**Participant Information Sheet**

**(Version 3, Date 21/09/2023)**

**Study Title**: Exploring the experiences of help and support seeking for people of Black African and Caribbean heritage experiencing long term psychosis

**Researcher**: Christabella Van Laarhoven

**ERGO number:** 81699

You are being invited to take part in the above research study. This study is part of an educational project. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

**What is the research about?**

This study is about understanding the experiences of help seeking from people of Black African and Caribbean backgrounds, with long term psychosis There has been research with people with early experiences of psychosis but we are interested in research with people who have had psychosis for a longer time and would like to understand the support they receive.

**Why have I been asked to participate?**

We are inviting people who identify as Black African, Black Caribbean and Black British, with experience of psychosis for more than 3 years, or a diagnosis of schizophrenia and/or schizoaffective disorder. In order to take part in the study you will have to be over the age of 18.

**What will happen to me if I take part?**

It is your choice there or not you decide to take part in the study. If you decide to take part in the study you will be asked to sign a consent form before the study begins. After giving consent, you are able to withdraw from the study at any time without a given reason. You will be invited to complete an interview face to face or online on Microsoft Teams, in order to provide some information about your experiences of help and support seeking. This interview should take no longer than 60 minutes. You can ask for a break whenever you need during the interview. The interview will be audio recorded if you are interviewed face to face or video and audio recorded if you are interviewed online and transcribed as part of the research process. Participants who are interviewed online can request to only be audio recorded.

**Are there any benefits in my taking part?**

There may not be any immediate benefits to taking part in the study, however, participation in the study will allow for contribution to potential changes to supportive structures in NHS services and provide further understanding of help and support seeking for Black people with long term psychosis.

You will also receive a £25 voucher from Love2Shop ( https://www.love2shop.co.uk/) as a thank you for taking part in the study.

**Are there any risks involved?**

The topics that will be discussed in the interviews may include sensitive questions during the interviews, for example discussing experiences of racism and discrimination.

If taking part in this study has caused you discomfort or distress, you can contact the following non-NHS organisation for support:

The Black, African and Asian Therapy Network <https://www.baatn.org.uk/>

The Samaritans https://www.samaritans.org/

Counselling for Ethnic Minorities - Talking Elephants Counselling https://talkingelephantscounselling.com/counselling-for-ethnic-minorities

You can also contact your key worker, GP or health visitor for support.

**What data will be collected?**

Data collected from you will involve your full name and email address in order to contact you and arrange a suitable date and time for the interview. Having your details will also allow for the voucher to be sent to you after the study. We will collect data on your demographics such as age, gender and ethnicity to ensure that you meet the essential criteria of the study. Data needed for the voucher and interview appointment will be stored in a password protected file, separated and not linked to the study data ( e.g transcripts).

All personal data collected for the study will be anonymised. Video and audio data that will be recorded is to be destroyed after the study too.

**Will my participation be confidential?**

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

**Do I have to take part?**

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

**What happens if I change my mind?**

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected. However, information that has been anonymised and submitted cannot be withdrawn and will be kept for data analysis. If you withdraw from the study, we will keep the information about you that we have already obtained for the purposes of achieving the objectives of the study only.

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

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent. You are able to request a copy of the findings.

**Where can I get more information?**

For more information or if you have any further questions please contact Christabella Van Laarhoven ( key investigator) by email **cvl1n21@soton.ac.uk**

**What happens if there is a problem?**

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Head of Research Ethics and Clinical Governance (**023 8059 5058,** [**rgoinfo@soton.ac.uk**](mailto:rgoinfo@soton.ac.uk)**).**

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**Data Protection Privacy Notice**

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, ‘Personal data’ means any information that relates to and is capable of identifying a living individual. The University’s data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University’s policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason (‘lawful basis’) to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the ‘Data Controller’ for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University’s data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University’s Data Protection Officer ([data.protection@soton.ac.uk](mailto:data.protection@soton.ac.uk)).

**Thank you for taking the time to read the information sheet and considering taking part in the research.**