

FIRST QUESTIONNAIRE – HARD COPY

An initial identification of important research questions about severe paranoia: what research questions would you like answered about paranoia?

Welcome! Please find a summary of our study below.

Contact details

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Summary of study

Aim - *The aim of this study is to identify potential research questions for understanding and treating severe paranoia in the context of psychosis.*

What is severe paranoia? – *Paranoia is a form of mistrust. We're interested in severe paranoia, which is excessive mistrust. The severest form of paranoia is persecutory delusions, which refers to the exaggerated belief that others want to harm the individual. Such beliefs could include the strong conviction that others want to physically hurt the person, or try to hurt them socially.*

Who do we want to hear from? - If you are:

- 1) *A person who attends/attended mental health services with lived experience of severe paranoia;*
- 2) *A person who does **not** attend mental health services, with lived experience of severe paranoia;*
- 3) *A family member of someone who has experienced severe paranoia at any point in their lives;*
- 4) *An NHS (or other mental health service) mental health professional who has, or is currently, caring for someone with severe paranoia;*
- 5) *A researcher;*
- 6) *A person matching more than one of the categories above,*

...then we want to hear from you about research questions!

What do we want to know? - *We would like to know if there are certain issues that you feel should be addressed, and if so which research questions should then go on to be prioritised. Whilst we recognise that paranoia can occur widely across the population, we want to focus on the experience when individuals feel very certain that they are being persecuted. There has been no research priority setting on this so far.*

What are we asking you to do? - *We are asking you to complete the very short questionnaire below.*

What else happens in this research study? - *There will be two questionnaires. The first will be used to gather potential questions. After screening, the questions will be refined and placed into a second questionnaire. In this second questionnaire, the same participant groups will be asked to rank which questions they feel should be prioritised. Finally, representatives from each participant group will meet*

in a workshop and establish a list of research questions for severe paranoia. This research is being carried out as part of a doctorate project.

You may read the participant information sheet by accessing it from the main survey weblink. By submitting this questionnaire, you confirm that you have read the participant information sheet and consent to take part in the study. Please print, complete, and post this questionnaire to David Sher, Department of Psychiatry, University of Oxford, Warneford Hospital, Oxford, OX3 7JX, United Kingdom

CONSENT FORM

Please tick the boxes below to indicate your consent.

By submitting the questionnaire:	<i>Please tick the boxes below if you agree</i>
1. I confirm that I have read and understood the information sheet for this study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	<input type="checkbox"/>
3. I understand that data collected during the study may be looked at by authorised individuals from the University of Oxford, from regulatory authorities, and from Oxford Health NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	<input type="checkbox"/>
4. I understand that my questionnaire responses (and/or workshop contributions) will be recorded and that anonymised quotes may be used in research reports, publications, and presentations.	<input type="checkbox"/>
5. I agree to take part in the above study.	<input type="checkbox"/>
Date:	

Survey

We would like you to come up with questions based on your personal experience but that can be relevant to other people's experience as well.

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.

Question 1

What research questions on the **treatment** of severe paranoia do you think should be answered?

(Treatment may include medication, talking therapies, and other therapies etc.)

Please write these questions in the box below.

Question 2

What research questions on the **impact** of severe paranoia do you think should be answered?

(Impact might include physical and emotional impact, impact of paranoia in the workplace, and/or impact on family, relationships, friends, relaxation etc.)

Please write these questions in the box below.

Question 3

What research questions on **recovery** from severe paranoia do you think should be answered?

(By recovery we mean paranoia having little or no impact on one's life)

Please write these questions in the box below.

Question 4

What research questions on **how people view** severe paranoia do you think should be answered?

(This can include stigma, stereotypes, or the way family, professionals, psychologists, friends, the media, and the general public talk about or view severe paranoia)

Please write these questions in the box below.

Question 5

What research questions on **managing and living with** severe paranoia do you think should be answered?

Please write these questions in the box below.

Question 6

What research questions on **NHS (or other mental health service) services** for people with severe paranoia do you think should be answered?

(This can include what would be helpful for service providers to implement to be able to better relate, interact, and communicate with people with severe paranoia)

Please write these questions in the box below.

Question 7

Are there any other research questions on severe paranoia that you think are important to address?

If so, please write these questions in the box below.

Background information

Please now tell us a little about yourself.

A. Please select one or more of the following categories (please circle the correct answer/s):

I am:

A person with lived experience of severe paranoia who attended/attends mental health services

A person with lived experience of severe paranoia who does **not** attend mental health services

A family member of someone with lived experience of severe paranoia

An NHS (or other mental health service) mental health professional

A researcher

Other; please specify:

B. How would you define your gender? (please circle the correct answer)

Prefer not to say

Male

Female

Other, please specify:

C. What is your ethnic group? (please circle the correct answer)

Prefer not to say

White – English/Welsh/Scottish/Northern Irish/British

White – Irish

White – Gypsy or Irish Traveller

Any other White Background

Mixed/multiple ethnic groups – White and Black Caribbean

Mixed/multiple ethnic groups – White and Black African

Mixed/multiple ethnic groups – White and Asian

Any other Mixed/multiple ethnic group background

Asian/Asian British – Indian

Asian/Asian British – Pakistani

Asian/Asian British – Bangladeshi

Asian/Asian British – Chinese

Any other Asian background

Black/African/Caribbean/Black British - Black/African

Black/African/Caribbean/Black British - Black/Caribbean

Any other Black/African/Caribbean background

Arab

Other ethnic group, please specify:

D. What is your age? (please write this in the box below or circle ‘prefer not to say’)

Prefer not to say

E. Where do you live? (please circle the correct answer)

Prefer not to say

England – East

England – East Midlands

England – Greater London

England – North East

England – North West

England – South East

England – South West

England – West Midlands

England – Yorkshire

Northern Ireland

Scotland

Wales

Other country, please specify:

Important note

We would like to invite you to participate in the next phase of this study. If you are happy to do so, please write your email address in the box below:

Once completed, please post this questionnaire to:

David Sher, Department of Psychiatry, University of Oxford, Warneford Hospital, Oxford, OX3 7JX, United Kingdom

Thank you for your time.