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**Patient/ Carer/ Significant other: Participant Information sheet. This PIS should be read in conjunction with** [**The University’s privacy notice**](http://documents.manchester.ac.uk/display.aspx?DocID=37095)**’**

**Title: Mental health assessments and psychological therapies following self-harm**

We would like to invite you to take part in an online research study. Before you decide whether to take part or not, please take time to read the following information carefully. This information will help you to understand why the research is being done and what it would involve for you.

# What is the purpose of the study?

# Good quality mental health assessments (interviews with a doctor or clinician about what led to the hospital visit for self-harm) are an important part of patient care when people go to hospital after harming themselves. Clinicians may have the opportunity to develop a therapeutic relationship with the patient and evaluate their willingness to stay for further treatment. Patients and clinicians can develop care plans together and access psychological therapies that may prevent repeat self-harm episodes.

Evidence suggests that the psychological treatments and mental health assessments can be beneficial in reducing repeat self-harm. However, there are wide differences in the quality of care received by people after they harm themselves. Not everyone receives an assessment or referral to psychological services.

Much of the research conducted to date has used hospital data to investigate the relationship between mental healthcare and repeat self-harm or suicide. We do not know why there are wide differences across hospital services in the number of people who receive a mental health assessment or psychological therapy. This information is important to enable the design of better services for people who have self-harmed.

The aim this study is to find out what helps and does not help people receive mental health assessments and psychological therapies following self-harm. We will seek the views of hospital staff, people with personal experience of self-harm and carers/ significant others to meet this aim.

We also plan to explore patient and carer experiences and views of mental health assessments and psychological therapies.

# Why have I been invited?

# You have been invited to take part in this research as you are:

# Aged 18 and over;

# Have experience of the emergency department/ mental health services following self-harm; and/or

# Have experience of receiving psychological therapy following self-harm (accessing/ receiving); or

# Caring/ supporting a person with these experiences within the last two years.

**What will happen if I agree to take part?**

You will be invited to complete an online survey asking for your experiences of mental health assessments and psychological therapy following self-harm. There are no right or wrong answers; we are simply interested in your experiences, views, and opinions.

**What is the duration of the research?**

The survey should take around 20-40 minutes to complete but may take longer depending how much information you would like to share with us. There are three sections. Section 1 asks for some non-identifying information about you (e.g., age, gender, ethnicity). Section 2, asks for your experiences and opinions on mental health assessments; and Section 3, asks for your experiences and opinions on psychological therapy following self-harm. You can write as much or as little as you would like to share.

**What happens if I do not want to take part or if I change my mind?**

Taking part in the research is entirely voluntary. If you decide to take part you are still free to withdraw at any time without giving a reason. Your normal healthcare will not be affected should you decide not to take part or withdraw from the study. However, it will not be possible to remove your data from the project because it is anonymous and we will not be able to identify your specific data. This does not affect your data protection rights.

**Where will the research be conducted?**

The survey is available online. You can complete it anywhere as long as there is an internet connection and access to a laptop, computer, or mobile technology such as a phone or tablet.

**Informed consent**

Clicking continue on the survey indicates that you are aged 18 and over, understand the information, and are well enough to consent to participate in the study.

**What are the possible disadvantages of taking part?**

Some people may find it emotional talking about their experiences with mental health services. However, research suggests that taking part in research studies can be helpful for vulnerable groups, and that talking about suicide or self-harm does not raise the risk of further suicidal behaviour. If you become upset you can take a break any time. You can also finish the survey whenever you wish. Contact details of organisations where you can get support are provided along with the survey.

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

We are hopingthat the results of this study will contribute to the development of better hospital services for people who self-harm, and will thereby ultimately contribute to informing suicide prevention strategies.

**Will I be paid for participating in the research?**

Completion of the questionnaire is on a voluntary base, and as such you will not be paid for this time.

**Will I be told the results of the study?**

Due to the anonymity of the data, we will be unable to tell individual participants of the results of the study. However, we will provide summaries and infographics of the results on our websites (<http://www.patientsafety.manchester.ac.uk/> <http://research.bmh.manchester.ac.uk/cmhs/>). We aim to publish the results in academic journals and present the research at conferences.

**Will my taking part in this study be kept confidential?**

We will not request any identifiable information and a number will be used to identify your survey. We will ensure that you cannot be identified from the information. Any potentially identifiable information that may be in the comments will be removed from the survey. We hope to publish the results of the research in academic journals, and we may use direct quotes from the survey to illustrate themes but we will ensure that you cannot be identified from this information.

The study information will be handled following the principles of the Data Protection Act (2018). Any information in hard copy will be stored under lock and key in a restricted access area at the University of Manchester. Any information on computers will be stored on a secure password protected encrypted network that is backed-up daily. Individuals from the University of Manchester, NHS Trust 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.

**Will my data be used for future research?**

When you agree to take part in a research study, the information about you may be provided to researchers running other research studies in this organisation and the anonymised data may be used for future research studies. The future research should not be incompatible with this research project and will concern involvement of the public in research. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the [UK Policy Framework for Health and Social Care Research](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/)**.** This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you regarding any other matter or to affect your care. It will not be used to make decisions about future services available to you.

**What will happen to my personal information?**

In order to undertake this research, we need to collect the following personal information about you:

* Age
* Ethnicity
* The part of the UK that you live it.

You will not be identifiable by the information. Only the core research team will have access to your personal information. We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis upon which we are using your personal information is “public interest task” and “for research purposes” if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our [Privacy Notice for Research Participants](http://documents.manchester.ac.uk/display.aspx?DocID=37095).

The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures.

All researchers are appropriately trained and your data will be looked after in the following way: The study team at the University of Manchester will have access to your information. They will assign you a participant number on entry to the study. The data will be electronically stored on our secure password protected password for five years after the last publication which is in keeping with research best practice.

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. This is known as a Subject Access Request. If you would like to know more about your different rights, please consult our [privacy notice for research](http://documents.manchester.ac.uk/display.aspx?DocID=37095) and if you wish to contact us about your data protection rights, please email [dataprotection@manchester.ac.uk](mailto:dataprotection@manchester.ac.uk) or write to The Information Governance Office, Christie Building, 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](https://ico.org.uk/concerns), Tel 0303 123 1113.

*Complaints*

If you take part, we hope that you will find this a positive experience. However, if you have a minor complaint about any aspect of this study, you should ask to speak to the lead researcher, **LEAH QUINLIVAN, by emailing** [**leah.quinlivan@manchester.ac.uk**](mailto:leah.quinlivan@manchester.ac.uk)**, or telephoning 0161 275 0727,** in the first instance who will do their best to answer your questions.

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance, then please contact theResearch Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: [research.complaints@manchester.ac.uk](mailto:research.complaints@manchester.ac.uk)  or by telephoning 0161 275 2674 or 275 2046.

*Harm*

Although it is extremely unlikely, in the 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 and NHS Trust, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

# Who is organising and funding the research?

# The research is being organised by the NIHR Greater Manchester Patient Safety Translational Research Centre (Greater Manchester PSTRC). The Chief Investigators, based at the University of Manchester, are Professors Navneet Kapur and Roger Webb. The researchers on the team are Dr Leah Quinlivan and Dr Donna Littlewood. The lead researcher is Dr Leah Quinlivan. The research is funded by the NHS through the National Institute of Health Research.

# Who has reviewed the study?

# The study has been reviewed by the North West-Greater Manchester Central Research Ethics Committee (REC Reference number 18/NW/0839) and approval was given on the 17/01/19.

**Contacts for further information**

If you have any questions about the research, please contact the lead researcher Dr Leah Quinlivan, on 0161 275 0727 or leah.quinlivan@manchester.ac.uk. Thank you for taking the time to read this information.

Links to the with [The University privacy notice](http://documents.manchester.ac.uk/display.aspx?DocID=37095)