

INFORMATION SHEET FOR PERSON WITH PARENTAL RESPONSIBILITY



Research Study Title

voice-hearing In young people: distress factors and social relating

We would like to invite your son/daughter/young person for whom you have parental responsibility ('relative') to take part in a **research study**. It is up to them to decide whether or not to take part in the research.

Please take as much time as you need to read and understand this information. If there is anything you don't understand you can speak to the research team.

Why are we doing this research project?

Many young people and adults hear a voice or voices that other people cannot hear. Some people find this experience upsetting. From research with adults we know some of the reasons they might feel upset when they hear voices. For example, they are upset when they believe the voices are bad. However, we don't know much about voice-hearing in young people and would like to find out more.

What is our goal?

- To find out more about voice hearing for young people
- To know when voice hearing might be upsetting for young people
- To find out more about the social lives of young people who hear voices but also of those who do not, to see if voice-hearing affects this.
- To find better ways to help young people to get on with their lives

Why has my relative been invited to take part?

Because they are:

- ✓ 14-18 years old **and**
- ✓ under the care of Early Intervention Services or Children and Adolescent Mental Health Services (CAMHS) in Sussex.
- ✓ We would like to invite both young people who do and do not hear voices that others cannot hear to take part in this research project.


Does my relative have to take part?

No, it's up to them. If they decide to take part:

- They will be asked to sign a form to say that they agree to take part (a consent form)
- They will be given a participant information sheet, which similar to this one, and a copy of their signed consent form to keep.
- You will be asked to sign a similar form to indicate your agreement to your relative taking part.

Your relative will be free to change their mind at any time without having to give a reason.

Their decision about taking part in this study will not affect their care from the NHS in any way.

 If you relative is **under 16 years of age**, you will need to provide written consent, agreeing for them to take part. Otherwise, your relative will not be able to take part.

What will happen if my relative decides to take part?

First contact with the research team

- A researcher from our team will contact your relative to explain the study and give them the opportunity to ask questions they may have. The researcher will also ask your relative some questions to work out whether this project is appropriate for them. Our researcher will not be a member of your relative's usual NHS care team.
- If the study is appropriate for your relative and they are interested, the researcher will ask your relative to attend an assessment session.

During the assessment session

- Your relative will complete some questionnaires and interviews with the help of a researcher. There are no right or wrong answers to these. The assessment interviews and questionnaires will ask:
 - *Information about your relative, their mood, mental health and wellbeing*
 - *Information about your daily activities, social relationships and social groups*
 - *If they have heard voices that others cannot, we will also ask them questions about this experience.*
- The assessment will take approximately **3 to 4 hours** altogether. The assessment can be completed on one day, or be spread over two sessions – whichever is more convenient and comfortable for your relative.
They can invite a friend, family member or NHS worker to be with them during the assessment if they like.
- During the assessments, we will offer them breaks and they can pause or stop at any time.

After the assessment session

- We will give your relative **£20** as a thank you for giving up their time.
- If your relative has heard voices that others cannot, we will ask them to give us permission to contact them again to take part in a separate optional interview. This interview will ask them about any support they may or may not have received for this experience.
 - If they decide to take part, this separate interview will be on a different day and time that is convenient for them.

Where would the study take place?

In a convenient location for your relative. This may be their local NHS service, the University of Sussex or at their home.

Is there anything else involved?

We would also like your permission and your relative's permission for a member of the research team to have access to their medical notes. This will help us to:

- *collect other information for the project, such as any medication your relative is taking,*
- *record that they are taking part in the project, so that they can discuss this with their care team if they wish to,*
- *provide a summary of the assessment to their care team, if your relative agrees.*



What are the benefits of taking part?

There are no immediate benefits to taking part in this study.

However, what we learn will help us:

- understand voice hearing experiences for young people and
- provide young people with better care in the future

We also hope that taking part will be a positive experience for your relative and will give them an opportunity to talk about and explore their experiences.

After the study is finished, we can send your relative a summary of the study results if they would like this.

What are the disadvantages of taking part?

It's possible talking about some of their experiences may be upsetting, but:

- they only need to tell us as little as they want to
- if they do feel upset at all during the assessments, we will help you to feel supported
- they would also be free to access help from their care team, if they wish to
- they could also stop taking part in the project at any time
- they could also ask us to delete any information they have already given us, as long as they do this before the 30th March 2019.

We understand that the assessments are quite long so your relative may get tired. To help with this, they can take as many breaks as they like. We will try to plan the assessment session(s) to suit them.

Who will know that my relative is taking part in this study?

The only people that will know your relative is taking part in this study will be the research team, their care team, and anyone else that they choose to tell. If they are **under 16 years old**, you have to know they are taking part as you need to provide consent for them to participate.

Who will have access to information collected about my relative?

All the information we collect in this study will be kept **confidential** and securely stored. This means that only we know the information your relative gave us. We will remove anything that could be used to recognise them from the information, such as their name or address. Only members of the research team will have access to this information.

If they agree, we can give their care team a summary of information from their assessment. If they do not agree, then we will not tell their care team about anything they tell us. However, if your relative tells us anything that shows that their safety or someone else's safety may be at risk, we would not be able to keep this information to ourselves. We would need to share this information with their care team. But we would always try to talk about this with your relative first.

Sometimes, officials from the university or other governing authorities might need to check that a research project has been done properly. These people may check your relative's information, but they would have a strict duty of confidentiality to your relative as a research participant to keep their information safe and private.

Where and how long will the data be stored?

Data (information) will be stored in locked cabinets and secure computer systems on NHS or university premises. Anonymised information on paper and on computers will be kept for 10 years after the study is finished, then all the information will be destroyed. Personal information (such as your relative's name and address) will be kept up to 12 months after the study is finished and then be destroyed.

What will happen to the results of this study?

The results of the study will be used as part of a PhD thesis. We will also write reports of the results that will be published in psychology journals and will be presented at scientific conferences. It would **not** be possible for people to recognise

your relative in any of these reports, as the information will be anonymously presented. Also, other genuine researchers might be able to access your relative's anonymised data and use it for research reports.

Who is organising and funding this study?


The study is being supported by the University of Sussex. The study is being paid for by the Sussex Partnership NHS Foundation Trust and a research council called the Economic and Social Research Council.

Who has checked and approved this study?

Research like this one can't go ahead without being approved by an NHS Research Ethics Committee. This is an independent group of people who checks that research studies are safe for people to take part. This research study has been approved by the University of Sussex Research Sponsorship Review Group, the London - Brighton & Sussex NHS Research Ethics Committee, and the Health Research Authority.

Next steps

We would like your relative to take at least **24 hours** to think about whether they want to take part in the project. This is to make sure they have had time to think about it.

 **If your relative is under 16 years of age:** You would also need your consent for them to take part. This could happen by either coming to the first research appointment or by asking the researcher (**Aikaterini Rammou**) to send a copy of the consent form via post or email. You would then need to sign the form and return it with your relative at the first research appointment or send it via post or email to the researcher.

To find out further information about the study, please contact:		For any further information or concern about the study, please contact the rest of the research team:	
	Kat (Aikaterini) Rammou Principal Investigator/Researcher	Dr. Mark Hayward Project Supervisor	Professor David Fowler Project Supervisor
	School of Psychology University of Sussex Brighton BN19QH	School of Psychology University of Sussex Brighton BN19QH	School of Psychology University of Sussex Brighton BN19QH
	Email: A.Rammou@sussex.ac.uk	M.I.Hayward@sussex.ac.uk	D.Fowler@sussex.ac.uk
Call/text: 07391868645		C.Berry@sussex.ac.uk	

Other useful contacts

- To talk to someone independent about research, you can also contact your local **Service Experience Team**, tel: 01903 843026 or email: service.experience@sussexpartnership.nhs.uk
- If you would like to give a compliment or make a complaint, please contact the **Patient Advice and Liaison Service (PALS)**, tel: 01323 446042 or email: pals@sussexpartnership.nhs.uk
- If you are unhappy about anything regarding your relative's participation in this study and wish to complain formally, then please contact the **University of Sussex**, tel: 01273 872748 or email: researchsponsorship@sussex.ac.uk

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

Please ask any questions you need to.