

Loneliness and Social Isolation in Individuals with Neurodegenerative Diseases

Information Sheet

REC reference:

Chief Investigator: Prof Roger Barker

IRAS number:

You are being invited to take part in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. You can contact us through ms2709@cam.ac.uk or 01223 767379.

What is the purpose of the study?

The aim of this study is to learn about how individuals with neurodegenerative diseases such as Huntington's Disease, Progressive Supranuclear Palsy, Frontotemporal Dementia or Parkinson's Disease are affected by loneliness and social isolations.

Why have I been invited?

You have been invited because we believe that you have been diagnosed with one of the neurodegenerative diseases of interest. To take part, you must be aged over 18 and either a confirmed gene carrier of the Huntington's gene (with or without disease symptoms), or diagnosed with Progressive Supranuclear Palsy, or Frontotemporal Dementia, or Parkinson's Disease.

Alternatively, you have been invited as a healthy control, meaning that you have no diagnosis of any neurodegenerative disease. If you are a potential healthy control, we also ask only individuals to participate who are not carers to someone else.

Do I have to take part?

Participation is voluntary and you are free to withdraw at any time, without giving any reason and without your medical care or legal rights being affected. To withdraw, simply close your browser window with the questionnaire. Due to the data being anonymised it will not be possible to withdraw once the questionnaires have been submitted.

What will happen to me if I take part?

The study is online and will take about 20 minutes. Once you have consented to participating in this project you will be asked to answer 7 short questionnaires. The questionnaires will be about loneliness, social isolation, social functioning, daily functioning, and mood disturbances. It would be ideal if you could complete the questionnaires by yourself in a quiet area.

What are the possible disadvantages and risks of taking part?

There are no foreseeable discomforts, disadvantages and risks for taking part. However, the study will ask about feelings of loneliness, social isolation, low mood, and anxiety. If you do feel uncomfortable, please feel free to stop the study at any time.

What are the possible benefits of taking part?

There will be no direct benefits to you from participating in this study but the information we get from this study may help improve the understanding of loneliness and social isolation in individuals with neurodegenerative diseases in the future.

Will my taking part in the study be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. Participation will be fully anonymous, meaning no one will be able to connect individual participants to the data collected. The information collected during this study will be kept securely at the University of Cambridge. It will be treated in the strictest confidence, with Prof. Roger Barker acting as custodian. All data will be held in accordance with the Data Protection Act. Data will be kept for at least 15 years and possibly indefinitely in accordance with good research practice. Anonymous data may be sent to other academic collaborators within and outside of the UK.

What if there is a problem?

In the unlikely event that if you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay for it yourself. The normal National Health Service complaints mechanisms will still be available to you (if appropriate). Indemnity is also provided by University of Cambridge.

Cambridge University Hospitals NHS Foundation Trust, as a member of the NHS Clinical Negligence Scheme for Trusts, will accept full financial liability for harm caused to participants in the study caused through the negligence of its employees and honorary contract holders. There are no specific arrangements for compensation should a participant be harmed through participation in the study, but no-one has acted negligently. The University of Cambridge will arrange insurance for negligent harm caused as a result of protocol design and for non-negligent harm arising through participation in the study. If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (Professor Roger Barker 01223 331160 or Miriam Schaeppers 01223 331160). If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from the hospital. The Patient Advice and Liaison Services (PALS) can also be contacted on 01223 216 756.