Participant Information Sheet, surveys with Individuals with a progressive neurological condition

PARTICIPANT INFORMATION SHEET

20/01/2025, V.3,
Reference code [PLWPNC Survey]

"Promoting and supporting participation and social connectedness for people with progressive neurological conditions to reduce loneliness and isolation: empowering local communities through coordination of social care, local community support, and digital technology."

You are being invited to take part in a research project. Before you decide whether to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others, if you wish.

Thank you for reading this.

1. What is the purpose of this research project?

Many people with progressive neurological conditions experience difficulties in joining in with activities, which can lead to feeling isolated, lonely, or disconnected from others. Through conversations with people living with these conditions, we learned that these feelings often come from challenges like dealing with symptoms, fear of going out, negative experiences with others, stigma, or not knowing how or where to find support.

When people take part in fewer activities, it can lead to both physical and mental health problems, potentially making conditions worse over time. This research aims to explore, through surveys, how people with progressive neurological conditions are supported to join in community activities and stay connected with others. It will also look at topics such as what support is currently available, the barriers to getting involved, and how technology could help people connect with others and feel less isolated.

2. Why have I been invited to take part?

You have been invited to take part because you meet the following criteria for participation in this study:

Age: You are aged 18 or older.
Diagnosis: You are living with a progressive neurological condition. Progressive neurological conditions include, but are not limited to, multiple sclerosis, Parkinson's, ataxia, dystonia, motor neuron disease, and Huntington's.
Geographical Location: You are currently residing in Wales.
Language: You are able to understand and communicate in English, as the survey will be conducted in English.
Capacity to Consent: You are able to provide informed consent.

NOTE:
This study excludes individuals with a primary diagnosis of Dementia or Alzheimer's.
If you have a progressive neurological condition **and** have a secondary diagnosis, such as dementia, you can still take part in this study as long as you have the capacity to provide informed consent.

This study does not include individuals with non-progressive neurological conditions, such as cerebral palsy, stroke, traumatic brain injury, or epilepsy.

3. Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether to take part. If you decide to take part, you will have to complete a consent form on the following page for the survey. If you decide not to take part, you can exit off this survey and you do not have to explain your reasons.

You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form.

If you choose to withdraw from the study when undertaking the survey, any partially completed survey data will not be included in the analysis and will be securely deleted. ***If you have completed the survey in full, please contact the student researcher via email (trotmanh@cardiff.ac.uk) as soon as possible before May 2025 if you wish to withdraw your responses. After data this date, data will be anonymised, and it will not be possible to remove your data.*** *Similarly, if you find you want to withdraw your participation after publication of results, this will also not be possible as data will be fully anonymised and not traceable.*

4. What will taking part involve?

You are being invited to complete a one-time online survey, which will take approximately 15–25 minutes to complete. The survey includes questions about the types of support you receive, the challenges you face in staying socially connected, and your views on how support and opportunities for social participation could be improved. The survey is designed to be straightforward and can be completed at a time that is convenient for you.

If you need assistance completing the survey, your primary caregiver, a family member, or a friend may help you by filling it out on your behalf. However, it is important that the survey is completed as if the responses are coming from you. If someone is helping you complete this survey, please ensure this is noted by marking the appropriate box in the demographics section of the survey.

Once you have submitted your survey, responses will be anonymised by the student researcher, ensuring no personal identifying information is linked to the data. If you wish to withdraw your responses after completing the survey, please contact the student researcher as soon as possible, and no later than May 2025. After this point, data will be fully anonymised, making it impossible to trace or remove specific responses.

At the end of the survey, you will have the option to indicate whether you would be willing to participate in a follow-up interview to discuss your responses in more depth. Participation in the follow-up is entirely voluntary, if you do not wish to participate you can indicate this by clicking ‘no’ and you will not need to do anything further. If you choose ‘yes’ you will be shown a link to a Microsoft Form where you will be provided with the participant information sheet. You can register your interest by inputting your email address and selecting preferred mode of participation.

If you would prefer to complete the survey over the phone or by post, please contact the student researcher at TrotmanH@Cardiff.ac.uk to make arrangements.

5. Will I be paid for taking part?

No. You should understand that any data you give will be as a gift and you will not benefit financially in the future should this research project lead to the development of a new treatment/method/test/assessment.

6. What are the possible benefits of taking part?

There will be no direct advantages or benefits to you from taking part, but your contribution will help us understand what people with different progressive neurological conditions need and would like to enable participation in activities, what is currently being provided, and ultimately lead to the development of recommendations and an intervention to implement and evaluate across Wales in a further funded study.

7. What are the possible risks of taking part?

The nature of the surveys should not cause any physical, emotional, or psychological harm or distress. However, if you find that certain topics cause discomfort, you can withdraw from the survey at any time.

8. Will my taking part in this research project be kept confidential?

All information gathered from or about you during this research project will remain confidential, and any personal details you provide will be handled in compliance with data protection laws. Any data relating to you will be anonymised, and no questions requiring identifiable responses will be asked. If any identifiable information is shared, it will be replaced with a pseudonym or de-identified phrase in any subsequent reporting. For more details, please refer to the section below, titled ‘What will happen to my Personal Data?’.

If you choose to withdraw from the study when undertaking the survey, any partially completed survey data will not be included in the analysis and will be securely deleted. Please contact the student researcher before May 2025 if you wish to withdraw your responses if you have completed the survey in full, as after data is anonymised it will not be possible to remove your data.

9. What will happen to my Personal Data?

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University’s Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner’s Office

may be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

After data collection has ceased (May 2025) the research team will anonymise all the personal data it has collected from, or about, you in connection with this research project, with the exception of your consent form. Your consent form will be retained for five years and may be accessed by members of the research team members of the University's governance and audit teams or by regulatory authorities if necessary. Anonymised information will be kept for a minimum of five years but may be published in support of the research project and/or retained indefinitely, where it is likely to have continuing value for research purposes.

You have the right to withdraw from the research project at any time without giving a reason. If you choose to withdraw, any personal data collected up until the point of withdrawal will be securely deleted and will not be used in the research analysis. However, please note that it may not be possible to withdraw any anonymised data that has already been included in published results or where identifiers have been irreversibly removed. This process will take place after May 2025, so you are encouraged to contact the student researcher via email (TrotmanH@Cardff.ac.uk) as soon as possible if you wish to withdraw your data. Once your data has been anonymised, meaning all personal identifiers have been removed, it cannot be linked back to you and therefore cannot be withdrawn from the research.

If you email the researcher to request an alternative survey format, your email address will be stored securely on their university password protected account. This information will only be used to arrange your participation, such as sending surveys and confirming receipt of the alternative format. Once your request has been fulfilled, and the study is completed (May 2025), your email address will be securely deleted. All personal information will be handled in line with data protection regulations to ensure your privacy and confidentiality.

10. What happens to the data at the end of the research project?

Upon completion of the research project, the data collected will be handled with the utmost care and in compliance with data protection regulations, ensuring confidentiality and participant privacy. All personal identifiers will be removed from the data before any sharing or dissemination occurs, safeguarding the anonymity of the participants involved in the study.

The anonymised data will be securely stored within the student researchers Cardiff University One Drive account, to ensure restricted access. In addition, the study findings will be shared through academic publications. The research data will not be made publicly available in open-access repositories due to the sensitivity of the subject matter and to protect the confidentiality of participants.

All steps will be taken to assure that personal data will be fully anonymised before any data is shared or published. No identifying information will be included in any future dissemination of the research findings.

11. What will happen to the results of the research project?

It is our intention to publish the results of this research project in academic journals and present findings at conferences. Participants will not be identified in any report, publication or presentation. Whilst verbatim quotes may be used in the write up of this project, these will not include any personally identifiable information such as location of residence, name, age, or occupation. Each participant will be given a de-identifiable data code, which will only be accessible by the student researcher. Following publication of the results, the deidentified data code linking you to your answers will be deleted, further anonymising results.

12. What if there is a problem?

If you wish to complain or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact the student researcher's lead supervisor Dr Katy Hamana, (HamanaK@Cardiff.ac.uk). If your complaint is not managed to your satisfaction, please contact Dr Jennifer Davies, Chair of the School of Healthcare Sciences Research Ethics Committee: Email DaviesJ@cardiff.ac.uk; Telephone 0290 688581.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

13. Who is organising and funding this research project?

The research is currently funded by Health and Care Research Wales under their 2023 Studentship award for social care research. Cardiff University is the sponsor of this work, which will be submitted as part of a PhD at Cardiff University.

14. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the School of Healthcare Science Research Ethics Committee, Cardiff University.

15. Further information and contact details

Should you have any questions relating to this research project, you may contact us during normal working hours:

Hannah Trotman (PhD student)
Trotmanh@cardiff.ac.uk

Dr Katy Hamana (Lead supervisor)
02920687841
HamanaK@Cardiff.ac.uk

Thank you for considering taking part in this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and a signed consent form to keep for your records.