toxicity may be mediated by inflammatory response. Suggests that the inflammatory response and toxicity may contribute to neuropsychiatric events seen with montelukast use." Eriksson, Kalm et al.(https://pubmed.ncbi.nlm.nih.gov/29991719/) The anti-asthmatic drug, montelukast, modifies the neurogenic potential in the young healthy and irradiated brain. Cell Death Dis. 2018 Jul; 9(7): 775. This study found detrimental effects in the developing brains of juvenile healthy control mice, including inhibited cellular growth in the hippocampus under conditions of typical development. Marschallingar et al.(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4639806/) Structural and functional rejuvenation of the aged brain by an approved anti-asthmatic drug. Oct 2015. Nat Commun, 2015;6: 8466 conducted an extensive analysis, including a re-examination of Merck NDA 20-829's	

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				1998 original CNS pharmacology data, revealing that montelukast's distribution across the blood-brain barrier (BBB) is significant rather than minimal. Marschallinger, et al. also confirmed that montelukast exerts structural and functional impacts on the central nervous system, mediated through the GPR17 receptor. It also suggests the existence of an active transport mechanism for Montelukast through the BBB. The US National Center for Toxicological Research (NCTR) Division of Systems Biology (DSB) of the US FDA is conducting "multiple studies to evaluate concerns of potential drug-induced neuropsychiatric risks associated with montelukast, including verification of montelukast's binding potential to candidate protein targets in human neural cells" and a recent presentation at the American College of Toxicology Conference in November 2024 *(https://actam2024.eventscribe.net/searchGlobal.asp)*, presents the early findings identifying off-target receptors in the brain where there is both cell binding and cell activity. Ref: Neuropsychiatric concerns and potential molecular mechanisms associated with widely used medication montelukast. J. Oliphant is the presentation of early-stage research which points to potential mechanisms.	
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	General	General	Lack of Detail on Frequency and Intensity of Psychological Support The guideline does not provide any clear recommendations on the minimum expected frequency, duration, or intensity of psychological therapy input at different levels of care (e.g., Level 2a vs. Level 1). This missing detail undermines local commissioning and resource planning and contributes to significant inequalities across regions. Psychology is often underfunded or misunderstood by those commissioning neurorehab services, and guidance should offer indicative staffing models or caseload assumptions to guide provision.	Thank you for your comment. The committee highlighted that the interventions for adjustment and engagement were different in their duration, intensity, and delivery, therefore it was difficult to recommend a specific type of CBT or mindfulness intervention other than talking therapy for adjustment and engagement in people with CND. Due to the broad population covered, the committee could only outline key components of holistic rehabilitation services. The committee noted that commissioning and resource planning should reflect local needs, and it would be infeasible to provide indicative staffing levels. Aware of geographical variation, they made recommendations on service specifications that include emotional health and mental wellbeing. There are also recommendations on building capacity in mental health services and ensuring responsive services. Emotional wellbeing also features in assessment and intervention sections. They hope their recommendations will be implemented and funded accordingly. Your comment will also be shared with the NICE implementation team.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	General	General	Psychology Not Consistently Recognised in Specialist Service Definitions The guideline mentions multidisciplinary teams but does not always explicitly include psychology or neuropsychology, especially in sections	Thank you for your comment. We have added some new recommendations throughout the section 'rehabilitation to maintain, improve and support function' to ensure that registered practitioners with expertise in that particular professional discipline, and with an understanding of the effects

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				on "specialist services" or support roles. Given the core role of psychological formulation in managing complex ABI presentations, this lack of explicit naming risks de-prioritising psychological input.	of the persons particular condition or injury should always oversee assessments and that particular element of the persons rehabilitation plan. So, for example, we have made particular reference to clinical psychologists and neuropsychologists in relation to the cognitive functioning element of the person's rehabilitation plan. We have also included a definition for the term rehabilitation practitioner within the 'terms used in this guideline' and have amended throughout to be clear and consistent when we are referring to health, mental health and social care practitioners. However it is also acknowledged that some people contributing to rehabilitation may not be registered health, mental health or social care practitioners, for example those working in health or fitness at local sports clubs and teachers. We also included a recommendation about developing local workforce skills to build capacity for both neurorehabilitation and mental health services and in relation to general community rehabilitation services supported by specialist services.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	General	General	Idealism vs. Commissioning Reality The document reads as idealistic without addressing the practical limitations in current commissioning structures and funding allocations. Without clear levers to enforce parity of access, local areas will continue to vary significantly in what provision is available. Consider rephrasing or dividing guidance into what is essential, optimal, and aspirational, so that services and commissioners can pragmatically plan phased implementation.	Thank you for your comment. The committee acknowledged current challenges throughout their rationale and evidence reviews. They believe that funding constraints should not prevent recommendations based on the best available evidence. The committee hopes these best practice recommendations will be implemented and appropriately funded.
Sheffield Teaching Hospital NHS Foundation Trust	Guideline	General	General	There needs to be mandated training or a competency framework for commissioners in neurorehabilitation. The repeated use of IFRs (Individual Funding Requests) for core rehab input highlights systemic misunderstanding by commissioners who do not seek to consult individuals with clinical experience or lived experience of neurorehab. These decisions are made, inconsistently, without any rationale or input from clinical specialists in these services.	Thank you for your comment. The committee were also concerned about commissioning for neurorehabilitation and wrote recommendations about this including a recommendation about what service specifications needed to cover in order to design pathways of care for people with chronic neurological disorders. We hope that commissioners will use this guideline in the future. However, NICE is not involved in funding decisions. .
The British Psychological Society	Guideline	General	General	Accessing treatment for cognitive, emotional and mental health issues is consistently highlighted as a significant challenge for people with neurological conditions. To strengthen the guidance, the issues highlighted below should be included throughout the document: • Patient surveys show that people with neurological conditions and mental health problems are often excluded from traditional mental health services, or feel they do not adequately meet their needs (reference: Parity of Esteem for People affected by Neurological Conditions).	Thank you for your comment. The guideline committee were aware that some mental health services have admittance criteria that specifically exclude people with a diagnosis of a chronic neurological disorder, which was supported by qualitative evidence. In view of this, the guideline executive document will highlight to NHS England the inequality in accessing mental health services for people with chronic neurological disorders to review. The committee recognised that services differ in their capacity and expertise, in view of this the committee agreed to write recommendations

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				• Mainstream talking therapies such as the kind provided by NHS Talking Therapies, are often not appropriate for people with Acquired Brain Injury, especially for those with significant cognitive deficits post injury. NHS Talking Therapies does not currently provide training any training for their staff in working with people with neurological conditions within their long-term conditions training. Also typically, the duration of NHS Talking Therapies is limited and likely inadequate for people with complex presentations who require support (reference: Parity of Esteem for People affected by Neurological Conditions). • People with neurological conditions often experience a combination of emotional, cognitive and behavioural consequences. Practitioners need to be able to understand these difficulties to adapt mental health support to account for them. Cognitive changes need to be assessed, and support offered to patients to understand and cope with these. Changes in cognitive function can also be accompanied by a lack of awareness of such changes in the individual. Family members need to be included in the support. All of this means that an individual psychotherapy model of care is often not appropriate for the needs of this population. • A matched care model, where those with the most complex problems related to their neurological condition receive the most specialist support, would be favourable. This would depend on skilled triage in the neuroscience centre. • There should be adequate training and supervision for all mental health therapy staff working with those with neurological conditions, to help them develop the essential skills required to adapt therapy to working with people with neurological conditions. Supervision arrangements need to be in place between the mental health staff and the tertiary neuroscience service, with opportunities for patient transfer if the individual patient needs cannot me met by the mental health service. • Clinical neuropsychologists should be involved in the assessment and delivery of interventions for those with the most complex cognitive, behavioural and emotional problems linked to their neurological condition, and in the supervision and training of staff delivering mental health interventions for people with neurological conditions. This is because of the	on building local capacity and expertise in the guideline. Specifically, the committee recommended to build capacity for mental health services for people with a chronic neurological disorder through local workforce skills development and communication protocols between different services involved in rehabilitation. Furthermore, the committee recognised that GPs or other primary care practitioners may not be equipped to treat people with chronic neurological disorders and recommended that GPs and other primary care practitioners know how to recognise emerging rehabilitation needs because of an existing chronic neurological disorder, and know when and how to refer people to rehabilitation specialists. For example, using expertise from specialist neurorehabilitation services and maintaining up-to-date information on options for local rehabilitation services. The committee agreed that people with neurological conditions often experience a combination of emotional, cognitive and behavioural consequences. The assessment section in emotional health and wellbeing has been extensively edited and a more collaborative approach with the cognitive section is adopted. A new recommendation has been made in the emotional health and wellbeing section of the guideline that states a registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse), and an understanding of the person and the effects of their condition or injury, should develop and oversee the emotional health and wellbeing element of the person's rehabilitation plan. Furthermore, a recommendation was made to assess emotional health and wellbeing, behaviour and cognitive function (see the section on cognitive function), when completing a neuropsychological assessment, indicating a collaborative approach. Throughout the guideline, there is reference to the integration of family members and carers in the planning, assessment and management, there is a recommendation in the emotional health and wellbeing section of the guideline to work with family, carers, people important to the person and the person's social networks when agreeing the most appropriate interventions to improve or sustain emotional health and mental wellbeing. The committee agree that there should be adequate training and supervision for all mental health therapy staff working with those with neurological conditions, to help them develop the essential skills required to adapt therapy to working with people with neurological conditions. There is a new recommendation in the building local capacity and expertise section of the guideline to develop local workforce skills to build capacity for neurorehabilitation and mental health services for people with a chronic

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				need to tailor mental health interventions to the cognitive, behavioural and emotional consequences of the neurological condition. • The cognitive and behavioural changes for people with neurological conditions and the need for family support should be addressed within the planned psychological support. • Mental health/ cognitive/ behavioural interventions for people with complex problems related to neurological conditions are often not effective if they are only carried out by one discipline in isolation, and if they are carried out only with the individual, without family involvement. The mental health care of people with complex cognitive, emotional or behavioural difficulties linked to neurological conditions should be addressed by a multidisciplinary team approach that supports the person with the neurological condition and their family. This could be incorporated within the interventions offered by a community brain injury team, if clinical neuropsychology were appropriately funded to be a core member of a community team. There is insufficient acknowledgement of the specific needs of people with Functional Neurological Disorder (FND), which differ from the needs of people with other neurological disorders. In particular, psychological treatment of functional/ dissociative seizures needs to be highlighted. For example, importance of a coordinated multidisciplinary approach in functional motor syndromes, including psychological contributions to multidisciplinary working with FND.	neurological disorder. Furthermore, a new recommendation was made in the cognitive section of the guideline states that a registered practitioner with expertise in neuropsychology (for example, a clinical psychologist, counselling psychologist or neuropsychologist), and an understanding of the person and the effects of their condition or injury, should oversee and interpret cognitive assessments and oversee the cognitive functioning element of the person's rehabilitation plan. Additionally, neuropsychologists have been listed in the glossary alongside other registered professions by the health and care professions council as rehabilitation practitioners. We recognise that the guideline did not offer enough helpful advice for practitioners working with people with FND. We have now added a number of new recommendations specific to people with FND throughout the guideline, including one about information and psychoeducation for people with FND and the importance of validating presence of symptoms whilst avoiding reinforcing beliefs that there is structural damage or disease to the nervous system and emphasising the potential for recovery.
South London and Maudsley NHS Foundation Trust	Guideline	General	General	Consideration needs to be given to the specialists suggested to provide services within the guidelines. We consider it imperative that the right level of expertise is present. In particular when considering emotional health and wellbeing this should require neuropsychiatry and neuropsychology input	Thank you for your comment. Neuropsychologists have been listed in the glossary alongside other registered professions by the health and care professions council as rehabilitation practitioners. Significant changes have also been made to the emotional health and wellbeing assessment and cognitive assessment sections of the guideline, which do broadly address your point. For example, in the emotional health and wellbeing section we have edited a recommendation emphasising that a registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse), with an understanding of the person and the effects of their condition or injury, should develop and oversee the emotional health and wellbeing element of the person's rehabilitation plan. Furthermore, the committee agreed a new recommendation to assess

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					emotional health and wellbeing, behaviour and cognitive function (see the section on cognitive function), when completing a neuropsychological assessment. In the cognitive section of the guideline, we have recommended that a registered practitioner with expertise in neuropsychology (for example, a clinical psychologist, counselling psychologist or neuropsychologist), and an understanding of the person and the effects of their condition or injury, should oversee and interpret cognitive assessments and oversee the cognitive functioning element of the person's rehabilitation plan.
South London and Maudsley NHS Foundation Trust	Guideline	General	General	Whilst there is a section on emotional health and wellbeing there is very limited reference to specific psychiatric comorbidities, and the impact that this has on recovery from chronic neurological disorders, and how treatment may benefit this. We would consider that this may warrant a separate heading for consideration	Thank you for your comment. Treatment of specific psychiatric co-morbidities is outside of the guideline scope. We agree it is important to treat specific psychiatric co-morbidities in people with CND, therefore cross-references have been made in the emotional health and wellbeing section to NICE guidelines on post-traumatic stress disorder in adults, anxiety in adults and depression in adults and children and young people with a chronic neurological disorder as part of their rehabilitation.
South London and Maudsley NHS Foundation Trust	Guideline	General	General	Overall within the guidelines there is very limited detail regarding interventions for individuals with functional neurological disorder. Whilst we are pleased that NICE and the committee have included individuals with FND within these guidelines given that some of the considerations and neuorehabilitation approaches within FND are different we believe this should be reflected in the guidelines.	Thank you for your comment. We recognise that the guideline did not offer enough helpful advice for practitioners working with people with FND. We have now added the following recommendations specific to people with FND. New recommendation in the holistic needs assessment section to be aware that FND can exist alongside other neurological disorders and to adjust assessment accordingly. New recommendation in the section about information, advice and learning about information and psychoeducation for people with FND and the importance of validating presence of symptoms whilst avoiding reinforcing beliefs that there is structural damage or disease to the nervous system and emphasising the potential for recover. A similar new recommendation in the Physical activity and exercise section about using activities that encourage and enable recovery of movement (goal-orientated movement) A new recommendation considering the potential harms of inappropriate use of some physical interventions for people with FND (e.g. serial or removal casting) A new recommendation to consider replacing standard cognitive tests with observation and dynamic testing for people with FND A new recommendation considering the potential harms of inappropriate use of compensatory aids, assistive devices and adaptive approaches to support independent living We have also removed the reference to group work and people with FND in recommendation 1.3.8 as the committee agreed this was misleading.

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South London and Maudsley NHS Foundation Trust	Guideline	General	General	The guidelines do not discuss the role of psychological formulation, and psychoeducation, as a starting point for the treatment of FND. We would suggest that this is of particular importance for individuals with FND.	Thank you for your comment. We recognise that the guideline did not offer enough helpful advice for practitioners working with people with FND. We have now added the following recommendations specific to people with FND. New recommendation in the holistic needs assessment section to be aware that FND can exist alongside other neurological disorders and to adjust assessment accordingly. New recommendation in the section about information, advice and learning about information and psychoeducation for people with FND and the importance of validating presence of symptoms whilst avoiding reinforcing beliefs that there is structural damage or disease to the nervous system and emphasising the potential for recover. A similar new recommendation in the Physical activity and exercise section about using activities that encourage and enable recovery of movement (goal-orientated movement) A new recommendation considering the potential harms of inappropriate use of some physical interventions for people with FND (e.g. serial or removal casting) A new recommendation to consider replacing standard cognitive tests with observation and dynamic testing for people with FND A new recommendation considering the potential harms of inappropriate use of compensatory aids, assistive devices and adaptive approaches to support independent living We have also removed the reference to group work and people with FND in recommendation 1.3.8 as the committee agreed this was misleading.
South London and Maudsley NHS Foundation Trust	Guideline	General	General	Specific interventions delivered for FND within a neuropsychiatric setting do not appear to be considered in terms of management of the symptoms of FND, and are only briefly included within the emotional health and wellbeing section. We believe that the Goldstein et al, 2020, CODES trial in the Lancet supports the use of psychological interventions for individuals with dissociative seizures (https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(20)30128-0/fulltext). Please note the study included in evidence review H is in fact only the health technology review, and not the full trial. Furthermore the study on outcomes of an inpatient neuropsychiatric led unit for FND, Saunders et al, 2024 (https://pmc.ncbi.nlm.nih.gov/articles/PMC11227748/pdf/bmjno-2024-000675.pdf) demonstrates the potential value of such approaches in a multidisciplinary inpatient setting.	Thank you for your comment. We recognise that the guideline did not offer enough helpful advice for practitioners working with people with FND. We have now added the following recommendations specific to people with FND. New recommendation in the holistic needs assessment section to be aware that FND can exist alongside other neurological disorders and to adjust assessment accordingly. New recommendation in the section about information, advice and learning about information and psychoeducation for people with FND and the importance of validating presence of symptoms whilst avoiding reinforcing beliefs that there is structural damage or disease to the nervous system and emphasising the potential for recover. A similar new recommendation in the Physical activity and exercise section about using activities that encourage and enable recovery of movement (goal-orientated movement) A new recommendation considering the potential harms of inappropriate

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South London and Maudsley NHS Foundation Trust	Guideline	General	General	We believe it is regrettable that the committee does not contain anyone with expertise in assessment and treatment of functional neurological disorder, given the different considerations for this condition.	New recommendation in the holistic needs assessment section to be aware that FND can exist alongside other neurological disorders and to adjust assessment accordingly.
South London and Maudsley NHS Foundation Trust	Guideline	General	General	Throughout the guidelines there is regular reference to neurorehabilitation practitioners. Whilst we acknowledge that practitioners can have expertise that cover various areas, we believe it is imperative to ensure that the correct specialists are involved throughout the pathway. We would recommend consideration is given throughout the guidelines to highlight where this expertise may best come from i.e. neurologist, neuropsychiatrist, neuropsychologist, rehab medicine etc.	New recommendation in the section about information, advice and learning about information and psychoeducation for people with FND and the importance of validating presence of symptoms whilst avoiding reinforcing beliefs that there is structural damage or disease to the nervous system and emphasising the potential for recover.
The Association of Clinical Psychologists UK	Guideline	General	General	Given the paper has been written for a wide audience, ACP-UK comments that it would be beneficial to explicitly state that people with neurological conditions and brain injury should be able to access all health and social care services, as required. It is good that the guidance highlights they may need adjustments, additional support and collaboration with neuro services in order to access these services, but that their diagnosis is not an exclusion for accessing other services. Referral to a neuro rehabilitation service would be for symptoms related to a person's neurological condition – either maintenance, improvement or compensation. ACP-UK comments that in providing holistic assessments there is a risk that people with neurological conditions and brain injury will ONLY be directed to the neuro rehabilitation service in the first instance because they have this diagnosis, and that neuro rehabilitation is seen as the service for people with these conditions when they may have other co-morbidities or needs better served by other services.	A new recommendation to consider replacing standard cognitive tests with observation and dynamic testing for people with FND
The Association of Clinical Psychologists UK	Guideline	General	General	ACP-UK points out that specific staff mix within neuro rehabilitation services are not explicitly set out in the guidance. In the communication section, it refers to speech and language therapists completing screens;	A new recommendation considering the potential harms of inappropriate use of compensatory aids, assistive devices and adaptive approaches to support independent living

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				however, much of the document refers to rehabilitation practitioners. Although we recognise that different types of services and patient populations would need different skill mixes, it would be helpful for those commissioning services to understand who the core members of the multi-disciplinary team (MDT) in neuro-rehabilitation services are. We advise that the guidance should state that clinical psychologists and clinical neuropsychologists are essential members of the MDT, providing assessment and intervention in cognition, behaviour and emotional wellbeing as part of the holistic assessment by the neuro-rehabilitation team. These are core areas of the assessment and, as such, the clinical psychologist role should be appropriately highlighted. To meet the needs of the people with neurological conditions and brain injury having emotional wellbeing embedded within the neuro-rehabilitation team is essential, given the prevalence of cognitive and mood difficulties known in these populations. We are concerned by not highlighting clinical psychology, commissioners may feel this role can be undertaken by other members of the team who do not have the same level of training and experience in assessing and providing interventions in this area. There needs to be recognition that there is a sufficient level of staffing of clinical psychologists to deliver what is recommended per the guideline.	
The Association of Clinical Psychologists UK	Guideline	General	General	At several points in the guidance, reference is made to having a key person identified in order to co-ordinate care. Although in principle, having a named individual for communication and co-ordination would be beneficial, in practice this can be hard to deliver. Most services that provide a case holding and reviewing role have a team to contact – e.g., specialist nurses, which means there is cover when a member of staff is not available. It would be preferable to be advocating that more than one person is holding the responsibility for communication and care coordination even if there is still a named lead.	We have also removed the reference to group work and people with FND in recommendation 1.3.8 as the committee agreed this was misleading.
The Association of Clinical Psychologists UK	Guideline	General	General	ACP-UK comments that the guidelines do not provide bench-marking recommendations for staff per population. The guidance is comprehensive in what is expected to be assessed and treated for people with neurological conditions and brain injury. However, in order to deliver this level of service, most neuro-rehabilitation services would require additional resources primarily, but not exclusively, in staffing. The guidance does not give reference to what staffing is needed to deliver a comprehensive neuro-rehabilitation service, with the capacity as stated in this guidance. It is, therefore, hard for existing services to benchmark and make the case for additional resources to improve their delivery of neuro rehabilitation.	A similar new recommendation in the Physical activity and exercise section about using activities that encourage and enable recovery of movement (goal-orientated movement)

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The Association of Clinical Psychologists UK	Guideline	General	General	It is recognised that rehabilitation can save money on potential social care and further medical costs. This is made reference to in the guidance. However, reference is made to a lack of evidence regarding economic modelling. Given the current climate of service delivery, it feels essential to be considering the costs and financial benefits of investing in rehabilitation. ACP-UK asks that if the committee feels that there is currently insufficient evidence, could this be recommended as part of the research questions? It would be important in maintaining these services to have longitudinal economic modelling.	A new recommendation considering the potential harms of inappropriate use of some physical interventions for people with FND (e.g. serial or removal casting)
The Association of Clinical Psychologists UK	Guideline	General	General	ACP-UK is pleased to see the important role that family and friends have within this guidance. However, in some areas it can read as if the needs of the family and friends are almost more important than the patient. It should be recognised that there can be disagreements between the person and their family and friends. The role of the professionals is primarily based on the needs and wishes of the patient – and this should be emphasised. It is important that the needs of family and friends are identified and supported but not eclipsing those of the patient. It is important to emphasise that there can be many reasons as to why it is harder to hear the voice of this patient group.	Thank you for your comment. We disagree that the needs of family and friends are given undue prominence in the guideline. We do not include interventions specifically aimed at family and friends but we do recognise that family and friends often have a role in delivering rehabilitation interventions and in that respect are an important consideration when agreeing a rehabilitation plan. The consideration of family is friends as part of rehabilitation is only included following the express wishes of the person (see the section about Assessing rehabilitation needs and goal setting") or their advocates.
The Association of Clinical Psychologists UK	Guideline	General	General	The guideline emphasises a holistic assessment which is welcomed. However, ACP-UK feels that acknowledgement should be made that providing a holistic service that the person can be re-referred back to will enable continuity of care with a care team who is familiar with this patient and network. ACP-UK would like it emphasised that that any holistic assessment would be building on clinical knowledge obtained from previous assessments, and that there is good communication at all steps in the pathway to ensure that the patient is not put through any unnecessary assessments. These patients often undergo a lot of previous assessment, which should be acknowledged prior to deciding what further assessments are required.	Thank you for your comment. The guideline recognises that people might be accessing rehabilitation services for the first time or might be re-referred for changed rehabilitation needs. The early part of the accessing rehabilitation needs and goal setting section recognises that rehabilitation needs may first be identified when someone is in the community or when they are in an inpatient hospital setting. The section on rehabilitation planning and delivery includes recommendations about review and follow-up.
The Association of Clinical Psychologists UK	Guideline	General	General	ACP-UK comments that it is unclear why the guidelines do not cover congenital neurological conditions that would not be seen in other services, for example, congenital hydrocephalus, epilepsy from birth, birthing injuries that would not meet criteria for cerebral palsy or learning disability. People with congenital neurological conditions will need holistic assessments throughout their lives and are seen in neuro rehabilitation services. There should be equity of provision for those with congenital as well as acquired conditions.	Thank you for your comment. We have added clearer information to the overview section about the conditions, diseases, disorders and injuries covered and not covered by this guideline. The guideline does cover congenital disorders that result in long term chronic neurological disorders. Epilepsy is not covered because a NICE guideline already exists covering people with this condition
Epilepsy Action	Guideline	General	General	While the guideline encompasses a broad range of neurological disorders, it does not provide tailored rehabilitation approaches for epilepsy. Epilepsy patients often face challenges such as cognitive	Thank you for your comment. NICE already has published guidance on management of epilepsy, which can be found in NG217 Epilepsies in children, young people and adults. Therefore, the condition is out of scope

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				impairments, psychosocial issues, and physical limitations resulting from seizures or treatment side effects. Addressing these requires specialized rehabilitation strategies, which are not delineated in the current draft.	for this guideline and no change has been made. However, the committee were aware that epilepsy can be a symptom of many disorders that are covered by the guideline and included a cross-reference to these recommendations at the beginning of the document.
The Wolfson Neurorehabilitation Service	Guideline	General	General	Terms Used in the Guideline We suggest reviewing the definitions of "Initial contact" and "Key worker" to encompass a broader range of relevant professionals, such as speech and language therapists. Furthermore, we recommend that the guideline acknowledges the potential impact on direct therapy time if these roles are absorbed by existing practitioners, and considers highlighting the benefits of dedicated external roles, such as neuro-navigators, for comprehensive patient support across pathways.	Thank you for your comment. We have updated our glossary definitions in the terms used in this guideline for 'initial contact for rehabilitation', a 'lead practitioner for holistic assessment' and as a single point of contact for rehabilitation, covering key contact, key worker and complex case managers. Lists of practitioners who could perform these roles are also included. We are unable to go into detail about how much time these roles take up as this will vary enormously depending on the person and their needs. However, given that we have gone into some detail about the responsibilities and coordination role we would envisage these services being delivered by a range of dedicated practitioners (especially the complex case manager role) and practitioners who split their time between clinical and coordination/key worker duties.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	General	General	We recommend that ICF terminology is used consistently throughout the document in line with the Framework e.g. sections 1.8 & 1.19	Thank you for your comment. A definition for the term 'rehabilitation' had been added to the "Terms used in this guideline" section. This aligns the term with the ICF framework in all uses of 'rehabilitation' throughout the guideline.
Nottingham University Hospitals NHS Trust - National Rehabilitation Centre	Guideline	General	General	We believe the word 'vocation' should be used instead of 'work', to be more representative of this cohort of patients' needs e.g. vocational work, lifestyle occupations, stay at home parents and carers	Thank you for your comment. When we use the term 'work' in the guideline we mean employment, volunteering or self -employment. We have separate sections about social and leisure activities , family life and friendships.
The Neurological Alliance	Guideline	General	General	The Neurological Alliance welcomes the development of this guideline and appreciates its ambition to improve access to and outcomes from rehabilitation for people with neurological conditions. The Neurological Alliance undertakes 'My Neuro Survey' every two years. It provides a unique evidence base to understand unmet need and experience of care amongst people affected by neurological conditions in England. More than 10,000 responses were received from adults and children living with a neurological condition, together with those caring for the for the latest survey, undertaken between July and November 2024. The data, which will be published in June 2025, shows: - 6,197 responses were received from adults living with a neurological condition in England. 64% of those who felt they would benefit from inpatient neurorehabilitation had not been able to access it. 55% said the same about outpatient rehabilitation and pain services.	Thank you for your comment, for welcoming the guideline and thank you for sharing these figures with us.

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				33% of those who felt they would benefit from speech and language therapy had not been able to access it. 31% said the same about physiotherapy. 28% of adult respondents to My Neuro Survey agreed that they need specific support in order to retain employment. 21% agreed that they have had to leave a job because of my employers actions/inaction. - 251 responses were received from carers supporting a child living with a neurological condition in the UK. Of these, 84% of those who felt they would benefit from inpatient rehabilitation for their child had not been able to access it. 83% said the same about outpatient neurorehabilitation. 24% said this about speech and language therapy, 19% said this about physiotherapy. - 151 responses were received from children and young people living with a neurological condition across the UK. 74% said how they think and learn were impacted by living with a neurological condition. 61% said the same about how they move, and 61% also said their sleep and energy were impacted. 65% said their mood was impacted. In this context, we offer the following comments to strengthen the guideline's impact and implementation given the extent to which appropriate rehabilitation could help address the needs expressed in the survey.	
The Neurological Alliance	Guideline	General	General	**Rehabilitation Workforce Capacity** We strongly support the inclusion of recommendations that address workforce capacity and capability. The current shortages in the neurorehabilitation workforce are a significant barrier to delivering comprehensive, person-centred care. Current challenges include insufficient workforce and inadequate skill mix across settings which can be less responsive to needs to prevent admissions to secondary care. There are very low numbers of rehabilitation medicine consultants which have not increased in proportion with the growth in neurologists. Without concerted efforts to invest in and support the rehabilitation workforce—including Allied Health Professionals—the guideline's implementation risks being unachievable in practice. Notably, current NHSE provision for AHP training (£300 per person annually) falls significantly short of the £800 provided to doctors, which risks further compounding these inequities.	Thank you for your comment. The committee was aware of workforce capacity and recruitment issues, acknowledging these in their supporting discussions and full evidence reviews. They made several recommendations on service design to improve efficiency, potentially releasing resources, including staff and funds, for other uses which may include workforce capacity building. The committee also made recommendations on service specification with staffing implications. They hope their recommendations will be adopted and funded accordingly. We will also pass your comment to our implementation team.

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Rehabilitation for chronic neurological disorders including acquired brain injury

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The Neurological Alliance	Guideline	General	General	**Partnership with the VCSE Sector** We welcome recognition of the role of the voluntary, community and social enterprise (VCSE) sector. Charities and community organisations are often a key source of ongoing support, information and peer connection, particularly where statutory provision is limited. We encourage more explicit guidance on how services can integrate VCSE partners in care planning and delivery.	Thank you for your comment. We have now given greater emphasis to the role of voluntary, community and social enterprise organisations (VCSE) in the designing and commissioning rehabilitation services section and in building local capacity. We have also added some further detail to the section about agreeing, delivering and reviewing a coordinated rehabilitation plan emphasising the importance of interdisciplinary working and timely and joined-up delivery and the role of VCSEs in ongoing support and care.
The Neurological Alliance	Guideline	General	General	We recommend referencing the *National Neurosciences Advisory Group (NNAG) Optimal Pathway for Rehabilitation*, which provides an excellent evidence base to support local planning, service configuration and improvement. The pathway is supported by the British Society of Physical Rehabilitation Medicine (BSPRM), Royal College of Psychiatry Faculty of Neuropsychiatry, British Psychological Society (Division of Neuropsychology), Association of Chartered Physiotherapists in Neurology (ACPIN), Association of British Neurologists (ABN) and the Neurological Alliance. The pathway is available here: https://www.nnag.org.uk/optimal-clinical-pathway-adults-neurological-conditions-rehabilitation	Thank you for your comment and for sharing information about the National Neurosciences Advisory Group (NNAG) Optimal Pathway for Rehabilitation. NICE guidelines do not usually reference other good practice guideline in the context of their recommendations. We appreciate that the NNA group will be key to supporting the implementation of this guideline and we thank you for all the listed organisations have done in responding so helpfully and constructively to this consultation.
The Neurological Alliance	Guideline	General	General	We note a lack of clarity around how implementation of this guideline will be measured and benchmarked. Routine data on rehabilitation access and outcomes is limited, inconsistent and generally not publicly available. We urge NICE to recommend the inclusion of patient experience metrics—such as those derived from *My Neuro Survey*—as a valuable and essential data source.	Thank you for your comment. The implementation of this guideline will need to be led by NHS England and ICBs with input from professional bodies, and integrated care systems. NICE is not involved in funding decisions. The committee made recommendations on commissioning rehabilitation services and service specifications, and they hope these will be implemented, funded accordingly and the impact of the guidelines on patient care monitored through existing inspection and standards frameworks. NICE will be reviewing published quality standards to identify if they need to be updated in relation to this guideline.
The Neurological Alliance	Guideline	General	General	We recommend more explicit guidance on planning and delivering services for groups most affected by health inequalities—such as those experiencing homelessness, people with English as a second language, and individuals with limited digital access. We recognise these populations are reference in the Equality and Health Inequalities Assessment (EHIA) for the guideline. Rehabilitation services must be accessible and inclusive, with navigation support embedded in care models.	Thank you for your comment. We acknowledge that there are currently health inequalities associated with these groups. We have added in links to the NICE guideline: Integrated health and social care for people experiencing homelessness throughout. We have also added additional detail to some of the recommendations to give greater consideration to cultural factors when designing services and building local capacity and given greater emphasis to the role of voluntary, community and social enterprise organisations (VCSE) in this . We have also added a greater emphasis on practitioner proactive follow up and review and navigation support remains central to the recommendations with the role of a single point of contact and various forms that this may take depending on the needs of the individual which would include consideration of potential health

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					inequalities in ability to access services. . We also made some specific additions related to your comments such as in the cognitive function section where we have added the importance of considering the person's cultural, linguistic and educational background when deciding which assessment techniques to use.
Brainkind	Guideline	General	General	Some of the recommendations within this guideline can be delivered by any health or social care professional or other staff under their supervision, while others require discipline specific professional training. However, this is not always acknowledged or specified. The need for involvement of specific professionals should be included within recommendations or interventions that require specialist training (e.g. Clinical Psychologists or Clinical Neuropsychologists should carry out or oversee cognitive assessments, and lead on formulation around adapting interventions in the context of cognitive impairments or anxiety, low mood and lack of motivation. Occupational Therapists should oversee functional assessments, etc.).	Thank you for your comment. We have added some new recommendations throughout the section 'rehabilitation to maintain, improve and support function' to ensure that registered practitioners with expertise in that particular professional discipline, and with an understanding of the effects of the persons particular condition or injury should always oversee assessments and that particular element of the persons rehabilitation plan. So, for example, we have made particular reference to clinical psychologists and neuropsychologists in relation to the cognitive functioning element of the person's rehabilitation plan.
Brainkind	Guideline	General	General	We are concerned that the references to 'neurobehavioural approaches' within this guideline give the impression that these approaches are only indicated for those presenting with behaviours that challenge, when there are approaches of the neurobehavioural type (Cattelani, Zettin, & Zoccolotti, 2010) which would be recommended for a broader patient population, including those presenting with behaviours that challenge, but also those for whom the impact of their neurological condition on cognitive and emotional processing may affect their ability to engage in rehabilitation – even when not presenting with such behaviours.	Thank you for your comment. We agree that there may be a benefit for neurobehavioural approaches for populations outside those with behaviours that challenge. However, the recommendation is addressing a specific population with challenging behaviours and suggesting that neurobehavioural approaches such as positive behaviour support is an option that population. Therefore, no changes were made.
Brainkind	Guideline	General	General	The terms 'third sector' and 'voluntary sector' are used interchangeably, consider referring to 'third sector' only, or 'independent sector' as a broad range of rehabilitation services may be delivered both by not-for-profit and by voluntary organisations.	Thank you for your comment. We have been through the guideline and made the terminology consistent, referencing 'voluntary, community and social enterprise (VCSE)' throughout.
Brainkind	Guideline	General	General	There are several references to funding being available for a range of recommendations. However, this is not reflected in the experiences of many health and social practitioners and service providers, who find challenges in securing funding for rehabilitation. Could the recommendation go so far as suggesting that 'funding should be supported' if the relevant circumstances are met?	Thank you for your comment. However, NICE is not involved in funding decisions. The committee made recommendations on commissioning rehabilitation services and service specifications, and they hope these will be implemented and funded accordingly.
Royal College of Speech and Language Therapists	Guideline	General	General	The scope of this guideline is incredibly broad, encompassing a very wide range of disorders and the whole lifespan. It is useful that references to other more detailed NICE guidelines are included where relevant (e.g. for Parkinson's, stroke or motor neurone disease) but for conditions like functional neurological disorders this is not possible. For children and young people there are particular challenges: paediatric	Thank you for your comment. We have both amended existing recommendations and added recommendations specific to FND. The committee were also concerned about commissioning for neurorehabilitation for a paediatric population and wrote recommendations about this including a recommendation about what service specifications needed to cover in order to design pathways of care for children and young

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				rehabilitation is less well developed than adult rehabilitation, and children and young people have specific needs which may not be well addressed through generic rehabilitation. Recommendations have had to be very general and unfortunately the result is that this guideline is likely to have limited impact in terms of clinical decision-making and patient care.	people. They recommended the importance of agreeing locally (via the ICB)who has overall designated responsibility for implementing clinical pathways for children, and, separately, for adults, taking into account local and national commissioning responsibilities The committee also agreed it was important to ensure there are separate clear local service level agreements in place for the provision of mental health services as part of rehabilitation for adults, and separately for children and young people, with a chronic neurological disorder. One of the aims of the guidelines was to ensure that more people with chronic neurological disorders were able to access rehabilitation services than currently are able - due to pathways of care being often very condition based - with some people never being offered rehabilitation, whilst others routinely offered services. In this respect we hope the guideline will succeed, but acknowledge that better clinical guidance if still needed for many conditions to support this.
Royal College of Speech and Language Therapists	Guideline	General	General	Throughout this guideline there is a separation of different areas of difficulty, in particular between cognition and communication, which does not account for the complex interplay between different sequela. Cognitive communication disorder (CCD) is highly prevalent in this patient group and has significant impact on functional outcomes and engagement with services. It is important that the guideline appropriately acknowledges the need for coordinated, interdisciplinary assessment and planning of rehabilitation, to ensure that patients receive appropriate support. See: Bayley, M. T et al (2023) INCOG 2.0 Guidelines for Cognitive Rehabilitation Following Traumatic Brain Injury: Methods, Overview, and Principles *Journal of Head Trauma Rehabilitation* 38(1):p 7-23 https://doi.org/10.1097/HTR.0000000000000083	Thank you for your comment. The committee agreed and have added a specific recommendation to assess and plan a rehabilitation plan with speech and language therapy if a cognitive communication order is suspected.
Cambridge University Hospital NHS Foundation Trust	Guideline	General	General	Thank you for all the work on this guideline. We need the service specification to be updated in order for commissioners to make this possible.	Thank you for your comment and your appreciation of the guideline. The committee made recommendations about commissioning rehabilitation services and service specifications, and they hope these will be implemented and funded accordingly. NICE is not involved in funding decisions.
Central London and Community Healthcare Trust	Guideline	General	General	There is considerable weight and evidence given to taking a holistic approach to rehabilitation in chronic neurological disorder, especially within the field of neuropsychological rehabilitation. Would the committee consider revisiting other guidelines which make reference to this e.g. Scotland SIGN guidelines (2013) as well as re-visiting evidence such as that reviewed by Cicerone? I can see that these were excluded	Thank you for your comment. Unfortunately, there is not enough detail provided in your comment for us to locate the studies that you are referencing. However, if certain papers were excluded as not meeting the inclusion criteria for our evidence reviews, we are not able to include them post hoc. This would introduce selection bias into our methodology and undermine the rigour of the guideline. Therefore, no change has been

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				studies, however in practice, taking a holistic approach and working together in rehabilitation with an MDT approach is considered good practice.	made. However, as you mention, a holistic approach to rehabilitation for chronic neurological disorders is considered best practise and the committee have made sure to highlight it throughout the guideline. Recommendations in the designing and commissioning rehabilitation services section stress that services should be co-designed with everyone involved in rehabilitation (including a range of services and practitioners), as well operating access all settings and sectors. The minimum services specifications set out in this guideline include a wide variety of rehabilitation services to provide integrated rehabilitation care. The comprehensive section on what to cover in a holistic rehabilitation needs assessments highlights the need to not only consider multiple rehabilitation domains, but also the background of the individual and how this will impact rehabilitation planning and delivery. The committee have also ensured that this biopsychosocial approach is carried through to the resulting rehabilitation plan. Finally, there are several recommendations that stress the need for collaboration and communication between professionals (both within rehabilitation services and with wider organisations involved in a person's day-to-day activities) in order to increase the efficiency of service provision.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	General	General	We agree that many of the recommendations throughout the document are excellent, and essential to the paediatric population, however in most cases it is unclear who is able to provide this support as paediatric commissioning does not support these roles – upcoming service specification should highlight this and include recommendations to commissioners for developing rehab teams that deliver this across all CYP development as the brain injury evolves.	Thank you for your comment. The committee were also concerned about commissioning for neurorehabilitation for a paediatric population and wrote recommendations about this including a recommendation about what service specifications needed to cover in order to design pathways of care for children, young people and adults with chronic neurological disorders. They recommended the importance of agreeing locally (via the ICB)who has overall designated responsibility for implementing clinical pathways for children, and, separately, for adults, taking into account local and national commissioning responsibilities The committee also agreed it was important to ensure there are separate clear local service level agreements in place for the provision of mental health services as part of rehabilitation for adults, and separately for children and young people, with a chronic neurological disorder. We hope that commissioners will use this guideline in the future. However, NICE is not involved in funding decisions.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	General	General	There is an absence of documentation of the core team structure – some essential team members are omitted such as neuropsychology. There are specific assessments that need to be completed which should be performed by specific registered trained professionals with expertise in these areas e.g. dysphagia assessment by SLT, neurocognitive assessment by neuropsychology.	Thank you for your comment. We have added some new recommendations throughout the section 'rehabilitation to maintain, improve and support function' to ensure that registered practitioners with expertise in that particular professional discipline, and with an understanding of the effects of the persons particular condition or injury should always oversee assessments and that particular element of the persons rehabilitation plan.

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					So, for example, we have made particular reference to clinical psychologists and neuropsychologists in relation to the cognitive functioning element of the person's rehabilitation plan. We have also added in reference to a neuropsychological assessment in both the emotional health and wellbeing and cognitive functioning sections. With regards dysphagia assessment we have added reference to a registered practitioner (e.g. a speech and language therapist) We have also included a definition for the term rehabilitation practitioner within the 'terms used in this guideline' and have amended throughout to be clear and consistent when we are referring to health, mental health and social care practitioners. However it is also acknowledged that some people contributing to rehabilitation may not be registered health, mental health or social care practitioners, for example those working in health or fitness at local sports clubs and teachers.
Nottingham University Hospitals Department of Clinical Psychology and Neuropsychology	Guideline	General	General	We welcome the research recommendations recognising the lack of evidence for rehab interventions for CYP. Funding pathways need to be considered to enable evidence to be collated.	Thank you for your support for this research recommendation.
NHS England	Guideline	General	General	No comments to make on the recommendations from a primary care perspective.	Thank you for your comment.
NHS England	Guideline	General	General	This is an important topic, but the difficulty will be in implementing as current rehabilitation models are fragmented and the patient will often present to primary care for advice or medication decisions that would better be answered by the specialist MDTs.	Thank you for your comment. There was only limited qualitative evidence on multidisciplinary teams. The committee noted that such teams aren't feasible in and across all settings and recommending them would represent a major change in practice with significant resource impact. Instead, they recommended developing a personalised, coordinated rehabilitation plan with input from relevant practitioners (which may of course amount to a flexible MDT approach). Recommendations on service design and a single point of contact also aim to support more joined-up, coordinated care. We hope this addresses your concerns.
NHS England	Guideline	General	General	While it is recommended in page 15 line 22 and page 51 line 21 to ask the person about spiritual and religious practices, the draft doesn't mention about how to access someone with expertise in these practices. These patients may rely on a faith-based resilience system to cope with the condition.	Thank you for your comment. The committee felt that it was beyond the possible scope of the guideline to go into that level of detail above accessing people with the skills needed to implement the recommendations. However, we have added additional detail to some of the recommendations to give greater consideration to cultural factors when designing services and building local capacity and given greater emphasis to the role of voluntary, community and social enterprise organisations (VCSE) in this. We have also made some specific additions, such as in the cognitive function section, where we have added the importance of

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					considering the person's cultural, linguistic and educational background when deciding which assessment techniques to use.
Association of Chartered Physiotherapists in Neurology	Guideline	General	General	Good that the draft guidelines recognise the complexity of the chronic neurological population and the need for rehabilitation interventions to be tailored to their individual needs. The current evidence base does not support any one intervention over another. The key finding is the individualised approach needed to develop targeted opportunities for successful task practice. This can only be delivered with clear rehabilitation pathways and highly trained staff able to use advanced clinical reasoning skills to set up these treatment programs using adjuncts such as, suitable technology and exercise programmes, alongside facilitated therapy input to augment the patients opportunities for rehabilitation.	Thank you for your comment.
British Society of Physical and Rehabilitation Medicine	Guideline	General	General	The scope should explicitly define "chronic" (e.g., >6 months post-injury for ABI) to avoid ambiguity in service eligibility.	Thank you for your comment. Due to the range of diseases, disorders and injuries covered by the guideline it has not been possible to offer guidance on the definition of chronic, as used in this guideline so this will need to be left to local service eligibility arrangements. There is also the issue that the guideline indicates rehabilitation should not be delayed when diagnosis is uncertain, but should be offered on the basis of symptoms. We realise this may lead to some ambiguity regarding service eligibility which we hope implementation over time will iron out, as guidance criteria emerges.
British Society of Physical and Rehabilitation Medicine	Guideline	General	General	Mention the differentiation between static (e.g., cerebral palsy), progressive (e.g., MND), and recovering (e.g., TBI) conditions which require distinct rehab approaches.	Thank you for your comment. As a general rule, the committee have designed their recommendations to be applicable throughout the entire guideline population. There are certain areas of rehabilitation where the committee have agreed that sub-populations (for example, people with functional neurological disorder or people with difficulties with executive function) will benefit from additional guidance. The beginning of these recommendations clearly state who they are aimed at.
University College London Hospital	Guideline	N/A	N/A	The role of the palliative care consultant and teams should be mentioned in this document. Even in cases where patients are not imminently dying but have a life-limiting condition, these teams can play important roles in managing the symptoms of our patients.	Thank you for your comment. The committee acknowledge the important role palliative care can have for people with chronic neurological disorders. However, as noted in the scope, end of life care was never due to be covered in this guideline. Therefore, no changes have been made.
PTSD UK	Guideline	PTSD UK	025	We appreciate the committee's recognition that emotional health is often overlooked in rehabilitation. We would like to highlight that traumatic brain injuries (including concussions) can act as both a physical and psychological trauma, significantly increasing the risk of PTSD. Given the overlap in symptoms between PTSD and post-concussion syndrome, it's vital that practitioners are trained to recognise the differences and screen appropriately.	Thank you for your comment. Given the symptom overlap between mental health conditions and chronic neurological disorders, we agree that screening for mental health conditions is important in chronic neurological disorders. Therefore, we have therefore added "screen for" to the recommendation on treating diagnosed post-traumatic stress disorder, anxiety and depression in adults with chronic neurological disorders, and depression in children and young people with a chronic neurological disorder, as part of their rehabilitation.

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Epilepsy Action	Guidelines	007	024	Interventions should also include managing side-effects of medication. Some anti-seizure medications can have severe side-effects, including on mental health and cognitive function, which need to be taken into account when considering potential interventions.	Thank you for your comment. This recommendation is drafted as a high-level list of minimum service specifications, as well as serving to link different sections of the guideline. Any presenting side-effects of medications will be covered by the existing bulletpoints (including mental health and cognitive function). Therefore, no change has been made.
Epilepsy Action	Guidelines	008	019	GPs lack knowledge of epilepsy and would need extra training and support to identify and recognise emerging rehabilitation needs of patients with epilepsy.	Thank you for your comment. NICE already has published guidance on management of epilepsy, which can be found in NG217 Epilepsies in children, young people and adults. Therefore, the condition is out of scope for this guideline and no change has been made.
Huntington's Disease Association	Guidelines	008	024	After recommendation 1.3.4 add - Ensure that Community Mental Health Teams (CMHTs) are aware that debilitating mental health and cognitive symptoms are a common feature of some chronic neurological conditions (such as Huntington's disease). Develop clear pathways with CMHTs on how people with chronic neurological conditions who are experiencing severe mental illness can access their services.	Thank you for your comment. The committee were very aware of the increased risk of mental health needs in this guideline population. The provision of mental health services for people with chronic neurological disorders is already covered in a preceding recommendation that on ensuring local service level agreements for the mental health needs of this population. Additionally, we have recommended increasing capacity for these mental health services by developing local workforce skills, which would include the knowledge of how chronic neurological disorders can present to mental health services. As a final safeguard for this vulnerable population, the committee have now included people with complex mental health needs as a criteria for when to consider appointing a complex case manager to help coordinate rehabilitation care across multiple services (including mental health services). Therefore, no changes have been made.
Epilepsy Action	Guidelines	012	001	Guidance here should include signposting to voluntary sector organisations and patient groups, who would be able to provide support to new diagnosed individuals	Thank you for your comment. This section is purely about early discussions between rehabilitation professionals and people with chronic neurological disorders about their likely prognosis and their potential rehabilitation needs. Signposting to voluntary organisations and local support groups, at any stage of the rehabilitation journey, is covered in the section on information, advice and learning as part of rehabilitation.
Epilepsy Action	Guidelines	034	018	MND and MS are specified here, but mental health issues such as anxiety and depression are also prevalent among people with epilepsy and should also be referenced here.	Thank you for your comment. Conditions for which NICE rehabilitation and rehabilitation related recommendations already exist e.g. Epilepsy were excluded from the guideline, therefore is not referenced in the recommendations.
Epilepsy Action	Guidelines	036	010	Anti-seizure medications can also affect mental health, include suggestion to review medication	Thank you for your comment. We agree that it is important to review the person's medication as part of rehabilitation, we already have a recommendation under holistic rehabilitation needs assessment to consider the possible impact of any existing medication on impairment and review as part of rehabilitation planning.
Central London and Community Healthcare Trust	Guidelines	037	General	1.19.1 Would the committee consider more explicitly acknowledging the utility of provision of helping the wider systems (e.g. family, carers, other health professionals, employers, educators) to understand people with chronic neurological disorders' cognitive strengths and challenges in	Thank you for your comment and suggestion. We have added more detail in the benefits and harm section of the evidence review for cognitive function (review G) to highlight the importance of provision of helping the wider system.

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				order to support adjustment through developing realistic expectations beyond the individual and into those wider systems?	
Epilepsy Action	Guidelines	038	014	Side-effects of anti-seizure medication should also be taken into account as part of the assessment	Thank you for your comment. We agree that it is important to review the person's medication as part of rehabilitation, we already have a recommendation under holistic rehabilitation needs assessment to consider the possible impact of any existing medication on impairment and review as part of rehabilitation planning.
Epilepsy Action	Guidelines	039	002	Cognitive impairment is a prevalent and important feature of epilepsy there is a potential worsening of cognition with the use of many standard antiepileptic drugs (AEDs), countered by the possibility of greater levels of decline observed in those with poorly controlled seizures	Thank you for your comment and concern. Unfortunately, epilepsy is out of scope for this guideline, no evidence was reviewed and therefore no recommendations have been made on this topic.
Epilepsy Action	Guidelines	049	019	Explaining adjustments and adaptations needed for people with epilepsy to access a venue or activity is likely to include the need for awareness and first aid training	Thank you for your comment and concern. Unfortunately, epilepsy is out of scope for this guideline, no evidence was reviewed and therefore no recommendations have been made on this topic.
Epilepsy Action	Guidelines	General	General	Despite intentions for universal applicability, there are still concerns about implementation in underserved areas. The document recognizes variation in service availability but offers limited concrete solutions for ensuring equitable access across different regions. We would recommend incorporating telehealth models and mobile diagnostic services to support rural or underserved populations.	Thank you for your comment. We have now added telehealth as a potential mode of delivery to increase access to specialist neurorehabilitation services in areas where availability is restricted. We have also included it as an example of how to deliver rehabilitation in preferred settings. Regarding your second suggestion of mobile diagnostic services, diagnosis is out of scope for this guideline. Therefore, no changes have been made.
Epilepsy Action	Guidelines	General	General	Although multidisciplinary care is recommended, there's limited practical guidance on how to coordinate between neurologists, primary care, mental health services, and social care — especially in resource-constrained settings. We would recommend using shared digital care plans accessible by neurology, mental health, primary care, and social services.	Thank you for your comment. We agree and have included a section on agreeing and delivering a coordinated rehabilitation plan. We also made recommendations on service design to support more joined-up working. The committee further recommended a single point of contact to facilitate coordinated care across services.
Epilepsy Action	Guidelines	General	General	There's little mention of leveraging technology (apps, wearables, digital diaries) that could empower patients and support clinicians with real-time data. Digital tools improve patient engagement, enable real-time data capture, and support remote care models. We would recommend promoting use of seizure-tracking apps, wearable devices, and remote monitoring tools as part of self-management. And evaluating apps for inclusion in NHS-approved digital health libraries.	Thank you for your comment. Evidence review D (Personal care and daily activities) covered interventions, equipment and devices to support function and adapt the environment, including technology and wearables. Limited low or very low quality evidence showed little or no effect and was insufficient to support recommendations. Assistive technology for prospective memory impairment was included in evidence review G on cognitive rehabilitation and informed related recommendations on compensatory aids.
Epilepsy Action	Guidelines	General	General	While patient care is central, specific guidance for supporting families and carers — especially those managing children with epilepsy or severe intellectual disabilities — could be expanded.	Thank you for your comment. The committee acknowledge the central role families and carers take in supporting people with a chronic neurological disorder. Unfortunately, making recommendations for people who do not have a chronic neurological disorder is beyond the scope of this guideline.

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					Therefore, no changes have been made. However, we have expanded several recommendations to include families and carers where appropriate. One of these is information on voluntary, community, and social enterprise organisations who may be able to provide further information and support. The committee anticipate that this will include organisations that can also support carers in their roles. Additionally, NICE already has published guidance on how to support carers (NG150 Supporting adult carers), which has been clearly referenced at the beginning of each guideline section.
Epilepsy Action	Guidelines	General	General	Epilepsy care often intersects with cultural beliefs and stigma. Cultural beliefs and socioeconomic factors can influence epilepsy management and rehabilitation adherence. The guideline does not explore these aspects, which are important for developing personalised and effective rehabilitation plans. The updated guidelines would benefit from explicit strategies to improve culturally sensitive care.	Thank you for your comment. The committee were aware of the delicate interplay between cultural beliefs and rehabilitation for chronic neurological disorders. They have made several recommendations to consider the impact a person's cultural background may have on their rehabilitation planning and delivery. Identifying a person's meaningful activities, spiritual and religious practices is highlighted in the 'What to cover' section of the holistic rehabilitation needs assessment, with the aim of using this to inform and build their rehabilitation plan. Similarly, discussing potential barriers that culture may present to engaging in rehabilitation is recommended in the section on physical activity and exercise, and intimate or sexual relationships, and sex. These were areas that the guideline committee believed that cultural beliefs could have a big impact on engagement with rehabilitation. Since consultation, we have also added the need to consider cultural factors to the sections on cognitive rehabilitation and social participation. Finally, the committee have asked commissioners to take cultural factors into account when funding community social and leisure group activities.
Epilepsy Action	Guidelines	General	General	Provide clinicians with decision aids or summary guides about fitness-to-drive laws, employment rights, and workplace adjustments.	Thank you for your comment. Unfortunately, provision of decision aids and summary guides is beyond the remit of this guideline. Implementation of recommendations (including how to provide education for rehabilitation practitioners) will be at the discretion of individual local authorities, as needs will vary region by region. Therefore, no changes have been made.
EMDR UK	Methods	008	006	Supplement 2 (Economics) appears to be missing.	Thank you for spotting this. The missing appendix detailed the search strategy for economic studies, included a PRISMA diagram and listed excluded economic studies with reasons for exclusion. However, all existing studies were summarised and discussed within individual evidence reviews. We will ensure all supporting documents are included with the final guideline document.
Anglia Ruskin University	Methods	General	General	The search strategy did not appear to include "music therapy". I would suggest including search terms involving "art therapy", "music therapy", "music interventions", "interdisciplinary team working "and "family	Thank you for your suggestion. The evidence review in which 'creative therapies' was an intervention was review H, about interventions for improving emotional health and wellbeing. The search strategy, which can

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				involvement" when considering approaches to assessment and treatment for this population. The arts therapies (music therapy, art therapy and dramatherapy) are holistic interventions that can address functional, social, emotional and psychological needs of people with chronic neurological disorders.	be found in appendix B of the report, specifically includes music - and other creative therapies, '((art* or drama* or dance* or music* or play*) adj3 (therapy* or intervention?)).ti,ab.'
Recolo UK	Standard Comment Form Questions	N/A	N/A	1. Would it be challenging to implement of any of the draft recommendations? Please say why and for whom. Please include any suggestions that could help users overcome these challenges (for example, existing practical resources or national initiatives. 2. Would implementation of any of the draft recommendations have significant cost implications? Recolo delivers psychological rehabilitation to children with acquired brain injury and their families and the wider system, e.g. education settings, who have a medical negligence (usually birth injury) or personal injury claim. Working in this sector gives us a unique privilege to frequently deliver a full package of intervention inclusive of the recommendations in the draft guidelines and for the period that a young person and their family and the wider team supporting them requires it. Rehabilitation includes individual therapeutic work with children and young people and young adults, support to parents and siblings, and input into the education and community setting. As such for us in our setting, it would not be a challenge to implement the draft recommendations.	Thank you for sharing your experience. We hope this guidance will enable NHS services to support people and their families as you describe.
Royal College of Speech and Language Therapists	Standard Comment Form Questions	N/A	N/A	**Would it be challenging to implement of any of the draft recommendations? Please include any suggestions that could help users overcome these challenges** • The RCSLT suggests that the guideline itself and communications around it need to be very clear about what is and isn't covered by the guideline. There is a risk of confusion around the reach of this guideline, which will impact on its implementation. For instance, it was only clear to RCSLT that children who have had a stroke were covered by the guideline following specific communication with NICE. There is also overlap with a large number of other guidelines.	Thank you for your comment and for your offer to help implement the guideline. We have now included clearer information at the front of the guideline about all the diseases, disorders and injuries that are and are not covered by this guideline. We have also included clearer information about the areas of care that are covered by other guidelines that these recommendations should be read in conjunction with , such as early management and early rehabilitation for traumatic injuries to the brain and spine. The committee was very aware of resource constraints, implementation challenges, and variation in practice. The committee made recommendations on commissioning rehabilitation

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				The RCSLT would be happy to work with NICE to share clear and direct communications with our members, as well as with other allied health professional bodies. This will help to ensure better understanding and successful implementation. • The RCSLT welcomes many of the recommendations in this guideline, however the reality of community rehabilitation services in the UK may make them challenging to implement, without further action. Access to and availability of rehabilitation specialists, such as allied health professionals, along with the intensity of therapy, varies in community services. Clear pathways must be funded, with specialist speech and language therapy input as part of interdisciplinary assessment and management. We hope that this guideline will help facilitate the development of such pathways and support the delivery of high-quality, person-centred rehabilitation in the community. • Implementation of recommendation 1.20.8 requires particular consideration: o The voice banking process involves complex and emotionally sensitive discussions about future communication loss and end-of-life planning. Speech and language therapists are best placed to conduct sensitive conversations and support around voice banking, but they need adequate time, training, and resources. o There is no coordinated pathway for voice banking and provision varies. The rationale and impact section of the guideline acknowledges that voice banking services are usually self-funded or covered by personal independence payments (this is also often via charity support). This creates a system dependent on personal situation which deepens existing inequalities. To ensure equity for service users, there need to be clear, centralised and funded pathways for voice banking, storage and retrieval.	services and service specifications, and they hope these will be implemented and funded accordingly. The recommendation on voice banking was included in a way that provides options for how this is funded and as you say it was acknowledged by the committee that this is a service that is often self-funded. The committee simply wanted practitioners to make people aware that the technology was there to do this, which is why the recommendation reads 'early referral for ' rather than 'offer'. Offering this to everyone would have had serious resource implications which we did not have the economic evidence to justify.

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Royal College of Speech and Language Therapists	Standard Comment Form Questions	N/A	N/A	**Would implementation of any of the draft recommendations have significant cost implications?** • As noted on p95 of the guideline, speech, language and communication is often overlooked and there is potential for these recommendations to improve identification and increase demand for speech and language therapy. As part of investment in a national specialised neurological workforce, it is crucial to invest in and fund speech and language therapy within community services to meet this growing demand. • As also noted on p95, however, costs of increased funding of speech and language therapy to support communication may have cost-savings in other parts of the system, such as better engagement with other services. • Similarly, increased funding of speech and language therapy input related to eating, drinking and swallowing can also create savings, for example in reducing risk of pneumonia, malnutrition and hospitalisation. See: o Kondwani, J. B. e t al (2022) Prevalence of Oropharyngeal Dysphagia and Risk of Pneumonia, Malnutrition, and Mortality in Adults Aged 60 Years and Older: A Meta-Analysis. *Gerontology* 68 (8): 841–853. https://doi.org/10.1159/000520326 o Marin S, Ortega O, Serra-Prat M, Valls E, Pérez-Cordón L, Clavé P. Economic Evaluation of Clinical, Nutritional and Rehabilitation Interventions on Oropharyngeal Dysphagia after Stroke: A Systematic Review. *Nutrients*. 2023; 15(7):1714. https://doi.org/10.3390/nu15071714 • Recommendation 1.20.8 recommends referral to voice banking but the rationale and impact section of the guideline acknowledges that these services are usually self-funded or covered by personal independence payments (this is also often via charity support). Inclusion in the NICE guideline needs to be accompanied by appropriate funding and infrastructure to support consistent implementation and reduce inequality.	Thank you for your response. We agree that the recommendations need appropriate funding and infrastructure to ensure implementation and reduce inequality. However, NICE is not involved in funding decisions. The committee hopes their recommendations will be adopted, resourced and funded accordingly. Due to the lack of eligible effectiveness and economic evidence, potential cost savings are based on the committee's expert opinion. While hospital admissions are mentioned, outcomes such as pneumonia and malnutrition are outside the review protocol and would be inappropriate to include.
Independent Neurorehabilitation Providers Alliance	Standard Comment Form Questions	N/A	N/A	**Question 1:** The guidelines for "Rehabilitation for chronic neurological disorders including acquired brain injury is a positive step towards improving services nationally for those with a chronic neurological condition. The guide emphasises the need for coordinated,	Thank you for your response. We agree that current services need improvement and have made recommendations to facilitate more joined-up working. The committee

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				multidisciplinary rehabilitation services across various settings which will require significant collaboration amongst all sectors concerned i.e. healthcare, social care, private sector and voluntary sector. This will be complex especially when existing services are fragmented. This can only be achieved if national and regional plans are developed with step-by-step guidance on implementing these recommendations. Consider the NNAG rehab optimal pathway as an evidence base to plan services. Tools should be provided to commissioners to enable them to plan these services effectively. There is already a shortage of neurologists and neurorehabilitation professionals. If need for services is to be increased or offered in a variety of settings including domiciliary and work environments then these staff shortages have to be addressed in the short to medium term. This includes recruiting more trainees as well as offering training and career progression for those already in the service. The guidance suggests using a mix of general and neuro rehabilitation services but training will still have to be provided to the general workforce if they are to treat patients effectively. Training could be done remotely via digital means. It should also be noted that there is a huge number of neurological diagnoses and training/information must be made available to professionals who may be asked to provide rehabilitation to a condition they have not come across before. They can only provide effective rehabilitation and support the person if they understand the progression of the disease. The guidance recommends drawing on all sectors to provide a coordinated and complete service to patients but many commissioners and professionals are unaware of exactly what services and support mechanisms are available in their area or nationally. A comprehensive database needs to be created which lists all of these so that those providing support can easily signpost the person to the best service to address their needs. Once created, this database must be maintained if it is to be effective. It should be noted also that many of the support organisations are charities, many of which are experiencing financial difficulty and therefore they may have limited resources to produce information or have staff to support patients or other professionals. In order to provide a seamless and coordinated service, digital record keeping will have to be reviewed and steps taken to enable sharing of notes and information electronically between all sectors which is not available at the moment.	hopes their recommendations will be adopted, and appropriate national and regional plans developed to support implementation. We acknowledge the challenges services are facing throughout the guidance and supporting discussions. We recommend that care for a person is overseen by someone with knowledge of their specific condition, which may have staff training implications. Given the broad scope of the guideline, we cannot be overly prescriptive about specific practices but can outline general principles for effective service specification and care. We will also pass your comment to our implementation team to see how they could best support the implementation of this guidance, considering the current challenges faced by rehabilitation and other support services.

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				Using outcome measures and benchmarking tools would help providers determine efficacy and implement improvements once the guidelines have been implemented. If the service is to be equitable across the country, then mechanisms for sharing best practice should be developed and encouraged.	
Independent Neurorehabilitation Providers Alliance	Standard Comment Form Questions	N/A	N/A	**Question 2:** There will be greater cost implications in the short to medium term if the vision of providing equitable timely access to specialist and generalist rehabilitation is to be achieved. We do not feel that the current workforce could meet the actual need if all those with a chronic condition were actually referred to these services. Many of those with a diagnosis already have lengthy waiting times for a rehabilitation appointment. The guidance recommends input at an earlier stage and for longer periods with easy access back to the service as their condition changes which can only add to the workload of already stretched services. Longer term service provision increases cumulative costs and individualised flexible service delivery models can be resource intensive. Additional funds must be made available to recruit, train and maintain the skills of those working in rehabilitation. The guidelines recommend seamless transition between services and continuous support over time and recommends the implementation of key workers or complex case managers. The role of key worker can be time consuming and if undertaken by a current member of staff can take them away from seeing other patients. This potential demand on resources should be recognised and resources in terms of staff numbers allocated to ensure this role can be undertaken effectively and consistently across all regions. Additional costs may also possibly be incurred by joint commissioning structures and administrative support. Development and implementation of shared digital records will incur costs as there are currently many systems being used across different sectors which do not communicate with each other. These need to be reviewed and aligned. There will be cost implications in developing and maintaining data collection systems to systematically evaluate outcomes and service effectiveness. In addition there could be further cost implications in terms of staff time for audit, reporting and participation in quality improvement programmes.	Thank you for your response. The committee discussed current services being siloed and disjointed, with a lack of communication resulting in duplication, delays in assessments and care, and reliance on expensive inpatient and crisis care. The committee acknowledged the potential resource impact but noted that the recommended service design and reconfiguration should represent a cost-effective use of NHS resources. Regarding the single point of contact, the committee was aware that staff within services already fulfil the roles of key contact and key worker. Their recommendations imply officially nominating this person as a single point of contact and communicating this to individuals with chronic neurological disorders. The committee acknowledged the potential lack of complex case managers within the NHS and discussed the resource implications, but also noted the benefits, including potentially reducing expensive A&E visits and hospital admissions. These issues, including potential cost-effectiveness arguments, are presented in supporting evidence review I on clinical case management and evidence review A on rehabilitation delivery, summarised in the committee's discussion of the evidence sections. Many points you outline are also acknowledged in the service design rationales and impact sections and supporting evidence reviews. Unfortunately, NICE is not involved in funding decisions, but we made several recommendations on service design and specification, and the committee hopes these will be implemented and appropriately funded. We will also pass your comment to the implementation team.
Midlands and South Essex ICB	Standard Comment	N/A	N/A	**1.Would it be challenging to implement of any of the draft recommendations? Please say why and for whom. Please include**	Thank your response. We agree that current services need improvement and have made recommendations to facilitate more joined-up working. The

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	Form Questions			**any suggestions that could help users overcome these challenges (for example, existing practical resources or national initiatives.** It is likely to be challenging to implement some of the recommendations as outlined above as will need additional resource, likely from workforce groups (such as OT, SLT, Neuropsychology) that are currently under resourced and also have a limited pipeline. It may be possible to explore the role that advanced assistants may be able to have in the provision of rehabilitation services. ICBs in their current function may need further higher quality evidence to implement some of the recommendations (e.g. around CCM) as the cost effectiveness is not yet established. It may also be challenging to implement within current resource the recommendations around family life, intimate and sexual relationships as will require additional training and resource to support current workforce in confidence.	committee hopes their recommendations will be adopted and appropriate national and regional plans developed to support implementation. We acknowledge the challenges services are facing throughout the guidance and supporting discussions. We recommend that care for a person is overseen by someone with knowledge of their specific condition, which may have staff training implications. Given the broad scope of the guideline, we cannot be overly prescriptive about specific practices but can only outline general principles for effective service specification and care.
Midlands and South Essex ICB	Standard Comment Form Questions	N/A	N/A	**2.Would implementation of any of the draft recommendations have significant cost implications?** We believe that the implementation of a key contact for all of those with chronic neurological conditions and associated rehabilitation needs who would manage the full pathway will have a significant cost implication and whilst it will improve experience of the pathway it is unlikely to realise a cost benefit. Individuals would likely be better served by a key contact across different parts of the pathway. Primary care – acute – inpatient rehab services – community services – social care who can link together as part of system wide working. Services that are time limited are currently the norm. Implementing guidelines which suggest open access is likely to require further investment in services to meet demand.	Thank you for your comment. The committee discussed the complexity of services, issues with timely re-access and the challenges faced by people with chronic neurological disorders who often have impaired executive functioning and can not navigate services themselves. They considered your suggestion and agreed that the most feasible approach would be to have one designated practitioner. This individual would serve as a single point of contact to streamline communication and coordination of care across all services, as needed. The committee noted that there are already individuals within services acting as key contacts and key workers. However, this recommendation would require officially nominating this person and communicating their role to individuals with chronic neurological disorders. We acknowledge that there may be some resource implications, particularly in relation to the complex case manager role. The committee made recommendations on service design and specification to facilitate access to a single point of contact, ensuring ongoing access, re-access and self-referral. They also highlighted many benefits that could offset any additional costs, including less reliance on expensive crisis care, reduced duplication and less pressure on GPs. The committee hopes their recommendations will be adopted, resourced and funded accordingly. We will also pass your comment to our implementation team.

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Midlands and South Essex ICB	Standard Comment Form Questions	N/A	N/A	**3.Any specific questions about the recommendations from the Developer, or delete if not needed** There is limited information within the guideline about specialist commissioned pathways (e.g. neuropsychiatry) which are currently not sufficient to meet the needs of individuals with complex neuropsychiatric needs. This is a big gap and will be required to change commissioning patterns currently in place to support this cohort of patients. Is there a further separate guidance expected around this? Has the role of community and voluntary sector partners been considered in the implementation of the guidelines?	We will also pass your comment to the NICE implementation team to see how they could best support the implementation of this guidance, considering the current challenges faced by rehabilitation and other support services.
SmellTaste: Support, Education, Research	Guideline	General	General	**Submission Focus: The overlooked impact of smell and taste impairment on health and wellbeing** As the only charity representing those living with impaired smell and taste, SmellTaste welcomes the opportunity to contribute to the consultation on the draft NICE guideline on rehabilitation for people with chronic neurological disorders, including acquired brain injury (ABI). We would like to highlight the significant, yet frequently under-recognised and overlooked impact that smell and taste impairment has on people experiencing these issues, and why it needs to be accounted for in neurological rehabilitation.	Thank you for your comment. Interventions regarding smell and taste were not covered by the guideline scope and no evidence was sought in these areas. We will therefore consider your comments when the guideline is next updated.
SmellTaste: Support, Education, Research	Guideline	General	General	**High prevalence in neurological conditions but a lack of recognition** Loss of (and sometimes distortions of) smell and sometimes taste is common in people with ABI and is a factor in other neurological conditions, such as Parkinson's disease, multiple sclerosis, and post-infectious or traumatic brain injuries. However, these sensory deficits are frequently under-recognised, under-assessed (if assessed at all) and because of this those affected do not get support or care in relation to this within the current rehabilitation pathways. Additionally, those affected (and their carers) often fail to realise they have a problem with their sense of smell/taste and often don't appreciate how this affects aspects of their life, i.e. safety vulnerabilities, enjoyment of food, mental	Thank you for your comment. Interventions regarding smell and taste were not covered by the guideline scope and no evidence was sought in these areas. We will therefore consider your comments when the guideline is next updated.

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				health etc due to a lack of education, knowledge and routine testing of the sense of smell.	
SmellTaste: Support, Education, Research	Guideline	General	General	**The importance of smell and taste to our lives** The ability to smell and taste is essential to our daily lives, health and wellbeing. Smell provides an important emotional connection to the world around us and those in it, helping us form memories of places and people, enjoy food and drink, pleasurable smells and also warning us of dangers.	Thank you for your comment. Interventions regarding smell and taste were not covered by the guideline scope and no evidence was sought in these areas. We will therefore consider your comments when the guideline is next updated.
SmellTaste: Support, Education, Research	Guideline	General	General	**Impact on physical health and safety** **Impairment of these senses can affect people's physical health and also personal safety.** Impaired smell results in the loss of ability to perceive the flavour of food. Loss of taste is less common, but results in the ability to perceive basic tastes. This affects eating preferences and enjoyment, leading to dietary change and nutritional impact. Those with smell loss often gravitate towards foods they can still taste for example salty and sweet foods, whilst some people end up eating less overall as their appetite diminishes. This leads to with weight loss or gain and poorer nutrition. Loss of smell compromises safety, such as the inability to detect smoke, gas leaks, or spoiled food. When SmellTaste undertook a safety survey of its beneficiaries up to 85% of those responding stated that they feared exposure to the dangers of gas or spoiled foods.	Thank you for your comment. Interventions regarding smell and taste were not covered by the guideline scope and no evidence was sought in these areas. We will therefore consider your comments when the guideline is next updated.
SmellTaste: Support, Education, Research	Guideline	General	General	**Mental health consequences** The loss of smell and/or taste is linked to: Depression and anxiety: The inability to smell one's partner or children, ones' home, garden or other environments, enjoy	Thank you for your comment. Interventions regarding smell and taste were not covered by the guideline scope and no evidence was sought in these areas. We will therefore consider your comments when the guideline is next updated.

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				food and drink results in a poorer quality of life and loss of emotional connection to the world. In research undertaken by the University of East Anglia and SmellTaste, 61% of respondents stated that they suffered with depression as a result of smell and taste impairment. Social withdrawal and isolation: due to reduced enjoyment of social eating, leading to people eating out, or with friends/family, less, and fear of personal hygiene issues (e.g. being unaware of body odour). Feelings of grief and loss: those who are aware of their sensory loss sometimes refer to it as a bereavement, such is the emotional impact. Some of the reasons for this impact are linked to the following Memory. Our ability to smell links to our memory, once this link is lost there is also a loss of that sensory memory. Which in the longer term, can have a very real impact on an individual's mental health. The ability to smell, affects how we engage with and remember the world. These impacts are well-documented in published research but there is a widespread lack of knowledge and understanding of these issues amongst the wider health and social care system. They are rarely incorporated into psychological or emotional support frameworks within neurological rehabilitation services.	
SmellTaste: Support, Education, Research	Guideline	General	General	**Rehabilitation should include testing of smell and taste and appropriate support and information to be provided** We strongly recommend the inclusion of: Routine smell and taste testing in individuals with ABI or chronic neurological conditions to identify those in need of care and support Referral pathways to ENT specialists and smell/taste clinics where available	Thank you for your comment. Interventions regarding smell and taste were not covered by the guideline scope and no evidence was sought in these areas. We will therefore consider your comments when the guideline is next updated.

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				Access to psychological support specifically addressing the impacts of the sensory impairment Patient education and safety guidance (e.g. food advice, ensuring gas and smoke alarms are fitted)	
SmellTaste: Support, Education, Research	Guideline	General	General	**Interdisciplinary Collaboration** Rehabilitation teams should include or consult with smell and taste specialists and SmellTaste for further information. Addressing smell and taste loss should not be viewed as peripheral, but central to person-centred, functional rehabilitation. Suggested Amendments to the Guideline: Include specific mention of smell and taste impairment as part of the sensory assessment. Incorporate clinical pathways or recommendations for managing smell and taste impairment, including rehabilitation strategies, coping mechanisms, and referral options. Acknowledge the psychological impact of these sensory impairments in mental health support planning. We hope these comments help shape a more inclusive, patient-centred approach in the final guidelines. We would be pleased to provide further input or evidence if helpful.	Thank you for your comment. Interventions regarding smell and taste were not covered by the guideline scope and no evidence was sought in these areas. We will therefore consider your comments when the guideline is next updated.

Organisation name – Stakeholder or respondent	Disclosure on tobacco funding / links	Comments/Action
N/A	N/A	N/A

**None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*

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