Research Study Title:
Psychosocial factors and Impulse Control Disorders in Parkinson's disease.

Volunteers are needed to complete a series of short questionnaires, giving their views on how some aspects of Parkinson's have affected them. Participation should take no longer than 45 minutes and could help to improve the understanding of how the illness affects mood and impulsive behaviour. Before you decide to take part you need to understand why the research is being done and what would be involved for you. Please take your time to read the following information carefully and feel free to contact the researcher with your questions.

What is the purpose of the study?
We are trying to understand some of the symptoms relating to impulse control that can occur from either Parkinson's disease or medications. By asking people with Parkinson’s disease what they think about their illness, their day-to-day mood and experiences we hope to investigate this further. This study is being undertaken as part of a Doctorate in Clinical Psychology (DClinPsy) for Jack Garlovsky at the University of Sheffield.

Why have I been invited?
You have been invited because you have a diagnosis of Parkinson's disease.

Do I have to take part?
Your involvement in this study is entirely voluntary. Your medical care will not be affected. If you agree to take part you are free to withdraw at any time without giving any reason.

What will happen if I decide to take part?
You will be asked to complete several short questionnaires about your illness, mood and impulsivity. The questionnaires take approximately 45 minutes to complete. You can complete them at home (online or by post) or at the Royal Hallamshire Hospital when you attend an appointment. Assistance this can be provided with prior arrangement if required. You may also be asked to complete one of the questionnaires again after one month.

What are the possible disadvantages and risks of taking part?
There are minimal risks. However, thinking about your mood and illness may increase your awareness of your feelings. If you have any worries or concerns about your diagnosis or mood (which are not related to this study), we suggest you contact your GP or neurologist.
What are the possible benefits to taking part?
We cannot promise that this study will help you, but that the information we collect will help improve the understanding of problems associated with Parkinson’s disease.

What will happen if I don’t want to carry on with the study?
You may withdraw from the study at any time without giving any reason. If you decide to withdraw, any information that you have provided will be taken out of the study.

Will my taking part in this study be kept confidential?
All information collected about you will be kept strictly confidential. We will allocate you a study number so that your answers will be anonymous and stored separately to your contact details. Only members of the study team will view the information gathered. However, anonymised information may be used for publication or educational purposes in the future. All questionnaires will be stored securely and destroyed after 10 years.

Involvement of the General Practitioner/Family doctor (GP)
We will not contact your GP about taking part in this study. However, if you are a patient at the Royal Hallamshire Hospital we may request access your medical notes to obtain further information about your diagnosis and medication for your Parkinson’s disease with your permission. You can still take part in the research if you do not wish to grant access.

What will happen to the results of the study?
You will not be individually informed about the final results. You may request a summary from the researcher. The scientific results will be published in a peer-reviewed journal and used for educational purposes. All published information will be anonymous.

Who is organising and funding the research?
This study is being carried out by The University of Sheffield and is being supported by Sheffield Teaching Hospitals NHS Foundation Trust and Parkinson’s UK.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the North West - Lancaster Ethics Committee.

What if there is a problem?
In the first instance you should speak to the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can contact the Research Director at Sheffield Teaching Hospitals (Professor Simon Heller, Research and Development, 1st Floor, 11 Broomfield Road, Sheffield, S10 2SE, 0114 226 5938).

Researcher contact details
Jack Garlovsky, Trainee Clinical Psychologist, University of Sheffield
Dr Richard Grünewald, Consultant Neurologist, Sheffield Teaching Hospitals
Professor Paul Overton, University of Sheffield/Dr Jane Simpson, University of Lancaster

You can contact the researchers by telephone on 0114 2226650, email or post using the addresses above. Please say that you are calling about “Psychosocial factors and Impulse Control Disorders in Parkinson’s disease” and leave your contact details so that they can return your call as soon as possible.

Thank you for taking time to read this sheet and considering taking part.