University of the Sunshine Coast
Australia

Research Project Information Sheet

Using Ecological Momentary Analysis to explore stigma experiences in the real world for adults with Parkinson's Disease

Ethics Approval Number: S252164

Research Team Contact Details

Chief Investigator	Associate Investigators	Student Investigators
Dr Sarah Davies Lecturer in Occupational Therapy Email: sdavies4@usc.edu.au Phone: 07 5409 8693	**Associate Professor Florin Oprescu** Public Health **Robyn Higgins** Consumer researcher with Parkinson's Disease	**Christine Fosberry** Occupational Therapy Student **Jenna Walker** Occupational Therapy Student **Santika Miller** Occupational Therapy Student

Project Description

We are running a research study to improve our understanding about the real-life stigma that people with Parkinson's Disease experience. We'll do this by asking study participants to record their experiences as they happen, using their smartphones. We are looking for people to join the study who:

- Are 18 year or older
- Have been diagnosed with Parkinson's Disease,
- Live at home (in the community)
- Have a smartphone with internet/data and know how to use it.

The research aims to get a clearer picture of the discrimination people with Parkinson's Disease face every day. We want to improve our understanding of how this discrimination happens by focusing on the contextual features, situations, prevalence and types of stigma experienced by people with Parkinson's Disease as they occur in daily life. This addresses the known gap in research about the daily social and emotional dimensions of Parkinson's Disease stigma.

Participation

If you agree to participate in this research project, you will be asked to complete an initial assessment, followed by multiple short online surveys, using your smartphone, for seven days. The surveys include multiple-choice questions that will take about 3 minutes each to complete, and there will be a maximum of 4 surveys each day. They will ask you information about your experiences of stigma and how you coped/responded and your emotional state. For example: Where it happens (e.g., public places, private settings), who is the source (e.g., strangers, family, medical professionals), how it was expressed (e.g., verbal comments, body language). Once the surveys are complete, focus groups will be conducted to further explore your experiences. You may be asked questions like: How does the ongoing concern about stigma affect your willingness to engage in social activities, work, or seek healthcare? What support or resources do you feel are most needed to help individuals with PD better manage or challenge stigma in their lives? Participants will receive a $20 electronic gift voucher at the completion of the EMA survey period, regardless of the rate of daily survey completion or attendance at focus groups.

Your participation is voluntary, and you may withdraw from the study at any time. Your participation, or not, will not affect your relationship with UniSC or members of the research team. If you decide to take part and later change your mind, you are free to withdraw at any time. You will need to provide the researchers with your code/name if you would like to have your data removed. Please contact the Chief Investigator (listed above) to discuss withdrawal. Your consent to participate will be confirmed via survey question before progressing to the initial assessment survey. You will be asked to consent to the use of your data and information from the surveys and focus groups to be collected, stored, and used in analysis and publications in a non-identifiable format. You will have the choice to limit your consent to this project only, or provide extended consent, which means we can use your data and information for this project and future related research by this research team.

What will you do?	Surveys	Focus Group
Time Required	90-minute initial assessment completed with researchers, either online or in person. The initial assessment will gather participant information including age in years, sex, cultural background, relationship/marital status, work status, education, year of diagnosis, members of household and availability of support. Measures of PD stage, PD symptoms, cognition, stigma consciousness, stigma experience, health-related QoL, and mood will also be collected at baseline. 3 minutes anonymous survey, total of 12 minutes per day. Surveys will be triggered once within a random within 3-hour intervals (8am-11am, 11am-2pm, 2pm-5pm, 5pm-8pm), capped at 4 surveys per day. Participants can also self-initiate survey in response to a stigma experience. These surveys focus on the contextual features, situations, prevalence and types of stigma experienced by People with PD as they occur in daily life. 84 minutes total over 7 days will be required (not including self-initiated surveys). After the 7 day period, the stigma consciousness scale will be administered again.	1 hour in person or online focus group with 4-5 others discussing the surveys and lived experiences of stigma and PD.
Data collection method	Either online or in person, initial assessment Online surveys through the SEMA3 phone app. It is anticipated that completing the surveys (4/day for 7 days) will use less than 1MB of data. The SEMA3 app is 12.11MB to download and this can be done from home, while using the Wi-Fi connection. Your data will be stored in a secure database.	Focus group with 4-5 others facilitated by the research team. This will be held at the UniSC Sippy Downs campus or online based on location and participant preferences.
Example questions/activities	The survey will include information about experiences of stigma and how you coped/responded and your emotional state. For example: Where it happens (e.g., public places, private settings) Who is the source (e.g., strangers, family, medical professionals) How it was expressed (e.g., verbal comments, body language).	How does the ongoing concern about stigma affect your willingness to engage in social activities, work, or seek healthcare? What support or resources do you feel are most needed to help individuals with PD better manage or challenge stigma in their lives?
Consent	Consent to participate will be confirmed via survey question before progressing to the initial assessment survey. You will be asked to consent to the use of your data and information for this project and future related research	You will be asked to verbally reconfirm your consent for the focus groups. You will be asked to consent to the use of your data and information for this project and future related research
Withdrawal	If you decide to take part and later change your mind, you are free to withdraw at any time.	If you decide to take part and later change your mind, you are free to withdraw at any time.

Consent

Consent is for your data and information to be collected in a non-identifiable format, stored in a non-identifiable format, and used in analysis and publications in a non-identifiable format. You will have the option to consent to the use of your data and information for this project and/or future related research.

Risks and Benefits

There are no anticipated physical risks associated with your participation. Sometimes thinking about the themes discussed in the surveys and focus groups can create uncomfortable or distressing feelings. You are not required to answer any questions you don't want to and you may discontinue or pause the surveys at any time if required. If you need to talk to someone you may wish to contact family or friends, your General Practitioner, or Beyond Blue (1300 224 636). Parkinson's Queensland also provides a range of support services available to people with Parkinson's (1800 644 189). Additionally, repeatedly answering surveys over multiple hours and days may become burdensome. To mitigate this, surveys include multiple-choice questions which take only 3 minutes to complete and will be capped at 4 surveys per day for 7 days. Surveys can also be snoozed and completed at later times if you are unable to complete them immediately, such as when you are driving or in the middle of an important activity.

It is not anticipated that this research project will directly benefit you, but we appreciate your input as a contribution to the discipline. Your contribution will assist with understanding how adults with Parkinson's Disease experience stigma and future progress to addressing these issues.

Privacy, Confidentiality and Results

Any data collected as a part of this research project will be stored securely as per UniSC's Research Data Management Procedures. All comments and responses will be treated confidentially unless required by law.
The research team will be able to identify if you choose to participate. Survey data will be de-identified and stored in a secure R-drive, accessible only by the research team. Participation status or individual comments will not be shared with UniSC.

It is not possible to participate in the focus groups without being recorded. The recording/transcript will be stored in a non-identifiable format in a secure R-drive, accessible only by the members of the research team.

The results of this research project may be presented at external or internal conferences or meetings, or by publication. If you would like a summary of findings of this research project, please contact the Chief Investigator (listed above).

Respectful Behaviour

UniSC prides itself on providing a safe environment to staff, students and visitors. It is expected that the research team and participants treat each other with respect. Aggressive, abusive, threatening, discriminatory, or offensive behaviour or language will not be tolerated. If unacceptable behaviour occurs, we will take steps to reduce any detrimental impact of such behaviour, which may include research participation being ceased.

Concerns or Complaints

If you have any concerns or complaints about the way this research project is being conducted, you may raise them with the Chief Investigator (listed above). If you prefer an independent person, you may contact the Chair of the UniSC Human Research Ethics Committee: telephone +61 7 5430 2823; email humanethics@usc.edu.au).

Please save the information above if you choose to participate.