National Institute for Health and Care Excellence

Draft for consultation

Rehabilitation for chronic neurological disorders including acquired brain injury

[A] Evidence review for rehabilitation delivery

NICE guideline <number>

Evidence reviews underpinning recommendations 1.1.1 to 1.1.5, 1.2.2, 1.3.1, 1.4.1 to 1.4.2, 1.4.4, 1.5.4, 1.6.1 to 1.6.3, 1.8.5, 1.8.9, 1.8.14 to 1.8.16, 1.10.2, 1.10.4, 1.11.1, 1.11.4 to 1.11.5, 1.12.1 to 1.12.5, and 1.13.4 to 1.13.5 in the NICE guideline

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This evidence review was developed by NICE

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Review question

Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

Introduction

Continued improvement in treatment options for a range of chronic neurological diseases and early post central nervous system trauma care are contributing to an increased longevity in people with chronic neurological disorders. However, inevitably this means more people are living with chronic neurological conditions and ensuring we optimise delivery of care to this group is therefore an essential component of providing efficient and effective rehabilitation. High quality care delivery may improve outcomes for people with chronic neurological disorders, of all ages.

The aim of this qualitative review is to determine what works well and what could be improved in the delivery of rehabilitation for people with chronic neurological disorders.

Summary of the protocol

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

Table 1: Summary of the protocol

Population	• Adults and children with rehabilitation needs due to the following chronic neurological disorders: ○ Acquired brain injury ○ Acquired spinal cord injury ○ Acquired peripheral nerve disorders ○ Progressive neurological diseases ○ Functional neurological disorders • Family and carers of people with chronic neurological disorders. • Health and social care practitioners who work with people with chronic neurological disorders, including voluntary and third sector providers • Practitioners involved in rehabilitation for education, employment and social participation.
Phenomenon of interest	• **Acceptability.** Data may relate to people's experiences of the way in which rehabilitation services are provided, including, for example, interactions between people with chronic neurological disorders and practitioners, settings in which care and support are provided and the timing or duration of rehabilitation. • **Provision of information.** Data may relate to information given to people as part of their rehabilitation, for example in relation to their condition or other available support. • **Integration and co-ordination (including communication and case management practices) within and between rehabilitation services.** Data may relate to people's experiences of care and support provided by multiple practitioners or teams. • **Personalisation of rehabilitation programmes, packages and goals.** Data may relate to people's views on whether their care and support were appropriate to their individual needs, circumstances and preferences.

	• **Transition into and out of rehabilitation services.** There may be evidence about improvements that could be made to the way in which people are referred into or discharged from rehabilitation services. • **Sustainability of rehabilitation and consideration of chronic nature of conditions.** There may be evidence about the way in which people are supported when they are discharged from a particular service, for example support for self-management or for rehabilitation in the context of end-of-life care. • **Equalities considerations.** Data may relate to the provision of rehabilitation for people facing inequalities relating to race and gender and people with pre-existing physical, mental health or behavioural conditions, communication impairments and physical or learning disabilities. It will also consider age-related service assumptions, service access and engagement and cultural differences.

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).

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

Qualitative evidence

Included studies

A systematic review of the literature was conducted using a combined search for 2 of the qualitative review questions included in this guideline: this evidence review and evidence review C (‘Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?’).

Twenty-seven studies (reported in 29 papers) were included for this review. Fourteen studies (reported in 16 papers) were general qualitative inquiries (Abrahamson 2017, Ando 2021, Botchway 2022 [also reported in Botchway-Commey 2022 and Pollock 2022], Daker-White 2013, Dennett 2020, Donovan-Hall 2011, Gill 2012, Grose 2014, McKevitt 2019, Mueller 2017, O’Brien 2012, Rashid 2018, Salas 2021, Sixsmith 2014); 5 studies were general qualitative inquiries within a mixed-methods study (Grayson 2020, Hartley 2013, Holloway 2019, Kumar 2013, Shore 2022); 3 studies were grounded theory (McPherson 2018, Preston 2012, Thomson 2015); 2 studies were case studies (Bernard 2010, Twigg 2021); 2 studies were phenomenological (Paguinto 2023, Spurgeon 2015); and 1 study was an ethnographic study (Setchell 2018).

The included studies are summarised in Table 2.

Twenty-one studies were conducted in the UK (Abrahamson 2017, Ando 2021, Bernard 2010, Daker-White 2013, Dennett 2020, Donovan-Hall 2011, Gill 2012, Grose 2014, Hartley 2013, Holloway 2019, Kumar 2013, McKevitt 2019, McPherson 2018, Mueller 2017, O’Brien 2012, Preston 2012, Salas 2021, Sixsmith 2014, Spurgeon 2015, Thomson 2015, Twigg 2021); 3 studies were conducted in Canada (Rashid 2018, Setchell 2018, Shore 2022); 1 study was conducted in UK and Australia (Grayson 2020); 1 study was conducted in Australia and the US (Paguinto 2023). One study (reported in 3 papers) was conducted in multiple countries (Australia, UK, New Zealand, Canada and the US) (Botchway 2022 [also reported in Botchway-Commey 2022 and Pollock 2022]).

Eighteen studies investigated chronic neurological disorders in the adult population (Abrahamson 2017, Ando 2021, Bernard 2010, Daker-White 2013, Dennett 2020, Gill 2012, Grayson 2020 [defined as 16 years and over], Grose 2014, Hartley 2013, Holloway 2019, McPherson 2018, Mueller 2017, O'Brien 2012, Preston 2012, Salas 2021, Sixsmith 2014, Spurgeon 2015, Twigg 2015); 6 studies (reported in 8 papers) investigated chronic neurological disorders in paediatric population populations (Botchway 2022 [also reported in Botchway-Commey 2022 and Pollock 2022], McKevitt 2019, Paguinto 2023, Rashid 2018, Setchell 2018, Shore 2022); 2 studies did not specify the age rage of their population (Donovan-Hall 2011, Thomson 2015); 1 study investigated delivery of rehabilitation for chronic neurological disorders in people aged 12 years and over (Kumar 2013).

Ten studies investigated the delivery of rehabilitation services in people with acquired brain injury (Abrahamson 2017, Gill 2012, Grayson 2020, Holloway 2019, McKevitt 2019, McPherson 2018, Mueller 2017, Rashid 2018, Salas 2021, Shore 2022); 1 study investigated delivery in acquired spinal cord injury (Donovan-Hill 2011); 1 study (reported in 3 papers) investigated delivery in populations with a mixture of acquired brain injury and acquired spinal cord injury (Botchway 2022 [also reported in Botchway-Commey 2022 and Pollock 2022]); 12 studies investigated delivery in progressive neurological diseases (Ando 2021, Daker-White 2013, Dennett 2020, Grose 2014, Kumar 2013, O'Brien 2012, Paguinto 2023, Preston 2012, Setchell 2018, Spurgeon 2015, Thomson 2015, Twigg 2021); 3 studies investigated delivery in populations with unspecified chronic neurological disorders (Bernard 2010, Harley 2013, Sixsmith 2014).

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
Abrahamson 2017 General qualitative inquiry UK **Aim** To explore the transition experiences of people with traumatic brain injury and their carers within the first month of being discharged home from a neurorehabilitation unit, including potential gaps in service provision.	N=19 adults with traumatic brain injury plus carers CND category: Acquired brain injury **Adults with traumatic brain injury, n=10** Age in years [Mean (SD)]: 63 (14) Sex: Not reported **Carers of people with traumatic brain injury, n=9**	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Acceptability ○ Interactions between professionals and people with chronic neurological disorders • Integration and co-ordination within and between rehabilitation services ○ Care coordination ○ Communication between services • Personalisation of rehabilitation programmes, packages, and goals ○ Tailoring of rehabilitation content and support

Study	Participants	Methods	Themes applied after thematic synthesis
	Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported		• Transition into and out of rehabilitation services ○ Co-ordinated discharge planning between services ○ Gradual discharge and home visits ○ Planning and preparation with people with chronic neurological disorders and carers
Ando 2021 General qualitative inquiry UK **Aim** To explore the experiences of the Careportal® telehealth monitoring service in people with motor neurone disease using non-invasive ventilation.	N=12 adults with motor neurone disease plus their carers CND category: Progressive neurological disease **Adults with motor neurone disease, n=7** Age in years [Mean (SD)]: 63 (SD not reported) Sex (M/F): n=5/n=2 **Carers of adults with motor neurone disease, n=5** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported, age range 49-68 Sex of people with chronic neurological disorders (M/F): n=3/n=2	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Acceptability ○ Telehealth/remote delivery
Bernard 2010 Case study UK **Aim** To explore how long-term neurological condition services are	N=222 adults with long-term neurological conditions plus practitioners CND category: Acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorder, and progressive neurological disease	**Data Collection:** Semi-structured interviews and non-participant observation **Analysis:** Thematic framework analysis	• Acceptability ○ Amount, timing and duration of rehabilitation • Acceptability ○ Interactions between professionals and people with chronic neurological disorders

Study	Participants	Methods	Themes applied after thematic synthesis
integrated within the healthcare system, as well as with social care and other relevant services. Also, to explore how long-term neurological condition services adapt to provide care to a population of diverse needs.	**Adults with long-term neurological conditions, n=71** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported but all over 18 Sex: Not reported **Practitioners working with people with long-term neurological conditions, n=151** Age of people with chronic neurological disorders in years: Not reported Sex: Not reported		• Provision of information ○ Accessibility and timing of information • Provision of information ○ Content of information • Integration and co-ordination within and between rehabilitation services ○ Care coordination ○ Care navigation ○ Commissioning biopsychosocial rehabilitation ○ Communication between services ○ Multi-disciplinary approach • Transition into and out of rehabilitation services ○ Co-ordinated discharge planning between services • Sustainability of rehabilitation and consideration of chronic nature of conditions ○ Continued support ○ Flexibility of provision ○ Long-term follow-up
Botchway 2022 General qualitative inquiry Australia, UK, New Zealand, Canada and the US **Aim** To explore national and international rehabilitation service models and programmes for children who have experienced major traumatic brain injury and/or traumatic	N=20 practitioners working with children with traumatic brain injury and traumatic spinal cord injury CND category: Acquired brain injury and acquired spinal cord injury **Practitioners working with children with traumatic brain injury and traumatic spinal cord injury, n=20** Age of children with chronic neurological	**Data Collection:** Semi-structured interviews **Analysis:** Thematic content analysis	• Personalisation of rehabilitation programmes, packages, and goals ○ Family-centred care ○ Tailoring of rehabilitation content and support • Transition into and out of rehabilitation services ○ Planning and preparation with people with chronic neurological disorders and carers

Study	Participants	Methods	Themes applied after thematic synthesis
spinal cord injury, including how these systems are family-centred and how they support children through key developmental transitions.	disorders in years [Mean (SD)]: Not reported but all under 18 Sex of children with chronic neurological disorders: Not reported		
Botchway-Commey 2022 General qualitative inquiry Australia, UK, New Zealand, Canada and the US **Aim** To explore how national and international systems are designed to support paediatric traumatic brain injury and traumatic spinal cord injury rehabilitation services, as well as the barriers and facilitators to providing these services.	N=16 practitioners working with children and young people with traumatic brain injury and traumatic spinal cord injury CND category: Acquired brain injury and acquired spinal cord injury Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all under 21 Sex of children and young people with chronic neurological disorders: Not reported	**Data Collection:** See Botchway 2022 **Analysis:** See Botchway 2022	• Integration and co-ordination within and between rehabilitation services ○ Care coordination ○ Communication between services ○ Multi-disciplinary approach • Personalisation of rehabilitation programmes, packages, and goals ○ Family-centred care • Transition into and out of rehabilitation services ○ Co-ordinated discharge planning between services ○ Planning and preparation with people with chronic neurological disorders and carers
Daker-White 2013 General qualitative inquiry UK **Aim** To explore neurological physiotherapy service provision for people with ataxia in North West England.	N=46 adults with progressive ataxia plus practitioners CND category: Acquired brain injury and progressive neurological disease **Adults with progressive ataxia, n=38** Age in years [Mean (SD)]: 52.5 (SD not reported), age range 22-77 Sex (M/F): n=20/n=18	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Acceptability ○ Amount, timing and duration of rehabilitation • Sustainability of rehabilitation and consideration of chronic nature of conditions ○ Long-term follow-up

Study	Participants	Methods	Themes applied after thematic synthesis
	Practitioners working with people with progressive ataxia, n=8 Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported		
Dennett 2020 General qualitative inquiry (within mixed-methods study) UK **Aim** To gather user feedback on a web-based physiotherapy intervention and determine its impact on physical activity.	N=11 adults with multiple sclerosis CND category: Progressive neurological disease Age in years [Mean (SD)]: Not reported, age range 28-68 Sex (M/F): n=1/n=10	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Acceptability ○ Amount, timing and duration of rehabilitation • Acceptability ○ Telehealth/remote delivery
Donovan-Hall 2011 General qualitative inquiry UK **Aim** To explore the experiences of using functional electrical stimulation and views on future use within British clinical practice.	N=36 people with spinal cord injury plus practitioners CND category: Acquired spinal cord injury **People with spinal cord injury, n=20** Age in years: Not reported Sex: Not reported **Practitioners working with people with spinal cord injury, n=16** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data Collection:** Focus groups **Analysis:** Thematic analysis	• Provision of information ○ Accessibility and timing of information ○ Content of information

Study	Participants	Methods	Themes applied after thematic synthesis
Gill 2012 General qualitative inquiry UK **Aim** To explore the experiences of people with acquired brain injury in a community residential rehabilitation setting.	N=7 adults with acquired brain injury CND category: Acquired brain injury Age in years [Mean (SD)]: 37.71 (SD not reported), age range 24-50 Sex (M/F): n=6/n=1	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Acceptability ○ Interactions between professionals and people with chronic neurological disorders • Personalisation of rehabilitation programmes, packages, and goals ○ Tailoring of rehabilitation content and support • Transition into and out of rehabilitation services ○ Gradual discharge and home visits
Grayson 2020 General qualitative inquiry (within mixed-methods study) UK and Australia **Aim** To explore the needs of family members of people with traumatic brain injury in supporting communication, participation, and relationships.	N=102 family members of adults with traumatic brain injury CND category: Acquired brain injury Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported, n=15 aged 16-29, n=40 aged 30-49, n=40 aged 50-69, n=7 aged ≥70 Sex of people with chronic neurological disorders (M/F): n=79/n=23	**Data Collection:** Quantitative survey with free-text question **Analysis:** Thematic content analysis of free-text question	• Provision of information ○ Content of information
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	**Data Collection:** Focus groups and semi-structured interviews **Analysis:** Thematic analysis	• Acceptability ○ Community- and home-based rehabilitation • Provision of information ○ Accessibility and timing of information • Integration and coordination within and between rehabilitation services ○ Care coordination ○ Care navigation ○ Communication between services

Study	Participants	Methods	Themes applied after thematic synthesis
	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		• Sustainability of rehabilitation and consideration of chronic nature of conditions ○ Long-term follow-up
Hartley 2013 General qualitative inquiry (within mixed-methods study) UK **Aim** To explore user experiences of a physiotherapy service within a specialist neuromuscular centre.	N=104 adults with neuromuscular disorders CND category: Progressive neurological disease Age in years [Mean (SD)]: 46.4 (15.1) Sex (M/F): n=70/n=34	**Data Collection:** Quantitative survey with free-text questions **Analysis:** Thematic content analysis of free-text questions	• Provision of information ○ Content of information • Personalisation of rehabilitation programmes, packages, and goals ○ Tailoring of rehabilitation content and support
Holloway 2019 General qualitative inquiry (within mixed-methods study) UK **Aim** To understand the experiences of family members of people with an acquired brain	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	• Acceptability ○ Interactions between professionals and people with chronic neurological disorders • Provision of information ○ Accessibility and timing of information ○ Content of information

Study	Participants	Methods	Themes applied after thematic synthesis
injury in relation to health and social care.	Sex of people with chronic neurological disorders (M/F): n=14/n=96		○ Involving family and friends • Integration and co-ordination within and between rehabilitation services ○ Care coordination • Personalisation of rehabilitation programmes, packages, and goals ○ Family-centred care • Transition into and out of rehabilitation services ○ Co-ordinated discharge planning between services • Sustainability of rehabilitation and consideration of chronic nature of conditions ○ Long-term follow-up
Kumar 2013 General qualitative inquiry (within mixed-methods study) UK **Aim** To explore the views and experiences of people with neuromuscular conditions who use power mobile arm supports.	N=13 people with neuromuscular conditions CND category: Progressive neurological disorder. Age in years [Mean (SD)]: Not reported, age range 13-69 Sex (M/F): n=12/n=1	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Provision of information ○ Content of information
McKevitt 2019 General qualitative inquiry UK **Aim** To explore parents' experiences of paediatric stroke and identify needs and preferences to inform service provision.	N=12 parents of children and young people with stroke CND category: Acquired brain injury Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all within paediatric services	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Acceptability ○ Amount, timing and duration of rehabilitation • Provision of information ○ Content of information • Personalisation of rehabilitation programmes, packages and goals

Study	Participants	Methods	Themes applied after thematic synthesis
	Sex of children and young people with chronic neurological disorders: Not reported		○ Designing holistic rehabilitation programmes • Transition into and out of rehabilitation services ○ Co-ordinated discharge planning between services ○ Planning and preparation with people with chronic neurological disorders and carers • Sustainability of rehabilitation and consideration of chronic nature of conditions ○ Long-term follow-up
McPherson 2018 Grounded theory UK **Aim** To explore the experiences of recovery and adaptation in people with traumatic brain injury and their family members within the initial 2 years after traumatic brain injury.	N=62 adults with traumatic brain injury plus family members CND category: Acquired brain injury **Adults with traumatic brain injury, n=40** Age in years [Mean (SD)]: Not reported, n=12 aged 16-34, n=19 aged 35-64, n=9 aged ≥65 Sex (M/F): n=28/n=12 **Family members of people with traumatic brain injury, n=22** 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:** Grounded theory	• Acceptability ○ Interactions between professionals and people with chronic neurological disorders • Provision of information ○ Content of information • Integration and co-ordination within and between rehabilitation services ○ Care coordination
Mueller 2017 General qualitative inquiry	N=10 adults with traumatic brain injury	**Data Collection:** Semi-structured interviews	• Provision of information

Study	Participants	Methods	Themes applied after thematic synthesis
UK **Aim** To explore the experiences of community-based health and social care provision for people following traumatic brain injury, as well as a novel traumatic brain injury clinic in West London.	CND category: Acquired brain injury Age in years [Mean (SD)]: Not reported, median (IQR) 50 (34) Sex (M/F): n=5/n=5	**Analysis**: Thematic analysis	○ Accessibility and timing of information • Integration and co-ordination within and between rehabilitation services ○ Care navigation • Transition into and out of rehabilitation services ○ Planning and preparation with people with chronic neurological disorders and carers • Sustainability of rehabilitation and consideration of chronic nature of conditions ○ Long-term follow-up
O'Brien 2012 General qualitative inquiry UK **Aim** To explore the experiences of family carers of people with motor neurone disease and identify their needs in support services.	N=28 former and current family carers of people with motor neurone disease 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:** Narrative interviews **Analysis:** Thematic framework analysis	• Provision of information ○ Accessibility and timing of information ○ Content of information
Paguinto 2023 Phenomenological Australia and the US **Aim** To explore the views and experiences of healthcare professionals when discussing wheelchair usage for the first time in children with neuromuscular conditions.	N=21 practitioners working with children and young people with progressive neuromuscular conditions CND category: Progressive neurological disease Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but	**Data Collection:** Semi-structured interviews **Analysis:** Phenomenological analysis	• Acceptability ○ Amount, timing and duration of rehabilitation ○ Interactions between professionals and people with chronic neurological disorders • Provision of information ○ Accessibility and timing of information

Study	Participants	Methods	Themes applied after thematic synthesis
	all within paediatric services Sex of children and young people with chronic neurological disorders: Not reported		○ Content of information • Integration and coordination within and between rehabilitation services ○ Multi-disciplinary approach • Personalisation of rehabilitation programmes, packages, and goals ○ Tailoring of rehabilitation content and support
Pollock 2022 General qualitative inquiry Australia, UK and New Zealand **Aim** To explore how rehabilitation services for children and young people with traumatic brain injury and/or traumatic spinal cord injury, and insurance services, amended their delivery during the Coronavirus pandemic.	N=15 practitioners working with children and young people with traumatic brain injury and traumatic spinal cord injury CND category: Acquired brain injury and acquired spinal cord injury Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all under 21 Sex of children and young people with chronic neurological disorders: Not reported	**Data Collection:** See Botchway 2022 **Analysis:** See Botchway 2022	• Acceptability ○ Telehealth/remote delivery
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 or carers and practitioners CND category: Progressive neurological disease **Adults with multiple sclerosis, n=30** Age in years [Mean (SD)]: Not reported, age range 31-63 (median 49) Sex (M/F): n=7/n=23	**Data Collection:** Focus groups **Analysis:** Grounded theory	• Acceptability ○ Community- and home-based rehabilitation ○ Interactions between professionals and people with chronic neurological disorders • Provision of information ○ Content of information • Integration and coordination within and between rehabilitation services

Study	Participants	Methods	Themes applied after thematic synthesis
	Partners or carers of people with multiple sclerosis, n=10 Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported **Practitioners working with people with multiple sclerosis, n=6** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported		○ Multi-disciplinary approach • Personalisation of rehabilitation programmes, packages, and goals ○ Tailoring of rehabilitation content and support
Rashid 2018 General qualitative inquiry Canada **Aim** To explore the views and experiences of healthcare professionals working with children with acquired brain injury in relation to families' needs throughout rehabilitation.	N=15 practitioners working with children and young people with acquired brain injury CND category: Acquired brain injury Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all within paediatric service Sex of children and young people with chronic neurological disorders: Not reported	**Data Collection:** Focus groups **Analysis:** Framework analysis	• Provision of information ○ Format of information • Integration and coordination within and between rehabilitation services ○ Care coordination ○ Multi-disciplinary approach • Personalisation of rehabilitation programmes, packages and goals ○ Designing holistic rehabilitation programmes
Salas 2021 General qualitative inquiry UK **Aim**	N=12 adults with traumatic brain injury CND category: Acquired brain injury Age in years [Mean (SD)]: 49 (9.2)	**Data Collection:** Semi-structured interviews **Analysis:** Thematic analysis	• Sustainability of rehabilitation and consideration of chronic nature of conditions ○ Continued support

Study	Participants	Methods	Themes applied after thematic synthesis
To explore the reasons why people with chronic traumatic brain injury attend Headway and their experiences of activities offered by the centre, and to propose a theoretical long-term social rehabilitation programme model for traumatic brain injury.	Sex (M/F): n=10n=/12		
Setchell 2018 Ethnographic Canada **Aim** To explore how a neuromuscular clinic addresses human aspects of muscular dystrophy rehabilitation, and to pilot procedures to increase this aspect of delivery.	N=27 children and young people with neuromuscular dystrophy plus practitioners CND category: Progressive neurological disease **Children and young people with neuromuscular dystrophy, n=15** Age in years [Mean (SD)]: Not reported, age range 8-17 Sex: Not reported **Practitioners working with children and young people with neuromuscular dystrophy, n=12** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all within paediatric service Sex of children and young people with chronic neurological disorders: Not reported	**Data Collection:** Ethnographic observation of clinical appointments and team discussions **Analysis:** Thematic analysis	• Acceptability ○ Interactions between professionals and people with chronic neurological disorders • Personalisation of rehabilitation programmes, packages, and goals ○ Designing holistic rehabilitation programmes ○ Family-centred care
Shore 2022 General qualitative inquiry (within mixed-methods study)	N=6 children and young people with concussion plus parents CND category: Acquired brain injury	**Data Collection:** Semi-structured interviews **Analysis:** Inductive thematic analysis	• Acceptability ○ Community- and home-based rehabilitation

Study	Participants	Methods	Themes applied after thematic synthesis
Canada **Aim** To explore user views and experiences regarding the remote delivery of the Tele-Active Rehabilitation intervention, as well as what worked well and the benefits of the programme.	**Children with concussion, n=3** Age in years [Mean (SD)]: Not reported, age range 14-17 Sex (M/F): n=1/n=2 **Parents of children and young people with concussion, n=3** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: As above Sex of children and young people with chronic neurological disorders (M/F): As above		○ Telehealth/remote delivery • Provision of information ○ Accessibility and timing of information • Personalisation of rehabilitation programmes, packages, and goals ○ Tailoring of rehabilitation content and support
Sixsmith 2014 General qualitative inquiry UK **Aim** To explore the experiences of people with long-term neurological conditions and service providers regarding the implementation of the National Service Framework for Long-term Neurological Conditions.	N=95 adults with long-term neurological conditions plus practitioners CND category: Acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorder, and progressive neurological disease **Adults with long-term neurological conditions, n=50** Age in years [Mean (SD)]: Not reported, age range 20-79 Sex (M/F): n=29/n=21 **Practitioners working with people with long-term conditions, n=45** Age of people with chronic neurological disorders in years: Not reported	**Data Collection:** Semi-structured interviews. **Analysis:** Thematic analysis.	• Acceptability ○ Amount, timing and duration of rehabilitation ○ Community- and home-based rehabilitation ○ Opportunity for feedback • Integration and coordination within and between rehabilitation services ○ Communication between services • Sustainability of rehabilitation and consideration of chronic nature of conditions ○ Continued support

Study	Participants	Methods	Themes applied after thematic synthesis
	Sex of people with chronic neurological disorders: Not reported		
Spurgeon 2015 Phenomenological UK **Aim** To explore the experiences of people with Parkinson's disease regarding speech and language therapy, to inform potential therapy programmes and outcomes.	N=9 adults with idiopathic Parkinson's disease CND category: Progressive neurological disease Age in years [Mean (SD)]: Not reported, age range 54-76 Sex (M/F): n=7/n=2	**Data Collection:** Semi-structured interviews **Analysis:** Thematic network analysis	• Acceptability ○ Interactions between professionals and people with chronic neurological disorders
Thomson 2015 Grounded theory UK **Aim** To explore how analogies and props can facilitate interactions between staff and people with multiple sclerosis, to inform improvements to a multiple sclerosis outpatient service.	N=13 people with multiple sclerosis plus practitioners CND category: Progressive neurological disease **People with multiple sclerosis, n=5** Age of people with chronic neurological disorders in years: Not reported Sex (M/F): n=2/n=3 **Practitioners working with people with multiple sclerosis, n=8** Age of people with chronic neurological disorders in years: Not reported Sex of people with chronic neurological disorders: Not reported	**Data Collection:** Focus groups **Analysis:** Grounded theory	• Provision of information ○ Format of information
Twigg 2021 Case study	N=2 (1 adult with POEMS syndrome plus carer)	**Data Collection:** Semi-structured interviews	• Integration and coordination within and between rehabilitation services

Study	Participants	Methods	Themes applied after thematic synthesis
UK **Aim** To understand the lived experience of a person with a rare condition (POEMS syndrome) including their experiences of health care.	CND category: Progressive neurological disease **Adult with POEMS syndrome, n=1** Age in years: 71 Sex (M/F): n=0/n=1 **Carer of adult with POEMS syndrome, n=1** Age of people with chronic neurological disorders in years [Mean (SD)]: As above Sex of people with chronic neurological disorders (M/F): As above	**Analysis:** Constant comparative approach	○ Communication between services • Personalisation of rehabilitation programmes, packages, and goals ○ Tailoring of rehabilitation content and support • Transition into and out of rehabilitation services ○ Planning and preparation with people with chronic neurological disorders and carers

CND: chronic neurological disorder; IQR: interquartile range; PCT: primary care trust; 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

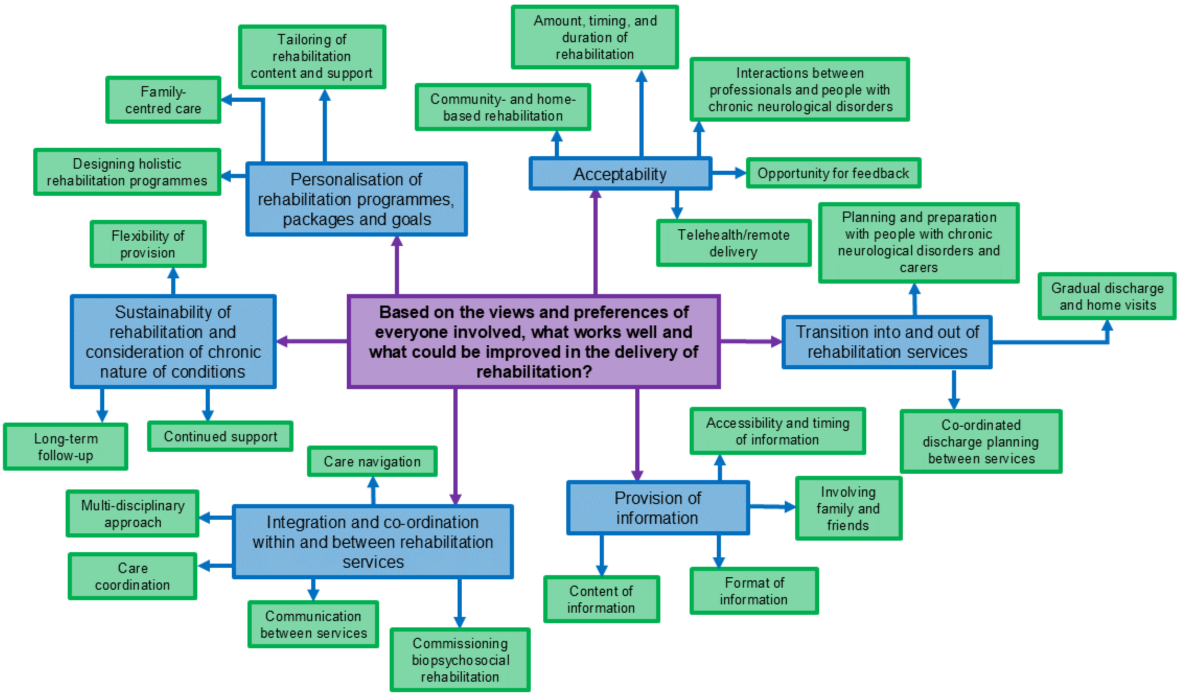
The synthesis of the evidence generated the following 6 main themes:

- A1 Acceptability
- A2 Provision of information
- A3 Integration and co-ordination (including communication and case management practices) within and between rehabilitation services
- A4 Personalisation of rehabilitation programmes, packages, and goals
- A5 Transition into and out of rehabilitation services
- A6 Sustainability of rehabilitation and consideration of chronic nature of conditions

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 ‘A’) 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 what works well and what can be improved in the delivery of rehabilitation for chronic neurological disorders



A1 Acceptability

Five sub-themes were identified under acceptability. In the ‘A1.1 Amount, timing, and duration of rehabilitation’ sub-theme (moderate confidence), evidence from 6 studies showed that people with chronic neurological disorders were not satisfied with short rehabilitation programmes only designed to address particular issues and for a finite period. In the ‘A1.2 Community- and home-based rehabilitation’ sub-theme (moderate confidence), evidence from 4 studies showed that providing some aspects of rehabilitation in either home or community, rather than inpatient settings, was more convenient and comfortable for people with chronic neurological disorders. In the ‘A1.3 Interactions between professionals and people with chronic neurological disorders’ sub-theme (moderate confidence), evidence from 9 studies showed that people with chronic neurological disorders found services more acceptable when they were able to build strong and long-lasting relationships with practitioners because this made them feel more supported. In the ‘A1.4 Opportunity for feedback’ sub-theme (low confidence), evidence from 1 study showed that people with chronic neurological disorders did not always feel empowered to feed back about their rehabilitation experiences, which meant gaps in services were not identified. In the ‘A1.5 Telehealth/remote delivery’ sub-theme (moderate confidence), evidence from 4 studies showed that remote delivery was a convenient way of delivering rehabilitation and monitoring people in the community, but it also presented some engagement and safeguarding issues.

A2 Provision of information

Four sub-themes were identified under provision of information. In the ‘A2.1 Accessibility and timing of information’ sub-theme (moderate confidence), evidence from 8 studies showed that people with chronic neurological disorders wanted rehabilitation services to provide easily accessible and timely information. In the ‘A2.2 Content of information’ sub-theme (low confidence) evidence from 11 studies showed that people with chronic neurological disorders required information to cover a range of areas (for example, information on their condition and how to navigate the rehabilitation system). In the ‘A2.3 Format of information’ sub-theme (very low confidence), evidence from 2 studies showed that information should be provided in multiple formats to people with chronic neurological disorders. In the ‘A2.4 Involving family and friends' sub-theme (very low confidence), evidence from 1 study showed that information should also be given to family and friends in order to help them better support people with chronic neurological disorders.

A3 Integration and co-ordination within and between rehabilitation services

Five sub-themes were identified under integration and co-ordination within and between services. In the ‘A3.1 Care co-ordination’ sub-theme (high confidence), evidence from 7 studies showed that people with chronic neurological disorders appreciated having a single point of contact or key worker to coordinate their care between and within services. In the ‘A3.2 Care navigation’ sub-theme (moderate confidence), evidence from 3 studies showed that people with chronic neurological disorders needed assistance in navigating the rehabilitation system. In the ‘A3.3 Commissioning biopsychosocial rehabilitation’ sub-theme (high confidence), evidence from 1 study showed that rehabilitation services should concentrate on providing a holistic rehabilitation service, and this should be integrated into commissioning goals. In the ‘A3.4 Communication between services’ sub-theme (moderate confidence), evidence from 6 studies showed that poor communication between services causes a lack of continuity in rehabilitation delivery. In the ‘A3.5 Multi-disciplinary approach’ sub-theme (moderate confidence), evidence from 5 studies showed that a multi-disciplinary approach, encompassing a breadth of expertise was needed to provide effective rehabilitation for chronic neurological disorders.

A4 Personalisation of rehabilitation programmes, packages, and goals

Three sub-themes were identified under this theme. In ‘A4.1 Designing holistic rehabilitation programmes’ sub-theme (moderate confidence), evidence from 3 studies showed that rehabilitation services were often exclusively focused on the biomedical aspects of care at the expense of addressing emotional and psychological needs. In the ‘A4.2 Family-centred care’ sub-theme (moderate confidence), evidence from 3 studies showed that rehabilitation services needed to include the entire family to deliver effective rehabilitation, especially for children and people who may lack mental capacity. In the ‘A4.3 Tailoring of rehabilitation content and support’ sub-theme (high confidence), evidence from 8 studies showed that people with chronic neurological disorders were unhappy with generic rehabilitation packages that failed to focus on their needs and rehabilitation goals.

A5 Transition into and out of rehabilitation services

Three sub-themes were identified under transition into and out of rehabilitation services. In the ‘A5.1 Co-ordinated discharge planning between services’ sub-theme (high confidence), evidence from 5 studies showed that people often received poorly coordinated rehabilitation delivery when transferring between services and settings, which could result in them not receiving appropriate care for a period of time. In the ‘A5.2 Gradual discharge and home visits’ sub-theme (moderate quality), evidence from 2 studies showed that people found home visits useful and that there was a gradual decrease in support when moving back into the community from inpatient rehabilitation. In the ‘A5.3 Planning and preparation with people with chronic neurological disorders and carers sub-theme (high confidence), evidence from 5 studies showed that failing to include people with chronic neurological disorders and their carers in discharge planning resulted in confusion and needs being unmet in new settings.

A6 Sustainability of rehabilitation and consideration of chronic nature of conditions

Three sub-themes were identified under this theme. In the ‘A6.1 Continued support’ sub-theme (low confidence), evidence from 3 studies showed that people with chronic neurological disorders want continuous and consistent access to support networks. In the ‘A6.2 Flexibility of provision’ sub-theme (moderate confidence), evidence from 1 study showed that a flexible approach to rehabilitation provision better suited the long-term nature of chronic neurological disorders. In the ‘A6.3 Long-term follow-up’ sub-theme (moderate confidence), evidence from 6 studies showed that people with chronic neurological disorders prefer to have a long-term follow-up, complete with regular review appointments and ongoing contact with rehabilitation services.

See appendix F for full GRADE-CERQual tables.

Economic evidence

Included studies

In the development of this qualitative review, 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 works well and what can be improved in the delivery of rehabilitation, 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.

- Acceptability. For example, how people view positive interactions between people with chronic neurological disorders and practitioners, how acceptable people find different settings of care in which rehabilitation can be delivered, and the timing or duration of rehabilitation.
- Provision of information. For example, how people are given rehabilitation information in relation to their condition and additional support.
- Integration and co-ordination within and between rehabilitation services. For example, people’s experiences of care and support provided by multiple practitioners or teams (including communication and case management practices).
- Personalisation of rehabilitation programmes, packages and goals. For example, how people viewed the appropriateness of their rehabilitation programme to their individual needs, circumstances and preferences.
- Transition into and out of rehabilitation services. For example, experiences of discharge from rehabilitation services and improvements that could be made to make transfers smoother.
- Sustainability of rehabilitation and consideration of chronic nature of conditions. For example, how supported people feel once they have been discharged from a rehabilitation service, self-management support or rehabilitation provision within end-of-life care.

- Equalities considerations. For example, how people's experiences of delivery and engagement with rehabilitation services may differ with gender, race, co-morbidities, communication difficulties, and physical or learning disabilities

These themes were chosen as they were expected to be the key aspects that inform opinion and preferences about the way in which rehabilitation services for chronic neurological disorders should be delivered.

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 high to very low, with the majority being judged as moderate.

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 to relevance concerns (for example, when themes only used findings on specific rehabilitation therapies or services, or if they included participants who were outside of the protocol population). Studies were also downgraded due to coherence of themes (for example, when themes included both positive and negative findings) and concerns over adequacy (for example, when only 3 studies contributed moderately rich data to a theme, or only 1 study contributed very rich data to a theme).

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

- Equality considerations

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

Benefits and harms

Service design

Through their discussions on the evidence presented in this review, the committee kept returning to the principle of rehabilitation being holistic and involving collaboration between a wide range of individuals. This was reflected in high quality evidence from the theme 'A3.3 Commissioning biopsychosocial rehabilitation', which showed that holistic rehabilitation requires collaboration between a wide range of organisations and services, and that these sectors should all be represented in the delivery model to be effective. The committee agreed that coproduction should be a value highlighted from the very beginning in order to fully delivery a biopsychosocial model of care. Therefore, they recommended that service users and health and care professionals be involved in designing rehabilitation services and care pathways.

The committee discussed low quality evidence from the theme 'A1.4 Opportunity for feedback', which showed that some people with chronic neurological disorders did not feel empowered to raise feedback suggestions, meaning that gaps in rehabilitation service delivery remained unidentified. The committee agreed with this theme, adding that their experience showed that not all forms of feedback are appropriate for all people. Therefore, they recommended that commissioners should ensure that feedback is sought proactively by rehabilitation services, and that this should be in an inclusive format.

The committee discussed evidence from 5 themes when considering recommendations what specifics rehabilitation services should encompass. Moderate quality evidence from the theme 'A1.1 Amount, timing, and duration of rehabilitation' showed that early rehabilitation targeted at prevention was also not regularly offered. Instead, rehabilitation was only offered once symptoms started to affect functioning. Additionally, rehabilitation for chronic neurological disorders was often only provided as short-term programmes designed to address particular symptoms. This was supported by moderate quality evidence from the theme ‘A6.3 Long-term follow-up’ showed that people with chronic neurological disorders would like long-term follow-up for their rehabilitation, with a regular review from specialist services. The committee agreed with both findings, and recommended that local service design should consider rehabilitation services from initial presentation of symptoms or impairments, and with a life-long approach in mind. This will encompass the need for any further rehabilitation to be anticipated, allowing timely access to services when needed. High quality evidence from the theme ‘A3.3 Commissioning biopsychosocial rehabilitation’ showed that an effective delivery model should encompass healthcare, social care, and the voluntary sector. Therefore, the committee recommended that design of services should be across all settings, and include a combination of specialist neurorehabiliation and general rehabilitation services. Moderate quality evidence from the theme ‘A6.2 Flexibility of provision’ showed that a flexible approach to rehabilitation delivery (that is, ongoing access to rehabilitation services with periods of increased support around changing rehabilitation needs) was preferable to people with chronic conditions. Further moderate quality evidence from the theme ‘A1.2 Community- and home-based rehabilitation’ showed that it was helpful for service delivery for some aspects of rehabilitation to be delivered in the community or at home rather than always being provided in a clinical setting. Both themes reflected the committee’s experiences and expertise, and were supported by the other themes discussed previously. Therefore, the committee recommended designing collaborative and flexible clinical pathways that span settings (clinical and community) and a person’s life course (paediatric and adult).

Finally, in the committee’s experience, there is a lack of clarity regarding which organisation is locally responsible for the coordination of these large, multi-service rehabilitation pathways. Therefore, the committee recommended that this be clarified to avoid confusion, and that clearly accountable leads be nominated for both adults and children’s services.

The committee discussed that some additional resources may be needed to implement some of these recommendations (for example, involving service users and practitioners in designing rehabilitation services and pathways). However, this should not cause a significant resource impact as solutions are generally low-cost. Additionally, instances of service design co-production are already in place in some rehabilitation services, so may not need to be implemented in each area. Commissioning rehabilitation services and service specifications

The committee discussed high quality evidence from the theme ‘A3.3 Commissioning biopsychosocial rehabilitation’, which showed that commissioners should focus on a holistic rehabilitation approach across involved sectors (including healthcare, social care, and voluntary) and involved organisations. Further moderate evidence from the theme ‘A4.1 Designing holistic rehabilitation programmes’ showed that people with chronic neurological disorders did not feel as though they were receiving truly holistic care when their rehabilitation provision was concentrated around their physical disabilities at the expense of their emotional and cognitive symptoms. The committee agreed that commissioners and those responsible for budgets within integrated care systems should be encouraging a biopsychosocial approach to rehabilitation for chronic neurological disorders within their services, and that required prodicing service specifications to build capacity in all areas of rehabilitation so they can be drawn upon as needed. The committee then used their expertise and experience to set out the elements of expenditure which should be included in local area service specifications in order to commission integrated care. The committee drew on areas covered by evidence reviews D to O to inform this recommendation, including the elements required to form an integrated service and deliver the recommendations set out in this guideline.

Building local capacity and growing expertise

The committee discussed moderate quality evidence from the theme ‘A3.4 Communication between services’, which showed that poor continuity of care between services was often due to poor communication, especially when transitioning between public and private healthcare services. The committee agreed that poor communication was an issue, but organisational barriers mean that this can be quite difficult to overcome in practice. For example, electronic patient notes should be a way to increase communication between services, but incompatible software between services can make it impossible. Therefore, the committee recommended collaboration between services starting with the commissioning bodies from different sectors making decisions together to enhance communication between individual services. This should include health and social care, but also other services that will be need to deliver rehabilitation or communicate with rehabilitation in the community (for example, education services).

Providing responsive services

The committee discussed high quality evidence from the theme ‘A5.1 Co-ordinated discharge planning between services’, which showed that provision of rehabilitation for chronic neurological disorders is poorly coordinated when transferring between services, leading to a lack of care continuity and poorer physical and mental functioning outcomes. The committee agreed with this evidence, noting that this lack of coordination is normally due to poor communication between different services. Therefore, they recommended that different service providers throughout the rehabilitation pathway (including voluntary and private sectors) communicate and collaborate in order to be responsive and to better support people transitioning between settings (for example, following changes in their health, between key life stages, starting a new job role, or moving into residential care). These communication channels and areas of collaborative decision making should be built into service design in order for them to be as effective as possible.

The committee discussed moderate quality evidence from the theme ‘A3.2 Care navigation’, which showed that people with chronic neurological disorders would like help navigating the rehabilitation system. Further moderate quality evidence from the theme ‘A6.2 Flexibility of provision’ showed that people with chronic neurological diseases prefer ongoing access and low-grade contact with rehabilitation services, with the option for periods of increased intensity contact as needed. The committee’s experience agreed with both themes, noting that rehabilitation for chronic conditions can sometimes feel like an overbearing presence in an individual’s life. However, they also highlighted that there needs to be a reliable and simple process in place to enable timely re-access to rehabilitation services, including self-referral methods. Without this, there is a possibility of people being left without the rehabilitation care they need during relapses or when they identify emerging rehabilitation needs. Therefore, the committee recommended that clear referral and re-referral (including self-referral) methods should be implemented to allow for quick and easy access to appropriate rehabilitation services when needed, and that this should extend after discharge. The committee also recommended that rehabilitation services kept this possible need for increased capacity and expertise in mind when planning resources, as they may find themselves facing short-term above-average demand on their services.

Please note that these recommendations also based on evidence from evidence review B, where the remainder of the committee’s discussion can be found.

Early discussion about prognosis and rehabilitation

The committee discussed high quality evidence from the theme ‘A3.1 Care coordination’, which showed that people with chronic neurological disorders wanted a point of contact throughout rehabilitation to help coordinate their care across services, and healthcare and social care. The committee agreed that rehabilitation for chronic neurological disorders is a very complex system of different services and organisations. Additionally, many people accessing these services will be experiencing cognitive difficulties as a result of their disorder, which makes organising their care even more difficult. Therefore, the committee recommended that people be assigned a contact to act as a focus for advice, information on, or help navigating rehabilitation services. This should be done at the beginning of rehabilitation, following diagnosis or initial treatment, even if a rehabilitation needs assessment is not being initiated at this point. A person’s primary care practitioner will also need to be informed, to ensure they know who to contact for future information on a person’s condition or rehabilitation plan. Please note that this recommendation also uses evidence from evidence review B, where the remainder of the committee’s discussion can be found.

Hospital discharge

The committee discussed high quality evidence from the theme ‘A3.1 Care coordination’, which showed that people with chronic neurological disorders wanted a single point of contact to provide them with information about their condition, what services are available to them, and to coordinate care. This was supported by further high quality evidence from the theme ‘A5.3 Planning and preparation with people with chronic neurological disorders and carers’, which showed that lack of information or provision of contradictory information at discharge led to unmet needs in new settings. The committee agreed with both findings, and noted that appointing a key clinical contact and a contact for rehabilitation from the time of discharge would increase continuity of care during this period of transition and moving forward throughout rehabilitation. It is important for this to occur as early as possible in order to anticipate future rehabilitation needs and increase the chance for early intervention to prevent functional deteriorate and more invasive interventions. The committee noted that rehabilitation needs assessments and rehabilitation provision may already have started prior to a person being discharged from hospital. In these cases, a professional within the inpatient multidisciplinary team would have already been acting as a point of contact. However, it is unlikely that this would be able to continue to help coordinate care once in a community or residential setting. Therefore, all teams involved in a person’s rehabilitation delivery and planning should agree a professional who is most appropriate to continue this role outside of the hospital setting. The committee agreed with the evidence that reported this person did not need to be a rehabilitation professional. However, they do need to have a good knowledge of an individual’s condition, their rehabilitation needs, and the local and national services available to them. The committee used their experience and expertise to list who might be able to fulfil this role (for example, clinical nurse specialist, social worker, or neuro-navigator).

The committee discussed high quality evidence from the theme ‘A5.1 Co-ordinated discharge planning between services’, which showed that poor coordination when transitioning between services often mean that receiving services were not appropriately informed of rehabilitation needs, leading to delays in rehabilitation delivery. This was supported by further high quality evidence from the theme ‘A5.3 Planning and preparation with people with chronic neurological disorders and carers, which showed that lack of transition planning with individuals and their support units ultimately led to unmet needs in new settings. The committee agreed with both themes, noting that the process of getting equipment and adaptations ordered and installed often takes far longer than people appreciate. A consequence of this is that people may be left in inpatient settings for longer than they need to be. Therefore, they recommended that this provision of equipment and environmental adaptations is arranged as soon as possible, ideally as soon as rehabilitation needs are identified, to increase the chances that they are available when the person is ready to be discharged. Please note that this recommendation also use evidence from evidence review B, where the remainder of the committee’s discussion can be found.

Holistic rehabilitation needs assessment

Initiating a rehabilitation needs assessment and who to involve

The committee discussed moderate quality evidence from the theme ‘A4.2 Family-centred care’ which showed that rehabilitation planning and delivery should include the whole family unit to achieve the best outcomes for people with chronic neurological disorders. The committee agreed with this theme, but noted that family could mean different things to different people. Therefore, they recommended identifying people who are most important to individuals undergoing rehabilitation and confirm how people with chronic neurological disorders would prefer them to be involved in their rehabilitation.

What to cover

The committee discussed moderate quality evidence from the theme ‘A4.1 Designing holistic rehabilitation programmes’, which showed that rehabilitation appointments were heavily focused on biomedical functioning, with emotional well-being and mental health seeming less important. The committee agreed that it is often the neurological condition or injury itself that is the main focus in rehabilitation delivery, which is correct, but other co-morbidities will still have a significant impact on the rehabilitation process and should not be forgotten. For example, if a person has depression, it may be quite difficult to engage in rehabilitation early in the morning when symptoms are more prominent. The committee therefore recommended that in addition to their neurological condition or injury, considering how other health or mental health conditions may affect rehabilitation is important.

The committee discussed moderate quality evidence from the theme ‘A4.1 Designing holistic rehabilitation programmes’, which showed that rehabilitation appointments were heavily biased towards biomedical functioning, and resulting rehabilitation plans were not holistic. Additional high quality evidence from the theme ‘A4.3 Tailoring of rehabilitation content and support’ showed that people with chronic neurological disorders wanted a rehabilitation programme that was bespoke to them and their preferences, rather than the generic programmes that were normally offered by services. The committee agreed with both of these themes, and started off by recommending that practitioners assess the full range of domains included in this guideline to develop a complete baseline profile that can be used to inform a person’s rehabilitation plan. Alongside this, practitioners should ask supplementary questions to understand how this rehabilitation plan could be properly embedded in a person’s daily life. People are more likely to engage in rehabilitation if they believe that it will improve all aspects of their functioning, if it includes goals and activities that are important to them, and if it takes into consideration short- and long-term variations of functioning, needs and abilities. Finally, the committee recommended assessing rehabilitation needs to allow full participation in daily life and signposted readers to subsequent guideline sections for further recommendations covering support for education, work, leisure and personal relationships. Please note that this recommendation also uses evidence from evidence review C, where the remainder of the committee’s discussion can be found.

Agreeing and delivering a coordinated rehabilitation plan

The committee discussed moderate quality evidence from the theme A1.1 Amount, timing, and duration of rehabilitation’, which showed that people with chronic neurological disorders were dissatisfied with the short time frame of many rehabilitation programmes, noting that these were often only designed to address discrete complaints. Early rehabilitation was not regularly offered, so people with mild or moderate symptoms had to wait for their disabilities to progress before being able to access rehabilitation. The committee agreed with this theme, and noted that concerns of timing and intensity of rehabilitation can also cause people to feel overloaded and disengaged. This is particularly true when considering the probability that people will be receiving rehabilitation for several different domains within their holistic rehabilitation plan. Therefore, the committee recommended that timing, intensity, and frequency of interventions should be discussed and approved before being included in rehabilitation plans. Similarly, professionals should also consider how different interventions will interact within the proposed rehabilitation plan. Practitioners will also have to consider how to modify interventions so they remain appropriate to an individual (for example, factoring in a person’s developmental age or cogntive strengths). Please note that this recommendation also uses evidence from evidence review C, where the remainder of the committee’s discussion can be found.

The committee discussed moderate quality evidence from the theme ‘A1.2 Community- and home-based rehabilitation’, which showed that some people with chronic neurological disorders prefer rehabilitation to be delivered in a mixture of home, community and clinical settings. The committee agreed that varying delivery settings is important, as it allows for skills to be practiced in different environments and for new rehabilitation needs to emerge in different contexts. However, in their experience, this setting should be the most appropriate according to a person's goals and preferences (for example, school or remotely), not just the 3 mentioned in the finding.

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

The committee discussed high quality evidence from the theme 'A3.1 Care coordination' which showed that people wih chronic neurological disorders preferred to have a single point of contact that can help them with information and coordinate their rehabilitation (especially across teams and between health and social care). This was supported by additional moderate quality evidence from the theme 'A3.2 Care navigation', which showed that people wanted assistance with navigating a complex and convoluted neurological rehabilitation system. Additional moderate quality evidence from the theme 'A1.3 Interactions between professionals and people with chronic neurological disorders', which showed that people appreciated the opportunity to build rapport and long-term relationships with rehabilitation providers. Therefore, the committee recommended providing people with chronic neurological disorders a key contact or key worker (depending on the level of their support needs) to fulfil these education, coordination and navigation needs, as well as to provide a consistent professional contact with which to start to build a relationship. The committee went on to consider who will need a lower intensity key contact and who should be receiving higher intensity support from key workers. This will depend on the capability of the individual with the chronic neurological disorder but professionals should take into account the nature of potential coordination, the intensity needed, level of navigation, and required support (for example, is advocacy going to be a responsibility) before agreeing who is best to serve as this single point of contact. The committee used their experience and expertise to note several groups of people who would benefit from a higher-intensity key worker model (for example, people with impaired cognitive functioning or people with multiple rehabilitation needs across multiple services). Please note that this recommendation also uses evidence from evidence review C, where the remainder of the committee's discussion can be found.

After the rehabilitation plan

Moderate quality evidence from the theme 'A6.2 Flexibility of provision' showed that people with chronic neurological disorders preferred to have a flexible service delivery for rehabilitation. They wanted low-grade contact during the times when their condition and rehabilitation needs were stable, with easy referral and a quick access back into services if needed. This was supported by low quality evidence from the theme 'A6.1 Continued support', which showed that people like continuous access to support networks during periods of time when they had reduced contact with rehabilitation services. Moderate quality evidence from the theme 'A6.3 Long-term follow-up' showed that people with chronic neurological disorders would like long-term follow-up, including regular review and follow-up appointments with key specialist centres and practitioners. General follow-up in the community can then be used to supplement contact with healthcare services. The committee agreed with these themes, noting that they all highlighted a core principle of follow-up for chronic neurological disorders, that of safe but sustainable contact and access during a person's life span. The committee noted that, before follow-up and the review process could be determined, a continuing single point of contact needed to be nominated (for example, key contact, key worker, or complex case manager) in order to facilitate the coordination of potential future rehabilitation. This will need to be communicated to individuals if the professional will be changing. After this has been done, a decision will need to happen regarding whether a follow-up appointment is needed. This will be different for each individual, their disorder, and their rehabilitation needs, but should consider future anticipated needs, a person's ability to contact services if rehabilitation needs change, and the support (both formal and informal) surrounding an individual. In order to ensure proper communication and coordination, it should also be agreed which practitioners will need to be involved in reviewing rehabilitation needs so they can be informed of the review schedule. The committee were aware that rehabilitation needs and preferences of children and young people will change as they grow and develop. Therefore, follow-ups and reviews should be planned around these milestones to capture any amendments to a child or young person's rehabilitation needs and goals. Professionals will also need to continue adapting support, information and complexity of rehabilitation discussions in line with a child's chronological and neurodevelopmental age. Finally, access to identified equipment and technology, as well as consistent advice, should be ensured before active rehabilitation provision ends.

Information, advice and learning as part of rehabilitation

The committee discussed several themes on the provision of information to people with chronic neurological disorders. Moderate quality evidence from the theme 'A2.1 Accessibility and timing of information' showed that people wanted information to be easily accessible and timely, and highlighted transition between services as a time period where information was very beneficial. Low quality evidence from the theme 'A2.2 Content of information' showed that people with chronic neurological disorders would like information on a variety of rehabilitation topics, including more details on how specific therapies and equipment available. Finally, very low quality evidence from the theme 'A2.4 Involving family and friends' showed that people wanted this information to be conveyed to family and friends in order to integrate them into delivery of rehabilitation. The committee agreed with all findings, which highlighted the importance of education in rehabilitation for chronic neurological disorders. In their experience, provision of information should not be a passive action where services are expecting people to request it from them. As shown by the example given in the evidence, the committee noted that this is especially important during periods of change and transition. Additionally, this information should not be a generic offering but should be individualised to the person, their rehabilitation needs, and their circumstances. The committee also recommended providing coordinated education and training, in order to include a practical application of information gained and increase people's confidence in their gained knowledge (for example, use of memory aids for independent living alongside training in cognitive memory strategies). Despite the evidence, they did not explicitly include friends in these recommendations, as most friends will not be involved in the delivery of rehabilitation to this extent. However, as noted in previous recommendations, identified friends should be involved if the person with a chronic neurological disorder so wishes.

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 some additional resources may be needed to facilitate the involvement of service users and health and care practitioners in the design and development of rehabilitation services and clinical pathways, and to seek their feedback. However, this is not expected to require significant additional resources. For example, some rehabilitation services already seek feedback from people with chronic neurological disorders regarding their rehabilitation experiences. These initiatives are generally low cost, for example, utilising electronic feedback questionnaires that can be widely used.

The committee discussed the problem of inconsistent provision, where people often do not receive the right care at the right time. They either get comprehensive rehabilitation in inpatient settings or none in the community, leading to poor outcomes. For chronic neurological problems, executive function is often impaired, and rehabilitation needs develop over time. These needs emerge in real-world environments where skills are used, but community support and services are currently lacking. Designing rehabilitation services as recommended may require additional resources and put pressure on existing services. However, the committee discussed that this could largely be implemented by repurposing existing funds. Early neurorehabilitation can improve functional outcomes, independence, and reduce long-term healthcare service utilisation. By addressing impairments and promoting recovery early, individuals may need fewer interventions, hospital admissions, and ongoing care. The committee was of a view that early rehabilitation is especially likely to be cost effective for children and young people, who may experience lifetime benefits. The committee further discussed that inpatient care is expensive, so some provision could be effectively diverted to community-based support, aligning with the NHS England community rehabilitation model. Also, the committee explained that many services have already adopted hybrid models, delivering interventions in various settings such as homes, community settings, or remotely, potentially mitigating some of the resource impact.

The committee discussed that while there are good services and pathways for severe neurological problems, there are significant gaps for moderate and mild conditions. Also, generally, there are no well-established pathways beyond inpatient services, and the situation is worse for children and young people. Only one pathway exists in the UK for acute to post-acute care for children and young people (in Cambridge).

The committee further discussed that existing pathways are often flawed, and services either do not exist or operate in silos. Rehabilitation is not a stepped progression for most, and people enter different services at various ages, needing flexibility in pathways. There is a clinical need for flexible pathways and integrated services. They explained that the lack of flexible pathways and current service configurations lead to wasted resources, inefficiencies, delays in care, and reliance on expensive emergency, hospital, or residential care. Unaddressed rehabilitation needs significantly impact other public resources, including the criminal justice sector, employment, and mental health services.

The committee discussed the lack of accountability and clarity regarding responsibility for provision. Therefore, agreeing on who has overall designated responsibility for implementing clinical pathways is crucial for the successful implementation of this guidance. This will facilitate consistency and coordination between services, ensuring people receive the right care at the right time. It will also lead to more efficient use of resources, avoiding duplication, and directing resources where they are most needed. They discussed that effectively implemented pathways can reduce reliance on unplanned care, unnecessary interventions, and long-term costs by ensuring timely care.

The committee noted the complexity of services, issues with timely re-access to services, and many having impaired executive function. They agreed that the most feasible approach to overcome these issues is to have a designated practitioner. This individual would serve as a single point of contact to streamline communication and coordinate care.

The committee discussed that a key contact or key worker role could be achieved by nominating an existing practitioner, which does not imply creating a new role or significant resource impact. However, there is a lack of complex case managers within the NHS, and ensuring their provision, even for those with the most complex needs, is likely to result in a significant resource impact. Nevertheless, exploratory economic analysis undertaken for the evidence review I on clinical case management and committee experience indicate that a complex case manager can potentially represent a cost-effective use of NHS resources. Also, the committee discussed that there may be cost savings for other sectors, such as criminal justice sector, since many people in contact with criminal justice system have a history of traumatic brain injury.

The committee discussed that while components of service specification for integrated rehabilitation care do currently exist, there is a lack of provision, timely access, and services often operate in silos. Therefore, commissioners will need to ensure more consistent provision of services to meet the outlined specification. As a result, more people may access holistic assessments, appropriate care and treatments, and other support services. The committee noted that this recommendation may require additional funding and could have a significant resource impact. However, it is driven by the clinical needs of people with chronic neurological conditions. They discussed the many health, economic, and wider social benefits associated with integrated service provision that meets people's needs. They also referred to existing economic literature showing that neurorehabilitation represents value for money. For example, Turner-Stokes 2016 researched the cost-efficiency of specialist inpatient rehabilitation for working-aged adults with complex neurological disabilities. However, this evidence was out of scope for this guideline, as it did assess the overall value of neurorehabilitation.

The committee noted that most rehabilitation services have established cross-sector and cross-organisation collaborations to address the multidimensional nature of rehabilitation for people with chronic neurological disorders. Currently, commissioning involves collaboration between commissioners from healthcare, social care, and voluntary and community services. However, there is variation in practice. Facilitating greater collaboration may involve increased information sharing, joint working, and service level agreements. Establishing frameworks to support this may have some resource implications, but these are unlikely to be significant.

Similarly, resources may be needed to ensure GPs and primary care professionals are equipped to support people with chronic neurological disorders. This could involve, for example, sharing expertise from specialist centres and maintaining up-to-date information on local services. These practices are already in place in some areas and are not expected to require significant additional resources, mainly more healthcare practitioner time. However, supported GPs and primary care professionals will ensure timely and appropriate signposting, care or referral, leading to better outcomes for people with chronic neurological disorders.

The committee noted a lack of mental health services for people with chronic neurological disorders. This recommendation may require additional funding for more consistent provision. General mental health services are currently not well-equipped to address the challenges faced by these individuals. Therefore, this recommendation may require additional resources for staff training and workforce expansion.

NHS England already funds high-cost specialist equipment and services, but there are often delays in access. Raising awareness of pathways among health and care practitioners will only potentially expedite access.

Additional resources may be needed to establish systems for greater collaboration between integrated care systems where local availability of specialist services is limited, such as communication channels and shared representatives. However, these are unlikely to be significant.

The committee discussed the current challenges of commissioning care for people with chronic neurological disorders, especially during transitions from child to adult services. These challenges arise from differences in service organisation and funding, and variations in specialist service availability across the country. They discussed that addressing these challenges and ensuring clear commissioning responsibility may require establishing consistent eligibility criteria and adopting joint commissioning approaches. It may also require reallocating existing resources and funds between services to meet the needs of individuals transitioning from children and young people to adult services.

The committee explained that referral and re-access to rehabilitation services are significant challenges for practitioners and individuals. Despite existing referral procedures, delays can occur due to capacity issues, time taken to assess needs, or practitioners' lack of awareness of available services. Those who did not initially need services but later require re-access due to emerging needs also currently face difficulties in obtaining support. The recommendation in this area may lead to more people accessing necessary services, potentially increasing pressure on existing services and resulting in resource implications. For example, this may require establishing a single point of contact to ensure a continuous link with rehabilitation services, increase capacity and expertise. The committee discussed many health benefits and potential cost savings from timely access to essential services, such as reduced use of costly emergency care, shorter inpatient or residential stays, improved independence and lower related formal care costs. Additionally, establishing re-access to rehabilitation services could help alleviate some pressure on overburdened GPs.

The committee noted that services are often understaffed. Therefore, to respond promptly and appropriately to changing needs, expansion and investment in the workforce may be necessary, potentially requiring additional resources. However, better integration, clear clinical pathways, and reconfiguration of existing services and funding may help mitigate these resource implications.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.1 to 1.1.5, 1.2.2, 1.3.1, 1.4.1 to 1.4.2, 1.4.4, 1.5.4, 1.6.1 to 1.6.3, 1.8.5, 1.8.9, 1.8.14 to 1.8.16, 1.10.2, 1.10.4, 1.11.1, 1.11.4 to 1.11.5, 1.12.1 to 1.12.5, and 1.13.4 to 1.13.5.

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Included studies

Qualitative

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Other

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Appendices

Appendix A Review protocols

Review protocol for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

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	Delivery of rehabilitation for people with chronic neurological disorders.
2.	Review question	Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?
3.	Objective	• To establish the views and preferences of people with chronic neurological disorders, their families and carers about what works well and what could be improved in the delivery of rehabilitation. • To establish the views and preferences of practitioners in health and social care, education and employment and the charitable and voluntary sectors, about what works well and what could be improved in the delivery of rehabilitation for people with chronic neurological disorders.
4.	Searches	The following databases will be searched: • Medline All • Embase • Cochrane Database of Systematic Reviews (CDSR) • PsycInfo • Social Policy and Practice Searches will be restricted to: • Date: 2010 - present • English language

ID	Field	Content
		• Human studies • OECD Geographic filter (amended) Conference proceedings, editorials, case reports, new, historical articles and letters will be excluded. Other searches: • Additional searching may be undertaken if required. With the agreement of the guideline committee the searches will be re-run 6 weeks before final submission of the review and further studies retrieved for inclusion. The full search strategies will be published in the final review.
5.	Condition or domain being studied	Views and preferences about the way in which rehabilitation for chronic neurological disorders is provided; for example in terms of timing, intensity, setting and person-centredness.
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:** • 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

ID	Field	Content
		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 what works well and what could be improved in the delivery of rehabilitation for people with chronic neurological disorders. They anticipate that data from included studies will cover a number of key themes although they are aware that other relevant themes may also be identified. Expected themes include: • **Acceptability**. Data may relate to people’s experiences of the way in which rehabilitation services are provided, including, for example, interactions between people with chronic neurological disorders and practitioners, settings in which care and support are provided, and the timing or duration of rehabilitation. • **Provision of information**. Data may relate to information given to people as part of their rehabilitation, for example in relation to their condition or other available support. • **Integration and co-ordination (including communication and case management practices) within and between rehabilitation services**. Data may relate to people’s experiences of care and support provided by multiple practitioners or teams. • **Personalisation of rehabilitation programmes, packages and goals**. Data may relate to people’s views on whether their care and support were appropriate to their individual needs, circumstances and preferences. • **Transition into and out of rehabilitation services**. There may be evidence about improvements that could be made to the way in which people are referred into or discharged from rehabilitation services.

ID	Field	Content
		• **Sustainability of rehabilitation and consideration of chronic nature of conditions**. There may be evidence about the way in which people are supported when they are discharged from a particular service, for example support for self-management or for rehabilitation in the context of end-of-life care. • **Equalities considerations**. Data may relate to the provision of rehabilitation for people facing inequalities relating to race and gender and people with pre-existing physical, mental health or behavioural conditions, communication impairments and physical or learning disabilities. It will also consider age-related service assumptions, service access and engagement and cultural differences.
8.	Comparator/Reference standard/Confounding factors	Not applicable as this is a qualitative review.
9.	Types of study to be included	• Systematic reviews of qualitative studies • Studies using qualitative methods: data collection via focus groups, semi-structured and structured interviews, observations • Surveys conducted using open ended questions and a qualitative analysis of responses Note: Mixed-methods studies will be included but only qualitative data will be extracted and risk of bias assessed.
10.	Other exclusion criteria	Inclusion: • Full text papers • Studies conducted in the UK • If insufficient* UK data are available to support decision making about children and young people, then evidence from Australia, New Zealand and Canada will be considered. *Sufficiency will be judged on considerations such as number of studies and size and breadth of population. Exclusion: • 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).

ID	Field	Content
		• Surveys using mainly closed questions or which quantify open ended answers for analysis. • Non-English language articles • Conference proceedings • Abstract only • Books, book chapters and theses Thematic saturation: 1. Data or theme(s) from included studies will not be extracted for particular theme(s) if thematic saturation is reached. 2. Papers included on full text will subsequently be excluded when the whole anticipated framework of phenomena (7 anticipated themes listed in row 7) has reached thematic saturation. That is, when evidence synthesis and the application of GRADE-CERQual show that data about all 7 aspects of the phenomenon of interest are ‘adequate’ and ‘coherent’. See row 7 above for details of the anticipated framework of phenomenon and associated rationale.
11.	Context	Settings: • Included: ○ All inpatient, outpatient and community settings in which either fully or partially publicly funded rehabilitation interventions for chronic neurological disorders are provided. • Excluded: ○ 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.

ID	Field	Content	
		• Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. • Dual sifting will be performed on at least 10% of records (or 300 records, whichever is smaller); 90% agreement is required and disagreements will be resolved via discussion with the senior systematic reviewer. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed along with the reason for its exclusion. • The included and excluded studies lists will be circulated to the Topic Group for their comments. Resolution of disputes will be by discussion between the senior reviewer, Topic Advisor and Chair. • A standardised form will be used to extract data from included studies, providing study reference, research question, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (with supporting quotes). One reviewer will extract relevant data into a standardised form. This will be quality assessed by the senior reviewer.	
15.	Risk of bias (quality) assessment	Risk of bias of individual qualitative studies will be assessed using the CASP qualitative checklist, and systematic reviews of qualitative studies will be assessed using the CASP Systematic Review checklist. See Appendix H in Developing NICE guidelines: the manual for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by the senior reviewer.	
16.	Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes as ‘review findings’. • The GRADE-CERQual approach will be used to summarise the confidence in the review findings synthesized from the qualitative evidence (‘Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series’; Lewin 2018). • 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

ID	Field	Content		
		☐	Prognostic	
		☒	Qualitative	
		☐	Epidemiologic	
		☐	Service Delivery	
		☐	Other (please specify)	
19.	Language	English		
20.	Country	England		
21.	Anticipated or actual start date	November 2021		
22.	Anticipated completion date	December 2023		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☑	☑
		Piloting of the study selection process	☑	☑
		Formal screening of search results against eligibility criteria	☑	☑
		Data extraction	☑	☑
		Risk of bias (quality) assessment	☑	☑
		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**		

ID	Field	Content
		National Institute for Health and Care Excellence (NICE)
25.	Review team members	NICE review team
26.	Funding sources/sponsor	This systematic review is being completed by NICE which receives funding from the Department of Health and Social Care.
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10181/documents.
29.	Other registration details	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

ID	Field	Content	
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: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

Database: Ovid MEDLINE(R) ALL

Date of last search: 23/02/2023

1	(CRANIOCEREBRAL TRAUMA/ or brain injuries/ or exp brain hemorrhage, traumatic/ or exp brain injuries, diffuse/ or exp brain injuries, traumatic/ or exp brain injury, chronic/ or Shaken Baby Syndrome/ or HYPOXIA, BRAIN/ or Brain Damage, Chronic/ or exp INTRACRANIAL HEMORRHAGE, TRAUMATIC/ or exp BRAIN NEOPLASMS/ or BRAIN DISEASES/ or BRAIN ABSCESS/ or BRAIN DISEASES, METABOLIC/ or CEREBELLAR DISEASES/ or cerebrovascular disorders/ or basal ganglia cerebrovascular disease/ or cerebrovascular trauma/ or intracranial arteriovenous malformations/ or "intracranial embolism and thrombosis"/ or intracranial hemorrhages/ or vascular headaches/ or exp ENCEPHALITIS/ or exp HYDROCEPHALUS/) not (exp STROKE/ or dementia/)
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)).ti,ab.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
5	(brain* adj2 abscess*).ti,ab.
6	(carotid arter* adj2 (disease* or injur*)).ti,ab.
7	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
8	exp STROKE/ and (ADOLESCENT/ or MINORS/ or exp CHILD/ or exp INFANT/ or exp PEDIATRICS/ or exp PUBERTY/)
9	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.
10	exp SPINAL CORD INJURIES/ or exp SPINAL CORD NEOPLASMS/ or EPIDURAL ABSCESS/ or SPINAL CORD DISEASES/ or exp SPINAL CORD VASCULAR DISEASES/ or SPINAL CORD COMPRESSION/ or MYELITIS, TRANSVERSE/
11	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
12	(Central cord syndrome* or transverse myelitis).ti,ab.
13	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
14	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
15	PERIPHERAL NERVE INJURIES/ or exp CRANIAL NERVE INJURIES/ or PERIPHERAL NERVOUS SYSTEM NEOPLASMS/ or exp CRANIAL NERVE NEOPLASMS/ or exp PERIPHERAL NERVOUS SYSTEM DISEASES/ or exp CRANIAL NERVE DISEASES/
16	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
17	(Guillain* adj1 Barr*).ti,ab.
18	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
19	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
20	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
21	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
22	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
23	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.

24	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.
25	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
26	(periph* adj2 neuropath*).ti,ab.
27	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
28	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
29	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.
30	exp MOTOR NEURON DISEASE/ or POSTPOLIOMYELITIS SYNDROME/ or exp PARKINSONIAN DISORDERS/ or MUSCULAR DYSTROPHY, DUCHENNE/ or exp MULTIPLE SCLEROSIS/ or NEUROMUSCULAR DISEASES/ or SPASTIC PARAPLEGIA, HEREDITARY/ or FRIEDREICH ATAXIA/ or exp MULTIPLE SYSTEM ATROPHY/ or SUPRANUCLEAR PALSY, PROGRESSIVE/ or CORTICOBASAL DEGENERATION/ or LEUKODYSTROPHY, METACHROMATIC/ or exp MITOCHONDRIAL MYOPATHIES/ or exp MUCOPOLYSACCHARIDOSES/ or WILLIAMS SYNDROME/ or GENETIC DISEASES, INBORN/ or RETT SYNDROME/ or FETAL ALCOHOL SPECTRUM DISORDERS/ or DYSTONIC DISORDERS/ or "HEREDITARY SENSORY AND MOTOR NEUROPATHY"/ or SPINAL DYSRAPHISM/
31	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
32	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
33	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
34	(bulbar adj1 pals*).ti,ab.
35	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
36	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
37	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
38	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
39	(muscular adj1 dystroph*).ti,ab.
40	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
41	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
42	"friedreich* ataxia*".ti,ab.
43	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
44	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
45	(progressive adj1 supranuclear adj1 pals*).ti,ab.
46	(richardson* adj1 (disease? or syndrome?)).ti,ab.
47	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
48	(white adj1 matter adj1 disorder?).ti,ab.
49	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.
50	(lysosomal adj1 storage adj1 disorder?).ti,ab.
51	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
52	(perinatal illness* or perinatal hypoxia*).ti,ab.
53	(primary adj1 dystonia?).ti,ab.
54	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
55	(spina bifida? or spinal dysraphism?).ti,ab.
56	MOVEMENT DISORDERS/ or MOTOR DISORDERS/ or CONVERSION DISORDER/
57	((functional* or psychogenic* or dissociative*) adj1 neurologic* adj1 (disorder* or dysfunction* or difficult*)).ti,ab.
58	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.
59	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
60	(pseudo-seizure* or pseudoseizure*).ti,ab.
61	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
62	or/1-61
63	exp REHABILITATION/ or rehab.fs.
64	Rehabilitation Nursing/ or Hospitals, Rehabilitation/ or Social Work/ or exp Nutrition Therapy/ or Neuropsychiatry/ or Rehabilitation Centers/ or Social Workers/ or occupational therapists/ or physical

	therapists/ or nutritionists/ or Psychology/ or Consultants/ or "Prostheses and Implants"/ or exp Physical Therapy Modalities/
65	(rehab* or telerehab* or neurorehab*).ti,ab.
66	or/63-65
67	62 and 66
68	patients/px or Inpatients/px or caregivers/px or exp family/px
69	attitude/ or "Attitude of Health Personnel"/ or attitude to health/ or Health Knowledge, Attitudes, Practice/ or "patient acceptance of health care"/ or patient satisfaction/ or patient preference/ or emotions/ or consumer behavior/
70	(care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*).ti.
71	((care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
72	(brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*).ti.
73	((brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
74	(attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*).ti.
75	or/68-74
76	67 and 75
77	((rehab* or telerehab* or neurorehab*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
78	62 and 77
79	76 or 78
80	letter/
81	editorial/
82	news/
83	exp historical article/
84	Anecdotes as Topic/
85	comment/
86	case report/
87	(letter or comment*).ti.
88	or/80-87
89	randomized controlled trial/ or random*.ti,ab.
90	88 not 89
91	animals/ not humans/
92	exp Animals, Laboratory/
93	exp Animal Experimentation/
94	exp Models, Animal/
95	exp Rodentia/
96	(rat or rats or mouse or mice).ti.
97	or/90-96
98	79 not 97
99	limit 98 to english language
100	(2010* or 2011* or 2012* or 2013* or 2014* or 2015* or 2016* or 2017* or 2018* or 2019* or 2020* or 2021* or 2022* or 2023*).ed,dt.

101	99 and 100
102	exp United Kingdom/
103	(national health service* or nhs*).ti,ab,in.
104	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
105	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in.
106	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in.
107	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in.
108	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in.
109	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in.
110	or/102-109
111	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp australia/ or exp oceania/) not (exp United Kingdom/ or europe/)
112	110 not 111
113	101 and 112
114	exp Infant/ or Infant Health/ or Infant Welfare/
115	(prematur* or pre-matur* or preterm* or pre-term* or infan* or newborn* or new-born* or perinat* or peri-nat* or neonat* or neo-nat* or baby* or babies or toddler*).ti,ab,in,jn.
116	exp Child/ or exp Child Behavior/ or Child Health/ or Child Welfare/
117	Minors/
118	(child* or minor or minors or boy* or girl* or kid or kids or young*).ti,ab,in,jn.
119	exp pediatrics/
120	(pediatric* or paediatric* or peadiatric*).ti,ab,in,jn.
121	Adolescent/ or Adolescent Behavior/ or Adolescent Health/
122	Puberty/
123	(adolescen* or pubescen* or prepubescen* or pre-pubescen* or pubert* or prepubert* or pre-pubert* or teen* or preteen* or pre-teen* or juvenil* or youth* or under*age*).ti,ab,in,jn.
124	Schools/
125	Child Day Care Centers/ or exp Nurseries/ or Schools, Nursery/
126	(pre-school* or preschool* or kindergar* or daycare or day-care or nurser* or school* or pupil* or student*).ti,ab,jn.
127	("under 18*" or "under eighteen*" or "under 25*" or "under twenty five*").ti,ab.
128	or/114-127
129	Qualitative Research/
130	Nursing Methodology Research/
131	Interview.pt.
132	exp Interviews as Topic/

133	Questionnaires/
134	Narration/
135	Health Care Surveys/
136	(qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw.
137	(ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw.
138	(hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw.
139	(metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw.
140	"critical interpretive synthes*".tw.
141	(realist adj (review* or synthes*)).tw.
142	(noblit and hare).tw.
143	(meta adj (method or triangulation)).tw.
144	(CERQUAL or CONQUAL).tw.
145	((thematic or framework) adj synthes*).tw.
146	or/129-145
147	101 and 113 and 146
148	101 and 128 and 146
149	147 or 148

Database: Embase

Date of last search: 23/02/2023

1	(head injury/ or exp brain injury/ or chronic brain disease/ or brain hemorrhage/ or brain hypoxia/ or exp brain tumor/ or brain disease/ or brain abscess/ or metabolic encephalopathy/ or cerebellum disease/ or exp cerebrovascular disease/ or encephalitis/ or hydrocephalus/) not (exp cerebrovascular accident/ or dementia/)
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or infarcti* or hypoxi* or drown*)).ti,ab.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
5	(brain* adj2 abscess*).ti,ab.
6	(carotid arter* adj2 (disease* or injur*)).ti,ab.
7	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
8	exp cerebrovascular accident/ and (adolescent/ or "minor (person)"/ or exp child/ or exp infant/ or pediatrics/ or exp pediatrics/ or exp puberty/)
9	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.
10	exp spinal cord injury/ or exp spinal cord tumor/ or epidural abscess/ or spinal cord disease/ or exp spinal cord vascular disease/ or spinal cord compression/ or transverse myelitis/
11	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
12	(Central cord syndrome* or transverse myelitis).ti,ab.
13	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
14	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
15	peripheral nerve injury/ or exp cranial nerve injury/ or peripheral nerve tumor/ or exp cranial nerve tumor/ or exp peripheral neuropathy/ or exp cranial neuropathy/

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

58	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.
59	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
60	(pseudo-seizure* or pseudoseizure*).ti,ab.
61	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
62	or/1-61
63	exp rehabilitation/ or rh.fs.
64	rehabilitation nursing/ or rehabilitation center/ or social work/ or diet therapy/ or neuropsychiatry/ or social worker/ or occupational therapist/ or physiotherapist/ or dietitian/ or psychologist/ or exp physiotherapy/ or exp consultation/ or prosthesis/ or "prostheses and orthoses"/
65	(rehab* or telerehab* or neurorehab*).ti,ab.
66	or/63-65
67	62 and 66
68	health personnel attitude/ or dietitian attitude/ or nurse attitude/ or occupational therapist attitude/ or physician assistant attitude/ or physician attitude/ or physiotherapist attitude/ or psychotherapist attitude/ or social worker attitude/ or consumer attitude/ or patient attitude/ or patient satisfaction/ or patient preference/ or attitude to health/ or attitude to illness/ or family attitude/ or parental attitude/ or paternal attitude/ or maternal attitude/ or attitude to illness/ or attitude/ or emotion/ or protocol compliance/ or knowledge/ or satisfaction/
69	(care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*).ti.
70	((care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
71	(brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*).ti.
72	((brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
73	(attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*).ti.
74	or/68-73
75	67 and 74
76	((rehab* or telerehab* or neurorehab*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
77	62 and 76
78	75 or 77
79	letter.pt. or letter/
80	note.pt.
81	editorial.pt.
82	case report/ or case study/
83	(letter or comment*).ti.
84	or/79-83
85	randomized controlled trial/ or random*.ti,ab.
86	84 not 85
87	animal/ not human/
88	nonhuman/
89	exp Animal Experiment/
90	exp Experimental Animal/
91	animal model/

92	exp Rodent/
93	(rat or rats or mouse or mice or rodent*).ti.
94	or/86-93
95	78 not 94
96	limit 95 to english language
97	(2010* or 2011* or 2012* or 2013* or 2014* or 2015* or 2016* or 2017* or 2018* or 2019* or 2020* or 2021* or 2022* or 2023*).dc.
98	96 and 97
99	(conference abstract* or conference review or conference paper or conference proceeding).db,pt,su.
100	98 not 99
101	exp United Kingdom/
102	(national health service* or nhs*).ti,ab,in,ad.
103	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
104	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad.
105	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad.
106	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad.
107	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad.
108	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad.
109	or/101-108
110	(exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/) not (exp united kingdom/ or europe/)
111	109 not 110
112	98 and 111
113	exp juvenile/ or Child Behavior/ or Child Welfare/ or Child Health/ or infant welfare/ or "minor (person)"/ or elementary student/
114	(prematur* or pre-matur* or preterm* or pre-term* or infan* or newborn* or new-born* or perinat* or peri-nat* or neonat* or neo-nat* or baby* or babies or toddler*).ti,ab,in,ad,jw.
115	(child* or minor or minors or boy* or girl* or kid or kids or young*).ti,ab,in,ad,jw.
116	exp pediatrics/
117	(pediatric* or paediatric* or peadiatric*).ti,ab,in,ad,jw.
118	exp adolescence/ or exp adolescent behavior/ or adolescent health/ or high school student/ or middle school student/
119	(adolescen* or pubescen* or prepubescen* or pre-pubescen* or pubert* or prepubert* or pre-pubert* or teen* or preteen* or pre-teen* or juvenil* or youth* or under*age*).ti,ab,in,ad,jw.
120	school/ or high school/ or kindergarten/ or middle school/ or primary school/ or nursery school/ or day care/

121	(pre-school* or preschool* or kindergar* or daycare or day-care or nurser* or school* or pupil* or student*).ti,ab,jw.
122	("under 18*" or "under eighteen*" or "under 25*" or "under twenty five*").ti,ab.
123	or/113-122
124	Qualitative Research/
125	exp Interview/
126	exp Questionnaire/
127	exp Observational Method/
128	Narrative/
129	(qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw.
130	(ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw.
131	(hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw.
132	(metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw.
133	"critical interpretive synthes*".tw.
134	(realist adj (review* or synthes*)).tw.
135	(noblit and hare).tw.
136	(meta adj (method or triangulation)).tw.
137	(CERQUAL or CONQUAL).tw.
138	((thematic or framework) adj synthes*).tw.
139	or/124-132
140	100 and 112 and 139
141	100 and 123 and 139
142	140 or 141

Database: Cochrane Database of Systematic Reviews

Date of last search: 23/02/2023

#1	MeSH descriptor: [Craniocerebral Trauma] this term only
#2	MeSH descriptor: [Brain Injuries] this term only
#3	MeSH descriptor: [Brain Hemorrhage, Traumatic] explode all trees
#4	MeSH descriptor: [Brain Injuries, Diffuse] explode all trees
#5	MeSH descriptor: [Brain Injuries, Traumatic] explode all trees
#6	MeSH descriptor: [Brain Injury, Chronic] explode all trees
#7	MeSH descriptor: [Shaken Baby Syndrome] this term only
#8	MeSH descriptor: [Brain Damage, Chronic] this term only
#9	MeSH descriptor: [Hypoxia, Brain] this term only
#10	MeSH descriptor: [Intracranial Hemorrhage, Traumatic] explode all trees
#11	MeSH descriptor: [Brain Neoplasms] explode all trees
#12	MeSH descriptor: [Brain Diseases] this term only
#13	MeSH descriptor: [Brain Abscess] this term only
#14	MeSH descriptor: [Brain Diseases, Metabolic] this term only
#15	MeSH descriptor: [Cerebellar Diseases] this term only
#16	MeSH descriptor: [Cerebrovascular Disorders] this term only
#17	MeSH descriptor: [Basal Ganglia Cerebrovascular Disease] this term only
#18	MeSH descriptor: [Cerebrovascular Trauma] this term only
#19	MeSH descriptor: [Intracranial Arteriovenous Malformations] this term only
#20	MeSH descriptor: [Intracranial Embolism and Thrombosis] this term only
#21	MeSH descriptor: [Intracranial Hemorrhages] this term only
#22	MeSH descriptor: [Vascular Headaches] this term only

#23	MeSH descriptor: [Encephalitis] this term only
#24	MeSH descriptor: [Hydrocephalus] this term only
#25	{or #1-#24}
#26	MeSH descriptor: [Stroke] explode all trees
#27	MeSH descriptor: [Dementia] this term only
#28	#26 or #27
#29	#25 NOT #28
#30	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) NEAR/2 (injur* or trauma* or damage* or disease* or dieases* or disorder* or infect* or hemorrhag* or haemorrhag* or neoplasm* or cancer* or tumour* or tumor* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)):ti,ab
#31	(chronic* NEAR/1 trauma* NEAR/2 encephalopath*):ti,ab
#32	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) NEAR/2 (neoplasm* or cancer* or tumour* or tumor* or carcinom* or adenocarcinom*)):ti,ab
#33	(brain* NEAR/2 abscess*):ti,ab
#34	(carotid arter* NEAR/2 (disease* or injur*)):ti,ab
#35	("basal ganglia disease" or "basal ganglia diseases" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cerebellar degenerate" or "paraneoplastic cerebellar degenerated" or "paraneoplastic cerebellar degenerative" or "paraneoplastic cerebellar degeneration" or "shaken baby syndrome" or "shaken baby syndromes" or "shaking baby syndrome" or "shaking baby syndromes"):ti,ab
#36	MeSH descriptor: [Stroke] explode all trees
#37	MeSH descriptor: [Adolescent] this term only
#38	MeSH descriptor: [Minors] this term only
#39	MeSH descriptor: [Child] explode all trees
#40	MeSH descriptor: [Infant] explode all trees
#41	MeSH descriptor: [Pediatrics] explode all trees
#42	MeSH descriptor: [Puberty] explode all trees
#43	{or #37-#42}
#44	#36 and #43
#45	((stroke or strokes) NEAR/3 (paediatric* or pediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age" or "under ages" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school ages" or "school age" or schoolage* or "under 16" or "under sixteen" or "under sixteens")):ti,ab
#46	MeSH descriptor: [Spinal Cord Injuries] explode all trees
#47	MeSH descriptor: [Spinal Cord Neoplasms] explode all trees
#48	MeSH descriptor: [Epidural Abscess] this term only
#49	MeSH descriptor: [Spinal Cord Diseases] this term only
#50	MeSH descriptor: [Spinal Cord Vascular Diseases] explode all trees
#51	MeSH descriptor: [Spinal Cord Compression] this term only
#52	MeSH descriptor: [Myelitis, Transverse] this term only
#53	((spinal* or spine or spines) NEAR/2 (injur* or trauma* or tumour* or tumor* or neoplasm* or cancer* or infect* or insult* or disease or diseases or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or hemorrhag* or haemorrhag*)):ti,ab
#54	("Central cord syndrome" or "Central cord syndromes" or transverse myelitis):ti,ab
#55	(epidural* NEAR/2 (neoplasm* or cancer* or tumour* or tumor* or abscess*)):ti,ab
#56	((spinal* or spine or spines) NEAR/2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)):ti,ab
#57	MeSH descriptor: [Peripheral Nerve Injuries] this term only
#58	MeSH descriptor: [Cranial Nerve Injuries] explode all trees
#59	MeSH descriptor: [Peripheral Nervous System Neoplasms] this term only
#60	MeSH descriptor: [Cranial Nerve Neoplasms] explode all trees
#61	MeSH descriptor: [Peripheral Nervous System Diseases] explode all trees
#62	MeSH descriptor: [Cranial Nerve Diseases] explode all trees
#63	((periph* or cranial*) NEAR/1 (nerve or nerves or nervous system) NEAR/2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumour* or tumor* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome or syndromes)):ti,ab
#64	(Guillain* NEAR/1 Barr*):ti,ab

#65	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or "ocular motility" or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) NEAR/1 nerve* NEAR/1 injur*):ti,ab
#66	(optic* NEAR/1 nerve* NEAR/2 (neoplasm* or cancer* or tumour* or tumor*)):ti,ab
#67	(brachial-plexus NEAR/1 (neuropath* or neuritis)):ti,ab
#68	("complex regional pain syndrome" or "complex regional pain syndromes" or causalgia or mononeuropath* or "nerve compression syndrome" or "nerve compression syndromes"):ti,ab
#69	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) NEAR/1 neuropath*):ti,ab
#70	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) NEAR/1 syndrome*):ti,ab
#71	(pudendal-neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*):ti,ab
#72	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or "ocular motility" or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) NEAR/1 nerve* NEAR/1 disease*):ti,ab
#73	(periph* NEAR/2 neuropath*):ti,ab
#74	(((periph* or cranial*) NEAR/2 (nerve or nerves or nervous system)) and lupus):ti,ab
#75	((multi-focal* or multifocal*) NEAR/2 motor NEAR/1 neuropath*):ti,ab
#76	(((periph* or cranial*) NEAR/2 (nerve or nerves or nervous system)) and alcohol*):ti,ab
#77	{or #29-#35, #44-#76}
#78	MeSH descriptor: [Motor Neuron Disease] explode all trees
#79	MeSH descriptor: [Postpoliomyelitis Syndrome] this term only
#80	MeSH descriptor: [Parkinsonian Disorders] explode all trees
#81	MeSH descriptor: [Muscular Dystrophy, Duchenne] this term only
#82	MeSH descriptor: [Multiple Sclerosis] explode all trees
#83	MeSH descriptor: [Neuromuscular Diseases] this term only
#84	MeSH descriptor: [Spastic Paraplegia, Hereditary] this term only
#85	MeSH descriptor: [Friedreich Ataxia] this term only
#86	MeSH descriptor: [Multiple System Atrophy] explode all trees
#87	MeSH descriptor: [Supranuclear Palsy, Progressive] this term only
#88	MeSH descriptor: [Corticobasal Degeneration] explode all trees
#89	MeSH descriptor: [Leukodystrophy, Metachromatic] this term only
#90	MeSH descriptor: [Mitochondrial Myopathies] explode all trees
#91	MeSH descriptor: [Mucopolysaccharidoses] explode all trees
#92	MeSH descriptor: [Williams Syndrome] this term only
#93	MeSH descriptor: [Genetic Diseases, Inborn] this term only
#94	MeSH descriptor: [Rett Syndrome] this term only
#95	MeSH descriptor: [Fetal Alcohol Spectrum Disorders] this term only
#96	MeSH descriptor: [Dystonic Disorders] this term only
#97	MeSH descriptor: [Hereditary Sensory and Motor Neuropathy] this term only
#98	MeSH descriptor: [Spinal Dysraphism] this term only
#99	(neurolog* NEAR/1 (condition* or disease* or damage* or disorder* or impair*)):ti,ab
#100	((motor-neuron* or gehrig* or charcott* or kennedy*) NEAR/1 disease*):ti,ab
#101	((amyotroph* or primary) NEAR/1 lateral* NEAR/1 sclero*):ti,ab
#102	(bulbar NEAR/1 pals*):ti,ab
#103	((muscular or muscle* or bulbo) NEAR/1 atroph* NEAR/1 spin*):ti,ab
#104	(progressiv* NEAR/1 (muscular or muscle*) NEAR/1 atroph*):ti,ab
#105	((postpolio* or post-polio*) NEAR/1 (syndrome or syndromes)):ti,ab
#106	(Parkinson* or duchenne* or multiple-sclerosis* or sclerosos* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy):ti,ab
#107	(muscular NEAR/1 dystroph*):ti,ab
#108	(neuromusc* NEAR/1 (disease* or disorder or disorders)):ti,ab
#109	(heredit* NEAR/1 spastic* NEAR/1 parapleg*):ti,ab
#110	("friedreich ataxia" or "friedreich ataxias" or "friedreichs ataxia" or "friedreichs ataxias"):ti,ab
#111	((multiple-system or olivopontocerebellar) NEAR/1 atroph*):ti,ab
#112	(shy-drager syndrome* or striatonigral-degenerat* or batten-disease or batten-diseases):ti,ab
#113	(progressive NEAR/1 supranuclear NEAR/1 pals*):ti,ab

#114	(richardson* NEAR/1 (disease or diseases or syndrome or syndromes)):ti,ab
#115	((corticobasal or cortico basal) NEAR/1 degenerat*):ti,ab
#116	(white-matter NEAR/1 (disorder or disorders)):ti,ab
#117	(metachromatic-leukodystroph* or mitochondrial-myopath* or mucopolysaccharidos*):ti,ab
#118	(lysosomal NEAR/1 storage NEAR/1 (disorder or disorders)):ti,ab
#119	((genetic or William* or catch-22 or rett* or congenital or fetal or foetal alcohol) NEAR/1 (syndrome or disorder*)):ti,ab
#120	(perinatal NEAR/1 (illness* or hypoxia*)):ti,ab
#121	(primary NEAR/1 (dystonia or dystonias)):ti,ab
#122	(heredit* NEAR/1 motor* NEAR/1 sens* NEAR/1 neuropath*):ti,ab
#123	(spina-bifida or bifidas or spinal-dysraphism or dysraphisms):ti,ab
#124	MeSH descriptor: [Movement Disorders] this term only
#125	MeSH descriptor: [Motor Disorders] this term only
#126	MeSH descriptor: [Conversion Disorder] this term only
#127	((functional* or psychogenic* or dissociative*) NEAR/1 neurologic* NEAR/1 (disorder* or dysfunction* or difficult*)):ti,ab
#128	((movement* or motor* or convers*) NEAR/1 (disorder* or dysfunct*)):ti,ab
#129	((psychogenic or dissociative or non-epilep* or nonepilep*) NEAR/1 (seizure* or convulsion* or fit or fits or spasm* or attack*)):ti,ab
#130	(pseudo-seizure or pseudoseizure):ti,ab
#131	(medical* NEAR/1 (unexplain* or un-explain*) NEAR/1 (symptom or symptoms)):ti,ab
#132	{or #77-#131}
#133	MeSH descriptor: [Rehabilitation] explode all trees
#134	MeSH descriptor: [] explode all trees and with qualifier(s): [rehabilitation - RH]
#135	MeSH descriptor: [Rehabilitation Nursing] this term only
#136	MeSH descriptor: [Hospitals, Rehabilitation] this term only
#137	MeSH descriptor: [Social Work] this term only
#138	MeSH descriptor: [Nutrition Therapy] explode all trees
#139	MeSH descriptor: [Neuropsychiatry] this term only
#140	MeSH descriptor: [Rehabilitation Centers] explode all trees
#141	MeSH descriptor: [Social Workers] this term only
#142	MeSH descriptor: [Occupational Therapists] this term only
#143	MeSH descriptor: [Physical Therapists] this term only
#144	MeSH descriptor: [Nutritionists] this term only
#145	MeSH descriptor: [Psychology] this term only
#146	MeSH descriptor: [Consultants] this term only
#147	MeSH descriptor: [Prostheses and Implants] this term only
#148	MeSH descriptor: [Physical Therapy Modalities] explode all trees
#149	(rehab* or telerehab* or neurorehab*):ti,ab
#150	{or #133-#149}
#151	#132 and #150
#152	MeSH descriptor: [Patients] this term only and with qualifier(s): [psychology - PX]
#153	MeSH descriptor: [Inpatients] this term only and with qualifier(s): [psychology - PX]
#154	MeSH descriptor: [Caregivers] this term only and with qualifier(s): [psychology - PX]
#155	MeSH descriptor: [Family] this term only and with qualifier(s): [psychology - PX]
#156	MeSH descriptor: [Attitude] this term only
#157	MeSH descriptor: [Attitude of Health Personnel] this term only
#158	MeSH descriptor: [Attitude to Health] this term only
#159	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
#160	MeSH descriptor: [Patient Acceptance of Health Care] this term only
#161	MeSH descriptor: [Patient Satisfaction] this term only
#162	MeSH descriptor: [Patient Preference] this term only
#163	MeSH descriptor: [Emotions] this term only

#164	MeSH descriptor: [Consumer Behavior] this term only
#165	(care NEXT team* or caring NEXT team* or caseworker* or case NEXT worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social NEXT worker* or specialist* or staff or therap*):ti
#166	((care NEXT team* or caring NEXT team* or caseworker* or case NEXT worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social NEXT worker* or specialist* or staff or therap*) NEAR/6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)):ab
#167	(brother* or carer* or caregiver* or care NEXT giver* or famil* or father* or guardian* or husband* or inpatient* or in NEXT patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*):ti
#168	((brother* or carer* or caregiver* or care NEXT giver* or famil* or father* or guardian* or husband* or inpatient* or in NEXT patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*) NEAR/6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)):ab
#169	(attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*):ti
#170	{or #152-#169}
#171	#151 and #170
#172	((rehab* or telerehab* or neurorehab*) near/6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)):ab
#173	#132 and #172
#174	#171 or #173
#175	conference:pt or (clinicaltrials or trialsearch or "www.who.int"):so
#176	#174 not #175 with Cochrane Library publication date Between Jan 2010 and Dec 2022

Social Policy and Practice

Date of last search: 23/02/2023

1	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)).ti,ab.
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) and (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)).hw.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	(chronic* and trauma* and encephalopath*).hw.
5	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
6	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) and (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).hw.
7	(brain* adj2 abscess*).ti,ab.
8	(brain* and abscess*).hw.
9	(carotid arter* adj2 (disease* or injur*)).ti,ab.
10	(carotid arter* and (disease* or injur*)).hw.
11	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
12	("basal ganglia disease*" or encephalitis* or meningoencephalitis* or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").hw.
13	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or

	boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.
14	(stroke* and (p?ediatric* or child* or adolescen* or kid* or youth* or youngster* or minor* or underage* or under-age* or "under age*" or teen* or juvenile* or boy* or girl* or schoolchild* or "school age*" or schoolage* or "under 16*" or "under sixteen*")).hw.
15	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
16	((spinal* or spine*) and (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease* or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).hw.
17	(Central cord syndrome* or transverse myelitis).ti,ab.
18	(Central cord syndrome* or transverse myelitis*).hw.
19	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
20	(epidural* and (neoplasm* or cancer* or tumo?r* or abscess*)).hw.
21	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
22	((spinal* or spine*) and (viral* or virus* or polio* or acquired immunodeficiency syndrome* or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).hw.
23	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
24	((periph* or cranial*) and (nerve* or nervous system*) and (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome*)).hw.
25	(Guillain* adj1 Barr*).ti,ab.
26	(Guillain* and Barr*).hw.
27	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
28	((abducen* or accessor* or facial* or glossopharyngeal* or hypoglossal* or oculomotor* or ocular* motility* or olfactory* or optic* or trigeminal* or trochlear* or vestibulocochlear*) and nerve* and injur*).hw.
29	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
30	(optic* and nerve* and (neoplasm* or cancer* or tumo?r*)).hw.
31	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
32	(brachial plexus* and (neuropath* or neuritis*)).hw.
33	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
34	(complex regional pain syndrome* or causalgia* or mononeuropath* or nerve compression syndrome*).hw.
35	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
36	((femoral* or median* or peroneal* or radial* or sciatic* or tibial* or ulnar*) and neuropath*).hw.
37	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.
38	((carpal-tunnel* or piriformis-muscle* or tarsal-tunnel* or thoracic-outlet*) and syndrome*).hw.
39	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.
40	(pudendal neuralgia* or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).hw.
41	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
42	((abducen* or accessory* or facial* or glossopharyngeal* or hypoglossal* or oculomotor* or ocular motility* or olfactory* or optic* or trigeminal* or trochlear* or vestibulocochlear*) and nerve* and disease*).hw.
43	(periph* adj2 neuropath*).ti,ab.
44	(periph* and neuropath*).hw.
45	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
46	((periph* or cranial*) and (nerve* or nervous system*) and lupus*).hw.
47	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
48	((multi-focal* or multifocal*) and motor* and neuropath*).hw.
49	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.

50	((periph* or cranial*) and (nerve* or nervous system*) and alcohol*).hw.
51	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
52	(neurolog* and (condition* or disease* or damage* or disorder* or impair*)).hw.
53	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
54	((motor-neuron* or gehrig* or charcott* or kennedy*) and disease*).hw.
55	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
56	((amyotroph* or primary*) and lateral* and sclero*).hw.
57	(bulbar adj1 pals*).ti,ab.
58	(bulbar* and pals*).hw.
59	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
60	((muscular* or muscle* or bulbo*) and atroph* and spin*).hw.
61	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
62	(progressiv* and (muscular* or muscle*) and atroph*).hw.
63	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
64	((postpolio* or post-polio*) and syndrome*).hw.
65	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
66	(Parkinson* or duchenne* or multiple scleros?s* or aphasia* or creutzfeldt-jakob* or huntington* or kluver-bucy*).hw.
67	(muscular adj1 dystroph*).ti,ab.
68	(muscular* and dystroph*).hw.
69	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
70	(neuromusc* and (disease* or disorder*)).hw.
71	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
72	(heredit* and spastic* and parapleg*).hw.
73	"friedreich* ataxia*".ti,ab.
74	"friedreich* ataxia*".hw.
75	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
76	((multiple system* or olivopontocerebellar*) and atroph*).hw.
77	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
78	(shy-drager syndrome* or striatonigral degenerat* or batten* disease*).hw.
79	(progressive adj1 supranuclear adj1 pals*).ti,ab.
80	(progressive* and supranuclear* and pals*).hw.
81	(richardson* adj1 (disease? or syndrome?)).ti,ab.
82	(richardson* and (disease* or syndrome*)).hw.
83	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
84	((corticobasal* or cortico basal*) and degenerat*).hw.
85	(white adj1 matter adj1 disorder?).ti,ab.
86	(white* and matter* and disorder*).hw.
87	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.
88	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).hw.
89	(lysosomal adj1 storage adj1 disorder?).ti,ab.
90	(lysosomal* and storage* and disorder*).hw.
91	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
92	((genetic* or William* or catch-22* or rett* or congenital* or f?etal alcohol*) and (syndrome* or disorder*)).hw.
93	(perinatal illness* or perinatal hypoxia*).ti,ab.
94	(perinatal illness* or perinatal hypoxia*).hw.
95	(primary adj1 dystonia?).ti,ab.
96	(primary* and dystonia*).hw.
97	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
98	(heredit* and motor* and sens* and neuropath*).hw.

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

126	or/116-125
127	115 and 126
128	((rehab* or telerehab* or neurorehab*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
129	((rehab* or telerehab* or neurorehab*) and (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback* or feeling* or improv* or knowledge* or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).hw.
130	or/128-129
131	111 and 130
132	127 or 131
133	limit 132 to yr="2010 -Current"

Database: PsycInfo

Date of last search: 23/02/2023

1	(exp Brain Injuries/ or anoxia/ or exp brain disorders/ or exp cerebrovascular disorders/ or exp headache/) not (exp Dementia/ or Cerebrovascular Accidents/)
2	((brain* or cereb* or craniocereb* or cranial or intracrani* or neurocognit*) adj2 (injur* or trauma* or damage* or disease*1 or disorder* or infect* or h?emorrhag* or neoplasm* or cancer* or tumo?r* or insult* or impair* or ischemi* or ischaemi* or infarcti* or hypoxi* or drown*)).ti,ab.
3	(chronic* adj1 trauma* adj2 encephalopath*).ti,ab.
4	((infratentorial* or supratentorial* or hypothalam* or pituitar* or choroid plexus) adj2 (neoplasm* or cancer* or tumo?r* or carcinom* or adenocarcinom*)).ti,ab.
5	(brain* adj2 abscess*).ti,ab.
6	(carotid arter* adj2 (disease* or injur*)).ti,ab.
7	("basal ganglia disease*" or encephalitis or meningoencephalitis or hydrocephal* or "paraneoplastic cereb* degenerat*" or "shak* baby syndrome*").ti,ab.
8	Cerebrovascular Accidents/ and (exp childhood development/ or exp adolescent development/ or pediatrics/ or puberty/)
9	(stroke? adj3 (p?ediatric* or child* or adolescen* or kid or kids or youth* or youngster* or minor or minors or underage* or under-age* or "under age*" or teen or teens or teenager* or juvenile* or boy or boys or boyhood or girl or girls or girlhood or schoolchild* or "school age*" or schoolage* or "under 16" or "under sixteen*")).ti,ab.
10	spinal cord injuries/ or (Spinal Cord/ and neoplasms/) or (Cardiovascular Disorders/ and spinal cord/) or exp myelitis/
11	((spinal* or spine?) adj2 (injur* or trauma* or tumo?r* or neoplasm* or cancer* or infect* or insult* or disease? or disorder* or degenrat* or compress* or vascular* or ischemi* or ischaemi* or infarct* or h?emorrhag*)).ti,ab.
12	(Central cord syndrome* or transverse myelitis).ti,ab.
13	(epidural* adj2 (neoplasm* or cancer* or tumo?r* or abscess*)).ti,ab.
14	((spinal* or spine?) adj2 (viral* or virus* or polio* or acquired immunodeficiency syndrome or AIDS or HIV or bacterial* or neurosyphili* or neuro-syphili* or tubercul*)).ti,ab.
15	(exp Peripheral Nervous System/ and (Injuries/ or neoplasms/)) or nervous system disorders/
16	((periph* or cranial*) adj1 (nerve? or nervous system) adj2 (injur* or trauma* or disorder* or disease* or damage* or neoplasm* or cancer* or tumo?r* or inflamm* or autoimmun* or paraneoplastic* or neuropath* or syndrome?)).ti,ab.
17	(Guillain* adj1 Barr*).ti,ab.
18	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 injur*).ti,ab.
19	(optic* adj1 nerve* adj2 (neoplasm* or cancer* or tumo?r*)).ti,ab.
20	(brachial plexus adj1 (neuropath* or neuritis)).ti,ab.
21	(complex regional pain syndrome* or causalgia or mononeuropath* or nerve compression syndrome*).ti,ab.
22	((femoral or median or peroneal or radial or sciatic or tibial or ulnar) adj1 neuropath*).ti,ab.
23	((carpal-tunnel or piriformis-muscle or tarsal-tunnel or thoracic-outlet) adj1 syndrome*).ti,ab.

24	(pudendal neuralgia or polyneuropath* or polyradiculoneuropath* or polyradiculopath* or radiculopath*).ti,ab.
25	((abducen* or accessory or facial or glossopharyngeal or hypoglossal or oculomotor or ocular motility or olfactory or optic* or trigeminal or trochlear or vestibulocochlear) adj1 nerve* adj1 disease*).ti,ab.
26	(periph* adj2 neuropath*).ti,ab.
27	(((periph* or cranial*) adj2 (nerve? or nervous system)) and lupus).ti,ab.
28	((multi-focal* or multifocal*) adj2 motor adj1 neuropath*).ti,ab.
29	(((periph* or cranial*) adj2 (nerve? or nervous system)) and alcohol*).ti,ab.
30	motor neurons/ or exp muscular disorders/ or exp neuromuscular disorders/ or multiple sclerosis/ or neurodegenerative diseases/ or Progressive Supranuclear Palsy/ or corticobasal degeneration/ or Metabolism Disorders/ or Williams Syndrome/ or genetic disorders/ or rett syndrome/ or fetal alcohol syndrome/ or exp peripheral neuropathy/ or spina bifida/
31	(neurolog* adj1 (condition* or disease* or damage* or disorder* or impair*)).ti,ab.
32	((motor-neuron* or gehrig* or charcott* or kennedy*) adj1 disease*).ti,ab.
33	((amyotroph* or primary) adj1 lateral* adj1 sclero*).ti,ab.
34	(bulbar adj1 pals*).ti,ab.
35	((muscular or muscle* or bulbo) adj1 atroph* adj1 spin*).ti,ab.
36	(progressiv* adj1 (muscular or muscle*) adj1 atroph*).ti,ab.
37	((postpolio* or post-polio*) adj1 syndrome?).ti,ab.
38	(Parkinson* or duchenne* or multiple scleros?s* or aphasia or creutzfeldt-jakob or huntington* or kluver-bucy).ti,ab.
39	(muscular adj1 dystroph*).ti,ab.
40	(neuromusc* adj1 (disease* or disorder?)).ti,ab.
41	(heredit* adj1 spastic* adj1 parapleg*).ti,ab.
42	"friedreich* ataxia*".ti,ab.
43	((multiple system or olivopontocerebellar) adj1 atroph*).ti,ab.
44	(shy-drager syndrome* or striatonigral degenerat* or batten* disease?).ti,ab.
45	(progressive adj1 supranuclear adj1 pals*).ti,ab.
46	(richardson* adj1 (disease? or syndrome?)).ti,ab.
47	((corticobasal or cortico basal) adj1 degenerat*).ti,ab.
48	(white adj1 matter adj1 disorder?).ti,ab.
49	(metachromatic leukodystroph* or mitochondrial myopath* or mucopolysaccharidos*).ti,ab.
50	(lysosomal adj1 storage adj1 disorder?).ti,ab.
51	((genetic or William* or catch-22 or rett* or congenital or f?etal alcohol) adj1 (syndrome or disorder*)).ti,ab.
52	(perinatal illness* or perinatal hypoxia*).ti,ab.
53	(primary adj1 dystonia?).ti,ab.
54	(heredit* adj1 motor* adj1 sens* adj1 neuropath*).ti,ab.
55	(spina bifida? or spinal dysraphism?).ti,ab.
56	conversion disorder/
57	((functional* or psychogenic* or dissociative*) adj1 neurologic* adj1 (disorder* or dysfunction* or difficult*)).ti,ab.
58	((movement* or motor* or convers*) adj1 (disorder* or dysfunct*)).ti,ab.
59	((psychogenic or dissociative or non-epilep* or nonepilep*) adj1 (seizure* or convulsion* or fit or fits or spasm* or attack*)).ti,ab.
60	(pseudo-seizure* or pseudoseizure*).ti,ab.
61	(medical* adj1 (unexplain* or un-explain*) adj1 symptom?).ti,ab.
62	or/1-61
63	exp rehabilitation/ or rehabilitation counseling/ or rehabilitation counselors/ or exp Occupational Therapy/ or exp Social Casework/ or exp Social Workers/ or physical therapists/ or neuropsychiatry/ or psychology/ or Psychiatrists/ or Professional Consultation/ or Psychologists/ or prostheses/
64	(rehab* or telerehab* or neurorehab*).ti,ab.
65	or/63-64
66	62 and 65

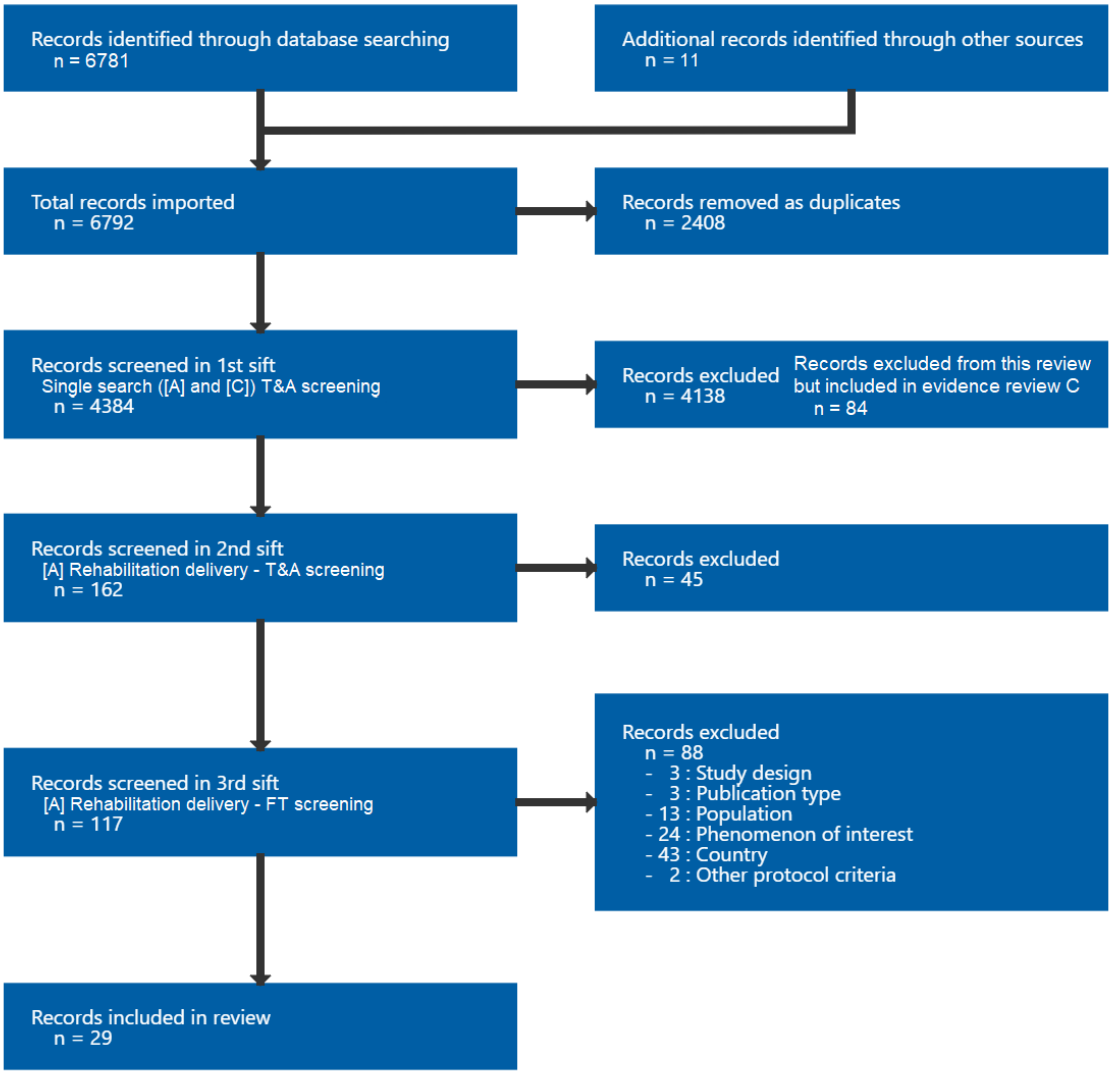
67	attitudes/ or exp health personnel attitudes/ or therapist attitudes/ or psychologist attitudes/ or counselor attitudes/ or exp client attitudes/ or consumer attitudes/ or consumer behavior/ or parental attitudes/ or health attitudes/ or Health Knowledge/ or Health Behavior/ or emotions/
68	(care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*).ti.
69	((care team* or caring team* or caseworker* or case worker* or clinician* or consultant* or dietician* or instructor* or neuropsychiatrist* or neuropsychologist* or nurse* or nutritionist* or orthotist* or physio* or practitioner* or professional* or prosthetist* or psychologist* or social worker* or specialist* or staff or therap*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
70	(brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*).ti.
71	((brother* or carer* or caregiver* or care-giver* or famil* or father* or guardian* or husband* or inpatient* or in patient* or mother* or partner* or patient* or parent* or relative* or sibling* or sister* or spous* or wife* or wive*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
72	(attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*).ti.
73	or/67-72
74	66 and 73
75	((rehab* or telerehab* or neurorehab*) adj6 (attitud* or belief* or choice* or concern* or experience* or expectation* or feedback or feeling* or improv* or knowledge or opinion* or perceive* or perception* or perspective* or priorit* or preferen* or satisf* or thought* or uncertain* or unsatisf* or view*)).ab.
76	62 and 75
77	74 or 76
78	(letter or editorial or comment reply).dt. or case report/
79	(letter or comment*).ti.
80	78 or 79
81	exp randomized controlled trial/
82	random*.ti,ab.
83	81 or 82
84	80 not 83
85	animal.po.
86	(rat or rats or mouse or mice or rodent*).ti.
87	or/84-86
88	77 not 87
89	(2010* or 2011* or 2012* or 2013* or 2014* or 2015* or 2016* or 2017* or 2018* or 2019* or 2020* or 2021* or 2022* or 2023*).up.
90	88 and 89
91	Qualitative Research/
92	Interviews/
93	exp Questionnaires/
94	Narratives/
95	exp Surveys/
96	(qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw.
97	ethnography/
98	(ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw.
99	phenomenology/ or hermeneutics/ or grounded theory/ or group discussion/
100	(hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw.
101	(metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw.

102	"critical interpretive synthes*".tw.
103	(realist adj (review* or synthes*)).tw.
104	(noblit and hare).tw.
105	(meta adj (method or triangulation)).tw.
106	(CERQUAL or CONQUAL).tw.
107	((thematic or framework) adj synthes*).tw.
108	or/91-107
109	(national health service* or nhs*).ti,ab,in,cq.
110	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
111	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,cq.
112	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,cq.
113	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,cq.
114	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,cq.
115	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,cq.
116	or/109-115
117	exp Pediatrics/
118	(prematur* or pre-matur* or preterm* or pre-term* or infan* or newborn* or new-born* or perinat* or peri-nat* or neonat* or neo-nat* or baby* or babies or toddler*).ti,ab,in,jn.
119	child behavior/ or exp Child Health/ or child welfare/
120	(child* or minor or minors or boy* or girl* or kid or kids or young*).ti,ab,in,jn.
121	(pediatric* or paediatric* or peadiatric*).ti,ab,in,jn.
122	Puberty/ or Adolescence/ or adolescent behavior/ or adolescent health/
123	(adolescen* or pubescen* or prepubescen* or pre-pubescen* or pubert* or prepubert* or pre-pubert* or teen* or preteen* or pre-teen* or juvenil* or youth* or under*age*).ti,ab,in,jn.
124	exp Schools/ or child day care/
125	students/ or high school students/ or junior high school students/ or kindergarten students/ or middle school students/ or preschool students/
126	(pre-school* or preschool* or kindergar* or daycare or day-care or nurser* or school* or pupil* or student*).ti,ab,jn.
127	("under 18*" or "under eighteen*" or "under 25*" or "under twenty five*").ti,ab.
128	or/117-127
129	90 and 108 and 116
130	90 and 108 and 128
131	129 or 130

Appendix C Qualitative evidence study selection

Study selection for: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

Figure 2: Study selection flow chart



Appendix D Evidence tables

Evidence tables for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

Table 4: Evidence tables

Abrahamson, 2017

Bibliographic Reference	Abrahamson, Vanessa; Jensen, Jan; Springett, Kate; Sakel, Mohamed; 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; 2017; vol. 39 (no. 17); 1683-1694

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Inpatient neurorehabilitation unit and in the community **Aim** To explore the transition experiences of people with traumatic brain injury and their carers within the first month of being discharged home, including potential gaps in service provision.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Conducted around 1-month post-discharge. Location: Homes of people with traumatic brain injury.

	Format: Face-to-face, audio recorded and transcribed verbatim. Field notes were completed by the researcher to record observations and thoughts after each interview, in order to give greater context to the transcript. Topic guides were used, which were developed from a literature review and a focus group of people with TBI and carers involved in Headway. **Analysis** Thematic analysis. Two researchers carried out the analysis independently, familiarising themselves with the data by listening and reading, before producing initial codes. One researcher did this manually, 1 used NVivo10. Preliminary codes were then organised into broader themes, with anomalous data being kept in a miscellaneous group. Themes were discussed between the 2 researchers and refined, with results recorded in NVivo 10. The miscellaneous group was also reviewed alongside the refined themes. Finally, themes were named and defined before a report of findings was produced.
Recruitment strategy	Consecutive eligible people were identified 2 weeks before their expected discharge date from the neurorehabilitation unit by their consultant clinician and given information on the study. They were given a week to consider participation and ask any follow-up questions. Recruitment continued until sample size was achieved.
Study dates	Recruitment: May to December 2013 Interviews: June 2013 to February 2014
Sources of funding	Not reported
Inclusion criteria	• People aged 18 years and over who were admitted to the neurorehabilitation unit with a severe traumatic brain injury, able to communicate and provide informed consent. ○ Defined as people with a Glasgow Coma Scale score below or equal to 8 at the time of injury, who had loss of consciousness for over 24 hours and post-traumatic amnesia above or equal to 7 days. • Carers of the people described above. ○ Defined as relatives or friends who was the main source of practical and/ or emotional support for the person with traumatic brain injury, either living with them or visiting their residence regularly.
Exclusion criteria	• People with significant communication or cognitive impairment that prevented meaningful engagement in interviews. • People judged to be unable to give informed consent.

Sample size	N=19 adults with traumatic brain injury plus carers
Participant characteristics	**Adults with traumatic brain injury, n=10** Age in years [Mean (SD)]: 63 (14) Sex (M/F): Not reported Time since injury: Not reported but interviews conducted around 1 month after discharge from neurorehabilitation unit Chronic neurological disorder category: Acquired brain injury **Carers of people with traumatic brain injury, n=9** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported
Results	Themes as described in paper: • Perceptions of support: Inpatient experiences ○ Participants reported that, although they assumed GP's would be informed of their traumatic brain injury, this did not happen, which impacted the ability of primary care to offer advice and support (for example, regarding emotional responses, practical concerns such as transport to and from the hospital, and financial and legal matters). Participants also reported frustration that there was not a single point of contact within the inpatient team to answer their questions. This lack of communication and perceived lack of understanding from staff underpinned many negative experiences. Another area of complaint was a lack of rehabilitation care in the interim period between acute care and admission to a neurorehabilitation unit. ○ *"My world had fallen apart but there was no communication with down here to alert anyone… I rung so many people in that first month and nobody wanted to know because there was nothing official" (page 11)* • Perceptions of support: Transitions between units ○ Participants noted several issues when transitioning between units. Examples included poor communication, lack of planning, chaotic transfers without warning or information, and long delays waiting for transportation. Carers commonly reported having to advocate for their loved ones. Examples included contacting government representatives, contacting hospital management, and employing private services. Despite this, 1

	respondent reported their husband being inappropriately discharged which resulted in another emergency admission to the local hospital the following day. Participants also reported that hospital staff seemed to be uncaring about matters that they considered trivial (for example, being transferred without personal belongings). ○ *"It was just like, is he coming? Is he going? There's a bed. No, you can't go after half-past seven at night because there's not enough doctors on the ward… … Now we've filled the bed. Now you're back on the waiting list again" (page 13*) • Perceptions of support: Preparation for discharge ○ Participants reflected that pre-discharge home visits were helpful, but the issues identified during this period were not explored or addressed prior to discharge. Unidentified and unmet needs included visual issues, continence concerns, dietary restrictions, pain management, medication changes, pre-existing conditions and co-morbidities, and outpatient appointments. Regarding the actual discharge process, most reported a smooth discharge. However, some people reported that they were not consulted, prepared or informed adequately. ○ *"He had a couple of weekend visits, but that still wasn't somehow really enough to prepare us" (page 14)* • Struggling to accept a new reality: Autonomy and control ○ Some participants reported feeling under supported when they attempted to take control of their rehabilitation. ○ *"The physio will say things to you and it's very difficult when... someone tries to tell you something what you know more about yourself…. she [OT] was talking to me like I was a bit of an idiot" (page 18)* • Fear and anxiety for the future: Post-discharge experiences ○ Gaps between 1 rehabilitation service ending and another starting, lack of information about when community services would start, and the lack of a contact point were the factors commonly cited as causing concern. Furthermore, the duration and appropriateness of intermediate care was questioned. Participants were aware that services were stretched but wanted more rehabilitation than was offered. ○ *"I just think it's that one missing link because the intermediate care team try so, so hard. But even they're pushed with the resources that were available… … if there was just one person that was dedicated to that family… … who could co-ordinate everything" (page 20)*

N/n: number of participants; OT: occupational therapist; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No information on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Ando, 2021

Bibliographic Reference	Ando, Hikari; Ashcroft-Kelso, Helen; Halhead, Rob; Chakrabarti, Biswajit; Young, Carolyn A; Cousins, Rosanna; Angus, Robert M; Experience of telehealth in people with motor neurone disease using noninvasive ventilation.; Disability and rehabilitation. Assistive technology; 2021; vol. 16 (no. 5); 490-496

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Within 24-week trial of the Careportal® telemonitoring device **Aim** To explore the experiences of the Careportal® telehealth monitoring service in people with motor neurone disease using non-invasive ventilation.

Data collection and analysis	**Data collection** Method: Semi-structured interviews. Duration lasted an average of 35 minutes (range 30-50 minutes). Location: At home. Format: Face-to-face, audio recorded and transcribed verbatim. Dyadic interviews were conducted. Two participants used a communication device and 3 needed communication support from carers. Carer's interpretations of answers were double-checked for accuracy with the person with motor neurone disease. **Analysis** Thematic analysis. Transcripts were uploaded into NVivo 11 and analysis was performed by same researcher who conducted the interviews. Initial themes were inductively identified from the transcripts and arranged into overarching themes. These themes were checked against raw data to ensure they were an accurate reflection. Findings were presented to the whole research team at a team meeting, and a list of codes and transcripts was also shared to enable an informed credibility examination.
Recruitment strategy	Opportunity sampling. People who had completed the 24-week Careportal® intervention study were invited to participate, along with their carers.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• People with motor neurone disease and their carers taking part in the parent intervention study. ○ Note: Inclusion criteria of parent study not reported.
Exclusion criteria	Not reported
Sample size	N=12 adults with motor neurone disease plus their carers
Participant characteristics	**Adults with motor neurone disease, n=7** Age in years [Mean (SD)]: 63 (SD not reported)

	Sex (M/F): n=5/ n=2 Time since diagnosis in years [Mean (SD)]: Not reported, range 8 months - 13 years 7 months Chronic neurological disorder category: Progressive neurological disorder **Carers of adults with motor neurone disease, n=5** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported, age range 49-68 Sex of people with chronic neurological disorders (M/F): n=3/n=2
Results	Themes as described in paper: • Benefits of timely intervention ○ The majority of participants reported accessing timely interventions as a result of the continual monitoring (for example, when oximetry results prompted interventions), which contributed to physical and mental well-being. Participants who did not experience these throughout the trial agreed that this could be beneficial at a later stage. ○ *"You know that was very good. Because the oximetry, when it worked, it was very good because [physio] could be on the work: "Well, we need to alter these settings [on NIV]". You had that once, didn't you?" (page 492)* • Reducing the unnecessary ○ Many participants wanted to use the monitoring intervention to reduce the amount of hospital appointments that they needed to attend, especially when there was little change to physical symptoms. It was felt that virtual monitoring was more cost and time effective and reduced the practical hassles of attending clinic appointments. However, a few participants did want to keep on attending regular in-person appointments in order to continue direct contact with a consultant. ○ *"I go to [hospital 1] every six months with [neurologist] and that [it] lasts for between 30 seconds and 2 minutes. He goes, "How are you? Yeah, yeah. Okay. See you then." And the same [physician] I've probably seen – is it every 6 months? Or 12 months? I think it's 6 months I see [physician] or one of his people. Same sort of thing – I walk in and "How are you?" "Yeah, fine off you go." If it stops you doing that it would be brilliant. There is no need." (page 492)*

	- Taking initiative
	  - Participants appreciated being able to log concerns as they arose, then following up with a healthcare professional at a later date. This gave them peace of mind, even if their questions were not answered immediately. Types of concerns included symptoms, general information, and equipment queries. This needs-based communication was reported to be very different than current communication with hospitals, which was either one-way or with severe delays.
	  - *"We don't really have a great deal of communication. The only thing you have is they send you out an appointment and you go to your appointment and you come away until next one and that's pretty much all the communication that you have." (page 493)*
	- Technical challenges
	  - Participants were generally happy with using the telehealth intervention, but a few technical issues were noted. Most were minor or quickly resolved, but the messaging system was highlighted as being difficult, particularly the on-screen keyboard.
	  - *"The keyboard is that frustrating I just couldn't be bothered trying to get it to work because it wouldn't." (page 493)*

N/n: number of participants; NIV: non-invasive ventilation; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(No information on relationship between researcher and participants; poor description of data analysis methods; lack of discussion of credibility.)*
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates particular rehabilitation therapy or service [*Careportal®*teleheath intervention] which may not be broadly transferable.)*

Bernard, 2010

Bibliographic Reference	Bernard, Sylvia; et, al; Integrated services for people with long-term neurological conditions: evaluation of the impact of the national service framework; 2010; 179p

Study Characteristics

Study type	Case study
Country/ies where study was carried out	UK
Setting and aim	**Setting** Academic, hospital and community-based neurorehabilitation services **Aim** To explore how long-term neurological condition services are integrated within the healthcare system, as well as with social care and other relevant services. Also, to explore how long-term neurological condition services adapt to provide care to a population with diverse needs.
Data collection and analysis	**Data collection** Method: Semi-structured interviews[1] and non-participant observation of meetings. Semi-structured interviews lasted on average 1 hour. Meetings focusing on long-term neurological conditions, specifically Local Implementation Teams and other strategic planning and commissioning meetings. Location: Not specified but decided on by participants (examples given were at home and at a day opportunity centre). Format: Telephone and face-to-face. Generally audio recorded and transcribed, but comprehensive notes taken if consent for recording not given. Field notes, agenda, minutes and discussion documents from meetings were also kept to inform data analysis. Separate topic guides for service users and professionals were informed by the programme advisory group (made up of service users and representatives from voluntary organisations), and piloted. **Analysis**

	Thematic framework analysis. Interviews were analysed thematically, with each member of the team reading transcripts and identifying initial themes to form the basis of the framework. Sub-themes were determined if appropriate. Data was then extracted into these themes by 1 researcher and checked for accuracy and compliance by a different researcher. Discrepancies were solved through discussion. Findings were also supplemented with non-participating observation and documentary evidence. Data from people with long-term neurological conditions and practitioners were analysed separately before being compared and contrasted to triangulate findings.
Recruitment strategy	People with long-term neurological conditions • Service users were identified (no further details) and sent the study information by the corresponding healthcare professional or service. Potential participants returned a form if they wished to enrol. Practitioners working with people with long-term neurological conditions • A key person (with a central role in commissioning, development and management of chronic neurological disorder services) from each of 6 participating primary care trust areas was identified and they then advised on contacting other key people within long-term neurological condition commissioning services. Chairs of relevant meetings in the trust area and individual staff were invited to participate. Individual participants were also recruited by the researchers during attendance of the meetings. After interviews, participants (both professional and service users) were asked to nominate other organisations and staff that might be suitable to contact.
Study dates	November 2007 – May 2008
Sources of funding	Not industry funded
Inclusion criteria	People with long-term neurological conditions: • Over 18 years old. Practitioners working with people with long-term neurological conditions: • Over 18 years old, and able to give informed consent and participate in an interview held in the English language.
Exclusion criteria	People with long-term neurological conditions: • People with cognitive impairments (as reported by healthcare professionals).

	Practitioners working with people with long-term neurological conditions: Not reported.
Sample size	N=222 adults with long-term neurological conditions plus practitioners
Participant characteristics	**Adults with long-term neurological conditions, n=71** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported but all over 18 Sex people with chronic neurological disorders (M/F): Not reported Time since diagnosis or injury: Not reported Chronic neurological disorder category: Acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorder, and progressive neurological disease. **Practitioners working with people with long-term neurological conditions, n=151** 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 PCT commissioners, n=12 health care senior managers, n=8 health service managers, n=21 nurse specialists, n=13 consultants, n=19 other clinical professionals, n=4 social care senior managers, n=12 social care managers, n=7 social care practitioners, n=6 independent sector service managers, n=33 voluntary sector representatives, n=3 general practitioners
Results	Themes as described in paper: • Approaches to integration of services and joint working ○ Participants reported that integration allowed opportunities for innovative and cross-team developments. For example, a social care support team had branched out from only working with social workers to support clients of health teams. Another example was social workers being allowed to refer directly to community therapists without having to involve a General Practitioner. ○ Specialist community neurological services were commissioned by the primary care trust and linked to social care by a specialist neurological care worker. Several participants reported poor management continuity

  between healthcare and social care, as 1 professional did not have the required capacity to ensure smooth communication and transition across the population.

  - A community interdisciplinary neurological rehabilitation team had recently been formed by combining an impairment therapy-based team and a social inclusion team. This combined team helped to promote a more social model of rehabilitation.
  - *"A significant issue for us is that rehabilitation for us is about context-based rehabilitation, about social inclusion … so it still remains a complexity. We are a very innovative team. We find that the PCT and local authority will listen to what we say, but their systems are not yet flexible enough to deliver care that might be unusual or off the norm."* (page 49)

- Strategic partnerships and strategic approaches
  - Respondents noted some strategic leadership collaboration, but effectiveness differed across areas. One site kept healthcare and social care budgets separate, despite having a team that encompassed both areas and that was responsible for implementing the National Service Framework. Due to this, planning National Service Framework developments could be joint, but commissioning of services was more difficult. Combining the budget of healthcare and social care from the outset would make commissioning much simpler.
  - A suggestion for a better model of delivering services for people with long-term neurological conditions was to separate physical and sensory impairments for working age adults.
  - At 1 site, social care services moved from a specific team to generic teams based on locality. Respondents reflected that this had resulted in a dilution of professional expertise and decreased opportunities for collaboration with other disability services.
  - A central recommendation of the National Service Framework was to establish neuroscience networks in order to coordinate planning, commissioning and provision of chronic neurological disorder services. Despite this, only 33% of the sites surveyed belongs to a neuroscience network, and only 1 was fully functioning. Some respondents reported that these networks focused too much on acute, medical care for neurological conditions, and had a poor social care representation.
  - *"In theory [the neuro-network is] very important in planning and developing services, in practice it still seems to spend a lot of time talking about developments in the neurosciences centre rather than monitoring what is happening around the region, though that is one of its remits."* (page 54)
- Local Implementation Teams (LITs)

  - Respondents from the voluntary sector reflected that Local Implementation Teams could play an important role in collaborating with statutory bodies. However, their effectiveness in this role depended on the amount of involvement of the voluntary sector and the cooperation of people in charge. Voluntary sector professionals reported feeling excluded due to the over-representation of healthcare services and use of technical language, with only selected groups being fully involved. Some sites did not have representation from the local authority, service users or the private sector.
  - One site established a Local Implementation Team during the study, with immediate effects. It facilitated communication across the service system and helped raise awareness of gaps in the services. Respondents did note that representation within the group did not cover all relevant areas of the system which could limit the scope of the service. Another site had a Local Implementation Team that partially covered the primary care trust, leading to confusion from other areas about whether the group existed and how they were meant to become involved. One site had 2 Local Implementation Teams in place - 1 covering the hospital and 1 covering the primary care trust. As there was no procedure for information exchange between the 2 teams, they were frequently unaware of what the other was doing.
  - *"It's very difficult when you're on the outside, to get inside information, and know who the best people are for you to speak to."* (page 55)
- National Service Framework for long-term neurological conditions in the context of national policies
  - Despite the need for continuing follow-up and timely access to services for people with long-term neurological conditions, some people reported follow-up appointments taking 18 months.
  - *No first-order quotes to support this theme.*
- Facilitators and barriers to joint working: Facilitators: Co-location, leadership and a shared approach
  - Respondents noted that co-location of services was a way of facilitating collaboration, ongoing communication, and continuation of care. Another practical advantage was a greater opportunity for informal communication between professionals which saved time and helped referral processes.
  - *"Health and social care have really come together here in a joint partnership."* (page 64)
- Facilitators and barriers to joint working: Facilitators: Key workers and Community Interdisciplinary Neurological Rehabilitation Teams (CINRTs)

	○ Many sites used individual key workers rather than teams to coordinate services, particularly nurse specialists (although other professionals from the voluntary sector and adult social care were sometimes reported). Nurse specialists were seen to be effective because they could work across services and bridge the gap between voluntary and statutory sectors. ○ None of the sites surveyed had a single integrated assessment and information sharing system working across services. Electronic records were used but tended to only be effective within organisations rather than between them, which was problematic. ○ *"Specialist nurses are very good at establishing links and networking."* (page 68) • Facilitators and barriers to joint working: Barriers: Organisational boundaries ○ Continuity of care broke down at several points in the rehabilitation pathway: between primary and secondary care; social care and healthcare; and mental health services. People with long-term neurological conditions were especially impacted with the lack of continuity into mental health services as there was often disagreements amongst professionals about whether they were experiencing symptoms related to their condition, related to their mental health, or a combination. The boundary between where the responsibility of the primary care trust and acute services stopped and where that of mental health trusts and social care started was unclear in these cases. ○ A lack of communication and adherence to formal procedures meant that community services were often not informed when people were discharged from hospital, meaning they were poorly equipped to receive their care. ○ *"I think we do tend to get into more battles these days with mental health and social work about, you know, you should be doing this, we shouldn’t be trying to, not that it gets us very far, but we do try I think."* (page 69) • Facilitators and barriers to joint working: Barriers: Ineffective pathways and silo working ○ Respondents noted that there were a lack of effective and formal pathways to guide people with long-term neurological conditions throughout the complicated rehabilitation system. This results in siloed working, with each practitioner taking responsibility for their own areas of the pathway and not communicating with other professionals and services. A way of combating this was bringing together individual professionals into interdisciplinary teams.

    - *"We pick people up after they've been missing out on things for years … you don't see it happening in isolation, you see it happening time and time again, because nobody's taken responsibility for it. They'll do their own bit, and then it just doesn't get referred on anywhere."* (page 72)

- Relationship continuity: Long-term continuity
    - Long-term continuity was valued by people with long-term neurological conditions, who believed that services should be ongoing. People with long-term neurological conditions highlighted the need for regular review and follow-up appointments from a variety of professionals (including consultants, nurse specialists, social workers, community interdisciplinary neurological rehabilitation teams and regional specialist centres) in order for them to feel supported. Ad hoc access to services between reviews should also be provided even if it was through a telephone call. Most people reported that they only received support for a particular issue or complaint, without any follow-up after this was treated, and having to go through the whole referral and assessment procedure again for subsequent concerns.
    - Some participants reported that regular follow-up was not always appreciated if they had to repeat information about themselves, or if they had to visit multiple professionals with no sense of coordination.
    - People wanted ongoing access to services and professionals rather than continuous input from professionals, allowing people to remain empowered about their healthcare access.
    - *"The Physio [from the CINRT] is coming out to see me quite regularly at the moment because I've had problems with my arms, so she's given me exercises to do, she came out to see how they were going. She's been out a couple of times and now she's coming back on six weekly check-ups to make sure that things are still going."* (page 77)
    - *"… knowing someone is there, absolutely correct. And they're ready and prepared to, sort of, come over and to see what stage and development of needs that you require and they'll be supportive in that respect."* (page 78)

- Relationship continuity: Longitudinal continuity
    - For participants using a cross-sector interdisciplinary team, they appreciated the ability to cater to a variety of needs via 1 team. For example, 1 community interdisciplinary neurological rehabilitation team helped a person with spinal cord injury to access physiotherapy services, obtain adaptation to their house, apply for benefits, contact a debt counsellor, and arrange for education and training at a local day centre. They co-ordinated the care of another person with a brain injury, identifying discontinuities over time. Ongoing care from 1 team or person increased continuity of care and helped provide smoother rehabilitation services.

  - *No first-order quotes to support this theme.*

- Relationship continuity: Relational, personal and therapeutic continuity
  - Participants reported that a good relationship with general practitioners was central to managing chronic conditions. This was facilitated by seeing the same person over time, who knew them as an individual as well as their family circumstances. Nurse specialists were named as being especially good at fostering personal relationships, and therefore a valuable source of advice and information. At least 1 participant was prepared to travel longer distances to see a consultant with whom they had a good relationship. This rapport also helps healthcare professionals to spot changes in people’s conditions, which is important in fluctuating disorders. A keyworker was noted as a way of providing this personal and ongoing relationship.
  - *"[MS nurse specialist] would be my first port of call because she’s nice and she’s always there to, you know, to listen to you, they’re specialist in MS, and know what I’m going through more so than the doctor, ‘cause doctors, sort of, like generalise on everything, don’t they, really? It’s not just specialising in MS, so it’s always first port of call is always the MS Nurse."* (page 83)
- Management continuity: Flexible continuity
  - Respondents noted that it was difficult to re-access specialist services during a relapse of their progressive disorder. Community interdisciplinary neurological rehabilitation teams were praised for being flexible towards clients’ needs (for example, varying the location of appointments). Motor neurone specific services were found to be flexible and responsive, which was valued by people with a terminal illness.
  - *"You can ring anybody at any time and the motor neurone’s number is 24 hours anyway, to ring them, and it’s up to ten p.m. every night. You can always get contact with somebody. And we’ve got [MNDA care adviser’s] mobile and home number, and the works number, so you can literally ring her at any time, doesn’t matter when, if you need to speak, feel a bit down. Because let’s face it, with motor neurone, you’re dying, you know you’re dying."* (page 89)
- Management continuity: Cross-boundary and team continuity
  - Co-ordination in the community decreased as the number of professionals involved increased, if there was no single person or team with overall responsibility for rehabilitation. One respondent reported that having 1 team in charge of their spinal cord injury rehabilitation allowed consideration of immediate physical needs, but also wider financial advice and retraining needs. This support needs to have a long-term lens, not just at the point of discharge from inpatient to community. Day opportunities and resource centres were also

	identified as settings for coordination of care. This is because they often straddle service boundaries, including healthcare, social care, local authorities and voluntary services. ○ *"their job was to prepare you in – closely, you know, for coming out, and trying to work out – and they'd all been here to the house. I mean, [physical disability nurse specialist] led a great party of people here to the house to have a look at, you know, what I'd got and what I would need, and things like this. So that was brilliant."* (page 94) • Information continuity ○ Respondents noted the importance of information about their disorder that was both high quality and timely, as well as encompassing support that was currently available to them, how to get extra support, and future information (for example, likely prognosis). During diagnosis, communication between professionals and people with long-term neurological conditions should be open and clear. An ongoing point of contact was valued so that people knew who to contact if their condition changed or if they wanted more information. Some people appreciated being asked how much information they would like, and for that to be factored into conversations. Participants reported that being given information about the existence of a national voluntary sector agency was enough for them to access this support. ○ *"I feel if I had not taken the trouble to get myself involved with the Parkinson's Society, I think I would have just sat here and not known about all these things, 'cause I don't think anybody else would have bothered" (page 96)*

MNDA: Motor Neurone Disease Association; MS: multiple sclerosis; N/n: number of participants; NSF: national service framework; PCT: primary care trust; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
Overall risk of bias and relevance	Relevance	Highly relevant

Botchway, 2022

Bibliographic Reference	Botchway, Edith N; Knight, Sarah; Muscara, Frank; Greenham, Mardee; D'Cruz, Kate; Bonyhady, Bruce; Anderson, Vicki; Scheinberg, Adam; 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; 2022; vol. 32 (no. 4); 537-559

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Australia, UK, New Zealand, Canada and the US
Setting and aim	**Setting** Within paediatric rehabilitation services, insurance services and education service providers **Aim** To explore national and international rehabilitation service models and programmes for children who have experienced major traumatic brain injury and/or traumatic spinal cord injury, including how these systems are family-centred and how they support children through key developmental transitions.
Data collection and analysis	**Data collection** Method: Semi-structured interviews, lasting approximately 100 minutes each. Interview guide was piloted and adjusted prior to data collection. Seven interviews were conducted with individual respondents, 4 were group interviews, involving multiple (2-3) respondents. Location: Not reported. Format: Face-to-face (2 interviews) or online video conference (9 interviews), recorded on an iPad (not reported if audio and/or video format), transcribed by professional transcription service. **Analysis**

	Thematic content analysis, performed by 4 researchers. Transcripts uploaded to NVivo 12 and analysed by first author, using the themes of service structure, service organisation, and the barriers and facilitators of service provision. Content was organised into discrete codes within each of these themes, with sub-themes defined and refined through comparing and contrasting data over subsequent stages. Developing sub-themes were discussed at all stages with the other 3 researchers and finalised after agreement from all 4 researchers. To aid data analysis, field notes were kept and reflective journaling was performed after each interview, with reflective writing and analytical discussions throughout the process.
Recruitment strategy	Deductive selection process. A global online search for paediatric rehabilitation services for traumatic brain injury and traumatic spinal cord injury were performed, plus expert knowledge from the study steering committee. Identified services were emailed about participating in the study and asked to nominate (multiple if possible) service representatives to be interviewed.
Study dates	March-June 2019
Sources of funding	Not industry funded
Inclusion criteria	• Healthcare practitioners or care managers working within rehabilitation services caring for people with traumatic brain injury or traumatic spinal cord injury. • Practitioners working within private or public services supporting people with childhood traumatic brain injury or traumatic spinal cord injury.
Exclusion criteria	• Services solely caring for adults (defined as older than 18 years) with traumatic brain injury or traumatic spinal cord injury.
Sample size	N=20 practitioners working with children and young people with traumatic brain injury and traumatic spinal cord injury
Participant characteristics	Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all under 18 Sex of children and young people with chronic neurological disorders (M/F): Not reported Role or specialism: n=12 medical rehabilitation service practitioners, n=4 community-based rehabilitation practitioners, n=2 insurance provider professionals, n=2 education service provider professionals Chronic neurological disorder category: Acquired brain injury and acquired spinal cord injury

Results	Themes as described in paper: • Family-centred care: Challenges associated with family-centred care ○ Respondents reported the main challenges of family-centred care were: managing family relationships, needs and expectations; supporting priority populations; and involving families in challenging conversations. Other examples given were inadequate funding, unfamiliarity with home-based care, and impacts on family cohesion. ○ *"Our clinicians in particular always think that they're acting in the child's best interest, not necessarily the family's best interest. And so that's where the conflict comes up" (page 547)* • Psychosocial support: Challenges associated with providing psychosocial support ○ Two participants reported that programmes offered were either generically designed for children and young people with any disability or were not suitable for those with spinal cord injury. ○ *No first-order quotes to support this theme.* • Support through key developmental transitions: Transition to home and community ○ An issue when transitioning back into the community from medical rehabilitation services was when therapy supports were provided too late for people. ○ *"It's about…I think the issue with transition is when the therapy supports come in too late" (page 551)*

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

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Poor description of recruitment methods; no information on relationship between researcher and participants; lack of discussion of credibility.)*

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Relevant *(At least 1/16 participants from the US [outside of protocol].)*

Botchway-Commey, 2022

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

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Australia, UK, New Zealand, Canada and the US
Setting and aim	**Setting** National and international paediatric rehabilitation services for traumatic brain injury and traumatic spinal cord injury. **Aim** To explore how national and international systems are designed to support paediatric traumatic brain injury and traumatic spinal cord injury rehabilitation services, as well as the barriers and facilitators to providing these services.
Data collection and analysis	**Data collection** Method: See Botchway 2022

	Location: See Botchway 2022 Format: See Botchway 2022 **Analysis** See Botchway 2022
Recruitment strategy	See Botchway 2022
Study dates	See Botchway 2022
Sources of funding	See Botchway 2022
Inclusion criteria	See Botchway 2022
Exclusion criteria	See Botchway 2022
Sample size	N=16 practitioners working with children and young people with traumatic brain injury and traumatic spinal cord injury
Participant characteristics	Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all under 21 Sex of children and young people with chronic neurological disorders (M/F): Not reported Role or specialism: n=12 medical rehabilitation service practitioners, n=4 community-based rehabilitation practitioners Chronic neurological disorder category: Acquired brain injury and acquired spinal cord injury
Results	Themes as described in paper: • Service structure: Disciplinarity/teamwork models ○ The community-based rehabilitation services used transdisciplinary (where 1 professional has a key worker role, acting as a central point to collate information on a client from other disciplines), interdisciplinary, or multidisciplinary team approaches depending on their service structure and the needs of their clients. This can be flexible throughout the child's rehabilitation.

	○ *"If we get a referral for a child that's under the age of six or seven…, we are using a key worker model. Which means that there'll be one therapist that works with that child and…family and that that therapist can get secondary consultation from other disciplines but clearly the family are working with one therapist. So after the age of seven we then have a model of interdisciplinary practice and then the person might have… OT [occupational therapy], speech, and physio working with them." (page 14)* • Service organization: Care planning ○ All participants reported that families were involved in care planning, but that older children were more active compared to younger counterparts. The majority of services designed rehabilitation plans that extended beyond inpatient admission, to include care management at discharge. Children and young people were normally discharged into a specific rehabilitation outpatient team, or a child-based rehabilitation service, which then took over their continuing care. During the inpatient period, families were normally linked to rehabilitation services local to their community, which helped continuity of care after discharge and decreased time needed to attend clinic appointments. The rehabilitation services could provide allied health services, helping families to build capacity for care. ○ *"So we like the family and the child to be involved as much as possible when it's appropriate. And then obviously depending upon their age and their function, we'll tailor their, the actual delivery of care and therapy that we're giving." (page 15)* ○ *"We have a family meeting at the beginning of the admission and near the end, if it's an extended stay to talk about the plans for discharge home, a discharge date, what kind of equipment and services they're going to need after discharge. I work with getting all of the equipment and appointments and therapies that they'll need for home." (page 15)* • Barriers and facilitators: Strengths of services ○ Respondents noted the following strengths of rehabilitation services: increasing informal support for families; building capacity for care; implementation of the key-worker model; providing evidence-based practice; providing a service that is flexible and mobile. ○ *"I think the strength is being a very fluid and mobile team. We're able to respond to the evolving needs of our clients and their families" (page 17)* • Barriers and facilitators: Challenges/barriers associated with service provision

	○ Respondents noted that employing the right professionals to fit the community-based model of care was a challenge, as most staff training follows the medical model. ○ *“We just can’t get the therapists that are the right fit, and part of that is that the universities are not focusing enough on training graduates to work in natural environments under a social model.” (page 18)* • Barriers and facilitators: Key learnings ○ Half of the participants reported that service providers needed to learn to focus on families, concentrate on forming partnerships and collaborations, and find creative ways to overcome challenges. ○ *“I think we often default to the answer of it all comes down to budget, which it does, but I think if you can come up with creative and innovative ways…I think for me, one of the challenges to the team I believe is that if we’re not going to get more money it doesn’t mean we can’t do it, it just means we have to rethink how we do it.” (page 18)*

OT: occupational 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 recruitment methods; no information on relationship between researcher and participants; lack of discussion of credibility.)*
Overall risk of bias and relevance	Relevance	Relevant *(At least 1/16 participants from the US [outside of protocol].)*

Daker-White, 2013

Bibliographic Reference	Daker-White, Gavin; Greenfield, Julie; Ealing, John; "Six sessions is a drop in the ocean": an exploratory study of neurological physiotherapy in idiopathic and inherited ataxias.; Physiotherapy; 2013; vol. 99 (no. 4); 335-40

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Within neurorehabilitation services **Aim** To explore neurological physiotherapy service provision for people with ataxia in North West England.
Data collection and analysis	**Data collection** Method: Semi-structured interviews Location: • People with ataxia: At home • Physiotherapists: At place of work Format: Face-to-face, audio recorded (except for 2 interviews where permission was not obtained and therefore notes were taken by hand) and transcribed. Interview guide used. **Analysis** Thematic analysis. Interview transcripts and notes for people with ataxia were uploaded into Atlas.ti qualitative data software, where they were coded in batches of 5 or 10 by the lead author as the study progressed, before being combined and renamed. Physiotherapist interview transcripts were uploaded to Atlas.ti and were coded all together after the interviews for people with ataxia were analysed.
Recruitment strategy	• People with ataxia – Purposive sampling. Eligible participants within the study region were identified from Ataxia UK's membership list, from a Clinical Genetics department, and from a Neurology department. Additionally, participants were recruited at local branch meetings of Ataxia UK by the lead author.

	- Physiotherapists – Eligible physiotherapists were recruited initially via letters and emails sent to all neurological rehabilitation teams within the study region, the email list from the local Chartered Society of Physiotherapists, and Ataxia UK's healthcare professional database. This only resulted in 1 participant being recruited, so recruitment methods were expanded to personal invitation of people known to have an interest in ataxia treatment or research, advertising at a local training day hosted by Ataxia UK, and snowball recruitment using an already enrolled physiotherapist.
Study dates	February 2010 - March 2011
Sources of funding	Not industry funded
Inclusion criteria	- People with idiopathic or inherited ataxia living in Greater Manchester. - Specialist neurological physiotherapists with an interest in ataxia treatment and research.
Exclusion criteria	Not reported
Sample size	N=46 adults with progressive ataxia plus practitioners
Participant characteristics	**Adults with progressive ataxia, n=38** Age in years [Mean (SD)]: 52.5 (SD not reported), age range 22-77 Sex (M/F): n=20/n=18 Time since diagnosis: Not reported Chronic neurological disorder category: Acquired brain injury and progressive neurological disease **Practitioners working with people with progressive ataxia, n=8** 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 specialist neurological physiotherapists

Results	Themes as described in paper: • Engagement with services ○ Participants with progressive ataxia reflected that short packages of rehabilitation followed by structured exercises at home were not helpful. ○ *No first-order quotes to support this theme.* • Making a difference? ○ Participants who were satisfied with and adherent to home physiotherapy tended to also be those who had longstanding and ongoing contact with a neurological physiotherapy specialist. Both people with progressive ataxia and physiotherapists working with them were not satisfied with the standard 6–8-week physiotherapy package, which was then followed by a structured exercise programme to be completed at home. Some participants reflected that these types of physiotherapy packages could work if there was a pathway for re-referral or follow-up if needed. ○ *“Partner: The improvement with the physio is untold [interviewer], it’s just because both of us just didn’t give hope for it. . . Interviewer: How much physiotherapy do you get? Interviewee: I can ring up . . . and speak to the physiotherapist and say, ‘Yeah I feel I need to come in.’ And she’ll say, ‘Right I’ll fit you in, come in.’ Partner: [Interviewee] does all his exercises and he fully believes, and I know the difference [interviewer], because . . . before [he] went to this physio he couldn’t move from side to side.” (page 338)*

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	Serious concerns *(Participants recruited via personal invitation; no information on relationship between researcher and participants; no information on ethical issues; poor description of data analysis methods; no discussion of credibility; lack of discussion of study value.)*

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Relevant *(Specialisms of practitioners not explicitly stated but 'The more common experience in the interview sample was of ataxia presenting as resulting of MS, stroke or traumatic brain injury.' (page 337).)*

MS: multiple sclerosis

Dennett, 2020

Bibliographic Reference	Dennett, Rachel; Coulter, Elaine; Paul, Lorna; Freeman, Jennifer; A qualitative exploration of the participants' experience of a web-based physiotherapy program for people with multiple sclerosis: Does it impact on the ability to increase and sustain engagement in physical activity?; Disability and rehabilitation; 2020; vol. 42 (no. 21); 3007-3014

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 (within a larger 6-month randomised controlled trial investigating the experiences of a web-based physiotherapy intervention) **Aim** To gather user feedback on a web-based physiotherapy intervention and determine its impact on physical activity.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Lasted up to an hour.

	Location: Not specified. Format: Face-to-face, audio recorded and transcribed verbatim. Interview guide was piloted with a person with multiple sclerosis not involved in the study. **Analysis** Thematic analysis using a general inductive approach. A researcher listened to interview audio recordings twice and read transcripts multiple times to familiarise themselves with the data, before noting initial codes alongside relevant data extracts. A second researcher independently coded 3 transcripts as well. Codes were then collated and patterns in the data identified, which were then discussed with 3 other team members to create themes and sub-themes. Example quotes to illustrate participant views were selected. A summary of the main themes were sent to participants for accuracy review before finalising the report.
Recruitment strategy	Participants assigned to the web-based physiotherapy group from the Plymouth study centre were sent an invitation letter with an information sheet within 1 month of their final follow-up appointment from the trial.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	• Adults with a diagnosis of multiple sclerosis and known to a multiple sclerosis consultant within the geographical recruitment areas, with an Expanded Disability Status Scale score between 4 and 6.5 (corresponding to mild to moderately impaired walking). • Participants also had to have access to a personal computer/tablet/smart television, an internet connection, and a valid email address.
Exclusion criteria	• People already achieving 2 or more physical exercise or physiotherapy sessions per week. • People with a Mini Mental State Examination Score below 24 (corresponding to poor cognitive function). • People undergoing a significant change to their medication or a relapse requiring treatment in the previous 3 months. • People with co-morbidities resulting in exercise being contraindicated.

	• People unwilling to be randomised to either group. • People currently participating in another clinical trial.
Sample size	N=11 adults with multiple sclerosis
Participant characteristics	Age in years [Mean (SD)]: Not reported, age range 28-68 Sex (M/F): n=1/n=10 Time since diagnosis in years [Mean (SD)]: Not reported, range 1-40 Chronic neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • "It's all in one place": Accessibility ○ Participants reported that having their physiotherapy exercise programme on their electronic device was very convenient, which increased the chance that they would complete it. Having the programme in 1 place also decreased the likelihood that people would lose it and have to hunt for it. Additionally, electronic devices are also now so ingrained into modern life that people are more likely to see the programme link or icon on a daily basis, which acted as a prompt to complete their exercises. ○ *“I just find it quite difficult to manage lots of bits of paper which seems silly but I do, so having it online actually I found easier way to keep on track with it…papers do easily get lost, or dog-eared, or thrown away by mistake so it was good to have it all on computer in one place so you always know where your laptop is... Because it’s there and easier to find and you’re not faffing [colloquialism, struggling to get things together] around because of not being able to move very easily, I don’t know, you value it more in a way.” (page 13)* • "It's all in one place": Flexibility ○ Participants appreciated the ability to access the website when and where they wanted to. Examples given were people preferring to complete their programme at home because they felt self-conscious about exercise around others or because they wanted a safe and familiar environment to push themselves, or people wanting to fit their physiotherapy around family life or changes in symptom severity. On the other hand, some people did not like missing the social nature of exercising with other people.

	○ *“I don’t particularly want to be part of a group um, I’m much happier doing at my own level and my own pace really um, and so that was good for me and it was good for me because I’m reasonably computer literate so it was easy, I did it on my phone…. It’s difficult for me, not physically, to get to the same place regularly in the course of a week cos I just find work’s quite, encroaches on my free time and also the children.” (page 16)* • "It's all in one place": Portability ○ Some participants reported enjoying the portability of the intervention (for example, being able to take their exercises when travelling). ○ *“You can take it with you because it’s on your phone, and the first time I did it I put it on the iPad and we went away for the weekend and I thought it was great because I could do it, take it with me. It’s been to Malta…. Tenerife, been to France.” (page 19)* • "Keeping an eye" ○ Roughly half of the participants reported sufficient remote support from physiotherapists during the intervention, noting that it allowed discussion of their programme, progression of exercises, and continued engagement with the intervention. Additionally, people liked the instant access to a physiotherapist that the website allowed. This means that they could get professional advice when having difficulties with an exercise or if their symptoms prevented certain movements. However, the remainder felt as though they did not receive sufficient support for engagement. Similarly, 1 respondent disliked the fact they were unable to build relationships with other users through the website, which could have encouraged and supported them through the programme. ○ *“If you see a physio, you see the physio for a period and then you are left to go away and then it is up to you to ring them up again if you want more help and then again it is difficult to get appointments.” (page 21)*

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	No or very minor concerns
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates a particular rehabilitation therapy or service [web-based physiotherapy intervention] which may not be broadly transferable.)*

Donovan-Hall, 2011

Bibliographic Reference	Donovan-Hall, Maggie K; Burridge, Jane; Dibb, Bridget; Ellis-Hill, Caroline; Rushton, David; The views of people with spinal cord injury about the use of functional electrical stimulation.; Artificial organs; 2011; vol. 35 (no. 3); 204-11

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Within 4 spinal centres **Aim** To explore the experiences of using functional electrical stimulation and views on future use within British clinical practice.
Data collection and analysis	**Data collection**

	Method: Focus groups (x8). Groups were facilitated by 2 researchers (1 acting as facilitator and the other making notes) and lasted between 90-120 minutes. Location: Not specified. Format: Face-to-face, audio recorded and transcribed verbatim. Interview schedule used. **Analysis** Thematic analysis. Two researchers familiarised themselves with the transcripts before dividing them into sections and creating initial codes. These codes were then examined to identify how they might relate to one another. The 2 researchers continued discussing, comparing and verifying key themes before reviewing and finalising them.
Recruitment strategy	• People with spinal cord injury – Eligible participants were identified by 4 spinal centres in the UK and sent information packs (containing invitation letter, an information sheet, and a screening questionnaire). Final participants were selected using purposive sampling from the completed screening questionnaires, ensuring to include a variety of demographic and clinical characteristics. These included: complete and incomplete paraplegia and tetraplegia; age and time since injury; wheelchair dependent and independent; experience with functional electrical stimulation. • Healthcare professionals working with people with spinal cord injury – recruited using a professional internet network for people interested in using functional electrical stimulation for rehabilitation.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• People with spinal cord injury (with and without functional electrical stimulation experience) attending a participating spinal centre. • Healthcare professionals (with and without functional electrical stimulation experience) working in a participating spinal cord centre.
Exclusion criteria	Not reported
Sample size	N=36 people with spinal cord injury plus practitioners

Participant characteristics	**People with spinal cord injury, n=20** Age in years [Mean (SD)]: Not reported Sex (M/F): Not reported Time since diagnosis or injury: Not reported Chronic neurological disorder category: Acquired spinal cord injury **Practitioners working with people with spinal cord injury, n=16** 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=7 medical researchers, n=5 allied healthcare professionals, n=2 consultants, n=1 assistance psychologist, n=1 charity professional
Results	Themes as described in paper: • Decision to use FES ○ Healthcare professional participants reported that they needed to exercise caution when screening people for functional electrical stimulation, in order to temper expectations and not give false hope. Despite this, it was seen to be important to give people with spinal cord injury enough information to help them make an informed decision. Respondents with spinal cord injury felt as though information on functional electrical stimulation should not be offered early in rehabilitation due to the amount of other information being given during this period. Instead, it should be raised later in the rehabilitation process (for example, during discharge from the spinal unit). ○ *“As a doctor you have to give them the choice. I can’t say to a patient ‘Yes, I’m going to treat you with the operation’ without giving them the other options. And the patient’s choice sometime would not be my choice, but that’s the patient’s choice. It’s my job to make it clear for him and give him enough information to make a decision about what he wants to do . . .” (page 207)*

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	Serious concerns *(No information on relationship between researcher and participants; poor description of recruitment and data analysis methods; no discussion of credibility; lack of discussion of study value.)*
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates particular rehabilitation therapy or service [functional electrical stimulation] which may not be broadly transferable.)*

Gill, 2012

Bibliographic Reference	Gill, Ian J; Wall, Gemma; Simpson, Jane; Clients' perspectives of rehabilitation in one acquired brain injury residential rehabilitation unit: a thematic analysis.; Brain injury; 2012; vol. 26 (no. 78); 909-20

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community within a community residential unit **Aim** To explore the experiences of people with acquired brain injury in a community residential rehabilitation setting.

Data collection and analysis	**Data collection** Method: Semi-structured interviews. Lasted between 40-90 minutes. Location: At home. At home for participants who had moved out of the residential unit, and within individual flats for people still residing there. Format: Face-to-face, audio recorded, and transcribed verbatim. Interview guide used. **Analysis** Thematic analysis. Using an essentialist perspective, 1 researcher familiarised themselves with the transcripts, identifying initial codes which were applied throughout the data set. These codes were collated into a thematic table, and themes checked both against the individual codes and the data set to ensure accuracy. For rigour, each analysis stage was reviewed by a different team member.
Recruitment strategy	All individuals who resided or who had been discharged from the rehabilitation unit for acquired brain injury were contacted to participate in the study.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	People with acquired brain injury who had lived experience of residing in the study residential rehabilitation unit.
Exclusion criteria	Not reported
Sample size	N=7 adults with acquired brain injury
Participant characteristics	Age in years [Mean (SD)]: 37.71 (SD not reported), age range 24-50 Sex (M/F): n=6/n=1 Time since diagnosis or injury in years (Mean [SD]): Not reported, n=4 <5 years, n=1 5-9 years, n=1 10-14 years, n=0 15-19 years, n=1 20-25 years Chronic neurological disorder category: Acquired brain injury

Results	Themes as described in paper:
	- ‘I can live a normal life’—Rebuilding self-belief
	  ○ Participants said that communication in the unit was non-patronising. They felt as though they were treated as an equal in the care process and responsible for most decision-making, with staff encouraging but not forcing them to do certain activities. Furthermore, staff ensured that activities were scheduled in a way that suited their abilities and needs.
	  ○ *“Because if they’re talking to you on an equal level, you can relate to it, you’re more natural. I don’t like somebody just saying what they think they should, and with brain injury it can happen a lot” (page 345)*
	- ‘It all boils down to each individual’— Recognition of personal identity
	  ○ Participants reported that the staff knew each client's preferences and abilities very well, with the facility regime flexible around their needs, which increased their sense of individuality and identity.
	  ○ *“But it was about them [the staff] knowing me as well, and knowing what I could and couldn’t do for myself. Because other people have problems in different areas” (page 345)*
	- ‘It’s like having our own tribe’—Sense of community atmosphere
	  ○ Participants reported that it was helpful when the facility continued care and support after they had transitioned back into the community. Home visits would initially be frequent, gradually decreasing in amount as a person’s needs decreased. This allowed difficulties encountered during the transition process to be adequately addressed.
	  ○ *“They used to visit me every day in the first few weeks. They helped me decorate this place. Then I started ringing them, telling them I was going out so not to bother coming” (page 349)*

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 *(No information on relationship between researcher and participants; poor description of data analysis methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Grayson, 2020

Bibliographic Reference	Grayson, Lynn; Brady, Marian C; Togher, Leanne; Ali, Myzoon; A survey of cognitive-communication difficulties following TBI: are families receiving the training and support they need? International journal of language & communication disorders; 2020; vol. 55 (no. 5); 712-723

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)
Country/ies where study was carried out	UK and Australia
Setting and aim	**Setting** Within neurorehabilitation services **Aim** To explore the needs of family members of people with traumatic brain injury in supporting communication, participation, and relationships.

Data collection and analysis	**Data collection** Method: Quantitative survey with free-text responses completed by participants. Free-text question within survey on training and support needs was analysed. Location: Not applicable. Format: Paper or online (hosted on Survey Monkey). **Analysis** Thematic content analysis. The free-text question responses were read through to obtain an overall sense of information, before initial codes were identified and collated into themes. These themes were then finalised by the entire research team and illustrative data extracts chosen to accompany them.
Recruitment strategy	Convenience sampling. Survey participants from the UK were recruited using poster advertisements placed in brain injury rehabilitation settings and carer centres, and online links were advertised on social media sites, carer groups, brain injury charities and groups. Additionally, speech and language therapists working in brain injury rehabilitation in both the UK and Australia were contacted and asked to advertise the survey to family members of people with traumatic brain injury. This was followed by weekly reminder emails and advertisements on social media. Interested parties could access the survey through scanning a code on a poster, clicking an online link or completing a paper copy. Eligible participants were identified using 6 screening questions at the beginning of the survey.
Study dates	October-December 2018
Sources of funding	Not industry funded
Inclusion criteria	Adult (over 18 years old) family members of people experiencing cognitive–communication difficulties following traumatic brain injury. • Cognitive–communication difficulties were defined as difficulties paying attention to conversations, staying on topic, with memory, responding accurately, understanding jokes and following directions. • Traumatic brain injury defined as injury resulting from a road traffic accident, fall or assault.
Exclusion criteria	Family members of people sustaining a traumatic brain injury less than 3 months prior or people still experiencing post-traumatic amnesia.

	- Post-traumatic amnesia defined as period of disorientation after a coma.
Sample size	N=102 family members of adults with traumatic brain injury
Participant characteristics	Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported, n=15 aged 16-29, n=40 aged 30-49, n=40 aged 50-69, n=7 aged ≥70 Sex of people with chronic neurological disorders (M/F): n=79/n=23 Chronic neurological disorder category: Acquired brain injury
Results	Themes as described in paper: - Response to the open question ○ Family members reported the following needs in the initial 2 years following a traumatic brain injury: information and training sessions to facilitate communication and manage social and psychological changes; information on future needs; education for the wider social network of the person with traumatic brain injury. ○ *"Written information that I could give to our extended family and close friends. In particular those that don't live in same town so haven't seen him and think he looks fine so is back to normal." (page 720)*

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	Serious concerns *(Poor description of recruitment, data collection and data analysis methods; free-text-question, data likely to be limited; no discussion on credibility; lack of discussion of study value.)*
Overall risk of bias and relevance	Relevance	Relevant *(13/102 participants from Australia [outside of protocol for adult participants].)*

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 participants' place of work. 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 were supported by their experience. Further categorisation then took place. No further details on whether the whole dataset was coded by more than one analyst.
Recruitment strategy	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). • Aged 18 years or above. • 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 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 physiotherapist, n=2 neurologist, n=2 specialist neuro-physiotherapist, n=1 general practitioner, n=1 specialist genetic nurse, n=1 specialist neuro-nurse
Results	Themes as described in paper: • ‘‘I think our coordination could be much better’’: therapy, treatment and the delivery of care: Gaps in service ○ Healthcare professional respondents noted a lack of specialised support for children with hereditary spastic paraplegia, as well as a lack of coordinated care for people with chronic conditions. Reasons for this were cited as lack of time, historically poor coordination across disciplines, and an absence of electronic patient notes. This poor communication and coordination was heightened if care involved private and public services (for example, if complementary therapies were being accessed). ○ *“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)* • ‘‘I think our coordination could be much better’’: therapy, treatment and the delivery of care: Access to services

- Participants and their carers had mixed opinions about the patient-led service. They reported that the pressure to find therapy for themselves created a dichotomy between wanting to be independent and wanting to receive more active care.
- *“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)*

- ‘‘I think our coordination could be much better’’: therapy, treatment and the delivery of care: Helpful therapy
    - Participants reported the importance of physiotherapy in accessing current information and support to relieve symptoms, especially when they were not taking medication. However, it is difficult finding an appropriate physiotherapy service. Hospital-based physiotherapy services were noted to have better communication with neurologists when monitoring. Meanwhile, community-based physiotherapy services may be more convenient for travelling to appointments. Physiotherapists reported the need for specialist approaches to care, instead of general approaches. A lack of appropriate rehabilitation or drug treatments also meant that some people's condition deteriorated while in a hospital setting.
    - *No first-order quotes to support this theme.*
- ‘‘. . .there’s no point in managing a void, lets fill it’’: the way forward: Care coordination
    - Every respondent highlighted the need for a 'named gatekeeper' who could coordinate care and act as a central contact point for people with hereditary spastic paraplegia, their carers, healthcare professionals, and social care professionals. There was no specification on what discipline this practitioner needed to be from, but they needed to understand the condition as well as available rehabilitation services that might be able to help their clients.
    - *No first-order quotes to support this theme.*
- ‘‘. . .there’s no point in managing a void, lets fill it’’: the way forward: Poor coordination
    - Participants were aware that it would be unlikely to find a local specialist healthcare professional for hereditary spastic paraplegia due to its rarity but thought it would be possible for neuro-specialist professionals to have a special interest in the disorder. The availability of these neuro-specialists would be particularly beneficial for people in rural communities who found it difficult to travel to specialist centres located in big cities. Respondents were aware that travelling to these centres may provide them with up-to-date treatment but would prefer ongoing neurophysiotherapy and neurorehabilitation treatments to be provided closer to home.

		Respondents reflected that community physiotherapists were not always told when people were admitted to hospital, meaning they were unable to provide information to acute clinical teams about someone's rehabilitation needs. Some services had successfully implemented a neuro-care pathway to increase communication between community and acute care. However, participants noted that this enhanced communication needs to be in place from the time of diagnosis to ensure people do not get missed. ○ *“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 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 *(People with hereditary spastic paraplegia interviewed before carers, potentially affecting carer's interviews; no information on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Relevant *(33% of participants from the US [outside of protocol criteria].)*

Hartley, 2013

Bibliographic Reference	Hartley, Sandra; Stockley, Rachel; It's more than just physical therapy: reported utilization of physiotherapy services for adults with neuromuscular disorders attending a specialist centre.; Disability and rehabilitation; 2013; vol. 35 (no. 4); 282-90

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)

Country/ies where study was carried out	UK
Setting and aim	**Setting** Within a voluntary sector neuromuscular rehabilitation centre in North West England. **Aim** To explore user experiences of a physiotherapy service within a specialist neuromuscular centre.
Data collection and analysis	**Data collection** Method: Quantitative survey with free-text questions completed by participants. Within the survey, open ended questions about reasons for attending physiotherapy at neuromuscular centre and any barriers to attendance. Location: Not applicable. Format: Written. **Analysis** Thematic content analysis. Responses to open questions were written on separate pieces of paper, before being read and re-read by a researcher to familiarise themselves with the data. Initial codes were generated from recurring words and phrases, before being collated into themes. These were collated again into overarching themes. A second reviewer independently confirmed the accuracy of identified themes. Content analysis was used regarding the frequency of responses relating to each theme. Finally, illustrative quotes were selected for each theme.
Recruitment strategy	All adults who attended the neuromuscular centre for physiotherapy between July and September 2010 were invited to participate, with questionnaires plus information sheets being provided during physiotherapy sessions. Note: This time period is different from that stated in the inclusion criteria section of the article, with no explanation.
Study dates	Not reported
Sources of funding	Not reported

Inclusion criteria	People aged 18 years and over attending physiotherapy at the study centre between July-October 2010. Note: This time period is different from that stated in the recruitment section of the article.
Exclusion criteria	Not reported
Sample size	N=104 adults with neuromuscular disorders
Participant characteristics	Age in years [Mean (SD)]: 46.4 (15.1) Sex (M/F): n=70/n=34 Time since diagnosis in years (Mean [SD]): 21.45 (12.82) Chronic neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • Reasons for attending for physiotherapy: Access specialised resources ○ Participants reported that they were able to receive information about other support and equipment available to them when they accessed the physiotherapy service as well as information on the latest treatment and research on their condition. Respondents also saw professionals as a source of expert knowledge on motor neurone disease and believed that staff were able to tailor their treatment to their needs and preferences. ○ *“NMC [neuromuscular centre] physiotherapists are specialised and highly skilled in the appropriate treatments needed for this type of condition” (page 11)*

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

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Poor description of data collection and data analysis methods; free-text-questions, data likely to be limited; lack of discussion of study value.)*
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 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	None reported
Exclusion criteria	None reported
Sample size	N=110 carers of people with an 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 CND 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?

	○ Respondents noted several negative experiences with using the services: they found the system hard to navigate; they had to fight to be involved in formal plans for supporting their loved one; there was a lack of information given to relatives (particularly at hospital discharge); there was a lack of family involvement; discharge from inpatient settings was badly planned; and there was a lack of continuity or co-ordination. Suggestions for improvements to the services included: accurate information provided in a timely fashion; involving family in rehabilitation and discharge planning; and having a single point of contact to co-ordinate other services and provide information on the client when needed. ○ *"Intermediate rehab unit was extremely poor. Not enough physios or OTs [occupational therapists]. Nursing and therapy staff did not work as a cohesive team so no continuity possible." (page 104)* • Q3: Were you given the information you needed to understand brain injury and services? ○ Respondents noted that information was hard to come by and they had to actively search for it (which could take years). Some participants felt well supported by staff, who worked with the entire family rather than simply the person with a 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? ○ Respondents noted that lack of support and understanding was one of the most difficult things to deal with. ○ *"I do not feel that I have been supported at all. Having to fight for every piece of support or rehabilitation for my husband. No empathy towards us." (page 104)* • Q6: Please use the space below to provide more information regarding the changes and difficulties that you and your relative/friend face. What would you suggest professionals need to do to improve the services provided? ○ Respondents notes several improvements to the services: involving families more in the rehabilitation process (including have a positive attitude to including families); providing accurate information; providing a single point of contact; continuity of care into the community; provision of long-term follow-up if needed. ○ *"It took some 6 years for us to get a brain injury case manager. We went through various people being case manager including a district nurse, community matron, mental health case manager, domiciliary agency*

		manager. None could fulfil the role. Only when brain injury case manager became involved did my son start to get a proper multi-disciplinary team approach." (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; lack of discussion of study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Kumar, 2013

Bibliographic Reference	Kumar, A.; Phillips, M.F.; Use of powered mobile arm supports by people with neuromuscular conditions; Journal of Rehabilitation Research and Development; 2013; vol. 50 (no. 1); 61-70

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)
Country/ies where study was carried out	UK
Setting and aim	**Setting** Not reported

	Aim To explore the views and experiences of people with neuromuscular conditions who use power mobile arm supports.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Location: Preferred location (no further details reported). Format: Face-to-face or via telephone (proportions not reported), digitally recorded, and transcribed. Interview guide piloted with powered mobile arm support user and refined based on this feedback and that of researchers using the guide. **Analysis** Thematic analysis. Codes were deductively and inductively identified from interview transcripts, which were then checked back with the data for accuracy. Codes were collated into clusters using NVivo 8 software, before emerging themes were collectively analysed and discussed. Quantitative and qualitative data were compared to assess potential discrepancies.
Recruitment strategy	Eligible participants were identified from the records of a UK company supplying powered mobile arm supports and sent a letter of invitation (plus a 3-week reminder). Interested people returned a form. Researchers then responded with age-specific participant information sheets (1 version for participants aged 12-15 years and 1 version for participants aged over 15 years), a consent form, a demographic form and 2 outcome assessment forms (ABILHAND and the Upper Limb Functional Index).
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	People aged 12 and over with a neuromuscular condition using a power mobile arm support and residing within 200 miles of Derby.
Exclusion criteria	Not reported
Sample size	N=13 people with neuromuscular conditions

Participant characteristics	Age in years [Mean (SD)]: Not reported, age range 13-69 Sex (M/F): n=12/n=1 Time since diagnosis: Not reported Chronic neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • Participants’ initial reaction to and use of their PMAS and influencing factors ○ Participants reported differences in training for their powered mobile arms. Some people reported learning through trial-and-error, which others reported occupational therapists becoming very involved in the set-up process (although not all occupational therapists were experienced in their use and set up). ○ *No first-order quotes to support this theme.* • Occupational Therapists raising awareness and advocating for funding ○ Participants reported that occupational therapists were the most common professional who raised awareness of arm supports, but that their experiences, involvement and education on the technology could vary. ○ *No first-order quotes to support this theme.*

N/n: number of participants; PMAS: powered mobile arm support; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns *(Participants recruited via opportunity sampling by the company supplying equipment; poor description of data analysis methods; no information on relationship between researcher and participants; lack of discussion of study value.)*

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates particular rehabilitation therapy or service [powered mobile arm supports] which may not be broadly transferable.)*

McKevitt, 2019

Bibliographic Reference	McKevitt, Christopher; Topor, Marta; Panton, Anna; Mallick, Andrew A; Ganesan, Vijeya; Wraige, Elizabeth; Gordon, Anne; Seeking normality: Parents' experiences of childhood stroke.; Child: care, health and development; 2019; vol. 45 (no. 1); 89-95

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Within paediatric regional specialist stroke services **Aim** To explore parents’ experiences of paediatric stroke and identify needs and preferences to inform service provision.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Lasted between 1-2 hours. Location: Not specified.

	Format: Face-to-face (n=7) or via telephone (n=5), audio recorded and professionally transcribed. Interview guide was reviewed by 2 parents and 1 young person who experienced stroke in childhood, resulting in minor changes. **Analysis** Thematic analysis. Using the realist method, 3 researchers familiarised themselves with the data, identifying potential patterns and coding each line. Frequency of themes and sub-themes were monitored to allow identification of participant concerns.
Recruitment strategy	Participants were identified from a prior needs survey and sampled to include a variety of characteristics (including age of child at initial stroke and time since first stroke).
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	Parents of children with stroke attending 3 specialist regional services.
Exclusion criteria	Not reported
Sample size	N=12 parents of children and young people with stroke
Participant characteristics	Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all within paediatric services Sex of children and young people with chronic neurological disorders (M/F): Not reported Chronic neurological disorder category: Acquired brain injury
Results	Themes as described in paper: • Perceptions of the quality of clinical care ○ Participants reported how poorly prepared the discharge process left them. They felt as though they had been given inadequate information on how to care for their child once home, and what services they were eligible for. Discharge summaries were described as too medicalised to be helpful. The majority of parents

		were happy with the care their child received in the community, including assessments for nursey and school settings. However, some noted delays in accessing community services and limitations in the services available. ○ Some participants elected to pay for private rehabilitation therapies, citing that they were either dissatisfied with the amount of rehabilitation their child received, believed that greater rehabilitation would speed up recovery time, or they were attracted to the wider range of therapies offered by non-NHS practitioners. ○ Most respondents were dissatisfied with primary care input, mainly due to the perceived poor knowledge of primary care practitioners regarding paediatric stroke. However, some interviewees were not happy due to a lack of regular appointments and check-ups. ○ Parents of children with subsequent emotional and psychological challenges following stroke reported that it was difficult to access these services and advice on these issues, particularly when their child was becoming a teenager. If children had managed to access professional input, it was usually via other services the child was registered with. ○ Parents reflected on the need for a diagnosis and information on the implications of stroke. Around half of the respondents felt they were not given enough information on paediatric stroke, including what to expect in the future and how it could impact their child's education. Other parents reported needing a single point of contact following hospital discharge to ask for information and advice as new rehabilitation needs emerged, information on sources of support after discharge, and advice on managing subsequent issues such as emotional challenges. ○ *“Because you need to know what’s available in your area because otherwise you just spread yourself so thin that you wouldn’t know where to go.” (page 13)*

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 methods and data analysis methods; no discussion on credibility.)*

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Highly relevant

McPherson, 2018

Bibliographic Reference	McPherson, Kathryn; Fadyl, Joanna; Theadom, Alice; Channon, Alexis; Levack, William; Starkey, Nicola; Wilkinson-Meyers, Laura; Kayes, Nicola; Living Life After Traumatic Brain Injury: Phase 1 of a Longitudinal Qualitative Study.; The Journal of head trauma rehabilitation; 2018; vol. 33 (no. 1); e44-e52

Study Characteristics

Study type	Grounded theory
Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community **Aim** To explore the experiences of recovery and adaptation in people with TBI and their family members within the initial 2 years after traumatic brain injury.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted between 60-90 minutes and held within 6-9 months of traumatic brain injury.

	Location: Not specified. Format: Not reported beyond mixture of individual and dyadic interviews. Interview guide and prompts used. **Analysis** Grounded theory. A purpose-built data analysis system using an open-source relational database software was used for analysis. Multiple researchers read the transcripts and organised related data into codes. Using the constant comparative method, these codes were compared within and between transcripts to identify and refine potential themes. Identification of themes was guided by the research aims of people's experiences of recovery and adaptation, which were them used to explore how these relate to current service provision and potential areas for improvement. Regular meetings of the core 4 researchers were used to discuss and refine interpretations, with all analysis decisions affecting coding and interpretation logged for audit purposes. A small community reference group was created, using people with personal experience of traumatic brain injury and a professional representative of a voluntary sector organisation supporting people with traumatic brain injury. This group met twice a year to sense check interpretations and emerging themes. Feedback on preliminary findings from healthcare and social care professionals were also sought.
Recruitment strategy	Purposeful sampling. Eligible participants were initially identified from a population-based epidemiological study. In order to capture more people with moderate to severe TBIs, subsequent methods included recruitment from a TBI service provider and local patient support organisations. As the study progressed, additional characteristics were targeted for inclusion: female gender, Maori ethnicity, middle aged. Identified participants were contacted with study information and to gain consent. If appropriate, a significant other was nominated to participate at this juncture to increase the level of interpersonal connectivity that was important to indigenous groups.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	People aged 16 and over with disabling traumatic brain injury. • Disabling traumatic brain injury included mild traumatic brain injury if it resulted in persistent impairment or disability 6 months post-injury.
Exclusion criteria	People unable to participate in interviews even when provided with communication support.

Sample size	N=62 adults with traumatic brain injury plus family members
Participant characteristics	**Adults with traumatic brain injury, n=40** Age in years [Mean (SD)]: Not reported, n=12 aged 16-34, n=19 aged 35-64, n=9 aged ≥65 Sex (M/F): n=28/n=12 Time since injury in months: Not reported but inclusion criteria states 6-month post-injury Chronic neurological disorder category: Acquired brain injury **Family members of people with traumatic brain injury, n=22** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported
Results	Themes as described in paper: • "Understanding what having a TBI means for, and to, me" ○ Participants reported being provided with optimistic time frames for results of particular interventions or recovery, which had an impact on their rehabilitation choices. They later found these were not as reliable as expected. ○ *No first-order quotes to support this theme.* • Being looked out for and someone to help drive the process as valued supports ○ Participants reflected that they often needed to push for access to professionals, support and healthcare or social care services. If the person with traumatic brain injury was unable to advocate for themselves, they needed others to do so for them (for example, by taking on a coordination role to ensure appointments did not conflict with others, documenting rehabilitation needs, or providing emotional support). These other people could be healthcare professionals, friends, family, employers and professionals from voluntary services. ○ *“This lady came from victim support and she was just my godsend [. . .] to have her do that and take time away from her family, I was absolutely blown away that it was just . . . it just meant so much to me. It was huge.” (page 49)*

N/n: number of participants; SD: standard deviation; TBI: traumatic brain injury

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 and data collection methods; some interviews conducted in dyads with no consideration given around how dyadic interaction can affect interview; no information on relationship between researcher and participants; lack of discussion of study value)*
Overall risk of bias and relevance	Relevance	Highly relevant

Mueller, 2017

Bibliographic Reference	Mueller, C.; Wang, Y.; Brooks, A.; Morant, N.; Sullivan, P.; Raymont, V.; 'Attending to the wound and the person'-patients' experiences and expectations of a newly established traumatic brain injury clinic; Brain Injury; 2017; vol. 31 (no. 1314); 1863-1870

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community and within neurorehabilitation services

	Aim To explore the experiences of community-based health and social care provision for people following traumatic brain injury, as well as a novel traumatic brain injury clinic in West London.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Interviews lasted roughly 30 minutes and were conducted by clinician not involved in care. Location: At home or outpatient clinic. Format: Face-to-face, audio recorded and transcribed. Written notes were completed after interview to aid analysis. An interview guide was designed based on literature, clinical experience and current service structure. Further refined through discussion with key stakeholders. **Analysis** Thematic analysis. Using NVivo 10 for Mac software, the lead author familiarised themselves with the data by reading and re-reading transcripts and noting patterns. Eighteen initial codes were generated. Two other researchers identified potential themes, which were collated and judged for distinction between themes and coherence within themes. Analysts routinely reviewed the raw dataset to ensure accuracy of the themes. These were then further collated into overarching themes, which were triangulated with themes identified from focus groups held at a UK-based brain injury charity.
Recruitment strategy	Maximum variation sampling. Participants were identified from referrals to the pilot traumatic brain injury service at the study centre and selected to include a variety of characteristics (including severity of brain injury, time since injury, living situation, and education level).
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	People aged 18 and over with traumatic brain injury who were able to participate in an extended English language interview.
Exclusion criteria	Not reported

Sample size	N=10 adults with traumatic brain injury
Participant characteristics	Age in years [Mean (SD)]: Not reported, median (IQR) 50 (34) Sex (M/F): n=5/n=5 Time since injury in years (Mean [SD]): Not reported, <1 year, n=4; 1-2 years, n=2; 2-5 years, n=2; >5 years, n=2 Chronic neurological disorder category: Acquired brain injury
Results	Themes as described in paper: • Need for information and education through the continuum of care ○ People reported a need for information and education early on in rehabilitation (for example, prior to discharge from emergency and acute settings). Information that was given was usually via leaflets and tended to cover short-term deterioration rather than medium- to long-term impact. Follow-up with primary care took a long time (or was non-existent) and was not well informed. The diagnosis of traumatic brain injury was not adequately explained in acute care. Participants reported that a post-discharge meeting to explain the diagnosis and possible symptoms in simple language would help reassure people and their loved ones, as well as provide another opportunity for information to be given in a less stressful environment. ○ *"What to expect afterwards, and not just a day afterwards or two days afterwards. (…) I needed information to say you can expect that. (…) The medium term expectations after a head injury, I think that's a bit unclear." (page 10)* • Need for support to overcome lack of motivation, to socialise and engage in activities ○ Respondents noted that emotional and motivational support is needed when transitioning back to the community setting, and that this should be provided in the home. Care navigation would also be helpful, as well as an emergency phone line. ○ *"Somebody to talk to. Somebody who could be your crutch for that time that you have no legs. Somebody to tell you that you are not going mad." (page 15)*

IQR: interquartile range; N/n: number of participants; SD: standard deviation

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Poor description of recruitment methods.)*
Overall risk of bias and relevance	Relevance	Highly relevant

O'Brien, 2012

Bibliographic Reference	O'Brien, M.R.; Whitehead, B.; Jack, B.A.; Mitchell, J.D.; The need for support services for family carers of people with motor neurone disease (MND): views of current and former family caregivers a qualitative study; Disability and rehabilitation; 2012; vol. 34 (no. 3); 247-256

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** In the community and a specialist motor neurone disease centre **Aim** To explore the experiences of family carers of people with motor neurone disease and identify their needs in support services.
Data collection and analysis	**Data collection**

	Method: Narrative interviews. Initial prompt question followed by clarification questions if needed. Conducted by 2 researchers. Location: At home. Format: Face-to-face, audio recorded, and transcribed verbatim. Prompt questions used if needed, developed from the literature. **Analysis** Thematic framework analysis. Transcripts were uploaded to NVivo 8 computer software, with analysis of initial transcripts occurring while data collection was still occurring. These data were then used to inform further data collection. This initial analysis was completed by 3 independent researchers, who resolved discrepancies through discussion and consensus. Identified themes were used as a framework for the remainder of the data analysis. A constant comparative approach was used to explore agreements and disagreements across findings. Additionally, transcripts were given to participants to check the accuracy of the interpretations.
Recruitment strategy	Maximum purposive sampling. Eligible participants were recruited through a motor neurone disease centre, plus advertisements in newsletters targeted to the motor neurone disease community and information sheets given to healthcare professionals in contact with families. Participants were selected to include carers of people with a variety of disease severities, and former carers.
Study dates	2008-2009
Sources of funding	Not industry funded
Inclusion criteria	People with experience (either current or previous) of caring for a family member with motor neurone disease.
Exclusion criteria	Not reported
Sample size	N=28 former and current family carers of people with motor neurone 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

	Chronic neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • Information ○ Participants were concerned about the impact of the disease as it progressed, which they felt was not addressed. Carers also felt that they were forced to find out information on service availability and the contribution of different healthcare and social care professionals towards rehabilitation care themselves, which took time and increased the financial and emotional burdens that carers can experience. ○ *“I don’t think at any point anybody has, certainly not discussed with me, … but nobody has ever discussed the progress of the disease, how it might affect you in the future or what is likely to happen in the future…I don’t think anybody discussed it formally, so there was very little information, it was taken as a given that you knew what was going to happen.” (page 250)* • Carers' training needs ○ Respondents reported that there was a need for education and training on the physical aspects of a carer role (for example, manual handling and using hoists), as there could be safety considerations. They additionally noted that support and guidance on managing specific situations was helpful (for example, how to get up from a fall). ○ *“[Physiotherapist] gave her exercises to do, actually showing her what to do if she fell and how you get up easier and how I could assist her a little” (page 253)*

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 and data analysis methods; no information on relationship between researcher and participants; lack of discussion of study value)*

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Highly relevant

Paguinto, 2023

Bibliographic Reference	Paguinto, Sarah-Grace; Kasparian, Nadine A; Bray, Paula; Farrar, Michelle; Multidisciplinary perspectives and practices of wheelchair prescription for children with neuromuscular conditions.; Disability and rehabilitation. Assistive technology; 2023; vol. 18 (no. 2); 166-174

Study Characteristics

Study type	Phenomenological
Country/ies where study was carried out	Australia and the US
Setting and aim	**Setting** In the community and hospital paediatric neuromuscular healthcare services **Aim** To explore the views and experiences of healthcare professionals when discussing wheelchair usage for the first time in children with neuromuscular conditions.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Location: Not specified.

	Format: Face-to-face or via telephone, audio recorded and transcribed verbatim. Interview guide developed from literature review, consultation with experts and previous findings on experiences with wheelchair prescriptions. **Analysis** Phenomenological analysis. Transcripts were uploaded to NVivo 12 qualitative software, coded and analysed in 4 phases. Two researchers read the data independently, noting patterns and reflections. A set of themes was agreed. After this, a narrative summary of each transcript was generated to identify overall themes, which were further discussed and interpreted. Important findings across all interviews were described by a final set of descriptive and interpretive themes. These were collated into overarching themes which were then critically appraised. Results were discussed with other colleagues.
Recruitment strategy	Purposive sampling. Eligible Australian healthcare professionals were identified through professional networks (including Sydney Children’s Hospitals Network and Australasian Neuromuscular Network). Eligible American healthcare professionals were identified through professional networks and neuromuscular clinics. Participants were selected to include a variety of characteristics, including professionals, years of clinical experience, and healthcare settings.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	Healthcare professionals with experience (either current or previous) of working with children with a neuromuscular disorder in Australia and the US.
Exclusion criteria	Not reported
Sample size	N=21 practitioners working with children and young people with progressive neuromuscular conditions
Participant characteristics	Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all within paediatric services Sex of children and young people with chronic neurological disorders (M/F): Not reported Role or specialism: n=7 occupational therapists, n=4 neurologists, n=4 physiotherapists, n=3 social workers, n=2 nurses, n=1 psychologist Chronic neurological disorder category: Progressive neuromuscular disease

Results	Themes as described in paper:
	- Parental emotional responses influence wheelchair acceptance and commitment
	  - Healthcare professionals started discussions about wheelchair usage well before ambulation loss, in order to allow parents time to grieve and adjust. Acceptance of this change was normally incremental over a period of time. They reflected that is was better to re-frame the discussion to talk about the benefits of wheelchairs, in order to help the emotional aspect of conversations.
	  - *"I think it's quite a frightening concept for many of the parents because it signals the inevitable progression of the disease. I think there is some resistance initially … some families worry that use of a wheelchair will make their kids lose function because they wouldn't be walking as much." (page 169)*
	- Psychologically-informed care to support transition to wheelchair use
	  - Participants reflected that wheelchair prescriptions were a key transition, during which time both informal and formal psychological input was needed. Despite this, psychologically informed care was rarely mentioned. Healthcare professionals were not aware of the evidence supporting integrated models of psychological care for people with chronic and life-limiting conditions. Referral into these services was limited and patchy, which created many barriers. There was a noted absence of integrated psychological care within both Australian and American hospitals, as well as a lack of knowledge about service availability.
	  - *"If there was more of a psychosocial component built into our clinic and structure, such as a psychologist that could see patients more frequently … I think that that would be incredibly beneficial." (page 170)*
	- Facilitating readiness for change as part of individualised, family-centred wheelchair prescription
	  - Participants reported that it was paramount to build a therapeutic collaboration, including active listening and empowering families to prepare for the transition. The majority of healthcare professionals supported early and continual education to support families' knowledge of the disorder and wheelchair prescriptions. Informal support strategies include: checklists to describe the steps in wheelchair prescription; signposting to credible websites; attending equipment conferences; summarising the evidence of the benefits of wheelchair use; and information on advocacy resources and funding sources. Healthcare professionals also allow families time to gradually adjust to this new future, in their own time, which decreased the emotional challenges of transition. Examples included: introducing wheelchairs for specific activities; using alternative mobility devices; and encouraging incidental exposure or no-cost loans of equipment within paediatric hospitals.

	○ *"No matter how much we tell parents, having their own experience of a wheelchair helps them to have more confidence in understanding and making informed decisions about what sort of mobility device their child is going to have." (page 170)* • Collaboration, consistency and communication across hospital and community-based services ○ Participants reported that effective wheelchair prescription care was collaborative care, using consistent and compassionate family-centred conversations about introducing wheelchair use. Healthcare professionals who were less familiar with neuromuscular disorder should collaborate with neuromuscular clinics and seek educational opportunities in order to facilitate wheelchair uptake. ○ *"I think to have access to somebody who is a specialist in neuromuscular conditions and for a general therapist to have the access to that. To talk through some of the high-level technical things is really valuable." (page 170)* • Bureaucracy and logistics: accessibility, funding, technology and time ○ Healthcare professionals located in Australia noted that trials were barriers to uptake if there were limited wheelchair choices, durations of trials and size of wheelchairs. ○ *"A barrier is the availability of the right sizes and setup for trial. There's a lot of estimated guesses going on at times when it's not the right size or back rest, but you think this will work in theory." (page 171)*

N/n: number of participants

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 data collection methods; no information on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates particular rehabilitation therapy or service [wheelchair prescriptions] which may not be broadly transferable; 7/21 professionals from the US [outside of protocol criteria].)*

Pollock, 2022

Bibliographic Reference	Pollock, Anna; D'Cruz, Kate; Scheinberg, Adam; Botchway, Edith; Harms, Louise; Amor, David J; Anderson, Vicki; Bonyhady, Bruce; Knight, Sarah; 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; 2022; vol. 12 (no. 6); e059534

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	Australia, UK and New Zealand
Setting and aim	**Setting** National and international paediatric rehabilitation services for traumatic brain jury and traumatic spinal cord injury **Aim** To explore how rehabilitation services for children and young people with TBI and/or traumatic SCI, and insurance services, amended their delivery during the Coronavirus pandemic.
Data collection and analysis	**Data collection** Method: See Botchway 2022 Location: See Botchway 2022 Format: See Botchway 2022 **Analysis** See Botchway 2022

Recruitment strategy	See Botchway 2022
Study dates	See Botchway 2022
Sources of funding	See Botchway 2022
Inclusion criteria	See Botchway 2022
Exclusion criteria	See Botchway 2022
Sample size	N=15 practitioners working with children and young people with traumatic brain injury and traumatic spinal cord injury
Participant characteristics	Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all under 21 Sex of children and young people with chronic neurological disorders (M/F): Not reported Role or specialism: Not reported for individual professionals. Specialism of services: n=7 medical rehabilitation services, n=2 community-based rehabilitation services, n=2 insurance services.
Results	Themes as described in paper: • Recognising and responding to the experiences of families during the pandemic: impact on family-centred care and adapting service response in consideration of family needs ○ Healthcare professionals reported that telehealth was a good way of maintaining contact with families throughout lockdown restrictions. It also provided insight into family living conditions, which helped to facilitate a greater sense of engagement. ○ *“I think we do learn a bit more about their family functioning… just them being in their homes” (page 5)* • Impact of greater use of telehealth on care delivery: the benefits to using telehealth ○ Respondents noted that the main benefit of telehealth was the increased convenience for families who could attend sessions remotely rather in person. Remote delivery also allows for more flexibility for different family members to sit in on different appointments. Community-based healthcare professionals also noted that it was easier to include multiple healthcare professionals in a single meeting using this method.

	○ *"I've even had families who live in…our suburb, saying how much easier it is for them to do a telehealth. It takes them two hours to get here by the time they've got the kids in the wheelchairs, and driven here, and parked, and got them out." (page 6)* • Impact of greater use of telehealth on care delivery: limitations to the provision of telehealth ○ Participants noted that efficient telehealth delivery depended on a variety of factors: the age of the child (for example, it was reported that children under 12 were less likely to engage with this format); the nature and complexity of their condition; the type of appointment for example, it was reported that physical therapy was less effective using this format). Respondents were also worried that families from vulnerable backgrounds would be disadvantaged by this method of rehabilitation delivery. This was due to possible issues with access to equipment and internet, and the fact that this type of communication is more removed. ○ *"My personal concern about COVID-19 pandemics and telehealth, for some of those vulnerable families, I'm worried about domestic violence or abuse. I think you can hide behind telehealth. I have concerns about some of those families that are more vulnerable, if we don't have face-to-face you might not see some things that you probably do want to see." (page 6)*

COVID-19: Coronavirus; 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 recruitment strategy; no information on relationship between researcher and participants; lack of discussion of study value.)*
Overall risk of bias and relevance	Relevance	Relevant *(Findings limited to delivery of rehabilitation services during COVID-19.)*

COVID-19: coronavirus

Preston, 2012

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

Study Characteristics

Study type	Grounded theory
Country/ies where study was carried out	UK
Setting and aim	**Setting** Occupational therapy service **Aim** To explore the experiences of people with multiple sclerosis when accessing a local occupational therapy service.
Data collection and analysis	**Data collection** Method: Focus groups (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 were sent to all occupational therapy staff currently working in the service, junior staff who had completed clinical rotations, and staff who had retired from employment within the team in the previous 12 months. Number of invitations sent to staff is not reported.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	People with multiple sclerosis • Clinically definite diagnosis of multiple sclerosis. • Attendance at occupational therapy service within previous 12 months. • Adequate communication abilities allowing participation without causing distress. Partners/carers of people with multiple sclerosis • Occupational therapy personnel who had worked within the service within last 12 months.
Exclusion criteria	Not reported
Sample size	N=46 adults with multiple sclerosis plus carers or partners 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 (median 10) Chronic neurological disorder category: Progressive neurological disease **Carers or partners of people with multiple sclerosis, n=10**

	Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported **Practitioners working with people with multiple sclerosis, n=6** Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: Not reported but all participants currently or had previously worked in an occupational therapy service
Results	• Themes as described in paper: • Comprehension of occupational therapy ○ Healthcare professionals reflected that occupational therapy is poorly defined, meaning it is often misunderstood by people with multiple sclerosis and their carers. Consequently, they may fail to recognise when and how an occupational therapist could help. ○ *“There is so much ambiguity around OT [occupational therapy] when someone comes in initially from the ward or as an out-patient they don’t know what to expect” (page 267)* • Home visits ○ Healthcare professional respondents were aware of potential differences occurring in different environments. Home visits can provide an opportunity to explore wider issues and further understand a client's needs, but it could also appear intimidating. Privacy was also a worry, causing reticence in sharing information in front of carers or family members. ○ *“They come out and see you. And, I mean, that in itself is like … that’s private and they see you in your own surroundings” (page 267)* • Levels of support ○ The majority of participants were content with the level of input from the occupational therapy service, maintaining a balance between support and encouraging independence. Clients and carers were reassured that they would receive follow-up contact from the service if they didn't contact them first. Healthcare professional

		respondents also appreciated that the programme allowed a consistency of staff, although this was not important to all participants. ○ *"And I would say that throughout the treatment … it's always been a two-way thing … It's never just now I'm telling you to do this … you're letting them know you're progressing, how different you're feeling – oh that's getting easier to do, so then they'll change the exercise" (page 269)*

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; very brief discussion of credibility; lack of discussion of study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Rashid, 2018

Bibliographic Reference	Rashid, M.; Caine, V.; Newton, A.S.; Goez, H.R.; Healthcare professionals' perspective on the delivery of care to children with Acquired Brain Injury (ABI) and communication with their parents; Journal of Pediatric Rehabilitation Medicine; 2018; vol. 11 (no. 2); 125-131

Study Characteristics

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

Setting and aim	**Setting** Brain injury clinic in urban rehabilitation centre **Aim** To explore the views and experiences of healthcare professionals working with children with ABI in relation to families' needs throughout rehabilitation.
Data collection and analysis	**Data collection** Method: Focus groups. Lasted between 60-90 minutes. Location: At rehabilitation hospital. Format: Face-to-face, audio recorded and transcribed verbatim. Interview guide used. **Analysis** Framework analysis. Transcripts were uploaded to NVivo 9 qualitative data analysis software. Data were reviewed before deciding future steps needed to enhance data interpretation. Text was reviewed carefully to organise interpretations before connections were made between themes and patterns to make sense of the data. Next, researchers verified interpretations to ensure emerging themes were consistent with the raw data. Finally, the best format for presenting the findings to different audiences was discussed and decided. Peer debriefing was carried out during analysis to critique findings, and results were presented to healthcare professionals at the clinic.
Recruitment strategy	Convenience sampling. An administrative staff member invited all healthcare professionals working in a multidisciplinary team within a brain injury clinic of a large rehabilitation hospital. The email included a study information sheet and contact details for the researchers.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	Professionals working within a multidisciplinary team from the brain injury clinic of the study rehabilitation hospital.
Exclusion criteria	Not reported

Sample size	N=15 practitioners working with children and young people with acquired brain injury
Participant characteristics	Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all within paediatric service Sex of children and young people with chronic neurological disorders (M/F): Not reported Role or specialism: Not reported but noted that the study included social workers, neuropsychologists, occupational therapists, paediatric neurologists, developmental paediatricians and school headteachers Chronic neurological disorder category: Acquired brain injury
Results	Themes as described in paper: • Reframing HCP' roles and perceptions ○ Respondents appreciated that the medical model was also a hierarchical model. However, this way of working meant that not all information was shared with every team member. Parents often knew who to contact within this hierarchy regarding physician-based needs, but healthcare professionals were not always able to provide care for a child's full range of concerns. In these cases, the structure of the system meant that they had to refer to other practitioners (for example, those in the community), even when this was not optimal. ○ *"[i]t's behind the scenes that the parents certainly know the hierarchy here" (page 128)* • Recognized gaps in practice ○ Respondents reported that care was focused on physical needs, rather than the emotional and psychological impact of acquired brain injury. ○ *No first-order quote to support this theme.* • Finding ways forward ○ Participants reported that large multidisciplinary teams could create a false impression that a child and their family are taken care of, which could be particularly damaging in families that do not have strong advocacy skills. A suggestion to mitigate this would be implementing a case manager to act as a point of contact between families, healthcare professionals and community services. Social media could also be an effective avenue for families to access care resources.

	○ *“for our complex cases with so many people involved there is the illusion that somebody will have their eyes on the child when discharged” (page 128)*

ABI: acquired brain injury; N/n: number of participants; HCP: healthcare professionals

Critical appraisal – CASP qualitative studies checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No information on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Salas, 2021

Bibliographic Reference	Salas, Christian; Casassus, Martin; Rowlands, Leanne; Pimm, Steve; Developing a model of long-term social rehabilitation after traumatic brain injury: the case of the head forward centre.; Disability and rehabilitation; 2021; vol. 43 (no. 23); 3405-3416

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** A social rehabilitation day centre service **Aim**

	To explore the reasons why people with chronic traumatic brain injury attend Headway and their experiences of activities offered by the centre, and to propose a theoretical long-term social rehabilitation programme model for traumatic brain injury.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Lasted roughly 30 minutes each. Conducted by 2 researchers Location: Head Forward Centre. Format: Face-to-face, audio recorded, and transcribed verbatim. Interview guide developed based on existing literature. **Analysis** Thematic analysis. Data was uploaded into a Microsoft Excel spreadsheet. Using an essentialist perspective, 2 researchers familiarised themselves with the transcripts before systematically coding them. Initial themes were discussed between coders and collated into a thematic table. These themes were further refined and named according to different codes, extracts, and the wider data set. Illustrative quotes were selected for each theme. A summary of results was presented to Head Forward attendees during a focus group to check the accuracy of interpretations.
Recruitment strategy	Not reported beyond inclusion criteria
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	People with traumatic brain injury attending Head Forward Centre.
Exclusion criteria	Not reported
Sample size	N=12 adults with traumatic brain injury
Participant characteristics	Age in years [Mean (SD)]: 49 (9.2) Sex (M/F): n=10/n=2

	Time since injury in years [Mean (SD)]: 17 (8.3) Chronic neurological disorder category: Acquired brain injury
Results	Themes as described in paper: • Head Forward as a network of continuous support ○ Participants reported that the Head Forward Centre acted as a back-up for life. A common example of this support was volunteers acting as a source of lived experience, which was particularly important when people needed to reflect on their new needs and preferences. Other types of support were assistance with everyday life chores that were too difficult cognitively or dealing with relationship concerns in the outside world. ○ *“Oh yeah, yeah! It’s always like your back up as well. Yeah, I mean the old Professor before you [the former psychologist], you could tell him anything. I’m just getting to trust you now, you know, you won’t say nothing to anybody. So, if I’ve got any problems I can just say “why am I doing this, what’s…” and they’ll just say “oh well it’s just this and that.” And I feel like… yeah… that’s handy… that, never thought of that.” (page 3410)*

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	Serious concerns *(Poor reporting of recruitment strategy; previous relationship between participants and researchers; lack of discussion of study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Setchell, 2018

Bibliographic Reference	Setchell, J.; Thille, P.; Abrams, T.; McAdam, L.C.; Mistry, B.; Gibson, B.E.; Enhancing human aspects of care with young people with muscular dystrophy: Results from a participatory qualitative study with clinicians; Child: care, health and development; 2018; vol. 44 (no. 2); 269-277

Study Characteristics

Study type	Ethnographic study
Country/ies where study was carried out	Canada
Setting and aim	**Setting** Outpatient neuromuscular clinic in paediatric rehabilitation hospital **Aim** To explore how a neuromuscular clinic addresses human aspects of muscular dystrophy rehabilitation, and to pilot procedures to increase this aspect of delivery.
Data collection and analysis	**Data collection** Method: Ethnographic observations of clinical appointments and team discussions. One researcher observed families during their 4-monthly clinic visits where they met with various healthcare professionals (typically lasting 3 hours), as well as formal and informal multidisciplinary team case discussions. A total of 107 consultations over 17 visits were observed. Location: Rehabilitation centre. Format: Field notes detailing: interactions between rehabilitation professionals, young people and their families; clinical proceedings; physical environments. **Analysis** Thematic analysis. Analysis was an iterative process and occurred alongside data collection to allow investigation of emerging information. Observation notes were reviewed monthly for 5 months by the research team, identifying patterns and

	novel areas for investigation. Initial deductive codes were identified, relating to choice and care logics within the family unit, biopsychosocial challenges for children, clinic care practices, and areas of disagreement or potential improvement. Additional inductive themes were then identified after reading through transcripts and observation notes, which were discussed and refined within team investigator meetings. Healthcare professionals and a parent advisor also assisted the analysis by reviewing the raw data, initial findings and recommendations.
Recruitment strategy	Families meeting the inclusion criteria and attending the clinic during the study period were sent study information by the study research coordinator, with consent obtained during a subsequent telephone conversation. Healthcare professionals were recruited during a study information seminar.
Study dates	January - September 2016
Sources of funding	Not industry funded
Inclusion criteria	• Children and their families attending an outpatient clinic at the study paediatric rehabilitation hospital. • Professionals working at an outpatient clinic at the study paediatric rehabilitation hospital.
Exclusion criteria	Not reported
Sample size	N=27 children and young people with neuromuscular dystrophy plus practitioners
Participant characteristics	**Children and young people with neuromuscular dystrophy, n=15** Age in years [Mean (SD)]: Not reported, age range 8-17 Sex (M/F): Not reported Time since diagnosis: Not reported Chronic neurological disorder category: Progressive neurological disease **Practitioners working with children and young people with neuromuscular dystrophy, n=12** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: Not reported but all within paediatric service Sex of children and young people with chronic neurological disorders (M/F): Not reported

	Role or specialism: n=2 nurses, n=2 occupational therapists, n=2 physiotherapists, n=2 respiratory therapists, n=1 paediatrician, n=1 recreational therapist, n=1 respirologist, n=1 social worker
Results	Themes as described in paper: • Routine clinical processes ○ There was a focus on biomedical symptoms and concerns within most sessions, with healthcare professionals mainly using biomedical checklists on routine measurements (for example, blood pressure, range of movement, and pulmonary function tests) to assess a child's rehabilitation progress. These examinations were all part of the best practice guidelines but were not necessarily needed. Healthcare professionals also reflected how biased their routines were towards the biomedical model - decisions were made on risks rather than priorities of children and young people with long-term neurological conditions, biomedical goals such as functional independence and physical safety were prioritised over more holistic goals such as psychosocial well-being. They also mentioned that their agenda during consultation was weighted in favour of these clinician-driven biomedical goals, which limited flexibility in appointments. Finally, the team noted that certain aspects of care might be facilitated by speaking separately with children and parents at certain times, a practice that would need a formal policy before implementation. ○ *No first-order quotes to support this theme.* • Clinician–child/family interactions ○ Participants reported that healthcare professionals focused their discussions on the biomedical aspect of rehabilitation, rather than the holistic and personalised aspects. Examples of this included: when hearing 1 child wanted to play on a trampoline, the clinician highlighted the fracture risk; when faced with a child uncomfortable and worried about being weighed in a suspension sling, the healthcare professional pushed for the weight measurement, citing it was needed to inform charting and medicine titration; when a child and their father wanted to ride an off-road vehicle as part of a bonding experience, the healthcare professionals stressed the biomedical risks involved. ○ *No first-order quotes to support this theme.* • Staffing allocations ○ Respondents noted that staff resources were weighted towards a traditionally biomedical model, with the team including nurses, doctors, respiratory therapists, and physiotherapists. A few healthcare professionals in mixed roles (in this case, social workers and occupational therapists) were trained to provide

	psychological aspects of care but mainly used appointment times for equipment fittings and funding applications. Both children with neuromuscular dystrophy and healthcare professionals did not receive much time with professionals capable to delivering a holistic model of care. ○ *"Dad indicated that he and his wife wanted to talk about altering Hayden's medication as it was affecting his behaviour. They began to discuss the medication Hayden was currently taking and why he was taking each one. … [it was] a frank conversation about the impacts of changing medication and the reasons dad would like them to change, even knowing that there might not be a change…" (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 *(Lack of consideration regarding relationship between researcher and participants; lack of discussion on credibility.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Shore, 2022

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

Study Characteristics

Study type	General qualitative inquiry (within mixed-methods study)

Country/ies where study was carried out	Canada
Setting and aim	**Setting** In the community, within a feasibility trial for remotely delivered Tele-AR intervention **Aim** To explore users' views and experiences regarding the remote delivery of the Tele-Active Rehabilitation intervention, as well as what worked well and the benefits of the programme.
Data collection and analysis	**Data collection** Method: Semi-structured interviews, duration not reported. Interviews conducted individually. Location: Not reported. Format: Remote via videoconference, audio recorded and transcribed verbatim. **Analysis** Inductive thematic analysis, using 3 researchers. Transcripts were read and independently coded by 2 researchers, meeting twice to discuss and refine emerging codes. One researcher organised codes into themes, which were then discussed, defined and agreed with 2 other researchers.
Recruitment strategy	Through advertisements placed with community organisations, community practitioners, and in social media.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	Adolescents with physician or nurse practitioner diagnosed concussion who continued to experience symptoms at least 2 weeks later, and their parents.

Exclusion criteria	Not reported
Sample size	N=6 children and young people with concussion plus parents
Participant characteristics	**Children and young people with concussion, n=3** Age in years [Mean (SD)]: Not reported, age range 14-17 Sex (M/F): n=1/n=2 Time since injury in weeks [Mean (SD)]: Not reported, range 5-24 Chronic neurological disorder category: Acquired brain injury **Parents of children and young people with concussion, n=3** Age of children and young people with chronic neurological disorders in years [Mean (SD)]: As above Sex of children and young people with chronic neurological disorders in years [Mean (SD)]: As above
Results	Themes as described in paper: • Enabling access to active rehabilitation ○ Participants reported that the Tele-AR programme gave them access to specialist concussion healthcare that their local clinics could not offer and would have been useful closer to the time of injury, and that the remote delivery helped to increase access for people who are not able to physically attend specialist appointments. ○ *"When I spoke to the [local concussion clinic] they weren't seeing anyone . . . so it was kind of like, 'uh it's too bad you have a concussion . . . basically you're doing a lot of the right things, he has some factors that are going to, you know, make his concussion potentially last a little bit longer than the average child', and that's really all they – that they could do for us at that time, except refer us to your . . . study . . . If [the local clinic] had said, you know, 'we're currently not able to see patients in-person, but we can do a virtual and this is what we can do to help you', I think that would have been really helpful." (page 1143)* • Focusing on individual needs

	○ Participants reported that the Tele-AR programme personalised support and activities to their individual needs and preferences, which was an important factor for intervention engagement and motivation. However, they noted the need to tailor appointment length to an adolescent's attention span, particularly due to the remote delivery format. ○ *“[the clinician] taught me how . . . concussion can also tie in with anxiety, how can that affect your breathing. So, that was pretty cool, and I felt kind of tied in.” (page 1143)* • Learning to take responsibility for recovery ○ Participants reported that remote delivery decreased the need for adolescents to depend on their parent or carers for scheduling and transportation and increased the level of responsibility that they took for their appointments. ○ *“You want your child to have some independence, and to take some own responsibility for their well-being and getting themselves better, so I think in that sense it was fantastic because I didn’t have to go to an office with her . . . I was at this point like . . . I’m going to leave this in your corner for you to do.” (page 1144)* • Convenience and comfort of engaging in rehabilitation from home ○ Participants reflected that the ability to complete rehabilitation appointments at home resulted in increased engagement in rehabilitation and a comfortable format for communication with rehabilitation professionals. Parents felt as though a home setting was more personal, and that this helped their child to build a rapport with healthcare professionals which in turn increased their ability to talk through progress and challenges. ○ *“I would say, perhaps [online] is better because . . . with her anxiety she’s more comfortable in a home setting anyways, so to get her out of the house to the appointment would have been a bigger fight, and then she shuts down when she’s out in public, so in – in our case I think this worked better.” (page 1145)*

N/n: number of participants; SD: standard deviation; Tele-AR: Tele-active rehabilitation

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Relevant *(Study investigates a specific rehabilitation intervention [Tele-Active Rehabilitation] which may not be broadly transferable; time since injury ranges from 5-24 weeks so some participants within 3 months of injury.)*

Sixsmith, 2014

Bibliographic Reference	Sixsmith, J.; Callender, M.; Hobbs, G.; Corr, S.; Huber, J.W.; Implementing the National Service Framework for Long-Term (Neurological) Conditions: service user and service provider experiences; Disability and rehabilitation; 2014; vol. 36 (no. 7); 563-572

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	UK
Setting and aim	**Setting** Within urban rehabilitation services **Aim** To explore the experiences of people with long-term neurological conditions and service providers regarding the implementation of the National Service Framework for Long-term Neurological Conditions.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Lasted 30-45 minutes.

	Location: - People with long-term neurological conditions: Day centres (n=31 interviews), residential care (n=10 interviews), voluntary centres (n=8 interviews), and warden housing (n=1 interview). - Practitioners working with people with long-term neurological conditions: Not specified. Format: - People with long-term neurological conditions: Face-to-face and transcribed verbatim (recording format not reported). Twenty-five participants were re-interviewed on 3 occasions to clarify and further develop complex findings and assess impacts of changes within rehabilitation delivery. - Practitioners working with people with long-term neurological conditions: Interviews transcribed verbatim (in-person and recording format not reported). **Analysis** Thematic analysis. Transcripts were uploaded to NVivo 8 along with research field notes. Five researchers and co-researchers familiarised themselves with the data individually, before using a 2-day collaborative workshop to generate codes and identify initial themes. These themes were then supplemented by a literature review and finalised in a written report.
Recruitment strategy	- People with long-term neurological conditions: ○ Two public workshop events held at the start of the study, aimed at forging working relationships with service users and healthcare providers. ○ Day centre contacts. No further details reported. ○ Snowball technique: No further details reported. - Practitioners working with people with long-term neurological conditions: ○ A sampling framework was constructed to identify important aspects of service delivery. No further details reported.
Study dates	2007-2009

Sources of funding	Not industry funded
Inclusion criteria	Not reported
Exclusion criteria	None applied
Sample size	N=95 adults with long-term neurological conditions plus practitioners
Participant characteristics	**Adults with long-term neurological conditions, n=50** Age in years [Mean (SD)]: Not reported, age range 20-79 Sex (M/F): n=29/n=21 Time since diagnosis or injury: Not reported Chronic neurological disorder category: Acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorder, and progressive neurological disease **Practitioners working with people with long-term neurological conditions, n=45** 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=15 health professionals (including consultants, nurses, occupational therapists, physiotherapists, speech and language therapists, and general practitioners), n=15 social care professionals (including managers and front-line service providers), n=15 third sector professionals (including condition-specific support workers and managers)
Results	Themes as described in paper: • Diagnosis and treatment: Access to specialist care ○ Participants reported that financial issues meant that people showing moderate symptoms and conditions were not eligible for referral for early and specialist rehabilitation. ○ *No first-order quotes to support this theme.*

	• Better connected services: Breakdowns between services during referral to treatment provider ○ Participants reflected that specific service closures were not always explained to service users, which led to people perceiving service provision as inconsistent and unpredictable. This in turn led to perceptions of insufficient and restricted rehabilitation care. Even though service users value consistent and continuous service delivery, they felt as though care was not fully integrated which impacted their overall health and well-being. ○ *“A while ago they had an office on the 1st floor [called] ‘Supporting People’. The government gave them money to do it but it [the funding] ran out and now the office is shut. It [the service] was good. We used to go out and the staff were more hands on, and they’d come and see if you were alright. Now if you need them you have to pull a cord or go down to them and they never have time for a chat they just send you off.” (page 568)* • Better connected services: Implementing integrated service provision ○ Providers of neurological services noted that better connected services could help to ensure smoother access to a complete range of health and social care services and enhance service user experiences. Effective communication of key information for people with long-term neurological conditions between different services is central to integrating provision. Despite this, service providers noted that summative reported were withheld from primary care and people with long-term neurological conditions themselves. ○ *“Key people within adult social care and NHS (name of place) have been brought together by the common thread, which is the National Service Framework. And it [NHS] has listened and consulted people a lot more as a result of the implementation of the National Service Framework.” (page 569)* • On-going rehabilitation: A lack of continuing rehabilitation ○ Respondents reported that rehabilitation was short (less than 6 weeks) and delivered mainly within hospital settings. People with long-term neurological conditions highlighted that rehabilitation often ceased when they were discharged back into the community, even if their rehabilitation needs were ongoing. When offered, community rehabilitation focused on housing adaptations, technological support and equipment needs for someone's immediate care needs, which were not flexible to change. Similarly, community rehabilitation was also seen to be too short, which impacted people's functional abilities and mental health. ○ *“I don’t need a lot of the stuff they gave me now. . . My needs have changed.” (page 569)* • On-going rehabilitation: Service provider and user power imbalances

	○ Some participants did not feel able to feedback about poor service delivery with their rehabilitation providers, leading to service gaps and issues remaining unidentified. This lack of empowerment was especially felt in residential care settings. ○ *No first-order quotes to support this theme.*

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

Critical appraisal – CASP qualitative studies checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No information on relationship between researcher and participants.)*
Overall risk of bias and relevance	Relevance	Relevant *(At least 11/50 participants had cerebral palsy or were adults with stroke (outside of scope).)*

Spurgeon, 2015

Bibliographic Reference	Spurgeon, Laura; Clarke, Carl E; Sackley, Cath; Subjective Experiences of Speech and Language Therapy in Patients with Parkinson's Disease: A Pilot Study.; Rehabilitation research and practice; 2015; vol. 2015; 839895

Study Characteristics

Study type	Phenomenological
Country/ies where study was carried out	UK

Setting and aim	**Setting** Speech and language therapy services **Aim** To explore the experiences of people with Parkinson's disease regarding speech and language therapy, to inform potential therapy programmes and outcomes.
Data collection and analysis	**Data collection** Method: Semi-structured interviews. Conducted by 1 researcher. Location: Not specified. Format: Via telephone, notes taken during interview. Interview guide developed from literature review. **Analysis** Thematic network analysis. Data was read, with key words being identified and collated into basic themes. Key common issues identified in the coded text were extracted and refined to achieve discrete and coherent organising themes. These were then arranged into superordinate global themes by 3 independent psychologists who were not involved in the study. Agreement between analysts was 70%, which increased to over 85% upon discussion.
Recruitment strategy	Convenience sampling. Eligible participants were recruited via a request posted to multiple online Parkinson's disease support websites.
Study dates	Not reported
Sources of funding	Not reported
Inclusion criteria	People with idiopathic Parkinson's disease with speech difficulties developing in the 12 months following diagnosis and completing either an NHS speech and language therapy programme or the Lee Silverman Voice Treatment programme within 3 years of study enrolment. • Referral for speech and language therapy was made through a general practitioner or consultant.

Exclusion criteria	• People with physical or mental health comorbidities. • People taking medication for a clinical condition besides Parkinson's disease.
Sample size	N=9 adults with idiopathic Parkinson's disease
Participant characteristics	Age in years [Mean (SD)]: Not reported, age range 54-76 Sex (M/F): n=7/n=2 Time since diagnosis in years (Mean [SD]): Not reported, range 1-18 Chronic neurological disorder category: Progressive neurological disease
Results	Themes as described in paper: • Practical concerns ○ There were mixed reports regarding the enthusiasm of the speech and language therapists - some felt they lacked enthusiasm while others thought the opposite. The reason for these different opinions could be due to the therapy provider. Generally, NHS therapists were associated with poor attitudes and Lee Silverman Voice Therapy therapists with good attitudes. ○ *"I got the sense the staff couldn't be bothered." (page 8)*

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	Serious concerns *(Concerns over recruitment strategy; no information on relationship between researcher and participants; lack of discussion on credibility; lack of discussion of study value.)*

Section	Question	Answer
Overall risk of bias and relevance	Relevance	Highly relevant

Thomson, 2015

Bibliographic Reference	Thomson, A.; Rivas, C.; Giovannoni, G.; Multiple sclerosis outpatient future groups: improving the quality of participant interaction and ideation tools within service improvement activities; BMC health services research; 2015; vol. 15; 105

Study Characteristics

Study type	Grounded theory
Country/ies where study was carried out	UK
Setting and aim	**Setting** Multiple sclerosis outpatient clinic **Aim** To explore how analogies and props can facilitate interactions between staff and people with multiple sclerosis, to inform improvements to a multiple sclerosis outpatient service.
Data collection and analysis	**Data collection** Method: Focus groups (5 in total). Three study stages: 2 future groups held in stage 1 (separate people with multiple sclerosis and professional participants), 1 future group held in stage 2 (combined people with multiple sclerosis and professional participants), and 2 future groups held in stage 3 (separate people with multiple sclerosis and professional participants). Conducted by 2 researchers (1 acting as facilitator and the other taking field notes to aid analysis).

	Note: Focus groups are called 'future groups' throughout the study. Location: At the MS outpatient clinic. Format: Face-to-face, audio recorded and transcribed. **Analysis** Grounded theory. Data were uploaded to NVivo 8 software. No further details reported.
Recruitment strategy	Purposive sampling. Eligible participants with multiple sclerosis were approached in the multiple sclerosis outpatient clinic by a clinical team member, and then met with the Design Researcher. Healthcare professionals were those working in the clinic. No further details reported.
Study dates	Not reported
Sources of funding	Not industry funded
Inclusion criteria	• People attending multiple sclerosis outpatient clinic at study centre. • Healthcare professionals working in multiple sclerosis outpatient clinic at study centre.
Exclusion criteria	Not reported
Sample size	N=13 people with multiple sclerosis plus practitioners
Participant characteristics	**People with multiple sclerosis, n=5** Age in years [Mean (SD)]: Not reported Sex (M/F): n=2/n=3 Time since diagnosis in years: Not reported Chronic neurological disorder category: Progressive neurological disease **Practitioners working with people with multiple sclerosis, n=8**

	Age of people with chronic neurological disorders in years [Mean (SD)]: Not reported Sex of people with chronic neurological disorders (M/F): Not reported Role or specialism: Not reported but noted that the focus groups included nurses, nursing assistants, junior sisters, and reception staff
Results	Themes as described in paper: • Service improvements ○ Participants suggested 3 potential improvements to the service: a volunteer in clinic; a guide to the clinic for new people with multiple sclerosis collated from the expert people with multiple sclerosis; and a multiple sclerosis clinic dictionary to help people translate medical words and procedures. ○ *No first-order quotes to support this theme.*

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 recruitment strategy; no information on relationship between researcher and participants; lack of discussion of study value.)*
Overall risk of bias and relevance	Relevance	Highly relevant

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) including their experiences of health care.
Data collection and analysis	**Data collection** Method: Semi-structured interview lasting for 62 minutes. Location: Neurorehabilitation centre. Format: Face to face, recorded and transcribed verbatim. **Analysis** Constant comparison approach. Codes derived from the data/open coding initially. Once open coding was completed, more focused and analytical coding took place to identify themes. Coding was completed by 2 independent researchers who met to finalise coding and analysis.
Recruitment strategy	Purposive selection due to participant's rare diagnosis and recent experience of health care.
Study dates	Not reported

Sources of funding	Not reported
Inclusion criteria	Not reported
Exclusion criteria	Not reported
Sample size	N=2 (1 adult with POEMS syndrome plus carer)
Participant characteristics	**Adult with POEMS syndrome, n=1** Age in years: 71 Sex (M/F): n=0/n=1 Time since diagnosis: Not reported Chronic neurological disorder category: Progressive neurological disease **Carer of adult with POEMS syndrome, n=1** Age of person with chronic neurological disorders in years [Mean (SD)]: As above Sex of person with chronic neurological disorders (M/F): As above
Results	Themes as described in paper: • Theme one: diagnosis and treatment of POEMS syndrome: Communication. ○ Both participants reported that there was poor communication between hospitals and other rehabilitation services, meaning that they had to keep their own medical notes to compensate. ○ *“I keep records all the time so when someone says, ‘well when that did happen?’, ‘Who said that?’, ‘Why did they give you this?’, ‘Why didn’t they give you that?’. And then it’s all there because one hospital isn’t talking to another one.” (page 2506)* • Theme three: recovery: Progression and decline.

	- The participant with POEMS reflected that her care was very individualised, despite many staff being unaware of her condition. It was important to have a good balance between being ambitious during rehabilitation sessions and having appropriate rest periods. - *"The rehab here is good. And although they don't know about POEMS they seem to have taken on board that one of the things about POEMS is how tired you get. And it is a case of balancing the exhaustion with the rehab to make sure you are doing the best you can without doing too much so that it doesn't set you back." (page 2508)* • Theme three: recovery: Service provision. - Participants reported that there was a lack of communication between rehabilitation services and hospitals, creating a lack of care continuity when transferring between settings. Information about what community care would be provided after hospital discharge was confusing despite regular discharge planning meetings. - *"So generally it is very, very confusing as to who provides what, so I asked the social worker yesterday are you now our social worker and she said 'only for the discharge'. So there will be another social worker after that. You feel you're not getting continuity there." (page 2507)*

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

Critical appraisal – CASP qualitative studies checklist

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

Appendix E Forest plots

Forest plots for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

This review is a qualitative review and so there are no forest plots.

Appendix F GRADE-CERQual tables

GRADE-CERQual tables for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

Table 5: GRADE-CERQual table for theme A1 Acceptability

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 A1.1: Amount, timing, and duration of rehabilitation						
6 studies • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders) • Daker-White 2013 (General qualitative inquiry, progressive neurological disease) • Dennett 2020 (General qualitative inquiry [within mixed-methods study], progressive neurological disease) • McKevitt 2019 (General qualitative inquiry, acquired brain injury) • Paguinto 2023 (Phenomenological, progressive neurological disease) • Sixsmith 2014 (General qualitative inquiry, general chronic neurological disorders)	People with chronic neurological disorders were not satisfied with the short duration of rehabilitation that they were routinely offered, with programmes often only designed to address a particular issue and support ending once this had been addressed. People reported accessing private rehabilitation options to increase the amount and duration of rehabilitation they could receive. Early rehabilitation was not offered, with people who only showed moderate symptoms not being offered rehabilitation options until their symptom severity had worsened. These concerns over amount, timing and duration of rehabilitation were identified in both hospital and community settings. *"If you see a physio, you see the physio for a period and then you are left to go away and then it is up to you to ring them up again if you want more help and then again it is difficult to get appointments." (Dennett 2020, page 21)*	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 individual themes about the amount, timing and duration of rehabilitation options)	Moderate concerns (Evidence downgraded due to findings being mainly derived from studies exploring a particular rehabilitation intervention or including participants outside of protocol. Findings may not be broadly applicable.)	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**
Sub-theme A1.2: Community- and home-based rehabilitation						
4 studies • Grose 2014 (General qualitative inquiry, progressive neurological disease) • Preston 2012 (Grounded theory, progressive neurological disease) • Shore 2022 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • Sixsmith 2014 (General qualitative inquiry, general chronic neurological disorders)	People with chronic neurological disorders and practitioners working with them preferred some aspects of rehabilitation to be provided in the community and home, rather than clinical settings. Assessing rehabilitation needs in different environments can lead to a better understanding of need and therefore more appropriate programmes, housing adaptations and equipment provisions. It also could be a more comfortable setting for people to participate in rehabilitation exercises and share sensitive information and can reduce the burden of people having to attend clinics. However, some people felt that home visits could be intimidating. *"They come out and see you. And, I mean, that in itself is like … that's private and they see you in your own surroundings" (Preston 2012, page 267)*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Evidence downgraded due to findings being derived from themes describing advantages and disadvantages of community and home rehabilitation)	Moderate concerns (Evidence downgraded due to findings being mainly derived from studies exploring a particular rehabilitation intervention or including participants outside of protocol. Findings may not be broadly applicable.)	Minor concerns (Evidence downgraded as findings derived from 4 studies with relatively rich data)	MODERATE
Sub-theme A1.3: Interactions between professionals and people with chronic neurological disorders						
9 studies • Abrahamson 2017 (General qualitative inquiry, acquired brain injury) • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders)	The opportunity to build long-lasting relationships with rehabilitation practitioners was important to people with chronic neurological disorders , as it made them feel more supported. Practitioners who showed commitment and enthusiasm to someone's rehabilitation were valued by people with chronic neurological disorders.	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 positive and	Minor concerns (Evidence downgraded due to findings being derived from studies exploring a particular rehabilitation	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
• Gill 2012 (General qualitative inquiry, acquired brain injury) • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • McPherson 2018 (General qualitative inquiry, acquired brain injury) • Paguinto 2023 (Phenomenological, progressive neurological disease) • Preston 2012 (Grounded theory, progressive neurological disease) • Setchell 2018 (Ethnographic, progressive neurological disease) • Spurgeon 2015 (Phenomenological, progressive neurological disease)	Having a supportive relationship also allowed practitioners to pick up on changes in people's condition (which is important in people with fluctuating and progressive disorders), encourage people during periods when engagement in the rehabilitation process diminished, and understand a person's wider social and familial needs. Conversely, poor communication, a perceived lack of compassion, and failing to take concerns seriously were commonly cited as reasons for poor experiences with rehabilitation services. *"[MS (multiple sclerosis) nurse specialist] would be my first port of call because she's nice and she's always there to, you know, to listen to you, they're specialist in MS, and know what I'm going through more so than the doctor, 'cause doctors, sort of, like generalise on everything, don't they, really? It's not just specialising in MS, so it's always first port of call is always the MS Nurse." (Bernard 2010, page 83)*		negative aspects of interactions)	intervention. Findings may not be broadly applicable.)		
Sub-theme A1.4: Opportunity for feedback						
1 study • Sixsmith 2014 (General qualitative inquiry, general chronic neurological disorders)	Some people with chronic neurological disorders did not feel comfortable raising issues they faced within rehabilitation services, which can lead to delivery gaps remaining unaddressed.	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations	No/very minor concerns	Moderate concerns (Evidence downgraded due to findings being derived	Serious concerns (Evidence downgraded as findings derived from 1 study	LOW

Study information	**Description of theme or finding**	**CERQual Quality assessment**				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
	This lack of empowerment was particularly felt in residential care settings. *No first-order quotes to support this theme.*	as per CASP qualitative checklist)		from study including participants outside of protocol. Findings may not be broadly applicable.)	without rich data)	
Sub-theme A1.5: Telehealth/remote delivery						
4 studies • Ando 2021 (General qualitative inquiry, progressive neurological disease) • Dennett 2020 (General qualitative inquiry [within mixed-methods study], progressive neurological diseases) • Pollock 2022 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury) • Shore 2022 (General qualitative inquiry [within mixed-methods study], acquired brain injury)	There was mixed evidence about the use of telehealth and remote interventions in the delivery of rehabilitation. On the one hand. Remote delivery allowed regular monitoring of symptoms, a reduction in clinic visits, and greater flexibility to rehabilitation completion (for example, when and where exercises were carried out). Practitioners believed that remote delivery allowed them to continue to connect with people when circumstances prevented seeing them in person (for example, during the coronavirus pandemic), as well as exposing them to the home circumstances of people with chronic neurological disorders, which might better inform their understanding of the person's rehabilitation needs. However, some people believed that telehealth interventions and remote delivery removed the personal aspect of a face-to-face appointment and decreased engagement in rehabilitation. Additional concerns were raised over people who could not afford the technology needed for this mode of delivery and	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 positive and negative aspects of interactions)	Moderate concerns (Evidence downgraded due to findings being derived from studies exploring a particular remotely delivered rehabilitation or including participants outside of protocol. Findings may not be broadly applicable.)	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
	people who were not technologically literate. *"I don't particularly want to be part of a group um, I'm much happier doing at my own level and my own pace really um, and so that was good for me and it was good for me because I'm reasonably computer literate so it was easy, I did it on my phone…. It's difficult for me, not physically, to get to the same place regularly in the course of a week cos I just find work's quite, encroaches on my free time and also the children." (Dennett 2020, page 16)*					

Table 6: GRADE-CERQual table for theme A2 Provision of information

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme A2.1: Accessibility and timing of information						
8 studies • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders) • Donovan-Hall 2011 (General qualitative inquiry, acquired spinal cord injury) • Grose 2014 (General qualitative inquiry, progressive neurological disease)	People with chronic neurological disorders wanted rehabilitation services to provide easily accessible and timely information on their condition, especially in the early rehabilitation stages and when transferring between settings. This should include a detailed prognosis (where possible) and information about what support may be available to them, as well as what they could expect in the future and what support they may need to access at that time. People with chronic	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	Minor concerns (Evidence downgraded due to findings being derived from themes describing positive and negative aspects of information)	Minor concerns (Evidence downgraded due to findings being derived from studies exploring a particular rehabilitation intervention or including participants outside of protocol.	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
- Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) - Mueller 2017 (General qualitative inquiry, acquired brain injury) - O'Brien 2012 (General qualitative inquiry, progressive neurological disease) - Paguinto 2023 (Phenomenological, progressive neurological disease) - Shore 2022 (General qualitative inquiry [within mixed-methods study], acquired brain injury)	neurological disorders and their carers were unhappy with the added pressure of having to search for this information themselves, possibly turning to less reliable sources such as internet forums. A scheduled post-diagnosis information session was identified as a way of providing this information without overwhelming people and their families or carers. Data emphasised the importance of practitioners being mindful about the level of detail given as people's preferences for this clearly differ. *"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." (Grose 2014, page 5)*			Findings may not be broadly applicable.)		
Sub-theme A2.2: Content of information						
11 studies - Bernard 2010 (General qualitative inquiry, general chronic neurological disorders) - Donovan-Hall 2011 (General qualitative inquiry, acquired spinal cord injury)	People with chronic neurological disorders required information to cover a range of topics. Examples include: information on their condition and what to expect (including expected timelines for disease progression); education on specific therapies, equipment, and services being offered; information on coping strategies for dealing with the mental and psychological effects of chronic neurological	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	Serious concerns (Evidence downgraded due to findings being derived from single suggestions of content of information)	Minor concerns (Evidence downgraded due to findings being derived from studies exploring a particular rehabilitation intervention or	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
• Grayson 2020 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • Hartley 2013 (General qualitative inquiry [within mixed-methods study], progressive neurological disease) • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • Kumar 2013 (General qualitative inquiry [within mixed-methods study], progressive neurological disease) • McKevitt 2019 (General qualitative inquiry, acquired brain injury) • McPherson 2018 (General qualitative inquiry, acquired brain injury) • O'Brien 2012 (General qualitative inquiry, progressive neurological disease) • Paguinto 2023 (Phenomenological, progressive neurological disease)	disorders; information on the rehabilitation system and how to navigate it; and information of support organisations (for example, voluntary organisations or government services). *"'I don't think at any point anybody has, certainly not discussed with me, … but nobody has ever discussed the progress of the disease, how it might affect you in the future or what is likely to happen in the future…I don't think anybody discussed it formally, so there was very little information, it was taken as a given that you knew what was going to happen." (O'Brien 2012, page 250)*			including participants outside of protocol. Findings may not be broadly applicable.)		

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
• Preston 2012 (Grounded theory, progressive neurological disease)						
Sub-theme A2.3: Format of information						
2 studies • Rashid 2018 (General qualitative inquiry, acquired brain injury) • Thomson 2015 (Grounded theory, progressive neurological disease)	Information should be provided in multiple formats in order to make it more acceptable to the wide range of people that attend rehabilitation services for chronic neurological disorders. Examples given included written information, social media posts and peer volunteers within clinics. *No first-order quotes to support this theme.*	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 individual preferences on information format)	No/very minor concerns	Moderate concerns (Evidence downgraded as findings derived from 2 studies with relatively rich data)	VERY LOW
Sub-theme A2.4: Involving family and friends						
1 study • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury)	Information should also be given to family and friends in order to successfully include and integrate them in the planning and delivery of rehabilitation. *No first-order quotes to support this theme.*	Serious concerns (Evidence downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	No/very minor concerns	Serious concerns (Evidence downgraded as findings derived from 1 study without rich data)	VERY LOW

Table 7: GRADE-CERQual table for theme A3 Integration and co-ordination within and between rehabilitation services

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme A3.1: Care coordination						

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
7 studies • Abrahamson 2017 (General qualitative inquiry, acquired brain injury) • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders) • Botchway-Commey 2022 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury) • Grose 2014 (General qualitative inquiry, progressive neurological disease) • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • McPherson 2018 (General qualitative inquiry, acquired brain injury) • Rashid 2018 (General qualitative inquiry, acquired brain injury)	People with chronic neurological disorders highlighted the importance of having a single point of contact that could provide them with information on their disorder, services available and coordinate their care by helping them to access rehabilitation services as needed. These single points of contact are also a good point of coordination for rehabilitation services, functioning across teams and bridging gaps between healthcare and social care. *"It took some 6 years for us to get a brain injury case manager. We went through various people being case manager including a district nurse, community matron, mental health case manager, domiciliary agency manager. None could fulfil the role. Only when brain injury case manager became involved did my son start to get a proper multi-disciplinary team approach." (Holloway 2019, page 106)*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	Minor concerns (Evidence downgraded due to findings being derived from studies including participants outside of protocol. Findings may not be broadly applicable.)	No/very minor concerns	HIGH
Sub-theme A3.2: Care navigation						
3 studies • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders)	People with chronic neurological disorders want help to navigate the system of rehabilitation services and have a range of suggestions for how this could be accomplished. For example, co-location of services allows	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations	No/very minor concerns	Minor concerns (Evidence downgraded due to findings being derived from studies	Minor concerns (Evidence downgraded as findings derived from 3 studies 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
• Grose 2014 (General qualitative inquiry, progressive neurological disease) • Mueller 2017 (General qualitative inquiry, acquired brain injury)	people access to multiple rehabilitation services at once, limiting the amount of movement or travel between services. If co-location was not possible, day centres and resource centres could also act as a focal point hosting multiple providers. Clear and formal care pathways also facilitated care navigation. *"I think we do tend to get into more battles these days with mental health and social work about, you know, you should be doing this, we shouldn't be trying to, not that it gets us very far, but we do try I think." (Bernard 2010, page 69)*	as per CASP qualitative checklist)		including participants outside of protocol. Findings may not be broadly applicable.)		
Sub-theme A3.3: Commissioning biopsychosocial rehabilitation						
1 study • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders)	Services should focus on a holistic approach to rehabilitation for chronic neurological disorders, which requires cross-sector and cross-organisation collaboration. This model should encompass healthcare, social care, and the voluntary sector, and be integrated into commissioning goals in order to be effective. Without equal representation and input for social care and the voluntary sector, the evidence suggested that rehabilitation services are at risk of focusing too much on the medical aspects of rehabilitation rather than the wider issues and needs experienced by people with chronic neurological disorders.	No/very minor concerns	No/very minor concerns	No/very minor concerns	Minor concerns (Evidence downgraded as findings derived from 1 study with rich data)	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	"A significant issue for us is that rehabilitation for us is about context-based rehabilitation, about social inclusion … so it still remains a complexity. We are a very innovative team. We find that the PCT [primary care trust] and local authority will listen to what we say, but their systems are not yet flexible enough to deliver care that might be unusual or off the norm." (Bernard 2010, page 49)					
Sub-theme A3.4: Communication between services						
6 studies • Abrahamson 2017 (General qualitative inquiry, acquired brain injury) • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders) • Botchway-Commey 2022 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury) • Grose 2014 (General qualitative inquiry, progressive neurological disease) • Sixsmith 2014 (General qualitative inquiry, general chronic neurological disorders)	Communication between different healthcare services was often poor, which lead to rehabilitation becoming disjointed between settings. This is especially apparent when transitioning between private and public healthcare providers, or when utilising complementary medical therapies. Electronic patient notes were suggested as an easy way to improve communication, but this is not always possible to implement due to different settings using different and incompatible software and interfaces. Enhancing communication between services would mean better sharing of medical histories and rehabilitation plans, increasing coordination and continuity of care. People with chronic neurological disorders also expect this communication to extend to their primary care provider.	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 exploring a particular rehabilitation intervention or including participants outside of protocol. Findings may not be broadly applicable.)	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**
• Twigg 2021 (Case study, progressive neurological disease)	*"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." (Grose 2014, page 4)*					
Sub-theme A3.5: Multi-disciplinary approach						
5 studies • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders) • Botchway-Commey 2022 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury) • Paguinto 2023 (Phenomenological, progressive neurological disease) • Preston 2012 (Grounded theory, progressive neurological disease) • Rashid 2018 (General qualitative inquiry, acquired brain injury)	A multi-disciplinary approach is needed to provide effective rehabilitation for chronic neurological disorders, as it increases the range of interventions and expertise that can be offered to individuals as well as increasing awareness amongst practitioners of the interconnectedness of rehabilitation services. Psychological care was an area that was highlighted as being poorly covered within rehabilitation teams. If it was not possible to have a multi-disciplinary team within one service, there was a need to make connections with other services that can cover these gaps and increase the ease of referrals. A wide range of disciplines and viewpoints also allowed greater innovation and problem-solving within rehabilitation services, improving delivery. *"I think to have access to somebody who is a specialist in neuromuscular conditions and for a general therapist to have the access to that. To talk*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	Minor concerns (Evidence downgraded due to findings being derived from studies exploring a particular rehabilitation intervention or including participants outside of protocol. Findings may not be broadly applicable.)	Minor concerns (Evidence downgraded as findings derived from 5 studies with relatively rich data)	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
	through some of the high-level technical things is really valuable." (Paguinto 2023, page 170)					

Table 8: GRADE-CERQual table for theme A4 Personalisation of rehabilitation programmes, packages, and goals

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 A4.1: Designing holistic rehabilitation programmes						
3 studies • McKevitt 2019 (General qualitative inquiry, acquired brain injury) • Rashid 2018 (General qualitative inquiry, acquired brain injury) • Setchell 2018 (Ethnographic, progressive neurological disease)	The skills and specialties of rehabilitation teams were mainly biomedical, and clinic appointments were concerned with medical assessments and equipment reviews. The emotional and psychological aspects of chronic neurological disorders are often overlooked, meaning that people do not receive a holistic package of care. Practitioners were quick to disregard activities and goals that carried some physical risks, even if people with chronic neurological disorders argued that the psychological benefits would outweigh these for them personally. *"Dad indicated that he and his wife wanted to talk about altering Hayden's medication as it was affecting his behaviour. They began to discuss the medication Hayden was currently taking and why he was taking each one. … [it was] a frank conversation about the impacts of changing medication*	Minor concerns (Evidence downgraded due to minor 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 3 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**
	and the reasons dad would like them to change, even knowing that there might not be a change…" (Setchell 2018, page 6)					
Sub-theme A4.2: Family-centred care						
3 studies reported in 4 papers • Botchway 2022 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury) • Botchway-Commey 2022 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury) • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • Setchell 2018 (Ethnographic, progressive neurological disease)	Rehabilitation services need to work with the whole family and practice family-centred care to effectively involve them in planning and delivery. This applies to families of children and people who may lack mental capacity. This is particularly important in community rehabilitation environments to build capacity for care in the context of support networks and family routines. However, to ensure that the rehabilitation needs and preferences of children and people who may lack mental capacity, services should have policies in place to allow separate conversations between people with chronic neurological disorders and families. *"So we like the family and the child to be involved as much as possible, when it's appropriate. And then obviously depending upon their age and their function, we'll tailor their, the actual delivery of care and therapy that we're giving." (Botchway-Commey 2022, page 15)*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	Minor concerns (Evidence downgraded due to findings being derived from studies including participants outside of protocol. Findings may not be broadly applicable.)	Moderate concerns (Evidence downgraded as findings derived from 3 studies without rich data)	MODERATE
Sub-theme A4.3: Tailoring of rehabilitation content and support						
8 studies	Rehabilitation programmes can often be a generic offering, lacking	Minor concerns	No/very minor concerns	Minor concerns	No/very minor concerns	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
- Abrahamson 2017 (General qualitative inquiry, acquired brain injury) - Botchway 2022 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury) - Gill 2012 (General qualitative inquiry, acquired brain injury) - Hartley 2013 (General qualitative inquiry [within mixed-methods study], progressive neurological disease) - Paguinto 2023 (Phenomenological, progressive neurological disease) - Preston 2012 (Grounded theory, progressive neurological disease) - Shore 2022 (General qualitative inquiry [within mixed-methods study], acquired brain injury) - Twigg 2021 (Case study, progressive neurological disease)	interventions specific to an individual's condition or rehabilitation goals. People with chronic neurological disorders wanted a collaborative rehabilitation programme that was tailored to their condition and specific needs. Examples given for attaining this were including activities meaningful to the individual within the programme and being mindful of the impact of fatigue on how often someone was able to complete rehabilitation exercises. *"And I would say that throughout the treatment … it's always been a two-way thing … It's never just now I'm telling you to do this … you're letting them know you're progressing, how different you're feeling – oh that's getting easier to do, so then they'll change the exercise" (Preston 2012, page 269).*	(Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)		(Evidence downgraded due to findings being derived from studies exploring a particular rehabilitation intervention or including participants outside of protocol. Findings may not be broadly applicable.)		

Table 9: GRADE-CERQual table for theme A5 Transition into and out of rehabilitation services

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme A5.1: Co-ordinated discharge planning between services						
5 studies • Abrahamson 2017 (General qualitative inquiry, acquired brain injury) • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders) • Botchway-Commey 2022 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury) • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • McKevitt 2019 (General qualitative inquiry, acquired brain injury)	People commonly experienced poorly coordinated rehabilitation care when transferring between services, especially when being discharged back into the community. Intermediate care between acute and other services was often lacking, and poor communication between services also meant that the receiving services were not always informed of incoming people with chronic neurological disorders and their rehabilitation plans, which undermined care continuity. These delays in receiving appropriate rehabilitation resulted in people not receiving rehabilitation for a period of time, which impacted their physical skills and mental health. *"I just think it's that one missing link because the intermediate care team try so, so hard. But even they're pushed with the resources that were available… … if there was just one person that was dedicated to that family… … who could co-ordinate everything" (Abrahamson 2017, page 20)*	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	Minor (Evidence downgraded due to findings being derived from studies including participants outside of protocol. Findings may not be broadly applicable.)	No/very minor concerns	HIGH
Sub-theme A5.2: Gradual discharge and home visits						
2 studies • Abrahamson 2017 (General qualitative inquiry, acquired brain injury)	People appreciated a gradual approach to discharge from inpatient settings or residential facilities, including home visits to help them prepare.	Minor concerns (Evidence downgraded due to minor concerns	No/very minor concerns	No/very minor concerns	Serious concerns (Evidence downgraded as	MODERATE

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
• Gill 2012 (General qualitative inquiry, acquired brain injury)	Home visits allowed people to identify challenges and issues that they had not foreseen or discussed, and which would otherwise go unaddressed. Family and carers can also observe people with chronic neurological disorders while at home, bringing a different perspective that can then be integrated into a rehabilitation programme. Visits from rehabilitation practitioners should continue after transfer home to allow timely action on aspects of transition that were not working well. This support can gradually be decreased in line with a person's adaptation, strengths and needs. *"He had a couple of weekend visits, but that still wasn't somehow really enough to prepare us" (Abrahamson 2017, page 14)*	about methodological limitations as per CASP qualitative checklist)			findings derived from 2 studies without rich data)	
Sub-theme A5.3: Planning and preparation with people with chronic neurological disorders and carers						
5 studies reported in 6 papers • Abrahamson 2017 (General qualitative inquiry, acquired brain injury) • Botchway 2022 (General qualitative inquiry, acquired brain injury and acquired spinal cord injury) • Botchway-Commey 2022 (General	Smooth transition between services was hindered by a lack of planning with people with chronic neurological disorders and their carers, including a lack of information on possible disorder progression and services available. This ultimately leads to confusion and unmet needs in new settings. When people did receive information, it could be too medical to understand or contradictory with other information they had been given. Data suggested that rehabilitation care plans should	Minor concerns (Evidence downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist)	No/minor concerns	Minor concerns (Evidence downgraded due to findings being derived from studies exploring a particular rehabilitation intervention or including participants outside	No/very minor concerns	HIGH

Study information	Description of theme or finding	CERQual Quality assessment				
		Methodological limitations	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
qualitative inquiry, acquired brain injury and acquired spinal cord injury) • McKevitt 2019 (General qualitative inquiry, acquired brain injury) • Mueller 2017 (General qualitative inquiry, acquired brain injury) • Twigg 2021 (Case study, progressive neurological disease)	not just include the current setting or service, but instead try to encompass care management at discharge, in order to better support ongoing rehabilitation provision. *“We have a family meeting at the beginning of the admission and near the end, if it’s an extended stay to talk about the plans for discharge home, a discharge date, what kind of equipment and services they’re going to need after discharge. I work with getting all of the equipment and appointments and therapies that they’ll need for home.” (Botchway-Commey 2022, page 15)*			of protocol. Findings may not be broadly applicable.)		

Table 10: GRADE-CERQual table for theme A6 Sustainability of rehabilitation and consideration of chronic nature of conditions

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 A6.1: Continued support						
3 studies • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders) • Salas 2021 (General qualitative inquiry, acquired brain injury) • Sixsmith 2014 (General qualitative inquiry,	People with chronic neurological disorders appreciate continuous and consistent access to support networks, which can act as a back-up for periods when they experience reduced contact with rehabilitation services. These services could help with every-day paperwork (for example, taxes) and relational problems (for example, discussing changing relationships with family and friends).	Serious concerns (Evidence downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	Minor concerns (Evidence downgraded due to findings being derived from studies including participants outside of protocol. Findings may	Moderate concerns (Evidence downgraded as findings derived from 3 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**
general chronic neurological disorders)	*"A while ago they had an office on the 1st floor [called] 'Supporting People'. The government gave them money to do it but it [the funding] ran out and now the office is shut. It [the service] was good. We used to go out and the staff were more hands on, and they'd come and see if you were alright. Now if you need them you have to pull a cord or go down to them and they never have time for a chat they just send you off. (Sixsmith 2014, page 568)*			not be broadly applicable.)		
Sub-theme A6.2: Flexibility of provision						
1 study • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders)	A flexible approach to rehabilitation service delivery was found to be advantageous, as this better suited the long-term nature of conditions. Continuous input from rehabilitation services can seem overbearing and disempowering to individuals learning to live with their chronic disorder. However, there were also periods where people would need increased support (for example, during relapses or presentation of new symptoms). Therefore, people with chronic neurological disorders preferred ongoing access rather than continual monitoring from rehabilitation services, which allows them to contact rehabilitation services as needed.	No/very minor concerns	No/very minor concerns	No/very minor concerns	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**
	"… knowing someone is there, absolutely correct. And they're ready and prepared to, sort of, come over and to see what stage and development of needs that you require and they'll be supportive in that respect." (Bernard 2010, page 78)					
Sub-theme A6.3: Long-term follow-up						
6 studies • Bernard 2010 (General qualitative inquiry, general chronic neurological disorders) • Daker-White 2013 (General qualitative inquiry, progressive neurological disease) • Grose 2014 (General qualitative inquiry, progressive neurological disease) • Holloway 2019 (General qualitative inquiry [within mixed-methods study], acquired brain injury) • McKevitt 2019 (General qualitative inquiry, acquired brain injury) • Mueller 2017 (General qualitative inquiry, acquired brain injury)	People with chronic neurological disorders prefer services to offer long-term follow-up, including regular review and follow-up appointments with key specialist centres and practitioners involved in their rehabilitation planning and provision. This specialist follow-up could then be supplemented by more general healthcare follow-ups in the community. This also allowed easier re-referral to services if needed. However, people reported that reviews and follow-up appointments were less helpful if they needed to repeat their stories or when it increased the number of practitioners they needed to see. *"The Physio [from the CINRT (community interdisciplinary neurological rehabilitation teams)] is coming out to see me quite regularly at the moment because I've had problems with my arms, so she's given me exercises to do, she came out to see how they were going. She's been out a couple of times and now she's coming back*	Moderate concerns (Evidence downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist)	No/very minor concerns	Minor concerns (Evidence downgraded due to findings being derived from studies including participants outside of protocol. Findings may not be broadly applicable.)	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
	on six weekly check-ups to make sure that things are still going." (Bernard 2010, page 77)					

Appendix G Economic evidence study selection

Study selection for: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

No economic searches were undertaken for this qualitative review.

Appendix H Economic evidence tables

Economic evidence tables for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

No economic searches were undertaken for this qualitative review.

Appendix I Economic model

Economic model for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

No economic analysis was conducted for this review question.

Appendix J Excluded studies

Excluded studies for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

Excluded qualitative studies

Table 11: Excluded studies and reasons for their exclusion

Study	Reason
Barclay, L., Lalor, A., Migliorini, C. et al. (2020) A comparative examination of models of service delivery intended to support community integration in the immediate period following inpatient rehabilitation for spinal cord injury. Spinal Cord 58(5): 528-536	- Country Study conducted in Australia using data from spinal cord injury units in the UK, Australia, New Zealand, Canada, US, Sweden, Switzerland and Norway. Results not presented separately for target countries.
Barnett, Caroline, Davis, Rebecca, Mitchell, Claire et al. (2022) The vicious cycle of functional neurological disorders: a synthesis of healthcare professionals' views on working with patients with functional neurological disorder. Disability and rehabilitation 44(10): 1802-1811	- Country Systematic review with 6/11 of the included studies conducted in the UK, 2/11 in Australia, 1/11 in New Zealand, 1/11 in the Netherlands, and 1/11 in multiple countries. UK, 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.
Barrett, Olivia E C; Ho, Aileen K; Finlay, Katherine A (2022) Supporting Sexual Functioning and Satisfaction During Rehabilitation after Spinal Cord Injury: Barriers and Facilitators Identified by Healthcare Professionals. Journal of rehabilitation medicine 54: jrm00298	- Phenomenon of interest Findings relate to supporting access to sexual function rehabilitation, and not the delivery of rehabilitation for people with chronic neurological disorders.
Basu, Anna Purna, Pearse, Janice Elizabeth, Baggaley, Jessica et al. (2017) Participatory design in the development of an early therapy intervention for perinatal stroke. BMC pediatrics 17(1): 33	- Phenomenon of interest Findings relate to feedback on an early therapy intervention for perinatal stroke, and not the delivery of rehabilitation for people with chronic neurological disorders.
Basu, Anna Purna, Pearse, Janice, Watson, Rose et al. (2018) Feasibility trial of an early therapy in perinatal stroke (eTIPS). BMC neurology 18(1): 102	- Phenomenon of interest Findings relate to feedback on an early therapy intervention for perinatal stroke, and not the delivery of rehabilitation for people with chronic neurological disorders.
Baumbusch, Jennifer; Mayer, Samara; Sloan-Yip, Isabel (2018) Alone in a Crowd? Parents of Children with Rare Diseases' Experiences of Navigating the Healthcare System. Journal of genetic counseling	- Population Unclear population. Parents of children with rare diseases (defined as lifetime prevalence of 1 in 2000) with no further details given.
Behn, Nicholas, Marshall, Jane, Togher, Leanne et al. (2021) Participants' perspectives of feasibility of a novel group treatment for people with cognitive communication difficulties following acquired brain injury. Disability and rehabilitation 43(2): 171-180	- Phenomenon of interest Findings relate to feedback on group treatment/ group intervention, and not the delivery of rehabilitation for people with chronic neurological disorders.
Bek, Judith, Holmes, Paul S, Craig, Chesney E et al. (2021) Action Imagery and Observation in	- Phenomenon of interest

Study	Reason
Neurorehabilitation for Parkinson's Disease (ACTION-PD): Development of a User-Informed Home Training Intervention to Improve Functional Hand Movements. Parkinson's disease 2021: 4559519	Findings relate to feedback on ACTION-PD intervention, and not the delivery of rehabilitation for people with chronic neurological disorders.
Bek, Judith, Leventhal, David, Groves, Michelle et al. (2022) Moving online: Experiences and potential benefits of digital dance for older adults and people with Parkinson's disease. PloS one 17(11): e0277645	- Population Mixed population. Includes participants who are in protocol (178/327 (54%) people with Parkinson’s disease) and out of protocol (149/327 (46%) healthy older adults). Results not presented separately for target population.
Bove, Riley, Rowles, William, Carleton, Mia et al. (2020) Unmet Needs in the Evaluation, Treatment, and Recovery for 167 Children Affected by Acute Flaccid Myelitis Reported by Parents Through Social Media. Pediatric neurology 102: 20-27	- Country Study conducted in the US.
Braaf, S.C., Lennox, A., Nunn, A. 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	- Country Study conducted in Australia with adult participants.
Buckingham, S.A., Sein, K., Anil, K. et al. (2022) Telerehabilitation for physical disabilities and movement impairment: A service evaluation in South West England. Journal of Evaluation in Clinical Practice 28(6): 1084-1095	- Population Unclear population. Patients and healthcare professionals from general practice, neurology, musculoskeletal and respiratory medicine. No further details reported.
Burnett, N.; Crook, V.; Sarkozy, A. (2021) THE USE OF VIRTUAL FOCUS GROUPS TO EVALUATE AND DEVELOP THE NEW NEUROMUSCULAR CLINICAL AND PHYSIOTHERAPY PROVISION FOR NON-AMBULANT BOYS WITH DUCHENNE MUSCULAR DYSTROPHY. Archives of Disease in Childhood 106(supplement3): a20	- Publication type Conference abstract.
Burton, L.-J., Forster, A., Johnson, J. et al. (2021) Experiences and views of receiving and delivering information about recovery in acquired neurological conditions: A systematic review of qualitative literature. BMJ Open 11(4): e045297	- Country Systematic review with 6/28 of the included studies conducted in the UK, 5/28 in Australia, 3/28 in Canada, 1/28 in Canada and France, 9/28 in the US, 2/28 in Italy, 1/28 in Sweden, and 1/28 in Turkey. UK, Australian and Canadian studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Caute, Anna, Cruice, Madeline, Devane, Niamh et al. (2022) Delivering group support for people with aphasia in a virtual world: experiences of service providers. Disability and rehabilitation 44(26): 8264-8282	- Phenomenon of interest Findings relate to feedback on the EVA Park virtual platform, and not the delivery of rehabilitation for people with chronic neurological disorders.
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	- Country Study conducted in Australia with adult participants.

Study	Reason
Cornwell, Petrea, Fleming, Jennifer, Fisher, Annette et al. (2009) Supporting the needs of young adults with acquired brain injury during transition from hospital to home: The Queensland service provider perspective. Brain Impairment 10(3): 325-340	- Country Study conducted in Australia with rehabilitation professionals working in adult services.
Currie, Genevieve and Szabo, Joanna (2020) Social isolation and exclusion: the parents' experience of caring for children with rare neurodevelopmental disorders. International journal of qualitative studies on health and well-being 15(1): 1725362	- Population Unclear population. Parents of children with rare neurodevelopmental disorders (defined as prevalence of less than 1 in 2000). No further details reported.
Currie, Genevieve and Szabo, Joanna (2019) 'It would be much easier if we were just quiet and disappeared': Parents silenced in the experience of caring for children with rare diseases. Health expectations : an international journal of public participation in health care and health policy 22(6): 1251-1259	- Population Unclear population. Parents of children with rare neurodevelopmental disorders (defined as prevalence of less than 1 in 2000). No further details reported.
Currie, Genevieve and Szabo, Joanna (2019) "It is like a jungle gym, and everything is under construction": The parent's perspective of caring for a child with a rare disease. Child: care, health and development 45(1): 96-103	- Population Unclear population. Parents of children with rare neurodevelopmental disorders (defined as prevalence of less than 1 in 2000). No further details reported.
Davies, Freya, Wood, Fiona, Bullock, Alison et al. (2018) Shifting mindsets: a realist synthesis of evidence from self-management support training. Medical education 52(3): 274-287	- Population Systematic review including participants who are in protocol (28/44 people with chronic neurological disorders), unclear (13/44 people with long-term conditions), and out of protocol (3/28 people with undefined disorders). Studies including participants with chronic neurological disorders and long-term conditions were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Diener, M.L., Kirby, A.V., Sumsion, F. et al. (2022) Community reintegration needs following paediatric brain injury: perspectives of caregivers and service providers. Disability and rehabilitation 44(19): 5592-5602	- Country Study conducted in the US.
Donnelly, Clare M, Quinlivan, Rosaline M, Herron, Aaron et al. (2022) A systematic review and qualitative synthesis of the experiences of parents of individuals living with Duchenne muscular dystrophy. Disability and rehabilitation: 1-14	- Country Systematic review with 8/26 of the included studies conducted in the UK, 5/26 in Canada, 1/26 in Australia, 5/26 in the US, 2/26 in Japan, 1/26 in Brazil, 1/26 in India, 1/26 in Jordan, 1/26 in The Netherlands, and 1/26 in Norway. UK, Canadian and Australian studies were checked against protocol criteria and were either not relevant or had been separately located by the literature search and screened.
Downing, M.G., Hicks, A.J., Braaf, S. et al. (2022) "It's been a long hard road": challenges faced in the first three years following traumatic brain injury. Disability and rehabilitation 44(24): 7439-7448	- Country Study conducted in Australia with adult participants.

Study	Reason
Dyer, Kerry and das Nair, Roshan (2014) Talking about sex after traumatic brain injury: perceptions and experiences of multidisciplinary rehabilitation professionals. Disability and rehabilitation 36(17): 1431-8	- Phenomenon of interest Findings relate to experiences with discussing sexuality, and not the delivery of rehabilitation for people with chronic neurological disorders.
Erlick, M.R., Vavilala, M.S., Jaffe, K.M. et al. (2020) Provider Perspectives on Early Psychosocial Interventions after Pediatric Severe Traumatic Brain Injury: an Implementation Framework. Journal of neurotrauma	- Country Study conducted in the US.
Fitzpatrick, L.; Simpson, J.; Smith, A. (2010) A qualitative analysis of mindfulness-based cognitive therapy (MBCT) in Parkinson's disease. Psychology and psychotherapy 83(pt2): 179-192	- Phenomenon of interest Findings relate to feedback on mindfulness-based cognitive therapy, and not the delivery of rehabilitation for people with chronic neurological disorders.
Fleming, Pete; King, Lorraine; Royle, Jane (2011) Perceptions of a clinical psychology support group for spinal injury. British journal of nursing (Mark Allen Publishing) 20(12): 750-5	- Phenomenon of interest Findings relate to feedback on staff meetings in spinal injury rehabilitation setting, and not the delivery of rehabilitation for people with chronic neurological disorders.
Flynn, A., Preston, E., Dennis, S. et al. (2023) Utilising telehealth to support exercise and physical activity in people with Parkinson disease: a program evaluation using mixed methods. BMC health services research 23(1): 224	- Country Study conducted in Australia with unclear population (no mention of adults or paediatric participants).
Foster, Michele; Allen, Shelley; Fleming, Jennifer (2015) Unmet health and rehabilitation needs of people with long-term neurological conditions in Queensland, Australia. Health and Social Care in the Community 23(3): 292-303	- Country Study conducted in Australia with adult participants.
Gibbs, Katie, Wilkie, Lowri, Jarman, Jack et al. (2022) Riding the wave into wellbeing: A qualitative evaluation of surf therapy for individuals living with acquired brain injury. PloS one 17(4): e0266388	- Phenomenon of interest Findings relate to feedback on surf therapy intervention, and not the delivery of rehabilitation for people with chronic neurological disorders.
Gilmore, Linda (2018) Supporting families of children with rare and unique chromosome disorders. Research and Practice in Intellectual and Developmental Disabilities 5(1): 8-16	- Phenomenon of interest Findings relate to experiences with diagnosis of rare chromosome disorders, and not the delivery of rehabilitation for people with chronic neurological disorders.
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.
Gustafsson, Louise, Hutchinson, Laura, Theodoros, Deborah et al. (2016) Healthcare students' experiences of an interprofessional, student-led neuro-rehabilitation community-based clinic. Journal of interprofessional care 30(2): 259-61	- Country Study conducted in Australia with unclear population (no mention if healthcare professionals working in adult or paediatric services).
Hanafy, Sara, Amodio, Vanessa, Haag, Halina Lin et al. (2022) Is it prime time for sex and gender considerations in traumatic brain injury?	- Country

Study	Reason
Perspectives of rehabilitation care professionals. Disability and rehabilitation 44(5): 684-692	Study conducted in Canada with unclear population (no mention of adults or paediatric participants).
Harrison, Anthony M, McCracken, Lance M, Jones, Katherine et al. (2017) Using mixed methods case-series evaluation in the development of a guided self-management hybrid CBT and ACT intervention for multiple sclerosis pain. Disability and rehabilitation 39(18): 1785-1798	- Phenomenon of interest Findings relate to feedback on multiple sclerosis pain intervention, and not the delivery of rehabilitation for people with chronic neurological disorders.
Hodges, Lucy and Dibb, Bridget (2010) Social comparison within self-help groups: views of parents of children with Duchenne muscular dystrophy. Journal of health psychology 15(4): 483-92	- Phenomenon of interest Findings relate to social comparisons and support experiences during self-help groups, and not the delivery of rehabilitation for people with chronic neurological disorders.
Hodgson, Alisa, Jones, Jacky, Campbell, Heather et al. (2023) National quality standards for neuro rehabilitation in a community setting: Do they achieve their purpose?. Journal of evaluation in clinical practice	- Population Mixed population. Included participants who are in protocol (adult neuro-rehabilitation services), unclear (general practice services), and out of protocol (adult stroke services). Data not presented separately for target populations.
Holmes, Jain Anne, Logan, Philippa, Morris, Richard 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	- Country Systematic review with 15/43 of the included studies conducted in the UK, 3/43 in Australia, 3/43 in Canada, 12/43 in the Netherland, 6/43 in the US, 2/23 in Germany, 1/23 in Norway, and 1/23 in multiple countries. UK, Canadian and Australian studies were checked against protocol criteria – 1 was identified as potentially relevant and retrieved for full text screening.
Jackson, Katherine and et, al (2018) 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: Assistive Technology	- Other protocol criteria Duplicate.
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	- Country Systematic review with 12/37 of the included studies conducted in Australia, 11/37 in the UK, 5/37 in Canada, 137 in New Zealand, 2/37 in Ireland, 2/37 in the US, 1/37 in the Netherlands, 1/37 in Sweden, 1/37 in South Africa, and 1/37 in Norway and Denmark. Australian, UK, Canadian 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.
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	- Study design Narrative review, not a systematic review.
Kenyon, Lisa K, Harrison, Kelsey L, Huettner, Megan K et al. (2021) Stakeholder perspectives of pediatric powered wheelchair standing	- Country Study conducted in the US.

Study	Reason
devices: a qualitative study. Developmental medicine and child neurology 63(8): 969-975	
Kesgin, Firat, Suddick, Kitty, Heesen, Christoph et al. (2021) Developing a fall prevention program: what are the views and opinions of people with multiple sclerosis?. Disability and rehabilitation 43(8): 1065-1073	- Country Study conducted in Germany.
Lam, Melanie Y, Tatla, Sandy K, Lohse, Keith R et al. (2015) Perceptions of Technology and Its Use for Therapeutic Application for Individuals With Hemiparesis: Findings From Adult and Pediatric Focus Groups. JMIR rehabilitation and assistive technologies 2(1): e1	- Phenomenon of interest Findings relate to feedback on video games and robotics in rehabilitation, and not the delivery of rehabilitation for people with chronic neurological disorders.
Lape, E.C., Katz, J.N., Losina, E. et al. (2018) Participant-Reported Benefits of Involvement in an Adaptive Sports Program: A Qualitative Study. PM and R 10(5): 507-515	- Country Study conducted in the US.
Latchem-Hastings, Julie; Latchem-Hastings, Geraldine; Kitzinger, Jenny (2023) Caring for People with Severe Brain Injuries: Improving Health Care Professional Communication and Practice Through Online Learning. The Journal of continuing education in the health professions	- Phenomenon of interest Findings relate to feedback on delivery of training course, and not the delivery of rehabilitation for people with chronic neurological disorders.
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 Adult stroke survivors and healthcare professionals involved in their care. Not relevant according to protocol population criteria.
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.
Lindsay, Sally, McAdam, Laura, Mahendiran, Tania et al. (2017) Enablers and barriers of men with duchenne muscular dystrophy transitioning from an adult clinic within a pediatric hospital. Disability and Health Journal 10(1): 73-79	- Country Study conducted in Canada with adult participants.
Lotan, Meir, Ippolito, Elena, Favetta, Martina et al. (2021) Skype Supervised, Individualized, Home-Based Rehabilitation Programs for Individuals With Rett Syndrome and Their Families - Parental Satisfaction and Point of View. Frontiers in psychology 12: 720927	- Country Study conducted in Israel.
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): 218-230	- 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.
Makela, Petra, Jones, Fiona, de Sousa de Abreu, Maria Ines et al. (2019) Supporting self-	- Phenomenon of interest

Study	Reason
management after traumatic brain injury: Codesign and evaluation of a new intervention across a trauma pathway. Health expectations : an international journal of public participation in health care and health policy 22(4): 632-642	Findings relate to feedback on a self-management intervention, and not the delivery of rehabilitation for people with chronic neurological disorders.
Margetts, K. (2018) THE NEUROLOGICAL HUB. BMJ Supportive and Palliative Care 8(supplement2): a72	- Publication type Conference abstract.
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.
McRae, Jackie; Hayton, Jennifer; Smith, Christina (2022) Speech and language therapy service provision in spinal injury units compared to major trauma centres in England: Are services matched?. International journal of language & communication disorders 57(1): 6-20	- Study design Limited to quantitative data analysis and reporting.
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.
Moreno, A., Gan, C., Zasler, N. et al. (2015) Experiences, attitudes, and needs related to sexuality and service delivery in individuals with traumatic brain injury. NeuroRehabilitation 37(1): 99-116	- Country Study conducted in Canada with adult participants.
Morris-Love, R. (2020) To explore the patients' perspective of physiotherapy intervention within the home environment for management of long term neurological conditions. Physiotherapy (United Kingdom) 107(supplement1): e202-e203	- Publication type Conference abstract.
Moscato, E.L., Fisher, A.P., Gies, L.M. et al. (2021) A Mixed-Methods Analysis of Family Perceptions of Neuropsychological Evaluation and Resources for Pediatric Brain Tumor Survivors. Archives of clinical neuropsychology : the official journal of the National Academy of Neuropsychologists	- Country Study conducted in the US.
Navarta-Sanchez, M Victoria, Palmar-Santos, Ana, Pedraz-Marcos, Azucena et al. (2023) Perspectives of people with Parkinson's disease and family carers about disease management in community settings: A cross-country qualitative study. Journal of clinical nursing	- Country Mixed countries. Study conducted in UK, Norway, Denmark, and Spain. Results not presented separately for target country.
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	- Country Study conducted in Australia with adult participants.

Study	Reason
O'Hara, Rebecca and Jackson, Sarah (2017) Integrating telehealth services into a remote allied health service: A pilot study. The Australian journal of rural health 25(1): 53-57	- Country Study conducted in the US.
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	- Study design Limited to quantitative data analysis and reporting.
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	- Study design Limited to quantitative data analysis and reporting.
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 experiences with diagnosis cauda equina syndrome, and not the delivery of rehabilitation for people with chronic neurological disorders.
Paul, Lorna, Coulter, Elaine H, Miller, Linda et al. (2014) Web-based physiotherapy for people moderately affected with Multiple Sclerosis; quantitative and qualitative data from a randomized, controlled pilot study. Clinical rehabilitation 28(9): 924-35	- Phenomenon of interest Findings relate to feedback on web-based physiotherapy intervention, and not the delivery of rehabilitation for people with chronic neurological disorders.
Pilli, K.; Worne, B.; Simpson, G. (2023) Clinician experiences with using assistive technology in brain injury rehabilitation: A survey of clinician capability, attitudes, and barriers. Brain Impairment 66(1)	- Country Study conducted in Australia with rehabilitation professionals working in adult services.
Poole, J., Mercadante, V., Singhota, S. et al. (2022) Exploring patient satisfaction of a joint-consultation clinic for trigeminal neuralgia: Enabling improved decision-making. British Journal of Pain 16(2): 237-242	- Phenomenon of interest Findings relate to experiences with surgery and medication treatment of trigeminal neuralgia, and not the delivery of rehabilitation for people with chronic neurological disorders.
REGULATION AND QUALITY IMPROVEMENT, AUTHORITY (2015) Review of brain injury services in Northern Ireland.: 61	- 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.
Renaud, M.I., Klees, C., van Haastregt, J.C. et al. (2020) Process evaluation of 'Brains Ahead!': an intervention for children and adolescents with mild traumatic brain injury within a randomized controlled trial. Clinical rehabilitation 34(5): 688-697	- Country Study conducted in The Netherlands.
Rowsell, Alison, Ashburn, Ann, Fitton, Carolyn et al. (2022) Participant expectations and experiences of a tailored physiotherapy intervention for people with Parkinson's and a history of falls. Disability and rehabilitation 44(5): 727-735	- Phenomenon of interest Findings relate to feedback on PDSAFE intervention and not the delivery of rehabilitation for people with chronic neurological disorders.

Study	Reason
Ryan, Clare and Roberts, Lisa (2019) 'Life on hold': The lived experience of radicular symptoms. A qualitative, interpretative inquiry. Musculoskeletal science & practice 39: 51-57	- Population People experiencing radicular symptoms caused by pressure to a nerve root in the spinal column. Not relevant according to protocol population criteria.
Sezier, A., Mudge, S., Kayes, N. et al. (2018) Development of a toolkit to enhance care processes for people with a long-term neurological condition: A qualitative descriptive study. BMJ Open 8(6): e022038	- Country Study conducted in New Zealand with adult participants.
Shamsabadi, A., Pashaei, Z., Karimi, A. et al. (2022) Internet of things in the management of chronic diseases during the COVID-19 pandemic: A systematic review. Health Science Reports 5(2): e557	- Country Systematic review with 1/18 of the included studies conducted in UK, 7/18 in Italy, 2/18 in Israel, 2/18 in Singapore, 2/18 in the US, 1/18 in Argentina, 1/18 in Iran, 1/18 in Libya, and 1/18 in Tunisia. UK study was checked against protocol criteria and was either not relevant or had been separately located by the literature search and screened.
Simpson, Robert, Simpson, Sharon, Wood, Karen 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 feedback on mindfulness-based stress reduction intervention, and not the delivery of rehabilitation for people with chronic neurological disorders.
Sirman, N.; Beeke, S.; Cruice, M. (2017) Professionals' perspectives on delivering conversation therapy in clinical practice. Aphasiology 31(4): 465-494	- Population Mixed population. Includes participants who are in protocol (rehabilitation professionals working in progressive neurology) and out of protocol (rehabilitation professionals working in adult stroke services). Results not presented separately for target population.
Soufi, S., Chabrier, S., Bertoletti, L. et al. (2017) Lived experience of having a child with stroke: A qualitative study. European Journal of Paediatric Neurology 21(3): 542-548	- Country Study conducted in France.
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 future role of digital technology. Journal of medical Internet research	- Population People with facial palsy (single nerve injury). Not relevant according to protocol population criteria.
Turner, B.J., Fleming, J., Ownsworth, T. et al. (2011) Perceived service and support needs during transition from hospital to home following acquired brain injury. Disability and rehabilitation 33(10): 818-829	- Country Study conducted in Australia with adult participants.
Voigt, Isabel, Benedict, Martin, Susky, Marcel et al. (2020) A Digital Patient Portal for Patients With Multiple Sclerosis. Frontiers in neurology 11: 400	- Country Study conducted in Germany.
Volkmer, A., Cartwright, J., Ruggero, L. et al. (2022) Principles and philosophies for speech and language therapists working with people with primary progressive aphasia: an	- Population People with primary progressive aphasia associated with dementia. Not relevant according to protocol population criteria.

Study	Reason
international expert consensus. Disability and rehabilitation: 1-16	
von der Lippe, C.; Neteland, I.; Feragen, K.B. (2022) Children with a rare congenital genetic disorder: a systematic review of parent experiences. Orphanet Journal of Rare Diseases 17(1): 375	- Country Systematic review with 4/33 of the included studies conducted in Canada, 3/33 in the UK, 1/33 in Australia, 6/33 in the US, 3/33 in Italy, 3/33 in Norway, 3/3 in Sweden, 3/33 in Taiwan, 2/33 in Spain, 1/33 in China, 1/33 in Ireland, 1/33 in the Netherlands, and 2/33 in multiple countries. Canadian, UK, Australian studies were checked against protocol criteria – 5 were identified as potentially relevant and retrieved for full text screening.
Webster, Amy, Poyade, Matthieu, Rea, Paul et al. (2019) The Co-design of Hand Rehabilitation Exercises for Multiple Sclerosis Using Hand Tracking System. Advances in experimental medicine and biology 1120: 83-96	- Phenomenon of interest Findings relate to feedback on a hand rehabilitation intervention and motivation for use, and not the delivery of rehabilitation for people with chronic neurological disorders.
Wilkinson, Holly, McGraw, Caroline, Chung, Karen et al. (2022) "Can I exercise? Would it help? Would it not?": exploring the experiences of people with relapsing remitting multiple sclerosis engaging with physical activity during a relapse: a qualitative study. Disability and rehabilitation: 1-12	- Phenomenon of interest Findings relate to participation in physical activity with multiple sclerosis, and not the delivery of rehabilitation for people with chronic neurological disorders.
Wright, Courtney J; Zeeman, Heidi; Biezaitis, Valda (2016) Holistic Practice in Traumatic Brain Injury Rehabilitation: Perspectives of Health Practitioners. PloS one 11(6): e0156826	- Country Study conducted in Australia with 63.2% adult participants and 38.8% paediatric participants. Results not presented separately for target population.
Zulauf-Czaja, Anna, Al-Taleb, Manaf K H, Purcell, Mariel et al. (2021) On the way home: a BCI-FES hand therapy self-managed by subacute SCI participants and their caregivers: a usability study. Journal of neuroengineering and rehabilitation 18(1): 44	- Phenomenon of interest Findings relate to feedback on the BCI-FES intervention, and not the delivery of rehabilitation for people with chronic neurological disorders.

Excluded economic studies

No economic searches were undertaken for this qualitative review.

Appendix K Research recommendations – full details

Research recommendations for review question: Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?

No research recommendations were made for this review question.