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Citation for final published version:

Buscemi, Valentian, Boaz, Annette, Dawes, Helen, Jaki, Thomas, Jones, Fiona, Marsden, Jonathan, Paul, Lorna, Playle, Rebecca, Randell, Elizabeth, Robling, Michael, Rochester, Lynn, Busse, Monica and Ramdharry, Gita 2024. Exploring the issues that influence how people with rare neurological conditions engage in physical activity. *Disability and Rehabilitation* 46 (13), pp. 2789-2798.
10.1080/09638288.2023.2230128

Publishers page: <https://doi.org/10.1080/09638288.2023.2230128>

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Exploring the issues that influence how people with rare neurological conditions engage in physical activity

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Abstract word count: 196

Manuscript word count: 5399

Abstract

Purpose

People with rare neurological conditions (RNCs) struggle to achieve regular physical activity (PA). This study explored experiences of people with RNC engaging in PA, their carers, and health care professionals (HCPs) working with them.

Materials & Methods

We developed three surveys: for individuals living with RNCs, their carers, and HCPs working with them. Themes from interviews with RNC charity representatives were used to co-design questions, together with people living with RNCs, their representatives, and an expert panel. Surveys were disseminated via charity mailing lists, social media accounts, and professional networks (HCPs).

Results

We received 436 responses (225 people with RNC, 94 carers, 117 HCPs). Most respondents with RNC achieved some level of regular PA but needed motivation to maintain it. Many felt they lacked knowledge on starting and staying active, with scarce resources and support. Most HCP respondents worked in specialist services, and overwhelmingly agreed that people with RNC should be physically active, while acknowledging lack of evidence and resources.

Conclusions

We identified key barriers at environmental/organisational, interpersonal, and intrapersonal levels, highlighting a critical lack of support for people with RNC across UK health services. These factors can be targeted to increase engagement in PA.

Key words: physical activity; engagement; rare neurological conditions

Implications for rehabilitation:

- People living with rare neurological conditions experience barriers to engaging in physical activity, with some common to more prevalent neurological diseases, e.g. access and facilities, but some notable differences due to the rarity of the condition
- For people living with rare neurological conditions, and their carers, there is a lack of knowledge on safe and appropriate engagement in physical activity
- Increasing the knowledge of health and exercise professionals may improve how they support people with rare neurological disease to engage with physical activity.
- Evidence based resources and recommendations for people living with rare neurological conditions, and professionals working with them, may facilitate engagement in physical activity

Background:

The benefits of physical activity for people living with lifelong neurological diseases are increasingly recognised by the inclusion and prominence of exercise and physical activity in clinical guidelines for many conditions ¹⁻³. Nevertheless, there remain many factors impacting engagement. There can be multi-level issues that determine engagement in physical activity, and has been explored using Bronfenbrenner's Social Ecological model with factors at an intrapersonal level (e.g., physical limitations, fatigue, motivation, cultural perspectives); an interpersonal level (e.g., family support, guidance from health professionals); or at institutional, community or policy levels (e.g., physical environment, organisational systems or access to facilities) ^{4,5}. For rare neurological diseases, there may be additional issues that can further hamper engagement in physical activity due to the scarcity of individual diseases, and this warrants further investigation.

Diseases are classified as rare if cases are ≤ 40 per 100,000 people ⁶, and collectively incur a significant cost burden to healthcare, social care services and informal care ⁷. Small, cross sectional studies have identified lower levels of physical activity in some diseases ⁸⁻¹⁰. While there are likely to be common barriers identified that are comparable to more prevalent diseases, some people living with rare diseases have suggested particular issues relevant to them, for example, knowledge and understanding of the effect of activity and exercise on the presentation and symptoms. This could be at an intrapersonal level, with the person unable to access information themselves on the safety or best choice of activity for their condition. It could also be at an interpersonal level with health professionals they interact with, having limited specialist knowledge ¹¹⁻¹³.

With only a handful of research studies in single rare diseases, the extent that a lack of specialist, disease specific knowledge impacts across all rare neurological conditions (RNCs) is currently not clear ^{12,14,15}. There may be additional, disease specific barriers that have not yet been explored.

There is also a need to understand what sort of interventions could help people with rare

neurological diseases engage in, and sustain physical activity. Will generic approaches help, or are interventions more tailored to the disease required?

We sought perspectives of individuals living with a rare neurological condition, their carers and representatives, and health care professionals in the United Kingdom. The aim was to compile a national picture across the UK of engagement in physical activity, with insights on factors that determine engagement: what helps, what hinders and what are potential solutions to aid engagement. For clarity, we adopted the definition of physical activity, as set out by the World Health Organisation, as *“any bodily movement produced by the muscles that require us to expend energy”*. This can include structured exercise, active transportation, household chores, and activity during work, play and recreation ¹⁶.

Methods:

To achieve our aim, we used a survey design as our research strategy. Three surveys were co-designed with stakeholders to ensure relevant and appropriate questions ¹⁷. This study was approved by the Human Research Ethics Committee of Cardiff University (SMREC 19/60).

Population and setting:

Our objective was to investigate views across three groups: people living with a rare neurological condition (RNC survey); carers of people with a rare neurological condition (Carer survey); health professionals involved with the care and management of people with RNC (HCP survey). We wished to include people living with RNC and for the purposes of this study involved charities from a subgroup of the more common conditions or groups of conditions. Groups of conditions, for example neuromuscular diseases (NMDs) or Ataxias, include many different diseases that can be very rare.

Study design:

This work was carried out in two phases: Phase 1- Collaborative survey development; Phase 2- Application of the surveys.

Phase 1: Collaborative Survey Development

We engaged with three stakeholder groups: (1) an expert clinical and academic panel, with specialism in RNCs; (2) representatives of rare neurological disease charities; (3) people living with a rare neurological condition. A three-step process was followed of survey design, development, testing and distribution ¹⁷ (figure 1). Face-to-face, semi-structured interviews were conducted with representatives of rare neurological disease charities, to obtain a preliminary understanding of the relevant issues.

<Insert Figure 1 here>

The interview topic guide was developed by the expert panel and covered key areas of interest: care pathways for people with rare neurological diseases, access to support for physical activity, resource availability, resource accessibility and barriers. All interviews were audio recorded and transcribed verbatim using a professional transcription service.

Themes emerging from the interviews (figure S1, supplement 1) were mapped to the Social-Ecological model. They were presented and discussed at a stakeholder workshop with people living with rare neurological diseases, charity representatives, clinicians, and academic experts in rare neurological diseases with a view to co-designing the subsequent surveys. Rigor and trustworthiness were achieved by using an interview schedule with clear definitions of terms used, and thorough member checking via the stakeholder workshops. All of the charity representatives interviewed were invited to participate in the stakeholder workshops and invited to raise any disagreements or queries over the presented themes. Any not able to attend were sent a summary of the themes and invited to feedback. No major disagreements were raised, and the agreed themes were used to guide the survey item development during the workshops.

The surveys of people with RNC and their carers were made up of 18 questions in 2 sections: Section 1 “*About You*” and section 2 “*About Physical Activity*” (supplement 2). A mixture of closed questions (dichotomous, multi-choice or six-point Likert scale) and open-ended questions were used to explore sociodemographic and disease specific details (e.g., condition, level of mobility), and domains exploring experience of being physically active (e.g., exercise type and intensity, assistance needed, challenges), positive and negative effects of physical activity, barriers and solutions to maintain engagement. The survey for health professionals was split into three sections: section 1 “*About you*”, section 2: “*About your service*” and section 3: “*Physical activity support*”. There were 16 items across the sections consisting of closed questions (dichotomous, multi-choice or six-point Likert scale) and open-ended questions exploring profession and work setting, types of rare conditions and the frequency they are encountered. Opinions were sought on: the role of physical activity in the management of these conditions, support given and responsiveness to needs, issues encountered when providing support, and sources of information to underpin their practice. Testing was through the stakeholder groups with workshop discussions and decisions on question refinement.

Phase 2: Application of the Surveys

Recruitment:

People were invited to be stakeholders via the Physical Activity in Rare Neurological Conditions (PARC) collaboration. This collaboration was formed in 2017 from people living with RNCs, carers, RNC charities, with clinical and academic experts in RNC management and physical activity in neurological diseases. The aim of PARC was to scope and understand a number of aspects of physical activity in RNCs, underpinned by shared ideas from perspectives of living with a rare disease, providing support for people with rare diseases, clinically managing and conducting rehabilitation research in these conditions.

Representatives of seven rare neurological disease charities (Muscular Dystrophy UK, Ataxia UK, Hereditary Spastic Paraplegia Support Group, Progressive Supranuclear Palsy Association,

Huntington's Disease Association, Multiple System Atrophy Trust, Motor Neurone Disease Association) were approached via the PARC collaboration and invited to participate in the individual, face-to-face interviews.

For the RNC and Carer surveys, individuals living in the UK with rare neurological condition and their family members were invited to participate by the support group/charity via their e-mail mailing list or social media post. The surveys were conducted between September and November 2019.

Healthcare professionals working in the UK (Neurologists, Physiotherapists, Occupational Therapists and Nurses) were invited to participate in the HCP survey via e-mail by their relevant professional bodies (Association of British Neurologists, Association of Chartered Physiotherapists in Neurology, College of Occupational Therapists Specialist Section Neurological Practice and British Association of Neuroscience Nurses). The e-mail included information about the study and a hyperlink to the electronic survey, participant information and consent statements. All responses were anonymous.

Data analysis:

Phase 1: survey development:

Content analysis was used to analyse the data from the face-to-face interviews of charity representatives. A systematic process of coding and generating of themes were adopted using a deductive approach¹⁸ and mapped to the Social-Ecological model. The coding was undertaken by one of the research team (VB), using qualitative data analysis package NVivo (version 12, 12.5.0.815, QSR International Pty Ltd, Doncaster, Victoria, Australia), where the transcripts of the interviews were coded and categorised into nodes (or themes). For each transcript, new themes were added when the data did not fit into existing themes. The transcripts were read and re-read for further coding and refinement. With the top-down, deductive approach, some themes gathered multiple quotes but with some subtler differences in meaning. These themes were read again and categorised into sub-themes. Similar aspects across transcripts were grouped together under overarching themes and a final list of distinct elements was identified for each theme and sub-theme.

Phase 2: Application of the surveys

Quantitative data collected from the surveys were analysed using descriptive statistics (using IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp) and free-text comments were coded, using NVivo (version 12, QSR International). The themes identified from the interviews in Phase 1 were used to code the free-text data and align it back to the original themes that guided the survey design.

Results:

Response proportions for the three surveys could not be ascertained as the online links were emailed to multiple charity members, professional networks and posted on social media via multiple charity and network accounts.

The results of the people living with RNC, and their carers are presented together to gain insight into the day-to-day issues affecting participation in physical activity. The health professionals survey results are presented separately to understand how service provision, knowledge and resources can impact the support provided.

Participant characteristics:

For the RNC survey, 233 individuals with RNC agreed to participate and data from 225 participants were analysed. Two participants did not provide written consent, five did not state their condition and one did not have a rare neurological condition. Of the 225 participants, 54% identified as females, 43% males, while the remaining respondents did not specify their gender. The mean age was 57.2 (SD 14.4) and 96% selected white ethnicity. Additional details and count data for region, ethnicity and condition are available in table 1. Most respondents had a neuromuscular disease (NMD) (39%) followed by ataxia (27%), Hereditary Spastic Paraplegia (HSP) (14%), Motor Neurone Diseases (MND) (7.5%) and Progressive Supranuclear Palsy (PSP) (7%). Only 4 people with

Huntington's Disease (HD), Multiple Systems Atrophy (MSA) or Cortico-basal Degeneration (CBD) responded. Most respondents with rare neurological condition required aids to walk (61%) whilst the rest could walk unaided (23%) and only a minority needed a wheelchair (15%).

Of 101 participants completing the Carer survey, two did not provide their consent at the beginning of the survey, four did not specify the name of the condition of the persons they cared for, and one was not a carer or family member. Data provided from 94 participants were analysed. Of these, 44% were spouses or partners, 32% a parent, 23% a family member and one was a paid carer. Ninety seven percent identified as ethnically white. The majority of respondents looked after a person having PSP (28%), followed by ataxia (23%), NMD (17%), HD (11%), HSP (10%) and MND (7%). Only four participants were caring for a person with CBD or MSA. Less than half of the people they cared for was able to walk with assistance (41%) and with no assistance (15%), while more than a third used a wheelchair (36%) and a small proportion were bedbound (5%). Geographic spread and ethnic category is available from table 1.

One-hundred and twenty participants completed the HCP survey, but two did not encounter people with rare neurological diseases and one did not complete all questions. Data from 117 surveys were collated, that included responses from 74 physiotherapists, 24 occupational therapists, 13 nurses, 3 speech and language therapists, 2 neurologists and 1 support worker.

Results of the RNC and Carer surveys:

Engagement in physical activity

The majority of people (90%) living with RNCs were interested in physical activity, with 76% of the 225 respondents participating regularly (40% with support). Similarly, 60% of family members and/or carers reported that the person they cared for was interested in physical activity, with 53% of the 94 respondents reporting regular participation (70% of these with support).

A higher proportion of respondents with RNCs (47%) described performing more than one physical activity in their routine, and 25% required support, according to their carers/family members. Activities varied, and the top three were swimming/hydrotherapy (21%), walking (20%) and exercising in the gym (15%) (full list of activities in table 2).

<Insert Table 1>

Effects of physical activity

Responses from the RNC and Carer surveys (234 from people with RNC, 110 from carers) reported that positive effects of engaging in physical activity were psychological (40% RNC, 42% carer), physical (45% RNC, 38% carer) and social (11% RNC, 12% carer). Psychological benefits described included: an overall sense of well-being and improved quality of life; confidence and increased independence; vitality and motivation; a sense of coping better with life and sense of achievement.

“When I go out walking and my bit of swimming it makes me feel more positive and still part of life, getting out in the fresh air is very uplifting”. (Person living with HSP)

Physical benefits included: improved mobility and muscle strength; weight loss; pain reduction; balance improvement; improved walking ability; better sleep and reduced fatigue; improved posture; respiratory and cardiovascular benefits. Moreover, participants reported a sense of control over the disease, and being able to fight or alter the disease progression. Respondents described the physical and psychological benefits for the person living with a rare neurological condition, but also positive impacts on carers/family members:

“Generally, the exercises I undertake keep me on my feet, allowing to keep some mobility. Without this I would probably need to use a wheelchair. It has also helped with my lung function which would be more limited than it already is”. (Person living MND)

“I think it is so important to remain physically active and I can see a direct correlation between the amount of exercise my husband has, to his degree of ataxia symptoms and his mental health on a week-by-week basis”. (Family member)

“[Physical activity] Has kept them more mobile for longer, has helped them retain their strength so easier to care for, has helped with other body functions, before their mobility was so limited it kept them more positive about life”. (Family member)

There were some negative experiences of physical activity reported (208 responses), such as: tiredness and fatigue (29%); pain (19%); frustration (10%); falls and imbalance (8%); awareness of disease progression (5%); time commitment (5%); and long recovery time after exercise (3%). People described running out of energy, and the psychological effects of making limited progress or seeing decline:

“Sometimes I run out of energy so quickly I get stuck and can't literally put one foot in front of the other. Then I need a wheelchair. It's unpredictable”. (Person living with NMD 1)

“Realising that I can't do things that I used to be able to do”. (Person living with CBD)

“No progress; don't feel fitter or stronger. If muscles are in progress of weakening, it can highlight the issues (which is depressing, but arguably useful)”. (Person living with NMD 2)

Challenges to engaging in physical activity

Eighty-nine percent of respondents living with a rare neurological condition experienced challenges to being physically active. The RNC and Carer surveys identified barriers to engaging in physical activity that reflected the themes emerging from the charity interviews (figure S1, supplement 1).

Participants reported issues at an **environmental & organisational** level, challenges at an **interpersonal** level (with professionals and carers) and identified **intrapersonal** factors (table 2).

<Insert Table 2>

Environmental & Organisational Factors: Exercise facilities provided barriers to engagement when they required lengthy travel, did not have parking close to the facility, poor accessibility for people with mobility issues and limited support from gym staff.

“I have to drive my partner to the gym. Not all of the equipment is wheelchair accessible. I have to attend the gym with my partner to facilitate him using the equipment and to assist him to use the toilet if necessary. I do not feel comfortable being in the gym environment in my role as a carer to my partner”. (Family member)

The cost of accessing facilities, classes and equipment was also identified as a barrier by a proportion of respondents.

Interpersonal factors: The surveys identified challenges relating to the rarity of the diseases and focused on interactions with other people who may support physical activity, including healthcare professionals, exercise trainers, family members and/or carers. Most issues were around specialist knowledge of professionals, and how some advice can be contradictory or potentially harmful as a result.

*“No one has been able to help as I’m too rare. I have had to literally make it up as I go along.”
(Person living with Brown Sequard Syndrome)*

“Again, most places have no idea about FSHD [Facioscapulohumeral Dystrophy] and in the past, support we have accessed has been actually harmful. There is a misconception that exercise is exercise, and that physio is physio. This is wrong and must be specific to the MD [muscular dystrophy] condition”. (Family member)

“Also challenging not actually knowing if physical activity will help or hinder my muscular dystrophy as I’ve been told and seen contradicting things, so there’s always worry that I could injure myself”. (Person living with muscular dystrophy (an NMD))

The support from carers to engage in physical activity was deemed necessary by some respondents. Physical limitations were identified by carers, however, when the person living with the rare neurological condition was significantly physically and/or cognitively disabled, they acknowledged the physical and emotional toll on them and the need for them to prioritise other tasks over physical activity at times.

“I understand from what I read what she needs to do, I understand if she doesn't use it she loses it, but actually getting her to walk and then enduring her anxiety, ranting at me throughout the walk, takes its toll on both our wellbeing” (Family member)

“Time to do the exercises, I only spend a few hours a day with my Mum and this time gets taken up with other things: appointments, laundry, taking Mum out (she wants to get out of her flat into the fresh air as much as possible), etc”. (Family member)

Intrapersonal factors: These included physical, psychological and cognitive aspects that were hindering the ability to be physically active, but motivation was frequently mentioned. This related to the effort required to overcome barriers and engage, but also to how a person sees their condition changing:

“I am getting weaker and feel very unstable a lot of the time so it's challenging just getting out and going to the gym. Windy weather is terrifying”. (Person living with NMD 3)

*“I have low motivation and am very limited in what I can safely do. My confidence is low”.
(Person living with PSP)*

‘Well, I know I need to maintain a level of exercise just to not feel so weak BUT in doing so I'll be punishing my body most of the time. Physical exertion has a big impact on me mentally in both a positive and negative way so this can be quite challenging’. (Person living with Charcot Marie Tooth disease (an NMD))

Factors required to engage in physical activity

Most individuals with RNCs (90%) and their family members/carers (60%) reported interest in engaging in physical activity. They acknowledged that motivation to engage was a significant factor, with support, encouragement and other resources identified as important to keep motivated, though there is a slight difference in ranked importance between the two groups (table 3).

<Insert Table 3>

Approximately half felt confident that they had sufficient resources, were able to access exercise facilities, and knew where to seek support when needed. Just over a fifth of RNC and carer survey respondents felt well supported by their community services (table 3). Around one third of respondents did not receive any type of support to be physically active or where it was received previously, it had not been reviewed (table 3).

Findings from the HCP Survey:

Healthcare professionals responding to the survey mainly worked in community services (35%), specialist services (15%) or more than one sector (21%). The rest of the respondents worked in general practice or local hospital settings (10%), private practice (5%), while the remaining 14% worked in the charity sector, regional centres, rehabilitation units or care homes. A greater proportion worked within South-East/West England regions and Greater London (48%), (see table 1 for the regional breakdown). Most respondents (94%) reported seeing a variety of RNCs, some at least once a week (62%).

Interestingly, 92% of respondents identified multi-level challenges in supporting engagement in physical activity for their patients with RNCs, which were in line with the themes from the face-to-face interviews (figure S1, supplement 1) and RNC and Carer surveys (table 2).

Environmental & organisational factors: Most respondents (84%) felt that the service they work in has the required expertise to support people with rare neurological diseases to be physically active and could respond quickly to patient needs (73%). Thirty-nine percent, however, reported that their service did not have sufficient resources to support physical activity for these patients, mainly due to lack of staff, not being able to provide intensive input, and that patients were often de-prioritised by risk level.

“We do not have enough nursing staff to promote mobility, often patients who require hoisting are only sat out of bed by therapists. This means that patients who have plateaued in their mobility and discharged from the physio caseload because we don't have the staffing to provide maintenance therapy, or for patients who came in as full hoist baseline, they may be left in bed days or even weeks at a time”.

“The service I work in can respond quickly if there is a need for these patient's to be seen i.e., new faller/increase in falls/general decline in mobility. However, their input is very limited, and they can only really give advice to the patient before discharging them. Patients like this need frequent, intensive input which the NHS cannot provide”.

Interpersonal factors: There was overwhelming agreement that people with RNCs should be physically active (91%), that all healthcare professionals should give physical activity advice (94%). Seventy-eight percent of respondents gave advice on physical activity as part of their practice, though details were not shared. One third of respondents monitored physical activity levels through patient feedback, 40% used other tools (e.g., diaries, logbooks, attendance records), while 18% did not record physical activity but believed it was important.

More than a third of the healthcare professionals believed there is a lack of evidence available to promote exercise for patients with RNCs, but conversely, they felt sufficiently trained (76%), confident to give advice (84%), and knew where to refer if further support is required (75%).

However, there was a recognition of the knowledge gap for others who may be supporting their patients to be physically active.

“Some patients/ family members/even Healthcare professionals perceive activity may be damaging [highlighting] education needs. Need for specialist knowledge in community activity centres/gyms/ other therapy services.

“Some patients are keen to use gym facilities in the community, but there can be a lack of understanding of their condition in these establishments, and a reluctance to work with NHS staff to support these patients to access the exercise equipment safely”.

Intrapersonal factors: Motivation was the main intrapersonal factor identified by HCPs which could be linked to attitudes towards disease progression as well as concurrent mental health conditions.

“Motivation can be a challenge for our residents with HD [Huntington’s Disease], particularly those who have associated mental health conditions such as depression or anxiety”.

“Feeling from some pts [patients] of ‘what’s the point?’ when they are living with a progressive neuro[logical] condition, specifically to exercise, less so to [sic] activity”.

Suggested strategies to support physical activity for people with rare neurological conditions:

Respondents to the RNC and carer surveys offered suggestions of what would enable them or the person they care for to be more physically active. The most common suggestions were around improved and timely access to support from others (healthcare professionals, carers, exercise trainers), accessible facilities, transport and availability of equipment. It was stipulated, however, that specialist knowledge of their condition needed to be assured in people supporting physical

activity. In addition, they saw benefit in psychological support, to maintain motivation, and financial assistance.

“physio should focus on maintaining of skills, not just rehabilitation. There should also be annual check-ups to see how people are progressing and if they need any additional input”.

(Person living with an RNC)

“Somewhere to go to get specific guidelines on safe practice and maintaining symptom management whilst he is continuing to be active”. (Family member)

Respondents described how personal resources (e.g., motivation) can be developed with other approaches (e.g., condition acceptance, routine building, working with others, time management, exploring research studies) and using technology to monitor physical activity.

“Going to classes, getting involved socially, means other members of the class encourage me if I'm feeling reluctant - usually end up feeling much better mentally as a result of joining in”.

(Person living with ataxia)

Respondents to the HCP survey suggested strategies for supporting physical activity, such as signposting exercise classes and peer support, goal setting following personal preference and values, working in collaboration with community facilities, providing educational interventions and reassurances. They also identified family and peer involvement, using apps and online resources, monitoring physical activity, and specified some self-management techniques e.g., pacing, problem-solving, graded exposure and exercise planning.

“Have a neuromuscular exercise class running weekly that patients can attend/drop into.

Group support and encouragement. Many attend the neuromuscular centres for physiotherapy/ hydrotherapy / complimentary therapy/ support and find this to be beneficial and can attend when they wish with no restraints on number of sessions (unlike NHS)”.

(Healthcare professional)

“Finding out what sort/approach of exercise/activity they would like to engage in e.g. preference for home based, gym, pool, functional approach etc. Personal preference regardless of diagnosis is more likely to be a winner”. (Healthcare professional)

Discussion

We have drawn together a national picture of engagement in physical activity, with insights on factors that determine engagement and potential solutions to inform intervention development. This work reflects multiple perspectives: from people living with rare neurological diseases, their carers and healthcare professionals involved in their management.

We found high levels of interest and engagement with physical activity among people with RNCs but recognise that this could be skewed by response bias, with people who engage in physical activity more likely to complete the questionnaire on the topic. Despite overall positivity towards physical activity, we identified a number of barriers and issues for people and families to maintain beneficial levels of physical activity similar to those observed in more common neurological diseases¹⁵. There were common themes emerging from the three groups surveyed: Organisational structures, interpersonal factors and intrapersonal factors, suggesting that a multi-level understanding is required when supporting people with RNCs to be physically active.

Organisational barriers related to overall poor levels of support and access to specialist resources for maintaining physical activity across the UK. Provision of good quality of care and services depended on geographical areas and was described as jeopardised. In fact, respondents with RNCs specifically identified insufficient resources or support, challenging access to exercise facilities, with even less support from community neurological services. Some of these barriers are present for people with more common neurological diseases, but the lack of access to specialist services reflects findings of another UK based study, which identified a lack of local specialist centres and coordination of health care for people with Hereditary Spastic Paraparesis¹¹. Our study expanded on those findings,

highlighting not only how a lack of specialist and community services but also local facilities, and trained staff, negatively impacted on participation in physical activity across rare neurological diseases.

There were concerns raised about insufficient knowledge on safe exercise prescription and finding a balance between improving physical fitness and not overburdening schedules or carers. These issues have been raised previously in a study involving healthcare professionals and individuals with neuromuscular diseases¹², reflecting our findings. In fact, barriers at the interpersonal level, identified from the RNC and Carer surveys, were related to the limited availability of specialist training and guidelines on how to support physical activity in RNCs for healthcare professionals. They identified limited awareness on benefits and risks of physical activity in both healthcare professionals and people living with RNCs. However, healthcare professionals reported they had the required expertise to support people with RNCs to be physically active. This disparity may be due to a selection bias with more healthcare professionals experienced with rare diseases tending to respond over colleagues with limited experience.

Another important aspect emerging in our study, which resonated with Nierse et al.'s findings¹⁹ is the lack of continuity after the rehabilitation phase, after diagnosis or following a period of deterioration. In their study, patients reported feeling 'left alone' and unsupported after the prescribed six weeks of rehabilitation. Similarly, in the current study healthcare professionals reported limited resources within their services (e.g., due to lack of staff) halting provision of input to maintain function once the rehabilitation phase has ended. Current community rehabilitation service models do not provide the long-term support needed for progressive diseases.

Publicly funded health services across the UK are unlikely to change their structures in the short term to provide a different model of support to people with RNCs. We can, however, look to address some of the other factors identified, such as gaps in knowledge for people with RNCs, healthcare professionals and exercise professionals.

We were keen to understand whether disease specific interventions are required to address engagement in physical activity. Although improving knowledge of activity prescription for individual diseases would address some of the concerns raised, there were also cross-cutting issues that may be amenable to more generic approaches e.g. confidence and motivation to engage in physical activity. Self-management support and behaviour change techniques could be implemented to address an individual's motivation, often associated with low self-efficacy. These approaches can address individual internal and external beliefs, cognitions and social needs²⁰. Given the long-term nature of many RNCs, ongoing support from health professionals in some format is vital to maintain motivation and engagement while limiting the burden and impact on carers. There has been a surge in how technology has been entering people's lives, that has accelerated since the Covid-19 pandemic. Technology can overcome isolation and access issues, such as tele-rehabilitation, apps, online peer-support, virtual platforms, and websites for self-management programmes²¹⁻²³. They give potential to address some of the challenges identified in the current study.

Study limitations: The recruitment to this study was based on self-selection and may not represent the views of people living with RNCs who have no interest or do not engage in physical activity. It would be helpful to understand issues that have contributed to non-engagement as they may be the most important to address in the first instance.

There was poor representation from people living with RNCs, and family members, who are from ethnic minorities. We understand that culture and health beliefs can influence engagement in physical activity^{24,25} so this factor has been underexplored in this study. This may be a wider reflection of intersecting health inequalities where people from minority groups and rare diseases struggle to access optimal support.

The insights from HCPs were mainly provided by physiotherapists who represented the majority of the sample, followed by occupational therapists. Although these professionals represent those who

mostly deal with supporting physical activity as a key part of their role, a wider overview from across other medical and health-related professions would have helped to expand the current findings.

Implications for practice:

This study emphasizes general barriers to physical activity for people with RNCs, but highlighted additional barriers relating to their rarity. Access to individuals with specialist knowledge, specialist services, and the availability of specialist information for people living with these conditions are key to overcoming some of the intrapersonal challenges. Where health service resources are limited, alternative modes of delivering information and tailored support may be warranted, targeting factors at the organisational, interpersonal and intrapersonal levels.

Conclusions

This work revealed barriers to participation in physical activity for people with rare neurological diseases at organisational, interpersonal and intrapersonal level. We recommend that interventions to successfully support engagement in physical activity need to be multi-level to achieve meaningful change, e.g. education and supported self-management programmes.

Funding

This work was funded by an NIHR Programme Development Grant RP-DG-0517-10002 (Co-Chief Investigators: G.R. & M.B.). This is a summary of independent research funded by the National Institute for Health Research (NIHR)'s Programme Development Grant Programme. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care. GR received funding from NIHR Biomedical Research Centre UCL/UCLH. ²⁶Centre for Trials Research receives funding from Health and Care Research Wales and Cancer Research UK.

Acknowledgments

We would like to acknowledge the input of our stakeholder groups and charity representatives from the Muscular Dystrophy Association, Ataxia UK, HSP support group, PSP Association, HD Association of England and Wales.

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Tables:

Respondants		People with RNC (N=225)	Carers (N=94)	Healthcare Professionals (N=117)		
Age (mean ±SD)		57.2 ±14.4	52.2 ±12.6			
Sex	Female	122	78	Medical doctor	2	
	Male	97	12	Physiotherapist	74	
	Prefer not to say	1	1	Occupational Therapist	24	
	Missing	5	4	Nurse	13	
				Speech & Language Therapist	3	
Ethnicity	South Asian	3	1	Support worker	1	
	Black	0	0	Scotland	7	
	East Asian	1	0	Northern Ireland	1	
	Mixed Heritage	2	0	NW England	16	
	White	218	91	Yorkshire & Humber	4	
	Prefer not to say	0	1	NE England	6	
Region	Missing	1	1	Wales	3	
	Scotland	11	7	West Midlands	8	
	Northern Ireland	5	2	East Midlands	7	
	NW England	22	16	SW England	15	
	Yorkshire & Humber	18	7	Greater London	24	
	NE England	7	3	SE England	18	
	Wales	11	9	Community team	41	
	West Midlands	15	11	Hospice/ care home	4	
	East Midlands	22	5	Neurological care centre	1	
	SW England	27	7	Primary care	4	
Condition	Greater London	14	3	Private practice	6	
	SE England	46	14	Regional centre	5	
	Ataxia	60	22	Specialist centre	16	
	CBD	4	3	Third sector	2	
	HD	4	10	More than one setting	25	
	HSP	32	9	Time in current speciality	0-5 years	32
	MND	17	7	6-10 years	25	
	MSA	4	0	>10 years	60	
Relationship with person with RNC	NM	89	16	Proportion of patients with RNC	Up to 25%	69
	PSP	15	26	Up to 50%	22	
	Spouse/partner	NA	41	Up to 75%	9	
	Parent	NA	29	Up to 100%	17	
	Paid carer	NA	2			
Other family member	NA	22				

Table 1: Summary of demographics of respondents to the three surveys

Activities in people living with rare neurological condition (self-reported)	N	Activities in people living with rare neurological condition (carer reported)	N
Hydrotherapy and swimming	48	Hydrotherapy and swimming	20
Walking	44	Walking	18
Gym exercises	34	Gym exercises	2
Cycling	27	Cycling	6
Other (volunteering, diet, tai-chi, boxing, fishing, singing, dancing, doing transfers, being active and keep moving)	26	Other (exercise classes, tai-chi, voice practice, dancing, wheelchair basketball, triathlon, running, football, trampolining, spinner cross trainer, boxing, boccia, badminton,)	13
Stretching	22	Stretching	1
Pilates	17	Pilates	2
Home exercise and exercise in general	17	Home exercises and exercise in general	17
Yoga	15	Yoga	4
Physiotherapy exercises	14	Physiotherapy	9
Strengthening exercise	10	Strengthening exercise	5
Balance exercise	7	Balance exercise	3
Cardiovascular exercises	7	Cardiovascular exercises	1
Household chores	6	Household chores	0
Gardening	4	Gardening	1
Going "out and about"	2	Going "out and about"	0
Chair exercises	2	Chair exercises	0
No exercise	12	No exercise	9

Table 2: Activities identified by people living with rare conditions, and their carers.

Organizational structures	Interpersonal relationships	Intrapersonal factors
<p>Healthcare systems:</p> <ul style="list-style-type: none"> • Difficulty accessing specialist and local support • Due to the rarity of certain conditions, clinicians [in some services] do not 'own' a speciality • Long waiting lists • Limited service resources (e.g., shortages in staffing) • Lack of continuous support 	<p>Professionals (health & leisure):</p> <ul style="list-style-type: none"> • Limited knowledge of specific rare conditions • Limited training availability • Reduced awareness of benefits and risks of physical activity in specific rare conditions • Belief in the role of physiotherapists (i.e., they only aim at physical improvement) 	<ul style="list-style-type: none"> • Limited knowledge of benefits and risks of physical activity • Physical activity considered a low priority • Lack of motivation due to: <ul style="list-style-type: none"> • frustration • not being able to exercise as much as they used to • loss of confidence in their body • not able to exercise independently • too many constraints
<p>Exercise facilities:</p> <ul style="list-style-type: none"> • Staff not knowledgeable in the condition • Inaccessibility and lack of adapted equipment • High costs • Limited options for people living with mobility issues (e.g., suitable classes) • Require travel, sometimes over long distances, and parking close to facilities • Lack support or supervision before and during the activity (e.g., changing clothes) • Long waiting list and higher costs for 	<p>Carers and family:</p> <ul style="list-style-type: none"> • Physical inability to assist • Time constraints • Emotional toll on the carer • Discomfort when exercising in public <p>Lack of family or carer support for some individuals</p>	<ul style="list-style-type: none"> • Physical factors: <ul style="list-style-type: none"> • fatigue • risk of falling • medication side effects • pain, spasms, stiffness • Cognitive factors: <ul style="list-style-type: none"> • lack of ability to plan activities • difficulty engaging with exercises provided • apathy • limited activity initiation • Psychological factors:

<p>specific facilities (e.g., hydrotherapy).</p>		<ul style="list-style-type: none"> • depression and anxiety • feeling isolated • mood changes • fear of deterioration • fear of falling • Lack of time • Reliance on a carer and/or aids to be physically active
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Table 3: Factors affecting engagement in physical activity, grouped under domains from the Social-Ecological model: organisational, interpersonal and intrapersonal factors

Accepted version 23.06.2023

RNC Survey		Carer Survey	
I need to be encouraged to be physically active	38%	I need to encourage the person I care for to be physically active	49%
I have enough knowledge on the benefits of physical activity for my condition	68%	I have enough knowledge on the benefits of physical activity for the person I care for	67%
I have had the opportunity to discuss physical activity and its benefits with a health care professional	60%	I have had the opportunity to discuss physical activity and its benefits with a health care professional	51%
I'm able to follow the advice about physical activity/exercise from health care professionals	63%	I'm able to follow the advice about physical activity/exercise from health care professionals	55%
I am confident about how to be physically active successfully	63%	I am confident about how to support the person I care for to be physically active successfully	32%
I am confident about how to be physically active safely	59%	I know how to support the person I care for to be physically active safely	51%
I feel I have enough resources (e.g. support, equipment) to be able to be physically active	49%	I feel I have enough resources (e.g. knowledge, equipment, access to facilities, time) to be able to support the person I care for to be physically active	36%
I can easily access exercise facilities	41%	The person I care for can easily access exercise facilities	24%
I know where to seek support to be physically active if I need to	40%	I know where to seek support if I need to, in order to help the person I care for to be physically active	42%
I can access support quickly to be physically active	28%	I can access support quickly if I need to, in order to be able to help/assist the person I care for to be physically active	24%
I feel well supported by my community services to be physically active	24%	I feel well supported by community services to be able to help/assist the person I care for to be physically active	23%

Table 4: Support for engaging in physical activity: proportions of RNC and Carer survey respondents who agree or strongly agree with the statements.

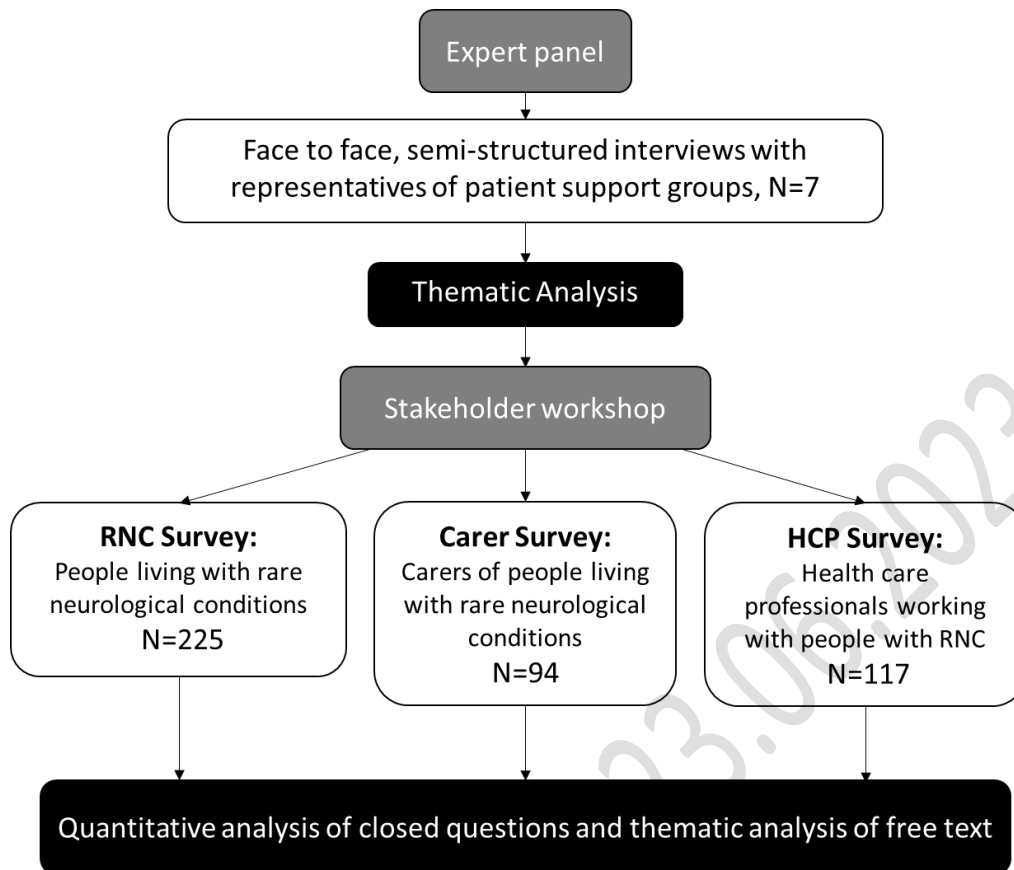


Figure 1: Overview of the engagement, co-design, and research process. Stakeholder group (1): expert panel; stakeholder group (2): charity representatives; stakeholder group (3): people living with RNC. RNC: rare neurological condition, HCP: healthcare professional.

Supplement 1:

Outcome of interviews with charity representatives:

The aim of the interviews with charity representatives was to identify themes to inform question generation for the three surveys. The themes were grouped into environmental/organisation factors, interpersonal factors and intrapersonal factors reflecting the Bronfenbrenner's Social Ecological model (figure 2, main manuscript). Respondents identified issues with local and regional healthcare systems with geographic access to specialist services, ongoing support and lack of knowledge in local and/or generic teams. Access and suitability of community facilities also came under the environment theme. The charity representatives highlighted the interpersonal support challenges for the family with a striking quote from one participant:

"I think for many carers, simply trying to manage their loved one with the disease is so chaotic and difficult on a day-to-day basis, that the thought of doing something about physical activity just wouldn't even enter their head..."

The specialist knowledge of individuals who provide exercise and activity support, in health services or the fitness industry, was also thought to impact at an interpersonal level. Limited knowledge was also mentioned in the context of the individual, in understanding the benefits of physical activity to their condition, plus any risks. In addition to the disease specific physical and/or cognitive factors influencing physical activity engagement, respondents also raised a number of psychological factors. These include motivation, fear, avoidance and dealing with stigma when active in front of others, as summarised in this quote:

“Feeling discriminated against because of the pain [of the condition], looking after yourself, because [you are] accused of being drunk, all sorts of things that you've probably read about, and then these are the challenges”.

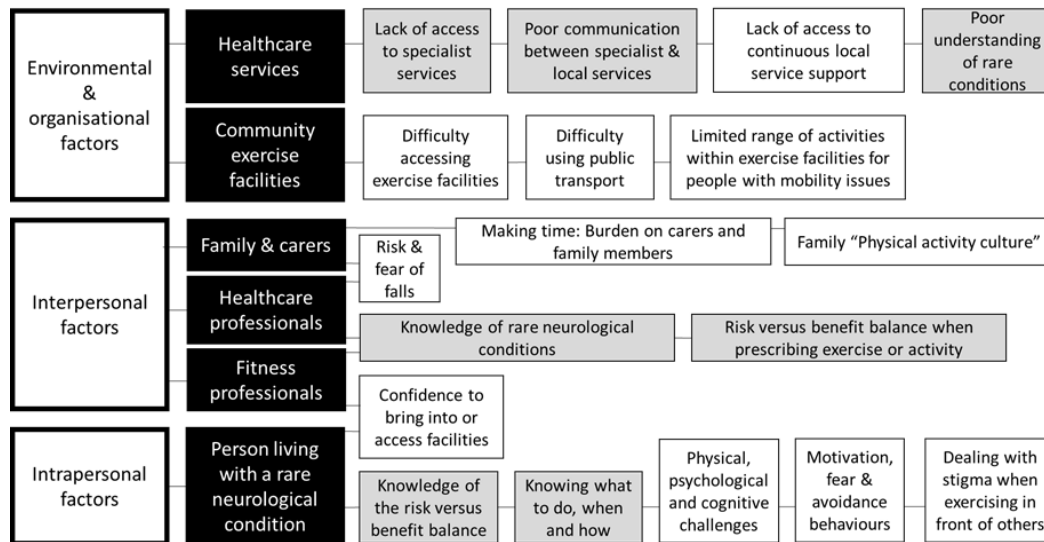


Figure S1: Results of the individual interviews with charity representatives, mapped to the Social-Ecological model

Supplement 2:

[Survey for people living with rare neurological conditions]

EXPLORING PHYSICAL ACTIVITY IN RARE NEUROLOGICAL CONDITIONS

About PARCC (Physical Activity for people with Rare neurological Conditions Collaboration)

The PARC program development work is currently gathering information prior to developing the PARC intervention at the next stage of funding. The PARC intervention will be a self-management program to support physical activity in rare neurological diseases, including ataxias (e.g. Friedreich's ataxia), hereditary spastic paraparesis, Huntington's disease, neuromuscular diseases (e.g. polyneuropathies, myasthenia and muscular dystrophies), motor neurone disease, atypical Parkinsonisms. If you have one of the conditions listed above, we would like to hear from you as we are interested in understanding if you do any type of physical activity, if you feel sufficiently confident in engaging in physical activity and what the major barriers and possible solutions are in case you do not feel motivated or engaged.

Definitions of physical activity and exercise according to the WHO definition:

Physical activity is defined as any bodily movement produced by skeletal muscles that requires energy expenditure. Physical activity includes exercise as well as other activities which involve bodily movement and are done as part of playing, working, active transportation, house chores and recreational activities. **Exercise**, is a subcategory of physical activity that is planned, structured, repetitive, and purposeful in the sense that the improvement or maintenance of one or more components of physical fitness is the objective".

The time expected to complete this survey is 15 minutes.

About you

1. What is your gender?

Please specify: _____

2. What is your age?

Please specify: _____

3. What region do you live in?

- South East England
- South West England
- London
- Wales
- Midlands
- East of England
- North East England
- North West England
- Scotland
- Northern Ireland

4. Which of the following best represents your ethnic heritage?

- Asian
- Black
- Chinese
- Mixed

- White
- Other, please give details _____
- Unknown

5. What neurological condition have you been diagnosed with?

- Ataxia (e.g. Friedreich's ataxia, cerebellar ataxia, episodic ataxia, idiopathic ataxia)
- Neuromuscular disease (e.g. muscular dystrophy, myasthenia gravis, myositis, peripheral nerve disease, mitochondrial disease)
- Hereditary spastic paraparesis
- Huntington's disease
- Motor neurone disease
- PSP (progressive supranuclear palsy)
- MSA (multiple systems atrophy)
- CBD (corticobasal degeneration)
- Other _____
- I don't know

6. What age were you when you noticed your first symptoms of the condition?

- Please specify _____
- Can't remember

7. What is your level of mobility?

- Walk with no assistance as far as I need to
- Walk with no assistance, but distance is limited
- Walk with assistance as far as I need to
- Walk with assistance, but distance is limited
- Use a wheelchair always
- Use a wheelchair sometimes
- Other _____

8. What aids to walking do you use (tick as many as apply)?

- Walk with the aid of splints or supports
- Walk with 1 stick
- Walk with 2 sticks
- Walk with 1 elbow crutch
- Walk with 2 elbow crutches
- Walk with rollator frame. Type _____
- Walk with another person
- Walk with a pushchair or buggy
- Wheelchair that I propel with my hands
- Electric scooter
- Powered wheelchair
- Wheelchair that someone else pushes
- Functional Electrical Stimulation
- Orthotics and splints
- I am unable to leave my bed
- I do not use any mobility aids
- Other _____

Please indicate the one you regard as most important _____

About your physical activity

1. Do you participate in physical activity regularly (e.g. more than once a week). Please see definition of physical activity above.

- Yes (please answer question 1a)
- No (please answer question 3)
- Sometimes (please answer question 1a)

1a. If you do, what do you do? Please, give details (type of activity, for how long and how often)

Activity or exercise	How long you do it for (minutes)?	How often (how many times per week)

2. Do you do physical activity independently?

- Yes (please go to question 3)
- No (please go to question 2a)
- Sometimes (please go to question 2a)

2a. If not, can you describe what time of assistance you need in order to be able to do physical activity (e.g. help of a person or carer, walking aid, reminders such as apps, facility adaptations etc.)

3. Please, tick the options on the table (ranging from strongly disagree to I don't know) that most suits you for each item:

	Strongly disagree	Disagree	Neither disagree or agree	Agree	Strongly agree	I don't know
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a. I am interested in keeping physically active						
b. I need to be encouraged to be physically active						
c. I have enough knowledge on the benefits of physical activity for my condition						
d. I have had the opportunity to discuss physical activity and its benefits with a health care professional						
e. I'm able to follow the advice about physical activity/exercise from health care professionals						
f. I am confident about how to be physically active successfully						
g. I am confident about how to be physically active safely						
h. I feel I have enough resources (e.g. support, equipment) to be able to be physically active						
i. I can access to facilities in order to be physically active easily						
j. I know where to seek support to be physically active if I need to						
k. I can access support quickly to be physically active						
l. I feel well supported by my community services to be physically active						

4. Is the support you receive to be physically active usually from: [please tick more than one]

- Local neurologist
- Local therapists (physiotherapy, occupational therapist)
- Local nurse
- Local exercise trainers
- Specialist neurologist
- Specialist therapists (physiotherapy, occupational therapist working in hospital)
- Specialist nurse
- Other: _____
- I have not received any type of support

5. Do you experience challenges or difficulties in being physically active?

- Yes (please answer questions 5a and 5b)
- No (please go to question 6)

5a. Please, describe what challenges you experience to be physically active

5b. Please describe what support you need in order to be physically active:

6. What solutions have you found to keep physically active?

7. Please describe the type of physical activity or exercise you have found beneficial for you so far:

8. Where do you access financial resources to engage with physical activity:

- NHS
- Charities
- Local funding schemes
- Self-funded (e.g. private group class)
- I don't need financial support to engage in physical activity
- Other, please give details _____

8. How do you monitor how active you are? Tick all that apply

- I don't monitor my activity, but I think it is important
- I don't believe monitoring is necessary
- Monitoring using online applications (Apps)
- I am regularly monitored by health care professionals (e.g. nurse or physiotherapist)
- Monitoring using diaries, log books or attendance records
- Other, give details _____

9. What have been the positive and negative effects of being physically active for you?

Positive	Negative
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10. Where do you go to seek more information on physical activity and exercise?

- Web pages
- Community initiatives
- Peers
- Health care specialists
- Gym and exercise trainers
- Charity website and publications
- Research reports
- Guidelines (e.g. NHS guidelines or from charity websites)
- Courses and conferences
- Other, give details _____

END OF THE SURVEY
THANK YOU!

[Survey for carers of people living with rare neurological conditions]

EXPLORING PHYSICAL ACTIVITY IN RARE NEUROLOGICAL CONDITIONS

About PARCC (Physical Activity for people with Rare neurological Conditions Collaboration)

The PARC program development work is currently gathering information prior to developing the PARC intervention at the next stage of funding. The PARC intervention will be a self-management program to support physical activity in rare neurological diseases, including ataxias (e.g. Friedreich's ataxia), hereditary spastic paraparesis, Huntington's disease, neuromuscular diseases (e.g. polyneuropathies, myasthenia and muscular dystrophies), motor neurone disease, atypical Parkinsonisms. If your family member is an adult with one of these conditions listed above, we would like to understand your opinion regarding your experience of supporting them in being physically active and possible barriers or challenges you may have faced in doing this.

Please see below how the definitions of physical activity and exercise (according to the WHO definition):

"**Physical activity** is defined as any bodily movement produced by skeletal muscles that requires energy expenditure. Physical activity includes exercise as well as other activities which involve bodily movement and are done as part of playing, working, active transportation, house chores and recreational activities. **Exercise**, is a subcategory of physical activity that is planned, structured, repetitive, and purposeful in the sense that the improvement or maintenance of one or more components of physical fitness is the objective".

The time expected to complete this survey is 15 minutes.

About you

1. What is your relationship with the person living with a rare neurological condition?

- Partner or spouse
- Parent
- Other family member (please specify) _____
- Friend
- Paid carer
- Other (please specify) _____

2. What is your gender?

Please specify: _____

3. What is your age? Please specify: _____

4. Which of the following best represents your ethnic heritage?

- Asian
- Black
- Chinese
- Mixed
- White
- Other, please give details _____
- Unknown

5. What region do you live in?

- South East England
- South West England

- London
- Wales
- Midlands
- East of England
- North East England
- North West England
- Scotland
- Northern Ireland

6. What is the neurological condition of the person you care for?

- Ataxia (e.g. Friedreich's ataxia, cerebellar ataxia, episodic ataxia, idiopathic ataxia)
- Neuromuscular disease (e.g. muscular dystrophy, myasthenia gravis, myositis, peripheral nerve disease, mitochondrial disease)
- Hereditary spastic paraparesis
- Huntington's disease
- Motor neurone disease
- PSP (progressive supranuclear palsy)
- MSA (multiple systems atrophy)
- CBD (corticobasal degeneration)
- Other _____
- I don't know

7. What age was the person you care for when they noticed the first symptoms?

Please specify _____

- Can't remember

8. What is the level of mobility of the person you care for?

- Walk with no assistance as far as he/she/they needs to
- Walk with no assistance, but distance is limited
- Walk with assistance as far as he/she/they needs
- Walk with assistance, but distance is limited
- Use a wheelchair always
- Use a wheelchair sometimes

9. What aids does the person you are caring for use?

- Walk with the aid of splints or supports
- Walk with 1 stick
- Walk with 2 sticks
- Walk with 1 elbow crutch
- Walk with 2 elbow crutches
- Walk with rollator frame: Type _____
- Walk with another person
- Walk with a pushchair or buggy
- Wheelchair that he/she/they propel with hands
- Electric scooter
- Powered wheelchair
- Wheelchair that someone else pushes
- He/she/they is unable to leave his/her/their bed
- Functional Electrical Stimulation
- Orthotics or splints
- He/she/they does not use any mobility aids

About physical activity

1. Does the person you care for participate in physical activity regularly (e.g. more than once a week)? Please see definition of physical activity above.

- Yes
- No (go to Q3)
- Sometimes

1a. If she/he/they does, what does he/she/they do? Please, give details (type of activity, for how long, and how often if you know)

Activity or exercise	How long does he/she/they do it for (minutes)?	How often (how many times per week)?

2. Does the person you care for do physical activity independently?

- Yes (please answer question 3)
- No (please answer question 2a)
- Sometimes (please answer question 2a)

2a. If not, can you describe what type of assistance he/she/they needs in order to be able to do physical activity (e.g. help of a person or carer, walking aid, reminders such as apps, facility adaptations etc.)

3. Please, tick the options on the table (ranging from strongly disagree to I don't know) that most suits your opinion for each item:

	Strongly disagree	Disagree	Neither disagree or agree	Agree	Strongly agree	I don't know
--	-------------------	----------	---------------------------	-------	----------------	--------------

a. He/she/they is not interested in being physically active						
b. I need to encourage the person I care for to be physically active						
c. I have enough knowledge on the benefits of physical activity for the person I care for						
d. I have had the opportunity to discuss physical activity and its benefits with a health care professional						
e. I'm able to follow the advice about physical activity/exercise from health care professionals						
f. I am confident about how to support the person I care for to be physically active successfully						
g. I know how to support the person I care for to be physically active safely						
h. I feel I have enough resources (e.g. knowledge, equipment, access to facilities, time) to be able to support the person I care for to be physically active						
i. We can easily access to facilities to be physically active						
j. I know where to seek support if I need to, in order to help the person I care for to be physically active						
k. I can access support quickly if I need to, in order to be able to help/assist the person I care for to be physically active						
l. I feel well supported by community services to be able to help/assist the person I care for to be physically active						
m. I have enough time to support the person I care for to be physically active						

4. Is the support you receive usually from: [please tick more than one]

- Local neurologist
- Local therapists (physiotherapy, occupational therapist)

- Local nurse
- Local exercise trainers
- Specialist neurologist
- Specialist therapists (physiotherapy, occupational therapist working in hospital)
- Specialist nurse
- Other: _____
- I have not received any type of support

5. Do you experience challenges or difficulties in supporting the person you care for to be physically active?

- Yes (please answer questions 5a and 5b)
- No (please go to question 6)

5a. Please, describe what challenges you experience in supporting the person you care for to be physically active:

5b. Please describe what you would need in order to be able to better support the person you care for to be physically active:

6. What solutions have you found in order to be able to support the person you care for to keep being physically active (i.e. what has worked so far)?

7. Please describe the type of physical activity or exercise you think has benefitted the person you care for?

8. Where do you access financial resources in order to support the person you care for to engage with physical activity:

- NHS
- Charities
- Local funding schemes
- Self-funded (e.g. private group class)
- He/she/they doesn't need financial support to engage in physical activity
- Other, please give details _____

9. How do you monitor how active is the person you care for? Tick all that apply

- I don't monitor his/her/their activity, but I think it is important
- I don't believe monitoring is necessary
- Monitoring using online applications (Apps)
- He/she/they is regularly monitored by health care professionals (e.g. nurse or physiotherapist)
- Monitoring using diaries, log books or attendance records
- Other, give details _____

10. What have been the positive and negative effects of being physically active for the person in your care (in your opinion)?

Positive	Negative

11. Where do you go to seek more information on physical activity and exercise?

- Web pages
- Community initiatives
- Peers
- Health care specialists
- Gym and exercise trainers
- Charity website and publications
- Research reports
- Guidelines (e.g. NHS guidelines or from charity websites)
- Courses and conferences
- Other, give details _____

END OF THE SURVEY
THANK YOU!

Accepted version 23.06.2023

[Survey for health care professionals working with rare neurological conditions]

EXPLORING CARE PATHWAYS FOR PHYSICAL ACTIVITY IN RARE NEUROLOGICAL CONDITIONS

About PARCC (Physical Activity for people with Rare neurological Conditions Collaboration)

The PARC program development work is currently gathering information prior to developing the PARC intervention at the next stage of funding. The PARC intervention will be a self-management programme to support physical activity in rare neurological diseases, including ataxias (e.g. Friedreich's ataxia), hereditary spastic paraparesis, Huntington's disease, neuromuscular diseases (e.g. polyneuropathies, myasthenia and muscular dystrophies), motor neurone disease, atypical Parkinsonisms. We would like to hear from you as we are interested in understanding if and how you support physical activity in people with these conditions, in the context of your service. This information will help us to understand clinicians' experiences and potential challenges faced in supporting physical activity in people with rare neurological conditions. The time expected to complete this survey is 15 minutes.

About you

1. What is your profession?

- Medical doctor
- Nurse [Please specify _____]
- Allied Health Professional [Please specify _____]
- Pharmacist
- Support worker/unregistered health care worker
- Other _____

2. What region do you live in?

- South East England
- South West England
- London
- Wales
- Midlands
- East of England
- North East England
- North West England
- Scotland
- Northern Ireland

3. What setting do you work in? (select all that apply)

- Primary care
- Community team
- Secondary care
- Rehabilitation unit
- Hospice
- Regional centre
- Specialist services
- Third sector
- Other _____

4. How long have you been in your current speciality for?

- 0-5 years
- 6-10 years
- More than 10 years

About your service

1. What proportion of the people that you usually care for have a rare neurological condition (Ataxias, e.g. Friedreich's ataxia, hereditary spastic paraparesis, Huntington's disease, neuromuscular diseases (e.g. polyneuropathies, myasthenia and muscular dystrophies), motor neurone disease, atypical Parkinsonisms)?

- Up to 25%
- Up to 50%
- Up to 75%
- Up to 100%
- I do not care for people with rare neurological conditions [closes survey]

2. Which rare neurological conditions do you work with (select all that apply)

- Atypical Parkinson's (MSA, PSP, CBD)
- Ataxia
- MND
- HSP
- Neuromuscular Diseases (muscle disease, e.g. muscular dystrophy, MG; peripheral nerve disease; mitochondrial disease)
- Huntington's Disease
- Other _____

3.? How frequently do you care for patients with rare neurological condition

- Frequently (at least once per week)
- Occasionally (at least once per month)
- Infrequently (less than once per month)

4. How frequently do you or your team follow up people with rare neurological diseases?

- Six monthly
- Yearly
- Greater than 1 year
- Open access or self-referral
- Discharged after a period of treatment/rehabilitation & will require re-referral Discharge after a period of input
- Other _____

5. Please, tick the option on the table (ranging from strongly disagree to I don't know) that most suits you for each item:

	Strongly disagree	Disagree	Neither disagree or agree	Agree	Strongly agree	I don't know
a. The service I work in has the required expertise needed to support people with rare neurological diseases to be physically active						
b. The service I work in is appropriately resourced to support people with rare neurological disease to be physically active (e.g. enough staff, equipment)						
c. The service I work in is responsive and can see people with rare neurological conditions quickly if needed						

Physical activity support

1. Do you give advice regarding physical activity to your patients with rare neurological conditions?

- Yes, routinely to most of my patients
- Yes, only if they request information regarding physical activity
- Yes, only to patients that I think would benefit from physical activity
- Yes, but only with certain conditions
- No, I do not recommend or give advice about physical activity to my patients

1a. To help us understand your answer, please, let us know when you are more likely to provide advice to your patients with rare neurological conditions (please tick the option that most suits you for each item):

	Strongly disagree	Disagree	Neither disagree or agree	Agree	Strongly agree	I don't know
a. They are older						
b. They are younger						
c. They appear 'fit' and able to undertake physical activity						
d. They are deconditioned or frail						

e. They have comorbidities that I believe could be minimised through regular physical activity						
f. They are fatigued						

SELECTION IS NOT COMPULSORY

1b. Who do you think should be giving advice on physical activity? (please tick all that apply)

- Medical doctor
- Advanced Clinical Practitioner (Advanced Nurse Practitioner)
- Clinical Nurse Specialist
- Inpatient/ward Nurse
- Outpatient/day care Nurse
- Allied Health Professional [Please specify _____]
- Exercise instructor or exercise physiologist
- Pharmacist
- Support worker/unregistered health care worker
- Other _____

2. Can you estimate to what percentage of your patients with rare neurological conditions you give advice about physical activity?

- 0-25%
- 26-50%
- 51-75%
- >75%

3. What interventions do you use to support people to be physically active? Tick all that apply

- Structured exercise programme
- Setting goals around physical activity
- Supporting/facilitating new activities in the community
- Supply education materials
- Signposting to online resources
- Signposting to community exercise initiatives
- Run exercise classes
- Educate carers and exercise professionals to support the person
- Set up activities at home
- Other, give details _____

4. How do you monitor how active your patients are? Tick all that apply

- I don't monitor their activity, but I think it is important
- I don't believe monitoring is necessary
- Monitoring using online applications (Apps)
- Monitoring using activity monitors
- Monitoring using diaries
- Monitoring using patient feedback

Other, give details _____

5. Please, tick the option (ranging from strongly disagree to I don't know) that most suits you for each item:

	Strongly disagree	Disagree	Neither disagree or agree	Agree	Strongly agree	I don't know
a. Patients with rare neurological conditions should be encouraged to be physically active						
b. There is a lack of evidence for health professionals to promote exercise to patients with rare neurological conditions						
c. I am sufficiently trained to give advice and/or support to people with rare neurological conditions						
d. I am confident that I can advise and/or support people with rare neurological conditions to be physically active						
e. I know where or who to refer with people with rare neurological conditions who require support to become more physically active						

6. Do you experience any challenges or barriers to supporting people with rare neurological conditions to be physically active? E.g. aspects of the disease, constraints of service etc.

- Yes (If yes, please provide some examples below)
 No

7. If you have supported people with rare neurological conditions to be physically active, what outcomes have you observed? Please give examples of positive or negative outcomes.

8. What factors have you found to facilitate engagement in physical activity in people with rare neurological conditions? Please describe in the box below:

9. Where do you go to seek more information on physical activity and exercise for people with rare neurological diseases? Tick all that apply.

- Peer reviewed articles
 Systematic reviews
 Charity websites and publications
 Online resources
 Guidelines
 Colleagues
 Courses and conferences

Other, give details _____

END OF THE SURVEY
THANK YOU!

Glossary:

MSA = Multiple System Atrophy

PSP = Progressive Supranuclear Palsy

CBD = Cortico Basal Degeneration

MND = Motor Neurone Disease

HSP = Hereditary Spastic Paraplegia

MG = Myasthenia Gravis

Accepted version 23.06.2023

Supplement 3:

Summary tables of survey results

Survey results tables for people living with a rare neurological condition:

Of 234 individuals with RNCs participating in the survey, two did not provide their consent at the beginning of the survey and were excluded. Five participants that did not provide the name of the condition living with, and one had a condition not included in the inclusion criteria (i.e. Brown-Sequard syndrome) were also excluded. One participant with HD filled the survey twice, therefore one set of data was excluded from the analysis. Data provided from 225 participants were analysed. Demographic characteristics are outlined in Table S1

Table S1. Participant demographics

GENDER (N)	AGE (Mean ± SD)	REGION (N)	ETHNICITY (N)	CONDITION (N)	AGE OF DIAGNOSIS (N)
Females = 122	57.2 ± 14.4	South East England = 46	Asian = 3	Ataxia = 60	At birth = 3
Males = 97	Missing = 7	South West England = 27	Black = 0	HSP = 32	1 year = 2
Prefer not to say = 1		Greater London = 14	Chinese = 1	HD = 4	1 ≥ 10 years = 14
Missing = 5		Wales = 11	Mixed = 2	NM = 89	11 ≥ 20 years = 30
		East Midlands = 22	White = 218	MND = 17	21 ≥ 30 years = 30
		West Midlands = 15	Missing = 1	PSP = 15	31 ≥ 40 years = 30
		North East England = 7		MSA = 4	41 ≥ 50 years = 33
		North West England = 22		CBD = 4	51 ≥ 60 years = 30
		Scotland = 11			61 ≥ 70 years = 27
		Northern Ireland = 5			≥ 71 years = 10
		East of England = 19			Can't remember = 10
		Yorkshire the Humber = 18			Missing = 6
		Missing = 8			

Table S2. Participant level of mobility

LEVEL OF MOBILITY (N)
1. Only walk with no assistance (or aid) as far as I need to = 25
2. Only walk with no assistance (or aid) but distance is limited = 28
3. Only walk with assistance (or aid) as far as I need to = 14
4. Only walk with assistance (or aid) but distance is limited = 76
5. Use a wheelchair always = 22
6. Only use a wheelchair sometimes = 11
7. Walk with both no assistance (limited distance) and assistance (or aid) as far as I need to = 3
8. Walk both with assistance (or aid), no assistance and sometimes wheelchair, but distance is limited = 1
9. Walk with no assistance (limited distance) and sometimes wheelchair = 4
10. Walk with assistance (or aid) as far I need to, but sometimes distance is limited = 1
11. Walk with assistance (or aid) as far as I need to and sometimes use the wheelchair = 2
12. Walk with assistance (or aid) (limited distance) and sometimes with no assistance (limited distance) or wheelchair = 1
13. Walk with assistance (or aid) (limited distance) and sometimes wheelchair = 34
14. Missing = 3

Table S3. List of aids used

LIST OF AIDS
1. Only walk with the aid of orthotics, splints, braces or supports = 9
2. Only walk with 1 stick = 22
3. Only walk with 2 sticks = 0
4. Only walk with 1 elbow crutch = 1
5. Only walk with 2 elbow crutches = 2
6. Only walk with rollator frame = 4
7. Only walk with another person = 10
8. Only walk with a pushchair or buggy = 1
9. Only wheelchair that I propel with my hands = 1
10. Only electric scooter = 2
11. Only powered wheelchair = 8
12. Only wheelchair that someone else pushes = 2
13. Only functional Electrical Stimulation = 0
14. More than one aid = 133
15. I am unable to leave my bed = 0

16. I do not use any mobility aids = 30
17. Other types of mobility aids = electric bike, bike

Table S4. Physical activity

Do you participate in physical activity regularly?	Do you do physical activity independently
Yes = 170	Yes = 131
No = 24	No = 47
Sometimes = 26	Sometimes = 40
Missing = 3	Missing = 7

Table S5. Understanding experiences of physical activity

	Strongly disagree (N)	Disagree (N)	Neither disagree or agree (N)	Agree (N)	Strongly agree (N)	I don't know (N)	MISSING
I am interested in keeping physically active	7	1	11	54	148	0	4
I need to be encouraged to be physically active	44	56	34	60	25	2	4
I have enough knowledge on the benefits of physical	11	15	33	76	78	8	4

activity for my condition							
I have had the opportunity to discuss physical activity and its benefits with a health care professional	23	31	32	81	53	1	4
I'm able to follow the advice about physical activity/exercise from health care professionals	9	20	40	79	63	10	4
I am confident about how to be physically active successfully	13	31	30	83	58	6	4
I am confident about how to be physically active safely	12	30	43	70	62	4	4
I feel I have enough resources (e.g. support, equipment) to be able to be physically active	18	45	42	64	47	5	4
I can easily access exercise facilities	27	58	39	53	40	4	4
I know where to seek support to be physically active if I need to	29	40	57	50	39	6	4
I can access support quickly to be physically active	36	60	53	35	27	10	4
I feel well supported by my community services to be physically active	47	65	44	28	26	11	4

Table S6. Support

Is the support you receive to be physically active usually from:
General practitioner = 1
Local neurologist = 2
Local therapists e.g. physiotherapy or occupational therapist = 28
Local nurse = 0

Local exercise trainers = 9
Specialist neurologist = 3
Specialist therapists e.g. physiotherapy occupational therapist = 25
Specialist nurse = 2
I have not received any type of support = 67
Missing = 4
More than one resource: 83
Other resources: family, friends, staff at council leisure centre, myself, caregiver, wife, private physio, spouse, carer, partner, private Pilates instructor, cardiologist, son

Table S7. Sources to gather information on physical activity

Where do you seek information on PA	
Web pages	28
Community initiatives	0
Peers	10
Health care specialists	29
Gym and exercise trainers	10
Charity website and publications	4
Research reports	0
Guidelines e.g. NHS guidelines	4
Courses and conferences	1
None	26 (said none/myself/nothing is available)
Other (previous knowledge)	2
2 or more resources	106
Missing	5

Table S8. Challenges in doing physical activity

Do you experience challenges in doing PA?	
Yes	197
No	25

Missing	3
---------	---

Table S9. Financial resources

Where do you access financial resources?	
Only NHS	6
Only Charities	0
Only Local funding schemes	4
Only Self-funded e.g. private group class	76
I don't need financial support to engage in physical activity	91
Only Other sources (DLA/ESA = 1, Police treatment centre = 1, PIP = 4, benefits = 1)	5
More than one source	13
Don't need financial support and self-funded	3
Don't need financial support + NHS	1
Other responses: Can't have access to communal fit	1
Not aware	3
Chore	1
Did not ask/no support	16
Missing	5

Table S10. Means to monitor physical activity

How do you monitor physical activity:	
Don't monitor my activity but I think it is important	116
Don't monitor my activity but I think it is important + I monitor using online applications	1
Don't monitor my activity but I think it is important + use smart watches	3
Don't monitor my activity but I think it is important + monitored by health care professionals	4
Don't monitor my activity but I think it is important and I don't believe monitoring is important	4
Don't monitor my activity but I think it is important + monitor using diaries log books or attendance records	1
I _don't believe monitoring is necessary	22
I _don't believe monitoring is necessary + monitoring using online applications and/or health care professionals	2
Monitoring using online applications Apps	1
Only smart watches and step counters e.g. Fitbits	29

I am only monitored by health care professionals	6
Monitoring using diaries log books or attendance records	9
Other (timer on exercise bike = 1, Wife = 1, Self-monitored supported by staff at the Gym = 2)	4
More than one types of monitoring (including myself)	17
Missing	6

Accepted version 23.06.2023

Survey results for carers of people living with a rare neurological condition:

Of 101 carers or family members participating in the survey, two did not provide their consent at the beginning of the survey and were excluded. Four participants that did not provide the name of the condition of the persons they cared for were also excluded. One person was excluded as was not a carer or family member/friend looking after a person with RNC (i.e. a instructor in PA). Data provided from 94 participants were analysed. Demographic characteristics are outlined in Table S11.

Table S11. Participant demographics

Relationship with the person living with RNC	Gender	Age	Region (N)	Ethnicity (N)
Spouse or partner = 41	Female = 78	Mean \pm SD = 52.2 \pm 12.6	South East England = 14	Asian = 1
Parent = 29	Male = 12	Prefer not to say = 2	South West England = 7	Black = 0
Parent and paid carer = 1	Prefer not to say = 1	Missing = 6	Greater London = 3	Chinese = 0
Friend = 0	Missing = 4		Wales = 9	Mixed = 0
Paid carer = 1			East Midlands = 5	White = 91
Family member = 22			West Midlands = 11	Prefer not to say = 1
Missing = 0			North East England = 3	Missing = 1
			North West England = 16	
			Scotland = 7	
			Northern Ireland = 2	
			East of England = 5	
			Yorkshire the Humber = 7	
			Missing = 5	

Table S12. Types of conditions and age of diagnosis of the person living with RNC

Condition of the person with RNC (N)	Age at diagnosis of the person living with RNC (N)
Ataxia = 22	At birth = 2
HSP = 9	0-1 year = 2
HD = 10	1 ≥ 10 years = 15
NM = 16	11 ≥ 20 years = 8
MND = 7	21 ≥ 30 years = 8
PSP = 26	31 ≥ 40 years = 3
MSA = 0	41 ≥ 50 years = 8
CBD = 3	51 ≥ 60 years = 18
Unsure between PSP or MSA = 1	61 ≥ 70 years = 14
	≥ 71 years = 7
	Can't remember = 3
	Missing = 6

Table S13. Level of mobility of the person living with RNC

LEVEL OF MOBILITY (N)
15. Walks with no assistance (or aid) as far as he/she/they need to = 7
16. Walks with no assistance (or aid), but distance is limited = 7
17. Only walks with no assistance (or aid) but distance is limited and he/she/they use wheelchair sometimes = 3
18. Walks with assistance (or aid) as far as he/she/they need to = 3
19. Walks with assistance (or aid), but distance is limited = 15
20. Uses a wheelchair always = 25
21. Uses a wheelchair sometimes = 9
22. Walks with assistance (or aid) (limited distance) and wheelchair = 17
23. Bed bound or no mobility = 5
24. Walks both with assistance (or aid) and sometimes with no assistance = 1
25. Missing = 2

Table S14. List of aids used

LIST OF AIDS
18. Only walks with the aid of orthotics, splints, braces or supports = 1
19. Only walks with 1 stick = 3
20. Only walks with 2 sticks = 1
21. Only walks with 1 elbow crutch = 1
22. Only walks with 2 elbow crutches = 0
23. Only walks with rollator frame = 0
24. Only walks with another person = 7
25. Only walks with a pushchair or buggy = 0
26. Only uses a wheelchair that he/she/they propel with hands = 0

27. Only electric scooter = 0
28. Only powered wheelchair = 7
29. Only wheelchair that someone else pushes = 15
30. Only functional Electrical Stimulation = 0
31. More than one aid = 47
32. He/she/they are unable to leave his/her/their bed = 4
33. He/she/they do not use any mobility aids = 8
34. Missing =1

Table S15. Physical activity

Does the person you care for participate in physical activity regularly?	Does the person you care for do physical activity independently?
Yes = 50	Yes = 17
No = 35	No = 54
Sometimes = 8	Sometimes = 18
Missing = 1	Responded only with an open answer = 4
	Missing = 1

Table S16. Understanding the experience of physical activity

	Strongly disagree (N)	Disagree (N)	Neither disagree or agree (N)	Agree (N)	Strongly agree (N)	I don't know (N)	MISSING
He/she/they are not interested in being physically active	29	27	12	10	11	1	4
I need to encourage the person I care for to be physically active	13	16	13	34	12	2	4
I have enough knowledge on the benefits of physical activity for the person I care for	3	9	13	31	32	2	4
I have had the opportunity to discuss physical activity and its benefits with a health care professional	7	11	24	30	18	0	4
I'm able to follow the advice about physical activity/exercise from health care professionals	6	10	21	36	16	1	4
I am confident about how to support the person I care for to be	7	18	18	29	17	1	4

physically active successfully							
I know how to support the person I care for to be physically active safely	6	21	15	28	20	0	4
I feel I have enough resources (e.g. knowledge, equipment, access to facilities, time) to be able to support the person I care for to be physically active	21	23	10	28	6	2	4
The person I care for can easily access exercise facilities	26	31	10	16	7	0	4
I know where to seek support if I need to, in order to help the person I care for to be physically active	17	16	16	34	6	1	4
I can access support quickly if I need to, in order to be able to help/assist the person I care for to be physically active	22	22	21	18	5	2	4
I feel well supported by community services to be able to help/assist the person I care for to be physically active	18	35	15	18	4	0	4
I have enough time to support the person I care for to be physically active	18	34	11	21	5	1	4

Table S17. Support

Is the support you receive to help/assist the person you care for to be physically active usually from :
Only general practitioner = 1
Only local neurologist = 3
Only local therapists e.g. physiotherapy or occupational therapist = 22
Only local nurse = 0
Only local exercise trainers = 3
Specialist neurologist = 3
Specialist therapists e.g. physiotherapy occupational therapist = 5

Specialist nurse = 3
I have not received any type of support = 24
More than one resource = 19
Other resources: carer (N = 3), PE teacher (N = 1), charity (N =1), care team (N =1), community group (N = 1), friends (N = 1)
Missing = 3

Table S18. Sources to gather information on physical activity

Where do you go to seek more information on physical activity and exercise for the person you care for?	
Web pages	12
Community initiatives	3
Peers	2
Health care specialists	18
Gym and exercise trainers	4
Charity website and publications	4
Research reports	0
Guidelines e.g. NHS guidelines	0
Courses and conferences	2
None	2
Other	3 (support groups = 2, in-house physiotherapy = 1)
No looked for information	3
2 or more resources	34
Missing	7

Table S19. Challenges in doing physical activity

Do you experience challenges or difficulties in supporting the person you care for to be physically active?	
Yes	72
No	20
Missing	2

Table S20. Financial resources

Where do you access financial resources to help to cover the costs to support the person you care for to be physically active?	
Only NHS	5
Only Charities	3
Only Local funding schemes	0
Only Self-funded e.g. private group class	31
I don't need financial support to engage in physical activity	17

I don't need financial support to engage in physical activity and self-funded	1
More than one source	10
Other sources	4 (NDIS = 1, PIP, ESA, DLA = 2, care team = 1)
Not aware	1
No support/did not ask for financial support	8
Missing	14

Table S21. Means to monitor physical activity

How do you monitor how active is the person you care for? Select all that apply	
Don't monitor my activity but I think it is important	37
I don't believe monitoring is necessary	9
Only monitoring using online applications Apps	0
Only smart watches and step counters e.g. Fitbits	4
I am only monitored by health care professionals	10
Only monitoring using diaries log books or attendance records	4
Other	self-monitored = 3
Don't monitor as the person with RNC is not physically active	2
Restrained for safety	1
More than one type of monitoring (including myself)	15
None	2
Not aware of physical activity monitoring	1
Missing	6

Survey results for health care professionals

One hundred twenty healthcare professionals participated in the survey of which two did not care for people with RNCs and, one did not complete the survey. Data provided from 117 participants were analysed. Participant professional characteristics are outlined in Table S21

Table S22. Participant professional characteristics

What is your profession?	Where do you work?	What setting do you work in?	How long have you been in your current speciality?
Medical doctor = 1	South East England = 18	Primary care = 4	0-5 years = 32
Neurologist = 1	South West England = 15	Community team = 41	6-10 years = 25
Physiotherapist = 74	Greater London = 24	Secondary care = 8	More than 10 years = 60
Occupational therapist = 24	Wales = 3	Rehabilitation unit = 5	
Nurse = 13	East Midlands = 7	Hospice/care home = 4	
Support worker/unregistered health care worker = 1	West Midlands = 8	Regional centre = 5	
Speech & language therapists = 3	North East England = 6	Specialist services = 15	
Missing = 0	North West England = 16	Third sector = 2	
	Scotland = 7	Other = private practice (N = 6), tertiary specialist centre (N = 1), neurological care centre (N = 1)	
	Northern Ireland = 1	More than one sector = 25	
	East of England = 8	Missing = 0	
	Yorkshire the Humber = 4		
	Missing = 0		

Table S23. Caseload of people living with RNC

What proportion of the people that you usually care for have a rare neurological condition	Which rare neurological conditions do you work with?
Up to 25% = 69	Only Ataxia = 0
Up to 50% = 22	Only HSP = 0
Up to 75% = 9	Only Huntington's Disease = 3
Up to 100% = 17	Only Neuromuscular disease (e.g. myasthenia gravis, muscular dystrophy, myositis, polyneuropathies, mitochondrial disease) = 4
Missing = 0	Only MND = 3
	Atypical Parkinson's (MSA, PSP, CBD) = 3
	More than one condition = 104

Table S24. Frequency of sessions with people living with RNC

How frequently do you care for patients with rare neurological conditions?	How frequently do you or your team follow up people with rare neurological conditions?
Frequently (at least once per week) = 73	Six monthly = 13
Occasionally (at least once per month) = 31	Yearly = 7
Infrequently (less than once per month) = 13	Greater than 1 year = 0
Missing = 0	Open access or self-referral = 37
	Discharged after a period of treatment/rehabilitation & will require re-referral after a period of input = 28
	Other = 32 (provision of end of life care, no discharge, initial referral and then subject to self-referral, weekly to six monthly, depends on individual needs, weekly, varies on needs
	Missing = 0

Table S25. Service support for people living with RNC

	Strongly disagree (N)	Disagree (N)	Neither disagree or agree (N)	Agree (N)	Strongly agree (N)	I don't know (N)	MISSING
The service I work in has the required expertise to support people with rare neurological diseases to be physically active	3	6	10	56	42	0	0
The service I work in is appropriately resourced to support people with rare neurological disease to be physically active (e.g. enough staff, equipment)	12	33	26	36	10	0	0
The service I work in is responsive and can see or contact people with rare neurological conditions quickly if needed	3	11	17	47	39	0	0

Table S26. Physical activity support for people living with RNC

Do you give advice regarding physical activity to your patients with rare neurological conditions?	Who do you think should be giving advice on physical activity?	Can you estimate to what percentage of your patients with rare neurological conditions you give advice about physical activity?
Yes, routinely to most of my patients = 91	Only medical doctor = 0	0-25% = 9
Yes, only if they request information regarding physical activity = 9	Only physiotherapist = 4	26-50% = 13
Yes, only to patients that I think would benefit from physical activity = 10	Only nurse = 0	51-75% = 26

Yes, but only with certain conditions = 5	Only occupational therapist = 0	>75% = 69
No, I do not recommend or give advice about physical activity to my patients = 2	Only exercise instructor or exercise physiologist = 0	
	Only support worker/unregistered health care worker = 0	
	More than one profession = 110	
	Other = MDT (N = 1), any member of the team (N = 1), not specified (N =1)	

Table S27. Sources to gather information on physical activity

What interventions do you use to support people to be physically active?	How do you monitor how active your patients are?
Only structured exercise programme = 0	I don't monitor their activity, but I think it is important = 21
Only setting goals around physical activity = 1	I don't believe monitoring is necessary = 1
Only supporting/facilitating new activities in the community = 0	Only monitoring using online applications (Apps) = 0
Only supply education materials = 0	Smart-watches and step counters (e.g. Fitbits) = 0
Only signposting to online resources = 0	Monitoring using diaries, log books or attendance records = 2
Only signposting to community exercise initiatives = 1	Monitoring using patient feedback = 39
Only run exercise classes = 0	Other = 5 (outcome measures/functional scales N = 2, patient health record N =1, research accelerometers N =1, feedback from colleagues N =1)
Only Educate carers and exercise professionals to support the person = 0	Don't monitor as other discipline would do = 1
Only set up activities at home = 0	More than one monitoring tool = 48
Other = suggest to be active (N = 1), individualised support (N = 1), referral to OT or Physiotherapist (N =1), not specified (N = 1)	
More than one intervention = 111	

*some participants said did not monitor but used different tools, I ticked off "I don't monitor" N = 7

Table S28. Evidence and training for physical activity

	Strongly disagree (N)	Disagree (N)	Neither disagree or agree (N)	Agree (N)	Strongly agree (N)	I don't know (N)	MISSING
Patients with rare neurological conditions should be encouraged to be physically active	4	1	5	26	81	0	0
There is a lack of evidence for health professionals to promote exercise to patients with rare neurological conditions	5	30	37	31	10	4	0
I am sufficiently trained to give advice and/or support to people with rare neurological conditions	1	9	18	66	23	0	0
I am confident that I can advise and/or support people with rare neurological conditions to be physically active	0	5	12	69	30	1	0
If a person with a rare neurological condition requires support to be more physically active, I know where and/or who to refer to	0	11	18	56	32	0	0

Table S29. Challenges and signposting

Do you experience any challenges or barriers to supporting people with rare neurological conditions to be physically active?	Where do you go to seek more information on physical activity and exercise for people with rare neurological diseases?
Yes = 108	Only peer reviewed articles = 0
No = 9	Only systematic reviews = 0
	Only charity websites and publications = 0
	Only online resources = 0
	Only guidelines = 1
	Only colleagues = 0
	Only courses and conferences = 1
	Other = refer to other services (N = 1)
	Two resources = 6
	Three or more resources = 108