

# Content validity and readability of patient-reported questionnaire instruments of hearing disability

Journal:	International Journal of Audiology
Manuscript ID	TIJA-2018-10-0301.R1
Manuscript Type:	Original Paper
Date Submitted by the Author:	n/a
Complete List of Authors:	Manchaiah, Vinaya; Lamar University, Department of Speech and Hearing Science; The Swedish Institute for Disability Research, Department of Behavioural Sciences and Learning; Audiology India, Speech and Hearing Granberg, Sarah; Audiological Research Centre, Örebro University Hospital; Swedish Institute for Disability Research, School of Health and Medical Sciences Grover, Vibhu; Lamar University, Department of Speech and Hearing Sciences Saunders, Gabrielle; Eriksholm Research Center, Portland VA Medical Center; Hall, Deborah; University of Nottingham, National Institute for Health Research Nottingham Biomedical Research Centre
Keywords:	Psycho-social/Emotional, Adult or General Hearing Screening, Behavioral Measures, Aging

SCHOLARONE™ Manuscripts

# Content validity and readability of patient-reported questionnaire instruments of hearing disability

Vinaya Manchaiah<sup>1,2,3</sup>, Sarah Granberg<sup>4,5</sup>, Vibhu Grover<sup>1</sup>, Gabrielle H. Saunders<sup>6</sup> & Deborah Ann Hall<sup>7,8,9,10</sup>

- Department of Speech and Hearing Sciences, Lamar University, Beaumont, Texas, USA
- Department of Speech and Hearing, School of Allied Health Sciences,
   Manipal University, Karnataka, India
- 3. Audiology India, Mysore, India
- 4. The Swedish Institute for Disability Research (SIDR), School of Health Sciences, Örebro University, Örebro, Sweden
- 5. Audiological Research Center, Örebro University Hospital, Örebro, Sweden
- 6. Eriksholm Research Center, Rørtangvej 20, DK-3070 Snekkersten, Denmark
- NIHR Biomedical Research Centre, Ropewalk House, 113 The Ropewalk,
   Nottingham NG1 5DU, United Kingdom
- 8. Hearing Sciences, Division of Clinical Neuroscience, School of Medicine, University of Nottingham, Nottingham, NG7 2UH, United Kingdom
- Nottingham University Hospitals NHS Trust, Queens Medical Centre, Derby Road, Nottingham NG7 2UH, United Kingdom
- University of Nottingham Malaysia, Jalan Broga 43500, Semenyih, Selangor
   Darul Ehsan, Malaysia

**Corresponding author:** Dr. Vinaya Manchaiah

**Communication address:** Department of Speech and Hearing Sciences,

Lamar University, Beaumont, Texas 77710, USA

Email: vinaya.manchaiah@lamar.edu

**Tel:** +1 (409) 880 8927

**Fax:** +1 (409) 880 2265

#### Authors ORCID iD

Vinaya Manchaiah: 0000-0002-1254-8407

Sarah Granberg: 0000-0002-2298-6806

Gabrielle H. Saunders: 0000-0002-9997-0845

Deborah Ann Hall: 0000-0002-3804-1452

# **Key Words**

Hearing disability, Hearing loss, Patient-reported questionnaire, Content validity,

Readability



# Content validity and readability of patient-reported questionnaire instruments of hearing disability

#### **Abstract**

**Objective:** The current study evaluates the content validity (i.e., domains assessed) and readability levels of patient-reported questionnaire instruments using internationally recognized procedures and tools.

**Design:** A review of the literature to identify candidate instruments and a synthesis of information including mapping extracted items onto the World Health Organization's – International Classification of Functioning, Disability, and Health (WHO-ICF) and estimating readability.

Study Sample: 14 patient-reported questionnaire instruments.

**Results:** In general, item content focused on body function and on activity limitations and participation restrictions, with less emphasis on environmental and personal factors, and with different emphases across instruments. Many items did not clearly map onto any of the WHO-ICF categories (i.e., *not coded* items ranged from 3.7% to 39.1% across the 14 questionnaires). All 14 instruments exceeded the 6<sup>th</sup> grade reading level when calculated according to the FORCAST formula which is appropriate for assessing a non-narrative text.

**Conclusions:** Clinical assessment of hearing disability is only as comprehensive as the items covered by the chosen measurement instrument. Our findings confirmed the diversity of domains covered by hearing disability instruments, and gaps in assessment. Some concern is raised about whether the item content is appropriate for those respondents with poor literacy.

# **Key Words**

Hearing disability, Hearing loss, Patient-reported questionnaire, Content validity, Readability



# Introduction

Hearing is a complex function that encapsulates sensory, psychological and social processes. Here, we follow the guidelines of World Health Organization to distinguish the concepts of impairment and disability (World Health Organization, 2001). We refer to *hearing impairment* as the dysfunction measurable in the laboratory or clinic and *hearing disability* as a measure of auditory difficulties experienced by the individual and of their non-auditory effects on everyday life (Manchaiah & Stephens, 2013; Stephens & Hétu, 1991). In other words, *hearing disability* refers to any restrictions or inability to perform an activity in a manner within the range expected for a normally hearing individual. Thereby, hearing disability is always situational. The experienced disability varies in different situations depending on circumstances. These could be factors in the environment (such as noise or technology) and/or more personal-related factors (such as cognitive deficits or low energy levels).

For this reason, audiological assessment should be viewed in the broad context of the biopsychosocial framework by evaluating both actual impairment and perceived hearing disabilities (Granberg, 2015; Manchaiah & Stephens, 2013). In other words, any patient assessment and management based on the biopsychosocial model should consider body structure and functions, individual experiences, and the individual's social and environmental context.

Assessment of these aspects is important because there are often discrepancies between impairment and disability (Hannula et al., 2011; Higson, Haggard, & Field, 1994; Rappaport, Phillips, & Gulliver, 1994; Saunders & Haggard, 1989; Tremblay et al., 2015). In standard clinical practice, hearing is measured based on threshold sensitivity despite the fact that hearing thresholds provide little information about speech understanding in the presence of background

noise (Jerger, 2011; Vermiglio, Soli, & Fang, 2018), the primary complaint of those with hearing loss (Vas, Akeroyd, & Hall, 2017). Indeed, hearing disability is a stronger predictor of help-seeking, hearing aid uptake, use, and satisfaction than is measured hearing sensitivity and is the only variable that studies consistently show to predict hearing health behaviors (Knudsen et al., 2010).

Hearing disability is most appropriately measured using patient-reported questionnaire instruments because such tools can capture a wide-ranging and comprehensive account of relevant experiences (Macefield et al., 2014). Numerous hearing disability instruments exist as illustrated by, Granberg et al., (2014a) who conducted a systematic review identifying 51 different patient-reported questionnaires that assess a range of hearing-related factors including disability, communication, and health-related quality of life. Of these, only 16 were used across several studies indicating that, at present, no instrument is accepted as a gold standard to assess the impact of hearing loss (Granberg et al., 2014a; Akeroyd et al., 2015).

Making an informed choice when selecting an appropriate tool for assessing hearing disability is critical. Important considerations include ensuring the tool addresses the intended purpose (Kirschner and Guyatt, 1985), that it has acceptable psychometric and other performance-related properties (Atcherson, Zraick, & Brasseux, 2011; Douglas & Kelly-Campbell, 2018; de Vet et al., 2011). Content validity and feasibility are two performance-related factors that should determine the choice of instrument (de Vet et al., 2011; Terwee et al., 2018). Content validity refers to the degree to which the questions and response options in the instrument adequately reflect the underlying construct that is to be measured (Mokkink et al., 2010; Terwee et al.,

2018). Good content validity would be indicated if all items in the questionnaire (i) referred to relevant aspects of the construct to be measured, (ii) were relevant for the target population, (iii) were relevant for the context of use, and (iv) together comprehensively reflected the construct to be measured (Prinsen et al., 2016; Terwee et al., 2018). This is especially important since assessment of a construct of interest is only as adequate as the items contained within the selected questionnaire. Indeed, it has been suggested that content validity is the most important property of patient-reported outcome measurement instruments (Terwee et al., 2018). Given recent advances in our understanding of the biopsychosocial aspects of hearing disability (Granberg et al., 2014a, 2014b, 2014c, 2014d; Vas, Akeroyd, & Hall, 2017), it is uncertain to what extent current questionnaires have good content validity since this attribute of questionnaire design is not always discussed explicitly by questionnaire developers.

A quality assessment of the instruments should consider the feasibility aspects of administering the questionnaire and the availability of supporting evidence on the measurement properties in the target population (Prinsen et al., 2016). Feasibility encompasses patient's and clinician's comprehensibility, ease of administration, interpretability of the scores, length of the instrument and completion time (Prinsen et al., 2016). With respect to comprehensibility, the instrument should have appropriate reading levels so that majority of the population of interest can read and understand the items. Research has shown that comprehension is higher when texts are easily read (Paz et al., 2009), but concerns have been expressed about the comprehensibility of hearing-related instruments as they may exceed recommended reading levels commensurate with good questionnaire design (Atcherson, Zraick, & Brasseux, 2011). Questionnaire instruments with reading levels that are too high for the user can result in: (a) non-completion by some patients

due to difficulties; (b) partial or missing of information while completing the instrument; and (c) completing the questionnaire by providing responses that are incongruent with actual health status (Atcherson, Zraick, & Brasseux, 2011). Hence, difficult-to-read questionnaires impose an unfair respondent burden and ultimately impact the reliability and validity of the tool. However, relatively few studies have been conducted to evaluate the readability of health-related questionnaires, particularly in terms of hearing (Atcherson, Zraick, & Brasseux, 2011; Douglas & Kelly-Campbell, 2018).

The purpose of the current study was therefore to evaluate the content validity and readability of the hearing disability questionnaire instruments. The World Health Organization's –

International Classification of Functioning, Disability and Health (WHO-ICF; World Health Organization, 2001) framework was used to map item content. This classification is founded on biopsychosocial assumptions of health and so our starting point was that a comprehensive hearing disability assessment should consider the key categories of ICF-WHO that are relevant to hearing health. These are body function, activity limitations and participation restrictions and contextual factors (i.e., environmental and personal factors). We would not expect a patient-reported instrument to ask about categories and domains of ICF-WHO that have not previously been judged as essential for assessing the degree of hearing health. For example, body structure is better assessed by clinical examination and history taking than by patient report (Danermark et al., 2013).

#### Method

Search Strategy and Inclusion Criteria

Questionnaires focusing on hearing disability were identified from two review articles (Granberg et al., 2014a; Barker et al., 2015). In addition, a literature search pertaining to patient-reported hearing disability measures was conducted independently by two researchers (VM and VG). We searched PubMed (MEDLINE) during August to December 2017 for published articles related to patient-reported hearing disability. *Hearing disability* encompasses other terms such as *hearing handicap*, *hearing difficulties*, and *hearing problems*. Therefore, the electronic search used key words such as: hearing disability questionnaire, hearing handicap questionnaire, hearing difficulties questionnaire, patient-reported hearing disability questionnaire, patient-reported hearing disability scale.

Hearing disability questionnaire instruments were included if they met the following criteria: (a) focused mainly on *hearing disability*; (b) were published in English language; and (c) reported the application of previously published patient-reported questionnaire instruments. In cases where multiple shortened versions of the full instrument existed only the most common shortened version was evaluated, in addition to the full version.

#### **Content** evaluation

Each category of the ICF contains a number of *domains*. Domain in this context refers to specific aspects measured by the questionnaire instruments (e.g., hearing, listening, or communicating). Each domain has a code and a description of the underlying theoretical construct (e.g. d3602 - Using communication techniques). Theoretical analysis of the domains assessed by each questionnaire item was conducted by mapping (or linking) each item to the ICF using established linking rules (Cieza et al., 2005; Granberg et al., 2014b, 2014d). Many items contained

statements to be evaluated in relation to the respondent's own hearing situation. Such statements contain underlying meanings that needs to be considered when linking them to the ICF (Granberg et al., 2014a, 2014b). Specific linking rules addressing qualitative data, statements or questions that contains underlying concepts, were used to assure that correct ICF code/codes were selected in order to capture the meaning of the statement (Granberg et al., 2014b). An example is presented in Table 1. The ICF does not provide detailed classification for personal factors. Hence, personal factors were classified using a separate coding system that has been proposed by audiologists and sociologists with expertise in hearing disability (Stephens, 2002; Stephens & Danermark, 2005). This classification system categorized personal factors as: (a) gender, race, age; (b) other health conditions; (c) fitness; (d) lifestyle; (e) habits; (f) upbringing; (g) coping styles; (h) social background; (i) education; (j) profession; (k) past and current experience; (1) overall behavior pattern and character style; and (m) individual psychological assets. Finally, the items that were not covered in the ICF coding system were coded as not coded (nc). It is important to note that the original linking rules (Cieza et al., 2005) were found to be insufficient during the ICF Core Sets project and so new linking rules specific to audiological measures have been developed (Granberg et al., 2014b). The linking rules developed especially for the audiological area were used to complement the linking rules revealed in the standardized classification. The rational for this matter is that the linking rules (coding rules) presented in the classification are generic in its characteristics and not sufficient to provide reliable and transparent linking of audiological research data.

#### <Table 1 near here>

Two researchers (SG and VG) independently reviewed the questionnaire items and conducted the linking process. Disagreements were notes in roughly 8% of the ICF codes, which were resolved by discussion between the two researchers who coded the items. A third reviewer (VM) provided input to resolve the discrepancies where necessary.

From the entire set of ICF categories (i.e., over 1400 categories), some ICF codes are more relevant to hearing disability than others. Previous work had identified what these are following a rigorous process (Danermark et al., 2013). A Comprehensive ICF Core Set for hearing loss lists 117 categories across the categories body functions, activity limitations, participation restrictions, environmental factors, and personal factors. All these are recommended when conducting a comprehensive, multidisciplinary assessment of hearing disability. In contrast, a Brief ICF Core Set of 27 categories can be used in settings in which a brief description and assessment of functioning of a person with hearing loss is sufficient. The brief set can also be used for research and in collecting data for population studies. In this study, the linked items were evaluated according to whether or not they matched the Brief ICF Core Set.

#### Readability

Readability is only one domain encompassed by comprehensibility. However, a quantitative readability estimate was used as a surrogate marker for comprehensibility. There are number of available readability measures, but currently there is no standard for choosing readability formulas (Breese & Burman, 2005). For this reason, four widely used readability measures were selected (Ley & Florio, 1996). These were: (i) Flesch Reading Ease (FRE); (ii) Flesch-Kincaid Grade Level Formula (F-KGL); (iii) Simple Measure of Gobbledygook (SMOG); and (iv)

FORCAST. Of these, the FORCAST formula is the most appropriate readability formula for use with a non-narrative text format, such as patient-reported questionnaires (Atcherson, Zraick, & Brasseux, 2011). The software Readability Studio Standard Edition 2012

(<a href="http://www.oleandersolutions.com/">http://www.oleandersolutions.com/</a>) was used to compute all four estimates in all the included questionnaire instruments.

FRE scores range from 0 to 100 whereby a higher score indicates easier reading. As a rule of thumb, scores of 90-100 can be understood by an average 5th grader. 8th and 9th grade students can understand documents with a score of 60-70; and college graduates can understand documents with a score of 0-30. An average document typically has an FRE score between 60 to 70. Results of F-KGL, SMOG and FORCAST analyses are presented as Reading Grade Level (RGL) with the U.S. school grade level as reference. The Reading Grade Level indicates the average student in that grade level can read the text. For example, a score of 7.4 indicates that the text is understood by an average student in 7th grade.

### Results

#### Identified questionnaire instruments

The initial search of two review articles identified 10 hearing disability questionnaire instruments. The database search with keywords identified ten additional questionnaire instruments. Of these 21 potentially eligible hearing disability questionnaire instruments, 7 were excluded for the following reasons: (i) three measures did not focus on the construct of hearing disability. First, the Hearing Handicap Support Scale (HHSS; Barrenäs & Holgers, 2000) appeared to have been adapted from an instrument that was originally developed for tinnitus (i.e.,

Tinnitus Handicap/Support Scale; Erlandsson et al., 1992). Second, the Hearing Coping

Assessment (Andersson et al., 1995) focused on acceptance and coping of hearing disability, and third, the Quantified Denver Scale (QDS; Schow & Nerbonne, 1980) focused on communication difficulties. (ii) the Hearing Performance Inventory (HPI; Giolas et al., 1979) and the shortened HPI (Lamb, Owens, & Schubert, 1983) were excluded because their application had not been reported after the corresponding original publication. (iii) two shortened versions of the Speech, Spatial, and Qualities of Hearing Scale (SSQ; Gatehouse & Noble, 2004) were excluded (the SSQ-5 (Demeester et al., 2012) and the SSQ-15 (Kiessling et al., 2011) in favor of the more popular SSQ-12 (Gatehouse & Noble, 2004). A Hearing Handicap and Disability Inventory (HHDI) was developed by van den Brink (1995) as part of his doctoral thesis, but the published 20-item version is now in common usage (van den Brink et al., 1996).

The remaining ten full instruments and four shortened instruments were subjected to further evaluation (see Table 2). All included instruments were predominantly developed for adults and/or older adults. We did not count the number of questionnaires that were excluded during abstract screening and so we are unable to provide information on the number of questionnaires that did not focus on hearing disability or that were published in non-English language.

#### <Table 2 near here>

#### **Content evaluation**

Table 3 shows the number of codes and linking of each questionnaire item to the ICF categories.

As expected, none of the questionnaire instruments covered items related to body structure. Also,

as expected, the questionnaires focused mainly on body functions and activity limitations and participation restrictions, with much less emphasis on environmental and personal factors. Fifty percent of the questionnaires (i.e., five out of ten full questionnaires and two out of four shortened versions) had no items referring to personal factors, and the majority of others did not cover it comprehensively as they asked only one or two questions. Moreover, the focus of each questionnaire instrument varied in terms of the main ICF categories that it covered. For example, the focus of hearing disability questionnaire in terms of body function varied from 34% to 78%, although one questionnaire (i.e., Social Hearing Handicap Index; SHHI), had no items related to body function.

#### <Table 3 near here>

Next, we examined the frequency of occurrence of the domains and subdomains in each ICF category for all the full versions of the questionnaire instruments (see Table 2). We eliminated the four included shortened (or screening) versions of the original measure to avoid bias in the calculation of the frequency distribution. Tables 4, 5, 6 and 7 provide details of ICF categories in terms of body function, activity limitations and participation restrictions, environmental factors and personal factors, respectively. The details of the *not coded* items are presented as Supplemental Material (Appendix). These were the items that could not be coded according to any of the >1,400 categories in the ICF classification system.

Body function items accounted for 0 to 77.8% of items across all questionnaire instruments (see Table 3). The most frequently occurring items in the body function category were domains of hearing function (b230) and emotional function (b152) (see Table 4). The Brief ICF Core Set

recommends assessing memory functions (b144), but this was not covered by any of the questionnaires. Conversely, questionnaires covered body functions that were not necessarily recommended as part of the Brief ICF Core Set including sleep functions (b134) and voice functions (b310).

#### <Table 4 near here>

Activity limitations and participation restrictions were covered from 8.7 to 57.1% by the different questionnaire instruments (see Table 3). The most frequently occurring items in this category were: domains of listening (d115), communicating with-receiving-spoken message (d310), conversation (d350), sustaining a conversation (d3501), recreation and leisure (d850), and family relationships (d760) (Table 5). The Brief ICF Core Set recommends assessing handling stress and other psychological demands (d240), using communication devices and techniques (d360), and school education (d820), but these were not covered by any of the included questionnaires. Conversely, questionnaires covered activity limitations and participation restrictions that were not necessarily recommended as part of the Brief ICF Core Set. Examples include watching (d110), focusing attention (d160), carrying out daily routine (d230), discussion (d355), using transportation (d470), driving (d475), relating with strangers (d730), formal relationships (d740), informal social relationships (d750), intimate relationships (d770), interpersonal interactions and relationships (d799), recreation and leisure (d920), and religion and spirituality (d930).

#### <Table 5 near here>

Environmental factors were covered from 0 to 29.1% by the different questionnaire instruments (see Table 3). The most frequently occurring items were domains of sound (e250) and products and technology for communication (e125) (Table 6). The Brief ICF Core Set recommends assessing immediate family (e310), health professionals (e355), individual attitudes of immediate family members (e410), and health services, systems, and policies (e580). Conversely, included questionnaires covered environmental factors that were not necessarily recommended as part of the Brief ICF Core Set including design, construction and building products and technology of buildings for public use (e150).

#### <Table 6 near here>

Personal factors items accounted for between 0 to 3.8% of items across the questionnaire instruments (see Table 3). Coping styles, overall behavior pattern and character style, and individual psychological assets were assessed, although their frequency was much less than other ICF categories (see Table 7). No personal factors were part of the Brief ICF Core Set.

#### <Table 7 near here>

#### Readability

Readability evaluations are shown in Table 8. When calculated according to the FORCAST formula, all included instruments exceeded the 6<sup>th</sup> grade reading level. The majority of the patient-reported hearing disability instruments exceeded the 6<sup>th</sup> Reading Grade Level

recommended by health literacy experts (Doak, Doak, & Root, 1996; Yin, Forbis, & Dreyer, 2007), regardless of the formula applied.

#### <Table 8 near here>

# **Discussion**

The current study assessed the domains measured by the patient-reported hearing disability questionnaire instruments, using the WHO-ICF classification. In addition, the study also examined the readability of these questionnaire instruments using a number of common reading grade formulas. Overall, these aspects relate to the content validity and feasibility of the questionnaire instruments (Terwee et al., 2018).

### Principal findings

The data show considerable variability in the domains measured by these instruments despite each one being referred to as a hearing disability questionnaire. The commonly-used questionnaires tend to focus on body function and activity limitations and participation restrictions categories of the ICF classification system. This is a strength as hearing disability predominantly affects these aspects of daily living (Manchaiah & Danermark, 2017; Stephens & Kramer, 2009). Nevertheless, there was limited emphasis on environmental factors covered by the questionnaire instruments.

While the ICF classification system defines the body functions and activities limitations and participation restrictions as the core elements of a disability, it also highlights that the contextual

factors (i.e., environmental and personal factors) can influence the degree to which the disability is noticed by an individual. Likewise, the ICF Core Sets for Hearing loss project highlighted a number of environmental factors (Granberg et al., 2014a, 2014b, 2014c, 2014d; ICF Research Branch, 2017) that were important for assessing hearing loss. However, these domains were not assessed by those hearing disability questionnaire instruments included in our evaluation. An important reason for this might be that the questionnaires embrace a very individual perspective on disability, i.e. disability is related to the individual and not to the situation. When taking such a perspective into account, influential environmental factors might become less important. However, a biopsychosocial perspective should consider all the elements including the contextual factors in patient assessment and management. This should be kept in mind if developing a new hearing disability questionnaire.

As noted above, some of the questionnaire items could not be linked to the ICF. There were two reasons for this. First, some questionnaire items were very detailed, while the ICF classification system relies on a broad or universally common elements. Second, when using the specific categories of the ICF (as one does in the linking process), it is the *content* of, in this case, the questionnaires that are covered. The magnitude of a problem (i.e. *difficulties*) are not focused.

Comparing the ICF linking of hearing disability questionnaire instruments to Brief ICF Core Sets reveled some discrepancies (Danermark et al., 2013). The hearing disability questionnaires did not include some items that were found in the Brief ICF Core Sets. On the other hand, various items were included in the hearing disability questionnaires that were not necessarily recommended by the Brief ICF Core Sets. The Brief ICF Core Set was developed by gathering

preliminary data from many countries across the globe and by reaching a consensus among various stakeholders (i.e., professionals, patients) on what aspect is important in the assessment of hearing loss. It is evident that most of the questionnaires were developed by researchers without basing their choice on any preliminary studies. Hence, we suggest that the questionnaire developers should consider the empirical data and also use a consensuses process in choosing what items to include in their new questionnaire instrument. For example, a recent project used the Leventhal's self-regulatory model to examine the psychosocial experiences related to adults with hearing loss (Heffernan et al., 2016). Based on their empirical findings and through consultation with adults with hearing loss, researchers, and clinician the authors developed a Social Participation Restrictions Questionnaire (SPaRQ) (Heffernan, Coulson, & Ferguson 2018a; Heffernan et al., 2018b). While this new scale does fill the gap in terms of measurement tools related to measuring social aspects of hearing loss, we argue that any full spectrum hearing disability instrument should additionally include items related to contextual factors (i.e., environmental and personal factors).

Based on the original publications, it appears that none of the questionnaires were developed taking the readability measures into account. The current study suggests that all the included instruments exceeded the recommended health literacy level of fifth to sixth RGL when examined using the FORCAST formula. Douglas and Kelly-Campbell (2018) recommend researchers to consider readability aspect while developing patient-reported outcome measures to be used in audiologic rehabilitation, as the adequate readability of audiologic patient-reported outcome measures is required if patient/family-centered care values are to be adhered to within the field of adult audiologic rehabilitation. Moreover, when considering a measure to be used

globally a challenge is to have an instrument that has equivalent readability and efficiency in different languages as sensitive to cultural context (Hall et al., 2018; Wild et al., 2009). For this reason, questionnaires developers should consider readability and cultural adequacy while developing the instruments and clinicians and researchers to should pay attention to these aspects while choosing them.

#### Comparison with other studies

It has been argued that patient-reported hearing disability should be an important component of audiological assessment (Knudsen et al., 2010; Vermiglio, Soli, & Fang, 2018). This is because assessment of hearing loss by audiometric test results alone are not adequate to assess the magnitude of the burden of hearing loss, especially in most frequently occurring age-related sensory impairment (Sindhusake et al., 2001). However, it is important to be aware of the factors influencing the patient-reported hearing disability (Kamil, Genther, & Lin, 2015; Kiely et al., 2012). In addition, audiological enablement and/or rehabilitation should be developed based on patient-reported hearing problems rather than solely using the observations based on objective measures such as pure-tone audiometry or speech reception thresholds (Stephens & Kramer, 2009). Considering these arguments, it is clear that patient-reported hearing disability is increasingly becoming an important tool for audiological practice. However, assessment of hearing disability is only as comprehensive as the items covered by the chosen questionnaire instrument. Various elements including conceptual clarity, psychometric properties, and chosen property (diagnostic accuracy versus treatment-related change) have been reported to be important while choosing the questionnaire instruments for clinical or research use (Kirshner & Guyatt, 1985; Prinsen et al., 2016; Hall, 2018). The current study demonstrates that no single

hearing disability questionnaire instrument comprehensively covers all of the Brief ICF Core Set domains. Nonetheless, several questionnaires (e.g., HHIA, HHIE) seem to have relatively better coverage as they do ask a few questions about environmental and personal factors. Hence, those questionnaires may be advantageous for capturing relevant information from patients. On the other hand, none of the questionnaire instruments are written in a plain language, highlighting the need for revision of these questionnaires to promote reading ease in majority of the population.

# Strengths and limitations of the study

The current study is the first to comprehensively examine the domains of hearing disability covered of hearing disability questionnaire instruments, and to assess their readability. However, there are some limitations. The study was limited to English language questionnaire instruments, which may have resulted in some selection bias. Also, there is some criticism of ICF framework in relation to hearing loss. In particular, Vas, Akeroyd, & Hall (2017) conducted a comprehensive review of published studies exploring the impact of hearing loss on those with lived experience and mapped them to ICF Core Sets and also developed their own model [i.e., Domains of Hearing Loss framework - Person with hearing loss (DoHL-P) framework]. They suggested that some of the patient-reported impacts of hearing loss might not be represented within the Brief ICF Core Set for Hearing Loss (Vas, Akeroyd, & Hall, 2017) and so mapping the questionnaire items onto another theoretical framework may have provided different results. For instance, their mapping identified that brief ICF Core Sets for hearing loss included all the *Auditory* domains and some of the *Social* domains are included in the ICF, but only one of the *Self* includes those domains relating to self-perception and personality (i.e.,

emotions, effort and fatigue, identity, and stigma). However, it is important to note that Brief ICF Core Sets has been identified by experts as comprising the most important aspects for assessing hearing disability, while the DoHL-P identified all domains no matter even if they had been mentioned only once or twice by patients and reported in the literature. For these reasons, we decided to map the hearing disability questionnaire instruments to Brief ICF Core Sets, rather than the DoHL-P framework. Our conclusions about content validity and readability alone do not necessarily lead to recommendations guiding choice of questionnaire for clinical use or for research since it is also important to consider the adequacy of psychometric properties for the intended purpose and target population.

#### Implications for clinical practice

Some of the questionnaires were developed prior to 2001, during a time when the WHO used a different classification to describe disability; the International Classification of Impairments, Disabilities and Handicaps (ICIDH). Questionnaires that were developed more than two decades ago therefore carry a higher risk that the items do not address the contemporary view of hearing disability. In particular, the ICIDH viewed disability as something specific to the individual and so it excluded environmental factors from the classification (World Health Organization, 1980). Environmental noise, hearing technology and accessibility of healthcare resources are all important environmental factors relevant to how people live with hearing difficulties. The audiologist would be advised to keep in mind the possibility that a questionnaire might not assess these issues, and alternative methods such as a semi-structured interview might be required instead.

The current study also highlights a similar gap with respect to personal factors. For example, a data-driven synthesis of the diverse range of published complaints reported by people with hearing loss highlighted that an over-arching supra-domain that the authors called *Self* (Vas, Akeroyd, & Hall, 2017). *Self* includes those domains relating to self-perception and personality (i.e., emotions, effort and fatigue, identity, and stigma). These observations highlight a potentially important gap in current patient-reported hearing disability instruments. The implication for clinical practice again is the risk of overlooking factors that might influence the success of an audiological intervention. For example, in failing to address a patient's concern about the personal and social stigma of wearing a behind-the-ear hearing aid might lead to noncompliance in use after fitting.

The questionnaire instruments examined in this study have much variability in terms of the domains covered in relation to the Brief ICF Core Set. However, some hearing disability questionnaire instruments contained a large percentage of items that could not be coded (e.g., SHQ), suggesting that those instruments may be targeting aspects that may not be critically important to hearing disability. Hence, we suggest that questionnaires which have better mapping to the Brief ICF Core Set could be favored for use in clinical practice.

Considering that almost all the questionnaires required reasonably high readability levels for respondents to fully understand the questions and response options, they may not be appropriate for people with lower literacy levels. Moreover, auditory comprehension level is usually higher than reading literacy level (Diakidoy et al., 2005). Therefore, for people with lower literacy levels, it may be more appropriate to administer these questionnaires in interview format so that

explanations can be given. For example, the original version of the SSQ was proposed to be administered using the interview format (Gatehouse & Noble, 2004). The interview method may have some advantages over self-administration, as it can help ensure that the meaning of each item is understood by all respondents. Moreover, an interview setting allows elaboration and further explanation especially where an item's meaning seems to have been misconstrued. On the contrary, the presence of hearing loss can add undue burden for some hearing-impaired patients when administering questionnaires in an interview format. Hence, clinicians must deliberate on whether to administer questionnaire instruments in an interview format or through self-report format.

#### **Conclusions**

The current study examined the content validity and readability of patient-reported hearing disability questionnaire instruments. Study results suggest that, in general, the hearing disability questionnaire instruments focus mainly on body function and also activity limitations and participation restrictions, whereas much lesser emphasis was placed on environmental and personal factors. The questionnaire instruments also varied in terms of its emphasis to different ICF categories and no currently available hearing disability questionnaire instrument comprehensively covers all of the Brief ICF Core Set domains. All patient-reported hearing disability measures exceeded the 6th grade reading level when calculated according to the FORCAST formula, the most appropriate readability formula for use with a non-narrative text (Atcherson, Zraick, & Brasseux, 2011). Clinical assessment of patient-reported hearing disability constructs are only as comprehensive as the items covered by the chosen questionnaire

instrument. Hence, the current mapping to the ICF Core Sets could be of interest to clinicians and researchers alike.

#### References

Abrams, H. 2000. Outcome measures in audiology: knowing we've made a difference. Audiology Online. Retrieved from: <a href="https://www.audiologyonline.com/articles/outcome-measures-in-audiology-knowing-1277">https://www.audiologyonline.com/articles/outcome-measures-in-audiology-knowing-1277</a> (Accessed on 08 January 2019).

Akeroyd, M.A., Wright-Whyte, K., Holman, J.A., and Whitmer, W.A. 2015. A comprehensive survey of hearing questionnaires: how many are there, what do they measure, and how have they been validated? *Trials* 16(Suppl 1): P26. https://doi.org/10.1186/1745-6215-16-S1-P26

Andersson, G., Melin, L., Lindberg, P., and Scott, B. 1995. Development of a short scale for assessment of experiences of hearing loss. The hearing coping assessment. *Scandinavian Audiology* 24(3): 147-54.

Atcherson, S. R., Zraick, R. I., and Brasseux, R. E. 2011. Readability of patient-reported outcome questionnaires for use with persons with tinnitus. *Ear and Hearing* 32(5): 671-673. doi:10.1097/AUD.0b013e3182134654

Barker, F., MacKenzie, E., Elliott, L., and de Lusignan, S. 2015. Outcome measurement in adult auditory rehabilitation: a scoping review of measures used in randomized controlled trials. *Ear and Hearing* 36(5): 567-73. doi: 10.1097/AUD.000000000000167.

Barrenäs, M.L., and Holgers, K-M. 2000. A clinical evaluation of hearing disability and handicap scale in men with noise induced hearing loss. *Noise and Health* 6(2): 67-78.

Breese, P., and Burman, W. 2005. Readability of notice of privacy forms used by major health care institutions. *Journal of the American Medical Association* 293(13): 1588-94. doi:10.1001/jama.293.13.1593

Cieza, A., Geyh, S., Chatterji, S., Kostanjsek, N., Üstün, B., and Stucki, G. 2005. ICF linking rules: an update based on lessons learned. *Journal of Rehabilitation Medicine* 37: 212-8.

Cox, R.M. 2005. Choosing a self-report measure for hearing aid fitting outcome. *Seminars in Hearing* 26(3): 149-156.

Danermark, B., Granberg, S., Kramer, S.E., Selb, M., and Möller, C. 2013. The creation of a comprehensive and a brief core set for hearing loss using the international classification of functioning, disability and health. *American Journal of Audiology* 22(2): 323-8. https://doi.org/10.1044/1059-0889(2013/12-0052

de Vet, H. C. W., Terwee, C.B., Mokkink, L.B., and Knol, D.L. 2011. Measurement in Medicine. Cambridge, UK: Cambridge University Press. doi: 10.1017/CBO9780511996214.

Demeester, K., Topsakal, V., Hendrickx, J.J., Fransen, E., van Laer, L., Van Camp, G., Van de Heyning, P., and van Wieringen, A. 2012. Hearing disability measured by the Speech, Spatial, and Qualities of Hearing Scale in clinically normal-hearing and hearing-impaired middle-aged persons, and disability screening by means of a reduced SSQ (the SSQ5). *Ear and Hearing* 33(5): 615-26. doi: 10.1097/AUD.0b013e31824e0ba7.

Diakidoy, I-N., Stylianou, P., Karefillidou, C., and Papageorgiou, P. 2005. The relationship between listening and reading comprehension of different types of text at increasing grade levels. *Reading Psychology*, 26(1), 55–80. https://doi.org/10.1080/02702710590910584

Doak, C., Doak, L., and Root, J. 1996. *Teaching patients with low literacy skills* (2nd ed.). Philadelphia, PA: J. B. Lippincott.

Douglas, A., and Kelly-Campbell, R. 2018. Readability of Patient-Reported Outcome Measures in adult audiologic rehabilitation. *American Journal of Audiology* 27(2): 208-18. doi: 10.1044/2018\_AJA-17-0095.

Erlandsson, S., Hallberg, L.R.M., and Axelsson, A. (1992) Psychological and audiological correlates to perceived tinnitus severity. *Audiology* 31: 168-179

Ewersten, H.W., and Birk-Nielsen, H. 1973. Social hearing handicap index: Social handicap in relation to hearing impairment. *Audiology* 12(3): 180-187.

Gatehouse, S., and Noble, W. 2004. The speech, spatial and qualities of hearing scale (SSQ). *International Journal of Audiology* 43(2): 85–99.

Giolas, T.G., Owens, E., Lamb, S.H., and Schubert, E.D. 1979. Hearing Performance Inventory. *Journal of Speech and Hearing Disorders* 44(2): 169-95.

https://doi.org/10.1044/jshd.4402.169

Granberg, S. 2015. Functioning and disability in adults with hearing loss: the preparatory studies in the ICF Core sets for hearing loss project (Doctoral dissertation). Örebro, Sweden: Örebro University.

Granberg, S., Dahlström, J., Möller, C., Kähäri, K., and Danermark, B. 2014a. The ICF Core Sets for hearing loss - researcher perspective. Part I: Systematic review of outcome measures identified in audiological research. *International Journal of Audiology* 53(2): 65-76. doi: 10.3109/14992027.2013.851799.

Granberg, S., Möller, K., Skagerstrand, Å., Möller, C., and Danermark, B. 2014b. The ICF Core Sets for Hearing Loss – researcher perspective, Part II: Linking outcome measures to the International Classification of Functioning, Disability and Health (ICF). *International Journal of Audiology* 53(2): 77-87. doi: 10.3109/14992027.2013.858279.

Granberg, S., Swanepoel, D.W., Englund., U., Möller, C., and Danermark, B. 2014c. The ICF Core Sets for hearing loss project: International expert survey on functioning and disability of

adults with hearing loss using the International Classification of Functioning, Disability and Health (ICF). *International Journal of Audiology* 53(8): 497-506. doi: 10.3109/14992027.2014.900196.

Granberg, S., Pronk, M., Swanepoel, DW., Kramer, S.E., Hagsten, H., Hjaldahl, J., Möller, C., and Danermark, B. 2014d. The ICF Core Sets for hearing loss project: Functioning and disability from the patient perspective. *International Journal of Audiology* 53(11): 777-86. doi: 10.3109/14992027.2014.938370.

Hall, D.A. 2018. Developing outcome measures for research. *ENT & Audiology News* 26(6): 68-70.

Hall, D.A., Domingo, S.Z., Hamdache, L.Z., Manchaiah, V., Thammaiah, S., Evans, C., and Wong, L. 2018. A good practice guide for translating and adapting hearing-related questionnaires for different languages and cultures. *International Journal of Audiology* 57(3): 161-75. doi: 10.1080/14992027.2017.1393565.

Hannula, S., Bloigu, R., Majamaa, R., Sorri, M., and Mäki-Torkko, E. 2012. Self-reported hearing problems among older adults: Prevalence and comparison to measured hearing impairment. *Journal of the American Academy of Audiology* 22(8): 550–59. doi: 10.3766/jaaa.22.8.7.

Heffernan, E., Coulson, N.S., Henshaw, H., Barry, J.G. and Ferguson, M.A. 2016.

Understanding the psychosocial experiences of adults with mild-moderate hearing loss: An application of Leventhal's self-regulatory model. *International Journal of Audiology* 55(S3): S3-S12. doi: 10.3109/14992027.2015.1117663.

Heffernan, E., Coulson, N.S., and Ferguson, M.A. 2018a. Development of the Social Participation Restrictions Questionnaire (SPaRQ) through consultation with adults with hearing loss, researchers, and clinicians: a content evaluation study. *International Journal of Audiology* 57(10): 791-9. doi: 10.1080/14992027.2018.1483585.

Heffernan, E., Maidment, D.W., Barry, J.G., and Ferguson, M.A. 2018b. Refinement and validation of the Social Participation Restrictions Questionnaire: an application of rasch analysis and traditional psychometric analysis techniques. *Ear and Hearing* Published Online. doi: 10.1097/AUD.0000000000000018.

Hétu, R., Getty, L., Philibert, L., Noble, W.G., and Stephens D. 1994. Development of a clinical tool for the measurement of severity of hearing disabilities and handicaps. *Journal of Speech-Language Pathology and Audiology* 18: 83-95.

High, W.S., Fairbanks, G., and Glorig, A. 1964. Scale for self-assessment of hearing handicap. *Journal of Speech and Hearing Disorders* 29: 215-30. <a href="https://doi.org/10.1044/jshd.2903.215">https://doi.org/10.1044/jshd.2903.215</a>

Higson, J.M., Haggard, M.P., and Field, D.L. 1994. Validation of parameters for assessing

obscure auditory dysfunction—robustness of determinants of OAD status across samples and test methods. *British Journal of Audiology* 28(1): 27–39.

ICF Research Branch. 2017. ICF Core Sets for Hearing Loss. Retrieved from: <a href="https://www.icf-research-branch.org/icf-core-sets-projects2/other-health-conditions/icf-core-set-for-hearing-loss">https://www.icf-research-branch.org/icf-core-sets-projects2/other-health-conditions/icf-core-set-for-hearing-loss</a> (Accessed on 08 January 2019).

Jerger, J. 2011. Why do people without hearing loss complain of hearing difficulties? *Journal of the American Academy of Audiology* 22(8): 490–1. doi: 10.3766/jaaa.22.8.1.

Kiely, K.M., Gopinath, B., Mitchell, P., Browning, C.J., and Anstey, K.J. 2012. Evaluating a dichotomized measure of self-reported hearing loss against gold standard audiometry: Prevalence estimates and age bias in a pooled national data set. *Journal of Aging and Health* 24(3): 439–58. doi: 10.1177/0898264311425088

Kiessling, J., Grugel, L., Meister, H., and Meis, M. 2011. German translations of questionnaires SADL, ECHO and SSQ and their evaluation. *Zeitschrift fur Audiologie* 50: 6–16.

Kirshner, B., and Guyatt, G. 1985. A methodological framework for assessing health indices. *Journal of Chronic Disorders* 38(1): 27–36. doi:10.1016/0021-9681(85)90005-0.

Knudsen, L.V., Öberg, M., Nielsen, C., Naylor, G., and Kramer, S.E. 2010. Factors influencing help seeking, hearing aid uptake, hearing aid use and satisfaction with hearing aids: A review of the literature. *Trends in Amplification* 14(3): 127–54. doi: 10.1177/1084713810385712.

Lamb, S.H., Owens, E., and Schubert, E.D. 1983. The revised form of the hearing performance inventory. *Ear and Hearing* 4(3): 152-157.

Ley, P., and Florio, T. 1996. The use of readability formulas in healthcare. *Psychology, Health, & Medicine* 1(1): 7-28. https://doi.org/10.1080/13548509608400003

Macefield, R.C., Jacobs, M., Korfage, I.J., Nicklin, J., Whistance, R.N., Brookes, S.T., Sprangers, M.A., and Blazeby, J.M. 2014. Developing core outcomes sets: Methods for identifying and including patient-reported outcomes (PROs). *Trials* 15: 49. doi:10.1186/1745-6215-15-49.

Manchaiah, V.K.C., and Freeman, B. 2011. Audiogram: Is there a need for change in the approach to categorize degree/severity of hearing loss? *International Journal of Audiology* 50(9): 638-40. doi: 10.3109/14992027.2010.539274.

Manchaiah, V.K.C., and Stephens, D. 2013. Perspectives on defining 'hearing loss' and its consequences. *Hearing, Balance and Communication* 11(1): 6-16. https://doi.org/10.3109/21695717.2012.756624

Manchaiah, V., and Danermark, B. (eds). 2017. *The experiences of hearing loss: Journey through aural rehabilitation*. Oxon, UK: Routledge.

Metselaar, M., Maat, B.M., Krijnen, P., Verschuure, H., Dreschler, W.A., and Feenstra, L. 2009. Self-reported disability and handicap after hearing-aid fitting and benefit of hearing aids: comparison of fitting procedures, degree of hearing loss, experience with hearing aids and uniand bilateral fittings. *European Archives of Oto-Rhino-Laryngology* 266(6): 907-17. doi: 10.1007/s00405-008-0847-x.

Mokkink, L.B., Terwee, C.B., Patrick, D.L., Alonso, J., Strat- ford, P.W., Knol, D.L., Bouter, L.M., and de Vet, H.C. 2010. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *Journal of Clinical Epidemiology* 63(7): 737–45. doi: 10.1016/j.jclinepi.2010.02.006.

Musiek, F.E., Shinn, J., Chermak, G.D., and Bamiou, D.E. 2017. Perspectives on the pure-tone audiogram. *Journal of the American Academy of Audiology* 28(7): 655-71. doi: 10.3766/jaaa.16061.

Newman, C.W., Weinstein, B.E., Jacobson, G.P., and Hug, G.A. 1990. The Hearing Handicap

Inventory for Adults: psychometric adequacy and audiometric correlates. *Ear and Hearing* 11(6): 430-3

Newman, C.W., Weinstein, B.E., Jacobson, G.P. and Hug, G.A. 1991. Test-retest reliability of the Hearing Handicap Inventory for Adults. *Ear and Hearing* 12(5): 355-7.

Noble, W.G., and Atherley, G.R.C. 1970. The Hearing Measurement Scale: A questionnaire for the assessment of auditory disability. *Journal of Auditory Research* 10(3): 229-50

Noble, W., Jensen, N.S., Naylor, G., Bhullar, N., and Akeroyd, M.A. 2013. A short form of the speech, spatial, and qualities of hearing scale suitable for clinical use: The SSQ12. *International Journal of Audiology* 52(6): 409–12. doi: 10.3109/14992027.2013.781278.

Ou, H., Perreau, A., and Tyler, R.S. 2017. Development of a shortened version of the Spatial Hearing Questionnaire (SHQ-S) for screening spatial-hearing ability. *American Journal of Audiology* 26(3): 293-300. doi: 10.1044/2017\_AJA-17-0030

Paz, S.H., Liu, H., Fongwa, M.N., Morales, L.S., and Hays, R.D. 2009. Readability estimates for commonly used health-related quality of life surveys. *Quality of Life Research* 18(7): 889-900. doi: 10.1007/s11136-009-9506-y

Prinsen, C.A.C., Vohar, S., Rose, M.R., Boers, M., Tugwell, P., Clarke, M., Williamson, P.R., and Terwee, C.B. 2016. How to select outcome measurement instruments for outcomes included

in a "Core Outcome Set" – a practical guideline. *Trials* 17: 449. https://doi.org/10.1186/s13063-016-1555-2

Rappaport, J.M., Phillips, D.P., and Gulliver, J.M. 1993. Disturbed speech intelligibility in noise despite a normal audiogram: A defect in temporal resolution? *Journal of Otolaryngology* 22(6): 447-53.

Schow, R.L., and Nerbonne, M.A. 1980. Hearing handicap and Denver Scales: Applications, categories and interpretation. *Journal of the Academy of Rehabilitative Audiology* 13: 66-77.

Sindhusake, D., Mitchell, P., Smith, W., Golding, M., Newall, P., Hartley, D., and Rubin, G. 2001. Validation of self-reported hearing loss. the Blue Mountains Hearing Study. *International Journal of Epidemiology* 30(6): 1371–1378. https://doi.org/10.1093/ije/30.6.1371

Stephens, D. 2002. *Audiological rehabilitation*. In: Luxon L, Furman JM, Martini A, (eds) Textbook of Audiological Medicine. London: Martin Dunitz, 513-531.

Stephens, D., and Danermark, B. 2005. The international classification of functioning, disability and health as a conceptual framework for the impact of genetic hearing impairment. In:

Stephens, D., and Jones, L. (eds). *The impact of genetic hearing impairment*. London: Whur, 54-67.

Stephens, D., and Kramer, S.E. 2009. Living with Hearing Difficulties: The Process of

Enablement. Chichester: Wiley.

Stephens, D., and Hétu, R. 1991. Impairment, disability and handicap in audiology: towards consensus. *Audiology* 30(4): 185-200.

Terwee, C.B., Prinsen, C.A.C., Chiarotto, A., Westerman, M.J., Patrick, D.L., Alonso, J., Bouter, L.M., de Vet, H.C.W., and Mokkink, L.B. 2018. COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. *Quality of Life Research* 27(5), 1159-70. doi: 10.1007/s11136-018-1829-0.

Tremblay, K.L., Pinto, A., Fischer, M.E., Klein, B.E.K., Klein, R., Levy, S., Tweed, T.S., and Cruickshanks, K.J. 2015. Self-reported hearing difficulties among older adults with normal audiograms: The Beaver Dam Offspring study. *Ear and Hearing* 36(6): e290-e299. doi: 10.1097/AUD.0000000000000195.

Tyler, R.S., Perreau, A.E., and Ji, H. 2009. Validation of the Spatial Hearing Questionnaire. *Ear and Hearing* 30: 466-74. doi: 10.1097/AUD.0b013e3181a61efe.

van den Brink RHS. 1995. Attitude and illness behavior in hearing impaired elderly (Doctor of Philosophy thesis). Netherlands: University of Groningen.

van den Brink, R.H.S., Wit, H.P., Kempen, G.I., and van Heuvelen, M.J. 1996. Attitude and help-seeking for hearing impairment. *British Journal of Audiology* 30(5): 313-24.

Vas, V., Akeroyd, M.A., and Hall, D. A. 2017. A data-driven synthesis of research evidence for domains of hearing loss, as reported by patients or their communication partner. *Trends in Hearing* 21: 2331216517734088. doi: 10.1177/2331216517734088

Ventry, I.M., and Weinstein, B.E. 1982. The hearing handicap inventory for the elderly: a new tool. *Ear and Hearing* 3(3): 128-34.

Ventry, I., and Weinstein, B. 1983. Identification of elderly people with hearing problems. American Speech-Language-Hearing Association 25(7): 37-42.

Vermiglio, A.J., Soli, S.D., and Fang, X. 2018. An argument for self-report as a reference standard in audiology. *Journal of the American Academy of Audiology* 29(3), 206-222. doi: 10.3766/jaaa.16128.

Weinstein, B.E. 1997. Outcome measures in hearing aid fitting/selection process. *Trends in Amplification* 2(4): 117-7. doi: 10.1177/108471389700200402

Wild, D., Eremenco, S., Mear, I., Martin, M., Houchin, C., Gawlicki M, Hareendran, A., Wiklund, I., Chong, L.Y., von Maltzahn, R., Cohen, L., and Molsen, E. 2009. Multinational trials-recommendations on the translations required, approaches to using the same language in different countries, and the approaches to support pooling the data: the ISPOR patient-reported

outcomes translation and linguistic validation good research practices task force report. *Value in Health* 12(4): 430–40. doi:10.1111/j.1524-4733.2008. 00471.x

World Health Organization. 1980. *ICIDH: International Classification of Impairments, Disabilities, and Handicaps*. Geneva, Switzerland: World Health Organization.

World Health Organization. 2001. ICF: *International Classification of Functioning, Disability and Health*. Geneva, Switzerland: World Health Organization.

Yin, H.S., Forbis, S.G., and Dreyer, B.P. 2007. Health literacy and pediatric health.

Current Problems in Pediatric and Adolescent Health Care 37(7): 258–86.

## **Tables**

Table 1: Example of the ICF domain linking procedure

Instrument	Meaning	Meaningful	Interpretati	Linking	ICF domain
	unit	concept	on of	unit	(code and
	0,		underlying		description)
			meaning		
Item #14	The people I	People I	People I	Bad attitude	e499 (attitudes
Hearing	associate	associate	associate	of people I	of [unspecified]
Handicap	with, think	with	with have a	associate	others)
and	it is	•	bad attitude	with	
Disability	bothersome	Bothersome	about me		
Inventory	when I ask		using a	Usage of	d3602 (using
(van den	them to	Ask them to	communicat	communicat	communication
Brink et al.,	repeat what	repeat what	ions strategy	ion strategy	techniques)
1996)	they said	they said			

Table 2: English-language patient-reported hearing disability measures

Measure (with original reference)	No of	Response options	Population
	Items		
Full versions of hearing-disability question	nnaire i	instruments	
Hearing Disability and Handicap Scale	20	4-point categorical scale	Adults
(HDHS; Hétu et al., 1994)		(never, sometimes, often,	
		always)	
Hearing Handicap and Disability	20	4-point categorical scale	Adults
Inventory (HHDI; van den Brink et al.,		([almost] never, sometimes,	
1996)	Ó	often, [almost] always)	
Hearing Handicap Inventory for Adults	25	3-point categorical scale (yes,	Adults
(HHIA; Newman et al., 1990)	1	sometimes, no)	
Hearing Handicap Inventory for the	25	3-point categorical scale (yes,	Older adults
Elderly (HHIE; Ventry & Weinstein,		sometimes, no)	
1982)			
Hearing Handicap Scale (HHS; High,	40	5-point categorical scale	Adults
Fairbanks, & Glorig, 1964)		(almost always to almost	
		never)	
Hearing Handicap Questionnaire (HHQ;	12	5-point categorical scale	Adults
Gatehouse & Noble, 2004)		(never to almost always)	

Hearing Measurement Scale (HMS; Noble	42	5-point categorical scale	Adults
& Atherley, 1970)		(always to never); and 2-point	
		scale (yes, no)	
Social Hearing Handicap Index (SHHI;	21	5-point categorical scale	Adults
Ewersten & Brik-Nielsen, 1973)		(almost always to almost	
		never)	
Spatial Hearing Questionnaire (SHQ;	24	0 to 100 continuous scale	Adults
Tyler, Perreau, & Ji, 2009)		(very difficult to very easy)	
Speech, Spatial, and Qualities of Hearing	49	0 to 10 continuous scale (not	Adults
Scale (SSQ; Gatehouse & Noble, 2004)		at all to perfectly)	
Shortened versions of hearing-disability	question	naire instruments	
Hearing Handicap Inventory for the	10	3-point categorical scale	Older adults
Elderly – Screening (HHIE-S; Ventry &		(yes, sometimes, no)	
Weinstein, 1983)		4	
Hearing Handicap Inventory for Adults –	10	3-point categorical scale	Older adults
Screening (HHIA-S; Newman et al., 1991)		(yes, sometimes, no)	
Shortened Version of the Spatial Hearing	6	0 to 100 continuous scale	Adults
Questionnaire (SHQ-S; Ou, Perreau, &		(very difficult to very easy)	
Tyler, 2017)			
Speech, Spatial, and Qualities of Hearing	12	5-point categorical scale	Adults
Scale – Short (SSQ-12; Gatehouse &		(never to almost always)	
Noble, 2004; Noble et al., 2013)			
Weinstein, 1983)  Hearing Handicap Inventory for Adults – Screening (HHIA-S; Newman et al., 1991)  Shortened Version of the Spatial Hearing Questionnaire (SHQ-S; Ou, Perreau, & Tyler, 2017)  Speech, Spatial, and Qualities of Hearing Scale – Short (SSQ-12; Gatehouse &	6	3-point categorical scale (yes, sometimes, no)  0 to 100 continuous scale (very difficult to very easy)  5-point categorical scale	Adults

Table 3: ICF domains covered in each patient-reported hearing disability measure.

Percentage was calculated by dividing the number of codes for each domain from the total number of codes occurring in that questionnaire.

	No of	n (%) of ICF Domains Measured in each category						
Questionnaire	ICF	Body	Activity	Environmental	Personal	Not coded		
	codes	function	limitations	factors	factors	(nc)		
			and					
			participation					
		,0	restrictions					
Full versions of	hearing	g-disability que	estionnaire inst	ruments	l	1		
HDHS	66	28 (42.4)	19 (28.8)	11 (16.7)	1 (1.5)	7 (10.6)		
HHDI	57	10 (17.5)	26 (45.6)	16 (28.1)	2 (3.5)	3 (5.3)		
HHIA	82	35 (42.7)	31 (37.8)	4 (4.9)	3 (3.6)	9 (11)		
HHIE	80	33 (41.2)	28 (35)	5 (6.2)	3 (3.8)	11 (13.8)		
HHS	142	16 (11.3)	67 (47.2)	37 (26)	0 (0)	22 (15.5)		
ННО	27	21 (77.8)	4 (14.8)	0 (0)	1 (3.7)	1 (3.7)		
HMS	88	28 (31.8)	33 (37.5)	20 (22.7)	0 (0)	7 (8)		
SHHI	56	0 (0)	32 (57.1)	14 (25)	0 (0)	10 (17.9)		
SHQ	94	25 (26.6)	16 (17)	24 (25.5)	0 (0)	29 (30.9)		
SSQ	199	48 (24.1)	68 (34.2)	58 (29.1)	0 (0)	25 (12.6)		
Shortened vers	ions of h	earing-disabil	ity questionnai	re instruments		1		
HHIE-S	34	11 (32.3)	13 (38.2)	4 (11.8)	1 (3)	5 (14.7)		
L		I	I.	l .	l	1		

HHIA-S	35	12 (34.3)	16 (45.7)	3 (8.6)	1 (2.8)	3 (8.6)
SHQ-S	23	6 (26.1)	2 (8.7)	6 (26.1)	0 (0)	9 (39.1)
SSQ-12	51	12 (23.5)	22 (43.1)	11 (21.6)	0 (0)	6 (11.8)



Table 4: Body functions domains covered in patient-reported hearing disability measures (n=244) and their relationship to the brief ICF core set. Key: 'included' = the corresponding domain is part of the brief ICF core set; 'not included' = the corresponding domain is not part of the brief ICF core set; 'under d###' = the subdomain falls underneath one of the domains in the brief ICF core set.

Body Function	n	Brief ICF core
		set
b126 - Temperament and personality functions	2	included
b1266 – Confidence	2	under b126
b134 - Sleep functions	1	not included
b1300 - Energy level	4	not included
b140 - Attention functions	1	included
b1401 - Shifting attention	1	under b140
b1402 - Dividing attention	2	under b140
b144 – Memory functions	0	included
b152 - Emotional functions	37	included
b1560 - Auditory perception	18	not included
b230 - Hearing functions	85	included
b2300 - Sound detection	43	under b230
b2301 - Sound discrimination	14	under b230
b2302 - Localization of sound source	23	under b230
b2303 - Lateralization of sound	3	under b230

b2304 - Speech discrimination	1	under b230
b240 - Sensations associated with hearing and vestibular function	0	included
b2400 - Ringing in ears or tinnitus	3	under b240
b310 - Voice functions	1	not included
b5102 - Chewing	1	not included
b7800 - Sensation of muscle stiffness	2	not included

Table 5: Activity limitations and participation restrictions domains covered in patient-reported hearing disability measures (n=324) and their relationship to the brief ICF core set. Key: 'included' = the corresponding domain is part of the brief ICF core set; 'not included' = the corresponding domain is not part of the brief ICF core set; 'under d###' = the subdomain falls underneath one of the domains in the brief ICF core set.

Activity Limitations and Participation Restrictions	n	Brief ICF core
		set
d110 – Watching	11	not included
d115 - Listening	31	included
d160 - Focusing attention	11	not included
d230 - Carrying out daily routine	1	not included
d240 - Handling stress and other psychological demands	0	included
d310 - Communicating with-receiving-spoken messages	84	included
d350 - Conversation	17	included
d3501 - Sustaining a conversation	17	under d350
d3503 - Conversing with one person	18	under d350
d3504 - Conversing with many people	14	under d350
d355 - Discussion	2	not included
d360 - Using communication devices and techniques	0	included
d3600 - Using telecommunication devices	5	under d360
d3602 - Using communication techniques	7	under d360
d470 - Using transportation	2	not included

d4701 - Using private motorized transportation	4	not included
d4702 - Using public motorized transportation	1	not included
d475 – Driving	1	not included
d4751 - Driving motorized vehicles	4	not included
d6200 - Shopping	6	not included
d730 - Relating with strangers	4	not included
d740 - Formal relationships	6	not included
d750 - Informal social relationships	6	not included
d7500 - Informal relationships with friends	7	not included
d7501 - Informal relationships with neighbours	3	not included
d760 - Family relationships	13	included
d770 - Intimate relationships	1	not included
d799 - Interpersonal interactions and relationships, unspecified	5	not included
d820 – School education	0	included
d850 - Remunerative employment	2	included
d910 - Community life	7	included
d9101 - Formal associations	2	under d910
d920 - Recreation and leisure	15	not included
d9202 - Arts and culture	2	not included
d9205 - Socializing	8	not included
d930 - Religion and spirituality	7	not included

Table 6: Environmental factors domains covered in patient-reported hearing disability measures (n=189) and their relationship to the brief ICF core set. Key: 'included' = the corresponding domain is part of the brief ICF core set; 'not included' = the corresponding domain is not part of the brief ICF core set; 'under d###' = the subdomain falls underneath one of the domains in the brief ICF core set.

Environmental Factors	T	<b>Brief ICF core</b>
Environmental Factors	n	brief icr core
		set
e115 - Products and technology for personal use in daily living	2	not included
e120 - Products and technology for personal indoor and outdoor	1	not included
mobility and transportation		
e1200 - General products and technology for personal indoor	1	not included
and outdoor mobility and transportation		
e125 - Products and technology for communication	0	included
e1250 - General products and technology for communication	31	under d125
e1251 - Assistive products and technology for communication	2	under d125
e150 - Design, construction and building products and	15	not included
technology of buildings for public use		
e250 - Sound	49	included
e2500 - Sound intensity	57	under d250
e2501 - Sound quality	25	under d250
e310 - Immediate family	0	included
e350 - Domesticated animals	1	not included

e355 - Health professionals	0	included
e410 - Individual attitudes of immediate family members	0	included
e460 - Societal attitudes	1	included
e499 - Attitudes, unspecified	4	not included
e580 - Health services, systems, and policies	0	included

Table 7: Personal factors domains covered in patient-reported hearing disability measures (n=10)

Personal Factors	n	Brief ICF core
		set
Coping styles	4	not included
Overall behavior pattern and character style	2	not included
Individual psychological assets	<mark>4</mark>	not included

**Table 8: Readability of commonly used English-language patient-reported hearing disability measures.** FRE scores range from 0–100. F-KGL, SMOG and FORCAST scores are presented as Reading Grade Level and also its corresponding age in years has been presented.

	Readability	Measures nde Level (Reader	Ago in Voors)		
Questionnaire	Flesch	Flesch-Kincaid	Simple Measure	FORCAST	
	Reading	Grade Level	of		
	Ease (FRE)	Formula	Gobbledygook		
		(F-KGL)	(SMOG)		
Full versions of h	nearing-disabili	ty questionnaire ii	nstruments		
HDHS	68	7.4 (12-13 yrs)	9.8 (14-15 yrs)	9.9 (14-15 yrs)	
HHDI	74	5.6 (10-11 yrs)	8.8 (13-14 yrs)	9.3 (14-15 yrs)	
HHIA	65	8.7 (13-14 yrs)	10.1 (15-16 yrs)	10.5 (15-16 yrs)	
HHIE	79	5.5 (10-11 yrs)	8.7 (13-14 yrs)	9.7 (14-15 yrs)	
ННО	53	9.1 (14-15 yrs)	10.7 (15-16 yrs)	11.3 (16-17 yrs)	
HHS	71	9.0 (14-15 yrs)	11.2 (16-17 yrs)	8.5 (13-14 yrs)	
HMS	79	6.7 (11-12 yrs)	8.8 (13-14 yrs)	8.6 (13-14 yrs)	
SHHI	70	8.4 (13-14 yrs)	11.4 (16-17 yrs)	8.9 (13-14 yrs)	
SHQ	84	4.5 (9-10 yrs)	8.6 (13-14 yrs)	8.4 (13-14 yrs)	
SSQ	80	6.2 (11-12 yrs)	9.0 (14-15 yrs)	8.7 (13-14 yrs)	
Shortened version	ns of hearing-d	isability questionr	naire instruments	1	
HHIA-S	51	10.2 (15-16 yrs)	13.5 (18-19 yrs)	11.1 (16-17 yrs)	

HHIE-S	56	9.8 (14-15 yrs)	12.2 (17-18 yrs)	10.9 (15-16 yrs)
SHQ-S	80	5.5 (10-11 yrs)	9.4 (14-15 yrs)	8.7 (13-14 yrs)
SSQ-12	54	8.9 (13-14 yrs)	10.6 (15-16 yrs)	11.1 (16-17 yrs)



## **Appendices**

## Appendix 1: Not coded (nc) domains covered in patient-reported hearing disability instruments (n=124)

Not Coded	n
A bus or truck	1
Adjoining room	1
Behavior of others	2
Busy street	1
Car	2
Child	2
Child's voice	2
Difficulty	13
Dinner table	1
Distance	12
Easily	8
Examples	7
Flying airplane	1
Footpath of a busy street	1
Home	4
In the street	1

Kitchen1Less often than you would like11Limits or hampers2Man3Man's voice2Misunderstand1	
Limits or hampers 2  Man 3  Man's voice 2	
Man 3 Man's voice 2	
Man's voice 2	
Misunderstand 1	
Music 2	
Music source 2	
Normal tone of voice 1	
One of them starts to speak	
Outdoor 5	
Outdoors in an unfamiliar place	
People will find out 1	
Recognize 1	
Restrict 1	
Room 1	
Sales woman 1	
Self 1	
Sitting around the table 1	
Sitting in between two persons 1	
Someone next to you start talking 1	
Speak 1	

Street	1	
	1	
Street corner	1	
Tea table	1	
Time	2	
Very much	1	
Visual cues	11	
Woman	3	
Woman's voice	2	