

Enhancing CAMHS Referrals 2 (EN-CAMHS 2)

Participant Information Sheet – Children and Young People

You are being invited to take part in a research study. This research aims to develop a digital tool to improve Child and Adolescent Mental Health Services (CAMHS) referrals; so that children and young people receive the help they need as quickly as possible.

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 email if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

Who will conduct the research?

This research is being led by Professor Kathryn Abel, Director of the Centre for Women's Mental Health in the Division of Psychology and Mental Health & Co-Director GM.Digital, and Dr Pauline Whelan, Co-Director GM.Digital & Digital Health Lead in the Centre for Health Informatics, both at the University of Manchester. Greater Manchester Mental Health NHS Foundation Trust and Manchester University NHS Foundation Trust are also research partners.

What is the purpose of the research?

This research aims to develop a digital tool to improve the CAMHS referral process so that children and young people receive the help they need as quickly as possible. The EN-CAMHS 2 project builds on EN-CAMHS 1 (NIHR 131379). EN-CAMHS 1 was the first phase of this piece of work and involved consultations with over 100 CAMHS stakeholders to identify pain points in the current referral process and potential solutions to these. A digital solution was identified in EN-CAMHS 1 by participants, and the features of this solution were discussed in the EN-CAMHS 1 focus groups.

We are working on the EN-CAMHS 2 research project from now until November 2026. To achieve the above aim, we will:

- Develop national standards for a digital CAMHS referral process through focus groups and discussions with policymakers.
- Develop a tool which is usable, acceptable and accessible across different CAMHS through workshops with children and young people, families, Trust staff and referrers.
- Collect data from referrers in terms of usage and engagement with the digital tool.
- Complete a series of interviews with referrers to discuss the acceptability of usage and engagement with the tool.
- Compare rates of successful referrals i.e. referrals accepted into CAMHS with the tool and traditional referral processes i.e. not using the tool.

We are providing you with this information sheet because you:

- Are a child or young person aged 16-30 who has experience of being referred to CAMHS in the past 5 years.

- Are not currently receiving support from CAMHS.
- Are able to speak and understand written English at a relatively high level.
- Have good internet access to take part in the focus group.
- Have the capacity to consent to this research.

Data we collect in the focus groups will be used to help inform the next stage of our research which is to develop a digital tool which will be implemented across selected CAMHS. The focus group you are being asked to take part in aims to understand which features would be most important for us to include in the tool.

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

We would like you to take part in a focus group, consisting of around 6-10 people and at least two researchers. The other people in the group may be young people, parents or carers, referrers, for example General Practitioners (GPs), or school staff, professionals working in CAMHS. We anticipate that involvement and preparation for the focus group should take between 1 and 1.5 hours of your time. The group will be held over Zoom/Microsoft Teams and could take place between 10am and 6pm. The groups are designed to prioritise the features of the digital tool. These requirements have been previously identified through EN-CAMHS 1 which involved extensive consultations with CYP, families, key referrers and CAMHS professionals.

We would like to audio record the focus groups. All personally identifiable information will be removed during transcription i.e. writing up the audio recording, and the audio recording will be permanently deleted following transcription.

You will also be asked to complete an optional demographic questionnaire relating to age, gender, ethnicity and level of education achieved. You will be sent a word document of the demographic questionnaire to complete, once you have returned a completed consent form.

There are no direct benefits to you from taking part in this study, but the research is an opportunity to share your thoughts on requirements for the digital tool. We will be asking you about which requirements you think would be most important. We will not be asking you, or expecting you, to share any details about your own mental health or experience of care within CAMHS. We will also not be offering any guidance on the referral process. We appreciate that discussions about mental health may come up, or you may have experienced distress during the CAMHS referral process. If you find the focus group upsetting you will be encouraged to take a break and you will be free to leave the group at any time.

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, we would like you to complete the attached consent form and return it to GM.Digital@gmmh.nhs.uk If you decide to take part, you are still free to withdraw at any time without giving a reason and without detriment to yourself. As the data will be anonymised during transcription, we will not be able to remove your data from the research if you withdraw after the focus group. This does not affect your data protection rights.

If you decide not to take part, you do not need to do anything further, but you may want to inform the team by email, so we do not send you further messages.

Will I be compensated for taking part?

We will be paying you £25 for roughly one hour of your time, in line with the NIHR INVOLVE rates.

What information will you collect about me?

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

- Your name
- Your email address
- Your ‘CAMHS stakeholder’ status, e.g. whether you are CAMHS staff (including job title), collaborator, young person, key referrer (including job title) e.g. GP, teacher, community paediatrician, social worker, special educational needs co-ordinator, parent/carer, CAMHS commissioner or mental health lead.
- Demographic details (age, sex, ethnicity, highest qualification/s), if you are happy to share them.

We will also collect the following research data:

- The audio recording of you in the focus group. Audio recordings will be transcribed by a member of the research team, and any personally identifiable information will be removed then the recordings will be deleted. No personally identifiable information will be included in the notes from the focus group.

Under what legal basis are we collecting this information?

We are collecting and storing this personal identifiable information in accordance with UK 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, up until the point they are deleted.

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](#).

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, and your data will be looked after in the following way:

- The electronic consent forms will be stored securely on drives with password protection at Greater Manchester Mental Health NHS Foundation Trust and will only be accessed by the research team. Consent forms will be retained for 5 years.
- Your name, email address, and stakeholder status will be stored securely on drives with password protection at Greater Manchester Mental Health NHS Foundation Trust. This information will only be accessible by the Project Manager, Research Associate, and Principal Investigators. Your contact details will be deleted when they are no longer needed to contact you about the research e.g., after you have completed the focus group and we have provided you with the results of the research.
- The transcriptions of the focus groups will be anonymised, and stored securely using a password protected secure drive on the Greater Manchester Mental Health NHS Foundation Trust server. The recordings will be transcribed as soon as possible, any identifiers will be removed, then the recordings will be deleted. Transcription will be completed by members of the research team who will sign a confidentiality agreement.
- The research data, that does not contain your personal data, will be analysed by an experienced qualitative researcher and the results will be written up and published. Any quotes used from the focus groups will be anonymised. Research data will be retained for 5 years.

The data from the project may be looked at by members of the research team from the organisations involved: The University of Manchester, Greater Manchester Mental Health NHS Foundation, Manchester University NHS Foundation Trust, and the Anna Freud National Centre for Children and Families.

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.

So that we can reimburse you as a thank you for your time, your full name and email address will be shared with the Trust Finance department who will process the payment/voucher. Your full name and email address will be securely retained by Trust 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.

Who has reviewed the research project?

This project has been reviewed and approved by the University of Manchester Research Ethics Committee (insert ethics reference).

Who is funding the research project?

The research is funded by the National Institute for Health Research Health Services and Delivery Research (HS&DR) Programme.

Will the outcomes of the research be published?

The outcomes from the research will be shared with the National Institute of Health Research (NIHR), MQ Mental Health charity, Anna Freud centre, McPin Foundation, CAMHS.Digital, CAMHS Network, NIHR GM ARC, PLACE, Calm Connections, GMMH Media Team and NHS

partners. We will also publish our findings in academic journals, at conferences/webinars/events and share a summary with participants (e.g., via social media, project website, GM.Digital website).

What if I have a complaint?

If you have a complaint that you wish to direct to members of the research team, please contact the Project Manager by emailing: heidi.tranter@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 in the first instance, then please contact:

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 306 8089.

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.

How do I contact the researchers?

If you have any queries about the study or if you are interested in taking part, then please contact the researcher(s): GM.Digital@gmmh.nhs.uk

If you consent to take part, please send your completed consent form to:
GM.Digital@gmmh.nhs.uk

Thank you for reading this information.