Participant Information Sheet for   
Participation in A Focus Group

**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 participate in a **focus group** 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.
* If you are happy to participate you will be asked to sign a consent form.

# 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. This is known as ‘treatment burden’. 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’. We are also interested in the factors that impact their ability to manage their health. This is termed ‘capacity’.

Our previous research has highlighted the main issues that impact the treatment burden and capacity of people living with Parkinson’s and their caregivers. We would like to discuss these issues further with various stakeholders who have experience in the care of people with Parkinson’s. The aim of this focus group is to develop recommendations for changes that can improve the future experiences of people with Parkinson’s and their caregivers.

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 have been invited to take part in this study because **you have been diagnosed with Parkinson’s or have an important role in the care of people with Parkinson’s**. This role can be as a caregiver of someone with Parkinson’s, a healthcare professional involved in the care of Parkinson’s, a volunteer, policy maker, manager and others.

# What does taking part in the study involve?

You are being asked to take part in a focus group. This is where a group of about 6 - 10 people are asked to come together to discuss a topic, guided by a facilitator. The group will last for approximately 1.5 hours. It may take place in person at a central location in your region (Bournemouth or Southampton) or online with video call. It can be difficult to arrange a time, date and location for everyone to get together at the same time. We will propose a date in the near future and ask that you contact the research team to confirm your attendance.

You will be asked to participate in the discussion and to give your experiences and views. There are no right or wrong answers. With your permission, the focus group will be digitally (audio and/or video) recorded to allow us to concentrate on what you are saying. This digital recording will be kept confidential.

# What will I have to do?

If you agree to take part in this interview, please let the research team know by contacting Dr Qian Tan (07824 895 791; [q.tan@soton.ac.uk](mailto:q.tan@soton.ac.uk)) or by completing and returning the reply slip provided in the invitation letter using the pre-paid envelope.

# Are there any benefits with being in the study?

We cannot guarantee that you will receive any direct benefits from participating in the study. However, your view and perspectives may help us develop ways that could improve the future experiences of people living with Parkinson’s and caregivers of someone with Parkinson’s.

# Are there any risks involved?

Aside from giving up your time, there are no risks associated with taking part in this focus group. It is possible that the discussion may cause you distress, although this is unlikely. If this happens, please discuss them with the researcher at any time. If you are a participant of the focus group with a diagnosis of Parkinson’s or a caregiver for someone with Parkinson’s and do experience any distress after the focus group, you can also 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 support.

# Expenses and Payment

No travel expenses or payments are made for participating in the focus group. 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, you will need to sign a consent form to show you have agreed to take part. Declining to participate in this study or withdrawing from this study will not impact the standard of care you receive from your doctor.

# What data will be collected?

We will be collecting basic information about yourself such as your age, gender and role related to the care of Parkinson’s. This information is gathered to ensure that we have included a wide range of stakeholders in the focus group.

# 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. Digital recordings of the focus groups will be deleted after transcription.

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

You have the right to change your mind and withdraw at any time without giving a reason. If you do decide to withdraw from the study, any information collected up to this point will be anonymised and may still be used for the purposes of achieving the objectives of the research only. We will not keep any of your personal data if you do decide to withdraw from the study.

# 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 contact:-

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| Dr Qian Yue Tan Research Fellow in Geriatric Medicine Academic Geriatric Medicine Southampton General Hospital  Telephone: 07824 895 791 Email: [q.tan@soton.ac.uk](mailto:q.tan@soton.ac.uk) | Professor Helen Roberts  Professor of Medicine for Older People Academic Geriatric Medicine  Southampton General Hospital  Telephone: 02381 204 354 |

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

**If you would like to participate in the study, please complete the reply slip on the next page and return to the research team using the freepost envelope.   
You can also contact the research team (Dr Qian Tan) by phone on   
07824 895 791 or email** [**q.tan@soton.ac.uk**](mailto:q.tan@soton.ac.uk)

**Reply Slip**

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Name: ­­­­­­­­­­­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Contact No: ­­­­­­­­­­­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

I would prefer to be contacted on:

Monday  Tuesday  Wednesday  Thursday  Friday

Between 9-5pm, in the:

Mornings (9am-12pm)  Afternoons (2-5pm)  Anytime

At a specific time: ­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Thank you. A member of the research team will be in touch to confirm your participation and provide details about the focus group.**