

**Blueprint**

**Service design for children and young people’s mental health**

**Interview Information Sheet: Young People (16+)**

My name is Rhiannon 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 and Cardiff University 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 the Coronavirus lockdown. 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 NHS Research Ethics Committee 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 your mental health support service or at your home address. The interview will focus on your experience of finding out about and (if applicable) accessing this 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. 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 your personal information such as your name 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 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?**

When you take part in the study we will ask for some 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 research data protection notice 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, Cardiff University is a Data Processor 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 will have access to your personal information. 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 (stored separately from consent forms and personal information removed) 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 Cardiff University supplier using secure encrypted data transfer procedures. Transcripts will be checked and fully anonymised (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 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.

**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:

**Dr Rhiannon Lane, Research Associate** (Tel: 07879111344 or email: [LaneRC1@@cardiff.ac.uk](mailto:claire.fraser@manchester.ac.uk))

Or,

**Dr Nicola Evans, Principal Investigator** (Tel: 02920 687298 or email: [EvansNE@cardiff.ac.uk](mailto: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:**

TheResearch 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](mailto:resgov@cardiff.ac.uk).

If you wish to contact us about your data protection rights, please email [inforequest@cardiff.ac.uk](mailto: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](https://ico.org.uk/concerns) about complaints relating to your personal identifiable information. Tel: 0303 123 1113

**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**](mailto:lanerc1@cardiff.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.**