Participant Information Sheet for People with Parkinson’s

**Study Title:** The PD Life Study   
**Researcher name:** Dr Qian Yue Tan  
**ERGO number:** 62623

# Would you like to take part in a research study?

* We would like to invite you to complete a **survey** as part of a research study, the PD Life Study. Parkinson’s is sometimes also referred to as PD.
* To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve.
* Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research.
* You may like to discuss it with others, but it is up to you to decide whether or not to take part. The care you get from your doctor will not be affected whether you say yes or no.
* By completing and returning the survey, you are consenting to participate in this study.

# What is the research about?

We are interested in the effort and day-to-day tasks required to look after the overall health of people living with Parkinson’s. Some people will find it easy managing their health, but others may find it more difficult. Some people with Parkinson’s require help from their partner, family member or friends to look after their health. We sometimes refer to this person as a ‘caregiver’. If you have a caregiver, we would also like to invite this person to take part in the study as we are also interested in their experiences of helping to support and care for someone with Parkinson’s.

This research study is being conducted by Dr Qian Tan who is a physician training in Geriatric Medicine and a PhD candidate at the University of Southampton.

# Why have I been asked to participate?

You are invited to take part this study because **you have been diagnosed with Parkinson’s.** As a person living with Parkinson’s, we want to better understand your experiences of looking after your health.

# What does taking part in the study involve?

If you do agree to take part in this study, please complete the “**Living with Parkinson’s” survey** included in this study pack. You may also complete the survey online using the link provided. If you have a caregiver, they will also be invited to complete a **separate survey**. The survey has been designed to find out about your experiences of looking after your health with Parkinson’s.

The survey should take 20-30 minutes to complete. Please try to answer each question as best you can. You may ask for help from your friends or family to answer the questions. Once you have completed the survey, please return the survey using the pre-paid envelope included in this study pack.

# Are there any benefits with being in the study?

We cannot guarantee that you will receive any direct benefit from participating in the study. However, the results of the study will help us better understand how you look after your health with Parkinson’s. This may help us develop ways that could improve the future experiences of people living with Parkinson’s including yourself and your caregiver.

# Are there any risks involved?

Aside from giving up your time, there are no risks associated with taking part in the survey. It is possible that some questions in the survey may cause you distress, although this is unlikely. If this happens and you would like to speak to somebody, please contact a member of the research team (Dr Qian Tan on 07824 895 791; email [q.tan@soton.ac.uk](mailto:q.tan@soton.ac.uk)) who will be able to provide you with support. Alternatively, you can contact the Parkinson’s UK helpline (0808 800 303; [hello@parkinson’s.org.uk](mailto:hello@parkinson’s.org.uk)) or visit their website on parkinsons.org.uk for further support.

# Expenses and Payment

No expenses or payments are made for completing the survey. However, we appreciate your participation and thank you for your time.

# Do I have to take part?

No, it is completely up to you to decide whether or not to take part. If you decide to take part, please complete and return the survey using the freepost envelope. Declining to participate in this study or withdrawing from this study will not impact the standard of care you receive from your doctor.

# Does my caregiver and I have to participate in this study together?

No. Although having separate responses to the surveys from you and your caregiver will be helpful, you can decide to enter the study on your own even if they are unable to or do not want to. The responses to the surveys are considered in its own entirety.

# What data will be collected?

We will be collecting data about you such as your age, gender, relationships status, living situation, ethnicity, education level etc. We will also collect data about your health, your Parkinson’s and your well-being. This information is gathered so that we can ensure that we have included a diverse group of respondents.

# Will my information be kept confidential?

Yes, your participation and the information we collect from you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

All data collected from you will be anonymised. This means each participant will be given a code and we will remove any information that might identify you. Data will only be analysed after any personal information that could directly identify you is removed. When the results are analysed, your information will be used anonymously.

Information collected about you during this study will be stored on a password-protected computer or locked filing cabinet in a secure office in our research unit. This will only be accessible by the research team. Any personal data that may identify you such as your name and contact details will only be kept if you are happy for us to contact you in the future for a summary of the study results. This will be destroyed at the end of the study.

# Can I withdraw from the study once I have started?

You can withdraw your participation any time before you have submitted the survey. However, once you have submitted the survey, your responses cannot be withdrawn because they are anonymous and therefore, we will not be able to identify which survey is from you.

# What will happen with the results of the study?

The results of this study will be published in medical scientific journals. Research staff may also present the results at national and international conferences. You will not be identified in any report produced. If you would like, we will send you a summary of the study findings once the study is completed.

# What if there is a problem?

If you have a concern about any aspects of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk)).

# Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, ‘Personal data’ means any information that relates to and is capable of identifying a living individual. The University’s data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University’s policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason (‘lawful basis’) to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the ‘Data Controller’ for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University’s data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University’s Data Protection Officer ([data.protection@soton.ac.uk](mailto:data.protection@soton.ac.uk)).

# Where can I get more information?

If you have any other questions, please feel free to contact:-

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**Thank you for reading this Participant Information Sheet.**