

This study has been approved by London-Surrey Borders Research Ethics Committee (16/LO/1300) and HRA (IRAS Project ID: 210571)

You will be given a copy of this information sheet

Information Sheet for Participants
EFFIP (E-support for Families and Friends of Individuals affected by Psychosis)
- Stage 2 focus group study with carers

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. 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. Ask us if there is anything that is not clear or if you would like more information.

What is the study about?

Psychosis is a medical term to describe a mental illness which commonly includes a range of distressing symptoms including hallucinations, delusions and paranoia. Coping with psychosis is often a challenging demand for the individual as well as everyone close to them, including family and friends (referred to as “carers” who provide caring support on an unpaid basis). The “EFFIP” project is a 5-year research aiming to develop and evaluate an online resource dedicated for carers to gain information about psychosis, and glean support and advice from others in the same position.

Research aims

From February 2017 for half a year, we are building the online resource incorporating the ideas and views many carers and individuals with lived experience of psychosis have given us in previous focus group meetings. Along this build process, we want carers to review our draft versions and give us feedback to ensure the final resource is as meaningful and useful for carers as possible.

Who are we inviting to participate?

We are inviting carers who provide caring support for a loved one with psychosis for the Stage 2 focus groups. Carers can be parents, partners, siblings, other family members or close friends who do not have a biological relationship with their cared-for person

Carers need to have at least weekly contacts with the cared-for person although these contact could be in a variety of formats, e.g. face to face, phone call, emails, social media such as facebook, text messages

All participants need to be aged 18 or above, and able to participate in discussion in English.

Who must we exclude?

Regrettably, we cannot include carers whose cared-for person suffer from a mental illness other than psychosis as their primary concern. We also cannot include those who cannot converse in English due to the lack of interpreter’s service and the limitation of resources for this study.

Where and when will the study take place?

Two focus groups for carers, each for about 4 to 10 participants with a maximum of two group facilitators, will take place in St George’s University of London (South London) or local venues of participating sites. We will organise the group meetings in a time most convenient for the majority of participants, including early evenings or weekends, between February 2017 and August 2017.

What will happen if you agree to take part in the study?

You will be invited to attend an one-off meeting with a few other peers. During the group meeting, We will show the participants the current draft of the EFFIP resource offline and ask them to feedback and comment on the resource design, layout and ease of use. The discussion is expected to last between 60 and 90 minutes. The discussion will be audio-recorded, with everyone's permission. The audio-recorded discussion will then be transcribed into a written record in an anonymised manner, i.e. no personal identifiable data included in the written record that could link you or any participants to the discussion. We will analyse the study findings from the transcripts. We will take on board the findings to further refine the online resource. Focus group participants will be given a summary of the main findings from the focus group study on request.

Will you be compensated for your time?

Yes. To thank you for taking the time to participate, we will offer you a £10 gift voucher at the conclusion of the focus group. We will also reimburse you for the travelling expenses incurred in your journeys for attending the meeting.

Are there any risks involved in participating?

The risk involved in participating is minimal. The discussion will be facilitated around the focus group discussion aim which is about the content and design of an online resource for carers. However, you may find sharing or hearing experiences relating to the experience of psychosis and its impact on the wider support network emotional or distressing. You do not need to feel compelled or under pressure to discuss any personal or sensitive information which are not the aims of this study anyway. If there are questions that you find distressing or intrusive, you are free to not answer those questions or to withdraw from participating. The researcher (who will facilitate the group discussion) will remind participants there are no right or wrong answers and to treat each other respectfully, but again there is a risk that participants may be rude to each other. Anyone who disrupts the group in this way will be asked to leave. The researcher, a qualified mental health nurse, will offer support for any participant who wants to discuss their experiences of participating in the focus group. For those who want input from an independent agency not involved in the study, we will signpost the participants to a non-governmental agency (e.g. Rethink Mental Illness, SANE, Carers' Trust).

If concerns arise in terms of possible risk to self or others, the researcher will offer support to the participant concerned and discuss with them together how best to seek further support for them depending on the services they are engaged with at the time. These may include making contact with their GP or appropriate clinical services.

Are there any benefits involved in participating?

We hope you will enjoy the opportunity to meet with other people with similar experience and to discuss your views on how best to design and build an online resource. Your ideas and perspectives will help make the resource meaningful and helpful for carers.

How will we maintain your privacy and confidentiality?

Everything you discuss will remain confidential within the limits of the law. Whilst every effort has been made to ensure the confidentiality of the focus group discussion, it is not possible to guarantee that these discussions will be kept strictly confidential, if concerns are identified about participant's or others' safety.

We will ask all participants to use only their own and one another's first name in their discussion. Discussion involving others, e.g. their family members or health professionals, will be kept to a minimum and if really necessary only involve non-identifiable data. We will ask all participants to respect one another's privacy and confidentiality that what discussed during the focus group stay within the group.

Your personal details that are collected for administrative purposes (e.g. consent form) will be stored in a locked cupboard within the researcher's office and only the researcher will have access to such data.

Only the audio-recording of the focus group discussion will be sent to an external transcribing agency for transcribing. This is an agency approved by St George's, University of London which is fully compliant with confidentiality and privacy codes. Written and anonymised transcripts (so that participants' first names if mentioned will be replaced by a code such as Focus Group 1, Participant AA) will be made from the recording and the analysis will be conducted on the transcribed materials. The recording will not be played in public. No names or other information that might identify you will be used in any publication or documentation arising from this study.

Who is organising and funding the research?

This study is part of a bigger project entitled "EFFIP (E-support for Families and Friends of Individuals affected by Psychosis): A randomised controlled trial of a co-produced online intervention for carers" which is organised by a team of researchers at St George's, University of London and King's College London. The primary researcher is Jacqueline Sin. The study is funded by the National Institute of Health Research, and sponsored and insured for indemnity by St George's, University of London.

What if I have questions about the project?

Please contact Jacqueline Sin, NIHR Post Doctoral Research Fellow, by email at: jasin@sgul.ac.uk; or by telephone at: 07817027035; or by post at: Population Health Research Institute, St George's, University of London, Cranmer Terrace, London SW17 0RE.

It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw at any time throughout the focus group discussion and without giving a reason. Unfortunately, due to the interdependent nature of focus groups it will not be possible to remove your ideas and views expressed in the discussion from the study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

If this study has harmed you in any way or if you want to raise a complaint, you can contact:

1. Dr Jacqueline Sin (Chief Investigator)
Population Health Research institute
St George's, University of London
Cranmer Terrace, London SW17 0RE
Email: jasin@sgul.ac.uk

2. If unresolved, please then contact:
Dr Steve Gillard
Population Health Research Institute
St George's, University of London
Cranmer Terrace, London SW17 0RE
Email: sgillard@sgul.ac.uk