**PARTICIPANT INFORMATION SHEET**

**Crisis care for children and young people with mental health problems: national mapping, models of delivery, sustainability and experience (CAMH-Crisis2)**

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the work is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Thank you for reading this.

1. **What is the purpose of this research project?**

This project aims to explore the provision of mental health crisis services currently available to children and young people up to the age of 25 in England and Wales, and examine how they are organised, perceived, and integrated within local care systems.

The first part of the project will:

* Map the provision of NHS, local authority, education and charity sector crisis services for children and young people across England and Wales
* Describe the services available
* Create a database of services
1. **Why have I been invited to take part?**

You have been invited because you are involved in the provision of dedicated crisis services for children and young people up to the age of 25, within England and Wales.

1. **What do you mean by ‘Crisis’ and ‘Crisis Services’?**

For the purposes of this work *crisis* is defined as ‘extreme psychosocial distress, with or without self-harm.’ *Crisis services* are the services provided in the statutory and non-statutory sectors to support the needs of those in crisis. These can be delivered in different settings, for example in the community, and in different formats, for example digital.

1. **Do I have to take part?**

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part.

If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights.

You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form. For example, you can close the web browser. It may not be possible to delete all data if it has already been anonymised.

1. **What will taking part involve?**

Taking part will involve completing a survey about the provision of child and adolescent mental health crisis care in individual services in England and Wales.

Access to the survey is via an online platform called Online Surveys, or as a Word attachment or hard copy.

Please contact the researchers (contact details are at the bottom of this information sheet) if you would prefer to receive a copy by email or post, or in a more accessible format. It is also possible to take part by telephone.

1. **What kind of information about services do you want?**

We want to find out what crisis services exist, who accesses them, how these services are organised, and what the services actually do.

1. **Can I get part-way through the online survey and return to it later?**

Yes, if you click save at the bottom of the survey page it is possible to leave the survey page and return to where you left off at a later stage by clicking the survey link again. When you click the survey link again it will take you to the first uncompleted page and allow you to finish the survey.

1. **What happens if I want to change my responses before I submit the survey?**

Whilst completing the survey it is possible to click the back button to go back and change responses. Once the survey is completed and submitted you will not be able to change your responses, but you can contact the project researchers (details below) to submit any additional information.

1. **What if I want to provide more information than there is room for?**

We have tried to provide open-ended text boxes to allow additional information to be added but if you want to tell us more about your service then please email the project researchers (details below).

1. **Will I be paid for taking part?**

No. You should understand that any information that you give will be as a gift and you will not benefit financially in the future should this research project lead to the development of a new treatment/method/test/assessment.

1. **What are the possible benefits of taking part?**

There will be no direct advantages or benefits to you from taking part, but your contribution will help us to better understand the crisis services that are available for children and young people in England and Wales.

1. **What are the possible risks of taking part?**

We do not foresee any risks from completing the survey.

1. **Will my taking part in this research be kept confidential?**

All information collected from (or about) you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see ‘What will happen to my personal data?’ (below) for further information.

In exceptional cases, the research team may be legally and/or professionally required to over-ride confidentiality and to disclose information obtained from (or about) you to statutory bodies or relevant agencies. For example, this might arise where the research team has reason to believe that there is a risk to your safety, or the safety of others. Where appropriate, the research team will aim to notify you of the need to break confidentiality.

1. **What will happen to my personal data?**

Both Cardiff University and The University of Manchester will act as joint Data Controllers for this research project.

Cardiff University and The University of Manchester are committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation.

Further information about Data Protection, including:

* your rights
* the legal basis under which Cardiff University and The University of Manchester processes your personal data for research
* Cardiff University’s and The University of Manchester’s Data Protection Policy
* how to contact the Cardiff University and The University of Manchester Data Protection Officers
* how to contact the Information Commissioner’s Office

may be found at:

<https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

<https://www.manchester.ac.uk/discover/privacy-information/data-protection/>

Data collected through the medium of Welsh will be translated through the Cardiff University approved translation service.

No personal data will be transferred to parties outside of the European Economic Area.

On download/receipt of the survey responses, the research team will anonymise all the personal data it has collected from, or about, you in connection with this research project, with the exception of your consent form. Personal data will be removed from the survey responses used for data analysis, and saved separately, securely and with restricted access. This data will be processed for the duration of the study (30th April 2025). Data collected in this project will be stored according to Cardiff University’s Research Records Retention Schedule for clinical or public health research. Data will be stored for a minimum period of 15 years after the end of the project or after publication of any findings based upon the data, whichever is later.

Your consent form will be retained according to Cardiff University’s Research Records Retention Schedule for clinical or public health research. Data will be stored for a minimum period of 15 years after the end of the project or after publication of any findings based upon the data, whichever is later.

Personal data may be accessed by members of the research team and, where necessary, by members of the University’s governance and audit teams or by regulatory authorities. Anonymised information will be kept for a minimum of 15 years according to Cardiff University’s Research Records Retention Schedule for clinical or public health research but may be published in support of the research project and/or retained indefinitely, where it is likely to have continuing value for research purposes.

If, after completing the survey you decide to withdraw from the research project, we will follow UK Government procedures around withdrawal of consent and delete any research data collected. It may not be possible to delete all data if it has already been anonymised.

Note that it will not be possible to withdraw any anonymised data that has already been published or in some cases, where identifiers are irreversibly removed during the course of a research project, from the point at which it has been anonymised.

1. **What happens to the data at the end of the research project?**

At the end of the project all of the data will be stored securely in Cardiff University’s Research Data Store and will be stored according to Cardiff University’s Research Records Retention Schedule for clinical or public health research. Data will be stored for a minimum period of 15 years after the end of the project or after publication of any findings based upon the data, whichever is later. After this time the data will be destroyed.

1. **What will happen to the results of the research project?**

It is our intention to publish the results of this research project in academic journals and present findings at conferences. Participants or organisations will not be identified in any report, publication or presentation.

1. **What if there is a problem?**

If you wish to complain, or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact the Principal Investigators for this study, Professor Ben Hannigan (hanniganb@cardiff.ac.uk) and Dr Clare Bennett (bennettcl3@cardiff.ac.uk).

If your complaint is not managed to your satisfaction, please contact Dr Jennifer Davies, Director of Research Governance, School of Healthcare Sciences, Cardiff University (DaviesJ@cardiff.ac.uk).

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

1. **Who is organising and funding this research project?**

The research is organised by Cardiff University, The University of Manchester, The University of Plymouth and Aneurin Bevan University Health Board with additional contributions from independent consultants. The research is funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research (HSDR) Programme (project number NIHR151811).

1. **Who has reviewed this research project?**

This project has undergone a peer review by the funder, the National Institute for Health and Care Research.

This research project has been reviewed and given a favourable opinion by the School of Healthcare Sciences Research Ethics Committee, Cardiff University (REC983).

1. **Further information and contact details**

Should you have any questions relating to this research project, you may contact the researchers during normal working hours:

Dr Leanne Sawle, Cardiff University

Email: SawleL2@cardiff.ac.uk

Telephone: 029225 14052

Address: 12.08, Eastgate House, Newport Road, Cardiff CF24 0YP

Claire Fraser, University of Manchester

Email: claire.fraser@manchester.ac.uk

Telephone: 0161 306 7882

Address: Division of Nursing, Midwifery & Social Work, School of Health Sciences, Faculty of Biology, Medicine and Health, Jean McFarlane Building, University of Manchester, Oxford Road, Manchester M13 9PL

**Thank you for considering taking part in this research project.**

**If you decide to participate, you will be able to download a copy of the Participant Information Sheet and Consent Form to keep for your records.**