Participant Information Sheet

Research Project Title

Health Professionals' Experiences of Time-Critical Medication for Parkinson's Disease.

Invitation to research

Parkinson's disease is a neurodegenerative condition which currently affects approximately 153,000 people in the UK (Parkinson's UK, 2018). People with Parkinson's suffer from a range of debilitating motor, cognitive and psychiatric symptoms (NHS, 2022) and are more likely to be hospitalised than the general population (Low et al., 2015). Unfortunately, people with Parkinson's also face a higher rate of complications whilst in hospital (Wood et al., 2010), often as the result of delayed or inaccurate medication administration (Gerlach et al., 2011). The time-critical nature of Parkinson's medication means even slight delays can result in patient deterioration (Nance et al., 2020), which becomes an issue when hospital ward rounds do not fit patients' individualised medication schedules (Yu et al., 2023). The Parkinson's UK '**Get It On Time' campaign** (Parkinson's UK, 2019) strives to ensure the timeliness of medication for hospitalised patients with Parkinson's, and has resulted in several efforts being made to rectify the issue, though such efforts have proved difficult to implement (Aslam et al., 2020), calling for an exploration of why this may be.

Through collaboration with Parkinson's UK, this project aims to gain interdisciplinary insight into the real-life barriers to timely medication management for hospitalised patients with Parkinson's.

My name is Georgia Wright, and I am an MSc Health Psychology student at Manchester Metropolitan University, supervised by Dr Chesney Craig. The current study will be conducted as my dissertation topic for my degree. This will involve 1:1 interviews with health professionals across a range of disciplines, which will explore the topics of awareness, lived experience, perceived barriers and possible solutions of timely medication management for hospitalised patients with PD.

Who can participate?

Any UK health professionals who have experience of working in hospitals and some awareness of time-critical medication for Parkinson's disease are invited to participate in this project. Participants should have been in their profession for a minimum of 1 year and speak fluent English. Professionals from the NHS and private sector may participate. Approximately 8-10 participants will be interviewed for this study.

Do I have to take part?

It is up to you to decide. This information sheet describes the study and may be downloaded at the end of this form. You may ask us any questions before taking part by using the emails at the bottom of this form. After reading this information, we will then ask you to give digital consent by ticking a series of boxes on the following page. Following this, you will be asked to complete a short online pre-screening survey to check your eligibility for the project and help us select a range of different health professionals for the interviews. If you are invited to interview, we will also take verbal consent at the beginning of the interview. Participants can withdraw at any time before or during the interview, and up to 2 weeks after the interview, after which time it won't be possible to withdraw due to the interview being fully transcribed and anonymised.

What will I be asked to do?

As stated above, if you choose to participate, you will first be asked to complete a pre-screening questionnaire via Qualtrics. This will assess your eligibility and also ask for some personal details, including your age, gender, job title, years in your role, number of roles you have had in NHS and/or private hospitals, and the geographical location of your role. This information will be used to help us decide who to interview to capture a range of experiences from relevant disciplines.

If selected for interview, you will be invited to book a 1:1 semi-structured interview which will take place via Microsoft Teams at a time of your convenience. The interview will follow a flexible Topic Guide, allowing you as the participant to guide the direction of the interview. The Topic Guide will explore your awareness, lived experience, perceived barriers and possible solutions to effective medication management for hospitalised patients with Parkinson's disease. Questions will include items such as *'What are your personal experiences of Parkinson's medication management in hospitals?'.* The interview will last no longer than 60 minutes and will be recorded through Microsoft Teams. Although the software uses a camera function, you will have no requirement to have your camera turned on. The recording will subsequently be transcribed and anonymised, for later analysis.

Are there any risks if I participate?

This project has been developed with guidance from people with Parkinson's and health professionals specialising in Parkinson's, to ensure that it is both appropriate and sensitive to the topic. Despite this, there may be some risk of distress or discomfort if you have had distressing experiences surrounding care of patients with Parkinson's, or if Parkinson's is a personal subject for you. You are invited to share only what you feel comfortable with sharing during the interview; you are not obliged to disclose personally upsetting information and you are not obliged to take part in the study if you feel it will be distressing for you.

In the event of distress, the interview will be paused until you feel able to continue and immediate support will be offered. If you do not feel able to continue, the interview will end and you may withdraw from the study. If you experience any discomfort because of the topics discussed, we recommend the following support services:

Parkinson's UK helpline: 0808 800 0303 Email: **hello@parkinsons.org.uk**

Support Line Tel: 01708 765200 Website: **https://www.supportline.org.uk/**

These support services will be shared again in the debrief at the end of the interview.

Are there any advantages if I participate?

Your contributions will be important in informing the Time-Critical campaign, which should ultimately lead to improved care for hospitalised patients with Parkinson's disease. This research will benefit from your insight of the barriers and solutions to timely medication management for this population group. The research may also offer you a chance to reflect on your experiences of working with this population and/or get involved in future projects developing interventions to prevent these hospital-based issues.

Informed consent

If you decide to participate, you will be required to provide electronic consent before the pre-screening survey and verbal consent before taking part in the interview. Verbal consent will be audio-recorded before the interview begins, whereby the researcher will read aloud all consent items, to which you can respond with 'agree' or 'disagree'. You may ask questions at any time during this consent stage. Upon completion of audio-recorded consent, the interviewer will stop the recording, which will be stored safely on the MMU secure OneDrive, separate to the subsequent interview recording.

What information about me will you collect and why?

As stated above, in addition to the interviews, you will also be asked for some demographic information, including your preferred contact details, age, gender, job title, years in your role, number of roles you have had in NHS and/or private hospitals, and the geographical location of your role. All contact details will be deleted after the interview occurs or after a summary of the results have been sent, if you select this option during the consent procedures. If you are not selected for interview, your contact details will be deleted at the study recruitment end date (31st July 2025) or after a summary of the results have been sent, if you select this option.

How will my information be stored and how will you look after it?

All personal data will be securely stored on the MMU OneDrive. Interview recordings will be transcribed and anonymised through the use of pseudonyms, with original recordings being deleted after transcription, and subsequent transcripts being stored safely on the MMU OneDrive. All personal data and anonymised transcripts will be stored separately. If you opt in to be contacted about future research, your contact details will be stored in a password-protected mailing list on the supervisor's OneDrive. You can opt out of the mailing list at any time by contacting Dr Chesney Craig (**c.craig@mmu.ac.uk**). A reminder of these contact details and ways to unsubscribe will be given in all future communications.

How will you use my information?

The information collected will be used in the write-up of an MSc Health Psychology Dissertation. In addition, the findings will be shared with Parkinson's UK and may be published in academic journals or presented at academic conferences. If published, a table of anonymous quotes to support each of the themes found in the data may be uploaded to an open science repository. Your participation in the study will be anonymous and not identifiable in the dissertation or in potential publications or in any summaries shared with Parkinson's UK.

Will my data be sent anywhere else, or shared with other people or organisations?

Your data will be shared with the project supervisor. A table of the study findings will also be shared with Parkinson's UK. All information however will be anonymised and you will not be identifiable.

When will you destroy my information?

All contact details will be deleted after the interview occurs or after a summary of the results have been sent, if you select this option during the consent procedures. If you are not selected for interview, your contact details will be deleted at the study recruitment end date (31st July 2025) or after a summary of the results have been sent, if you select this option.

Interview recordings will be deleted as soon as they are no longer needed, once the transcription process has been completed. Your anonymised data will be transferred to the project supervisor upon completion of the project. This data will be securely stored and then destroyed after 10 years.

Data Protection Law

Data protection legislation requires that we state the ‘legal basis’ for processing information about you. In the case of research, this is ‘a task in the public interest.’ If we use more sensitive information about you, such as information about your health, religion, or ethnicity (called ‘special category’ information), our basis lies in research in the public interest. Manchester Metropolitan is the Controller for this information and is responsible for looking after your data and using it in line with the requirements of the data protection legislation applicable in the UK.

You have the right to make choices about your information under the data protection legislation, such as the right of access and the right to object, although in some circumstances these rights are not absolute. If you have any questions, or would like to exercise these rights, please contact the researcher or the University Data Protection Officer using the details below.

You can stop being a part of the study at any time, without giving a reason. You can ask us to delete your data at any time, but it might not always be possible. If you ask us to delete information within 2 weeks following the interview**,** we will make sure this is done. If you ask us to delete data after this point, we might not be able to. If your data is anonymised, we will not be able to withdraw it, because we will not know which data is yours.

What will happen to the results of the research study?

The project report will be submitted for an MSc Health Psychology dissertation, as well as potential publication in academic journals, presentation at conferences and dissemination to stakeholders via the Parkinson’s UK website and North West Regional Interest Group mailing list. Participants can also be sent a lay summary via email if they opt in to this in the consent form.

Who has reviewed this research project?

The study has been reviewed by the University’s postgraduate ethics review process, via submission of an ethics application via EthOS.

Who do I contact if I have concerns about this study or I wish to complain?

If you have any concerns regarding this study, you can contact the project lead, Georgia Wright at **georgia.wright3@stu.mmu.ac.uk**, or their academic supervisor, Chesney Craig at **c.craig@mmu.ac.uk**, or in writing to: The Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

You can also contact the Faculty of Health and Education Ethics Committee at Manchester Metropolitan University, at FOHE-Ethics@mmu.ac.uk, or in writing to: The Department of Psychology, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX.

Manchester Metropolitan Data Protection Officer dataprotection@mmu.ac.uk

Tel: 0161 247 3331 Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH

UK Information Commissioner's Office
You have the right to complain directly to the Information Commissioner's Office if you would like to complain about how we process your personal data:
https://ico.org.uk/global/contact-us/

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT