National Institute for Health and Care Excellence

Final

Rehabilitation for chronic neurological disorders including acquired brain injury

[C] Evidence review for assessment, planning and review

NICE guideline NG252

Evidence review underpinning recommendations 1.8.9, 1.8.14 to 1.8.19, 1.9.1 to 1.9.9, 1.10.1 to 1.10.2, 1.10.5, 1.10.7, 1.10.8, 1.13.1 to 1.13.5, and 1.18.12 in the NICE guideline

October 2025

Final

This evidence review was developed by NICE

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Contents

Assessment, planning and review

Review question

Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

Introduction

Rehabilitation for chronic neurological disorders is a complex process. 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. Developing guidance on how to conduct a rehabilitation assessment or review, and developing an appropriate rehabilitation plan, will ultimately support the delivery of rehabilitation services.

Summary of the protocol

See Table 1 for a summary of the Population and Phenomenon of interest for this review.

Table 1: Summary of the protocol

Population	• Adults and children with rehabilitation needs due to the following chronic neurological disorders: ○ Acquired brain injury ○ Acquired spinal cord injury ○ Acquired peripheral nerve disorders ○ Progressive neurological diseases ○ Functional neurological disorders • Family and carers of people with chronic neurological disorders. • Health and social care practitioners who work with people with chronic neurological disorders, including voluntary and third sector providers. • Practitioners involved in rehabilitation for education, employment and social participation.
Phenomenon of interest	• **Acceptability.** Data may relate to people's experiences of the way in which rehabilitation needs are assessed and reviewed and plans are formulated, for example, interactions between patients and practitioners, the timing of assessment and planning or the settings in which assessments are conducted and reviews undertaken. • **Provision of information.** Data may relate to information given to people before an assessment or review, particularly information that would help them prepare for appointments and understand what to expect. • **Integration and co-ordination within and between rehabilitation services.** Data may relate to people's experiences of assessments, reviews and planning undertaken with multiple practitioners or teams. • **Personalisation of assessment and review including planning rehabilitation and goal setting.** Data may relate to people's views on whether their assessment, review and planning were appropriate to their individual and family needs and circumstances. Also whether they felt at the centre of these processes and enabled to express their preferences and aims for rehabilitation.

	• **Sustainability of rehabilitation and consideration of chronic nature of conditions.** Data may relate to the way in which people's changing needs and preferences are reviewed and plans changed to reflect movement between services or settings. • **Equalities considerations.** Data may relate to the assessment and review of rehabilitation needs and goal setting with people facing inequalities relating to race and gender and people with pre-existing physical, mental health or behavioural conditions, communication impairments and physical, learning disabilities and neurodiversity. It will also consider age-related assumptions, engagement and cultural differences. • **Addressing disputed assessments.** Data may relate to the views of people participating in assessments, which are disputed or contested by one party. Data may relate to the way in which contested assessments are handled and resolved and any learning for the future is implemented.

For further details see the review protocol in appendix A.

Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document (supplementary document 1).

Declarations of interest were recorded according to NICE's conflicts of interest policy.

Qualitative evidence

Included studies

A systematic review of the literature was conducted using a combined search for 2 of the qualitative review questions included in this guideline: this evidence review; and evidence review A ('Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?').

Ten studies were included for this review. Four studies were grounded theory (Collins 2023, Jenkin 2022a, Jenkin 2022b, Preston 2012); 2 were general qualitative inquires (within mixed-methods studies) (Shore 2022, Van De Weyer 2010); 2 were general qualitative inquiries (Botchway-Commey 2022, Hickling 2022), 1 study was phenomenological (Sexton 2013); and 1 was a case study (Twigg 2021).

The included studies are summarised in Table 2.

Four studies were conducted in the UK (Preston 2012, Sexton 2013, Twigg 2021, Van De Weyer 2010); 3 studies were conducted in Australia (Collins 2023, Jenkin 2022a, Jenkin 2022b); 2 studies were conducted in Canada (Hickling 2022, Shore 2022); and 1 study was conducted across multiple countries; Australia, UK, New Zealand, Canada and the US (Botchway-Commey 2022).

Six studies investigated chronic neurological disorders in the paediatric population (Botchway-Commey 2022, Collins 2023, Hickling 2022, Jenkin 2022a, Jenkin 2022b, Shore 2022); 3 studies investigated chronic neurological disorders in adult populations (Preston 2012, Sexton 2013, Twigg 2021); and 1 study did not specify the age rage of their population (Van De Weyer 2010).

Five studies investigated the assessment, planning and review of rehabilitation in people with acquired brain injury (Collins 2023, Hickling 2022, Jenkin 2022a, Jenkin 2022b, Shore 2022);

2 studies investigated assessment, planning and review of rehabilitation in progressive neurological disease (Preston 2012, Twigg 2021); 2 studies investigated assessment, planning and review of rehabilitation in populations with unspecified chronic neurological disorders (Sexton 2013, Van De Weyer 2010); and 1 study investigated assessment, planning and review of rehabilitation in populations with a mixture of acquired brain injury and acquired spinal cord injury (Botchway-Commey 2022).

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review are listed, and reasons for their exclusion are provided in appendix J.

Summary of included studies

Summaries of the studies that were included in this review are presented in Table 2.

Table 2: Summary of included studies

Study	Participants	Methods	Themes applied after thematic synthesis
Botchway-Commey 2022 General qualitative inquiry Australia, UK, New Zealand, Canada and the US **Aim** To explore how national and international systems are designed to support paediatric traumatic brain injury and traumatic spinal cord injury rehabilitation services, as well as the barriers and facilitators to providing these services.	N=16 practitioners working with children and young people with traumatic brain injury and traumatic spinal cord injury CND category: Acquired brain injury and acquired spinal cord injury Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all under 21 Sex of children and young people with chronic neurological disorders: Not reported	**Data Collection:** Semi-structured interviews **Analysis:** Thematic content analysis	• Personalisation of assessment and review including planning rehabilitation and goal setting ○ Including families ○ Person-centred rehabilitation planning
Collins 2023 Grounded theory Australia **Aim** To explore the experiences of children and their families with collaborative goal	N=21 children and young people with acquired bran injury plus parents CND category: Acquired brain injury **Children and young people with acquired brain injury, n=8**	**Data collection:** Semi-structured interviews **Analysis:** Constructivist grounded theory	• Integration and co-ordination within and between rehabilitation services ○ Rehabilitation services and external services • Personalisation of assessment and review including planning

Study	Participants	Methods	Themes applied after thematic synthesis
setting in acquired brain injury rehabilitation, and how this can affect participation and engagement.	Age in years [Mean (SD)]: Not reported, age range 9-17 Sex (M/F): n=2/n=6 **Parents of children and young people with acquired brain injury, n=13** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: 13.36 (3.61) Sex of children and young people with chronic neurological disorders (M/F): n=3/n=6		rehabilitation and goal setting ○ Goal setting - Achievable goals - Collaborative goal setting - Ongoing review and revision of goals - Role of rehabilitation professionals ○ Including families • Equalities considerations ○ Cognitive and communication difficulties ○ Encouraging children and young people
Hickling 2022 General qualitative inquiry Canada **Aim** To explore the experiences of children and parents of children who had participated in the interdisciplinary team-based assessment.	N=15 children and young people with persistent post-concussion symptoms plus parents CND category: Acquired brain injury **Children and young people with persistent post-concussion symptoms, n=8** Age in years [Mean (SD)]: 14.25 (SD not reported), age range 8-17 Sex (M/F): n=5/n=3 **Parents of children and young people with persistent post-concussion symptoms, n=7** Age of children and young people with chronic neurological disorders in years: Not reported	**Data collection:** Semi-structured interviews **Analysis:** Content analysis	• Provision of information ○ Format • Integration and co-ordination within and between rehabilitation services ○ Multi-disciplinary teams • Personalisation of assessment and review including planning rehabilitation and goal setting ○ Goal setting - Collaborative goal setting ○ Person-centred rehabilitation planning

Study	Participants	Methods	Themes applied after thematic synthesis
	Sex of children and young people with chronic neurological disorders: Not reported		
Jenkin 2022a Grounded theory Australia **Aim** To explore healthcare professionals' experience of rehabilitation goal setting for children with acquired brain injury and their families.	N=13 rehabilitation professionals working with children and young people with acquired brain injury CND category: Acquired brain injury Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all under 18 Sex of children and young people with chronic neurological disorders: Not reported	**Data collection:** Semi-structured interviews **Analysis:** Constructivist grounded theory	• Integration and co-ordination within and between rehabilitation services ○ Rehabilitation services and external services ○ Multi-disciplinary teams • Personalisation of assessment and review including planning rehabilitation and goal setting ○ Goal setting - Achievable goals - Collaborative goal setting - Ongoing review and revision of goals - Role of rehabilitation professionals • Personalisation of assessment and review including planning rehabilitation and goal setting ○ Including families ○ Additional capacity • Equalities considerations ○ Engagement by people with cognitive and communication difficulties ○ Encouraging children and young people
Jenkin 2022b Grounded theory Australia	N=19 children and young people with moderate to severe acquired brain injury plus family members	**Data collection:** Semi-structured interviews	• Personalisation of assessment and review including planning

Study	Participants	Methods	Themes applied after thematic synthesis
Aim To explore the experiences of children with moderate and severe acquired brain injury and their families when using a family-centred service, how families can participate in rehabilitation, and what improvements could be made to increase family participation in paediatric acquired brain injury rehabilitation.	CND category: Acquired brain injury **Children and young people with moderate to severe acquired brain injury, n=4** Age in years [Mean (SD)]: Not reported, age range 13-17 Sex (M/F): n=2/n=2 **Family members of children and young people with moderate to severe acquired brain injury, n=15** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported, age range 9-17 Sex of children and young people with chronic neurological disorders (M/F): n=6/n=2	**Analysis:** Constant-comparison constructivist grounded theory	rehabilitation and goal setting ○ Goal setting - Collaborative goal setting ○ Person-centred rehabilitation planning
Preston 2012 Grounded theory UK **Aim** To explore the experiences of people with multiple sclerosis when accessing a local occupational therapy service.	N=46 adults with multiple sclerosis plus partners, carers and practitioners CND category: Progressive neurological disease **Adults with multiple sclerosis, n=30** Age in years [Mean (SD)]: Not reported, age range 31-63 (median 49) Sex (M/F): n=7/n=23	**Data Collection:** Focus groups **Analysis:** Grounded theory	• Provision of information ○ Assessment tools • Personalisation of assessment and review including planning rehabilitation and goal setting ○ Including families

Study	Participants	Methods	Themes applied after thematic synthesis
	Partners and carers of people with multiple sclerosis, n=10 Age of people with chronic neurological disorders in years**:** Not reported Sex of people with chronic neurological disorders: Not reported **Practitioners working with people with multiple sclerosis, n=6** Age of people with chronic neurological disorders in years**:** Not reported Sex of people with chronic neurological disorders (M/F): Not reported		
Sexton 2013 Phenomenological UK **Aim** To explore the experiences of neurological occupational therapists when having conversations with people about likely long-term disabilities.	N=10 occupational therapists working with adults with neurological symptoms CND category: General chronic neurological disorders Age of people with chronic neurological disorders in years [Mean (SD)]**:** Not reported but inclusion criteria states participants must be between 18-75 Sex of people with chronic neurological disorders: Not reported	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Provision of information ○ Realistic planning • Integration and co-ordination within and between rehabilitation services ○ Multi-disciplinary teams • Personalisation of assessment and review including planning rehabilitation and goal setting ○ Goal setting - Achievable goals
Shore 2022 General qualitative inquiry (within mixed-methods study) Canada	N=6 children and young people with concussion plus parents CND category: Acquired brain injury	**Data Collection:** Semi-structured interviews **Analysis:** Inductive thematic analysis	• Personalisation of assessment and review including planning rehabilitation and goal setting

Study	Participants	Methods	Themes applied after thematic synthesis
Aim To explore users' views and experiences regarding the remote delivery of the Tele-Active Rehabilitation intervention, as well as what worked well and the benefits of the programme.	**Children and young people with concussion, n=3** Age in years [Mean (SD)]: Not reported, age range 14-17 Sex (M/F): n=1/n=2 **Parents of children and young people with concussion, n=3** Age of children and young people with chronic neurological disorders in years [Mean (SD)]**:** As above Sex of children and young people with chronic neurological disorders (M/F): As above		○ Person-centred rehabilitation planning
Twigg 2021 Case study UK **Aim** To understand the lived experience of a person with a rare condition (POEMS syndrome) including their experiences of health care.	N=2 (1 adult with POEMS syndrome plus carer) CND category: Progressive neurological disease **Adult with POEMS syndrome, n=1** Age in years: 71 Sex (M/F): n=0/n=1 **Carer of adult with POEMS syndrome, n=1** Age of person with chronic neurological disorders in years [Mean (SD)]: As above Sex of person with chronic neurological disorders (M/F): As above	**Data Collection:** Semi-structured interview **Analysis:** Constant comparative approach	• Personalisation of assessment and review including planning rehabilitation and goal setting ○ Goal setting - Collaborative goal setting ○ Person-centred rehabilitation planning

Study	Participants	Methods	Themes applied after thematic synthesis
Van De Weyer 2010 General qualitative inquiry (within mixed-methods study) UK **Aim** To explore rehabilitation professionals' experiences with goal setting in general, and about 2 specific goal setting techniques investigated in parent RCT.	N=15 rehabilitation practitioners working with people with chronic neurological disorders CND category: General chronic neurological disorders Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data collection**: Focus groups **Analysis**: Thematic analysis	• Provision of information ○ Early provision of information ○ Realistic planning • Integration and co-ordination within and between rehabilitation services ○ Multi-disciplinary teams • Personalisation of assessment and review including planning rehabilitation and goal setting ○ Goal setting - Collaborative goal setting - Role of rehabilitation professionals ○ Person-centred rehabilitation planning

CND: chronic neurological disorder; POEMS: Polyneuropathy Organomegaly Endocrinopathy Monoclonal gammopathy Skin changes; RCT: randomised controlled trial; SD: standard deviation

See the full evidence tables in appendix D. As this was a qualitative review, no meta-analysis was conducted (and so there are no forest plots in appendix E).

Summary of the evidence

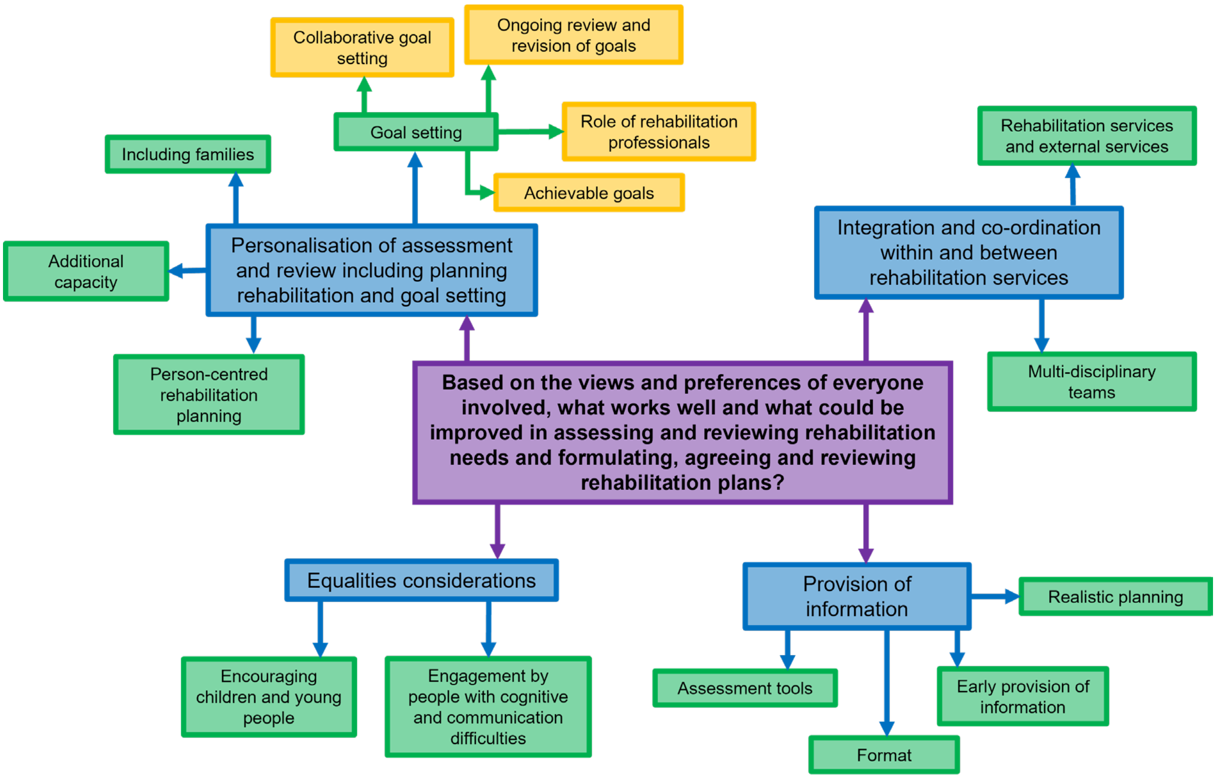
The synthesis of the evidence generated the following 4 main themes:

- C1 Provision of information
- C2 Integration and co-ordination within and between rehabilitation services
- C3 Personalisation of assessment and review including planning rehabilitation and goal setting
- C4 Equalities considerations

Themes and sub-themes for each qualitative review follow the same alphanumeric naming convention, with the first letter relating directly to the review letter (in this case ‘C’) and subsequent numbers relating to the order of main themes and sub-themes within the review.

The theme map illustrates the main themes (shown in blue) and their related sub-themes (shown in green) and minor sub themes (shown in yellow).

Figure 1: Theme map for what works well and what can be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans



C1 Provision of information

Four sub-themes were identified under provision of information. In the ‘C1.1 Assessment tools’ sub-theme (very low confidence), evidence from 1 study showed that some people with chronic neurological disorders felt as though assessment tools were patronising and should be explained by clinicians to alleviate this. In the ‘C1.2 Early provision of information’ sub-theme (very low confidence), evidence from 1 study showed that people with chronic neurological disorders preferred to receive information early in the rehabilitation process, to enable informed decision making and goal setting. In the ‘C1.3 Format’ sub-theme (low confidence), evidence from 2 studies showed that written rehabilitation plans were useful for people with chronic neurological disorders, alongside verbal conversations. In the ‘C1.4 Realistic planning’ sub-theme (low confidence), evidence from 2 studies showed that rehabilitation plans should be an honest depiction of possible rehabilitation programmes and future prognoses and include the potential for negative outcomes as well as good.

C2 Integration and co-ordination within and between rehabilitation services

Two sub-themes were identified. In the ‘C2.1 Rehabilitation services and external services’ sub-theme (low confidence), evidence from 2 studies showed that rehabilitation plans and goals should be regularly communicated between rehabilitation services and any other sectors that may be affected by a person’s rehabilitation. In the ‘C2.2 Multi-disciplinary teams’ sub-theme (moderate confidence), evidence from 4 studies showed that rehabilitation planning should be informed by practitioners from a variety of disciplines to promote holistic needs assessments.

C3 Personalisation of assessment and review including planning rehabilitation and goal setting

Four sub-themes and 4 minor sub-themes were identified. In the ‘C3.1 Goal setting’ sub-theme, 4 minor sub-themes were identified. In the ‘C3.1.1 Achievable goals’ minor sub-theme (low confidence), evidence from 3 studies showed that people with chronic neurological disorders were less motivated when goals were thought to be unachievable, and they should therefore be broken down into small, more manageable goals. In the ‘C3.1.2 Collaborative goal setting’ minor-sub-theme (high confidence), evidence from 6 studies showed that collaborative goal setting between rehabilitation practitioners, people with chronic neurological disorders and their family members was needed for goals to be relevant and appropriate. In the ‘C3.1.3 Ongoing review and revision of goals’ minor sub-theme (low confidence), evidence from 2 studies showed that as needs and preferences change over time, then rehabilitation practitioners should review goals on an ongoing basis. In the ‘C3.1.4 Role of rehabilitation professionals’ minor sub-theme (very low confidence), evidence from 3 studies showed that rehabilitation practitioners should provide information about the importance of and procedure for goal setting, place goals in the wider recovery context for people with chronic neurological disorders, and negotiate goals when opinions differ.

In the ‘C3.2 Including families’ sub-theme (moderate confidence), evidence from 4 studies showed that families should be included in rehabilitation planning to ensure people with chronic neurological disorders are supported in their rehabilitation outside of a clinical context. In the ‘C3.3 Person-centred rehabilitation planning’ sub-theme (high confidence), evidence from 6 studies showed that to promote engagement with rehabilitation, planning should be person-centred and individualised and should integrate meaningful activities and goals. In the ‘C3.4 Additional capacity’ sub-theme (very low confidence), evidence from 1 study showed that rehabilitation practitioners needed additional time to perform collaborative rehabilitation planning and goal setting, and to support people with chronic neurological disorders and their families through periods of stress and change.

C4 Equalities considerations

Two sub-themes were identified under equalities considerations. In the ‘C4.1 Engagement by people with cognitive and communication difficulties’ sub-theme (moderate confidence), evidence from 2 studies showed that rehabilitation professionals should make necessary accommodations to ensure the meaningful contribution of people with cognitive and communication difficulties in rehabilitation planning and goal setting. In the ‘C4.2 Encouraging children and young people’ sub-theme (moderate confidence), evidence from 2 studies showed that children and young people can feel disengaged from the rehabilitation planning and goal setting process, but felt more motivated when they had a good relationship with rehabilitation practitioners, enjoyed the rehabilitation activities, and felt it was important to their recovery.

See appendix F for full GRADE-CERQual tables.

Economic evidence

Included studies

In the development of this qualitative review, targeted search for evidence on cost-effectiveness was planned. The committee was asked to consider whether a recommendation represents a substantial change in practice and results in significant resource impact. If so, targeted searches in that area would be undertaken. However, the committee could not identify an area where such targeted searches would be beneficial. Therefore, no economic search was carried out for this review.

Excluded studies

No economic searches were undertaken for this qualitative review.

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation.

The committee's discussion and interpretation of the evidence

The outcomes that matter most

To address the question of what works well and what can be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans, this review was designed to include qualitative data and as a result, the committee could not specify in advance the data that would be located. Instead, they agreed, by informal consensus, on the following main themes to guide the review, although the list was not exhaustive, and the committee were aware that additional themes could be identified:

- Acceptability. For example, people's experiences of the way in which rehabilitation needs are assessed and reviewed and plans are formulated (including interactions between people with chronic neurological disorders and practitioners, the timing of assessment and planning or the settings in which assessments are conducted and reviews undertaken).
- Provision of information. For example, people's views on information given prior to an assessment or review, particularly information that would help them prepare for appointments and understand what to expect.
- Integration and co-ordination within and between rehabilitation services. For example, people's experiences of assessments, reviews and planning undertaken with multiple practitioners or teams.
- Personalisation of assessment and review including planning rehabilitation and goal setting. For example, people's views on whether their assessment, review and planning were appropriate to their individual and family needs and circumstances, whether people felt at the centre of these processes and were enabled to express their preferences and aims for rehabilitation.
- Sustainability of rehabilitation and consideration of chronic nature of conditions. For example, regarding the way in which people's changing needs and preferences are reviewed, and how plans may be changed to reflect movement between services or settings.
- Equalities considerations. For example, the assessment and review of rehabilitation needs and goal setting with people facing inequalities relating to race, gender, people with pre-existing conditions (including physical, mental health or behavioural conditions, communication impairments and physical, learning disabilities and neurodiversity), age-related assumptions, engagement and cultural differences.
- Addressing disputed assessments. For example, experiences of people participating in assessments which are disputed or contested by one party, and how these contested assessments are handled and resolved and any learning for the future is implemented.

These themes were chosen as they were expected to be the key aspects that influence people's preferences for assessment and reviewing of rehabilitation needs and formulation, agreement and review of rehabilitation plans.

The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology and the overall confidence in the findings for the qualitative review ranged from very low to high.

The review findings were generally downgraded due to concerns over methodological limitations of included studies (for example, a lack of consideration given to the relationship between researchers and participants or poor reporting of data collection methods) and to relevance concerns (for example, when themes only used findings on specific rehabilitation therapies or services, or if they included participants who were outside of the protocol population). Studies were also downgraded due to coherence of themes (for example, when themes included contradictory findings) and concerns over adequacy (for example, when studies only contributed moderately rich data to a theme, or when there were low numbers of studies contributing data).

Anticipated themes that were set out in the protocol but not reported by any studies include:

- Acceptability
- Sustainability of rehabilitation and consideration of chronic nature of conditions
- Addressing disputed assessments

See appendix F for full GRADE-CERQual tables with quality ratings of all review findings.

Benefits and harms

Holistic rehabilitation needs assessment

What to cover

High quality evidence from the theme ‘C3.3 Person-centred rehabilitation planning’ showed that people with chronic neurological disorders (CND), their family members, carers and rehabilitation practitioners all reported that in order to support a person’s life outside of their condition and promote engagement with rehabilitation, planning should be person-centred and individualised, integrating activities and tasks that are enjoyable to them. Placing people with CND at the centre of rehabilitation planning also allows for novel insights to easily be included. Factors to be considered include current physical and mental functioning (as well as developmental trajectory for children and young people), people’s ability to engage in the rehabilitation planning process, family and cultural needs, access to resources, the impact of changing settings (for example, transferring from inpatient to community rehabilitation services), and goal setting. The committee agreed with the findings, therefore recommended to ask the person about their background, relationships, work, education, meaningful activities, spiritual and religious practices, hobbies and interests as part of rehabilitation needs assessment. The committee highlighted that the person should also be asked about their activities of daily living and how these have changed or is changing, developmental milestones and play in the case of children, what is important in their life and potential motivating factors (for example, lifestyle, priorities, core values, and future aspirations), and environmental and wider societal factors that might encourage or prevent them from taking part in rehabilitation.

Very low quality evidence from the theme ‘C1.2 Early provision of information’ showed that information should be given to people with CND early in the rehabilitation process to support decision making and goal setting. This finding was supported by low quality evidence from the theme ‘C1.4 Realistic planning’ which showed that planning and goal setting are made realistic when conversations are honest and acknowledge the potential for negative outcomes. The committee agreed with the findings, therefore made a recommendation to assess the person’s need for information, advice and training about how their condition or injury is impacting on their level of functioning and ability to carry out their usual day to day activities.

Very low quality evidence from the theme ‘C1.4 Realistic planning’ showed that planning and goal setting are made realistic when conversations are honest and acknowledge the potential for negative outcomes. The committee agreed with this finding, and therefore made a recommendation to identify rehabilitation interventions that will help the person to prepare psychologically and physically for future changes to impairment and functioning, especially for rapidly progressive conditions (for example, starting wheelchair skills training while a person is still ambulatory, in order to help prepare them for when they may need one). Additional moderate quality evidence from the theme 'C3.2 Including families' showed that people with CND, their family members and rehabilitation practitioners were generally positive about involving families in rehabilitation planning. Mostly they said that families should be included, working together to build care capacity and design a rehabilitation plan that works around competing family needs and routines. Involving families in rehabilitation planning was also said to increase compliance with rehabilitation programmes as it ensures that people with chronic neurological disorders are supported in their rehabilitation outside of the clinical setting. However, some rehabilitation practitioners acknowledged that including family members sometimes affects the information shared during review appointments as people may wish to protect their loved ones from bad information. The committee agreed with both sides of this finding but argued that supporting the family during this stage of education can foster an open discussion about all possibilities and decrease reticence surrounding talking about poor outcomes later on in rehabilitation. Therefore, they extended the recommendation to include families and carers, with a caveat that this will not be appropriate in all situations (for example, in situations where safeguarding concerns are identified).

The committee discussed that all areas that can impact the function, symptoms and impairment of a person with CND should be assessed as part of a holistic rehabilitation needs assessment. The committee agreed that there is often a combination as opposed to single impairment that can affect a person with CND, thus ensuring appropriate assessment of key areas is critical to ensure that unmet needs are identified and managed. The committee highlighted the key areas as pain, fatigue, physical activity and exercise, limb function, stability, gait and mobility, emotional health and wellbeing, cognitive function, speech, language and communication, eating, drinking and swallowing, independent living needs, equipment requirements and adaptations to the home. The committee agreed that all areas prioritised are covered in the guideline and made a recommendation that refers readers to the specific sections when conducting a holistic assessment to identify any impairments that required further management. The committee also noted several areas that are not covered by this guideline but do need to be considered in the holistic rehabilitation needs assessment as they will impact on rehabilitation planning and delivery. The committee discussed that people with CND will often have problems with bladder and bowel function, which can impact other functioning domains such as activities of daily living. As there is already published guidance on the management of these conditions, the committee directed readers to NICE's guidelines on urinary incontinence in neurological disease: assessment and management and faecal incontinence in adults: management for further detailed recommendations. Similarly, they recommended that people be assessed for vision and hearing issues, which might impact an individual's rehabilitation.

The committee emphasised that the holistic assessment should take a person-centric approach. While the basic areas of functioning, symptoms and impairment will be standard between individuals, the way that these vary throughout settings, and with time, will be different for each individual. For example, a person with an acquired brain injury may be able to function at home in a quiet environment, whereas may be unable to complete the same task in a busy town centre with distractions. Similarly, abilities and needs may fluctuate at different times of the day or from day to day or over the longer term. The committee discussed examples such as some people finding it more difficult to move around and complete tasks in the morning as opposed to the afternoon, and some conditions getting worse over time. The committee agreed that healthcare professionals should factor into their holistic assessment whether a person's function, abilities and needs are likely to differ in real life environments, change or fluctuate on a day to day basis, and increase or decrease or fluctuate over the long term to support the needs of the individual going forward.

The committee agreed that, when a holistic assessment is being undertaken, not only is the person key but also their life and activities that they participate in. The committee discussed that, to ensure that the person's needs are addressed during assessment, consideration of what is important needs to be taken into account. The committee highlighted the key areas as education, work, social and leisure activities, family and friends, and relationships. The committee agreed that all areas prioritised are covered in the guideline and made a recommendation to refer to the specific areas when conducting a holistic assessment to enable participation in every aspect of the person's usual daily life.

Goal setting

Very low quality evidence from the theme 'C3.1.4 Role of rehabilitation professionals' showed that people with CND, their family member and rehabilitation practitioners said that rehabilitation professionals should provide information and education about the purpose and process of goal setting in neurorehabilitation (including how they can facilitate goal setting). They suggested using goal setting resources to discuss and elicit goals and explain how a small number of achievable goals can be built on to reach longer term goals. Rehabilitation practitioners may need to take more of an active role in goal setting for people with certain types of chronic neurological disorder or immediately after the onset of symptoms. Additionally, practitioners may need to use their expertise to negotiate goals when views differ between people with chronic neurological disorders, their family members or clinicians. The committee agreed with the all the findings, recommending that the process and reasons for goal setting should be explained to the person with CND.

Low confidence evidence from the theme 'C3.1.1 Achievable goals' showed that people with CND, their family members and rehabilitation practitioners reported that people were less motivated when goals were thought to be too difficult or unrealistic to achieve. Long-term goals should be made, but these should then be broken down into smaller short-term steps (for example, 2-4 weeks) that can be linked to the bigger picture of recovery. This was supported by high quality evidence from the theme 'C3.1.2 Collaborative goal setting rehabilitation', which showed that people with CND, their family members and rehabilitation practitioners believed that collaborative goal setting is needed to ensure that goals are relevant, appropriate and supported by those involved. These goals are developed through open and honest communication, with every person being able to contribute their thoughts and experiences. If needed, rehabilitation practitioners should use their experience and expertise to prompt discussion and guide goal setting. The committee agreed with the findings, therefore recommended that practitioners should work collaboratively to agree long-term rehabilitation goals broken down in short-steps that focus on what is most important to the person.

Moderate quality evidence from the theme 'C4.1 Engagement by people with cognitive and communication difficulties' showed that parents of children with CND and rehabilitation practitioners reported that when people have cognitive and communication difficulties there are additional challenges to engagement in rehabilitation planning and goal setting. When children are too young to understand the concept of goal setting, they tend to ignore goals that will provide them with basic life skills (for example, being able to use a knife and fork). For these reasons, parents tended to not include them in goal setting until they got older. Children with communication impairments often did not fully participate in rehabilitation planning and goal setting as they were not easily understood by rehabilitation practitioners. Several strategies were identified to help those with cognitive and communication difficulties participate meaningfully, including directing questions at children with CND, giving enough time to respond to queries, using alternative forms of communication and simplifying conversations. The committee agreed with the findings, therefore recommended that age-specific approaches to engage children and young people (CYP) in goal setting.

Very low quality evidence from the theme 'C1.4 Realistic planning' which showed that planning and goal setting are made realistic when conversations are honest and acknowledge the potential for negative outcomes. The committee discussed this, acknowledging that honesty is an important factor in building a trusting and productive rapport with people with chronic conditions. However, they noted the need to balance this with facilitating hope during the rehabilitation and highlighted that these planning discussions should be bi-directional in nature. It should not simply be rehabilitation professionals giving information to people with chronic neurological disorders, but also vice versa. The committee agreed with the findings, therefore recommended to agree goals based on the person's wishes and aspirations that focus on optimising participation in the most important aspects of the person's life, aim to improve, maintain or reduce deterioration in functioning over time, incorporate the need for psychological adaptation, acceptance and recovery, and take account of developmental challenges, in the case of CYP. The committee also recommended that when agreeing goals discuss the potential for both positive and negative outcomes, including the impact that future changes in the person's functioning may have and the need to review goals regularly in this context.

Very low confidence evidence from the theme 'C3.4 Additional capacity' showed that healthcare professionals identified that they needed additional time during consultations to plan rehabilitation and set goals collaboratively. Additional time is also needed to develop a rapport with people with CND, to better support them through a period of mental and emotional distress and help them to engage fully in the rehabilitation planning process. The committee agreed with the findings, recommending that sufficient time during consultations for both goal setting and rehabilitation planning with people. They noted that this process should also extend to family and carers, but only if this is acceptable to people with CND.

Low quality evidence from the theme 'C3.1.3 Ongoing review and revision of goals' showed that that people with CND, their family members and rehabilitation practitioners reported that the number and type of rehabilitation goals set, as well as the frequency of review changed throughout rehabilitation. More goals were set at the beginning of rehabilitation, with shorter times between review and with a focus on physical rehabilitation. These goals naturally become longer-term and more psychological as rehabilitation progresses, needs change and priorities are revised. There was consensus that this flexibility ensured rehabilitation goals are kept relevant and attainable. The committee agreed with the findings, therefore recommended that practitioners should keep the person at the centre of the goal setting process, and tailor the timeframe for reviewing goals to the person's condition, situation and nature of the goal.

Moderate quality evidence from the theme 'C4.2 Encouraging children and young people' showed that CYP with CND, their family members and rehabilitation practitioners said that the level of engagement for children and young people varied greatly throughout goal setting and rehabilitation planning. CYP felt more involved in conversations when clinicians tried to minimize medical terminology, explain processes clearly, were open about treatment and allowed questions to be asked. Similarly, children were more motivated to achieve goals if they had a good relationship with rehabilitation practitioners, enjoyed the goal, and felt it was functionally important. Conversely, CYP would pay less attention if they could not follow conversations, felt as though topics were not relevant to them or felt as though goals were imposed by their parents. To identify the most meaningful goals, rehabilitation practitioners should aim to develop a rapport with children and young people, getting to know what is important to them through meaningful conversations and ensure that their voices are heard alongside their parents. The committee agreed and noted that another reason for the wide variation in engagement was the growth and development children are experiencing. Frequent review of rehabilitation goals and plans can mean that rehabilitation professionals can adjust their approaches to goal setting along with a child's development, gradually increasing their participation in the process. Additionally, the committee's experience suggested that this need for regular review is true for all ages of people participating in rehabilitation for CND, as everyone will be changing throughout rehabilitation.

Agreeing, delivering and reviewing a coordinated rehabilitation plan

Moderate confidence evidence from the theme ‘C2.2 Multidisciplinary teams’ showed that people with CND, their family members and rehabilitation practitioners all reported that collaboration between clinicians helped to facilitate holistic assessments, and that multidisciplinary teams were an effective way to increase communication within rehabilitation. They also help to ensure that realistic plans and goals are discussed within the rehabilitation team, and that clear and consistent messages are conveyed to people with CND. The committee did not disagree with this, but they discussed that multidisciplinary teams were not possible in every setting and a recommendation specifying them would have too large a resource impact. Instead, they used their experience to identify the 2 most important aspects of the finding, that of co-production of rehabilitation plans and collaboration during care delivery. Additional moderate quality evidence from the theme ‘C3.2 Including families’ showed that families should be included in rehabilitation planning to ensure people with chronic neurological disorders are supported in their rehabilitation outside of a clinical context. Therefore, the committee recommended producing and agreeing a personalised rehabilitation plan with people with CND and those close to them, as well as the health, mental health and social care practitioners involved in their care.

High quality evidence from the theme ‘C3.3 Person centred rehabilitation planning’ showed that people with CND, their family members, carers and rehabilitation practitioners all reported that in order to support a person’s life outside of their condition and promote engagement with rehabilitation, planning should be person-centred and individualised, integrating activities and tasks that are enjoyable to them. Placing people with CND at the centre of rehabilitation planning also allows for novel insights to easily be included. Factors to be considered include current physical and mental functioning (as well as developmental trajectory for children and young people), people’s ability to engage in the rehabilitation planning process, family and cultural needs, access to resources, the impact of changing settings (for example, transferring from inpatient to community rehabilitation services), and goal setting. The committee agreed with the findings, therefore recommended that when agreeing the interventions and approaches that will constitute the rehabilitation plan always include the person’s most important rehabilitation goals and consider how interventions will help to achieve these. Please note that this recommendation also uses evidence from evidence review A, where the remainder of the committee’s discussion can be found.

Moderate confidence evidence from the theme ‘C2.2 Multidisciplinary teams’ showed that people with CND, their family members and rehabilitation practitioners all reported that collaboration between clinicians helped to achieve holistic assessments and this was facilitated by multidisciplinary teams. They also help to ensure that realistic plans and goals are discussed within the rehabilitation team, and that clear and consistent messages are conveyed to people with chronic neurological disorders. This finding was supported further by low quality evidence from theme ‘C2.1 Rehabilitation services and external services’ which showed that people with CND, their family members and rehabilitation practitioners reported that it was helpful when rehabilitation plans and goals were regularly communicated between rehabilitation services as well as with other sectors (for example, educational institutions). This communication ensured that everyone was working toward a clearly defined and common goal. The committee agreed with both findings, but acknowledged that various barriers (for example, incompatible software or organisational procedures) can prevent this happening in practice. The committee therefore recommended that practitioners involved in the person’s care should collaborate over delivery of interventions and approaches , to support the person and ensure coordinated, joined-up and timely delivery of the rehabilitation plan. Please note that this recommendation also uses evidence from evidence review B, where the remainder of the committee’s discussion can be found.

Low quality evidence from the theme ‘C3.1.3 Ongoing review and revision of goals’ showed that that people with CND, their family members and rehabilitation practitioners reported that the number and type of rehabilitation goals set, as well as the frequency of review changed throughout rehabilitation. More goals were set at the beginning of rehabilitation, with shorter times between review and with a focus on physical rehabilitation. These goals naturally become longer-term and more psychological as rehabilitation progresses, needs change and priorities are revised. The committee agreed with this evidence and noted that this period of transition between acute and longer-term goals should be accompanied by a review of goals and interventions as they will undoubtedly need updating.

Very low quality evidence from the theme ‘C1.4 Realistic planning’ showed that planning and goal setting are made realistic when conversations are honest and acknowledge the potential for negative outcomes. The committee agreed with this evidence, and noted that this includes negative outcomes of planned interventions or packages. In their experience, rehabilitation for chronic neurological disorders is not a ‘one-size fits all’ discipline, and may require some trialling to find what works for an individual and their circumstances. Therefore, they recommended to discuss and agree aspects of rehabilitation which may be delivered at a later date as well as what would inform decisions about the discontinuation of interventions. These honest and clear discussions will help to set expectations of rehabilitation outcomes, and clearly outline alternatives if a particular offering is not beneficial for an individual, which in turn will help with continues engagement in a long rehabilitation process. The committee stressed that these discussions and decisions can be very sensitive, as they include people with life-limited conditions and the decisions of when to stop certain treatments (for example, ventilatory support).

Pain management

The committee discussed the importance of identifying pain in people with CND in order to enable appropriate management. They highlighted that management of pain is fundamental in enabling the person to engage in rehabilitation activities and treatments that will improve overall health and wellbeing. The committee emphasised that it is paramount to ask this question as pain is common but not always independently raised by a person with CND. This could be because they assume it is normal for their disorder, or they mistakenly believe there is nothing that can be done about it. Given the significant impact pain can have, the committee recommended that healthcare professionals ask this question to people with CND as part of holistic rehabilitation needs assessment.

The committee discussed the importance of proactively supporting people with CND in pain management during rehabilitation. The committee highlighted that quite often people with CND may persevere with pain or be prescribed analgesia that is inadequate for the management of their pain, resulting in individuals being less likely to engage in rehabilitation activities and treatment that will improve overall health and wellbeing. The committee emphasised that healthcare professionals can support people with CND understand the nature of their pain and offer appropriate management options, which may include changing their analgesics to an alternative that better manages their level of pain or adjusting the timing of their analgesia in line with their rehabilitation activities. Therefore, the committee recommended to proactively support people in managing their pain and ensure they have adequate analgesia to facilitate rehabilitation. However, they highlighted that analgesia is only 1 pain management option and may not be appropriate for everyone.

The committee were aware that there is already published NICE guidance on chronic and neuropathic pain, which have been cross-referenced at the beginning of this section. However, they noted that these guidelines only cover the adult population. Given the highly complex nature of pain management in people with CND, and that none of the evidence reviews informing this guideline specifically searched for pain management interventions, the committee did not make any direct recommendations on treating paediatric pain. However, they did make a recommendation to seek specialist advice on pain management for children and young people with chronic and neuropathic pain.

Finally, the committee discussed that people with CND can often have a range of complex pain issues (for example, post-traumatic pain in the spine or skull). There is also an assumption that pain will always be secondary in nature so will respond well to analgesia, which is not always true. For example, people with Parkinson’s disease can have complex pain caused by altered sensory integration and have poorly explained pain of central origin. Rehabilitation professionals should consider referral to a pain specialist (for example, a local pain management team), for individuals presenting with a diagnostic difficulty or if they would like specialist advice on biopsychosocial interventions.

Cognitive function

Assessment

Very low quality evidence from the theme ‘C1.1 Assessment tools’ showed that people with CND had conflicting opinions about the cognitive assessment tools used in their reviews. Some believed that the tools were suitable given that they had to be applicable to a wide range of people and abilities. Others, especially those who had longer disease durations and more experience with rehabilitation reviews, felt as though cognitive assessment tools were unhelpful and patronising. People believed that this could be overcome by rehabilitation therapists explaining the assessment tools and what exactly they are being used for. The committee agreed with the finding, therefore recommended to explain the purpose of any cognitive tests before using them, unless this would invalidate the test.

Application of recommendations across the guideline population

Finally, the committee considered the breadth of the conditions included in this guideline and discussed whether these recommendations could be applied to all of them. As the recommendations are written at a high level and do not include references to specific interventions, the committee were confident that they would be applicable to all chronic neurological disorders included by this guideline.

There was 1 theme identified in this review that the committee did not use to inform any specific recommendations. Low quality evidence from the theme ‘C1.3 Format’ showed that people with CND, their family members and rehabilitation practitioners believe that written rehabilitation plans should be provided alongside verbal conversations. They were seen to be very helpful in clearly setting out the next rehabilitation stages and giving people an opportunity to absorb a lot of information in their own time. It helps if written rehabilitation plans include a range of formats, according to need (for example, both text and pictures). The committee agreed that multiple formats can be helpful helping people to digest and revisit information in a flexible timeframe. However, they noted that they have made several recommendations throughout the guideline on the provision of personalised information at multiple stages of the rehabilitation process, and that this personalisation extends to a format most suitable to an individual.

Cost effectiveness and resource use

During the development of this qualitative review, targeted searches for cost-effectiveness evidence were planned. However, the committee found no recommendations that would benefit from such searches. Consequently, there was no existing economic evidence for this review, and all recommendations are based on qualitative evidence and the committee's collective experience.

The committee explained that most recommendations outline good practice points and should already be happening. However, they acknowledged variation in practice and that undertaking a rehabilitation needs assessment in line with the recommendations may have resource implications where practices are sub-optimal. Any additional costs may be offset by timely and appropriate care, preventing costly hospital admissions and emergency care. It may also enable better planning and coordination of rehabilitation resources, reducing inappropriate appointments and service referrals, and ensuring more efficient service delivery.

The committee noted that more consistent consideration of functional capability, symptoms, and impairment could lead to more needs being identified and greater demand for related support and treatment services, which is justified by clinical needs.

Currently, many assessments are happening but are not coordinated to provide a holistic view of needs, leading to wasted healthcare resources, such as professional time and inappropriate care, incurring substantial costs to the NHS and wider public sector.

Similarly, goal setting is happening but varies in practice, potentially leading to resource implications where practices are sub-optimal. The committee discussed that appropriate goal setting can increase engagement and participation in rehabilitation, improving overall health and wellbeing.

The committee further discussed that rehabilitation plans are used but vary in extent and quality. They noted that more consistent needs assessments will result in more effective rehabilitation plans aligned with clinical needs, potentially increasing demand for support services and treatment, but this is justified by clinical needs.

The committee discussed that unaddressed needs due to, for example, lack of assessment, appropriate goal setting, and rehabilitation plans often require expensive interventions later, results in greater use of unplanned care and reliance on formal care, incurring substantial costs to the NHS and wider public sector.

It was discussed that more practitioner time may be needed to, for example, facilitate collaboration and sharing of rehabilitation assessments and plans. However, the committee discussed that any additional costs would be offset by benefits such as improved continuity of care, timely and holistic care, and cost savings from reduced unplanned care visits, avoiding crises and emergency care, and reducing caregiver burden and related costs.

The committee explained that pain management, including seeking specialist advice when needed, is already an integral part of rehabilitation. Including pain assessment in holistic needs assessments and consistently considering it throughout the rehabilitation journey may identify more people needing pain management. However, many existing rehabilitation interventions can reduce pain or improve pain management, so no significant increase in resource use is anticipated. Additionally, analgesics are widely used and generally are low cost.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.8.9, 1.8.14 to 1.8.19, 1.9.1 to 1.9.9, 1.10.1 to 1.10.2, 1.10.5, 1.10.7, 1.10.8, 1.13.1 to 1.13.5, and 1.18.12.

References – included studies

Qualitative

Botchway-Commey 2022

Botchway-Commey, Edith, Muscara, Frank, Greenham, Mardee et al. (2022) Rehabilitation models of care for children and youth with traumatic brain and/or spinal cord injuries: A focus on service structure, service organization, and the barriers and facilitators of rehabilitation service provision. Neuropsychological rehabilitation: 1-31

Collins 2023

Collins, Alana, D'Cruz, Kate, Jackman, Angie et al. (2023) Engaging children and adolescents with acquired brain injury and their families in goal setting: The family perspective. Neuropsychological rehabilitation 33(1): 1-23

Hickling 2022

Hickling, A., Mah, K., Al-Hakeem, H. et al. (2022) Exploring the experiences of youth with persistent post-concussion symptoms and their families with an interprofessional team-based assessment. Journal of interprofessional care: 1-10

Jenkin 2022a

Jenkin, Taylor, Anderson, Vicki, D'Cruz, Kate et al. (2022) Engaging children and adolescents with acquired brain injury and their families in goal setting: The clinician perspective. Neuropsychological rehabilitation 32(1): 104-130

Jenkin 2022b

Jenkin, Taylor, D'Cruz, Kate, Anderson, Vicki et al. (2022) Family-centred service in paediatric acquired brain injury rehabilitation: perspectives of children and adolescents and their families. Disability and rehabilitation: 1-12

Preston 2012

Preston, Jenny, Haslam, Simon, Lamont, Lynn et al. (2012) What do people with multiple sclerosis want from an occupational therapy service?. The British Journal of Occupational Therapy 75(6): 264-270

Sexton 2013

Sexton, Deborah (2013) ‘As Good as it's Going to Get’. Bad News Conversations in Neurology: Challenges for Occupational Therapists. British Journal of Occupational Therapy 76(6): 270-279

Shore 2022

Shore, Josh, Bernick, Alana, Nalder, Emily et al. (2022) Adolescent and parent experiences with Tele-Active Rehabilitation for concussion: an exploratory qualitative study. Brain injury 36(9): 1140-1148

Twigg 2021

Twigg, Jessica, Methley, Abigail, Lavin, Tim et al. (2021) Living with Polyneuropathy Organomegaly Endocrinopathy Monoclonal gammopathy Skin changes (POEMS) syndrome: a case study of healthcare experiences and quality of life. Disability and rehabilitation 43(17): 2502-2510

Van De Weyer 2010

Van De Weyer, R C; Ballinger, C; Playford, E D (2010) Goal setting in neurological rehabilitation: staff perspectives. Disability and rehabilitation 32(17): 1419-27

Appendices

Appendix A Review protocols

Review protocol for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

Table 3: Review protocol

ID	Field	Content
0.	PROSPERO registration number	Not registered with PROSPERO as review does not contain any health outcomes.
1.	Review title	Assessing and reviewing rehabilitation needs and agreeing and reviewing rehabilitation plans – views and preferences.
2.	Review question	Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?
3.	Objective	• To establish what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans – based on the views and preferences of people with chronic neurological disorders, their families and carers. • To establish what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans – based on the views and preferences of practitioners in health and social care, education and employment and the charitable and voluntary sectors.
4.	Searches	The following databases will be searched: • Medline All • Embase • Cochrane Database of Systematic Reviews (CDSR) • PsycInfo • Social Policy and Practice

ID	Field	Content
		Searches will be restricted to: • Date: 2010 - present • English language • Human studies • OECD Geographic filter (amended) Conference proceedings, editorials, case reports, new, historical articles and letters will be excluded Other searches: • Additional searching may be undertaken if required. With the agreement of the guideline committee the searches will be re-run 6 weeks before final submission of the review and further studies retrieved for inclusion. The full search strategies will be published in the final review.
5.	Condition or domain being studied	Views and preferences about the way in which rehabilitation needs are assessed and reviewed and rehabilitation plans are formulated, agreed and reviewed.
6.	Population	**Inclusion:** • Adults and children with rehabilitation needs due to the following chronic neurological disorders: ○ Acquired brain injury ○ Acquired spinal cord injury ○ Acquired peripheral nerve disorders ○ Progressive neurological diseases ○ Functional neurological disorders • Family and carers of people with chronic neurological disorders. • Health and social care practitioners who work with people with chronic neurological disorders, including voluntary and third sector providers. • Practitioners involved in rehabilitation for education, employment and social participation.

ID	Field	Content
		Exclusion: • Conditions which do not fit one of the 5 categories of chronic neurological disorder as defined in the guideline scope. These exclusions will be by exception and examined on a case-by-case basis rather than whole disorder groups. For example, this guideline will not cover autonomic neuropathy or the acute stabilisation of conditions such as encephalitis or hydrocephalus and will not cover degenerative disc disorder as spinal discs do not form part of the spinal cord. • Disorders for which interventions are primarily focused on altering body structure and functions, for example isolated peripheral nerve injuries, that is single nerve or plexus injuries. • Surgical management of conditions (for example brain tumours, orthopaedic complications). • Conditions for which NICE rehabilitation and rehabilitation related recommendations already exist, including stroke in people aged 16 years and over, dementia including Alzheimer’s disease, cerebral palsy, myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome and post-COVID-19 syndrome. • Early rehabilitation after spinal cord injury as this will be covered in the NICE guideline on rehabilitation after traumatic injury
7.	Phenomenon of interest	The committee wish to locate qualitative evidence on what works well and what could be improved about the way in which rehabilitation needs are assessed and reviewed and rehabilitation plans are formulated, agreed and reviewed. They anticipate that data from included studies will cover a number of key themes although they are aware that other relevant themes may also be identified. Expected themes include: • Acceptability – data may relate to people’s experiences of the way in which rehabilitation needs are assessed and reviewed and plans are formulated, for example, interactions between people with chronic neurological disorders and practitioners, the timing of assessment and planning or the settings in which assessments are conducted and reviews undertaken. • Provision of information – data may relate to information given to people before an assessment or review, particularly information that would help them prepare for appointments and understand what to expect. • Integration and co-ordination within and between rehabilitation services – data may relate to people’s experiences of assessments, reviews and planning undertaken with multiple practitioners or teams. • Personalisation of assessment and review including planning rehabilitation and goal setting – data may relate to people’s views on whether their assessment, review and planning were appropriate to their individual and

ID	Field	Content
		family needs and circumstances. Also whether they felt at the centre of these processes and enabled to express their preferences and aims for rehabilitation. • Sustainability of rehabilitation and consideration of chronic nature of conditions – there may be evidence about the way in which people's changing needs and preferences are reviewed and plans changed to reflect movement between services or settings. • Equalities considerations – data may relate to the assessment and review of rehabilitation needs and goal setting with people facing inequalities relating to race and gender and people with pre-existing physical, mental health or behavioural conditions, communication impairments and physical, learning disabilities and neurodiversity. It will also consider age-related assumptions, engagement and cultural differences. • Addressing disputed assessments – there may be data about the views of people participating in assessments, which are disputed or contested by one party. Data may relate to the way in which contested assessments are handled and resolved and any learning for the future is implemented.
8.	Comparator/Reference standard/Confounding factors	Not applicable as this is a qualitative review.
9.	Types of study to be included	• Systematic reviews of qualitative studies • Studies using qualitative methods: data collection via focus groups, semi-structured and structured interviews, observations • Surveys conducted using open ended questions and a qualitative analysis of responses Note: Mixed-methods studies will be included but only qualitative data will be extracted and risk of bias assessed.
10.	Other exclusion criteria	Inclusion: • Full text papers • Studies conducted in the UK • If insufficient* UK data are available to support decision making about children and young people, then evidence from Australia, New Zealand and Canada will be considered. *Sufficiency will be judged on considerations such as number of studies and size and breadth of population. Exclusion:

ID	Field	Content
		• Articles published before 2010 • Papers that do not include methodological details will not be included as they do not provide sufficient information to evaluate risk of bias/ study quality. • Studies using quantitative methods only (including surveys that report only quantitative data) • Surveys using mainly closed questions or which quantify open ended answers for analysis. • Non-English language articles • Conference proceedings • Abstract only • Books, book chapters and theses Thematic saturation: 1. Data or theme(s) from included studies will not be extracted for particular theme(s) if thematic saturation is reached. 2. Papers included on full text will subsequently be excluded when the whole anticipated framework of phenomena (7 anticipated themes listed in row 7) has reached thematic saturation. That is, when evidence synthesis and the application of GRADE-CERQual show that data about all 7 aspects of the phenomenon of interest are ‘adequate’ and ‘coherent’. See row 7 above for details of the anticipated framework of phenomenon and associated rationale.
11.	Context	Settings: • Included: ○ All inpatient, outpatient and community settings in which either fully or partially publicly funded rehabilitation assessments are conducted or reviewed and planning for rehabilitation programmes takes place.. • Excluded: ○ Accident and emergency departments. ○ Critical care units ○ Prisons

ID	Field	Content
12.	Primary outcomes (critical outcomes)	Not applicable as this is a qualitative review. For anticipated themes, see row 7 above, ‘Phenomenon of interest’
13.	Secondary outcomes (important outcomes)	Not applicable as this is a qualitative review. For anticipated themes, see row 7 above, ‘Phenomenon of interest’
14.	Data extraction (selection and coding)	• All references identified by the searches and from other sources will be uploaded into EPPI-Reviewer 5 and de-duplicated. • Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. • Dual sifting will be performed on at least 10% of records (or 300 records, whichever is smaller); 90% agreement is required and disagreements will be resolved via discussion with the senior systematic reviewer. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed along with the reason for its exclusion. • The included and excluded studies lists will be circulated to the Topic Group for their comments. Resolution of disputes will be by discussion between the senior reviewer, Topic Advisor and Chair. • A standardised form will be used to extract data from included studies, providing study reference, research question, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (that is, • supporting quotes). One reviewer will extract relevant data into a standardised form. This will be quality assessed by the senior reviewer.
15.	Risk of bias (quality) assessment	Risk of bias of individual qualitative studies will be assessed using the CASP qualitative checklist, and systematic reviews of qualitative studies will be assessed using the CASP Systematic Review checklist. See Appendix H in Developing NICE guidelines: the manual for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by the senior reviewer.
16.	Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes as ‘review findings’. • The GRADE-CERQual approach will be used to summarise the confidence in the review findings synthesized from the qualitative evidence (‘Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series’; Lewin 2018).

ID	Field	Content		
		• The overall confidence in evidence about each review finding will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance.		
17.	Analysis of sub-groups	As this is a qualitative review subgroup analysis is not possible. However, if data allow, the review will include information regarding differences in views held between certain groups, for example, the five identified 'types' of chronic neurological disorders. In these circumstances the committee will consider whether there is a case to make separate recommendations for different groups of for people in different circumstances.		
18.	Type and method of review	☐	Intervention	
		☐	Diagnostic	
		☐	Prognostic	
		☒	Qualitative	
		☐	Epidemiologic	
		☐	Service Delivery	
		☐	Other (please specify)	
19.	Language	English		
20.	Country	England		
21.	Anticipated or actual start date	November 2021		
22.	Anticipated completion date	December 2023		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☑	☑
		Piloting of the study selection process	☑	☑
		Formal screening of search results against eligibility criteria	☑	☑
		Data extraction	☑	☑
		Risk of bias (quality) assessment	☑	☑

ID	Field	Content		
		Data analysis	☑	☑
24.	Named contact	**5a. Named contact** National Institute for Health and Care Excellence (NICE) **5b. Named contact e-mail** rehabforcnd@nice.org.uk **5c. Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE)		
25.	Review team members	NICE review team		
26.	Funding sources/sponsor	This systematic review is being completed by NICE which receives funding from the Department of Health and Social Care.		
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10181/documents		
29.	Other registration details	Not applicable.		
30.	Reference/URL for published protocol	Not applicable.		
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as:		

ID	Field	Content	
		• notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
32.	Keywords	Rehabilitation; Delivery; Service improvement; Neurological disorders; Chronic conditions; Qualitative.	
33.	Details of existing review of same topic by same authors	Not applicable.	
34.	Current review status	☐	Ongoing
		☐	Completed but not published
		☒	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
35..	Additional information	Not applicable.	
36.	Details of final publication	www.nice.org.uk	

CASP: Critical skills appraisal programme; COVID-19: coronavirus; GRADE-CERQual: Grading of recommendations assessment, development and evaluation – confidence in the evidence from reviews of qualitative research; N/A: not applicable; OECD: Organisation for Economic Co-operation and Development; PROSPERO: International prospective register of systematic reviews

Appendix B Literature search strategies

Literature search strategies for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

Note: A single economic search was undertaken for all topics included in the scope of this guideline. Databases searched, and search strategies for the economic search are summarised in the Economics Supplement.

Note: A combined search was undertaken for Review A and Review C

Database: Ovid MEDLINE(R) ALL

Date of last search: 23/02/2023

1	(CRANIOCEREBRAL TRAUMA/ or brain injuries/ or exp brain hemorrhage, traumatic/ or exp brain injuries, diffuse/ or exp brain injuries, traumatic/ or exp brain injury, chronic/ or Shaken Baby Syndrome/ or HYPOXIA, BRAIN/ or Brain Damage, Chronic/ or exp INTRACRANIAL HEMORRHAGE, TRAUMATIC/ or exp BRAIN NEOPLASMS/ or BRAIN DISEASES/ or BRAIN ABSCESS/ or BRAIN DISEASES, METABOLIC/ or CEREBELLAR DISEASES/ or cerebrovascular disorders/ or basal ganglia cerebrovascular disease/ or cerebrovascular trauma/ or intracranial arteriovenous malformations/ or "intracranial embolism and thrombosis"/ or intracranial hemorrhages/ or vascular headaches/ or exp ENCEPHALITIS/ or exp HYDROCEPHALUS/) not (exp STROKE/ or dementia/)
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)).ti,ab.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
5	(brain* adj2 abscess*).ti,ab.
6	(carotid arter* adj2 (disease* or injur*)).ti,ab.
7	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
8	exp STROKE/ and (ADOLESCENT/ or MINORS/ or exp CHILD/ or exp INFANT/ or exp PEDIATRICS/ or exp PUBERTY/)
9	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.
10	exp SPINAL CORD INJURIES/ or exp SPINAL CORD NEOPLASMS/ or EPIDURAL ABSCESS/ or SPINAL CORD DISEASES/ or exp SPINAL CORD VASCULAR DISEASES/ or SPINAL CORD COMPRESSION/ or MYELITIS, TRANSVERSE/
11	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
12	(Central cord syndrome* or transverse myelitis).ti,ab.
13	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
14	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
15	PERIPHERAL NERVE INJURIES/ or exp CRANIAL NERVE INJURIES/ or PERIPHERAL NERVOUS SYSTEM NEOPLASMS/ or exp CRANIAL NERVE NEOPLASMS/ or exp PERIPHERAL NERVOUS SYSTEM DISEASES/ or exp CRANIAL NERVE DISEASES/

16	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
17	(Guillain* adj1 Barr*).ti,ab.
18	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
19	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
20	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
21	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
22	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
23	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.
24	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.
25	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
26	(periph* adj2 neuropath*).ti,ab.
27	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
28	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
29	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.
30	exp MOTOR NEURON DISEASE/ or POSTPOLIOMYELITIS SYNDROME/ or exp PARKINSONIAN DISORDERS/ or MUSCULAR DYSTROPHY, DUCHENNE/ or exp MULTIPLE SCLEROSIS/ or NEUROMUSCULAR DISEASES/ or SPASTIC PARAPLEGIA, HEREDITARY/ or FRIEDREICH ATAXIA/ or exp MULTIPLE SYSTEM ATROPHY/ or SUPRANUCLEAR PALSY, PROGRESSIVE/ or CORTICOBASAL DEGENERATION/ or LEUKODYSTROPHY, METACHROMATIC/ or exp MITOCHONDRIAL MYOPATHIES/ or exp MUCOPOLYSACCHARIDOSES/ or WILLIAMS SYNDROME/ or GENETIC DISEASES, INBORN/ or RETT SYNDROME/ or FETAL ALCOHOL SPECTRUM DISORDERS/ or DYSTONIC DISORDERS/ or "HEREDITARY SENSORY AND MOTOR NEUROPATHY"/ or SPINAL DYSRAPHISM/
31	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
32	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
33	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
34	(bulbar adj1 pals*).ti,ab.
35	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
36	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
37	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
38	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
39	(muscular adj1 dystroph*).ti,ab.
40	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
41	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
42	"friedreich* ataxia*".ti,ab.
43	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
44	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
45	(progressive adj1 supranuclear adj1 pals*).ti,ab.
46	(richardson* adj1 (disease? or syndrome?)).ti,ab.
47	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
48	(white adj1 matter adj1 disorder?).ti,ab.
49	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.
50	(lysosomal adj1 storage adj1 disorder?).ti,ab.
51	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
52	(perinatal illness* or perinatal hypoxia*).ti,ab.
53	(primary adj1 dystonia?).ti,ab.
54	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
55	(spina bifida? or spinal dysraphism?).ti,ab.
56	MOVEMENT DISORDERS/ or MOTOR DISORDERS/ or CONVERSION DISORDER/

57	((functional* or psychogenic* or dissociative*) adj1 neurologic* adj1 (disorder* or dysfunction* or difficult*)).ti,ab.
58	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.
59	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
60	(pseudo-seizure* or pseudoseizure*).ti,ab.
61	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
62	or/1-61
63	exp REHABILITATION/ or rehab.fs.
64	Rehabilitation Nursing/ or Hospitals, Rehabilitation/ or Social Work/ or exp Nutrition Therapy/ or Neuropsychiatry/ or Rehabilitation Centers/ or Social Workers/ or occupational therapists/ or physical therapists/ or nutritionists/ or Psychology/ or Consultants/ or "Prostheses and Implants"/ or exp Physical Therapy Modalities/
65	(rehab* or telerehab* or neurorehab*).ti,ab.
66	or/63-65
67	62 and 66
68	patients/px or Inpatients/px or caregivers/px or exp family/px
69	attitude/ or "Attitude of Health Personnel"/ or attitude to health/ or Health Knowledge, Attitudes, Practice/ or "patient acceptance of health care"/ or patient satisfaction/ or patient preference/ or emotions/ or consumer behavior/
70	(care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*).ti.
71	((care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
72	(brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*).ti.
73	((brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
74	(attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*).ti.
75	or/68-74
76	67 and 75
77	((rehab* or telerehab* or neurorehab*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
78	62 and 77
79	76 or 78
80	letter/
81	editorial/
82	news/
83	exp historical article/
84	Anecdotes as Topic/
85	comment/
86	case report/
87	(letter or comment*).ti.
88	or/80-87
89	randomized controlled trial/ or random*.ti,ab.
90	88 not 89
91	animals/ not humans/

92	exp Animals, Laboratory/
93	exp Animal Experimentation/
94	exp Models, Animal/
95	exp Rodentia/
96	(rat or rats or mouse or mice).ti.
97	or/90-96
98	79 not 97
99	limit 98 to english language
100	(2010* or 2011* or 2012* or 2013* or 2014* or 2015* or 2016* or 2017* or 2018* or 2019* or 2020* or 2021* or 2022* or 2023*).ed,dt.
101	99 and 100
102	exp United Kingdom/
103	(national health service* or nhs*).ti,ab,in.
104	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
105	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in.
106	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in.
107	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in.
108	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in.
109	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in.
110	or/102-109
111	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp australia/ or exp oceania/) not (exp United Kingdom/ or europe/)
112	110 not 111
113	101 and 112
114	exp Infant/ or Infant Health/ or Infant Welfare/
115	(prematur* or pre-matur* or preterm* or pre-term* or infan* or newborn* or new-born* or perinat* or peri-nat* or neonat* or neo-nat* or baby* or babies or toddler*).ti,ab,in,jn.
116	exp Child/ or exp Child Behavior/ or Child Health/ or Child Welfare/
117	Minors/
118	(child* or minor or minors or boy* or girl* or kid or kids or young*).ti,ab,in,jn.
119	exp pediatrics/
120	(pediatric* or paediatric* or peadiatric*).ti,ab,in,jn.
121	Adolescent/ or Adolescent Behavior/ or Adolescent Health/
122	Puberty/

123	(adolescen* or pubescen* or prepubescen* or pre-pubescen* or pubert* or prepubert* or pre-pubert* or teen* or preteen* or pre-teen* or juvenil* or youth* or under*age*).ti,ab,in,jn.
124	Schools/
125	Child Day Care Centers/ or exp Nurseries/ or Schools, Nursery/
126	(pre-school* or preschool* or kindergar* or daycare or day-care or nurser* or school* or pupil* or student*).ti,ab,jn.
127	("under 18*" or "under eighteen*" or "under 25*" or "under twenty five*").ti,ab.
128	or/114-127
129	Qualitative Research/
130	Nursing Methodology Research/
131	Interview.pt.
132	exp Interviews as Topic/
133	Questionnaires/
134	Narration/
135	Health Care Surveys/
136	(qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw.
137	(ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw.
138	(hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw.
139	(metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw.
140	"critical interpretive synthes*".tw.
141	(realist adj (review* or synthes*)).tw.
142	(noblit and hare).tw.
143	(meta adj (method or triangulation)).tw.
144	(CERQUAL or CONQUAL).tw.
145	((thematic or framework) adj synthes*).tw.
146	or/129-145
147	101 and 113 and 146
148	101 and 128 and 146
149	147 or 148

Database: Embase

Date of last search: 23/02/2023

1	(head injury/ or exp brain injury/ or chronic brain disease/ or brain hemorrhage/ or brain hypoxia/ or exp brain tumor/ or brain disease/ or brain abscess/ or metabolic encephalopathy/ or cerebellum disease/ or exp cerebrovascular disease/ or encephalitis/ or hydrocephalus/) not (exp cerebrovascular accident/ or dementia/)
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or infarcti* or hypoxi* or drown*)).ti,ab.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
5	(brain* adj2 abscess*).ti,ab.
6	(carotid arter* adj2 (disease* or injur*)).ti,ab.
7	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
8	exp cerebrovascular accident/ and (adolescent/ or "minor (person)"/ or exp child/ or exp infant/ or pediatrics/ or exp pediatrics/ or exp puberty/)
9	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.

10	exp spinal cord injury/ or exp spinal cord tumor/ or epidural abscess/ or spinal cord disease/ or exp spinal cord vascular disease/ or spinal cord compression/ or transverse myelitis/
11	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
12	(Central cord syndrome* or transverse myelitis).ti,ab.
13	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
14	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
15	peripheral nerve injury/ or exp cranial nerve injury/ or peripheral nerve tumor/ or exp cranial nerve tumor/ or exp peripheral neuropathy/ or exp cranial neuropathy/
16	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
17	(Guillain* adj1 Barr*).ti,ab.
18	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
19	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
20	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
21	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
22	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
23	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.
24	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.
25	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
26	(periph* adj2 neuropath*).ti,ab.
27	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
28	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
29	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.
30	exp motor neuron disease/ or postpoliomyelitis syndrome/ or exp parkinsonism/ or Duchenne muscular dystrophy/ or exp multiple sclerosis/ or neuromuscular disease/ or hereditary motor sensory neuropathy/ or Friedreich ataxia/ or exp Shy Drager syndrome/ or progressive supranuclear palsy/ or corticobasal degeneration/ or metachromatic leukodystrophy/ or exp mitochondrial myopathy/ or exp mucopolysaccharidosis/ or Williams Beuren syndrome/ or genetic disorder/ or Rett syndrome/ or fetal alcohol syndrome/ or dystonic disorder/ or hereditary motor sensory neuropathy/ or spinal dysraphism/
31	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
32	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
33	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
34	(bulbar adj1 pals*).ti,ab.
35	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
36	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
37	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
38	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
39	(muscular adj1 dystroph*).ti,ab.
40	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
41	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
42	"friedreich* ataxia*".ti,ab.
43	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
44	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
45	(progressive adj1 supranuclear adj1 pals*).ti,ab.
46	(richardson* adj1 (disease? or syndrome?)).ti,ab.
47	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
48	(white adj1 matter adj1 disorder?).ti,ab.
49	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.

50	(lysosomal adj1 storage adj1 disorder?).ti,ab.
51	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
52	(perinatal illness* or perinatal hypoxia*).ti,ab.
53	(primary adj1 dystonia?).ti,ab.
54	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
55	(spina bifida? or spinal dysraphism?).ti,ab.
56	motor dysfunction/ or motor dysfunction/ or conversion disorder/
57	((functional* or psychogenic* or dissociative*) adj1 neurologic* adj1 (disorder* or dysfunction* or difficult*)).ti,ab.
58	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.
59	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
60	(pseudo-seizure* or pseudoseizure*).ti,ab.
61	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
62	or/1-61
63	exp rehabilitation/ or rh.fs.
64	rehabilitation nursing/ or rehabilitation center/ or social work/ or diet therapy/ or neuropsychiatry/ or social worker/ or occupational therapist/ or physiotherapist/ or dietitian/ or psychologist/ or exp physiotherapy/ or exp consultation/ or prosthesis/ or "prostheses and orthoses"/
65	(rehab* or telerehab* or neurorehab*).ti,ab.
66	or/63-65
67	62 and 66
68	health personnel attitude/ or dietitian attitude/ or nurse attitude/ or occupational therapist attitude/ or physician assistant attitude/ or physician attitude/ or physiotherapist attitude/ or psychotherapist attitude/ or social worker attitude/ or consumer attitude/ or patient attitude/ or patient satisfaction/ or patient preference/ or attitude to health/ or attitude to illness/ or family attitude/ or parental attitude/ or paternal attitude/ or maternal attitude/ or attitude to illness/ or attitude/ or emotion/ or protocol compliance/ or knowledge/ or satisfaction/
69	(care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*).ti.
70	((care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
71	(brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*).ti.
72	((brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
73	(attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*).ti.
74	or/68-73
75	67 and 74
76	((rehab* or telerehab* or neurorehab*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
77	62 and 76
78	75 or 77
79	letter.pt. or letter/
80	note.pt.
81	editorial.pt.

82	case report/ or case study/
83	(letter or comment*).ti.
84	or/79-83
85	randomized controlled trial/ or random*.ti,ab.
86	84 not 85
87	animal/ not human/
88	nonhuman/
89	exp Animal Experiment/
90	exp Experimental Animal/
91	animal model/
92	exp Rodent/
93	(rat or rats or mouse or mice or rodent*).ti.
94	or/86-93
95	78 not 94
96	limit 95 to english language
97	(2010* or 2011* or 2012* or 2013* or 2014* or 2015* or 2016* or 2017* or 2018* or 2019* or 2020* or 2021* or 2022* or 2023*).dc.
98	96 and 97
99	(conference abstract* or conference review or conference paper or conference proceeding).db,pt,su.
100	98 not 99
101	exp United Kingdom/
102	(national health service* or nhs*).ti,ab,in,ad.
103	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
104	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad.
105	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad.
106	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad.
107	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad.
108	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad.
109	or/101-108
110	(exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/) not (exp united kingdom/ or europe/)
111	109 not 110
112	98 and 111
113	exp juvenile/ or Child Behavior/ or Child Welfare/ or Child Health/ or infant welfare/ or "minor (person)"/ or elementary student/

114	(prematur* or pre-matur* or preterm* or pre-term* or infan* or newborn* or new-born* or perinat* or peri-nat* or neonat* or neo-nat* or baby* or babies or toddler*).ti,ab,in,ad,jw.
115	(child* or minor or minors or boy* or girl* or kid or kids or young*).ti,ab,in,ad,jw.
116	exp pediatrics/
117	(pediatric* or paediatric* or peadiatric*).ti,ab,in,ad,jw.
118	exp adolescence/ or exp adolescent behavior/ or adolescent health/ or high school student/ or middle school student/
119	(adolescen* or pubescen* or prepubescen* or pre-pubescen* or pubert* or prepubert* or pre-pubert* or teen* or preteen* or pre-teen* or juvenil* or youth* or under*age*).ti,ab,in,ad,jw.
120	school/ or high school/ or kindergarten/ or middle school/ or primary school/ or nursery school/ or day care/
121	(pre-school* or preschool* or kindergar* or daycare or day-care or nurser* or school* or pupil* or student*).ti,ab,jw.
122	("under 18*" or "under eighteen*" or "under 25*" or "under twenty five*").ti,ab.
123	or/113-122
124	Qualitative Research/
125	exp Interview/
126	exp Questionnaire/
127	exp Observational Method/
128	Narrative/
129	(qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw.
130	(ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw.
131	(hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw.
132	(metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw.
133	"critical interpretive synthes*".tw.
134	(realist adj (review* or synthes*)).tw.
135	(noblit and hare).tw.
136	(meta adj (method or triangulation)).tw.
137	(CERQUAL or CONQUAL).tw.
138	((thematic or framework) adj synthes*).tw.
139	or/124-132
140	100 and 112 and 139
141	100 and 123 and 139
142	140 or 141

Database: Cochrane Database of Systematic Reviews

Date of last search: 23/02/2023

#1	MeSH descriptor: [Craniocerebral Trauma] this term only
#2	MeSH descriptor: [Brain Injuries] this term only
#3	MeSH descriptor: [Brain Hemorrhage, Traumatic] explode all trees
#4	MeSH descriptor: [Brain Injuries, Diffuse] explode all trees
#5	MeSH descriptor: [Brain Injuries, Traumatic] explode all trees
#6	MeSH descriptor: [Brain Injury, Chronic] explode all trees
#7	MeSH descriptor: [Shaken Baby Syndrome] this term only
#8	MeSH descriptor: [Brain Damage, Chronic] this term only
#9	MeSH descriptor: [Hypoxia, Brain] this term only
#10	MeSH descriptor: [Intracranial Hemorrhage, Traumatic] explode all trees
#11	MeSH descriptor: [Brain Neoplasms] explode all trees
#12	MeSH descriptor: [Brain Diseases] this term only

#13	MeSH descriptor: [Brain Abscess] this term only
#14	MeSH descriptor: [Brain Diseases, Metabolic] this term only
#15	MeSH descriptor: [Cerebellar Diseases] this term only
#16	MeSH descriptor: [Cerebrovascular Disorders] this term only
#17	MeSH descriptor: [Basal Ganglia Cerebrovascular Disease] this term only
#18	MeSH descriptor: [Cerebrovascular Trauma] this term only
#19	MeSH descriptor: [Intracranial Arteriovenous Malformations] this term only
#20	MeSH descriptor: [Intracranial Embolism and Thrombosis] this term only
#21	MeSH descriptor: [Intracranial Hemorrhages] this term only
#22	MeSH descriptor: [Vascular Headaches] this term only
#23	MeSH descriptor: [Encephalitis] this term only
#24	MeSH descriptor: [Hydrocephalus] this term only
#25	{or #1-#24}
#26	MeSH descriptor: [Stroke] explode all trees
#27	MeSH descriptor: [Dementia] this term only
#28	#26 or #27
#29	#25 NOT #28
#30	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) NEAR/2 (injur* or trauma* or damage* or disease* or dieases* or disorder* or infect* or hemorrhag* or haemorrhag* or neoplasm* or cancer* or tumour* or tumor* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)):ti,ab
#31	(chronic* NEAR/1 trauma* NEAR/2 encephalopath*):ti,ab
#32	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) NEAR/2 (neoplasm* or cancer* or tumour* or tumor* or carcinom* or adenocarcinom*)):ti,ab
#33	(brain* NEAR/2 abscess*):ti,ab
#34	(carotid arter* NEAR/2 (disease* or injur*)):ti,ab
#35	("basal ganglia disease" or "basal ganglia diseases" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cerebellar degenerate" or "paraneoplastic cerebellar degenerated" or "paraneoplastic cerebellar degenerative" or "paraneoplastic cerebellar degeneration" or "shaken baby syndrome" or "shaken baby syndromes" or "shaking baby syndrome" or "shaking baby syndromes"):ti,ab
#36	MeSH descriptor: [Stroke] explode all trees
#37	MeSH descriptor: [Adolescent] this term only
#38	MeSH descriptor: [Minors] this term only
#39	MeSH descriptor: [Child] explode all trees
#40	MeSH descriptor: [Infant] explode all trees
#41	MeSH descriptor: [Pediatrics] explode all trees
#42	MeSH descriptor: [Puberty] explode all trees
#43	{or #37-#42}
#44	#36 and #43
#45	((stroke or strokes) NEAR/3 (paediatric* or pediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age" or "under ages" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school ages" or "school age" or schoolage* or "under 16" or "under sixteen" or "under sixteens")):ti,ab
#46	MeSH descriptor: [Spinal Cord Injuries] explode all trees
#47	MeSH descriptor: [Spinal Cord Neoplasms] explode all trees
#48	MeSH descriptor: [Epidural Abscess] this term only
#49	MeSH descriptor: [Spinal Cord Diseases] this term only
#50	MeSH descriptor: [Spinal Cord Vascular Diseases] explode all trees
#51	MeSH descriptor: [Spinal Cord Compression] this term only
#52	MeSH descriptor: [Myelitis, Transverse] this term only
#53	((spinal* or spine or spines) NEAR/2 (injur* or trauma* or tumour* or tumor* or neoplasm* or cancer* or infect* or insult* or disease or diseases or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or hemorrhag* or haemorrhag*)):ti,ab
#54	("Central cord syndrome" or "Central cord syndromes" or transverse myelitis):ti,ab
#55	(epidural* NEAR/2 (neoplasm* or cancer* or tumour* or tumor* or abscess*)):ti,ab

#56	((spinal* or spine or spines) NEAR/2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)):ti,ab
#57	MeSH descriptor: [Peripheral Nerve Injuries] this term only
#58	MeSH descriptor: [Cranial Nerve Injuries] explode all trees
#59	MeSH descriptor: [Peripheral Nervous System Neoplasms] this term only
#60	MeSH descriptor: [Cranial Nerve Neoplasms] explode all trees
#61	MeSH descriptor: [Peripheral Nervous System Diseases] explode all trees
#62	MeSH descriptor: [Cranial Nerve Diseases] explode all trees
#63	((periph* or cranial*) NEAR/1 (nerve or nerves or nervous system) NEAR/2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumour* or tumor* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome or syndromes)):ti,ab
#64	(Guillain* NEAR/1 Barr*):ti,ab
#65	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or "ocular motility" or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) NEAR/1 nerve* NEAR/1 injur*):ti,ab
#66	(optic* NEAR/1 nerve* NEAR/2 (neoplasm* or cancer* or tumour* or tumor*)):ti,ab
#67	(brachial-plexus NEAR/1 (neuropath* or neuritis)):ti,ab
#68	("complex regional pain syndrome" or "complex regional pain syndromes" or causalgia or mononeuropath* or "nerve compression syndrome" or "nerve compression syndromes"):ti,ab
#69	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) NEAR/1 neuropath*):ti,ab
#70	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) NEAR/1 syndrome*):ti,ab
#71	(pudendal-neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*):ti,ab
#72	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or "ocular motility" or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) NEAR/1 nerve* NEAR/1 disease*):ti,ab
#73	(periph* NEAR/2 neuropath*):ti,ab
#74	(((periph* or cranial*) NEAR/2 (nerve or nerves or nervous system)) and lupus):ti,ab
#75	((multi-focal* or multifocal*) NEAR/2 motor NEAR/1 neuropath*):ti,ab
#76	(((periph* or cranial*) NEAR/2 (nerve or nerves or nervous system)) and alcohol*):ti,ab
#77	{or #29-#35, #44-#76}
#78	MeSH descriptor: [Motor Neuron Disease] explode all trees
#79	MeSH descriptor: [Postpoliomyelitis Syndrome] this term only
#80	MeSH descriptor: [Parkinsonian Disorders] explode all trees
#81	MeSH descriptor: [Muscular Dystrophy, Duchenne] this term only
#82	MeSH descriptor: [Multiple Sclerosis] explode all trees
#83	MeSH descriptor: [Neuromuscular Diseases] this term only
#84	MeSH descriptor: [Spastic Paraplegia, Hereditary] this term only
#85	MeSH descriptor: [Friedreich Ataxia] this term only
#86	MeSH descriptor: [Multiple System Atrophy] explode all trees
#87	MeSH descriptor: [Supranuclear Palsy, Progressive] this term only
#88	MeSH descriptor: [Corticobasal Degeneration] explode all trees
#89	MeSH descriptor: [Leukodystrophy, Metachromatic] this term only
#90	MeSH descriptor: [Mitochondrial Myopathies] explode all trees
#91	MeSH descriptor: [Mucopolysaccharidoses] explode all trees
#92	MeSH descriptor: [Williams Syndrome] this term only
#93	MeSH descriptor: [Genetic Diseases, Inborn] this term only
#94	MeSH descriptor: [Rett Syndrome] this term only
#95	MeSH descriptor: [Fetal Alcohol Spectrum Disorders] this term only
#96	MeSH descriptor: [Dystonic Disorders] this term only
#97	MeSH descriptor: [Hereditary Sensory and Motor Neuropathy] this term only
#98	MeSH descriptor: [Spinal Dysraphism] this term only
#99	(neurolog* NEAR/1 (condition* or disease* or damage* or disorder* or impair*)):ti,ab
#100	((motor-neuron* or gehrig* or charcott* or kennedy*) NEAR/1 disease*):ti,ab
#101	((amyotroph* or primary) NEAR/1 lateral* NEAR/1 sclero*):ti,ab
#102	(bulbar NEAR/1 pals*):ti,ab

#103	((muscular or muscle* or bulbo) NEAR/1 atroph* NEAR/1 spin*):ti,ab
#104	(progressiv* NEAR/1 (muscular or muscle*) NEAR/1 atroph*):ti,ab
#105	((postpolio* or post-polio*) NEAR/1 (syndrome or syndromes)):ti,ab
#106	(Parkinson* or duchenne* or multiple-sclerosis* or sclerosos* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy):ti,ab
#107	(muscular NEAR/1 dystroph*):ti,ab
#108	(neuromusc* NEAR/1 (disease* or disorder or disorders)):ti,ab
#109	(heredit* NEAR/1 spastic* NEAR/1 parapleg*):ti,ab
#110	("friedreich ataxia" or "friedreich ataxias" or "friedreichs ataxia" or "friedreichs ataxias"):ti,ab
#111	((multiple-system or olivopontocerebellar) NEAR/1 atroph*):ti,ab
#112	(shy-drager syndrome* or striatonigral-degenerat* or batten-disease or batten-diseases):ti,ab
#113	(progressive NEAR/1 supranuclear NEAR/1 pals*):ti,ab
#114	(richardson* NEAR/1 (disease or diseases or syndrome or syndromes)):ti,ab
#115	((corticobasal or cortico basal) NEAR/1 degenerat*):ti,ab
#116	(white-matter NEAR/1 (disorder or disorders)):ti,ab
#117	(metachromatic-leukodystroph* or mitochondrial-myopath* or mucopolysaccharidos*):ti,ab
#118	(lysosomal NEAR/1 storage NEAR/1 (disorder or disorders)):ti,ab
#119	((genetic or William* or catch-22 or rett* or congenital or fetal or foetal alcohol) NEAR/1 (syndrome or disorder*)):ti,ab
#120	(perinatal NEAR/1 (illness* or hypoxia*)):ti,ab
#121	(primary NEAR/1 (dystonia or dystonias)):ti,ab
#122	(heredit* NEAR/1 motor* NEAR/1 sens* NEAR/1 neuropath*):ti,ab
#123	(spina-bifida or bifidas or spinal-dysraphism or dysraphisms):ti,ab
#124	MeSH descriptor: [Movement Disorders] this term only
#125	MeSH descriptor: [Motor Disorders] this term only
#126	MeSH descriptor: [Conversion Disorder] this term only
#127	((functional* or psychogenic* or dissociative*) NEAR/1 neurologic* NEAR/1 (disorder* or dysfunction* or difficult*)):ti,ab
#128	((movement* or motor* or convers*) NEAR/1 (disorder* or dysfunct*)):ti,ab
#129	((psychogenic or dissociative or non-epilep* or nonepilep*) NEAR/1 (seizure* or convulsion* or fit or fits or spasm* or attack*)):ti,ab
#130	(pseudo-seizure or pseudoseizure):ti,ab
#131	(medical* NEAR/1 (unexplain* or un-explain*) NEAR/1 (symptom or symptoms)):ti,ab
#132	{or #77-#131}
#133	MeSH descriptor: [Rehabilitation] explode all trees
#134	MeSH descriptor: [] explode all trees and with qualifier(s): [rehabilitation - RH]
#135	MeSH descriptor: [Rehabilitation Nursing] this term only
#136	MeSH descriptor: [Hospitals, Rehabilitation] this term only
#137	MeSH descriptor: [Social Work] this term only
#138	MeSH descriptor: [Nutrition Therapy] explode all trees
#139	MeSH descriptor: [Neuropsychiatry] this term only
#140	MeSH descriptor: [Rehabilitation Centers] explode all trees
#141	MeSH descriptor: [Social Workers] this term only
#142	MeSH descriptor: [Occupational Therapists] this term only
#143	MeSH descriptor: [Physical Therapists] this term only
#144	MeSH descriptor: [Nutritionists] this term only
#145	MeSH descriptor: [Psychology] this term only
#146	MeSH descriptor: [Consultants] this term only
#147	MeSH descriptor: [Prostheses and Implants] this term only
#148	MeSH descriptor: [Physical Therapy Modalities] explode all trees
#149	(rehab* or telerehab* or neurorehab*):ti,ab
#150	{or #133-#149}
#151	#132 and #150

#152	MeSH descriptor: [Patients] this term only and with qualifier(s): [psychology - PX]
#153	MeSH descriptor: [Inpatients] this term only and with qualifier(s): [psychology - PX]
#154	MeSH descriptor: [Caregivers] this term only and with qualifier(s): [psychology - PX]
#155	MeSH descriptor: [Family] this term only and with qualifier(s): [psychology - PX]
#156	MeSH descriptor: [Attitude] this term only
#157	MeSH descriptor: [Attitude of Health Personnel] this term only
#158	MeSH descriptor: [Attitude to Health] this term only
#159	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
#160	MeSH descriptor: [Patient Acceptance of Health Care] this term only
#161	MeSH descriptor: [Patient Satisfaction] this term only
#162	MeSH descriptor: [Patient Preference] this term only
#163	MeSH descriptor: [Emotions] this term only
#164	MeSH descriptor: [Consumer Behavior] this term only
#165	(care NEXT team* or caring NEXT team* or caseworker* or case NEXT worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social NEXT worker* or specialist* or staff or therap*):ti
#166	((care NEXT team* or caring NEXT team* or caseworker* or case NEXT worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social NEXT worker* or specialist* or staff or therap*) NEAR/6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)):ab
#167	(brother* or carer* or caregiver* or care NEXT giver* or famil* or father* or guardian* or husband* or inpatient* or in NEXT patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*):ti
#168	((brother* or carer* or caregiver* or care NEXT giver* or famil* or father* or guardian* or husband* or inpatient* or in NEXT patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*) NEAR/6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)):ab
#169	(attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*):ti
#170	{or #152-#169}
#171	#151 and #170
#172	((rehab* or telerehab* or neurorehab*) near/6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)):ab
#173	#132 and #172
#174	#171 or #173
#175	conference:pt or (clinicaltrials or trialsearch or "www.who.int"):so
#176	#174 not #175 with Cochrane Library publication date Between Jan 2010 and Dec 2022

Social Policy and Practice

Date of last search: 23/02/2023

1	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)).ti,ab.
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) and (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)).hw.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	(chronic* and trauma* and encephalopath*).hw.
5	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.

6	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) and (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).hw.
7	(brain* adj2 abscess*).ti,ab.
8	(brain* and abscess*).hw.
9	(carotid arter* adj2 (disease* or injur*)).ti,ab.
10	(carotid arter* and (disease* or injur*)).hw.
11	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
12	("basal ganglia disease*" or encephalitis* or meningoencephalitis* or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").hw.
13	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.
14	(stroke* and (p?ediatric* or child* or adolescen* or kid* or youth* or youngster* or minor* or underage* or under-age* or "under age*" or teen* or juvenile* or boy* or girl* or schoolchild* or "school age*" or schoolage* or "under 16*" or "under sixteen*")).hw.
15	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
16	((spinal* or spine*) and (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease* or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).hw.
17	(Central cord syndrome* or transverse myelitis).ti,ab.
18	(Central cord syndrome* or transverse myelitis*).hw.
19	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
20	(epidural* and (neoplasm* or cancer* or tumo?r* or abscess*)).hw.
21	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
22	((spinal* or spine*) and (viral* or virus* or polio* or acquired immunodeficiency syndrome* or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).hw.
23	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
24	((periph* or cranial*) and (nerve* or nervous system*) and (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome*)).hw.
25	(Guillain* adj1 Barr*).ti,ab.
26	(Guillain* and Barr*).hw.
27	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
28	((abducen* or accessor* or facial* or glossopharyngeal* or hypoglossal* or oculomotor* or ocular* motility* or olfactory* or optic* or trigeminal* or trochlear* or vestibulocochlear*) and nerve* and injur*).hw.
29	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
30	(optic* and nerve* and (neoplasm* or cancer* or tumo?r*)).hw.
31	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
32	(brachial plexus* and (neuropath* or neuritis*)).hw.
33	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
34	(complex regional pain syndrome* or causalgia* or mononeuropath* or nerve compression syndrome*).hw.
35	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
36	((femoral* or median* or peroneal* or radial* or sciatic* or tibial* or ulnar*) and neuropath*).hw.
37	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.
38	((carpal-tunnel* or piriformis-muscle* or tarsal-tunnel* or thoracic-outlet*) and syndrome*).hw.
39	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.
40	(pudendal neuralgia* or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).hw.

41	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
42	((abducen* or accessory* or facial* or glossopharyngeal* or hypoglossal* or oculomotor* or ocular motility* or olfactory* or optic* or trigeminal* or trochlear* or vestibulocochlear*) and nerve* and disease*).hw.
43	(periph* adj2 neuropath*).ti,ab.
44	(periph* and neuropath*).hw.
45	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
46	((periph* or cranial*) and (nerve* or nervous system*) and lupus*).hw.
47	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
48	((multi-focal* or multifocal*) and motor* and neuropath*).hw.
49	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.
50	((periph* or cranial*) and (nerve* or nervous system*) and alcohol*).hw.
51	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
52	(neurolog* and (condition* or disease* or damage* or disorder* or impair*)).hw.
53	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
54	((motor-neuron* or gehrig* or charcott* or kennedy*) and disease*).hw.
55	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
56	((amyotroph* or primary*) and lateral* and sclero*).hw.
57	(bulbar adj1 pals*).ti,ab.
58	(bulbar* and pals*).hw.
59	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
60	((muscular* or muscle* or bulbo*) and atroph* and spin*).hw.
61	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
62	(progressiv* and (muscular* or muscle*) and atroph*).hw.
63	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
64	((postpolio* or post-polio*) and syndrome*).hw.
65	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
66	(Parkinson* or duchenne* or multiple scleros?s* or aphasia* or creutzfeldt-jakob* or huntington* or kluver-bucy*).hw.
67	(muscular adj1 dystroph*).ti,ab.
68	(muscular* and dystroph*).hw.
69	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
70	(neuromusc* and (disease* or disorder*)).hw.
71	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
72	(heredit* and spastic* and parapleg*).hw.
73	"friedreich* ataxia*".ti,ab.
74	"friedreich* ataxia*".hw.
75	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
76	((multiple system* or olivopontocerebellar*) and atroph*).hw.
77	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
78	(shy-drager syndrome* or striatonigral degenerat* or batten* disease*).hw.
79	(progressive adj1 supranuclear adj1 pals*).ti,ab.
80	(progressive* and supranuclear* and pals*).hw.
81	(richardson* adj1 (disease? or syndrome?)).ti,ab.
82	(richardson* and (disease* or syndrome*)).hw.
83	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
84	((corticobasal* or cortico basal*) and degenerat*).hw.
85	(white adj1 matter adj1 disorder?).ti,ab.
86	(white* and matter* and disorder*).hw.
87	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.
88	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).hw.
89	(lysosomal adj1 storage adj1 disorder?).ti,ab.

90	(lysosomal* and storage* and disorder*).hw.
91	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
92	((genetic* or William* or catch-22* or rett* or congenital* or f?etal alcohol*) and (syndrome* or disorder*)).hw.
93	(perinatal illness* or perinatal hypoxia*).ti,ab.
94	(perinatal illness* or perinatal hypoxia*).hw.
95	(primary adj1 dystonia?).ti,ab.
96	(primary* and dystonia*).hw.
97	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
98	(heredit* and motor* and sens* and neuropath*).hw.
99	(spina bifida? or spinal dysraphism?).ti,ab.
100	(spina bifida* or spinal dysraphism*).hw.
101	((functional* or psychogenic* or dissociative*) adj1 neurologic* adj1 (disorder* or dysfunction* or difficult*)).ti,ab.
102	((functional* or psychogenic* or dissociative*) and neurologic* and (disorder* or dysfunction* or difficult*)).hw.
103	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.
104	((movement* or motor* or convers*) and (disorder* or dysfunct*)).hw.
105	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
106	((psychogenic* or dissociative* or non-epilep* or nonepilep*) and (seizure* or convulsion* or fit* or fits* or spasm* or attack*)).hw.
107	(pseudo-seizure* or pseudoseizure*).ti,ab.
108	(pseudo-seizure* or pseudoseizure*).hw.
109	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
110	(medical* and (unexplain* or un-explain*) and symptom*).hw.
111	or/1-110
112	(rehab* or telerehab* or neurorehab*).ti,ab.
113	(rehab* or telerehab* or neurorehab*).hw.
114	or/112-113
115	111 and 114
116	(rehab* or telerehab* or neurorehab* or care team* or "caring team*" or caseworker* or "case worker*" or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or "social worker*" or specialist* or staff or therap*).ti.
117	(rehab* or telerehab* or neurorehab* or care team* or "caring team*" or caseworker* or "case worker*" or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or "social worker*" or specialist* or staff or therap*).hw.
118	(("care team*" or "caring team*" or caseworker* or "case worker*" or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or "social worker*" or specialist* or staff or therap*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
119	(("care team*" or "caring team*" or caseworker* or "case worker*" or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or "social worker*" or specialist* or staff or therap*) and (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback* or feeling* or improv* or knowledge* or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).hw.
120	(brother* or carer* or caregiver* or "care-giver*" or famil* or father* or guardian* or husband* or inpatient* or "in patient*" or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*).ti.
121	(brother* or carer* or caregiver* or "care-giver*" or famil* or father* or guardian* or husband* or inpatient* or "in patient*" or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*).hw.
122	((brother* or carer* or caregiver* or "care-giver*" or famil* or father* or guardian* or husband* or inpatient* or "in patient*" or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or

	spous* or wife* or wive*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
123	((brother* or carer* or caregiver* or "care-giver*" or famil* or father* or guardian* or husband* or inpatient* or "in patient*" or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*) and (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback* or feeling* or improv* or knowledge* or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).hw.
124	(attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*).ti.
125	(attitud* or belief* or choice* or concern* or experience* or expectation* or feedback* or feeling* or improv* or knowledge* or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*).hw.
126	or/116-125
127	115 and 126
128	((rehab* or telerehab* or neurorehab*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
129	((rehab* or telerehab* or neurorehab*) and (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback* or feeling* or improv* or knowledge* or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).hw.
130	or/128-129
131	111 and 130
132	127 or 131
133	limit 132 to yr="2010 -Current"

Database: PsycInfo

Date of last search: 23/02/2023

1	(exp Brain Injuries/ or anoxia/ or exp brain disorders/ or exp cerebrovascular disorders/ or exp headache/) not (exp Dementia/ or Cerebrovascular Accidents/)
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)).ti,ab.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
5	(brain* adj2 abscess*).ti,ab.
6	(carotid arter* adj2 (disease* or injur*)).ti,ab.
7	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
8	Cerebrovascular Accidents/ and (exp childhood development/ or exp adolescent development/ or pediatrics/ or puberty/)
9	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.
10	spinal cord injuries/ or (Spinal Cord/ and neoplasms/) or (Cardiovascular Disorders/ and spinal cord/) or exp myelitis/
11	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
12	(Central cord syndrome* or transverse myelitis).ti,ab.
13	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
14	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
15	(exp Peripheral Nervous System/ and (Injuries/ or neoplasms/)) or nervous system disorders/

16	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
17	(Guillain* adj1 Barr*).ti,ab.
18	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
19	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
20	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
21	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
22	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
23	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.
24	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.
25	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
26	(periph* adj2 neuropath*).ti,ab.
27	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
28	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
29	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.
30	motor neurons/ or exp muscular disorders/ or exp neuromuscular disorders/ or multiple sclerosis/ or neurodegenerative diseases/ or Progressive Supranuclear Palsy/ or corticobasal degeneration/ or Metabolism Disorders/ or Williams Syndrome/ or genetic disorders/ or rett syndrome/ or fetal alcohol syndrome/ or exp peripheral neuropathy/ or spina bifida/
31	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
32	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
33	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
34	(bulbar adj1 pals*).ti,ab.
35	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
36	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
37	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
38	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
39	(muscular adj1 dystroph*).ti,ab.
40	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
41	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
42	"friedreich* ataxia*".ti,ab.
43	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
44	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
45	(progressive adj1 supranuclear adj1 pals*).ti,ab.
46	(richardson* adj1 (disease? or syndrome?)).ti,ab.
47	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
48	(white adj1 matter adj1 disorder?).ti,ab.
49	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.
50	(lysosomal adj1 storage adj1 disorder?).ti,ab.
51	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
52	(perinatal illness* or perinatal hypoxia*).ti,ab.
53	(primary adj1 dystonia?).ti,ab.
54	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
55	(spina bifida? or spinal dysraphism?).ti,ab.
56	conversion disorder/
57	((functional* or psychogenic* or dissociative*) adj1 neurologic* adj1 (disorder* or dysfunction* or difficult*)).ti,ab.
58	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.

59	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
60	(pseudo-seizure* or pseudoseizure*).ti,ab.
61	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
62	or/1-61
63	exp rehabilitation/ or rehabilitation counseling/ or rehabilitation counselors/ or exp Occupational Therapy/ or exp Social Casework/ or exp Social Workers/ or physical therapists/ or neuropsychiatry/ or psychology/ or Psychiatrists/ or Professional Consultation/ or Psychologists/ or prostheses/
64	(rehab* or telerehab* or neurorehab*).ti,ab.
65	or/63-64
66	62 and 65
67	attitudes/ or exp health personnel attitudes/ or therapist attitudes/ or psychologist attitudes/ or counselor attitudes/ or exp client attitudes/ or consumer attitudes/ or consumer behavior/ or parental attitudes/ or health attitudes/ or Health Knowledge/ or Health Behavior/ or emotions/
68	(care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*).ti.
69	((care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
70	(brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*).ti.
71	((brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
72	(attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*).ti.
73	or/67-72
74	66 and 73
75	((rehab* or telerehab* or neurorehab*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
76	62 and 75
77	74 or 76
78	(letter or editorial or comment reply).dt. or case report/
79	(letter or comment*).ti.
80	78 or 79
81	exp randomized controlled trial/
82	random*.ti,ab.
83	81 or 82
84	80 not 83
85	animal.po.
86	(rat or rats or mouse or mice or rodent*).ti.
87	or/84-86
88	77 not 87
89	(2010* or 2011* or 2012* or 2013* or 2014* or 2015* or 2016* or 2017* or 2018* or 2019* or 2020* or 2021* or 2022* or 2023*).up.
90	88 and 89
91	Qualitative Research/
92	Interviews/
93	exp Questionnaires/

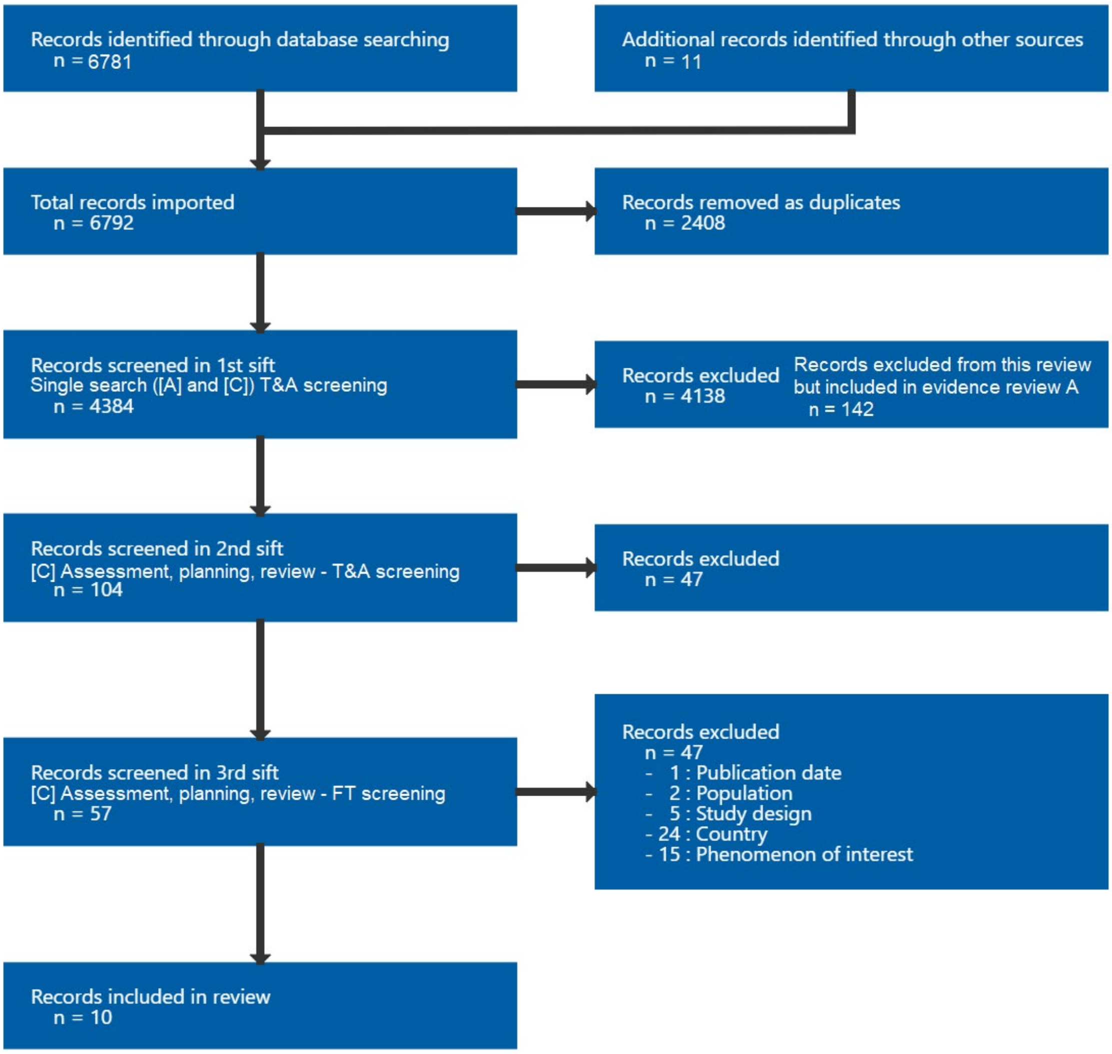
94	Narratives/
95	exp Surveys/
96	(qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw.
97	ethnography/
98	(ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw.
99	phenomenology/ or hermeneutics/ or grounded theory/ or group discussion/
100	(hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw.
101	(metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw.
102	"critical interpretive synthes*".tw.
103	(realist adj (review* or synthes*)).tw.
104	(noblit and hare).tw.
105	(meta adj (method or triangulation)).tw.
106	(CERQUAL or CONQUAL).tw.
107	((thematic or framework) adj synthes*).tw.
108	or/91-107
109	(national health service* or nhs*).ti,ab,in,cq.
110	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
111	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,cq.
112	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,cq.
113	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,cq.
114	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,cq.
115	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,cq.
116	or/109-115
117	exp Pediatrics/
118	(prematur* or pre-matur* or preterm* or pre-term* or infan* or newborn* or new-born* or perinat* or peri-nat* or neonat* or neo-nat* or baby* or babies or toddler*).ti,ab,in,jn.
119	child behavior/ or exp Child Health/ or child welfare/
120	(child* or minor or minors or boy* or girl* or kid or kids or young*).ti,ab,in,jn.
121	(pediatric* or paediatric* or peadiatric*).ti,ab,in,jn.
122	Puberty/ or Adolescence/ or adolescent behavior/ or adolescent health/
123	(adolescen* or pubescen* or prepubescen* or pre-pubescen* or pubert* or prepubert* or pre-pubert* or teen* or preteen* or pre-teen* or juvenil* or youth* or under*age*).ti,ab,in,jn.

124	exp Schools/ or child day care/
125	students/ or high school students/ or junior high school students/ or kindergarten students/ or middle school students/ or preschool students/
126	(pre-school* or preschool* or kindergar* or daycare or day-care or nurser* or school* or pupil* or student*).ti,ab,jn.
127	("under 18*" or "under eighteen*" or "under 25*" or "under twenty five*").ti,ab.
128	or/117-127
129	90 and 108 and 116
130	90 and 108 and 128
131	129 or 130

Appendix C Qualitative evidence study selection

Study selection for: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

Figure 2: Study selection flow chart



Appendix D Evidence tables

Evidence tables for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

Table 4: Evidence tables

Botchway-Commey, 2022

Bibliographic Reference	Botchway-Commey, Edith; Muscara, Frank; Greenham, Mardee; D'Cruz, Kate; Bonyhady, Bruce; Anderson, Vicki; Scheinberg, Adam; Knight, Sarah; Rehabilitation models of care for children and youth with traumatic brain and/or spinal cord injuries: A focus on service structure, service organization, and the barriers and facilitators of rehabilitation service provision.; Neuropsychological rehabilitation; 2022; 1-31

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Australia, UK, New Zealand, Canada and the US
Setting and aim	**Setting** National and international paediatric rehabilitation services for traumatic brain injury and traumatic spinal cord injury **Aim** To explore how national and international systems are designed to support paediatric traumatic brain injury and traumatic spinal cord injury rehabilitation services, as well as the barriers and facilitators to providing these services.
Data collection and analysis	**Data collection**

	Method: Semi-structured interviews, lasting approximately 100 minutes each. Interview guide was piloted and adjusted prior to data collection. Seven interviews included individual respondents, 4 were group interviews, involving multiple (2-3) respondents. Location: Not reported. Format: Face-to-face (2 interviews) or online video conference (9 interviews), recorded on an iPad (not reported if audio and/or video format), transcribed by a professional transcription service. **Analysis** Thematic content analysis, performed by 4 researchers. Transcripts uploaded to NVivo 12 and analysed by first author, using the themes of service structure, service organisation, and the barriers and facilitators of service provision. Content was organised into discrete codes within each of these themes, with sub-themes defined and refined through comparing and contrasting data over subsequent stages. Developing sub-themes were discussed at all stages with the other 3 researchers and finalised after agreement from all 4 researchers. To aid data analysis, field notes were kept and reflective journaling was performed after each interview, with reflective writing and analytical discussions throughout the process.
Recruitment strategy	Deductive selection process. A global online search for paediatric rehabilitation services for traumatic brain injury and traumatic spinal cord injury were performed, plus expert knowledge from the study steering committee. Identified services were emailed about participating in the study and asked to nominate (multiple if possible) service representatives to be interviewed.
Study dates	March-June 2019
Sources of funding	Not industry funded
Inclusion criteria	• Healthcare practitioners or care managers working within rehabilitation services caring for people with traumatic brain injury or traumatic spinal cord injury. • Practitioners working within private or public services supporting people with childhood traumatic brain injury or traumatic spinal cord injury.
Exclusion criteria	• Services solely caring for adults (defined as older than 18 years) with traumatic brain injury or traumatic spinal cord injury.

Sample size	N=16 practitioners working with children and young people with traumatic brain injury and traumatic spinal cord injury
Participant characteristics	Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all under 21 Sex of children and young people with chronic neurological disorders (M/F): Not reported Role or specialism: n=12 medical rehabilitation service practitioners, n=4 community-based rehabilitation practitioners Chronic neurological disorder category: Acquired brain injury and acquired spinal cord injury
Results	Themes as described in paper: • Service organization: Care planning ○ Over 50% of the rehabilitation services reported beginning care planning before admission, with plans considering a child's development trajectory, their ability to participate in planning and rehabilitation, family needs (including any cultural needs that might need to be accommodated), and access to resources. While the care planning framework was used across age groups, care plans were individualised to each child. Rehabilitation services always involved families in care planning but noted that older children tended to participate more in their care planning than younger ones. 89% of rehabilitation services produced care plans that extended past inpatient stays and included discharge plans (including any equipment that might be needed after discharge. Rehabilitation services focus on building a family's capacity for care and ensured to provide them with the information needed to make informed decisions regarding rehabilitation plans. ○ *“So we like the family and the child to be involved as much as possible, when it’s appropriate. And then obviously depending upon their age and their function, we’ll tailor their, the actual delivery of care and therapy that we’re giving” (page 15)* • Service organisation: Goal setting ○ Rehabilitation services started goal setting within 2 weeks after admission and included healthcare, social care and education professionals that were involved in each case, plus parents and the child where appropriate, making sure that the resulting plans were individualised. The frequency of goal reviews differed between services, from weekly to monthly and, again, tried to include healthcare, social care and education professionals that were involved in each case, plus parents and the child where appropriate. Goals were focused on improving independence, social and community participation, functioning and quality of life, and were designed to be attainable, time specific and meeting family expectations. When in the community,

	goals were set with the family and revolved around participation, functioning and integration. They were reviewed monthly. ○ *"When we first meet the family that's when we start the goals… it's very individualized because it will depend on where they're at the stage of, within the acute setting." (page 16)*

N/n: number of participants; SD: Standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No information given on how participating centres were chosen; no information given on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Relevant *(At least 1/16 participants from the US [outside of protocol].)*

Collins, 2023

Bibliographic Reference	Collins, Alana; D'Cruz, Kate; Jackman, Angie; Anderson, Vicki; Jenkin, Taylor; Scheinberg, Adam; Muscara, Frank; Knight, Sarah; Engaging children and adolescents with acquired brain injury and their families in goal setting: The family perspective.; Neuropsychological rehabilitation; 2023; vol. 33 (no. 1); 1-23

Study Characteristics

Study type	Grounded theory
Country/ies where study was carried out	Australia

Setting and aim	**Setting** State-wide paediatric rehabilitation service **Aim** To explore the experiences of children and their families with collaborative goal setting in acquired brain injury rehabilitation, and how this can affect participation and engagement.
Data collection and analysis	**Data collection** Method: Semi-structured interviews, lasting 15-50 minutes. Young people were given the choice of being interviewed individually or with parents; 11 interviews were conducted individually, 2 were conducted with both parents, 1 was conducted with the child and parents, and 1 was conducted with child, parents and sibling. Location: Private room in paediatric hospital (face-to-face interviews). Location of telephone interviews; not reported. Format: Face-to-face or remote via telephone, audio recorded and transcribed verbatim. Reflective notes from researcher completed after each interview. **Analysis** Constructivist grounded theory, using 2 researchers. Transcripts were entered alongside memos and reflective journal entries into NVivo 12 after each interview, before being coded by the first author. Half of the transcripts received secondary coding by another researcher. Initial coding was performed line-by-line, ensuring codes contain participant's own words, before constructing focused codes. Memo writing and diagrams were used throughout. Frequent codes were identified and relationships between them explored, resulting in final themes.
Recruitment strategy	Convenience sampling. Children with acquired brain injury and their parents attending the rehabilitation service were informed of the study by healthcare practitioners during routine clinical appointments and referred to the research team for further information if interested. Not all included parents were recruited with their children, although all children with acquired brain injury enrolled with at least 1 of their parents.
Study dates	Not reported
Sources of funding	Not industry funded

Inclusion criteria	- Children with a diagnosis of acquired brain injury attending outpatient rehabilitation at the study rehabilitation service. - Aged 8-18 years. - Parents of children meeting the above criteria.
Exclusion criteria	- Non-English speaking families. - Children with a diagnosis of concussion or cerebral palsy, and their parents.
Sample size	N=21 children and young people with acquired brain injury plus parents
Participant characteristics	**Children and young people with acquired brain injury, n=8** Age in years [Mean (SD)]: Not reported, age range 9-17 Sex (M/F): n=2/n=6 Time since diagnosis or injury in years [Mean (SD)]: Not reported, range of 'less than 1'-10 Chronic neurological disorder category: Acquired brain injury **Parents of children and young people with acquired brain injury, n=13** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: 13.36 (3.61) Sex of children and young people with chronic neurological disorders (M/F): n=3/n=6
Results	Themes as described in paper: - Experiences of goal setting - Practitioners felt as though families should have input into goals to ensure that interventions were tailored to needs and that overall goals could be directly related to family lives. Parents reported that their children received more intensive rehabilitation interventions in the acute stages of recovery and set more goals during this period. They also reported that the type of goals set changed over time, transferring from physical goals in the initial stages of rehabilitation, to cognitive and mental goals latterly.

	○ *"At the start there was a lot of physical goals, now, it's more emotional or cognitive" (page 10)* - Experiences of goal setting: The role of professionals ○ Parents reported that professionals should provide support to their daily routine, guiding them through their child's acquired brain injury, managing referrals to other departments and services as needed, advocating for the needs of the families, and informing them how to set goals. Parents and children noted that professionals should aid goal attainment by setting a smaller number of goals, developing an individual rehabilitation programme and providing strategies to overcome issues. Respondents noted that professionals could increase engagement in goal setting by minimising medical terminology, explaining options fully and being honest about the treatment and possible outcomes. ○ *"Provide us ways to do [the goal] and suggest ways to achieve it" (page 11)* - Experiences of goal setting: The role of the young person ○ Parents reflected that changes in their child's cognition and behaviour could impact their ability to engage in the goal setting process. Younger cognitive age was noted as a barrier to children's understanding of rehabilitation goals. Children tended to set short-term goals that were very centric to them as an individual, rather than basic activities of daily living goals (for example, being able to use a knife and fork). Some parents did not include their children at all in goal setting if they did not feel they had capacity, and some gradually increased their responsibility for goal setting as their child got older. Young people described themselves as setting their own personal goals and actively driving this process. However, many kept these goals internally and did not discuss them with other people as they were too personal. Young people would only raise goals with rehabilitation practitioners if they felt it was important or would impact their function. Young people reported paying less attention when they did not believe a topic was relevant, or if they could not follow the conversation between rehabilitation professionals and their parents. Conversely, when young people felt more engaged and involved in the goal setting process, they also felt more comfortable asking professionals for more information. Young people reported making a bigger effort to attain goals when the goal was attainable, when they had a good relationship with professionals, when they enjoyed the goal, and when they felt the goal was important. ○ *No first-order quotes to support this theme.* - Working as a team: Understanding each other and building trust

	○ Young people reported feeling more comfortable raising topics with professionals, and participating in conversations about goal getting, when they developed a good rapport with practitioners and felt they were viewed as equals in the process. ○ *No first-order quotes to support this theme.* • Working as a team: Communicating: Sharing knowledge and different perspectives ○ Participants reflected that good communication between themselves, and the treatment team was paramount for successful goal setting. If appropriate, goals should also be communicated with schools and colleges. ○ *No first-order quotes to support this theme.* • Working as a team: Being flexible ○ Parents reported that there may be a period of trial and error to identify a goal that suited both the family and matched the needs and ability of their child. Some parents believed that their children failed to achieve goals because they were too difficult, and their child became unmotivated. Respondents agreed that a consensus between themselves and healthcare professionals is needed to finalise rehabilitation goals. Parents wanted their children to agree to goals but acknowledged that they were more likely to support goals if they perceived them to be better for their child or for the family as a whole. ○ *"Either she lost interest in doing it, or she finds it too hard" (page 14)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Participants recruited during clinical appointments; some interviews jointly conducted with children and parents (although this was a choice given to child participants); poor presentation of data during analysis.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Hickling, 2022

Bibliographic Reference	Hickling, A.; Mah, K.; Al-Hakeem, H.; Scratch, S.E.; Exploring the experiences of youth with persistent post-concussion symptoms and their families with an interprofessional team-based assessment; Journal of interprofessional care; 2022; 1-10

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Canada
Setting and aim	**Setting** Urban paediatric rehabilitation hospital **Aim** To explore the experiences of children and parents of children who had participated in the interdisciplinary team-based assessment.
Data collection and analysis	**Data collection** Method: Semi-structured interviews, lasting between 15-45 minutes. Children and their parents were interviewed separately. Location: Private room, no further details reported. Format: Face-to-face, audio recorded, and transcribed. Field notes and team analysis notes were also kept to aid data analysis. **Analysis**

	Content analysis, number of researchers not reported. Transcripts were read multiple times, along with field and team analysis notes, followed by coding and concept mapping. No further details reported.
Recruitment strategy	Convenience sampling. Children and parents who had received interdisciplinary team-based assessment in the study paediatric rehabilitation hospital.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• Children or parents of children that had completed the interdisciplinary team-based assessment • Able to communicate in English • Had capacity to consent to participation Note: Children were allowed to participate without the participation of their parents and vice versa.
Exclusion criteria	Not reported
Sample size	N=15 children and young people with persistent post-concussion symptoms plus parents
Participant characteristics	**Children and young people with persistent post-concussion symptoms, n=8** Age in years [Mean (SD)]: 14.25 (SD not reported), range 8-17 Sex (M/F): n=5/n=3 Time since injury in months [Mean (SD)]: 17.88 (SD not reported), range 6-49 Chronic neurological disorder category: Acquired brain injury **Parents of children and young people with persistent post-concussion symptoms, n=7** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of children and young people with chronic neurological disorders (M/F): Not reported

Results	Themes as described in paper:
	- Engage in dialogue emphasizing collaboration
	  - Participants reported that conversations should be a collaboration between young people, their parents and healthcare professionals, with everyone able to contribute their thoughts and perspective. The assessment should not feel like a simple information gathering exercise but should be a meaningful dialogue. This collaboration should also exist between healthcare professionals, in order to increase communication within the rehabilitation team and consider all aspects of care.
	  - *"They all had input. They're going to fix [the concussion] as a team. It's not just individual "I'm doing this, you're doing this, this is this person doing this." They know exactly what each [other] is doing and we . . . made a plan on all aspects" (page 562)*
	- Prioritize the person over the injury
	  - The central component of the assessment should be the young person, rather than concussion and its symptoms, in order to consider the unique context of their life and create a plan to fit in with the child's priorities and interests.
	  - *"They asked me a lot about myself instead of my injury, so they knew what I liked to do before I got hurt. So I just felt like they cared about what I like to do, [and considered] that it would help me feel better . . ." (page 562)*
	- Co-create an individualized treatment plan
	  - Young people and parents appreciated the collaborative nature of the treatment plan, especially the active role they took in goal formation. Young people wanted healthcare professionals to understand their struggles and concerns, as well as what they hoped to improve with rehabilitation, in order to prioritise treatment goals. Treatment plans containing individual priority areas, and an action plan was beneficial as it clearly outlined next steps for people. Discussions were seen as helpful but receiving a written plan was also necessary for people to fully process the large amount of information these plans can contain.
	  - *"They took a lot of what I was saying and put it into the plan . . . For example, . . . one of the suggestions that they had made, that I also said was a good idea was emotionally getting better from [the concussion] and they took that idea and put a plan for it." (page 563)*

	○ *"I liked how first of all they didn't just tell me, they printed it out . . . they made priorities and things like that that were . . . part of my everyday life before and they started to incorporate it into my everyday life now." (page 563)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of recruitment strategy, data collection and analysis procedures.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Jenkin, 2022a

Bibliographic Reference	Jenkin, Taylor; Anderson, Vicki; D'Cruz, Kate; Collins, Alana; Muscara, Frank; Scheinberg, Adam; Knight, Sarah; Engaging children and adolescents with acquired brain injury and their families in goal setting: The clinician perspective.; Neuropsychological rehabilitation; 2022; vol. 32 (no. 1); 104-130

Study Characteristics

Study type	Grounded theory
Country/ies where study was carried out	Australia
Setting and aim	**Setting** State-wide paediatric rehabilitation service

	Aim To explore healthcare professionals' experience of rehabilitation goal setting for children with acquired brain injury and their families.
Data collection and analysis	**Data collection** Method: Semi-structured interviews, lasting 36-53 minutes (1 interview was carried out in 2 sessions of 30 minutes and 18 minutes respectively). Interviews carried out individually. Location: Private room in paediatric hospital (face-to-face interviews) and telephone interviews. Format: Face-to-face or remote via telephone, audio recorded and transcribed. Reflective notes from researcher completed after each interview. **Analysis** Constructivist grounded theory, using 2 researchers. Transcripts were entered alongside memos and reflective journal entries into NVivo 12 after each interview, before being coded by the first author. Five transcripts received secondary coding by another researcher. Open, in vivo coding was performed line-by-line to ensure codes were grounded in the data, before identifying emerging themes. Connection and relationships between themes were explored throughout, and visually represented using theme maps. Theoretical sufficiency was agreed by 3 researchers.
Recruitment strategy	Purposive sampling. Paediatric healthcare practitioners were recruited through posters, email and information dissemination at state-wide education days. Sampling ensured a range of disciplines and experience within the rehabilitation service.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	Not reported
Exclusion criteria	Not reported
Sample size	N=13 rehabilitation professionals working with children and young people with acquired brain injury

Participant characteristics	Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all under 18 Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported Role or specialism: n=3 occupational therapy, n=2 paediatric medicine, n=2 physiotherapy, n=2 speech therapy, n=1 educational consultancy, n=1 neuropsychology, n=1 team coordinator[1], n=1 social worker Chronic neurological disorder category: Acquired brain injury [1]"Team coordinators are responsible for the coordination of inpatient and outpatient rehabilitation streams. They coordinate intake of referrals, care planning, and goal setting processes, and ensure that children and families receive appropriate support from the rehabilitation team." (page 112)
Results	Themes as described in paper: • Seeing the bigger picture: Goals change over time ○ Goals set at the beginning of rehabilitation will change over time. This is due to priorities being revised, the relationship between families and healthcare professionals being strengthened, and as children's functional abilities change. Goal setting is a dynamic process that will need ongoing measurement, review and assessment. Healthcare professionals should acknowledge this progress by updating goals and making new ones when appropriate. ○ *“Even if we do have a goal setting session in that initial assessment, goals will become more refined as the sessions go on…as we build up our relationship with the family and the child…” (page 114)* • Seeing the bigger picture: Families set bigger picture goals ○ Participants reflected that families tend to set longer-term rehabilitation goals that may be unrealistic in a shorter-term rehabilitation programme. These aspirational goals need to be broken down into smaller, more achievable goals by healthcare professionals. However, these longer-term goals should not be forgotten, and it should be explained how the new, smaller goals can support future hopes to the young person and their families. ○ *"I have been involved with families that have set goals that are not necessarily goals that we’re going to achieve in rehabilitation, that are unrealistic for their child based on their level of brain injury…They’re goals that are going to be achieved further down the track…; It’s important to have the pie in the sky ideas from families, and then putting our clinician hat on and thinking “Well, that’s fantastic that you want to work on*

	running", or whatever it might be, "What are the next steps that we need to work on to get there?"…So still kind of working with the family, and having them – for their own mental health and their own wellbeing – to have that as a goal, even though we know that it might not be realistic. But I guess breaking it down for them a little bit more so that it can be achievable." (page 115) • Seeing the bigger picture: Need-to-dos: Goals that the child or adolescent wants to achieve ○ Rehabilitation goals should include ones children actually want, rather than ones they necessarily need to achieve. These goals should be discovered during conversations with children and young people, to ascertain what they enjoy and deem important. Setting these goals can increase motivation and engagement in rehabilitation, leading to better outcomes. ○ *"If the child's coming up with the goals themselves, then they're actually meaningful, and they're motivated to get towards those goals…it's all about how meaningful it is to them, not only to the child, but to the family…I think that's extremely important to be able to get the outcomes that they want." (page 115)* • Collaborating as a team ○ Goal setting should be a collaborative process that includes all participants in a child's rehabilitation. Open and honest communication helps to facilitate a shared understanding of rehabilitation goals and families' input in goal setting. Healthcare professionals should prompt, guide and enable child- and family- driven goal setting. Healthcare professionals' can help assist child- and family-driven goal setting by establishing a good relationship with both the child and their family, educating people on the importance of goal setting, providing information on what support rehabilitation professionals can provide, ensuring communication is appropriate for the needs of families', and using goal setting resources to discuss and develop goals. ○ *"Ideally I like the goal to be driven by the patient, or…the parent…I think it's important that we start…letting the client, the patient, the caregiver, whoever it is that's the main person in that setting, sort of direct it and then we're…the enablers of that rather than the other way around.; There's no use me telling you what your goals are…if it's not meaningful to them and they haven't had agency in that process, then it's not going to lead to outcomes that they…feel success or progress [in]." (page 116)* • Collaborating as a team: Everyone needs to be on the same page ○ Participants reflected that gathering as much information as possible about the child or young person with a chronic neurological disorder (including speaking to different professionals involved in their care and looking through previous medical history) facilitates the development of holistic rehabilitation goals. Participants noted that it is important to share rehabilitation goals with external service providers and education settings.

    - *“Make sure we’re all working towards the same goal and following the same sort of program so we’re not confusing the family and the child.” (page 118)*

- Collaborating as a team: Hearing the child’s or adolescent’s voice
    - Participants reflected that cognitive and communication difficulties can add another challenge to listening to children's acquired brain injury rehabilitation needs. Several strategies can help to overcome this, including direct questioning, allowing sufficient time for people to respond, alternative forms of communication, and simplifying discussions around goal setting.
    - *“[it’s] a real challenge to get the child’s voice, even if they can speak. So when they can’t speak it’s even more challenging.” (page 118)*
- Collaborating as a team: Parents as advocates.
    - Participants reported that, when families are involved in the goal setting conversations, compliance with rehabilitation exercises and tasks at home is increased and children feel better supported in working towards their rehabilitation goals. Sometimes parent's goals do not align with the rehabilitation goals of their children, and there is a danger of their voices overshadowing their child's opinion. In these cases, healthcare professionals should facilitate negotiation and prioritisation of different goals, to ensure that children's and adolescents' voices remain central in the goal setting process.
    - *"One of the biggest challenges for me…is a lot of the parents will drive what’s happening and what’s not happening [during goal setting]. And they sort of become the voice for them [the child], and sometimes that to me is really quite hard to see.; suggestion to ensure BCYP [babies, children and young people] contribute was '“specifically addressing questions to the child…rather than sort of keeping it broad and giving the parents a chance to take that ownership, because they’re quite used to doing that in the system.” (page 120)*
- Recognizing and navigating challenges: Child-/adolescent- and family-related challenges
    - Healthcare professionals noted several factors that can adversely impact goal setting: injury-related factors (for example, cognitive or communication difficulties); family dynamics; and cognitive fatigue. Suggestions for minimising the impact of cognitive fatigue included simplifying conversations and allowing children greater time to respond to questions. Healthcare professionals acknowledged that families often experience distress, trauma, anger, and grief following their child's acquired brain injury. For families to be fully engaged in goal setting, clinicians should establish open and honest communication in order to adequately support families.

	○ *"With the family you're dealing with grief and shock and their current level of stress, so that can be a real challenge in getting them to process what's happening now and then plan for the future. They might not be in [the] head space to plan goals…you need to be aware of where the family's at, to set the goal that's relevant to them right now." (page 120)* • Recognizing and navigating challenges: Time as a service-related challenge ○ Healthcare professionals noted that collaborative goal setting required longer appointment times than they currently offered, which is a barrier in setting child- and family-centred goals. This lack of time can lead to children and young people being poorly included in goal setting, which in turn leads to goals becoming clinician or parent driven. ○ *"Appointments are time-limited, and we've got the next kid coming in, or the room's booked, so we don't have a lot of time to do it [goal setting]. So generally speaking, kids who…have some impairment in understanding what we're talking about…we don't have the luxury of time to invest in eliciting those goals from them, so we do just fall back onto the family." (page 121)*

N/n: number of participants: SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Poor description of recruitment strategies; data analysis primarily carried out by 1 researcher.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Jenkin, 2022b

Bibliographic Reference	Jenkin, Taylor; D'Cruz, Kate; Anderson, Vicki; Scheinberg, Adam; Knight, Sarah; Family-centred service in paediatric acquired brain injury rehabilitation: perspectives of children and adolescents and their families.; Disability and rehabilitation; 2022; 1-12

Study Characteristics

Study type	Grounded theory
Country/ies where study was carried out	Australia
Setting and aim	**Setting** State-wide paediatric rehabilitation service **Aim** To explore the experiences of children with moderate and severe acquired brain injury and their families when using a family-centred service, how families can participate in rehabilitation, and what improvements could be made to increase family participation in paediatric acquired brain injury rehabilitation.
Data collection and analysis	**Data collection** Method: Semi-structured interviews, duration not reported. Interviews conducted individually. Location: Not reported. Format: Remotely via telephone or videoconference, audio-recorded and transcribed. **Analysis** Constant comparison constructivist grounded theory, using 2 researchers. Transcripts read and coded by first author, with secondary coding of 4 transcripts carried out by second researcher, who also checked initial codes. Coding continued line-by-line, ensuring that codes were grounded in participant actions and preserved their meanings. Frequent and meaningful

	codes were identified and used to develop categories by comparing between and within codes and participants. Axial coding further refined the categories into final themes and sub-themes.
Recruitment strategy	Purposive sampling. Families were identified using a state-wide registry on who attended the rehabilitation service and whose families had consented to be contacted for research purposes and contacted via letter. Non-responders were followed up after 12 weeks by telephone. Sampling was designed to include a variety of ages, injury types, acquired brain injury severity, time since injury and geographical location. After initial sampling and analysis, further sampling was undertaken, which was used to further develop identified themes.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• Families of children with moderate to severe acquired brain injury ○ Children aged 8-18 years Child had received either 1 month rehabilitation as an inpatient or 3 months rehabilitation as an outpatient within the study rehabilitation service. • Siblings could participate if they were aged 8-18 years and lived in the family home.
Exclusion criteria	• Families of children with mild acquired brain injury or concussion • Families of children with cerebral palsy • Families of children with moderate to severe acquired brain injury over 18 years old, regardless of when injury was sustained.
Sample size	N=19 children and young people with moderate to severe acquired brain injury plus family members
Participant characteristics	**Children and young people with moderate to severe acquired brain injury, n=4** Age in years [Mean (SD)]: Not reported, age range 13-17 Sex (M/F): n=2/n=2 Time since injury in years [Mean (SD]: Not reported, n=1, 6 months-2 years, n=3 over 2 years Chronic neurological disorder category: Acquired brain injury

	Family members of children and young people with moderate to severe acquired brain injury, n=15 Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported, age range 9-17 Sex of children and young people with chronic neurological disorders (M/F): n=6/n=2
Results	Themes as described in paper: • Working together as a team ○ Clinicians and family members have different roles and views in rehabilitation planning, with young people acting as a central focus for all parties. Respondents reflect working together as a team during rehabilitation, with this changing over time as needs change. ○ *"It feels like a really open discussion. I feel like we've bonded, it's been a number of years now. The paediatrician in the clinic has known Harry for many years … They all know him and they know me and my personality and I feel like we are a team. We remember what happened in the past. We know what works well. Any concerns I have are listened to and they, I think, are pretty open honest with me as well. It doesn't feel like I'm being talked at or directed, it feels like, if anything, they're saying to me, "What do you need? How can we help?". And I'm the one able to talk first and then they say, "Right this is what we can do to help you"." (page 4)* • Working together as a team: Doing rehabilitation together ○ Parents did not always agree with the advice of healthcare professionals, and appreciated when their opinions were seriously considered by clinicians. If opinions continued to differ, decisions on rehabilitation should be negotiated between parents and healthcare professionals. ○ *"Being a parent you sort of go, 'This is how I reckon it should go,' and that was taken on board. You know, they were fine with that; they understood." (page 6)* • Navigating rehabilitation as a family: Making rehabilitation work for the family ○ Participants said that for rehabilitation to be tailored to a family's needs, there should be a shared understanding and collaboration between healthcare professionals and families. In this way, rehabilitation can take a holistic approach where it is concerned with the child as whole (for example, integrating favourite sports into a rehabilitation programme).

	○ *“The OT [occupational therapist] and the physio, and all of those things were all tailored to his specific needs … And the frequency of it as well, recognising how much he could take and not overdoing it.” (page 7)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Data analysis primarily carried out by 1 researcher.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Preston, 2012

Bibliographic Reference	Preston, Jenny; Haslam, Simon; Lamont, Lynn; What do people with multiple sclerosis want from an occupational therapy service?; The British Journal of Occupational Therapy; 2012; vol. 75 (no. 6); 264-270

Study Characteristics

Study type	Grounded theory
Country/ies where study was carried out	UK
Setting and aim	**Setting** Occupational therapy service **Aim**

	To explore the experiences of people with multiple sclerosis when accessing a local occupational therapy service.
Data collection and analysis	**Data collection** Method: Focus groups, lasting around 1.5 hours each. Nine groups held in total: 6 for people with multiple sclerosis (stratified into groups according to disease duration, as a means of capturing the views of people with potentially different needs), 2 for partners/carers, and 1 for occupational therapy staff. Location: Local rehabilitation centre, at times convenient for the participants. Format: Face to face, and recorded **Analysis** Grounded theory. The recordings were transcribed and analysed by 2 researchers working independently from each other. The researchers then met to compare analyses and identify themes.
Recruitment strategy	Purposive sampling • Letters of invitation and an information sheet were sent to all potential participants known to the service and their partners/carers (n=322, n=53 positive responses received.) • Letters of invitation and an information sheet to all occupational therapy staff currently working in the service, junior staff who had completed clinical rotations, and staff who had retired from employment within the team in the previous 12 months. Number of invitations sent to staff is not reported.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• People with multiple sclerosis ○ Clinically definite diagnosis of multiple sclerosis. ○ Attendance at occupational therapy service within previous 12 months. ○ Adequate communication abilities allowing 'effective participation in a group without undue distress.' (p265)

	• Partners/carers of people with multiple sclerosis • Occupational therapy personnel who had worked within the service within last 12 months.
Exclusion criteria	Not reported
Sample size	N=46 adults with multiple sclerosis plus carers, partners and practitioners
Participant characteristics	**Adults with multiple sclerosis, n=30** Age [Mean (SD)] years: Not reported, age range 31- 63 (median 49) Sex (M/F): n=7/n=23 Time since diagnosis [Mean (SD)]: Not reported, range 6 months-26 years (median 10 years) Chronic neurological disorder category: Progressive neurological disease **Carers or partners of people with multiple sclerosis, n=10** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported **Practitioners working with people with multiple sclerosis, n=6** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: Not reported but all participants currently or had previously worked in an occupational therapy service
Results	Themes as described in paper: • Assessment and interventions ○ There were different opinions on the use of cognitive screening tools in annual reviews. Some respondents felt that they were appropriate despite being fairly simple, as they had to cover a wide range of people, disabilities and abilities. Other people with a longer disease duration, felt as though the assessments were

    childish. This could be due to increased exposure to the review process and assessment tool. Carers reflected that this could be less about what the assessment contains and more about the lack of explanation from clinicians about why people are being asked to perform certain tasks.
    - *"I think it needs to be explained to the patient why they're being asked to do these things … because it is an assessment to find out what they can actually do. It's kind of degrading for anyone to be asked to do a certain thing and then people to sit back and watch them" (page 267)*
- Home visits
    - Healthcare professionals reflected that some people with multiple sclerosis may prefer to attend reviews by themselves to report their progress and symptoms truthfully, instead of trying to make things look better in front of loved ones.
    - *"Sometimes I think that when people come in for their MS [multiple sclerosis] review they quite like to come in themselves to tell me the truth. You know, they felt that when their partner was there they sometimes had to make it look not as bad as it maybe was" (page 268)*

N/n: number of participants; SD: standard deviation:

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor reporting of data analysis; low value of research)*
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates a specific rehabilitation therapy or service [occupational therapy services] which may not be broadly transferable.)*

Sexton, 2013

Bibliographic Reference	Sexton, Deborah; 'As Good as it's Going to Get'. Bad News Conversations in Neurology: Challenges for Occupational Therapists; British Journal of Occupational Therapy; 2013; vol. 76 (no. 6); 270-279

Study Characteristics

Study type	Phenomenological
Country/ies where study was carried out	UK
Setting and aim	**Setting** Not reported **Aim** To explore the experiences of neurological occupational therapists when having conversations with people about likely long-term disabilities.
Data collection and analysis	**Data collection** Method: Semi-structured interviews, lasting 35-65 minutes. Interviews conducted individually. Location: Workplace, faculty, home and 'neutral' venues. Format: Face-to-face interviews (with 1 completed remotely via telephone), audio recorded and transcribed. **Analysis** Thematic analysis, using 2 researchers. Transcripts were read once, with identified themes noted on a single piece of paper and sub-themes listed beneath. Codes were assigned to blocks of data when re-reading the transcripts. Themes were refined until all interviews were coded. Two coded transcripts were sent to an independent colleague to check levels of agreement.
Recruitment strategy	• Members of the British Association of Occupation Therapists Neurological Specialist Section were contacted by email with information regarding the study. Participants contacted study researchers if interested. • Non-NHS neurological services were contacted to recruit occupational therapists directly.

Study dates	October 2009-March 2010
Sources of funding	Not reported
Inclusion criteria	Band 5-8c occupational therapists practicing in South-East England. • Working with adults with neurological symptoms aged 18-75 years. • Working in acute hospital, community and rehabilitation settings.
Exclusion criteria	Not reported
Sample size	N=10 occupational therapists working with adults with neurological symptoms
Participant characteristics	Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported but inclusion criteria states participants must be between 18-75 Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: Not reported beyond inclusion criteria Chronic neurological disorder category: General chronic neurological disorders
Results	Themes as described in paper: • The bad news conversation ○ Having discussions about bad news (for example, poor prognosis) can help people to plan their rehabilitation and goals more realistically. ○ *"I've actually had good … positive experiences of breaking bad news as well. I've had people who didn't actually realised [their true situations] and were glad now that they understood the picture … so that they could plan more what they were going to do" (page 275)* • Approaches to the bad news conversation ○ Participants reported stalling bad news conversations for a number of reasons. These included not having sufficient time to have a comprehensive conversation and clinicians not feeling as though people were

	emotionally ready to have the conversation (for example, if they thought that the conversation would negatively impact engagement in rehabilitation). Healthcare professionals believed that bad news conversations should be informed using a patient-centred approach according to the needs of the individual, rather than following a set of guidelines. ○ *"I knew it would be difficult for him but I'm not in a position to say 'you can only do that': he has to come through it for himself… and give him the opportunities to do that and so… he comes round and says "x". I have tried that a couple of times and it's really difficult isn't it?" (page 275)* • Goal setting ○ Functional goals were set to address the issues prioritised by people with chronic neurological disorders, within a short time frame (between 2-4 weeks), even if they were considered unrealistic by healthcare professionals, and this is how progress was measured. ○ *"Let's set goals for the next 4 weeks and see what we can achieve in that timeframe … you know, maybe half way through that 4-week period, stopping and reviewing what has happened." (page 276)* • Using others ○ Respondents reflected that working with other members of the multidisciplinary team was better than relying on 1 persons assessment, as it allowed a more rounded clinical picture. ○ *"...you get a rounded picture: you get everyone's opinion and everyone's bit of evidence" (page 276)*

N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of data analysis procedures; no information given on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Shore, 2022

Bibliographic Reference	Shore, Josh; Bernick, Alana; Nalder, Emily; Hutchison, Michael; Reed, Nick; Hunt, Anne; Adolescent and parent experiences with Tele-Active Rehabilitation for concussion: an exploratory qualitative study.; Brain injury; 2022; vol. 36 (no. 9); 1140-1148

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)
Country/ies where study was carried out	Canada
Setting and aim	**Setting** In the community, within a feasibility trial for remotely delivered Tele-AR intervention **Aim** To explore users' views and experiences regarding the remote delivery of the Tele-Active Rehabilitation intervention, as well as what worked well and the benefits of the programme.
Data collection and analysis	**Data collection** Method: Semi-structured interviews, duration not reported. Interviews conducted individually. Location: Not reported. Format: Remote via videoconference, audio recorded and transcribed verbatim. **Analysis** Inductive thematic analysis, using 3 researchers. Transcripts were read and independently coded by 2 researchers, meeting twice to discuss and refine emerging codes. One researcher organised codes into themes, which were then discussed, defined and agreed with 2 other researchers.

Recruitment strategy	Through advertisements placed with community organisations, community practitioners, and social media.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	Adolescents with physician or nurse practitioner diagnosed concussion who continued to experience symptoms at least 2 weeks later, and their parents.
Exclusion criteria	Not reported
Sample size	N=6 children and young people with concussion plus parents
Participant characteristics	**Children and young people with concussion, n=3** Age in years [Mean (SD)]: Not reported, age range 14-17 Sex (M/F): n=1/n=2 Time since injury in weeks (Mean [SD]): Not reported, range 5-24 Chronic neurological disorder category: Acquired brain injury **Parents of children and young people with concussion, n=3** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: As above Sex of children and young people with chronic neurological disorders (M/F): As above
Results	Themes as described in paper: • Focusing on individual needs ○ Healthcare professionals should endeavour to understand young people's issues and use these to tailor the rehabilitation programme to their needs and preferences (for example, tailoring education on concussion to

	include pre-existing conditions). Tele-AR included meaningful activities in the rehabilitation programme, which acted as motivation for young people and increased engagement in the intervention. ○ *"[The clinician] actually started suggesting some . . . like hand-eye coordination stuff . . . but he kept saying stuff like lacrosse and Hayley's like 'uhhh I've never played lacrosse before' where field hockey [as suggested in the Tele AR study] make more sense and kind of the same sort of . . . skills but with a different sport." (page 1144)*

N/n: number of participants; SD: standard deviation; Tele-AR: Tele-Active Rehabilitation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates a specific rehabilitation intervention [Tele-Active Rehabilitation] which may not be broadly transferable; time since injury ranges from 5-24 weeks so some participants within 3 months of injury.)*

Twigg, 2021

Bibliographic Reference	Twigg, Jessica; Methley, Abigail; Lavin, Tim; Dickinson, Gemma; Teager, Alistair; Living with Polyneuropathy Organomegaly Endocrinopathy Monoclonal gammopathy Skin changes (POEMS) syndrome: a case study of healthcare experiences and quality of life.; Disability and rehabilitation; 2021; vol. 43 (no. 17); 2502-2510

Study Characteristics

Study type	Case study

Country/ies where study was carried out	UK
Setting and aim	**Setting** Acute neurorehabilitation unit **Aim** To understand the lived experience of a person with a rare condition (POEMS) including their experiences of health care.
Data collection and analysis	**Data collection** Method: Semi-structured interview lasting for 62 minutes. Location: Neurorehabilitation centre. Format: Face to face, recorded and transcribed verbatim. **Analysis** Constant comparison approach. Codes derived from the data/open coding initially. Once open coding was completed, more focused and analytical coding took place to identify themes. Coding was completed by 2 independent researchers who met to finalise coding and analysis.
Recruitment strategy	Purposive selection due to participant's rare diagnosis and recent experience of health care.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	Not reported
Exclusion criteria	Not reported

Sample size	N=2 (1 adult with POEMS syndrome plus carer)
Participant characteristics	**Adult with POEMS syndrome, n=1** Age in years: 71 Sex (M/F): n=0/n=1 Time since diagnosis: Not reported Chronic neurological disorder category: Progressive neurological disease **Carer of adult with POEMS syndrome, n=1** Age of person with chronic neurological disorders in years [Mean (SD)]: As above Sex of person with chronic neurological disorders (M/F): As above
Results	Themes as described in paper: • Recovery: Progression and decline ○ Rehabilitation was person-centric despite healthcare professionals not being well informed on POEMS (for example, flexibility around balancing fatigue with rehabilitation). Setting collaborative goals allowed the person with POEMS to feel a sense of achievement and being provided with choices throughout rehabilitation allowed for a sense of independence and control. ○ *"The rehab here is good. And although they don't know about POEMS they seem to have taken on board that one of the things about POEMS is how tired you get. And it is a case of balancing the exhaustion with the rehab to make sure you are doing the best you can without doing too much so that it doesn't set you back." (page 2507)*

N/n: number of participants; POEMS: Polyneuropathy Organomegaly Endocrinopathy Monoclonal gammopathy Skin changes; SD: Standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Concerns over research design and recruitment strategy; previous relationship between participants and researchers not considered.)*
Overall risk of bias and relevance	Relevance	Partially relevant *(Case study of the experience of a single individual with a specific condition.)*

Van De Weyer, 2010

Bibliographic Reference	Van De Weyer, R C; Ballinger, C; Playford, E D; Goal setting in neurological rehabilitation: staff perspectives.; Disability and rehabilitation; 2010; vol. 32 (no. 17); 1419-27

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)
Country/ies where study was carried out	UK
Setting and aim	**Setting** Inpatient neurological rehabilitation unit **Aim** To explore rehabilitation professionals' experiences with goal setting in general, and about 2 specific goal setting techniques investigated in the parent RCT.
Data collection and analysis	**Data collection**

	Method: Focus groups, split over 2 groups with duration not reported. Location: Private room in rehabilitation unit. Format: Face-to-face, audio recorded and transcribed. **Analysis** Thematic analysis, using 3 researchers. The transcript of initial focus, from the first focus group, was read, and emerging codes noted and refined with repeated reading. The second focus group transcript was coded using these initial codes, comparing and refining new findings to produce the final list of codes. These codes were merged into overarching themes, which were agreed with 2 other researchers who had been supervising the analysis.
Recruitment strategy	Rehabilitation professionals working on the inpatient neurological rehabilitation unit were informed of the RCT at weekly team meetings, and interested participants were recruited.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	Not reported
Exclusion criteria	Not reported.
Sample size	N=15 rehabilitation practitioners working with people with chronic neurological disorders
Participant characteristics	Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: n=4 occupational therapists, n=4 physiotherapists, n=3 nurses, n=2 speech and language therapists, n=1 doctor, n=1 student occupational therapist Chronic neurological disorder category: General chronic neurological disorders
Results	Themes as described in paper:

- The goal setting tools
  - Participants reflected on the usefulness of a goal setting folder, which was used by a key worker during an interview upon admission. Healthcare professionals appreciated that it allowed them to get to know a person early in their admission, highlighting needs that could then be addressed quickly. The goal setting folder was designed to be given prior to admission or during admission, to increase engagement with its contents and give people time to think about what they wanted to achieve during their stay. To aid understanding, the folder contained both text and pictures to illustrate types of activity.
  - *". . . if someone has got a real issue, it could take the whole first week to come out, and that's a week gone by, at least with those questions things do come out, I think, earlier and we are on top of those issues from day one" (page 1422)*
- Barriers to goal setting
  - Rehabilitation planning should be realistic, which requires people to be well informed about what a service can offer. Participants reported that the increased time needed for conversations about what is important to accomplish in rehabilitation, and collaborative goal setting, was an issue in a busy clinical environment. More time would need to be allowed for, to effectively implement this style of goal setting. Different work patterns (for example, shift work) held by different members of the multidisciplinary team also impacted the practicality of collaborative goal setting. Respondents reflected that healthcare professionals holding conversations about goal setting may not have the expertise to decide what goals are and are not appropriate and realistic for every person with a chronic neurological disorder.
  - *"It's actually quite a skilled job ([hat is, being a keyworker] and difficult sometimes working through all those areas because it's very much from the patient's perspective and when they come up with things like going up the stairs, I think ''Oh, I'm not a physio and I'd have to think about all the steps involved in climbing the stairs'', so you'd have to work through the process and then I would come to the meeting with the patient and find ''Oh no, they are not going to do the stairs'', so some of it is perhaps not necessarily appropriate to do" (page 1423)*
- The keyworker role
  - Healthcare professionals often discussed conditions of people with chronic neurological disorders and possible rehabilitation goals prior to their arrival at the meeting to amend and finalise information given. Having the person with a chronic neurological disorder at the centre of rehabilitation conversations prevented healthcare professionals from making assumptions about their needs and abilities.

	○ *"Something about (the) collaborative (phase) is that you always have that patient at the centre. When we first went back to the conventional form, it almost (became) rude not to have the patient present. It actually felt like we were making our own assumptions about their status, rather than having them involved. It did feel rude, really" (page 1423)* • Patient characteristics ○ Some healthcare professionals believed that taking the lead in rehabilitation discussions, planning and goal setting was beneficial for people with certain types of chronic neurological disorders or immediately after diagnosis. ○ *"I sometimes think that the conventional way helps some people because they come in at, say, the onset of the illness and they actually wouldn't know what they wanted to work on, and they would say "Well, you tell me''" (page 1423)* • The nature of goals ○ Allowing people with chronic neurological disorders the freedom to craft their own rehabilitation goals meant that goals were more individual and realistic. Examples given were the ability to roll cigarettes, purchasing and writing a postcard, and painting toenails. ○ *"As therapists, we can get a bit stuck in our ways with the types of goals we come up with, so the cards (in the goal setting folder) were great for stimulating some thought from the patients to create interesting, individual goals, things we hadn't considered, making the goals more context based" (page 1424)*

N/n: number of participants; RCT: randomised controlled trial

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Poor description of data collection and analysis procedures; no information given on relationship between researcher and participants.)*

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates 2 specific goal setting methods which may not be broadly transferable.)*

Appendix E Forest plots

Forest plots for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

No meta-analysis was conducted for this review question and so there are no forest plots.

Appendix F GRADE-CERQual tables

GRADE-CERQual tables for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

Table 5: GRADE-CERQual table for theme C1: Provision of information

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme C1.1: Assessment tools						
1 study • Preston 2012 (Grounded theory, progressive neurological disease)	People with chronic neurological disorders had conflicting opinions about the cognitive assessment tools used in their reviews. Some believed that the tools were suitable given that they had to be applicable to a wide range of people and abilities. Others, especially those who had longer disease durations and more experience with rehabilitation reviews, felt as though cognitive assessment tools were unhelpful and patronising. People believed that this could be overcome by rehabilitation therapists explaining the assessment tools and what exactly they are being used for. *"I think it needs to be explained to the patient why they're being asked to do these things … because it is an assessment to find out what they can actually do. It's kind of degrading for anyone to be asked to do a certain thing and then people to sit back and watch them" (page 267, Preston 2012)*	Moderate concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Findings derived from themes describing advantages and disadvantages of community and home rehabilitation)	Minor concerns (Findings derived from study exploring a particular rehabilitation service. Findings may not be broadly applicable.)	Serious concerns (Findings derived from 1 study without rich data)	VERY LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme C1.2: Early provision of information						
1 study • Van De Weyer 2010 (General qualitative inquiry [within mixed-methods study], general chronic neurological disorders)	Rehabilitation practitioners said information should be given to people with chronic neurological disorders early in the rehabilitation process to support decision making and goal setting. Information can then be used to develop thoughts about what people want to accomplish during their rehabilitation, as well as highlight needs and preferences early on in the process. *". . . if someone has got a real issue, it could take the whole first week to come out, and that's a week gone by, at least with those questions things do come out, I think, earlier and we are on top of those issues from day one" (page 1422, Van De Weyer 2010)*	Serious concerns (Serious concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	Moderate concerns (Findings only derived from studies exploring a particular rehabilitation intervention. Findings may not be broadly applicable.)	Serious concerns (Findings derived from 1 study without rich data)	VERY LOW
Sub-theme C1.3: Format						
2 studies • Hickling 2022 (General qualitative inquiry, acquired brain injury) • Van De Weyer 2010 (General qualitative inquiry [within mixed-methods study], general chronic neurological disorders)	People with chronic neurological disorders, their family members and rehabilitation practitioners believe that written rehabilitation plans should be provided alongside verbal conversations. They were seen to be very helpful in clearly setting out the next rehabilitation stages and giving people an opportunity to absorb a lot of information in their own time. It helps if written rehabilitation plans include a range of formats, according to need (for example, both text and pictures).	Moderate concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	Minor concerns (Findings derived from studies exploring a particular rehabilitation intervention. Findings may not be broadly applicable.)	Serious concerns (Findings derived from 2 studies without rich data)	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	"I liked how first of all they didn't just tell me, they printed it out . . . they made priorities and things like that that were . . . part of my everyday life before and they started to incorporate it into my everyday life now." (page 563, Hickling 2022)					
Sub-theme C1.4: Realistic planning						
2 studies • Sexton 2013 (Phenomenological, general chronic neurological disorders) • Van De Weyer 2010 (General qualitative inquiry [within mixed-methods study], general chronic neurological disorders)	According to rehabilitation practitioners, planning and goal setting are made realistic when conversations are honest and acknowledge the potential for negative outcomes. However, as these planning conversations can be emotional and potentially de-motivating, professionals should have flexibility on how and when to have the discussion. *"I've actually had good … positive experiences of breaking bad news as well. I've had people who didn't actually realise [their true situations] and were glad now that they understood the picture … so that they could plan more what they were going to do" (page 275, Sexton 2013)*	Moderate concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	Minor concerns (Findings derived from studies exploring a particular rehabilitation intervention. Findings may not be broadly applicable.)	Moderate concerns (Findings derived from 2 studies with relatively rich data)	LOW

Table 6: GRADE-CERQual table for theme C2: Integration and co-ordination within and between rehabilitation services

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme C2.1: Rehabilitation services and external services						
2 studies • Collins 2023 (Grounded theory, acquired brain injury) • Jenkin 2022a (Grounded theory, acquired brain injury)	People with chronic neurological disorders, their family members and rehabilitation practitioners reported that it was helpful when rehabilitation plans and goals were regularly communicated between rehabilitation services as well as with other sectors (for example, educational institutions). This communication ensured that everyone was working toward a clearly defined and common goal. *"make sure we're all working towards the same goal and following the same sort of program so we're not confusing the family and the child." (page 118, Jenkin 2022a)*	Moderate concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Serious concerns (Findings derived from 2 studies without rich data)	LOW
Sub-theme C2.2: Multi-disciplinary teams						
4 studies • Hickling 2022 (General qualitative inquiry, acquired brain injury) • Jenkin 2022a (Grounded theory, acquired brain injury) • Sexton 2013 (Phenomenological, general chronic neurological disorders) • Van De Weyer 2010 (General qualitative inquiry [within mixed-	People with chronic neurological disorders, their family members and rehabilitation practitioners all reported that collaboration between clinicians helped to achieve holistic assessments and this was facilitated by multi-disciplinary teams. They also help to ensure that realistic plans and goals are discussed within the rehabilitation team, and that clear and consistent messages are conveyed to people with chronic neurological disorders.	Moderate concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	Minor concerns (Findings derived from studies exploring a particular rehabilitation intervention. Findings may not be broadly applicable.)	Minor concerns (Findings derived from 4 studies with relatively rich data)	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
methods study], general chronic neurological disorders)	*"They all had input. They're going to fix [the concussion] as a team. It's not just individual "I'm doing this, you're doing this, this is this person doing this." They know exactly what each[other] is doing and we . . . made a plan on all aspects" (page 562, Hickling 2022)*					

Table 7: GRADE-CERQual table for theme C3: Personalisation of assessment and review including planning rehabilitation and goal setting

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme C3.1: Goal setting						
Minor sub-theme C3.1.1: Achievable goals						
3 studies • Collins 2023 (Grounded theory, acquired brain injury) • Jenkin 2022a (Grounded theory, acquired brain injury) • Sexton 2013 (Phenomenological, general chronic neurological disorders)	People with chronic neurological disorders, their family members and rehabilitation practitioners reported that people were less motivated when goals were thought to be too difficult or unrealistic to achieve. Long-term goals should be made, but these should then be broken down into smaller short-term steps (for example, 2-4 weeks) that can be linked to the bigger picture of recovery. *"I have been involved with families that have set goals that are not necessarily goals that we're going to achieve in rehabilitation, that are unrealistic for their child based on their level of brain injury…They're*	Moderate concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Findings derived from 3 studies with relatively rich data)	LOW

Study information	Description of theme or finding	CERQual Quality assessment Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	goals that are going to be achieved further down the track…; It's important to have the pie in the sky ideas from families, and then putting our clinician hat on and thinking "Well, that's fantastic that you want to work on running", or whatever it might be, "What are the next steps that we need to work on to get there?"…So still kind of working with the family, and having them – for their own mental health and their own wellbeing – to have that as a goal, even though we know that it might not be realistic. But I guess breaking it down for them a little bit more so that it can be achievable." (page 115, Jenkin 2022a)					
Minor sub-theme C3.1.2: Collaborative goal setting						
6 studies • Collins 2023 (Grounded theory, acquired brain injury) • Hickling 2022 (General qualitative inquiry, acquired brain injury) • Jenkin 2022a (Grounded theory, acquired brain injury) • Jenkin 2022b (Grounded theory, acquired brain injury) • Twigg 2021 (Case study, progressive neurological disease)	People with chronic neurological disorders, their family members and rehabilitation practitioners believed that collaborative goal setting is needed to ensure that goals are relevant, appropriate and supported by those involved. These goals are developed through open and honest communication, with every person being able to contribute their thoughts and experiences. If needed, rehabilitation practitioners should use their experience and expertise to prompt discussion and guide goal setting. *"Something about (the) collaborative (phase) is that you always have that*	Moderate concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	No or very minor concerns	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
- Van De Weyer 2010 (General qualitative inquiry [within mixed-methods study], general chronic neurological disorders)	*patient at the centre. When we first went back to the conventional form, it almost (became) rude not to have the patient present. It actually felt like we were making our own assumptions about their status, rather than having them involved. It did feel rude, really" (page 1423, Van De Weyer 2010)*					
Minor sub-theme C3.1.3: Ongoing review and revision of goals						
2 studies - Collins 2023 (Grounded theory, acquired brain injury) - Jenkin 2022a (Grounded theory, acquired brain injury)	People with chronic neurological disorders, their family members and rehabilitation professionals reported that the number and type of rehabilitation goals set, as well as the frequency of review changed throughout rehabilitation. More goals were set at the beginning of rehabilitation, with shorter times between review and with a focus on physical rehabilitation. These goals naturally become longer-term and more psychological as rehabilitation progresses, needs change and priorities are revised. There was consensus that this flexibility ensured rehabilitation goals are kept relevant and attainable. *“Even if we do have a goal setting session in that initial assessment, goals will become more refined as the sessions go on…as we build up our relationship with the family and the child…” (page 114, Jenkin 2022a)*	Moderate concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Findings derived from 2 studies with relatively rich data)	LOW
Minor sub-theme C3.1.4: Role of rehabilitation professionals						

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
3 studies • Collins 2023 (Grounded theory, acquired brain injury) • Jenkin 2022a (Grounded theory, acquired brain injury) • Van De Weyer 2010 (General qualitative inquiry [within mixed-methods study], general chronic neurological disorders)	People with chronic neurological disorders, their family members and rehabilitation practitioners said that rehabilitation professionals should provide information and education about the purpose and process of goal setting in neurorehabilitation (including how they can facilitate goal setting). They suggested using goal setting resources to discuss and elicit goals and explain how a small number of achievable goals can be built on to reach longer term goals. Rehabilitation practitioners may need to take more of an active role in goal setting for people with certain types of chronic neurological disorder or immediately after the onset of symptoms. Additionally, practitioners may need to use their expertise to negotiate goals when views differ between people with chronic neurological disorders, their family members or clinicians. *"provide us ways to do [the goal] and suggest ways to achieve it" (page 11, Collins 2023)*	Moderate concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	Moderate concerns (Findings derived from different aspects of rehabilitation professionals' role)	Minor concerns (Findings derived from studies exploring a particular rehabilitation intervention. Findings may not be broadly applicable.)	Moderate concerns (Findings derived from 3 studies with relatively rich data)	VERY LOW
Sub-theme C3.2: Including families						
4 studies • Botchway-Commey 2022 (General qualitative inquiry, acquired brain injury and acquired SCI)	People with chronic neurological disorders, their family members and rehabilitation practitioners were generally positive about involving families in rehabilitation planning. Mostly they said that families should	Minor concern concerns about (Minor methodological limitations as per	Minor concerns (Findings described both advantages and disadvantages	Minor concerns (Findings derived from studies exploring a particular	No or very minor concerns	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
- Collins 2023 (Grounded theory, acquired brain injury) - Jenkin 2022a (Grounded theory, acquired brain injury) - Preston 2012 (Grounded theory, progressive neurological disease)	be included, working together to build care capacity and design a rehabilitation plan that works around competing family needs and routines. Involving families in rehabilitation planning was also said to increase compliance with rehabilitation programmes as it ensures that people with chronic neurological disorders are supported in their rehabilitation outside of the clinical setting. However, some rehabilitation practitioners acknowledged that including family members sometimes affects the information shared during review appointments as people may wish to protect their loved ones from bad information. *"But also we've got a strong focus on building the capacity of families to raise their children. So, we really focus on providing families with the information they need to make informed decisions." (page 15, Botchway-Commey 2022)*	CASP qualitative checklist)	of including families)	rehabilitation intervention or including participants outside of protocol. Findings may not be broadly applicable.)		
Sub-theme C3.3: Person-centred rehabilitation planning						
6 studies - Botchway-Commey 2022 (General qualitative inquiry, acquired brain injury and acquired SCI)	People with chronic neurological disorders, their family members, carers and rehabilitation practitioners all reported that in order to support a person's life outside of their condition and promote engagement with rehabilitation, planning should be person-centred and individualised, integrating activities and tasks that	Minor concerns (Minor concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	Minor concerns (Findings derived from studies exploring a particular rehabilitation intervention or including	No or very minor concerns	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
• Hickling 2022 (General qualitative inquiry, acquired brain injury) • Jenkin 2022b (Grounded theory, acquired brain injury) • Shore 2022 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • Twigg 2021 (Case study, progressive neurological disease) • Van De Weyer 2010 (General qualitative inquiry [within mixed-methods study], general chronic neurological disorders)	are enjoyable to them. Placing people with chronic neurological disorders at the centre of rehabilitation planning also allows for novel insights to easily be included. Factors to be considered include current physical and mental functioning (as well as developmental trajectory for children and young people), people's ability to engage in the rehabilitation planning process, family and cultural needs, access to resources, the impact of changing settings (for example, transferring from inpatient to community rehabilitation services), and goal setting. *"the OT [occupational therapist] and the physio, and all of those things were all tailored to his specific needs … And the frequency of it as well, recognising how much he could take and not overdoing it." (page 7, Jenkin 2022b)*			participants outside of protocol. Findings may not be broadly applicable.)		
Sub-theme C3.4: Additional capacity						
1 study • Jenkin 2022a (Grounded theory, acquired brain injury)	Healthcare professionals identified that they needed additional time during consultations to plan rehabilitation and set goals collaboratively. Additional time is also needed to develop a rapport with people with chronic neurological disorders and their families, to better support them through a period of mental and emotional distress and	Minor concerns (Minor concerns about methodological limitations as per CASP qualitative checklist)	Moderate concerns (Findings derived from internal and external barriers to collaborative rehabilitation planning)	No or very minor concerns	Serious concerns (Findings derived from 1 study without rich data)	VERY LOW

Study information	**Description of theme or finding**	**CERQual Quality assessment**				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
	help them to engage fully in the rehabilitation planning process. *"Appointments are time-limited, and we've got the next kid coming in, or the room's booked, so we don't have a lot of time to do it [goal setting]. So generally speaking, kids who…have some impairment in understanding what we're talking about…we don't have the luxury of time to invest in eliciting those goals from them, so we do just fall back onto the family." (page 121, Jenkin 2022a)*					

Table 8: GRADE-CERQual table for theme C4: Equalities considerations

Study information	**Description of theme or finding**	**CERQual Quality assessment**				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme C4.1: Engagement by people with cognitive and communication difficulties						
2 studies • Collins 2023 (Grounded theory, acquired brain injury) • Jenkin 2022a (Grounded theory, acquired brain injury)	Parents of children with chronic neurological disorders and rehabilitation practitioners reported that when people have cognitive and communication difficulties there are additional challenges to engagement in rehabilitation planning and goal setting. When children are too young to understand the concept of goal setting, they tend to ignore goals that will provide them with basic life skills (for example, being able to use a knife and fork). For these reasons, parents tended to not include them in goal	Minor concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	No or very minor concerns	No or very minor concerns	Moderate concerns (Findings derived from 2 studies relatively rich data)	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	setting until they got older. Children with communication impairments often did not fully participate in rehabilitation planning and goal setting as they were not easily understood by rehabilitation practitioners. Several strategies were identified to help those with cognitive and communication difficulties participate meaningfully, including directing questions at children with chronic neurological disorders, giving enough time to respond to queries, using alternative forms of communication and simplifying conversations. *"[it's] a real challenge to get the child's voice, even if they can speak. So when they can't speak it's even more challenging." (page 118, Jenkin 2022a)*					
Sub-theme C4.2: Encouraging children and young people						
2 studies • Collins 2023 (Grounded theory, acquired brain injury) • Jenkin 2022a (Grounded theory, acquired brain injury)	Children and young people with chronic neurological disorders, their family members and rehabilitation practitioners said that the level of engagement for children and young people varied greatly throughout goal setting and rehabilitation planning. Children and young people felt more involved in conversations when clinicians tried to minimize medical terminology, explain processes clearly, were open about treatment and allowed questions to be asked.	Moderate concerns (Moderate concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Findings derived from facilitators and barriers to including children and young people in rehabilitation planning)	No or very minor concerns	No or very minor concerns	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	Similarly, children were more motivated to achieve goals if they had a good relationship with rehabilitation practitioners, enjoyed the goal, and felt it was functionally important. Conversely, children and young people would pay less attention if they could not follow conversations, felt as though topics were not relevant to them or felt as though goals were imposed by their parents. To identify the most meaningful goals, rehabilitation practitioners should aim to develop a rapport with children and young people, getting to know what is important to them through meaningful conversations and ensure that their voices are heard alongside their parents. *"If the child's coming up with the goals themselves, then they're actually meaningful, and they're motivated to get towards those goals…it's all about how meaningful it is to them, not only to the child, but to the family…I think that's extremely important to be able to get the outcomes that they want." (page 115, Jenkin 2022a)*					

Appendix G Economic evidence study selection

Study selection for: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

No economic searches were undertaken for this qualitative review.

Appendix H Economic evidence tables

Economic evidence tables for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

No economic searches were undertaken for this qualitative review.

Appendix I Economic model

Economic model for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

No economic analysis was conducted for this review question.

Appendix J Excluded studies

Excluded studies for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

Excluded qualitative studies

Table 9: Excluded studies and reasons for their exclusion

Study	Reason for exclusion
Armstrong, Megan, Tuijt, Remco, Read, Joy et al. (2021) Health care professionals' perspectives on self-management for people with Parkinson's: qualitative findings from a UK study. BMC geriatrics 21(1): 706	- Phenomenon of interest Findings relate to barriers and facilitators to self-management and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Barlow, J; Edwards, R; Turner, A (2009) The experience of attending a lay-led, chronic disease self-management programme from the perspective of participants with multiple sclerosis. Psychology & health 24(10): 1167-80	- Phenomenon of interest Findings relate to chronic disease self-management course interventions and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Bhimani, Rozina H; McAlpine, Cynthia Peden; Henly, Susan J (2012) Understanding spasticity from patients' perspectives over time. Journal of advanced nursing 68(11): 2504-14	- Country Study conducted in the US.
Bove, Riley, Rowles, William, Carleton, Mia et al. (2020) Unmet Needs in the Evaluation, Treatment, and Recovery for 167 Children Affected by Acute Flaccid Myelitis Reported by Parents Through Social Media. Pediatric neurology 102: 20-27	- Country Study conducted in the US.
Buck, Page Walker, Laster, Rebecca G, Sagrati, Jocelyn Spencer et al. (2012) Working with mild traumatic brain injury: voices from the field. Rehabilitation research and practice 2012: 625621	- Country Study conducted in the US.
Burton, L.-J., Forster, A., Johnson, J. et al. (2021) Experiences and views of receiving and delivering information about recovery in acquired neurological conditions: A systematic review of qualitative literature. BMJ Open 11(4): e045297	- Country Systematic review with 6/28 of the included studies conducted in the UK, 5/28 in Australia, 3/28 in Canada, 9/28 in the US, 2/28 in Italy, 1/28 in Sweden, 1/28 in Turkey, and 1/28 in Canada and France. UK, Australian, and Canadian studies were checked against protocol criteria – 1 was identified as potentially relevant and retrieved for further screening.
Christie, Lauren, Egan, Cara, Wyborn, Josephine et al. (2021) Evaluating client experience of rehabilitation following acquired brain injury: a cross-sectional study. Brain injury 35(2): 215-225	- Country Study conducted in Australia with adult participants.

Study	Reason for exclusion
Collis, Jessica and Bloch, Steven (2012) Survey of UK speech and language therapists' assessment and treatment practices for people with progressive dysarthria. International journal of language & communication disorders 47(6): 725-37	- Study design Limited to quantitative data analysis and reporting.
Cruice, M. and Ten Kate, O. (2019) Clinicians' views and practices in quality of life in aphasia rehabilitation: a preliminary study. Aphasiology 33(11): 1293-1318	- Phenomenon of interest Findings relate to quality of life assessment tools, and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
D'Arcy, E., Evans, K., Afsharnejad, B. et al. (2023) Assessing functioning for individuals with neurodevelopmental conditions: Current clinical practice in Australia. Australian occupational therapy journal 70(1): 43-60	- Study design Limited to quantitative data analysis and reporting. Note: Qualitative analysis of free-text responses attempted but not completed due to insufficient data
Draaistra, Harriett, Singh, Mina D, Ireland, Sandra et al. (2012) Patients' perceptions of their roles in goal setting in a spinal cord injury regional rehabilitation program. Canadian journal of neuroscience nursing 34(3): 22-30	- Country Study conducted in Canada with adult participants.
Earle, S., O'Dell, L., Davies, A. et al. (2020) Views and Experiences of Sex, Sexuality and Relationships Following Spinal Cord Injury: A Systematic Review and Narrative Synthesis of the Qualitative Literature. Sexuality and Disability 38(4): 567-595	- Country Systematic review with 3/27 of the included studies conducted in the UK, 4/27 in Australia, 1/27 in Canada, 9/27 in the US, 2/27 in Greece, 2/27 in Iran, 1/27 in China, 1/27 in India, 1/27 in Sweden, 1/27 in South Africa, 1/27 in Hong Kong, and 1/27 in multiple Nordic countries. UK, Australian, and Canadian studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Entwistle, Vikki A, Cribb, Alan, Watt, Ian S et al. (2018) "The more you know, the more you realise it is really challenging to do": Tensions and uncertainties in person-centred support for people with long-term conditions. Patient education and counseling 101(8): 1460-1467	- Population Mixed population. Includes participants in protocol (11/26 healthcare professionals working in Parkinson's disease, and 6/26 healthcare professionals working in Parkinson’s disease and diabetes) and out of protocol (9/26 healthcare professionals working in diabetes). Results not presented separately for target population.
Erlick, M.R., Vavilala, M.S., Jaffe, K.M. et al. (2020) Provider Perspectives on Early Psychosocial Interventions after Pediatric Severe Traumatic Brain Injury: an Implementation Framework. Journal of neurotrauma	- Country Study conducted in the US.
Fairclough, G., Fox, J., Mercer, G. et al. (2014) Understanding the perceived treatment needs of patients with psychogenic nonepileptic seizures. Epilepsy and Behavior 31: 295-303	- Phenomenon of interest Findings relate to psychological referral for people with psychogenic nonepileptic seizures, and not the assessment and review of rehabilitation needs, or the formulation and

Study	Reason for exclusion
	review of rehabilitation plans, for people with chronic neurological disorders.
Gustafsson, Louise, Mitchell, Genna, Fleming, Jenny et al. (2012) Clinical utility of the Canadian Occupational Performance Measure in spinal cord injury rehabilitation. The British Journal of Occupational Therapy 75(7): 337-342	- Country Study conducted in Australia with unclear population (no description of whether healthcare professionals worked in adult or paediatric services).
Hartley, S E and Stockley, R C (2016) Collaborative goal setting with adults attending physiotherapy at a specialist neuromuscular centre: is it always appropriate? A cross-sectional survey. Physiotherapy 102(4): 320-326	- Phenomenon of interest Findings relate to types of rehabilitation goals and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Hawley, Rachael, Madden, Rosamond H, Brentnall, Jennie et al. (2016) Testing and development of an instrument for self-report of participation and related environmental factors-Your ideas about participation and environment (YIPE) among adults with brain injury. Disability and Rehabilitation: An International, Multidisciplinary Journal 38(23): 2315-2323	- Country Study conducted in Australia with adult participants.
Hersh, D., Worrall, L., Howe, T. et al. (2012) SMARTER goal setting in aphasia rehabilitation. Aphasiology 26(2): 220-233	- Study design Not a systematic review, literature review and summary of findings from a previous study with no description of methodology.
Holloway, Mark (2014) How is ABI assessed and responded to in non-specialist settings? Is specialist education required for all social care professionals?. Social Care and Neurodisability 5(4): 201-213	- Study design Opinion piece.
Holloway, Mark and Tasker, Ross (2019) The experiences of relatives of people with Acquired Brain Injury (ABI) of the condition and associated social and health care services. Journal of Long-Term Care: 99-110	- Phenomenon of interest Findings relate to delivery of rehabilitation and identification of rehabilitation needs for chronic neurological disorders, and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders. Paper has been included in evidence reviews on delivery of rehabilitation services and identification and referral for chronic neurological disorders.
Hunt, Anne W, Le Dorze, Guylaine, Trentham, Barry et al. (2015) Elucidating a goal-setting continuum in brain injury rehabilitation. Qualitative Health Research 25(8): 1044-1055	- Country Study conducted in Canada with unclear population (no description of whether healthcare professionals worked in adult or paediatric services).
Kaiser, S. and Kennedy, P. (2011) An exploration of cognitive appraisals following spinal cord injury. Psychology, health & medicine 16(6): 708-718	- Phenomenon of interest Findings relate to internal appraisals of spinal cord injury experience and anticipated recovery, and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Kirk, S., Fallon, D., Fraser, C. et al. (2015) Supporting parents following childhood traumatic	- Phenomenon of interest

Study	Reason for exclusion
brain injury: a qualitative study to examine information and emotional support needs across key care transitions. Child: care, health and development 41(2): 303-313	Findings relate to parental support needs after traumatic brain injury and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Lam Wai Shun, Priscilla; Swaine, Bonnie; Bottari, Carolina (2022) Clinical reasoning underlying acute care occupational therapists' assessment of rehabilitation potential after stroke or brain injury: A constructivist grounded theory study. Australian occupational therapy journal 69(2): 177-189	- Country Study conducted in Canada with healthcare professionals working in adult acute care services.
Lefebvre, Helene and Levert, Marie Josee (2012) The needs experienced by individuals and their loved ones following a traumatic brain injury. Journal of trauma nursing : the official journal of the Society of Trauma Nurses 19(4): 197-207	- Country Study conducted in France and Canada with adult participants.
Lemon, Jennifer, Cooper, Jessie, Defres, Sylviane et al. (2019) Understanding parental perspectives on outcomes following paediatric encephalitis: A qualitative study. PLoS ONE 14(9)	- Phenomenon of interest Findings relate to acute treatment and outcomes of paediatric encephalitis, and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Lucas, Lauren and Parker, Jack (2022) Physiotherapists perceived role in managing anxiety in patients with relapsing-remitting multiple sclerosis: a mixed-methods study. Archives of physiotherapy 12(1): 2	- Phenomenon of interest Findings relate to management of anxiety, and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Miley, A.E., Fisher, A.P., Moscato, E.L. et al. (2022) A mixed-methods analysis examining child and family needs following early brain injury. Disability and rehabilitation 44(14): 3566-3576	- Country Study conducted in the US.
Morrison, Cecily, D'Souza, Marcus, Huckvale, Kit et al. (2015) Usability and Acceptability of ASSESS MS: Assessment of Motor Dysfunction in Multiple Sclerosis Using Depth-Sensing Computer Vision. JMIR human factors 2(1): e11	- Study design Limited to quantitative data analysis and reporting.
O'Loughlin, Emer, Hourihan, Susan, Chataway, Jeremy et al. (2017) The experience of transitioning from relapsing remitting to secondary progressive multiple sclerosis: views of patients and health professionals. Disability and rehabilitation 39(18): 1821-1828	- Phenomenon of interest Findings relate to experiences of re-classification of multiple-sclerosis subtypes and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Odumuyiwa, Tolu (2019) Improving access to social care services following acquired brain injury: a needs analysis. Journal of Long-Term Care: 164-175	- Phenomenon of interest Findings relate to accessing rehabilitation services, and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders. Paper has been included in evidence review on delivery of

Study	Reason for exclusion
	rehabilitation services for chronic neurological disorders.
Osborne, Candice L, Juengst, Shannon B, Smith, Emily E et al. (2021) Identifying user-centered content, design, and features for mobile health apps to support long-term assessment, behavioral intervention, and transitions of care in neurological rehabilitation: An exploratory study. The British Journal of Occupational Therapy 84(2): 101-110	- Country Study conducted in the US.
Pettit, L.K.; Tonsing, K.M.; Dada, S. (2017) The perspectives of adults with aphasia and their team members regarding the importance of nine life areas for rehabilitation: A pilot investigation. Topics in Stroke Rehabilitation 24(2): 99-106	- Country Study conducted in South Africa.
Plant, Sarah E, Tyson, Sarah F, Kirk, Susan et al. (2016) What are the barriers and facilitators to goal-setting during rehabilitation for stroke and other acquired brain injuries? A systematic review and meta-synthesis. Clinical rehabilitation 30(9): 921-30	- Publication date Systematic review with 6/9 studies published 2010 or later, and 3/9 studies published pre-2010. Studies published 2010 or later were checked against protocol criteria – 1 was identified as potentially relevant and retrieved for further screening.
Prescott, Sarah; Fleming, Jennifer; Doig, Emmah (2019) Refining a clinical practice framework to engage clients with brain injury in goal setting. Australian occupational therapy journal 66(3): 313-325	- Country Study conducted in Australia with adult participants.
Rabbitte, Mary; Bates, Ursula; Keane, Michael (2015) Psychological and psychotherapeutic approaches for people with motor neuron disease: A qualitative study. Amyotrophic lateral sclerosis & frontotemporal degeneration 16(56): 303-8	- Country Mixed countries. Study conducted in Ireland with 1/10 rehabilitation practitioners located in UK, 8/10 in Ireland and 1/10 Italy. Findings not presented separately for target country.
Ramdharry, Gita M, Thornhill, Anna, Mein, Gill et al. (2012) Exploring the experience of fatigue in people with Charcot-Marie-Tooth disease. Neuromuscular disorders : NMD 22suppl3: 208-13	- Phenomenon of interest Findings relate to impact of fatigue, and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Sansonetti, Danielle; Nicks, Rebecca J; Unsworth, Carolyn (2018) Barriers and enablers to aligning rehabilitation goals to patient life roles following acquired brain injury. Australian occupational therapy journal 65(6): 512-522	- Country Study conducted in Australia with adult participants.
Scheel-Sailer, Anke, Post, Marcel W, Michel, Franz et al. (2017) Patients' views on their decision making during inpatient rehabilitation after newly acquired spinal cord injury-A qualitative interview-based study. Health expectations : an international journal of public participation in health care and health policy 20(5): 1133-1142	- Country Study conducted in Switzerland.
Schipper, K., Visser-Meily, J.M.A., Hendrikx, A. et al. (2011) Participation of people with	- Country Study conducted in the Netherlands.

Study	Reason for exclusion
acquired brain injury: Insiders perspectives. Brain Injury 25(9): 832-843	
Sisk, B.A., Keenan, M.A., Blazin, L.J. et al. (2021) "Don't be afraid to speak up": Communication advice from parents and clinicians of children with cancer. Pediatric Blood and Cancer 68(8): e29052	- Country Study conducted in the US.
Spiers, Gemma, Aspinal, Fiona, Bernard, Sylvia et al. (2015) What outcomes are important to people with long-term neurological conditions using integrated health and social care?. Health & social care in the community 23(5): 559-68	- Phenomenon of interest Findings relate to important individual outcomes, and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Symons, Jane, Clark, Hannah, Williams, Kerry et al. (2011) Visual art in physical rehabilitation: Experiences of people with neurological condition. The British Journal of Occupational Therapy 74(1): 44-52	- Country Study conducted in Australia with adult participants.
Turner, Benjamin, Fleming, Jennifer, Ownsworth, Tamara et al. (2011) Perceptions of recovery during the early transition phase from hospital to home following acquired brain injury: a journey of discovery. Neuropsychological rehabilitation 21(1): 64-91	- Country Study conducted in Australia with adult participants.
Weeks, K.R., Gould, R.L., Mcdermott, C. et al. (2019) Needs and preferences for psychological interventions of people with motor neuron disease. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration 20(78): 521-531	- Phenomenon of interest Findings relate to delivery of psychological interventions, and not the assessment and review of rehabilitation needs, or the formulation and review of rehabilitation plans, for people with chronic neurological disorders.
Worrall, L., Brown, K., Cruice, M. et al. (2010) The evidence for a life-coaching approach to aphasia. Aphasiology 24(4): 497-514	- Population Unclear population. People with post-stroke aphasia (no description of whether they are adult or paediatric participants).

Excluded economic studies

No economic searches were undertaken for this qualitative review.

Appendix K Research recommendations – full details

Research recommendations for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?

No research recommendations were made for this review question.