UNIVERSITY OF PLYMOUTH

Pilot: Factors associated with physical activity levels in people with Parkinson's

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Participant Information Sheet and Consent

Version2 24/03/22

Study Title: Factors affecting physical activity levels in people with Parkinson’s

Participant Information Sheet

Important information

- Before you decide whether or not you wish to take part in this survey, 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 survey. 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

Who am I and what is the purpose of the study?

My name is Heather Hunter and I am a researcher at the University of Plymouth with an interest in physical activity in people with Parkinson’s. I am undertaking this research as part of a programme of study for a Doctorate qualification.

People with Parkinson’s ability to undertake physical activity is varied and is influenced by a number factors. For example, support from family and friends, as well as, access to transport and local, affordable classes.

The aim of this research is to explore what affects people with Parkinson’s ability to undertake physical activity. For the purposes of the research study, this will involve answering questions about yourself (e.g. age, gender), how important physical activity is to you as a person, your ability to overcome obstacles to undertake physical activity, as well as how your Parkinson’s affects you. This knowledge will be useful to healthcare professionals and researchers working with people with Parkinson’s to inform future ways in which they might support people to be more physically active.

Who can participate in this research?

We are looking for people with a diagnosis of Parkinson’s who are living in the community (e.g. own home, retirement complex) and who would be willing to answer questions about what affects your ability to undertake physical activity. You will be asked to provide this information via an online survey and therefore would need to have access to a computer. Alternatively, you can request a paper copy of the survey to be sent to you.

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

- Age less than 18 years

What would taking part involve?

If you are interested, you will be asked whether you have read the information about the research at the beginning of the survey. You will then be asked to give your consent prior to completing the survey, which should take no longer than 20-30 minutes of your time.

Do I have to take part?

There is no obligation to participate but your assistance in this matter would be greatly appreciated.

What are the possible benefits of taking part?

There are no direct benefits to you for taking part. However, information collected will be used to develop a greater understanding of what influences physical activity behaviour in people with Parkinson’s. This knowledge will be useful to healthcare professionals and researchers working with people with Parkinson’s to inform future ways in which they might support people to be more physically active.

What are the possible disadvantages and risks of taking part?

It is not envisaged that there are any risks or disadvantages for you in taking part. However, completion of the survey will take 20-30 minutes of your time.

Do I have a right to withdraw?

As the survey does not ask for any identifiable data the results of the survey are anonymous. Therefore, once submitted it will not be possible to withdraw your consent, as your data will not be identifiable. However, if you change your mind during completion, you may choose not to submit the questionnaire responses and hence your information will not be used.

Will taking part be kept confidential?

All data that is collected will remain anonymous throughout and it will not be possible to identify you from your responses.

The Data Handler for the project is the University of Plymouth who is responsible for looking after information and using the information appropriately. All the information that is collected about you will be kept strictly confidential. As the survey does not ask for any identifiable information you will not be identifiable in any way. Therefore, it will be impossible to access or remove your data following submission of the survey. The University of Plymouth will keep the information for 10 years after the study has finished. Your data may be looked at by the research team or an audit team which is approved by the University. All data will be stored electronically on a secure web-based platform that is accessed via a password.

For more information regarding confidentiality you can access the research participant privacy notice for University of Plymouth https://www.plymouth.ac.uk/your-university/governance/information-governance/privacy-notices.

If you have any concerns about how your information will be used by the University or make a complaint about how you think your data is being used please contact the University's Data Protection Officer: dpo@plymouth.ac.uk

What if I have any concerns or wish to make a complaint?

If you have any concerns or are unhappy about the research or your participation in the research, please contact the researcher or researcher's supervisor. Contact details are provided below.

Alternatively, if you wish to raise a concern to somebody outside the research team please contact:

University of Plymouth Faculty of Health Research Ethics and Integrity Committee Administrator at: FOHEthics@plymouth.ac.uk

Who has reviewed this study?

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

What will happen to the result of the study?

The results of the study with contribute to the fulfilment of my Doctorate in Philosophy (PhD) and I intend to publish the findings. A lay summary of the results will be circulated via Parkinson's UK at the end of the study and this is likely to be at the end of 2022. Or you can contact me for a copy of the summary via the email address below.

Thank you for considering taking part in this research.

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