

# PARTICIPANT INFORMATION SHEET

## Survey on Deaf British Sign Language (BSL) Users' Experiences of adult NHS Hearing Aid Services in England

### 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 <https://sites.manchester.ac.uk/bslaudiology/>. 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. The purpose of this research study is to collect information from Deaf BSL users about their experiences of hearing aid services and their use of hearing aids. The information will be used to find out about how and why Deaf BSL users access hearing aid services; experiences of communication with audiology staff; how they perceive audiology staff attitudes, examples of good practice, and patient satisfaction. The findings from this study may have an impact on future audiology provision, audiology training and service access for Deaf BSL users.

### Why have I been chosen?

You have chosen to participate in the study yourself having seen an advert about the study on social media, a poster, or because someone has told you about it. You are able to take part because you are 18 years old or over, currently wear one or two hearing aids, you communicate in BSL and you use NHS adult hearing aid services in England.

If you only use cochlear implants even with a hearing aid or do not live in England, 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 fill in an online survey. The questions will be in BSL and in English. This will take between 45 minutes – 60 minutes. You have the choice of doing the survey in one go or you can take your time and return to the survey as many times as you like until you complete it. It is not compulsory to answer all the questions, but it would be appreciated if you do. To return to the survey, you will need to register your email on the survey site to retrieve a code to allow you future access. Once you have filled in the survey, you will not be asked to do anything else. You do not need to give your name or address to complete the survey.

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. If this happens, it is recommended to talk to friends or family about your feelings or visit the Help and Support section on the study website <https://sites.manchester.ac.uk/bslaudiology/helpandsupport/>. There is no direct personal benefit of taking part in the study and you will not be paid. 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?**

The survey is completely anonymous and confidential. There will be no personal data collected from you. We will only ask for your age, gender, ethnicity and the region your hearing aid clinic is in. We cannot identify who you are personally from that information. If you choose to return to the survey at a later stage, you will be required to register your email address to receive a code to return to the survey. Your email address will not be connected or be identifiable to your survey responses. Your email address and data responses are kept in different categories and cannot be crossed referenced. Celia Hulme (Primary Investigator) and Francisco Espinoza (Tech Support) will only have access to participants emails if they report any technical issues. However, the above could be seen as indirect identifiers therefore this study will adhere to the General Data Protection Regulation (GDPR) and Data Protection Act 2018.

All of the survey answers are stored in a secure, web-based software platform within the university system. 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 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:

Research records will be confidential. All data will be anonymised and encrypted on password protected computers. Questionnaires will only be identifiable by an anonymous participant number. Online consent form information will be recorded in a separate database and cannot be cross-referenced with the data from the questionnaire. Your IP address will not be collected by the survey software (this option will be switched off).

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. All data will be anonymised and each participant will have a code generated by the survey software. 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 you would like to know more about your different 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](mailto: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.

### **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 asked to fill in a consent form online and you are still free to withdraw up until the completion of the questionnaire without giving a reason and without detriment to yourself. However, it will not be possible to remove your data once it has been submitted. All data from the survey will be stored in a completely anonymous format and therefore will not be possible to identify or delete specific participant data.

### **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 Celia Hulme at this email address: [celia.hulme@postgrad.manchester.ac.uk](mailto: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](mailto:alys.young@manchester.ac.uk). Alternatively, you may send her a video message in BSL, or write to her at The Division 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](mailto: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 you can follow the research progress by visiting this website <https://sites.manchester.ac.uk/bslaudiology/>

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

If you have any queries about the study, please contact Celia Hulme. If you are happy to take part, please complete the online consent form before starting the survey.

### **Contact Details**

Celia Hulme (Researcher)	<a href="mailto:celia.hulme@postgrad.manchester.ac.uk">celia.hulme@postgrad.manchester.ac.uk</a>
Text Number	07919 298062
Skype	celia.hulme75
Website	<a href="https://sites.manchester.ac.uk/bslaudiology/">https://sites.manchester.ac.uk/bslaudiology/</a>

**This project has been approved by University of Manchester Research Ethics Committee**

**Reference 2019-8014-12227**