

**Investigating How Dedicated Youth Worker Services for Young People with Physical and/or Mental Health Conditions are Organised, Provided and Experienced**

**Health + Youth Work Project**

**Participant Information Sheet (PIS): Parents/Carers**

**We would like to invite you to participate in a research study about youth work services for young people experiencing long term physical and/or mental health conditions.** Before you decide whether you should 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 about taking 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.

If it would be helpful, we can send you an audio recording of this information sheet or a copy of it in a larger font or in high/low contrast, please **contact Rosie or Claire**, the project Research Associates:

**To call Rosie: 0161 275 2431 or call/text/WhatsApp: 07584 284337**

**To call Claire: 0161 306 7882 or call/text/WhatsApp: 07721 528384**

**You can also email us at:** **healthandyouthwork@manchester.ac.uk**

**Part 1: About the research**

* **Who will conduct the research?**

The study is being conducted by researchers in the Division of Nursing, Midwifery and Social Work from the School of Health Sciences, at the University of Manchester. Researchers and practitioners from Manchester University NHS Foundation Trust, Cardiff University, University of Dundee, Nottingham Children’s Hospital and Greater Manchester Integrated Care Partnership are also supporting the research.

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

The study aims to find out what is the best way of providing youth work services to improve the health and wellbeing of young people (aged 11 to 25) who experience long term physical and/or mental health conditions. We want to understand what young people, parents/carers and different professionals think about these services.

* **Am I suitable to take part?**

We would like to invite you to take part because you and/or your child has had contact with a health and youth work service. We would value hearing your views about the service.

* **Will the outcomes of the research be published?**

The researchers will use the information from this study to develop a set of guidance that services can use to provide youth work services that can improve the health and wellbeing of young people with long term physical and/or mental health conditions. We will write reports and articles to share what we find out from speaking with young people, the parents/carers of young people with health conditions, and different professionals. We can send you a copy of the results if you would like this. All information reported will be anonymous. The research will also have a website where you can see updates, blog posts, articles and reports about the research, which will be available to the public. We hope to hold a webinar at the end of the research, to share our findings. This will be a public event, and you are welcome to join us.

* **Disclosure and Barring Service (DBS) Check**

The researchers carrying out this research have all undergone an enhanced DBS check (as determined by their School and obtained either via The University of Manchester or another external organisation), to make sure they are suitable to work with children and vulnerable adults safely.

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

The research has been given a favourable opinion by West of Scotland Research Ethics Service in the NHS Health Research Authority on 28th May 2025**,** who are a group of people who work to protect your safety, rights, wellbeing and dignity (REC Reference: 25/WS/0069).

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

The research is funded by the National Institute of Health and Care Research (NIHR).

**Part 2: What would my involvement be?**

* **What would I be asked to do if I took part?**

If you agree to take part, we would like to arrange for you to chat with a researcher. This ‘research interview’ would last about 60 minutes and can take place whenever and wherever is most convenient for you, e.g., at the health and youth work service or at your home address. Alternatively, you might prefer to do the interview online using e.g., MS Teams or Zoom, or over the telephone. The interview will focus on your experiences of the service, the types of help given to your child, what you liked and/or disliked and what you felt was helpful. It will also be helpful for us to understand a little bit about the reasons your child is receiving support from the service. We will ask for your consent to record what we talk about in our interview, using a University of Manchester approved encrypted digital audio recorder. If you would prefer not to be recorded, then please let the researcher know and they will take written notes instead. Before the interview starts, we will ask you to read and sign a consent form to confirm that you understand what your participation involves and that you are happy to proceed. With your consent, we will also collect demographic details about you.

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

To say “thank you” for your time in taking part in the study, we will send you a digital shopping voucher (e-voucher) worth £20 at the end of the interview, which you can spend in lots of different shops. 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.

**Harm**

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.

* **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. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form and/or asked to provide audio recorded verbal consent at the beginning of the interview if you agree to be audio recorded. Please note that you are free to decline being audio recorded. If you do consent to being audio recorded, you should always be comfortable with the recording process and are free to stop recording at any time. 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.

* **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 to provide youth work services that improve the health and wellbeing of young people experiencing long term physical and/or mental health conditions.

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

**Part 3. Data Protection and Confidentiality**

* **How will we use information about you?**

We will need to use information from you for this research project.

This information will include:

* Your name
* Your contact details

We would also like to collect some demographic details about you, such as your:

* Age
* Gender
* Ethnicity
* Information about your child’s health condition (where appropriate)

You **do not** need to agree to provide us with demographic data to take part in the study.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. This is known as pseudonymisation. Only the research team at the University of Manchester will have access to the key that links the ID number/code to your personal information.

**Audio Recordings**

If the interview is conducted through a videoconferencing or telephone call, I will read out each statement on the consent form to you and record your answers. This will be audio recorded using a University of Manchester encrypted digital recorder and will be kept separately from the interview recording.

Only audio recordings will be taken during the interview. If you would prefer to speak in a language that is not English, an interpreter will join us during our interview. Audio recordings will only be made on an encrypted and password protected digital audio recorder. Recordings will then be deleted from the audio-recorders. You do not have to consent / assent to audio recording the interview, in which case the researcher will take notes during the interview instead.

**Sponsor**

The University of Manchester is the sponsor of this research.

**Data Sharing**

The University of Manchester is responsible for looking after your information. We will share your information related to this research project with the following types of organisations:

* Our collaborators in the wider research team: Researchers and practitioners from Manchester University NHS Foundation Trust, Cardiff University, University of Dundee, Nottingham Children’s Hospital and Greater Manchester Integrated Care Partnership are also supporting the research. Only pseudonymised data will be shared with the wider research team therefore external collaborators will be involved in processing/sharing of pseudonymised data.
* The approved transcription companies (who will type up the audio recordings) have signed agreements with the University which includes confidentiality clauses.

Prior to giving consent to take part in the project, you **can contact Claire or Rosie** using WhatsApp (e.g., phone calls or text messages) to ask questions or to discuss the project. Additionally, any information you provide over WhatsApp to organise your interview, such as your personal email and home address, will be kept securely by researchers at the University of Manchester in a password protected document and deleted from WhatsApp once received. We advise you not to share information relating to physical or mental health over WhatsApp.

If you decide to do your interview online, your participation in this research will **not** be audio recorded in **[MS Teams/Zoom]** but your personal data will be processed by **[Microsoft/Zoom].** This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place.

So that we can provide the e-voucher as a thank you for your time, your full name and email address will be shared with our Finance department who will send the voucher to you. Your full name and email address will be securely retained by Finance for a period of up to 7 years for audit purposes only and then destroyed. It will not be used for them for any other purpose.

If information is revealed during a research interview, which indicates that you or someone else might be hurt or in danger, the researcher will need to inform the research principal investigator (Professor Susan Kirk) and any relevant individuals such as your GP, support worker, or any relevant governance and/or regulatory authorities.

The University of Manchester requires researchers who are undertaking lone working (e.g., research fieldwork in the community) to use the SafeZone app on our university mobile devices and follow safeguarding protocols for researcher safety. SafeZone provides a check in system which users can use to inform security personnel of their presence and location. When I check in using the app, my location will be shared with the app Security team. I will also need to share your address with Professor Sue Kirk, who is part of the research team for this project. The app also allows for direct communication with Security personnel. All data collected through SafeZone is stored securely and retained in accordance with the University's data protection policies. SafeZone is fully GDPR compliant.

Please also note that individuals from The 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 as a research participant.

**We will keep you safe and secure by:**

* Keeping downloaded audio recordings stored in a secured Research Data Storage and then deleted from the audio-recorder as soon as practicable after the interview is completed. Recordings of audio-recorded verbal consent/assent will be stored separately from the main recording of the interview on the RDS.
* Transferring encrypted audio recordings to transcription and translation (where necessary) companies who are approved University of Manchester suppliers, using secure encrypted data transfer procedures. Digital audio recordings will be deleted from the University password-protected file storage at the end of the study.
* Checking transcripts and removing personal information and replacing it with a false name and study ID number/code by me. The pseudonymised transcripts will be stored on a University of Manchester file storage and shared with other members of the research team via a password protected OneDrive folder for analysis purposes.
* Double password protecting the key (an electronic file containing information linking a unique ID number to your personal information) and making it only accessible to the University researchers. The document will be stored separately to interview and audio data. The key will be permanently and irreversibly destroyed at the end of the study (31.03.27). Once the key is destroyed your data will be fully anonymised.
* Any data sharing with the wider research team will occur by secure University of Manchester approved data sharing platforms.
* We will only use your fully pseudonymised direct quotes without your name or any other identifiable information in reports and publications.
* Any data collected for this study will not be used in future research or shared with others outside the research team.
* We will make sure that any feedback on the service will not be shared with or identify the service or members of staff in the service.

**How will we use information about you after the study ends?**

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will preserve a fully anonymised dataset (e.g., including interview transcripts and demographic information) in the University of Manchester Research Data Storage. Written consent forms and hard copies of research data will be stored in a secured locked cabinet at the University of Manchester premise.

We will keep your study data for a maximum of 5 years. The study data will then be fully anonymised and securely archived or destroyed.

Your contact details will be retained by the research team for up to 12 months after the study is completed to share research findings with you (if requested).

**What are your choices about how your information is used?**

* You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
* You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information by consulting our [Privacy Notice for Research.](https://documents.manchester.ac.uk/display.aspx?DocID=76236)

**If you would like more general information on how researchers use data about patients, please visit:** [**www.hra.nhs.uk/patientdataandresearch**](http://www.hra.nhs.uk/patientdataandresearch)

**What if I have a complaint?**

* **Contact details for complaints**

You can contact the research team (please see contact details below) if you have any complaints about the study at any time. Or you can contact, **Professor Susan Kirk, Principal Investigator (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:** TheResearch Governance and Integrity Officer, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by telephoning: 0161 306 8089 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/>

**Contact Details**

If you have any queries about the study or **if you are interested in taking part,** then please contact the research team

**To call Rosie: 0161 275 2431 or call/text/WhatsApp: 07584 284337**

**To call Claire: 0161 306 7882 or call/text/WhatsApp: 07721 528384**

**You can also email us at:** **healthandyouthwork@manchester.ac.uk**

**Thank you for reading this information sheet.**