This document contains the participant information sheet for the qualitative (interview) study. The overall format and wording contained in the information sheets will be the same for people with Parkinson’s disease and people with early psychosis.

Dynamics of motived decision-making

Information sheet for qualitative interview

Please read this information carefully before deciding whether you wish to take part in the study. You may wish to discuss with your friends or family members before making a decision. If you have any further questions please contact Jamie Talbot at jxt289@student.bham.ac.uk or Matthew Apps at m.a.j.apps@bham.ac.uk. If you have any medical/ other problems which make it difficult for you to read this information, please contact Jamie Talbot who may adapt the format of this information sheet or address any problems.

Background

Following your recent participation in the decision-making study for this project, we would like to invite you to take part in a follow-up interview to explore your lived experience of motivation symptoms in further detail. This research is being conducted in the Department of Psychology at the University of Birmingham by Professor Matthew Broome, a clinical psychiatrist and mental health researcher, and Dr Matthew Apps, a researcher in motivation neuroscience. Our hope is that the study will enable us to better understand motivation problems in individuals with clinical disorders which lead to reduced motivation.

What will happen if you decide(s) to participate?

Where will the research take place?

The interview will either take place at the University of Birmingham or online, using a platform such as Microsoft Teams. You may state a preference for either location.

Who will be involved in performing the interview?

The interview will be conducted by Dr Jamie Talbot, a medical doctor specialising in neurology and currently completing a PhD in motivation neuroscience as part of this study. It is possible that another member of the research team may be present for the interview.

How long will the interview take?

The interview itself will take no longer than one hour. It will take 5-10 minutes to go through written consent at the start of the interview, with a short debrief at the end. The whole session should not take longer than 1 hour and 15 minutes.

What will happen during the interview?

The aim of the interview is to try to understand your lived experience of motivation and the way in which it impacts your life. You may choose to perform the interview alone, or with another person such as a friend, family member or carer. The interview will be structured according to a motivation questionnaire called the Lille Apathy Rating Scale, which groups motivation into different domains or dimensions. In the interview, we will use this interview structure as a guide but will explore some of your responses with additional questions. The interview will not aim to explore highly sensitive aspects of your personal life. As you will be asked to reflect on your experience of motivation in day-to-day life, it is possible you may find some of the discussions troubling or upsetting. You are free to terminate the interview at any point during the discussion without giving a reason.

Will assessments be recorded?

If you agree to participate in the interview, an audio recording of the discussion will be created. The research team will transcribe the audio recordings, after which they will be deleted.

What are the potential benefits for participants from taking part?

This study aims to examine motivation in individuals with or at higher risk of motivational impairments. Although we hope the results will contribute to our understanding of these processes, there will be no immediate benefit for participants. The interview is designed to compliment the results from your earlier experiment – in particular to try and understand your individual symptoms and how they might relate to your performance on the earlier task.

Please remember that we are a research facility rather than a clinic. All assessments will be completed for research purposes and therefore are not to be interpreted as part of a clinical evaluation. If you have any concerns regarding your performance, other services that may be able to offer you support are available, including clinical and educational assessment and treatment services through the National Health Service (NHS).

Where will data be stored?

We will need to use information from you for this research project.

This information will include your initials, name, contact details and information from the interview. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

The data collected will be kept in locked or password protected storage at the University of Birmingham. All information gathered about you will be stored separately from any information that would allow someone to identify who you are (this is known as personal identifying information, e.g. your full names, your address, your contact details). Your personal identifying information will be stored in a separate, password-encrypted data file held at the University of Birmingham and only members of our research team will have access to it. We will only be able to trace information we have collected about you back to you using a special reference number linked to your personal details in this datafile. Personal identifying information will be treated as strictly confidential and handled in accordance with the provisions of the General Data Protection Regulation 2018.

Audio recordings are considered to necessarily contain personal identifying information. We will therefore store the recordings of you separately to the other information we have collected about you. These recordings will not be labelled with your names or any other personal identifying information but will be labelled with your unique ID code. Recordings will be stored on a secure University of Birmingham server, in an area specific to the lab group, which will be password protected. Only members of our research team will have access to this.

Will I be paid compensation for my time?

You will be paid £25 for your participation in the interview. If you decide to come to the School of Psychology for the interview, we can compensate for reasonable travel costs (the researcher will get in touch prior to testing sessions to confirm transport arrangements) and can arrange for free parking in front of the School of Psychology during your visit.

If you decide to participate, what will happen after that participation?

All your responses will be treated in strict confidence. While certain quotes or descriptions may be used in subsequent research publications, no information will be published that could possibly lead to you being identified. You may choose to stop the interview at any point. Although the interview will be strictly confidential, in the event of any very serious disclosures – for instance, describing thoughts of harming yourself or other people – the interview would be stopped immediately and further action would be taken in line with the tenets of Good Clinical Practice (GCP) - this could include sharing information with other professionals such as your medical team, calling an ambulance or accompanying you to an emergency care facility.

The researchers will aim to publish the findings from the study in scientific journals and present the results at relevant conferences. You can request copies of the published papers by emailing jxt285@student.bham.ac.uk or m.a.j.apps@bham.ac.uk.

What will happen to the data afterwards?

At the end of the study, your personal details will be destroyed.

We would retain the research data for 10 years, in line with University of Birmingham policy. After this your data will be destroyed.

Confidentiality

The confidentiality of participants will be ensured. If published, information on the participant will be presented without reference to their name or any other identifying information.

Consent

After you have read all of the information and have received appropriate responses to any questions that you may have about the study you will be asked to give your consent to participate in the study if you decide that you do wish to participate. We will ask you to sign a consent form. Your choice about whether or not to participate will not in any way affect your usual medical treatment. For full information on the consent you will be giving, see each point on our consent form. We need to receive consent from you in order for you to participate.

Withdrawal

Even after consent has been granted, you can request to be withdrawn from the study and you will be able to decide if you would like your research data to be destroyed or retained by the project team. You will have up to 1 month after participation to indicate your withdrawal from the study, without giving a reason. This will not restrict access to other services and will not affect the right to treatment.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients / our leaflet available from www.hra.nhs.uk/patientdataandresearch / by asking one of the research team / by sending an email to dataprotection@contacts.bham.ac.uk

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact Jamie Talbot at jxt289@student.bham.ac.uk or Matthew Apps at m.a.j.apps@bham.ac.uk in the first instance. If you remain unhappy and wish to complain formally, you can contact: Prof. Ed Wilding; Head of School; School of Psychology, University of Birmingham, Birmingham, B15 2TT, by email: hos.psychology@contacts.bham.ac.uk or by phone on 0121 414 4931.

Review

The study is sponsored and insured by the University of Birmingham and is funded by the Wellcome Trust. The study has been approved by *** Ethical Review Committee.

Further information

If you would like any more information about the study please contact Jamie Talbot at jxt289@student.bham.ac.uk or Dr Matthew Apps at m.a.j.apps@bham.ac.uk or write to him at the School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT.