

## PARTICIPANT INFORMATION SHEET



Research Study Title

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

We would like to invite you to take part in a **research study**. It is up to you to decide whether or not you want to take part.

Before you decide, we would like to tell you about the study and answer any questions that you may have.

Please talk about it with other people if you want, for example your family, friends, or your care team. 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 have I been invited to take part?

Because you 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 to take part in this research project.

### Do you have to take part?

**No, it's up to you** and you are free to change your mind at any time without having to give a reason.

If you decide to take part:

- You will be asked to sign a form to say that you agree to take part (a consent form)
- You will be given this information sheet and a copy of your signed consent form to keep.

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



If you are **under 16 years of age**, your parent/legal guardian will need to sign a consent form like yours, agreeing for you to take part.

## What will happen if I decide to take part?




### First contact with the research team

- A researcher from our team will contact you to explain the study and give you the opportunity to ask questions. We will also ask you some questions to work out whether this project is right for you. Our researcher will not be a member of your usual NHS care team.
- If the study is right for you and you are interested, we will ask you to attend an assessment session.



### During the assessment session



- The researcher will help you to complete some questionnaires and interviews. There are no right or wrong answers to these. The assessment interviews and questionnaires will ask:
  - *Information about you, your mood, mental health and wellbeing*
  - *Information about your daily activities, social relationships and social groups*
  - *If you are hearing voices that others cannot, we will also ask you 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 – this is up to you!  
 You can invite a friend, family member or NHS worker to be with you during the assessment if you like.
- During the assessments, we will offer you breaks and you can pause or stop at any time.

### After the assessment session

- We will give you **£20** as a thank you for giving up your time.
- If you hear voices, we will ask for your permission to contact you again. This will be to invite you to take part in a separate interview that will ask you about any care and support you have had for the voice hearing experiences.
  - If you decide to take part, this separate interview will be on a different day and time that is convenient for you.

## Where would the study take place?

A location you are comfortable with. This may be:

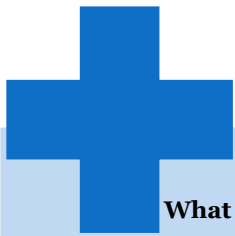
- your local NHS service
- the University of Sussex
- your home.



## Is there anything else involved?

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

- *collect other information for the project, like any medication you are taking,*
- *record that you are taking part in the project, so that you can discuss this with your care team if you wish to,*
- *provide a summary of the assessment to your care team, if you would like us to.*



### 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 you and will give you an opportunity to talk about and explore your experiences.

After the study is finished, we can send you some short information about what we found out if you would like this.

### What are the disadvantages of taking part?

It's possible talking about your experiences may be upsetting, but:

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

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

### Who will know I am taking part in this study?

The only people that will know you are taking part in this project will be the research team, your care team, and anyone else that you choose to tell. If you are **under 16 years old**, your parent/legal guardian has to know you are taking part as they need to agree for you to take part.

### Who will have access to information collected about me?



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

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

Sometimes, official employees from the university or other governing authorities might need to check that a research project has been done properly. These people may check your information, but they would also keep your 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. 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 (like your 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?

What we find will be used as part of a PhD thesis. A PhD is a type of educational qualification.



We will also put reports of the results in psychology magazines. We will present reports at events that researchers and health professionals attend.



It would **not** be possible for people to recognise you in any of these reports. Also, other genuine researchers might be able to access your anonymised data (that means information that does not have any identifiable information such as your name or address) 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 in. 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

Please take at least **24 hours** to think about whether you want to take part in the project. This is to make sure you have had time to think about it.

 **For those under 16 years of age:** Your parent/legal guardian would also need to give permission for you 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. Your parent/legal guardian would then need to sign the form and return it with you at the first research appointment or send it via post or email to the researcher.

To take part in the study, or to find out further information, please contact:

For any further information or concern about this study, please contact the rest of the research team:

**Kat (Aikaterini) Rammou**

Principal Investigator/Researcher



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### 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](mailto: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](mailto:pals@sussexpartnership.nhs.uk)
- If you are unhappy about anything regarding taking part in this study and wish to complain formally, then please contact the **University of Sussex**, tel: 01273 872748 or email: [researchsponsorship@sussex.ac.uk](mailto:researchsponsorship@sussex.ac.uk)

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

**Please ask any questions you need to.**