

CHOICE - cochlear implant home care

What is CHOICE?

CHOICE is a service that helps you to look after your cochlear implant at home using a computer or mobile device; we call this 'remote care'. If you decide to join the CHOICE service, we will ask you to register for an app.

With the CHOICE app, you can:

- Check your hearing and get feedback about your results
- Practise listening in background noise
- Practise listening to music
- Upload a photo of your cochlear implant site (behind your ear) if you have concerns
- Order spare parts e.g. a new cable
- Type in how many hours you wear your sound processor each day (if you are working to improve this)
- Check if you have any problems by filling in a questionnaire
- Receive reminders by email or text to help look after your processor e.g. to change your microphone covers

Staff at your cochlear implant centre will be able to see what you have done in the app. This helps them see if you need to come to the centre or need help with anything. They will also see how much you are using the app. You can use the app as often as you like. If you haven't used the app for 3 months, your centre may contact you to see if you are having any problems and check you are still happy to use CHOICE.

Do I have to do it?

No. It is up to you whether you decide to do remote care using the CHOICE app or continue coming to the clinic for your appointments as usual.

Are there any benefits to me?

You may enjoy caring for your hearing and cochlear implant at home and find it convenient, rather than coming to the clinic.

Are there any risks?

There are no significant risks. You can choose to come to the clinic any time if you have problems. You can stop using the CHOICE app at any time.

What information do I share with CHOICE?

When you sign up, you will give us details of your:

- Email address (this will be your login and so you can receive information about the project)
- NHS number
- Main sound processor(s)
- Cochlear implant centre (e.g. Manchester, Southampton etc.)
- Date of your last microphone cover change (if appropriate)
- Age in 10 year band e.g. 50 - 60 years
- Month and year of your cochlear implant operation
- Gender
- Highest qualification achieved
- Postcode (last letter of your postcode will not be saved for privacy)
- Mobile phone number if you would like us to send you text reminders

We need this information to make sure we know it is you that is using the CHOICE app, to help us give the best advice for your implant, to contact you about this project, and to send you reminders to help you care for your implant. We want to be sure the CHOICE app gives everyone equal access; that is why we are collecting information about your age, gender, qualifications, years of cochlear implant use and postcode. We will also know the times and dates that you use the app and any actions you take as a result of using the app e.g. you go to your centre because you are worried you are not hearing so well. We can also see the IP address of your computer or mobile device (this is the code that is used to identify each device).

You may choose to upload photos of your implant site (behind your ear) into the CHOICE app. Please do not include your face. There is a cropping tool in the app where you can cut out parts of the picture that may include your face. The photos will be visible to your clinician and the research team. They will be stored with the other information on a secure University of Southampton server.

Who will see my information?

We will ask your consent to share your information as follows. All the information will be shared with:

- Your own cochlear implant centre, so they can care for you appropriately
- The research team at University of Southampton who is in charge of this project
- The company that made and looks after the app (IE Digital)
- University of Southampton IT department, where all the project data is stored

The following people will only see the information without knowing who you are; we will not give them your email address, NHS number, and postcode:

- Researchers who are working with us to test the CHOICE service. These researchers work at University of Nottingham, Northumbria University, University of Southampton, and Wessex Academic Health Science Network
- The creators of RealSpeech – the listening in noise task and EQ-5D (the quality of life questionnaire) (so they can improve them)
- NHS England team who are providing the PAM questionnaire licence

- The company that makes your cochlear implant (only if they deal with your requests for spare parts)
- The Health Foundation who are funding this project

We look after your personal information very carefully. It will only be seen by people who strictly need to see it and will be stored securely.

You can also ask to see all the information we hold about you.

What else is involved?

This is the first time we have introduced a service like this in the UK so we will be testing how well it works. We are funded by The Health Foundation to look into how well remote care works. When you register for the app and at regular intervals, you will also be asked to fill in some questionnaires to see how you are getting on. Some of these will be on paper and some in the app. We will also be looking for people who may be willing to come to their centre for a focus group or interview to tell us what they think of the CHOICE service after they have used it for a while. We will ask you to consent to that separately at a later stage.

What happens if I change my mind?

It is totally up to you whether you take part or not. Your centre clinicians do not mind whether you take part or not and will continue to care for you in exactly the same way if you decide not to take part. You can choose to stop using the CHOICE service and go back to visiting your centre at any point. If you decide to stop using the CHOICE app, we will keep the information we have collected from you so far, unless you say you don't want that. It will not be possible to delete your data if it's already been anonymised (your name and details removed) because we won't know which are your results. If you do this, your centre may keep some of your results if they feel it helps your clinical care. It may not be possible to delete your data from focus groups.

You are free to withdraw at any point without telling us why.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you should contact the University of Southampton Research Governance Office:

Research Governance Office

Building 28

University of Southampton

Highfield

Southampton SO17 1BJ

rgoinfo@soton.ac.uk

Telephone: 02380 595058

or

Patient Advice and Liaison Services (PALS) (*) or local PALS for other centres)**

Southampton General Hospital

Tremona Road

Southampton SO16 6YD

patientsupportservices@uhs.nhs.uk

Telephone: 023 8120 8498

Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been given a favourable opinion by the National Research Ethics Committee (**insert here**).

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 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).

Please get in touch with Helen Cullington (the project lead) with any questions: choice@southampton.ac.uk or H.Cullington@Southampton.ac.uk, 07853 478343