



Research Participant Information Sheet (PIS)

Understanding the Experience of Psychosis

You have been sent this information because a member of your clinical team suggested you as someone who might be interested in being invited to take part in this research study.

Before you decide whether or not to participate, it is important that you know the purpose of the research and what it will involve. Please take time to read the following information and feel free to ask the researcher any questions you may have.

What is the purpose of the study?

The purpose of the study is to understand more about the experience of psychosis, which can involve hallucinations, delusions and / or intense beliefs or fears, by talking to individuals who experience it. The research is being carried out by the Division of Psychiatry, University College London, and led by Dr Vaughan Bell.

What is involved if I decide to take part?

Taking part in this project will involve meeting a researcher or a postgraduate student who is working with the research team who will ask you to complete some brief questionnaires before interviewing you. The meeting should take approximately one hour. This will happen only once and you won't be asked to volunteer any more of your time.

For the interview, there are no questions that you are required to answer but the interviewer will ask about your own experience and opinions on your experience of psychosis, hallucinations and / or unusual experiences. The interviewer will have a list of possible questions in front of him or her, but these are only a guide; and you can discuss your experiences in whichever way you wish.

The interview will be recorded, transcribed and all personal details removed from the text, so no one will be able to identify you from the text. We will then delete the recording.

We definitely do not expect you to discuss any topics that you don't want to. If you are asked any questions in the interview that you'd rather not answer, please say so and the interviewer will move on to a different question.

The meeting will take place either at an NHS site or at the University at a time and place most convenient for you. You can stop the meeting at any time without giving a reason.

What are the possible benefits of taking part?

Although some people find it helpful to talk about their experiences of psychosis, there are unlikely to be any direct benefits to taking part. However, you will be contributing to a better understanding of mental health problems, which will help to inform researchers, clinical staff and the public about what the experience of psychosis is really like.

What are the possible disadvantages and risks of taking part?

Talking about your experiences in your own way is unlikely to cause any particular difficulties. Very occasionally, people find something they mention unexpectedly upsetting, and if this happens we can talk to your care team on your behalf to have someone discuss it with you if this would be helpful.

Do I need to take part?

No, you do not need to take part, it is entirely your choice, and deciding or not deciding to take part will not affect your care in any way.

If you do decide that you are happy to take part in this study, the researcher will arrange the interview at a time and place convenient for you. In order to arrange the interview, you may consent to give your contact details to the researcher, who will delete them after you have taken part. Nobody outside the research team will ever have access to these details.

If you'd like to get in touch with the researcher for any reason, please use the contact details at the end of this form.

If you agree to participate, you will need to sign a consent form, which you will be given at the time of the interview.

Will anyone be able to find out what answers I give?

Firstly, we will not tell your doctor or clinical team what answers you give. They are entirely confidential. The only exception to this is if you tell us something that suggests there is an immediate risk to your safety or someone else's safety, then we have to pass the information on to your clinical team.

All data is stored anonymously with no personal details. This is how we do it:

Each interview will be recorded. One of the researchers will type up the interview but they will not include any information that could identify you, such as names, addresses or personal details. The recording of the interview will then be deleted.

Instead of your name or personal details, the typed-up interview and the answers you give on the questionnaire will be given a unique number so no one can work out who gave these answers.

We store the information sheets or any contact details separately from the numbers so after the recording is deleted the information you have provided will be anonymous.

Expenses and payments

We are offering £10 to compensate people who volunteer their time to participate in the interview.

What if I want to leave the study?

If you should want to stop participating in this study, you can withdraw at any time without providing a reason. Your decision will be respected. Any data that is collected before it becomes anonymised will be deleted. Your payment won't be affected.

What happens to the results of the research?

The findings from this study will be analysed by the research team and written up into papers for presentation at conferences and for publication, without any reference to any named individual and no-one who take part will be identifiable from the results. The results may also be used by postgraduate students who work with our research team who may include the results in their dissertation in the same way – so no one can be identified from the results they report.

Any encrypted audio or questionnaire data that is recorded will be kept by the chief investigator until it reaches UCL where it will be secure as per the data protection and security requirements of UCL and the NHS.

We feel that it is important that you are able to access the research findings and we welcome your feedback. If you would like to request wider information about the study and the findings so far, please contact the researcher using the details below.

Who has reviewed the study?

This research has been reviewed by the London-Dulwich Research Ethics Committee (IRAS ID 210323). It is being funded by University College London and a charity called the Wellcome Trust.

Contact for further information

If you have any questions, concerns or complaints regarding this project, please contact the researcher Dr Vaughan Bell, the study's lead investigator, on 07816 170 658 or at the email address: Vaughan.Bell@ucl.ac.uk

If you wish to complain formally, you can do this through Noclor Research Support with the form found on this page:

<https://www.noclor.nhs.uk/submit-feedback-or-complaint>

If you would like to contact your patient advice service, you can reach them with these details:

Phone number: 020 3317 7102

Email address: feedback@candi.nhs.uk