



Scottish Mental Illness Stigma Survey: Participant Information Sheet

1. Introduction

The Scottish Mental Illness Stigma Survey is the first national survey in Scotland designed to assess mental health stigma and discrimination experienced by people with severe, complex, and/or enduring mental illnesses. The aim of the study is to understand how people living with severe, complex, and/or enduring mental illnesses experience mental health stigma and discrimination, where they experience them most, and the impact this has on their lives and behaviours.

The study is being managed and conducted jointly by: Professor Simon Hunter, at Glasgow Caledonian University; Jo Finlay, Senior Research Manager at The Mental Health Foundation; and Lorraine Simpson, Managing Director at The Lines Between.

This research has been commissioned by See Me – Scotland’s national anti-stigma programme. The See Me programme in Scotland is at the forefront of international efforts to eliminate mental health stigma and discrimination. The programme aims to equip individuals, communities, practitioners, and organisations with the necessary language, skills, and confidence to talk about mental health and to take action to tackle stigma and discrimination.

Before you decide whether or not to take part in this survey, it is important for you to understand what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact the study team using the details below if you have any questions or would like more information.

2. What is this study about?

This study will help us to understand the stigma and discrimination experienced by adults with complex, severe and/or enduring mental illnesses in Scotland. Previous research has shown that people living with mental illnesses can experience stigma and discrimination in many areas of their lives and that the general public still stigmatise those with mental illnesses. This is a longstanding and persistent problem, especially for people with more severe mental illnesses.

The study will involve a survey which will ask questions about people’s experiences of mental illnesses, their experience of mental health stigma and discrimination and in which areas of life these have occurred. There has never before been a study carried out to explore these issues in Scotland.

3. What will the study be used for?

The data collected by this survey will be used by policy makers, service providers and change makers to develop policy recommendations and practical, solutions-focused interventions intended to change behaviours, cultures and enable action to eliminate mental health stigma and discrimination in Scotland.

This information that will be gathered is crucial to provide a deeper understanding of how people with experience of severe, complex and/or enduring mental illnesses experience stigma and discrimination and

what this looks like in Scotland. Without the evidence to show that stigma and discrimination still exists, and how and where it is experienced, it is difficult to challenge it.

This study aims to learn from those with lived experience and capture the evidence needed to support policy makers and practitioners to effectively challenge stigma and discrimination and help bring about lasting change. The research findings will inform the future direction of the See Me programme ensuring that its resources and efforts are focused where they are needed most.

4. Who are we looking for?

We are looking for adults (18+) who live in Scotland and who within the last 12 months have experienced stigma and discrimination because of severe, complex, and/or enduring mental illnesses including:

- Schizophrenia or other primary psychotic disorder
- Bipolar or related disorder
- Obsessive-compulsive or related disorder
- Disorder specifically associated with stress (e.g. post traumatic stress disorder)
- Dissociative disorder
- Feeding or eating disorder
- Personality disorder
- Severe and/or treatment-resistant depressive disorder
- Severe and/or treatment-resistant anxiety or fear-related disorder

We are inviting both people who have received a formal diagnosis, as well as those who have not been diagnosed formally but believe they may be experiencing one or more of these mental illnesses, to participate.

For this survey:

Stigma is defined as ‘The negative attitudes or beliefs based on a preconception, misunderstanding or fear of mental health and/or mental health problems.’

Discrimination is defined as ‘when a person performs an action, whether intentional or unintentional, that creates barriers and inequality for people with lived experience of mental health problems.’

5. What will I have to do if I take part?

If you are interested in taking part, you will first be asked to consent to taking part and will then be asked to complete a short online screening form which will ask some questions about your mental health to make sure that the study is a good fit for you – this should take no more than 5 minutes. If the study requirements meet your personal experiences, you will then be invited to complete an online survey that asks about experiences of mental health stigma and discrimination. Completion of this survey will take around 40-50 minutes and the answers will be anonymous. You can choose to complete the survey yourself online, have one of our researchers call you and go through the survey with you by telephone or on Zoom, or complete the survey with one of our researchers at the premises of the service provider that gave you this information sheet. This would involve the researcher supporting you to complete the survey, either by asking the questions and logging your answers, or being on hand to help whilst you complete it yourself.

If you choose to complete the online survey yourself, you will have the option of saving each section as you go. This means that you do not have to complete the whole survey at once – you can complete it over a number of sessions depending on how much time you have or for other reasons important to you.

If you take part in the research, you can halt your participation in the survey at any time. To withdraw from the research:

- If you choose to complete the survey yourself, online: Close the internet browser that you used to open the survey. We will presume that anyone who partially completes the survey has withdrawn from the research and when we reach the data analysis phase, will delete all responses where survey completion is halted part-way through.
- If you choose to complete the survey with support, via videocall or telephone: Tell the researcher during your call that you no longer wish to participate in the research. The researcher will ensure that any survey data collected to that point is destroyed.
- If you choose to complete the survey at the premises of a service provider: Tell the researcher during your participation that you no longer wish to take part in the research. The researcher will ensure that any survey data collected to that point is destroyed.
- If you decide you want to remove your data following completion: You have up to two weeks after completing the survey to request that your data is deleted, and after that it will not be possible. At the end of the survey, you will be given the opportunity to create a memorable password that is that you will recognise (day of birth and last three digits of your post code (e.g., 053AR) so that we can identify and delete your survey response if you wish us to. To remove your data in this way, please contact the research team using the details provided below.

6. What are the possible risks of taking part?

Whilst we hope that taking part in the study will be a positive experience, all studies involve some level of risk and inconvenience. The possible risks involved with this study are that the questions are about mental illnesses and stigma and discrimination; and you may be asked questions about experiences you might have found challenging or upsetting. The Mental Health Foundation has a clear safeguarding policy and processes in place to keep both participants and researchers safe during the research, in which all researchers involved in the study team are trained.

If you take part in the online survey, and experience distress because of the content, contact information for specialist support organisations will be made available to you. If you choose to complete the survey with support from a researcher (by telephone, video call or at a service provider location) then, before you take part, we will ask you for your name and contact telephone number. These details will be deleted immediately after the survey interview, unless there is a risk of harm to you or someone else, as described below. If you experience distress during the conversation, the researcher will pause the survey. The researcher will explain why the survey is being paused and discuss with you whether you would prefer to continue, take a break, or stop altogether. The researcher will signpost you to a number of specialist support organisations including the NHS Mental Health Hub.

If a researcher believes that during administering the survey that you are at risk of harming yourself or another person, the survey will be stopped and the researcher will discuss appropriate action with you, including contacting the emergency services. This will be done while on the call. If you stop the call and a researcher believes that you are at risk of harming yourself or another person, the researcher has a duty of care to contact the emergency services and give them your telephone number. This is the only circumstance under which your telephone number would be shared with a third party.

7. What are the possible benefits of taking part?

We can't promise the study will help you personally. However, the study will provide unique insights into the experiences of stigma and discrimination for people living with mental illnesses in Scotland.

The findings of the study will help to inform See Me's ongoing programme of work, and to inform policy and services to improve the lives of people living with mental illnesses. The research will also provide solutions-focused recommendations and insight into approaches that could be taken by individuals and organisations to tackle mental health stigma and discrimination.

Written reports of the study findings will be available from The Mental Health Foundation and See Me and a copy of the report can be requested from Jo Finlay (jfinlay@mentalhealth.org.uk).

8. What if there is a problem with the research?

If you are concerned about your participation in the survey and would like to speak with someone about the research outwith the study team, please contact:

Julie Cameron, Assistant Director, Mental Health Foundation: jcameron@mentalhealth.org.uk

9. What will happen to the information given during the study?

During the study we will collect your name, email and telephone number **only if you consent to this**. If you do provide these details in the consent form, your personal information will be separated from your survey answers, so you will not be able to be identified and your answers will be anonymous.

By providing your contact details in the consent form, you are agreeing to receive information about taking part in future research. You will be asked separately in the consent form whether the data you provide in this survey can be used in related future research studies. If you accept the invitation to receive information about future research, your information and contact details will be retained by named members of the research team in a secure databank for a period of five years. If you do not wish to receive this information, have your survey data used for future research, or to give your personal contact details, you can still take part in the survey. You will be able to download a copy of both this participant information sheet and the consent form from the online survey.

The survey data will be anonymised and a unique ID number will be created for each participant after consent to allow us to track the survey data in an anonymous way. Only the immediate study team will have access to this data and only they will carry out the data analysis. Data will be stored for a maximum of five years before being destroyed.

The study complies with the Data Protection Act (2018) and the General Data Protection Regulation (GDPR). The data controller is Glasgow Caledonian University. Information is being processed on the basis of Article 6(1)(e) of the General Data Protection Regulation and to perform a task carried out in the public interest. Enquiries specifically relating to data protection should be made to the University's Data Protection Officer (DPO). The DPO can be contacted by email: dataprotection@gcu.ac.uk. If you are unhappy with the response from the University, you have the right to lodge a complaint with the Information Commissioner's Office (ICO). The ICO can be contacted by email: casework@ico.org.uk.

GDPR also gives study participants the right to ask for their personal data to be erased. If you would like us to stop using your personal data, then you can contact the study team using the details below and ask for your personal data to be erased. However, it will only be possible to erase data that has not been anonymised and/or published. Further information about your rights can be found at: <https://www.gcu.ac.uk/dataprotection/rights/>.

10. Who has reviewed the study?

All studies involving human participants carried out at Glasgow Caledonian University are reviewed by an ethics committee. The role of the ethics committee is to protect the safety, rights, wellbeing, and dignity of study participants. This study was reviewed by the School of Health and Life Sciences departmental committee and given ethical approval on 9 November 2021 under the following approval code: HLS/PSWAHS/21/009.

11. What happens next?

If you are interested in taking part in the survey, you can do so online, or by telephone or video call. To take part in the online survey, please continue by clicking 'next' below. You will then be asked to:

1. Complete some **consent questions** that will tell us if you agree to take part in the survey or not, based on the information above. If you do not consent to take part in the survey, you will be directed to further signposting information.
2. Respond to questions about who you heard about the survey from and how you found out about it.
3. Complete some **eligibility questions** that will tell you if this research is suitable for you to take part in. If you are not eligible to take part in the survey, you will be directed to further signposting information.
4. You will then progress to the online survey, if you meet the eligibility requirements.

The first part of the survey will ask you some questions about what mental health illnesses that you have experienced over the last 12 months. Some people may find these questions sensitive and challenging to answer. The reason why we ask these questions first, before moving onto questions about experiences of stigma and discrimination, is so that we can get a better picture of your journey with mental health to give us context about how and where you have experienced stigma and discrimination.

If you would like to complete the survey with support (by telephone or videocall) from a researcher from the study team, please contact the study team using the email address below. You will be asked to give consent electronically or verbally if you choose one of these options.

12. How do I contact the study team?

If you have any questions about the survey, or wish to request a supported call to complete the survey, the easiest way to reach all team members is to use the following email address:

smistigmasurvey@thelinesbetween.co.uk

If you want to contact an individual member of the study team, please use the contact details below:

Jo Finlay: jfinlay@mentalhealth.org.uk

Lorraine Simpson: lorraine@thelinesbetween.co.uk

Derek Ewans: derek@thelinesbetween.co.uk

Simon Hunter: simon.hunter@gcu.ac.uk

Thank you for taking the time to read this information.