Participant Information Sheet (PIS):

Advance Statements for Black African and Caribbean People

**Version 4, Date: 25/01/2022**

**Project Title:** Advance Statements Project

Phase 2b: Co-production working groups

**Invitation & Summary – What is the purpose of this project?**

We would like to invite you to take part in this project about Advance Statements for Black African and Caribbean people.

An Advance Statement is a document that allows a service user to have a say in how they wish to be treated in the future if they become mentally unwell and are detained under the Mental Health Act. Advance Statements are normally made when a person is feeling mentally well and living in the community. Advance Statements can be made with the help of others such as, family/friends, mental health professionals such as their doctor or care coordinator, and people independent of their care such as an advocate.

The Advance Statements Project is a research project aimed at ensuring Advance Statements will work for Black African and Caribbean service users who have previously been detained under the Mental Health Act, carers/supporters and mental health staff. We aim to work directly with people from these groups to develop:

* a process for the completing of advance statements that is acceptable and workable for all service users, carers, and mental health staff.
* the usage of these Advance Statements at times of mental health crisis

**What does taking part involve?**

This information sheet is for Phase 2b of the project, where you will help to co-produce the advance statement resource to help those that will use advance statements in the future have an easier process of creating an advance document.

For the purposes of this project, we will ask for personal information such as your name, contact details (i.e., email address, phone number, home address) and your preferred method of contact for us to follow up with you for further stages of the project. This can also include a social media account name if you like. We will ask for your consent to keep this information, and it will only be available to the Advance Statements Project team.

The co-production working groups will be conducted face-to-face at [TO BE DECIDED] or by Microsoft Teams if COVID-19 restrictions are required. The working groups will last up to 2.5 hours, and will happen over the course of 3 days.

**Who can take part?**

This phase of the project aims to use recommendations from Phase 1 and 2a to co-produce the new advance statement resource. You can take part if you are over 16 years old, can speak English sufficiently, and:

1. You have been previously detained under the Mental Health Act and identify as being Black British or of Black African or Caribbean heritage (including mixed ethnicity).
2. Are a carer/supporter of someone who is Black British, or of Black African or Caribbean heritage and has previously been detained under the Mental Health Act.
3. A member of staff/who is likely to be involved in the advance statements process i.e., community mental health team staff, advocate, peer worker, emergency department, an approved mental health professional, a General Practitioner, or an approved doctor.

**How will my information be kept confidential? / Limits to confidentiality**

Your information that you share during the co-production working groups will be kept strictly confidential and stored safely and securely in line with the UK General Data Protection Regulation (UK GDPR). However, confidentiality may have to be broken under the following circumstances:

1. You share information about unreported incidents of criminal activity or malpractice, or information that suggest you or someone else is at risk of harm
2. If you are a member of staff and discuss unreported malpractice, this will need to be disclosed to a member of the Advance Statements Project team.
3. If any participants are at high risk of self-harm/suicide/abuse, there will be limits to the research teams’ confidentiality and the research team may deem it necessary to share information with your/their care team or the relevant authorities relating to yours/their care.
4. There is overriding public interest which requires the research team to share information

Your data will be pseudonymised, meaning that any information you give us during the co-production working groups will not be identifiable. Your personal information that we collect such as your name and contact details, will be kept separately to the information from the co-production working groups – you will have a unique identification number that will be used for analysis. This personal data, however, will be kept until the end of the project so that we can invite you to take place in later stages of the project and feedback to you the results of the project. During the project your data will be stored on a secure network within the Institute of Psychiatry, Psychology and Neuroscience at King’s College London and may be used for future research. Only members of the Advance Statements Project team will have access to the full dataset and your personal data. Consent forms that are completed digitally via Qualtrics will only be accessible to the research team; and any consent forms completed on paper will be stored in a locked filing cabinet, separate from any information you share during the co-production working groups.

All data from the co-production working groups will be saved to the King’s College R:Drive.

The co-production working groups’ information dataset will be held at the Institute of Psychiatry, Psychology and Neuroscience, King’s College London for 15 years after the project has ended – this is standard practice.

**How will we use information about you?**

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.

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

It is possible that discussing your experience in mental health services and your experiences related to mental illness and mental healthcare as they relate to using an advance statement, may be upsetting for some participants. You will not be asked to disclose details about distressing personal experiences unless you choose to do so. If you feel uncomfortable, upset, or distressed during the co-production working groups you can take a break or leave; a member of the research team will be there to talk if you wish. You can also, after the co-production working groups, contact the Advance Statements Project research team (Abigail Babatunde: abigail.babatunde@kcl.ac.uk).

**Safeguarding/Limits of confidentiality**

If any participants are at high risk of self-harm/suicide/abuse, there will be limits to the research teams’ confidentiality and we will

**Are there any benefits of taking part?**

You may not personally experience any immediate benefits from taking part in this project. However, we expect the findings of the project will have many direct benefits for Black African and Caribbean service users, carers, and staff who wish to complete Advance Statements in the future. For example, the process of completing advance statements will be made easier for service users, carers, and staff, in particular people from Black African and Caribbean communities, in the future as they will be equipped with a useful resource that they can refer to based on the resource that you help create.

**Do I have to take part?**

No, you do not have to take part. Participation in this project is entirely voluntary – you should only take part if you want to. If you choose not to be involved in this project, it will not affect your access to care in any mental health service.

**What if I don’t want to take part in this project anymore?**

You can withdraw from the project at any time without giving a reason. If you do change your mind before the co-production working groups, we will withdraw any data you have provided us with. However, if you wish to withdraw after the co-production working groups have taken place, we will keep any data that we already have.

**Expenses and payments**

All service users and carers/supporters will be compensated with a £150 (£50 per day) voucher following completion of the co-production working groups. The research team can reimburse service users’/carers/supporters travel expenses upon request.

**What if something goes wrong?**

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 (Dr Claire Henderson – claire.1.henderson@kcl.ac.uk or Dr Shubulade Smith – shubulade.smith@kcl.ac.uk).

If you remain unhappy and wish to complain formally, you can do this through the SLaM Patient Advice and Liaison Service (PALS) on 0800 731 2864, pals@slam.nhs.uk.

In the event that something does go wrong, and you are harmed during the research, you may have grounds for legal action for compensation against King’s College London and/or SLaM NHS Foundation Trust, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

**What will happen to the results of this project?**

We will use the results in the next stage of the project, in which service users, carers and Trust staff will discuss the results and vote on recommendations on how we promote the use of advance statements in ways that work for Black people. All results will be anonymised. We will also:

* share the results with the participants, the rest of the research team, our steering committee, and advisory groups (service users, carers and Trust staff and manager teams) and
* publish the results in scientific journal articles – direct quotations will be used, but will be kept anonymous and you will not be identifiable
* present the results at conferences for mental health professionals, carers and service users.

**What are the next steps if I’m interested in taking part?**

If you are interested in taking part, or would like more information, please contact Abigail Babatunde at abigail.babatunde@kcl.ac.uk.

If you have any questions about the project, you can contact a member of the research team. You have [insert weeks] to decide whether you want to take part, or if you have made a decision, you can let a researcher know your decision. If you do decide to take part, the research team will then ask you to complete a consent form, either in paper format or we will send you a Qualtrics link to complete the form digitally. We will then let you know when the co-production working groups will take place.

**Who is organising and funding this project?**

This project is being organised by research in King’s College London and the South London and Maudsley NHS Foundation Trust (SlaM). This project is funded by the Maudsley Charity.

**Who has reviewed this project?**

This project has been reviewed by the Research Ethics Committee (REC) at King’s College London and the Bradford Research Ethics Committee (REC).

**Data Protection**

Your data will be processed in accordance with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you would like more information about how your data will be processed in accordance with the UK GDPR, you can find out more by:

* asking a member of the research team
* accessing the [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
* by contacting King’s College London Data Protection Officer, Mr Albert Chan at info-compliance@kcl.ac.uk
* by contacting SLaM’s Data Protection Office at dataprotectionoffice@slam.nhs.uk
* accessing the King’s College London research privacy notice - <https://www.kcl.ac.uk/research/support/rgei/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

The Maudsley Charity is funding this project. SLaM and IoPPN, King’s College London are the data controller and the data processor. Your personal data will only be processed for the purpose of the research outlined within this information sheet. The legal basis for processing your personal data for research purposed under UK GDPR is Article 6 (public task) and Article 9 (research).

You have the right to access and withdraw information held about you. Your right of access can be exercised in accordance with the UK General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability.

**Thank you for considering taking part in this project. Please discuss the information with your family, friends, or mental health team if you wish to.**

**Further information and contact details**

If you have any questions or require more information about this project, please contact:

Abigail Babatunde

Research Associate, Advance Statements Project

Health Services and Population Research Department P028, David Goldberg Centre,

King’s College London Institute of Psychiatry, Psychology and Neuroscience

De Crespigny Park, London, SE5 8AF

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