

Participant Information Sheet for Professionals

Study Title: The perspectives and recommendations of cochlear implant professionals and users for the development of a wearable haptic device.

Researcher: Ahmed Bin Afif

ERGO number: 61075

Please read the following information carefully before you make your decision. If you are happy to participate, you will be asked to sign a consent form. If anything is unclear or if you need additional information, please do not hesitate to contact Ahmed Bin Afif (aaba1n17@soton.ac.uk).

What is the research about?

This research is part of a PhD project. The aims of this study are to explore the perspectives and experiences of UK cochlear implant (CI) users and professionals concerning:

- a) The listening challenges experienced by CI users,
- b) The current strategies and assistive technology devices used to minimise listening challenges and
- c) The perceived potential value of haptic stimulation (vibration to the skin) and variables that must be considered in the development of a potential assistive haptic device for CI users. Haptic or vibrotactile device is worn on skin, either one or both sides of the body, that picks up speech and sounds in the environment and converts them into gentle vibration that can be felt on the skin

Why have I been asked to participate?

You have been asked to take part because you are a professional working in the field of CIs with at least one year of clinical experience.

What will happen to me if I take part?

The research comprises three qualitative phases:

- a) initial questionnaire,
- b) focus group discussion and
- c) post-focus group survey.

Phase one

Interested participants who sign the consent form electronically will be sent the initial questionnaire via email. The initial questionnaire comprises two sections that might take approximately 10-15 minutes to complete. In the first section, you will be asked to identify your demographics to ensure you meet the eligibility criteria of the research. Eligible participants will be asked to complete section two, which consists of four open-ended questions about hearing challenges among CI users, strategies and assistive technologies used to minimise challenges and any experience with haptic devices among CI users.

Version 1: 24/08/2020

Phase two

Then, the researcher (the PhD student) will arrange with you via email the date and time of the focus group, which will be an approximately one hour online video meeting with four to six other CI professionals across the UK, guided and moderated by the study researcher(s). The invitation email will include some instructions and a reminder of the ground rules that you must read. The online video conference discussion will cover recommendations concerning the development of a haptic device for CI users. With your consent, the discussion will be recorded and anonymously transcribed. After the transcription, the recorded videos will be deleted.

Phase three

In this phase, you will receive a survey that will allow you to comment on the previous focus group discussion. You will also be asked to provide your feedback on the design of the haptic device prototype. The survey will take approximately 10-15 minutes to complete.

Are there any benefits in my taking part?

There will be no direct benefit to you as an individual. However, you will contribute towards the improvement of a potential haptic device for cochlear implant users.

Are there any risks involved?

There are no anticipated risks to participants who take part in this study. Contact details for the researcher and project supervisors have been included below in the event that you may require any support after taking part in the study.

Ahmed Bin Afif: aaba1n17@soton.ac.uk

Dr. Ben Lineton: Bl@isvr.soton.ac.uk

Prof. Nicci Campbell: N.G.Campbell@soton.ac.uk

Dr. Mark Fletcher: M.D.Fletcher@soton.ac.uk

What data will be collected?

The following is a list of all data obtained by the researcher (the PhD student):

- Your email address to contact you
- Your demographics (i.e. occupation, working location, years of experience, etc.)
- Your answers to the four open-ended questions about listening challenges among CI users, strategies and assistive technologies used to minimise challenges and any experience with haptic devices among CI users.
- The focus groups will be video-recorded for subsequent anonymous transcription. Following transcription, the recording will be deleted.
- Your answers to the post-focus group survey

All electronic data will be stored on a password-protected computer on the University of Southampton's secure servers. The data will be held in accordance with the University of Southampton's policy on data retention.

Version 1: 24/08/2020

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential..

The research team will not disclose whether you or anyone else have participated in this study. Furthermore, any names of individuals mentioned in the focus group will be replaced with a pseudonym. All electronic data will be stored on a password-protected computer. The data will be held in accordance with the University of Southampton policy on data retention. Only researchers and supervisors will have access to it.

With your consent, the researcher will retain your contact information so that you can be contacted once again in relation with future work on this project. The University's data protection policy governing the use of personal data by the University will apply which can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>). If at any time, you wish to remove your contact details from the future-research contact list, you can contact the researcher or the research team at any time.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

Please contact the researcher (aaba1n17@soton.ac.uk) if you wish to participate. You have to sign a consent form, and all other phases will be arranged.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected.

What will happen to the results of the research?

The results of the study will be written up and form the basis of my doctoral thesis. Some of the findings may be submitted for publication. All personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

Version 1: 24/08/2020

Where can I get more information?

Please contact Ahmed Bin Afif on aaba1n17@soton.ac.uk if you have any queries.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

The researcher: Ahmed Bin Afif (aaba1n17@soton.ac.uk)

Supervisor: Dr. Ben Lineton (Bl@isvr.soton.ac.uk)

Supervisor: Prof. Nicci Campbell (N.G.Campbell@soton.ac.uk)

Supervisor: Dr. Mark Fletcher: (M.D.Fletcher@soton.ac.uk)

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at

<http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the

Version 1: 24/08/2020

performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking the time to read the information sheet and considering taking part in the research.