

Please find the **Patient Information Sheet** below.

When you have finished reading,  
use the **back button** on your web  
browser to return to the survey.

If that does not work, click on the below link:

<https://nottingham.onlinesurveys.ac.uk/audiology>



Dr Helen Henshaw, Principal Research Fellow  
[Helen.henshaw@nottingham.ac.uk](mailto:Helen.henshaw@nottingham.ac.uk)  
Dr Emma Broome, Research Fellow  
[Emma.broome1@nottingham.ac.uk](mailto:Emma.broome1@nottingham.ac.uk)  
Dr Eithne Heffernan, Senior Research Fellow  
[Eithne.heffernan1@nottingham.ac.uk](mailto:Eithne.heffernan1@nottingham.ac.uk)

### **PARTICIPANT INFORMATION SHEET WP1.1**

Research Ethics Reference: FMHS 438-0122  
Version 3.0 Date: 28/09/2022

We would like to invite you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read this carefully and discuss it with others if you wish. Ask us anything that is not clear.

#### **What is the purpose of the research?**

We would like to find out more about the clinical pathway for the management of audiology patients with coexisting mild cognitive impairment/dementia and hearing conditions.

#### **Why have I been invited to take part?**

You have been invited to take part in this research because you have experience working in an audiology service. We are inviting a minimum of ten participants like you to take part.

#### **Do I have to take part?**

It is up to you to decide if you want to take part in this research. We will describe the study and go through this information sheet with you to answer any questions you may have. If you agree to participate, we will ask you to sign an electronic consent form. However, you would still be free to withdraw from the study at any time, without giving a reason, simply let the research team know.

#### **What will happen to me if I take part?**

This study involves completing a series of questions via an online survey. The survey relates to the clinical pathway for the management of audiology patients with coexisting mild cognitive impairment/dementia. No background knowledge is required.

After clicking the next button at the end of this information page you will be presented with a consent page. You will then be asked to provide some basic demographic information. The survey is expected to take no longer than 15 minutes to complete.

We would like you to answer all questions as honestly and completely as possible. You can withdraw at any point during the questionnaire for any reason, before submitting your answers by closing the



browser. The data will only be uploaded on completion of the questionnaire by clicking the FINISH button on the final page. At this point it will not be possible to withdraw your answers.

### **Are there any risks in taking part?**

There are no anticipated disadvantages of taking part other than giving up your spare time to help us develop and improve our research.

### **Are there any benefits in taking part?**

There will be no immediate benefit to you for taking part in this study; however, your contribution together with the contributions of others will help the researchers to understand more about the clinical pathway for audiology patients with coexisting mild cognitive impairment or dementia. The information obtained from this study will have far researching benefits to our understanding of the healthcare pathway, and how this can be optimised, for these patients in the future.

### **Will my time/travel costs be reimbursed?**

Participants will be entered into a prize draw for a £50 voucher and will have the opportunity to take part in a brief follow-up interview for which they will receive a £10 voucher.

### **What happens to the data provided?**

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security), JISC Online Surveys are the data processor (responsible for processing your personal data on behalf of the University) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

Your personal information and research data will be collected over encrypted connections and stored securely by Online Surveys within their datacentres while the study is active. Storage via Online Surveys' secure datacentres conform to the requirements of ISO 27001. At the end of the study, data will be downloaded to secure University of Nottingham servers and erased from Online Surveys. . Any backups of the Online Survey data will be deleted three months after the survey has closed. Your contact information will be kept by the University of Nottingham for up to 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.



In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware if the data are to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

We would like your permission to use fully anonymised direct quotes in research publications.

### **What will happen if I don't want to carry on with the study?**

Even after you have signed the consent form, you are free to withdraw from the study at any time without giving any reason. Any personal data will be destroyed.

If you withdraw, we will no longer collect any information about you or from you but we will keep the anonymous research data that has already been collected and stored as we are not allowed to tamper with study records. This information may have already been used in some analyses and may still be used in the final study analyses.

### **Who will know that I am taking part in this research?**

Data will be used for research purposes only and in accordance with the General Data Protection Regulations. Any electronic data will be anonymised with a code as detailed above. Electronic storage devices will be encrypted while transferring and saving of all sensitive data generated in the course of the research. All such data are kept on password-protected databases sitting on a restricted access computer system and any paper information (such as your consent form, contact details and any research questionnaires) would be stored safely in lockable cabinets in a swipe-card secured building and would only be accessed by the research team.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data).

You can find out more about how we use your personal information and to read our privacy notice at:

<https://www.nottingham.ac.uk/utilities/privacy.aspx/>

Designated individuals of the University of Nottingham may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines.

With your consent, we will keep your personal information on a secure database in order to contact you for future studies.

### **What will happen to the results of the research?**

The results of the study will inform research directions for individuals with coexisting mild-cognitive impairment or dementia and hearing conditions. Results will also be written up for academic publication and presentation at research conferences. Results can be requested from the NIHR



Nottingham Biomedical Research Centre. All study data will be anonymised and you will not be identified in any arising report or publication.

### **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 reviewed and given approval by the Faculty of Medicine and Health Sciences Research Ethics Committee (Reference number: FMHS 438-0122).

### **Who is organising and funding the research?**

This research is being funded by the National Institute for Health Research (NIHR) East Midlands Clinical Research Network (CRN). The study is being coordinated by the NIHR Nottingham Biomedical Research Centre.

### **What if there is a problem?**

If you have a concern about any aspect of this project, please speak to the researcher Dr Eithne Heffernan or the Principal Investigator Emma Broome who will do their best to answer your query. The researcher should acknowledge your concern and give you an indication of how he/she intends to deal with it. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: [FMHS-ResearchEthics@nottingham.ac.uk](mailto:FMHS-ResearchEthics@nottingham.ac.uk).

Please quote ref no: FMHS 438-0122

### **Contact Details**

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:



Dr Helen Henshaw  
Principal Research Fellow  
National Institute for Health Research (NIHR) Nottingham Biomedical Research Centre  
Ropewalk House, 113 The Ropewalk, Nottingham, NG1 5DU  
Tel: +44(0)115 8232606(direct) or +44 (0)7527 754398 (mobile)  
Email: [helen.henshaw@nottingham.ac.uk](mailto:helen.henshaw@nottingham.ac.uk)



**University of  
Nottingham**

UK | CHINA | MALAYSIA

**Faculty of Medicine & Health Sciences**  
**School of Medicine**  
NIHR Nottingham Biomedical Research Centre  
Ropewalk House  
113 The Ropewalk  
Nottingham, NG1 5DU



**Dr Emma Broome**

Research Fellow

National Institute for Health Research (NIHR) Nottingham Biomedical Research  
Centre

Ropewalk House, 113 The Ropewalk, Nottingham, NG1 5DU

Tel: +44 (0)115 823 2600 (reception) or +44 (0)7415472658 (mobile)

Email: [emma.broome1@nottingham.ac.uk](mailto:emma.broome1@nottingham.ac.uk)



**Dr Eithne Heffernan**

Senior Research Fellow

National Institute for Health Research (NIHR) Nottingham Biomedical Research  
Centre

Ropewalk House, 113 The Ropewalk, Nottingham, NG1 5DU

Tel: +44 (0)115 823 2600 (reception)

Email: [Eithne.heffernan1@nottingham.ac.uk](mailto:Eithne.heffernan1@nottingham.ac.uk)