Suicide risk during the transition of care from child and adolescent into adult mental health services

Information Sheet

Who will conduct the study?

The study will be conducted by the National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) based within the Centre for Mental Health and Safety, Division of Psychology and Mental Health, at the University of Manchester. It has been commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). The programme is funded by NHS England, the Welsh Government and other devolved administrations.

What is the purpose of the study?

Moving from child and adolescent into adult mental health services is a high-risk period for patients. Fewer than a third of young people with an ongoing clinical need transition from child to adult services with many discharged to primary care, continuing their treatment with child and adolescent services, or being left with no formal support. Evidence on the transition from child and adolescent into adult mental health services from a suicide prevention perspective remains limited. The main aim of the study is to reduce suicide risk during the transition of care, and improve safety for all young people in mental health services. More specifically, the objectives are to:

- Estimate how many patients under the age of 25 who died by suicide between 2018 and 2022 had moved from child and adolescent into adult mental health services, using existing routinely collected data;
- Highlight sociodemographic and mental health care characteristics within this group that services may wish to prioritise in their suicide prevention and quality improvement efforts;
- Review current clinical management to identify what is working well and what could be strengthened to help reduce suicide risk, and
- Gather feedback from patients, carers and clinicians on their experience of the move from child and adolescent into adult mental health services, to better understand how usual practice could be improved.

There are three parts to the study. In step 1, we will use information held by the NCISH to (i) estimate the number and proportion of patients under the age of 25 years who had their care moved from child and adolescent into adult mental health services and died by suicide in a five-year period (2018-2022), and (ii) identify sociodemographic and mental health characteristics that may help guide prevention for this group. In step 2, we will interview mental health professionals who have experienced the death by suicide of a patient whose care was transferred from child and adolescent into adult mental health services to

identify good practice and areas of improvement which could help to reduce suicide risk. In step 3, we will conduct anonymous online surveys (for people with lived experience, carers, and clinicians) to explore the differences in care and treatment young people experience before, during and after their move from child and adolescent into adult mental health services, and how this might affect suicide risk.

What information will be collected?

Step 1: analysis of NCISH data

Using the NCISH's patient suicide database, we will identify young people under the age of 25 who died by suicide between 1st January 2018 and 31st of December 2022 and moved from child and adolescent into adult mental health services. This UK-wide database holds information on the circumstances leading up to and surrounding the deaths by suicide of people under the recent (<12 month) care of specialist mental health services. The following variables which will be used to identify these deaths:

- Age in years;
- Has the patient ever been under CAMHS if under the age of 25 (i.e., historical transition);
- Had there been a transition from CAMHS to AMHS in the previous year (i.e., recent transition).

We will use this data to identify sociodemographic (i.e. sex, ethnicity, living circumstances) and mental health characteristics (i.e. diagnosis, clinical care history) that could be a focus of prevention in this group. This data will be pseudoanonymised.

Step 2: clinician interviews

In this stage of the study we will use information held by the NCISH to identify [a maximum of 12] mental health professionals who have experienced the death by suicide of a patient that they worked with in a clinical context. This patient:

- Had been in recent (12 month) contact with secondary mental health services;
- Was treated by either NHS or independently funded secondary mental health services in the UK;
- Died between the 1st January 2021 and 31st December 2024;
- Was aged the age of 25 years at the time of their death;
- Died within a year of transitioning from CAMHS to adult services.

Patient identifiable information (name, date of birth, date of death) will be included in the invitation to interview letter for the mental health professional to make them aware who the patient in question is, allowing them the opportunity to review clinical notes, if needed. The interview is not intended as any kind of incident review. It will last around 45 minutes and will explore the patient's transition between services, care settings, family involvement, safety planning, and how this potentially impacted their suicide. This will help us to identify what is working well and what could be strengthened to help reduce suicide risk. Interviews will be audio recorded on Microsoft Teams and transcribed for analysis. Audio

recordings will be deleted immediately after transcription. Data will be fully anonymised at the point of transcription and any patient identifiable information will be removed from the final transcript. We will not interview mental health professionals where the patient had opted out of their health data being used for anything other than care and treatment (i.e., people who have registered with the national data opt-out).

Step 3: online surveys

We will conduct anonymous online surveys with people with lived experience, carers, and clinicians to explore differences in care and treatment young people experience before, during and after their move from child and adolescent into adult mental health services, and how this might affect suicide risk. This will help us better understand how usual practice could be improved. The surveys focus on five themes (1) mental health and treatment, (2) care settings, (3) family involvement and decision making, (4) safety (including questions on suicidal thoughts, feelings or intentions), and (5) the transition process. Our eligibility criteria are (all must apply):

Patients:

- Aged between 16 and 25 years;
- Have been a patient of secondary mental health services in the UK and have moved from child and adolescent into adult mental health services in the last three years;
- Have experienced suicidal thoughts, feelings or intentions.

Carers:

- Aged 16 years and over;
- Family member/carer of a young person patient who has moved from child and adolescent into adult mental health services in the UK in the last three years;
- The young person has experienced suicidal thoughts, feelings or intentions.

Clinicians:

- Currently work in child and adolescent or adult mental health services in the UK;
- Have cared for patients who have (a) moved from child and adolescent into adult mental health services, and (b) experienced suicidal thoughts, feelings or intentions.

All responses will be completely anonymous, and participants may withdraw at any time by closing their web browser. However, it will not be possible to remove data from the study once a response has been submitted as they are collected anonymously, and we will not be able to identify specific data.

Under what legal basis are we collecting this information?

Information will be collected and stored in accordance with UK data protection law. These state that we must have a legal basis (specific reason) for collecting data. For this study, the specific reason is that it is

"a public interest task". According to GDPR Article 6 (1) (e), processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority (here, HQIP) vested in the controller. Additionally, GDPR Article 9 (2)(I) (processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy), is noted as the legal basis for processing.

What are participants rights in relation to the information collected?

There are a number of rights under UK data protection law regarding personal information. For example, people have the right to ask for personal information they believe we may hold about them and can request a copy of the information we hold about them, including audio recordings. However, as survey responses will be collected anonymously, it will not be possible to find or remove data once it has been submitted. The University of Manchester Privacy Notice explains more about these different rights and the way we use personal information to ensure we follow the law.

What will happen to the information we obtain?

In accordance with data protection law, the Healthcare Quality Improvement Partnership (HQIP) acts as the Data Controller for this study and is responsible for making sure personal information is kept secure, confidential and used appropriately. All study team members are trained with this in mind, and data will be looked after in the following way:

Interviews:

- Only the study team at The University of Manchester will have access to patient identifiable information for the purpose of interviewing clinicians;
- Audio recordings will be used solely to produce transcripts, after which all data will be fully anonymised;
- All personal identifiable information will be removed in the final transcript;
- Audio recordings will be stored securely on a study-specific drive on an isolated server that hosts an isolated network, i.e. the server is not connected to any other network or to the internet, until transcription;
- Audio recordings will be electronically shredded immediately after transcription.

Surveys:

- Survey data will be fully anonymous and individual responses will be treated as confidential;
- The survey will be hosted on a University of Manchester-approved platform and responses will be downloaded to a study-specific drive on an isolated server that hosts an isolated network;

- Only authorised study team members will have access to the information provided;
- The standard retention period for anonymous data is 5 years, after which it will be destroyed, according to the University of Manchester regulations;
- No data will be archived or shared with any other organisation.

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. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to study participants.

How will we use this information?

Findings will be published in a publicly available report. We will inform the Medical Directors of all Trusts/Health Boards providing secondary mental health services of the study findings and ask them to disseminate to clinical colleagues, as appropriate. Additional outputs may include infographics, short, animated videos of the key findings, and presentations at academic and professional conferences and meetings. Key findings will also be disseminated via the NCISH social media accounts (X, BlueSky, LinkedIn). Only aggregate data will be published.