Functioning and Disability in Adults with Hearing Loss
Functioning and Disability in Adults with Hearing Loss
Preparatory studies in the ICF Core Sets for Hearing Loss project
Abstract


Hearing loss (HL) is a health condition that affects more than 360 million people worldwide. The findings from previous research point at the adverse relationship between adults with hearing loss and important aspects of everyday life such as social relations, communication and work-related tasks. However, the overall picture concerning the functional and disabling aspects of adults with HL remains incomplete. To identify the functional and disabling aspects, a conceptual and/or theoretical framework is required. The International Classification of Functioning, Disability and Health (ICF) offer a multidimensional framework based on bio-psycho-social assumptions about health. In previous research investigations in which the ICF has been used, some utility problems in the linking (relating) of data to the classification have been highlighted.

The aims of the present thesis were to explore the areas of functioning and disability of relevance for adults with HL and to explore how audiological data can be linked to ICF. The aims were explored by applying the methodology of the ‘interdisciplinary evidence-based approach to functioning and disability in adults with HL’, acknowledging the merging of three perspectives designated the Researcher, the Patient and the Professional perspective. Four studies that focus on the three perspectives were conducted. All results were linked to the ICF classification. The results were merged into a model designated ‘the integrative model of functioning and disability in adults with HL’.

When the three perspectives were linked, the results revealed several aspects of relevance for the target group. Bodily (individual) dimensions, such as hearing, auditory perception, memory, attention, energy, and emotions, were acknowledged. Aspects of everyday life such as conversations, the usage of communication strategies, family relationships and work, were highlighted. Influential environmental factors, such as noise, assistive technical devices, the design of public buildings, social support and the attitudes of people in the environment, were also identified. In conclusion, interactions seemed to be vital as almost all identified aspects highlighted or were tied to this dimension of human functioning. Further, concerning the linking of the data it was acknowledged that the ICF and the research area of adult HL do not fully comply. Suggestions for improvements in future revisions of the ICF were highlighted and discussed.

Keywords: hearing loss, adults, ICF, classification, functioning, disability, linking.

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Original articles

Study I

Study II

Study III

Study IV

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**Abbreviations**

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<td>HA</td>
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<td>Self-assessment</td>
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<td>Sensorineural Hearing Loss</td>
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<td>SO</td>
<td>Significant others</td>
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1. Introduction

The present thesis explores areas of ‘functioning and disability in adults with hearing loss’. It is written with the vocabulary of the International Classification of Functioning, Disability and Health (ICF) in mind. Regarding the terms ‘functioning’ and ‘disability’, the uninitiated person may assume that somewhere in the text, I explain what ‘functioning’ means and what ‘disability’ means in relation to the present target group. I will not do that; instead the focus of this thesis is ‘relevance’. As I explain in section 1.3, the ICF contains different health domains. These domains can be evaluated in relation to persons with a specific health condition and are thus considered to be functional or disabling. The chosen designation depends on whether the person experiences problem in that specific health domain or not. Whether a specific health domain is considered to be functional or disabling for adults with HL is not in focus in the present thesis. Instead, the interest is what functioning and disability, from the ICF perspective, encompass in relation to the target group. That is, what in ICF is relevant for adults with hearing loss?

However, now I am jumping ahead; let us start from the beginning!

‘When someone in the family has a hearing loss, the entire family has a hearing problem’

(Mark Ross, PhD)

1.1 Hearing loss – a health condition

Perhaps there are few existing health conditions with so many terms as the hearing disorder ‘Hearing Loss’ (HL). Searching the audiological literature, one encounters expressions such as hearing loss, hearing impairment, hearing disorder, persons who are hard of hearing, persons with audiometric loss or persons who are deaf. All expressions are used inconsistently but with the same intent, i.e., to refer to a specific target group with a specific loss in the ear.

A fruitful way to reach consensus concerning this matter would be to simply adopt the terminology utilized by the US National Library of Medicine, which is responsible for the MeSH terms, applied when searching medical databases\textsuperscript{143}. In doing so, the term ‘hearing disorder’ serves as an umbrella term that indicates a disorder somewhere in the hearing system, whereas hearing conditions such as ‘hearing loss’ (reduced sensitivity to
sounds normally perceived), ‘tinnitus’ (sensation of sound without external sound source), and ‘hyperacusis’ (over-sensitivity to certain sounds) are examples of sub-terms related to ‘hearing disorders’ that indicate specific hearing disorders.

Hearing loss is a health condition that affects the anatomical and physiological parts of the ear and the hearing function. However, for the affected individual, the functional aspects of the condition in everyday life are more noticeable than the loss itself.

Hearing loss is one of the most common chronic health conditions worldwide, with more than 360 million people experiencing hearing loss $>40$ dB HL (see below for explanation) in the better hearing ear (adults). This figure corresponds to over 5% of the world’s population.

1.1.1 Hearing loss

From a physiological perspective, the characteristic for the condition of HL is impairment in the hearing function that results in various consequences, depending on the cause and location of the impairment but always accompanied by a reduced sensitivity to sounds normally perceived. There are different clinical criteria for HL, but a common method for classifying the condition is estimating the pure-tone-average (PTA), applied to the better ear, when conducting a pure-tone audiometry test of the hearing function. A PTA of four frequencies is typically used (PTA 4: 0.5; 1; 2 and 4 kHz). The classification distinguishes between mild hearing loss ($>20$ dB Hearing Level [HL], $\leq 40$ dB HL), moderate hearing loss ($>40$ dB HL, $\leq 70$ dB HL), severe hearing loss ($>70$ dB HL, $\leq 95$ dB HL) and profound hearing loss ($>95$ dB HL)\textsuperscript{59}. From an anatomical perspective, a common method for classifying is to distinguish according to the location of the loss. Somewhat rough but nonetheless clinically relevant, the classifications of conductive, sensorineural and mixed hearing loss are useful. Losses located in the outer or the middle ear, are referred to as conductive hearing losses (Fig. 1a, b). Examples are tympanosclerosis (the tympanic membrane contains formations of calcified portions resulting in reduced motion ability) and ossicular chain discontinuity (due to trauma or necrosis)\textsuperscript{169}. Because the main function of the outer and middle ear is to transfer and amplify the incoming sound wave, a loss in these areas primarily result in diminished sensitivity to sounds that are normally heard; i.e., sounds are typically non-audible or perceived as too weak.

Sensorineural HL (SNHL) is located in the inner ear, in the cochlear nerve or somewhere else in the central auditory system (Fig. 1a, b).
Fig. 1a The peripheral auditory system. Drawing by Anna Dahlin.

Fig. 1b The central auditory system. Drawing by Anna Dahlin.
This type of condition has multiple etiologies (causes), and a common distinction is between A) congenital and B) acquired. A) Congenital SNHL can be divided into genetic (syndromic and non-syndromic) and non-genetic. Although over 400 syndromes include SNHL, non-syndromic SNHL is more common, with a mutation in the connexin-26 gene being responsible for causing over half of the non-syndromic SNHL cases. Congenital non-genetic causes of SNHL include maternal infections, ototoxic drugs or birth trauma.

B) Acquired SNHL is also often divided into non-genetic and genetic. Examples of acquired non-genetic SNHL include infections, meningitis, ototoxic agents, noise and trauma. There have been many new discoveries of acquired genetic causes that are sensorineural, either recessive, dominant or mitochondrial. Recent research has also indicated that several types of age-related HL, such as presbycusis (a type of SNHL) might also, in fact, have genetic causes rather than simply being related to the normal aging process, as has previously been the common view.

Mixed HL indicates a combination of conductive and sensorineural HL. An example is late-stage otosclerosis (abnormal ossification), in which bones in both the middle and the inner ear are affected.

The main function of the inner ear is to transform the incoming sound wave into electrical impulses and transmit these via the cochlear nerve to the temporal lobes in the brain for interpretation and possible action. The loss is often located in such a manner that the transformation functions are reduced, resulting in inadequate sound transmission to the brain. The consequences are that sounds are perceived as blurred, weak, or constrainedly loud. Due to the construction of the inner ear and the wear of the ear, important speech sounds are often non-audible or perceived as weak, whereas others are perceived as normal, resulting in major gaps in the speech stream.

The condition of HL is a heterogeneous group with regard to degree, onset, localization and etiology, and it cannot be regarded as a single diagnosis but rather as a symptom included in several ICD-10 diagnoses.

1.1.2 Psychological aspects related to adults with hearing loss
Several studies have investigated the psychological impact on HL in relation to age and degree and/or onset of HL. There appears to be a predominant adverse relationship between adults with HL and psychological variables such as depression, anxiety, and feelings of loneliness. A study of working adults with mild or moderate HL, concluded that persons with
HL demonstrate higher levels of general psychological distress, depression, anxiety, interpersonal sensitivity, and phobic anxiety than the control group\textsuperscript{134}. Similar results have also been identified as valid for persons with profound HL, and persons with acquired profound HL especially seem to be affected by severe distress\textsuperscript{83}. In the Netherlands, a large survey based on 1511 young and middle-aged participants obtained similar results\textsuperscript{141}. The authors found that increased feelings of loneliness seem to be connected to decreased hearing ability. This significant relationship was also found to exist for moderate or severe depression. The authors strongly stressed these alarming results, given the amount of young and middle-aged people worldwide who suffer from HL. Being an older adult with HL also seems to be a risk factor with regard to emotional distress\textsuperscript{72, 142, 159, 193}. However, conflicting results have been presented. A large survey including 50 398 subjects in Norway concluded that there is a clear connection between decreased mental health (i.e., anxiety, depression, self-esteem, well-being) and HL but that this connection is only valid for young and middle-aged persons with HL whereas mental health seemed to be unaffected in older adults with HL. The authors conclude that this lack of correlation is most likely because the stigma\textsuperscript{1} attached to HL disappear when subjects grow older because HL is considered “normal” in the older population\textsuperscript{195}. The construct of stigma is otherwise well documented in the area of adult HL. It has been established that concepts such as ageism (the association of HL with old age), vanity (the fear of unattractiveness in relation to hearing aids), cognitive diminution and a fear of association with negative stereotypes are important with regard to stigma and HL\textsuperscript{94, 107, 190, 202}.

Over the last decade, an emerging branch of hearing science, labelled cognitive hearing science, has formed. The increasing number of publications in which the disciplines of traditional audiology and cognition merge to gain a better understanding of aspects such as working memory and language comprehension in difficult listening environments constitute the rationale behind the evolution of this new branch of audiology\textsuperscript{7}. It has long been known that cognitive capacity in humans is limited\textsuperscript{131}. When a task is significantly demanding (e.g., speech comprehension in noise), the ‘left-over’ cognitive capacity in this situation is heavily reduced. Several research investigations have proven this relationship\textsuperscript{149, 172}. These results

\textsuperscript{1} Stigma: negative attributes created by society and based on beliefs, connected to, e.g., certain groups in the society.
are important for HL because cognitive features, such as working memory capacity, have, e.g., been proven to predict word recognition in noise with hearing aids and even to do so in relation to various signal processing systems in hearing aids\textsuperscript{120, 171}. These findings are valuable information in the understanding of ‘who benefits from what’ in regard to hearing aids and in the development of new hearing aids. Furthermore, it has been suggested that those with higher cognitive abilities require less listening training when adapting to hearing aids compared to those with poorer cognitive abilities\textsuperscript{150}.

### 1.1.3 Societal impact on adults with hearing loss

The concept of ‘society’ is broad and has many dimensions. One can examine aspects such as socializing or interacting, aspects related to work or leisure, or even aspects such as health care systems or economic systems that are purely related to the society but with a significant impact on the everyday lives of adults with HL. Here I have chosen four aspects on which significant research has been conducted in the area of the societal impact on adults with HL; quality of Life (QoL), communication, significant others and work.

Quality of life (QoL) is a widely used concept and the definitions currently used stem from different theoretical views of the concept. Typically, a number of life conditions (such as physical health, social relationships or living conditions) serve as indicators of QoL. This position most likely emerges from the theoretical view that everyone has a right to life but not to satisfaction with life and that therefore, ‘QoL is the sum of a range of objectively measurable life conditions experienced by an individual’\textsuperscript{61}(p.54). In the area of health and medicine, the concept of health-related quality of life (HRQoL) is a spin-off concept used for assessing quality of life among different sub-groups, such as adults with HL. When assessing HRQoL, different self-assessment questionnaires, both generic and condition-specific, are typically used. HRQoL is often a combination of person-oriented variables, such as physical and psychological health, and socially oriented variables, such as social relationships and role functioning\textsuperscript{60}. Important critiques against this way of viewing QoL have been presented. An example is the work of Carr and Higginson, who express concerns regarding the construction and the applied statistics (how the results of the completed questionnaires are calculated) in many questionnaires. Further, they note that the underlying concepts in many concurrent
questionnaires are vague because they concern health status rather than QoL\textsuperscript{24}.

In the area of adult HL, by using these types of questionnaires, it has been concluded that persons with HL demonstrate low social functioning, show high odds for social isolation and report low well-being\textsuperscript{44, 88, 90, 166, 195}. These results have also proven to be true in longitudinal studies\textsuperscript{72, 73} and in relation to other sub-groups, such as people with deafness\textsuperscript{62}.

Closely connected to HRQoL is the concept of ‘communication’. Communication difficulties are known to be one of the foremost consequences of adult HL, confirmed both clinically and in research studies. Several studies have noted complications in perceiving speech, especially in noise, but also in aspects of interpersonal communication, resulting in isolation or reduced everyday activities\textsuperscript{68, 92, 107, 160}.

HL is a health condition that does not only affect the affected person. On the contrary, it is well documented that family members or other significant others (SO) are highly influenced by HL. Hétu\textsuperscript{93} describes how partners of adults with HL experience tension, effort, fatigue, frustration, anger and guilt due to the social dependence of the affected spouse, having to act as an interpreter, and the restriction of leisure activities and social events. Partners or spouses seem to be responsible for maintaining social activities and communication in the relationship, and these results seem to be especially true for female spouses who demonstrate greater frustration and anxiety than do men\textsuperscript{3, 178}. Keeping the relationship going has been proven to be difficult for people with profound HL, with extensive relationship tension and above-average divorce and separation rates\textsuperscript{84}. Hence, there seem to be a clear connection between the degree of HL and tension in the relationship. Anderson and Noble\textsuperscript{3} find that the most satisfied couples (according their own views on the relationship) are couples in which the partner rates the HL as less severe than does the affected person. The authors suggest that in successful relationships, the person with HL most likely uses effective coping strategies that result in less disabling consequences and impacts on social life.

Another important aspect of life is the possibility to contribute in work. Many studies have been conducted with various focuses on work and adults with HL. The group has proven to be a vulnerable group in the labor market, with studies demonstrating over-representation in early retirement\textsuperscript{48, 64, 153}. Women with HL especially tend to participate less in the workforce, partly in comparison to men but also in relation to the female population as a whole\textsuperscript{99, 153}. Adults with HL also experience nega-
tive psychosocial consequences at work, showing emotional distress due to misinterpretations of external information and lack of control of their work and in the work environment48, 114, 136.

HL is a health condition that has a substantial impact on the everyday lives of the affected individuals and their SO. Therefore, the great challenge for hearing health care professionals is to address all aspects of HL, from the anatomical to the societal perspectives of the condition.

1.2 Dealing with hearing loss – Audiological Rehabilitation (AR)

Of significant importance to many persons with hearing loss are different types of assistive listening devices such as hearing aids (HA), cochlear implants (CI) and other communication and/or auditory devices. Early on, HL was already regarded as a communication disability, and therefore the rehabilitation programs heavily emphasized speech reading and technology23. Since that time, the hearing technology area have progressed, developed and claimed its justification as the number one audiological rehabilitation option for most adults with hearing loss. Over the last decade, hearing aid technology has undergone tremendous development, attempting to, e.g., facilitate listening in noise and to address cosmetic concerns such as the size of hearing aids10. The HA industry has become a major business, with sales of $5.4 billion worldwide in 2012 and six manufacturers sharing 98% of the global market109.

It is very clear that technology plays a major role in the lives of persons with HL124. However, very little of the discussion concerns the fact that the majority of persons utilizing audiological rehabilitation services suffer from SNHL or, to be even more specific, sensory HL (loss located in the inner ear)6. As stated in section 1.1.1, the loss in the ear is located in such a place that it is impossible for a hearing device to fully compensate for it; there are limitations to what hearing aids can provide. This statement is true even for new, complex hearing aid technology. Research has actually proven exactly this point. In a recent study, participants were asked to distinguish between two types of HA, a newer HA and a conventional technology, according to established audiological outcome measures such as sound quality, speech recognition, and overall preference ratings. Seventy-five percent of the test persons preferred the new technology and also scored significantly better on the speech recognition tests and the sound quality ratings. The twist in this study is that there was actually no difference between the hearing aids: they were the same. The authors concluded that patients’ expectations influenced outcome, and that therefore the
outcomes in trials or in clinical work do not have anything to do with the
technology itself. Montano explains this phenomenon with the ‘ techno-centric model’ of
audiology service delivery and claims that too much emphasis has been
placed on technology instead of on the person experiencing the HL. Boothroyd states that ‘effective sensory management may, by itself, lead
to improved activity, participation and quality of life, but there is no guarantee that these outcomes will be automatic or optimal. In fact, there is
often a disconnection between clinical measures of assisted auditory func-
tion and self-assessed benefit’ (p.63). Instead of an acknowledgement from
health care systems that most HL are chronic conditions that require in-
terventions that targets everyday activities and participation issues, the
intervention(s) offered are almost only technical solutions.

So, what is audiological rehabilitation (AR), and what should be offered
as a complement to technology? Definitions on AR have varied over the
decades, but contemporary descriptions highlight the person-centered
approach which views AR as a process that target the everyday activities
and participation issues of the affected individual. The implication
is that the needs of the patient and the individual problems he or she actually experiences in his or her own life are always the starting point. The
goals of AR are always individual and established situationally so that they can be evaluated. That is, an aim could never be to adapt to hearing aids because technology is viewed as an intervention in AR and because a
goal in a person-centered rehabilitation process can never be to adapt to
an intervention. An important component in AR is the interactive perspec-
tive between the client and the clinician. This perspective places high de-
mands on the clinician because his or her communicative skill must be
adequate. The most critical part of the AR process is evaluating the specific
needs of the clients in the context of activity limitations and the restric-
tions in participation as a target.

In a review of current AR practices, seven areas of interventions have
been identified as significant in the AR process. These areas concerns clear speech (the training of family members in how to speak clearly to a
person with HL), group rehabilitation (education, counseling, rehabilita-

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II The model states that the purpose of the audiological practice revolves around
technology as opposed to patient-centered care, in which patients’ adjustment to
HL is central.
tion strategies provided in group sessions), significant others (SO) (the inclusion of SO in the rehabilitation process), auditory training (training to improve the perception of speech), lip-reading (learning to use visual cues in communication), self-assessment tools (standardized evaluations of the patient’s functional status), and outcome measures (proper measurements of rehabilitation outcomes). In summary, the review shows that, to a great extent, AR aims at improving communication from an interactive perspective. In recent years, important additions to AR have focused on principles of self-efficacy and patient motivation. This step is an acknowledgement in AR that all interventions are dependent on the motivation and skills within the patients.

AR is effective when confronting everyday problems connected to HL. Several studies have reached this conclusion, and the result is valid for both group- and single rehabilitation encounters.

1.2.1 Evaluation of AR – Conceptualization of functioning and disability

As stated in the review of current AR practices, an important part of the process is evaluation. Self-assessment (SA) instruments on functioning and disability have been used in clinical practice for a substantial period of time to evaluate the impact on the everyday life of patients. Importantly, when evaluating effects of AR, assessment should be performed in relation to functioning and disability because this is the main concerns addressed by AR.

Several SA questionnaires have been developed over the years. Different reviews on the topic have revealed that approximately 60 different questionnaires have been used in the area over the years, with new questionnaires continuing to be developed. In a review by Bentler and Kramer, no less than 33 self-assessment questionnaires targeting functioning or disability suitable for evaluating AR evaluations are identified. These questionnaires are all condition-specific (CS), i.e., they are designed to target HL. An interesting conclusion by the authors is that there are a great variety of SA-questionnaires, which indicates a disagreement in the research field over what constitutes functioning, disability and health.

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III Self-efficacy: a person’s confidence in his/her ability to succeed with a task, e.g., an intervention.

IV The term ‘disability’ is used here. However, the concept does not have a coherent purport in the research field, and therefore, terms such as ‘handicap’ or ‘communication difficulties’ occur somewhat frequently in the audiological literature.
Kramer has subsequently reviewed the psychosocial impact of HL among the elderly, making ‘a remarkable reflection’ (p.137) on the wide variety of definitions described as psychosocial health. The same remark concerning terminology issues is noted in the discussion paper on the ICF Core Sets for HL project, indicating a lack in the overall picture with regard to what health-related concepts such as functioning and disability actually encompass in adult HL.

Hence, there seem to be a wide variety of definitions and descriptions of important concepts such as ‘functioning’ and ‘disability’ within the research field, which has allowed a plethora of self-assessment questionnaires to evolve.

1.3 International Classification of Functioning, Disability and Health (ICF)

The idea of classifying health components in relation to persons experiencing a health condition has emerged over the last four decades. In the early 1970s, the World Health Organization recognized the shortcomings of the International Classification of Diseases (ICD) in describing the effects of non-acute diseases. In 1980, this recognition resulted in the International Classification of Impairment, Disability and Handicaps (ICIDH) for use in explaining and classifying disabilities (p.246). At that time, the ICIDH was considered a mark of progress in rehabilitation contexts because it focused on the consequences of diseases rather than the disease itself. Unfortunately, the ICIDH failed to incorporate the experiences of disability groups in the development process, and thus, the traditional way of viewing disability (the causal, linear approach rooted in impairment or disease) constituted the model. In the mid-1980s, as a result of a massive critique from the Disability Rights Movement, a revision of the ICIDH was initiated. This process resulted in the development of updated versions of the ICIDH, lastly designated the International Classification of Functioning, Disability, and Health (ICF) in 2001. Where, to a large extent, the ICIDH was based on the work of Dr. Philip Wood, the ICF was a creation by multiple working groups and the results of field trials. Several new concepts were introduced in the updated classification, with the most substantial improvements concerning terminology and labeling. In the ICF, in contrast to previous classifications, *positive concepts* were introduced. Where the ICIDH was highly focused on inabilities, the new classification, the ICF, embraced an *ability* terminology. Furthermore, the contextual influence on the creation of disability was introduced as an important
factor. The assumptions made earlier, that a causal relationship prevailed between impairment, disability and handicap, were ignored, and instead, the interaction complexity in the creation of disabilities was highlighted in the updated classification. As a result, the ICF was based on bio-psycho-social assumptions of disability: a biomedical dimension (impairments of body functions or structures), a person dimension (activities and activity limitations), and a fully contextualized social dimension (participation and participation restrictions)\(^1\)\(^6\) (p.50).

### 1.3.1 ICF – a conceptual model and a classification

The International Classification of Functioning, Disability and Health (ICF) is both a classification and a conceptual model that can be used when describing features related to health, such as human functioning or disability. A clear notion of the ICF is that it does not classify people but rather describes the health situation of persons with health conditions\(^2\)\(^0\)\(^9\) (p.8). In the introductory text on the properties of the ICF, one can read that “there is a widely held misunderstanding that ICF is only about people with disabilities; in fact, it is about all people. The health and health-related states associated with all health conditions can be described using the ICF. In other words, ICF has universal application”\(^2\)\(^0\)\(^9\) (p.7). The text reveals that a pre-understanding of the definition of disability is required to understand this statement. Although not discussed further in the ICF section, one assumption, based on previous ICIDH definitions of disability\(^2\)\(^0\)\(^8\), is that this section is meant to convey that the ICF is not exclusively for “people who experience restriction or lack, resulting from impairment, of ability to perform an activity in the manner or within the range considered normal for a human being” (p.24), but for people with all types of health conditions. Because health and illness during the course of a life time changes for individuals and this is universally common for all human beings\(^1\)\(^5\), \(^1\)\(^6\), \(^2\)\(^1\)\(^8\), the ICF is so to speak for all humans given that the individual at the time of classifying experiences a health condition. Therefore, the ICF is viewed as a snapshot of the present health state (the level of functioning within a given health domain of the ICF) and health-related state (the level of functioning within a health-related domain of the ICF [this is not fixed in the ICF because the conceptualization of health-related domains may vary across individuals or populations]). A health condition is defined as an umbrella term for disease, disorder, injury or trauma but may also include circumstances such as pregnancy or stress (p.212), and it constitutes the starting point in the classification model of which the
health and health-related states should be evaluated. The idea is to combine the International Classification of Diseases (ICD)\(^{210}\), the classification of health conditions, with the ICF to gain a broader and better understanding of health among people or in certain populations\(^{209}\) (p.4).

As stated above, the ICF is based on a bio-psycho-social approach to functioning and health. The operationalization of the concept is made from the perspective of the body, the individual and the society, and it denotes the opposite designations *functioning* and *disability*. The classification describes human functioning with the positive concepts of body functions, body structures, activities, and participation. Disability, in the ICF, is described with the negative terms impairments (i.e., problems in body structures or functions), activity limitations, and participation restrictions. Consequentially, disability in the ICF is described in terms of functioning, i.e., when the level of functioning is ‘below a determined threshold along a continuum for a specific health domain’\(^{17}\) (p.2), functioning transforms to become disability. Furthermore, to understand human functioning and disability, the ICF states that external influences (i.e., the context) might influence functioning. The context in the ICF is described as environmental factors and personal factors. Hence, the ICF is multidimensional, acknowledging the importance of both internal and external influences on human functioning and disability.

### 1.3.2 ICF – a conceptual model

In contrast to previous classifications, the ICF is an interactive model in which the different concepts can influence each other in complex interactions (Fig. 2). A very important standpoint in the model is the non-causal relationship between different components\(^{16, 34}\). Functioning is associated with a health condition; however, it is not viewed as a direct consequence thereof. Rather, functioning is the result of a complex interaction between the health condition and contextual factors \(^{164}\).
Activities & Participation
In the center of the model are activities. An activity refers to ‘the execution of a task or an action by an individual’ and should be valued in relation to the nine life areas listed in the ICF (e.g., communication, interpersonal interactions and relationships, major life areas). These life areas are shared between activities and participation, with the result that, in each area, there can be either of the two concepts. If an individual has difficulties in executing a task or an action, this difficulty is referred to as an activity limitation. When evaluating an activity or activity limitation, one is interested in the person’s capacity to execute a task or an action. This capacity is advantageously evaluated in a standardized environment, such as a ‘test setting’. If this is not possible, then an ‘assumed’ environment can be imagined. However, it is of the utmost importance, to ensure that the influences of the context, both positive influences such as e.g., hearing aids and negative influences such as e.g., noise, are minimized. In the ICF, activities are connected to the individual only, not to individual interactions with the environment in which individuals live their lives.

Closely connected to activity is ‘participation’, which is defined as ‘involvement in a life situation’. The problems that an individual may experience in the involvement in life situations are denoted as participation restrictions. Involvement in a life situation means ‘taking part’, ‘being included’ or ‘being engaged’ in an area of life. However, the ICF is very clear
that the subjective experience of participation is not included in the concept; i.e., participation is not equal to a ‘sense of belonging’. Participation refers to ‘how things work out in real life’ when ‘influenced by the context’, that is, how a person actually performs. Similarly to activity, participation or participation restriction should be evaluated in relation to the stated life areas of the ICF. Investigating how well a client can converse with one person wearing a hearing aid in noisy situations is one example of how the participation aspects of the ICF can be evaluated.

Although this explanation of the distinction between activities and participation seems reasonably clear, difficulties in distinguishing may occur when further elaborating this distinction. For instance, how can ‘major life areas’, such as engaging in work or socializing, be evaluated as activities? How can these domains be assessed in standardized environments with no influence from the context? The ICF recognizes this problem and offers some solutions for the distinction between the two concepts: ‘a) designate some domains as activities while others as participations, no overlap; b) same as (a), but partial overlap; c) designate all detailed domains as activities and the broad headings as participation; and d) to use all domains as both activities and participation’ (p.16). Hence, no consensus on this matter is reached within the classification. This problem has also been highlighted in scientific discussions. In the area of audiology, Stephens accuses the ICF of being ‘blurred’ by applying the same classification to both activities and participation. The author proposes definitions for the concepts in which activity limitations, in relation to, e.g., listening, should be interpreted as ‘specific auditory difficulties’ whereas participation restrictions should refer to ‘problems an individual may experience in involvement in life situations’ (p.9). A few years after the adoption of the ICF, Nordenfelt initiated the discussion regarding the lack of proper theory in the WHO conceptualization of activities and participation. The main critique by the author was that no activities can be performed independently of the environment and that there is no such thing as a ‘standardized’ environment because the presupposition of a standardized environment depends on cultures and contexts. Therefore, the suggested solution was to simply merge the two concepts and designate the new concept action. He further called for the incorporation of the notions of will and opportunity in the classification because these concepts play a major role in the execution of actions. This topic has caused a lively scientific discussion, with several responses to the suggestions made. Badley suggested that the activities and participation dimension can be divided
into acts, tasks and societal involvement with acts referring to ‘general things that a person can do’, such as walking, listening or standing, and involving several body structures and systems. Listening can, e.g., involve body functions such as hearing functions, auditory perception functions, memory functions and attention functions. Tasks, on the other hand, are explained as purposeful things that are composed of multiple acts and that people do in their everyday lives. A task such as conversing (orally) would require several acts, such as listening, comprehending speech and speaking and societal involvement, which refers to ‘the individual as a player in socially or culturally recognized areas of human endeavor’ (p. 2339) and which targets involvement in work, school or societal activities. Whiteneck and Dijkers addressed the same topic but chose the established domains in the classification. The authors argued that activity is performed at the individual level, i.e. ‘done alone’ whereas participation is considered to be more complex, is at the societal level, and includes the notion of ‘social roles’, such as being a student or a worker (p. 24). By distinguishing between activities and participation as presented, the authors further suggests adopting the first option offered by the ICF to distinguish between the concepts, namely, designating some domains as activities while designating others as participation, with no overlap. In reality, this distinction means that Ch. 1, 2, 3, 4, 5, and 6 are suggested to be activities whereas Ch.7, 8 and 9 are denoted as participation.

Body functions & Body structures
Located to the left in the model are the dimensions of body functions and body structures. Body functions refer to the physiological functions of body systems (including psychological functions), whereas body structures are the anatomical parts of the body (organs, limbs) (p.10). Although classified differently, body functions and body structures are viewed as one dimension and are to be used in parallel. The negative aspect of these two concepts is denoted as the shared notion of ‘impairment’. Scientific interest in this component has primarily addressed the concept of impairment and questioned the foundations of its conceptualization. Other researchers have addressed certain aspects of the component, but these discussions have been performed in relation to the content and specificity of certain categories; they have not addressed issues such as the relationship between body functions and body structures.
Contextual factors
In the ICF, contextual factors include two dimensions that might have an influence on the health of an individual with a health condition, environmental factors and personal factors. The main difference between these two factors is the actual localization in relation to the individual, with environmental factors being viewed as factors that are external to the individual, whereas personal factors are internal. At first glance, it might seem odd to view internal factors as contextual factors, but the ICF provides an explanation for this matter: ‘personal factors are the particular background of an individual’s life and living, and comprise features of the individual that are not part of a health condition or health state. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background…’209 (p.17). Thus, as opposed to body functions, body structures, activities and participation, which are domains that can all be part of a health condition, personal factors are not. The implication is that personal factors exist independently of the health condition, i.e., if the health condition were to be removed from a person, the personal factors would remain the same. This reasoning might seem slightly weak because vital aspects, such as coping style, fitness or profession, might be highly affected by a health condition and indeed would be determined by a health condition. Personal factors have rarely been recognized as a discussion topic in scientific studies, especially in relation to whether personal factors are affected by a health condition. Instead, discussion has heavily focused on the need for category codes within the component or on how personal factors have been operationalized in different areas and disciplines70, 105. One exception is Threats198, who divided personal factors into categories of demographic information, such as age, sex, nationality etc., and personality traits, such as upbringing, coping style etc. In the introduction of his paper, he highlighted the problem of conceptualization between certain aspects of the body function component and personal factors but provided a solution in relation to the time of onset of a health condition, such as aphasia. In particular, personal traits that existed prior to the onset of a health condition and still remain after the onset of the health condition should be viewed as personal factors. The author noted that personal traits, such as whether an individuals’ upbringing has given him or her a ‘can-do’ spirit, would affect how that person self-advocates after the onset of a health condition (p.75). However, it should be noted that certain health conditions, including hearing loss, seldom exhibit a distinct time of onset, which
is why this distinction might be difficult to make. Furthermore, in the health literature, a person’s choice of coping strategy (listed as an example of a personal factor in the ICF) is dependent on inner resources and is also known to be contextually dependent\textsuperscript{65, 86, 91}, which means that the choice of a certain coping strategy in stressful situations varies within individuals and that the choice could most likely be affected or even determined by a health condition.

Environmental factors in the ICF are viewed as human-related, i.e., social and attitudinal, or physical\textsuperscript{209}(p.16). Environmental factors are always viewed as having positive or negative influence on the functioning of an individual in the specific situation classified, and are therefore referred to as either facilitators or hindrances/barriers. On one hand, environmental factors are described as the individual environment, i.e., the direct environment or the ‘face-to-face’ environment, which the individual might come in to contact with. On the other hand, they include the societal environment, described as the informal and formal structural systems within the individuals’ living context\textsuperscript{209} (p.17). Although environmental factors have been added into the ICF classification, acknowledging their importance in the creation of a disability, the conceptualization of the environment in the ICF has not attached much research attention. Whiteneck and Dijkers\textsuperscript{207} criticized the lack of theory in relation to the environment in the ICF. Their main argument is that the presumably influential environmental factors for disability are far broader than those stated in the classification, and they call for a better conceptualization of the environment that is based on researchers’ operationalization of environmental concepts. However, as the authors also note, it should be stated that ‘the field of rehabilitation and disability research has hardly begun to quantify environments’ (p. S33). Advancing in that direction, Day and colleagues\textsuperscript{52} discuss the impact of the natural environment on health and disability. Their main concern is that several aspects of the natural environment are expressed from a hindrances perspective in the ICF but also that there are few actual categories with regard to this matter. They state that because it in has become evident in recent years that the natural environment has a significant positive impact on health and in the rehabilitation process of individuals with different type of health conditions, a revision of the natural environment aspects within the ICF might be adequate to also highlight the facilitative impacts of the environment.
1.3.3 ICF – a classification

Of course, the ICF is also a classification with numerical category codes that operationalize the concepts of bodily dimensions, activities and participation, and contextual factors. Within the ICF, the structure is hierarchical, with levels of detailed specifications (Fig. 3). The ICF consists of two parts: 1) functioning and disability and 2) contextual factors. Each part in turn consists of two components: 1a) body functions and body structures, 1b) activities and participation, 2a) environmental factors, 2b) personal factors. Each component has associated chapters (denoted as first-level categories), and each chapter has specific categories on different levels (second-, third- and fourth-level). Each level is a further specification of the previous level; thus, the hierarchical association. This is true for all components except personal factors which do not have any category codes associated with them. The domains assessed in the component activities and participation are given in a single list that covers the full range of possible life areas\textsuperscript{209} (p.14). These domains are (corresponding to the nine chapters within the component): d1 learning and applying knowledge, d2 general task and demands, d3 communication, d4 mobility, d5 self-care, d6 domestic life, d7 interpersonal interactions and relationships, d8 major life areas, and d9 community, social and civic life.
Fig 3. The hierarchical structure of the ICF with examples for each level provided. Note that all levels are connected to each other; the deeper category contains a more detailed specification of the previous category. The personal factors component lacks categories. Figure published in Granberg et al. 78.

Body functions and body structures have eight chapters that are each organized so that the structures associated with specific functions are located in corresponding chapters. An example of this phenomenon is the ear-related structures, which are located in Ch. 2, the eye, ear and related structures of the body structures component. Hearing functions, as associated with ear structures, are to be found in Ch. 2, sensory functions and pain of the body functions component. Environmental factors have five chapters: Ch. 1, products and technology, Ch. 2, natural environment and human-made changes to environment, Ch. 3, support and relationships, Ch. 4, attitudes, and Ch. 5, services, systems and policies.

Qualifiers
Although not part of the present thesis, the notion of ‘qualifiers’ in the ICF need to be addressed. Qualifiers are operationalized constructs of the different category codes and constitute the difference between functioning and disability. In the ICF, there are four constructs for the first part and a single construct for part two: change in body function, change in body
structure, capacity (for assessing activities), performance (for assessing participation) and facilitators/barriers in environmental factors. The qualifiers are used when assessing functioning and the magnitude of the potential problems. The WHO claims that the category codes in ICF do not have an inherent meaning without the qualifiers. The argument for this statement emerges from the functioning/disability operationalization in the ICF, i.e., category codes without qualifiers indicate absence of disability, which in the ICF is equal to full functioning.

1.3.4. Using the classification – linking
An outlined aim of the ICF is to provide research communities with a scientific basis for understanding and studying health and health-related states (p.5). A common method of implementing the ICF in scientific studies and discussions is incorporating the conducted research into the ICF framework, i.e., using the ICF as a theoretical framework. Within the audiological research field, this is how most studies have operationalized the ICF. Another method of using the classification is investigating the methods of classification (i.e., using the different ICF categories in the research). This type of research has attracted some interest within the audiological research community in relation to, e.g., Menière’s disorder, tinnitus, and third-party disability. Connecting research parameters such as outcome measures or other types of health data to the ICF is referred to as ‘linking’ within research communities, and is recognized as a very well-established method for analyzing and describing existing data from a health perspective. The ICF is a particularly useful classification tool in this respect, given its organized and hierarchical structure. Indeed, in a review of the scientific use of the ICF, Cerniauskaite and colleagues identified 73 ‘linking papers’. Most of these papers used established linking rules in different ways, proving the scientific recognition of the concept. The concept of the ICF linking rules was introduced in 2002, when ten rules were developed to describe the relationship between health-status measurements and the ICF. The rules were developed in a dynamic process by a group of ICF and QoL experts, who linked approximately 300 items from 20 condition-specific and generic health instruments to the ICF. The linking rules were further developed in 2005, when special rules for technical and clinical measures were introduced. This type of scholarly activity has been conspicuous in its absence in audiological research investigations. One important exception is the study by Scarinci and colleagues, who described the third-party disability of spouses of older
people with hearing impairment from the ICF perspective\textsuperscript{179}. The authors successfully used the established linking rules but also highlighted some very important linking issues.

Linking is a clever method for exploring a classification in relation to important notions such as its exhaustiveness, precision (granularity) and discrimination. In the present context, exhaustiveness refers to how well category codes in the ICF capture the health and health-related domains outlined in the ICF\textsuperscript{34}. According to Cieza and Stucki\textsuperscript{34}, the ICF exhibit good exhaustiveness. Their main arguments for this statement are the results from the linking process in the ICF Core Sets development projects (see next section) and the successful mapping (linking) of items from measurement instruments. However, contradictory claims regarding exhaustiveness have been made by others. In a literature survey on the use of the ICF, Jelsma\textsuperscript{105} concluded that one major problem with the ICF with regard to linking is actually missing codes. This problem is especially noticeable in the area of the respiratory system. One probable explanation for this finding could be that this is an area that has been thoroughly explored in relation to the ICF. The conflicting views regarding exhaustiveness in the ICF reveal that the results vary according to the investigative approach. If one considers the amount of data that has been successfully linked to the ICF, then the exhaustiveness is valued as satisfactory. However, with regard to the amount of data that could not be linked to the ICF, the exhaustiveness of the ICF is less acceptable.

Precision or granularity refers to the level of specificity in a health or a health-related domain\textsuperscript{34}. Several studies have highlighted poor granularity in specific domains, such as emotional functions and pain, resulting in poor compliance between, e.g., emotional domains in specific generic or condition-specific instruments and the ICF\textsuperscript{20, 33}

Discrimination refers to the discreteness or the mutual exclusiveness of the ICF categories. The review by Jelsma\textsuperscript{105} identified no less than 10 overlapping category codes in the ICF and stressed that in some case there is a great uncertainty regarding which of the overlapping codes to use, outlining the overlap in the description of the category codes. In the audiology-related study by Scarinci and colleagues\textsuperscript{179}, the authors identified problems with overlapping categories within components (e.g., between conversing and discussing in the activities and participation [d] component) and overlapping categories between components (e.g., between ‘attention functions’ in the body functions [b] component and ‘focusing attention’ in the activities and participation [d] component). The latter has also been identi-
fied as confusing by others, which calls into question the division of the concept into two components, given that the two category codes cannot be clinically distinguished\(^{165}\). Problems in overlapping have also been identified between certain aspects of the body functions component and the personal factor component. Threats\(^{198}\) highlighted the confusion surrounding concepts such as ‘confidence’ or ‘optimism’ (b126 temperament and personality functions) and how these should be separated from ‘individual psychological assets’ (personal factors), indicating the difficulties in defining the content of the personal factors. Several studies have further noted that it would be considerably helpful in research investigations if the personal factors component contained category codes. In 2011, a systematic review of the conceptualization of the personal factors in published scientific papers was conducted. After the analysis, the authors concluded that 238 examples of potential personal factors were identified in the literature. The authors further emphasized the importance and benefit of a categorization of personal factors within the ICF\(^{70}\).

### 1.3.5 ICF Core Sets projects

Some highly recognizable applications of the ICF should enable it to serve as a research and a clinical tool, facilitating functional outcome measurements or functional assessments prior to rehabilitation interventions. However, with 1424 category codes to choose from and be knowledgeable of, the comprehensiveness of the classification stands as a great barrier to the implementation of the ICF in research investigations or clinical encounters. This concern over feasibility was also acknowledged by the WHO immediately after the adoption of the ICF in 2001; hence, the ICF Core Sets Project was initiated\(^{103,194}\). A core set is a set of ICF categories of specific relevance to a target group, diagnosis or target area. In evaluating which ICF categories are specifically relevant for a group or area, the WHO has developed a rigorous three-phase procedure for this task (Fig. 4). The first phase, designated the preparatory phase, consists of four scientific studies that target three different perspectives. These are the perspectives of the patient, the professional (or the expert) and the researcher. The perspective of the patient includes two studies. The first study, a focus group or individual interview study, adopts an inductive approach to investigating the functional and disabling aspects of a health condition whereas the second study, a multicenter study, applies a deductive approach that use standardized measurements to assess functioning and disability in the target group.
Fig. 4 Procedure of the ICF Core Sets projects development. The preparatory studies included in the present thesis are marked. Figure published in Granberg et al. 2010.  

The perspective of the professional (expert) is assessed by conducting a cross-sectional web survey, applying open-ended questions with regard to the functioning and disability in a specific target group. The fourth study aims to convey the perspective of the researcher and is conducted as a systematic review that addresses outcome measures used in research in the area of interest. All data in the preparatory studies are linked to the ICF classification using standardized linking rules. The preparatory studies in phase one serve as a starting point for the consensus-reaching process that occur in phase two. Here, an international consensus conference is held that aims at determining the core aspects of the functioning and disability of the target of investigation by evaluating the evidence from the preparatory phases. Furthermore, given that the consensus conference includes experts from the target area, the evidence is evaluated in relation to their expertise. The main task of the consensus conference is to decide upon two core sets, a comprehensive and a brief core set. The comprehensive set can be used in multiprofessional settings while the brief, derived from the comprehensive set, is suitable for single clinical encounters or in research investigations. The last phase of the three phase procedure includes the validation and implementation of the established core sets.
In 2008, the international project ‘ICF Core Sets for Hearing Loss’ was initiated with the aim of developing a multidimensional tool for assessing the functioning and health of adults with hearing loss. The rationale for this project was the wide variety of available outcome measures in audiology and the poor consensus on adequate definitions of functioning and disability in relation to HL, which resulted in ambiguities concerning what to measure when assessing functioning and health in the target group \(^{49}\). Furthermore, the project was overseen by a steering committee engaging members from all six WHO regions. To date, the project, following the outlined WHO procedure for core sets development, has now finished the second phase in the development project, and two cores sets for adults with HL have been established \(^{50}\). The present thesis concerns three of the four preparatory studies that were conducted in the present project. Furthermore, in the present thesis, the term ‘professional’ is used instead of ‘expert’ when discussing professionals who work with adults with HL. The question of who is the expert on a health condition is highly contentious; the person experiencing the condition, or is it the professional?

1.4 Rationale for the thesis

The concepts of ‘functioning’ and ‘disability’ are highly important in, e.g., rehabilitation assessments because the emphasis of such services should be on the ‘everyday life’ aspects of a health condition. The starting point of audiological rehabilitation for adults with HL ought to be the fitting of technical devices, such as hearing aids, given that such devices are viewed as a prerequisite for the treatment process \(^{124, 201}\). However, even the most advanced hearing aid is incapable of addressing the functional and disabling factors associated with hearing loss. Instead, audiological rehabilitation interventions should be designed based on the established functional and disabling aspects of hearing loss. To some extent, these features are known to the audiological branch; however, rehabilitative interventions rely heavily on improved communication \(^{124}\). The existing models of audiological rehabilitation reveal that a person-centered approach, in which the patient perspective constitutes the core of the assessment, is essential \(^{67, 133}\). However, the most critical part of this approach, from the perspective of the rehabilitator, is to accurately identifying the aspects of functioning and disability of relevance \(^{67}\). No multidimensional and comprehensive view of the functional and disabling aspects of adult HL currently exists. On the contrary, the previous research has demonstrated difficulties in the conceptualization and operationalization in the designations of the concepts.
‘functioning’ and ‘disability’ within the present research field\textsuperscript{11,49,113}. These difficulties might be problematic, both from an assessment and an evaluation perspective. Therefore, an appropriate question to ask is the following: \textit{what are functioning and disability in adult HL?}

Given the possibility to adequately addressing this research question, a theoretical or conceptual framework is necessary. The ICF provides such a conceptual framework. First, because the ICF is a classification, with numerical category codes, it offers the possibility of providing clinicians and researchers worldwide with a common language. The implication is that functioning and disability may be described similarly around the world, facilitating national and international comparisons, both on the individual level and on the group level. Second, today, we can calculate the prevalence of different hearing health conditions worldwide based on disease classifications such as the ICD-10\textsuperscript{210}; however, we do not have sufficient tools to statistically describe the functional aspects of such hearing health conditions accurately. Although the condition of HL can occur as a symptom in several ICD-10 diagnoses, exploring the functional and disabling aspects in relation to the ICF classification would also facilitate the prevalence calculations of the functional aspects of HL. Third, the member states of the WHO (196 states, e.g., Sweden) have acknowledged the ICF for use in research, surveillances and reporting and thus have accepted the challenge of implementing the ICF in clinical settings and in research investigations\textsuperscript{214}.

However, there is a challenge associated with the usage of the ICF in relation to audiology. Several studies in various other areas have highlighted important linking issues when trying to connect different health data to the ICF\textsuperscript{105,165}. However, the linking of audiological data has been employed to a very limited extent. The research that has exhibited ‘linking’ and ‘linking rules’ has highlighted important difficulties in the process of connecting audiological data to the ICF\textsuperscript{179}. Therefore, an important part of using the ICF would also be to carefully \textit{explore how audiological data can be linked to the classification} to facilitate future clinical and research use of the ICF in relation to audiology.
2. Aims

The overall aims of the present thesis are as follows:

- from the perspective of the International Classification of Functioning, Disability and Health (ICF), to explore areas of functioning and disability of relevance for adults with hearing loss by merging the perspectives of the Researcher, the Professional and the Patient;
- to explore how audiological data can be linked to the ICF.

The specific research aims outlined in the four studies are as follows:

I, II) From the perspective of the ‘Researcher’, to identify the areas of functioning, disability and the specific environmental factors of influence for adults with hearing loss and to link these areas to the ICF classification:

I) To identify the outcome measures used in research about adults with hearing loss;
II) To identify the concepts contained in the outcome measures used in research on adults with hearing loss by linking them to the ICF;

III) From the perspective of the ‘Professional’, to identify the areas of functioning, disability and specific the environmental factors of influence for adults with hearing loss and to link these areas to the ICF classification;

IV) From the perspective of the ‘Patient’, to identify the areas of functioning, disability and specific the environmental factors of influence for adults with hearing loss and to link these areas to the ICF classification.
3. Methods

Several research methods were applied in the different perspectives. However, all data were merged into the ICF classification. This approach was necessary, not only from the perspective of the ICF Core Sets for HL (identifying relevant category codes) but also for reflections and comparisons despite the different designs of the three perspectives.

3.1 An interdisciplinary evidence-based approach to functioning and disability in adults with HL

In the present thesis, the model ‘an interdisciplinary evidence-based approach to functioning and disability’ is developed to explain the overall methodology applied (Fig. 5). The model proposes three research perspectives; those of the Researcher, the Professional and the Patient. These perspectives are analyzed when exploring functioning and disability in adults with HL, i.e., research evidence, professional expertise and patient experiences. The idea of including three perspectives into the design has its origins in the ICF Core Sets projects, which consider the assurance of expertise and broad representation in the projects to be essential. This methodology is in line with the ‘evidence-based practice (EBP)’ approach. EBP is a methodology that ensures that the methods and practices employed in clinics or similar contexts are of high quality. This approach can be defined as an integration of the best research evidence with clinical expertise and patient values, and it has become significantly important in areas such as adult audiological rehabilitation, acknowledging its importance in the decision-making process.

The present approach might also be considered to be evidence-based (EB). However, the EB approach in the present thesis, which explores functioning and disability in adults with HL solely through research investigations can be described as evidence-based research.
The EB research approach integrates the three perspectives equally when answering the research questions. Some conditions must be fulfilled to acknowledge the study as an EB approach to research. As in the EBP, a Researcher perspective, a Professional perspective and a Patient perspective are required. In the ‘evidence-based approach to functioning and disability in adult HL’, the same research question must be posed to all three perspectives. The researcher perspective consists of a systematic review in which the specific research question is posed to the literature. The other two perspectives are empirical, posing the same research question to professionals and patients as posed to the literature. The main idea is that clinical experience (i.e., patients and professionals) might add important information that otherwise would have been neglected in applying a different design. Given that the three perspectives (studies) apply different designs and methodologies, a conceptual framework must be used in which the results from the different studies can be interpreted. For the model to be complete, an interdisciplinary approach is also required. In-

Fig. 5 Interdisciplinary evidence-based approach to functioning and disability in adult HL, acknowledging the three outlined perspectives in EBP. FDAH = Functioning and disability in adults with HL.
terdisciplinary approaches are used advantageously in disability research, given that these types of research often include complex challenges to be solved\textsuperscript{47}. The interdisciplinary approach always requires some type of integration of knowledge based on either vertical or horizontal characteristics\textsuperscript{173, 174}. Vertical integration addresses the knowledge integration of the specific mechanisms identified in different strata of the reality. This approach is built on the assumption that the reality is stratified and that the content in one specific stratum constitutes the foundation for the next stratum. The strata (or levels) are hierarchically organized, with the physical level at the bottom, followed by the biological level, the psychological level, the psycho-social level, the socio-economic level, the cultural level and, at the top, the normative level. Importantly, each stratum has its specific qualities and properties but is simultaneously rooted in the underlying stratum\textsuperscript{14, 46}.

Horizontal integration, on the other hand, addresses knowledge integration in only one or a few levels. Here, the phenomena of interest (e.g., discrimination) are studied in different contexts or for different disability groups\textsuperscript{175} (p.1).

The first interdisciplinary perspective presented, the vertical integration, has been employed in the present thesis. Although not outlined in the classification, the ICF model is built on principles of stratification. As stated above, an important starting point in the model is the non-causal relationship between the concepts. Hence, it is the mechanisms in the different levels that interact in the constitution of functioning and disability in adults with HL.

3.2 Definitions

Hearing loss was defined according to the clinical criteria for degree of HL; mild hearing loss (>20 dB Hearing Level [HL], \(\leq 40\) dB HL), moderate hearing loss (>40 dB HL, \(\leq 70\) dB HL), severe hearing loss (>70 dB HL, \(\leq 95\) dB HL) and profound hearing loss (>95 dB HL)\textsuperscript{59}. The distinction was used merely to ensure that HL was present in the different studies. No analyses have been performed with regard to the degree of HL. The main reason for this decision is that previous research shows only moderate correlations between the degree of HL and experienced problems associated with the health condition\textsuperscript{27, 106, 204}.

The target group concerned adults (\(\geq 18\) years of age) who utilize oral communication as their primary communication mode. Although a heterogeneous group, it was assumed that persons of similar communication
mode would share more functional and disabling aspects than they would if the communication mode had not been considered. Previous research has shown that persons with HL experience different effects of the health condition with regard to emotional and social variables compared to deaf persons who use sign-language as their primary mode of communication62.

3.3 Study designs

Three different designs were applied in the present project: a systematic literature review, a cross-sectional web-survey and a qualitative study mainly utilizing the focus group methodology.

3.3.1 Researcher perspective (study I and II)

The researcher perspective covered two studies, part I and part II. Part I was a systematic literature review on the outcome measures used in the research area of adult HL. Part II, concerned linking the identified outcome measures of study I.

Study I

The inclusion criteria for the systematic review were the study population, study designs, sample size, publication type and language, publication year, and particulars. The studies were required to concern adults (≥18 years old) with HL, expressed as mild to profound HL, who utilize oral communication as their primary communication mode. The accepted study designs were controlled experimental studies (controlled clinical trials [CCTs], randomized controlled studies [RCTs], observational studies (longitudinal or cross-sectional studies), chart reviews, and economic evaluations based on first hand-data. The allowed sample size was arbitrarily set to ≥10 subjects in the included studies. Furthermore, the articles had to be published in journal articles between 2002 and 2007 and written in English. The focus in the articles had to be the target group. Conditions that were related to HL, such as tinnitus, were allowed if they were accompanied by HL. The primary focus in the article had to be issues related to HL.

In accordance with the inclusion criteria, the exclusion criteria were non-human populations, subjects <18 years old, mixed age groups, unclear (or

\[^v\] Due to the detailed designs and the development of different linking-methods especially suitable for research on HL, parts of sections 3.3-3.6 are directly derived from the published articles.
undefined) targets groups, reviews or meta-analyses, psychometric evaluation studies, study protocols, case reports, economic evaluation studies based on reviews or meta-analyses, qualitative studies, primary prevention studies, and single-subject experimental designs. Furthermore, sample size, year, and publication type and language other than those stated in the inclusion criteria were excluded. When the focus in the studies concerned health conditions in the target population other than HL, but HL existed comorbid with the primary health condition (e.g., multiple sclerosis), the studies were excluded if the emphasis of the articles was other than HL.

A systematic electronic search was conducted in nine databases: MEDLINE®, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), The Excerpta Medica Database (EMBASE), PsycInfo, the Allied and Complementary Medicine Database (AMED), the Education Resources Information Center (ERIC), Sociological Abstracts, PsycArticles, and the Cochrane Central Register of Controlled Trials (CENTRAL). Although extensive audiological research can be found in databases such as Medline/PubMed and CINAHL41, 89, 97, additional databases were selected to ensure a broad, interdisciplinary sampling approach.

To find the appropriate search terms, possible terms for different diagnoses for which HL could be a symptom were considered, in addition to the terminology used for the target group in the scientific literature. The standardized search terms in the different databases were also used. The strategy was adapted to the conditions of the different databases. Examples of text words used include the following: hearing loss, hearing impairment, hearing disability, hearing disorder, and deaf. Examples of subject headings included the following: hearing loss, otosclerosis, retrocochlear diseases, hearing disorder, high-frequency hearing loss, noise-induced hearing loss, and hearing aids.

Study II
In study II, the methodology of ‘linking’30, 32 was applied. To ‘link’ means to interpret data (e.g., outcome measures) and to translate the data into the ICF nomenclature, thereby creating the possibility of describing findings from the ICF perspective.

All identified outcome measures from pool I (246) and pool II (122) which were identified in study I, constituted the empirical material linked to the ICF in this study. When linking questionnaires, every item of a specific questionnaire was linked.
3.3.2 Professional perspective (study III)
The study employed an internet-based cross-sectional survey targeting professionals in the area of adult HL, using a stratified sampling procedure. The following three methods were used to recruit participants:

1. International and national professional organizations were contacted and requested to distribute the questionnaires to their members.
2. The members of the steering committee in the project ICF Core Sets for HL were requested to distribute the survey to their personal contacts.
3. Authors of the included studies in the systematic review (study I) received the survey questionnaire.

The professionals were required to meet the following criteria for inclusion in the survey: a professional involved with adult patients who have HL, with at least five years’ work experience, and competent to answer the questionnaire in English, Swedish, Danish or Norwegian.

A randomized stratified sampling procedure was conducted to select professionals according to WHO region and profession. In each country within a WHO region, a professional from each profession was randomly selected for inclusion to ensure representation of regional and professional perspectives. The stratified sample was assessed for saturation to determine whether a second sample of experts would be required.

3.3.3 Patient perspective (study IV)
Study IV was a qualitative study that used focus groups as the main data collection method. Three groups were held in South Africa and three in the Netherlands. The countries were chosen based on their differences in development status. South Africa is classified as a developing country, whereas the Netherlands is considered a developed country. The choice of six focus groups was based on previous reports on ICF Core Sets projects in which four to six focus groups were required to collect sufficient data on functioning and contextual factors. The focus groups were organized according to three age groups (18-40, 41-60, and ≥61). It was assumed that persons of similar ages and life phases (i.e., with regard to work and family life) would stimulate group interaction and discussion, yielding richer data. Normally, focus group size is based on aspects such as topic complexity, with six to ten participants being optimal. However, in the present study, the hearing disability was taken into considera-
tion, and therefore, it was decided that smaller groups should be used to facilitate communication between group members.

In South Africa, two of the focus groups (41-60 and ≥61) included limited participants as a result of recruitment difficulties and last-minute dropouts. Therefore, it was decided to supplement the focus groups with individual face-to-face interviews following the same ICF protocol as for the focus groups. Eight additional interviews were conducted (four in each age group).

Persons were included if they:

- fulfilled the clinical criteria for degree of HL (mild to profound)\textsuperscript{59}.
- were at least 18 years old.
- used oral language as their primary communication mode.
- were conversant in English (South Africa) or Dutch (the Netherlands).
- were willing to share and discuss aspects of functioning, disability and, contextual factors in relation to self-experienced HL.
- understood the purpose of the study.
- had signed an informed consent form.

Participants in South Africa were recruited from the patient population of the Department of Speech-Language Pathology and Audiology Clinic at the University of Pretoria and a tertiary-level public health care hospital in Pretoria. In the Netherlands, participants were recruited from the patient population of the Audiological Center of the VU University Medical Center in Amsterdam. Altogether, 36 informants participated in the study (Table 1).

Purposeful sampling was applied with a maximum variation strategy\textsuperscript{161}. In purposeful sampling, the participants are chosen for their ability to provide the researcher with information. A maximum variation strategy means that a number of characteristics that are important for the studied phenomena are identified and maximum diversity of these characteristics is strived for in the sample\textsuperscript{8}. In the present study, maximum variability was applied according to age, sex, and degree of HL. In South Africa, there was also an effort to obtain maximum variation according to cultural background (home language), ethnicity, and level of education.
Table 1. Characteristics of the participants in study IV. Table published in Granberg et al. 2014

<table>
<thead>
<tr>
<th></th>
<th>South African sample (n=20)</th>
<th>Dutch sample (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex (%)</strong></td>
<td>Male</td>
<td>65</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>35</td>
</tr>
<tr>
<td><strong>Age in age groups (M &amp; range)</strong></td>
<td>18-40</td>
<td>29.6 (25-39)</td>
</tr>
<tr>
<td></td>
<td>41-60</td>
<td>53.4 (42-62*)</td>
</tr>
<tr>
<td></td>
<td>≥61</td>
<td>76.3 (72-84)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>29.8 (29-31)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>49.0 (42-53)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>72.3 (62-87)</td>
</tr>
<tr>
<td><strong>Type of HL (%)</strong></td>
<td>Conductive</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Sensorineural</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Mixed</td>
<td>40</td>
</tr>
<tr>
<td><strong>Degree of HL (%)</strong></td>
<td>Mild</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
<td>55</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Profound</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>University</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>High School</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>Secondary School</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Primary School</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>(Missing data)</td>
<td>(5)</td>
</tr>
<tr>
<td><strong>Highest educational level (%)</strong></td>
<td>Afrikaans</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>Zulu</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>English</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Sotho</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Sepedi</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Ndebele</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>(Missing data)</td>
<td>(5)</td>
</tr>
</tbody>
</table>

*When one of the informants showed up to join the focus group, the true age of that person turned out to be 62. It was though decided to let the person stay and participate in the focus group session. This decision was made out of the assumption that the exceedance of two years of a person, still in working life, would not have a negative influence on the group discussion in any substantial way.
3.4 Materials

3.4.1 Survey questionnaire in study III

An internet-based survey questionnaire containing seven open-ended questions was used. The questionnaire consisted of three parts. The first part included an informed consent form, which the participants was required to sign before continuing. If the respondent refused to sign, the survey questionnaire did not appear, and the respondent was redirected to the end of the questionnaire. The second part included a section for demographic and work-related information. These questions concerned the country in which the respondent currently practiced, age, sex, profession, main duties, and years of work experience. The third part included seven open-ended questions on the perceived functioning, environmental and personal factors:

• Reflect on your adult clients with hearing loss; in your experience, how does the hearing loss affect them (e.g., their body, health, feelings, mind)?
• Reflect on your adult clients with hearing loss; in your experience, which parts of their body are affected (i.e., directly or indirectly by hearing loss/consequences of the hearing loss)? Please be as specific as possible!
• Reflect on how your adult clients with hearing loss describe their everyday life; in your experience, how does the hearing loss affect the things they can and cannot do (in general situations)?
• Reflect on you adult clients with hearing loss and how they describe the helpful and supportive things in their environment and where they work and live; in your experience, what and/or who do they find helpful and supportive?
• Reflect on your adult clients with hearing loss and how they describe difficulties in their environment and where they work and live; in your experience, what and/or who makes it difficult for them?
• Reflect on your adult clients with hearing loss; in your experience, what personal characteristics help them to handle their hearing loss?
• Reflect on your adult clients with hearing loss; in your experience, what personal characteristics make it difficult for them to handle their hearing loss?
Although the questions were based on ICF dimensions, the participants did not see the ICF labels embedded in the questions. Respondents were specifically required to list only dimensions that were relevant for adults with HL, use one line for each specific answer, and give answers as short and precise as possible. Answers were not limited in word-count. Prior to each question, example answers were given using ‘vision loss’ as the example condition for each question. The survey was conducted in English.

Prior to the main investigation, a pilot survey was conducted to enhance the reliability of the survey questionnaire. The objective of the pilot survey was to ensure that instructions, questions, and examples were phrased appropriately and that the completion time was less than 30 minutes. The pilot survey was conducted using eight participants, including the professions of audiologist, engineer, physician, social worker and physiotherapist. All questionnaires were completed in less than 30 minutes and only minor changes were made to the examples provided based on the pilot study respondent feedback.

### 3.4.2 Interview guide in study IV

The semi-structured interview guide that was used in study IV had previously been used in other ICF Core Sets projects. However, the questions were deemed to be too general to suit the present target group, and therefore, they were modified to better suit adults with HL. This decision and the modifications were made in cooperation with the steering committee of the ICF Core Sets for HL project. The questions were as follows (if necessary, the moderator added probing questions or clarified the questions):

- How does your hearing loss affect you? (Probe: How does it affect your health, your feelings?)
- If you think about your body, in which parts are your problems?
- If you think about your everyday life, how does your hearing loss affect the things you can and cannot do?
- If you think about your environment and where you work and live, what and/or who do you find helpful and supportive?
- If you think about your environment and where you work and live, what and/or who makes it difficult for you?
- If you think about yourself and about your hearing loss, what helps you to handle your hearing loss?
• If you think about yourself and about your hearing loss, what makes it difficult for you to handle your hearing loss?

3.5 Procedure

3.5.1 Researcher perspective (study I, II)

Study I
In the systematic review, it was impossible to narrow the search by adding more specific search term without risking the exclusion of potentially relevant articles. The use of broader search terms resulted in a large sample of possible studies to include and was managed by dividing the search into two different pools (Fig. 6). The databases varied largely according to database size, and the first pool contained articles located in large databases, i.e., MEDLINE® , CINAHL, EMBASE and PsycInfo (8355), to avoid any disadvantages due to database size. The second pool contained articles located in the smaller databases (AMED, ERIC, Sociological Abstracts, PsycArticles, and CENTRAL) (1038). All potentially relevant articles were handled through a reference system (EndNote® Windows Version X5, Copyright© 1988-2011 Thomson Reuters) to identify duplicates. After the duplicate check, 5715 (pool I) and 832 (pool II) potentially relevant articles remained. From the first pool, a simple random sample (1000) was selected. The sample was constructed so that the databases contributed proportionally to the total sample. This procedure resulted in 431 articles from MEDLINE®, 217 from CINAHL, 181 from EMBASE, and 171 from PsycInfo. In pool II, it was possible to manage all located articles.

When the potentially relevant articles from the two pools were identified, all of the abstracts from these articles were reviewed independently by two researchers. The abstracts were judged with the following designations: ‘yes’ to inclusion, ‘no’ to inclusion, or ‘ambiguous’ status. An article was deemed ambiguous when the reviewers disagreed in their decisions or when it was impossible to judge whether the inclusion criteria had been met. Articles with no available abstracts were also deemed ‘ambiguous’. When there was disagreement on inclusion status, a discussion was held. If the issue remained unsolved, a third reviewer decided on the inclusion status. All articles designated ‘yes’ or ‘ambiguous’ were retrieved in full text (278). All full-text articles were reviewed by the author of the present thesis, and approximately 33% of all of the other articles were reviewed.
by additional researchers. These steps were taken to enhance the reliability of the data extraction process. Altogether, 87 articles in pool I and 35 in pool II (122 in total) were used in this review.

A study protocol was developed for extracting data from the included studies. Data on country, study design, sex, diagnosis (or type of HL), and other information concerning the target group, in addition to the outcome measures used in each particular study, were retrieved. Outcome measures was defined as ‘any measure reported in the methods or results section if it provided information necessary to address the study aims of an included article’, following the procedure in other ICF Core Sets projects. The measures were extracted independently of the study results. Only the measures related to the target group were extracted, i.e., measures related to significant others were not extracted. Measures used only to describe the target group and that were unrelated to the study aim were not extracted. The measures were sorted by instrument type, and 10 different types were identified:

- **Patient-reported measures – standardized (PT-S):** generic and condition-specific self-reported measures, survey questionnaires in which the respondent answered standardized questions.
- **Health professional-reported measures – standardized (HP-S):** the health professional evaluated the patient performance using standardized forms.
- **Standardized tests:** quasi-objective measures following a standardized procedure, i.e., the test instructions, performance, evaluation, scoring, and interpretation of the achievement were standardized. Subject participation in the procedure was required.
- **Technical measures:** objective measures following a standardized procedure.
- **Laboratory measures:** e.g., blood count, blood lipids, immune tests.
- **Imaging techniques:** e.g., magnetic resonance imaging (MRI) or computed tomography (CT).
- **Health professional observations:** e.g., physical examinations.
- **Patient-reported measures – non-standardized (PT-non S):** e.g., patient answers to single questions.
- **Health care delivery indicators:** e.g., treatment costs.
- **Register data:** e.g., data from national statistical databases.
Fig. 6 Process of inclusion in Study I. Figure published in Granberg et al. 2014.

Reason for exclusion:

<table>
<thead>
<tr>
<th>Reason</th>
<th>Pool I</th>
<th>Pool II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wrong/unclear target group</td>
<td>21</td>
<td>25</td>
</tr>
<tr>
<td>Mixed age group</td>
<td>21</td>
<td>3</td>
</tr>
<tr>
<td>Wrong design</td>
<td>15</td>
<td>3</td>
</tr>
<tr>
<td>Too small of a sample size</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>Wrong publication type</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Wrong focus in article</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Wrong age group</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Reprint</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Wrong publ. language</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Mixed population</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>85</td>
<td>71</td>
</tr>
</tbody>
</table>
Study II

The intention in the present study was to link all measures containing statements or questions separately by two linkers and to perform an inter-rater reliability analysis on the linking, as conducted in similar projects \(^{58,74}\). However, after linking the first questionnaire, it was clear that the linking agreement between the two linkers was low. The main reason for this finding was that the established linking rules were not sufficient when linking audiological measures and allowed too much individual interpretation. There were also ambiguities regarding the descriptions of specific category codes in the ICF. Therefore, it was decided that additional linking rules, specifically designed for the audiological field, needed to be developed as a complement to the existing rules. The development of these rules continued throughout the linking process. The additional linking rules that were developed and used are available in Appendix 1.

The developed additional linking rules concerned latent interpretations, which turned out to be vital in the present research area. The concept of latent interpretation is common in traditional content analysis and refers to the identification of the underlying meanings of a concept or an expression \(^{80,112}\). This aspect was especially important not only in relation to hearing-related notions, such as how to interpret and link the concepts of hearing, listening, comprehending speech, and conversing, but also in relation to environmental factors and the coping concept. It was recognized that it was extremely important to carefully read the original article accompanying the questionnaires to learn the intent of the latent variables in the questionnaires. Doing so provided guidance on how to interpret the statements expressed in the questionnaires.

When linking other types of outcome measures, such as clinical measures, it was learned that both the aim and the procedure of, e.g., standardized methods needed to be taken into consideration when linking. The reason for doing so was that several methods in audiology, such as pure-tone audiometry (a sound detection test \(^{168}\)), require an ‘active’ patient even though the aim of the method is to evaluate a ‘passive’ body function. This requirement has consequences for the linking because the hearing function is a body function, but the ‘active’ patient (who determines when the sound is detected) indicates a higher level of auditory processing (‘listening’), which is part of the activities and participation component.
3.5.2 Professional perspective (study III)
The pool of possible respondents received an e-mail, either from national and international professional organizations or from the project coordinator, with details about the survey and a web-link to the on-line questionnaire.

3.5.3 Patient perspective (study IV)
The focus groups in South Africa were all chaired by one moderator and one assistant, who was responsible for taking notes, observing the group, and making audio recordings of the discussions. The individual interviews were conducted jointly by two interviewers. The moderators/interviewers were clinical research audiologists with experience in moderating/interviewing groups and individuals with HL. In the Netherlands, the moderator was a psychologist working in the field of audiology who had trained in focus group moderation and had chaired several focus groups in the past. Each session/interview was recorded and later transcribed verbatim. The participants filled out a form containing brief questions concerning socio-demographic information and some details about their HL. After an introduction, the seven questions (based on the different ICF components) were formulated, and the discussions began.

3.6 Analysis

3.6.1 Researcher perspective (study I and II)
The absolute and relative frequencies (%) of all identified outcome measures in study I were reported (relative to the total number of outcome measures within each pool). In study II, ICF categories (1st- to 4th-level) were reported (relative to the total number of outcome measures). When calculating the total number of used outcome measures, the prevalence of an identified measure (result from study I) was considered. If an ICF category was used frequently in the linking of a specific outcome measure, this category was only calculated once to avoid bias. All levels used in the linking process were reported rather than only the second level. The rationale for this approach was the fear of losing the rich, detailed information that the more specific categories provided, given that this information may be important within the audiological field. In addition, by reporting all levels, it was possible to identify categories or areas in which more specific hearing-related categories need to be developed in future revisions of the ICF.
Quality assurance
A peer-review process was conducted to assure the quality of the linking of the outcome measures containing statements or questions. Two linkers who were familiar with the audiological field, the ICF, and the linking rules conducted all of the linkings of these measures. All statements or questions were linked by one of these linkers and were checked by the other linker to ensure linking agreement. If the linking was not identical, linking agreement was reached by discussion between the two linkers. All other outcome measures were linked by three linkers in a joint process in which the two linkers worked together when linking measures of a specific instrument type. This approach was necessary because the linking required detailed knowledge of the aim, performance, and procedures of a specific test. The decision regarding which of the linkers should link certain instrument types was based on their area of expertise and knowledge of the ICF category codes.

3.6.2 Professional perspective (study III)
All responses from the stratified professional sample were linked to the ICF based on the established linking rules. A simplified content analysis approach followed in linking the responses to the ICF categories. The respondents occasionally provided statements that required a more traditional content analysis with meaningful concepts condensed from statements. However, in many cases, single words or phrases were considered to be the meaningful concept and thus linked. Information that was impossible to assign to ICF categories was labeled pf (personal factors), nd (not definable), nc (not covered by ICF), or hc (health condition). In some cases, the component could be identified from a statement, but no specific category (on any level) could be assigned. In such cases, the concept was coded nc, preceded by a component letter, e.g., e-nc. The relative frequencies of the linked ICF categories were calculated. If a category was assigned repeatedly to the answer of one respondent, it was counted only once to avoid bias. As in previous ICF Core Sets studies, a cut-off of 5% (rounded up to the nearest %) was chosen for the frequencies of the linked categories as reported by professionals.

Quality assurance
Two ICF trained researchers jointly reviewed the responses and conducted the linking accordingly to increase the reliability of the linking procedure.
In the case of a disagreement, a discussion was held, and if agreement still could not be reached, a third ICF-trained researcher was consulted.

A saturation check on the linked categories was conducted after the analysis of the initial random stratified sample of participants. A randomized subset, 10% of the total number of included respondents, was excluded to investigate whether saturation was reached for the remaining 90% of the sample. Saturation was evaluated by documenting a) whether there were any 2nd-level ICF categories omitted or b) whether the number of 2nd-level ICF categories represented by at least 5% of the entire sample changed in any way. The saturation probe, excluding the random 10% subset, introduced no new 2nd-level categories and no changes in the 2nd-level categories, indicating that saturation had been reached. As a result, no further respondent data were sampled and linked.

3.6.3 Patient perspective (study IV)
The method of analysis applied was based on summative content analysis. The method starts with identifying and counting certain words. The aim of quantifying words is to explore usage and, hence, identify patterns. However, the method goes beyond the mere counting of words and involves an interpretation to identify the underlying meanings of utterances. All data were linked to the ICF by using an analytical method, developed especially for this study. The method was designated ‘the seven-step linking procedure’. This method combined the established ICF linking rules and the linking rules developed specifically for audiological data. The method consisted of seven steps:

1. Identification of meaning units,
A meaning unit is a specific unit of text that contains either a few words or a few sentences with a common theme. A meaning unit division does not need to follow linguistic grammatical rules; a meaning unit ends when a shift in meaning is detected.

2. Defining meaningful concepts
A meaningful concept is a condensed part of the meaning unit that covers a specific topic (condensing means shortening it while preserving the core). This step entails identifying the individual meaningful concept(s) of the meaning unit and noting them. A meaning unit can contain several meaningful concepts.
3. **Interpretation of the underlying meaning (if necessary)**
If the text holds a ‘deeper’ meaning, perform a latent interpretation on the meaningful concept and note this interpretation.

4. **Determine the linking unit**
Carefully consider both the meaningful concept and its latent interpretation (if applicable) and note what will be actually linked (i.e., determine the ‘linking unit’).

5. **Deriving to ICF category, i.e., linking**
Use the linking rules by Cieza\(^30,\ 32\) and Granberg\(^78\) to link the linking unit to the suitable ICF category code and note this category code.

6. **Documentation of linking rule applied (if necessary)**
If special considerations were needed in the linking process, note what linking rule was applied.

7. **Checking the representativeness of the ICF categories**,
Carefully re-read the meaning unit to see if the identified category codes reflect the essence of the meaning unit. If not, return to step 2.

Each of the three age groups in the two countries represented a unit of analysis. The individual interviews were included in the units of analysis according to the age of the interviewee. Altogether, there were six units of analysis. The frequencies of ICF categories were calculated across units of analysis. To avoid favoring groups/individuals who expressed statements repeatedly, an ICF category was only calculated once within a unit of analysis. The maximum appearance of a single ICF category was therefore six (one per unit of analysis).

**Quality assurance**
The analyses of the data were conducted separately by two researchers who were trained in the ICF and in the linking process. Co-authors checked and reanalyzed a proportion of each other’s analyses to ensure quality assurance.

### 3.7 Merging three perspectives

In the present thesis, the three perspectives were merged together and analyzed as one unit. Following the principles of consensus, only the categories that appeared in *all* three perspectives were considered. The merging was conducted on 2\(^{nd}\)-level basis. As a consequence, a category was considered only if it appeared on the 2\(^{nd}\)-level in all three perspectives or if any
of the 3rd- or 4th-level categories connected to that specific 2nd-level category had been used.

### 3.8 Ethical considerations

There is a possibility that the ICF would be misused, given the multi-use of the classification, and therefore, ethical considerations must follow a comprehensive framework\(^{16}\). The ICF provides a set of ethical guidelines in Annex 6: Ethical guidelines for the use of ICF\(^{209}\) (p.244). This section is meant to set some basic guidelines for the ethical use of the classification and concerns respect and confidentiality, clinical use ICF, and social use of ICF information. In this section, various statements of relevance for the present thesis are important. First, if one overlooks the application possibilities of the results in the present thesis and focuses solely on the usage of the ICF in the present research process, from an ethical standpoint, the ICF states that the classification ‘should always be used so as to respect the inherent value and autonomy of individual persons’\(^{209}\) (p.244). Following the guidelines of the WMA Declaration of Helsinki — Ethical principles for medical research involving humans\(^{215}\) and the Ethics of research involving humans\(^{25}\), the studies in the present thesis have considered this ethical standpoint. In study III, no ethical approval was necessary due to Swedish regulations on human research. However, the information for the participants followed the recommendations made by the Swedish central ethical review board on study information\(^{25}\). In study IV, ethical applications were necessary and approved by the Medical Ethics Committee of the VU University Medical Center in Amsterdam, the Netherlands, and by the Research Ethics Committee of the Faculty of Humanities, University of Pretoria, South Africa.

Furthermore, ‘ICF should never be used to label people or otherwise identify them solely in terms of one or more disability categories’ (p.244), and ‘individuals classed together under ICF may still differ in many ways. Laws and regulations that refer to ICF classifications should not assume more homogeneity than intended and should ensure that those whose levels of functioning are being classified are considered as individuals’\(^{209}\) (p.245). Some critiques of the ICF Core Sets projects have noted that conducting condition-specific core sets emulates the medical model instead of embracing a more holistic view of disability, reinforcing exactly what the above statements from the WHO mean to avoid\(^{126}\). However, one must consider the amount of category codes that are available to use (1424) in ICF. The extensive number could result in a non-usage of the classification.
in clinical encounters or in research investigations. This possibility must be set against the risk of labeling people. The latter concern lies in the usage of the classification or the core sets. One must consider that the results in the present thesis are most likely more valid on the group level than on the individual level, where categories might need to be removed or added. Therefore, the responsible use of the results in clinical encounters or similar situations is required.
4. Summary results

4.1 Study I – Researcher perspective (I)

In this study, the outcome measures used in audiological research on the target group were identified to be linked to the ICF in the subsequent study. Of the 122 included studies, 32 were extracted from MEDLINE®, 27 from CINAHL, 17 from CENTRAL, 15 from EMBASE, 14 from AMED, 13 from PsycInfo, three from ERIC, and one from PsycArticles. The extensive number of outcome measures that were extracted is worth noting. A total of 246 different outcome measures were identified in pool I, and 122 were identified in pool II. The measures were divided into ten different ‘instrument types’ (Table 2). Most measurements occurred only once in this review given that only 21.1% of the measures in pool I and 17.2% in pool II were extracted as outcome measures twice or more.

Table 2. Outcome measures divided into instrument types from the included studies

<table>
<thead>
<tr>
<th>Instrument Type</th>
<th>Pool I (n=246)</th>
<th>Pool II (n=122)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Frequency</td>
</tr>
<tr>
<td>PT-S</td>
<td>39 (15.8%)</td>
<td>22 (18.0%)</td>
</tr>
<tr>
<td>Standardized</td>
<td>87 (35.4%)</td>
<td>25 (20.5%)</td>
</tr>
<tr>
<td>HP-S</td>
<td>4 (1.6%)</td>
<td></td>
</tr>
<tr>
<td>Technical</td>
<td>22 (8.9%)</td>
<td>3 (2.5%)</td>
</tr>
<tr>
<td>Laboratory</td>
<td>24 (9.8%)</td>
<td>33 (27.1%)</td>
</tr>
<tr>
<td>Imaging</td>
<td>3 (1.2%)</td>
<td>1 (&lt;1.0%)</td>
</tr>
<tr>
<td>HPO</td>
<td>7 (2.9%)</td>
<td>4 (3.3%)</td>
</tr>
<tr>
<td>PT - not S</td>
<td>56 (22.8%)</td>
<td>26 (21.3%)</td>
</tr>
<tr>
<td>Health Care Delivery Ind.</td>
<td>4 (1.6%)</td>
<td>1 (&lt;1.0%)</td>
</tr>
<tr>
<td>Register data</td>
<td></td>
<td>7 (5.7%)</td>
</tr>
</tbody>
</table>
Patient-oriented measures – standardized (PT-S)
The results from pool I identified 39 different PT-S that were used as outcome measures. Of these, 11 appeared twice or more in this sample. A total of 69% of the PT-S were condition specific (i.e., questionnaires designed for audiology). In the second pool, 23 different PT-S were found, but only two appeared twice or more; 70% were condition-specific. Altogether, 51 different PT-S were found in this review, which contained 122 included articles. Sixteen were used twice or more when combining pools I and II.

Standardized measures
In pool I, 87 different standardized measures were found. The measures were subcategorized according to the overall aims of each specific measure, and 25 subgroups were constructed. Seven of these subgroups contained outcome measures that were identified twice or more in this review. The largest subgroup (i.e., the group with the most measures) was speech/word measures with/without noise. This subgroup was further divided into four subdomains: speech awareness (the detection of speech sounds), speech discrimination (the detection of changes in the acoustic stimuli), speech recognition (the recognition of speech sounds with no semantic processing required; the patient repeats the stimuli), and speech comprehension (the patient is required to attach meaning to the stimulus). When dividing and labeling the different speech/word measures, attention was paid to the descriptions of the measurement objectives and test procedures within the included studies. In total, 35 different speech/word measures with/without noise were identified in pool I, all labeled as speech recognition tests. Speech/word measures represented 40.2% of all standardized outcome measures. The second largest group was labeled ‘cognitive measures’. This group composed 21.8% of all standardized measures and contained 19 different measurements, each with a prevalence of one (<1%). Within pool II, seven categories were established from the 25 identified standardized measures. Speech/word measures with/without noise formed the largest group in this pool as well, containing 64.0% of all standardized measures in this pool. All of the measures in this subgroup except one were labeled as measures of speech recognition (16 different measures). The one exception was assigned speech discrimination. As in pool I, cognitive measures were the second largest group. This subgroup contained four different measurements, each with a prevalence of one (<1%).
Technical measures
In pool I, 22 different technical measurements were extracted from the included studies. Several of these measurements were related to vestibular function, such as measures of caloric testing, different types of nystagmus testing, eye tracking, and the velocity step test. In pool II, three measures were extracted. Two of these were different immitance measures.

Laboratory measures
A total of 24 laboratory measures were extracted in pool I and categorized according to the aims of the measurements. Eight different types were identified. Immune tests were the most frequently used (4.1%). In pool II, 33 different types of laboratory measurements were identified and divided into nine subgroups. In that pool, ‘blood count’ was the most frequently used in the identified studies (12.3%).

Other instrument types
The other instrument types, different from those specified above, contained 74 (pool I) and 39 (pool II) outcome measures. The instrument type PT-not S contained single questions, and every unique question was counted as a separate outcome measure. The outcome measure in pool I with the highest prevalence was ‘magnetic resonance imaging [MRI]’ (imaging technique) (3.3%). The corresponding outcome measure in pool II was ‘presence of tinnitus’ (PT-not S) (2.5%).

4.2 Study II – Researcher perspective (II)
In study II, the identified outcome measures (study I) were linked to the ICF classification using the established linking rules. Concerning the linked outcome measures, interesting facts were revealed. In total, the identified outcome measures were used 537 times in the 122 included studies (approximately 4.4 per study). A total of 285 ICF categories (1st to 4th level) were used in the linking process, albeit, most of them infrequently. Of these categories, 111 belonged to body functions (b), 19 to body structures (s), 117 to activities and participation (d) and 37 to environmental factors (e). Personal factors (pf) lacked categories and was therefore counted as 1 category. A total of 91 categories were identified ≥5 times (≥0.9%). Most body functions (b) were related to b230, hearing functions (29.2%). Emotional functions (b152) was utilized somewhat frequently in the linking process (12.1%). The corresponding categories in the body structures (s) were related to s260, structures of inner ear...
(1.5%). In the activities and participation (d) domain, d115, listening was the outstanding category most linked (35.4%). The second most commonly used category in that domain was d310, communicating-with-receiving-spoken messages (8.0%). Sound quality (e2501) followed by assistive products and technology for communication (e1251), the categories most commonly used when linking noise and hearing aids, were the most frequently used in the environmental factors (e) component, with 16.1% and 10.1%, respectively. When ranking all of the ICF categories used according to occurrence, categories related to communication or conversing were ranked in tenth and eleventh place.

When analyzing the results on the component-level basis, most measures were linked to the (d) domain, followed by (b), (e), (pf) and (s). However, when analyzing in a narrower perspective, on the 1st-level basis, the most frequently used chapter belonged to the (b) component (b1, mental functions) (Fig. 7). In the (e) component, only the chapters belonging to the physical environment were used with a notable frequency.
Fig. 7 Relative frequencies of ICF chapters (first levels) identified after the linking of outcome measures extracted from 122 studies (n=537). The sizes of the bubbles are proportional, i.e., a larger bubble indicates a chapter has been used more frequently in the linking process. The frequency also affects the bubble size for components (d), (e), (s), (b) and (pf). Figure published in Granberg et al. (2014)
4.3 Study III – Professional perspective

A total of 218 professionals completed the survey. After the stratified sampling procedure, 63 participant surveys were analyzed. The majority of the respondents were older than 50 years of age and had more than 15 years of professional experience. Most professionals were audiologists (27.0%), but nine distinct professions were identified. The majority of the respondents worked in a clinical setting (58.7%). The sample represented 27 countries across all WHO regions. Most respondents were from Europe (49.2%), followed by Africa (20.6%) and the Americas (17.5%).

The professionals mentioned concepts that were linked to 209 distinct ICF categories. Similarly to study II, many categories were used infrequently. In the present study, 106 of the total linked ICF categories were mentioned by 5% (rounded up to the nearest %) or more of the respondents. Of these, most categories belonged to the activities and participation (d) component (30.2%), followed by environmental factors (29.2%), body functions (23.6%) and finally body structures (17.0%). The most frequently used ICF categories in the (d) domain related to ‘communication’, such as d310, communicating-with-receiving-spoken messages (74.6%); d350, conversation (57.1%); and d3602, using communication techniques (55.6%). The corresponding categories in the environmental factors (e) component were e1251, assistive products and technology for communication (82.5%); e2501, sound quality (82.5%); and e1250, general products and technology for communication (50.8%).

Regarding body functions (b), b1266, confidence (71.4%); b152, emotional functions (65.1%); and b1560, auditory perception (46.0%), occurred most frequently. In the body structures (b) component, s250, structures of middle ear (55.6%); s260, structures of inner ear (52.4%); and s110, brain (41.3%), were linked most commonly. A total of 59 (3.4%) of the concepts were linked to personal factors (pf).

When analyzing from a broader perspective (1st level), six out of nine chapters in the activities and participation domain were used, all five chapters in the environmental factors component were used, three out of eight body functions chapters were used and two of eight chapters in the body structures component were used. These results correspond to 53.3% of the entire classification. In the present study, the term ‘component-not covered’ was introduced to address the many cases in which concepts could not be linked to the classification, but a component could be identified (most commonly, e-nc). A total of 65 concepts (3.8%) in the present study were labeled ‘e-nc’.
4.4 Study IV – Patient perspective

The results from study IV revealed that in total 143 ICF categories (on all levels) were used in the linking of the transcribed interviews. Of these, 34% were categories of activities and participation, 33% were environmental factors, 27% were body functions, and 6% were body structures. Nineteen categories from all ICF components were identified in all six units of analysis.

All chapters except Ch. 5, self-care, were used in the activities and participation component. Most linked categories (31%) belonged to Ch. 7, interpersonal interactions and relationships, followed by Ch. 3, communication (21%). Seven ICF categories were recognized in all six units of analysis. Five of these were directly related to communication (d310, d350, d3504, d3602) whereas the other two (d850, remunerative employment; d9205, socializing) represented other types of interactions in which HL was considered highly influential.

In the environmental factor component (e), all five chapters were used in the linking process. Most categories were linked to Ch. 1, products and technology (25%), and the least categories were used in Ch. 5, services, systems and policies (17%). Eight categories were identified in all six units of analysis; five belonged to the physical surrounding (such as technical devices and external sounds such as noise), and the other three were related to the human and social environment.

Four chapters were identified in the body function (b) component: mental functions (Ch. 1) 44%; sensory functions and pain (Ch. 2) 38%; voice and speech functions (Ch. 3) 15%; and neuromusculoskeletal and movement-related functions (Ch. 7) 3%. The two specific categories most commonly used were b230, hearing functions and b152, emotional functions.

Very few body structures (s) were identified (6%). All belonged to Ch. 1, structures of the nervous system; or Ch. 2, the eye, ear, and related structures. All categories were related to the auditory system with most categories belonging to the auditory sensory system. Two categories were related to the central auditory system, i.e., s110, structures of brain, and the more specific 3rd-level category, s1106, structure in cranial nerve. The latter was expressed in the meaning unit:

‘I think it’s the auditory nerve [that’s affected], I think.’
In all units of analysis, the coding ‘e-nc’ appeared. The sub-categorization of this coding revealed that ‘behaviors of others’ had an impact on functioning with HL.
5. Main results

Section five in the present thesis is connected to the overall aims of the thesis. Section 5.1 concerns the first aim, and section 5.2 the second aim.

5.1 Functioning & disability in adults with HL – merging three perspectives

The results from the linking procedure merging the three perspectives (studies II, III, IV) are presented in Tables 3, 4, 5, and 6. Note that only the ICF categories (on the 2nd-level or in any of the connected 3rd- or 4th-levels) that appeared in all three perspectives have been acknowledged. As in section 4.2, from the ‘Researcher perspective’, only the categories that appeared ≥0.9% were considered. From the ‘Professional perspective’, only the categories that were used ≥5% in the linking process were considered, and all categories identified in the ‘Patient perspective’ were used.

Concerning the component body structures, only three 2nd-level categories were supported by the three perspectives. These aspects were related to the peripheral and the central auditory system. Structures of the middle ear were not present in this analysis. The reason for this matter was that reporting on middle-ear structures accounted for less than 0.9% in the researcher perspective.

Table 3. Presentation of all (s) that appeared in all three perspectives. 2nd-level categories (in bold) are the left column, with the connected 3rd-level (or 4th-level) categories in the middle.

<table>
<thead>
<tr>
<th>Body structures</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>s110  Structure of brain</td>
<td></td>
</tr>
<tr>
<td>s11001 Temporal lobe</td>
<td>41.3</td>
</tr>
<tr>
<td>s1101 Structure of midbrain</td>
<td>-</td>
</tr>
<tr>
<td>s1102 Structure of diencephalon</td>
<td>1.1</td>
</tr>
<tr>
<td>s1105 Structure of brainstem</td>
<td>-</td>
</tr>
<tr>
<td>s1106 Structure of cranial nerves</td>
<td>23.8</td>
</tr>
<tr>
<td>s240  Structure of external ear</td>
<td></td>
</tr>
<tr>
<td>s260  Structure of inner ear</td>
<td></td>
</tr>
<tr>
<td>s2600 Cochlea</td>
<td>52.4</td>
</tr>
<tr>
<td>s2601 Vestibular labyrinth</td>
<td>9.5</td>
</tr>
<tr>
<td>s2602 Semicircular canals</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: Only the ICF categories (on the 2nd-level or in any of the connected 3rd- or 4th-levels) that appeared in all three perspectives have been acknowledged. As in section 4.2, from the ‘Researcher perspective’, only the categories that appeared ≥0.9% were considered. From the ‘Professional perspective’, only the categories that were used ≥5% in the linking process were considered, and all categories identified in the ‘Patient perspective’ were used.
Table 4. Presentation of all (b) that appeared in all three perspectives. 2nd-level categories (in bold) are in the left column, with the connected 3rd-level (or 4th level) level categories in the middle.

<table>
<thead>
<tr>
<th>2nd level ICF Categories (n=10)</th>
<th>3rd and 4th level ICF Categories (n=24)</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Researcher (%)</td>
</tr>
<tr>
<td>b126 Temperament and personality functions</td>
<td>b1260 Extraversion</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>b1262 Conscientiousness</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>b1263 Psychic stability</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>b1264 Openness to experience</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>b1265 Optimism</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>b1266 Confidence</td>
<td>2.6</td>
</tr>
<tr>
<td>b130 Energy and drive functions</td>
<td>b1300 Energy level</td>
<td>4.1</td>
</tr>
<tr>
<td></td>
<td>b1301 Motivation</td>
<td>-</td>
</tr>
<tr>
<td>b140 Attention functions</td>
<td>b1400 Sustaining attention</td>
<td>1.5</td>
</tr>
<tr>
<td></td>
<td>b1402 Dividing attention</td>
<td>-</td>
</tr>
<tr>
<td>b144 Memory functions</td>
<td>b1440 Short-term memory</td>
<td>2.0</td>
</tr>
<tr>
<td>b152 Emotional functions</td>
<td>-</td>
<td>12.1</td>
</tr>
<tr>
<td>b156 Perceptual functions</td>
<td>b1560 Auditory perception</td>
<td>27.6</td>
</tr>
<tr>
<td></td>
<td>b1561 Visual perception</td>
<td>0.9</td>
</tr>
<tr>
<td>b164 Higher-level cognitive functions</td>
<td>b1644 Insight</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>b1646 Problem-solving</td>
<td>-</td>
</tr>
<tr>
<td>b230 Hearing functions</td>
<td>b2300 Sound detection</td>
<td>29.2</td>
</tr>
<tr>
<td></td>
<td>b2301 Sound discrimination</td>
<td>9.7</td>
</tr>
<tr>
<td></td>
<td>b2302 Localization of sound source</td>
<td>2.4</td>
</tr>
<tr>
<td></td>
<td>b2303 Lateralization of sound</td>
<td>1.9</td>
</tr>
<tr>
<td>b240 Sensations associated with hearing and vestibular functioning</td>
<td>b2400 Ringing in ears or tinnitus</td>
<td>1.3</td>
</tr>
<tr>
<td></td>
<td>b2401 Dizziness</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>b2404 Irritation in the ear</td>
<td>-</td>
</tr>
<tr>
<td>b280 Sensation of pain</td>
<td>b2801 Pain in body part</td>
<td>2.6</td>
</tr>
<tr>
<td></td>
<td>b28010 Pain in head and neck</td>
<td>-</td>
</tr>
</tbody>
</table>
A wide variety of body functions was regarded as essential for the target group. Several shared categories belonged to Ch. 2, sensory functions and pain, which is the chapter in which categories that specifically acknowledge hearing functions are outlined. The second-level category b230, hearing functions, and all third-level categories connected to b230 were supported in the three perspectives except from b2304, speech discrimination, which, in the ICF is described as ‘sensory functions relating to determining spoken language and distinguishing it from other sounds’ (p.65). Pain was highlighted in the present studies, especially in relation to the head and neck.

The component of activities and participation identified several shared categories. Almost all categories were relational, i.e., a dimension of interaction was revealed. Four categories could be assigned to the individual. These categories were as follows: watching (d110), e.g., watching a specific object; listening (d115), e.g., listening to sounds; communicating-with-receiving-spoken messages (d310), e.g., comprehending speech; and walking (d450), e.g., walking short distances. All other categories indicated a higher level of ‘purposiveness’, e.g., the use of communication devices or techniques to enhance communication in specific situations, walking in traffic, or interacting, creating and maintaining different types of relationships. Furthermore, engaging aspects in vital areas of life are also highlighted, e.g., work, community life, recreational aspects of life or religion and spirituality.

The merging of influential environmental factors showed that all chapters in this component were relevant for the target group. Most categories used in the linking process belonged to the physical environment, e.g., technical devices (hearing aids, cochlear implants), acoustics or noise. According to the human-related environment (i.e., social support [Ch. e3] and attitudes of others [Ch. e4]), the same ‘actors’ were highlighted as important environmental factors, namely, the immediate family. Regarding social support, friends or acquaintances were also highlighted as influential actors with regard to functioning and disability. Only one 2nd-level category of administrative characteristics (services, systems and policies) was supported by the three studies. The connected 3rd-level category, e5800, health services, conveys ‘services and programmes at local, community, regional state or national level, aimed at delivering interventions to individual for their physical, psychological and social well-being...’209 (p.203), while e5802, health policies, concerns, ‘legislation, regulations
and standards that govern the range of services provided to individuals..." (p.204).
Table 5. Presentation of all (d) that appeared in all three perspectives. 2\textsuperscript{nd}-level categories (in bold) are in the left column, with the connected 3\textsuperscript{rd}-level (or 4\textsuperscript{th}-level) categories in the middle.

<table>
<thead>
<tr>
<th>Activities &amp; Participation</th>
<th>Frequency</th>
<th>2\textsuperscript{nd} level ICF Categories (n=14)</th>
<th>3\textsuperscript{rd} and 4\textsuperscript{th} level Categories</th>
<th>Researcher (%)</th>
<th>Expert (%)</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Watching</td>
<td>3.5</td>
<td>d110</td>
<td>3\textsuperscript{rd} and 4\textsuperscript{th} level Categories</td>
<td>15.9</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Listening</td>
<td>35.4</td>
<td>d115</td>
<td></td>
<td>49.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicating with</td>
<td>8.0</td>
<td>d310</td>
<td></td>
<td>74.6</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>- receiving - spoken</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>messages</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Conversation</td>
<td>7.6</td>
<td>d350</td>
<td></td>
<td>57.1</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>- Sustaining a</td>
<td></td>
<td>d3501</td>
<td></td>
<td></td>
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<tr>
<td>conversation</td>
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<td></td>
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<td></td>
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<tr>
<td>- Conversing with one</td>
<td>3.9</td>
<td>d3503</td>
<td></td>
<td>9.5</td>
<td>4</td>
<td></td>
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<td>person</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Conversing with many</td>
<td>4.3</td>
<td>d3504</td>
<td></td>
<td>30.2</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>people</td>
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<td></td>
<td></td>
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<tr>
<td>Using communication</td>
<td></td>
<td>d360</td>
<td></td>
<td></td>
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<tr>
<td>devices and techniques</td>
<td></td>
<td>d3600</td>
<td></td>
<td></td>
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<tr>
<td>- Using telecommunication</td>
<td>4.7</td>
<td>d3601</td>
<td></td>
<td>25.4</td>
<td>4</td>
<td></td>
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<td>devices</td>
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<td></td>
<td></td>
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<tr>
<td>- Using writing machines</td>
<td></td>
<td>d3602</td>
<td></td>
<td></td>
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<tr>
<td>- Using communication</td>
<td></td>
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<tr>
<td>techniques</td>
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</tr>
<tr>
<td>Walking</td>
<td>1.1</td>
<td>d450</td>
<td></td>
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<tr>
<td>- Walking short distances</td>
<td>0.9</td>
<td>d4500</td>
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<tr>
<td>- Walking around</td>
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<td>d4503</td>
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</tr>
<tr>
<td>obstacles</td>
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<td></td>
<td>4.8</td>
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<td>Complex interpersonal</td>
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<td>d720</td>
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<tr>
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<td></td>
<td>d7203</td>
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</tr>
<tr>
<td>- Interacting according</td>
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<td>4</td>
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<td>to social rules</td>
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<td>Relating with strangers</td>
<td>5.4</td>
<td>d730</td>
<td></td>
<td>6.3</td>
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<td>Formal relationships</td>
<td>3.0</td>
<td>d740</td>
<td></td>
<td>7.9</td>
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<tr>
<td>- Relating with persons</td>
<td></td>
<td>d7400</td>
<td></td>
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<tr>
<td>in authority</td>
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<td></td>
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<tr>
<td>- Relating with</td>
<td></td>
<td>d7401</td>
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<td>subordinates</td>
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<td>- Relating with equals</td>
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<td>d7402</td>
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<td>d760</td>
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<td>d7600</td>
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<td>- Parent-child relations</td>
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<td>relations</td>
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<td>Remunerative employment</td>
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<td>d850</td>
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<td>- Sports</td>
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<td>d9201</td>
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<td>- Arts and culture</td>
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<td>d9202</td>
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<td>- Socializing</td>
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<td>d9205</td>
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<td>Religion and spirituality</td>
<td>3.5</td>
<td>d930</td>
<td></td>
<td>6.3</td>
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<tr>
<td>- Organized religion</td>
<td>1.3</td>
<td>d9300</td>
<td></td>
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Table 6. Presentation of all (e) that appeared in all three perspectives. 2\textsuperscript{nd}-level categories (in bold) are in the left column, with the connected 3\textsuperscript{rd}-level (or 4\textsuperscript{th}-level) level in the middle.

<table>
<thead>
<tr>
<th>Environmental factors</th>
<th>2\textsuperscript{nd} level ICF Categories (n=9)</th>
<th>3\textsuperscript{rd} level ICF Categories (n=10)</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Researcher (%)</td>
</tr>
<tr>
<td>e115</td>
<td>Products and technology for personal use in daily living</td>
<td></td>
<td>-</td>
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<tr>
<td>e1150</td>
<td>General products and technology for personal use in daily living</td>
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<td>1.3</td>
</tr>
<tr>
<td>e1151</td>
<td>Assistive products and technology for personal use in daily living</td>
<td></td>
<td>1.1</td>
</tr>
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<td>e125</td>
<td>Products and technology for communication</td>
<td></td>
<td>-</td>
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<td>e1250</td>
<td>General products and technology for communication</td>
<td></td>
<td>8.4</td>
</tr>
<tr>
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<td>Assistive products and technology for communication</td>
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<td>10.1</td>
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<td>e150</td>
<td>Design, construction and building products and technology of buildings for public use</td>
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<td>6.7</td>
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<td>e1501</td>
<td>Design, construction and building products and technology for gaining access to facilities inside buildings for public use</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>e1502</td>
<td>Design, construction and building products and technology for way finding, path routing and designation of locations in buildings for public use</td>
<td></td>
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<td>c250</td>
<td>Sound</td>
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<td>c2500</td>
<td>Sound intensity</td>
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<td>e2501</td>
<td>Sound quality</td>
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<td>Immediate family</td>
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<td>c320</td>
<td>Friends</td>
<td></td>
<td>1.1</td>
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<tr>
<td>c325</td>
<td>Acquaintances, peers, colleagues, neighbours and community members</td>
<td></td>
<td>2.2</td>
</tr>
<tr>
<td>e410</td>
<td>Individual attitudes of immediate family members</td>
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<td>1.5</td>
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<td>c580</td>
<td>Health services, systems and policies</td>
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<td>-</td>
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<td>c5800</td>
<td>Health services</td>
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<tr>
<td>e5802</td>
<td>Health policies</td>
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</table>

SARAH GRANBERG  Functioning and Disability in Adults with Hearing Loss
5.2 How can audiological data be linked to the ICF?

As an important part of the present project, linking audiological data to the ICF has been performed (in studies II, III and IV). Although conducted in a scientific manner with established linking and coding rules, several issues were identified when connecting audiological data to the ICF. Organized into sub-categories, these linking issues are presented here.

5.2.1 The definition of hearing-related terms in the ICF

In study II, the outcome measures, such as self-assessment questionnaires and clinical measures, used in research on adults with HL were linked. The outcome measures were chosen as representatives of the ‘Researcher perspective’ because they reflect the conducted research. Another valuable characteristic was that they could also (relatively easily) be connected (linked) to the ICF. The experience from study II revealed several issues to consider. Some descriptions of hearing-related ICF categories were found to be unclear or to overlap in the classification. To facilitate the linking process and to avoid ambiguities in general, the linkers in the present project agreed that the definitions of hearing-related terms needed to be separated in some way. Therefore, the suggestions of hearing definitions made by Kiessling and colleagues\textsuperscript{108} and Pichora-Fuller and Singh\textsuperscript{150} were used and tied to the specific category codes in the classification.

Hearing

“Hearing is a passive\textsuperscript{VI} body function that provides access to the auditory world via the perception of sound. It concerns sensing the presence of sounds and discriminating the location, pitch, loudness and quality of sounds\textsuperscript{108} (p.93). This statement corresponds to b230, hearing functions, in the ICF. However, it is worth noting that b2304, speech discrimination, is not similarly described in the ICF as the audiological concept of ‘speech discrimination’; therefore, this category was not used when linking this concept in the current study. Instead, the second-level b230 classification was used for this matter, as the established linking rules\textsuperscript{30, 32} prescribed.

\textsuperscript{VI} The concept ‘passive’ is used in this quotation for the hearing (auditory) system. However, it is important to clarify that the hearing system is not passive in the sense that it is inactive; rather, the hearing system works without the influence of consciousness.
Auditory Perception
Auditory perception is a concept that occurs in the ICF as a specific category code (b1560) assigned in Ch. b1, mental functions. In audiological theory, hearing is a passive sense that provides sound information to the brain, where action, such as sound localization, can be undertaken. Indeed, this action is in fact a mental process referred to as auditory perception. However, in the ICF, all categories associated with auditory perception functions such as discrimination, localization and lateralization are placed in b230, hearing functions. Therefore, there was an agreement in this project to use multiple linking (b1560 and the suitable b230 category codes) when required.

Listening
“Listening is the process of hearing with intention and attention for purposeful activities demanding the expenditure of mental effort”\(^{150}\) (p. 30). In the ICF, listening is assigned to d115, listening. The description of this category in the ICF is ambiguous with regard to listening to speech (i.e., speech comprehension)\(^{209}\) (p. 125), but it was decided that this category should be used exclusively for listening when no speech comprehension was involved.

Comprehending speech
“Comprehending is an activity beyond the processes of hearing and listening\(^{108}\)” (p.S93), and it is defined as the “unidirectional reception of information, meaning and intent”\(^{150}\) (p.30). In the ICF, speech comprehension is best described with d310, communicating with-receiving-spoken messages. This category was solely used for (as the designation implies) the receiving portion of speech communication.

Communication
“Communication requires the bi-directional transfer of information, meaning or intent between two or more people”\(^{108}\) (p. S93). In the ICF, communication between two or more persons is referred to as conversation (d350), and categories related to conversation were used when bi-directional communication was linked. This category closely resembles d355, discussion. This latter category was used when a meaningful concept explicitly highlighted the argumentation dimension of a conversation or if a conversation was described as very intense.
5.2.2 Latent interpretation of data

From an audiological perspective, study II highlighted the fact that a great deal of the data needed to be latently interpreted (i.e., to identify underlying meanings) to avoid mislinking (i.e., linking to the wrong components and categories). Latent interpretation was especially necessary in relation to the concepts of hearing, listening, comprehending speech and communication. In several of the linked condition-specific questionnaires, ‘hearing’ was expressed but actually referred to a higher level of auditory processing such as ‘listening’ or ‘comprehending speech’.

Furthermore, the notion of coping is assigned as a personal factor in the ICF. In audiology, problem-focused coping strategies are often discussed in relation to communication strategies. In the ICF, communication strategies are not viewed in terms of coping but rather as part of the activities and participation component (d3602), and hence, the interpretation of e.g., statements in questionnaires was necessary to distinguish between coping and communication strategies. In many cases, latent interpretations regarding the environment were also necessary. Given that the items in the questionnaires often were expressed as a statement, the questions did not specifically address noisy environments but rather exemplified such environments and why interpretations were necessary. An example is a statement that reads ‘Carrying on a conversation in a busy street or shop’. This was interpreted as ‘sustaining a conversation in noise’. A meaningful concept was sometimes interpreted as an ‘arena’ in which a conversation was taking place, such as a restaurant environment, a shop or a large office. The latent interpretation was performed according to both noise and acoustics because it was assumed that the arenas chosen in the questionnaires served as barriers to conversation due to the design of the environments (e.g., large, open areas), where environmental noise (from other people and things) becomes problematic. Other latent interpretations were necessary when a concept contained more dimensions than expressed in the statement. An example of this matter was the concept of ‘watching the news on TV’, where ‘watching’ was interpreted as both ‘watching’ and ‘comprehending speech’ because these statements were retrieved from condition-specific questionnaires that targeted HL.

Latent interpretations were further necessary when linking the transcribed interviews (study IV). It was established that a particular linking procedure (the seven-step linking procedure; see section 3.6.3), based on summative content analysis acknowledging the identifications of underlying meanings, was necessary to avoid mislinking. The rationale for this
method was the important linking lessons on audiological data learned in previous studies, and the lack of available linking methods, in line with these experiences as the methods of analysis applied in prior ICF Core Sets projects, was deemed insufficient in the present study\textsuperscript{38, 71, 75}.

### 5.2.3 Primary concepts

During the linking process, it was occasionally difficult to recognize the correct component of interest in a statement, e.g., distinguishing whether a concept was part of the activities and participation (d) component or the environmental factors (e) component. An example of this matter is the concept of ‘telephone’, which can convey ‘telephone usage’ (part of the [d] component) or be considered to be ‘a telecommunication device’ (part of the [e] component). In those cases, it was helpful to recognize the primary concepts (i.e., what the statement was meant to convey) contained in the statements. In several statements, the primary concept focused on ‘conversing’, whereas, for example, ‘telephone’ was considered a difficult context for conversations. Therefore, it was helpful to first consider the relevant components that a meaningful concept should be linked to and then select the final category codes (for example, see Fig. 8). Occasionally, this matter still could not be resolved; in those cases multiple linking (i.e., linking to several relevant categories) was applied.

![Fig. 8 Example of primary concept analysis.](image)

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*Functioning and Disability in Adults with Hearing Loss*
5.2.4 Overlapping categories

In study II, the problem with overlapping categories was highlighted. This problem occurred both between different components and within the same component. In some cases, there were problems distinguishing between body functions (b) and personal factors (pf), which was the case with e.g., the concept of ‘optimism’. An example of this situation was observed with item no. 3 of the Glasgow Benefit Inventory (GBI)\textsuperscript{167}: ‘Since your operation/intervention, have you felt more or less optimistic about the future?’ The concept ‘optimistic about the future’ was interpreted as an ability to produce a personal disposition, ‘optimism’ (body function), as opposed to being an ‘optimistic person in general’ (a personal factor), which could result from other circumstances. These circumstances could include childhood experiences and family relationships, in addition to personal disposition and factors not related to the health condition. In this project, the distinction was made in the linguistic context. When statements about personal disposition in relation to the health condition were expressed, this information provided a clue that the factor was related to body functions, whereas statements about personal disposition not related to hearing loss were considered to be personal factors. Another important difficulty was discovered when linking the concepts related to ‘attention’. Attention can be a body function in the ICF (b140, attention functions) and in the activities and participation component (d160, focusing attention). This was not easy to distinguish; however, it was very helpful to identify primary concepts and to decide whether the statement should be classified as (b) or (d). Overlapping categories within a component were identified when using hearing functions (b230s) and auditory perception (b1560), as stated above. However, it was very helpful to use the agreed-upon hearing-related concepts and how these should be linked.

5.2.5 Linking of clinical or laboratory outcome measures

When linking outcome measures, such as clinical measures, the aim of the measurements should be linked\textsuperscript{32}. A specific measurement may be used for different purposes in different studies, and therefore, the linking can vary from study to study. In the researcher perspective (studies I and II), several of the clinical measures required an ‘active patient’, even though the aim of the measurement was to evaluate a body function. This situation was the case with pure-tone audiometry, which, in the literature is described as a sound detection test. Importantly, the patient decides when a sound is detected or not\textsuperscript{169}. Therefore, although the aim of the test is objective, the
procedure is subjective. To overcome this issue, it was decided that both the aim and the procedure had to be taken into account when linking. The consequence for a test such as pure-tone audiometry was that the passive hearing function (b2300, sound detection), the mental function (b1560, auditory perception) and, finally, the action taken necessary to participate in such test (d115, listening) were acknowledged.

5.2.6 Missing categories
When linking technical measures, it was impossible to assign several of the measurements to categories at the second-level or more specific levels, such as with ‘tympanometry’, which is used to evaluate the function of the middle ear\(^3\). Unfortunately, functions of hearing related structures, such as the tympanic membrane or the ossicles, are not included in the ICF. When linking this example, the first-level category b2 Ch. 2, sensory functions and pain was used. In the ICF, the auditory system is divided (occurs in different chapters). When, e.g., referring to ‘structures of the auditory system’, the peripheral and central parts of the auditory system are separated. The peripheral hearing system is found in Ch. 2, structures of the eye, ear and related structures, whereas the central auditory system (the auditory nerve and beyond) is located in Ch. 1, structures of the nervous system. This is important because audiological measurements of the function of brain structures were linked to b1 Ch. 1, mental functions. In conclusion, the functions of hearing-related structures are missing in the ICF, both in chapter 1 and in chapter 2.

5.2.7 Elaborating ‘not covered by ICF, nc’
In study III, the linking experiences from study II, i.e., the additional linking rules suitable for audiological data, were used when linking the survey data. An additional linking issue to consider from study III was the elaboration on ‘nc’, i.e., ‘not covered by ICF’. According to the established linking rules, information that is not possible to assign to ICF categories should be labeled pf (personal factors), nd (not definable), nc (not covered by ICF) or hc (health condition). In study III, it was occasionally possible to solely identify a component (i.e. b, s, d or e) from a concept, but no chapter or category code could be assigned. In such cases, the concept was coded as ‘nc’, preceded by the component letter. This type of information was further subcategorized. The substantial portion of this classification was linked to ‘e-nc’. Almost all identified ‘e-nc’ classifications indicated that ‘how other people behaved’ had an impact on the person with hearing loss.
loss. Examples included ‘other people are mumbling’, ‘other people may cover their mouth’, and ‘other people may speak from a distance’. This linking experience was further used in study IV, in which several statements could also be linked to ‘e-nc’ and subcategorized into ‘how other people behaved’. An example of such statement is:

“… for me it’s, when people give, you know, longer sentences, talking longer, then I can eh, get more information, you know…”
6. Discussion

6.1 Function and disability in adults with HL

As part of the ICF Core Sets for HL project, the present thesis explored and described the functioning and disability of adults with HL in relation to the ICF framework. The present thesis identified a number of domains of relevance for adults with hearing loss that can serve as guidance when assessing functioning and disability in e.g., audiological rehabilitation services. Based on the results, when all three perspectives were merged and with the conceptual model of ICF as a base, an integrative model of functioning and disability in adult HL was constructed (Fig. 9). The model uses the concepts of acts, tasks and societal involvements, introduced by Badley, to overcome the conceptualization issues with regard to activities and participation.

6.1.1 The integrative model of functioning and disability in adult HL

Acts

As stated above, distinguishing between activities and participation is very difficult. Activities in the ICF should be understood as a person’s capacity to execute tasks or actions without influence of the environment. This latter aspect is important; the environment (as a concept) is always influential in the ICF, i.e., it is either facilitating or hindering. Distinguishing between ‘activities’ and ‘participation’ is perhaps especially difficult in the present research area because almost all categories identified in this joint domain turned out to be relational, i.e., some type of interaction was required. Indeed, I will now argue that, given the empirical evidence in this thesis (project) and the description of the two concepts of ‘activities’ and ‘participation’ in the ICF, the domain of ‘activities’ hardly appears in the area of adult HL.

First, the concept of ‘interaction’ warrants a further explanation. The significance of this concept is that at least two actors or forces (e.g., in physics) are involved. In the present context, the first actor is the individual who possesses the hearing health condition and the other actor can be a human being (or several), animals, features in the environment such as forces (light, air, sound) and also material objects (a TV, a radio, etc.). The implication is that the outcome of an interaction is always dependent on the two actors. When we are listening (d115) or watching (d110), we
are always doing this in relation to other actors. Indeed, these two categories do not exist unless there are at least two actors; one always listens to or watches something. The meaning of this phenomenon is that, if we consider ‘listening’ in the ICF from the individual perspective, then the object or the other actor (what you are listening to), as defined (in the ICF), would be the environment, given that it influences the listening. Thus, in the terms of the ICF, listening should be regarded as participation. Attempting to assess the listening domain will always be in relation to the context. If we attempt to assess ‘listening’ in a standardized environment or in an assumed environment; what would be the standardized actor to listen to?

Furthermore, attempting to assess how well a person with HL ‘can comprehend speech in a standardized environment’, as you would do when evaluating the activity dimension of the category d310, communicating with-receiving-spoken messages, is, in fact, impossible. Here, the outcome would also always be dependent on the other actor (person) to whom you are listening (comprehending speech). This phenomenon is also highly recognizable, from a clinical standpoint, because patients often respond to such questions with ‘it depends on who you are listening to’. The latter statement can be further reinforced by the results in the present study. For instance, in studies III and IV, several ‘e-nc’ classifications and sub-categories such as the ‘behaviors of others’ were identified. Patients and experts claimed that ‘how other people behaved in communicative situations had impact on functioning with HL’ and gave examples such as ‘other people are mumbling’, ‘other people may cover their mouth’, and ‘other people may speak from a distance’.

To summarize the argument: the ICF categories that involve more than one actor (interactive categories) cannot be regarded as activities or as activity limitations, at least not based on how the concepts are described in the ICF (for proper descriptions and explanations, see e.g., Cieza and Stucki or ICF (pp.14-16).
Fig. 9 The integrative model of functioning and disability in adults with HL. The model shows how the concepts of acts, tasks and societal involvement relate to the ICF from a HL perspective. Note that one category ‘walking’ (acts), is related to ‘activities’ in the ICF. All other acts, tasks and societal involvements of relevance for the target group correspond to ‘participation’ in the ICF.
This argument is in line with Badley’s reasoning on acts, tasks and societal involvement. She describes acts as follows: ‘acts serve as a link between body functions and structures and tasks as they concern the impact of impairments on the functioning of the body, which in turn affects how tasks might be carried out’ (p. 2339). Furthermore, Badley explains that acts always involve multiple body functions and structures, including mental functions and structures, and relates them to the functioning of a person ‘as a whole’. Badley further introduces the concept of the environment as a possible ‘scene-setter’. This ‘scene-setter’ should be understood as implied or undefined environmental factors that collaborate [interact, my interpretation] with an act, and ‘acts do not vary by culture and are universally understood’ (p.2340). The implication is that, while in the ICF, the distinction between activities and participation is mainly made according to the influence of the environment, Badley allows the environment to be a part of acts, tasks and societal involvements. Instead, the distinction between acts, tasks and societal involvement is made according to the level of functional complexity.

The title ‘acts’ is used in the present model. Four concepts have been merged under the umbrella designation ‘acts’: watching, listening, comprehending speech, and walking. Two senses are represented here: acts relating to hearing and an act related to vision. Regarding the first sense, the distinction was made according to the level of auditory processing. Processing speech is more complex than merely listening because the assignment of meaning requires e.g., (apart from sound input) language memory and learning. The term ‘listening’ was defined in study II, and differed slightly from the term in the ICF due to the overlap with other categories within the classification. Instead, the definition by Pichora-Fuller and Singh was used: ‘Listening is the process of hearing with intention and attention for purposeful activities demanding the expenditure of mental effort’ (p.30). The concept of listening simply means ‘listening and comprehending environmental sounds’. These sounds could be, e.g., birds or other animal sounds, noise or tones. However, it cannot be speech. Comprehending speech was defined as ‘an activity beyond the

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VII It can be speech, provided that it is ‘a non-comprehension dimension’ of speech. That is, I could listen to Chinese (a language I do not understand), and this act could be explained as ‘listening’. However, as soon as there is a component of comprehension involved, the concept changes to ‘speech comprehension’.
processes of hearing and listening defined as the unidirectional reception of information, meaning, and intent.

Watching is a concept that traditionally has a significant place in audiological rehabilitation services. Indeed, several interventions are based on notions such as ‘lip-reading’ or ‘visual cues’. However, recent studies have indicated increased dual-sensory loss among adults with HL. This phenomenon is especially true among older adults, a target group that commonly utilizes audiological services. Therefore, this trend in recent findings might be an indication to reconsider and elaborate the established rehabilitation interventions based on the concepts of watching.

The concept of ‘walking’ has been acknowledged in the present model. In examining the evidence, one can quickly conclude that there are two probable reasons for such a health domain to exist in relation to HL. First, in their research investigations, researchers have used generic SA questionnaires in which ‘walking’ is considered to be a health domain (results from study I). The concept of ‘walking’ occurs in e.g., EQ-5D and SF-36. However, there is no previous evidence that the concept of ‘walking’ is connected to the general group of adults with HL. Second, some patient(s) mentioned ‘walking’ in the focus group interviews. This phenomenon might be connected to (a) specific individual(s) who also experienced dizziness (mentioned in three units of analysis). However, this possible link has not been investigated in the present thesis. As opposed to the other identified acts, walking is a concept that could be connected to the activities (a) domain in the ICF because it is not dependent on another actor. There is a dimension of the concept of walking that is highly relevant for adults with HL, namely, ‘walking through traffic’. However, this notion is considered to be a ‘task’ in the present model and is discussed below under that heading.

Tasks
Further elaborating the concepts that distinguish between activities (a) and participation (p), as suggested by Badley, tasks are purposive with a specific objective. As expected, communicative interactions such as conversations or the usage of telecommunication or communication strategies are indicated as relevant. Several studies within the field of audiological research have previously highlighted these dimensions as relevant to this specific target group. Note, the specific inter-personal interactions and relationships addressed in all three perspectives. One must consider that, out of the 33 linkable second-level and third-level categories
outlined in Ch. 7, interpersonal interactions and relationships, *family relationships, formal relationships, relating with strangers* and *interacting according to social rules* were highlighted. The fact that family relationships are important might not come as a surprise; on the contrary, significant others are viewed as an important factor in rehabilitation interventions\(^{156}\), and studies have also shown that the significant others of persons who experience a hearing loss are highly influenced by HL, which reinforces the interactive perspective of the health condition\(^ {178}\). More surprising, according to the evidence, relating with strangers and interacting according to social rules are relevant for the target group. An important question arises in this context: how is that, out of the 33 interaction categories to choose from, the categories relating to ‘strangers’ and ‘social conventions’ are highlighted above categories such as ‘interacting with friends’ or ‘intimate relationships’? The definition of d730, relating with strangers, reads as follows: ‘engaging in temporary contacts and links with strangers for specific purposes, such as when asking for directions or making a purchase’. The category d7203, interacting according to social rules, reads as follows: ‘acting independently in social interactions and complying with social conventions governing one’s role, position or other social status in interactions with others’. These two categories are not hierarchically related; nevertheless, they are closely connected. It is important to realize that a significant part of both of these categories constitutes communication. Humans are social beings, and a fear of misbehaving in communication situations, which may be the case when the communication partner is not familiar to you or when the conversation topic or the speaker changes rapidly, could be associated with cognitive deficiencies or old age, which are well-established stigmatizing attributes related to HL\(^ 94, 107, 202\). Contemporary theorizations of the stigma concept are frequently made in terms of ‘identity-threats’; that is, ‘the effects of a stigma are mediated through targets’ understanding of how others view them’\(^ {121}\) (p.397). Therefore, a possible reason for the indicated relevance of these categories in the present study might be that individuals with HL value ‘miscommunication’ as an identity threats. This ‘insider perspective’ of stigma is important to highlight in understanding the individual needs of adults with HL because stigma can serve as a barrier to audiological rehabilitation interventions. The same conclusions have also been drawn by others within the research area\(^ {188, 189, 202}\).

Walking through traffic or other crowded areas was especially highlighted by professionals and patients. Although the limited previous re-
search findings on traffic and HL indicate no general insecurity due to HL in traffic situations, the target group is a vulnerable group in traffic situations due to, e.g., sound localization problems\textsuperscript{119,197}.

Societal involvement

Societal involvement addresses the individual as an actor in larger ‘plays’, such as cultural or socially recognized areas in society that include work, community life or, more abstractly, socializing. Importantly, societal involvement always addresses the ‘social role’ and not the performance connected to the concepts\textsuperscript{9}. Considering the social role, several aspects have been highlighted in the three perspectives, albeit with different levels of significance. Although an aspect such as ‘religion and spirituality’ is regarded as relevant as it actually appears, the occurrence of the category is low in the three perspectives compared to other aspects such as ‘socializing’ or ‘work’. This finding is not surprising given the growing body of evidence regarding, e.g., research studies on adults with HL in work situations. People with HL are established as a vulnerable group in the labor market, with overrepresentation in early retirement \textsuperscript{48,55,64,153}, increased emotional distress due to misinterpretation of external information at work and lack of control in the work environment \textsuperscript{48,114,136}. With regard to ‘socializing’, given that it was identified in all units of analysis in the patient perspective and mentioned very frequently by experts (42.9\%), it is noteworthy that the concept has attracted so little research interest (4.1\%). This discrepancy between the target of investigations compared to professional and patient experiences was also highlighted in study II in relation to ‘tasks’ such as conversation or communication strategies. A suggested solution to this discrepancy could be to actually include patients in the research process to a higher extent when discussing topics for research investigations. Previous studies of this type have proven to be beneficial for both researchers and patients\textsuperscript{56,157,158}.

The Body

Body function (b) categories of various types were identified as relevant for the target group. In addition to obvious categories related to auditory functions and structures, other bodily aspects of more psychological or mental nature, such as attention, energy, and memory functions, were addressed. When relating data to (b), it is soon made to discuss this component in relation to impairment. However, in the present project, it was evident that some categories belonging to (b) were relevant to the target
group, not in relation to impairment but rather as ‘neutral’ categories (i.e., full function) that, nonetheless, are highly influential to the health condition or, rather, highly influential interactions. One such category is b152, emotional functions. Several outcome measures in the field of audiology used variables such as ‘anxiety’ and ‘embarrassment’, and many questionnaires, both generic such as HADS and CS such as HHIE, used statements related to emotions. Category b152 was used very frequently in the linking procedure, thus indicating a high degree of prevalence in all three perspectives in the present project (Table 4). An interesting theory with regard to ‘social bonds’, originating from the field of sociology, could be applicable when attempting to understand the high prevalence of emotions in relation to adults with HL. There is a close connection between human interaction and emotions, and the maintenance of social bonds is crucial for social life. Threats of the social bonds, which can occur when interaction is disrupted by HL, could generate negative emotions. Emotions have been reported as the most consequential outcome of interaction. As stated above, interaction is one of the most significant findings in this thesis, indicating a correlation between these two concepts.

Furthermore, previous research findings in the field of ‘cognition and HL’, such as attention and memory, indicate a connection to aspects of interaction. There is an established link between working memory and speech comprehension. The capacity of cognitive processing increases during speech comprehension for persons with HL, resulting in fewer resources available for other simultaneous cognitive tasks. Additionally, several cognitive variables, such as sustaining attention and working memory, have been reported as having an association with hearing disability.

In the present model, ‘hearing-related functions’ such as tinnitus were highlighted. Tinnitus is regarded as a body function in the ICF, whereas it is viewed as a diagnosis in the ICD-10 (H93.1). Nevertheless, tinnitus is an important comorbidity to HL, showing high prevalence worldwide (e.g., 17 million in the USA), reinforcing its position in the current model of functioning and disability.

The Context
With regard to environmental factors (e), interesting facts were revealed in the present studies. It is no surprise that the physical environment, such as hearing technology or noise, was highlighted as influential in functioning for adults with HL. The probable reason for the high prevalence of assis-
tive devices in all three perspectives is their status as primary interventions\textsuperscript{123}. Although assistive devices provide sophisticated solutions for amplifying residual hearing, background noise remains one of the most significant barriers to hearing aid use and satisfaction\textsuperscript{110, 213}. Social support (Ch. e3) was reported as an environmental factor that is influential in functioning. The immediate family is an especially important factor for adults with HL because they form the closest communication partners in relation to whom the effects of the HL become evident\textsuperscript{98, 130, 179}. These communication partners are also very important in the decision-making process to pursue intervention and in the subsequent acceptance\textsuperscript{122}.

In study II, it was concluded that little research attention had been paid to the human-related environment, i.e., social support and the attitudes of others (Fig. 7), in the audiological research field. Other review findings have reinforced this result, stating that few studies on the attitudinal social environment over the last two decades have been performed in the research field\textsuperscript{129}. When merging the perspectives, it became evident that the human-related environment is also relevant for the target group. There is obviously a discrepancy between the target of research investigations and the relevant functional aspects indicated by the target group or professionals. Further research that explores the human-related environment in relation to adults with HL is required.

Information on personal factors (pf) was not obtained to a larger extent in the present studies. From the researcher perspective (studies I, II), it was concluded that pf was used 26.2\% in the linking process, whereas in the professional perspective (study III), pf was used 3.2\%. In the patient perspective, unfortunately, no such data are currently available. Undoubtedly, personal factors are important in the ICF classification and in the understanding of functioning and disability. When using the ICF in clinical encounters on an individual basis, pf must be considered, despite the fact that no category codes for pf currently exist.

6.1.2 Measuring functioning and disability – The current state of play

One important rationale for the ‘ICF Core Sets for HL’ project was the outlined ambiguities regarding measurements and the conceptualization of the terms ‘functioning’ and ‘disability’ in the present research field\textsuperscript{49}. This statement was further reinforced in study I, reflecting the outcome measures identified in the research field of adults with HL. First, an extensive number of different outcome measures used within the field were identified. Furthermore, it was stated that the identification of the ten
instrument types reflected the comprehensiveness of and variation in the research field, whereas the significant number of different outcome measures within an instrument type revealed a poor consensus on which instruments should actually be used when measuring different functional aspects of HL. A discussion regarding the type of measurements and the construction of the measurements identified was performed in study I. This section highlights two important findings from study I, SA questionnaires and speech measures.

Self-assessment questionnaires
An important problem regarding the existing generic ‘health-related quality of life’ (HRQoL) SA questionnaires was highlighted. Studies have concluded that several existing HRQoL questionnaires exhibit poor sensitivity to HL populations\(^1\), \(^{13}\), \(^{137}\), \(^{216}\). It should be noted that several HRQoL questionnaires failed to recognize ‘communication’ as a health domain \(^2\), \(^{42}\). Consequently, given that communication restriction is known to be one of the most frequently reported disability of hearing loss\(^{44}\), \(^{92}\), \(^{107}\), \(^{160}\), this failure might explain the poor consensus with regard to which generic instrument to utilize, as concluded in study I.

A significant number of condition-specific (CS) self-assessment questionnaires were identified in this review. Notably, there was also a low prevalence of the CS questionnaires. The Hearing Handicap Inventory for the Elderly (HHIE)\(^{205}\) was the most frequently identified (5 times or 2.0%). Compared to other areas, such as acute inflammatory arthritis\(^{221}\) or depressive disorders\(^{21}\), where there is a high prevalence relying on a few questionnaires, the field of audiology has not agreed upon the most appropriate questionnaires for use. One important aspect of this matter, outlined in study I, might be connected to the construction and design of the current CS questionnaires. It was concluded that there was a clear tradition of constructing statements upon which the respondent should reflect, given that 64% of the included CS questionnaires were constructed in this manner. Many items across questionnaires contained statements expressing an action (such as conversing) that was performed contextually (e.g., in a noisy grocery store). It was highlighted that constructing the questionnaires as described, limited the international equivalence\(^5\). Hence, persons outside a specific cultural context could experience difficulties relating to certain statements because the described contexts within the questionnaires were focused to a specific cultural setting. Thus, this validity issue can be problematic both on the individual level and on the group
level, as also highlighted in previous research studies\(^40, 66\). Furthermore, it was acknowledged that several of the CS questionnaires held more than 20 items, and it was noted that item reduction was an important part of the validation process of a particular questionnaire\(^60\). Different reviews of CS questionnaires have been conducted within the audiological research field\(^11, 144\). These reviews have highly focused on the psychometric properties of existing questionnaires, such as the statistical measures of reliability and aspects of construct validity. In her review about the psychosocial impact of hearing loss on elderly, Kramer\(^113\) highlighted the great variety of methods by which the concept of ‘psychosocial health’ has been operationalized within the research field, with an extensive amount of SA questionnaires being used in relation to the concept. In conclusion, a discussion regarding the aspects of content validity of existing questionnaires, including the appropriateness of latent variables, item generation including the wording of questions and item reduction, seems to be missing in the research field. This factor might be important in explaining the overuse of CS questionnaires given that there seem to be a poor consensus on definitions, conceptualizations and operationalizations of the relevant concepts.

**Speech measures**

The amount of different speech measures used in the research area of adult HL was further highlighted. Concerns were raised about the labeling of different measures in relation to what they meant to convey and the lack of proper references to descriptions in the literature of the specific measurement. The unclear labeling of the speech measures in the included articles in study I was a considerable problem. Although aiming at the same auditory processing level, terms such as ‘speech discrimination’, ‘speech perception’, ‘speech reception’, ‘speech understanding’, and ‘speech recognition’ were used when assessing ‘speech recognition’. Notably, 36 different speech measures for ‘speech recognition’ were identified. ‘Speech recognition’ tests are tests that require the patient to attach a label to the stimulus by, e.g., repeating the word orally\(^196\). Importantly, no semantic processing is required, and the test does not evaluate speech understanding or speech comprehension. There are a plethora of different speech recognition measures available according to the contextual conditions (noise/no noise, fixed/varied noise levels), presentation mode (fixed/varied speech levels), or scoring options (percentage of correctly identified speech stimuli/SNR at a speech recognition score of 50%) in the present research area.
The conclusion is that the consensus on which of these measures to use in the audiological research field is low.

6.1.3 An integrative model of functioning and disability in adults with HL versus the ICF Core Sets for Hearing Loss

As described above, the present thesis is based on preparatory studies in the ICF Core Sets for HL project. Phase II of the project (Fig. 4), was performed as a consensus conference in Helsingør, Denmark, in May 2012. Two core sets were established during the conference: a comprehensive (containing 117 ICF categories) and a brief core set (containing 27 categories) \(^{50}\). The two core sets resulted from a consensus process in which both the evidence from the four preparatory studies and the views of the invited experts were incorporated. The brief core set was derived from the comprehensive, but only 2nd-level categories were included. The rationale for this decision was that it was considered important to ‘go in width instead of depth’, i.e., capturing as many health domains as possible in a wide perspective instead of narrowing a few perspectives down to specific categories. Thus, this decision fulfilled the aim of a brief core set, described as ‘the most likely areas of functioning associated with a health condition as well as those areas for which information is required’\(^{163}\) (p.25).

The result in the present thesis is based on three out of the four preparatory studies in the project, merging them into a model designated ‘the integrative model of functioning and disability in adults with HL’. Therefore, how the results in this thesis differ from the core sets and how the results should be understood in relation to the two ‘ICF Core Sets for HL’ are appropriate questions.

In ‘the integrative model of functioning and disability in adults with HL’, only categories that appear in all three perspectives have been recognized (36 2nd-level and 63 3rd-level categories). This was not the case during the consensus conference, which resulted in the recognition of 117 categories (comprehensive core set). During the consensus conference, the participants were free to evaluate an ICF category regardless of whether it appeared in all preparatory studies or not, or how frequently the category was used in each study. Some decisions made by the participants relied heavily on the research evidence, whereas other participants were more sensitive to their own experience. This situation is what occurs in a consensus process, given that the entire project practiced a Delphi technique (for the proper explanation of the Delphi technique, see e.g., Rowe and Wright\(^{170}\)). However, the integrative model outlined in the present thesis is
built only on research evidence, following the practice of ‘an interdisciplinary evidence-based-practice approach to functioning and disability’, as outlined in section 3.1. It is possible that a few more categories will be included when adding the results from the fourth preparatory study, the multicenter study. The future will tell.

The integrative model of functioning and disability in adult HL can be used in educational or theoretical contexts that describe functioning and health in adult HL and could contribute to the scientific literature on audiological rehabilitation models (see below). The two core sets, on the other hand, are operationalized tools of the model for use in clinical encounters or in research investigations. The brief core set, is particularly suitable in research contexts due to its brevity. The future intention is to make a SA questionnaire that is derived from it, representing an important step forward and a step closer to consensus on how to measure functioning and disability in adults with HL.

6.1.4 Application for Audiological Rehabilitation (AR)

In 2011, Montano presented ‘The Person-Centered Model of Audiological Practice’132, 133. The model focuses on interactive processes and acknowledges the importance of the cooperation between the clinician and the patient. Furthermore, it highlights the interventions that are important to the target group. The outlined interventions focus on communication strategies, technology, auditory/visual training, and consumer support. Furthermore, it also stresses the importance of the patient’s story, the usage of self-assessment and verification of the interventions. The cooperation between the patient and the clinician is essential because it forms the foundation for decision-making concerning interventions. As a result, audiological counseling constitutes the core of this model133. In addition to rehabilitative interventions, the model further emphasizes the inclusion of the patient’s story, i.e., the inclusion of individual experiences and beliefs in relation to HL. The patient narrative is essential and the most critical component of the AR process when identifying the limitations and restrictions connected to HL. The clinician’s task is to ensure that all essential aspects have been acknowledged67.

The integrative model of functioning and disability for adults with HL could serve well in assessing the patient’s story. Although the idea is to let the patients ‘tell their story’, it is important to have some sort of interview guide when exploring this dimension. Otherwise, it is easy to forget to also include dimensions that are not so obvious, however relevant, for the tar-
get group. Therefore, the model has been integrated into ‘the person-centered model of AR’ as a guideline when assessing the patient’s story. Importantly, the model should be used as a checklist of interview topics that emphasizes the important interactive dimension of AR, not as a standardized intake form.

Additional interventions or complements to existing interventions in the Montano model have been suggested in the present elaborated model (Fig 10). These include interventions related to communication strategies in which conversation training has also been added. The findings in the present thesis stress not only the individual part of the concept of ‘communication’ but also the interactive part of the concept. Therefore, interventions related to ‘conversation’ should include communication strategy training, and behavioral aspects of conversations could also be highlighted. Additionally, conversation training is a concept used when addressing cognitive training (included in auditory/visual training), and therefore, these interventions might be overlapping in the present elaborated model. Pichora-Fuller151 summarized the need for cognitively oriented interventions based on current research findings on cognition and HL. She called for training exercises such as listening to different rates of speech. Furthermore, conversational techniques to influence or control the information speed and the management of conversational topics related to divided attention or shifting attention have been suggested as important factors that might concern future AR interventions.

Furthermore, when applicable, work-related interventions should be stressed. The organization of work-related interventions varies worldwide, and is far from always included in AR. An important reason might be that professionals of AR are unaware of the complex challenges that adults with HL experience in work and at the workplace115. However, it should be highlighted in the AR process, and if necessary, proper referral to adequate rehabilitation facilities must be made.

Pain- and energy related interventions are not traditionally part of AR. However, in certain clinics there might be access to physiotherapists or similar professionals for consultation regarding e.g., pain related to tension in the head and neck. Interestingly, complementary or alternative medicine techniques such as yoga and mindfulness training have made a foray into the traditional range of rehabilitation practices. The effects of yoga interventions have especially been scientifically investigated and show promising results with regard to stress and self-reported fatigue176, 186. Fatigue and increased energy levels in adults with HL are problematic,
and therefore, in the future, the target group could be a suitable group to investigate in yoga trials.

Comorbidities to HL must be considered in a model of AR. Tinnitus is known to be comorbid to HL, albeit to a varying degree. Hearing aids can reduce the experience of tinnitus, but for certain individuals, tinnitus requires additional interventions. A recognized intervention with high scientific support is cognitive behavior therapy (CBT), which, in clinical trials, has proven to be the most evidence-based treatment option that currently exists. Additional aspects of comorbidity to evaluate might be in relation to dizziness or irritation in the ears.

Furthermore, topics to address during audiological counseling have been suggested in the elaborated model to include, emotional response to HL, interaction concerns, relations, stigma, safety (e.g., when navigating in the surroundings), and the clients own approach to HL.
Fig. 10 The elaborated person-centered model of AR, originally developed by Montano. The original figure is used, elaborated and published with permission from Dr. Montano.
6.2 The ICF classification and audiology

The result of the linking process from the present project revealed two important perspectives:

1) Data (such as outcome measures or transcribed interviews) from the research field of adult HL needs to be interpreted to avoid mislinking and, in the long run, to avoid misinterpretations of how results from research (or similar) investigations can be explained with ICF terminology. Interpretation is an important experience that is related to the chosen methodology. Other project (targeting other health conditions) might consider this issue when designing projects concerning linking.

2) The ICF classification and the research field of adult HL do not fully comply. Indeed, there seems to be a mismatch between some concepts in the classification and some theories related to adult HL. This mismatch can be summarized based on the concepts of exhaustiveness, granularity and discrimination introduced above in section 1.3.4.

Exhaustiveness

Exhaustiveness refers to the width of the classification, i.e., whether it adequately covers the aspects of health. From an adult HL perspective, there seem to be missing categories both on the first-level basis and further down in the hierarchical structure. In the environmental factors component, the evidence from the studies suggests an additional human aspect in which also behaviors of others, in addition to attitudes and support, also have an influence on the health condition. Adding these behaviors to the ICF on 1st-level basis would be beneficial to the target group and make the ICF even better. In the present study, the brief analysis of the ‘nc’ immediately pointed to the lack in the exhaustiveness of the ICF. Conducting a rigorous analysis of the ‘nc’ identified in the entire project could definitely contribute to the exploration of the exhaustiveness of the ICF. This type of analysis could generally be conducted in any project applying the established linking rules and discussed in the context of exhaustiveness.

Deeper down in the classification, on a 2nd-level basis, categories relevant to adults with HL were identified as missing. The missing categories concerned the functions of specific hearing structures. Compared to Seeing functions, in which the second-level category b215, functions of structures...
adjoining the eye is clearly connected to the eye structures, no such category is found for ‘hearing functions’. In this context, it is important to note that, while ICF considers the auditory system to be separated (outer-ear to the cochlea in Ch. 2, sensory functions and pain; auditory nerve and beyond in Ch. 1, mental functions), audiological theories view the hearing system as a compound system that starts with the outer ear and ends at the temporal lobe in the brain. There are important hearing functions that are difficult to place in the ICF when the hearing system is divided. Moore refers to examples of this phenomenon as, ‘supra threshold signal analysis’ abilities. These abilities could, e.g., concern ‘frequency selectivity’ (the ability of the auditory system to separate or resolve the components in a complex sound). It has been concluded that frequency selectivity depends heavily on the filtering mechanism executed in the cochlea. Thus, it is partly a hearing function and partly a mental function (perceptual function). This task is difficult to handle and throws into question the view of bodily concepts in the ICF.

Furthermore, there is an obvious lack of functions of structures related to the brain in the ICF (Ch. 1, mental functions). This chapter only concerns somewhat high levels of mental functions, such as memory, attention and cognition. The result is that important measures in audiology, such as measurements of auditory brainstem response (ABR) (the test provides information from the beginning of the auditory nerve to the midbrain), are difficult to link, resulting in poor granularity.

**Precision or Granularity**

Precision or granularity refers to the level of specificity in a health or a health-related domain. Precision problems have been acknowledged in the audiology–ICF relationship. One very important problem concerns the notion of coping. In the ICF, coping is listed as an example of a personal factor (p.17). In general, there are two broad approaches to coping. The first approach is designated ‘trait-oriented coping’. This type of coping is characterized by its emphasis on stability. Coping is viewed as a personal disposition, and therefore, it is not influenced by the situation or the context. The second approach, ‘process-oriented coping’ consider coping to be a response to stressful situations, thus also acknowledging that a coping strategy can change over time and in different situations. Process-oriented coping is often described as either problem-focused or emotion-focused. The latter approach has been approved in the area of audiology. In the present area, communication strategies (d3602, using communi-
cation techniques) are typically grouped into two categories: facilitation strategies and repair strategies\textsuperscript{199}. Facilitation strategies are applied in preparation for conversation or to manage an ongoing conversation, whereas repair strategies aim at repairing communication breakdowns. Communication strategies are viewed as problem-focused coping strategies, whereas, e.g., ‘avoidance’ (pf) is considered to be an example of emotion-focused coping\textsuperscript{4, 86}.

Here, the major issue is that, in the ICF, communication strategies are part of activities and participation domain and are not considered to be part of the coping concept. Although it is not stated anywhere, one can assume that the contemporary coping view in the ICF is based on the trait-oriented approach. If this is the case and coping remains as part of the personal factors component, then this is unfortunate for the present research area because coping strategies are considered to highly influence disability, but can also be determined by the disability in adult HL\textsuperscript{85, 87, 217}. Personal factors are (as stated above) not part of a health condition or the health state in the ICF\textsuperscript{209}.

Another finding with regard to poor granularity concerns the hearing function category b2304, speech discrimination. In the ICF, this category is described as ‘sensory functions relating to determining spoken language and distinguishing it from other sounds’\textsuperscript{209} (p.65). Different types of speech/word measures are a very common type of measurement in adults with HL (results from study I) and are often referred to when discussing outcome measures in the present area\textsuperscript{69, 177}. It is not established that the speech/word measures utilized in the present area aim at determining spoken language and distinguishing it from other sounds. Rather, distinguishing between speech features or to detect differences in non-phoneme aspects of speech (e.g., rate or intensity) is more common. Therefore, the 2\textsuperscript{nd}-level category b230 was used instead of b2304. In future revisions of the ICF, it would be wise to consider whether the description of b2304 is accurate or whether it should be altered. Of course, another solution would to add another speech category.

**Discrimination**
Discrimination concerns how well categories in the ICF can be separated from each other. In this context, the term ‘overlap’ is useful. Several research investigations that utilize the linking strategy have noted the problem with overlapping categories between components. Examples of this phenomenon are the overlap between b140, attention functions and d160,
focusing attention, and between, b126, personality functions and personal factors. This problem was also experienced in the present studies and with the same categories. Regarding ‘attention’, Reed and colleagues state that these two categories cannot be clinically distinguished and, more importantly, that it is not clinically relevant to distinguish between these two categories. Category d160 reads as follows: ‘Intentionally focusing on specific stimuli, such as filtering out distracting noises’. Although one can intentionally focus one’s attention, whether one can intentionally ‘block’ (filter) distracting noises remains subject to debate. Rather, ‘blocking’ is a consequence of ‘focusing’ and filtering is a non-intentional body function. Perhaps the solution to this matter is simple, the distinction is not clinically relevant (as Reed states), and thus, either of the categories should be excluded.

In the present project, overlapping categories within components were also identified. These categories were related to hearing, listening, comprehending and communication. In the ICF, listening is described as follows: ‘Using the sense of hearing intentionally to experience auditory stimuli, such as listening to a radio, music or a lecture’ (p.125). In this statement, some examples are related to comprehending speech. This category was identified as an overlap with d310, communicating with-receiving-spoken messages. The description of this category reads as follows: ‘comprehending literal and implied meanings of messages in spoken language, such as understanding that a statement asserts a fact or is an idiomatic expression’. This type of understanding is actually exactly what you do when you are listening to a lecture (example of d115). Furthermore, all 3rd-level categories connected to b230, hearing functions (e.g., sound localization, lateralization, detection) are in fact auditory perception functions, and b1560, auditory perception lacks sub-categories. This situation is connected to the way the body is viewed in the ICF (see exhaustiveness), and therefore, the solution is not crystal clear. However, the subject needs to be attended to in scientific discussions prior to a revision.

6.3 Methodological discussion

6.3.1 The researcher perspective
In study I, the systematic literature review, an electronic search was conducted in different adequate databases. When conducting these types of searches, adding more specific search terms is a common method for tapering the searches. Doing so was impossible in the present study because...
the entire adult HL research field was the target of inquiry. No limitations were possible but the inclusion criteria. Creating a simple random sample of articles in large databases was a useful solution for limiting the search.

Statistics would typically be used to assess the reliability of the sample; however because the search was conducted in several steps (searching in databases, checking for duplicates, taking a random sample, reviewing abstracts, reviewing full texts, final decision regarding inclusion), there was no accurate method for statistically evaluating the sample in relation to all of the identified articles in the search. The question was simply what to consider as the total finding of relevant articles. However, the face validity of the sample was high. First, the search was conducted in cooperation with a librarian trained specifically in database searches, enhancing the reliability of the conducted searches. Second, we reviewed 1000 abstracts in the large databases, which is a substantial number. Third, the results revealed that speech/word measures were very common and these types of tests have a long tradition in the present field as commonly utilized outcome measures. Furthermore, the Hearing Handicap Inventory for the Elderly (HHIE) was identified as the most frequently used PT-S in this review. This result is in line with other similar findings in the research field.

Because the present study was conducted as the first step in the ICF Core Sets for HL project, the search limit was set to 2002-2007. Therefore, a relevant question to ask would concern the reliability of the present results after the year 2007. As a reliability check of the results, a prevalence search of the PT-S was conducted from 2008 to the second week of 2013 in MEDLINE® and CINAHL. PT-S is easy to identify in database searches, and in the CINAHL database, it is possible to exclude MEDLINE® records, avoiding duplicate results. The search applied the relevant search terms used in the study in combination with multiple search terms for SA questionnaires. In total, 11.5% of the hits contained articles that used some type of PT-S. Compared to the result in the present study (16.2%), this observation is an indication that PT-S are still rarely used for outcome measures within the audiological research field. Given that HHIE was the most frequently identified PT-S, a prevalence check was further conducted, utilizing the same limits. The result indicated that the HHIE had been used in 12 studies in MEDLINE® and once in CINAHL. Thus, the conclusion is that, although the HHIE might be a frequently used PT-S, the prevalence of the questionnaire in audiological studies is low.
When searching the EMBASE database (the first database searched in this review), a search filter related to *study type* was added to the search strategy. This restriction considerably limited the number of results. Unfortunately, when searching the other databases, it was realized that this limitation excluded records that were potentially relevant. Therefore, this search filter was removed when searching the other databases. Many studies, particularly non-experimental studies, were not indexed in the databases according to study type. EMBASE is a medical database, and many duplicates were found between EMBASE and other medical databases, such as MEDLINE®. It is not likely that many potentially relevant articles were excluded due to this limitation. Furthermore, the medical dimension of the research field of adult HL was well represented among the included studies, and therefore, it is not likely that this limitation affected the overall result considerably.

In study II, new linking rules were developed, especially with regard to audiological data. This development was necessary because many self-assessment questionnaires have a different structure compared to the established, generic HRQoL scales from which the established linking rules were originally developed. Several CS questionnaires used statements or questions based on a specific activity that occurs in a specific context, requiring interpretations of the underlying meanings. In study II, several statements expressed the term ‘hearing’ but referred to higher levels of auditory processing, such as ‘listening’ or ‘conversing’. If interpretations of underlying meanings had not been applied in reference to ‘hearing’, then a large amount of the data would have been misplaced in the ICF, i.e., placed in the body function component instead of the activities and participation section. The consequence would have been that due to a linguistic deficiency, bodily dimensions in ICF would have been that favoured instead of aspects of everyday activities.

### 6.3.2 The professional perspective

In the internet-based survey conducted in study III, the respondents had the opportunity to answer the questions in the Scandinavian languages or in English. This step was taken to enhance the response rate. The question was raised of whether this step would bias the results towards the Scandinavian countries. It is impossible to answer this question retrospectively. However, given that the study employed a stratified sampling procedure; it is not likely that the number of countries represented would have benefited from this language option. Nonetheless, it is possible that the number
of professions would have been lower if responding in the Scandinavian languages had not been an option.

Using a saturation check, the sample size in study III was deemed sufficient because the random 10% sub-sample revealed no additional 2\textsuperscript{nd}-level category codes. However, it is possible that additional 3\textsuperscript{rd}- or 4\textsuperscript{th}-level categories would have occurred with additional participants. Importantly, if that had been the case, the data would not have added any further health domains. Doing so is only possible at the 2\textsuperscript{nd}-level in the ICF because 3\textsuperscript{rd}- and 4\textsuperscript{th}-level categories are detailed specifications of the 2\textsuperscript{nd}-level categories.

6.3.3 The patient perspective

To obtain cultural variation, study IV was conducted in two countries that differed substantially from each other according to development status and ethnicity. This approach increased the probability of capturing the range of views of adults with HL.

In other ICF Core Sets projects, the sample size, according to the number of focus groups, was determined based on saturation principles\textsuperscript{18, 38, 39, 75}. When saturation of the results was reached, the results were considered valid, and it was determined that no further focus groups were required. In the present work, conducting a study based on these principles was not possible. It was impossible to coordinate the studies in the two countries simultaneously as would have been required to conduct data collection based on saturation principles. Furthermore, it was decided that it was not ethically or economically justifiable, to coordinate, recruit and conduct focus groups and then not analyze them. Additionally, it is debatable whether saturation enhances the quality of a study. The information obtained is always dependent on the specific individuals participating in the study and what they choose to reveal during the interviews. Instead, to enhance the quality of the present study, the four principles of trustworthiness (credibility [truth value], transferability [applicability], dependability [stringency], and conformability [neutrality]) were followed\textsuperscript{82, 184}.

South Africa has eleven official languages. Despite the inclusion criterion of being \textit{conversant in English}, some of the informants spoke English poorly and preferred to speak Afrikaans instead. In those cases, an interpreter was used during the individual interview, which might be considered a limitation of the study. However, after the interviews, a native Afrikaans speaker listened to the recordings and compared the interpretations made by the interpreter to the statements made by the informants.
and also checked the transcriptions. Only minor corrections were made in the transcripts as a result.

The decision to complement the focus groups with individual interviews for the South African data may be considered a weakness of the study. Questions may arise regarding richer or different data would have been obtained if the persons had been included in the groups in the first place. Although the analysis clearly showed that the individual interviews revealed information that was also rich to an extent similar to the focus group interviews, a focus group context might have disclosed other experiences.

One important procedure to enhance the validity of the present study is related to the method of analysis, the *seven-step linking procedure*. In previous ICF Core Sets projects, the first three steps of the meaning condensation methodology described by Kvale were used. The essence of that method is the condensation part (i.e., shortening the text while preserving the core) of the material until only the meaningful concept remains. Lastly, the meaningful concepts are linked to the ICF by applying the established linking rules. However, in examining the present material, it was obvious that there was a need for a method of analysis that also allowed for interpretations of the underlying meanings of the expressions. The rationale for this phenomenon has been discussed above in sections 3.6.3 and 5.2.2. The summative content analysis offered a solution to this problem because it reveals both obvious and more obscure aspects of the text. This analytical method was regarded as a strength of study II.

It is also necessary to discuss the concept of underlying meanings or latent interpretations. All of the latent interpretations conducted in the present studies used the field of adult HL as the starting point. Every researcher involved in all of the analyses had a distinctive knowledge of the target group, reflecting the interpretations. In my opinion, this knowledge is also necessary. It is impossible to analyze such texts without this knowledge because the risk of misinterpretations increases dramatically. Some may say that knowledge of the ICF is generic and that this knowledge can be applied to any target group. I, on the other hand, am very convinced that linking data to the ICF requires a sufficient knowledge of the functional issues in the target group and adequate knowledge of the ICF.
6.3.5 Evidence-based research approach

The interdisciplinary evidence-based approach to functioning and disability was applied as the overall research approach in the present thesis. This methodology is a consensus model that is based exclusively on research evidence. When merging the three perspectives, categories that are important in one perspective, although significant, may be ignored if they are not considered in the other two perspectives. Therefore, it is critical to emphasize the consensus part of the present model.

When analyzing the excluded categories, it appears that several body functions belonging to ‘Ch. 4, functions of the cardiovascular, haematological, immunological and respiratory system’ were addressed in the Researcher perspective. The reason for these results may be that several research investigations have addressed specific HL populations for whom these types of functions might be relevant. Concerning body structures (s), relevant structures such as eye structures or structures of the head and neck regions were exclusively addressed by professionals. Professionals most likely have detailed knowledge of the affected structures in relation to the health condition. It was also concluded in study IV that asking patients about affected body structures was difficult, given that patients noted obvious structures, such as the outer, middle, and inner ear. However, it was concluded that other structures might be affected due to the patients’ responses concerning the affected body functions, such as pain in the head and neck (b28010). Professionals also mentioned categories related to education (d810-d830). The regional distribution of professionals was high in study III, which might be an indication that areas where accessibility to educational systems for disability groups might be a concern were represented in the sample.

Further analysis of the excluded ICF categories in the environmental factors (e) component revealed interesting results (Table 7). Notably, only one category was addressed in the Researcher perspective but 24 were mentioned by patients. Of these, 12 categories belonged to human support or human attitudes (Ch. e3 and Ch. e4). One must bear in mind that the patient perspective was a qualitative study in which open-ended questions were addressed. The results were given contextually, as expected when someone reveals functional aspects of a health condition in everyday life. However, by addressing topics contextually, one also points exactly to the aspects of everyday life in which the influence of the context is vital to understanding a health condition such as HL. Whether our perspective (in research or in society as such) of disability mostly concerns the affected
individual is a very interesting question to ask (based on the fact that the environment as a research topic seems subordinated to other research topics; see also section 5.2) and to investigate more thoroughly in future research investigations. In our perceptions, is there a causal relationship between impairment and disability?

Table 7. Excluded ICF categories in the environmental factors (e) component. Results are only on the 2nd-level. Categories related to human support and attitudes are shaded.

<table>
<thead>
<tr>
<th>ICF Categories, 2nd level</th>
<th>Perspective</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Researcher</td>
</tr>
<tr>
<td>e110 Products or substances for personal consumption</td>
<td>-</td>
</tr>
<tr>
<td>e120 Products and technology for personal indoor and outdoor mobility and transportation</td>
<td>-</td>
</tr>
<tr>
<td>e135 Products and technology for employment</td>
<td>-</td>
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<tr>
<td>e155 Design, construction and building products and technology of buildings for private use</td>
<td>-</td>
</tr>
<tr>
<td>e165 Assets</td>
<td>-</td>
</tr>
<tr>
<td>c220 Flora and fauna</td>
<td>-</td>
</tr>
<tr>
<td>c225 Climate</td>
<td>-</td>
</tr>
<tr>
<td>c240 Light</td>
<td>-</td>
</tr>
<tr>
<td>c255 Vibration</td>
<td>-</td>
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<tr>
<td>e315 Extended family</td>
<td>-</td>
</tr>
<tr>
<td>e330 People in positions of authority</td>
<td>-</td>
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<tr>
<td>e340 Personal care providers and personal assistants</td>
<td>-</td>
</tr>
<tr>
<td>e345 Strangers</td>
<td>-</td>
</tr>
<tr>
<td>e350 Domesticated animals</td>
<td>-</td>
</tr>
<tr>
<td>e355 Health professionals</td>
<td>-</td>
</tr>
<tr>
<td>e360 Other professionals</td>
<td>-</td>
</tr>
<tr>
<td>e415 Individual attitudes of extended family members</td>
<td>-</td>
</tr>
<tr>
<td>e420 Individual attitudes of friends</td>
<td>-</td>
</tr>
<tr>
<td>e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members</td>
<td>-</td>
</tr>
<tr>
<td>e430 Individual attitudes of people in positions of authority</td>
<td>-</td>
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<tr>
<td>e450 Individual attitudes of health professionals</td>
<td>-</td>
</tr>
<tr>
<td>e460 Societal attitudes</td>
<td>-</td>
</tr>
<tr>
<td>e465 Social norms, practices and ideologies</td>
<td>-</td>
</tr>
<tr>
<td>e535 Communication services, systems and policies</td>
<td>-</td>
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<tr>
<td>e545 Civil protection services, systems and policies</td>
<td>-</td>
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<tr>
<td>e555 Associations and organizational services, systems and policies</td>
<td>-</td>
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<tr>
<td>e560 Media services, systems and policies</td>
<td>-</td>
</tr>
<tr>
<td>e570 Social security services, systems and policies</td>
<td>-</td>
</tr>
<tr>
<td>e590 Labour and employment services, systems and policies</td>
<td>-</td>
</tr>
</tbody>
</table>
7. Conclusions and contributions

The present thesis:

- Concludes that functioning and disability in adult HL is imbued with *interaction dimensions*. This is a significant conclusion and reinforces the need for audiological rehabilitation services that emphasize the aspects of everyday life of the health condition rather than the impairment or the loss solely.
- Introduces the *integrative model of functioning and disability in adults with HL*. Based on the ICF, it provides the audiological research and educational communities with a scientific base for functioning and disability in adults with HL.
- Introduces the *elaborated person-centered model of AR*. Originally introduced by Montano, this model integrates the integrative model of functioning and disability in adults with HL with the person-centered model of AR. It further illustrates the audiological rehabilitation interventions that are necessary to address functioning and disability in adults with HL.
- Highlights the *extensive amount of existing self-assessment questionnaires and speech measures* in the research field. It is concluded that there is most likely a low consensus on which measures to use when assessing different functional dimensions related to HL.
- Identifies the *problems in distinguishing between activities (a) and participation (p) in the ICF*. Most categories in the present research area are interactive, indicating that the environment is influential; thus, activities (as described in the ICF) are difficult to identify. Alternative views on activities and participation, based on Badley’s concepts of acts, tasks and societal involvement, are presented.
- Presents *topics* to consider in the *ICF revision process* based on the linking experiences in the present studies.
8. Svensk sammanfattning

Hörselnedsättning (HNS) är en hälsobetingelse som drabbat ca 360 miljoner vuxna människor över hela världen. Karaktäristiskt för HNS är att den drabbade upplever en reducerad förmåga att upptätta ljud klassade som normalt hörbara. Beroende på var i hörselsystemet skadan/skadorna är lokaliserade och graden av HNS, upplevs hörselproblemen olika vilket gör att gruppen vuxna med HNS är en förhållandevis heterogen grupp. Tidigare forskning har visat att det endast finns mycket svaga samband mellan grad av HNS och upplevt funktionshindrer. Istället menar man att det är aspekter kopplade till den dagliga livsföringen som avgör funktionshindrets karaktär för personer med HNS. En relevant fråga att ställa i sammanhanget är naturligtvis vad ”aspekter kopplade till den dagliga livsföringen” egentligen är. Inom forskningssamhället talar vi om funktion (det som fungerar) och funktionshindre (det som inte fungerar optimalt) när vi diskuterar detta. Beträffande funktion och funktionshindre i relation till vuxna med HNS har vi idag ingen heltäckande bild av vad det egentligen är. Olika studier har påvisat att många vuxna med HNS upplever t.ex. oro, nedstämdhet, ensamhet och isolering till följd av hörselnedsättningen. Det är också mycket vanligt att drabbade personer upplever kommunikationssvårigheter, dels när det gäller att uppfatta tal i bullriga miljöer, dels i konversationssammanhang med olika människor och i olika miljöer. Vi vet också att hörrapparater och andra tekniska hjälpmedel underlättar lyssnande och kommunikationen för personer med HNS. Även det stöd och support som omgivningen kan bistå med är viktiga komponenter i upplevelsen av funktionshindre.


ICF har använts förhållandevis mycket inom forskning sedan klassifikationen antogs 2001. Att knyta forskningsdata till ICF kallas att ”länka”
(eng. ”to link”). För att länka data till ICF krävs s.k. länkningsregler. Detta är regler som anger vilken typ av information som kan länkas samt hur själva länkningen skall gå till. Ett stort antal forskningsprojekt inom olika områden har använt etablerade länkningsregler i sin forskning och då identifierat en rad olika problem. Dessa problem har handlat t.ex. om hur man kan förstå vissa koder i klassifikationen, avsaknaden av relevanta koder eller att vissa ICF-koder verkar vara överlappande. Relationen mellan audiologi och ICF är förhållandevis lite utforskad. De få studier som använt etablerade länkningsregler har pekat på problem i klassifikationen som är relevanta ur ett audiologiskt perspektiv.

Syfte
Det övergripande syftet med avhandlingen är att: 1) undersöka, från ett ICF perspektiv, funktion och funktionhinder hos vuxna med hörselnedsättning genom att sammanfoga tre perspektiv (forskarperspektivet, de professionellas perspektiv och patientperspektivet), samt att 2) undersöka hur audiologiska data kan länkas till ICF.

Metod
I denna avhandling har fyra delstudier genomförts. Dessa har sammanfogats i ett huvudresultat som avser att besvara det första syftet. I samtliga delstudier har resultatet länkats till ICF och dessa länkningserfarenheter har använts för att besvara det andra syftet. För att få bred representation i det empiriska materialet har tre olika perspektiv företräts i de fyra delstudierna; forskarperspektivet (studie I och II), de professionellas perspektiv (studie III) och patientperspektivet (studie IV).

Målgruppen som ingått i avhandlingens olika studier var vuxna (≥18 år) med olika typer och grader av hörselnedsättning (från mild [≥20 dB HL] till mycket svår [≥95dB HL]. Personerna hade talat språk som primär språkmodalitet.

Sammanfattning av delstudierna I-IV (metod och resultat)
Studie I och II representerade forskarperspektivet. I studie I utfördes en systematisk litteraturstudie som syftade till att identifiera utfallsmått (det man mäter i en forskningsstudie, t.ex. en självskattningsskala för livskvalitet) som används inom audiologisk forskning (dvs. den forskning som rör aktuell målgrupp). Att just utfallsmått användes för att representera forskarperspektivet berodde främst på att de avspeglar forskningssyftet i en studie samt att utfallsmått går att knyta till ICF. Det ger därmed en bra
bild av det aktuella forskningsläget sett ur ICF-perspektiv. En databassökning genomfördes i nio olika databaser. Både medicinska och mer beteendevetenskapligt inriktade databaser användes. Sökningen var omfattande och krävde att resultatet delades in i två poler, pol I och pol II. Sammanlagt 122 studier inkluderas. En stor mängd utfallsmått hade använts i de 122 studierna; 246 olika identifierades i pol I och 122 i pol II. Måtten delades in i 10 olika instrumenttyper (t.ex. standardiserade, tekniska osv.). I båda polerna var det vanligt att olika typer av självskattningsskalor, både generiska och sjukdomsspecifika, hade använts. Det var också mycket vanligt med olika typer av taltest. Ett viktigt resultat var att de allra flesta utfallsmåtten endast kunde identifieras en gång eftersom endast ca 20 % av alla utfallsmått hade prevalens som översteg ett (1). En viktig konklusion av detta var att det verkar föreligga låg konsensus inom forskningsområdet om vilka mått som skall användas. Detta ställdes mot andra systematiska litteraturstudier riktade mot andra målgrupper (t.ex. depression). Inom dessa områden fanns ett par utfallsmått som hade använts extra mycket och som var vanliga inom forskningen på den specifika målgruppen. Någon sådan tendens kunde inte ses inom forskningsområdet vuxna med HNS.

I studie II länkades samtliga utfallsmått till ICF för att kunna tolka innehörden av dem. Etablerade länkningsregler användes men även nya utvecklades, som anpassats för audiologisk data. Även den relativa frekvensen av förekomsten av olika ICF-kategorier beräknades. Sammanlagt användes 285 ICF-kategorier i länkningsarbetet men de flesta av dessa användes sparsamt. Resultatet visade att hela ICF-klassifikationen (alla komponenter) hade använts i länkningsprocessen med 111 kategorier som tillhörde komponenten ”kroppsfunktion”, 19 som tillhörde ”kroppssstruktur”, 117 klassades som ”aktiviteter och delaktigheter” och 37 som ”omgivningsfaktorer”. ICF-koden ”Att lyssna”, en kategori som tillhör aktivitet och delaktighetsdomänen i ICF, användes mest i länkningsprocessen (35,4%). En viktig konklusion i studie II var att utfallsmått som avser att mäta ”kommunikationsförmåga” hamnade förhållandevis långt ner (plats elva) i hierarkin när samtliga ICF-kategorier rankades efter förekomst. Eftersom kommunicationsproblem är mycket vanligt i målgruppen antogs att det föreläg en diskrepans mellan vad man å ena sidan forskar om, gentemot vad personer själva upplever vara problematiskt med hörselnedsättningen.

Studie III var en tvärsnittsstudie som utfördes i form av en internetsurvey. Denna studie fokuserade på de professionellas perspektiv och därför
var de som arbetade med målgruppen på olika sätt föremål för undersökningen. Ett frågeformulär konstruerades som bestod av sju öppna frågor. Frågorna handlade om funktion och funktionshinder sett ur ett ICF-perspektiv. Respondenterna uppmunrades att ange faktorer av olika karaktär, såsom kroppsliga, mentala samt aktivitet- och delaktighetsrelaterade. Respondenterna uppmunrades även att ange faktorer i omgivningen som upplevdes ha inflytande på deras patienters upplevelse av funktion och funktionshinder. Innan analys av resultatet genomfördes en stratifierad samplingsprocedur av svarande respondenter. De stratiferades i enlighet med två variabler; vilket land de uppgav sig tillhöra samt vilken profession de hade. Detta resulterade i en urvalsgrupp bestående av 63 respondenter ifrån 27 olika länder. Dessa tillhörde nio olika professioner vars resultat analyserades och användes i studien. Resultatet visade att de flesta ICF-kategorier som använts relaterade till omgivningsfaktorer (31,2%), följt av aktivitet och delaktighetsfaktorer (28,9%). Att kommunicera genom att ta emot talade meddelanden (d310), angavs ofta av de professionella som relevant för målgruppen (74,6%) liksom stödjande produkter och teknik för kommunikation (e1251) (82.5%), självförtroende (b1266) (71.4%) samt strukturer i mellanörat (s250) (55,6%). I studie III uppmärksammades att många kategorier som använts i länkningsprocessen var interaktiva. Interaktion tolkades därför vara ett viktigt koncept i relation till vuxna med HNS.

Studie IV var en kvalitativ studie som i huvudsak använde fokusgruppmetodik. Studien utfördes i Sydafrika och i Holland. Totalt ingick 36 informanter i studien med varierande art och grad av HNS, hemspråk (i Sydafrika) och etnicitet (i Sydafrika). Totalt sett användes 143 ICF-kategorier inom kroppsfunctioner, kroppsstrukturer, aktiviteter och delaktigheter samt omgivningsfaktorer i länkningsprocessen. Liksom i studie III var kategorier relaterade till aktivitet och delaktighet (34%) samt omgivningsfaktorer (33%) mest förekommande. I denna studie utvecklades också en speciell analysmetod kallad ”the seven-step linking procedure” eftersom det inte fanns någon adekvat analysmetod tillgänglig. Metoden byggde på etablerade tekniker för innehållsanalys samt de länkningsregler anpassade för audiologisk data som togs fram i studie I.

Huvudresultat I – funktion och funktionshinder hos vuxna med hörselnedsättning
När resultaten av samtliga delstudier sammanfogats, visade det sig att funktion och funktionshinder hos vuxna med HNS är ett multidimension-
ellt fenomen. När det gäller kroppsliga och mentala aspekter handlar HNS dels om hörselsystemet och om olika hörselfunctioner, dels om minne, uppmärksamhet, känslor, energinivåer, kognition, smärta och komorbida tillstånd såsom tinnitus och yrsel. Beträffande aktivitet och delaktighetsaspekter visade det sig att nästan samtliga ICF-kategorier handlade om interaktion. Resultatet visade att aspekter såsom att se, att lyssna, att kommunicera, att gå, att interagera med personer i omgivningen (både kända och främlingar), familjerelationer, arbetsliv, samhällsliv, rekreation och fritid, religion och andlighet var relevanta för målgruppen. De omgivningsfaktorer som ansågs relevanta var kopplade till teknik (både allmän och speciellt anpassad för kommunikation), design av och teknik i offentliga byggnader, ljud i omgivningen (såsom buller), stöd och support av familj, vänner, kollegor och liknade, attityder hos den egna familjen samt olika hälsosystem, hälsoservice och hälsopolicies.

Resultatet sammanfogades och diskuterades i modellen ”the integrative model of functioning and disability in adults with HL” (figur 9) som problematiserar resultatet i relation till ICF. Resultatet sattes också in i ett audiologiskt rehabiliteringsperspektiv, där interventioner identifierades som är nödvändiga att införliva för att adressera funktion och funktionshinder.

Huvudresultat II – länkning av audiologisk data till ICF
funktioner av specifika hörselstrukturer såsom funktion av trumhinnan. Ett viktigt fynd i avhandlingen relaterade till uttrycket: *omfattas inte av ICF*. I flera studier gick det inte att länka aspekter som uppfattades som relevanta för målgruppen. Detta handlade t.ex. om hur andra människor beter sig (t.ex. i kommunikativa sammanhang) och att det har en inverkan på upplevd funktion och funktionshinder för personer med hörselnedsättning.

Resultatet av länkningen diskuterades i relation till hur föreliggande avhandling kan bidra i ICF:s revideringsprocess.
Acknowledgments

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Appendix 1

Linking rules specifically designed for audiological data

These linking rules should be used in combination with the coding guidelines for the ICF\textsuperscript{209} (p.219) and the established ICF linking rules\textsuperscript{30, 32} and are especially applicable for audiological data. These rules can be used when linking statements, words, clinical measures or other types of audiological data.

1. When linking outcome measures, read the original article (when available) to understand the authors’ intentions with regard to the measurement and to identify any latent variables.

2. Make latent interpretations (identifying the underlying meaning) of concepts when linking statements to avoid mislinking (i.e., linking to the wrong components and categories).

3. First, identify the appropriate component when linking meaningful concepts; second, identify the appropriate category/categories.

4. When linking statements, identify the primary concepts for guidance in what a statement is meant to convey. A primary concept describes the main activity/main focus of a statement. An example of this concept is as follows: ‘I can’t hear what my mom says over the phone’, where the primary concept is ‘can’t hear what my mom says’.

5. If it is impossible to determine the primary concept and to select the correct categories to link, use multiple linking, i.e., choose several categories. For example, it may be difficult to distinguish whether a bus is the context (e1200) or whether the statement concerns using public transportation (d4702).

6. Distinguish between hearing, listening, comprehending and communicating (conversing). The second-level categories (or third-level categories related to the second-level designations) can be used when linking hearing-related concepts. For example, hearing (b230) can be used for descriptions of impairments in the hearing functions, listening (d115)
can be used when describing the intentional part of ‘hearing’ but when no speech comprehension is present, communicating with-receiving-spoken messages (d310) can be used when linking speech comprehension (i.e., the receiving portion of communication) and conversation (d350) can be used when linking the bi-directional component of communication.

7. Noisy public ‘arenas’ (e.g., restaurants, grocery stores, large open offices, etc.) should be coded with the codes for both ‘noise’ (e2501) and ‘acoustics’ (e150) if not otherwise specified.

8. Assign ‘coping’ as a personal factor (pf) if the meaningful concept is not judged as a communication strategy; in those cases, use d3602.

9. When an expressed hearing health condition has an ICD-10 code (e.g., presbycusis or sensorineural HL), use the designation of ‘health condition’ (hc). When statements use expressions such as ‘hearing impairment’, use the category code b230.

10. The concept ‘watching TV’ (or similar) should be coded with both the category code d110, watching and with d310, communicating with-receiving-spoken messages.

11. Several concepts commonly addressed in audiology should be assigned as ‘not covered’ (nc). For example, these concepts can include ‘visual cues’, ‘home’, ‘hearing aid usage (frequency)’, ‘time aspects’, and the ‘number of hearing aids’.

12. When linking clinical measures, consider both the aim and the test procedure when choosing the appropriate ICF categories.
References


12. Berget S, Karlsson C. Självskattningsskalor och länkning till ICF: en litteraturstudie [Self assessment questionnaires and linking to ICF]: Degree project, Örebro University, School of Health and Medical Sciences, Sweden; 2010.


54. de Kleijn-de Vrankrijker MW. On health, ability and activity: comments on some basic notions in the ICF. Response on some issues raised by Nordenfelt. *Disability and Rehabilitation* 2006;28(23):1475-6.


57. Escorpizo R, Finger M, Glässel A, Cieza A. An international expert survey on functioning in vocational rehabilitation using the


67. Gagné J-P, Jennings MB. Audiologic rehabilitation intervention services for adults with acquired hearing impairment. In: Valente


125. McCoy SL, Tun PA, Cox LC, Colangelo M, Stewart RA, Wingfield A. Hearing loss and perceptual effort: Downstream


127. McPherson K. What are the boundaries of health and functioning -- and who should say what they are? *Disability and Rehabilitation* 2006;28(23):1473-4.


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