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**Developing psychological wellbeing support for patients with Parkinson’s disease**

Patient information sheet

Version 1.5, 07/01/21

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| **Chief Investigator:** Dr Breda Cullen, Clinical Psychologist | **Research Supervisors:** Dr Breda Cullen and Dr Susan O'Connell |
| **Trainee Clinical Psychologist**: Jessica Whyte |  |

You are being invited to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

**What is the research about?**

This study is aiming to investigate how Psychology services can improve the support they offer to patients with Parkinson's disease to help improve their mental health, and how we can make Psychology services easier to access for people with Parkinson's disease. To do this, we will be interviewing people with Parkinson's disease over the phone or over video call. The results of the interviews will be used to help us improve the mental health support we offer to patients with Parkinson's disease in NHS Ayrshire and Arran and wider services.

**Who is being asked to take part?**

We are inviting people with a diagnosis of Idiopathic Parkinson’s Disease to take part in the study. We are looking for 10-12 people to take part.

**Why have I been invited?**

You have been invited to take part in this research because you have a diagnosis of Idiopathic Parkinson’s Disease, are registered with the Parkinson's disease team in NHS Ayrshire & Arran, are aged 18 years or over, and may have reported experiencing difficulties with your mental health.

Please return the reply slip to the researcher using the pre-addressed and pre-paid envelope provided if you are interested in taking part.

If you are interested in taking part, a researcher will telephone to give you the opportunity to ask any questions you may have about the study and to arrange a time for the interview if you would like to take part.

**What will taking part involve?**

Consenting to participate in this study means that you will be asked to take part in an interview with a researcher, either over the telephone or over video call. During the interview the researcher will ask you some general questions about yourself, followed by questions about your experiences of support for your mental health and how we can improve these. In total this should take 30-45 minutes and the interview will be audio recorded. At the end of the interview the researcher will ask if you would like to take part in checks of the study results. This is an optional part of the study and would involve the researcher sending you a summary of the study results by post and contacting you at a later date to ask for your opinion on the results.

As well as taking part in the interview, we will also request your permission for NHS Ayrshire & Arran Clinical Nurse Specialists to access details from your medical records to send to the research team at the University of Glasgow. This information would include your date of birth, gender, name of diagnosis, date of diagnosis, if you have a history of mental health problems and if you have previously been offered support for your mental health.

To thank you for your time taking part in the interview you will be given a £5 supermarket voucher.

If at any point you are no longer able to consent during the study, you would be withdrawn from the study and no new data would be collected. If you have already taken part in an interview we may keep recordings and transcripts of your interview and may use these as originally agreed in the consent form.

**What are the possible benefits of taking part?**

We do not expect there to be any particular benefits to yourself by taking part. Your participation will help us improve the mental health support we provide for people with Parkinson's disease.

**Are there any disadvantages or risks to taking part?**

Although we do not expect that participating in this study will cause you any distress, if you express distress when speaking to the researcher or through your responses to the interview questions, we will help you to access appropriate support if needed. Following the interview we will send you a post-interview sheet containing the details of individuals and organisations you can contact if you are feeling distressed. If you share information that makes the researcher concerned for your safety or the safety of other people, we may need to tell others involved in your care (e.g. your GP).

**Do I have to take part?**

No. It is up to you to decide whether to take part. This study is completely voluntary. You do not have to take part if you do not want to.

**What happens if I decide not to take part?**

Nothing. Taking part is entirely up to you. If you do not wish to take part, it will not affect any treatment that you currently receive and will not affect any future care you may need. Also, if you decide to take part, you can change your mind and withdraw from the study at any time, without giving a reason, and without it affecting your care either now or in the future.

**What will happen to my data?**

We will collect your basic personal data such as your name, contact details, date of birth and, limited special categories data (such as health data) in order to carry out the research study. We will only collect data that we need in order to conduct the research study.

**Legal basis for processing your data**

We must have a legal basis for processing all personal data. In this instance, the legal basis is a task in the public interest and consent.

**What we do with your data and who we share it with**

All the personal data in the study is processed by staff at the University of Glasgow and NHS Ayrshire and Arran in the United Kingdom. Appropriate security measures will be in place such as encryption and pseudonymisation.

**Will my information be kept confidential?**

All the information you provide will be kept confidential and the recordings and transcripts of your interview will only be identified by code, not your name. The consent forms and study data will be stored on NHS Ayrshire and Arran and University of Glasgow premises and will be accessible only to researchers who are directly involved with the research, or other authorised staff for audit purposes. Electronic information will be stored on secure NHS or University of Glasgow computer systems. When the study has finished the transcripts from your interview will continue to be stored anonymously, and the recording of your interview will be deleted.

If you share information that makes us concerned for your safety or the safety of other people, we may need to tell others involved in your care (e.g. your GP).

The University of Glasgow is the sponsor for this study based in Scotland. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Glasgow will keep identifiable information about you for 10 years after the study has finished. After this time, data will be securely deleted.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at https://www.nhsaaa.net/data-protection-notice/

**What will happen to the results of the research study?**

The results will be compiled in a report completed as part of an academic qualification (Doctorate in Clinical Psychology). They may later be published in a scientific journal and through other routes to ensure that the public are also aware of the findings. Some anonymised quotes from the interviews may be used in publications but you will not be identified in any report or publication arising from this study. During the interview the researcher will ask if you wish to be informed of results from the present study. If so, a summary of the results will be sent to you once the research is completed.

**Who is organising the research?**

The study is being undertaken in partial fulfilment of an academic qualification at the University of Glasgow and is organised by the Chief Investigator (Dr Breda Cullen) and research supervisor (Dr Susan O'Connell) and Trainee Clinical Psychologist (Jessica Whyte).

**Who has reviewed the study?**

The study has been reviewed by the University of Glasgow to ensure that it meets standards of scientific conduct. It has also been reviewed by an NHS Research Ethics Committee, and the NHS Ayrshire and Arran Research and Development Department.

**What will happen if there is a problem or if I want to make a complaint?**

If you have any concerns about the study or the way it is conducted, or if you wish to complain about any aspect of this study, please contact Dr Breda Cullen, Mental Health and Wellbeing, Gartnavel Royal Hospital, Admin Building, 1st Floor, 1055 Great Western Road, Glasgow, G12 0XH, or the Research and Development Department, NHS Ayrshire and Arran on 01563 825850.

The normal NHS complaint mechanisms will also be available to you. NHS Ayrshire and Arran Complaints Team: 01292 513620

**Contact for further information about the study**

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| Jessica Whyte | Dr Breda Cullen | Dr Luke Williams |
| Mental Health and Wellbeing  Admin Building, 1st Floor, Gartnavel Royal Hospital  1055 Great Western Road  Glasgow G12 0XH  07583218206 | Mental Health and Wellbeing  Admin Building, 1st Floor, Gartnavel Royal Hospital  1055 Great Western Road  Glasgow G12 0XH  0141 2113912 | Psychology Department  Horseshoe Building  Ayrshire Central Hospital  Kilwinning Rd,  Irvine  KA12 8SS  01294 322057 |

**Other useful contacts**

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| Nick Brydon & Paula Hewatt, Parkinson's Disease Clinical Nurse Specialists | Contact number: 01292 665628  Email: Clinical\_Specialty\_ParkinsonsService\_BiggartHospital@aapct.scot.nhs.uk |
| Parkinson's Disease UK, Ayrshire branch contact: Gill MacGregor | Contact number: 0344 225 9836  Email: vc.scotland2@parkinsons.org.uk |
| Breathing Space telephone support line | Contact number: 0800 83 85 87 |
| The Samaritans | Contact number: 116 123  Email: jo@samaritans.org |

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