



Study Information Sheet for Participants

Study topic:	What research questions would you like answered about paranoia?
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Department:	Department of Psychiatry, University of Oxford

You are being invited to participate in a research study. Before taking part, it is important that you understand why the research is being done and what participating will involve. Please read the information below carefully and discuss it with others if you wish. Please feel free to ask about anything you find unclear. The researchers will be very happy to give any further information and answer any questions you may have. Once you have read this sheet you will be asked for your consent to take part in this study prior to completing the online or hard copy questionnaire by reading and completing the consent form.

What is this study about?

Many people experience mistrustful or suspicious thoughts, including worries that others are deliberately trying to harm them. The technical term for these worries is paranoia. Whilst we recognise that paranoia can occur widely across the population, we would like to focus on the views on research priorities of people who feel very certain that they are being persecuted. We are interested in the experiences of both people with lived experience who attend/attended mental health services and people with lived experience who do not attend mental health services. We also want to understand the research priorities of family members, NHS (or other mental health service) mental health professionals, and researchers. We want to know which issues people would like to be addressed and which research questions they feel should be prioritised. There has been no research priority setting on this so far. Therefore, the aim of this study is to create a list of the key questions for paranoia research. The list will be published for the research community. This study is being carried out as part of a doctorate.

Who can take part?

People who self-identify as having lived experience of severe paranoia, family members, NHS (or other mental health service) mental health professionals, and researchers may take part. People with lived experience of severe paranoia may be currently experiencing severe paranoia, or have experienced it in the past. If you have any queries, would like further information about the research study, or would like to participate, then please contact David Sher using the contact details listed at the end of this document.

Do I have to take part in this study?

No. Participation in this study is completely voluntary. Even if you complete the informed consent form, you can change your mind and leave the study at any point, without any negative consequences for you. If you wish to withdraw your data from the study, and have listed an email address to facilitate the researchers being able to link your questionnaire with your request, your personal data will be deleted. If you have not listed an email address, it is likely you will be unable to withdraw your data as there will be no means of linking your request with your questionnaire response. However, the researchers will make every endeavour, where possible, to comply with such requests for withdrawal of data.

What will taking part involve?

If you decide to take part in this study, you will be invited to complete a questionnaire. The online questionnaire will capture your role (i.e. whether you are: a person who attends/attended mental health services who self-identifies as having lived experience of severe paranoia; a person who does not attend mental health services who self-identifies as having lived experience of severe paranoia; a family member;



an NHS/other mental health service mental health professional; a researcher; a combination of these). To contextualise the study, you will be asked your gender, age, ethnicity, and the UK region in which you live; these questions are optional and you do not need to answer them if you prefer not to. You will be asked to list questions on paranoia you would like to be answered by research. If you leave your email address, it is possible that you will be invited to participate in a second questionnaire, where you will be asked to rank questions in order of importance. You may also be invited to take part in a priority-setting workshop, where you will have the opportunity to relay insights concerning severe paranoia and join other representatives of the different groups of people in collaboratively approving a final list of top research questions for research on severe paranoia. Participation in the workshop and the questionnaires is entirely voluntary. Similarly, you may choose to participate in one phase of the study and to not participate in another phase. We welcome several suggestions per question, however if you feel you are only able to suggest one or two research questions, this would be valued as well.

What will happen to the study's results?

Information entered on the online questionnaire(s) will be saved and/or printed. The questionnaire PDF will be stored securely and anonymised to remove any identifying information other than a unique participant identification number. The researcher will include research questions from those who have participated when the results of the study are written up. It will not be possible to identify who said what, as questions will be anonymous. If there are any questions that you do not want to be used in the study then you can let us know by contacting a member of the team at a later time, using the contact information listed at the end of this information sheet. We will store the de-identified research data and any research documents with personal information securely at the University of Oxford for five years after the end of the study. All data collected will be kept strictly confidential. The personal information collected will be used to carry out academic research in the public interest. The study's results may be submitted in academic or professional journal articles, books and/or presented at conferences. For further information, you can consult the data protection webpages of the University of Oxford at <http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/>

What are the possible benefits of taking part in the study?

We hope that this study will give people an opportunity to discuss their views on research questions relating to severe paranoia. Some people may find it helpful to convey their views on questions that are important to them. This research will help clinicians and researchers to develop a better understanding of views on research questions on severe paranoia. We hope that this might lead to future research into improving treatments that will facilitate recovery.

What are the risks of taking part?

There are no social, financial, legal, physical or psychological risks involved in taking part in this study. We have designed this study to ensure that you will feel no discomfort. It may be worth noting that sometimes reflecting on past experiences can be challenging. As such, you will be able to end participation at any point if you do not wish to continue.

Who can I contact for further information?

If you have any questions, or would like more information, you can contact the chief investigator, David Ariel Sher (email: david.sher@psych.ox.ac.uk telephone: +44 (0) 7874129928) or his supervisors, Professor Daniel Freeman (email: daniel.freeman@psych.ox.ac.uk telephone: +44 (0) 1865 613109) and Dr Felicity Waite (email: felicity.waite@oxfordhealth.nhs.uk telephone: +44 (0) 1865 618192).

Thank you for taking the time to read this information sheet.