

Participant Information Sheet

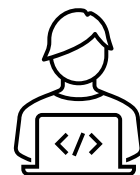
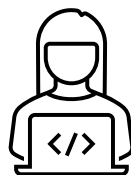
Online Hearing Voices Peer Support Groups: A Feasibility and Acceptability Study

You are being invited to take part in a research study about an online peer support group for individuals who hear voices. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

SUMMARY

- This study is for adults who hear voices and are interested in taking part in an online peer support group for voice hearers
- The study will test whether it is possible to run a peer support group for voice hearers online, and if so, how and why the group work. If we find it is helpful, we will aim to make these groups more widely available
- The group will meet on Zoom or MS Teams once a week for 90 minutes for 6 months.
- If you are interested in taking part, you will first meet with the researcher to see if this study is right for you.
- If the study is suitable for you, you will meet with the researcher at the beginning and end of the study to discuss your voice hearing experiences and experiences within the group. Each meeting will last about 2 hours. You will be asked to fill out some questionnaires in your own time as well.

If you are interested, please read on for more information about the study.



Who will conduct the research?

This study is being conducted as part of a PhD for Alison Branitsky and is being supervised by Dr Filippo Varese, Professor Sandra Bucci, Professor Tony Morrison, and Dr Eleanor Longden at the University of Manchester Faculty of Biology, Medicine and Health, School of Health Sciences, Division of Psychology and Mental Health.

What is the purpose of the research?

Hearing voices that nobody else can hear (sometimes called auditory hallucinations) can be a distressing and isolating experience. Many people who hear voices find it helpful to talk to others with similar experiences. Attending peer support groups is one way of finding these types of connections. Peer support groups are groups where people with similar experiences (in this case, voice hearing), can come together and discuss those experiences. In-person peer support groups for voice hearers exist across the world; however, they have recently started to take place online as well.



The purpose of this study is to set up and evaluate a peer support group for voice hearers that is run entirely online. The peer support group will run for 6 months and will have 6-10 people in it. The study aims to find out if it is possible to run a peer support group online and what, if anything, participants get out of taking part in the group.

Am I suitable to take part?

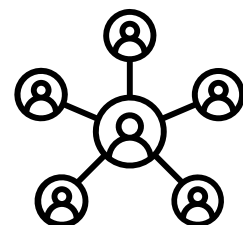
We are looking for people who:

1. Aged 18 or older
2. Currently residing in the UK
3. Have heard voices for at least the past 6 months
4. Are able to provide informed consent
5. Are willing to participate in group support
6. Have consistent access to the internet and the ability to use videoconferencing platforms (for example: Zoom, MS Teams)
7. Are fluent in English



Do I have to take part?

No, you do not have to take part. It is entirely up to you to decide whether you want to take part. You can take your time to think about it. If you decide to take part, you will be asked to sign a study consent form, which means you agree to take part. Even after signing this, you are still free to withdraw consent at any time, and you don't need to give a reason. Whether you decide to take part or not, or stop part way through the study, it will not affect your usual care or rights in any way.



What would I be asked to do if I took part?

Suitability meeting (around 15 minutes – 1 hour)

At this meeting, you will have the opportunity to find out more about the study and ask any questions you may have. I will ask you some questions to confirm that you are eligible to participate in the study. These questions will mainly be about whether you are currently hearing voices and if you have access to a computer/phone and the internet to take part in the group. You will not be asked to go into detail about your voice hearing experiences at this meeting.



If it looks like this study is suitable for you and you would like to participate, you will be asked to sign a consent form, which will be emailed to you to sign on a website called Qualtrics. I will let your care coordinator or GP know that you have consented to take part in the study. You will then be invited to a baseline assessment meeting with me.

First assessment (up to 2 hours)

The first assessment will consist of both an interview and some questionnaires. The interview will take place on Zoom or MS Teams, whichever you prefer, and will be about your current and past voice hearing experience, what you hope to get out of the peer support group, and any hesitations you have about the group. The interview will be recorded. After the interview, you will be asked to complete some questionnaires about demographics, your current voice hearing experiences, how you understand your voices, how you feel about yourself, and your quality of life. These questionnaires will be emailed to you for you to complete on Qualtrics.

Online Hearing Voices Peer Support Group (90 minutes a week for 6 months)

After finishing the first assessment, you will be sent the joining details for the peer support group, which will take place on either Zoom or MS Teams. The group will take place at the same time every week for 90 minutes and will run for 6 months. The group will be facilitated by the two people: the researcher who has lived experience of voice hearing and is a trained hearing voices peer support group facilitator, and a clinical psychologist from the NHS.

Hearing voices peer support groups are very open in terms of their content and agenda. This means that you will be able to talk about whatever you want to. However, the group tend to focus on your voice hearing experiences, where you think the voices come from, how the voices make you feel, and how you manage the voices. You hopefully will have the opportunity to learn from and connect with other group members as well.



During the group, you will be able to turn your camera off if you wish. The groups will not be recorded; however, the researcher will keep track of attendance and make reflective notes about each group meeting. These reflective notes will be about the general topics not contain any information that could identify you.

Group assessments (about 15 minutes)

To see how well the group is going, you will be asked to complete a questionnaire about the group three times during the study. You will complete the questionnaire at weeks 4, 12, and

26 (after the last group). These questionnaires will be completed electronically on the Qualtrics website.

End-of-Study Assessment (up to 2 hours)

Once the peer support group ends, you will be invited to take place in a final interview over Zoom or MS Teams. This interview will focus on your experiences in the group, if you gained anything from participating in the group, challenges of participating in the group, and ways the group can be improved in the future. The interview will be recorded. You will also be asked to answer the same questionnaires that you completed during the baseline assessment. This is to see if anything has changed over time. These questionnaires will be completed electronically on Qualtrics.

Will I be compensated?

You will be compensated £20 after the first assessment and £20 after the end-of-study assessment either via cash, bank transfer or with a shopping/Amazon voucher.

What are the risks of taking part in the online hearing voices peer support group?

It is possible that upsetting issues may come up during the assessments with me. If this happens, I will try to help you feel at ease and remind you that you do not have to answer any questions you do not want to. You are free to ask me to move on or stop the assessment altogether if you find any of the questions upsetting.



It is also possible that upsetting issues may come up during the peer support group. You never have to share more than you are comfortable with, and you have the right to leave the group at any point. If you feel distressed by something that has come up in the group, you will always be able to speak one-to-one with one of the facilitators.

Disagreement is a common and expected part of groups. It is possible that disagreement between group members may arise during the peer support group. If this happens, we will try to address the conflict clearly within the group and come up with a solution that works for everybody. If there is a conflict that cannot be resolved in the group, then the facilitators will handle it with the individuals outside the group.

What are the benefits of taking part in the online hearing voices peer support group?



We hope that you will find participating in the peer support group helpful, but this cannot be guaranteed. The information you share with us may help us support people with similar problems in the future. If the peer support group is shown to work, then we hope to make it more widely available in the future.

What happens if I do not want to take part or if I change my mind.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign an electronic consent form. If you decide to take part **you are still free to withdraw at any time** without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised (after the end of the study). This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.



One-to-one interviews for this study will be audio recorded on Zoom or MS Teams. You can choose whichever platform you prefer. Zoom automatically records both audio and video, but the video recordings will be permanently deleted immediately after the interview. MS Teams automatically records both audio and video together in one file, so it will not be possible to delete your video until after the interview has been transcribed. You are also welcome to turn off your camera at any time, however Zoom/MS Teams will still record your name and profile picture (if you have one). If you start to feel uncomfortable with the recording process, then you are free to stop the interview at any time. We would unfortunately not be able to continue the interview without recording since this interview provides important data that will be used to determine whether the groups are helpful.

What information will you collect about me?

In order to participate in this research project we will need to collect some information that could identify you, called “personal identifiable information”. Specifically we will need to collect:

- Your name
- Your birthday
- Your contact information (phone number, address and email)
- Demographic information (ethnicity, gender, etc.)
- Your care team’s contact information, if you have one
- Your GP’s contact information, if you do not have a care team
- Audio recordings of the research interviews

Under what legal basis are you collecting this information?

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is a “public interest task” and “a process necessary for research purposes.”



What are my rights in relation to the information you will collect about me?

You have a number of rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about you, including audio recordings. Sometimes your rights may be limited if it would prevent or delay the research. If this happens you will be informed by the research team.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](#).

If you would like more general information about how researchers use data about patients, please visit: www.hra.nhs.uk/information-about-participants/.

Will my participation in the study be confidential and my personal identifiable information be protected?

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure all your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following ways:

- The study team at the University of Manchester will have access to your personal information. Your interviews will be transcribed by the research team and all your research data will be pseudonymised as soon as possible, which means that all personal identifying information will be removed and replaced with a participant number (e.g., P01, P02). The research team will have access to the key that links this ID number to your personal information. This research key will be stored on a separate secure university server to your research data. This key will be destroyed at the end of the study once all the data have been analysed. At this point your data will be completely anonymous.
- If, during the study, we have concerns about your safety or the safety of others, we will inform your care team or GP.
- Your consent form will be retained for 7 years on the university's secure server for audit purposes.
- With your consent, your contact information will be stored for 5 years in order to provide you with a summary of the findings for this study and also to inform you about future studies you may be interested in. If you consent to this, your details will be stored on the university's secure server in a digital folder only accessible to the study team and used only for the purposes described above.
- Any document containing personal identifiable information that are not in electronic format will be kept securely in locked filing cabinets at the university.
- When you participate in interviews over Zoom, your data is processed by Zoom. This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place. The recordings will be removed from the above third-party platform and stored on a University of Manchester managed file storage system as soon as possible following the completion of data collection.
- So that we can provide you with the shopping/Amazon voucher as a thank you for your time, your full name and email address will be shared with our Finance department who will send the voucher to you. Your full name and email address will be securely retained by Finance for a period of up to 7 years for audit purposes only and then destroyed. It will not be used for any other purpose.

Please also note that individuals from The University of Manchester, NHS Trust or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

Will the outcomes of the research be published?

This study will be published in an academic journal as part of a PhD for Alison Branitsky. Additionally, study findings will be sent to organisations where participants were recruited from. The results may also be used in reports, training, conferences, and other presentations. All of your data will be anonymous, and you will not be able to be identified in any of these.



Who has reviewed the research project?

This research project is being overseen and has been approved by *NHS REC reference XX/XX/XX*.

Disclosure and Barring Service (DBS) Check

The researcher has undergone a satisfactory DBS check.

Harm related to the study

In the unlikely event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester but you may have to pay your legal costs. The normal National Health Service complaints mechanism will still be available to you. The University of Manchester will arrange insurance for research involving human subjects that provides cover for legal liabilities arising from its actions or those of its staff or supervised students, subject to policy terms and conditions.

What if I have a complaint?

If you have a complaint that you wish to direct to members of the research team, please contact:

Filippo Varese (Academic Supervisor): 2.40 Zochonis Building, University of Manchester, Oxford Road, Manchester, M13 9PL. Tel: 0161 306 0434. Email: Filippo.Varese@manchester.ac.uk.

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact:

The Research Ethics Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL. Tel: 0161 306 8089. Email: research.complaints@manchester.ac.uk.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have the right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information](#). Tel: 0303 123 1113.

What do I do now?

If you have any queries about the study or if you are interested in taking part then please contact the researcher at:



alison.branitsky@postgrad.manchester.ac.uk



07936 813441

Thank you for taking the time to read this information sheet