

INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: HR/DP-21/22-25892



Title of study

The Lancet Commission on Stigma and Discrimination in Mental Health – Lived Experience Survey

Invitation Paragraph

I would like to invite you to participate in this online survey, conducted as a part of the 'The Lancet Commission on Stigma and Discrimination in Mental Health'. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish.

You can contact the research team via the contact emails at the end of this information sheet if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

This study aims to collect the lived experiences of people with mental disorder regarding stigma and discrimination from across continents. The data collection takes place in the context of preparing the Lancet Commission on Stigma and Discrimination in Mental Health (LCS) report. The Lancet is a renowned medical journal, at the Lancet Commissions are reports on urgent and often neglected or understudied health issues.

The LCS report will summarise the current state and provide recommendations on how to reduce stigma related to mental health conditions. In this context, the lived experiences of people with mental health conditions will be collected through this online survey.

Why have I been invited to take part?

You are being invited to participate in this study because we invite people with lived experience of a mental health condition to take part in this survey, to help us collect perspectives for perspectives on stigma and discrimination from people with such lived experience across continents.

Do I have to take part?

No, participation is fully voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. If you choose to take part you will be asked to provide your consent. To do this you will be asked to indicate that you have read and understand the information provided and that you consent to your anonymous data being used for the purposes explained.

What will happen if I take part?

If you choose to take part in the study you will be asked to complete an online survey in which you are asked to describe your experiences regarding diagnoses, language/terminology related to mental health, impact of stigma and discrimination on your

life, experiences with anti-stigma interventions, and your opinion of how digital and traditional media contribute to stigma and discrimination. The information from this survey will be used to highlight the importance of reducing stigma and discrimination related to mental disorders worldwide. Completing this questionnaire should take approximately 15-20 minutes. If you wish to edit your responses before completing the survey, you can do so by scrolling back to the relevant question/s to change your response before pressing the “Done” button.

Your participation is fully anonymous. If you agree to take part you will complete a survey anonymously (please do not include any personal identifiable information in your responses). The research team or the person who sent you the invitation link will not know whether or not you have chosen to take part in this study.

What are the possible risks and benefits of taking part?

There are no anticipated risks in participating in the study. It is, however, possible that some participants might find reflecting on issues regarding stigma and discrimination upsetting. If completing this questionnaire causes you to feel upset or distressed, we encourage you to get support for this, for example by speaking about how you feel with a person you trust such as a member of your family or a close friend, seeking self-help resources (e.g. posters, booklets or leaflets) from doctor’s surgeries, local health centres, or self-help organisations, or on the internet, or by speaking to your doctor. For further guidance on support resources, you can also contact the Global Mental Health Peer Network (GMHPN; via Charlene.Sunkel@gmhpn.org) for peer support or signposting to options of support in your country/area. If relevant, the GMHPN can also escalate your query to a clinician for further consultation.

The information provided through the survey participation will help the study team develop recommendations to guide action locally, nationally, and globally to address mental health-related stigma and discrimination. If you wish to request a copy of the ‘The Lancet Commission on Stigma and Discrimination in Mental Health’ report, this will be available once published via our website (<https://indigo-group.org/the-lancet-commission-on-stigma-and-discrimination-in-mental-health-lcs/>).

Data handling and confidentiality

Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018).

This research is anonymous. This means that nobody, including the researchers, will be aware of your identity, and that nobody will be able to connect you to the answers you provide, even indirectly. Your answers will be treated confidentially and the information you provide will not allow you to be identified in any research outputs/publications.

Your data will be held securely by the research team as password-protected electronic files, on secure servers. Your research data will be stored for a period of 7 years following the completion of this study, in line with King’s College London’s data retention schedule.

Your anonymous research data will be used by the immediate research team, and also possibly researchers who are not a part of the immediate research team. Any such use of

data would be reviewed and approved by a research ethics committee, and would be shared in line with appropriate data sharing agreements. In such cases, as with this project, data would/would not be identifiable in any report.

Data Protection Statement

If you would like more information about how your data will be processed under the terms of UK data protection laws please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

What if I change my mind about taking part?

You are free to withdraw from taking part without having to give a reason. Once you have started completing the questionnaire, you are free to change your mind and stop participating by leaving your questionnaire unfinished and closing the page. You do not need to give any reason for this, and withdrawing from the study will not affect you in any way.

Once you submit the survey by clicking on the “Done” button at the end of the survey, it will no longer be possible to withdraw from the study because the data will be fully anonymous (i.e. it is not possible for us to identify your data in order to remove it).

What will happen to the results of the study?

The results of the study will be summarised in the ‘The Lancet Commission on Stigma and Discrimination in Mental Health’, and our research findings will be disseminated through publications and conferences as relevant. We also intend to share our findings via platforms such as our study website (<https://indigo-group.org/the-lancet-commission-on-stigma-and-discrimination-in-mental-health-lcs/>) and other relevant online platforms (e.g. <http://www.centreforglobalmentalhealth.org/> and www.gmhpn.org).

Who should I contact for further information?

If you have any questions or require more information about this study, please contact us using the following contact details:

- Graham Thornicroft; graham.thornicroft@kcl.ac.uk
- Charlene Sunkel; Charlene.Sunkel@gmhpn.org

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

- The Chair, Health Faculties Research Ethics Sub-Committee, rec@kcl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.