

Developing a questionnaire for children with hearing loss – the York Binaural Hearing Related Quality of Life – Youth (YBHRQL-Y)

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Background

The YBHRQL-Y was developed as part of the ‘Both Ears Training Package’ (BEARS). It was designed to fill the gap as currently there is no measure that is:

1. Designed for children, by children
2. Specific to hearing loss
3. A preference-based-measure (PBM)

A PBM enables health economists to assess if health care is cost effective.

The York Binaural Hearing Related Quality of Life (YBHRQL) developed by Summerfield et al (2022)¹ is a hearing specific PBM developed for adults. The YBHRQL consists of 3 domains, speech perception in noise, localisation and effort and fatigue. We took the original domains and re-operationalised for use in children.

Stages of design

Stage 1 Adaptation

We took the original domains of the YBHRQL-Y and using the qualitative pre-test interview (QPI)² checked the suitability and understanding with children with hearing loss aged 8 to 16 years. We conducted two rounds of interviews with children.

Interview 1	Interview 2
Open ended questions	QPI approach
Based on YBHRQL domains	Equal partners
Everyday situations where domains were a challenge	Language use, structure, reliability, presentation, understanding
Analysed inductively using theme analysis	Analysed deductively using the response process model

Stage 2 Validation and reproducibility

Reproducibility was assessed by administering the YBHRQL-Y at two time-points to 60 young people (age 8 to 16) who have a severe-to-profound hearing loss and their parents / carers.

Validation of the YBHRQL-Y was assessed by administering the following outcome measures to participants; HUI3, CHU9D, SSQ-Ch and VFS-Peds.

Stage 3 Health-Utility Calculation

The time trade-off method was used with 150 young adults aged (18 to 24 years). The method asks participants to imagine themselves with the hearing loss described in the YBHRQL-Y and 10 years left of life. Participants indicate how many years of life they are willing to trade to obtain perfect hearing. These responses were converted to health-utility values for use in economic evaluation.

Results

Stage 1 The original language of the YBHRQL was too complicated and the scenarios were not relatable for children with severe to profound hearing loss. Working alongside the children as equal partners we developed scenarios and the structure of the final questionnaire. A total of 12 children were involved in the QPI aspect of the development.

Stage 2 71 parent/carer and their child (8-16 with severe to profound hearing loss) were recruited. They completed YBHRQL, YBHRQL-Y, HUI3, CHU9D, SSQ-Ch, VFS-Peds at 2 time points, 2 weeks apart. Statistical analysis using general linear models, intraclass correlations and bland-altman plots demonstrate the YBHRQL-Y is both valid and reliable.

Stage 3 Recruited 155 young adults aged 18 to 24 years (average age 21 years). Health utility values have been generated from this for use in health economic evaluation.

York Binaural Hearing Related Quality of Life - Youth

Understanding speech when there is background noise

It is lunch time, and you are in the place where you eat food. Imagine the noises that are here, people chatting, cutlery and plates being used. You are sat around a table with your friends. One of them speaks to you but you cannot see their face. Can you understand what they are saying?

I can understand most of the words	<input type="checkbox"/>
	<input type="checkbox"/>
I can understand some of the words	<input type="checkbox"/>
	<input type="checkbox"/>
I can understand none of the words	<input type="checkbox"/>

Finding where a sound is coming from

It is break time and you are in an outdoor space. You may play games here or be with your friends. People are chatting or playing and there are outside noises like birds tweeting and vehicles passing. You are in a group of friends. A friend speaks to you but is not looking at you. Do you know where they are?

I know exactly where they are	<input type="checkbox"/>
	<input type="checkbox"/>
I can point to an area where I think they are	<input type="checkbox"/>
	<input type="checkbox"/>
I do not know where they are	<input type="checkbox"/>

Effort and fatigue

I have to concentrate on listening at school in lessons. At the end of the school day...

I am not tired from listening	<input type="checkbox"/>
	<input type="checkbox"/>
I am a little tired from listening	<input type="checkbox"/>
	<input type="checkbox"/>
I am tired from listening	<input type="checkbox"/>

[1] Summerfield, A. Q., Kitterick, P. T., & Goman, A. M. (2022). Development and Critical Evaluation of a Condition-Specific Preference-Based Measure Sensitive to Binaural Hearing in Adults: The York Binaural Hearing-Related Quality-of-Life System. *Ear and Hearing*, 43(2), 379-397

[2] Buschle, C., H. Reiter and A. Bethmann(2021). "The qualitative pretest interview for questionnaire development: outline of programme and practice." *Quality & Quantity*.

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