



## Advance Choice Document Implementation

### Work Package 1 Focus Groups

#### Participant Information Sheet – CAMHS Service Users:

**Version 1.1, Date: 03.07.2025**

**Project Title:** Advance Choice Document Implementation

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

We would like to invite you to take part in this project about the use of Advance Choice Documents (ACDs).

ACDs are documents that allow you to express your wishes for future treatment if you are in crisis or lose the capacity to make decisions. They help healthcare professionals understand what you would like them to do, and how to treat you, if you become mentally unwell. ACDs are used if you need to go to hospital or if you're detained under the Mental Health Act.

ACDs are made when someone is feeling mentally well, living in the community, and wants to make one. The South London and Maudsley NHS Trust (SLaM) is introducing the use of ACDs across its mental health services. The process of making one will be supported by a mental health professional independent of the treating team called a facilitator, who will ask the service user to consider what they would like written on the ACD. The facilitator will arrange meetings to get input from the mental health professionals in the person's community care team including their care coordinator and psychiatrist, and from anyone the service user wants to invite such as family/friends. The facilitator will check the ACD with the service user before it goes in their medical notes.

We are an independent team of researchers from King's College London. We will be evaluating whether the use of ACDs has an impact on people's experience of using SLaM services.

There are some mental health services, such as those for Children and Adolescent Mental Health Services (CAMHS), where ACDs have not been used before in SLaM. Part of the research we are doing is to understand young people's views on ACDs, to make sure they will be used in a way that works for everyone. We will hold focus groups to talk to people about their opinions and preferences around ACDs. We are inviting you to take part in these focus groups, as someone who has been detained ("sectioned") under the Mental Health Act and who has recent experience of mental health services for young people.

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## **What does taking part involve?**

You will be asked to attend a focus group. A focus group is a group discussion about a specific topic, usually led by a researcher. There will be a maximum of nine other people, who will also have experienced detention under the Mental Health Act whilst under the care of CAMHS.

Before the focus groups we will send you the current Advance Choice Document template, so you can familiarise yourself with the document. We can send it by email or post, depending on your preference.

The focus groups will be led by one or two people from the research team and held either at an agreed location or on Microsoft Teams. Even though this is not a student project, any postgraduate students involved in data collection will follow the study protocol.

During the focus group we will further explain what ACDs are; the current process for completing them; who is involved (professionals, staff, and carers/informal supporters); and why SLaM is using ACDs.

We will then lead a discussion, where you and the other participants can discuss:

- What you think of the current process of completing an ACD
- How you think this process could be improved
- The ways an ACD can be accessed
- How the Trust can ensure the requests written in ACDs are followed by staff
- When and how people review their ACD
- What you think of the document currently being used in the Trust

The focus group will last up to 1.5 hours, with a break in the middle. It will be audio recorded so that it can be transcribed (written down). Once the research team have approved the transcription, the audio files will be deleted.

Refreshments will also be provided for in-person meetings.

## **Who can take part?**

We are looking for people who have experience of being detained under the Mental Health Act, whilst under the care of CAMHS in SLaM.

You can take part if you:

1. Are aged 16- 25 years old
2. Have previously been detained under the Mental Health Act, whilst under the care of CAMHS
3. Are currently under the care of community mental health services (CAMHS / Early Intervention / Community Mental Health Team)

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You cannot take part if:

1. Are under 16 years or over 25 years old
2. You are currently being detained under the Mental Health Act
3. You are currently receiving inpatient care.
4. You are currently under the care of eating disorder services

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

We will need to use information from you, and as an option, your medical records for this research project. This information will include:

- Your name
- Initials
- Personal information
- Contact details (i.e. email address, phone number, home address)
- GP contact details (optional)

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.

SLaM and King's College London are the co-sponsors of this research and are responsible for looking after your information. We will share your information related to this research project with:

- Your GP (optional; you can still participate in the study even if you do not consent to this).
- An approved third-party transcription service 'Devon Transcription Services' to produce a transcript of your responses. The transcript won't include your name or any personal information, we will use your unique reference number instead

We will keep all information about you safe and secure by:

- Attaching a code number to all your data instead of your name, which only the research team can link you
- Storing consent forms completed on paper in a locked filing cabinet, separate from any information you share in the focus groups
- Saving any recording of completion of consent forms via Microsoft Teams or phone call on secure King's College London servers
- Using encrypted recording devices or Microsoft Teams stream for all audio files from the focus groups
- Giving you an option to choose whether to have your camera turned on or off during the focus group

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- Converting online video recordings into audio files and deleting the video footage

Anything discussed in the focus groups will be kept confidential, and only the research team will have access to it. 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 in distress while taking part, we may inform your GP/clinical care team
3. The Trust is obliged by law to share the information or are required to share the information in response to a court order
4. There is overriding public interest which requires the research team to share information

### **International Transfers**

Your data will not be shared outside the UK.

### **How will we use information about you after the study ends?**

Once we have finished the study, we will keep some of the data so that 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.

We will keep your study data for a maximum of 20 years. The study data will then be fully anonymised and securely archived or destroyed.

### **What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

If you wish to withdraw, before the focus group, we can delete any personal information you have shared if desired. However, if you decide to no longer take part after the focus group has started or taken place, we won't be able to delete what you have shared in the group as we won't be able to differentiate between different people and the information that they shared during the focus group. All this information will be anonymised so no one will know that it was you if you are quoted.



If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study [on Open Science Framework: <https://doi.org/10.17605/OSF.IO/PY5XE>]

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

You can find out more about how we use your information by:

- Visiting the HRA page: <http://www.hra.nhs.uk/patientdataandresearch>
- Visiting SLaM's privacy policy page: <https://slam.nhs.uk/privacy-policy>
- Asking a member of the research team via [acdi@kcl.ac.uk](mailto:acdi@kcl.ac.uk)
- Contacting King's College London Data Protection Officer at [info-compliance@kcl.ac.uk](mailto:info-compliance@kcl.ac.uk)
- Contacting SLaM's Data Protection Officer, Claire Delaney-Pope at [informationgovernance@slam.nhs.uk](mailto:informationgovernance@slam.nhs.uk)
- Accessing the King's College London research privacy notice leaflet: <https://www.kcl.ac.uk/research/support/rgei/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

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

It is possible that discussing experiences of mental health services, and experiences related to mental health, may be upsetting for some participants. You will not be asked to talk about distressing personal experiences at any time, and you choose what you will share. If you feel uncomfortable, upset, or distressed during the focus group you can take a break or leave; a member of the research team will be there to talk with you if you wish to. After the interview you can also contact the ACD Implementation research team at [ACDI@kcl.ac.uk](mailto:ACDI@kcl.ac.uk).

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

You will 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 children and young people who use mental health services, carers/supporters, and staff who wish to complete ACDs in the future. For example, your recommendations from these focus groups will help develop a useful resource that will make the process of completing ACDs easier for children and young people, carers/supporters, and staff in the future.

### **Do I have to take part?**

No, you do not have to take part. Participation in this project is completely voluntary, and 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 in any way.

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## Expenses and payments

For both online and in-person meetings, you will be reimbursed with a £20 voucher for your time. The research team can reimburse 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 (Prof Claire Henderson – [claire.1.henderson@kcl.ac.uk](mailto:claire.1.henderson@kcl.ac.uk) or Dr Shubulade Smith – [shubulade.smith@kcl.ac.uk](mailto: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](mailto: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 combine the results of this project with the results from other focus groups. We will use this information to adapt the process of making an ACD in CAMHS.

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)
- Publish the results in scientific peer-reviewed journal articles – direct quotations will be used but will be kept anonymous and you will not be identifiable
- Present the results at conferences and research clubs for mental health professionals, carers, and service users.
- Share the results on websites in an anonymised form
- Provide anonymised data to researchers who make reasonable requests

## 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 [ACDI@kcl.ac.uk](mailto:ACDI@kcl.ac.uk). Or if you have given consent to your care coordinator or another mental health professional for them to provide your contact information to the research team, we will contact you directly.

If you have any questions about the project, you can contact a member of the research team. Once you have made a decision, you can let a researcher know. If we have not heard

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from you in a week, we will follow-up with you via your preferred contact method to see if you would like to take part. If you do decide to take part, a researcher will then ask you to complete a consent form. Before you complete the consent form, the researcher will make sure that you understand what the project is about and what taking part involves. They will also answer any questions you may have.

If you would prefer to complete the consent form in person, you will meet with a researcher at an agreed location (such as a hospital, in the community, or at your home) and you will be asked to sign and date a paper consent form. There is also the option to be posted or emailed the consent form, which you would sign and date and then return to us. If you would prefer to give your consent via phone call or Microsoft Teams, the researcher will record you verbally giving your consent and then they will sign and date the form on your behalf. We will then let you know when the focus group 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 West Midlands-Coventry & Warwick NHS Research Ethics Committee (REC).

**Thank you for considering taking part in this project. Please discuss the information with your family, friends, supporters, advocates, 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 the research team: [ACDI@kcl.ac.uk](mailto:ACDI@kcl.ac.uk).