

Blueprint

Service design for children and young people's mental health

Family Participation Information Sheet

We would like to invite you and your child to participate in a research study. Before you decide whether you would like 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 making a decision. Please discuss the information with your child and 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?**

A team of researchers from the University of Manchester and Cardiff University are carrying out this study along with co-researchers (young adults) with lived experience of mental health issues. The researchers and young person co-researchers carrying out this research have all undergone an enhanced Disclosure and Barring Service (DBS) check 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 for 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 and what their views are on them. We are also interested in speaking to children and families who, for whatever reason, were unable to, or chose not to, access these services.

➤ **Why has my family been invited to take part?**

Because your family has had contact with a mental health support service. We are inviting about 100 people to take part in this study including children, young people, parents, carers and service providers across England and Wales.

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

We will write reports and articles to share our findings with people who use services and those who fund and provide 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 NHS Research Ethics Committee 20/SC/0174.

Who is funding the research project?

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

➤ **What will we be asked to do if we take part?**

If you and your child want to take part, we would like to arrange for you to chat to a researcher. This 'research 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 the mental health support service or at your home address. We can arrange to interview you together or to interview you separately depending on what you both prefer.

The interview will focus on your family's experiences of finding out about and accessing support at the mental health support service, the types of help given and what you liked or disliked. It will also be helpful for us to understand a little bit about the difficulties your child is experiencing (or has experienced in the past) which led to your family seeking support. We would also like to explore whether service access has been affected recently by the Coronavirus lockdown.

During some interviews the researcher may be joined by a co-researcher. 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. The Co-Researchers are employed by The McPin Foundation.

Before the interview starts we will ask you to read and sign a parent/carer consent form and your child to read and sign an assent form to confirm that you both understand what participation involves and that you are happy to proceed. We will also ask you both to consent to audio recording the interview using an encrypted digital recorder. If you or your child 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 and your family but we hope it will help the NHS to design and transform services for children and young people experiencing common mental health problems in the future.

Many children and families enjoy taking part in research as it enables them to share their views about matters which affect them directly. Occasionally in research, children, young people and adults can feel upset if they think about something that has happened to them. If this happened we would pause the interview and ask if you wanted to take a break or stop the interview completely. You and your child will not have to talk about anything you don't want to and the interview can be stopped at any time.

➤ **Will my family be compensated for taking part?**

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

➤ **What happens if one of us does not want to take part or if we change our mind?**

It is up to you and your child to make a decision about taking part in the study. Your decision will not affect any services you or your child receives. If you want to take part (in a parent/carer interview) but your child does not want to, we can arrange to just interview you on your own. Similarly, if your child wants to take part (and you are happy for them to do so) but you don't want to, we can arrange to just interview your child.

If you and/or your child decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself or your child. However, it will not be possible to remove your family's data from the project once personal information has been removed as we will not be able to identify your specific

data. This does not affect your data protection rights. If you decide you do not want your family to take part you do not need to do anything further.

Part 2: Data protection and confidentiality

➤ What information will you collect about my family?

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

- Your name, gender & ethnicity
- Your contact details
- Your child’s name, gender, age & ethnicity
- Your child’s 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 child’s data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

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

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 research data protection notice provided with this information sheet.

➤ Will my family’s participation in the study be confidential and our personal identifiable information protected?

In accordance with data protection law, Cardiff University/University of Manchester are Data Processors 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.

Only the study team at Cardiff University/University of Manchester will have access to your personal information. Your names 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 complete in order to share research findings with you (if requested). Consent forms and anonymised (names and personal information removed) research data (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 be obliged to break confidentiality and share their concerns with the research principal investigator and any relevant governance and / or regulatory authorities.

Digital audio recordings will only be made on an encrypted and password protected digital audio recorder. Recordings will be downloaded and deleted from the device on return to University premises as soon as practicable after the interview is completed. Encrypted audio recordings will be transferred to the

transcription company (an approved University 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 Cardiff University/University of Manchester 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 and your child.

What if I have a complaint?

➤ Contact details for complaints (Cardiff University)

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

Dr Rhiannon Lane, Research Associate (Tel: 07879111344 or email: LaneRC1@cardiff.ac.uk)

Or,

Dr Nicola Evans, Principal Investigator (Tel: 02920 687298 or email: EvansNE@cardiff.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 and Innovation Services, Cardiff University, 30-36 Newport Road, Cardiff, CF24 0DE, by telephoning 02920 879 131 or by emailing resgov@cardiff.ac.uk.

If you wish to contact us about your data protection rights, please email inforequest@cardiff.ac.uk or write to: Assurance Services, Cardiff University, Friary House, Greyfriars Road, Cardiff, CF10 3AE 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. 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.

➤ Contact details for complaints (University of Manchester)

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 about the study please contact the research team:

Rhiannon Lane, Research Associate
Cardiff University
Tel: 07879111344
Email: lanerc1@cardiff.ac.uk

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

**If you are happy for your family 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.**