



Participant Information Sheet

Exploring experiences of disclosure and non-disclosure amongst young adolescents who hear voices

Hi. My name is Rachel (Rai) Waddingham. I am a student on an MSc by Research programme at Canterbury Christ Church University. I would like to invite you to take part in a research study about your experiences of hearing voices and talking about it to other people. It's important that you know what this study is about, and what it involves, before you decide if you want to take part. You can talk about this with your family, friends, parents, guardians, support workers or anyone else you want to.

If you – or one of your supporters - have any questions, you can contact me at rw431@canterbury.ac.uk or 07472 102 208.

You can also contact my supervisors: Kate Gee (kate.gee@canterbury.ac.uk) and Anne Cooke (anne.cooke@canterbury.ac.uk).

What is the research about?

I am doing this research to learn more about what it's like for young people who hear voices to talk about their experiences, as well as what it's like not to tell people about their voices. I hope that this will help us to understand more about young people's experiences so that we can better support people. One of the reasons I am interested in this area is because I hear voices, myself, but did not speak about it until I was a young adult.

Why have I been invited to take part?

I would like to speak to young people who are:

- aged between 12 and 16 years old
- have experience of hearing voices (either now or recently)

People hear voices for all kinds of reasons. Some people who hear voices may also have a diagnosis of a mental health problem. Others don't. You are welcome to take part in this study whether you have a mental health problem or not. I'm interested in your experiences and how you understand them.

Do I have to take part?

No. It's up to you if you want to take part, or not.

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If you decide that you don't want to take part in this research, that's OK. You can decide you don't want to take part at any time – before the interview, during the interview or afterwards. You don't need to give a reason, and no one will be upset or annoyed. This research is separate to any support you are getting from Voice Collective or any other service, so taking part does not affect any support you get.

If you want to take part, but change your mind in the months after the interview – that's OK too. I will be handing in my research to the university in September 2017, so if you contact me before then I can take out any information that comes from this interview.

What would I have to do if I decide to take part?

If you decide to take part in this research, I will arrange a time to meet with you so I can ask you some questions about your experiences of hearing voices and talking about it to other people. This should take about 1 hour, but we can split our meeting up into smaller chunks if this feels too long.

During our conversation, I will give you the chance to choose from some pictures and photographs that help you explain how you feel.

At the end of our meeting I will ask if you would like to meet again for another hour or so, so that we can talk more about what you have told me. I will ask if you want to bring some artwork, writing, music, words or pictures that help me understand what it's like for you to talk or not talk about the voices. This is optional. If you prefer we can stick to just one meeting..

What will happen to the information that I give you?

I will record our conversation to help me remember what we have said. This means that I won't need to take lots of notes as we speak, and I can listen to it a few times to make sure I hear everything you tell me. I will type up the interview as soon as possible after we meet.

All of the information you share with me is private and confidential within the research team (myself and my supervisors Kate Gee and Anne Cooke who are there to help make sure the study is done well). However, I may use some of the words you say in the report of this study. I will not name you, and will take out any information that would identify you. You can choose a pseudonym for the study if you like (a name that your contributions will be known by).

My supervisors may help me as I think about and make sense of the different interviews I have, so they may read the write up of our talk.

All of the information about you will be kept in a password-protected file. Your name will be kept in a different place to the write up of our conversation, and I will make sure that there is no information that is kept that could identify you. I will keep the write up of our conversation for 10 years and then delete it.

Who else will know that I am taking part?

If you are under 16, I would like to speak with your parent or guardian to get their consent for you to take part in the study. If you do not want your parents to know about your study, I will ask you to have a conversation with a support worker or a member of the Voice Collective team about this study so that I can be confident you're OK to take part and have enough support available to you. Voice Collective, or another youth service, may know that you are taking part in this study if we meet at their offices.

What you say during the interview is private and confidential. That means that I would not tell your parent, guardian, Voice Collective or other youth service what you said when we met. The only time I would break our confidentiality is if I was worried that you – or someone else – was being, or was likely to be, hurt. If that happens, I would talk with you about it so that we could make a plan together to get you the help and support you need.

Even though what you tell me is private, and I won't share it with other people outside of our research team, it's OK for you to talk with other people about it. I really encourage you to talk through your experience of this study with someone you trust – a parent, a friend, a support worker or a member of the Voice Collective team.

Has anyone checked that the study is safe?

This research has been checked by a group of people at Canterbury Christ Church University called a Research Ethics Committee. They have decided that this research is worthwhile, fair and safe.

What are the possible benefits of taking part?

Some people find it helpful to talk about their experiences to someone who is able to listen and really wants to understand. Aside from this, you probably won't get any direct benefits from taking part in this study. However, I plan to publish the results of this study and it may help people understand more about the experiences of young people who hear voices.

I will send you a summary of the research when I've completed it, so you can hear what other young people experience too. I will also send this summary to Voice Collective so that they can share it with other young people, families and youth workers.

I will reimburse your travel costs for attending the interview (£10 maximum). I can also offer a £10 high street shopping voucher in thanks for the time you have taken to take part in this research.

Could anything negative happen as a result of taking part?

Whilst I hope that this interview is a positive experience for you, I know that it can sometimes be difficult to talk about personal things like voices and feelings. If anything we talk about is difficult for you, it's OK to stop the interview or take a break.

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It's up to you how much you tell me, and it's OK to not answer any question that makes you feel uncomfortable.

If anything we talk about leaves you feeling upset or worried, we can talk about it and decide what we can do to help you get some support after the interview. I will be giving you a sheet with some extra ideas of people you can talk to, and I can also help you talk with a supporter if you would find that useful.

If you are unhappy about the way you've been treated in this study, or have any worries about it, you can ask to speak to the project supervisors who will do their best to answer your questions and deal with any issues. The project supervisors are Kate Gee (kate.gee@canterbury.ac.uk) and Anne Cooke (anne.cooke@canterbury.ac.uk).

If I want to take part, what should I do now?

If you decide you want to take part you can either contact me on rw431@canterbury.ac.uk or ask a parent, supporter or a member of the Voice Collective team to contact me on your behalf.

We will work out the best time and place to meet. I can meet you at the Voice Collective office, a youth service you feel comfortable in (if they agree) or your home (if your parents/guardian agrees and it feels comfortable for both of us).

When we meet I will answer any questions you have, explain the study and ask you to sign a consent form if you'd like to go ahead and take part. If you're under 16 years old I'll need your parent or guardian to sign a consent form too before you can take part.

Thank you.

Rachel Waddingham

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Can you help us learn more about what it's like to talk, or not talk, with other people about the voices you hear?

Hi. My name is Rachel (Rai) and I am studying an MSc by Research in Psychology at Canterbury Christ Church University. I hear voices myself, but didn't tell anyone about my experiences until I was an adult. I'm doing a research study to understand more about young people's experiences of talking, or not talking, with others about voices.

Who can take part in this study?

I am looking to speak with young people who are:

- ★ aged between 12 and 16 years old
- ★ have experience of hearing voices (either now or recently)

People hear voices for all kinds of reasons. Some people who hear voices may also have a diagnosis of a mental health problem. Some may not. You are welcome to take part in this study whether you have a mental health problem or not. I'm interested in your experiences and how you understand them.



What will I be asked to do?

If you decide to take part, I will arrange to meet with you to talk about your experiences of hearing voices and talking about it to other people. I will bring some photos as, if you like, you can use them to help you explain how you feel. If you are aged under 16 you will need the consent of your parent or guardian to take part.

I can reimburse travel costs and can also offer a £10 high street shopping voucher in thanks for the time you have taken to take part in this research.