

Blueprint

Service design for children and young people's mental health

Interview Information Sheet: Young People (16+)

My name is Claire and I would like to invite you to take part in a research study about services in England and Wales for children and young people experiencing common mental health problems. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

Part 1: Information about the research

➤ **Who will carry out this research?**

Researchers from the University of Manchester are carrying out this study along with co-researchers (young adults) with lived experience of mental health issues from the McPin Foundation. The researchers and co-researchers carrying out this research have all been checked by their employer to make sure they are suitable to work with children and vulnerable adults.

➤ **What is the purpose of the research?**

The Blueprint study aims to explore services available to children and young people in England and Wales who are experiencing common mental health problems. We want to find out how children, young people and their families find out about and access these services, what the services actually do, and what young people and families think about them. We would also be interested to find out if accessing services has been affected recently as a result of Coronavirus. We are also interested in speaking to those who, for whatever reason, were unable to, or did not want to, access these services.

➤ **Why have I been invited to take part?**

Because you have had contact with a mental health support service. We are inviting about 100 people to take part in this study including children and young people, parents and carers and people providing services across England & Wales.

➤ **Will the findings of the research be published?**

We will write reports and articles to share what we find out with people who use services, service providers and managers and people who fund services.

➤ **Who has reviewed the research project?**

All research is reviewed by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed and approved by South Central - Berkshire Research Ethics Committee (Ref: 20/SC/0174).

➤ **Who is funding the research project?**

This study is funded by the National Health Service (National Institute for Health Research).

➤ **What would I be asked to do if I take part?**

If you decide to take part we would like you to take part in an interview with a researcher. The interview would last about 60 minutes and we can arrange to chat by video or telephone call or, when social distancing rules allow us, at [insert service name] or at your home address. The interview will focus on your experience of finding out about and (if applicable) accessing the mental health support service, the types of help you have received there and what you liked or disliked about it. It will also be helpful for us to understand a little bit about the difficulties you are experiencing or have experienced in the past which led you to seek support.

During some interviews the researcher may be joined by a co-researcher from the McPin Foundation. The co-researchers on this project are young adults with lived experience of mental health issues who are helping us to conduct this research. We will ask you in advance if you are happy for the co-researcher to help conduct the interview.

Before the interview starts we will ask you to read and sign a consent form to confirm that you understand why you are taking part and that you are happy to do so. We will also ask for your consent to audio record the interview using an encrypted digital recorder. If you would prefer not to be recorded then please let the researcher know and they will take written notes instead.

➤ **What are the possible benefits and possible disadvantages of taking part?**

The study may not directly benefit you but we hope what you tell us will help the funders and providers of services to design and transform services for children and young people experiencing common mental health problems in the future.

Many people enjoy taking part in research but occasionally people can feel upset if they think about something that has happened to them. If this happened during the interview we would ask you if you would like to take a break or stop the interview completely. You don't have to talk about anything you don't want to and the interview can be stopped at any time.

➤ **Will I be compensated for taking part?**

To say "thank you" for your time in taking part in the interview we will send you a £10 high street gift voucher at the end of the interview. We will also cover the cost of any out of pocket expenses, e.g., travel expenses to the venue where the interview is taking place.

➤ **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part in the study. Your decision will not affect any services you receive. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

Part 2: Data protection and confidentiality

➤ What information will you collect about me?

In order to participate in the study we will need to collect information that could identify you, called “personal identifiable information”. Specifically we will collect:

- Your name
- Your gender
- Your ethnicity
- Your contact details
- Your mental health condition or diagnosis (where applicable)

We will also seek consent to record the interview (audio recording of voices only).

➤ Under what legal basis are you collecting this information?

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

➤ What are my rights in relation to the information you will collect about me?

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings. If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research provided with this information sheet.

➤ Will my participation in the study be confidential and my personal identifiable information be protected?

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind.

Your name and any other identifying information will be removed and replaced with a random ID number. Your contact details will be retained for up to 12 months after the study is completed in order to share research findings with you (if requested). Consent forms and research data (with names and personal information removed and stored separately from consent forms) will be retained for 10 years in a secure university archive.

If during a research interview information is revealed which indicates that someone might be hurt or in danger the researcher will need to share their concerns with the research principal investigator and any relevant governance and / or regulatory authorities.

Audio recordings will only be made on an encrypted and password protected digital audio recorder. Recordings will be downloaded and deleted from the device as soon as practicable after the interview is completed.

Encrypted audio recordings will be transferred to the transcription company who is an approved University of Manchester supplier using secure encrypted data transfer procedures. Transcripts will be checked and personal information removed by the researcher. Digital audio recordings will be deleted from the University password protected server on receipt of the completed transcript.

Please also note that individuals from The University of Manchester, NHS Trust or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

The University of Manchester requires researchers who are undertaking lone working (e.g., research fieldwork in the community) to use a SkyGuard MySOS device. This system requires the researcher to share the fieldwork address (i.e., your home address if we are visiting you at home) with their escalation contact (usually their line manager or administrator) and to record the address into the device using a voice memo. The SkyGuard devices can also be activated by a 3rd party (a SkyGuard operator) if they are concerned about researcher safety. When activated remotely in this way the device allows two-way audio, which is recorded. We need to inform you of this in line with data protection law.

What if I have a complaint?

➤ Contact details for complaints

If you have a complaint that you wish to direct to members of the research team, please contact:

Claire Fraser, Research Associate (Tel: 0161 306 7882 or email: claire.fraser@manchester.ac.uk) Or,
Professor Sue Kirk, Principal Investigator (Tel: 0161 306 7872 or email: sue.kirk@manchester.ac.uk)

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers then please contact:

The Research Governance and Integrity Officer, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by telephoning: 0161 275 2674 or by emailing: research.complaints@manchester.ac.uk.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to: The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information. Tel: 0303 123 1113 or Web: <https://ico.org.uk/make-a-complaint/>

In the unlikely event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Research Team Contact Details

If you have any questions, please contact the research team:

Claire Fraser, Research Associate,
University of Manchester
Tel: 0161 306 7882 / 07879 038149
Email: Claire.fraser@manchester.ac.uk

If you would like to take part in the study, please complete and return the Consent to Contact form enclosed or contact us using the details above.

Thank you for reading this information sheet.