National Institute for Health and Care Excellence

Draft for consultation

Rehabilitation for chronic neurological disorders including acquired brain injury

[B] Evidence review for identification and referral

NICE guideline <number>

Evidence reviews underpinning recommendations 1.3.4 to 1.3.6, 1.4.1 to 1.4.3, 1.5.1 to 1.5.4, 1.7.1 to 1.7.3, 1.8.1 to 1.8.7, 1.8.10 to 1.8.11, 1.8.20, 1.10.3, 1.10.7, 1.11.1 to 1.11.3 1.13.3, 1.13.1, and 1.22.8 in the NICE guideline

April 2025

Draft for consultation

This evidence review was developed by NICE

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ISBN:

Contents

Identification and referral

Review question

What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

Introduction

People with chronic neurological disorders report multiple challenges in identifying and accessing rehabilitation. These include person and condition specific factors, but also wider social and healthcare dynamics. These complex and poorly understood barriers to rehabilitation contribute to inequitable healthcare for people with chronic neurological disorders. By developing a deeper understanding of the barriers and facilitators experienced by people with chronic neurological disorders when accessing rehabilitation services, we can develop targeted recommendations and strategies to improve rehabilitation access.

The aim of this qualitative review is to determine what are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral.

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	• **Availability.** Views may be expressed about the availability of services including inpatient rehabilitation, community outpatient, third sector services, residential options, specialist care and personalised care such as named contacts or key workers. Also, about opening times, appointment systems, eligibility criteria and routes for re-referral as needs fluctuate. These issues may be particularly pronounced for people with comorbid conditions, including drug and alcohol use disorders. • **Acceptability.** Experiences relating to provider expectations and user expectations might suggest ways of improving referral to rehabilitation services. • **Affordability.** There may be data about the costs (perceived or real) of rehabilitation services, including direct and indirect costs, public funding and charitable donations. • **Equalities considerations.** The extent to which services are felt to demonstrate due regard to the equality duty may support or undermine referral to appropriate services. For example, whether the needs of people from

	protected groups are met, such as having facilities for people whose first language is not English. Perceptions about the cultural competence of services may also affect referrals. • **Physical barriers.** Data may be located about physical barriers, such as location of services or a lack of ramps or other built environment adjustments for disabled access, which may deter referrals to those services. Examples of other barriers might relate to conveying children and young people to appointments especially where these are community based. • **Information and awareness.** The role of information and awareness surrounding chronic neurological disorders is expected to influence the identification of rehabilitation needs and referral to services (whether self-referrals or referrals from primary care or intermediary organisations). This may apply to people with chronic neurological disorders, their families or practitioners. • **Attitudes and beliefs.** Data are anticipated about the way in which people's beliefs might lead to biases, in turn affecting decision making around issues such as risk taking. These might also affect people's insight and awareness about conditions and rehabilitation needs and potential. This could apply equally to people with neurological disorders, their families or relevant practitioners. • **Organisation of services.** Data may be located which suggest that the planning and provision (including timeliness) of appropriate services is limited by the nature of service planning, organisation or funding, as well as communication and joint working within and between healthcare and rehabilitation services. Local variation in the existence of single access points to services is also likely to be relevant here. • **The role of technology and other developments in diagnostics.** Data may relate to the role of new technologies to support the identification of rehabilitation needs arising from chronic neurological disorders. Examples including online or AI models for diagnosis.

AI: artificial intelligence

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 (Supplement 1: methods) although there was one difference between the protocol and the review, which the committee agreed and this was to exclude non-UK evidence, except where it was lacking for children and young people. This decision was taken because after full text screening on the original protocol it became clear there was a large volume of relevant studies from a wide range of countries. The committee wanted to ensure the results of the review were as relevant as possible to the UK practice context to improve the likely implementation of recommendations stemming from the evidence. However, aware of the relative lack of studies on rehabilitation for children and young people with chronic neurological disorders, the committee agreed a stepwise approach; if there was insufficient UK evidence to support their decision making then evidence about children and young people would also be considered from Australia, Canada and New Zealand. In the committee's view, the health systems and approach to rehabilitation in those countries are sufficiently in step with the UK that research findings are likely to be transferable. The committee were also aware of ongoing developments in rehabilitation for children and young people in those countries which would provide an important addition and point of learning where UK evidence was lacking

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

Qualitative evidence

Included studies

Eleven studies (reported in 12 papers) were included for this review, and all were general qualitative inquiries (Cheung 2022, Grose 2014, Holloway 2019, Jervis Rademeyer 2022, McCartney 2011, Methley 2017, Norman 2020 [also reported in Odumuyiwa 2019], Preston 2012, Treadgold 2019, Twigg 2021, Woodward 2022).

The included studies are summarised in Table 2.

Nine studies (reported in 10 papers) were conducted in the UK (Grose 2014, Holloway 2019, McCartney 2011, Methley 2017, Norman 2020 [also reported in Odumuyiwa 2019], Preston 2012, Treadgold 2019, Twigg 2021, Woodward 2022). Two studies were conducted in Canada (Cheung 2022, Jervis Rademeyer 2022).

Six studies (reported in 7 papers) did not specify the age range of participants (Cheung 2022, Holloway 2019, Jervis Rademeyer 2022, McCartney 2011, Norman 2020 [also reported in Odumuyiwa 2019], Woodward 2022); 5 studies investigated chronic neurological disorders in an adult population (Grose 2014, Methley 2017, Preston 2012, Twigg 2021); and 1 study investigated chronic neurological disorders in the paediatric population (Treadgold 2019).

Five studies investigated identification and referral for rehabilitation for people with progressive neurological disorders (Grose 2014, Methley 2017, Preston 2012, Twigg 2021, Woodward 2022); 3 studies (reported in 4 papers) investigated identification and referral for rehabilitation for people with acquired brain injury (Holloway 2019, McCartney 2011, Norman 2020 [also reported in Odumuyiwa 2019]); 2 studies investigated identification and referral for rehabilitation for people with acquired spinal cord injury (Cheung 2022, Jervis Rademeyer 2022); and 1 study investigated identification and referral for rehabilitation for people with both acquired brain injury and acquired spinal cord injury (Treadgold 2019).

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
Cheung 2022 General qualitative inquiry Canada **Aim** To explore how activity-based therapy and technologies associated with it are	N=13 practitioners working with people with spinal cord injury or disease CND category: Acquired spinal cord injury Age of people with chronic neurological disorders in years**:** Not reported	**Data Collection:** Semi-structured interviews **Analysis:** Interpretive description analysis	• Availability ○ Availability of specialist centres and/or services • Affordability • Information and awareness ○ Education for non-specialist healthcare professionals

Study	Participants	Methods	Themes applied after thematic synthesis
being used by therapists.	Sex of people with chronic neurological disorders: Not reported		• Early identification of needs
Grose 2014 General qualitative inquiry UK **Aim** To explore the health care experiences of people with hereditary spastic paraplegia.	N=32 adults with hereditary spastic paraplegia plus carers and practitioners CND category: Progressive neurological disease **Adults with hereditary spastic paraplegia, n=14** Age in years [Mean (SD)]: Not reported, age range 26-90 Sex: Not reported **Carers of people with hereditary spastic paraplegia, n=6** 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 hereditary spastic paraplegia, n=12** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data Collection:** Focus groups and semi-structured interviews **Analysis:** Thematic analysis	• Availability ○ Availability of specialist chronic neurological rehabilitation knowledge ○ Presence of key contacts • Organisation of services ○ Adequate follow-up and signposting • Organisation of services ○ Communication and coordination • Early identification of needs
Holloway 2019 General qualitative inquiry (within mixed-methods study) UK **Aim**	N=110 carers of people with acquired brain injury CND category: Acquired brain injury Age of people with chronic neurological disorders in years: Not reported	**Data Collection:** Quantitative survey with free-text questions **Analysis:** Qualitative analysis of free-text questions	• Availability ○ Availability of specialist centres and/or services ○ Availability of specialist chronic neurological rehabilitation knowledge ○ Presence of key contacts

Study	Participants	Methods	Themes applied after thematic synthesis
To understand the experiences of family members of people with an acquired brain injury in relation to health and social care.	Sex of people with chronic neurological disorders (M/F): n=14/n=96		• Information and awareness ○ Education for non-specialist healthcare professionals ○ Education for people with chronic neurological disorders and family ○ Understanding the importance of 'invisible' symptoms • Attitudes and beliefs ○ The role of family and friends throughout rehabilitation • Organisation of services ○ Auxiliary services ○ Existence of an official referral pathway
Jervis Rademeyer 2022 General qualitative inquiry Canada **Aim** To explore how therapists use activity-based therapy when providing care to individuals with spinal cord injury or disease.	N=22 practitioners working with people with spinal cord injury or disease CND category: Acquired spinal cord injury Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data Collection:** Focus group meetings using semi-structured interview questions **Analysis:** Interpretive description	• Availability ○ Availability of specialist centres and/or services ○ Availability of specialist chronic neurological rehabilitation knowledge ○ Limited capacity of services • Affordability • Organisation of services ○ Communication and coordination • Organisation of services ○ Existence of an official referral pathway
McCartney 2011 General qualitative inquiry UK **Aim** To determine practitioners' views regarding the barriers to rehabilitation for people with primary high-grade brain tumours.	N=8 practitioners working with people with primary high-grade brain tumours CND category: Acquired brain injury Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data Collection:** Semi-structured interviews **Analysis:** Inductive thematic analysis	• Availability ○ Availability of specialist centres and/or services ○ Availability of specialist chronic neurological rehabilitation knowledge ○ Meeting eligibility criteria • Information and awareness ○ Education for non-specialist healthcare professionals

Study	Participants	Methods	Themes applied after thematic synthesis
			○ Education for people with chronic neurological disorders and family ○ Understanding roles of other professionals • Attitudes and beliefs ○ Pre-conceived ideas on appropriateness of rehabilitation • Organisation of services ○ Adequate follow-up and signposting ○ Communication and coordination ○ Waiting times
Methley 2017 General qualitative inquiry UK **Aim** To understand the experiences of people with multiple sclerosis, and practitioners in relation to mental health support.	N=58 adults with multiple sclerosis plus practitioners CND category: Progressive neurological disease **Adults with multiple sclerosis, n=24** Age in years [Mean (SD)]: Not reported, age range 31-80 Sex (M/F): n=6/n=18 **Practitioners working with people with multiple sclerosis, n=34** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Availability ○ Limited capacity of services ○ Meeting eligibility criteria • Information and awareness ○ Education for non-specialist healthcare professionals ○ Understanding roles of other professionals • Attitudes and beliefs: pre-conceived ideas on appropriateness of rehabilitation • Organisation of services ○ Auxiliary services ○ Waiting time
Norman 2020 General qualitative inquiry UK **Aim** To determine practitioners' knowledge	N=117 people with acquired brain injury plus carers and practitioners CND category: Acquired brain injury **People with acquired brain injury, n=30**	**Data Collection:** Quantitative survey with free-text questions and semi-structured interviews **Analysis:** Thematic analysis, summative approach of free-text questions, and direct content analysis	• Information and awareness: ○ Education for non-specialist healthcare professionals ○ Understanding the importance of 'invisible' symptoms • Attitudes and beliefs

Study	Participants	Methods	Themes applied after thematic synthesis
regarding working with people with an acquired brain injury and identify areas for improvement.	Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders (M/F): n=21/n=9 **Carers of people with acquired brain injury, n=20** 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 acquired brain injury, n=61** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported		○ Focusing on physical injuries and impairments • Organisation of services ○ Adequate follow-up and signposting
Odumuyiwa 2019 General qualitative inquiry UK **Aim** To explore the long-term rehabilitation needs of people with an acquired brain injury and their experience of services, as well as the needs and experiences of their family and carers	N=76 adults with acquired brain injury plus carers or relatives and practitioners CND category: Acquired brain injury **Adults with acquired brain injury, n=19** Age in years [Mean (SD)]: 44.6 (SD not reported), age range 20-73 Sex (M/F): n=10/n=9 **Carers or relatives of people with acquired brain injury, n=26** Age of people with chronic neurological	**Data Collection:** See Norman 2020 **Analysis:** See Norman 2020	• Availability: ○ Availability of specialist centres and/or services ○ Limited capacity of services • Information and awareness ○ Education for non-specialist healthcare professionals • Attitudes and beliefs ○ Focusing on physical injuries and impairments ○ The role of family and friends throughout rehabilitation • Organisation of services ○ Adequate follow-up and signposting

Study	Participants	Methods	Themes applied after thematic synthesis
	disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported **Practitioners working with people with acquired brain injury, n=32** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported		○ Auxiliary services
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 and 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 **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	**Data Collection:** Focus groups **Analysis:** Grounded theory	• Attitudes and beliefs ○ The role of family and friends throughout rehabilitation • Early identification of needs

Study	Participants	Methods	Themes applied after thematic synthesis
	disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported		
Treadgold 2019 General qualitative inquiry UK **Aim** To explore the provision of specialist paediatric neuro-oncology rehabilitation services and determine if they meet the needs of children and young people with central nervous system tumour and their families.	N=37 carers of children and young people with central nervous system tumour plus practitioners CND category: Acquired brain injury, acquired spinal cord injury **Carers of children and young people with central nervous system tumour, n=18** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all noted as 'children and young people' Sex of children and young people with chronic neurological disorders: Not reported **Practitioners working with children and young people with central nervous system tumour, n=19** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all noted as 'children and young people' Sex of children and young people with chronic neurological disorders: Not reported	**Data Collection:** Surveys with free-text questions. **Analysis:** Narrative summary of free-text questions. No further details reported.	• Availability ○ Availability of specialist centres and/or services ○ Meeting eligibility criteria • Organisation of services ○ Communication and coordination ○ Existence of an official referral pathway
Twigg 2021 Case study UK **Aim**	N=2 (1 adult with POEMS syndrome plus carer) CND category: Progressive neurological disease	**Data Collection:** Semi-structured interview **Analysis:** Constant comparative approach	• Attitudes and beliefs ○ Pre-conceived ideas on appropriateness of rehabilitation ○ The role of family and friends throughout rehabilitation

Study	Participants	Methods	Themes applied after thematic synthesis
To understand the lived experience of a person with a rare condition (POEMS syndrome), particularly in relation to health care.	**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		
Woodward 2022 General qualitative inquiry UK **Aim** To understand practitioners' views regarding management of bowel dysfunction in people with multiple sclerosis.	N=18 practitioners working with people with multiple sclerosis CND category: Progressive neurological disease Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Availability ○ Limited capacity of services • Information and awareness ○ Education for non-specialist healthcare professionals ○ Education for people with chronic neurological disorders and family • Organisation of services ○ Existence of an official referral pathway • Early identification of needs

ABT: activity-based therapy; CND: chronic neurological disorder; POEMS: polyneuropathy organomegaly endocrinopathy monoclonal gammopathy skin changes; 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

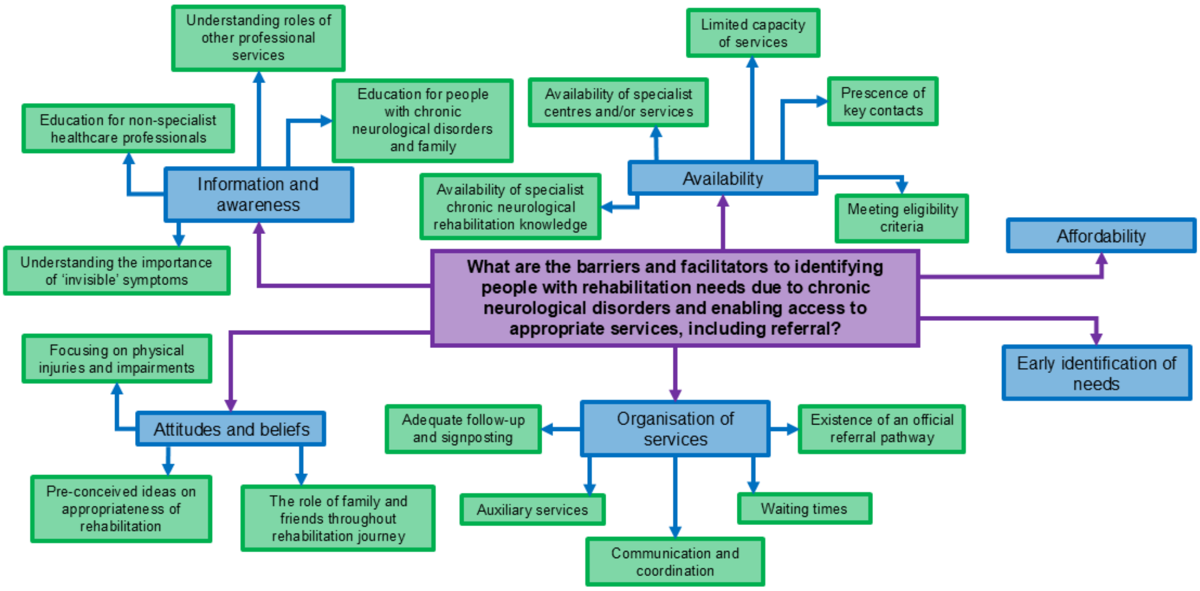
The synthesis of the evidence generated 6 main themes:

- B1 Availability
- B2 Affordability
- B3 Information and awareness
- B4 Attitudes and beliefs
- B5 Organisation of services
- B6 Early identification of needs

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 'B') 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).

Figure 1: Theme map for barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services



B1 Availability

Five sub-themes were identified under availability. In the 'B1.1 Availability of specialist centres and/or services' sub-theme (moderate confidence), evidence from 7 studies showed that poor provision of specialist chronic neurological disorder rehabilitation centres and services designed for this population was a barrier to accessing appropriate rehabilitation services. In the 'B1.2 Availability of specialist chronic neurological rehabilitation knowledge' sub-theme (moderate confidence), evidence from 4 studies showed that both identification of rehabilitation needs and access to appropriate services is increased when services provide specialist chronic neurological disorder rehabilitation care, compared to general rehabilitation services. In the 'B1.3 Limited capacity of services' sub-theme (low confidence), evidence from 4 studies showed that factors such as lack of funding, availability of resources or length of appointment time affected both identification of rehabilitation needs and access to appropriate services. In the 'B1.4 Meeting eligibility criteria' sub-theme (very low confidence), evidence from 3 studies showed that differing eligibility criteria across rehabilitation services can affect access to appropriate rehabilitation services and continuity of care. In the 'B1.5 Presence of key contacts sub-theme (low confidence), evidence from 2 studies showed that having a single point of contact helped people to access appropriate services by co-ordinating services and providing accurate information.

B2 Affordability

This theme (moderate confidence) related to the personal cost of interventions and equipment for people with chronic neurological disorders. Evidence from 3 studies showed that expensive therapies and equipment can prevent people from accessing appropriate rehabilitation services. No sub-themes were identified for this theme.

B3 Information and awareness

Four sub-themes were identified under information and awareness. In the ‘B3.1 Education for non-specialist healthcare professionals’ sub-theme (moderate confidence), evidence from 6 studies suggested that increasing chronic neurological disorder rehabilitation knowledge within primary healthcare improved both the identification of rehabilitation needs and access to appropriate services. In the subtheme ‘B3.2 Education for people with chronic neurological disorders and family’ (low confidence), evidence from 3 studies showed that educating people with chronic neurological disorder and their family about areas such as disease pathology and prognosis increased identification of rehabilitation needs and access to appropriate services. In the ‘B3.3 Understanding the importance of ‘invisible’ symptoms’ sub-theme (moderate confidence), evidence from 2 studies showed that a lack of understanding about the less easily recognisable behavioural and cognitive symptoms of chronic neurological disorders can adversely impact both the identification of rehabilitation needs and access to appropriate services. In the ‘B3.4 Understanding roles of other professional services’ sub-theme (low confidence), evidence from 2 studies showed that a poor understanding of the roles of other professionals within the chronic neurological disorder rehabilitation pathway can lead to people either being inappropriately referred to services or not referred at all.

B4 Attitudes and beliefs

Three sub-themes were identified under attitudes and beliefs. In the ‘B4.1 Focusing on physical injuries and impairments’ sub-theme (moderate confidence), evidence from 1 study showed that identification of rehabilitation needs is delayed and access to appropriate services is adversely affected when healthcare professionals concentrate on treating visible injuries. In the ‘B4.2 Pre-conceived ideas on appropriateness of rehabilitation’ sub-theme (moderate confidence), evidence from 3 studies showed that people with chronic neurological disorders might not be referred to appropriate services if healthcare professionals believe (for a variety of reasons) that they will not benefit from rehabilitation. In the ‘B4.3 The role of family and friends throughout rehabilitation’ sub-theme (low confidence), evidence from 4 studies showed that family and friends can be a valuable source of information for healthcare professionals and should be included in rehabilitation where possible to aid identification of rehabilitation needs and accessing appropriate services.

B5 Organisation of services

Five sub-themes were identified under organisation of services. In the ‘B5.1 Adequate follow-up and signposting’ sub-theme (high confidence), evidence from 3 studies showed that poor follow-up procedures (including any signposting that may increase a person’s knowledge of chronic neurological disorder rehabilitation) at transfer between services is a barrier to appropriate rehabilitation for chronic neurological disorders. In the ‘B5.2 Auxiliary services’ sub-theme (very low confidence), evidence from 3 studies showed that measures taken to increase accessibility to appropriate services should be sure to include any auxiliary services that people with a chronic neurological disorder may also wish to utilise. In the ‘B5.3 Communication and coordination’ sub-theme (moderate confidence), evidence from 4 studies showed that poor communication and coordination between rehabilitation services was a barrier to both identifying rehabilitation needs and accessing appropriate services. In the ‘B5.4 Existence of an official referral pathway’ sub-theme (moderate confidence), evidence from 4 studies showed that a lack of an official referral pathway was a barrier to accessing appropriate services as people were unsure of 'next steps' in their rehabilitation. In the ‘B5.5 Waiting times’ sub-theme (moderate confidence), evidence from 2 studies showed that long wait times were a barrier to accessing appropriate services as rehabilitation needs may have changed by the time people were invited to attend services.

B6 Early identification of needs

In this theme (high confidence), evidence from 4 studies showed that identifying people's potential needs early in their rehabilitation was an important factor for both identification of rehabilitation needs and access to appropriate services. No sub-themes were identified for this theme.

See appendix F for full GRADE-CERQual tables.

Economic evidence

Included studies

In the development of these qualitative reviews, targeted searches for evidence on cost effectiveness were planned. The committee was asked to consider whether a recommendation represents a substantial change in practice and results in significant resource impact and if so targeted searches around that area would be undertaken. The committee could not identify a recommendation that would benefit from targeted searches for the supporting economic evidence.

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 the barriers and facilitators are to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services (including re-referral), this review was designed to include qualitative data. As a result, the committee could not specify in advance the data that would be located. Instead, they agreed, using 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.

- Availability – for example, the availability of services (including inpatient rehabilitation, community outpatient, third sector services, residential options, specialist care, and personalised care), opening times, appointment systems, eligibility criteria and routes for re-referral as needs fluctuate (particularly for those people with comorbidities).
- Acceptability – for example, how provider expectations and user expectations could affect referrals to rehabilitation services.
- Affordability – for example, perceived or real costs of rehabilitation services (including direct and indirect costs), public funding, and charitable donations.
- Equalities considerations – for example, whether the needs of people with chronic neurological disorders from protected groups are met, such as having facilities for people whose first language is not English.
- Physical barriers – for example, location of services, a lack of adjustments for disabled access (including ramps and other built environments), and a lack of transport available for children and young people attending appointments.

- Information and awareness – for example, how available information and awareness surrounding chronic neurological disorders is may influence the identification of rehabilitation needs and referral to services.
- Attitudes and beliefs – for example, how people’s beliefs can affect decision making around issues such as risk taking, or how biases affect insight and awareness about conditions and rehabilitation needs and potential.
- Organisation of services – for example, how the planning and provision of rehabilitation services for chronic neurological disorders could be affected by service planning, organisational funding, and communication and joint working within and between healthcare and rehabilitation services.
- The role of technology and other developments in diagnostics – for example, the role of new technologies (including online or artificial intelligence models for diagnosis) to support the identification of rehabilitation needs arising from chronic neurological disorders.

These themes were chosen as they were expected to be the key aspects that inform opinion and preferences about the way in which rehabilitation needs arising from chronic neurological disorders can be identified and how appropriate rehabilitation services for these needs could be accessed.

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 thematic analysis methods) and concerns over adequacy (for example, when only 2 studies contributed to a theme, or when there was a lack of first order quotes to support themes). Studies were also downgraded due to relevance concerns (for example, when themes only used findings on specific rehabilitation therapies or services, or if they only used findings from 1 specific chronic neurological disorder) and coherence of themes (for example, when themes included both positive and negative findings).

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

- Acceptability
- Equalities considerations
- Physical barriers
- Role of technology and other developments in diagnostics

Themes for which evidence was reported but had not been set out in the protocol:

- Early identification of needs

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

Benefits and harms

Building local capacity and expertise

Moderate quality evidence from the theme ‘B3.1 Education for non-specialist healthcare professionals’ which showed that increasing knowledge of chronic neurological disorders within general healthcare settings helps to improve identification of rehabilitation needs and referral to appropriate specialist services. This finding was supported by further moderate quality evidence from the themes ‘B4.1: Focusing on physical injuries and impairments’ and ‘B4.2 Preconceived ideas on appropriateness of rehabilitation’ showed that healthcare professionals tend to focus on physical and visible symptoms, and can act as barriers to accessing rehabilitation services when they have prejudged ideas about how well people with chronic neurological disorders will respond. Finally, low quality evidence from the theme ‘B3.4 Understanding roles of other professional services’ showed that referrals to appropriate rehabilitation services were adversely impacted when healthcare professionals were poorly informed about the roles of these services. The committee agreed with all of the findings, recommending that healthcare professionals should be educated in chronic neurological disorders. They noted that this knowledge should include the wide range of symptoms that people can present with, but also which specialists services to refer on to once potential rehabilitation needs have been identified. Increasing professional knowledge will also help to rectify any misbeliefs about who will and who will not benefit from accessing rehabilitation services. The committee were aware that education on such a heterogeneous and large topic is not easy for already busy healthcare professionals to action, and therefore suggested 2 ways to do so (sharing expertise with specialist centres and keeping current information on local services) that would have minimal impact on their resources.

The committee discussed moderate quality evidence from the theme ‘B2 Affordability’, which showed that expensive treatments can be a barrier to accessing rehabilitation services. The committee agreed with this finding. They noted that there is assistance for many of these more costly treatments or services, available through commissioning pathways. Unfortunately these are not always publicised or widely known about. Therefore, the committee recommended that rehabilitation professionals should educate themselves on what processes need to be followed in order to commission high-cost equipment and services.

The committee discussed the 3 themes identified in this evidence review that related to availability and capacity of rehabilitation services for people with chronic neurological disorders. Moderate quality evidence from the theme ‘B1.1 Availability of specialist centres and/or services’ showed that poor availability of specialist chronic neurological disorder rehabilitation centres and services prevents people from accessing appropriate services. This lack of availability could be due to physical factors (for example, geographical location of services) or due to there being no local services designed to meet the rehabilitation needs of people with rare conditions. Similarly, moderate quality evidence from the theme ‘B.1.2 Availability of specialist chronic neurological disorder rehabilitation knowledge’ showed that increasing specialist knowledge leads to a larger variety of skills and training, which in turn can lead to the provision of a wider variety rehabilitation services and therapies for chronic neurological diseases. Finally, low quality evidence from the theme ‘B1.3 Limited capacity of services’ showed that increasing the capacity of healthcare services helps to improve both the identification of rehabilitation needs and access to appropriate services. The committee were conscious that recommendations on increasing availability of specialist centres and services would have a resource impact, so focused their discussion on increasing specialist knowledge and unlocking capacity within existing services. In their experience, collaboration is key to both of these endeavours. They noted that this can be within and between integrated care systems, and will help to increase the knowledge of local services, community and specialist expertise within them.

Providing responsive services

The committee discussed moderate quality evidence from the theme ‘B5.3 Communication and coordination’ which showed that poor communication and coordination between rehabilitation services adversely impacted identification of rehabilitation needs and access to rehabilitation services. The committee agreed with this finding, adding that this is often very pertinent when people transfer between services as this is when information can be lost. Therefore, they recommended that service providers communicate and collaborate across specialities and services to create pathways that are up-to-date and responsive. They highlighted that this will not only need to include public healthcare services, but also voluntary and private organisations. Please note that this recommendation also uses evidence from evidence review B, where the remainder of the committee’s discussion can be found.

The committee discussed moderate quality evidence from the theme ‘B5.4 Existence of an official referral pathway’, which showed that creating official referral pathways would help people with chronic neurological disorders navigate the rehabilitation system by setting out subsequent steps in the process. The committee agreed with this finding, adding that pathways were often unnecessarily complicated which only adds to confusion of people trying to navigate them. Therefore, they recommended rehabilitation services to set up simple referral procedures to allow timely access to assessments, treatment, and support services. The committee wanted to highlight that this referral should not only encompass first contact, but also re-referral (including self-referral), which is especially important in chronic conditions and in disorders where symptoms may fluctuate. These procedures should also be simple and coordinated to ensure timely re-access with correct sharing of information. Please note that this recommendation also uses evidence from evidence review A, where the remainder of the committee’s discussion can be found.

Alongside the evidence on referral pathways, the committee again discussed moderate quality evidence from the theme ‘B5.3 Communication and coordination’, which showed that poor communication and coordination across rehabilitation services led to poor identification of rehabilitation needs and access to rehabilitation services. The committee agreed that this is an area that could be improved between rehabilitation services (for example, using trusted assessments). By giving practitioners a process to share information and learn from each other, they can develop approaches that are faster, more efficient, and responsive to individual rehabilitation and local service needs.

Early discussion about prognosis and rehabilitation

The committee discussed high quality evidence from the theme ‘B6 Early identification of needs’, which showed that early identification of rehabilitation needs promotes early referral to services, allowing people with chronic neurological conditions to access interventions to slow symptom progression or start to plan for future rehabilitation needs. The committee agreed with this finding and recommended that rehabilitation needs be identified as early as possible, even if chronic neurological disorders are only suspected.

The committee went on to discuss low quality evidence from the theme ‘B3.2 Education for people with chronic neurological disorders and family’, which showed that education should include information about disease pathology and likely symptom progression. In the committee’s experience, provision of information is hugely important in rehabilitation for chronic conditions, equipping people with the knowledge needed to successfully monitor their rehabilitation needs and prepare for future needs. The committee recommended discussing likely prognoses shortly after diagnosis or injury, possibly even before anticipated symptoms start to manifest. However, due to the unpredictable nature of many of the neurological conditions covered in this guideline, they noted that it should always be stressed to individuals that actual progression of their disorder may differ. Similarly, the committee were aware that people may not always be emotionally prepared to have these discussions soon after their diagnosis or injury. In these cases, their wishes should be respected but further opportunities for the conversation should continue to be provided to ensure that people can talk through their prognosis if they decide they want to.

The committee discussed low quality evidence from the theme ‘B1.5 Presence of key contacts’, which showed that having a single point of contact can help people with accessing appropriate rehabilitation services. The committee agreed with this evidence, noting that one of the benefits of key contacts is the fact that it is also a single point of contact. This provides people with 1 person that an individual needs to contact in relation to rehabilitation needs, who can then act to provide access to the appropriate services. The committee recommended that this rehabilitation contact be provided by the responsible clinician, and at the very earliest opportunity (even if a rehabilitation assessment is not currently being initiated) to ensure consistency of information. If assessments are needed, this initial point of contact can also help to navigate these different assessments. This is not always a specific person, but could also be a link to a rehabilitation unit or team. The committee highlighted that this information will also need to be relayed to primary care, so they are also kept informed of who to contact if a need arises. Please note that this recommendation also uses evidence from evidence review A, where the remainder of the committee's discussion can be found.

When to undertake, or make a referral for, a holistic rehabilitation needs assessment

The committee discussed high quality evidence from the theme 'B6 Early identification of needs', which showed that early identification of rehabilitation needs and referral can benefit people with chronic neurological disorders by allowing timelier access to interventions to slow symptom progression or enable early referral for a holistic rehabilitation needs assessment. In order to effectively plan interventions or for future rehabilitation needs, current rehabilitation needs need to be established. Due to the complexity of rehabilitation for chronic neurological diseases, and the interconnectedness of many functioning domains, the committee discussed the need for rehabilitation assessments to consider the person and their disability in a holistic manner, identifying all rehabilitation needs collectively and building a complete rehabilitation plan. The committee acknowledged that this will not always be necessary (for example, if a person re-presents with an existing symptom), but should be considered for more complex cases. Healthcare professionals should organise a holistic rehabilitation needs assessment as soon as possible. This can be done after an official diagnosis, but can also be done on a disability-specific basis, when an underlying chronic neurological disorder is still under investigation.

The committee discussed moderate quality evidence from the theme 'B4.1 Focussing on physical injuries and impairments', which showed that healthcare professionals often direct their attention to physical disabilities, leading to them overlooking the less visible areas of cognitive impairments and emotional well-being. This lack of consideration can cause delays in people accessing appropriate rehabilitation services. This theme was supported by moderate quality evidence from the theme 'B3.3 Understanding importance of 'invisible' symptoms in chronic neurological disorder rehabilitation', which showed that non-specialist healthcare professionals often did not understand these less visible disabilities, and how they might present. The committee agreed with this finding, adding that it was not just cognitive and emotional areas that can be overlooked. Other neglected areas for identifying rehabilitation needs include social and communication impairments. However, rehabilitation needs in all these areas can increase the need for a holistic needs assessment to ensure a comprehensive rehabilitation plan that will be effective for the individual. Therefore, the committee recommended that non-physical needs be briefly assessed to help decide whether a holistic rehabilitation needs assessment should be undertaken.

As described above, there are certain situations where a holistic needs assessment will not be needed, and may be an inconvenience for the person and a waste of NHS resources. For example, people with chronic disorders experiencing a long periods of static symptoms may find full holistic rehabilitation needs assessments to be repetitive and onerous. However, people should still be informed of how to request an assessment if they believe their rehabilitation needs are no longer being adequately addressed (for example, worsening of symptoms or changing environments). Children and young people may also need to be re-addressed at key developmental milestones.

Holistic rehabilitation needs assessment

Support and advocacy for making decisions during rehabilitation

The committee discussed low quality evidence from the theme 'B4.3 The role of family and friends throughout rehabilitation', which showed that involving friends and family can improve identification of rehabilitation needs and access to appropriate services, as they can monitor day-to-day changes in functioning and emerging rehabilitation needs in an individual. The committee agreed with this finding, and recommended that people with chronic neurological disorders be supported when making decisions about their health and social care. However, the committee noted that the people best placed to offer support may not always be traditional family members. Carers, other people within an individual's support network, and formally-appointed advocates may be better suited for this role. The committee also caveated that additional people should only be included in rehabilitation assessments with the consent of the individual with a chronic neurological disorder, as some people may not wish to involve other parties.

Initiating a rehabilitation needs assessment and who to involve

Throughout the formulation of the guideline, from scoping to drafting recommendations, the committee have highlighted the importance of rehabilitation for chronic neurological disorders being a holistic process, incorporating all aspects of a person's functioning and how these may interact. In their experience and expertise, it is only when this full picture is compiled that a complete and effective rehabilitation plan can be produced. For example, a person's presenting symptom may be gait difficulties, but rehabilitation exercises to address these will not be adhered to if they don't also consider other symptoms such as fatigue or executive dysfunction). However, people's contact with rehabilitation services commonly starts with a specific rehabilitation needs assessment regarding a single impairment. Therefore, the committee recommended completing a holistic needs assessment upon referral of a specific functional needs assessment, making this the default offering for rehabilitation service. The committee acknowledged that initiating a full holistic assessment alongside a specific functional assessment every time was not always an efficient use of time and resources. They noted 2 exceptions: if there is an active and current holistic needs assessment; and the referral need is not complex so any identified rehabilitation needs can be met solely with a specific functional needs assessment. The committee also highlighted that an individual could decline a holistic assessment at any time, but that this should not prevent them from being offered one.

The committee went on to discuss the challenges associated with setting up a holistic rehabilitation needs assessment before the appointment of key workers or complex case managers, considering the different specialties that will need to be coordinated. They noted that it is best that a single professional has oversight of this process from the very beginning, and therefore nominated the person initiating the rehabilitation needs assessment to manage the initial stages, including contacting health and social care professionals likely to be involved in the needs assessment. The committee agreed that the person initiating the assessment might not be the best person to lead it. In this case, they should identify a suitable person to take on this responsibility going forward. This will depend on the initial indications of rehabilitation needs and anticipated complexity. The committee also wanted to highlight that non-rehabilitation needs might be identified during this process, which would not be covered by the subsequent holistic assessment. Therefore, referrals to relevant health and social care services will need to be made. Once a lead practitioner for the holistic rehabilitation needs assessment has been identified, they should continue the multi-disciplinary approach by seeking further input from health and social care professionals, as well as other professionals that may be involved in rehabilitation arrangements.

The committee discussed low quality evidence from the theme 'B4.3 The role of family and friends throughout rehabilitation', which showed that people close to an individual with a chronic neurological disorder are often in the best place to observe changes in cognitive and physical functioning, as well as emotional well-being. The committee agreed with this, noting that this extends to delivery of rehabilitation as well, as some individuals will need support with carrying out activities of daily living and performing rehabilitation exercises. However, the committee also highlighted that the people closest to an individual are not always what is traditionally considered family, and that some people may not always want family and friends involved in every aspect of their rehabilitation. Conversely, people identified as important by individuals with chronic neurological disorders may not wish to be involved in rehabilitation discussions and arrangements. Therefore, they recommended talking through who to involve in rehabilitation (for example, family members, carers, or friends), and to what extent they would like them to be involved. Consent will also have to be obtained from those people nominated in this process. These identified people should also be involved in the holistic needs assessment to ensure that all relevant observations are captured and considered.

Finally, the committee wanted to highlight that provision of rehabilitation should not be delayed by the holistic needs assessment. Although this comprehensive assessment is expected to identify all rehabilitation needs that will need to be incorporated into rehabilitation planning, it should not prevent people receiving treatment for clearly identified and more urgent needs.

What to cover

The committee discussed moderate quality evidence from 2 themes. ‘B4.1 Focussing on physical injuries and impairments’ showed that healthcare professionals often focus on physical functioning at the expense of cognitive impairments and emotional well-being. ‘B3.3 Understanding importance of ‘invisible’ symptoms in chronic neurological disorder rehabilitation’ showed that these hidden symptoms of chronic neurological disorders and their consequences are often poorly understood by healthcare professionals. The committee agreed with both themes, noting that evidence of these hidden disabilities is often discovered accidentally while people are talking about other concerns. This can be due to people lacking awareness of their condition and therefore not recognising symptoms as such, or they may struggle to articulate their rehabilitation needs. Therefore, the committee recommended healthcare professionals encourage people to speak freely about different areas of their life, organically describing where they encounter difficulties. These discussions can then be used to explore underlying causes and formally identify rehabilitation needs.

Related assessments

The committee discussed the people with chronic neurological disorders will often have additional social care needs, that will not be able to be assessed or addressed by the healthcare system. However, these needs will inevitably impact on identification of rehabilitation needs, rehabilitation planning and accessing appropriate rehabilitation services. Therefore, the committee recommended that a social care needs assessment be considered in partnership with the individual, their family or carers. The committee recognised that the NICE guideline on social work in adults with complex needs has further detailed recommendations on this area, and included a cross-reference for readers.

Agreeing and delivering a coordinated rehabilitation plan

The committee discussed moderate quality evidence from the theme ‘B4.2 Pre-conceived ideas on appropriateness of rehabilitation’, which showed that people can be prevented from accessing appropriate rehabilitation services when healthcare professionals do not believe rehabilitation will have any positive effects for the person. The committee agreed that some healthcare professionals have pre-conceived ideas about what type of disorders and symptoms will not benefit from rehabilitation (for example, people with poor prognoses or people whose disability is deemed to be minor). In their experience, this can stem from the belief that rehabilitation is to treat a disability rather than to optimise or maintain functioning. Therefore, the committee recommended aiming interventions at optimising or maintain functioning, even if rehabilitation may be thought to be of minimal benefit.

The committee discussed moderate quality evidence from the theme ‘B5.3 Communication and coordination’, which showed that poor communication and coordination led to healthcare professionals not having correct and up-to-date information when treating a person with a chronic neurological disorder. The committee agreed with this finding, noting that this is a common issue that is only exacerbated by the large number of health and social care services involved in neurological rehabilitation, as well as the time scales involved in chronic conditions. Therefore, they recommended professionals should work together to increase consistency between services and increase continuity of care for individuals. They highlighted that it is not just health and social care rehabilitation services that should be involved in this collaboration, but also non-rehabilitation services (for example, education sector) and charity organisations that may be involved in a person's care. Please note that this recommendation also uses evidence from evidence review C, where the remainder of the committee's discussion can be found.

Assigning a single point of contact and assessing the person's ability to coordinate their own care

The committee discussed that rehabilitation for chronic neurological disorders is complex, and navigating the services assumes a level of knowledge that people with chronic neurological disorders and their families do not have at the beginning of rehabilitation. Therefore, the committee recommended that everyone is assigned a single point of contact as part of their rehabilitation plan. This role can either be to provide information or directly support people in navigating the rehabilitation pathway, coordinating care, accessing services and referrals, and providing consistent contact with rehabilitation services. Additionally, this single point of contact should remain in place throughout a person's life, even when not receiving active treatments.

The committee discussed low quality evidence from the theme 'B1.5 Presence of key contacts', which showed that a single point of contact can help people with chronic neurological disorders to coordinate their care and provide information on accessing different services (for example, eligibility criteria). This was supported by very low quality evidence from the theme 'B1.4 Meeting eligibility criteria', which showed that differing eligibility criteria across services can affect continuity of care between services. The committee agreed that a single point of contact would be very beneficial for people with chronic neurological disorders, but that the level of support and their ability to self-manage their rehabilitation (or parents and representatives) will differ between people. Not everyone will need a key worker or complex case manager. People who may not be able to coordinate their own rehabilitation, and might therefore benefit from a more intensive level of support from their single point of contact, may include: people with complex needs across multiple domains of care; individuals with no other support with accessing health and social care across multiple domains (for example, housing, employment, education and the criminal justice system); and people with impaired executive function. The committee stressed that this judgement should not be considered concrete. It is likely to change throughout a person's rehabilitation, especially considering the time period covered by chronic disorders and an individual's changing circumstances (both disease-specific and in their wider person life). Therefore, they recommended that a person's ability to self-manage is reviewed if difficulties are noticeable or if their needs have progressed and become more complex.

The committee went on to agree in what scenarios people would benefit from having a key worker. They decided that this level of support should be considered for people with an added layer of complexity to their condition, although they noted that this increased level of support may only be needed for a specific time period during care when rehabilitation needs were increased. It will not always be a life-long provision, unlike the key contact. They highlighted several groups of people that would benefit from this additional support: people with impaired cognitive executive functioning; people who may experience unpredictable or rapidly evolving rehabilitation needs, people with multiple different needs across services, and people with potentially emerging needs. Children and young people are constantly developing, so are at increased risk for this last group.

Please note that these recommendations also use evidence from evidence review A, where the remainder of the committee's discussion can be found.

Information, advice and learning as part of rehabilitation

The committee discussed low quality evidence from the theme 'B5.3 Education for people with chronic neurological disorders and family' that showed identification of rehabilitation needs and access to services can be increased by teaching people and their support units about their disorder, as well as availability of rehabilitation services. This was supported by high quality evidence from the theme 'B5.1 Adequate follow-up and signposting', which showed that poor signposting to resources to educate people about rehabilitation for chronic neurological disorders can impact access to these services. Additional very low quality evidence from the theme 'B5.2 Auxiliary services' showed that this signposting should extend to external services (for example, specialist legal practitioners). The committee agreed with all 3 themes, recommending that people and their (chosen) family unit be given the information they need to identify their rehabilitation needs and access appropriate services. This information should include information about their diagnosis and prognosis, how to access relevant healthcare and social care services, complementary non-rehabilitation services (for example, services offering advice on housing or benefits), and external support organisations (for example, local support groups or national charities). The committee went on to stress that provision of information can be an intervention in itself, and will take time to deliver. Healthcare professionals and people with chronic neurological disorders will need to agree the level of information required (for example, this could be dependent on an individual's current condition, their ability to understand and retain information, and the context it is delivered), as well as to manage the exchange process. It is also important to note that these needs will change over time, which should also be considered. Therefore, the committee caveated that any information should be tailored to the individual, in order for it to be effective. Please note that these recommendations also use evidence from evidence review K, where the remainder of the committee's discussion can be found.

The committee also wanted to highlight to readers the statutory requirement of local authorities to assess care and support needs. This is enshrined in the Care Act 2014 and Children and Families Act 2014, covering both paediatric and adult populations. However, as this has to be requested (that is, it is not offered unsolicited), people with chronic neurological disorders and their families are often unaware of this right. Some people also need health and social care professionals to advocate for them in this regard.

Independent living, equipment and environmental adaptations

Environmental adaptations, assistive technology and equipment

The committee discussed moderate quality evidence from the theme 'B2 Affordability', which showed that expensive therapies or equipment could be prohibitive if not covered by existing funding or healthcare insurance. The committee agreed that some rehabilitation interventions can be very expensive but noted that there is funding available for a wide variety of needs (for example, Personal Independence Payments), including for support in home, education and workplace settings. They therefore recommended that people with chronic neurological disorders are helped to access these funds, if they are applicable. Please note that these recommendations also use evidence from evidence review K, where the remainder of the committee's discussion can be found.

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.

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 discussed that educating primary care practitioners about chronic neurological conditions may require some additional resources. However, these are unlikely to be substantial. For example, the committee discussed that it does not have to be formal training but could be achieved by, for example, sharing expertise with specialist centres and keeping current information on local services.

The committee noted that there are already examples of good practice in collaboration between services. However, some additional resources may be required to facilitate such practices, for example, designing shared pathways, referral processes, and communication channels. The committee discussed that any additional costs may be offset by reduced hospital admissions, better access to expertise and timely care, reducing long-term costs associated with unaddressed care needs, and reducing duplication of effort.

The committee discussed that while rehabilitation services have referral procedures in place, delays often occur when accessing services when needs arise. These delays may be due to capacity issues or the time taken to identify and assess people's needs. The committee acknowledged that establishing responsive and flexible referral procedures is essential. It was noted that this may lead to an increase in referrals and people accessing treatment and support services, potentially creating pressure on existing services. Commissioners may need to invest more in such services to ensure they have the necessary capacity and expertise to respond in a timely manner. It was discussed that any additional costs associated with facilitating responsive and flexible referral procedures may be offset by, for example, reductions in emergency care and hospital admissions due to timely and proactive management, also potentially delaying progression and reducing the need for intensive care and reliance on caregivers.

Similarly, the committee noted that re-entering rehabilitation services is challenging and recommendation in this area may incur costs. Establishing systems for individuals with chronic neurological disorders to maintain ongoing access and self-referral to these services could increase pressure on existing resources. However, this will ensure that any issues are identified before they become severe or costly to manage, potentially also relieving pressure on overburdened GPs. There may also be broader public sector benefits, such as reducing the risk of homelessness or contact with the criminal justice system as a result of not being able to access timely support and services.

The committee discussed that for some conditions, it takes time for the full clinical picture to emerge, and therefore initiating needs assessment before diagnosis is established is needed. There is currently variation in practice and potentially more people will be accessing needs assessment before a confirmed diagnosis. However, people may already be experiencing significant problems before diagnosis is confirmed, and delaying care may significantly exacerbate problems requiring costly emergency, crisis-related care. Therefore, such approach is likely to represent value for money for the NHS.

The committee explained that it is current practice to involve, for example, family members and carers where appropriate. These recommendations also reinforce some other existing NICE guidance and are therefore not expected to require additional resources to implement.

Currently, many assessments are inconsistent and uncoordinated, leading to wasted healthcare resources and substantial costs to the NHS and wider public sector. Offering a holistic rehabilitation needs assessment by default, with clear roles and responsibilities, and in line with approaches like the trusted assessor, could ensure more people receive appropriate assessments, identify more needs, and access related support and treatment services.

While people undertaking these assessments are already within services, capacity may need to increase to meet additional demand. More resources may be required to ensure people are skilled in conducting such assessments and developing care plans. Additionally, processes for managing referral coordination, scheduling, and IT systems enabling communication across health and social care providers will be needed. However, such holistic assessment, early in the process may help to ensure that needs are identified and timely care and treatments are provided, preventing the need for more expensive care later.

The committee noted that sometimes there is an assumption that some people (for example, those with poor prognoses) may not benefit from rehabilitation. Recommendations in this area may mean more people receive interventions to optimise or maintain their functioning. This is not expected to result in significant resource impact and may, for example, help maintain independence, reduce formal care costs, and positively impact mental health and emotional wellbeing, and reduce any related NHS costs.

More resources may be required to facilitate collaboration and sharing of rehabilitation assessments with other services. This could involve setting up formal routes to share information, collaborative teams, and having a single point of contact proportional to individual needs (for example, key contact, key worker, or complex case manager). While key contact and key worker roles exist within the NHS, there is a lack of complex case managers. Ensuring people with the most complex needs have clinical case managers may result in significant resource impact. However, any additional costs could be offset by reducing duplication in assessment, delays in care, and reliance on emergency or crisis care, while improving patient outcomes. Please refer to the evidence review I for a further discussion and cost analysis on clinical case managers.

The committee recognised the importance of providing personalised information and education about conditions, available services, and how to access them. This recommendation reinforces good practice, as most services should already offer such information tailored to individual needs. However, the committee noted variation in practice, and where this is not currently done, additional resources may be required, such as staff time to develop or collate relevant resources.

The committee discussed that other recommendations may also require more staff time where such practices are not currently undertaken. For example, educating people about their prognosis and how their rehabilitation needs may change over time, conducting rehabilitation needs assessments in line with recommendations, and encouraging discussions about the impact of neurological conditions. However, they discussed that any additional costs would be very likely offset by better identification and assessment of needs, reduced use of emergency and crisis care, reduced reliance on paid carers or social services, and enabling social participation, potentially resulting in broader benefits to the public sector and society. Therefore, the committee was of a view that these recommendations would represent value for money for the NHS.

The committee discussed that there are already pathways and funding provided by NHS England for equipment, assistive technology, and environmental adaptations. More people may access this support earlier in the pathway, but since funding is already available, this recommendation is not expected to require additional resources to implement.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.3.4 to 1.3.6, 1.4.1 to 1.4.3, 1.5.1 to 1.5.4, 1.7.1 to 1.7.3, 1.8.1 to 1.8.7, 1.8.10 to 1.8.11, 1.8.20, 1.10.3, 1.10.7, 1.11.1 to 1.11.3 1.13.3, 1.13.1, and 1.22.8.

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Appendices

Appendix A Review protocols

Review protocol for review question: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

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	Identification and referral to rehabilitation services for people with chronic neurological disorders.
2.	Review question	What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including re-referral?
3.	Objective	• To understand the difficulties in identifying rehabilitation needs arising from chronic neurological disorders • To understand the difficulties in enabling people with chronic neurological disorders to access appropriate rehabilitation services, including referrals (by practitioners as well as self-referrals). • To understand what helps in identifying rehabilitation needs due to chronic neurological disorders. • To understand what enables people with chronic neurological disorders to access appropriate rehabilitation services, including referrals (by practitioners as well self-referrals).
4.	Searches	The following databases will be searched: • Medline and Medline In-Process • Embase • Cochrane Database of Systematic Reviews (CDSR) • PsycInfo • Social Policy and Practice Searches will be restricted to:

ID	Field	Content
		• 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	Rehabilitation needs arising from chronic neurological conditions.

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.
		
		Exclusion:

ID	Field	Content
		• 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 such as 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 about identifying people with rehabilitation needs arising from chronic neurological disorders and making referrals to appropriate services. 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: • **Availability.** Views may be expressed about the availability of services including inpatient rehabilitation, community outpatient, third sector services, residential options, specialist care and personalised care such as named contacts or key workers. Also, about opening times, appointment systems, eligibility criteria and routes for re-referral as needs fluctuate. These issues may be particularly pronounced for people with comorbid conditions, including drug and alcohol use disorders. • **Acceptability.** Experiences relating to provider expectations and user expectations might suggest ways of improving referral to rehabilitation services. • **Affordability.** There may be data about the costs (perceived or real) of rehabilitation services, including direct and indirect costs, public funding and charitable donations. • **Equalities considerations.** The extent to which services are felt to demonstrate due regard to the equality duty may support or undermine referral to appropriate services. For example, whether the

ID	Field	Content
		needs of people from protected groups are met, such as having facilities for people whose first language is not English. Perceptions about the cultural competence of services may also affect referrals. • **Physical barriers.** Data may be located about physical barriers, such as location of services or a lack of ramps or other built environment adjustments for disabled access, which may deter referrals to those services. Examples of other barriers might relate to conveying children and young people to appointments especially where these are community based. • **Information and awareness.** The role of information and awareness surrounding chronic neurological disorders is expected to influence the identification of rehabilitation needs and referral to services (whether self-referrals or referrals from primary care or intermediary organisations). This may apply to people with chronic neurological disorders, their families or practitioners. • **Attitudes and beliefs.** Data are anticipated about the way in which people's beliefs might lead to biases, in turn affecting decision making around issues such as risk taking. These might also affect people's insight and awareness about conditions and rehabilitation needs and potential. This could apply equally to people with neurological disorders, their families or relevant practitioners. • **Organisation of services.** Data may be located which suggest that the planning and provision (including timeliness) of appropriate services is limited by the nature of service planning, organisation or funding, as well as communication and joint working within and between healthcare and rehabilitation services. Local variation in the existence of single access points to services is also likely to be relevant here. • **The role or technology and other developments in diagnostics.** Data may relate to the role of new technologies to support the identification of rehabilitation needs arising from chronic neurological disorders. Examples including online or AI models for diagnosis.
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.

ID	Field	Content
10.	Other exclusion criteria	Inclusion: • Full text papers • Studies conducted in high income European countries (according to the World Bank) and Australia, New Zealand and Canada. Exclusion: • 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 (10 of 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 10 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 interventions for chronic neurological disorders are provided. • Excluded:

ID	Field	Content
		○ Accident and emergency departments. ○ Critical care units ○ Prisons
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 or duplicate screening will be undertaken for 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 (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’.

ID	Field	Content		
		• 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]()). • 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	☑	☑

ID	Field	Content		
		Formal screening of search results against eligibility criteria	☑	☑
		Data extraction	☑	☑
		Risk of bias (quality) assessment	☑	☑
		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-ng10210.		

ID	Field	Content	
29.	Other registration details	N/A	
30.	Reference/URL for published protocol	N/A	
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • 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	N/A	
34.	Current review status	☐	Ongoing
		☐	Completed but not published
		☒	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
35..	Additional information	N/A	
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: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

Database: Ovid MEDLINE(R) ALL <1946 to November 04, 2022>

Date of last search: 04/11/2022

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 (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 rh.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* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or

	nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*).ti.
66	or/63-65
67	Needs Assessment/ or "Health Services Needs And Demand"/ or exp Patient Care Planning/ or Patient Care Management/ or Eligibility Determination/ or exp Decision Making/ or Decision Support Systems, Clinical/ or Risk Assessment/ or Transitional Care/ or Continuity of Patient Care/ or Patient Handoff/ or Patient Transfer/ or Access to Health Care/ or Choice Behavior/ or exp "Appointments and Schedules"/
68	(need* or handoff* or hand off* or handover* or hand over* or transition* or barrier* or facilitat*).ti.
69	or/67-68
70	66 and 69
71	exp "Referral And Consultation"/ or refer*.ti.
72	71 and (66 or 69)
73	70 or 72
74	((refer* or sign-post* or signpost* or transfer*) adj5 (rehab* or telerehab* or neurorehab* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
75	((rehab* or telerehab* or neurorehab*) adj5 (social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
76	((rehab* or telerehab* or neurorehab* or refer* or sign-post* or signpost* or transfer* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*) adj5 (identif* or access* or barrier* or facilitat* or disparit* or challeng* or imped* or utilis* or utiliz* or uptak* or take up or taking up or increas* or impact* or effect* or improv* or enhanc* or encourag* or support* or promot* or optimiz* or optimis* or adher* or motivat* or incentiv* or persuad* or persuasion or accept* or satisf* or compliance or comply or complie* or availab* or provision or provid* or offer* or incentiv* or start* or attend* or sustain* or maintain* or help* or enabl* or eligib* or decide* or decision*)).ti,ab.
77	((need* or handoff* or hand off* or handover* or hand over* or transition*) adj5 (rehab* rehab* or telerehab* or neurorehab* or refer* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
78	or/73-77
79	62 and 78
80	afghanistan/ or africa/ or africa, northern/ or africa, central/ or africa, eastern/ or "africa south of the sahara"/ or africa, southern/ or africa, western/ or albania/ or algeria/ or andorra/ or angola/ or "antigua and barbuda"/ or argentina/ or armenia/ or azerbaijan/ or bahamas/ or bahrain/ or bangladesh/ or barbados/ or belize/ or benin/ or bhutan/ or bolivia/ or borneo/ or "bosnia and herzegovina"/ or botswana/ or brazil/ or brunei/ or bulgaria/ or burkina faso/ or burundi/ or cabo verde/ or cambodia/ or cameroon/ or central african republic/ or chad/ or exp china/ or comoros/ or congo/ or cote d'ivoire/ or croatia/ or cuba/ or "democratic republic of the congo"/ or cyprus/ or djibouti/ or dominica/ or dominican republic/ or ecuador/ or egypt/ or el salvador/ or equatorial guinea/ or eritrea/ or eswatini/ or ethiopia/ or fiji/ or gabon/ or gambia/ or "georgia (republic)"/ or ghana/ or grenada/ or guatemala/ or guinea/ or guinea-bissau/ or guyana/ or haiti/ or honduras/ or independent state of samoa/ or exp india/ or indian ocean islands/ or indochina/ or indonesia/ or iran/ or iraq/ or jamaica/ or jordan/ or kazakhstan/ or kenya/ or kosovo/ or kuwait/ or kyrgyzstan/ or laos/ or lebanon/ or liechtenstein/ or lesotho/ or liberia/ or libya/ or madagascar/ or malaysia/ or malawi/ or mali/ or malta/ or mauritania/ or mauritius/ or mekong valley/ or melanesia/ or micronesia/ or monaco/ or mongolia/ or montenegro/ or morocco/ or mozambique/ or myanmar/ or namibia/ or nepal/ or nicaragua/ or niger/ or nigeria/ or oman/ or pakistan/ or palau/ or exp panama/ or papua new guinea/ or paraguay/ or peru/ or philippines/ or qatar/ or "republic of belarus"/ or "republic of north macedonia"/ or romania/ or exp russia/ or rwanda/ or "saint kitts and nevis"/ or saint lucia/ or "saint vincent and the grenadines"/ or "sao tome and principe"/ or saudi arabia/ or serbia/ or sierra leone/ or senegal/ or seychelles/ or singapore/ or somalia/ or south africa/ or south sudan/ or sri lanka/ or sudan/ or suriname/ or syria/ or taiwan/ or tajikistan/ or tanzania/ or thailand/ or timor-leste/ or togo/ or tonga/ or "trinidad and tobago"/ or tunisia/ or turkmenistan/ or uganda/ or ukraine/ or united arab emirates/ or uruguay/ or uzbekistan/ or vanuatu/ or venezuela/ or vietnam/ or west indies/ or yemen/ or zambia/ or zimbabwe/
81	"organisation for economic co-operation and development"/
82	australasia/ or exp australia/ or austria/ or baltic states/ or belgium/ or czech republic/ or exp denmark/ or estonia/ or europe/ or finland/ or exp france/ or exp germany/ or greece/ or hungary/ or iceland/ or ireland/ or israel/ or exp italy/ or latvia/ or lithuania/ or luxembourg/ or netherlands/ or new zealand/ or exp norway/ or poland/ or portugal/ or "scandinavian and nordic countries"/ or slovakia/ or slovenia/ or spain/ or sweden/ or switzerland/ or exp united kingdom/
83	european union/
84	developed countries/

85	or/81-84
86	80 not 85
87	79 not 86
88	Qualitative Research/
89	Nursing Methodology Research/
90	Interview.pt.
91	exp Interviews as Topic/
92	Questionnaires/
93	Narration/
94	Health Care Surveys/
95	(qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw.
96	(ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw.
97	(hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw.
98	(metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw.
99	"critical interpretive synthes*".tw.
100	(realist adj (review* or synthes*)).tw.
101	(noblit and hare).tw.
102	(meta adj (method or triangulation)).tw.
103	(CERQUAL or CONQUAL).tw.
104	((thematic or framework) adj synthes*).tw.
105	or/88-104
106	87 and 105
107	letter/
108	editorial/
109	news/
110	exp historical article/
111	Anecdotes as Topic/
112	comment/
113	case report/
114	(letter or comment*).ti.
115	or/107-114
116	randomized controlled trial/ or random*.ti,ab.
117	115 not 116
118	animals/ not humans/
119	exp Animals, Laboratory/
120	exp Animal Experimentation/
121	exp Models, Animal/
122	exp Rodentia/
123	(rat or rats or mouse or mice or rodent*).ti.
124	or/117-123
125	106 not 124
126	limit 125 to yr="2010 -Current"
127	limit 126 to English language

Database: Embase <1974 to 2022 November 04>

Date of last search: 04/11/2022

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 (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 consultation/ or exp physiotherapy/ or prosthesis/ or "prostheses and orthoses"/
65	(rehab* or telerehab* or neurorehab* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*).ti.
66	or/63-65
67	needs assessment/ or exp health care need/ or patient care planning/ or patient care/ or eligibility/ or health care access/ or eligibility criteria/ or right to health/ or exp decision making/ or clinical decision support system/ or risk assessment/ or health risk assessment/ or transitional care/ or clinical handover/ or patient transport/
68	(need* or handoff* or hand off* or handover* or hand over* or transition* or barrier* or facilitat*).ti.
69	67 or 68
70	66 and 69
71	patient referral/ or refer*.ti.
72	71 and (66 or 69)
73	70 or 72
74	((refer* or sign-post* or signpost* or transfer*) adj5 (rehab* or telerehab* or neurorehab* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.

75	((rehab* or telerehab* or neurorehab*) adj5 (social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
76	((rehab* or telerehab* or neurorehab* or refer* or sign-post* or signpost* or transfer* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*) adj5 (identif* or access* or barrier* or facilitat* or disparit* or challeng* or imped* or utilis* or utiliz* or uptak* or take up or taking up or increas* or impact* or effect* or improv* or enhanc* or encourag* or support* or promot* or optimiz* or optimis* or adher* or motivat* or incentiv* or persuad* or persuasion or accept* or satisf* or compliance or comply or complie* or availab* or provision or provid* or offer* or incentiv* or start* or attend* or sustain* or maintain* or help* or enabl* or eligib* or decide* or decision*)).ti,ab.
77	((need* or handoff* or hand off* or handover* or hand over* or transition*) adj5 (rehab* rehab* or telerehab* or neurorehab* or refer* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
78	or/73-77
79	62 and 78
80	afghanistan/ or africa/ or "africa south of the sahara"/ or albania/ or algeria/ or andorra/ or angola/ or argentina/ or "antigua and barbuda"/ or armenia/ or exp azerbaijan/ or bahamas/ or bahrain/ or bangladesh/ or barbados/ or belarus/ or belize/ or benin/ or bhutan/ or bolivia/ or borneo/ or exp "bosnia and herzegovina"/ or botswana/ or exp brazil/ or brunei darussalam/ or bulgaria/ or burkina faso/ or burundi/ or cambodia/ or cameroon/ or cape verde/ or central africa/ or central african republic/ or chad/ or exp china/ or comoros/ or congo/ or cook islands/ or cote d'ivoire/ or croatia/ or cuba/ or cyprus/ or democratic republic congo/ or djibouti/ or dominica/ or dominican republic/ or ecuador/ or el salvador/ or egypt/ or equatorial guinea/ or eritrea/ or eswatini/ or ethiopia/ or exp "federated states of micronesia"/ or fiji/ or gabon/ or gambia/ or exp "georgia (republic)"/ or ghana/ or grenada/ or guatemala/ or guinea/ or guinea-bissau/ or guyana/ or haiti/ or honduras/ or exp india/ or exp indonesia/ or iran/ or exp iraq/ or jamaica/ or jordan/ or kazakhstan/ or kenya/ or kiribati/ or kosovo/ or kuwait/ or kyrgyzstan/ or laos/ or lebanon/ or liechtenstein/ or lesotho/ or liberia/ or libyan arab jamahiriya/ or madagascar/ or malawi/ or exp malaysia/ or maldives/ or mali/ or malta/ or mauritania/ or mauritius/ or melanesia/ or moldova/ or monaco/ or mongolia/ or "montenegro (republic)"/ or morocco/ or mozambique/ or myanmar/ or namibia/ or nauru/ or nepal/ or nicaragua/ or niger/ or nigeria/ or niue/ or north africa/ or oman/ or exp pakistan/ or palau/ or palestine/ or panama/ or papua new guinea/ or paraguay/ or peru/ or philippines/ or polynesia/ or qatar/ or "republic of north macedonia"/ or romania/ or exp russian federation/ or rwanda/ or sahel/ or "saint kitts and nevis"/ or "saint lucia"/ or "saint vincent and the grenadines"/ or saudi arabia/ or senegal/ or exp serbia/ or seychelles/ or sierra leone/ or singapore/ or "sao tome and principe"/ or solomon islands/ or exp somalia/ or south africa/ or south asia/ or south sudan/ or exp southeast asia/ or sri lanka/ or sudan/ or suriname/ or syrian arab republic/ or taiwan/ or tajikistan/ or tanzania/ or thailand/ or timor-leste/ or togo/ or tonga/ or "trinidad and tobago"/ or tunisia/ or turkmenistan/ or tuvalu/ or uganda/ or exp ukraine/ or exp united arab emirates/ or uruguay/ or exp uzbekistan/ or vanuatu/ or venezuela/ or viet nam/ or western sahara/ or yemen/ or zambia/ or zimbabwe/
81	exp "organisation for economic co-operation and development"/
82	exp australia/ or "australia and new zealand"/ or austria/ or baltic states/ or exp belgium/ or czech republic/ or denmark/ or estonia/ or europe/ or exp finland/ or exp france/ or exp germany/ or greece/ or hungary/ or iceland/ or ireland/ or israel/ or exp italy/ or latvia/ or lithuania/ or luxembourg/ or netherlands/ or new zealand/ or exp norway/ or poland/ or exp portugal/ or scandinavia/ or sweden/ or slovakia/ or slovenia/ or exp spain/ or switzerland/ or exp united kingdom/ or western europe/
83	european union/
84	developed country/
85	or/81-84
86	80 not 85
87	79 not 86
88	Qualitative Research/
89	exp Interview/
90	exp Questionnaire/
91	exp Observational Method/
92	Narrative/
93	(qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw.
94	(ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw.
95	(hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw.
96	(metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw.

97	"critical interpretive synthes*".tw.
98	(realist adj (review* or synthes*)).tw.
99	(noblit and hare).tw.
100	(meta adj (method or triangulation)).tw.
101	(CERQUAL or CONQUAL).tw.
102	((thematic or framework) adj synthes*).tw.
103	or/88-102
104	87 and 103
105	letter.pt. or letter/
106	note.pt.
107	editorial.pt.
108	case report/ or case study/
109	(letter or comment*).ti.
110	or/105-109
111	randomized controlled trial/ or random*.ti,ab.
112	110 not 111
113	animal/ not human/
114	nonhuman/
115	exp Animal Experiment/
116	exp Experimental Animal/
117	animal model/
118	exp Rodent/
119	(rat or rats or mouse or mice or rodent*).ti.
120	or/112-119
121	104 not 120
122	limit 121 to (English language and yr="2010 -Current")

Database: Cochrane Database of Systematic Reviews Issue 11 of 12, November 2022

Date of last search: 04/11/2022

#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" next disease* or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cerebellar" next degenerat* or "shaken baby" next syndrome* or "shaking baby" next syndrome*):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 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" next syndrome* 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 next 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*)):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 next plexus NEAR/1 (neuropath* or neuritis)):ti,ab
#68	("complex regional pain" next syndrome* or causalgia or mononeuropath* or "nerve compression" next syndrome*):ti,ab
#69	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) NEAR/1 neuropath*):ti,ab
#70	((carpal next tunnel or piriformis next muscle or tarsal next tunnel or thoracic next 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 next 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 (disease* or damage* or disorder* or impair*)):ti,ab
#100	((motor next 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 next polio*) NEAR/1 (syndrome*)):ti,ab
#106	(Parkinson* or duchenne* or multiple next scleros* or sclerosos* or aphasia or creutzfeldt next jakob or huntington* or kluver next bucy):ti,ab
#107	(muscular NEAR/1 dystroph*):ti,ab
#108	(neuromusc* NEAR/1 (disease* or disorder*)):ti,ab
#109	(heredit* NEAR/1 spastic* NEAR/1 parapleg*):ti,ab
#110	(friedreich* next ataxia*):ti,ab
#111	(("multiple system" or olivopontocerebellar) NEAR/1 atroph*):ti,ab
#112	((shy next drager next syndrome*) or striatonigral next degenerat* or batten next disease*):ti,ab
#113	(progressive NEAR/1 supranuclear NEAR/1 pals*):ti,ab

#114	(richardson* NEAR/1 (disease* or syndrome*)):ti,ab
#115	((corticobasal or "cortico basal") NEAR/1 degenerat*):ti,ab
#116	("white matter" NEAR/1 (disorder*)):ti,ab
#117	(metachromatic next leukodystroph* or mitochondrial next myopath* or mucopolysaccharidos*):ti,ab
#118	(lysosomal NEAR/1 storage NEAR/1 disorder*):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 next bifida or bifidas or spinal next 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 next seizure or pseudoseizure):ti,ab
#131	(medical* NEAR/1 (unexplain* or un next explain*) NEAR/1 (symptom*)):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] this term only
#141	MeSH descriptor: [Social Workers] this term only
#142	MeSH descriptor: [Nutritionists] this term only
#143	MeSH descriptor: [Psychology] this term only
#144	MeSH descriptor: [Occupational Therapists] this term only
#145	MeSH descriptor: [Physical Therapists] 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* or social next work* or casework* or case next work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) near/1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*):ti
#150	{or #133-#149}
#151	MeSH descriptor: [Needs Assessment] this term only
#152	MeSH descriptor: [Health Services Needs and Demand] this term only
#153	MeSH descriptor: [Patient Care Planning] explode all trees
#154	MeSH descriptor: [Patient Care Management] this term only
#155	MeSH descriptor: [Eligibility Determination] this term only
#156	MeSH descriptor: [Decision Making] this term only
#157	MeSH descriptor: [Decision Support Systems, Clinical] this term only
#158	MeSH descriptor: [Risk Assessment] this term only
#159	MeSH descriptor: [Transitional Care] this term only
#160	MeSH descriptor: [Continuity of Patient Care] this term only
#161	MeSH descriptor: [Patient Handoff] this term only

#162	MeSH descriptor: [Patient Transfer] this term only
#163	MeSH descriptor: [Health Services Accessibility] this term only
#164	MeSH descriptor: [Choice Behavior] this term only
#165	MeSH descriptor: [Appointments and Schedules] this term only
#166	(need* or handoff* or hand off* or handover* or hand next over* or transition* or barrier* or facilitat*):ti
#167	{or #151-#166}
#168	#150 and #167
#169	MeSH descriptor: [Referral and Consultation] explode all trees
#170	refer*:ti
#171	#169 or #170
#172	#171 and (#150 or #167)
#173	#168 or #172
#174	((refer* or sign next post* or signpost* or transfer*) near/5 (rehab* or telerehab* or neurorehab* or social next work* or casework* or case next work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) near/1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)):ti,ab
#175	((rehab* or telerehab* or neurorehab*) near/5 (social next work* or casework* or case next work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) near/1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)):ti,ab
#176	((rehab* or telerehab* or neurorehab* or refer* or sign next post* or signpost* or transfer* or social next work* or casework* or case next work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) near/1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*) near/5 (identif* or access* or barrier* or facilitat* or decide* or decision* or disparit* or challeng* or imped* or utilis* or utiliz* or uptak* or take next up or taking next up or increas* or impact* or effect* or improv* or enhanc* or encourag* or support* or promot* or optimiz* or optimis* or adher* or motivat* or incentiv* or persuad* or persuasion or accept* or satisf* or compliance or comply or complie* or availab* or provision or provid* or offer* or incentiv* or start* or attend* or sustain* or maintain* or help* or enabl* or eligib*)):ti,ab
#177	((need* or handoff* or hand next off* or handover* or hand next over* or transition*) near/5 (rehab* rehab* or telerehab* or neurorehab* or refer* or social work* or casework* or case next work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) near/1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)):ti,ab
#178	{or #173-#177}
#179	#132 and #178
#180	conference:pt or (clinicaltrials or trialsearch):so
#181	#179 not #180 with Cochrane Library publication date Between Jan 2010 and Dec 2022

Database: Social Policy and Practice

Date of last search: 07/11/2022

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 cerebellar degenerat* or shaken baby syndrome* or shaking baby syndrome*).ti,ab.
12	(basal ganglia disease* or encephalitis* or meningoencephalitis*or hydrocephal* or paraneoplastic cerebellar degenerat* or shaken baby syndrome* or shaking 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 (disease* or damage* or disorder* or impair*)).ti,ab.
52	(neurolog* and (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* or friedreichs ataxia*).ti,ab.
74	(friedreich ataxia* or friedreichs 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* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*).ti.
113	(rehab* or telerehab* or neurorehab* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) and therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*).hw.
114	or/112-113
115	(need* or handoff* or hand off* or handover* or hand over* or transition* or barrier* or facilitat*).ti.
116	(need* or handoff* or hand off* or handover* or hand over* or transition* or barrier* or facilitat*).hw.
117	or/115-116
118	114 and 117
119	refer*.ti.
120	refer*.hw.
121	or/119-120
122	121 and (114 or 117)
123	118 or 122
124	((refer* or sign post* or signpost* or transfer*) adj5 (rehab* or telerehab* or neurorehab* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
125	((refer* or sign post* or signpost* or transfer*) and (rehab* or telerehab* or neurorehab* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) and therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).hw.
126	((rehab* or telerehab* or neurorehab*) adj5 (social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
127	((rehab* or telerehab* or neurorehab*) and (social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) and therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).hw.
128	((rehab* or telerehab* or neurorehab* or refer* or sign-post* or signpost* or transfer* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*) adj5 (identif* or access* or barrier* or facilitat* or disparit* or challeng* or imped* or utilis* or utiliz* or uptak* or take up or taking up or increas* or impact* or effect* or improv* or enhanc* or encourag* or support* or promot* or optimiz* or optimis* or adher* or motivat* or incentiv* or persuad* or persuasion or accept* or satisf* or compliance or comply or complie* or availab* or provision or provid* or offer* or incentiv* or start* or attend* or sustain* or maintain* or help* or enabl* or eligib* or decide* or decision*)).ti,ab.
129	((rehab* or telerehab* or neurorehab* or refer* or sign-post* or signpost* or transfer* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) and therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*) and (identif* or access* or barrier* or facilitat* or disparit* or challeng* or imped* or utilis* or utiliz* or uptak* or take up or taking up or increas* or impact* or effect* or improv* or enhanc* or encourag* or support* or promot* or optimiz* or optimis* or adher* or motivat* or incentiv* or persuad* or persuasion or accept* or satisf* or compliance or comply or complie* or availab* or provision or provid* or

	offer* or incentiv* or start* or attend* or sustain* or maintain* or help* or enabl* or eligib* or decide* or decision*)).hw.
130	((need* or handoff* or hand off* or handover* or hand over* or transition*) adj5 (rehab* rehab* or telerehab* or neurorehab* or refer* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
131	((need* or handoff* or hand off* or handover* or hand over* or transition*) and (rehab* rehab* or telerehab* or neurorehab* or refer* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) and therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).hw.
132	or/123-131
133	111 and 132
134	limit 133 to yr="2010 -Current"

Database: APA PsycInfo <1987 to October Week 4 2022>

Date of last search: 07/11/2023

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 (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* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*).ti.
65	or/63-64
66	exp needs assessment/ or exp treatment planning/ or exp decision making/ or decision support systems/ or exp Risk Assessment/ or "Continuum of Care"/ or client transfer/ or exp health care access/
67	(need* or handoff* or hand off* or handover* or hand over* or transition* or barrier* or facilitat*).ti.
68	or/66-67
69	65 and 68

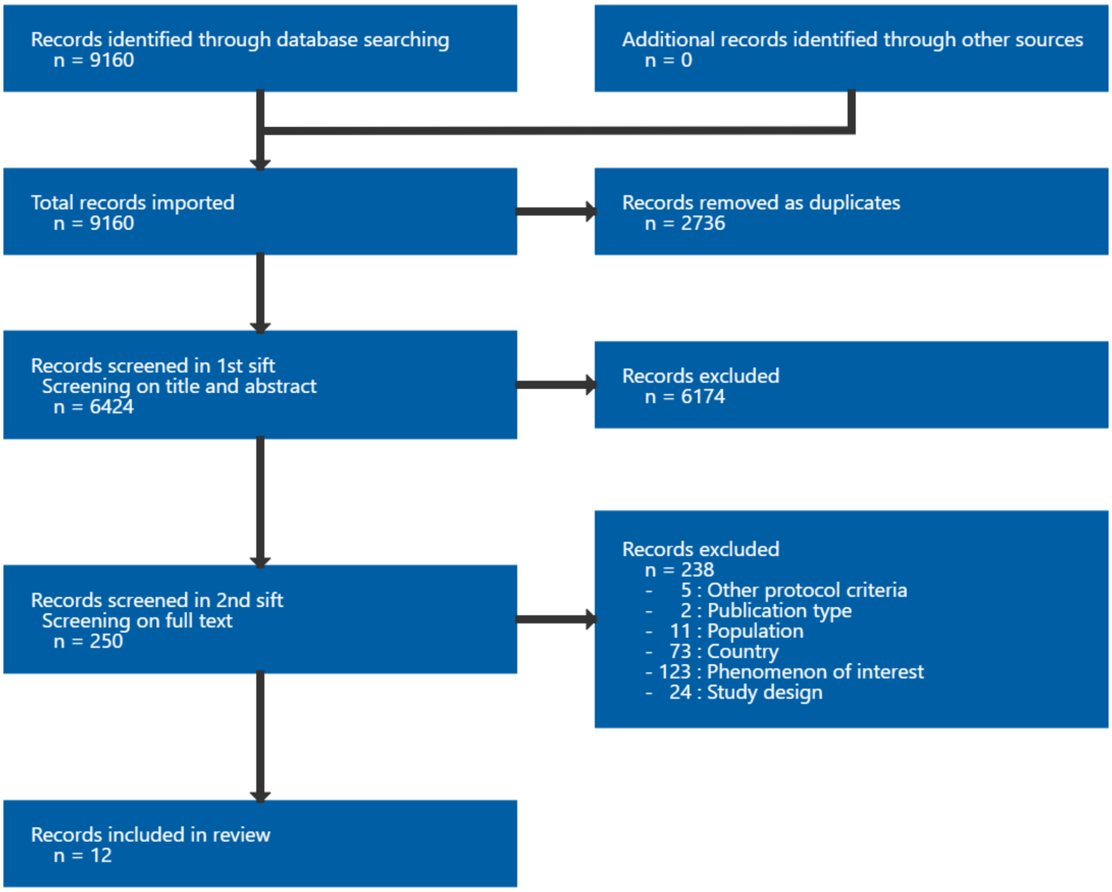
70	professional referral/ or self-referral/
71	refer*.ti.
72	or/70-71
73	72 and (65 or 68)
74	69 or 73
75	((refer* or sign-post* or signpost* or transfer*) adj5 (rehab* or telerehab* or neurorehab* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
76	((rehab* or telerehab* or neurorehab*) adj5 (social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
77	((rehab* or telerehab* or neurorehab* or refer* or sign-post* or signpost* or transfer* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*) adj5 (identif* or access* or barrier* or facilitat* or disparit* or challeng* or imped* or utilis* or utiliz* or uptak* or take up or taking up or increas* or impact* or effect* or improv* or enhanc* or encourag* or support* or promot* or optimiz* or optimis* or adher* or motivat* or incentiv* or persuad* or persuasion or accept* or satisf* or compliance or comply or complie* or availab* or provision or provid* or offer* or incentiv* or start* or attend* or sustain* or maintain* or help* or enabl* or eligib* or decide* or decision*)).ti,ab.
78	((need* or handoff* or hand off* or handover* or hand over* or transition*) adj5 (rehab* rehab* or telerehab* or neurorehab* or refer* or social work* or casework* or case work* or physio* or ((physical or exercise or occupation* or speech or language or assistant) adj1 therap*) or instructor* or specialist* or nutritionist* or dietician* or neuropsychiatr* or psychologist* or prosthe* or orthot* or consultant* or consultation*)).ti,ab.
79	or/74-78
80	62 and 79
81	Qualitative Research/
82	Interviews/
83	exp Questionnaires/
84	Narratives/
85	exp Surveys/
86	(qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw.
87	ethnography/
88	(ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw.
89	phenomenology/ or hermeneutics/ or grounded theory/ or group discussion/
90	(hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw.
91	(metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw.
92	"critical interpretive synthes*".tw.
93	(realist adj (review* or synthes*)).tw.
94	(noblit and hare).tw.
95	(meta adj (method or triangulation)).tw.
96	(CERQUAL or CONQUAL).tw.
97	((thematic or framework) adj synthes*).tw.
98	or/81-97
99	80 and 98
100	(letter or editorial or comment reply).dt. or case report/
101	(letter or comment*).ti.
102	100 or 101
103	exp randomized controlled trial/
104	random*.ti,ab.
105	103 or 104
106	102 not 105
107	animal.po.

108	(rat or rats or mouse or mice).ti.
109	or/106-108
110	99 not 109
111	limit 110 to (English language and yr="2010 -Current")

Appendix C Qualitative evidence study selection

Study selection for: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

Figure 2: Study selection flow chart



Appendix D Evidence tables

Evidence tables for review question: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

Table 4: Evidence tables

Cheung, 2022

Bibliographic Reference	Cheung, Lovisa; Musselman, Kristin E; Kaiser, Anita; Jervis Rademeyer, Hope; Walden, Kristen; Marshall, Sandi; Gauthier, Cindy; Activity-based therapy in the community for individuals living with spinal cord injury or disease: qualitative interviews with clinicians.; Disability and rehabilitation; 2022; vol. 44 (no. 17); 4821-4830

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Canada
Setting and aim	**Setting** Community activity-based therapy services **Aim** To explore how activity-based therapy and technologies associated with it are being used by therapists.
Data collection and analysis	**Data collection** Method: Semi-structured interviews (conducted in French or English), each lasting between 41 and 93 minutes. Each interview included 1 or 2 participants from a single site. Location: Participants' place of work. Format: Face to face, audio-recorded and transcribed verbatim.

	Analysis Interpretive description analysis conducted by 4 researchers. Two researchers independently conducted initial analysis by reading all transcripts, highlighting text of interest, and identifying initial codes. They then discussed and agreed the final codes. Two other researchers helped to iteratively refine the codes and identify themes. Themes were reviewed by all 4 researchers until consensus was reached.
Recruitment strategy	Internet searches and information from members of the Canadian Activity-based therapy community were used to identify relevant centres. No further details reported.
Study dates	November 2019 – March 2020
Sources of funding	Not industry funded
Inclusion criteria	• Licensed or allowed to practice in Canada. • Working at a community-based activity-based therapy facility providing care to people with spinal cord injuries or diseases.
Exclusion criteria	Not reported
Sample size	N=13 practitioners working with people with spinal cord injury or disease
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=6 kinesiologists, n=4 physical therapists, n=2 clinic directors, n=1 occupational therapy Chronical neurological disorder category: Acquired spinal cord injury
Results	Themes as described in paper: • Characteristics of ABT in the community: Clinicians: Clinician training

	○ Educational and training background of clinicians who were able to deliver ABT varied across facilities (for example, kinesiologists, physiotherapists, or occupational therapists). Some facilities only had 1 type of clinician delivering ABT. This could be a financial decision (for example, when insurance is cheaper for a specialist clinician) or due to demand for the speciality as a whole (for example, where an occupational therapist will not be useful to the majority of a centre’s population). Participants noted that ABT was not popular in Canada, leading to a variety in professionals’ levels of understanding and training. Some attended education in the US to overcome this gap. ○ *“ABT is not very big in Canada” (page 4825)* • Perceived challenges: Accessibility: Cost of ABT ○ Finances were highlighted as a particularly big barrier for participants having to pay for ABT, as clinics are not government funded. This meant people either had to pay out of pocket or rely on insurance. This became even more of a challenge when people were completing a particularly intense course of ABT or required access to equipment that required additional fees. Professionals expressed the need to keep costs as low as possible for people using ABT. ○ *“The more that you exercise, the better you feel and the more results you see, but you have to pay every time you go to the gym” (page 4826)* • Need for advocacy: Earlier implementation ○ Most professionals stated that people should have access to and use ABT as early as possible, potentially in the acute care setting, to increase the benefits of the therapy. Earlier implementation of ABT, at a higher intensity, will lead to a smoother continuum of care and stress the importance of physical activity in clients. ○ *“Activity-based training should be implemented in the acute care setting” because “the earlier intervention, the earlier you can intervene, the better chances the person has of regaining mobility and function and strength” (page 4826)* • Need for advocacy: Increased education ○ Professionals stated that there is a need for increasing ABT education for both the spinal cord injury and disease population and clinicians (particularly in the public system). To implement ABT earlier, the public healthcare system would need to increase the number of professionals with the necessary training to deliver

	the therapy, and for larger centres to raise awareness of upper extremity ABT. Some participants noted that the attitude to ABT in the public sector was beginning to improve, but resistance was still there. Expanding the skills of clinicians already trained to deliver ABT was also noted. ○ *"Change the attitude towards it…from the medical system, from the government, from the public, from everybody" (page 4826)*

ABT: activity-based therapy; N/n: number of participants

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns *(No information given on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates a particular rehabilitation therapy or service [activity-based therapy and technology] which may not be broadly transferable.)*

Grose, 2014

Bibliographic Reference	Grose, Jane; Freeman, Jennifer; Marsden, Jonathon; Service delivery for people with hereditary spastic paraparesis living in the South West of England.; Disability and rehabilitation; 2014; vol. 36 (no. 11); 907-13

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK

Setting and aim	**Setting** Not reported **Aim** To explore the health care experiences of people with hereditary spastic paraplegia.
Data collection and analysis	**Data collection** Method: Focus groups (n=6) and semi-structured interviews (n=3). Two focus groups for people with hereditary spastic paraplegia, 2 for carers, and 2 for practitioners, lasting around 90 minutes and observed by a researcher who made contextual notes. Interviews (n=3) with practitioners lasted up to 1 hour. Location: People with hereditary spastic paraplegia and carer focus groups; at the Hereditary Spastic Paraplegia Annual General Meeting. Focus groups and interviews with practitioners at the place of work of people with hereditary spastic paraplegia. Format: Face to face, recorded, and transcribed verbatim. **Analysis** Thematic analysis. Two researchers initially coded two transcripts each of which were compared for interpretation and accuracy. All data were then grouped according to theme and discussed amongst the research group to determine if these themes accurately reflected experience of people with hereditary spastic paraplegia. Further categorisation then took place. No further details on whether whole dataset was coded by more than one analyst.
Recruitment strategy	Sampling: Purposive sampling with the aim of gathering a diverse range of views from people with hereditary spastic paraplegia, and their carers, and health care professionals. People with hereditary spastic paraplegia: • Letter sent to all members of the Hereditary Spastic Paraplegia Society within rural areas of the country (n=30 letters sent) • Via discussion about the aims of the study at a local support group meeting (no further details provided) • Via an advert on the Hereditary Spastic Paraplegia Society website and in the National Hereditary Spastic Paraplegia newsletter.

	Healthcare professionals: - Adverts placed on the Plymouth University website and the websites of a range of professional bodies and special interest groups (no further details provided).
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	People with hereditary spastic paraplegia and their carers: - Confirmed diagnosis of hereditary spastic paraplegia (or carer of someone with a confirmed diagnosis). - Over 18 years old. - Able to travel to a focus group session and provide informed consent. Practitioners: - Current involvement in providing services to people with long-term neurological conditions, and past, or current experience of providing services to someone with hereditary spastic paraplegia.
Exclusion criteria	Not reported
Sample size	N=32 adults with hereditary spastic paraplegia plus carers and practitioners
Participant characteristics	**Adults with hereditary spastic paraplegia, n=14** Age in years [Mean (SD)]: Not reported, age range 26-90 Sex (M/F): Not reported Time since diagnosis in years [Mean (SD)]: Not reported, range 0-40 years Chronic neurological disorder category: Progressive neurological disease **Carers of people with hereditary spastic paraplegia, 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 **Practitioners working with people with hereditary spastic paraplegia, n=12** 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=5 physiotherapists, n=2 neurologists, n=2 specialist neuro-physiotherapists, n=1 general practitioner, n=1 specialist genetic nurse, n=1 specialist neuro-nurse
Results	Themes as described in paper: • Diagnosis, symptoms and finding support: Symptoms ○ People with hereditary spastic paraplegia reported a variety of challenges in managing their evolving physical impairments, which often required adaptations to be made at home and at work. Preparation and planning were noted as effective methods to manage these needs. Short term, preparation could include gaining information on the accessibility of a location. Long term, planning could include accessing additional mobility aids and home adaptations. However, even with this level of preparation, people still faced unforeseen obstacles affecting their access. Preparation extended to how to easily explain the condition and its symptoms to other people, due to the rareness and lack of knowledge of the disorder. ○ *“. . .We were struggling, it was freezing cold, we had to walk around quite a way. And then we were faced with this huge array of steps. . . . There was no entrance for disabled, there’s no wheelchair access and I can’t, that’s a public building that annoys me that there’s nothing.” (page 4)* • Diagnosis, symptoms and finding support: Finding support ○ People with hereditary spastic paraplegia, their carers and professionals highlighted their need for psychological and emotional support, and that this would ideally be delivered by professionals with knowledge of neurological conditions. The rarity of the condition and geographical area were identified as reasons why access to these services might be reduced. To increase access to this knowledge, people used the internet or travelled long distances to access specialist services. A local support group was also identified as a good way to share information and experiences.

	○ *". . . we have to think about what type of psychologist. Because we don't want a psychologist who comes in and just does testing and then doesn't feed back to the team anything relevant." (page 4)* • Therapy, treatment and the delivery of care: Gaps in service ○ Professional respondents highlighted a lack of specialist services for hereditary spastic paraplegia, as well as poor coordination between the services involved in the management of long-term conditions. Factors such as lack of time, historically poor communication between healthcare disciplines, a lack of electronic patient notes, and people using a mix of medical and alternative therapies exacerbated this aspect of rehabilitation provision. ○ *"I think our coordination could be much better. I don't meet regularly with the therapists involved in seeing my patients so we communicate at an arm's length, really by letter. . . . the communication is rather distant and not particularly swift." (page 4)* • Therapy, treatment and the delivery of care: Access to services ○ Participants reported that the level of care provision for hereditary spastic paraplegia varied across the healthcare system. Professionals believed that people with hereditary spastic paraplegia should take responsibility for the day-to-day management of their diagnosis, only accessing specialist services when absolutely necessary (for example, accessing prescribed therapies). However, this view was not always endorsed by of people with hereditary spastic paraplegia and their carers who thought that this added pressure could increase tension with healthcare services. ○ *"I think once you've come out of their office and you've been diagnosed they don't want to know, you hit a brick wall, they've done their job, that's your condition and that's it, you're back to your GP and your GP's got 2000 odd patients and that's it." (page 5)* • Therapy, treatment and the delivery of care: Helpful therapy ○ Participants highlighted that physiotherapy was paramount to accessing current information and support for symptoms, especially when pharmaceutical therapies were not available. However, the format of this service was debated. For example, inpatient physiotherapy may decrease certain barriers in communication between healthcare disciplines while community-based physiotherapy could reduce geographical barriers.

	People’s condition could deteriorate while in hospital due to a lack of specialist rehabilitation knowledge or inappropriate drug management. ○ People with hereditary spastic paraplegia listed a range of alternative therapies that they accessed to reduce certain symptoms (for example, acupuncture, hydrotherapy, hypnosis, and massage). ○ *No first order quotes to support this theme.* • The way forward: Care coordination ○ Participants reported a need for an assigned key worker to coordinate care and act as a central point of contact for of people with hereditary spastic paraplegia, their carers, and professionals alike. This professional could be from healthcare or social care but needed to understand hereditary spastic paraplegia and be aware of local and national resources available. This is particularly helpful for people living in rural or remote areas, as it was not always easy to access specialist centres that might be located in larger, urban areas. ○ *No first-order quotes to support this theme.* • The way forward: Poor coordination ○ Professional respondents noted that poor communication and coordination (often due to lack of resources or funding) was a barrier in developing local secondary care services for this condition. An example was when community therapists were not informed of a person with hereditary spastic paraplegia being admitted to hospital, hindering communication of current care plans and rehabilitation needs. A neuro-care pathway could facilitate the exchange of information between community and acute care settings. ○ *“Well, money number one, two, three, four and five. . . . If you’ve got a big patient group like MS [multiple sclerosis] patients you can set up an MS [multiple sclerosis] service in [the South West]. Something as rare as HSP [hereditary spastic paraplegia] over an area like the peninsular [a large geographical area], well that’s tough, that’s difficult.” (page 6)*

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 *(Interviews of people with hereditary spastic paraplegia before carers might affect carer's interviews; no information given on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Holloway, 2019

Bibliographic Reference	Holloway, Mark; Tasker, Ross; 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; 2019; 99-110

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)
Country/ies where study was carried out	UK
Setting and aim	**Setting** Not applicable **Aim** To understand the experiences of family members of people with an acquired brain injury in relation to health and social care.
Data collection and analysis	**Data Collection** Method: Quantitative survey with free-text questions completed by participants.

	Location: Not applicable. Format: Online quantitative survey (hosted on Survey Monkey) with 6 free-text questions have been extracted and analysed for this review. **Analysis** Qualitative analysis of free-text questions. No further details provided.
Recruitment strategy	A link to the survey was distributed via a range of groups and organisations including Headway, the Child Brain Injury Trust, the United Kingdom Acquired Brain Injury Forum, the Brain Injury Rehabilitation Trust, the Brain Injury Social Work Group, and the British Association of Brain Injury Case Managers.
Study dates	3 months during 2014
Sources of funding	Not industry funded
Inclusion criteria	Not reported
Exclusion criteria	Not reported
Sample size	N=110 carers of people with acquired brain injury
Participant characteristics	Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): n=14/n=96 Chronical neurological disorder category: Acquired brain injury
Results	Themes as described in paper:

	• Q2: How well did these services include you and your knowledge/experience of the brain-injured party in their work? Thinking about the services you have used, what is the one thing that could have been done differently that would have improved your experience? ○ Positive responses to this question included the provision of specialist acquired brain injury services (including long-term management), independent and highly specialised brain injury rehabilitation units, brain injury case managers and specialist litigation solicitors. Some participants highlighted the need to include family members in rehabilitation planning, to make the service more efficient and responsive to the person's changing rehabilitation needs of the person with acquired brain injury. Families may have to advocate to involve themselves in this process. ○ Negative responses included the impact of a brain injury being missed by healthcare professionals, poor information provision for family (particularly when being discharged from acute services), a lack of specialist rehabilitation, a delay in accessing services, poor discharge planning. An overall lack of communication and coordination between disciplines was also mentioned. Family members suggested that a single point of contact would help to coordinate services and provide useful information. ○ *"I was included once I had found the way through to the correct people. The problem was knowing where to start and then being told to contact somewhere else." (page 103)* • Q3: Were you given the information you needed to understand brain injury and services? ○ Many people who responded that they were given adequate information to understand their brain injury identified specialist voluntary sector organisations (for example, Headway, Child Brain Injury Trust, and the Stroke Association) or specialist services (for example, independent brain injury case managers or neurorehabilitation services) as providing this information. Others noted that they had to conduct their own research to increase their knowledge of their diagnosis. This information was not always easy to access and consolidate, and it could take a long time to obtain. Professionals who worked with the whole family unit were identified as being particularly supportive and helpful (for example, giving information on how best to deal with behavioural changes that might accompany acquired brain injury). ○ *"No one sat us down and explained what the brain injury was or which part of the brain had been affected. No one discussed the long-term effects or what we might expect." (page 104)*

	• Q4: What are the three most difficult things that you face now as a relative/friend of a brain-injured person, and how well have you been supported to face these? ○ Participants noted that the most difficult aspect of dealing with acquired brain injury was the physical, cognitive and behavioural changes that accompany acquired brain injury. Other respondents identified a primary difficulty being that healthcare professionals may base their identification of a person's rehabilitation needs on their physical appearance, rather than completing more in-depth, formal assessments. This can lead to issues accessing rehabilitation services in the longer term. Another area mentioned by respondents was a lack of support and understanding by wider family, healthcare professionals, and social care services, which was particularly difficult when trying to adapt to new routines and the 'invisible' symptoms of acquired brain injury. This was exacerbated by a lack of specialist services and delays in receiving services. ○ *"By getting the professionals who know about brain injuries involved and having a very good legal team that was able to fight for him helped us to deal with this very upsetting and very emotional time." (page 105)* • Q5: Knowing what you know now, what would you do differently if you could go back to the time when your relative/friend was first injured? ○ A minority of participants responded that they would not change anything, but most did have suggestions. These included becoming more involved earlier in the rehabilitation process, trying to gain more knowledge of the condition and advocating for access to specialist (rather than generalist) services. People reflected that poor knowledge in the early stages of acquired brain injury especially affected their decisions and actions during this stage of rehabilitation. Caregivers and family members also noted that they would have tried to access services for themselves, as well as the person with acquired brain injury. These themes were consistent across the acquired brain injury pathway, but particularly when discussing discharge into community services. ○ *"The professionals still need educating in the needs of brain injury, especially Social Services; they seem to have no understanding." (page 106)*

N/n: number of participants

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Free-text questions, data likely to be limited; no information given on relationship between researcher and participants; poor thematic analysis; low value of research)*
Overall risk of bias and relevance	Relevance	Highly relevant

Jervis Rademeyer, 2022

Bibliographic Reference	Jervis Rademeyer, H.; Gauthier, C.; Zariffa, J.; Walden, K.; Jeji, T.; McCullum, S.; Musselman, K.E.; Using activity-based therapy for individuals with spinal cord injury or disease: Interviews with physical and occupational therapists in rehabilitation hospitals; Journal of Spinal Cord Medicine; 2022

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Canada
Setting and aim	**Setting** Rehabilitation hospitals providing activity-based therapy (inpatient and outpatient) in urban areas **Aim** To explore how therapists use activity-based therapy when providing care to individuals with spinal cord injury or disease.
Data collection and analysis	**Data collection** Method: Focus group meetings using a series of semi-structured interview questions, facilitated by 2 researchers, each lasting between 30 and 45 minutes.

	Location: Not reported. Format: Telephone or face to face, audio-recorded and transcribed verbatim. **Analysis** Interpretive description. Two researchers (with physical therapy backgrounds) immersed themselves in the data to jointly develop codes using an iterative approach to identify themes and categories which were refined in consultation with a third researcher. Themes and example quotes were sent to researchers with different backgrounds and feedback was sought from study participants.
Recruitment strategy	Purposive sampling through Rick Hansen Spinal Cord Injury Registry network, which is comprised of publicly funded trauma and rehabilitation hospitals.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• Licensed to practice in Canada. • Working at a rehabilitation hospital.
Exclusion criteria	Not reported
Sample size	N=22 practitioners working with people with spinal cord injury or disease
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=10 occupational therapists, n=10 physical therapists Chronical neurological disorder category: Acquired spinal cord injury
Results	Themes as described in paper:

	• Therapists' decision-making approach to ABT and technology: Site specific dynamics ○ Participants reported various site-specific dynamics which affected how services implemented ABT, and these varied across geographical areas. While some teams experimented with including technological-based ABT into spinal cord injury rehabilitation, most teams did not want to deviate from their current therapies and equipment. Professionals preferred manual ABT because of the reduced set-up time and the belief that technology cannot replicate the movements needed for a restorative approach. Clinical teams also differed in their approach to ABT due to the knowledge of involved professionals, with many sites only implementing part of the ABT process. Even when professionals were familiar with ABT in general, they may not have been familiar with specific procedures. Poor staffing levels can act as a barrier to providing ABT due to the training and experience needed for the necessary skills. Additionally, some equipment required multiple people to operate. In order to overcome this, training should be ongoing and timely. ○ *"People were trained by an FES specialist so that was really well received. After that there was a real boost in in confidence and use by most of the therapists. And then, there were also resources that were adapted based on the course (clinical decision-framework) to make it easier for therapists to refer to and make clinical decisions." (page 5)* • Access to ABT and equipment: Visible barriers and facilitators ○ Participants listed a variety of visible barriers and facilitators to accessing ABT and equipment. Examples include equipment price, written policy, hours of operation. Services could increase the access to ABT by offering group therapy sessions or extended opening hours. Affordability of equipment was also noted as a barrier to procurement (especially when not covered by department funding), as well as challenges associated with importation. Geographical location was also included as a barrier, with professionals highlighting the difficulties of accessing ABT in rural locations. ○ *"We've started the MEC [modules to enhance care]. So, we've started more group facilitators programming. For example, on the inpatient side of things, in addition to physiotherapy and occupational therapy, a patient can be referred to a machine-based exercise group and there's a rehab therapist who facilitates an additional session in the gym when they access NuStepe, Motomedf, that sort of thing." (page 5)* • Access to ABT and equipment: Invisible barriers and facilitators ○ Participants listed a variety of invisible barriers and facilitators to accessing ABT and equipment. Examples include funding structures, departmental relations, and protectionism over therapy practices. Competition

	between departments (for example, for access to funding) can cause tension, decreasing cooperation and ability to share equipment and practitioners. ○ *"I think we're a lot more limited in the history of [occupational therapy/physical therapy] and what we can use and then we just don't have specialized training in certain things." (page 5)*

ABT: activity-based therapy; FES: functional electrical stimulation; N/n: number of participants

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 process; telephone format of interviews; no information given on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates a particular rehabilitation therapy or service [activity-based therapy and technology] which may not be broadly transferable.)*

McCartney, 2011

Bibliographic Reference	McCartney, A.; Butler, C.; Acreman, S.; Exploring access to rehabilitation services from allied health professionals for patients with primary high-grade brain tumours; Palliative Medicine; 2011; vol. 25 (no. 8); 788-796

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK

Setting and aim	**Setting** Hospices, general practitioner practices and an acute oncology centre **Aim** To determine practitioners’ views regarding the barriers to rehabilitation for people with primary high-grade brain tumours.
Data collection and analysis	**Data Collection** Method: Semi-structured interviews (using a pre-piloted interview guide). Length of interview not reported. Location: Participants’ place of work. Format: Face to face. Recordings, supported by field notes. **Analysis** Inductive thematic analysis. Initial data analysis of all transcripts conducted by a single researcher using paper records to become fully immersed in the data. General themes were recorded and as data were re-analysed, the themes were refined, and new ones added as necessary. Two other analysts also independently analysed the transcripts, and all potential themes compared. After agreement on the main themes, these were labelled with a key phrase and further analysis and consensus between the researchers confirmed sub-themes. The 3 researchers analysed the data independently and then shared their findings on categories and themes.
Recruitment strategy	Purposive sampling to identify healthcare professionals with experience of providing care to people with a primary high-grade brain tumour. • General practitioners were identified via regional cancer centres who provided contact details for the general practitioners of the last 10 people with primary high-grade brain tumours attending the outpatient clinic. • Clinical nurse specialists were sampled from a group of 3 hospices and were approached via their team manager who distributed study packs. • Specialist therapy radiographers were approached via Macmillan. The radiographers also identified an oncology nursing sister with considerable experience who was approached to take part.
Study dates	June – September 2009

Sources of funding	Not industry funded
Inclusion criteria	• Qualified professionals identified as being actively involved in the care of a person with a grade III or IV brain tumour in the previous 2 years. • Professionals working in NHS and Primary Care Trusts and independent hospices where ethical approval was obtained. • Consent to take part.
Exclusion criteria	Not reported
Sample size	N=8 practitioners working with people with primary high-grade brain tumours
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=2 general practitioners, n=3 hospice clinical nurse specialists, n=2 Macmillan therapy radiographers, n=1 oncology nursing sister Chronical neurological disorder category: Acquired brain injury
Results	Themes as described in paper: • Professional knowledge and behaviours: Lack of experience with brain tumours ○ Professionals reported that their lack of experience in managing people with brain tumours adversely impacted their ability to give clear answers to issues. It was also noted that this lack of knowledge and experience with brain tumours may extend to rehabilitation professionals, which could affect their ability to provide suitable rehabilitation. ○ *"I don't have enough experience to give you a straight answer to that. . .It's difficult when you don't have much experience" (page 791)* • Professional knowledge and behaviours: Knowledge of the concept of rehabilitation

	○ Participants defined rehabilitation to different depths and details, with the most common revolving around the concept of living life as well as possible. Mobility was highlighted, along with daily activities, and equipment and adaptations. All participants noted the need for physiotherapists to be involved, most mentioned occupational therapy, and half mentioned speech and language therapy. Many professionals used the terms physiotherapy and occupational therapy interchangeably, which indicates a lack of understanding of the central roles of each profession. ○ *"That's probably where my knowledge isn't very good, certainly with primary brain tumours, I'm not sure what they could help with specifically. . .certainly I said like the OT I'm not quite sure, I'm vague as to where OT stops and physio starts" (page 791)* • Professional knowledge and behaviours: Knowledge of potential AHP role for brain tumour patients ○ Professionals were not aware about how allied health (and rehabilitation) professionals could help people with brain tumours. Rehabilitation was also considered to be inappropriate if people were too unwell to benefit or had a poor prognosis. Some professionals waited until someone had deteriorated before referring them for rehabilitation, which could indicate a lack of understanding on the preventative aspect of rehabilitation. This approach also carries the risk of missing the chance of rehabilitation. ○ *"Well I think he is in decline I don't think rehab is the prime interest at the moment. Its just managing his symptoms, I think he's got a poor prognosis, the rehab aspect is limited" (page 791)* • Professional knowledge and behaviours: Behaviours/responses to referrals ○ Most professionals (particularly general practitioners) relied on other people to make the referral to rehabilitation services or to indicate to them when the referral should be made, due to their inexperience in dealing with and managing people with brain tumours. Generally, professionals would refer to hospice services and expect them to provide all the needed services (including rehabilitation). However, professionals working in hospices noted that it was not always easy for them to access rehabilitation services, which could lead to gaps in service provision. ○ *"One tends to hope if you've referred on to someone like an OT, if they really felt someone needed a physio they would say but then maybe that's just a cop out and I'm just hoping" (page 791)* • Services and systems: Resources of rehabilitation services

	○ Participants reported that rehabilitation service provision (both general and specialist) varied throughout the region, and services (particularly physiotherapy) took a long time to invite people with brain tumours to appointments. When they were invited, rehabilitation could be short-term and inflexible in its delivery. However, people were aware that this was likely due to services having to cover a wide variety of people with brain tumours only representing a small proportion of referrals. ○ *"I just don't think it's out there, if we do those referrals it can take weeks you know and patients don't sometimes have weeks, you know they need it and they need it now" (page 792)* • Services and systems: Pathways, patient flows and access routes ○ Professionals reported that people with brain tumour had to navigate a complex route to access services. There was a belief that, if people were not referred through a hospice service, they may not receive any services. Rehabilitation services may have eligibility criteria that prevent certain people from accessing them (for example, people with brain tumours not meeting eligibility criteria due to having a cancer diagnosis and a poor prognosis). ○ *"They go off into the community where quite frankly I'm sure they could be forgotten about because once they have gone out of the hospital unless you can refer on its that much more difficult" (page 792)* • Services and systems: Categorisation of brain tumour patients ○ Many participants reported that rehabilitation services neglect referrals from people with brain tumours, instead prioritising other conditions such as motor neurone disease, head and neck cancer and head injuries. Professionals highlighted that the rarity of these conditions was similar to brain tumours but that these conditions often have dedicated services catering to them. ○ *"They fall between different stalls really they're not really brain injured as such and sometimes their needs are a bit different as well and nobody knows quite where they should sit" (page 792)* • The disease and its effects: Rarity and prognosis ○ All participants mentioned the low incidence and poor prognosis of people with brain tumours, suggesting that this limits the availability of specialist knowledge. In services managing mixed populations, increasing this knowledge may not take priority as people with brain tumours will only form a small proportion of their

	caseloads. Additionally, the belief that people with brain tumours will always have a poor prognosis may affect whether a person is considered appropriate for rehabilitation, despite the individual's actual situation. ○ *"Not only are they rare, they are not going to live that long which is a bit of an against as well, you know when they've got a prognosis 6 or 9 months or so then you know there's not always the impetus or sadly the resources for people to pour in for that length of time" (page 793)* • The disease and its effects: Effect on patient behaviours and abilities ○ Some participants mentioned that the personality changes and cognitive difficulties that often accompany brain tumours can affect a person's ability to access rehabilitation services. People may not be aware that rehabilitation is available or how it could benefit them. Additionally, some people with brain tumours may not be able to recognise a need for rehabilitation due to cognitive impairment or they might reject a referral when having to come to terms with a diagnosis. Professionals may avoid referring some people with brain tumours to rehabilitation services to prevent unrealistic hope of what these services can achieve. ○ *"He's quite fit and well you know and getting on with things, like, he doesn't want any kind of input to remind him of his diagnosis" (page 793)* • Solutions to barriers ○ The most common solutions identified by professionals were multidisciplinary meetings for people with brain tumours and a rehabilitation service directory. There were no multidisciplinary meetings held for people with brain tumours in this geographical area, as their surgery was conducted at a tertiary centre outside of the usual catchment area. Professionals also wanted to be better educated about brain tumours in general, the role of rehabilitation in palliative care, and what services specifically were available for their brain tumour patients. Another suggestion was a dedicated specialist nurse (or other professionals) for people with brain tumours. ○ *No first-order quotes to support this theme.*

AHP: allied healthcare professional; N/n: number of participants; OT: occupational therapy/therapist

Critical appraisal – CASP qualitative studies checklist

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

Methley, 2017

Bibliographic Reference	Methley, Abigail; Campbell, Stephen; Cheraghi-Sohi, Sudeh; Chew-Graham, Carolyn; Meeting the mental health needs of people with multiple sclerosis: a qualitative study of patients and professionals.; Disability and rehabilitation; 2017; vol. 39 (no. 11); 1097-1105

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Not reported **Aim** To understand the experiences of people with multiple sclerosis, and practitioners in relation to mental health support.
Data collection and analysis	**Data collection** Method: Semi-structured interviews lasting around 23 – 150 minutes for people with multiple sclerosis, and 19 – 53 minutes for health professionals.

	Location: Participants' homes, place of work, research centre, or private quiet space within a public area – arranged on the basis of participants' preferences. Format: Telephone or face to face, audio-recorded (except where consent was not given) and transcribed verbatim. Field notes were recorded to incorporate context into analysis. **Analysis** Thematic analysis using constant comparative analysis within and across data sets. Theoretical framework of candidacy used to interrogate data. Participants who represented unusual cases were sought to test and refine the themes identified (for example, people who had disengaged from health care services or were not members of a multiple sclerosis society).
Recruitment strategy	Maximum variation sampling used to identify participants with characteristics that research suggests can affect the experience of receiving or providing health care (for example, age, gender, ethnicity, level of disability.) Snowball sampling recruited men with multiple sclerosis, and people with progressive multiple sclerosis, who may be more reluctant to respond to community recruitment strategies. Recruitment via community groups and primary care practices across North West England. Practitioners were approached through professional networks and direct contact, people with multiple sclerosis were recruited through general practitioner surgeries, charities, online forums and community recruitment materials, for example, posters displayed in shops.
Study dates	October 2012 – April 2014
Sources of funding	Not industry funded
Inclusion criteria	Not reported
Exclusion criteria	Not reported
Sample size	N=58 adults with multiple sclerosis plus practitioners
Participant characteristics	**Adults with multiple sclerosis, n=24** Age in years [Mean (SD)]: Not reported, age range 31-80 Sex (M/F): n=6/n=18

	Time since diagnosis in years [Mean (SD)]: Not reported, range 0-40 Chronic neurological disorder category: Progressive neurological disease **Practitioners working with people with multiple sclerosis, n=34** 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=13 general practitioners, n=13 practice nurses, n=9 specialist nurses
Results	Themes as described in paper: • Candidates for care ○ Participants reported difficulties in identifying appropriate referrals to mental health services, as it is hard to differentiate low mood caused by multiple sclerosis from low mood caused by the impact of living with multiple sclerosis. Professionals identified certain time periods where people were more likely to experience mental health problems, particularly noting the impact that relapses might have. ○ Healthcare professionals were resistant to pathologizing depressive symptoms in people with multiple sclerosis, instead focusing on other explanations (for example, the stigma people with multiple sclerosis face). However, this view was not shared by specialist nurses who referenced research suggesting depression could be linked to brain pathology or treatments related to their disease. These social reasonings believed by more general healthcare professionals could lead people to not viewing symptoms as discrete mental health problems requiring specialist referral. The threshold at which referrals should be made is similarly unclear, often relying on a professional’s experience and confidence in dealing with mental health issues. ○ Another reason professionals gave for not addressing the mental health concerns of people with multiple sclerosis was the worry of exposing a large number of newly-identified needs, which they did not have the time or expertise to deal with. ○ *“If we open that can of worms and we’ve got nothing to support them with, are we actually doing them a favour? Yes, it’s ignoring them [MH (mental health) problems] in one sense, because you could actually take away all their boundaries and that concerns me with the lack of back up available” (page 10)*

	• Defining roles ○ Nursing participants were confident in their abilities to identify depressive symptoms in people with multiple sclerosis but were not knowledgeable enough to perform the role of a mental health specialist. However, lack of specialist services meant that they often had to work outside of their professional remit, leaving them feeling untrained and unsupported. This was exacerbated when other healthcare professionals overestimated nurses' responsibility for managing mental health symptoms. ○ *"The problem lies, sometimes in the community they think well we are MS [multiple sclerosis] nurses, this person is low in mood, sort it out and we can only do a certain degree of it, if they really need a course of counselling or something that's a bit more intense it really needs to be done by properly supported counsellors, the ones who are educated in doing it." (page 14)* • Permeability and responsiveness of services ○ Respondents described long waiting periods when accessing mental health services (particularly secondary and community care services), which could leave people with multiple sclerosis without support when needed. Access to services varied across geographical areas and settings (for example, when people required psychological services delivered at home). Primary care practitioners face a conflict between referring people to services that are generalist but with short waiting lists, or more specialist services with longer waiting lists. When unable to access appropriate mental health services, many general practitioners felt responsible for ensuring people with multiple sclerosis received regular follow-up appointments. Participants also noted eligibility criteria were a barrier to accessing services, with differing eligibility criteria causing inequalities and fragmented care. ○ *"By the time you get to the counsellor the heat has gone off it because its 12 months later, 18 months. Nothing is instantaneous. You don't get the support and the help when you need it. I had to wait 18 months." (page 15)*

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 *(Lack of information on credibility; No information given on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates a particular rehabilitation therapy or service [mental health support] which may not be broadly transferable.)*

Norman, 2020

Bibliographic Reference	Norman, Alyson; Holloway, Mark; Odumuyiwa, Tolu; Kennedy, Machaela; Forrest, Hannah; Suffield, Freya; Dicks, Hilary; Accepting what we do not know: A need to improve professional understanding of brain Injury in the UK.; Health & social care in the community; 2020; vol. 28 (no. 6); 2037-2049

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)
Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community, after transfer from acute care **Aim** To determine practitioners’ knowledge regarding working with people with an acquired brain injury and identify areas for improvement.

Data collection and analysis	**Data collection** Method: Quantitative survey with free-text questions and semi-structured interviews. Interviews lasted between 25 minutes and 1 hour. Location: Not reported. Format: Online surveys (platform not described) and interviews conducted over telephone or face to face and transcribed verbatim. **Analysis** Thematic analysis, summative approach, and direct content analysis. Free-text sections of questionnaires were analysed using a summative approach to quantify the textual content presented as well as to interpret the underlying meanings behind its use. One researcher coded the data, but the validity of the identified themes was checked by other members of the research team. Themes identified from this process were then used to create a framework for coding the follow-up interviews. Interview data were analysed using a mixed inductive and deductive approach to thematic analysis by one researcher. After the final analysis of interview data had taken place a second member of the research team checked validity and all participants were invited to comment (n=7 responded).
Recruitment strategy	Recruitment took place via social media and local branches of Headway as well as independent case management organisations.
Study dates	February 2017 – April 2018
Sources of funding	Not industry funded
Inclusion criteria	Not reported Note: Further details reported in Odumuyiwa 2019.
Exclusion criteria	Not reported
Sample size	N=117 people with acquired brain injury plus carers and practitioners Note: All participants completed the online questionnaire, and 31 of these participants also took part in interviews.

Participant characteristics	**People with acquired brain injury, n=30** Age in years [Mean (SD)]: Not reported Sex (M/F): n=21/n=9 Time since diagnosis or injury: Not reported Chronic neurological disorder category: Acquired brain injury **Carers/relatives of people with acquired brain injury, n=20** 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 acquired brain injury, n=61** 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=13 brain injury case managers, n=9 general practitioners, n=6 brain injury support workers/Headway staff, n=6 occupational therapists, n=6 social workers, n=5 care workers/managers, n=4 mental health practitioners/psychiatrists, n=4 police people, n=2 nurses, n=2 personal injury solicitors, n=2 speech therapists, n=1 neuropsychologist, n=1 neurorehabilitation manager
Results	Themes as described in paper: • Knowledge and understanding of healthcare professionals ○ Participants expressed concerns over the poor knowledge and understanding of the long-term management of acquired brain injury shown by healthcare professionals in hospital settings (including acute care and in-patient neurorehabilitation services). This lack of education caused people to be discharged from hospitals without a scheduled follow-up, signposting to appropriate services or information on their diagnosis. ○ *No* first-*order quotes to support this theme.*

- Service provision
    - Participants with traumatic brain injury specifically reported that poor access to rehabilitation services during hospital stays can cause further issues managing the consequences of acquired brain injury (for example, concentrating on physical injuries rather than a brain injury). People with traumatic brain injury, their carers and professionals all identified poor understanding of the impact of acquired brain injury as a reason for this prioritisation, as well as reduced staffing levels and time constraints. Once discharged, community-based acquired brain injury services were identified as an area of particularly poor knowledge.
    - More generally, people with acquired brain injury, their carers and professionals noted the importance of scheduling follow-up appointments for mild acquired brain injuries that did not require people with acquired brain injury to be admitted to hospital, in order to allow professionals more opportunities to identify longer-term rehabilitation needs. Signposting to longer-term support would also assist this longer-term follow-up.
    - “You'd be a bit more in the system…you’d have a follow up appointment…they would know…have you on file” (page 2042)
- Signposting
    - People with acquired brain injury reported not receiving proper signposting to appropriate resources upon discharge from hospital, increasing uncertainty and distress, and leaving them underprepared about life with acquired brain injury. This lack of knowledge and support was felt most clearly in the immediate discharge period and left them having to seek out information themselves. People with acquired brain injury and their family members suggested that this absence of signposting was due to professionals not taking responsibility for providing this information, either because it was not in their remit (for example, professionals in primary care believing signposting had already been provided by specialist services) or because it was outside their field of expertise (for example, generalist healthcare services with poor knowledge of local acquired brain injury services).
    - “I think I’d probably assume, and maybe that’s a very wrong assumption, that in their rehab you know just initially in hospital or…perhaps physio or something afterwards that in those sort of services…other health professionals… tell them about stroke association or you know…” I’m assuming that that’s all there for that sort of rehab stuff rather than us.” (page 2044)
- Knowledge and understanding among social care professionals

	○ Participants reported that not every service has the knowledge needed to understand the impact of acquired brain injury, particularly long-term community-based services. This is especially true regarding cognitive and behaviour changes that often present after acquired brain injury, taking the form of a ‘hidden’ disability. This lack of understanding leads to these services being unable to provide access to appropriate services. Additionally, there is poor knowledge surrounding the long-term psychosocial impact of acquired brain injury on both these people and their families (for example, lack of understanding from benefits assessors, employment services and employers when people with acquired brain injury are returning to work). ○ “Mental health services […] told a brain injured client that they have capacity to deal with their own finances despite the client telling them 'I will spend all my money if I was to have a large sum of money. MHS [mental health services] proceeded to tell the client that they could help the client have capacity to manage their money.” (page 2044) • Empathy ○ Participants identified a lack of empathy being shown by a variety of professionals throughout their rehabilitation. People with acquired brain injury and their families wanted healthcare professionals to be invested in their recovery, supporting them and caring about their progress. Some people reported being labelled as problematic or malingerers by services, including education and employment sectors. Where professionals were seen to be empathetic, people with acquired brain injury reported feeling supported and gained a better understanding or their diagnosis. ○ “The way people in various organisations look and treat you ......just because you look ok.” (page 2045) • Hidden disability ○ Many respondents described the cognitive and behavioural difficulties that often accompany acquired brain injury as ‘hidden’ or ‘invisible’ disabilities. These tended to be poorly understood by professionals who were not specialised in acquired brain injury and acted as a barrier to identifying and assessing the severity of an acquired brain injury. People with acquired brain injury and their families felt that their disorder was often stereotyped. Unless symptoms align with professionals’ pre-conceived ideas of acquired brain injury sequelae, these were often ignored. ○ “Where do you want to start? There is a terrible lack of underpinning knowledge amongst non-specialist professionals – insight and executive impairments are virtually always missed.” (page 2045)

	- Safeguarding
	  - Participants reported safeguarding issues directly caused by the lack of understanding of hidden disabilities following acquired brain injury and how vulnerable this can leave survivors. There is a need for increased training for professionals who may come into contact with people with acquired brain injury, with a particular focus on invisible cognitive disabilities (for example, executive dysfunction, memory impairments, and processing speed difficulties).
	  - “Inexperienced social worker assessed my client as having no needs and no risk […] Following complaint and re-assessment, he was identified as high risk and needing a significant support package.” (page 2045)

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 *(People with acquired brain injury could be interviewed with supporters which could affect reporting; no information given on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Relevant *(6/30 (20%) people with acquired brain injury were adults with stroke (outside of scope). No report that carers of people with acquired brain injury and professionals working with adults with acquired brain injury exclude adults with stroke, but unlikely considering previous inclusion.)*

Odumuyiwa, 2019

Bibliographic Reference	Odumuyiwa, Tolu; Improving access to social care services following acquired brain injury: a needs analysis; Journal of Long-Term Care; 2019; 164-175

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Not reported **Aim** To explore the long-term rehabilitation needs of people with an acquired brain injury and their experience of services, as well as the needs and experiences of their family and carers.
Data collection and analysis	**Data collection** Method: See Norman 2020 Location: See Norman 2020 Format: See Norman 2020 **Analysis** See Norman 2020
Recruitment strategy	See Norman 2020
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	• People with an acquired brain injury. • People who had experienced a brain injury at any point in their lives severe enough to cause some form of disability • Carers or relatives of people with an acquired brain injury.

	• A family member of someone who had experienced a brain injury at any point in their lives severe enough to cause some form of disability. • Practitioners working with people with an acquired brain injury. • Working with people with brain injuries for at least 2 years.
Exclusion criteria	Not reported
Sample size	N=76 adults with acquired brain injury plus carers or relatives and practitioners Note: All participants completed the online questionnaire, and 21 of these participants also took part in interviews.
Participant characteristics	**Adults with acquired brain injury, n=19** Age in years [Mean (SD)]: 44.6 (SD not reported), age range 20-73 Sex (M/F): n=10/n=9 Time since diagnosis or injury: Not reported Chronic neurological disorder category: Acquired brain injury **Carers or relatives of people with acquired brain injury, n=26** 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 acquired brain injury, n=32** 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: All specialists in acquired brain injury, no further details reported

Results	Themes as described in paper: • Impact of ABI: Cognitive and behavioural effects of ABI ○ Participants reported that community-based healthcare and social care had a lack of knowledge regarding the cognitive and behavioural aspects of acquired brain injury (including memory impairments, behavioural and personality changes, and executive impairments), meaning that they were not able to provide appropriate services. This poor understanding is especially harmful when it concerned executive impairments, which can lead to safeguarding concerns when services incorrectly believe people with acquired brain injury have understood certain implications and consequences. ○ *"If you met him now you wouldn't think there was a problem…this is where the so-called professionals have kind of not…kind of seen, what was there, I've seen it urm my friends have seen it, my family have seen it because when he has gone to these professionals he has kind of made a supreme effort…" (page 167)* • Types of services required ○ Participants reported needing rehabilitation services that are tailored and personalised to their individual needs, rather than a generic approach to care. Another important aspect was holistic healthcare, using interdisciplinary teams that can treat the whole variety of impairments due to acquired brain injury. It is important to note that it was felt this multidisciplinary approach would only be effective if it included professionals with specialist acquired brain injury training and experience. Services should also try to include family members and carers in discussions concerning rehabilitation planning (if appropriate), as well as actively encourage the development of skills needed to support people with acquired brain injury. ○ More specific examples of how to improve acquired brain injury rehabilitation services included proving more information on brain injury at diagnosis, increasing the number of routine follow-ups after discharge from hospital, increased focus on longer-term community rehabilitation and support, and better communication between services about a person's impairments and treatment plan. Financial support (for example, compensation packages to cover long-term care needs, or increased government benefits) was highlighted here, with people reporting having to appeal an increasing number of benefit decisions, mainly due to systems being heavily biased towards physical (rather than cognitive) disorders. ○ *"You'd be a bit more in the system … you'd have a follow up appointment…and they would know why you needed help, like they would know they would have you on file." (page 169)*

- Poor access to support: Limited service provision
    - Respondents identified a lack of general and acquired brain injury-specific services throughout the UK after discharge from hospital, particularly mental health services and adult social care services. This can either result in people having to wait for long periods of time to access these services, or not be able to attend them at all. Furthermore, it affects the availability of the interdisciplinary care needed by people with acquired brain injury and their families.
    - *“They might do a program for a sh short period of time…the specialist services that were available were quite generic services, urm it’s limited, it’s when I say limited I mean none.” (page 170)*
- Poor access to support: Lack of professional knowledge
    - Participants reported that a lack of access to appropriate services is often due to the lack of acquired brain injury knowledge and education amongst professionals, especially those who function as gatekeepers to services. Poor understanding of the cognitive, behavioural and psychological symptoms post-brain injury makes accurate assessment of rehabilitation needs difficult. There is also a focus on rehabilitating physical injuries rather than cognitive impairments, which exacerbates this gap in service provision. This might also be attributed to lack of professional knowledge concerning the impact these hidden disabilities have on long term functional outcomes for people with acquired brain injury.
    - *“Everyone seems to focus on getting the person active again, getting them moving, getting their arms working, their legs walking, no one seems to focus on the cognitive health of the person who’s had the accident, or speech and language, as long as he is up and walking and everything you can see is in the right order, mm, that’s how it feels.” (page 170)*
- Poor access to support: Hidden disability
    - Respondents reflected that professionals’ lack of acquired brain injury-specific knowledge can increase the impact of hidden disabilities seen with acquired brain injury survivors, as professionals are less able to accurately assess acquired brain injury severity (particularly concerning impact on executive functioning) and therefore identify rehabilitation needs. This insufficient assessment can lead to difficulties in accessing services in the longer term.

	○ *“Going to see the neurologist was quite a big deal. But I had to do that myself like nothing was really offered.” (page 170)* • Poor access to support: Organisational factors ○ Respondents noted several organisational factors that affected their ability to access appropriate services and support post-brain injury. These included structural issues that impair multidisciplinary team working between services (for example, healthcare, social care and the criminal justice system) and information sharing. Some organisations discouraged active participation of family members for people with acquired brain injury, despite these people often being good sources of information (for example, how people have changed since their injury or how the injury has impacted their daily life). This in turn leads to less comprehensive assessments and provision of care. Additional issues that were identified included poor funding, lack of resources for professionals, high staff turnover, and large workloads affecting the time professionals can spend with people prior to their assessment (including home visits). ○ *“One of the resources that I found that was really lacking in my care was that, I got a very close family and my family members, knew an awful lot about my personality, and about my interests before the injury, and lots of things like that and urm I didn’t feel that…the immediate sort of medical services drew on that support they almost tended to exclude my family members from rehabilitation or meetings and things like that and I think that, they really could have really learnt a lot about the way that my interest have formed, and the way that I was involved in my family to a greater degree.” (page 170)*

ABI: acquired brain injury; 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 *(People with acquired brain injury could be interviewed with supporters which could affect reporting; no information given on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Relevant

Section	Question	Answer
		(6/30 (20%) participants with acquired brain injury were adults with stroke (outside of scope). No report that carers people with acquired brain injury and professionals working with adults with acquired brain injury exclude adults with stroke, but unlikely considering previous inclusion.)

Preston, 2012

Bibliographic Reference	Preston, Jenny; Haslam, Simon; Lamont, Lynn; What do people with multiple sclerosis want from an occupational therapy service? 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 (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). The focus groups lasted around 1.5 hours. 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 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 the previous 12 months. • Adequate communication abilities allowing participation in a group setting without causing distress. Partners/carers of people with multiple sclerosis Occupational therapy personnel who had worked within the service within the last 12 months.
Exclusion criteria	Not reported
Sample size	N=46 adults with multiple sclerosis plus partners, carers and practitioners
Participant characteristics	**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 Time since diagnosis in years [Mean (SD)]: Not reported, range 0.5-26 years (median 10) Chronic neurological disorder category: Progressive neurological disease **Carers 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: All participants currently or had previously worked in an occupational therapy service
Results	Themes as described in paper: • Comprehension of occupational therapy ○ Many participants noted that they were unaware or mis-informed of occupational therapy prior to their referral. A large cause of confusion for people with multiple sclerosis and their carers was due to occupation being falsely attributed to work environments. Professionals believed that the confusion was due to the fact that the profession is poorly defined. Either way, this lack of understanding leads to people being unable to identify their rehabilitation needs and or appreciate how accessing occupational therapy might impact their overall rehabilitation. In turn, this can be a barrier to earlier, timely referrals. Once people with multiple sclerosis had experience of the service, they were better able to identify other or emerging areas of need. ○ *“Sometimes people with MS may not be referred until they’re having difficulties with transfers or other amenities a bit further down the line. I think there’s potential for us to be involved when people are still at work and very much more active” (page 267)* • Home visits

	○ There were mixed feelings about home visits by occupational therapists. Some participants reported not wanting to take up resources from other people deemed to have more significant need of home visiting. Furthermore, home visits can be considered more intimidating compared to hospital appointments and there is a decreased sense of privacy from healthcare professionals. However, participants reflected that home visits would allow a more comprehensive assessment of rehabilitation needs, as professionals would be able to view people in a variety of different environments and explore wider issues (for example, how family members are coping with adjustments). ○ *"… if the patient didn't want the family there or if they turned up on their own you would see them on their own … sometimes we might request that they come in with a family member or if someone's in the ward get them to come in and join the conversation" (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 particular rehabilitation therapy or service [occupational therapy services] which may not be broadly transferable.)*

Treadgold, 2019

Bibliographic Reference	Treadgold, B.; Kennedy, C.; Spoudeas, H.; Sugden, E.; Walker, D.; Bull, K.; Paediatric neuro-oncology rehabilitation in the UK: Carer and provider perspectives; BMJ Paediatrics Open; 2019; vol. 3 (no. 1); e000567

Study Characteristics

Study type	General qualitative inquiry

Country/ies where study was carried out	UK
Setting and aim	**Setting** Not applicable **Aim** To explore the provision of specialist paediatric neuro-oncology rehabilitation services and determine if they meet the needs of children and young people with central nervous system tumour and their families.
Data collection and analysis	**Data collection** Method: 2 surveys, one with quantitative and free-text questions and a second with free-text questions completed by participants. Location: Not applicable. Format: Online surveys (hosted on Survey Monkey). **Analysis** Narrative content from free-text responses summarised. No further details reported.
Recruitment strategy	• Survey 1 – Email invitations to neuro-oncologist members of the Children's Cancer and Leukaemia Group, nurse specialists at all Children's Principle Treatment Centres and nurse specialists at some Teenagers and Young Adult's Principle Treatment Centres. Participants were asked to complete the survey on behalf of their centre. • Survey 2 – Email invitations to members of The Brain Tumour Charity Research Involvement Network, which consists of current and previous children and young people with central nervous system tumour and their families.
Study dates	March 2017 – August 2017
Sources of funding	Not industry funded
Inclusion criteria	Not reported

Exclusion criteria	Not reported
Sample size	N=37 carers of children and young people with central nervous system tumour plus practitioners
Participant characteristics	**Carers of children and young people with central nervous system tumour, n=18** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all noted as children and young people. Sex of children and young people with chronic neurological disorders (M/F): Not reported Chronical neurological disorder category: Acquired brain injury and acquired spinal cord injury **Practitioners working with children and young people with central nervous system tumour, n=19** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all noted as children and young people. Sex of children and young people with chronic neurological disorders (M/F): Not reported Role or specialism: n=11 paediatric or adult neuro-oncologist, n=3 lead or specialist nurses in neuro-oncology, n=3 physiotherapists, n=1 occupational therapist, n=1 paediatric psychologist
Results	Themes as described in paper: • Lack of establishment of neuro-oncology rehabilitation services and dedicated space and resources ○ No thematic description presented. ○ *“There are not any designated neuro rehabilitation beds within the centre and no neuro rehabilitation tariff for these patients.” (page 5)* • Lack of communication with other departments and services ○ No thematic description presented. ○ *“local services refusing to support patients with complex needs.” (page 5)*

	- Lack of individual components of the multidisciplinary team ○ No thematic description presented. ○ *"Lack of local SALT [speech and language therapy] and educational rehab." (page 5)* - Outpatient-specific barriers ○ No thematic description presented. ○ *"Patients access community-based services during follow up however there are variable issues with waiting time and intensity of treatment that patients need" (page 5)*

N/n: number of participants

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Serious concerns (*Free-text questions, data likely to be limited; poor description of thematic analysis or presentation of themes; no information given on relationship between researcher and participants.*)
Overall risk of bias and relevance	Relevance	Relevant (*Study investigates a particular rehabilitation therapy or service [paediatric neuro-oncology services] which may not be broadly transferable.*)

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 syndrome), particularly in relation to 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 comparative approach. Codes initially derived from the data/open coding. 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: Service provision ○ Participants reported that long waiting lists and complex referral services limited the availability of general rehabilitation services. Referrals were also difficult to obtain when the person with POEMS syndrome's expectations differed from that of healthcare professionals and required the person and their husband to challenge decisions before they were made. Not all services explained to family members what services were available and how the referral process works, which adversely affected their ability to advocate for rehabilitation needs in a complex healthcare system. ○ Continuity of care was decreased when providers are changed frequently, and this is exacerbated by poor communication between services and hospitals. Despite regular discharge planning, it became confusing

	who was providing what care, and for how long (particularly when being discharged back into the community). ○ Finances were another major barrier to accessing appropriate rehabilitation services and were perceived to increase healthcare inequalities. Participants reported feeling penalised that they may have to end up paying for certain services that other people would get for free. ○ *"Before she [participant] was discharged [to the INRU (inpatient neurological rehabilitation unit)] we had an informal meeting with the ward consultant and the impression I was getting was that you might as well be discharged now because you have reached a plateau, that was the word they used, and to me that meant we are going to give up now because you aren't getting any better and I was not having that because I knew the improvements that could happen." (page 2507)*

N/n: number of participants; POEMS; polyneuropathy organomegaly endocrinopathy monoclonal gammopathy skin changes

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Serious concerns *(Previous relationship between participants and researchers)*
Overall risk of bias and relevance	Relevance	Partially relevant *(Case study of the experience of a single individual with a specific condition)*

Woodward, 2022

Bibliographic Reference	Woodward, Sue; Coggrave, Maureen; Dibley, Lesley; McClurg, Doreen; Norton, Christine; A Qualitative Study of Health Care Professionals' Views on Bowel Care in Multiple Sclerosis: Whose Job Is It Anyway?.; International journal of MS care; 2022; vol. 24 (no. 2); 81-89

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Primary, secondary and tertiary services and a bladder and bowel charity **Aim** To understand practitioners' views regarding management of bowel dysfunction in people with multiple sclerosis.
Data collection and analysis	**Data collection** Method: Semi-structured interviews, conducted by 2 researchers and each lasting 30 to 45 minutes. Location: Participants' place of work. Format: Telephone or face to face, audio-recorded and transcribed verbatim. **Analysis** Thematic analysis. Using an inductive approach, data were read and reread before coding and emerging broader themes from the coded data were identified. Two researchers performed preliminary analyses to identify themes, which were then discussed with other team members.
Recruitment strategy	Purposive and chain referral sampling. No further details reported.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	Not reported

Exclusion criteria	Not reported
Sample size	N=18 practitioners working with people with multiple sclerosis
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: Not reported Chronical neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • Whose job is it anyway? Responsibilities of People with multiple sclerosis ○ Participants noted that bowel problems (particularly constipation) were common in people with multiple sclerosis, accounting for 50-80% of their caseload, although people may not link their bowel dysfunction with their multiple sclerosis. After appropriate education (and supported by medical guidelines) the main responsibility of people with multiple sclerosis should be to report any issues to healthcare professionals. Professionals believed that people should self-manage (including titrating laxative doses or managing transanal irrigation) if possible, especially in the early disease stages. ○ *"Maybe a bit more information … there could be self-management areas … speaking about bowels and, you know, if you do get into sort of particular problems … discussing this with your GP (general practitioner) or MS nurse." (page 84)* • Practicalities of Bowel Management: Delayed reporting ○ Professionals reported that people with multiple sclerosis often delay their reporting of bowel issues, sometimes until a crisis point had been reached. A reason for this might be because people with multiple sclerosis accept bowel dysfunction as part of their disease, which normalises it for them but increases caregiver burden. A way of combatting this would be to refer people with multiple sclerosis to specialist bladder and bowel services earlier, as bowel problems often only become apparent after this referral is made for bladder dysfunction.

	○ *"[There's] … a lot of acceptance before there's a tipping point. And it's normally the carer calls us first, because they can't cope." (page 84)* • Practicalities of Bowel Management: Assessment ○ All participants reported asking people with multiple sclerosis about potential bowel issues, but only after developing a relationship with their patient as this was perceived to be a delicate and potentially embarrassing topic. This could lead to people with bowel dysfunction being missed if healthcare professionals remain too embarrassed to discuss the issue, or if they do not know what to offer. Another reason for people not being asked the question related to insufficient appointment time. ○ In the case of multiple sclerosis specialist nurses, they did not ask about bowel dysfunction as they did not wish to overwhelm people with too much information after diagnosis and worry people who might not develop an issue. Conversely, bladder and bowel specialist nurses thought that people with multiple sclerosis should be given information on what might happen and the need for an assessment if symptoms occurred. This assessment could be informal or formal (for example, self-assessment scales, bowel diaries, physical examination and further investigations). ○ *"So I think people actually asking the question is really, really important" (page 84)* • Improving service delivery: Education, education, education ○ Healthcare professionals reported a need for increased formal education in managing bowel dysfunction in people with multiple sclerosis, rather than just receiving training from clinical experience or attending conferences. They acknowledged a duty to self-educate on these issues. This increased education would increase the number of appropriate referrals, improving service delivery. ○ *"The first I think is to educate health care professionals to know that there's something they can do ... we see them early on because the referring teams … know that something can be done." (page 84)* • Improving service delivery: Referral Pathways ○ Participants reflected on the need for referral pathways into and onward from bladder and bowel services, and highlighted the need to develop networks within the local healthcare system and publicise services. This would help to clarify who is responsible for which stages of a pathway and reduce unnecessary hospital admissions. Most referrals came from other healthcare professionals (for example, general practitioners,

		neurologists, gastroenterologists, or multiple sclerosis specialist nurses) but some services operated an open referral system. This limited the number of potentially embarrassing conversations people with multiple sclerosis needed to have, increasing access to these services. However, these sorts of options need to be adequately promoted to people with multiple sclerosis (and triage would be needed as part of the process). ○ *“So if I looked at other things, I’d say ‘Oh this is the process, this is my red flag, I need to refer on here’ … so I know I work by guidance for lots of things … with MS (multiple sclerosis), it’s slightly different.” (page 84)*

N/n: number of participants

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; no information given on relationship between researcher and participants; low value in research)*
Overall risk of bias and relevance	Relevance	Highly relevant

Appendix E Forest plots

Forest plots for review question: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

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: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

Table 5: GRADE-CERQual table for theme B1 Availability

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 B1.1: Availability of specialist centres and/or services						
7 studies • Cheung 2022 (General qualitative inquiry, acquired spinal cord injury) • Grose 2014 (General qualitative inquiry, progressive neurological disease) • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • Jervis Rademeyer 2022 (General qualitative inquiry, acquired spinal cord injury) • McCartney 2011 (General qualitative inquiry, acquired brain injury) • Odumuyiwa 2019 (General qualitative inquiry, acquired brain injury) • Treadgold 2019 (General qualitative inquiry, acquired brain injury and	Limited availability of specialist chronic neurological disorder rehabilitation centres and services is a barrier to accessing appropriate services. This lack of availability could be due to physical factors (for example, geographical location of services) or due to there being no local services designed to meet the rehabilitation needs of people with rare conditions. *"Need to be in-patient for formal neuro-rehab - haven't got a developed out-patient neuro-rehab service." (page 5, Treadgold 2019)*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	No/very minor concerns	No/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**
acquired spinal cord injury)						
Sub-theme B1.2: Availability of specialist chronic neurological rehabilitation knowledge						
4 studies • Grose 2014 (General qualitative inquiry, progressive neurological disease) • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • Jervis Rademeyer 2022 (General qualitative inquiry, acquired spinal cord injury) • McCartney 2011 (general qualitative inquiry, acquired brain injury)	The availability of specialist chronic neurological disorder rehabilitation knowledge affects both the identification of rehabilitation needs and access to appropriate services. People with chronic neurological disorder rehabilitation needs preferred healthcare services to offer specialist care over generalist care as it allowed professionals to provide better tailored and more appropriate rehabilitation. At a systemic level, increased specialist knowledge leads to a larger variety of skills and training, allowing people to access a wider variety of chronic neurological disorder rehabilitation services and therapies. *"At the moment I would just refer to the general physio department or the general OT [occupational therapist] but I don't know if they would be specialised enough, probably not" (page 791, McCartney 2011)*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Evidence downgraded due to findings being derived from themes describing availability of specialist knowledge at both individual healthcare professional and systemic levels)	Minor concerns (Evidence downgraded due to findings including studies exploring a particular rehabilitation intervention or service. Findings may not be broadly applicable.)	No/very minor concerns	MODERATE
Sub-theme B1.3: Limited capacity of services						
4 studies • Jervis Rademeyer 2022 (General qualitative inquiry, acquired spinal cord injury)	The capacity of healthcare services affects both the identification of rehabilitation needs and access to appropriate services. Factors such as lack of funding, lack of resources and lack of time in appointments prevented healthcare professionals from asking	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP	Moderate concerns (Evidence downgraded due to findings being derived from themes	Moderate concerns (Evidence downgraded due to findings being mainly derived from	No/very minor concerns	LOW

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
• Methley 2017 (General qualitative inquiry, progressive neurological disorder) • Odumuyiwa 2019 (General qualitative inquiry, acquired brain injury) • Woodward 2022 (General qualitative inquiry, progressive neurological disease)	questions about the broad spectrum of a person's rehabilitation needs and referring on to appropriate services. Conversely, factors such as extended opening hours or longer appointment times allowed more flexibility and access to rehabilitation services. It also gave healthcare professionals time to develop a rapport with people with CND and identify less obvious rehabilitation issues. *"If we open that can of worms and we've got nothing to support them with, are we actually doing them a favour? Yes, it's ignoring them [MH mental health] problems] in one sense, because you could actually take away all their boundaries and that concerns me with the lack of back up available" (page 10, Methley 2017)*	qualitative checklist)	describing diminished and enhanced service capacity)	studies exploring a particular rehabilitation intervention or service. Findings may not be broadly applicable.)		
Sub-theme B1.4: Meeting eligibility criteria						
3 studies • McCartney 2011 (General qualitative inquiry, acquired brain injury) • Methley 2017 (General qualitative inquiry, progressive neurological disease) • Treadgold 2019 (General qualitative inquiry, acquired brain injury)	Eligibility criteria can both facilitate and restrict access to appropriate rehabilitation services for people with chronic neurological disorders (for example, services refusing to take people with certain co-morbidities). Differing criteria across services can affect continuity of care between services as well as increase inequalities in rehabilitation access.	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	Moderate concerns (Evidence downgraded due to findings being mainly derived from studies exploring a particular rehabilitation intervention or service. Findings may not	Moderate concerns (Evidence downgraded as findings derived from 3 studies 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**
	"local services refusing to support patients with complex needs." (page 5, Treadgold 2019)			be broadly applicable.)		
Sub-theme B1.5: Presence of key contacts						
2 studies • Grose 2014 (General qualitative inquiry, progressive neurological disease) • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury)	Having a single point of contact can help people to access appropriate services by co-ordinating services and providing accurate information about eligibility for services and about their condition. The key contact did not have to be a rehabilitation professional but did need to have specialist knowledge of a person's condition and be informed about the local and national services that would be available to them. *No first-order quotes to support this theme.*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	No/very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	LOW

Table 6: GRADE-CERQual table for theme B2: Affordability

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 • Cheung 2022 (General qualitative inquiry, acquired spinal cord injury) • Jervis Rademeyer 2022 (General qualitative inquiry, acquired spinal cord injury)	The cost of a rehabilitation intervention is a big consideration when accessing rehabilitation services. Expensive therapies or equipment could be prohibitive if not covered by existing funding sources or healthcare insurance. *No first-order quotes to support this theme.*	No/minor concerns	No/very minor concerns	Moderate concerns (Evidence downgraded as findings being mainly derived from studies exploring a particular rehabilitation	Minor concerns (Evidence downgraded as findings derived from 3 studies with moderately 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
• Twigg 2021 (General qualitative inquiry, progressive neurological disease)				intervention or service. Findings may not be broadly applicable.)		

Table 7: GRADE-CERQual table for theme B3: Information and awareness

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 B3.1: Education for non-specialist healthcare professionals						
6 studies reported in 7 papers • Cheung 2022 (General qualitative inquiry, acquired spinal cord injury) • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • McCartney 2011 (General qualitative inquiry, acquired brain injury) • Methley 2017 (General qualitative inquiry, progressive neurological disease) • Norman 2020 (General qualitative inquiry, acquired brain injury) • Odumuyiwa 2019 (General qualitative inquiry, acquired brain injury)	Increasing chronic neurological disorder rehabilitation knowledge in generalist healthcare settings is important to improve both the identification of rehabilitation needs and access to appropriate ser-vices. Increasing education on symptoms and disease progression allowed professionals to better identify emerging rehabilitation needs, and judge when referral to more specialist services was needed. Education should also include what rehabilitation ser-vices are available in order for generalist healthcare professionals to have more confidence in how a referral could benefit people with chronic neurological disorders. *"That's probably where my knowledge isn't very good, certainly with primary brain tumours, I'm not sure what they could help with specifically. . .certainly I said like the OT [occupational*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	Moderate concerns (Evidence downgraded due to findings being derived from themes describing disorder	No/very minor concerns	No/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
- Woodward 2022 (General qualitative inquiry, progressive neurological disease)	*therapy] I'm not quite sure, I'm vague as to where OT stops and physio starts" (McCartney 2011, page 791)*					
Sub-theme B3.2: Education for people with chronic neurological disorders and family						
3 studies • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • McCartney 2011 (General qualitative inquiry, acquired brain injury) • Woodward 2022 (General qualitative inquiry, progressive neurological disease)	Educating people with chronic neurological disorders and their families is important to improve both the identification of rehabilitation needs and access to appropriate services. Information about disease pathology and symptom progression allowed people with chronic neurological disorders to better identify rehabilitation needs and report them to their primary healthcare professional to obtain an appropriate and timely referral. Knowledge of what rehabilitation services were available and how these could benefit people with chronic neurological disorders was also important in navigating rehabilitation services. *"No one sat us down and explained what the brain injury was or which part of the brain had been affected. No one discussed the long-term effects or what we might expect." (page 104, Holloway 2019)*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	Moderate concerns (Evidence downgraded due to findings being derived from themes describing disorder education and knowledge of healthcare systems)	Minor concerns (Evidence downgraded due to findings including studies exploring a particular rehabilitation intervention or service. Findings may not be broadly applicable.)	Minor concerns (Evidence downgraded as findings derived from 3 studies with moderately rich data)	LOW
Sub-theme B3.3: Understanding the importance of 'invisible' symptoms						
2 studies • Holloway 2019 (General qualitative inquiry [within	A lack of understanding about the hidden (or less easily recognisable) symptoms of chronic neurological disorders can affect both the identification of rehabilitation needs and	Moderate concerns (Evidence downgraded due to moderate	No/very minor concerns	Minor concerns (Evidence downgraded as findings solely derived from	Minor concerns (Evidence downgraded as findings derived from 2 studies	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
mixed-methods study], acquired brain injury) • Norman 2020 (General qualitative inquiry, acquired brain injury)	access to appropriate services. 'Invisible' symptoms can encompass cognitive and behavioural changes, which are often not understood by healthcare professionals without specialist knowledge of brain injuries. This leads to services being unable to provide appropriate services and support to people with chronic neurological disorders, and their families or carers. *"Mental health services […] told a brain injured client that they have capacity to deal with their own finances despite the client telling them 'I will spend all my money if I was to have a large sum of money. MHS [mental health services] proceeded to tell the client that they could help the client have capacity to manage their money." (page 2044, Norman 2020)*	concerns about methodological limitations as per CASP qualitative checklist)		studies exploring people with acquired brain injuries. Findings may not be broadly applicable.)	with moderately rich data)	
B3.4: Understanding roles of other professional services						
2 studies • McCartney 2011 (General qualitative inquiry, acquired brain injury) • Methley 2017 (General qualitative inquiry, progressive neurological disease)	When professionals have a poor understanding of the role of other professionals, this can prevent access to appropriate services. At best, it can lead to people being inappropriately referred to services that are unable to provide the rehabilitation they need. At worst, it could lead to people not receiving referrals at all as professionals assume referrals will be made by another service.	No/very minor concerns	No/very minor concerns	Moderate concerns (Evidence downgraded due to findings being mainly derived from studies exploring a particular rehabilitation intervention or service.	Moderate concerns (Evidence downgraded as 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**
	“One tends to hope if you’ve referred on to someone like an OT [occupational therapist], if they really felt someone needed a physio they would say but then maybe that’s just a cop out and I’m just hoping” (page 791, McCartney 2011)			Findings may not be broadly applicable.)		

Table 8: GRADE-CERQual table for theme B4: Attitudes and beliefs

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 B4.1: Focusing on physical injuries and impairments						
1 study reported in 2 papers • Norman 2020 (General qualitative inquiry, acquired brain injury) • Odumuyiwa 2019 (General qualitative inquiry, acquired brain injury)	Identification of rehabilitation needs can be delayed when healthcare professionals focus treatment exclusively on visible, physical injuries and impairments. This leads to cognitive and behavioural difficulties being overlooked which, in turn, can lead to long-term difficulties in accessing appropriate rehabilitation services. *“Everyone seems to focus on getting the person active again, getting them moving, getting their arms working, their legs walking, no one seems to focus on the cognitive health of the person who’s had the accident, or speech and language, as long as he is up and walking and everything you can see is in the right order, mm, that’s how it feels.” (page 170, Odumuyiwa 2019)*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	Minor concerns (Evidence downgraded as findings solely derived from studies about people with acquired brain injuries. Findings may not be broadly applicable.)	Moderate concerns (Evidence downgraded as findings derived from 1 study with 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**
Sub-theme B4.2: Pre-conceived ideas on appropriateness of rehabilitation						
3 studies • McCartney 2011 (General qualitative inquiry, acquired brain injury) • Methley 2017 (General qualitative inquiry, Progressive neurological disease) • Twigg 2021 (General qualitative inquiry, progressive neurological disease)	A barrier to accessing appropriate rehabilitation services is beliefs in the appropriateness of rehabilitation. Data from people with chronic neurological disorders, their carers, and rehabilitation professionals suggested that some healthcare professionals believe that people with chronic neurological disorders will not benefit from rehabilitation services for a variety of reasons, including a poor prognosis, being too unwell to participate or that their disability is not sufficiently severe to warrant rehabilitation. *"Well I think he is in decline I don't think rehab is the prime interest at the moment. Its just managing his symptoms, I think he's got a poor prognosis, the rehab aspect is limited" (page 791, McCartney 2011)*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Evidence downgraded due to findings being derived from themes describing multiple reasons for inappropriateness of rehabilitation)	Minor concerns (Evidence downgraded due to findings being derived from studies about a particular rehabilitation intervention or service. Findings may not be broadly applicable.)	Minor concerns (Evidence downgraded as findings derived from 3 studies with moderately rich data)	MODERATE
Sub-theme B4.3: The role of family and friends throughout rehabilitation						
4 studies • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • Odumuyiwa 2019 (General qualitative inquiry, acquire brain injury) • Preston 2012 (Grounded theory, progressive neurological disease)	Identification of rehabilitation needs and access to appropriate services is improved when family and friends are involved. They are often best placed to observe the physical and cognitive changes that might be experienced by a person with a chronic neurological disorder and this understanding can better inform rehabilitation assessments. Family and friends can also enable access to appropriate services	Serious concerns (Evidence downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Evidence downgraded due to findings being derived from themes describing support for people with CND and support of family members of	No/very minor concerns	Minor concerns (Evidence downgraded as findings derived from 4 studies with moderately 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
• Twigg 2021 (General qualitative inquiry, progressive neurological disease)	by advocating for referrals to certain services or interventions. *“One of the resources that I found that was really lacking in my care was that, I got a very close family and my family members, knew an awful lot about my personality, and about my interests before the injury, and lots of things like that and urm I didn’t feel that…the immediate sort of medical services drew on that support they almost tended to exclude my family members from rehabilitation or meetings and things like that and I think that, they really could have really learnt a lot about the way that my interest have formed, and the way that I was involved in my family to a greater degree.” (page 170, Odumuyiwa 2019)*		people with CND)			

Table 9: GRADE-CERQual table for theme B5: Organisation of 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 B5.1: Adequate follow-up and signposting						
3 studies reported in 4 papers • Grose 2014 (General qualitative inquiry, progressive neurological disease)	Poor follow-up procedures at discharge from services is a barrier to appropriate chronic neurological disorder rehabilitation. A lack of signposting to resources that could increase a person’s knowledge of chronic neurological disorder	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP	No/very minor concerns	No/very minor concerns	No/very minor concerns	HIGH

<table>
<tr><th rowspan="2">Study information</th><th rowspan="2">Description of theme or finding</th><th colspan="5">CERQual Quality assessment</th></tr>
<tr><th>Methodological limitations</th><th>Coherence of findings</th><th>Relevance of evidence</th><th>Adequacy of data</th><th>Overall confidence</th></tr>
<tr><td>• McCartney 2011 (General qualitative inquiry, acquired brain injury)
• Norman 2020 (General qualitative inquiry, acquired brain injury)
• Odumuyiwa 2019 (General qualitative inquiry, acquired brain injury)</td><td>rehabilitation also hinders access to appropriate services. Suggestions to improve this include more routine follow-ups post-discharge and a wider focus of longer-term rehabilitation and support for chronic neurological disorders within the community setting.

<i>“I think once you’ve come out of their office and you’ve been diagnosed they don’t want to know, you hit a brick wall, they’ve done their job, that’s your condition and that’s it, you’re back to your GP [general practitioner] and your GP’s got 2000 odd patients and that’s it.” (page 5, Grose 2014)</i></td><td>qualitative checklist)</td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="7">Sub-theme B5.2: Auxiliary services</td></tr>
<tr><td>3 studies
• Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury)
• Methley 2017 (General qualitative inquiry, progressive neurological disease)
• Odumuyiwa 2019 (General qualitative inquiry, acquired brain injury)</td><td>Access to appropriate services should include referral or signposting to auxiliary services such as specialist legal practitioners.

<i>“I have worked with solicitors who specialise in working with clients with catastrophic injuries including brain injuries. They have been instrumental in instructing appropriate experts and appropriate brain injury case managers.” (page 169, Odumuyiwa 2019)</i></td><td>Moderate concerns
(Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)</td><td>No/very minor concerns</td><td>Serious concerns
(Evidence downgraded due to findings being derived from themes about non-rehabilitation services. Findings may not be broadly applicable.)</td><td>Moderate concerns
(Evidence downgraded as findings derived from 3 studies without rich data)</td><td>VERY LOW</td></tr>
<tr><td colspan="7">Sub-theme B5.3: Communication and coordination</td></tr>
<tr><td>4 studies</td><td>Both identification of rehabilitation needs and access to appropriate services are adversely affected when</td><td>Minor concerns
(Evidence downgraded due to</td><td>No/very minor concerns</td><td>Minor concerns
(Evidence downgraded</td><td>Minor concerns
(Evidence downgraded as</td><td>MODERATE</td></tr>
</table>

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
- Grose 2014 (General qualitative inquiry, progressive neurological disease) - Jervis Rademeyer 2022 (General qualitative inquiry, acquired spinal cord injury) - McCartney 2011 (General qualitative inquiry, acquired brain injury) - Treadgold 2019 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury)	there is poor communication and co-ordination between services involved in rehabilitation for chronic neurological disorders, particularly if there is a cross over between private and public sector. It can lead to professionals in 1 service not having correct or current information on someone's chronic neurological disorder status or rehabilitation plan. Suggestions to improve this factor included multidisciplinary team meetings and electronic patient notes. *No first-order quotes to support this theme.*	minor concerns about methodological limitations as per CASP qualitative checklist)		due to findings being derived from studies about a particular rehabilitation intervention or service. Findings may not be broadly applicable.)	findings derived from 4 studies without rich data)	
Sub-theme B5.4: Existence of an official referral pathway						
4 studies - Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) - Jervis Rademeyer 2022 (General qualitative inquiry, acquired spinal cord injury) - Treadgold 2019 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury) - Woodward 2022 (General qualitative inquiry,	A lack of an official referral pathway is a barrier to accessing appropriate services. Data from people with chronic neurological disorders, their carers, and rehabilitation professionals suggested that the creation of official referral pathways would embed next steps for people with chronic neurological disorders once a rehabilitation need has been identified. This would in turn reduce the sense among people and their families of having to fight to navigate a complex healthcare system. *"So if I looked at other things, I'd say 'Oh this is the process, this is my red flag, I need to refer on here' … so I*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	Moderate concerns (Evidence downgraded due to findings being mainly derived from studies about a particular rehabilitation intervention or service. Findings may not be broadly applicable.)	Minor concerns (Evidence downgraded as findings derived from 4 studies without 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
progressive neurological disease)	*know I work by guidance for lots of things … with MS [multiple sclerosis], it's slightly different." (page 84, Woodward 2022)*					
Sub-theme B5.5: Waiting times						
2 studies • McCartney 2011 (General qualitative inquiry, acquired brain injury) • Methley 2017 (General qualitative inquiry, progressive neurological disease)	Long waiting times for referrals are a barrier to accessing appropriate rehabilitation services. Long waiting times can mean that rehabilitation needs have changed by the time of the initial appointment. It can also lead to generalist healthcare professionals having to choose between placing people with chronic neurological disorders on waiting lists for specialist services or referring them to more general services that can see them sooner. *"By the time you get to the counsellor the heat has gone off it because its 12 months later, 18 months. Nothing is instantaneous. You don't get the support and the help when you need it. I had to wait 18 months." (page 15, Methley 2017)*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	Moderate concerns (Evidence downgraded due to findings being mainly derived from studies about a particular rehabilitation intervention or service. Findings may not be broadly applicable.)	Moderate concerns (Evidence downgraded as findings derived from 2 studies without rich data)	MODERATE

Table 10: GRADE-CERQual table for theme B6: Early identification of needs

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
4 studies • Cheung 2022 (General qualitative inquiry, acquired spinal cord injury)	Identifying people's potential needs early in their rehabilitation was an important factor for both identification of rehabilitation needs and access to	Minor concerns (Evidence downgraded due to moderate	No/very minor concerns	No/very minor concerns	Minor concerns (Evidence downgraded as findings derived	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
• Grose 2014 (General qualitative inquiry, progressive neurological disease) • Preston 2012 (Grounded theory, progressive neurological disease) • Woodward 2022 (General qualitative inquiry, progressive neurological disease)	appropriate services. Evidence from people with chronic neurological disorders, their carers and rehabilitation professionals suggests that early identification would increase referrals into services before rehabilitation needs became more serious. This early referral would allow people access to therapies that could slow symptom progression or properly plan for inevitable symptom presentation. It would also give them time to become comfortable with equipment (for example, such as mobility aids or home adaptations) before they become a necessity. *"Sometimes people with MS [multiple sclerosis] may not be referred until they're having difficulties with transfers or other amenities a bit further down the line. I think there's potential for us to be involved when people are still at work and very much more active" (page 267, Preston 2012)*	concerns about methodological limitations as per CASP qualitative checklist)			from 4 studies with moderately rich data)	

Appendix G Economic evidence study selection

Study selection for: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

No economic searches were undertaken for this qualitative review.

Appendix H Economic evidence tables

Economic evidence tables for review question: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

No economic searches were undertaken for this qualitative review.

Appendix I Economic model

Economic model for review question: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

No economic analysis was conducted for this review question.

Appendix J Excluded studies

Excluded studies for review question: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

Excluded qualitative studies

Table 11: Excluded studies and reasons for their exclusion

Study	Reason for exclusion
Abrahamson, Vanessa, Jensen, Jan, Springett, Kate et al. (2017) Experiences of patients with traumatic brain injury and their carers during transition from in-patient rehabilitation to the community: a qualitative study. Disability and rehabilitation 39(17): 1683-1694	- Phenomenon of interest Findings relate to ongoing treatment and general support in the community, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Abril-Jimenez, P., Merino-Barbancho, B., Vera-Munoz, C. et al. (2021) Co-designing a remote rehabilitation tool for Parkinson's disease: exploratory values and challenges. BMC Neurology 21(1): 491	- Phenomenon of interest Findings relate to planning, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Ahmad, M., Genuis, S.K., Luth, W. et al. (2022) Amyotrophic lateral sclerosis (ALS) health charities are central to ALS care: perspectives of Canadians affected by ALS. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration	- Country Study conducted in Canada with adult participants.
Al Dandan, Hawra B, Galvin, Rose, McClurg, Doreen et al. (2022) Management strategies for neurogenic lower urinary tract dysfunction: a qualitative study of the experiences of people with multiple sclerosis and healthcare professionals. Disability and rehabilitation 44(15): 3805-3815	- Country Study conducted in Ireland.
Albrecht, J.S., O'Hara, L.M., Moser, K.A. et al. (2017) Perception of Barriers to the Diagnosis and Receipt of Treatment for Neuropsychiatric Disturbances After Traumatic Brain Injury. Archives of Physical Medicine and Rehabilitation 98(12): 2548-2552	- Country Study conducted in the US.
Alhasani, R., Radman, D., Auger, C. et al. (2021) Clinicians and individuals with acquired brain injury perspectives about factors that influence mobility: creating a core set of mobility domains among individuals with acquired brain injury. Annals of Medicine 53(1): 2365-2379	- Phenomenon of interest Findings relate to assessment and planning, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Ando, Hikari, Ashcroft-Kelso, Helen, Halhead, Rob et al. (2021) Experience of telehealth in people with motor neurone disease using noninvasive ventilation. Disability and rehabilitation. Assistive technology 16(5): 490-496	- Phenomenon of interest Findings relate to experiences of using a weekly telemonitoring service, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Aoun, Samar M, Cafarella, Paul A, Hogden, Anne et al. (2021) Why and how the work of Motor Neurone Disease Associations matters	- Phenomenon of interest Findings relate to experiences of bereavement support, and not to the identification of people

Study	Reason for exclusion
before and during bereavement: a consumer perspective. Palliative care and social practice 15: 26323524211009537	with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Armstrong, Elizabeth, Coffin, Juli, Hersh, Deborah et al. (2021) "You felt like a prisoner in your own self, trapped": the experiences of Aboriginal people with acquired communication disorders. Disability and rehabilitation 43(13): 1903-1916	- Phenomenon of interest Findings relate to experiences of impairment and delivery of care, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Aukema, E.J., Last, B.F., Schouten-Van Meeteren, A.Y.N. et al. (2011) Explorative study on the aftercare of pediatric brain tumor survivors: A parents' perspective. Supportive Care in Cancer 19(10): 1637-1646	- Study design Limited to quantitative data analysis and reporting.
Bahn, Susanne and Giles, Margaret (2012) Evaluation of the Neurodegenerative Conditions Coordinated Care Program (NCCCP) in Western Australia: barriers to better service provision. Evaluation and program planning 35(1): 40-6	- Country Study conducted in Australia with adult participants.
Bakker, M., Creemers, H., Schipper, K. et al. (2015) Need and value of case management in multidisciplinary ALS care: A qualitative study on the perspectives of patients, spousal caregivers and professionals. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration 16(34): 180-186	- Country Study conducted in the Netherlands.
Bannon, S.M., Fishbein, N.S., Lovette, B.C. et al. (2022) A Meta-Synthesis of Individual, Interpersonal, and Systemic Factors Impacting Resilience After Traumatic Brain Injury. Rehabilitation Psychology	- Phenomenon of interest Findings relate to barriers and facilitators to mental resilience for persons with traumatic brain injury, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Beaudet, Line and Ducharme, Francine (2013) Living with moderate-stage Parkinson disease: intervention needs and preferences of elderly couples. The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses 45(2): 88-95	- Phenomenon of interest Findings relate to participants views on support in general, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Bentley, B. and O'Connor, M. (2016) The End-of-Life Experiences of People with Motor Neuron Disease: Family Carers' Perspectives. Journal of Palliative Medicine 19(8): 857-862	- Phenomenon of interest Findings relate to end-of-life care in general, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Bernard, Sylvia and et, al (2010) Integrated services for people with long-term neurological conditions: evaluation of the impact of the national service framework: summary.: 4p	- Other protocol criteria Duplicate paper.
Bernard, Sylvia and et, al (2010) Integrated services for people with long-term neurological conditions: evaluation of the impact of the national service framework.: 179p	- Phenomenon of interest Findings relate to the delivery of integrated care from different frameworks nationally, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.

Study	Reason for exclusion
Bishop, Malachy, Rumrill, Stuart, McDaniels, Bradley et al. (2020) Information and resources important to the quality of life of people living with multiple sclerosis. Australian Journal of Rehabilitation Counselling 26(2): 92-104	- Country Study conducted in the US.
Blank, Lindsay, Baird, Wendy, Reuber, Markus et al. (2014) Patient perceptions of the referral of older adults to an epilepsy clinic: Do patients and professionals agree who should be referred to a specialist?. Epilepsy & Behavior 34: 120-123	- Population Epilepsy not leading to spinal cord injury or acquired brain injury. Not relevant according to protocol population criteria.
Bogart, Kathleen R, Frandrup, Erika, Locke, Taylor et al. (2017) "Rare place where I feel normal": Perceptions of a social support conference among parents of and people with Moebius syndrome. Research in developmental disabilities 64: 143-151	- Phenomenon of interest Findings relate to the peer support gained by attending a condition specific event, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Borrett, S. and Gould, L.J. (2021) Mental capacity assessment with people with aphasia: understanding the role of the speech and language therapist. Aphasiology 35(11): 1463-1481	- Phenomenon of interest Findings relate to speech and language therapist experience of delivering the mental capacity assessment, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Botchway, Edith N, Knight, Sarah, Muscara, Frank et al. (2022) Rehabilitation models of care for children and youth living with traumatic brain and/or spinal cord injuries: A focus on family-centred care, psychosocial wellbeing, and transitions. Neuropsychological rehabilitation 32(4): 537-559	- Phenomenon of interest Findings relate to the evaluation of family centred models of care, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Braaf, Sandra C, Lennox, Alyse, Nunn, Andrew et al. (2018) Experiences of hospital readmission and receiving formal carer services following spinal cord injury: a qualitative study to identify needs. Disability and rehabilitation 40(16): 1893-1899	- Phenomenon of interest Findings relate to provision care for activities of daily living and hospital services, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Bragge, Peter, Wright, Breanna, Grundy, Emily et al. (2022) What Happens Next? Traumatic Brain Injury in the Community. The Journal of head trauma rehabilitation	- Other protocol criteria Paper does not report sufficient methodological detail (such as research question, sampling, data collection and data analysis) to evaluate risk of bias/ study quality.
Brucker, B.M., Nitti, V.W., Kalra, S. et al. (2017) Barriers experienced by patients with multiple sclerosis in seeking care for lower urinary tract symptoms. Neurourology and Urodynamics 36(4): 1208-1213	- Country Study conducted in the US.
Campbell, E., Coulter, E., Mattison, P. et al. (2017) Access, delivery and perceived efficacy of physiotherapy and use of complementary and alternative therapies by people with progressive multiple sclerosis in the United Kingdom: An online survey. Multiple Sclerosis and Related Disorders 12: 64-69	- Study design Limited to quantitative data analysis and reporting.

Study	Reason for exclusion
Cappellato, V., Bosco, N., Chio, A. et al. (2016) Curable or treatable? The implications of different definitions of illness when treating patients suffering from amyotrophic lateral sclerosis. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration 17(12): 15-20	- Country Study conducted in Italy.
Carroll, Louise M, Morris, Meg E, O'Connor, William T et al. (2022) Community aquatic therapy for Parkinson's disease: an international qualitative study. Disability and rehabilitation 44(16): 4379-4388	- Phenomenon of interest Findings relate to experience of participating in community aquatic therapy, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Chou, K.L., Zamudio, J., Schmidt, P. et al. (2011) Hospitalization in Parkinson disease: A survey of National Parkinson Foundation Centers. Parkinsonism and Related Disorders 17(6): 440-445	- Country Study conducted in the US using healthcare professionals from Australia, Canada, the UK, Germany, Israel, the Netherlands, Singapore, Taiwan, and the US. Proportions not reported. Results not presented separately for target countries.
Christie, L., Egan, C., Wyborn, J. et al. (2021) Evaluating client experience of rehabilitation following acquired brain injury: a cross-sectional study. Brain Injury 35(2): 215-225	- Phenomenon of interest Findings relate to assessment, planning, and delivery of rehabilitation, and not the identification of people with rehabilitation needs arising from chronic neurological disorders.
Chu, Yi, Brown, Pat, Harniss, Mark et al. (2014) Cognitive support technologies for people with TBI: current usage and challenges experienced. Disability and rehabilitation. Assistive technology 9(4): 279-85	- Country Study conducted in the US.
Chui, Adora, Dainty, Katie N, Kirsh, Bonnie et al. (2022) Hope for "Continued Vitality": Qualitative Study of Adults With Traumatic Brain Injury and Low Mood on Their Rehabilitation. Frontiers in rehabilitation sciences 3: 848575	- Country Study conducted in Canada with adult participants.
Coady, V., Warren, N., Bilkhu, N. et al. (2019) Preferences for rural specialist health care in the treatment of Parkinson's disease: Exploring the role of community-based nursing specialists. Australian Journal of Primary Health 25(1): 49-53	- Phenomenon of interest Findings relate to delivery, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Cocks, E., Bulsara, C., O'Callaghan, A. et al. (2014) Exploring the experiences of people with the dual diagnosis of acquired brain injury and mental illness. Brain Injury 28(4): 414-421	- Phenomenon of interest Findings relate to experiences of injury and delivery of services, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Cogley, Clodagh, D'Alton, Paul, Nolan, Maeve et al. (2021) "You were lying in limbo and you knew nothing": a thematic analysis of the information needs of spinal cord injured patients and family members in acute care. Disability and rehabilitation: 1-11	- Country Study conducted in Ireland.
Collins, Katrina (2017) Developing a community based service model for disability: Listening to the needs of all beneficiaries and providers.	- Phenomenon of interest Findings relate to delivery of rehabilitation, and not the identification of people with rehabilitation

Study	Reason for exclusion
Journal of pediatric rehabilitation medicine 10(34): 227-230	needs arising from chronic neurological disorders or referrals to appropriate services.
Conneeley, A.L. (2012) Transitions and brain injury: A qualitative study exploring the journey of people with traumatic brain injury. Brain Impairment 13(1): 72-84	- Phenomenon of interest Findings relate to experiences of impairment and relationships with others, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Conti, A., Dimonte, V., Rizzi, A. et al. (2020) Barriers and facilitators of education provided during rehabilitation of people with spinal cord injuries: A qualitative description. PLoS ONE 15(10october): e0240600	- Phenomenon of interest Findings relate to provision of rehabilitation care, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Conti, Alessio, Garrino, Lorenza, Montanari, Paola et al. (2016) Informal caregivers' needs on discharge from the spinal cord unit: analysis of perceptions and lived experiences. Disability and rehabilitation 38(2): 159-67	- Phenomenon of interest Findings relate to the needs and experiences of carers around the transition from Spinal Cord Injury Unit to the home/community, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Copley, A.; McAllister, L.; Wilson, L. (2013) We finally learnt to demand: Consumers' access to rehabilitation following traumatic brain injury. Brain Impairment 14(3): 436-449	- Country Study conducted in Australia with adult participants.
Cornwell, P., Dicks, B., Fleming, J. et al. (2012) Care and support needs of patients and carers early post-discharge following treatment for non-malignant brain tumour: Establishing a new reality. Supportive Care in Cancer 20(10): 2595-2610	- Phenomenon of interest Findings relate to general support after discharge, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Cowan, Christine K; Pierson, Jane M; Leggat, Sandra G (2020) Psychosocial aspects of the lived experience of multiple sclerosis: personal perspectives. Disability and rehabilitation 42(3): 349-359	- Phenomenon of interest Findings relate to the lived experience of multiple sclerosis and only the first 3 themes (fatigue, independence and dependence and loss) were discussed with regards to provision and perception of care, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Croonen, E.A., Harmsen, M., Van der Burgt, I. et al. (2016) Perceived motor problems in daily life: Focus group interviews with people with Noonan syndrome and their relatives. American Journal of Medical Genetics, Part A 170(9): 2349-2356	- Phenomenon of interest Findings relate to experience of impairment, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Cup, Edith H C, Pieterse, Allan J, Hendricks, Henk T et al. (2011) Implementation of multidisciplinary advice to allied health care professionals regarding the management of their patients with neuromuscular diseases. Disability and rehabilitation 33(9): 787-95	- Study design Limited to quantitative data analysis and reporting.
Cuperus, P., de Kok, D., de Aguiar, V. et al. (2022) Understanding User Needs for Digital Aphasia Therapy: Experiences and Preferences of Speech and Language Therapists. Aphasiology	- Study design Limited to quantitative data analysis and reporting.

Study	Reason for exclusion
Daker-White, Gavin, Ealing, John, Greenfield, Julie et al. (2013) Trouble with ataxia: A longitudinal qualitative study of the diagnosis and medical management of a group of rare, progressive neurological conditions. SAGE open medicine 1: 2050312113505560	- Phenomenon of interest Findings relate to diagnosis and ongoing treatment, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Daker-White, Gavin; Greenfield, Julie; Ealing, John (2013) "Six sessions is a drop in the ocean": an exploratory study of neurological physiotherapy in idiopathic and inherited ataxias. Physiotherapy 99(4): 335-40	- Phenomenon of interest Findings relate to experiences of physiotherapy, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Dawes, Kate, Carlino, Ashley, van den Berg, Maayken et al. (2022) Life altering effects on children when a family member has an acquired brain injury; a qualitative exploration of child and family perceptions. Disability and Rehabilitation: An International, Multidisciplinary Journal 44(2): 282-290	- Phenomenon of interest Findings relate to identification of support for family members/carers, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Degeneffe, Charles Edmund and Bursnall, Samantha (2015) Quality of professional services following traumatic brain injury: adult sibling perspectives. Social work 60(1): 19-27	- Country Study conducted in the US.
Devlieger, Patrick and Balcazar, Fabricio (2010) 'Bringing them back on the right track': perceptions of medical staff on the rehabilitation of individuals with violently acquired spinal cord injuries. Disability and rehabilitation 32(6): 444-51	- Country Study conducted in the US.
Downing, Marina G, Hicks, Amelia J, Braaf, Sandy et al. (2021) "It's been a long hard road": challenges faced in the first three years following traumatic brain injury. Disability and rehabilitation: 1-10	- Country Study conducted in Australia with adult participants.
Duits, A., van der Heijden, C., van het Hoofd, M. et al. (2020) Psychosocial needs of patients and spouses justify a position of psychosocial health professionals in the multidisciplinary care for Parkinson's disease. Clinical Parkinsonism and Related Disorders 3: 100064	- Phenomenon of interest Findings relate to the ability of people living with Parkinson's to ask for support and the availability of the appropriate professional, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
El-Wahsh, Sarah, Balandin, Susan, Bogaardt, Hans et al. (2022) Managing communication changes in persons with multiple sclerosis: Findings from qualitative focus groups. International journal of language & communication disorders 57(3): 680-694	- Country Study conducted in Australia with adult participants.
Fadyl, J.K.; McPherson, K.M.; Kayes, N.M. (2011) Perspectives on quality of care for people who experience disability. BMJ Quality and Safety 20(1): 87-95	- Phenomenon of interest Findings relate to experiences of care in general and person-centred care, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
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 concerns about diagnosis and psychological therapy, and what happens after diagnosis, and not the identification of people

Study	Reason for exclusion
	with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
FAKOLADE, Afolasade; FINLAYSON, Marcia; PLOW, Matthew (2017) Using telerehabilitation to support people with multiple sclerosis: a qualitative analysis of interactions, processes, and issues across three interventions. British Journal of Occupational Therapy 80(4): 259-268	- Phenomenon of interest Findings relate to effectiveness/positive impact of the intervention, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Fleming, Jennifer, Sampson, Jennifer, Cornwell, Petrea et al. (2012) Brain injury rehabilitation: the lived experience of inpatients and their family caregivers. Scandinavian journal of occupational therapy 19(2): 184-93	- Phenomenon of interest Findings relate to experiences with the inpatient rehabilitation environment and physical support needs within it, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Foley, Geraldine; Timonen, Virpi; Hardiman, Orla (2012) Patients' perceptions of services and preferences for care in amyotrophic lateral sclerosis: a review. Amyotrophic lateral sclerosis : official publication of the World Federation of Neurology Research Group on Motor Neuron Diseases 13(1): 11-24	- Phenomenon of interest Findings relate to delivery, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Foster, Abby M, Worrall, Linda E, Rose, Miranda L et al. (2016) 'I do the best I can': an in-depth exploration of the aphasia management pathway in the acute hospital setting. Disability and rehabilitation 38(18): 1765-79	- Population Unclear population. Healthcare professionals working with aphasia due to stroke (no mention of adults or paediatric services).
Foster, M., Legg, M., Hummell, E. et al. (2020) Right people, right time? a qualitative study of service access experiences of adults with acquired brain injury following discharge from inpatient rehabilitation. Brain Impairment	- Country Study conducted in Australia with adult participants.
Fox, S., Cashell, A., Kernohan, W.G. et al. (2016) Interviews with Irish healthcare workers from different disciplines about palliative care for people with Parkinson's disease: A definite role but uncertainty around terminology and timing. BMC Palliative Care 15(1): 15	- Phenomenon of interest Findings relate to palliative care as end-of-life care and management, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Galushko, M., Golla, H., Strupp, J. et al. (2014) Unmet needs of patients feeling severely affected by multiple sclerosis in Germany: A qualitative study. Journal of Palliative Medicine 17(3): 274-281	- Phenomenon of interest Findings relate to people with chronic neurological disorders views on the care and support they need (in general), and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Garrino, L., Curto, N., Decorte, R. et al. (2011) Towards personalized care for persons with spinal cord injury: A study on patients' perceptions. Journal of Spinal Cord Medicine 34(1): 67-75	- Phenomenon of interest Findings relate to experience of spinal cord injury rehabilitation, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Geraldo, Andreia, Dores, Artemisa R, Carvalho, Irene P et al. (2022) At-distance neurocognitive rehabilitation during COVID-19 pandemic: A first	- Phenomenon of interest Findings relate to delivery of remote care, and not the identification of people with rehabilitation

Study	Reason for exclusion
glance of patients' perspectives about the process and an online platform. Applied neuropsychology. Adult: 1-10	needs arising from chronic neurological disorders or referrals to appropriate services.
Ghaidar, Donya, Sippel, Anna, Riemann-Lorenz, Karin et al. (2022) Experiences of persons with multiple sclerosis with rehabilitation-a qualitative interview study. BMC health services research 22(1): 770	- Country Study conducted in Germany.
Giovannetti, A.M., Pietrolongo, E., Borreani, C. et al. (2020) Conversion to secondary progressive multiple sclerosis: Multistakeholder experiences and needs in Italy. PLoS ONE 15(2): e0228587	- Phenomenon of interest Findings relate to experiences of conversion, impairments and care and support in general, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Girardi, G., Farnese, M.L., Scarponi, F. et al. (2021) User-centered practices in the eyes of informal caregivers of in-patients with severe acquired brain injury: needs, caring experience, and satisfaction. Brain Injury 35(11): 1402-1412	- Study design Limited to quantitative data analysis and reporting.
Glintborg, C. and Hansen, T.G.B. (2016) Bio-psycho-social effects of a coordinated neurorehabilitation programme: A naturalistic mixed methods study. NeuroRehabilitation 38(2): 99-113	- Country Study conducted in Denmark.
Goel, Ritu, Santurri, Laura, Fruth, Stacie et al. (2022) Telerehabilitation Use With Spinal Cord Injury: Occupational Therapists' Perspective. The American journal of occupational therapy : official publication of the American Occupational Therapy Association 76(2)	- Country Study conducted in the US.
Goicochea Briceno, H., Higueras Hernandez, Y., Fontan Vela, M. et al. (2021) Focus group on the experience of patients and family members in the multiple sclerosis unit of a tertiary hospital. Revista Cientifica de la Sociedad Espanola de Enfermeria Neurologica 54: 20-29	- Phenomenon of interest Findings relate to diagnosis and ongoing treatment, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Golla, H., Galushko, M., Pfaff, H. et al. (2012) Unmet needs of severely affected multiple sclerosis patients: The health professionals' view. Palliative Medicine 26(2): 139-151	- Phenomenon of interest Findings relate to unmet daily living needs, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Goodridge, Donna, Rogers, Marla, Klassen, Laura et al. (2015) Access to health and support services: perspectives of people living with a long-term traumatic spinal cord injury in rural and urban areas. Disability and rehabilitation 37(16): 1401-10	- Country Study conducted in Canada with adult participants.
Graff, Heidi J, Christensen, Ulla, Poulsen, Ingrid et al. (2018) Patient perspectives on navigating the field of traumatic brain injury rehabilitation: a qualitative thematic analysis. Disability and rehabilitation 40(8): 926-934	- Country Study conducted in Denmark.
Grayson, Lynn, Brady, Marian C, Togher, Leanne et al. (2020) A survey of cognitive-communication difficulties following TBI: are families	- Phenomenon of interest Findings relate to family training and support needs after traumatic brain injury, and not to the

Study	Reason for exclusion
receiving the training and support they need?. International journal of language & communication disorders 55(5): 712-723	identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Grieve, Sharon; Adams, Jo; McCabe, Candida (2016) 'What I Really Needed Was the Truth'. Exploring the Information Needs of People with Complex Regional Pain Syndrome. Musculoskeletal care 14(1): 15-25	- Phenomenon of interest Findings relate to access to information and expertise for complex regional pain syndrome, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Hamann, T., Lemke, S., Kropp, P. et al. (2021) Optimizing telemedical care in neurological outpatients by characterizing the patients' needs in the physician-patient relationship-content analysis of guideline-based interviews. BMC Neurology 21(1): 291	- Phenomenon of interest Findings relate to views on telemedicine in general, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Handberg, Charlotte and Werlauff, Ulla (2022) Cross-sectorial collaboration on policy-driven rehabilitation care models for persons with neuromuscular diseases: reflections and behavior of community-based health professionals. BMC health services research 22(1): 1168	- Country Study conducted in Denmark.
Harrington, R.; Foster, M.; Fleming, J. (2015) Experiences of pathways, outcomes and choice after severe traumatic brain injury under no-fault versus fault-based motor accident insurance. Brain Injury 29(1314): 1561-1571	- Country Study conducted in Australia with adult participants.
Hasson, F., Kernohan, W.G., McLaughlin, M. et al. (2010) An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. Palliative Medicine 24(7): 731-736	- Phenomenon of interest Findings relate to former carers needs for palliative care as a form of respite, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Hayward, Kate, Mateen, Bilal A, Playford, E. Diane et al. (2019) Developing vocational rehabilitation services for people with long-term neurological conditions: Identifying facilitators and barriers to service provision. The British Journal of Occupational Therapy 82(6): 337-347	- Phenomenon of interest Findings relate to delivery of vocational rehabilitation, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Helland, Caroline Bruun; Holmoy, Trygve; Gulbrandsen, Pal (2015) Barriers and Facilitators Related to Rehabilitation Stays in Multiple Sclerosis: A Qualitative Study. International journal of MS care 17(3): 122-9	- Country Study conducted in Norway.
Hellqvist, Carina and Bertero, Carina (2015) Support supplied by Parkinson's disease specialist nurses to Parkinson's disease patients and their spouses. Applied nursing research : ANR 28(2): 86-91	- Phenomenon of interest Findings relate to experiences of general care and support provided, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Hemmings, Laura and Soundy, Andrew (2020) Experiences of physiotherapy in mental health: an interpretative phenomenological analysis of barriers and facilitators to care. Physiotherapy 109: 94-101	- Phenomenon of interest Findings relate to motivations for engagement with physiotherapy, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.

Study	Reason for exclusion
Hersh, Deborah; Armstrong, Elizabeth; Bourke, Noni (2015) A narrative analysis of a speech pathologist's work with Indigenous Australians with acquired communication disorders. Disability and rehabilitation 37(1): 33-40	- Phenomenon of interest Findings relate to the process of adapting rehabilitation services for Indigenous Australians, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Hilton, R., Leenhouts, S., Webster, J. et al. (2014) Information, support and training needs of relatives of people with aphasia: Evidence from the literature. Aphasiology 28(7): 797-822	- Phenomenon of interest Findings relate to the information and training needs of informal carers, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Hocaloski, Shea, Elliott, Stacy, Hodge, Karen et al. (2017) Perinatal Care for Women with Spinal Cord Injuries: A Collaborative Workshop for Consensus on Care in Canada. Topics in spinal cord injury rehabilitation 23(4): 386-396	- Phenomenon of interest Findings relate to experiences of perinatal care, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Holloway, M.; Orr, D.; Clark-Wilson, J. (2019) Experiences of challenges and support among family members of people with acquired brain injury: a qualitative study in the UK. Brain Injury 33(4): 401-411	- Phenomenon of interest Findings relate to ongoing treatment and support in general, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Holmes, J.A., Logan, P., Morris, R. et al. (2020) Factors affecting the delivery of complex rehabilitation interventions in research with neurologically impaired adults: a systematic review. Systematic Reviews 9(1): 268	- Phenomenon of interest Findings relate to difficulties in implementing interventions as part of research programmes, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Hopkins, Jan and Irvine, Fiona (2012) Qualitative insights into the role and practice of epilepsy specialist nurses in England: A focus group study. Journal of Advanced Nursing 68(11): 2443-2453	- Phenomenon of interest Findings relate to the role and service delivery of the epilepsy specialist nurses, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Hunter, A., Marck, C.H., Butler, E. et al. (2021) Improving the detection and treatment of depression in Australians with multiple sclerosis: A qualitative analysis. Multiple Sclerosis and Related Disorders 56: 103290	- Country Study conducted in Australia with adult participants.
Hunter, H., Lovegrove, C., Haas, B. et al. (2019) Experiences of people with Parkinson's disease and their views on physical activity interventions: A qualitative systematic review. JBI Database of Systematic Reviews and Implementation Reports 17(4): 548-613	- Country Systematic review with 5/19 of the included studies conducted in the UK, 3/19 in Canada, 2/19 in Australia, 1/19 in New Zealand, 4/19 in the US, 2/19 in Sweden, and 2/19 in Jordan. UK, Canadian, Australian, and New Zealand studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Hutchinson, Karen, Herkes, Geoffrey, Shih, Patti et al. (2020) Identification and referral of patients with refractory epilepsy from the primary to the tertiary care interface in New South Wales, Australia. Epilepsy & Behavior 111	- Population Refractory epilepsy not leading to spinal cord injury or acquired brain injury. Not relevant according to protocol population criteria.

Study	Reason for exclusion
Jackson, Katherine, Hamilton, Sharon, Jones, Susan et al. (2019) Patient reported experiences of using community rehabilitation and/or support services whilst living with a long-term neurological condition: A qualitative systematic review and meta-aggregation. Disability and Rehabilitation: An International, Multidisciplinary Journal 41(23): 2731-2749	- Other protocol criteria Paper does not report sufficient methodological detail (such as research question, sampling, data collection and data analysis) to evaluate risk of bias/ study quality.
James, Natalie, Power, Emma, Hogden, Anne et al. (2019) Patients' perspectives of multidisciplinary home-based e-Health service delivery for motor neurone disease. Disability and rehabilitation. Assistive technology 14(7): 737-743	- Phenomenon of interest Findings relate to experiences of motor neurone disease healthcare in general, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
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	- Phenomenon of interest Findings relate to experiences of injury and the delivery of care, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Jeyaraj, J.A., Clendenning, A., Bellemare-Lapierre, V. et al. (2013) Clinicians' perceptions of factors contributing to complexity and intensity of care of outpatients with traumatic brain injury. Brain Injury 27(12): 1338-1347	- Country Study conducted in Canada with professionals working in adult healthcare services.
Jeyathevan, G., Cameron, J.I., Craven, B.C. et al. (2019) Identifying required skills to enhance family caregiver competency in caring for individuals with spinal cord injury living in the community. Topics in Spinal Cord Injury Rehabilitation 25(4): 290-302	- Phenomenon of interest Findings relate to development of caregiver skills, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Jeyathevan, Gaya, Catharine Craven, B, Cameron, Jill I et al. (2020) Facilitators and barriers to supporting individuals with spinal cord injury in the community: experiences of family caregivers and care recipients. Disability and rehabilitation 42(13): 1844-1854	- Phenomenon of interest Findings relate to support for carers, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Jimenez, N., Fuentes, M., Frias-Garcia, M. et al. (2020) Transitions to outpatient care after traumatic brain injury for hispanic children. Hospital Pediatrics 10(6): 509-515	- Country Study conducted in the US.
Johansson, Monica B; Carlsson, Marianne; Sonnander, Karin (2011) Working with families of persons with aphasia: a survey of Swedish speech and language pathologists. Disability and rehabilitation 33(1): 51-62	- Phenomenon of interest Findings relate to services available for family members of people with aphasia, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Jones, Belinda, Hopkins, Genevieve, Wherry, Sally-Anne et al. (2016) Evaluation of a Regional Australian Nurse-Led Parkinson's Service Using the Context, Input, Process, and Product Evaluation Model. Clinical nurse specialist CNS 30(5): 264-70	- Phenomenon of interest Findings relate to the evaluation of a nurse led service for general health care provision, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Jones, Samantha; Davis, Naomi; Tyson, Sarah F (2018) A scoping review of the needs of	- Phenomenon of interest

Study	Reason for exclusion
children and other family members after a child's traumatic injury. Clinical rehabilitation 32(4): 501-511	Findings relate to planning and delivery of ongoing treatment and support after traumatic injury, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Jourdan, C., Bahrami, S., Azouvi, P. et al. (2019) Practitioners' opinions on traumatic brain injury care pathways in Finland and France: different organizations, common issues. Brain Injury 33(2): 205-211	- Country Study conducted in Finland and France.
Keetley, R., Bennett, E., Williams, J. et al. (2021) Outcomes for children with acquired brain injury (ABI) admitted to acute neurorehabilitation. Developmental Medicine and Child Neurology 63(7): 824-830	- Other protocol criteria Qualitative data are presented as part of a process evaluation. However the paper does not include details on how this research was conducted and it is not therefore possible to critically appraise these data.
Keetley, R.; Radford, K.; Manning, J.C. (2019) A scoping review of the needs of children and young people with acquired brain injuries and their families. Brain Injury 33(9): 1117-1128	- Study design Scoping review, not a systematic review.
Keetley, R.; Westwater-Wood, S.; Manning, J.C. (2021) Exploring participation after paediatric acquired brain injury. Journal of Child Health Care 25(1): 81-92	- Phenomenon of interest Findings relate to participation in education and leisure activities, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Keightley, Michelle L, King, Grace E, Jang, Shu-Hyun et al. (2011) Brain injury from a first nations' perspective: teachings from elders and traditional healers. Canadian journal of occupational therapy. Revue canadienne d'ergotherapie 78(4): 237-45	- Phenomenon of interest Findings relate to links between spirituality and experiences of impairments and care, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Keightley, Michelle, Kendall, Victoria, Jang, Shu-Hyun et al. (2011) From health care to home community: an Aboriginal community-based ABI transition strategy. Brain injury 25(2): 142-52	- Phenomenon of interest Findings relate to access to general services and assistance for activities of daily living, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Kelly, C., Cornwell, P., Copley, A. et al. (2022) Community-based rehabilitation for adults with cognitive-communication disorders following traumatic brain injury: A mixed methods investigation. Brain Injury 36(8): 1010-1018	- Phenomenon of interest Findings relate to service delivery and tailoring of therapy, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Kennedy, N., Barnes, J., Rose, A. et al. (2012) Clinicians' expectations and early experiences of a new comprehensive rehabilitation case management model in a specialist brain injury rehabilitation unit. Brain Impairment 13(1): 62-71	- Country Study conducted in Australia with professionals working in adult healthcare services.
Kerkemeyer, L., Claus, I., Kutscher, M. et al. (2022) Strengthening Communication and Collaboration in the Fragmented German Healthcare System: A Mixed-Method Evaluation of an Interdisciplinary Network for Parkinson's	- Phenomenon of interest Findings relate to collaborative care and treatment in general, and not the identification of people with rehabilitation needs arising from

Study	Reason for exclusion
Disease. Journal of Parkinson's Disease 12(4): 1307-1317	chronic neurological disorders or referrals to appropriate services.
Kern, Stephen B, Hunter, Louis N, Sims, Ashley C et al. (2019) Understanding the Changing Health Care Needs of Individuals Aging With Spinal Cord Injury. Topics in spinal cord injury rehabilitation 25(1): 62-73	- Country Study conducted in the US
Kimmel, Lara A, Holland, Anne E, Lannin, Natasha et al. (2017) Clinicians' perceptions of decision making regarding discharge from public hospitals to in-patient rehabilitation following trauma. Australian health review : a publication of the Australian Hospital Association 41(2): 192-200	- Population Mixed population. Study included participants in protocol (neurorehabilitation professionals) and out of protocol (non-neurological rehabilitation professionals). Proportions not reported. Findings not presented separately for target population.
Klippi, A, Sellman, J, Heikkinen, P et al. (2012) Current clinical practices in Aphasia Therapy in Finland: challenges in moving towards national best practice. Folia phoniatrica et logopaedica : official organ of the International Association of Logopedics and Phoniatrics (IALP) 64(4): 169-78	- Phenomenon of interest Findings relate to ongoing care, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Knollman-Porter, Kelly, Brown, Jessica A, Wallace, Tracey et al. (2021) First-Line Health Care Providers' Reported Knowledge of and Referrals to Speech-Language Pathologists for Clients With Mild Traumatic Brain Injury. American journal of speech-language pathology 30(5): 2214-2227	- Country Study conducted in the US.
Lafiatoglou, Panagiota, Ellis-Hill, Caroline, Gouva, Mary et al. (2022) A systematic review of the qualitative literature on older individuals' experiences of care and well-being during physical rehabilitation for acquired brain injury. Journal of advanced nursing 78(2): 377-394	- Phenomenon of interest Findings relate to care in general and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Lam Wai Shun, Priscilla, Bottari, Carolina, Ogourtsova, Tatiana et al. (2017) Exploring factors influencing occupational therapists' perception of patients' rehabilitation potential after acquired brain injury. Australian occupational therapy journal 64(2): 149-158	- Country Study conducted in Canada with professionals working in adult healthcare services.
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 adult participants.
Larsson-Lund, Maria; Pettersson, Agneta; Strandberg, Thomas (2022) Team-based rehabilitation after traumatic brain injury: a qualitative synthesis of evidence of experiences of the rehabilitation process. Journal of rehabilitation medicine 54: jrm00253	- Country Systematic review with 2/10 of the included studies conducted in the UK, 6/10 in Australia (with adult participants), 1/10 in Demark, and 1/10 in Sweden. UK studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.

Study	Reason for exclusion
Law, James, Huby, Guro, Irving, Anne-Marie et al. (2010) Reconciling the perspective of practitioner and service user: findings from The Aphasia in Scotland study. International journal of language & communication disorders 45(5): 551-60	- Population Adults with stroke. Not relevant according to protocol population criteria.
Le Dorze, Guylaine and Signori, France-Helene (2010) Needs, barriers and facilitators experienced by spouses of people with aphasia. Disability and rehabilitation 32(13): 1073-87	- Phenomenon of interest Findings relate to the experiences of carers for people with aphasia as a result of stroke, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Learmonth, Yvonne C, Adamson, Brynn C, Balto, Julia M et al. (2018) Investigating the needs and wants of healthcare providers for promoting exercise in persons with multiple sclerosis: a qualitative study. Disability and rehabilitation 40(18): 2172-2180	- Country Study conducted in the US.
Lefebvre, H. and Levert, M.-J. (2012) The close relatives of people who have had a traumatic brain injury and their special needs. Brain Injury 26(9): 1084-1097	- Phenomenon of interest Findings relate to provision of information to family members and carers about available services and how they operate, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate 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	- Phenomenon of interest Findings relate to experiences of acute care and general support services required, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Lefkovits, Aviva Margaret, Hicks, Amelia J, Downing, Marina et al. (2021) Surviving the "silent epidemic": A qualitative exploration of the long-term journey after traumatic brain injury. Neuropsychological rehabilitation 31(10): 1582-1606	- Phenomenon of interest Findings relate to experiences of impairments and care, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Levasseur, Melanie, Pigot, Helene, Couture, Melanie et al. (2016) Identifying participation needs of people with acquired brain injury in the development of a collective community smart home. Disability and rehabilitation. Assistive technology 11(8): 636-44	- Country Study conducted in Canada with adult participants.
Lexell, E.M.; Alkhed, A.-K.; Olsson, K. (2013) The group rehabilitation helped me adjust to a new life: Experiences shared by persons with an acquired brain injury. Brain Injury 27(5): 529-537	- Country Study conducted in Sweden.
Lind Irgens, E.; Henriksen, N.; Moe, S. (2016) Acquired brain injury rehabilitation: dilemmas in neurological physiotherapy across healthcare settings. European Journal of Physiotherapy 18(4): 202-209	- Phenomenon of interest Findings relate to ongoing care and treatment, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Lindberg, J., Kreuter, M., Taft, C. et al. (2013) Patient participation in care and rehabilitation from the perspective of patients with spinal cord injury. Spinal Cord 51(11): 834-837	- Phenomenon of interest Findings relate to ongoing treatment and person-centred care, and not the identification of people with rehabilitation needs arising from

Study	Reason for exclusion
	chronic neurological disorders or referrals to appropriate services.
Lucke, Kathleen T, Martinez, Hernando, Mendez, Thomas B et al. (2013) Resolving to go forward: the experience of Latino/Hispanic family caregivers. Qualitative health research 23(2): 218-30	- Country Study conducted in the US.
Lundine, J.P., Utz, M., Jacob, V. et al. (2019) Putting the person in person-centered care: Stakeholder experiences in pediatric traumatic brain injury. Journal of Pediatric Rehabilitation Medicine 12(1): 21-35	- Country Study conducted in the US.
Ma, J.K., Cheifetz, O., Todd, K.R. et al. (2020) Co-development of a physiotherapist-delivered physical activity intervention for adults with spinal cord injury. Spinal Cord 58(7): 778-786	- Study design Limited to quantitative data analysis and reporting.
Machan, M., Jahraus, C., Debert, C.T. et al. (2022) The impact of the COVID-19 pandemic on the well-being of individuals with persistent postconcussive symptoms: A qualitative study. PM and R 14(9): 1068-1079	- Phenomenon of interest Findings relate to the impact of coronavirus on people’s experiences of care and treatment, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Magliano, Lorenza, Citarelli, Giulia, Esposito, Maria Grazia et al. (2022) Impact of the COVID-19 pandemic on neuromuscular rehabilitation setting. Part 2: patients and families' views on the received health care during the pandemic. Acta myologica : myopathies and cardiomyopathies : official journal of the Mediterranean Society of Myology 41(2): 89-94	- Study design Limited to quantitative data analysis and reporting.
Manders, Eric; Marien, Annelies; Janssen, Vicky (2011) Informing and supporting partners and children of persons with aphasia: a comparison of supply and demand. Logopedics, phoniatrics, vocology 36(4): 139-44	- Study design Limited to quantitative data analysis and reporting.
Marck, C.H., Hunter, A., Butler, E. et al. (2022) Assessment and treatment of depression in people with multiple sclerosis: A qualitative analysis of specialist clinicians' experiences. Multiple Sclerosis and Related Disorders 57: 103362	- Country Study conducted in Australia with professionals working in adult healthcare services.
Marier-Deschenes, Pascale; Gagnon, Marie-Pierre; Lamontagne, Marie-Eve (2021) Co-creation of a post-traumatic brain injury sexuality information toolkit: a patient-oriented project. Disability and rehabilitation 43(14): 2045-2054	- Phenomenon of interest Findings relate to participant views on the content and format of an information sheet and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Maring, Joyce, Croarkin, Earllaine, Morgan, Sylvia et al. (2013) Perceived effectiveness and barriers to physical therapy services for families and children with Friedreich ataxia. Pediatric physical therapy : the official publication of the Section on Pediatrics of the American Physical Therapy Association 25(3): 305-13	- Country Study conducted in the US.
Marinho-Buzelli, A.R., Gauthier, C., Chan, K. et al. (2022) The state of aquatic therapy use for	- Phenomenon of interest

Study	Reason for exclusion
clients with spinal cord injury or disorder: Knowledge and current practice. Journal of Spinal Cord Medicine 45(1): 82-90	Findings relate to delivery, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Maurer-Karattup, P., Zasler, N., Thibaut, A. et al. (2022) Neurorehabilitation for people with disorders of consciousness: an international survey of health-care structures and access to treatment, (Part 1). Brain Injury 36(7): 850-859	- Study design Limited to quantitative data analysis and reporting.
McCabe, M., Ebacioni, K.J., Simmons, R. et al. (2015) Satisfaction with service needs among people living with multiple sclerosis. NeuroRehabilitation 36(2): 167-173	- Study design Limited to quantitative data analysis and reporting.
McKevitt, Christopher, Topor, Marta, Panton, Anna et al. (2019) Seeking normality: Parents' experiences of childhood stroke. Child: care, health and development 45(1): 89-95	- Phenomenon of interest Findings relate to parents experiences of coping with and caring for their child who has had a stroke, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Meehan, M. and Doody, O. (2020) The role of the clinical nurse specialist multiple sclerosis, the patients' and families' and carers' perspective: An integrative review. Multiple Sclerosis and Related Disorders 39: 101918	- Study design Systematic review with 9/17 qualitative studies, 3/17 mixed-methods studies, 2/17 systematic reviews, 5/17 quantitative studies, and 1/17 non-systematic literature review. Qualitative studies, mixed-methods studies, and systematic reviews were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Meijering, Louise and Lettinga, Ant (2022) Hopeful adaptation after acquired brain injury: The case of late referrals in the Netherlands. Social science & medicine (1982) 293: 114651	- Phenomenon of interest Findings relate to participants hopeful adaptation after late referral, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Meixner, Cara; O'Donoghue, Cynthia R; Witt, Michelle (2013) Accessing crisis intervention services after brain injury: a mixed methods study. Rehabilitation psychology 58(4): 377-85	- Country Study conducted in the US.
Miley, A.E., Elleman, C.B., Chiu, R.Y. et al. (2022) Professional stakeholders' perceptions of barriers to behavioral health care following pediatric traumatic brain injury. Brain Injury 36(4): 536-543	- Country Study conducted in the US.
Miley, Aimee E, Fisher, Allison P, Moscato, Emily L et al. (2022) A mixed-methods analysis examining child and family needs following early brain injury. Disability and rehabilitation 44(14): 3566-3576	- Phenomenon of interest Findings relate to parents’ experiences of caring for their child after traumatic brain injury or non-accidental trauma, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Minney, M.J., Roberts, R.M., Mathias, J.L. et al. (2019) Service and support needs following pediatric brain injury: perspectives of children with	- Phenomenon of interest Findings relate to experiences of injury, support provided, and accommodation at school, and not to the identification of people with rehabilitation

Study	Reason for exclusion
mild traumatic brain injury and their parents. Brain Injury 33(2): 168-182	needs arising from chronic neurological disorders or referrals to appropriate services.
Mistry, Kriten and Simpson, Jane (2013) Exploring the transitional process from receiving a diagnosis to living with motor neurone disease. Psychology & health 28(8): 939-53	- Phenomenon of interest Findings relate to diagnosis and experiences of the progression of impairments, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Mitsch, V.; Curtin, M.; Badge, H. (2014) The provision of brain injury rehabilitation services for people living in rural and remote New South Wales, Australia. Brain Injury 28(12): 1504-1513	- Phenomenon of interest Findings relate to delivery, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Morgan, Angela T and Skeat, Jemma (2011) Evaluating service delivery for speech and swallowing problems following paediatric brain injury: an international survey. Journal of evaluation in clinical practice 17(2): 275-81	- Study design Limited to quantitative data analysis and reporting.
Morris Megan, A.; Dudgeon Brian, J.; Yorkson, Kathryn (2013) A qualitative study of adult AAC users' experiences communicating with medical providers. Disability and Rehabilitation: Assistive Technology 8(6): 472-481	- Country Study conducted in the US.
Morris, M.E., Slade, S.C., Bruce, C. et al. (2020) Enablers to Exercise Participation in Progressive Supranuclear Palsy: Health Professional Perspectives. Frontiers in Neurology 11: 635341	- Phenomenon of interest Findings relate to experiences of providing and enabling exercise and physical therapy, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Mozeiko, J. and Pascariello, A. (2020) How are SLPs managing services for people with mild aphasia?. Journal of Communication Disorders 84: 105983	- Country Study conducted in the US.
Mueller, C., Wang, Y., Brooks, A. et al. (2017) 'Attending to the wound and the person'-patients' experiences and expectations of a newly established traumatic brain injury clinic. Brain Injury 31(1314): 1863-1870	- Phenomenon of interest Findings relate to participants experiences of living with a newly diagnosed traumatic brain injury, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Munce, S.E.P., Webster, F., Fehlings, M.G. et al. (2014) Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: A qualitative descriptive study. BMC Neurology 14(1): 48	- Phenomenon of interest Findings relate to the participant, their caregivers and care managers management of activities of daily living and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Nalder, E., Fleming, J., Cornwell, P. et al. (2013) Reflections on life: Experiences of individuals with brain injury during the transition from hospital to home. Brain Injury 27(11): 1294-1303	- Country Study conducted in Australia with adult participants.
Nasrabadi, A.N., Mohammadi, N., Davatgaran, K. et al. (2019) Designing a client and family empowerment model to promote constructive life recovery among persons with spinal cord injury:	- Country Study conducted in Iran.

Study	Reason for exclusion
A qualitative study. Archives of Neuroscience 6(3): e87867	
Nassehi, A., Nayeri, N.D., Abbaszadeh, A. et al. (2022) Spinal Cord Injury Patient's Physical and Psychological Care Needs at Home from Patients' and Caregivers' Perspectives: A Qualitative Study. Archives of Neuroscience 9(3): e123462	- Country Study conducted in the US.
New, P.W., Marshall, R., Stubblefield, M.D. et al. (2017) Rehabilitation of people with spinal cord damage due to tumor: literature review, international survey and practical recommendations for optimizing their rehabilitation. Journal of Spinal Cord Medicine 40(2): 213-221	- Study design Literature review, not systematic review. Survey results limited to quantitative data analysis and reporting.
New, P.W., Scivoletto, G., Smith, E. et al. (2013) International survey of perceived barriers to admission and discharge from spinal cord injury rehabilitation units. Spinal Cord 51(12): 893-897	- Study design Limited to quantitative data analysis and reporting.
Ng, Louisa; Talman, Paul; Khan, Fary (2011) Motor neurone disease: disability profile and service needs in an Australian cohort. International journal of rehabilitation research. Internationale Zeitschrift fur Rehabilitationsforschung. Revue internationale de recherches de readaptation 34(2): 151-9	- Study design Limited to quantitative data analysis and reporting.
Nielsen, Glenn, Buszewicz, Marta, Edwards, Mark J et al. (2020) A qualitative study of the experiences and perceptions of patients with functional motor disorder. Disability and rehabilitation 42(14): 2043-2048	- Phenomenon of interest Findings relate to experiences of people with functional motor disorder around understanding their diagnosis, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Nilsson, M.H., Iwarsson, S., Thordardottir, B. et al. (2015) Barriers and facilitators for participation in people with Parkinson's Disease. Journal of Parkinson's Disease 5(4): 983-992	- Phenomenon of interest Findings relate to participation in the community in general, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Nitsch, K.P., Stipp, K., Gracz, K. et al. (2021) Integrating Spinal Cord Injury-Quality of Life instruments into rehabilitation: Implementation science to guide adoption of patient-reported outcome measures. Journal of Spinal Cord Medicine 44(6): 940-948	- Country Conducted in the US.
Norrbrink, Cecilia and Lofgren, Monika (2016) Needs and requests--patients and physicians voices about improving the management of spinal cord injury neuropathic pain. Disability and rehabilitation 38(2): 151-8	- Population Participants were people experiencing neuropathic pain. Not relevant according to protocol population criteria.
Northcott, Sarah, Simpson, Alan, Moss, Becky et al. (2017) How do speech-and-language therapists address the psychosocial well-being of people with aphasia? Results of a UK online survey. International journal of language & communication disorders 52(3): 356-373	- Population Participants were healthcare professionals working with adults with aphasia after stroke. Not relevant according to protocol population criteria.

Study	Reason for exclusion
Nunnerley, J L; Hay-Smith, E J C; Dean, S G (2013) Leaving a spinal unit and returning to the wider community: an interpretative phenomenological analysis. Disability and rehabilitation 35(14): 1164-73	- Phenomenon of interest Findings relate to experience of community reintegration by people with a spinal cord injury, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Nunnerley, J.L., Martin, R.A., Aldridge, M. et al. (2021) Access to community support workers during hospital admission for people with spinal cord injury: a pilot study. Spinal Cord Series and Cases 7(1): 3	- Phenomenon of interest Findings relate to participant experiences of having their support workers providing selected cares for them during an elective or emergency admission into public hospital/non-specialist ward, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
O'Brien, M.R., Whitehead, B., Jack, B.A. et al. (2011) From symptom onset to a diagnosis of amyotrophic lateral sclerosis/motor neuron disease (ALS/MND): Experiences of people with ALS/MND and family carers - A qualitative study. Amyotrophic Lateral Sclerosis 12(2): 97-104	- Phenomenon of interest Findings relate to the diagnosis of amyotrophic lateral sclerosis, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
O'Callaghan, A.; McAllister, L.; Wilson, L. (2012) Insight vs readiness: Factors affecting engagement in therapy from the perspectives of adults with TBI and their significant others. Brain Injury 26(1314): 1599-1610	- Phenomenon of interest Findings do not relate to identifying people with rehabilitation needs arising from chronic neurological disorders or making referrals to appropriate services.
O'Callaghan, Anna Mary; McAllister, Lindy; Wilson, Linda (2010) Experiences of care reported by adults with traumatic brain injury. International journal of speech-language pathology 12(2): 107-23	- Country Study conducted in Australia with adult participants.
O'Callaghan, Anna, McAllister, Lindy, Wilson, Linda et al. (2012) Healthcare consumers' need for brain-injury services: The critical importance of timing in planning future services. Brain Impairment 13(3): 316-332	- Country Study conducted in Australia with adult participants.
O'Shannessy, E., Reeder, S., Vishwanath, S. et al. (2022) Mixed methods study to understand the experiences of adults with acquired brain injury and their family members who receive specialised rehabilitation. Brain Impairment	- Phenomenon of interest Findings relate to experience of specialised rehabilitation for people with brain injury and their family members, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
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.
Osborne, Jake B, Rocchi, Meredith A, McBride, Christopher B et al. (2022) Couples' experiences	- Phenomenon of interest Findings relate to the changes in sexuality after spinal cord injury, and not the identification of

Study	Reason for exclusion
with sexuality after spinal cord injury. Disability and rehabilitation: 1-9	people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Ospina, Paula A, Wiart, Lesley, Eisenstat, David D et al. (2020) Physical Rehabilitation Practices for Children and Adolescents with Cancer in Canada. Physiotherapy Canada. Physiotherapie Canada 72(2): 207-216	- Phenomenon of interest Findings relate to provision of rehabilitation interventions and experiences of delivering interventions, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Ott, Joelle; Biller-Andorno, Nikola; Glassel, Andrea (2022) First Insights into Barriers and Facilitators from the Perspective of Persons with Multiple Sclerosis: A Multiple Case Study. International journal of environmental research and public health 19(17)	- Phenomenon of interest Findings relate to analysis of secondary data on participant experiences of the important aspects of general multiple sclerosis healthcare, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Oyesanya, T. (2017) The experience of patients with ABI and their families during the hospital stay: A systematic review of qualitative literature. Brain Injury 31(2): 151-173	- Country Systematic review with 2/11 of the included studies conducted in the UK, 6/11 in the US, 2/11 in Australia (with adult participants), and 1/10 in Canada (with adult participants). UK studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Paling, Claire and Hebron, Clair (2021) Physiotherapists' experiences of managing persons with suspected cauda equina syndrome: Overcoming the challenges. Musculoskeletal care 19(1): 28-37	- Phenomenon of interest Findings relate to physiotherapist experiences in managing and/or diagnosing cauda equina syndrome, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Pallesen, H., Lund, L.B., Jensen, M. et al. (2018) The body participating: a qualitative study of early rehabilitation participation for patients with severe brain injury and low level of consciousness. European Journal of Physiotherapy 20(1): 2-11	- Phenomenon of interest Findings relate to how therapists attempted to achieve the involvement of people with severe brain injury in therapeutic and daily-life situations in early rehabilitation, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Panday, Janelle, Velikonja, Diana, Moll, Sandra E et al. (2022) Experiences of inpatient rehabilitation from the perspective of persons with acquired brain injury. Disability and rehabilitation 44(19): 5539-5548	- Phenomenon of interest Findings relate to participant experience of inpatient rehabilitation, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Parkinson, Anne, Drew, Janet, Hall Dykgraaf, Sally et al. (2021) 'They're getting a taste of our world': A qualitative study of people with multiple sclerosis' experiences of accessing health care during the COVID-19 pandemic in the Australian Capital Territory. Health expectations: an international journal of public participation in health care and health policy 24(5): 1607-1617	- Phenomenon of interest Findings relate to the impact of coronavirus on the provision of ongoing treatment, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.

Study	Reason for exclusion
Peacock, D., Baumeister, P., Monaghan, A. et al. (2020) Perception of Healthcare Access and Utility of Telehealth among Parkinson's Disease Patients. Canadian Journal of Neurological Sciences 47(5): 700-704	- Country Study conducted in Canada with adult participants.
Pedlow, K.; Lennon, S.; Wilson, C. (2014) Application of constraint-induced movement therapy in clinical practice: An online survey. Archives of Physical Medicine and Rehabilitation 95(2): 276-282	- Study design Limited to quantitative data analysis and reporting.
Peev, N., Komarov, A., Osorio-Fonseca, E. et al. (2020) Rehabilitation of spinal cord injury: WFNS spine committee recommendations. Neurospine 17(4): 820-832	- Phenomenon of interest Findings relate to delivery of interventions, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Pellegrini, C.A., Burkhart, L., Jones, K. et al. (2021) Health provider identified barriers and facilitators to weight management for individuals with spinal cord injury. Spinal Cord 59(10): 1061-1071	- Country Study conducted in the US.
Persson, H.C., Tornbom, K., Sunnerhagen, K.S. et al. (2017) Consequences and coping strategies six years after a subarachnoid hemorrhage - A qualitative study. PLoS ONE 12(8): e0181006	- Phenomenon of interest Findings relate to the consequences of subarachnoid haemorrhage and coping strategies afterwards, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Philip, Jennifer, Collins, Anna, Brand, Caroline et al. (2018) A proposed framework of supportive and palliative care for people with high-grade glioma. Neuro-oncology 20(3): 391-399	- Phenomenon of interest Findings relate to a framework for palliative care without rehabilitation, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Piil, K, Jakobsen, J, Christensen, K B et al. (2018) Needs and preferences among patients with high-grade glioma and their caregivers - A longitudinal mixed methods study. European journal of cancer care 27(2): e12806	- Phenomenon of interest Findings relate to delivery of care, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Plouvier, Annette O A, Olde Hartman, Tim C, de Bont, Olga A et al. (2017) The diagnostic pathway of Parkinson's disease: a cross-sectional survey study of factors influencing patient dissatisfaction. BMC family practice 18(1): 83	- Phenomenon of interest Findings relate to the satisfaction with the process of diagnosis, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Pollock, A., D'Cruz, K., Scheinberg, A. et al. (2022) Family-centred care for children with traumatic brain injury and/or spinal cord injury: a qualitative study of service provider perspectives during the COVID-19 pandemic. BMJ Open 12(6): e059534	- Phenomenon of interest Findings relate to healthcare professionals’ experiences of service provision during coronavirus, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
POPPLETON, Rob and et, al (2012) Journey in trying to achieve eligibility level 1 rehabilitation	- Study design Narrative/opinion piece.

Study	Reason for exclusion
service. Social Care and Neurodisability 3(3): 131-139	
Pucillo, E.M., Christensen-Mayer, N., Poole, S.D. et al. (2016) Same-day physical therapy consults in an outpatient neuromuscular disease physician clinic. Journal of Multidisciplinary Healthcare 9: 493-497	- Country Study conducted in the US.
Pugh, Judith Dianne, McCoy, Kathleen, Williams, Anne M et al. (2019) Rapid evidence assessment of approaches to community neurological nursing care for people with neurological conditions post-discharge from acute care hospital. Health & social care in the community 27(1): 43-54	- Phenomenon of interest Findings relate to the effectiveness of community neurological nursing care, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Qiang, Judy K, Nyhof-Young, Joyce, D'Souza, Rohan et al. (2016) Support systems of women with epilepsy in pregnancy: A retrospective needs assessment. Seizure 36: 1-3	- Population Epilepsy not leading to spinal cord injury or acquired brain injury. Not relevant according to protocol population criteria.
Rietdijk, Rachael, Power, Emma, Attard, Michelle et al. (2022) Acceptability of telehealth-delivered rehabilitation: Experiences and perspectives of people with traumatic brain injury and their carers. Journal of telemedicine and telecare 28(2): 122-134	- Country Study conducted in Australia with adult participants.
Rietman, Andre B, van Helden, Hanneke, Both, Pauline H et al. (2018) Worries and needs of adults and parents of adults with neurofibromatosis type 1. American journal of medical genetics. Part A 176(5): 1150-1160	- Phenomenon of interest Findings relate to treatment, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Rintell, D.J., Frankel, D., Minden, S.L. et al. (2012) Patients' perspectives on quality of mental health care for people with MS. General Hospital Psychiatry 34(6): 604-610	- Country Study conducted in the US.
Rosqvist, K., Kylberg, M., Lofqvist, C. et al. (2021) Perspectives on Care for Late-Stage Parkinson's Disease. Parkinson's Disease 2021: 9475026	- Country Study conducted in Sweden.
Rothing, Merete; Malterud, Kirsti; Frich, Jan C (2015) Family caregivers' views on coordination of care in Huntington's disease: a qualitative study. Scandinavian journal of caring sciences 29(4): 803-9	- Phenomenon of interest Findings relate to competencies and involvement of family caregivers in the care of people with Huntington's disease, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Rothlisberger, Fabian, Boes, Stefan, Rubinelli, Sara et al. (2017) Challenges and potential improvements in the admission process of patients with spinal cord injury in a specialized rehabilitation clinic - an interview based qualitative study of an interdisciplinary team. BMC health services research 17(1): 443	- Country Study conducted in Switzerland.
Sarkic, B.; Douglas, J.M.; Simpson, A. (2022) 'I had nothing. It's just life experience that helped me through that situation': Australian audiologists' perspectives on audiological clinical	- Country Study conducted in Australia with adult participants.

Study	Reason for exclusion
practice for traumatic brain injury and rehabilitation. Brain Injury 36(7): 886-897	
Schmid, F.; Rogan, S.; Glassel, A. (2021) A swiss health care professionals' perspective on the meaning of interprofessional collaboration in health care of people with ms-a focus group study. International Journal of Environmental Research and Public Health 18(12): 6537	- Phenomenon of interest Findings relate to the use of inter-professional collaboration for people living with multiple sclerosis, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Schwartz, R., Trivedi, R., Gray, C. et al. (2019) Neurologist Strategies for Optimizing the Parkinson's Disease Clinical Encounter. Journal of Geriatric Psychiatry and Neurology 32(5): 246-256	- Other protocol criteria Conference abstract.
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	- Phenomenon of interest Findings relate to participant experiences of participating in rehabilitation for concussion, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Silveira, Stephanie L; Richardson, Emma V; Motl, Robert W (2021) Informing the design of exercise programs for persons with multiple sclerosis who use wheelchairs: a qualitative inquiry of perceived components. Disability and rehabilitation 43(13): 1838-1848	- Country Study conducted in the US.
Simpson, R., Simpson, S., Wood, K. et al. (2019) Using normalisation process theory to understand barriers and facilitators to implementing mindfulness-based stress reduction for people with multiple sclerosis. Chronic Illness 15(4): 306-318	- Phenomenon of interest Findings relate to service delivery, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Singh, G., MacGillivray, M., Mills, P. et al. (2020) Patients' Perspectives on the Usability of a Mobile App for Self-Management following Spinal Cord Injury. Journal of Medical Systems 44(1): 26	- Phenomenon of interest Findings relate to a specific intervention/delivery of intervention, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Slomic, M., Soberg, H.L., Sveen, U. et al. (2017) Transitions of patients with traumatic brain injury and multiple trauma between specialized and municipal rehabilitation services-Professionals' perspectives. Cogent Medicine 4(1): 1320849	- Country Study conducted in Norway.
Soofi, A.Y., Bello-Haas, V.D., Kho, M.E. et al. (2018) The impact of rehabilitative interventions on quality of life: a qualitative evidence synthesis of personal experiences of individuals with amyotrophic lateral sclerosis. Quality of Life Research 27(4): 845-856	- Phenomenon of interest Findings relate to participants experiences of participating in rehabilitation, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Souesme, Guillaume, Voyer, Manon, Gagnon, Eric et al. (2022) Barriers and facilitators linked to discharge destination following inpatient rehabilitation after traumatic brain injury in older adults: a qualitative study. Disability and rehabilitation 44(17): 4738-4749	- Phenomenon of interest Findings relate to the role of general support at home and the influence this has on discharge, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.

Study	Reason for exclusion
Stone, Louise (2014) Managing the consultation with patients with medically unexplained symptoms: a grounded theory study of supervisors and registrars in general practice. BMC family practice 15: 192	- Phenomenon of interest Findings relate to treatment and delivery of services, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Sutter, Ellen N, Francis, Linda Smith, Francis, Sunday M et al. (2021) Disrupted Access to Therapies and Impact on Well-Being During the COVID-19 Pandemic for Children With Motor Impairment and Their Caregivers. American journal of physical medicine & rehabilitation 100(9): 821-830	- Country Study conducted in the US.
Sutton, Kathleen M, Kitzman, Patrick H, Hunter, Elizabeth G et al. (2019) Engaging Individuals with Neurological Conditions and Caregivers in Rural Communities in a Health Research Team. Progress in community health partnerships : research, education, and action 13(2): 129-139	- Country Study conducted in the US.
Swaffield, Emma, Cheung, Lovisa, Khalili, Avideh et al. (2022) Perspectives of people living with a spinal cord injury on activity-based therapy. Disability and rehabilitation 44(14): 3632-3640	- Country Study conducted in Canada with adult participants.
Swaine, Bonnie, Cullen, Nora, Messier, Frederic et al. (2018) Post-acute care referral and inpatient rehabilitation admission criteria for persons with brain injury across two Canadian provinces. Disability and rehabilitation 40(6): 697-704	- Study design Limited to quantitative data analysis and reporting.
Szczepura, A., Holliday, N., Neville, C. et al. (2020) Raising the digital profile of facial palsy: National surveys of patients' and clinicians' experiences of changing UK treatment pathways and views on the future role of digital technology. Journal of Medical Internet Research 22(10): e20406	- Phenomenon of interest Findings relate to people with chronic neurological disorders and clinician experiences of neuromuscular retraining adherence, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Thomas, R.H., Hammond, C.L., Bodger, O.G. et al. (2010) Identifying and prioritising epilepsy treatment uncertainties. Journal of Neurology, Neurosurgery and Psychiatry 81(8): 918-921	- Population Epilepsy not leading to chronic neurological disorder. Not relevant according to protocol population criteria.
Tomaszewski, W. and Manko, G. (2011) An evaluation of the strategic approach to the rehabilitation of traumatic brain injury (TBI) patients. Medical Science Monitor 17(9): cr510-cr516	- Study design Limited to quantitative data analysis and reporting.
Toor, Gurjit K, Harris, Jocelyn E, Escobar, Michael et al. (2016) Long-Term Health Service Outcomes Among Women With Traumatic Brain Injury. Archives of physical medicine and rehabilitation 97(2suppl): 54-63	- Study design Limited to quantitative data analysis and reporting.
Tseng, Sung-Hui and Chang, Feng-Hang (2017) Transitioning from hospitals to the community: Perspectives of rehabilitation patients with neurological disorders and their service providers. Disability and Rehabilitation: An International, Multidisciplinary Journal 39(23): 2420-2427	- Country Study conducted in Taiwan.

Study	Reason for exclusion
Turner, Benjamin James, Fleming, Jennifer, Ownsworth, Tamara et al. (2011) Perceived service and support needs during transition from hospital to home following acquired brain injury. Disability and rehabilitation 33(10): 818-29	- Country Study conducted in Australia with adult participants.
Tyerman, E.; Eccles, F.J.R.; Gray, V. (2017) The experiences of parenting a child with an acquired brain injury: A meta-synthesis of the qualitative literature. Brain Injury 31(12): 1553-1563	- Phenomenon of interest Findings relate to parents' experiences of parenting a child with acquired brain injury, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Veenhuizen, Ruth B, Kootstra, Branda, Vink, Wilma et al. (2011) Coordinated multidisciplinary care for ambulatory Huntington's disease patients. Evaluation of 18 months of implementation. Orphanet journal of rare diseases 6: 77	- Study design Limited to quantitative data analysis and reporting.
Vlaanderen, F.P., Rompen, L., Munneke, M. et al. (2019) The voice of the Parkinson customer. Journal of Parkinson's Disease 9(1): 197-201	- Phenomenon of interest Findings relate to collaborative care and treatment in general, and not the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Volkmer, Anna, Spector, Aimee, Warren, Jason D et al. (2020) Speech and language therapy for primary progressive aphasia: Referral patterns and barriers to service provision across the UK. Dementia (London, England) 19(5): 1349-1363	- Study design Limited to quantitative data analysis and reporting.
Warren, N., Walford, K., Susilo, A. et al. (2018) Emotional consequences of delays in spinal rehabilitation unit admission or discharge: A qualitative study on the importance of communication. Topics in Spinal Cord Injury Rehabilitation 24(1): 54-62	- Phenomenon of interest Findings relate to delays in admission to and discharge from rehabilitation, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Webster, Fiona, Fehlings, Michael G, Rice, Kathleen et al. (2014) Improving access to emergent spinal care through knowledge translation: an ethnographic study. BMC health services research 14: 169	- Phenomenon of interest Findings relate to inter-professional education and collaboration in the area of emergent care for people with spinal injury, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
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 uptake and engagement with psychological interventions, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Wiart, Lesley (2016) How do we ensure sustainable physical activity options for people with disabilities?. Developmental Medicine & Child Neurology 58(8): 788	- Publication type Commentary piece.
Woo, C., Guihan, M., Frick, C. et al. (2011) What's happening now! Telehealth management of spinal cord injury/disorders. Journal of Spinal Cord Medicine 34(3): 322-331	- Country Study conducted in the US.

Study	Reason for exclusion
WURR, Judy (2012) Have I got it wrong or is it them? Difficulties in access to specialist brain injury social work services. Social Care and Neurodisability 3(3): 111-115	- Publication type Commentary piece.
Xiang, L., Bansal, S., Wu, A.Y. et al. (2022) Pathway of care for visual and vestibular rehabilitation after mild traumatic brain injury: a critical review. Brain Injury 36(8): 911-920	- Study design Narrative review of quantitative studies.
Yoshida, Karen K, Self, Hazel M, Renwick, Rebecca M et al. (2015) A value-based practice model of rehabilitation: consumers' recommendations in action. Disability and rehabilitation 37(20): 1825-33	- Phenomenon of interest Findings relate to a value-based rehabilitation practice model focused on independent living, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Zamanipoor Najafabadi, A.H., Van De Mortel, J.P.M., Lobatto, D.J. et al. (2020) Unmet needs and recommendations to improve meningioma care through patient, partner, and health care provider input: A mixed-method study. Neuro-Oncology Practice 7(2): 239-248	- Country Study conducted in the Netherlands.
Zarshenas, Sareh, Couture, Melanie, Bier, Nathalie et al. (2022) Potential advantages, barriers, and facilitators of implementing a cognitive orthosis for cooking for individuals with traumatic brain injury: the healthcare providers' perspective. Disability and rehabilitation. Assistive technology 17(8): 938-947	- Phenomenon of interest Findings relate to implementation of the Cognitive Orthosis for coOking (COOK) for adults with traumatic brain injury, and not to the identification of people with rehabilitation needs arising from chronic neurological disorders or referrals to appropriate services.
Zhou, Leming and Parmanto, Bambang (2019) Reaching People With Disabilities in Underserved Areas Through Digital Interventions: Systematic Review. Journal of medical Internet research 21(10): e12981	- Country Systematic review with 7/11 of the included studies conducted in the US, 1/11 in Australia (with adult participants), 1/11 in Canada (with adult participants), 1/11 in New Zealand (with adult participants), and 1/11 in Italy. Therefore no studies checked against protocol.

Excluded economic studies

No economic searches were undertaken for this qualitative review.

Appendix K Research recommendations – full details

Research recommendations for review question: What are the barriers and facilitators to identifying people with rehabilitation needs due to chronic neurological disorders and enabling access to appropriate services, including referral?

No research recommendations were made for this review question.