

# The ICF Core Sets For Hearing Loss Project: International Expert Survey On Functioning and Disability of Adults with Hearing Loss using the International Classification of Functioning, Disability and Health (ICF)

**Sarah Granberg<sup>1,2</sup>, De Wet Swanepoel<sup>3,4,5</sup>, Ulrika Englund<sup>1</sup>, Claes Möller<sup>1</sup>, and Berth  
Danermark<sup>1</sup>**

<sup>1</sup> Audiological Research Centre, Örebro University Hospital, School of Health and Medical Sciences/Swedish Institute for Disability Research, Örebro University, Örebro, Sweden

<sup>2</sup> HEAD Graduate School, Linköping University, Linköping, Sweden

<sup>3</sup> Department of Speech-Language Pathology and Audiology, University of Pretoria, Pretoria, South Africa

<sup>4</sup> Ear Sciences Centre, School of Surgery, the University of Western Australia, Nedlands, Australia

<sup>5</sup> Ear Science Institute Australia, Subiaco, Australia

**Correspondence:** De Wet Swanepoel, Department of Speech-Language Pathology and Audiology, University of Pretoria, Pretoria, South Africa, 0002

E-mail: dewet.swanepoel@up.ac.za

## **Abbreviations:**

ICF	International Classification of Functioning, Disability and Health
HL	Hearing Loss
WHO	World Health Organization

## **Abstract**

*Objective:* To identify relevant aspects of functioning, disability and contextual factors for adults with Hearing Loss (HL) from hearing health professional perspective summarized using the ICF classification as reference tool. *Design:* Internet-based cross-sectional survey

using open-ended questions. Responses were analyzed using a simplified content analysis approach to link concept to ICF categories according to linking rules. *Study sample:* Hearing health professionals (experts) recruited through email distribution lists of professional organizations and personal networks of ICF Core Set for Hearing Loss steering committee members. Stratified sampling according to profession and world region enhanced the international and professional representation. *Results:* 63 experts constituted the stratified sample used in the analysis. 1726 meaningful concepts were identified in this study resulting in 209 distinctive ICF categories, with 106 mentioned by 5% or more of respondents. Most categories in the Activities & Participation component related to communication while the most frequent environmental factors related to the physical environment such as hearing aids or noise. Mental functions, such as confidence or emotional functions were also frequently highlighted. *Conclusions:* More than half (53.3%) of the entire ICF classification categories were included in the expert survey results. This emphasizes the importance of a multidimensional tool, such as the ICF, for assessing persons with hearing loss.

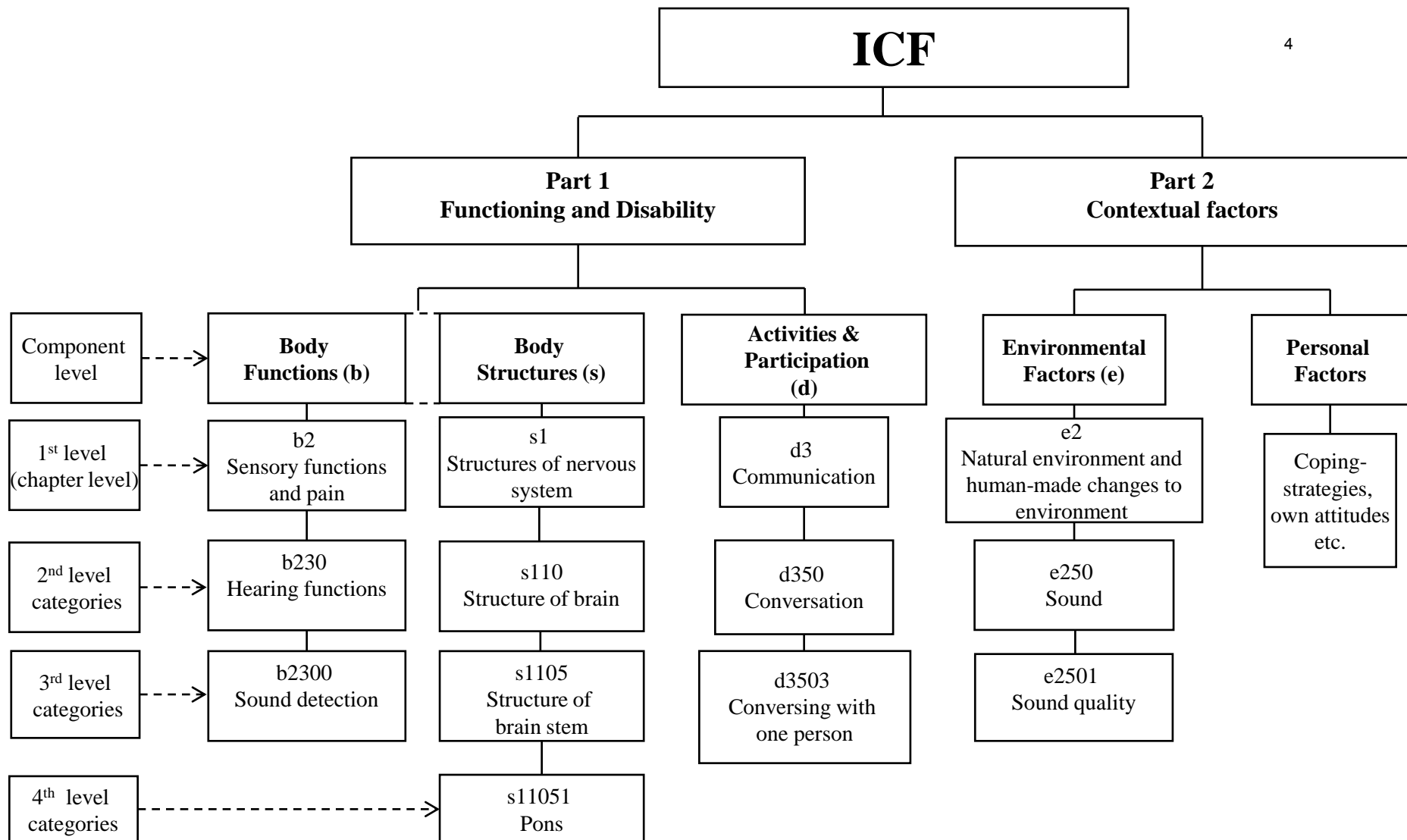
**Keywords:** hearing loss, audiology, ICF, ICF Core Sets, hearing health professionals, expert survey

## Introduction

In 2008, an international project was initiated aiming to develop a multidimensional tool for assessing 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 hearing loss, which resulted in ambiguities of *what* to measure when assessing the functioning and health in the target group (Danermark et al., 2010). The tool, ‘The ICF Core Sets for Hearing Loss (HL)’ should be based on the numerical category codes of the International Classification of Functioning,

Disability and Health (ICF) (WHO, 2001a) and be applicable both in clinical encounters and in research investigations. Built on a multidimensional view of functioning and disability, ICF is especially suitable to obtain this type of health information because it recognizes the individual as one part in a larger context. It states that *internal influences*, such as the body, can influence daily living but also *external influences*, such as persons or things in the environment, can facilitate or hinder daily living. Both internal and external influences are recognized as important and highly influential features for functioning, disability and health.

These theoretical assumptions are further operationalized into a classification with numerical category codes. The main features of the classification are the four *components* (with their associated abbreviation), in line with these theoretical assumptions 1) Body functions (b) & Body structures (s), 2) Activities & Participation (d), 3) Environmental factors (e) and, 4) Personal factors. *Body functions* are defined as ‘physiological functions of body systems (including psychological functions)’, *Body structures* as ‘anatomical parts of the body such as organs, limbs and their components’, *Activities* as ‘execution of a task or action by an individual’, *Participation* as ‘involvement in a life situation’, *Environmental factors* as ‘the physical, social and attitudinal environment in which people live and conduct their lives’ and *Personal factors* as ‘the particular background of an individual’s life and living’ (WHO, 2001a pp. 10, 17). The ICF has a hierarchical structure with category codes at different levels. Each new level is a more detailed specification of the previous level (Fig. 1). The Personal factors component currently lack specific categories due to the great social and cultural variance associated with this component and therefore personal factors are unable to be specifically coded (WHO, 2001a pp. 8).



**Fig 1.** The hierarchical structure of ICF with examples from each level is 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 adopted from Granberg et al. in press.

The procedure and design of the ‘ICF Core Sets for HL project’, stems from the time the ICF classification was initially adopted. When the ICF was internationally accepted in 2001, the World Health Assembly urged the member states to use ICF in research investigations, surveillances etc. (WHO, 2001b). However, it was almost immediately recognized that this was a complicated task, due to the comprehensiveness of the classification. The ICF has 1424 categories to choose from, which requires extensive experience and familiarity with the classification system and categories before it can be used. To facilitate the clinical and research use of the ICF, the World Health Organization (WHO) initiated the ‘Core Sets projects’ (ICF Research Branch, 2012; Stucki & Grimby, 2004).

A Core Set is a set of the ICF categories of specific relevance to a target group, diagnosis or target area. When evaluating which ICF categories are specifically relevant for a group or an area, the WHO has developed a rigorous three-phase procedure for this task. The objective of the first phase is to collect evidence, from different perspectives, of areas of functioning and health that are considered relevant for the group or target area. The second phase consists of a consensus conference where all the evidence from the first phase is evaluated and a first version of the Core Sets is agreed upon. In the third phase, the Core Sets are implemented into the target field and validated. Two Core Sets are developed for each area, a Comprehensive and a Brief Core Set. The Comprehensive Set can be used in multiprofessional settings while the Brief, derived from the Comprehensive, is suitable for single clinical encounters or in research investigations. The procedure is thoroughly described in Danermark et al. (2010). Following this outlined procedure, the ‘ICF Core Sets for HL’ members have now completed the second phase of the project (Danermark et al., in press). In the first phase, four scientific studies were conducted, representing three different perspectives; the Researcher perspective,

the Patient perspective and the Professional perspective (Granberg et al., in press; Granberg et al., in press). The present article focuses on the ‘Professional perspective’ or ‘Expert perspective’.

Professionals in the area of audiology are often referred to as *hearing health professionals* but the designation for these professionals vary across the world. Worldwide, many audiologists work with adults who have hearing loss, but other common professionals are otolaryngologists, audiological physicians or hearing aid dispensers. However, many professionals, such as psychologists, engineers, speech-language pathologists, social workers or teachers of the deaf, with training in other related fields may work in the field of audiology and have valuable experiences of the target group. As such, a broad definition for professionals involved in hearing health was employed for the purpose of this study. The perspective of hearing health professionals has been of interest in former scientific studies such as Menièrès disease management, audiological rehabilitation activities and cerumen management (Johnson et al., 2013; Smith et al., 2005; White et al., 1996). However, to our knowledge, no former study within the audiological field targets the perspective of hearing health professionals in relation to functioning of target groups they might work with.

The objectives of this study were:

1. To identify relevant aspects of functioning, disability and contextual factors of adults with hearing loss from the perspective of hearing health professionals, working in the field of adult hearing loss, and
2. To summarize these aspects using the ICF classification as a reference tool

## **Methods**

### ***Study design***

The study employed an internet-based cross-sectional survey using a stratified sampling procedure.

### ***Recruitment procedure and study population***

Participants (professionals) were included in the email distribution of the questionnaire using a number of techniques including the following: International and national professional organizations around the world were contacted and requested to distribute the questionnaire to their members. The national and international personal network of ICF Core Set for Hearing Loss steering committee members' contacts were included (Danermark et al., 2010). Finally prominent published authors in the field of audiology were included (through a concurrent systematic review, Granberg et al., in press). Potential participants were invited to participate in the study via the email distribution lists of relevant international and national professional organizations around the world.

The population of experts across the six WHO world regions (Africa, the Americas, Eastern Mediterranean, Europe, South-East Asia and Western Pacific) were required to meet the following criteria for inclusion in the survey: a professional with involvement with adult patients who have hearing loss; work experience of a minimum of 5 years; competent to answer the questionnaire in English, Swedish, Danish or Norwegian.

Recruitment of experts was performed from May until September 2011. A randomized stratified sampling procedure was used to select experts according to WHO region and profession. In each WHO region an expert from each profession was randomly selected for inclusion to ensure representation of regional and professional perspectives. The initial

stratified sample responses were assessed for saturation (see below) to determine whether a second sample of experts across WHO regions and professions would be required.

### ***Survey instrument***

The internet-based questionnaire applied in the expert survey consisted of three parts. The first part included an informed consent letter, which the participant was required to sign before continuing. The second part included a section for demographic and work-related information and the third part included seven open-ended questions on the perceived functioning, environmental and personal factors associated with adult hearing loss. The open-ended questions were based on the ICF components but the participants did not see the ICF labels embedded in the questions (Table 1). Participants were instructed to list only aspects

**Table 1.** Questions applied in the expert survey

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- 1 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)
  - 2 Reflect on your adult clients with hearing loss; in your experience, ***which parts of their body*** do you believe are affected? (i.e. directly or indirectly affected by the hearing loss/consequences of the hearing loss), please be as specific as possible.
  - 3 Reflect on how your adult clients with hearing loss ***describe their daily life***; in your experience, ***how does the hearing loss affect the things they can and cannot do*** (in general situations)?
  - 4 Reflect on your adult clients with hearing loss and how they describe ***helpful and supportive*** things ***in their environment*** and where they work and live; in your experience, ***what and/or whom do they find helpful and supportive?***
  - 5 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 whom makes it difficult for them?***
  - 6 Reflect on your adult clients with hearing loss; in your experience, ***what personal characteristics help*** them to handle their hearing loss?
  - 7 Reflect on your adult clients with hearing loss; in your experience, ***what personal characteristics make it difficult*** for them to handle their hearing loss?



related to hearing loss, use one line for each answer and give short and precise answers.

Answers were not limited in word-length. Example answers were given using “vision loss” as the example condition for each question. The survey was conducted in English although the opportunity was given respondents to answer the questionnaire in Danish, English, Norwegian or Swedish.

To enhance the reliability of the survey questionnaire, prior to the main investigation, a pilot study was conducted on eight participants, including the professions of audiologist, engineer, physician, social worker and physiotherapist, to ensure the instructions, questions and examples were phrased appropriately and that the completion time was less than 30 minutes.

All questionnaires were completed in less than 30 minutes and only minor changes were made to examples provided based on pilot study respondent feedback.

### ***Data collection procedure***

The pool of possible expert survey respondents received an email, either from national and international professional organizations or from the ICF Core Set for Hearing Loss administrative office directly, with details about the expert survey and a web link to the online questionnaire.

### ***Data analysis***

All responses from the sampled expert respondents were translated (“linked”) to the ICF based on established linking rules (Cieza et al., 2002; Cieza et al., 2005; Granberg et al., in press). The objective of the linking process is to translate concepts found in the experts’ responses into the most appropriate ICF categories. A simplified content analysis approach was followed in linking the responses to ICF categories. The respondents provided statements that in some cases required a more traditional content analysis with *meaningful concepts*

condensed from statements (Graneheim & Lundman, 2004), e.g. ‘*they have a hard time with conversations in noisy situations*’ (‘conversations’, ‘noisy situations’). In many cases, however, single words or short phrases were used requiring no real content analysis. In those cases, the single word or phrases was considered as the meaningful concept. Information that was not possible to assign to ICF categories were labeled *pf* (personal factors), *nd* (not definable), *nc* (not covered by ICF) or *hc* (health condition). In some cases only the component (i.e. *b*, *s*, *d* or *e*) could be identified from a statement but no category chapter could be assigned. In such cases the concept was coded as *nc* followed by the component e.g. *e-nc*. Two ICF trained researchers (principal investigator and a steering committee member) reviewed the responses together and conducted the linking accordingly to increase the reliability of the linking procedure. If there was a disagreement, it was discussed and if agreement could still not be reached, a third ICF trained researcher was consulted.

The relative frequencies of the linked ICF categories (first, second, third and fourth level) were calculated. If an ICF category was assigned repeatedly to the answer of one respondent, it was counted only once to avoid bias. As in previous studies (Escorpizo et al., 2011; Scheuringer et al., 2010) a cut-off of 5% (rounded up to the nearest %) was chosen for the frequencies of the linked ICF categories as reported by experts (a full list of all linked ICF categories are provided in a supplementary appendix available in the online version of the journal. Please find this material with the direct link to the article at:

[http://www.informaworld.com/\(DOI number\)](http://www.informaworld.com/(DOI number))). A saturation check on the linked ICF categories was conducted after analysis of the initial random stratified sample of participants from all represented professions across each WHO region. A randomized subset, 10% of the total number of included respondents, was excluded to investigate if saturation was reached for the remaining 90% of the sample. This was evaluated by a) documenting if there were any

second level ICF categories omitted or b) if the number of second 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 second level categories and no changes in the second level categories. This was an indication that saturation had been reached and therefore no further respondent data was sampled or linked.

## **Results**

There were 218 experts who completed the web-based questionnaire. After the stratified randomized sample was drawn across the professions in each WHO region, 63 expert surveys were analysed.

### ***Characteristics of expert respondents***

Study characteristic indicators of the sample are included in Table 2. The majority (58.8%) was older than 50 years of age and had more than 15 years of professional experience (63.5%). Experts represented 27 countries across all six WHO regions and were from a range of professional groups who worked with adults with hearing loss.

### ***ICF categories***

Expert responses mentioned 1726 meaningful concepts. Of these, 1566 (90.7%) were linked to ICF categories (first to fourth level). The remaining concepts (n=161; 9.3%) could not be coded to the ICF because they were attributed to ICF 'pf, personal factors' (n=59; 3.4%), or were identified as 'nc, not covered by ICF' (n=24; 1.4%), 'nd, not definable' (n=8; 0.5%), or 'hc, health condition' (n=5; 0.3%). There was a number of concepts (n=65; 3.8%) that could be linked to a component but not to a specific chapter or category (e.g. labeled as *e-nc*). The majority of the ICF categories were linked to Environmental factors (n=489; 31.2%) and

**Table 2.** Study characteristics of participants (n=63)

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<b>Sex (%):</b>	
Females	55.6 (n=35)
Males	44.4 (n=28)
<b>Age (Ave; SD; Range):</b>	52.9 ( $\pm$ 11 SD; Range 34-76)
<b>Profession (%):</b>	
Audiologist	27.0 (n=17)
Ear-Nose-Throat physician	22.2 (n=14)
Other	19.0 (n=12)
Audiological physician	6.3 (n=4)
Engineer	6.3 (n=4)
Speech-Language-Pathologist	6.3 (n=4)
Psychologist	4.8 (n=3)
Social worker	3.2 (n=2)
Teacher for the deaf/special pedagogue	3.2 (n=2)
Hearing Aid dispenser	1.6 (n=1)
<b>Working area (%):</b>	
Clinical	58.7 (n=37)
Mixed	14.3 (n=9)
Education	12.7 (n=8)
Research	9.5 (n=6)
Management	1.6 (n=1)
Other	1.6 (n=1)
Sales	1.6 (n=1)
<b>WHO- region (%):</b>	
Europe	49.2 (n=31)
Africa	20.6 (n=13)
Americas	17.5 (n=11)
Western Pacific	6.3 (n=4)
Eastern Mediterranean	4.8 (n=3)
South East Asia	1.6 (n=1)
<b>Professional experience (%):</b>	
>21 years	47.6 (n=30)
11-15 years	20.6 (n=13)
5-10 years	15.9 (n=10)
16-20 years	15.9 (n=10)

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Activities & Participation (n=453; 28.9%) components followed by Body functions (n=376; 24.0%) and Body structures (n=248; 15.8%) components.

There were 209 distinctive ICF categories and approximately half (n=106) of these were mentioned by 5% or more of respondents. Tables 3 and 4 provide a breakdown of the ICF category codes (first to fourth level) mentioned by 5% or more of the respondents.

Considering these ICF categories, Activities & Participation category codes (d) represented 30.2% (n=32) of all linked ICF code categories followed by Environmental factors (e) 29.2% (n=31), Body functions (b) 23.6% (n=25), and Body structures (s) 17.0% (n=18).

When analyzing from a broader perspective, the results reveal that (in total, by 5% or more of the respondents) six of the nine ICF Activities & Participation chapters were represented, all five of the Environmental factors chapters were covered, two of the eight Body functions chapters were used, and three of the eight Body structures chapters were covered in the linking process (Fig 2). This corresponds to 53.3% of the entire classification, as there are 30 chapters in total in the ICF.

As stated previously, the personal factors component lack categories, however, experts mentioned concepts such as ‘stress’, ‘coping’, ‘isolation’, ‘empowerment’ and ‘acceptance’ which were all assigned as personal factors (pf).

## **Discussion**

To our knowledge this is the first survey exploring the perspective of hearing health professionals when investigating functional aspects related to adults with hearing loss. When collecting evidence for the Core Sets it is valuable to embrace knowledge and evidence, not only from researchers or clients, but also from those who work closely with the target group, and thereby have a solid knowledge of functioning and disability experienced by the target group. Moreover, professionals have met *many* clients with a *variety* of problems and the

**Table 3.** Relative frequencies of category codes from the Activities & Participation (d) and Environmental factors (e) components mentioned by  $\geq 5\%$  of the respondents.

(d)	Activities & Participation	Frequency (%)	(e)	Environmental factors	Frequency (%)
d310	Communicating with-receiving-spoken messages	74.6	e1251	Assistive products and technology for communication	82.5
d350	Conversation	57.1	e2501	Sound quality	82.5
d3602	Using communication techniques	55.6	e1250	General products and technology for communication	50.8
d115	Listening	49.2	e150	Design, construction and building products and technology of buildings for public use	42.9
d9205	Socializing	42.9	e2500	Sound intensity	41.3
d3	Communication	38.1	e250	Sound	39.7
d850	Remunerative employment	34.9	e240	Light	33.3
d760	Family relationships	33.3	e1151	Assistive products and technology for personal use in daily living	31.7
d9	Community, social and civic life	31.7	e355	Health professionals	30.2
d3504	Conversing with many people	30.2	e310	Immediate family	28.6
d3600	Using telecommunication devices	25.4	e155	Design, construction and building products and technology of buildings for private use	25.4
d110	Watching	15.9	e5800	Health services	23.8
d7	Interpersonal interactions and relationships	12.7	e4	Attitudes	17.5
d830	Higher education	12.7	e5600	Media services	17.5
d815	Preschool education	11.1	e325	Acquaintances, peers, colleagues, neighbors and community members	15.9
d820	School education	11.1	e315	Extended family	15.9
d825	Vocational training	11.1	e1501	Design, construction and building products and technology for gaining access to facilities inside buildings for public use	15.9
d3503	Conversing with one person	9.5	e340	Personal care providers and personal assistants	14.3
d740	Formal relationships	7.9	e3	Support and relationships	12.7
d810	Informal education	7.9	e360	Other professionals	12.7
d9202	Arts and culture	6.3	e1150	General products and technology for personal use in daily living	11.1
d910	Community life	6.3	e460	Societal attitudes	11.1
d355	Discussion	6.3	e320	Friends	9.5
d8	Major life areas	6.3	e1551	Design, construction and building products and technology for gaining access to facilities in buildings for private use	9.5
d730	Relating with strangers	6.3	e410	Individual attitudes of immediate family members	7.9
d930	Religion and spirituality	6.3	e580	Health services, systems and policies	6.3
d320	Communicating with-receiving-formal sign language messages	4.8	e5550	Associations and organizational services	4.8
d7203	Interacting according to social rules	4.8	e5350	Communication services	4.8
d8451	Maintaining a job	4.8	e350	Domesticated animals	4.8
d340	Producing messages in formal sign language	4.8	e1650	Financial assets	4.8
d4503	Walking around obstacles	4.8	e5	Services, systems and policies	4.8
d920	Recreation and leisure	4.8			

**Table 4.** Relative frequencies of category codes from the Body Functions (b) & Body Structures (s) component mentioned by  $\geq 5\%$  of the respondents.

(b)	Body functions	Frequency (%)	(s)	Body structures	Frequency (%)
b1266	Confidence	71.4	s250	Structure of middle ear	55.6
b152	Emotional functions	65.1	s260	Structure of inner ear	52.4
b1560	Auditory perception	46.0	s110	Structure of brain	41.3
b1265	Optimism	42.9	s240	Structure of external ear	41.3
b1300	Energy level	38.1	s2600	Cochlea	31.7
b1264	Openness to experience	31.7	s710	Structure of head and neck region	31.7
b1260	Extraversion	28.6	s1106	Structure of cranial nerves	23.8
b230	Hearing functions	28.6	s11001	Temporal lobe	12.7
b2300	Sound detection	28.6	s2602	Semicircular canals	9.5
b1646	Problem-solving	19.0	s230	Structures around eye	9.5
b2302	Localization of sound source	19.0	s220	Structure of eyeball	9.5
b2303	Lateralization o sound	17.5	s210	Structure of eye socket	9.5
b1263	Psychic stability	14.3	s720	Structure of shoulder region	9.5
b126	Temperament and personality functions	14.3	s2601	Vestibular labyrinth	9.5
b1301	Motivation	12.7	s2502	Ossicles	7.9
b1262	Conscientiousness	11.1	s7104	Muscles of head and neck region	7.9
b167	Mental functions of language	11.1	s2500	Tympanic membrane	6.3
b1400	Sustaining attention	9.5	s7	Structures related to movement	4.8
b2301	Sound discrimination	7.9			
b140	Attention functions	6.3			
b164	Higher- level cognitive functions	6.3			
b144	Memory functions	6.3			
b1	Mental functions	6.3			
b28010	Pain in head and neck	4.8			
b2400	Ringings in ears or tinnitus	4.8			

Body Functions	Body Structures	Activities & Participation	Environmental Factors
Ch.1 Mental functions	Ch.1 Structures of nervous system	Ch.1 Learning and applying knowledge	Ch.1 Products and technology
Ch.2 Sensory functions and pain	Ch.2 The eye, ear and related structures	Ch.2 General tasks and demands	
Ch.3 Voice and speech functions	Ch.3 Structures involved in voice and speech	Ch.3 Communication	Ch.2 Natural environment and human-made changes to environment
Ch.4 Functions of the cardiovascular, haematological, immunological and respiratory systems	Ch.4 Structures of cardiovascular, immunological and respiratory systems	Ch.4 Mobility	Ch.3 Support and relationships
Ch.5 Functions of the digestive, metabolic and endocrine systems	Ch.5 Structures related to the digestive, metabolic and endocrine systems	Ch.5 Self-Care	
Ch.6 Genitourinary and reproductive functions	Ch.6 Structures related to the genitourinary and reproductive systems	Ch.6 Domestic life	Ch.4 Attitudes
Ch.7 Neuromusculoskeletal and movement- related functions	Ch.7 Structures related to movement	Ch.7 Interpersonal interactions and relationships	Ch.5 Services, systems and polices
Ch.8 Functions of the skin and related structures	Ch.8 Skin and related structures	Ch.8 Major life areas	
		Ch.9 Community, social and civic life	

**Fig 2.** Presentation of all the chapters (first level) in ICF. The chapters covered in the present study (by  $\geq 5\%$  of the respondents) are shadowed, corresponding to 53.3% of the entire classification.



experiences they will share are presumably based on these indicators. Professionals are an important group when assessing issues related to functioning, disability and health within a specific target group and therefore the expert perspective is one of the studies underlying the development of a ICF core set (Danermark et al. 2010).

This survey embraces an international perspective including experts across different professions involved with adults with hearing loss from all six WHO regions (Africa, the Americas, Eastern Mediterranean, Europe, South-East Asia and Western Pacific). Although the present study sample is smaller (n=63) than some previous Core Set studies (Gradinger et al., 2011; Scheuringer et al., 2010; Weigl et al., 2004) the results reveal a large variety of categories. The fact that 53.3% of the entire classification, from all components, was used in the linking process is evidence of the necessity for a multidimensional tool like ICF when assessing data emanating from a representative international expert perspective. It is necessary to map both internal and external influences to establish important features of functioning and disability of a target group.

Using a data saturation check, the sample size was deemed sufficient since a random 10% sub-sample revealed no additional second level category codes. However, it is possible that more third and fourth level categories would have occurred with additional participants but the data would not have added any *further* body functions or body structures, life areas or external influences on functioning and disability because this is only possible at the second level in ICF. Given the hierarchical structure in ICF, the third and fourth levels provide more *detailed* specifications of second level categories.

The study sample included a variety of professional grouper who work with adults with hearing loss (>9) across 27 countries from the six WHO regions. In previous WHO ICF Core Set expert survey projects, an acknowledged limitation has been the shortage of respondents representing developing countries, especially the African region (Escorpizo et al., 2011; Gradinger et al., 2011; Scheuringer et al., 2010). In the present study the African region was best represented after the Europe region demonstrating the international validity of the sample.

Altogether, of the categories mentioned by 5% and more of the respondents, 32 different ICF categories (first to third level) were identified in the Activities & Participation (d) component. Most categories belonged to chapter 3, *Communication* (31.3%). Problems related to communication are known to have a significant impact on the daily life of adults with hearing loss (e.g. Dalton et al., 2003; Héту et al., 1988; Karlsson Espmark & Hansson Scherman, 2003; Pryce & Gooberman-Hill, 2012; Scarinci et al. 2009; Hickson et al. 2014). Experts in this study emphasized the receiving portion of communication, i.e. difficulties in comprehending speech. Speech comprehension is on a high level of the auditory processing hierarchy and involves hearing, listening and language knowledge (Kiessling et al., 2003; Thibodeau, 2007). In relation to speech recognition, speech comprehension requires the person to attach meaning to the message and no single audiological measure has been identified in this area (Granberg et al., 2013, in press).

The category *Using communication technique* (d3602) was also acknowledged by many experts as important to facilitate effective communication (55.6%). This category was used when linking active problem- focused communication strategies, i.e. strategies to enhance communication like lip-reading, as opposed to more emotional reactions like withdrawal

(Hallberg & Carlsson, 1991). Especially in sensorineural hearing losses, hearing aids are not capable of restoring normal hearing and, hence, add-on interventions targeting communication enhancement are necessary. The results from the present study clearly support this. However, Hawkins (2005) conducted a systematic review on the effectiveness of counseling-based adult aural (AR) group rehabilitation programs. The author concluded that the evidence for adult AR programs were ‘reasonably good’ but not ‘overwhelming’ despite the convincing clinical experience and beliefs about its benefits. According to the author, one possible explanation for the mediocre evidence for the effectiveness of AR programs was connected to the lack of well-controlled studies and the limited outcome measures included in the studies. This is an important finding and an indication that the field needs more programs and interventions with robust designs that are tested and scientifically proven to benefit clients. Examples of group and individual communication programs evaluated in high quality interventions developed after this review are e.g. the ‘Active Communication Education Program’ (ACE) by Hickson et al. (2007) and the adaptive Listening And Communication Enhancement (LACE™) program by Sweetow and Sabes (2006). The development of these types of standardized AR programs are important because results from effectiveness studies might be the only valid argument when planning for and implementing modern hearing health care, especially in clinical practices relying on resource allocation as is the case for many public hearing health care facilities around the world.

Several categories also belonged to chapter 8, *Major life areas* (28.1%). The category *Remunerative employment* (d850) was mentioned by more than a third (34.9%) of experts as it represents an area of significant importance in the lives of adults. This is not surprising because people with hearing loss are established as a vulnerable group in the labour market with overrepresentation in early retirement (Danermark & Coniavitis Gellerstedt, 2004),

increased emotional distress due to misinterpretation of external information at work (Morata et al., 2005) and experiencing lack of control in the work environment (Kramer et al., 2006).

Notably, the majority of the identified categories in the Activities & Participation (d) component require *interaction* either by direct communication or by engagement such as school education, work, in social or in the community life. Hence, limitations or restrictions in interacting might be the *main* issue for persons with hearing loss according to the experts in this survey. This aspect is more than just ‘communication’ and touches deeply human existential issues. This hypothesis is further reinforced by the fact that the Body function category *Emotional functions* (b152) were prevalent among the respondents (65.1%). Several emotions were expressed such as ‘depressed’, ‘irritated’, ‘fear of serious diseases’, ‘anxiety’, ‘embarrassment’, ‘loneliness’, ‘insecurity’ and ‘feeling of loss’. One important explanation for the high prevalence of b152 could be the close connection between interactions and emotions. According to sociological theory, maintaining social bonds is crucial for social life. Threatening of the social bonds, as can occur when the interaction is interrupted by a hearing loss, may generate negative emotions (Scheff, 1990). Emotions have been reported as the most consequential outcome of interaction (Danermark, 1998; Mets & Bowers, 1994).

The entire *Body functions* component included 25 categories identified from the expert responses (reported by  $\geq 5\%$  of the respondents) in the present study. All categories belonged either to chapter 1, *Mental functions* (72.0%), or to chapter 2, *Sensory functions and pain* (28.0%). Almost two thirds (28%) of the body functions categories were connected to *Temperament and personality functions* (b126). In ICF this category is explained as ‘*General mental functions of constitutional disposition of the individual to react in a particular way to situations, including the set of mental characteristics that makes the individual distinct from*

*others'* (WHO, 2001a, pp. 50). The ability to develop confidence (b1266) and optimism (b1265) were mentioned frequently by the experts and is viewed as important abilities when managing a hearing loss. Several experts also mentioned '*optimism*' as an important *personal characteristic* when handling a hearing loss. According to ICF, personal characteristics are labeled as *personal factors* (pf), a component currently without categories (WHO, 2001a). There are, however, difficulties in distinguishing between certain categories in ICF (here: b126 Temperament and personality functions) and personal factors due to unstandardized and insufficient description of *personal factors* in ICF (Threats, 2007). Previous authors have also recognized the need for standardization of the pf component (Geyh et al., 2011; Stephens et al., 2001; Scarinci et al. 2009).

*Hearing functions* (b230), and related third level categories, are obvious categories when assessing functional aspects of hearing loss. All linkable third level categories (see Cieza et al., 2002; Cieza et al., 2005) related to hearing functions except b2304 *Speech discrimination* were used. Speech discrimination in ICF is described as '*Sensory functions relating to determining spoken language and distinguish it from other sounds*' (WHO, 2001a pp. 65). None of the experts made statements that were interpreted to fit this category. Though, several experts expressed issues considered in the analysis as speech recognition. In accordance with an earlier preparatory study in this project, speech recognition was linked as b230 *Hearing functions* (Granberg et al., in press).

The component *Environmental factors* revealed 31 categories acknowledged as significant by  $\geq 5\%$  of the experts. The eight most commonly reported ICF categories were from chapter 1 and 2 and related to the physical environment including products and technology. Across all categories, two categories from this component were most prevalent. These two were e1251

*Assistive products and technology for communication* and e2501 *Sound quality*. The first one was used when linking hearing aids, cochlear implant or other hearing assistive devices while the latter was used when respondents expressed noise as an important environmental barrier.

The probable reason for the high prevalence of assistive devices is their status as primary interventions (McArdle et al., 2005). Amplification is of significant importance for many adults with hearing loss as they compensate well for reduced hearing sensitivity. Hearing aid and other assistive devices are prerequisite for many subsequent interventions such as communication strategy programmes or hearing aid counseling programmes (Abrams et al., 2002; Chisolm et al., 2004; Saunders & Forsline, 2012). Even though assistive devices provide sophisticated solutions for amplifying residual hearing, background noise remains one of the most significant barriers to hearing aid use and satisfaction (Kochkin, 2000; Wong et al., 2003). Expert responses corresponded with this phenomenon with 82.5% indicating this category.

Another commonly represented category was from chapter 3 *Support and relationships*. *Health professionals* (e355) and *Immediate family* (e310) were reported as environmental factors influencing functioning. Immediate family is an important environmental factor for adults with hearing loss because they form the closest communication partners in which the effects of the hearing loss become evident (Scarinci et al. 2009; Meyer, Hickson & Fletcher, 2014; Hickson et al., 2014). These communication partners are also very important in the decision process to pursue intervention and in the subsequent acceptance (Manchaiah et al., 2012). Interestingly, according to a previous preparatory study in this project, the ICF chapter 3, *Support and relationship* was highlighted as a chapter with low linking frequency, indicating that in research, this is not a common topic (Granberg et al., in press). That study concluded that there might be a discrepancy between the problems of the target group and the

target of the researchers. The result of the present study reinforces the importance of empirical evidence and the need for studies where this focus is explored.

Several *e-nc* were identified in this study where respondents indicated that ‘how other people behaved’ had an impact on the person with hearing loss, reinforcing the interaction dimension of hearing loss. Example of this could be: ‘other people are mumbling’, ‘other people may cover their mouth’, ‘other people may speak from a distance’ and ‘other people may be rude about the person’s not hearing well’. Although of significance for the target group, unfortunately, ‘behavior of other people’, a category deemed to be separated from *e3 Support and relationships* or *e4 Attitudes*, is not part of ICFs environmental factors component and could thereby not be coded.

All the Body structures mentioned related to ear (including vestibular structures) and ear related brain functions except for some mention of eye structures and head/neck/shoulder structures. Interestingly, structures around the eyes were mentioned by several of the respondents. This may relate in part to the role of eyes in speech reading for adults with hearing loss. Recent evidence has also however indicated that there is an increasing dual sensory impairment i.e. vision and hearing loss among older adults (Wittich et al., 2012). Structures of the head, neck and shoulders were mentioned by experts as probable secondary presentations related to hearing loss. Individuals may experience increased stress and fatigue when living with a hearing loss related to greater cognitive effort exerted in everyday listening situations (Stewart & Wingfield, 2009). Recent evidence also indicates that adults with hearing loss have an increased risk for emotional distress and restrictions in social engagement (Gopinath et al., 2012).

## Conclusions

In total, 1726 meaningful concepts were identified in this study resulting in 209 distinctive ICF categories (first to fourth level) mentioned by the experts as relevant categories of functioning, disability and contextual factors of adults with hearing loss. Approximately half of these categories (106) were mentioned by 5% or more of the respondents. Most categories mentioned in the Activities & Participation component involve interaction, and thus, *interaction* is an important concept, beyond communication, identified for adults with HL. The most frequent external factors influencing functioning and disability mentioned by the experts were related to the physical environment such as hearing aids (e1251) or noise (e2501). According to the experts, internal factors, such as confidence (b1266) or emotional functions (b152) were also highly influential in functioning and disability. Altogether, 53.3% of the entire ICF classification was represented in the present study emphasizing the importance of a multidimensional tool, such as the ICF, when assessing lived experiences of a health condition such as adult hearing loss.

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Supplementary appendix. All category codes identified in the present study.

## Supplementary Appendix. All category codes identified in the present study.

### (b) Body functions

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b1	Chapter 1, Mental functions
b117	Intellectual functions
b126	Temperament and personality functions
b1260	Extraversion
b1261	Agreeableness
b1262	Conscientiousness
b1263	Psychic stability
b1264	Openness to experience
b1265	Optimism
b1266	Confidence
b1300	Energy level
b1301	Motivation
b1302	Appetite
b140	Attention functions
b1400	Sustaining attention
b1401	Shifting attention
b1402	Dividing attention
b144	Memory functions
b152	Emotional functions
b1560	Auditory perception
b164	Higher-level cognitive functions
b1643	Cognitive flexibility
b1646	Problem-solving
b167	Mental functions of language
b1670	Reception of language
b1671	Expression of language
b210	Seeing functions
b230	Hearing functions
b2300	Sound detection
b2301	Sound discrimination
b2302	Localization of sound source
b2303	Lateralization of sound
b2304	Speech discrimination
b2351	Vestibular function of balance
b2400	Ringling in ears or tinnitus
b2401	Dizziness
b2801	Pain in body part
b28010	Pain in head and neck
b3	Chapter 3, Voice and speech functions
b3101	Quality of voice
b515	Digestive functions
b7	Chapter 7, Neuromusculoskeletal and movement-related functions
b760	Control of voluntary movement functions
b770	Gait pattern functions
b7800	Sensation of muscle stiffness

Supplementary appendix. All category codes identified in the present study.

## **(s) Body Structures**

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s1	Chapter 1, Structures of the nervous system
s110	Structure of brain
s1101	Structure of midbrain
s11001	Temporal lobe
s1105	Structure of brain stem
s1106	Structure of cranial nerves
s210	Structure of eye socket
s220	Structure of eyeball
s230	Structures around eye
s240	Structure of external ear
s250	Structure of middle ear
s2500	Tympanic membrane
s2501	Eustachian canal
s2502	Ossicles
s260	Structure of inner ear
s2600	Cochlea
s2601	Vestibular labyrinth
s2602	Semicircular canals
s3	Chapter 3, Structures involved in voice and speech
s330	Structure of pharynx
s530	Structure of stomach
s7	Chapter 7, structures related to movement
s710	Structure of head and neck region
s7104	Muscles of head and neck region
s720	Structure of shoulder region
s7202	Muscles of shoulder region
s7702	Muscles

## **(d) Activities & Participation**

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d1	Chapter 1, Learning and applying knowledge
d110	Watching
d115	Listening
d155	Acquiring skills
d160	Focusing attention
d170	Writing
d210	Undertaking a single task
d220	Undertaking multiple tasks
d230	Carrying out daily routine
d240	Handling stress and other psychological demands
d2401	Handling stress
d3	Chapter 3, Communication
d310	Communicating with - receiving - spoken messages
d315	Communicating with - receiving - nonverbal messages
d3150	Communicating with - receiving - body gestures
d320	Communicating with - receiving - formal sign language messages
d330	Speaking
d335	Producing nonverbal messages

Supplementary appendix. All category codes identified in the present study.

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d3350	Producing body language
d340	Producing messages in formal sign language
d345	Writing messages
d350	Conversation
d3501	Sustaining a conversation
d3503	Conversing with one person
d3504	Conversing with many people
d355	Discussion
d3551	Discussion with many people
d3600	Using telecommunication devices
d3601	Using writing machines
d3602	Using communication techniques
d4	Chapter 4, Mobility
d4503	Walking around obstacles
d460	Moving around in different locations
d470	Using transportation
d4702	Using public motorized transportation
d4751	Driving motorized vehicles
d620	Acquisition of goods and services
d650	Caring for household objects
d660	Assisting others
d7	Chapter 7, Interpersonal interactions and relationships
d710	Basic interpersonal interactions
d720	Complex interpersonal interactions
d7203	Interacting according to social rules
d730	Relating with strangers
d740	Formal relationships
d750	Informal social relationships
d7500	Informal relationships with friends
d760	Family relationships
d7603	Extended family relationships
d770	Intimate relationships
d8	Chapter 8, Major life areas
d810	Informal education
d815	Preschool education
d820	School education
d825	Vocational training
d830	Higher education
d840	Apprenticeship (work preparation)
d845	Acquiring, keeping and terminating a job
d8450	Seeking employment
d8451	Maintaining a job
d850	Remunerative employment
d855	Non-remunerative employment
d860	Basic economic transactions
d865	Complex economic transactions
d870	Economic self-sufficiency
d9	Chapter 9, Community, social and civic life
d910	Community life
d9100	Informal associations

Supplementary appendix. All category codes identified in the present study.

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d9102	Ceremonies
d920	Recreation and leisure
d9202	Arts and culture
d9204	Hobbies
d9205	Socializing
d930	Religion and spirituality

## **(e) Environmental factors**

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e1150	General products and technology for personal use in daily living
e1151	Assistive products and technology for personal use in daily living
e120	Products and technology for personal indoor and outdoor mobility and transportation
e1200	General products and technology for personal indoor and outdoor mobility and transportation
e125	Products and technology for communication
e1250	General products and technology for communication
e1251	Assistive products and technology for communication
e130	Products and technology for education
e135	Products and technology for employment
e1351	Assistive products and technology for employment
e140	Products and technology for culture, recreation and sport
e145	Products and technology for the practice of religion and spirituality
e150	Design, construction and building products and technology of buildings for public use
e1501	Design, construction and building products and technology for gaining access to facilities inside buildings for public use
e1502	Design, construction and building products and technology for way finding, path routing and designation of locations in buildings for public use
e155	Design, construction and building products and technology of buildings for private use
e1551	Design, construction and building products and technology for gaining access to facilities in buildings for private use
e165	Assets
e1650	Financial assets
e2201	Animals
e240	Light
e250	Sound
e2500	Sound intensity
e2501	Sound quality
e3	Chapter 3, Support and relationships
e310	Immediate family
e315	Extended family
e320	Friends
e325	Acquaintances, peers, colleagues, neighbors and community members
e330	People in positions of authority
e335	People in subordinate positions
e340	Personal care providers and personal assistants
e345	Strangers
e350	Domesticated animals
e355	Health professionals
e360	Other professionals
e4	Chapter 4, Attitudes
e410	Individual attitudes of immediate family members

Supplementary appendix. All category codes identified in the present study.

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e415	Individual attitudes of extended family members
e420	Individual attitudes of friends
e425	Individual attitudes of acquaintances, peers, colleagues, neighbors and community members
e430	Individual attitudes of people in positions of authority
e460	Societal attitudes
e5	Chapter 5, Services, systems and policies
e515	Architecture and construction services, systems and policies
e520	Open space planning services, systems and policies
e535	Communication services, systems and policies
e5350	Communication services
e540	Transportation services, systems and policies
e555	Associations and organizational services, systems and policies
e5550	Associations and organizational services
e560	Media services, systems and policies
e5600	Media services
e565	Economic services, systems and policies
e570	Social security services, systems and policies
e575	General social support services, systems and policies
e5750	General social support services
e580	Health services, systems and policies
e5800	Health services
e5802	Health policies
e585	Education and training services, systems and policies
e590	Labour and employment services, systems and policies
e5900	Labour and employment services