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## **Participant Information Sheet**

### **Exploring people with Parkinson's disease views on physical activity**

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#### **We invite you to take part in this research study**

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- We would like to find out more about how people with Parkinson's disease experience physical activity. This would help us to develop strategies to support people to take part in regular physical activity, as this is beneficial for health and wellbeing.
- We are particularly keen to talk to people who do not perceive themselves to be physically active. We would take this to mean that you participate in no more than one physical activity per week.
- As a guide, by physical activity we mean any exercise (for example exercise groups or classes), or activity you do in your leisure time, such as walking, dancing or gardening.

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#### **Important information**

- Before you decide whether or not you wish to take part in this study, it is important for you to understand why the research is being done and what it will involve.

- Please take time to read the following information carefully. Discuss it with friends and relatives if you wish.
- You are free to decide whether or not you take part in this study. If you decide not to take part, this will not affect any care that you receive.
- Do ask me if there is anything that is not clear, or if you would like more information.

### **What is the purpose of the study?**

Physical activity has been shown to improve health and wellbeing in people with Parkinson's disease. But, many people do not take part in physical activity regularly. Previous research has mainly focused on the views of people who are active. Therefore we would like to understand this topic from the viewpoint of people with Parkinson's disease who do not describe themselves as physically active.

### **Who are we looking for?**

We are looking for participants with a diagnosis of Parkinson's disease who take part in no more than one physical activity a week. Physical activity may be an exercise programme, or a leisure time physical activity, for example walking, dancing or gardening. Participants will need to be willing to discuss their experiences of physical activity.

### **Are you suitable?**

The following criteria would **exclude** you from taking part in the study:

- Age less than 18 years
- Take part in physical activity **more** than once a week
- Unable to give written informed consent

### **Do I have to take part?**

No. There is no obligation for you to take part in this research study. If you are interested, the researcher will contact you to answer any questions that you may have and to check your eligibility to take part. You will be asked to sign a consent form. You are free to withdraw from the study at any time without giving a reason. This will not affect the care you receive.

### **What will I need to do if I take part?**

People who want to take part are invited to make contact with the researcher. The researcher will then contact you by telephone to discuss the study with you. If you are still interested, we will check that you are suitable for the study by asking some questions. If you are not suitable to participate, we will destroy any personal information that you have given us, but record the reason you were unable to participate anonymously. However, if eligible, you will also be asked about your Parkinson's symptoms, how long you have had Parkinson's disease and general details such as gender and age.

During this call a convenient location, date and time for a face to face interview will be arranged. On the agreed date and time, you will meet with the researcher to discuss your experiences of physical activity. The interview will normally last for about one hour with rest breaks as required. The interviews will take place between November 2018 and March 2019. The location of the interview will be your choice and it could be at your home or at the local support group setting if there is a suitable room.

The conversation will be audio recorded. The recording is strictly confidential and only the researcher and their supervisor will have access to the recordings. However, if you disclose information which may put yourself or anybody else at risk then the appropriate professionals will be informed.

### **What are the possible disadvantages and risks of taking part?**

There are no disadvantages or risks of taking part, however participants may become tired from talking, therefore you will be asked if you require a short break. You will be asked about your experiences and it is possible that you may find this upsetting. You do not have to explain anything you do not wish to and can stop the interview at any time.

### **What are the possible benefits of taking part?**

There will be no direct benefit to you for taking part in this research study. Your experiences may help health care professionals gain a greater understanding of people with Parkinson's disease. It may also help to provide ideas for future research.

### **What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions. Any complaint regarding the way you have been dealt with or, in the unlikely event you experienced distress; you can contact the researcher's supervisor. Their details can be found on the bottom of this information sheet.

If you wish to make a complaint about the conduct of the research then please contact the Research Administrator to the Ethics & Integrity Committee of the Faculty of Health and Human Sciences. Their details can be found at the bottom of this information sheet.

### **Will taking part be kept confidential?**

Our discussion will be audio recorded and transcribed. All recordings and documents will be locked in a cabinet that only the researcher has access to and all electronic data will be stored on the researcher's password protected laptop. The consent forms and your contact details will be locked separately from all other data. Only the researcher and their supervisor will have access to identifiable information.

All information will be anonymised and coded with no reference to be able to identify you as an individual. Quotations may be used in the final report and subsequent publications, however they will be anonymised and you will not be personally identifiable. Upon completion of the research study in 2019 all identifiable data will be anonymised, but we will keep all anonymised research data for 10 years according to the University's policies.

### **What if you change your mind about taking part in the study?**

If you decide that you no longer wish to take part in the study, you are free to withdraw at any point, without any explanation or repercussions. With your consent any information collected up until this point will still be used for analysis, however

you retain the right to decide whether that information can be used. You can withdraw your data up to one month after your interview.

### **What will happen to the results?**

If you wish, you will be sent a written summary of your interview to check for accuracy and to provide further comments. At the end of the research study the researcher intends to publish the findings. You will not be identifiable in any report or publication.

### **Who has reviewed this study?**

The research study has been approved by the Ethics & Integrity Committee of the Faculty of Health and Human Sciences.

### **If I want to take part, what do I do now?**

If you have questions about this study or have decided you would like to take part then please email or phone the researcher, Heather Hunter. Please leave a clear message with your name and contact details and Heather will be in contact with you.

### **Further information**

If you have any questions or concerns please contact the researcher:

Heather Hunter, University of Plymouth

Email: [heather.hunter@plymouth.ac.uk](mailto:heather.hunter@plymouth.ac.uk)

Tel: 01752 588842

Project Supervisor: Dr Hilary Gunn, University of Plymouth

Email: [hilary.gunn100@plymouth.ac.uk](mailto:hilary.gunn100@plymouth.ac.uk)

Tel: 01752 588825

**Please keep this information sheet for your records.**

**Thank you for considering taking part in this study.**

**If you wish to raise a concern to somebody outside the research team please contact:**

**Research Ethics Administrator (Maurice Bottomley)**

**Tel 01752 586992**

**Email [hhsethics@plymouth.ac.uk](mailto:hhsethics@plymouth.ac.uk)**