

PARTICIPANT INFORMATION SHEET

Patient Experience, Service Access and Outcomes in Adult Hearing Aid Services for Deaf Adults who use British Sign Language

BSL Version

You can view this Participation Information Sheet online in BSL via this URL

<https://sites.manchester.ac.uk/bslaudiology/>

Introduction

This PIS should be read in conjunction with [The University Privacy Notice](#). A BSL version of this is available on [insert URL]. You are invited to take part in a PhD research study on BSL users who use NHS adult hearing aid services in England. 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 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. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

Who will conduct the research?

Celia Hulme, PhD student, School of Health Sciences, Division of Nursing, Midwifery and Social Work, University of Manchester. Celia is Deaf and a BSL user who has undergone a satisfactory DBS check.

What is this research project about?

This project is about British Sign Language (BSL) users who use NHS adult hearing aid services in England. As a first step in this project I would like to interview a small number of Deaf BSL users who wear hearing aids and ask them about their experiences of adult hearing aid services and what they think makes a good service for Deaf BSL users. This is why I am approaching you.

The experiences you share will be used in two different ways. Firstly, they will help me develop Deaf-informed questions which will be put into an England-wide survey aimed at BSL users who use NHS adult hearing aid services. Secondly, this information will contribute from a Deaf perspective to increasing our understanding of how well or not NHS adult hearing aid services work for Deaf BSL users.

Why have I been chosen?

I am looking for eight Deaf BSL users to take part in individual interviews. You must be 18-year-old or over, currently wear one or two hearing aids, and use NHS adult hearing aid services in England.

If you only use cochlear implants you are not eligible for this study. If you used to wear hearing aids in the past but do not wear them now, you are also not suitable for this research study because it focuses on those who currently wear hearing aids.

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

You will be asked to do two things. The first is to participate in a one to one interview that will be filmed as it is the only way to capture BSL. In May/June you will be asked to provide feedback on a list of key questions for the Deaf-informed survey which will be available in BSL and written English. The list of questions will be based on all of the participant interviews, not just yours.

If you decide to take part, we will discuss your experiences of adult hearing aid services in an informal interview setting, at a location agreed by both of us. The interview will be filmed and will take up to one hour depending on how much there is to talk about. You will have an opportunity to ask more about the research project. You will need to sign a consent form before the interview starts. You should be comfortable with the video recording process. You can stop the recording at any time.

After the interview, I will analyse all the interviews that have been filmed, which will help me to identify potential survey questions to send out to Deaf BSL users in England who wear hearing aids. The draft survey questions and a feedback form will be sent to you via email/post in May/June after the interview. You will have one week to look at the questions and offer feedback. Feedback can be provided in written English using the form or in person if you wish to provide feedback in BSL. There will be no more contact after you have given your feedback unless you have opted to receive a summary of the research when it is completed.

There are no direct risks in taking part in this research, although it is possible that you might experience some negative emotions in recalling your experiences. There will be a debrief sheet explaining what you can do if this happens to you. There is no direct personal benefit of taking part in the study. But your views will help to shape understanding of Deaf people's experience of audiology services. This may have an impact on audiology provision, audiology training and service access.

What will happen to my personal information? And will my information be kept confidential?

In order to undertake the research project, we will need to collect the following personal information/data about you:

- Name, contact details, age and ethnicity
- Video of the interview using encrypted equipment.
- Filmed interviews will be translated and analysed only by Celia Hulme

Only myself and my supervisors, Professor Alys Young, Professor Kevin Munro and Dr Katherine Rogers will have access to this information.

We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal

information. The legal basis upon which we are using your personal information is “public interest task” and “for research purposes” if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our [Privacy Notice for Research Participants](#).

The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures. All researchers are appropriately trained, and your data will be looked after in the following way:

All of your personal data in this research will be handled confidentially in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018. It will be pseudonymised and anonymised, which means your data will be given a code number and a false name, and your contact details will be stored separately. The video recordings will be translated and transcribed only by me. Myself and the Data Custodian (Professor Alys Young) will sign a Confidentiality Agreement for Transcription. The only people who will be allowed to have access to the consent forms, video recordings and full data transcripts are myself and my research supervisors from the University of Manchester (Professor Alys Young, Professor Kevin Munro, and Dr Katherine Rogers). Under no circumstances will your details be identifiable in the research. The research will be reported in one or more of the following ways: articles in peer-reviewed academic journals; presentations at conferences; research posters; workshops seminars; and thesis publication. Your details will be kept for 5 years after the end of the project in a secure password-protected location on a University of Manchester secure server. All of the project information will be removed and destroyed after 5 years.

If during the interview you disclose information that causes some serious concern about your safety, it is my responsibility to inform my supervisor, Professor Alys Young, of my concerns by filling in a ‘Safeguarding Concern Recording Sheet’. Before I contact my supervisor, we will discuss what I plan to do and what I will say. You will be informed of any decisions made, which could be to offer you advice or refer you to the appropriate organisation such as social services. All information related to this will be stored confidentially.

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 video recordings. This is known as a Subject Access Request. If you would like to know about your data protection rights, please consult the [privacy notice for research](#). If you wish to know more about your data protection rights please email: dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, University of Manchester, Oxford Road, 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, Tel 0303 123 1113.

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 be asked to sign a 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 and forms part of the dataset as we will not be able to identify your specific data. If you decide after the interview that you do not wish for your data to be included, please contact me within one month after the interview has taken place, and request that all your data be removed. After one month, it will not be possible to remove your data because it will have been pseudonymised and anonymised and will be part of the dataset; this means we will not be able to identify your specific data. This does not affect your data protection rights.

Who has reviewed the research project?

All research at the University of Manchester is reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given approval by the University of Manchester Proportionate Research Ethics Committee.

What if I want to make a complaint?

If you have a minor complaint, contact me at this email address: celia.hulme@postgrad.manchester.ac.uk. If you are not satisfied with the response, please contact lead research supervisor Professor Alys Young via email at alys.young@manchester.ac.uk. Alternatively, you may send her a video message in BSL, or write to her at The School of Nursing, Midwifery and Social Work, The University of Manchester, Room 4.327b, Jean McFarlane Building, University Place, Oxford Road, Manchester, M13 9PL. If you wish to make a formal complaint or if you are not satisfied with the responses from the named people above, please contact The Research Governance & Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9P. Email: research.complaints@manchester.ac.uk or telephone 0161 275 2674.

Will my data be used for future research?

When you agree to take part in a research study, the information about you may be provided to researchers running other research studies in this organisation. The future research should not be incompatible with this research project and will concern NHS Adult Hearing Aid services. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the [UK Policy Framework for Health and Social Care Research](#).

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research and cannot be used to contact you regarding any other matter or to affect your care. It will not be used to make decisions about future services available to you.

Will the outcomes of this research be published?

It is anticipated that the outcomes will be published by the end of 2021 and in the consent form you have the option to opt in to receive a summary of the main findings.

I am interested in being involved. What do I need to do now?

Please get in touch with me to say that you are interested in taking part and tell me if you would prefer to receive information via email or post. I will email/post you a Participant Detail Form and Consent Form that you must return within 7 days. After I have received the forms, I will then arrange an interview date and venue with you.

Contact Details

Celia Hulme (Researcher)	celia.hulme@postgrad.manchester.ac.uk
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Website	https://sites.manchester.ac.uk/bslaudiology/

**This Project Has Been Approved by the University of Manchester's Research Ethics Committee –
2018-5130-7915**