



Agency, Justice and Social Identity in Youth Mental Health – Phase 1

Participant Information Form: Interview Participant

Name of Chief Investigator: Michael Larkin

Invitation

We would like to invite you to take part in a research study.

Before you decide if you would like to participate, take time to read the following information carefully and, if you wish, discuss it with others such as your family, friends or colleagues.

Please ask a member of the research team, whose contact details can be found at the end of this information sheet, if there is anything that is not clear or if you would like more information before you make your decision.

Privacy notice

Your trust is very important to us. This means that Aston University and City University of London are committed to protecting the privacy and security of your personal information.

It is important that you read this notice so that you are aware of how and why we are using personal data. This privacy notice describes how we collect and use personal information about you during and after your relationship with us, in accordance with data protection law.

What is the purpose of the study?

Young people need mental health care interactions that involve them, address their needs and respect their agency. We want to learn how agency can be fostered in mental health care for young people.

Why have I been chosen?

You are being invited to take part in this study because you are a young adult (aged 18-25) who has spoken to a health professional about their mental health.

What will happen to me if I take part?

If you choose to take part in the study, you will participate in an interview with a researcher.

In this interview, you will not have to disclose anything specifically about your prior mental health experiences, but *we are interested in finding out about the best way to have these kinds of conversations with research participants*. If you think it would be distressing to talk about that, then you may prefer not to take part.

If you do choose to take part in the study, the interview will be recorded. No one outside the research team will have access to recordings or transcripts of the things you say unless you give your written consent.

Do I have to take part?

No. It is up to you to decide whether or not you wish to take part.

If you do decide to participate, you will be asked to sign and date a consent form. You would still be free to withdraw from the interview at any time without giving a reason. You can also contact us within 14 days of the interview, if you have concerns about the information you have shared: during that time, you can withdraw some or all of the interview data.

Will my taking part in this study be kept confidential?

Yes. A code will be attached to all the data you provide to maintain confidentiality.

Analysis of your data will be undertaken using coded data. The data we collect will be stored electronically on a secure encrypted hard drive, password protected encrypted server or secure cloud storage device.

Please note: if you tell the research team something that causes them to have concerns about immediate risks to your health and/or welfare, they may need to breach your confidentiality. They will discuss this with you, if they are concerned.

What data will we collect?

We will collect and process the personal information that you provide to us about yourself. This includes your name, contact information and affiliations.

We will also collect and process certain special categories of more sensitive personal information that you provide. This includes information you may share today about your health or mental health history, race or ethnicity, sex or sexual orientation, political opinions, and religious or philosophical beliefs. We will only record information that you choose to disclose, and we will only do so in order to help us to understand and contextualise your preferred ways of talking about your mental health experiences.

How will we use your data?

The personal information and special categories of information that you provide will be processed securely for the purposes of research on mental healthcare services for young people in the UK. You will also have the option to provide written consent for use of direct quotes, audio or video clips to be used in publications and reports, training of professionals, presentations, and/or online resources.

How long will we store your data?

The research team will retain the data we collect today for twenty years.

Lawful basis for processing your data

Aston University is the 'data controller' of this information. This means that Aston decides what your personal information is used for and the ways in which it is processed. Aston is an

educational and research establishment and in particular its educational and research activity is conducted in a public interest.

Who will we share your data with?

We will share the information you provide with individuals on the research team. No one outside the research team will have access to recordings or transcripts of the things you say unless you give written consent for these things to be shared outside the team.

What are the possible benefits of taking part?

There are no direct benefits to you. You may help us to identify solutions that will improve mental health care for young people.

What are the possible risks and burdens of taking part?

You will be participating in a conversation about sensitive mental health topics. You may end the conversation at any point if it becomes distressing. That conversation will be recorded.

What will happen to the results of the study?

The results of this study may be published in scientific journals, used for training purposes, and/or presented at conferences. Your identity will remain confidential. Recordings and transcripts will only be shared outside the research team if you give your written consent.

A lay summary of the results of the study will be available for participants when the study has been completed and the researchers will ask if you would like to receive a copy.

Who has reviewed this research?

This research has been reviewed and approved by the School of Life and Health Sciences Ethics Committee at Aston University.

Who is funding the research?

This study has been awarded an MRC AHRC ESRC Engagement Award. These awards support building cross-disciplinary communities around adolescence, mental health and the developing mind.

Who is involved in this research?

The interviews at Aston are overseen by Dr Michael Larkin. The wider project team also includes Prof. Rose McCabe and Dr Clara Bergen (City University), Rachel Temple (the McPin Foundation) and Prof. Lisa Bortolotti and Prof. Matthew Broome (University of Birmingham).

Further information

If the research team are unable to address your concerns or you wish to make a complaint about how the study is being conducted you should contact the Aston University Research Integrity Office at research_governance@aston.ac.uk or telephone 0121 204 3000.

v2. LARKIN. June 2021.

If you raise a concern with Aston about the way it has handled your personal information, you are entitled to lodge a concern with a supervisory authority. In the UK, the supervisory authority is the [Information Commissioner's Office \(ICO\)](#).

Contact information

If you have questions about the study, please contact:

Michael Larkin – Researcher | m.larkin@aston.ac.uk

Appendix A



Aston University takes its obligations under data and privacy law seriously and complies with the General Data Protection Regulation (“GDPR”) and the Data Protection Act 2018 (“DPA”).

Aston University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study. Aston University will process your personal data in order to register you as a participant and to manage your participation in the study. It will process your personal data on the grounds that it is necessary for the performance of a task carried out in the public interest (GDPR Article 6(1)(e)). Aston University may process special categories of data about you which includes details about your health. Aston University will process this data on the grounds that it is necessary for statistical or research purposes (GDPR Article 9(2)(j)). . Aston University will keep identifiable information about you for 6 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order 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 www.aston.ac.uk/dataprotection or by contacting our Data Protection Officer at dp_officer@aston.ac.uk.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).