

Participant Information Sheet

Title of project

A qualitative assessment of transition experiences from different perspectives: individuals with a neurological condition, significant others and Health and Social Care professionals

University of Dundee School Research Ethics Committee Approval Number: E2020-144

You are being invited to take part in a research project about your experiences of transitions as an adult with a neurological condition. Before you decide whether you would like to participate it is important that you read the information provided below. This will help you to understand why and how the research is being carried out and what your participation will involve. Please contact the researcher by email (jane.green650@gmail.com) if anything is unclear or if you have any questions.

Who is conducting the research?

The research is being carried out by the following team: Principal Investigator: Professor Divya Jindal-Snape, School of Education and Social Work, University of Dundee. Contact: d.jindalsnape@dundee.ac.uk

Co-Investigators: Dr Jenny Preston, Douglas Grant Rehabilitation Centre, Irvine, Dr Jane Green, Cerebral Palsy Scotland, Glasgow, Stephanie Fraser, CEO Cerebral Palsy Scotland, Rebecca Williams, (Policy and Development Officer) ARC Scotland.

Who is funding the research?

This research is funded by the Scottish Government through the Neurological Care and Support in Scotland: A Framework for action 2020- 2025.

What is the purpose of the research?

The purpose of this research is to gather information from individuals with a neurological condition about their lived experiences of transitions (life changes). This could include for example, Children to Adult Services or Secondary to Further/ Higher Education or employment or socialising or relationships. This will help us to get a better understanding of how transitions processes work and the types of experiences that you have had.

Why have I been invited to take part?

We are inviting adults (18 years and older) with a neurological condition to take part.

Do I have to take part?

No. Participation in this project is entirely voluntary so choosing not to take part will not disadvantage you in any way. If you do choose to take part you may withdraw from participation in the project at any time without explanation and without any disadvantage to yourself. If you choose to withdraw from the project after you have participated you will be able to withdraw your data from the study prior to data analysis.

What will happen if I take part?

This project involves an interview with a researcher. Due to the COVID 19 restrictions the interviews will take place virtually (Microsoft Teams) or on the telephone. If COVID 19 restrictions allow and it is your preference face to face interviews may also be arranged. We will also arrange the use of assistive technology based on your communication preferences.

Each interview will be arranged at a time that is convenient to you. The interview will be between a researcher and a participant i.e. one to one. Each interview will last between 45-60 minutes.

In the interviews a short list of open questions will be used to explore your experiences of transition and the type of support you received. There will be an opportunity to discuss and share specific examples of your experiences and how they affected you.

All interviews will be audio-recorded and transcribed using a confidential transcription company. Everything you say within the interviews will be anonymised. When we disseminate our findings from the project we will ensure that personal anonymity is maintained.

Are there any risks in taking part?

There are no known risks associated with taking part in this study however you may find that recalling some of your experiences is upsetting. If this is the case, you can contact the Principle Investigator (Divya Jindal-Snape d.jindalsnape@dundee.ac.uk), or [your GP. Other organisations that may also be able to offer support are:](#)

Penumbra (supporting mental health and wellbeing) <http://www.penumbra.org.uk/>

Aberdeen (North area) 01224 642 854

Edinburgh (East area) 0131 221 9607

Glasgow (West area) 0141 229 2580

Neurological Alliance <https://www.neural.org.uk/> Tel: [01923 882 590](tel:01923882590)

What are the possible benefits of taking part?

It is possible that there will be no direct benefits to you for taking part in the project. However it is anticipated that understanding your experiences might help other people with neurological conditions in future. The data collected from this project will be used to inform the development of a national transitions framework which will help to support individuals with neurological conditions across the life span.

Will my taking part in this project be kept confidential?

Everything you say in the interview will be kept confidential. Only three research team members (Divya Jindal-Snape, Jenny Preston, Jane Green) will have access to your data. You will be allocated a unique identifier code and any data used in the project will be fully anonymised before being shared outside the University's secure cloud-based system called OneDrive.

What will happen to the information I provide?

All electronic data will be stored on an encrypted, password protected cloud-based University drive.

In order to facilitate the management and analysis of large volumes of qualitative data, computer-assisted qualitative data analysis software (CAQDAS, e.g. NVivo) will be used. Data will be stored for a restricted period, namely two years, to allow for the completion and/or publication of the study.

Results from the study will be disseminated through publications in journals; development of infographics for sharing on social media, comics, posters and conference presentations. All methods used for disseminating the results will be carefully anonymised.

Data Protection

The personal data that will be collected and processed in this study are your demographic information and your neurological condition or health care background, which will allow us to explore how geographic location or condition may have affected your experiences. Any information shared in this area will be grouped with other participants with similar characteristics and therefore will be unidentifiable as that of a specific participant.

The University asserts that it is lawful for it to process your personal data in this study as the processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller. The University of Dundee is the data controller for the personal data processed in this project.

The University respects your rights and preferences in relation to your data and if you wish to update, access, erase, or limit the use of your information, please let us know by emailing d.jindalsnape@dundee.ac.uk. Please note that some of your rights may be limited where personal data are processed for research, but we are happy to discuss that with you. If you wish to complain about the use of your information please contact the University's Data Protection Officer in the first instance (email: dataprotection@dundee.ac.uk). You may also wish to contact the Information Commissioner's Office (<https://ico.org.uk/>).

You can find more information about the ways that personal data are used at the University at: <https://www.dundee.ac.uk/information-governance/dataprotection/>.

Is there someone else I can complain to?

If you wish to complain about the way the research has been conducted please contact the Convener of the University Research Ethics Committee (<https://www.dundee.ac.uk/research/ethics/contacts/>).

For more information about this study, please contact Professor Divya Jindal-Snape d.jindalsnape@dundee.ac.uk in the first instance. Alternatively contact Dr Jenny Preston jenny.preston@aapct.scot.nhs.uk

Thank you for taking time to consider participating