The development and validation of a patient reported experience measure (PREM) for people with hearing loss: the PREM-HeLP

Helen Pryce1, Georgina Burns-O’Connell1, Sian Smith1, Rebecca Knibb1, Rosemary Greenwood2, Rachel Shaw1, Saira Hussain1, Amanda Hall1, Jonathan Banks3, Jean Straus4, Sian Noble5.


Introduction & Background

Patient Reported Experience Measures (PREMs) are simple questionnaires about specific conditions. An audiology PREM could be used to explore patients’ experiences of hearing loss, of using hearing health services, and the efforts they make to manage their hearing.

Audiology services vary throughout the UK and a PREM would provide us with more information about the experience of audiology patients.

Aim:

To develop and validate a PREM to capture the experiences of those living with hearing loss and their experience of receiving audiology care.

Methods

This is part of the larger HeLP (Hearing loss and patient reported experience) study (Pryce et al. 2023). There are 3 stages to this stage of the HeLP project. These include developing the items for the PREM questionnaire, testing the PREM, and validating the questionnaire.

Development of PREM items

Development of initial questionnaire items were based on findings from the first phase of the HeLP project. This explored the experience of living with hearing loss and included interviews, a narrative review, and PPI work. From these, a conceptual model to explain living with hearing loss was developed.

Testing the PREM

Cognitive testing was conducted using a ‘think aloud’ approach to identify important and relevant items for inclusion on the PREM. 17 people with hearing loss talked through their thoughts whilst completing the draft PREM. 50 PPI participants provided feedback 72 responses to test our validation questionnaire

Reliability and validity testing

• 300+ participants to complete the validation questionnaire
• Validation measures include short forms of: Decisional conflict scale, EQ5D5L, Chew health literacy scale, Denver scale of communication, UCLA loneliness scale, ICECAP-A
• Reliability and validity testing to be conducted

Next Steps...

• Recruit 300+ participants to complete validation questionnaire
• Conduct reliability and validity testing
• Implement PREM in study clinical sites
• Continue working with PPI members

Acknowledgements

We would like to thank all of those who have shown interest and contributed to this research to date; your input has been invaluable.

Funding: This study is funded by an NIHR HSDR grant. (Funding stream REF NIHR131597). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Sponsor: University Hospitals Bristol and Weston NHS Foundation Trust, Research and Innovation, Level 3, UH Bristol Education and Research Centre, Upper Maudlin Street, Bristol BS2 8AE.

For updates, follow us on X (formerly Twitter): @HELPAstonHear

Author Contact Details: audiology_helpstudy@aston.ac.uk
https://research.aston.ac.uk/en/persons/helen-pryce

PREM Validation Questionnaire

The questionnaire is now live. Please complete it if you have hearing loss or share it with family and friends who have hearing loss, are aged over 16, and live in the UK.