

Participant Information Sheet

Understanding self-care practices in Parkinson's: A survey study

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. We encourage you to contact us if there is anything that is not clear.

What is the purpose of the study?

Parkinson's causes a variety of symptoms, which have a variable rate of progression and differ from person to person. This unpredictability can affect the overall quality of life and makes management difficult. Individuals know and understand their own symptoms better than anyone else. We are interested in understanding your self-care and symptom management practices.

While common practice suggests a healthy diet, regular exercise and other coping mechanisms can help to improve general health and wellbeing, the effect of these on Parkinson's symptoms may vary greatly from person to person. Researchers at Monash University have knowledge and skills that could help people learn, design and create ways to track, monitor and understand the effect of these everyday lifestyle practices on Parkinson's.

We are conducting this survey to better understand what you currently do to support your general health and wellbeing, and how you manage your Parkinson's symptoms. We would like to understand the existing tracking practices, tools (if any) and challenges that people with Parkinson's are experiencing due to their condition. This will help us to deliver future research that meets the needs of the Parkinson's community.

Why have I been invited?

We are inviting you to take part as a member of the Parkinson's Victoria community. You have been identified as someone who might be experiencing the impact of Parkinson's on day-to-day life, wanting to manage your conditions more effectively.

Do I have to take part?

No. Participation is entirely voluntary and it is up to you to decide whether or not to take part. Your decision to take part in this study will not affect any health or social care services that you are receiving now or in the future.

What will happen to me if I take part and what will I have to do?

You will be asked to participate in an online survey. The survey will take approximately 20 minutes and will discuss the overall impact of Parkinson's on your life. It will ask you about your experience living with Parkinson's, how it impacts your day-to-day living and the self-care practices you follow to manage your symptoms. We will not collect or store any personal or potentially identifying information from you (e.g. name, address, phone number, email address).

What are the possible risks and benefits of taking part?

We do not anticipate any risks associated with this interview. While we cannot promise the study will benefit you personally, the information we get from this study will help us to understand the outlooks and self-management practices of people with Parkinson's. This will help us to develop future technologies that can accommodate the diverse needs of people with Parkinson's.

Are there any additional costs or reimbursements?

There are no additional costs associated with participating in this research project, nor will you be paid.

What will happen if I don't want to carry on with the study?

If you begin the survey and then decide that you no longer want to participate, you can simply exit the survey. Partially filled in survey responses will be discounted and will not be included in the final analysis.

Will my taking part in this study be kept confidential?

We respect your privacy and maintaining your information as confidential is of utmost importance to us. Any information obtained for the purpose of this research project will be accessed, used and stored in accordance with Commonwealth Privacy Laws (The Privacy Act 1988).

The survey is completely anonymous. We will not have access to your personal information such as your name, date of birth or contact details.

The anonymous survey responses will be stored on a password protected computer, which would be only accessible to the members of the research team. Storage of the data collected will adhere to the University regulations and be kept on University premises in a locked filing cabinet/secure server for 7 years. In any publication and/or presentation, information will be provided such as the following examples: a) 20.1% of participants engaged in self-care practices; b) Several participants reported how they track their symptoms: "I use a diary and share it with my son"

Will my data be re-usable to other researchers?

In accordance with the Australian Code for the Responsible Conduct of Research we would like to make the anonymous data available to other researchers (who will undergo a permissions and application process prior to having access). Data will be checked to ensure

there is no identifiable information within free text responses before being uploaded to the Monash University Research Repository.

What will happen to the results of the research study?

The results of the study will help us to understand the requirements and practices for self-management by people with Parkinson's. Each person will have a different experience and outlook, which we aim to understand better. Knowing this will help us to direct future work focusing on the redesign of services to support wellbeing and changing needs of people with Parkinson's. We intend to do future work to make sure their views are at the centre of everything that we do. We anticipate that the summarised findings from this survey study will also form part of academic publications and presentations. All data is anonymous so no-one will be identified in any report or publication. You will have the opportunity to request a summary of the findings when the study is complete.

Can I access the information kept about me?

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access the information collected and stored by the researchers about you. Please contact Dr. Roisin McNaney roisin.mcnaney@monash.edu if you would like to access your information.

Who has reviewed the study?

The study has been reviewed and approved by the Faculty of Information Technology Research Ethics Committee at Monash University.

Further information and contact details

For further information please contact Pranav Kulkarni pranav.kulkarni1@monash.edu

If you have a concern about any aspect of this study, the researchers will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint, you are welcome to contact the Executive Officer, Monash University Human Research Ethics (MUHREC):

Executive Officer, Monash University Human Research Ethics Committee (MUHREC)
Room 111, Building 3e, Research Office, Monash University VIC 3800

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