



## Results of the Testing of the ESCAP/WG Extended Question Set on Disability

*This report contains the authors' opinions and does not necessarily reflect those of the corresponding agencies*

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## Introduction

The United Nations Economic and Social Commission for Asia and the Pacific (UN ESCAP) has undertaken a set of projects to improve disability statistics in the Asia/Pacific region. The first project (2004 – 2006) focused on Improving Disability Statistics and Measurement; introduced the International Classification of Functioning, Disability and Health (ICF) as a framework for the development of questions on disability and functioning; discussed question design and testing for census to measure disability through censuses, and produced a Disability Statistics Training Manual. The current UN Development Account project (2008 – 2010) entitled ‘Improvement of Disability Measurement and Statistics in Support of Biwako Millennium Framework and Regional Census Programme’, is a follow up to the earlier project and focuses on the cognitive and field testing of an extended set of disability questions for surveys.

The aim of the project is to further promote better disability data collection by developing standard measurement tools, assessing and ensuring cross-national comparability, and improving national technical capacity. The project takes into account individual country needs in the region while contributing to the ongoing global initiatives on disability statistics. Its focus is on designing standard question sets for surveys, and conducting pilot tests and post-pilot test data analyses, thus providing an empirical basis for establishing standard survey measurement for disability data collection. Among several partners such as the World Health Organization (WHO), the Economic Commission for Europe (ECE), an active partner was the Washington Group on Disability Statistics (WG) which has the main objective of developing comparable disability measures for international use.

Disability measurement and statistics have received growing attention over the last two decades. This report looks at the measurement of disability within self-report surveys of disability. The traditional set of questions asking household members (or a single household respondent) whether they are ‘deaf, blind, crippled or mentally retarded’ have been shown to be limited and biased as measures of disability.<sup>1</sup> Globally, the number of disabled people identified using such an approach has been low and has allowed governments to largely ignore the problem of disability or relegate the ‘problem’ to provision of medical care and medical rehabilitation and if these fail to cure the problem, to institutionalize the person.<sup>2</sup> Though somewhat dated, the UN Statistics Division (UNSD) maintains an international disability database that includes many countries that have used questions that reflect the medical model of disability as depicted above, and illustrates the resulting very low prevalence rates they have generated. (See: <http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp>). The outcome of these disparate efforts at the collection of disability data on an international basis is that disability statistics internationally are not comparable. The lack of comparability coupled with the rise of the disability rights movement and a growing awareness that people with disabilities are not a

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<sup>1</sup> See UN Statistical Division’s Disability database (DISTAT) at [www.un.org/disability](http://www.un.org/disability); Schneider, 2009, Schneider, Dasappa, Khan and Khan, 2009; Loeb, Eide & Mont, 2007);

<sup>2</sup> Dr Izabel Maior. Rehabilitation Physician, Brazil. Personal communication, April 2008. Bangkok, Thailand

minority to be relegated to marginalization and institutionalization, not to mention the recent ratification of the Convention on the Rights of Persons with Disabilities (CRPD) have all lead to the need for improved measures of disability.

The WG has been tasked by the UN's Statistical Commission to develop new measures of disability suitable for censuses and surveys. Early in its work the WG realized the stated purposes for the collection of disability data would require: 1) different approaches to the measurement of disability and therefore, 2) the development of different questions and question sets. The WG chose as its main purpose for the collection of data on disability the equalization of opportunities between those with and those without disabilities. Questions developed therefore were intended to identify persons who are at greater risk than the general population of experiencing limited social participation because of difficulties with certain basic actions. The work of the WG has been ongoing with the support of organization such as ESCAP and the World Bank, since February 2002 when the first meeting was held in Washington DC. Currently, the completed work for census questions includes a Short Set (WG SS) comprising of 6 questions on functioning.

The recommended short set of questions will identify the majority of the population with difficulties in functioning in basic actions, that is, difficulties that have the potential to limit independent living or social integration if appropriate accommodation is not made. For each of the six domains of functioning (basic actions) included in this set, the WG SS asks a single question about difficulties people experience in that domain. The questions are as follows:

Because of a health problem:

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

The following scaled response options apply to all questions:

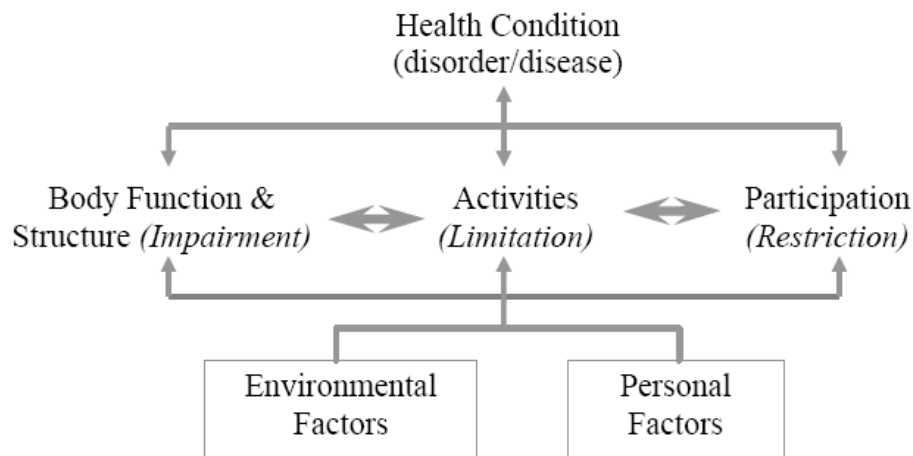
- a. No - no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

The underlying framework of the WG is the WHO's International Classification of Functioning, Disability and Health also known as the ICF (WHO, 2001) which aims to provide a common language for describing disability and functioning (see ICF model below).

The basic principles set out in the ICF include:

- Universalism of functioning and disability where disability is understood to be part of everyone's life to some degree and at some point in their life course
- Describing profiles of functioning rather than relegating individuals to categorization based on the type of impairment (e.g. a blind person, a deaf person, a person with a physical disability)
- Understanding disability as a complex phenomenon including aspects of the individual, the environment and processes of interaction between these.

**Figure 1: The ICF Model**



According to the ICF and the social model, disability arises out of the interaction between functional limitations and an unaccommodating environment (Altman, 2001; Hughes & Paterson, 1997; Shakespeare & Watson, 1997). In the ICF people are not identified as having a disability based upon a medical condition but rather according to a detailed description of their functioning within various domains: Body Function and Structure, Activities, and Participation. (Mont & Loeb, 2010) If the environment is designed for the full range of human functioning and incorporates appropriate accommodations and supports, then people with functional limitations would not be “disabled” in the sense that they would be able to fully participate in society. Interventions are thus not only at the individual level (e.g., medical rehabilitation) but also at the societal level, for example, the introduction of universal design to make infrastructure more accessible, inclusive education systems, and community awareness programs to combat stigma.

The ICF “provides a consistent and complete conceptualization of disability” (Leonardi et al., 2006) and accordingly, the ICF definition of disability focuses on the negative aspects of the interaction (measured as impairments affecting the body; activity limitations affecting an individual’s actions or behavior or participation restrictions affecting a person’s experience of life) between an individual (with a health condition) and that individual’s contextual – personal and environmental – factors.

The basic actions described by the WG SS are located at the level of *activities* and describe a set of single limitations or difficulties experienced by individuals at the person-level. These will define a sub-

population that is, because of the difficulties they experience, at risk for limited involvement in social activities and other life activities. These basic domains merely identify the population at risk and do not provide information on whether the risk has been realized as disability or not. The analysis of activity limitation status (as defined by the WG SS) in relation to a range of other variables such as employment status, educational attainment and school attendance, social inclusion and access to services (health, education, rehabilitation and basic amenities) will then provide the full picture of disability in a holistic manner. In addition, a series of questions on environmental barriers and facilitators would complement the picture and provide information as to where interventions need to focus. Thus, the connection between limitations in basic domains and limitations and restrictions in more complex domains (e.g. life activities in the ICF) is done through analysis.

In addition to the different levels of functioning, the ICF provides a classification of environmental factors that would allow for a clear description of the way in which disability is generated through the interaction of the person and the context in which she or he lives. In order to effectively and accurately describe disability, it is important to document and measure these different aspects of functioning. This task, however, becomes complex when data are collected at the population level using self reported responses to questions.

The first aim of population measures of disability is to ensure that the people with difficulties are clearly identified. The second aim then is to ensure that the experiences of these people are described accurately, reliably and comprehensively, including aspects such as employment status, school attendance and social inclusion, to name a few.

Considering that the identification of the population at risk of experiencing limited social involvement as described above has been the focus of the WG as well as agencies such as ESCAP, a review of approaches to measuring disability showed that the best approach was to ask people about basic activities that they undertake on a daily basis. These are felt to be least influenced by social, cultural and geographical factors (e.g. all cultures know about and have terms for walking, seeing, communicating, hearing, etc.) and most likely to provide reliable and comparable measures.

Impairments, on the other hand, are difficult to capture on self-report (unless they are obvious such as an amputation or spinal cord injury) and are affected to a large extent by access to health care services. The lack of access to health care services means that many of these impairments are not recognized by the individual. This results in a significant difference in reporting of impairments between countries that offer good access to health care services compared to those with poor access.

The measurement of participation restrictions (as per the ICF) represents an additional possibility for identifying people with disabilities. However, since this level of functioning assumes the interaction of the individual and the context in which they live, it is open to wide cultural variability and hence poor comparability. In addition, it seems (although this requires further analysis) that very few people who have participation restrictions do not also have difficulties in basic actions.

Thus a measure of basic actions difficulty provides what seems to be the best starting point for measuring disability and identifying people at risk of limited social involvement. The link between

disability and participation can be made during the analysis of the data collected. Once disability has been defined in the population using the WG SS, data already collected on, for example, employment, education, and social & political participation, can be cross tabulated to determine the degree on social involvement achieved by those with disability compared to those without, giving a measurement of the gap in access to opportunities between people with and without disabilities (based on responses to the WG SS and extended sets). The aim of further question development by the WG through the Budapest Initiative and ESCAP's present project, is to ensure that all these different aspects of disability are effectively measured in surveys.

The WG acknowledges that the six questions (WG SS) do not capture all people at risk of experiencing the disadvantage associated with disability, and has therefore embarked upon the development of an extended set of questions that goes into greater depth on the same 6 domains covered by the short set of questions – including questions on functioning with and without assistance or assistive technologies. The extended set of questions also includes more domains such as learning, affect, pain and fatigue; and captures information on the age at onset and impact of the difficulty on peoples' lives.

The following matrix depicts the extended set modules being developed - dark purple represent the existing six questions, added columns representing additional domains and rows depict the different aspects of those domains.

### Washington Group/Budapest Initiative/UNESCAP Activities and Workplan

Row	Questionnaire Topic/Type	Basic Activity Domains										Complex Activity Domains			
		Vision (1)	Hearing (1)	Mobility	Communication	Cognition/remembering	Upper Body	Learning/understanding	Affect	Pain	Fatigue	ADL/IADL	Getting Along with People	Life Activities	Participation in Society
Capacity	Short Set Single Questions (1)						d	a				d			
	Extended Set Multiple Questions (1)					c			c	c	c	b			
Performance	Use of Assistive Devices Micro-E (2)														
	Functioning with Assistance, Micro-E (2)														
5	Age at Onset														
6	Cause														
7	Duration														
8	Impact											---	---	---	---
9	Meso-Environment (3)														
10	Macro-Environment (4)	To be obtained through other sources, not personal survey data collections													
	ICF Chapter Reference - Activities/Participation	ICF-1	ICF-1	ICF-4	ICF-3	ICF-1,2	ICF-4	ICF-1	ICF-2	(5) See Note below	ICF-5,6	ICF-7	ICF-8	ICF-9	

NOTES:

1. Measurement is WITHOUT the use of assistive devices or other help WITH THE EXCEPTION OF VISION (glasses/lenses) and HEARING (hearing aids). These are both measured WITH the use of assistive devices and thus do NOT represent true measures of Capacity. As such, Extended Set multiple questions are captured under Performance (Row 4). NB - SEVERITY is captured in response categories.
2. Micro environment - technical and personal assistance that follows the person wherever they go (e.g. wheelchair, eye glasses, personal attendant). ICF Environment Chapter 1 & 3
3. Meso environment - the environment beyond the person (e.g. transportation infrastructure, accessibility, service provision at local level, attitudes of others). ICF Environment Chapters 2 & 4  
Meso environmental questions may also be non-domain specific.
4. Macro environment - that which affects a whole country, such as policies and legislation, general societal attitudes and practices. ICF Environment Chapter 5  
Macro-environmental questions are NOT domain specific.
5. Pain and Fatigue are not obvious functional domains (nor are they in the ICF) however they are included here as domains.
  - a) one question for children / one question for adults
  - b) available for special populations
  - c) No mention of functioning without AD - includes Intensity (How often?)
  - d) Upper body short set question is the ADL short set question

This report focuses on the results of the cognitive and field testing of the questions that were developed for the extended set in the Asia and the Pacific region, through funding provided to ESCAP by the UN Development Account. The aim of the testing is to recommend the best set of extended questions for surveys. These would be questions that clearly identify the correct individuals as intended by the question; that are understood and interpreted easily and that generate similar trends across a number of countries (e.g. increasing difficulty with increasing age).

The aim of this report is to present the evidence on the performance of the WG/BI/ESCAP extended set of questions which has been collected in two phases. The first phase includes a series of cognitive testing interviews in 10 countries in Asia and the Pacific, North America and one in Africa. These interviews provide a rich source of information on how people understand and interpret the questions. The analysis of these interviews determined the revisions to the questions undertaken, in preparation for the field testing of the extended question set. The second phase presents the findings of the field test in the 6 Asia-Pacific project countries using the revised questions. Each chapter presents domain specific results for these two phases of the research.

The report also discusses the methodology used in each of the phases, and describes how best these data from the extended set of questions can be utilized in national statistics.



## METHODS CHAPTER

### Introduction

In developing survey questions as a measurement for disability, a notable challenge is to account for the numerous ways that respondents across differing cultures, languages and socio-economic conditions might interpret and process those questions. The challenge is further heightened because disability is a particularly complex concept, involving numerous and varied meanings, attitudes and types of experiences across individuals and socio-cultural sub-populations. Because social context and cultural circumstances inform the way respondents interpret, consider and ultimately respond to questions, these differences can lead to systematic measurement error in survey data. Rather than interpreting differences in survey estimates as response process bias, they can be wrongfully construed as real differences in the phenomena of study.

To ensure comparability of measures across socio-cultural groups, it is necessary to understand the degree of interpretive and response process variation across groups. Survey questions can then be redesigned, or measurement cut-off points can be revised to account for the variation. For this reason, question evaluation studies, particularly those intended for a heterogeneous populations, should address the following line of inquiry:

- How do respondents understand each survey question?
- Do respondents understand the questions differently?
- Does each of the questions mean the same in all the languages that it is asked?
- Does each question mean the same in all of the cultures that it is asked?
- In processing each question, do all respondents recall information and construct an answer with similar processes?
- What other sub-groups (e.g. gender, age, socio-economic status, and health or disability status) should be considered for comparability?
- To what extent are survey data elicited from each question a true representation of the intended phenomena of study?
- In what ways is the picture distorted because the questions do not accurately capture the intended construct?

In successfully addressing these issues, a question evaluation study can provide rich understanding of how questions perform. In turn, this understanding allows designers the opportunity to improve measurement validity and increase equivalence or, at least, to provide documentation regarding the appropriate interpretation of the resulting data.

The WG/ESCAP question evaluation project is based on this line of inquiry and is reflected in the project's mixed method design. Specifically, to address this goal, a 2-step mixed method approach for question evaluation was utilized. First, 143 total semi-structured, qualitative cognitive interviews were conducted in the participating countries in order to understand the ways in which each question performed. The specific objectives of the cognitive interviewing component were to identify the following interpretive patterns: 1) respondents' understandings of what specific questions were asking, 2) calculation and other processes used by respondents to formulate their answers to the questions, and 3) types of response error problems.

Based on the analysis of those interviews, follow-up probe questions were developed and placed on the field test questionnaire. Each country then conducted approximately 1000 standardized survey interviews drawn from a random sample. Resulting survey data from the follow-up probe questions were used to examine the extent of valid and non-valid interpretive themes. The probe questions were also pivotal in developing item thresholds for respondents' level of disability. Finally, the multi-national design allowed us to evaluate cross-cultural equivalence of the questions, specifically, whether particular interpretive patterns were more likely to occur in particular countries or demographic sub-group.

Findings from the cognitive interviewing component, then, established hypotheses to be examined in the second component – the field test. While the cognitive interviewing study determined what the specific patterns of interpretation were, the field test was used to understand the extent to which those patterns existed. More specifically, it was used to examine the extent of problematic patterns, such as unintended interpretations, and whether those patterns occurred more often in particular subgroups. In addition, various analytic and modeling strategies were employed to evaluate the quality of the information produced by the follow-up probe questions. Overall, the mixed-method approach was a powerful technique that provided valuable insight into question performance.

The remainder of this chapter will more thoroughly describe the two components of the mixed-method approach and will detail the specific protocols as they were carried out in the six countries.

## **Component 1: Cognitive Interviewing**

The general purpose of cognitive testing is to investigate how well questions perform when asked of survey respondents, that is, if respondents understand the questions according to their intended design and if they can provide accurate answers based on that intent. As a qualitative method, the primary benefit of cognitive interviewing is that it provides rich, contextual insight into the ways in which respondents 1) interpret a question, 2) consider and weigh out relevant aspects of their lives and, finally, 3) formulate a response based on that consideration. As such, cognitive interviewing provides in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and how it ultimately serves (or fails) the scientific goal. Findings from a cognitive interviewing project typically lead to recommendations for improving a survey question, or results can be used in post-survey analysis to assist in data interpretation.

Traditionally, cognitive testing is performed by conducting in-depth, semi-structured interviews with a small, purposefully drawn sample of approximately ten to thirty respondents. The typical interview structure consists of respondents first answering the evaluated question and then answering a series of follow-up probe questions that reveal what respondents were thinking and their rationale for that specific response. In this regard, cognitive interviews unfold within a narrative format and are often personal and, in comparison to traditional survey interviews, are unique to each respondent. Through this semi-structured design, various types of question-response problems, such as interpretive errors or recall accuracy, are uncovered—problems that often go unnoticed in traditional survey interviews. By asking respondents to provide textual verification and the process by which they formulated their answer, elusive errors are revealed.

By examining how respondents interpret or apply their life to particular questions, it is possible to see how questions can diverge from the intended scientific goal. In addition to response errors, analysis of cognitive interviews can be conducted to reveal patterns of question interpretation. By comparing each respondent's interpretation to a particular question, patterns can be identified and then examined for

consistency and degree of variation among respondents. This type of interpretive analysis does not necessarily illustrate overt response errors, but rather provides deeper insight into the substance or the actual meaning that constitutes the survey data.

As a qualitative method, the sample selection for a cognitive testing project is purposive. Respondents are not selected through a random process, but rather are selected for specific characteristics such as gender or race or some other attribute that is relevant to the type of questions being tested. When studying questions designed to identify persons with disabilities, for example, the test sample would likely consist of respondents with a previously known disability and, to discover potential causes of false positive reporting, some respondents with no known disability. Because of the small sample size, not all social and demographic groups are represented. Cognitive interviewing does not produce generalizable findings, but rather, provides an explicit exploration of response processes including patterns of interpretation which could lead to response error.

### **Cognitive interviewing methodology for the project**

Initially, the six participating UNESCAP countries (Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka) were invited to attend a training session in Bangkok, Thailand in February 2009 to learn about cognitive interviewing methodology, its purpose, and details on how to conduct cognitive interviews. Specific instructions for the cognitive interview protocol were provided. Each country conducted 20 interviews. Samples were to be broadly reflective of different disability statuses (types/severities), ages, gender, and socio-economic status. Since the sample was purposive and based on specific requirements, countries were able to recruit by whatever means were most efficient for them, for example, by placing an advertisement, handing out fliers, or through existing networks of respondents.

The interview was semi-structured, consisting of the test questions followed by a few general pre-scripted probe questions, for example, 'why did you answer this way?' The protocol was written in English; countries conducting interviews in languages other than English were responsible for producing a translated protocol.

Interviewers were instructed to keep detailed notes during interviews so that they would be able to write up a thorough narrative regarding how each respondent went about answering each of the test questions. For this project, a new data entry and analysis application (Q-Notes) was developed and placed on-line for full access to those involved in the project. After interviews were conducted, interviewers were expected to enter notes for each question into the Q-Notes application. Cognitive interviewing experts were then able to oversee the quality of the cognitive interview data and provide feedback for improvement. The application also allowed for a fast, in-depth analysis of the interviews.

### **Component 2: Field Test**

There is little consistency or agreement on terminology that is used to characterize different pretesting activities, including field tests. Indeed, a variety of activities, which may be referred to as pilot surveys, feasibility studies or tests, embedded experiments, methodological studies, and dress rehearsals, can be considered field tests. Field tests, however, are typically seen as a "dress rehearsal" for a survey, and are used to ensure that the survey processes and procedures are worked out prior to full scale implementation.

With respect to question evaluation, however, simply performing a “dress rehearsal” provides little information regarding the actual performance of individual questions. While a dress rehearsal field test may provide many frequency distributions and cross-tabulations, these will not, in and of themselves, supplement question design issues. Even uncovering an abundance of non-responses or responses classified as “don’t know” will provide little to inform why this is occurring. Questions cannot be evaluated based on frequency distributions or cross-tabulations.

Results from the cognitive interview question evaluation component described above can be used to improve field tests, and field tests can relay the extent to which the interpretive patterns exist. For example, results from cognitive interviewing that provide evidence that there is no problem with the question; can be substantiated through field testing. The field test also includes questions that will address areas where evidence from the cognitive interviews suggests there is a problem (either a comparability issue across countries or a more generic design problem) so quantitative evidence can be collected regarding the comparability and/or magnitude of the problem.

Field testing of the extended set of questions is carried out in part to determine the prevalence of the patterns of interpretation uncovered through cognitive interviewing and to provide a comparability study across subgroups that are randomly selected to be more representative of the population.

## Field test methodology for the project

For the WG/UNESCAP project the six participating countries were asked to randomly select a sample of approximately 1000 respondents for face-to-face interviews. In addition to the disability questions that were cognitively tested, the questionnaire that was fielded contained specific probe questions designed to provide additional information on those questions where the cognitive interviews indicated that there was some residual problem of interpretation.

Probe questions included in the field test were of three types:

- (1) **Interviewer probes** (to be answered by the interviewer) designed to learn more about issues of question content and delivery:

*BC\_1a*            *Did the respondent need you to repeat any part of the question?*  
1. *Yes*  
2. *No*

*BC\_1b*            *Did the respondent have any difficulty using the response options?*  
1. *Yes*  
2. *No*

*BC\_1c*            *Did the respondent ask for clarification or qualify their answer?*  
1. *Yes*  
2. *No*

- (2) **Respondent probes** (to be answered by the respondent) designed to provide detailed evidence on specific questions that were shown in the cognitive interviews to have been somewhat problematic. For example, cognitive interviews indicated that there were some problems

among respondents with the term *anxiety* and what that might encompass. For that reason, the following probe question was included in the field test:

*P\_ANX\_4* Please tell me which of the following statements, if any, describe your feelings.  
Response options: 1. Yes, 2. No, 7. Refused, 9. Don't know.

- A. *My feelings are caused by the type and amount of work I do.*
- B. *Sometimes the feelings can be so intense that my chest hurts and I have trouble breathing*
- C. *These are positive feelings that help me to accomplish goals and be productive.*
- D. *The feelings sometimes interfere with my life, and I wish that I did not have them.*
- E. *If I had more money or a better job, I would not have these feelings.*
- F. *Everybody has these feelings; they are a part of life and are normal.*
- G. *I have been told by a medical professional that I have anxiety.*

(3) **Impact probes** were added for each domain in an attempt to determine the extent to which an identified functional difficulty impacted the individual's activities of daily living. Each domain included a question:

*How much does your difficulty limit your ability to carry out daily activities?*

Response options: 1. Not at all, 2. A little, 3. A lot, 4. Completely, 7. Refused, 9. Don't know.

For each domain this question was followed by the probe:

*Which of the following activities, if any, are you unable to do, or find it hard to do, because of your difficulty?*

- A. *Working to support you or your family?*
- B. *Working outside the home to earn an income?*
- C. *Going to school or achieving your education goals?*
- D. *Participating in leisure or social activities?*
- E. *Getting out with friends or family?*
- F. *Doing household chores such as cooking and cleaning?*
- G. *Using transportation to get to places you want to go?*
- H. *Participating in religious activities?*
- I. *Participating in community gatherings?*

## Field Test Analyses

For this report, analyses were performed for each domain on the entire combined data set. Where appropriate, breakdowns by country are provided; however, detailed country by country analyses are not included. Individual country analyses were performed by the countries conducting the cognitive and field tests and will accompany this report under separate cover.

Analyses performed are for the most part descriptive in nature (frequency analyses and cross-tabulations) and designed to highlight findings derived from the qualitative analyses.

For certain domains (e.g. pain, fatigue, and affect), questions were included that covered multiple dimensions: frequency, duration and intensity. In order to assess the multiplicity of these components of the difficulty, binary logistic regression analyses were performed. Addressing pairs of dimensions, for

each “2by2 cell” (e.g. frequency=*some days* & intensity=*a little*), satisfying the conditions for cell ‘membership’ was the dependent variable and the independent variables (in bold) were: the **impact** experienced in activities of daily living (the general question: *How much does your difficulty limit your ability to carry out daily activities?*), and the items identified through the cognitive probe questions regarding the respondent’s reason(s) for responding as they did. For Pain, for example, the probe question was:

*Please tell me which of the following statements, if any, describe your pain.*

- A. *It is constantly present. (**Constant**)*
- B. *Sometimes I’m in a lot of pain and sometimes it’s not so bad. (**Sometimes bad**)*
- C. *Sometimes it is unbearable and excruciating. (**Unbearable**)*
- D. *When I get my mind on other things, I am not aware of the pain. (**Other things**)*
- E. *Medication can take my pain away completely. (**Medication**)*
- F. *My pain is because of work. (**Work**)*
- G. *My pain is because of exercise. (**Exercise**)*

The table analysis of both positive and negative significant relationships is included for the domains in question, and these reveal how multiple aspects of the domains (frequency, duration and intensity) are reflected in the respondent’s answers. Positive and negative associations are indicative of responses that fall within or out of scope for individual cells – and offer an overall picture of how well the questions ‘work’ in terms of the respondent’s interpretation of the domain in question. These findings are described in greater detail in the domain chapter in question.

## Vision chapter

### Introduction

Vision is one of the basic senses and statistics on vision difficulties provides information on the need for services such as optometry and provision of glasses. Many causes of difficulties seeing can be avoided or treated with minimal interventions. For example, poor nutrition can lead to night blindness or blindness from measles, and cataracts can easily be operated on and vision restored. Changes in prevalence of seeing difficulties, especially for the less severe difficulties, can be used as good measures of successful interventions such as improved nutrition and provision of basic eye surgery.

The objective of the domain is to identify individuals who report difficulties seeing, and to identify within this group those people who have near vision, and far vision difficulty or both. The use of assistive devices such as glasses (and contact lenses) is to be taken into account when responding; i.e. the response is 'with accommodation' and the actual wearing or not wearing of glasses is identified in a separate question.

The more common problems with vision are those of far and near sightedness. However, there are a number of other visual problems that occur frequently such as loss of peripheral or central vision and night blindness.

### Vision and the ICF

Vision is an aspect of 'sensory functions' contained in Chapter 2 of the WHO's ICF. More specifically b210 'seeing functions' and b215-219. When respondents are asked an interview question related to vision, the aspects that they might consider when answering could also include aspects within the ICF activity and participation chapters e.g. d210 'watching', as well as aspects of reading and communicating

### Cognitive testing

#### Box 1: Questions included in the cognitive interview protocol for vision:

Questions	Response Options
SS1a Do you have difficulty seeing, even when wearing glasses?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do
1.1a Do you wear glasses to see far away?	1) yes 2) no
1.1b Do you wear glasses to see up close?	<i>If Yes, read glasses in room question</i>  1) yes 2) no  <i>If Yes, read glasses in coin question</i>

1.1c Do you wear glasses for another reason (other): _____?	1) yes 2) no  <i>If Yes, record other.</i>
1.3 Do you have difficulty clearly seeing someone's face across a room [even when wearing your glasses?]	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do  <i>If No go to 1.4.</i>
11.1ai How old were you when the difficulty seeing far away began?	_____ age in years
12.1i Is your difficulty seeing far away due to a health problem or something else?	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty seeing far away limit your ability to carry out daily activities?	1) yes 2) no
13.2bi Does your difficulty seeing far away limit your ability to carry out other activities that are not part of your day-to-day life?	1) yes 2) no

The questions were analysed according to individual country responses as shown in table 1.

Table 1: Responses for all countries to question SS1a

	<b>Do you have difficulty seeing, even when wearing glasses?</b>					
	<b>No</b>	<b>Some</b>	<b>A lot</b>	<b>Unable to</b>	<b>Skipped: not asked</b>	<b>Total persons</b>
Cambodia	9	5	4	<1	<1	18
Canada	10	4	3	<1	<1	17
Kazakhstan	8	8	3	1	<1	20
Maldives	11	8	1	<1	<1	20
Mongolia	11	6	2	1	<1	20
Philippines	10	6	3	1	<1	20
South Africa	6	1	<1	<1	<1	7
Sri Lanka	5	6	<1	3	<1	14
United States	2	13	2	<1	2	19
<b>Total persons</b>	<b>72</b>	<b>57</b>	<b>18</b>	<b>6</b>	<b>2</b>	<b>155</b>
Percent	46%	37%	12%	4%	1%	100%

Table 1 indicates that of the respondents that completed the cognitive interviews, 46% reported 'no difficulty', 37% 'some difficulty', 12% 'a lot of difficulty' and 4% (6 people) could not see at all. These should not be interpreted as prevalence estimates as the sample was very small and selected purposively. These responses are important not so much on their own, but in relation to responses on the further questions on this domain.



Table 2: Responses for all countries to question 1.1a

	Do you wear glasses to see far away?			Total
	Yes	No	Skipped: not asked	
Cambodia	1	17	0	18
Canada	14	3	0	17
Kazakhstan	4	15	1	20
Maldives	7	13	0	20
Mongolia	6	14	0	20
Philippines	4	16	0	20
South Africa	0	7	0	7
Sri Lanka	4	9	0	13
United States	10	6	2	18
<b>Total persons</b>	<b>50</b>	<b>100</b>	<b>3</b>	<b>152</b>
Percentage	33	66	1	100

Detailed analysis of responses revealed that there was some confusion created by the ‘...even when wearing glasses’ clause in SS1a. It would seem that some respondents focussed on the glasses clause rather than the vision difficulty. They responded with either what their vision might be if they did wear glasses, (which they did not currently have), or simply stated that they did not wear glasses. The cognitive testing also highlighted some difficulties in translating this clause in a consistent way across all languages.

The cognitive testing showed instances where the WG short set question (SS1) identified people with difficulties not picked up by either the close or far sight questions. This is due to the range of other conditions such as night blindness or injury to an eye as described in the Introduction to the chapter.

For Question 1.3 ‘Do you have difficulty clearly seeing someone’s face across a room’ some respondents considered whether they could ‘recognise’ the person across the room. This is a very different concept, as they may be able to recognise the person from a range of visual and other clues (e.g. voice and smell) without being able to see their face clearly. There was also quite a lot of variation in the size of the room considered when answering this question. Some respondents referred to the, sometimes quite small, room that they were in at time of interview, whilst, at the other extreme, some respondents thought of quite large spaces such as when watching a basketball game.

When answering question 1.4 (seeing the picture on a coin), respondents raised a number of queries as to the distance being referred to in the question. Some suggestions from the respondents included at arms length, with arm bent, or up close to the eye, with one respondent even thinking of seeing the coin on the street, and another respondent viewing the coin up very close as would be done by a coin inspector.

### Impact of vision difficulties on daily activities

When asked what activities they were considering when answering a question about the impact of their seeing difficulties on their daily activities, the examples of activities given included paid employment (for those employed), housework, preparing meals, looking after children, watching television and sleeping.

## Conclusions from cognitive testing and revisions of questions

The analysis of the cognitive test question identified some problems with the extended questions for vision. These included the confusion in SS1 of the eye glasses clause, and the need for ordering the sequence of questions differently to simplify the response task for respondents.

The changes made to the vision questions included wording and ordering ones, and deletion of some questions.

### Wording change:

- Question 1.1b had the words 'for reading' included for extra clarification/prompting,

### Ordering changes:

- The questions on glasses use and difficulties for far vision were placed together, and similarly for the near vision glasses use and difficulties questions.
- 'Age of onset', and limitation in daily activities questions were asked about 'difficulty seeing' in general rather than individually for close and far vision difficulty.

### Deletion and addition of questions:

- Question 1.1c "do you wear glasses for another reason" was deleted as results suggested that the majority of positive responses related to non-health reasons (e.g. sunglasses), and the question was confusing to respondents.
- The question on limitations in activities that are not part of day-to-day life was dropped, as the concept was found to be too confusing for respondents.
- An additional set of questions was added (P\_VIS\_6 in field test) to obtain more detail on the type of activity that people might have difficulty with or be unable to do as a result of a range of conditions/disabilities. The activities included were based on responses to the cognitive test probes and group discussion.

Despite problems with it, the glasses clause for SS1a was retained for VIS\_SS as this is the agreed WG short set question. However, recommendations are provided at the end of this chapter for a possible means of overcoming this problem.

## Field testing

The field testing was carried out in 6 countries and included a standard structured questionnaire administered to around 1000 respondents in each of the 6 countries.

**Box 2: Questions included in the Vision field test:**

Questions	Response Options
<p>VIS_SS Do you have difficulty seeing, even when wearing glasses?</p> <p><i>If "Cannot do at all/Unable to do" to VIS_SS, skip to VIS_5.</i></p>	<p>1) no difficulty            2) some difficulty            3) a lot of difficulty            4) Cannot do at all/unable to do            7) <i>Refused</i>            9) <i>Don't know</i></p>
<p>VIS_1 Do you wear glasses to see far away?</p> <p><i>[If Yes, include glasses clause in VIS_2]</i></p>	<p>1) Yes            2) No            7) <i>Refused</i>            9) <i>Don't know</i></p>
<p>VIS_2 Do you have difficulty clearly seeing someone's face across a room [even when wearing these glasses]?</p>	<p>1) no difficulty            2) some difficulty            3) a lot of difficulty            4) Cannot do at all/unable to do            7) <i>Refused</i>            9) <i>Don't know</i></p>
<p>VIS_3 Do you wear glasses for reading or to see up close?</p>	<p>1) Yes            2) No            7) <i>Refused</i>            9) <i>Don't know</i></p>
<p>VIS_4 Do you have difficulty clearly seeing the picture on a coin [even when wearing these glasses]?</p>	<p>1) no difficulty            2) some difficulty            3) a lot of difficulty            4) Cannot do at all/unable to do            7) <i>Refused</i>            9) <i>Don't know</i></p>
<p>VIS_5 How old were you when the difficulty seeing began?</p>	<p>_____ age in years            777) <i>Refused</i>            999) <i>Don't know</i></p>
<p>VIS_6 How much does your difficulty seeing limit your ability to carry out daily activities?</p>	<p>1) Not at all            2) A little            3) A lot            4) Completely            7) <i>Refused</i>            9) <i>Don't know</i></p>

The question VIS\_SS is the vision question from the Washington Group Short Set, and is the same as was included in the cognitive test. The aim of the question is to measure the extent of vision difficulty, taking into account any accommodation made through the wearing of glasses or contact lenses.

Table 3: Responses for all countries to question VIS\_SS

<b>Do have difficulty seeing, even when wearing glasses?</b>						
	<b>No</b>	<b>Some</b>	<b>A lot</b>	<b>Unable to</b>	<b>Skipped: not asked</b>	<b>Total persons</b>
	<b>(%)</b>	<b>(%)</b>	<b>(%)</b>	<b>(%)</b>	<b>(%)</b>	
Cambodia	68	27	5	<1	<1	18
Kazakhstan	63	31	6	<1	<1	20
Maldives	81	13	6	<1	<1	20
Mongolia	77	19	3	<1	<1	20
Philippines	83	15	2	<1	<1	20
Sri Lanka	73	23	3	<1	<1	14
<b>Total persons</b>	<b>74</b>	<b>21</b>	<b>4</b>	<b>&lt;1</b>	<b>&lt;1</b>	<b>155</b>

Table 3 indicates the responses for extent of vision difficulty by country and the overall responses. Overall 74% of respondents reported no vision difficulty. Philippines and the Maldives had by far the highest percentage reporting 'no difficulty' (83% and 81% respectively), whilst Kazakhstan and Cambodia had the lowest (63% and 68%). Respondents with more severe vision difficulty, either 'a lot of difficulty' or 'cannot do at all', ranged from 2% (Philippines) to 6% (Kazakhstan and Maldives), with the overall percentage being 4%.

The glasses clause was reported as being confusing for many respondents (similar to what was found in the cognitive test), with the wording being distracting from the main focus of the question, and eliciting sometimes incorrect responses as reported by interviewers.

VIS\_1 And VIS\_3 measure the extent of use of glasses for distance and close vision correction respectively, with 25% of respondents overall reporting wearing glasses. Glasses were worn for reading or to see up close by 13%, and for seeing far away by 21%. Glasses were worn for both near and far vision by 8% of respondents (Table 4).

Table 4: close distance glasses use by far distance glasses use

<b>Do you wear glasses for reading or to see up close?</b>				
		<b>Yes</b>	<b>No</b>	<b>Total</b>
		<b>(%)</b>	<b>(%)</b>	<b>(%)</b>
<b>Do you wear glasses to see far away?</b>	<b>Yes</b>	8	12	21
	<b>No</b>	4	75	79
<b>Total</b>		<b>13</b>	<b>87</b>	<b>100</b>

Table 5: Use of glasses by severity of vision difficulty

		<b>No glasses</b>	<b>Glasses</b>	<b>Total</b>
		<b>(%)</b>	<b>(%)</b>	<b>(%)</b>
<b>Do you have difficulty seeing, even when wearing glasses?</b>	<b>No</b>	84	16	100
	<b>Some</b>	50	50	100
	<b>A lot</b>	42	58	100
	<b>Unable to do</b>	100	0	100

Of those people reporting 'no difficulty' in VIS\_SS, 16% (761 people) reported using glasses for either close or far vision, thus reporting full visual correction and considering the eye

glasses clause appropriately in giving their response. Of those reporting 'some' vision difficulty 50 reported wearing glasses, and this figure rose to 58% of those with 'a lot of difficulty'. We cannot be clear on how many people using glasses are responding appropriately to the glasses clause, but it is likely that a number have improved vision (if not fully corrected) by the use of glasses. Thus a number of responses of 'some' and 'a lot of difficulty' may have been given as more severe without the use of glasses. As might be expected, the people reporting 'cannot do at all' for vision did not wear glasses as these are unlikely to provide any benefit for a blind person (table 5).

Table 6: Responses for all countries to VIS\_2

<b>Do you have difficulty clearly seeing someone's face across a room [even when wearing these glasses]?</b>						
	<b>No difficulty</b>	<b>Some difficulty</b>	<b>A lot</b>	<b>Unable to do</b>	<b>Don't know</b>	<b>Total persons</b>
	<b>(%)</b>	<b>(%)</b>	<b>(%)</b>	<b>(%)</b>	<b>(%)</b>	
Total persons	88	10	2	<1	<1	6,309

Table 7: Responses for all countries to VIS\_4

<b>Do you have difficulty clearly seeing the picture on a coin [even when wearing these glasses]?</b>						
	<b>No difficulty</b>	<b>Some difficulty</b>	<b>A lot</b>	<b>Unable to do</b>	<b>Don't know</b>	<b>Total persons</b>
	<b>(%)</b>	<b>(%)</b>	<b>(%)</b>	<b>(%)</b>	<b>(%)</b>	
Total persons	88	10	2	<1	<1	6,309

VIS\_2 and VIS\_4 measure reported vision difficulties for far vision (seeing someone's face across a room) and near vision (clearly seeing the picture on a coin) respectively, taking into consideration correction to vision provided by the use of glasses (or contact lenses) if a person reported using glasses for near or far vision. The reported levels of difficulty were very similar for both activities, ranging from 88% with 'no difficulty', through 10% for 'some difficulty', 2% with 'a lot of difficulty', down to less than 1% for 'cannot do at all' (Tables 6 & 7).

Even though the percentages are very close, they do not necessarily represent the same people as indicated in Table 8. Of people with 'no close vision difficulty', 5% reported 'some far vision difficulty', and the reverse was also true with 6% of those with 'no far vision difficulty' reporting 'some close vision difficulty' (Table 8).

Table 8: Responses for all countries, VIS\_4 by VIS\_2

		<b>Do you have difficulty clearly seeing someone's face across a room?</b>			
		No difficulty	Some difficulty	A lot	Unable to do
<b>Do you have difficulty clearly seeing the picture on a coin?</b>	No difficulty	5,237	270	22	0
	Some difficulty	288	308	30	2
	A lot	24	33	45	0
	Unable to do	1	4	4	2

Feedback from interviewers, and from the training sessions, indicated that there were some issues needing to be addressed in the use of these questions. For VIS\_2, there needs to be some guidance provided on the size of the room to be considered. If the size is too big most people might have some difficulty thus generating many false positives, and if the size is too small the question might omit some people who do have some significant level of far vision difficulty generating false negatives.

For VIS\_4, some countries do not have coins as part of their currency and hence this wording could confuse respondents from these countries. It was agreed at training that alternative examples such as a suitably sized picture on a banknote could be referred to instead.

Lastly, the responses to VIS\_SS are compared to the combined responses to either far (VIS\_2) or near vision (VIS\_4) as shown in Table 9.

Table 9: Comparisons of responses to VIS\_SS and difficulties on Far OR Near vision. (N)

		<b>Do you have difficulty seeing, even when wearing glasses?</b>					
		None	Some	A lot	Cannot do	Don't know	Total
<b>Do you have difficulty clearly seeing someone's face across a room OR Do you have difficulty clearly seeing the picture on a coin?</b>	Missing	1	1	0	16	0	18
	No difficulty	4548	636	62	0	0	5246
	Some difficulty	142	640	87	0	4	873
	A lot of difficulty	5	44	105	0	0	154
	Cannot do at all	1	2	10	0	0	13
	Don't know	0	2	1	0	2	5
<b>Total</b>		<b>4697</b>	<b>1325</b>	<b>265</b>	<b>16</b>	<b>6</b>	<b>6309</b>

Table 9 shows that just over 3% of respondents (N=148) had no difficulty on VIS\_SS but did have difficulty on either far or near vision. The reverse is also true but to a much greater extent. Just under half of respondents (N=636) had no difficulty on near or far vision but did have 'some difficulty' on VIS\_SS. The other half had difficulty on both VIS\_SS and near or far vision. The same relationship is found for 'a lot of difficulty' on VIS\_SS but with under a quarter of respondents (N=62) being missed by the combined near or far vision responses.

This suggests that the general questions on seeing (VIS\_SS) in fact counts in more people than the two individual questions on far or near vision. The possible reasons for this include:

- VIS\_SS probably picks up difficulties due to conditions other than difficulties with close or far vision, such as loss of peripheral or central vision or nightblindness;
- The response to the glasses clause for the two specific questions may have worked better than the one for VIS\_SS. The position of the questions on use of glasses for seeing far (VIS\_1) just before VIS\_2 may have facilitated the correct interpretation of the clause, and similarly for VIS\_3 and VIS\_4. The effect of this would be that less people in fact report difficulties as the glasses would have corrected their vision. This may explain the high number of people ‘missed’ by the far or near vision responses. They (correctly) have no difficulty when wearing those glasses.

In total, 25.5 percent of respondents had any difficulty on VIS\_SS compared to 16.5 percent on either far or near vision.

### Age and level of difficulty with vision

Table 10 presents the responses for all respondents on the VIS\_SS question by age categories.

Table 10: Overall vision difficulty on VIS\_SS by age

		Age Groups							
		0-17	18-30	31-40	41-50	51-60	61-70	71+	Total
		(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Do you have difficulty seeing, even when wearing glasses?</b>	No	93.1	89.3	82.4	59	48.1	41.8	29.4	74.4
	Some	5.9	9.4	14.5	35	44.3	47.8	39.8	21
	A lot	0.9	1.2	3.1	5.5	7.2	9.9	26.1	4.2
	Can't do	0	0.1	0	0.3	0.1	0.3	4.7	0.3
Total		100	100	100	100	100	100	100	100

There is a generally acknowledged association between vision loss and ageing. The field test data is consistent with this pattern, with data presented in table 9 showing a steady decrease in ‘no difficulty’ with increasing age (from 93% of 0 – 17 year olds to only 29% of those aged 70 years or older), and a corresponding increase in the higher levels of difficulty with increasing age - ‘cannot do’ increases from no one in the 0 – 17 age group, to 5% of those in the oldest group (71 years and older).

### Impact of vision difficulty on daily activities

The question on the degree to which the vision difficulty affects a person’s ability to do daily activities was asked of all respondents who reported any degree of vision difficulty. The results are presented in Table 11.

Table 11: VIS\_SS by limitation of daily activities\*\*

		How much does your difficulty seeing limit your ability to carry out daily activities?				Total persons
		Not at all	A little	A lot	Completely	
		(%)	(%)	(%)	(%)	
<b>Difficulty seeing, even when wearing glasses</b>	None	39	53	6	2	150
	Some difficulty	44	49	6	<1	1,323
	A lot of difficult	20	38	38	3	265
	Cannot do	0	0	25	75	16
<b>Total</b>		<b>40</b>	<b>48</b>	<b>11</b>	<b>1</b>	<b>1,760</b>

\*\*Limiting of daily activities only asked of respondents reporting some difficulty in one or more of VIS-SS, VIS\_2 or VIS\_4  
10 respondents answered 'don't know' to one or both questions

The 150 people with no reported difficulty in VIS\_SS are those with some difficulty in one or more of VIS\_2 or VIS\_4 (with the exception of 3 respondents who were asked VIS\_6 in error).. Table 11 indicates that as reported difficulty seeing increases the subsequent impact on the respondent's ability to carry out daily activities also increases. Of those with 'some difficulty' only 6% reported having their daily activities limited 'a lot' or 'completely', whereas this figure rises to 41% for those with 'a lot of difficulty' and to 100% for those that report being 'unable to see'.

Table 12: difficulty seeing overall (VIS\_SS, VIS\_2 and VIS\_4) by limitation of daily activities

		How much does your difficulty seeing limit your ability to carry out daily activities?				Total persons
		Not at all	A little	A lot	Completely	
		(%)	(%)	(%)	(%)	
<b>Overall difficulty seeing**</b>	None	0	100***	0	0	3
	Some difficulty	45	50	4	<1	1,422
	A lot of difficulty	19	40	39	3	304
	Cannot do	3	17	28	52	29
<b>Total</b>		<b>40</b>	<b>48</b>	<b>11</b>	<b>1</b>	<b>1,760</b>

\*\*Limiting of daily activities only asked of respondents reporting 'some difficulty' in one or more of VIS-SS, VIS\_2 or VIS\_4  
10 respondents answered 'don't know' to one or both questions. The most severe response on the three question was taken as the final level of severity for that respondent. For example, if a respondent reported 'some' for VIS\_SS, 'a lot' for VIS\_2 and 'none' for VIS\_4 the overall severity rating in the table would be 'a lot'

\*\*\*error response, question should not have been asked.

When a similar analysis is undertaken grouping the data for the general vision question (VIS\_SS) and far (VIS\_2) and near (VIS\_4) vision as presented in Table 11, the general trends are similar to those for VIS\_SS alone.

## Conclusions and recommendations

The vision questions provide generally clear and conclusive findings, suggesting that the current set of extended questions is working well. Some minor changes should, however, be made to increase the accuracy of the measures.



Due to the identified and oft reported problem with the glasses clause in VIS\_SS, it has been suggested that the clause could be deleted from the question, and a preceding question on glasses use be added. This is not possible for the WG Short Set but could be accommodated for the extended set. The questions would start with asking whether the person uses glasses and would then ask VIS\_SS with or without the glasses clause depending on the response to the first question on use of glasses. The benefit of including the use of glasses question at the start and not asking it separately for near and far vision is that the effect of the glasses clause would then be the same for all three questions, VIS\_SS, far and near vision.

Guidelines should be provided as to suitable room sizes for consideration when answering VIS\_2, 'seeing someone's face across a room'. Similarly, for the distance from the eyes for seeing the picture on a coin.

With reference to a coin in VIS\_4, for those countries that do not use coins the reference should still remain, but an explanation provided as to what should be considered.

The proposed set for vision is as follows:

1. Do you wear glasses for seeing? If yes, include glasses clause in Question 2, and if no exclude the glasses clause in Question 2.
2. Do you have difficulty seeing [even when wearing glasses]?
3. Do you have difficulty clearly seeing someone's face across a room [even when wearing glasses]?
4. Do you have difficulty clearly seeing the picture on a coin [even when wearing glasses]?

The additional questions on age of onset and impact of the vision difficulty on daily activities would be developed for all domains and are not given here.

# Hearing Chapter

## Introduction

Hearing is a sense that includes a number of specific functions – perception of loudness (measured using decibels), pitch (measured using frequencies), discrimination of speech signals vs background noise, and localization of sounds (e.g. direction that a car is coming from when crossing a road). These latter two functions require bilateral hearing. Background noise is a distractor for hearing and this distraction becomes worse with increasing levels of hearing loss. In addition, sensori-neural hearing loss (affecting the inner ear cochlea and neural pathways to the brain) is often accompanied by a phenomenon of recruitment where the range is greatly reduced from threshold of hearing to threshold of pain. Recruitment often causes confusion as a person doesn't hear many sounds but reacts to loud sounds that a normal hearer would not react to.

Thus hearing is not a simple sensory function and a hearing loss is not easily rectified by the use of a hearing aid – unlike the possibility of eye glasses restoring vision to normal vision. Self reporting is sometimes difficult as people do not easily identify that they have a hearing loss, nor are audiological services easily available (especially in middle and low resources contexts) to identify mild and moderate hearing losses. All these characteristics of hearing and hearing loss could complicate the self reporting on this domain. People with hearing loss are often isolated in a social context and confuse words in conversation (e.g. 'bad' vs 'bat', 'willow' vs 'pillow') and responding often inappropriately. People with moderate to severe hearing losses experience significant difficulties in group contexts such as at a dinner party or group discussion.

The questions used in the cognitive and field testing asked about two levels of difficulty in hearing – in quiet (easier activity) and in noise (more difficult activity). If people respond as having difficulty hearing in quiet, the extent of the problem is likely to be moderate to severe (in terms of a measurable hearing loss), while many more people are likely to find hearing in noise difficult.

## Hearing and the ICF

Hearing is a body function classified under Chapter 2: Sensory Functions and Pain of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) – codes b230 – b249. The domain of hearing is divided into further sub-domains of sound detection, sound discrimination, localization of sound source, lateralization of sound, and speech discrimination. Vestibular functions are also classified under the domain of hearing. Some sensations associated with hearing functions are noted as tinnitus, irritation in the ear and aural pressure.

## Cognitive testing

The questions asked about hearing difficulties (WG Short Set), use of a hearing aid and frequency of use, hearing in noise followed by hearing in quiet. People with no difficulty hearing in noise skipped the question on hearing in quiet. All respondents who indicated having hearing difficulties were asked the

age when the difficulty started, and whether it had any impact on their ability to carry out daily activities.

**Box 1: Hearing questions asked in the cognitive testing interviews**

Questions	Response Options
SS2: Do you have difficulty hearing, even if using a hearing aid?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
2.1 Do you use a hearing aid?	1) Yes 2) No <i>If Yes, read <b>hearing aid in noisy room and quiet room.</b></i>
2.2 <b>If yes:</b> How often do you use your hearing aid(s)?	1) All of the time 2) Some of the time 3) Rarely 4) Never
2.3 Do you have difficulty hearing what is said in a conversation with one other person in a noisy room [ <b>even when wearing your hearing aid(s)</b> ]?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do <i>If <b>No difficulty</b>, go to <u>next section</u>.</i>
2.4 Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [ <b>even when wearing your hearing aid(s)</b> ]?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
11.1i How old were you when the difficulty hearing began?	_____ age in years
12.1i Is your difficulty hearing due to a health problem or something else?	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty hearing limit your ability to carry out daily activities?	1) Yes 2) No
13.2bi Does your difficulty hearing limit your ability to carry out other activities that are not part of your day-to-day life?	1) Yes 2) No

The analysis of the cognitive testing responses look at whether the intent of the questions was understood and what confusions, if any, arose from the response options. In addition, the interpretation of the hearing aid clause was analysed.

Table 1: Responses for all countries to question SS2

<b>'Do you have difficulty hearing, even if using a hearing aid?'</b>						
	<b>No</b>	<b>Some</b>	<b>A lot</b>	<b>Unable to</b>	<b>Skipped: not asked</b>	<b>Total persons</b>
Cambodia	11	3	3	<1	4	21
Canada	14	1	1	<1	1	17
Kazakhstan	14	2	1	1	2	20
Maldives	15	2	3	<1	<1	20
Mongolia	15	3	2	<1	<1	20
Philippines	12	5	2	1	<1	20
South Africa	5	<1	<1	<1	2	7
Sri Lanka	2	1	1	1	10	15
United States	13	3	<1	<1	3	19
<b>Total Persons</b>	<b>101</b>	<b>20</b>	<b>13</b>	<b>3</b>	<b>22</b>	<b>159</b>
Percentage (excl. Skipped)	74%	15%	9%	2%	-	100%

The intent of the question SS2 (see table 1) seems to have been clear to most respondents. Of the 92 respondents who provided comments on their responses 67 indicated that they had understood the question intent and provided a response that met their description of 'no difficulty' or 'difficulty'. This is noted by the number of examples provided by the respondents highlighting the activity of hearing in different contexts. These included examples of listening to a range of sounds, loud and soft, far and near, playing a musical instrument, hearing birds, diseases of and trauma to the ear. One teacher, who responded with 'no difficulty', commented 'I really don't have any difficulty and my students know that I can even hear them whispering'. Some referred to having had a hearing test which indicated normal hearing even if there was some loss in some of the higher frequencies, or being in 'fine physical form'.

The respondents who reported having difficulty tended to report examples such as difficulty on the phone, in noise, being completely deaf, having a recognized unilateral hearing loss, having tinnitus<sup>1</sup>, having problems even when wearing a hearing aid, ageing and reporting various forms of illness or trauma (e.g. noise damage, being kicked on the side of the head).

The 25 respondents (out of 92) who provided ambiguous responses varied in the reasons for this ambiguity. One example was the confusion with the hearing aid clause. Nine respondents responded to the hearing aid clause rather than about hearing. Most were able to respond appropriately once the confusion was explained. The confusion occurred only with respondents who reported 'no' or 'some difficulty'. None of the respondents reporting 'a lot of difficulty' or 'cannot do' were confused by the clause. Some of the confusions lead to respondents saying 'no difficulty' because they interpreted the question to be about a hearing loss that is severe enough to warrant the use of a hearing aid. For example, one USA respondent said 'Yes I do have a problem hearing but I don't wear a hearing aid'. He reported having 'no difficulty' hearing, when in fact he should have responded as having 'some' or 'a lot of difficulty'. Another USA respondent described his confusion well:

<sup>1</sup> Tinnitus is a constant humming, rushing/roaring or high pitched sound in the ears often but not always associated with a hearing loss.

'You asked about a hearing aid and I'm thinking I don't have no hearing aid but I can still hear pretty good. So that's what threw me off, when it said *with a hearing aid*, I'm like I don't even have one of them, so why is that...how's that going to help me'.

A second USA respondent reported 'no difficulty' and clarified this by saying 'Because I don't wear a hearing aid. Yes I do have a problem hearing but I don't wear a hearing aid.'

A number of respondents in the middle and low income countries did not know what a hearing aid was. Unlike eye glasses, hearing aids are not common and people may have ignored the hearing aid clause because of this unfamiliarity.

A number of problems experienced in relation to hearing were reported as being listening in noise and having a unilateral hearing loss. Responses were reported as either 'no' or 'some' difficulty for the similar description by different respondents. These are good examples of borderline cases. The respondents who reported 'no difficulty' would give examples such as too much noise at a concert, ceremony or party, or other similar contexts as the only time when they have some difficulty hearing. A few respondents reported a unilateral hearing loss but having no difficulty, with one South African respondent considering the setting in which she finds herself to decide whether she has a hearing loss or not. She replied 'no difficulty' because the setting of the interview was a quiet one. A respondent from the Maldives reported having 'some difficulty' because of a hearing loss in one ear and problems hearing at a distance of about 10 feet.

A further ambiguity arose from people conflating concentrating with hearing. One Canadian respondent described how her family have learnt to get her attention before talking to her. When asked the questions (SS2) again, she responded 'no, what I have is not a hearing problem.' While this was not a common response, it does reflect the close relationship between hearing and concentrating.

Only 5 respondents reported using a hearing aid and, of these, three reported using it 'all the time'. The other two used them rarely or never. Some of the reasons for not using a hearing aid other than not needing one, included:

- Not knowing about a hearing aid with the added response that if they were given one they would like to use it. One such respondent indicated having 'a lot of difficulty' hearing while another reported 'no difficulty'. This was the most common reason for not using a hearing aid after the reason of not needing one.
- Being told that use of a hearing aid is not indicated for respondents who cannot hear at all or who have a unilateral hearing loss.
- Getting no benefit from using a hearing aid from respondents reporting 'a lot of difficulty' hearing or 'unable to hear at all'.
- Running out of batteries (when hearing aid was provided for free) and so giving up using it by a respondent reporting 'some difficulty' hearing.
- Unable to afford it

Table 2: Responses by country, difficulty hearing a conversation with one other person in a noisy room and in a quiet room.

Questions 2.3 and 2.4 - Responses by country												
	Do you have difficulty hearing in a noisy room?						Do you have difficulty hearing in quiet room?					
	None	Some	A lot	Can't do	Skipped	Total	None	Some	A lot	Can't do	Skipped	Total
Cambodia	4	7	<1	<1	10	21	8	5	<1	<1	8	21
Canada	10	5	<1	<1	2	17	8	<1	<1	<1	9	17
Kazakhstan	10	5	<1	1	4	20	12	1	<1	1	6	20
Maldives	12	4	1	<1	3	20	5	2	1	<1	12	20
Mongolia	10	7	1	<1	2	20	8	1	1	<1	10	20
Philippines	11	2	<1	1	6	20	3	3	<1	1	13	20
South Africa	5	1	<1	<1	1	7	2	<1	<1	<1	5	7
Sri Lanka	2	1	<1	3	8	15	2	<1	<1	2	11	15
USA	4	9	<1	<1	7	19	12	2	<1	<1	5	19
Total persons	68	41	2	5	43	159	60	14	2	4	79	159
Percent	43%	26%	1%	3%	27%	100%	38%	9%	1%	3%	50%	100%
Percent excl. Skipped	59%	22%	<1%	4%	-	100%	75%	18%	3%	5%	-	100%

In total 116 respondents answered Question 2.3 (difficulties hearing in noisy room) and 73 of these provided explanations for their responses. The large majority of these explanations (63 out of 73) showed that the question intent had been correctly understood. The comments provided by respondents suggested, however, that Question 2.3 may be difficult to answer if the type and level of noise are not specified. Respondents with 'no difficulty' hearing in noise described different types and levels they were considering when answering the question, such as being in a meeting, group activity or watching TV with some children around, recreation time at school, travelling in a bus compared to being at a concert, night club or other similar loud noise environment. These respondents, thus qualified their response by saying that 'no difficulty' would be in a less noisy type of environment or when placed near the person speaking. A couple of respondents reported no difficulty hearing in a noisy room as they work in a noisy environment and have become accustomed to hearing in a noisy room.

Those respondents who reported 'some difficulty' hearing in noise provided examples of noise that were less extreme and similar to those provided by the 'no difficulty' respondents. These generally included having more than two people talking in the room, combining talking and music, singing and shouting, talking in a car or over the phone (especially cell/mobile phone), rooms with an echo, loud machinery, familiarity with the speaker and the conversation and the distance away from the speaker. These respondents also described ways in which they arrived at their response of 'some difficulty': averaging out across a number of contexts, attributing it to age, whether paying attention to the conversation, and noting that they often ask for repetition of what people said.

Respondents that gave the two most severe response categories – 'a lot of difficulty' and 'cannot hear at all' – gave clear reasons for their responses, usually that of being deaf.

The second question (2.4) asked about difficulties hearing in a quiet room. The responses are provided in Table 2. The main explanations given for reporting 'no difficulty' hearing in quiet were that there is no disturbing noise and would include contexts such as library or conference rooms and other quiet and peaceful rooms where one can concentrate. The example of the cognitive interview context was given as a good example of a quiet room.

The respondents with 'some difficulty' hearing in quiet gave as examples of what they were thinking about as being at a distance from the speaker, having a moderate to severe hearing loss and not managing well even in a quiet room, when a speaker speaks too fast or too softly and asking for repetition even when there was no background noise. Two respondents described comprehending complex words and a language that is not familiar as the reasons why they reported 'some difficulty' hearing in quiet. A Deaf respondent said that he responded as having only 'some difficulty' in a quiet room as he generally can hear and understand conversation in a quiet room. This same respondent reported 'a lot of difficulty hearing' for SS2 and skipped the question on hearing in noise.

Respondents seem to express little confusion on either question with very few respondents providing explanations that were contrary to the question intent. There were a few instances of people conflating to some extent concentration (paying attention) and hearing although most seemed to be doing it consciously and saying that if they have a problem it is rather one of paying attention than hearing.

Question 2.3 (hearing in noise) is more likely to pick up people than question 2.4 (hearing in quiet) as hearing in noise is a more difficult task. This is borne out by the responses given as shown in Tables 1 and 2. Three quarters of respondents (75 percent) reported no difficulty hearing in quiet compared to only 59 percent for hearing in noise. Conversely, 22 percent reported some difficulty hearing in noise compared to 18 percent reporting some difficulty hearing in quiet. The responses for the main question (SS2) shows similar responses for 'no' and 'some difficulty' as for hearing in quiet (74 percent and 15 percent respectively). The responses for the two most severe categories ('a lot of difficulty' and 'cannot do at all') show no significant difficulties in understanding the questions and provided consistent responses.

### **Impact of hearing difficulties on activities**

When asked whether the hearing difficulties had an impact on their daily and non-daily activities, the examples given included working outside of the normal workplace, attending religious ceremonies, social situations, visiting cultural establishments, receiving visitors at home, shopping, talking to a bank teller, hearing approaching traffic (for more severe difficulties) and negotiating airports. Non-daily activities were seen as being infrequent in occurrence and hence some respondents reported no impact on these.

### **Conclusions from cognitive testing of hearing questions**

In view of the trends in the hearing questions from the cognitive testing interviews, the questions were revised only minimally for the pilot testing. The first question was kept unchanged as it forms part of the Washington Group Short Set of questions. The questions on use and frequency of use of a hearing aid were left unchanged. The two questions on hearing in quiet and in noise were reversed starting with 'hearing in a quiet room'. If respondents reported 'cannot hear at all' in a quiet room, they were not asked about difficulties hearing in a noisier room.

## Field testing

The pilot testing questionnaire included the following questions that were revised based on the analysis of the cognitive testing responses.

### Box 2: Hearing questions asked in the pilot testing

Questions	Response Options
HEAR_SS Do you have difficulty hearing, even when using a hearing aid?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>  <i>If "Cannot do at all / Unable to do" to HEAR_SS, skip to HEAR_5.</i>
HEAR_1 Do you use a hearing aid?	1) Yes 2) No 7) <i>Refused</i> 9) <i>Don't know</i>  <i>If "No" to HEAR_1, skip to HEAR_3 and omit [hearing aid clause] in HEAR_3 and HEAR_4.</i>  <i>If "Yes" to HEAR_1, continue with HEAR_2 and include [hearing aid clause] in HEAR_3 and HEAR_4.</i>
HEAR_2 How often do you use your hearing aid(s)?	1) All of the time 2) Some of the time 3) Rarely 4) <i>Never</i> 7) <i>Refused</i> 9) <i>Don't know</i>
HEAR_3 Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [even when wearing your hearing aid(s)]?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>  <i>If "Cannot do at all / Unable to do" to HEAR_3, skip to HEAR_5.</i>
HEAR_4 Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [even when wearing your hearing aid(s)]?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>



	If “No difficulty” to HEAR_SS and “No difficulty” to HEAR_3 and “No difficulty” to HEAR_4, skip to Section D Mobility.
HEAR_5 How old were you when the difficulty hearing began?	_____ age in years 777) Refused 999) Don't know
HEAR_6 How much does your difficulty hearing limit your ability to carry out daily activities?	1) Not at all 2) A little 3) A lot 4) Completely 7) Refused 9) Don't know

### Hearing Difficulties by country and by HEAR\_SS and hearing aid use

Table 3: Difficulty hearing even when wearing a hearing aid by country (HEAR\_SS)

		Cambodia	Kazakhstan	Maldives	Mongolia	Philippines	Sri Lanka	Total
<b>Do you have difficulty hearing, even when using a hearing aid?</b>	No difficulty	87%	87%	93%	91%	93%	89%	90%
	Some difficulty	12%	10%	6%	8%	6%	10%	8%
	A lot of difficulty	2%	2%	2%	1%	1%	1%	1%
	Cannot do	0%	1%	0%	0%	0%	0%	0%
	Refused	0%	0%	0%	0%	0%	0%	0%
	Don't know	0%	0%	0%	0%	0%	0%	0%
	Total Persons		1008	1000	1013	1222	1066	1000

All 6 countries show similar trends in reported hearing difficulties with 90 percent of respondents having ‘no difficulty’. Cambodia showed the lowest rate of ‘no difficulty’ (87 percent) and Maldives and Philippines the highest rate. Cambodia, Kazakhstan and Sri Lanka showed the highest rate of ‘some difficulty’. Across all countries 90 percent of respondents reported ‘no difficulty’ in hearing. This is much higher than the 74 percent who reported ‘no difficulty’ seeing (VIS\_SS). This does not necessarily indicate that fewer people have difficulties hearing than seeing but more likely that services to identify hearing loss compared to vision loss are few and far between especially in the 6 countries of the pilot testing. Furthermore, loss of hearing is more easily confused with other problems of too much noise, or people mumbling, and thus not seen as a personal problem of hearing but rather a problem of the external environment, compared to a loss of vision which an individual can clearly identify when they are not able to read the paper as easily, start holding written text at a distance to see them properly or find it difficult to thread a needle, and so on.

Very few respondents use a hearing aid – 35 in total across all countries. Kazakhstan had the highest usage (14 respondents) while Maldives and Mongolia had 7 and 8 hearing aid users respectively. The lowest number of hearing users were in Cambodia (5 respondents), Philippines (1 respondent) and Sri Lanka (0 respondents). Of the 35 hearing aid users, only 29 responded to the question on the frequency of use of their hearing aid. Only 7 respondents reported using their hearing aid all the time, and 13 using it some of the time. A further 8 respondents rarely or never used their hearing aid. Since these numbers are so small no further analysis has been undertaken.

### Difficulties reported on the extended questions: hearing in a quiet room (HEAR\_3) and hearing in a noisier room (HEAR\_4)

The two extended questions provided an indication of difficulties in quiet and in noise. Since very few respondents reported 'cannot hear at all', the question on hearing in noise (HEAR\_4) was asked of the majority of the respondents. Thus it is possible to compare responses on both of these questions. In addition, the response rate for each is compared to the HEAR\_SS responses to see if the same trends are noted as in the cognitive testing interviews (i.e. hearing in quiet yields similar rates to the single hearing question).

Table 4: HEAR\_3 – Hearing in quiet room

		Cambodia	Kazakhstan	Maldives	Mongolia	Philippines	Sri Lanka	Total
<b>Do you have difficulty hearing what is said in a conversation with one other person in a quiet room?</b>	No	92%	92%	94%	88%	96%	93%	93%
	Some	7%	5%	4%	11%	3%	4%	6%
	A lot	1%	0%	1%	1%	0%	1%	1%
	Unable to	0%	2%	0%	0%	0%	0%	0%
	Total							
	Persons	1008	992	1012	1220	1055	996	6283

Table 5: HEAR\_4 – Hearing in noisier room

		<b>Hear in noise (HEAR_4) by country</b>						
		Cambodia	Kazakhstan	Maldives	Mongolia	Philippines	Sri Lanka	Total
<b>Do you have difficulty hearing what is said in a conversation with one other person in a noisier room?</b>	No	83%	84%	90%	79%	89%	86%	85%
	Some	13%	13%	6%	16%	9%	10%	11%
	A lot	3%	2%	4%	5%	2%	2%	3%
	Unable to	0%	0%	0%	0%	0%	0%	0%
	Total							
	Persons	1008	976	1012	1220	1060	996	6272

Hearing in noise is reported more often as a difficulty in all countries than hearing in quiet. The single question on hearing (HEAR\_SS) consistently picks up more people as having a difficulty than hearing in quiet

The HEAR\_SS question also consistently picks up less people with difficulties than hearing in noise but more people than the 'hearing in quiet' question. Asking only the question on hearing in noise would give too many false positives, while asking only the question of hearing in quiet may underestimate the number of people with mild to moderate hearing loss who struggle to hear mainly in noisy contexts.

### Comparison of overall responses for a) HEAR\_SS vs Hear in quiet, b) HEAR\_SS vs Hear in noise and c) Hear in quiet vs Hear in noise

Crosstabulations of the responses for the single question with each of the two extended questions was done to determine the overlap between the respondents for each question. This provides some information on the extent to which the three questions pick up the same respondents for the same degree of difficulty.

Table 6: HEAR\_SS vs hearing in quiet

		Do you have difficulty hearing what is said in a conversation with one other person in a quiet room?				Total
		No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	
Do you have difficulty hearing, even when using a hearing aid?	No	5543	94	5	16	5658
	Some	272	246	11	0	530
	A lot	17	30	43	0	90
Total		5833	373	59	16	6283

There seems to be a good correspondence between responses on the single HEAR\_SS question and those for hearing in quiet as noted in the shaded cells. However, there is some concern about the 21 respondents who reported 'no difficulty' on HEAR\_SS but 'a lot of difficulty' or 'cannot hear at all' for hearing in quiet. The characteristics of these respondents should be investigated further to determine if there is some confusion with the hearing aid clause or whether these are just error responses since they represent less than 1 percent of the total sample. The 289 respondents who reported 'some' or 'a lot of difficulty' on HEAR\_SS but 'no difficulty hearing' in quiet are likely to be people who experience difficulties hearing in noise.

Table 7: HEAR\_SS vs hearing in noisier room

		Do you have difficulty hearing what is said in a conversation with one other person in a noisier room?				Total
		No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	
Do you have difficulty hearing, even when using a hearing aid?	No difficulty	5255	341	40	5	5648
	Some difficulty	64	357	99	9	529
	A lot of difficulty	1	14	62	13	90
Total		5321	714	203	27	6272

The pattern of responses for HEAR\_SS and hearing in noise is somewhat different to the preceding one. The cells off the diagonal show the lack of a neat correspondence between the respondents on both questions. However, there is a good overlap of respondents with 'no difficulty' on both question. The respondents with 'some difficulty' hearing in noise and 'no difficulty' in HEAR\_SS, and those with 'a lot of difficulty' in noise but only 'some difficulty' on HEAR\_SS reflect the fact that hearing in noise is a more difficult task than is reflected by the single question HEAR\_SS. Thus these respondents are not problematic and a decision needs to be made as to whether responses of 'some difficulty' hearing in noise and 'no difficulty' on HEAR\_SS should be counted as part of the disability statistics or not. The off diagonal cells generally follow this pattern.

There are very few people (around 1 percent) who report difficulties on HEAR\_SS (some or a lot of difficulty) but 'no' or only 'some difficulties' hearing in noise. The reason for this pattern of response could be the lack of specifications of what noise to consider or these could be error responses. The 14 respondents who report 'a lot of difficulties' on HEAR\_SS but 'no' or only 'some difficulty' on hearing in noise could be those with a severe hearing loss where noise (unless very loud) does not have as much of an impact as for people with milder hearing loss.

Table 8: Hearing in quiet room and hearing in noisier room

		Do you have difficulty hearing what is said in a conversation with one other person in a noisier room?				Total
		No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	
Do you have difficulty hearing what is said in a conversation with one other person in a quiet room?	No difficulty	5284	747	54	6	5828
	Some difficulty	24	232	109	8	373
	A lot of difficulty	1	5	40	13	59
Total		5311	714	203	27	6262

When comparing responses on hearing in quiet and those for hearing in noise, the same pattern of correspondence is found to that comparing HEAR\_SS to hearing in noise. This confirms that hearing in quiet is less likely to be a problem than hearing in noise.

The responses from hearing in quiet, HEAR\_SS and hearing in noise suggest a clear continuum of hearing difficulty, starting hearing in quiet as the easiest (least difficulty reported), followed by HEAR\_SS and ending with hearing in noise (most difficulty reported).

### Age and level of difficulties hearing

Table 9: Percentage of respondents with difficulties hearing by age category

		Age							Total
		0-17	18-30	31-40	41-50	51-60	61-70	71+	
Do you have difficulty hearing, even when using a hearing aid?	No	96%	96%	93%	89%	83%	74%	50%	90%
	Some	4%	4%	6%	10%	15%	22%	35%	8%
	A lot	0%	1%	1%	1%	2%	4%	14%	1%
	Unable to	0%	0%	0%	0%	0%	1%	1%	0%
	Total	100	100	100	100	100	100	100	100

The analysis of the responses by age in Table 9 shows that as age increases so does the degree of and number of people with difficulty hearing increase. This is to be expected due to hearing loss in ageing (Presbycusis). For HEAR\_SS the number of people with 'some' or 'a lot of' hearing difficulties increases from 3.7 percent in the youngest age group (0-17 yrs) to 48.8 percent in the oldest age group (71+ yrs). This increase is the same but less marked for hearing in quiet and more marked for hearing in noise.

### Impact of hearing difficulties on daily activities

People who reported difficulties were asked about the impact of this difficulty on their daily activities. The responses are provided for the overall data only.

Table 10: Impact of hearing difficulties on daily activities (%)

		<b>Percent of respondents with any difficulty hearing</b>
<b>How much does your difficulty hearing limit your ability to carry out daily activities?</b>	Not at all	45%
	A little	44%
	A lot	9%
	Completely	1%

Table 10 shows clearly that not everyone who reports hearing difficulty, reports an impact on their daily activities. The majority report 'no' or 'only a little' impact.

Table 11: Reported impact on daily activities by severity of reported difficulties on HEAR\_SS

		<b>How much does your difficulty hearing limit your ability to carry out daily activities?</b>				
		Not at all	A little	A lot	Completely	Total
<b>Do you have difficulty hearing, even when using a hearing aid?</b>	No difficulty	229	151	10	1	391
	Some difficulty	214	278	31	4	527
	A lot of difficulty	18	27	41	3	89
	Cannot do at all	2	2	6	4	14
	Total	463	460	90	12	1025

Table 11 shows that there is no clear link between the degree of impact and the severity of difficulty on HEAR\_SS. When 'no difficulty' is reported on HEAR\_SS, 'a little', 'a lot' and 'complete' impact is reported on daily activities. This impact is likely to be from difficulties hearing in noise as there is a clearer pattern (than for HEAR\_SS) of increasing impact with increasing difficulties hearing in noise. In addition, the impact could be due to difficulties other than hearing. Conversely reporting of 'some' or 'a lot of difficulty' hearing is accompanied by no impact from these difficulties.

Table 12: Reported impact on daily activities by severity of reported difficulties on hearing in noise

		<b>How much does your difficulty hearing limit your ability to carry out daily activities?</b>				
		Not at all	A little	A lot	Completely	Total
<b>Do you have difficulty hearing what is said in a conversation with one other person in a noisier room?</b>	No difficulty	43	23	2	0	68
	Some difficulty	368	316	11	2	697
	A lot of difficulty	44	93	62	3	202
	Cannot do at all	6	9	9	3	27
	Total	461	441	84	8	994

For hearing in noise the pattern is similar as for HEAR\_SS (Table 12) although the lack of impact from 'some difficulty' hearing in noise is more pronounced. This is confirmation that hearing in noise is a measure that is not specific enough and creates false positives.

## Conclusions and recommendations on hearing domain

The results from the hearing field test are reasonably conclusive and clear. These results show quite clearly that hearing in noise is a more difficult activity than hearing in quiet. Asking only the question on hearing in noise could generate significant numbers of false positives while asking only about hearing in quiet could miss a significant number of people. The general Short Set question on hearing seems to fall somewhere in between, but is complicated by the potentially confusing hearing aid clause (although not as much as for the glasses clause in the vision domain).

The recommendation is to retain the three questions but possibly change the order to match with that proposed for the vision domain where the question about using a hearing aid is asked as the first question. The use of the three questions provides a good gradation of difficulty from easy (hearing in quiet) through to difficult activities (hearing in noise).

The revised extended set of questions for hearing include two options, Option 1 where space is not at a premium in the questionnaire, and Option 2 where space is limited and a compromise is made to measure hearing difficulty somewhere in between hearing in quiet and hearing in noise.

### Option 1:

1. Do you use a hearing aid? (If no then the hearing aid clause is omitted from the following questions and question 2 is omitted).
2. How often do you use your hearing aid(s)?
3. Do you have difficulty hearing [even when wearing your hearing aid]?
4. Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [even when wearing your hearing aid(s)]?
5. Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [even when wearing your hearing aid(s)]?

Examples of a quiet and noisier room could include talking in a library vs talking in a room with 5 to 10 other people talking or where there is a radio or music playing at a moderate level. A noisier room does not include loud music or lots of people shouting.

### Option 2:

1. Do you use a hearing aid? (If no then the hearing aid clause is omitted from the following questions and question 2 is omitted).
2. How often do you use your hearing aid(s)?
3. Do you have difficulty hearing [even when wearing your hearing aid]?

## Mobility chapter

### Introduction

Mobility is an important function as it determines people's ability to be independent. The trend in most measures of disability is that difficulties in mobility are one of the more prevalent difficulties or disabilities.

Mobility difficulties arise from a range of health conditions or impairments. The more common ones include spinal cord injuries, chronic diseases such as rheumatoid arthritis, amputations and malformations. Less commonly considered underlying causes, but that also generate a high rate of mobility, include chronic or acute illnesses that render the person weak and unable to move around, blindness or severe visual problems especially for the person who is in unfamiliar contexts, and Deafness where some difficulties climbing stairs are evident when there is poor lighting and lack of visual cues.

### Mobility in the ICF

Mobility is the title of chapter 4 under the Activities/Participation in the World Health Organization's International Classification of Functioning Disability and Health (ICF). The chapter includes both lower and upper body mobility. Lower body mobility comprises functions such as changing and maintaining body positions, carrying, moving and handling objects, walking and moving around, and moving around using transportation. The mobility domain for the cognitive and field testing focuses on lower body mobility and only includes walking and climbing steps. Upper body mobility is presented in the chapter by that name.

### Cognitive testing

The cognitive testing included questions on moving around inside one's home, walking short and longer distances and climbing steps. Respondents were also asked about use of any mobility assistive devices. Any difficulties with these activities were rated by respondents without the use of any assistive devices. For those who did use some mobility assistive device, difficulties for these same activities were rated with the use of this device.

The questions included in the cognitive testing protocol are presented in Box 1.

#### Box 1: Questions on mobility used in the cognitive testing

Questions	Response Options
SS3. Do you have any difficulty walking or climbing steps?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
3.1a Do you use any equipment or receive help for getting around? 3.2 <b>If Yes:</b> Do you use any of the following? a. cane or walking stick? b. walker? (Zimmer frame)	1) Yes 2) No If <b>no</b> go to 3.4

<p>c. crutches?  d. wheelchair?  e. prosthesis(es)?  f. someone's assistance?  g. other? (specify: _____)</p> <p>3.3 <b>If more than one:</b> Which [aid/assistance] do you use most often?</p>	<p>1) Yes 2) No  1) Yes 2) No  1) Yes 2) No  1) Yes 2) No  1) Yes 2) No  1) Yes 2) No  1) Yes 2) No</p> <p>Specify aid from a-g list: _____</p> <p><b>**Insert most used aid in the following questions.</b></p>
<p>3.4 Do you have difficulty walking 100 (meters/yards) on level ground, that would be about (<i>insert country-specific example</i>) [<b>without the use of your [insert aid]</b>]?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/ unable to do</p> <p><i>If Cannot do at all, go to 3.6 -- stairs question.</i></p>
<p>3.5 Do you have difficulty walking 500 (meters/yards) on level ground, that would be about (<i>insert country-specific example</i>) [<b>without the use of your [insert aid]</b>]?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/ unable to do</p>
<p>3.6 Do you have difficulty walking up or down [<i>insert country-specific example: a flight of stairs / 12 steps / a small hill</i>] [<b>without the use of your [insert aid]</b>]?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/ unable to do</p>
<p>*****EXPERIMENT*****</p>	
<p><b>For first 10 interviews:</b></p> <p>3.7 Do you have difficulty walking around in your home [<b>without the use of your [insert aid]</b>]?</p> <p><b>For second 10 interviews:</b></p> <p>3.7a How much difficulty did you have in moving around inside your home? [<b>without the use of your [insert aid]</b>]?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/ unable to do</p> <p>1) None  2) Mild  3) Moderate  4) Severe  5) Extreme/Cannot Do</p> <p><i>If no aid, go to next section.</i></p>
<p><b>Only if respondent uses an aid:</b></p> <p>3.8 Do you have difficulty walking 100 (meters/yards) on level ground, that would be about (<i>insert country-specific example</i>), even when using your [<b>insert aid</b>]?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/ unable to do</p> <p><i>If Cannot do at all, go to 3.10 – stairs question.</i></p>
<p>3.9 Do you have difficulty walking 500 (meters/yards) on level ground, that would be about (<i>insert country-specific example</i>), even when using your [<b>insert aid</b>]?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/ unable to do</p>



11.1ai How old were you when the difficulty walking began?	_____ age in years
12.1i Is your difficulty walking due to a health problem or something else?	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty walking limit your ability to carry out daily activities?	1) Yes 2) No
13.2bi Does your difficulty walking limit your ability to carry out other activities that are not part of your day-to-day life?	1) Yes 2) No
3.10 Do you have difficulty walking up or down [ <i>insert country-specific example: a flight of stairs / 12 steps / a small hill</i> ], even when using your [ <b>insert aid</b> ]?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
*****EXPERIMENT*****	
<b>For first 10 interviews:</b> 3.11 Do you have difficulty walking around in your home, even when using your [ <b>insert aid</b> ]?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
<b>For second 10 interviews:</b> 3.11a How much difficulty did you have in moving around inside your home, even when using your [ <b>insert aid</b> ]?	1) None 2) Mild 3) Moderate 4) Severe 5) Extreme/Cannot Do

The sample was split in two for question 3.7. The first 10 interviews were to be asked about difficulty walking around in one's home, while the second 10 interviews were to be asked the WHO-DAS II question about moving around inside one's home. The response categories were also different – the usual WG 4 point response scale for the first, and a 5 point response scale for the second. This split was repeated for question 3.11 but this time for difficulties WITH using an assistive device. As only respondents who use assistive devices were asked question 3.11, the number of respondents for this question was limited.

The analysis of the cognitive testing responses look at whether the intent of the questions was understood and what confusions, if any, arose from the response options. In addition, the interpretation of questions with and without assistive devices was analyzed.

Table 1: Responses for all countries to SS3

<b>Do you have any difficulty walking or climbing steps?</b>						
	<b>No</b>	<b>Some</b>	<b>A lot</b>	<b>Unable to</b>	<b>Skipped: not asked</b>	<b>Total persons</b>
Cambodia	9	5	4	<1	<1	18
Canada	2	8	5	1	<1	16
Kazakhstan	10	5	3	<1	<1	18
Maldives	8	6	6	<1	<1	20
Mongolia	8	7	3	2	<1	20
Philippines	2	13	3	<1	<1	18
South Africa	4	1	<1	1	<1	6
Sri Lanka	3	7	<1	2	<1	12
United States	2	9	6	1	1	19
<b>Total Persons</b>	<b>48</b>	<b>61</b>	<b>30</b>	<b>7</b>	<b>1</b>	<b>147</b>

The consistency of responses was high for this question. Of 78 respondents who gave responses a second time, 71 were consistent in their responses (91 percent), 5 gave a different response the second time the question was asked, and 2 changed their responses during the discussion.

Some of the main themes that emerged from the cognitive testing interviews highlighted the variables that potentially undermine the stability of the measure of mobility. These include

- a) the multiple type of activities incorporated into this domain (walking near and far, going up and going down). Which ones do people refer to in their responses?
- b) The distance of walking – near or far
- c) Use of an aid and what counts as an aid
- d) The context of walking or climbing stairs
- e) Underlying etiology of the difficulty – e.g. a problem with feet or legs vs a cardiovascular difficulty vs a vision difficulty.
- f) The consistency and magnitude of the problem; i.e. occasional problems (e.g. flare up of rheumatoid arthritis) vs continuous problems (spinal cord injury) vs progressive degeneration.

Table 2: Reported use of assistive devices (mobility aids)

	<b>All respondents</b>	<b>No mobility aid</b>	<b>Mobility aid</b>
<b>No difficulty</b>	39	36	3
<b>Some difficulty</b>	50	38	11
<b>A lot of difficulty</b>	21	9	14
<b>Cannot do at all</b>	5	0	5

Of the 115 respondents who answered the question on use of assistive devices, 83 did not use any aids and 31 used one or more aids to assist their mobility. Table 2 shows that the more severe a person's difficulty was for walking and climbing stairs (SS3), the more likely they were to use an assistive device.

The problem of what to count as a mobility aid was reflected in respondents asking whether shoe inserts, parking stickers for a reserved parking bay, and someone’s assistance should be counted. Some aids are seen as ‘so much part of the person’ that is not clear whether it is an aid or not. Examples given included a prosthesis or bolt in the knee.

The use of someone else’s assistance is hard to define – on what occasions, for what purpose, etc. This response was common as an ‘aid’ and seemed to create more problems than other aids in how it should be considered. Some wheelchair users did not consider ‘without your aid’ as being without their wheelchair when answering questions about moving around.

When asked about climbing stairs the consideration of handrails (as an assistance) was inconsistent and could create problems in comparison of responses across groups. Furthermore, not all stairs have handrails and different size and slopes of stairs make a comparison difficult. Thus the field test asked about the use of handrails specifically.

When asking about distance it is important to make the distance clear and this is best done by providing a good example that is relevant for the respondent. The examples provided must be familiar to both men and women (e.g. using the size of a football field may be gender biased). Similarly the number of stairs is important to specify. This was particularly noted in countries with high buildings and few lifts/elevators (e.g. Almaty in Kazakhstan). Where people are used to climbing many flights of stairs, they may report a problem for 7 – 10 floors but not 12 steps. Thus giving an example is crucial to ensure comparable responses.

The notion of progression in complexity is well reflected in the questions with the assumption that moving around one’s home is the easiest (smallest area, most familiar and probably adapted), and climbing stairs and walking 500m the most difficult. The responses to the different questions in relation to each other were analyzed to investigate whether this holds true.

Table 3: Comparison of responses to SS3 with moving around in one’s home without use of aid

		Do you have any difficulty walking or climbing steps?			
		No	Some	A lot	Unable to
<b>How much difficulty did you have in moving around inside your home? [without an aid]?</b>	No difficulty	28	24	7	
	Some difficulty	1	6	5	
	A lot of difficulty			2	
	Cannot do at all		1	1	1

Table 3 shows that there are a number of respondents who have ‘no difficulty’ moving around their home but who report ‘some’ or ‘a lot of difficulty’ walking and climbing stairs is high (31 out of 71). Similarly 5 out of 11 people with ‘some difficulty’ moving around their home had ‘a lot of difficulty’ walking and climbing stairs. These results suggest that moving around in one’s home is easier than walking and climbing stairs.

Table 4: Comparison of responses to SS3 with walking 100m without an aid

		Do you have any difficulty walking or climbing steps?			
		No	Some	A lot	Unable to
<b>Do you have difficulty walking 100 (meters/yards) on level ground, [without an aid]?</b>	No difficulty	38	28	6	0
	Some difficulty	1	14	9	0
	A lot of difficulty	1	4	4	2
	Cannot do at all	0	5	6	3

Table 4 shows that more people have ‘some difficulty’ walking or climbing than walking 100m. Of the 72 respondents who said they have ‘no difficulty’ walking 100m, just over half (38) had ‘no difficulty’ on SS3. Similarly, of the 24 respondents with ‘some difficulty’ walking 100m, 9 had ‘a lot of difficulty’ with SS3. This suggests that SS3 is measuring a more difficult activity than walking 100m or that the differences are due to difficulties in climbing stairs rather than walking.

It is, however, not clear why 11 out of 14 people who are ‘unable to’ walk 100m only had ‘some’ or ‘a lot of difficulty’ with SS3.

Table 5: Comparison of responses to SS3 with walking 500m without an aid

		Do you have any difficulty walking or climbing steps?			
		No	Some	A lot	Unable to
<b>Do you have difficulty walking 500 (meters/yards) on level ground, [without an aid]?</b>	No difficulty	34	20	2	0
	Some difficulty	1	20	8	0
	A lot of difficulty	1	5	7	1
	Unable to	0	3	4	2

Table 5 shows a similar trend to that in Table 4, although to a lesser degree. There seems to be more congruence between people having difficulties on SS3 and walking 500m. The 20 respondents with ‘some difficulty’ and 8 with ‘a lot of difficulty’ on SS3 who had ‘no difficulty’ or only ‘some difficulty’ respectively in walking 500m, could be people with difficulties climbing steps rather than walking. Table 5 suggests a closer match between responses on SS3 and walking for 500m than for SS3 and walking for only 100m.

Table 6: Comparison of responses to SS3 with climbing up or down flight of stairs with

		Do you have any difficulty walking or climbing steps?			
		No	Some	A lot	Unable to
<b>Do you have difficulty climbing up and down a flight of stairs [without an aid]?</b>	No difficulty	37	8	1	0
	Some difficulty	2	33	5	0
	A lot of difficulty	0	5	16	0
	Unable to	0	4	2	5

There is a close correspondence between responses on SS3 and those on climbing up or down stairs as shown in the diagonal on Table 6. The off diagonal cells have very low numbers compared to the diagonals.

### Conclusions for cognitive testing of mobility questions

The cognitive testing showed that the Short Set question, ‘Do you have difficulty walking and climbing stairs?’, seems to identify the most people with difficulties together with the question about climbing a flight of stairs (Q3.6). Moving around one’s home identifies the least number of people with difficulties followed by walking 100m and walking 500m. These findings show a clear progression of activity difficulty with moving around one’s home being the easiest (and the one we accommodate to most) through to climbing a flight of stairs. The easier the activity the less people have difficulties.

Some of the respondent comments suggest that it would be useful to add concrete examples of distances and clarify the need to use only one example for climbing a flight of stairs and not leave all three (climbing a flight of stairs/12 steps/a small hill). The choice of which one to use would be made at the country level and the single one included in the question.

The question on assistive devices use seems to provide few problems for respondents, but the use of assistance from another person seems difficult to ask about. The analysis of the impact of using assistive devices is limited in the cognitive testing interviews as few people had mobility difficulties and so even fewer used assistive devices. Thus the field testing was seen as a better context in which to analyze this relationship.

Since there did not seem to be a standard flight of stairs in respondents’ minds when responding it was decided to add a question asking specifically about the impact of having a handrail on the stairs.

The recommendations from the cognitive testing was to keep the questions relatively unchanged but keeping only one question about moving around one’s home. The order of the questions was slightly changed to reflect the increasing difficulty of the activities from moving around one’s home to climbing up or down a flight of stairs. The questions asking about difficulties when using any assistive devices were retained and placed in the same order as the questions without use of an assistive device.

## Field testing

The field testing questions as revised based on the cognitive testing analysis are presented in Box 2.

### Box 2: Mobility questions asked in the pilot testing

Questions	Response Options
MOB_SS Do you have difficulty walking or climbing steps?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>  <i>If "Cannot do at all / Unable to do" to HEAR_SS, skip to HEAR_5.</i>
MOB_1 Do you have difficulty moving around inside your home?	1) Yes 2) No 7) <i>Refused</i> 9) <i>Don't know</i>
MOB_2 Do you use any equipment or receive help for getting around?	1) Yes 2) No 7) <i>Refused</i> 9) <i>Don't know</i>  <i>If "Yes" to MOB_2, continue with MOB_3 and include [aid clause] in MOB_4, MOB_5 and MOB_6.</i>  <i>If "No" to MOB_2, skip to MOB_4 and omit [aid clause] in MOB_4, MOB_5 and MOB_6.</i>
MOB_3 Do you use any of the following?	a) Cane or walking stick? b) Walker or Zimmer frame? c) Crutches? d) Wheelchair? e) Artificial limb (leg/foot)? f) Someone's assistance? g) Other (please specify):  <i>If respondent only answers "Wheelchair" to MOB_3, skip to MOB_10.</i>
MOB_4 Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the use of your aid]?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>  <i>If "Cannot do at all / Unable to do" at MOB_4, skip to MOB_6.</i>

<p>MOB_5 Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [without the use of your aid]?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/unable to do  7) <i>Refused</i>  9) <i>Don't know</i></p>
<p>MOB_6 Do you have difficulty walking up or down 12 steps [without the use of your aid]?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/unable to do  7) <i>Refused</i>  9) <i>Don't know</i></p>
<p>P_MOB_6 How much difficulty would you have walking up or down those steps without using a handrail?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/unable to do  7) <i>Refused</i>  9) <i>Don't know</i></p> <p><i>If "Some difficulty", "A lot of difficulty" or "Cannot do at all" to any of MOB_SS, MOB_1, MOB_4, MOB_5, MOB_6 and "No" to MOB_2 skip to MOB_10.</i></p> <p><i>If "No difficulty" to MOB_SS, MOB_1, MOB_4, MOB_5, MOB_6 and "No" to MOB_2 then skip to Section E Communication. Otherwise, continue with MOB_7</i></p>
<p>MOB_7 Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using your aid?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/unable to do  7) <i>Refused</i>  9) <i>Don't know</i></p>
<p>MOB_8 Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks, when using your aid?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/unable to do  7) <i>Refused</i>  9) <i>Don't know</i></p> <p><i>If "Cannot do at all / Unable to do" to MOB_7, skip to MOB_9.</i></p>
<p>MOB_9 Do you have difficulty walking up or down 12 steps, even when using your aid?</p>	<p>1) no difficulty  2) some difficulty  3) a lot of difficulty  4) Cannot do at all/unable to do  7) <i>Refused</i></p>

	9) <i>Don't know</i>
MOB_10 How old were you when the difficulty walking or climbing began?	_____ Age in years 777. <i>Refused</i> 999. <i>Don't know</i>
MOB_11 How much does your difficulty walking or climbing limit your ability to carry out daily activities?	1) none 2) A little 3) A lot 4) Completely

## Overall results for MOB\_SS by country and age groups

Table 7: Responses to MOB\_SS by country

		Cambodia	Kazakhstan	Maldives	Mongolia	Philippines	Sri Lanka	Total
<b>Do you have difficulty walking or climbing steps?</b>	No diff (%)	78	76	80	74	88	65	77
	Some diff (%)	16	18	10	20	10	27	17
	A lot of diff (%)	5.1	5.8	10	6	2	7	6
	Cannot do (%)	1	<1	<1	1	<1	1	<1
	Total (%)	100	100	100	100	100	100	100
	<b>Total Persons</b>	<b>1008</b>	<b>1000</b>	<b>1013</b>	<b>1222</b>	<b>1066</b>	<b>1000</b>	<b>6309</b>

Table 7 shows the proportion of respondents with 'no difficulty' ranging from 88 percent in Philippines to 65 percent in Sri Lanka. The proportion of respondents with 'some difficulty' ranges from 27 percent in Sri Lanka to 10 percent in Philippines. Maldives and Sri Lanka had the highest proportion of respondents with 'a lot of difficulty' with walking or climbing stairs and Philippines had the least. Less than 1 percent of all respondents in all countries reported being 'unable to' walk or climb stairs at all.

Table 8: Responses to MOB\_SS(1) by age groups

<b>Do you have difficulty walking or climbing steps?</b>					
<b>Age Group</b>	<b>No</b>	<b>Some</b>	<b>A lot</b>	<b>Unable to</b>	<b>Total persons</b>
	(%)	(%)	(%)	(%)	
<b>0-17</b>	95	4	1	<1	1,475
<b>18-30</b>	91	8	1	0	1,478
<b>31-40</b>	80	16	3	<1	1,004
<b>41-50</b>	70	22	8	<1	1,008
<b>51-60</b>	51	37	11	<1	738
<b>61-70</b>	44	37	19	<1	395
<b>71+</b>	23	36	34	8	211
<b>Total</b>	<b>77</b>	<b>17</b>	<b>6</b>	<b>0.4</b>	<b>6,309</b>

[1] While in the cognitive testing the Washington Group Short Set question was numbered as SS3, in the pilot test, it is numbered as MOB\_SS.

Table 8 shows a clear pattern of increasing difficulties in walking and climbing with increasing age. In the youngest age group (0 – 17 years) only 5 percent of respondents have 'some' or 'a lot of difficulty'



walking of climbing stairs, compared to 70 percent with these difficulties in the age group 71 years and older.

### Correspondence between MOB\_SS and the extended questions (MOB\_1, MOB\_4, MOB\_5 and MOB\_6)

Table 9: Question MOB\_SS by MOB\_1

		Do you have difficulty moving around inside your home?				
		No	Some	A lot	Unable to	Total
Do you have difficulty walking or climbing steps?	No	4,839	11	0	0	4,851
	Some	783	271	4	0	1,059
	A lot	122	139	109	1	371
	Unable to	0	3	6	19	28
	Total	5,744	424	119	20	6,309

Table 9 shows a similar trend to that found in the cognitive testing – that moving around one’s home is an easier activity than walking and climbing stairs. A number of respondents reporting ‘no difficulty’ with moving around their home, report ‘some’ or ‘a lot of difficulty’ walking or climbing stairs as shown in the shaded cells. Similarly, people with ‘some difficulty’ moving around their home report ‘a lot of difficulty’ walking and climbing stairs.

Table 10: Question MOB\_SS by MOB\_4

		Do you have difficulty walking 100 meters on level ground?				
		No	Some	A lot	Unable to	Total
Do you have difficulty walking or climbing steps?	No	4,764	72	11	1	4,851
	Some	630	386	38	3	1,059
	A lot	81	127	142	18	369
	Unable to	1	1	3	14	20
	Total	5,476	586	194	36	6,299

Table 10 shows a reasonable correspondence between MOB\_SS and MOB\_4, with the trend being that MOB\_SS picks up more people with difficulties than MOB\_4. This is shown in the shaded cells where, out of just under 5500 respondents with ‘no difficulty’ in walking 100m, 630 reported ‘some difficulty’ and 81 ‘a lot of difficulty’ on MOB\_SS. Similarly, out of 369 respondents who reported ‘a lot of difficulty’ on MOB\_SS, 208 reported ‘no’ or only ‘some difficulty’ on walking 100m. This suggests that MOB\_SS picks more people as having mobility difficulties than MOB\_4 and confirms that it is measuring a more difficult activity than walking 100m.

In the cognitive test some respondents reported ‘no difficulty’ or ‘some difficulty’ for walking or climbing steps (SS3) but reported ‘unable to walk 100m’. In the field test only 4 such responses were noted. Thus it seems that this is likely to be an error response.

Table 11: Question MOB\_SS by MOB\_5

		Do you have difficulty walking 500 meters on level ground?				
		No	Some	A lot	Unable to	Total
Do you have difficulty walking or climbing steps?	No	4,610	186	45	1	4,850
	Some	354	541	147	6	1,056
	A lot	34	74	204	34	351
	Unable to	0	2	2	1	6
	Total	4,998	803	398	42	6,263

Table 11 shows that there is a good correspondence between MOB\_SS and MOB\_5. This suggests that walking and climbing as a measure picks up the same number of people as walking 500m. There are three exceptions:

- 388 respondents with ‘no difficulty’ walking 500m reported ‘some difficulty’ or ‘a lot of difficulty’ on MOB\_SS, suggesting that their difficulties could be related to climbing stairs rather than walking on a flat surface. These respondents may have thus only considered only the climbing stairs part of MOB\_SS.
- 192 respondents with ‘a lot of difficulty’ walking 500m, had ‘no difficulty’ or only ‘some difficulty’ with MOB\_SS. These are probably people who considered walking from MOB\_SS and who do have difficulties walking long distance such as 500m.
- 34 people who are ‘unable to’ walk 500m reported having ‘a lot of difficulty’ on MOB\_SS. While these may be error responses they could also reflect consideration of a walking distance of less than 500m for MOB\_SS and thus reporting less difficulty than walking 500m.

Table 12: Question MOB\_SS by MOB\_6

		Do you have difficulty walking up or down 12 steps?				
		No	Some	A lot	Unable to	Total
Do you have difficulty walking or climbing steps?	No	4,663	160	16	2	4,851
	Some	233	712	97	8	1,059
	A lot	15	94	215	43	369
	Unable to	0	0	3	16	20
	Total	4,911	966	331	69	6,299

As for MOB\_6, there is a good correspondence between MOB\_SS and climbing 12 steps as shown on Table 12. Only 233 respondents (5 percent) with ‘no difficulty’ climbing steps reported difficulty with MOB\_SS. This suggests that these people were considering walking more than climbing. Of the 331 respondents with ‘a lot of difficulty’ climbing steps, 16 (just under 5%) had ‘no difficulty’ on MOB\_SS. These suggest errors in responses. A further 97 of these 331 respondents (29%) had only ‘some difficulty’ on MOB\_SS. These latter responses could be an attempt to average out difficulties between walking and climbing stairs. Lack of any difficulty walking could have reduced the severity of the

climbing stairs part of MOB\_SS. This is merely a hypothesis which would require further cognitive testing.

Table 13: Comparison of identification as disabled by MOB\_SS compared to MOB\_1, MOB\_4, MOB\_5 and MOB\_6

	MOB_SS	MOB_1	MOB_4	MOB_5	MOB_6
Some difficulty	1059	424	586	803	966
A lot of difficulty	371	119	194	398	331
Cannot do at all	28	20	36	42	69
Total number of people with difficulties (Some, a lot or cannot do)	1413 - 1458[1]	563	816	1243	1366
A lot of diff / Cannot do	399	139	230	440	400
Any difficulty on MOB_SS and no difficulty on extended question (Some, a lot or cannot do) – missed by extended set	--	905	712	388	248

[1] The number varies by which extended question MOB\_SS is crosstabulated with. The lowest number was for MOB\_5 which was skipped if people could not walk 100m (MOB\_4).

The figures presented in table 13 show:

- There is a clear progression in difficulty from MOB\_1 to MOB\_6. The more difficult the activity the more people will report difficulties.
- MOB\_5 and MOB\_6 most closely approximate the number of people identified as having difficulties by MOB\_SS
- MOB\_SS seems to be situated somewhere between MOB\_4 and MOB\_5 in the scale of difficulty.
- MOB\_6 picks up many more people who cannot climb steps than MOB\_SS further suggesting a process of averaging out applied by respondents for MOB\_SS between walking and climbing activities.

### Impact of using a mobility aid

MOB\_7 to MOB\_9 were only asked of people who reported using an aid. The following table presents the crosstabulations of the same questions with and without use of the aid, i.e. MOB\_4 by MOB\_7, MOB\_5 by MOB\_8 and MOB\_6 by MOB\_9.

Table 14: Impact of using a mobility aid

	MOB_4: walk 100m without aid	MOB_7: walk 100m with aid
No Difficulty	23	24
Some Difficulty	46	58
A lot of difficulty	46	37
Cannot do at all	20	9
Total persons	135	128
	MOB_5: walk 500m without aid	MOB_8: walk 500m with aid
No Difficulty	17	7
Some Difficulty	22	49
A lot of difficulty	62	48
Cannot do at all	14	16
Total persons	115	120
	MOB_6: climb 12 step without aid	MOB_9: climb 12 steps with aid
No Difficulty	12	4
Some Difficulty	25	55
A lot of difficulty	67	49
Cannot do at all	29	18
Total persons	133	126

Table 14 suggests that when a person has ‘a lot of difficulty’ walking or climbing stairs without the use of their aid, this difficulty is reduced to only ‘some difficulty’ with the use of their aid. However, the use of an aid does not seem to reduce all difficulties.

### Impact of a handrail on stairs

Table 15: Mob\_6 by P\_Mob\_6 - Difficulties climbing a flight of stairs without and with a handrail

		Do you have difficulty climbing stairs with a handrail?				
		No	Some	A lot	Unable to	Total
<b>Do you have difficulty walking up or down 12 steps?</b>	No	4,724	150	13	2	4,911
	Some	68	785	90	20	966
	A lot	3	26	236	64	331
	Unable to	0	0	2	67	69
	Total	4,795	961	341	153	6,299

The shaded cells on Table 15 show that there is a reasonable congruence between difficulties on MOB\_6 and P\_MOB\_6. The results along the diagonal suggest that when answering MOB\_6 the majority of respondents were probably thinking about handrails. The cells above the diagonal suggest, oddly that having handrails makes it more difficult for people to climb stairs. This does not assist in resolving the issue raised by the cognitive testing analysis of the question on climbing stairs.

## Impact of mobility difficulties on everyday activities

The 1775 respondents who reported at least ‘some difficulty’ on one or more of the mobility questions were asked about the impact this difficulty has on their everyday activities. Table 16 shows that 38 percent of these ‘mobility disabled’ respondents reported no impact, 48 percent a little impact and 14 percent reported a lot of or complete impact of these difficulties.

Table 16: Percentage of respondents with mobility difficulties on MOB\_SS reporting different levels of impact

<b>MOB_11: Impact on everyday activities</b>		
<b>Degree of impact</b>	<b>Frequency</b>	<b>Percent</b>
Not at all	670	37.7
A little	849	47.8
A lot	203	11.4
Completely	41	2.3
<b>Total</b>	<b>1775</b>	<b>100</b>

Table 17: Impact on everyday activities by degree of difficulty on MOB\_SS (%)

		<b>Impact on everyday activities (%)</b>				
		Not at all	A little	A lot	Completely	Total
<b>Do you have difficulty walking up or down 12 steps?</b>	No	27.8	13.8	4.9	2.4	17.9
	Some	63	68.4	24.6	2.4	59.6
	A lot	9.1	17.7	67	48.8	20.9
	Unable to	<1	<1	3.4	46.3	1.6
	<b>Total</b>	100	100	100	100	100

Table 17 shows that as the degree of difficulty increases so the impact increases as well. The respondents who had no difficulty on MOB\_SS but who responded to the impact question would have had difficulties on one of the other mobility questions (e.g. walking 500m or climbing a flight of stairs).

## Conclusions and recommendations on mobility questions

The mobility questions used in the field test provide a useful scale of difficulty and are able to show the impact of using assistive devices such as walkers and wheelchairs. The results do not clarify the issue of what people are considering in relation to handrails and climbing stairs.

Since the single Short Set question (MOB\_SS) considers both walking and climbing, it is recommended that MOB\_6 be retained to obtain information on climbing stairs and that MOB\_4 be retained for walking since it lies somewhere in between the easy activity of moving around one’s home and the more complex activity of walking 500m. However, if space is not at a premium on a questionnaire, the use of 4 questions – walking or climbing stairs, moving around in one’s house, walking 100m and climbing stairs – is recommended. Difficulties walking 500m may be too sensitive and pick up false positives.

## Recommended extended set for Mobility

Two options are proposed for the extended set for the mobility domain. The first is preferred if there is sufficient space on the questionnaire, while the second option would be for questionnaires with limited space.

### **Option 1: (skip patterns not fully included)**

1. Do you have difficulty walking or climbing steps?
2. Do you have difficulty moving around inside your home?
3. Do you use any equipment or receive help for getting around?  
*If "Yes" to Q3, continue with Q4 and include [aid clause] in Q5, 6 and 7.*
4. Do you use any of the following? [Use list as for field testing questionnaire]
5. Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the use of your aid]?
6. Do you have difficulty walking half a km (500m) on level ground, that would be the length of five football fields or five city blocks [without the use of your aid]?
7. Do you have difficulty walking up or down 12 steps [without the use of your aid]?  
*If person has no difficulty on any of the questions or has difficulty but doesn't use an assistive device.*
8. Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using your aid?
9. Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks, when using your aid?
10. Do you have difficulty walking up or down 12 steps, even when using your aid?

### **Option 2: (skip patterns not fully included)**

1. Do you have difficulty walking or climbing steps?
2. Do you use any equipment or receive help for getting around?
3. Do you use any of the following? [Use list as for field testing questionnaire]
4. Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the use of your aid]?
5. Do you have difficulty walking up or down 12 steps [without the use of your aid]?
6. Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using your aid?
7. Do you have difficulty walking up or down 12 steps, even when using your aid?

# Communication chapter

## Introduction

Communication is a domain of function that is crucial for expressing our 'humanness'. People with difficulties in communicating face significant barriers in their everyday lives – intolerance from people who do not understand them, feelings of isolation when they cannot understand what people are saying and generally struggling to get their needs and feelings to be understood by others. The point of communication is to get meaning across and in order for that to happen, a person must be able to express him/herself (expressive communication) and understand others (receptive communication).

Successful expressive language requires a series of processes starting with an idea, generating a meaningful and grammatical sentence to express that idea and ending off with the voice and mouth movements or signs (in Sign Language) that 'speak' this idea and related sentence. All of this requires a functioning cognitive system, knowledge of the language rules (grammar, semantics and phonology), and intact voice and oral structures (for spoken language) and hands (for sign language).

Successful receptive language starts off with adequate hearing of the communication segment (or seeing for sign language use) followed by the ability to process the phonology, grammar and semantics of the message ending off with the cognitive processing of the message.

People who have communication difficulties have problems such as aphasia and or dysarthria<sup>1</sup> from a stroke, head injury or cerebral palsy (acquired at birth), stuttering, poor articulation due to a cleft lip and/or palate, loss of dentition, or loss of their voice through removal of their larynx or other trauma. People with cognitive problems will be unable to understand people or produce meaningful language. These are some of the more typical causes of communication difficulties due to factors other than hearing loss, which in itself affects communication significantly.

### **The impact of hearing on communication:**

Hearing loss has a range of possible impacts on communication related to both the degree and the age of onset of the hearing loss. Seemingly contradictory patterns of responses on communication difficulty can often be explained by these different impacts of hearing loss.

A person who is deaf from birth will struggle to speak and would most likely respond as having only 'some' or 'no difficulty' in communicating in their usual language (if they use and consider sign language as their usual language) but would have significant difficulty in speaking and being understood by others.

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<sup>1</sup> Aphasia is the loss of receptive and/or expressive language abilities and dysarthria is the loss of the ability to voice and articulate sounds clearly (only expressive language).

People who acquire a hearing loss later in life would have good ability to speak and hence would have little or no difficulty being understood by others, but would have significant difficulty understanding others when they speak (hence difficulty in communicating).

The degree of hearing loss will vary the impact on communication, with mild and moderate hearing loss having minimal impact on communicating, while more severe hearing loss having greater impact.

**Communication in the ICF:**

Communication is a chapter level domain of functioning in the Activity/Participation classification of the ICF. Chapter 3 of the classification describes domains of receiving and producing messages in spoken language, formal sign language, written language and non-verbal messages. The additional domain is that of starting, sustaining and ending conversations and discussions, and using communication devices and techniques. The questions asked in the WG Extended Set includes a general question on using one’s usual language (be it spoken or sign language) including both receptive and expressive language, and about speaking specifically (production of or expressive language). Thus the questions are quite general and cover both production and reception of language.

**Cognitive testing**

The communication questions included in the cognitive interviews are presented in the box below. As a set, the intent of the questions is to ask about difficulties communicating in one’s usual language which could include either spoken or sign language, followed by a specific consideration of speaking or expressive language which could include physical aspects such as voicing and articulation, as well as producing a meaningful sentence or message which would include aspects of cognition. The intent is not to capture people who are communicating in a foreign language and experiencing problems, or other aspects that are not related to one’s ability to communicate in one’s own language.

**Box 1: Communication questions for cognitive testing**

Questions	Response Options
SS4 Using you usual (customary) language, do you have difficulty communicating, for example understanding or being understood?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) cannot do at all/ unable to do
4.1 Do people have difficulty understanding you when you speak?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) cannot do at all/ unable to do
4.2 Do you use any of these forms of communication?	a) sign language b) hand writing c) typed or text messages d) communication or picture board cards e) computer assisted communication device f) an interpreter g) other (specific)

Investigation into the performance of the questions addresses 1) how well questions tapped into the intended construct of communication and 2) the extent to which the second and third questions were



able to add additional information about those difficulties. Additionally, as with all of the domains, examining the questions' performance across countries indicates the extent of comparability in the measures across different language groups and socio-cultural regions.

Table 1: Responses for all countries on Questions 1 and 2

	Do you have difficulty communicating, for example understanding or being understood?				Do people have difficulty understanding you when you speak?			
	No	Some	A lot	Unable to	No	Some	A lot	Unable to
Australia	1	1	<1	<1	1	1	<1	<1
Cambodia	7	1	2	<1	8	<1	1	<1
Canada	12	<1	<1	<1	9	4	<1	<1
Kazakhstan	15	5	<1	<1	12	7	<1	<1
Maldives	14	1	4	<1	14	2	3	1
Mongolia	17	1	2	<1	17	1	2	<1
Philippines	14	2	1	<1	14	5	<1	<1
S Africa	6	<1	<1	<1	6	<1	<1	<1
Sri Lanka	4	<1	1	<1	3	1	<1	1
USA	13	5	<1	<1	11	7	<1	<1
<b>Total</b>	<b>103</b>	<b>16</b>	<b>10</b>	<b>&lt;1</b>	<b>95</b>	<b>28</b>	<b>6</b>	<b>2</b>

Of the 129 respondents who were asked the initial Washington Group short set question on communication, 80 percent reported no difficulty communicating. (See table 1 ). While no respondents reported that they were 'unable' to communicate, 12 percent reported 'some difficulty' and another 8 percent that they had 'a lot of difficulty' communicating. For the extended set question (Q4.1), 72 percent reported having no difficulty being understood, almost 22 percent having 'some difficulty' and almost 5 percent having 'a lot of difficulty' communicating. Two respondents answered that they are 'unable to be understood' (Q 4.1) while reporting only 'a lot of difficulty' to the first question. The first of these respondents (from Maldives) seems to have indicated 'unable to do' for both questions but it seems that the interviewer felt that she more likely had 'a lot of difficulty' and noted it as such. Thus the respondent may have chosen 'unable to do' for both questions reflecting her own over estimation (since she was able to do the interview) of the level of difficulty she has. The second respondent (from Sri Lanka) is a deaf man who does not speak but communicates well with his family using sign language. This would explain his report of 'unable to be understood' when speaking but only 'a lot of difficulty' when communicating in his usual language. The difficulty in the latter would be evident for him when communicating with people who do not use sign language. It is unlikely that a response of 'unable to communicate' would be reported on any of these interviews as they were all direct interviews (not proxy). But it is very likely that a person is unable to be understood but can communicate, such as for a Deaf person who uses sign language.

Regarding the assistive device question (Q 4.2), 24 respondents indicated that they used at least one of the presented forms of communication. While some of those respondents clearly did rely on a particular method, such as sign language, to communicate, many respondents simply did not understand the intent of the question. For example, a Kazakhstan teacher explained that he did not use

any of the methods for means of dialogue, but at lessons used special picture and cards. The narrative provided for one United States respondent also illustrates the extent of the misunderstanding:

She interpreted these questions very strangely because she didn't get that the question was asking about the use of alternative forms of communication. For typed or text messages she said, "Do I text messages to other messages as far as communicating? Yes." Cards were interpreted as Hallmark cards. "Cards." I probed with what kind of cards are you thinking about and she said, "Oh I was thinking of the regular cards - Hallmark. You're probably talking about the other kind of cards so no." She thought of regular computer usage for "computer assisted communication device." "Computer assisted - what do you mean by that? I use the computer for e-mail." I asked if she thought that should count here and she said, "I don't know, but I use the computer."

This respondent reported having 'some difficulty' on both communication questions. There are no notes available to understand why she reported 'some difficulty'. However, a person with some difficulty communicating is not likely to need assistive devices for improving their communication. Communication assistive devices are not common (due to expense and few people requiring them) and hence not familiar. It is possible that were she more familiar with such devices she would not have been confused as to the intent of the question on using assistive devices.

With regard to the first question, examination of the narratives indicates that at least 9 respondents experienced some kind of comprehension difficulty because they either asked for the question to be repeated, asked for clarification or simply stated that they did not understand the question. It is also possible that more respondents experienced this difficulty but this was not documented in the narratives. There appeared to be fewer difficulties associated with the second question, although, again, it may be that the difficulties were simply not documented. Because of the limited amount of detail in the narratives, it is difficult to determine the exact nature of the respondents' difficulty, although it appears that the difficulty stems from respondents not entirely understanding what the question is attempting to measure. For example, the narrative from a Cambodian respondent quotes the respondent as saying, "What mean Communication here? You mean in speaking? I don't have any problems at all in speaking."

It appears that respondents ultimately based their answers on a handful of various interpretations of the questions. Those respondents with no difficulty typically described their ability in general terms, such as "I have no difficulty communicating or in being understood." However, those who reported difficulty described more specific problems. As would be expected, the first question captured a broader range of communication-related problems than did the second question. Those types of problems for the first question are presented in the table below for each country and include:

*Physical impairments*, whereby respondents described problems with their tongues or mouths that prevent them from being able to speak clearly,

*Cognition-related problems*, in which respondents described difficulties remembering or concentrating such that it is not easy to focus on what others are saying or to speak at length, for example, to tell a story.

*Hearing-related problems* that prevent respondents from being able to clearly hear what others are saying, and

*Social or interactional difficulties*, whereby respondents described having problems interacting or relating to others. These social difficulties could also be broken down into sub-categories, specifically, a) respondents expressing difficulty because they are shy, b) because they talk too fast, c) because of interpersonal problems relating to others such as a spouse or child, or d) because they do not have much education and feel insecure talking to those who do.

Table 2: Type of communication problems for cognitive interview respondents for 9 countries

	General- communication skills	Physical	Cognition	Hearing	Social/Interactional			
					Shy	Fast- talking	Inter- personal	Education
Cambodia	7	<1	1	<1	2	1	1	4
Canada	1	<1	<1	1	<1	1	3	<1
Kazakhstan	6	<1	<1	2	<1	<1	<1	<1
Maldives	2	1	<1	2	<1	<1	<1	<1
Mongolia	2	<1	<1	1	<1	<1	<1	<1
Philippines	2	1	<1	2	<1	<1	<1	<1
South Africa	1	<1	<1	<1	<1	<1	<1	<1
Sri Lanka	1	1	<1	<1	<1	<1	1	<1
United States	7	<1	1	<1	<1	2	2	1
Total (70)	29	3	2	8	2	4	7	5
% (out of 70)	41	4	3	11	3	6	10	7

\* Table includes only the cases that were included enough detail to categorize within a particular interpretive theme.

While the first three themes (physical, cognitive and hearing) clearly fall within the intended scope of the question, this is not entirely true for the social or interactional theme. Indeed, some of these latter difficulties could be learning or affect-related problems or out-of-scope problems. For example, the narrative provided by one Canadian respondent appears to indicate that the respondent based her answer (some difficulty) on the quality of her marital relationship:

just trying to get my point across ... say if my partner isn't listening ...(Do you feel that you have difficulty describing things to me?) no ...well it's not so much delivery of the message...it's being heard

Similarly, the narrative for a Cambodian respondent appears to indicate that the respondent has interpreted the question as being about literacy:

when I ask her this question, she answer “a lot of difficulty” and she interpreted this question in this way “I never go to school, I cannot write or read, I have no education at all, so it is very difficult for communicating with other people, specifically with people who has high education”.

In other cases, it is difficult to discern whether a respondent’s reported difficulty is within scope, but closer to the normative end of a severity continuum. For example, it is not clear from the narrative whether a Cambodian respondent quoted below is reporting a type of social or personal disability or

whether he is simply reporting that, as a general rule, extra effort is required to hold a conversation with a new person:

when I ask him this question, he thinks awhile and answer some difficulty and he responded this question in this way “ if we are not friendly to each other and we are just know each other, it mean just meet each other at the first time, it may be have some difficulty in communicating”.

Similarly, it is not clear whether one of the respondents from the United States is reporting an actual difficulty or whether he is simply describing an attribute of his personality:

He says some difficulty because he's "tongue-tied". He explains that sometimes he speaks very fast and his words run together. He can tell that people don't understand him by the expressions on their faces. He can't think of the last time that this happened, but he knows it happens by their body language. It doesn't happen that often, but it will happen when he is excited or in a hurry. He says this could be a problem but it's "fixable" because he knows what it is, he just has to practice slowing down.

One clear out-of-scope pattern, however, did emerge through the analysis of the narratives. Specifically, some respondents described their communication problems as being related to having a “thick accent” or not knowing a language that is commonly spoken in their neighborhood. For example, the narrative from a Kazakhstan respondent explains that “more often the respondent speaks in Russian, but some people who badly know Russian sometimes do not understand him”. Similarly, a respondent from the Philippines notes that “the respondent mentioned that sometimes people do not understand him since he speaks in the traditional language (not the usually spoken language).”

It is important to note that, of the 13 respondents who appeared to interpret the question as being language-related, only 3 reported having at least ‘some difficulty’. The other 10 respondents reported ‘no difficulty’. When justifying their answer, these respondents reported that they are bi-lingual. Therefore, while the majority of these respondents did not ultimately produce error, the finding illustrates the existence of this particular interpretive pattern that is potentially problematic. For the field test, it was important to determine the extent that this interpretive pattern produces actual error and whether it is more of a problem for specific countries or ethnic groups.

With regard to the constructs captured, the second communication question appears to repeat the first question for many respondents, although respondents considered a more limited range of experiences in the second question. Specifically, in the second question, respondents focused more on speaking as opposed to listening, understanding or writing and reading. However, the same speaking-related themes (e.g. language, fast-talking) carried over to the second question.

Table 3: Comparison of responses on Question 1 and Question 2

		Do you have difficulty communicating, for example understanding or being understood?		
		No difficulty	Yes, Some	Yes, A Lot
<b>Do people have difficulty understanding you when you speak?</b>	No difficulty	97	6	3
	Yes, Some	14	16	2
	Yes, A Lot	<1	<1	7
	Cannot Do	<1	<1	2

Examining the crosstab of the two questions illustrates how the two questions are highly related (See table 3). By examining the narratives, the seemingly contradictory, off-diagonal cases can be explained. Many of the cases fall off the diagonal simply because the first question refers to communication in general, while the second question is more specifically about spoken and expressive language. For example, a United States respondent answered ‘some’ on Question SS4 because of a concentration problem that prevents him from listening and fully understanding what others say. However, he has no problem speaking (question 4.1). Additionally, the 3 respondents who answered ‘a lot of difficulty’ to the first question, but ‘no difficulty’ to the second question, were all Cambodian respondents who answered the first question thinking about their lack of education and low literacy. In the second question, they were thinking specifically about their ability to speak.

The respondents who answered ‘no difficulty’ on question SS4 but ‘some difficulty’ on question 2 could be people with problems such as talking too fast or a more significant difficulty such as stuttering, dysarthria or a voice problem (e.g. when a person’s larynx has been removed). From the narratives, it does appear that some of these respondents were unclear about the meaning of the question and either asked for the question to be repeated or asked for clarification. There is no systematic explanation, and the apparent contradictions seem idiosyncratic to each respondent. For example the narrative for a Kazakhstan respondent notes that he answered ‘no difficulty’ to the first question because the respondent is a teacher and is in the “habit to speak accurately and clearly.” However, the narrative for the second question explains that he answered some difficulty because sometimes he must explain things twice to students. This is clearly an out of scope response and should be recorded as a false positive.

In terms of examining how and why respondents came to choose their answer, there is little to no information in the narratives to inform our understanding of these processes.

### Conclusions from cognitive testing of Communication questions

Findings from analysis of the cognitive interviews informed several decisions regarding the revision of questions (see Box 2) as well as to generate hypotheses about the questions’ performance that would be further investigated in the field test. The main change was to drop the assistive device question and

replace it with a simpler question asking about sign language use (Com\_2). While more detailed information may be important, it seemed unlikely that another question could be written in the time required. Furthermore, as described above, the need for communication assistive devices is rare and thus not familiar to many people, unlike hearing aids, eye glasses and wheelchairs. The lack of familiarity leads to some confusion on what is being asked in the full question asked in the cognitive testing.

Because of the lack of information in the cognitive interviews, it was also determined that the field test would be used to fill in those gaps of knowledge. In particular, the field test would be used to determine the existence of the various patterns of interpretation used by respondents to answer the questions. To this end, probe questions (P\_COM\_1 A - E) were generated from the interpretive patterns identified in the cognitive interviews. This field test data, then, would be used to determine the actual prevalence of these patterns and their variance within different socio-cultural groups. As in the other domains, questions about age of onset and limitation in daily activities (ANX\_6, P\_ANX\_6A - P\_ANX\_6I; DEP\_6, P\_DEP\_6A-P\_DEP\_6I) were also included.

### Field testing

Box 2 presents the questions as they appeared on the field testing questionnaire.

#### Box 2: Communication questions asked in the pilot testing

Questions	Response Options
COM_SS Using your usual language, do you have difficulty communicating, for example understanding or being understood?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>
COM_1 Do people have difficulty understanding you when you speak?	1) Yes 2) No 7) <i>Refused</i> 9) <i>Don't know</i>  <i>If "No difficulty" or "Don't know" to COM_SS and COM_1 then skip to COM_2</i>
P_COM_1 Is this difficulty:	a) Because you sometimes feel shy or have trouble expressing yourself? b) Because of a physical problem with your mouth or tongue? c) Because you need to understand other languages or different ways of speaking? d) Because you sometimes talk too fast? e) Because you have trouble hearing?  <i>If "No" to all P_COM_1, continue with P_COM_2. Otherwise, skip to COM_2.</i>
P_COM_2 What is your difficulty related to?	<i>Interviewer: Record answer</i> _____

COM_2 Do you use sign language?	1. Yes 2. No 7. <i>Refused</i> 9. <i>Don't know</i>  <i>If "No difficulty" to COM_SS and "No difficulty" to COM_I, skip to Section F Cognition.</i>
COM_3 How old were you when the difficulty communicating began?	_____ age in years 777) <i>Refused</i> 999) <i>Don't know</i>
COM_4 How much does your difficulty communicating limit your ability to carry out daily activities?	1) Not at all 2) A little 3) A lot 4) Completely 7) <i>Refused</i> 9) <i>Don't know</i>

### Difficulty communicating and being understood by others when speaking

The communication section of the field test includes two questions. The first question (COM\_SS) asks respondents, "Using your usual language, do you have difficulty communicating, for example understanding or being understood?" The distribution of the responses to this question by country is illustrated in Table 4a. Approximately one in twenty respondents (5.1 percent) reported at least some difficulty with communication. The table shows very little variation by country.

Table 4a. Difficulty communicating by country.

Frequency	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
No difficulty	93%	95%	95%	96%	95%	95%	95%
Some difficulty	5%	4%	4%	3%	4%	3%	4%
A lot of difficulty	1%	1%	1%	1%	1%	2%	1%
Cannot do at all	0%	0%	1%	0%	0%	0%	0%
Refused	0%	0%	0%	0%	0%	0%	0%
Don't know	0%	0%	0%	0%	0%	0%	0%
Total persons	1000	1008	1000	1013	1222	1066	6309

The second question (COM\_1) in this section asks respondents, "Do people have difficulty understanding you when you speak?" The distribution of the responses to this question by country is shown in Table 4b. Once again, approximately one in twenty respondents (4.9 percent) reported at least some difficulty with being understood by others when speaking. There was some variation by country in the responses. Mainly, respondents from Kazakhstan reported slightly higher levels of difficulty than respondents from other countries.

Table 4b. Difficulty being understood by others when speaking by country.

Frequency	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
No difficulty	92%	96%	97%	94%	95%	96%	95%
Some difficulty	6%	4%	2%	4%	4%	4%	4%
A lot of difficulty	1%	1%	0%	1%	1%	1%	1%
Cannot do at all	0%	0%	0%	0%	0%	0%	0%
Refused	0%	0%	0%	0%	0%	0%	0%
Don't know	0%	0%	0%	1%	0%	0%	0%
Total persons	1000	1008	1000	1013	1222	1066	6309

There is some variation in the response to both of these questions by age. In general, the percentage of respondents reporting difficulty remains steady at about five percent until age 70. In contrast, more than ten percent of respondents over age 70 - for both questions - report at least some difficulty with communication. This could be explained in part by increases in the incidence of stroke and hearing loss in older people.

### Reasons for communication difficulty

Analysis of the cognitive interview data revealed several reasons why respondents might express communication problems. These potential reasons include feeling shy or having trouble expressing yourself, physical problems with the mouth or tongue, needing to understand different languages, talking too fast, or trouble hearing. The percent reporting these various reasons by country is shown in Table 5. There is significant variation by country with respect to these reasons for communication difficulty. Overall, nearly half of respondents report that their difficulty communicating is either because they feel shy or have trouble expressing themselves. Slightly more than one third of respondents report that their communication difficulty is due to a physical problem with their mouth or tongue or trouble hearing. Approximately three in ten respondents report that their communication difficulty is due to understanding different languages or talking too fast.

Table 5. Percentage of respondents reporting various reasons for communication problems by country.

Description of feelings	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
Shy**	60%	47%	22%	34%	62%	42%	47%
Mouth**	33%	55%	21%	14%	59%	20%	35%
Language**	44%	30%	4%	23%	46%	24%	31%
Fast**	21%	34%	17%	36%	37%	36%	30%
Hear	35%	45%	33%	19%	39%	36%	34%

\*\*Denotes significant differences ( $p < .05$ ) across countries.

The percentage of respondents reporting these reasons for communication difficulty by the level of difficulty that they experience communicating is shown in Table 6a. Respondents who answered 'some difficulty' to the first communication question (COM\_SS) were more likely to report difficulty due to shyness or trouble expressing themselves than respondents who answered 'a lot of difficulty' or 'cannot do at all'. Respondents who answered 'a lot of difficulty' or 'cannot do at all' were more likely to report difficulty due to problems with their mouth or tongue than respondents who answered 'some difficulty'.



Table 6a. Percentage of respondents reporting various reasons for communication problems by difficulty communicating.

Description of feelings	Some difficulty	A lot of difficulty/ Cannot do at all
Shy**	52%	30%
Mouth**	29%	56%
Language	34%	26%
Fast	29%	18%
Hear	39%	42%

\*\*Denotes significant difference ( $p < .05$ ) across levels of difficulty.

As shown in Table 6b, similar patterns were found for difficulty being understood by others when speaking (COM\_1). In addition, respondents who answered 'some difficulty' to the second question were more likely to report difficulty due to talking too fast than respondents who answered 'a lot of difficulty' or 'cannot do at all'. Respondents who answered 'a lot of difficulty' or 'cannot do at all' were more likely to report difficulty due to trouble hearing.

Table 6b. Percentage of respondents reporting various reasons for communication problems by amount of difficulty being understood by others when speaking.

Description of feelings	Some difficulty	A lot of difficulty/ Cannot do at all
Shy**	57%	25%
Mouth**	36%	62%
Language	33%	27%
Fast**	40%	16%
Hear**	30%	46%

\*\*Denotes significant difference ( $p < .05$ ) across levels of difficulty.

In summary, it seems that giving responses of 'a lot of difficulty' or 'unable to do' on the communication questions is most likely to indicate problems that are real communication disabilities rather than due to problems such as being shy or talking too fast.

Table 7 analyses the responses on the reasons given for the difficulty communicating. Since Kazakhstan showed responses that seemed to be different from the other 5 countries, the data were analysed for Kazakhstan separately. The response patterns were categorized into:

- Physical: only mouth or hearing problem
- Social: only shy, language or fast talking problem
- Hybrids: report both types of problems, physical and social.

Table 7: Analysis of reasons for communication difficulty

		Difficulty communicating						
		No difficulty		Some difficulty		A lot of difficulty / can't do at all		
		Kazakhstan	Others	Kazakhstan	Others	Kazakhstan	Others	
Difficulty being understood by others when speaking	No difficulty	None			0	13		2
		Physical			1	26		3
		Social			10	22		0
		Hybrid			0	6		2
		Total persons			11	67	0	7
	Some difficulty	None	2	5	0	10	0	3
		Physical	0	5	9	21	0	1
		Social	15	25	17	33	0	4
		Hybrid	1	20	16	50	1	7
		Total persons	18	55	42	114	1	15
	A lot of difficulty/ Can't do at all	None		0		1	0	11
		Physical		3		0	7	11
		Social		1		0	1	5
		Hybrid		0		4	5	14
		Total persons		4		5	13	41

The table suggests the following patterns of responses:

- *No difficulty communicating with some difficulty speaking:* 15 Kazakhstan respondents gave a social reason compared to only one who gave a hybrid reason; for the other countries the same number (25) gave a social reason as gave a physical or hybrid reason.
- *No difficulty communicating with a lot of difficulty or unable to speak:* from the 5 countries (excluding Kazakhstan) 3 people gave a hybrid reason while 1 person gave a social reason.
- *Some difficulty communicating but no difficulty speaking:* 10 out of 11 respondents Kazakhstan gave a social reason while only 22 respondents from other countries gave a social reasons compared to 32 who gave a physical or hybrid reason.
- *Some difficulty communicating with a lot of difficulty or unable to speak:* the 4 respondents from the countries excluding Kazakhstan gave hybrid reasons.
- *A lot of difficulty/unable to communicate with no difficulty speaking:* No respondents in Kazakhstan gave such responses, while all reasons given by other countries were physical or hybrid (2 respondents did not give any reason)
- *Some difficulty both communicating and speaking:* In Kazakhstan 17 gave a social reason while 25 respondents gave a physical or hybrid reason. For the other countries, the pattern is the same but with many more reasons given being physical or hybrid (71) compared to social ones (33).
- *A lot of difficulty communicating with some difficulty speaking:* the single respondent in Kazakhstan gave a hybrid reason, while 8 respondents in the other countries gave a physical or hybrid reason compared to only 4 giving a social reason.
- *A lot of difficulty/unable to communicate and speak:* the majority of respondents gave physical or hybrid reasons for both Kazakhstan (12) and the other countries (25) while very few gave social reasons – 1 for Kazakhstan and 5 for the other countries.
- *No responses (none):* It is not clear why people did not give reasons.

These patterns confirm that the more severe the responses the more likely a person is to have a physical reason even if they also gave a social reason in addition (hybrid). Kazakhstan respondents tend to give social reasons more frequently than in the other 5 countries. The reasons for this require further investigation.

### Age and difficulties with Communication

Table 8: Percentage of respondents with difficulties with communication by age category

		Age							Total
		0-17	18-30	31-40	41-50	51-60	61-70	71+	
<b>Do you have difficulty communicating, for example understanding or being understood?</b>	No difficulty	94%	96%	97%	96%	94%	93%	83%	95%
	Some difficulty	4%	3%	3%	3%	4%	5%	10%	4%
	A lot of difficulty	1%	1%	0%	1%	1%	3%	5%	1%
	Cannot do at all	0%	0%	0%	0%	0%	0%	1%	0%

Table 8 shows that there is some increase in difficulty communicating with increasing age. The increase for respondents with 'some' or 'a lot of difficulty' communicating is from 5.2 percent for the age group 0 – 17 years to 15.6 percent of the 71+ years age group. Much of the increase in the older age groups could be due to increased hearing loss and reduced memory and concentration functions.

### Limitation in daily activities due to communication difficulty

Table 9a demonstrates the relationship between difficulty communicating and limitation in daily activities. More than four in five (86.6 percent) respondents who reported 'some difficulty' to the first communication question (COM\_SS) reported that they were 'not at all' or 'a little' limited in their daily activities. In contrast, more than half of respondents who answered 'a lot of difficulty' or 'cannot do at all' reported that they are 'a lot' or 'completely' limited in their daily activities.

Table 9a Limitation in daily activities by difficulty communicating

Limitation in daily activities	Some difficulty	A lot of difficulty/ Cannot do at all
Not at all	36%	13%
A little	50%	26%
A lot	9%	41%
Completely	1%	12%
Refused	1%	8%
Don't Know	2%	1%
Total persons	239	78

A very similar relationship is shown in Table 9b between difficulty being understood when speaking (COM\_1) and limitation in daily activities.

Table 9b. Limitation in daily activities by difficulty being understood by others when speaking.

Limitation in daily activities	A lot of difficulty/	
	Some difficulty	Cannot do at all
Not at all	42.90%	11.10%
A little	41.3	28.6
A lot	9.7	41.3
Completely	2	12.7
Refused	2.4	6.4
Don't Know	1.6	0
Total Persons	247	63

## Use of Sign Language

All respondents were asked whether they use sign language even if they reported no difficulty for both communicating and speaking. A bivariate logistic regression was undertaken to predict the response to the difficulty communicating and difficulty being understood questions in relation to a series of factors including sign language use. The results for sign language use are reported here while the other results will be reported in future publications.

For the communication question (COM\_SS), the use of sign language was significantly more likely to predict a response of 'a lot of difficulty/unable to do' (1.31) compared to a 'some difficulty' response (-.37). For the question on difficulties speaking, the same pattern was obtained but with greater coefficients : a coefficient of -.81 for predicting 'some difficulty', and a coefficient of 1.65 for predicting 'a lot of difficulty/unable to do'.

The use of this question thus confirms the issue of severity being related to problems with hearing already noted in the analysis for the two other questions.

## Conclusions and recommendations

The analysis presented in this chapter suggests the following:

1. The two questions on communicating (understanding and being understood) and speaking (being understood) perform well when people report more severe difficulties
2. Few people report severe difficulties on one question and not on the other.
3. There seems to be much duplication of information from both questions
4. The less severe difficulties tend to be clouded with what may be false positives where people report difficulties in a language that is not their usual language, or are shy or talk too fast as reasons for 'some difficulty' in communicating or speaking.
5. Few people generally report difficulties in communicating compared to other domains of functioning.
6. Few people report severe impact of communication difficulties on their everyday activities.
7. The question on use of sign language provides further confirmation of the severity of communication and speaking difficulties and provides useful information on the prevalence of sign language users in a population.

In order to ensure the most accurate information is collected with the least number of questions the recommendations for the extended are as follows:

- Retain the WG Short Set Question – COM\_SS as is
- The question on the use of sign language should remain as is.

## Cognition chapter

### Introduction

Cognition is a mental function which includes specific functions such as remembering, concentrating, learning and being able to analyze problems, find solutions and taking decisions. This chapter looks specifically at measuring remembering and concentrating. Measures of learning are dealt with in a separate chapter.

Problems in cognition, when severe, typically lead to a loss of independence that is difficult to manage with any assistive devices – there are none. This is contrary to the importance of assistive devices in ensuring independence for people with sensory and physical disabilities. Severe cognition difficulties are typically associated with senility, Alzheimer’s disease, intellectual disability, and other brain diseases and traumas. The objective of measures of cognition is thus to identify individuals who have an intellectual difficulty recalling and/or focusing on a task due to a health condition.

### Cognition and the ICF

Cognitive functions are enlisted in chapter one ‘Mental Functions’ of the WHO’s International Classification of Functioning, Disability and Health (ICF). Sub domains *b140: Attention functions* and *b144: Memory functions* are the focus of the cognition measures. Attention functions include concentrating and focusing on stimuli for the required period of time to complete a task, while memory functions refer to storing and retrieval of information when required.

### Cognitive testing

Of interest in the cognitive testing of cognition questions is the overlap between the task required of respondents and the domain of functioning being measured. Cognitive testing is about understanding the cognitive skills and processes that people bring to bear on responding to questions. This of course means that it is unlikely that any person with severe cognitive difficulties would take part in a cognitive testing interview.

#### Box 1: The questions included in the cognitive interview protocol

SS5. Do you have difficulty remembering or concentrating?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
<b>For first 10 interviews:</b> <b>SET A:</b> 5A.1 How often do you have difficulty remembering important things?	1) Never If <b>Never</b> , go to 5.C 2) Sometimes 3) Often 4) All of the time
5A.2 Thinking about the last time you had difficulty remembering important things, how much difficulty did you have?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do

<b>For second 10 interviews:</b> <b>SET B:</b> 5B.2 Do you have difficulty remembering a few things, a lot of things, or almost everything?	1) A few things 2) A lot of things 3) Almost everything
5.C How much difficulty did you have in concentrating on doing something for ten minutes?	1) None 2) Mild 3) Moderate 4) Severe 5) Extreme/Cannot Do

As outlined above, the sample was split in two in order to observe a) the periodicity and degree of difficulty remembering and, b) the number of things that are forgotten. The WHO's Disability Assessment Schedule (WHODAS II) question about concentrating for 10 minutes was added to provide some more detailed focus on concentrating. For all countries the response rate of reporting difficulty to this domain was quite high and similar patterns were identified for most questions throughout age, sex and geographical groups.

Question SS5 aims to assess a person's difficulty recalling and concentrating. The intention is to pick up difficulties that are more than what would be regarded as usual for the general population, such as difficulties concentrating because of a distracting environment or occasionally forgetting a minor or day-to-day matter. The question appears to be double-barreled, but the cognitive test shows, that, while most people throughout countries focus on the remembering part of the question, there is a mix in terms of persons that refer to both remembering and concentrating and those that refer to either separately.

Table 1 shows that around 40 percent of respondents did not report any difficulty either remembering or concentrating, as opposed to 50 percent who report 'some difficulty' and only nine percent reporting 'a lot of difficulty'. Types of responses chosen varied among interviewees, but were in most cases day-to-day matters such as telephone numbers, names, words, household chores, taking certain medicine, birthdays or other dates and appointments, misplacing items, pin numbers, and so on. In general, this appears to explain the high percentage of persons answering positively to only having 'some difficulty' to this question.

Table 1: Responses for all countries to SS5

<b>Do you have difficulty remembering or concentrating?</b>						
	<b>No</b>	<b>Some</b>	<b>A lot</b>	<b>Unable to</b>	<b>Skipped: not asked</b>	<b>Total persons</b>
Cambodia	3	9	5	<1	<1	17
Canada	4	11	<1	<1	<1	15
Kazakhstan	7	10	1	<1	<1	18
Maldives	9	7	4	<1	<1	20
Mongolia	9	11	<1	<1	<1	20
Philippines	12	7	1	<1	<1	20
South Africa	7	2	<1	<1	<1	9
Sri Lanka	3	5	1	<1	<1	9
United States	4	13	1	<1	1	19
<b>Total Persons</b>	<b>58</b>	<b>75</b>	<b>13</b>	<b>&lt;1</b>	<b>1</b>	<b>147</b>

Based on these results and a lack of conclusive evidence as to whether the doubled barrelled structure of the question is a problem, an additional question was included for the field test, namely: ‘Do you have difficulty remembering, concentrating, or both?’, the analysis of which will be further elaborated on, in the next section on the field test.

Question 5A.1 addresses the nature of a person’s difficulty remembering, in particular, its frequency. Previous tests of this question (Miller et. al., 2008) suggested that the word ‘important’ did not add any relevant information and furthermore introduced some ‘noise’ given that each interviewee interpreted the notion of ‘important’ in different ways. During the 8th Washington Group meeting in 2008, however, the particular working group addressing this domain recommended to keep the word ‘important’, given that the intention of this domain was to, as mentioned before, pick up difficulties that are more than what is regarded as day-to-day or mundane problems.

The cognitive test confirmed that the interpretation of the phrase ‘important things’ varied widely among respondents, from mundane issues such as appointments and meetings with friends or birthdays, to more relevant things like remembering to eat, bath or changing clothes. Comments from one Maldives respondent stated, for example: ‘She takes meals when she sees someone eating otherwise she won’t remember and she cry (sic)[,] after she feels hungry.’ Moreover, several respondents directly asked interviewers what they should consider or understand as important. Based on these findings the word ‘important’ was dropped for the field test.

In terms of frequency, ‘sometimes’ was the most reported category with 33 percent, as opposed to 23 percent who said they ‘never’ experienced difficulty remembering important things, while only 6 percent answered ‘often’ as observed in table 2. Based on such results, it was decided to keep the question in the same form except for deleting the expression ‘important things’, to see how respondents would react to the question in the field test.

Table 2: Responses for all countries to 5A1

<b>Do you have difficulty remembering important things?</b>						
	<b>No</b>	<b>Some</b>	<b>A lot</b>	<b>Unable to</b>	<b>Skipped: not asked</b>	<b>Total persons</b>
Cambodia	3	6	1	0	7	17
Canada	3	4	2	0	7	16
Kazakhstan	5	3	2	0	7	17
Maldives	1	6	2	1	8	18
Mongolia	4	8	0	0	8	20
Philippines	7	5	1	0	4	17
South Africa	3	2	0	0	1	6
Sri Lanka	1	5	0	0	2	8
United States	4	6	0	0	8	18
<b>Total Persons</b>	<b>31</b>	<b>45</b>	<b>8</b>	<b>1</b>	<b>52</b>	<b>137</b>

Although question 5A.2 is a subset of the previous one, most respondents either expressed confusion with the question or suggested it was similar to the prior one. One US respondent pointedly commented: ‘either [you] remember something or you don’t’. This appeared to reflect a general pattern found in the overall results of the cognitive test for this question.

Hence, the confusion created by this question and the number of times it was misinterpreted, lead to it being dropped for the field test.

In the second subset, question 5B.2 intended to address the number of things that are forgotten. The category ‘few things’ is by far the most frequently reported one at 30 percent, followed by ‘a lot of things’ with 8 percent and ‘almost everything’ with 5 percent (see table 3). The ‘few things’ category is also almost always linked to day-to-day items such as telephone numbers, names, household chores, dates, misplacing items, and appointments – all more minor things.

Table 3: Responses for all countries to 5B2

<b>Do you have difficulty remembering a few things, a lot of things, or almost everything?</b>					
	A few things	A lot of things	Almost everything	Skipped: Not asked	Total
Cambodia	5	1	2	6	14
Canada	10	1	0	5	16
Kazakhstan	7	0	0	7	14
Maldives	4	2	0	12	18
Mongolia	3	4	1	12	20
Philippines	1	1	1	13	16
South Africa	1	1	0	5	7
Sri Lanka	4	0	0	3	7
United States	4	0	2	11	17
<b>Total Persons</b>	39	10	6	74	129

More interestingly, if this last question is cross-tabulated with the main question for the domain, it can be observed that no one who reported having a ‘lot of difficulty’ to remembering or concentrating indicates having difficulties in remembering only ‘a few things’. Quite in contrast, the large majority, 70 percent of those reporting difficulty only forgetting ‘a few things’ also report ‘no difficulty’ or just ‘some difficulty’ to the main question of this domain. This points to the fact that for those respondents just indicating ‘some difficulty’ to SS5, the majority just has difficulty remembering ‘a few things’.<sup>1</sup>

<sup>1</sup> Noticeable exceptions are two Mongolia respondents who report ‘no difficulty’ to SS5 and one reporting ‘almost everything’ and the other ‘a lot of things’ to 5B.2. Little information is available in the cognitive test data to explain these responses. One states ‘sometimes I mix up things’, while the other states: ‘She is muddled when remembering a lot of things. For instance, she is confused about when something will happen.’ This scarce and inconclusive information seems too little as to challenge an overall pattern and it probably a false positive in question 5B.2.



Table 4: Responses SS5 vs 5B.2

		Do you have difficulty remembering or concentrating?					
		No	Some	A lot			
Do you have difficulty remembering a few things, a lot of things, or almost everything?	A few things	Cambodia	1	Cambodia	4		
		Canada	2	Canada	7		
		Kazakhstan	1	Kazakhstan	6		
		Maldives	0	Maldives	4		
		Mongolia	1	Mongolia	2		
		Philippines	1	Philippines	0		
		South Africa	0	South Africa	1		
		Sri Lanka	1	Sri Lanka	3		
		United States	0	United States	4		
		<i>Total</i>	7	<i>Total</i>	31		
		<i>13 percent of cases</i>	<i>57 percent of cases</i>				
	A lot of things	Mongolia	1	Canada	1	Cambodia	1
				Mongolia	3	Maldives	2
			Philippines	1	Sri Lanka	1	
		<i>2 percent of cases</i>	<i>9 percent of cases</i>	<i>7 percent of cases</i>			
	Almost everything	Mongolia	1	Philippines	1	Cambodia	2
				United States	2		
		<i>2 percent of cases</i>	<i>6 percent of cases</i>	<i>4 percent of cases</i>			

Question 5.C was included in the cognitive protocol to highlight the concentrating component of the short set question for censuses SS5 as all other extended questions focus on remembering. One interesting characteristic observed for this question was the fact that the majority of respondents focused on the ‘10 minutes’ clause. While some interviewees suggested that 10 minutes was too short to concentrate on anything, others indicated little could be accomplished in terms of focusing in such a short period. Hence, the analysis of the cognitive test suggests that the focus on this part of the question was a leading cause for confusion among respondents.

Additional confusion seems to have derived from respondents’ understanding of the word concentrating, indicated by a heterogeneous mix of responses amongst countries. In some cases such as for three Maldives respondents, the term was linked to things they found could catch their personal interest. A somehow similar case was found in Canada, where enjoyment of an activity was put forward as an example of not having difficulty concentrating for just 10 minutes. Four South African respondents, in contrast, described focusing on a specific task or activity such as their daily work or jobs, and avoided providing clear responses on concentrating.<sup>2</sup>

On the whole, question 5.C seemed to generate mixed and confusing results, with ‘it depends’ being one of the most frequently used response to this question. In the absence of a viable alternative, however, it was retained for the field test as to get further information

<sup>2</sup> In South Africa (except for one English speaking respondent) there was an issue with translation where concentrating was translated more as ‘doing’ something than ‘focusing’ on a task.

on how people understand and respond to this question. The answer category was modified, nevertheless, to make the field survey response options consistent throughout.<sup>3</sup>

While no conclusive evidence was found in the cognitive analysis that SS5's double-barreled structure was a problem, answers to 5.C suggest that few respondents have difficulties concentrating. Over three-quarters of all interviewees reported having 'none' or only 'mild difficulties' concentrating. Four percent of respondents mentioned having moderate difficulties while only two percent reported having severe difficulties concentrating.<sup>4</sup>

Table 5: Responses for all countries to 5.c

<b>Do you have difficulty in concentrating on doing something for ten minutes?</b>							
	None	Mild	Moderate	Severe	Extreme/ Cannot do	Skipped: Not asked	Total
Cambodia	6	6	2	2	<1	<1	16
Canada	11	3	2	<1	<1	<1	16
Kazakhstan	11	5	<1	<1	<1	<1	16
Maldives	16	3	<1	<1	<1	1	20
Mongolia	12	3	<1	<1	<1	5	20
Philippines	3	2	1	<1	<1	12	18
South Africa	5	1	<1	<1	<1	<1	6
Sri Lanka	5	1	<1	1	<1	<1	7
United States	8	3	1	<1	<1	6	18
<b>Total Persons</b>	<b>77</b>	<b>27</b>	<b>6</b>	<b>3</b>	<b>&lt;1</b>	<b>24</b>	<b>137</b>

## Conclusions from the Cognitive testing

Based on the results from the cognitive test, it was decided to retain SS5 (renamed COG\_SS for the field test) and add some questions to test more conclusively if SS5 functions as a single or double barrelled question.

Revision of questions from cognitive test (see Box 2 in next section for the questions):

- Add COG\_1 to address the issue of the double-barrelled structure of SS5/COG\_SS
- Reword 5A.1 eliminating the phrase 'important things';
- Retaining questions 5B.2, (COG\_3 in box 2) and 5.C (COG\_4 in box 2).
- Given the wide range of different items reported between those answering 'some difficulty' and those responding a 'lot of difficulty' and 'cannot do at all', a set of probe questions (P\_COG\_3 in box 2), to investigate what respondents were thinking about when answering positively to having difficulty remembering and concentrating. In particular, the probe set was intended as a way to separate those respondents who report forgetting usual or day-to-day things as opposed to those persons with intellectual difficulties or a health condition and more severe difficulties. The answers to this probe as well as the pilot test questions are discussed in the next section.

<sup>3</sup> It is worth mentioning that no particular problems were encountered in terms of the WHODAS response category options as opposed to the WG ones for this and other domains. Further testing of this would, however, be highly beneficial in any future exercise.

<sup>4</sup> Worth clarifying is that 11 of the 24 cases skipped, i.e. around 10 percent of this sample were strangely not asked this question even whilst having reported at least some difficulty to SS5.

## Field test

### Box 2: Field test questions on cognition

Questions	Response Options
COG_SS. Do you have difficulty remembering or concentrating	1) no difficulty <i>If 'No difficulty', skip Cognition</i> 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
COG_1. Do you have difficulty remembering, concentrating, or both?	1) Difficulty remembering only 2) Difficulty concentrating only <i>If 'Difficulty concentrating only' skip to cog_4</i> 3) Difficulty with both remembering and concentrating
COG_2. How often do you have difficulty remembering?	1) Sometimes 2) Often 3) All of the time
COG_3 Do you have difficulty remembering a few things, a lot of things, or almost everything?	1) A few things 2) A lot of things 3) Almost everything
P_COG_3 Which of the following statements, if any, describe your difficulty remembering?	a) I forget things because I am busy and have too much to remember b) My difficulty is getting worse c) My difficulty has put me or my family in danger d) I only forget little or inconsequential things e) I must write down important things, such as my address or when to take medicine, so that I do not forget. f) My family members or friends are worried about my difficulty remembering g) My difficulty is normal for someone my age
COG_4 – <i>'if difficulty remembering only' to COG_1, skip to COG_6</i> How much difficulty do you have concentrating for ten minutes?	1) A little 2) A lot 3) Somewhere in between a little and a lot
COG_5 – <i>if difficulty concentrating for ten minutes 'somewhere in between a little and a lot of difficulty'</i>  Is difficulty closer to a little, closer to a lot, or exactly in the middle?	1) Closer to a little 2) Closer to a lot 3) Exactly in the middle
COG_6. How old were you when the difficulty remembering or concentrating began?	____ Age in years
COG_7 How much does your difficulty remembering or concentrating limit your ability to carry out daily activities?	1) Not at all 2) A little 3) A lot 4) Completely

Table 6 shows how the study population responded to question COG\_SS intended to assess respondents' difficulty, if any, remembering and concentrating. Around 28 percent of all

respondents reported a cognition difficulty of which around four percent (269 individuals) reported having a severe cognition difficulty, that is, they reported ‘a lot of difficulty’ or ‘cannot do at all’.

Table 6: Responses to COG\_SS by country

Do you have difficulty remembering or concentrating?							
	Kazakhstan	Cambodia	Maldives	Sri Lanka	Mongolia	Philippines	All countries
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
No difficulty	74	52	77	73	74	81	72
Some difficulty	23	41	20	20	22	17	24
A lot of difficulty	3	6	2	7	4	2	4
Cannot do at all	1	1	1	0	0	0	0
Refused	0	0	0	0	0	0	0
Don't know	0	0	0	0	0	0	0

The rate of self-identified cognitive difficulty was generally similar across pilot test countries, except for Cambodia. Khmer respondents were twice as likely to report a cognition difficulty compared to other nationalities. This difference suggests that Cambodian respondents - a) genuinely had a significantly higher prevalence of people who experienced only ‘some difficulty’ remembering or concentrating; b) Cambodians interpreted the COG\_SS question response levels differently to other countries, or c) that this is a translation issue from English to Khmer that was not previously identified.

Differences by sex are reported in Table 7. More women (31 percent) report having ‘some’ or ‘a lot of difficulty’ remembering and concentrating than men (23 percent). On the other hand, the age profile of respondents does not produce any surprises. As age increases, the likelihood of a person reporting a cognition difficulty of any level also rises. From the ages of 60 onwards half of the population report at least ‘some difficulty’ remembering or concentrating.

Table 7: Difficulty remembering and concentrating by sex and age

		Sex		Age groups						
		Male	Female	<18	18-30	31-40	41-50	51-60	61-70	>70
		(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Do you have difficulty remembering and concentrating?</b>	No	76	69	84	81	74	69	55	47	32
	Some	20	26	14	18	23	26	37	43	42
	A lot	3	5	1	1	3	5	7	9	25
	Cannot do	0	0	0	0	0	0	0	0	2
	Refused	0	0	0	0	0	0	0	0	0
	Don't know	0	0	0	0	0	0	0	0	0

The inclusion of question COG\_1 required respondents with difficulties on COG\_SS to specify whether their difficulty related to remembering, concentrating, or both. The results are used to determine whether the double-barrelled structure of COG\_SS is a problem or not. Table 8 presents the results of the cross-tabulation between COG\_SS and COG\_1.

Table 8: Do you have difficulty remembering or concentrating & do you have difficulty remembering, concentrating, or both?

Do you have difficulty remembering, concentrating, or both?					
		Remembering only	Concentrating only	Both	Total number of persons
		(%)	(%)	(%)	
<b>Do you have difficulty remembering or concentrating?</b>	Some	68	9	23	1,495
	A lot	40	3	57	252
	Cannot do	14	0	86	14
	Total	63	8	28	1,761

The first remarkable observation from Table 8 is that for no level of difficulty does the COG\_1 ‘concentrating only’ category surpass the 10 percent threshold, reaching nine percent for those reporting ‘some difficulty’ in COG\_SS. This points to the fact that concentrating is not recognized as the main difficulty in this question by the large majority of respondents. It is thus evident that respondents register either having a difficulty remembering, or both remembering and concentrating, but rarely concentrating alone.<sup>5</sup>

More interestingly though is that as the degree of difficulty reported in COG\_SS increases, the percentage reporting difficulty both remembering and concentrating increases considerably, from 23 percent for ‘some difficulty’, 57 percent for ‘a lot of difficulty’, to 86 percent for ‘cannot do at all’ in COG\_SS. Although the number of cases for these last two categories is small in comparison to the overall sample, this does imply a consistent correlation between the two cognition items, supporting the argument that the double-barrelled structure of COG\_SS is not a problem and that these two aspects of cognitive functioning should remain in a single question.

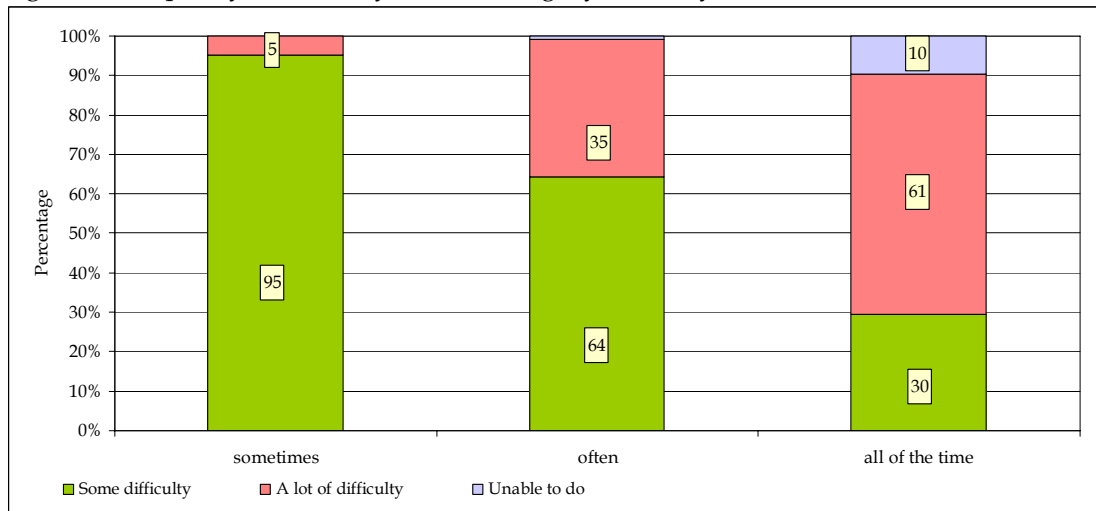
## Difficulties remembering

COG\_2 asks about the frequency of ‘remembering’ difficulties to determine whether this is a seldom or a regular and continuous occurrence. Around 71 percent of eligible respondents – those who at least answered ‘some difficulty’ to COG\_SS – reported difficulty remembering ‘sometimes’, compared with 22 percent ‘often’ and seven percent ‘all of the time’. A relationship between the severity of person’s difficulty remembering (COG\_SS) and the frequency of the difficulty COG\_2, is of course, to be expected and is confirmed by these results.

Figure 1 confirms that this relationship exists. Nearly all respondents (95 percent) who experienced difficulty remembering only ‘sometimes’ reported their difficulty as ‘some difficulty’. In contrast, only 30 percent of respondents with memory difficulties ‘all the time’ reported having ‘some difficulty’, while a further 61 percent reported ‘a lot of difficulty’ and 10 percent ‘unable to do’. These results further support the expectation that the frequency at which a person has difficulty remembering is closely related to the severity of their difficulty remembering and concentrating.

<sup>5</sup> Some possible reasons for this trend could be that concentrating is a) a more robust mental function than remembering and thus less difficulties arise; b) a developmental function that is consolidated in adulthood while memory is less developmentally influenced. This latter reason is borne out to some extent by the analysis of the responses by age in addition to that from Table 8. The age group 0 – 17 years old have the highest rates of all age groups for ‘concentrating only’ problems for both ‘some’ and ‘a lot of difficulty’ on COG\_SS. Overall 17 percent of this youngest age group report problems in concentrating only, compared to only 1.4 percent of 71+ year olds. The pattern is similar for ‘some difficulty’ on COG\_SS ranging from 18 percent for the youngest age group through to 0 percent for the oldest group. For ‘a lot of difficulty’ on COG\_SS, 12 percent of the youngest age group, 0 percent of the 51 – 60 year old group and 4 percent of the oldest age group report concentrating difficulties only.

Figure 1: Frequency of difficulty remembering, by difficulty level



The field test findings also support expectations regarding the relationship between the frequency of a person’s forgetfulness and the quantity of things forgotten– that is, the more often a respondent forgets things, the more things he or she will forget (figure 2). Results show that 87 percent of people who have difficulty remembering only ‘sometimes’ tend to forget only ‘a few things’ as observed in figure 2. This compares with those who have difficulty remembering ‘often’ – they are more likely to forget ‘a lot of things’ at 51 percent. Those with difficulty remembering ‘all the time’ are most likely to forget ‘a lot of things’ (44 percent) or ‘almost everything’ (39 percent).

As pointed out from the cognitive test findings, people who have difficulty remembering only a ‘few things’ were most likely referring to day-to-day or mundane things. In line with this finding, of the 1,152 people who have difficulty remembering ‘a few things’, 83 percent ‘only forget little or inconsequential things’ (P\_COG\_3d). In contrast, 65 percent and 45 percent, respectively, forgot ‘a lot of things’ and ‘almost everything’, as will be later elaborated when addressing the P\_COG\_3 probe question.

Overall, questions COG\_SS, COG\_2 and COG\_3 produce reasonably consistent results. Of the 993 people who stated they have difficulty remembering ‘a few things’ (COG\_3) and only ‘sometimes’ (COG\_2), 96 percent assessed their difficulty remembering as ‘some difficulty’. At the other end of the spectrum, of the 41 people who stated they have difficulty remembering ‘almost everything’ and ‘all of the time’, 88 percent assessed their difficulty remembering as severe.

Figure 2: Frequency of difficulty remembering, by how many things respondent forgets

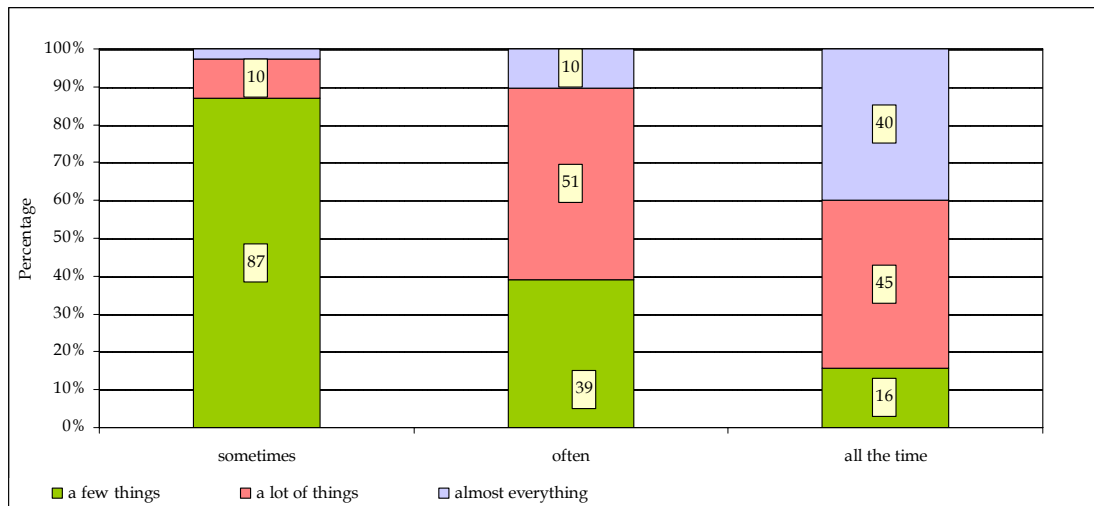


Table 9: Responses Cog\_2 by Cog\_3

		Do you have difficulty remembering a few things, a lot of things or almost everything? (intensity)			
		A few things	A lot of things	Almost everything	Total persons
How often do you have difficulty remembering? (frequency)	Sometimes	993	117	30	1,140
	Often	140	181	37	358
	All of the time	16	46	41	103
	Total Persons	1,149	344	108	1,601

Nonetheless, some gaps reveal groups worthy of inspection. For instance, of the 103 people who stated they have difficulty remembering 'all of the time', 16 individuals stated they have difficulty remembering only 'a few things'. Of these, 14 people said they only had 'some difficulty' remembering or concentrating. The memory probe shows that 13 of them 'only forget little or inconsequential things'. This suggests the response category 'all the time' probably also captures some people who forget many things daily, but who represent 'false positives' given that these forgotten things are of little importance, and therefore respondents only consider themselves to have 'some difficulty' remembering.

These results are in line with the correlation between both frequency (COG\_2) and intensity (COG\_3) variables on the one hand and, and activity limitations (COG\_7) on the other. As observed in table 10, the higher the intensity and frequency, the higher the correlation with activity limitations (cell highlighted in red). This means, as the difficulty becomes more frequent and intense, the more it limits day-to-day activities. At the opposite end (upper left corner in green) low frequency and intensity correlate negatively with activity limitations.

Overall, patterns between these variables lie in line with what would be expected, with those highlighted in yellow being the strongest positive correlations between frequency/intensity and activity limitations, and the cells highlighted in grey represent weak if not close-to-zero correlations. The only unexpected relationship occurred between the variables 'a lot of things' and 'all the time' where one would anticipate a stronger correlation with activity limitations given the high frequency and strong intensity of the cognition difficulty.

Table 10: Correlation between frequency and intensity with activity limitation.

		Do you have difficulty remembering...		
		A few things	A lot of things	Almost everything
How often do you have difficulty remembering?	Sometimes	-0.52	0.16	0.27
	Often	0.06	0.41	0.37
	All the time	-0.01	0.44	0.71

### In and out of scope probes for remembering

The probe options in the Cognition domain (P\_COG\_3) were derived from the most common explanations of responses obtained through the cognitive test. They were included in the field test to try to identify, firstly, the extent to which the trends noted in the cognitive test were apparent in a larger and more representative sample. Secondly, they provide a way of sorting out those respondents who are reporting a cognition difficulty which fits clearly into the targeted population (i.e. at risk for experiencing the disadvantage related to disability) compared to those reporting more minor difficulties that would not be considered a disability. While it is important to sort out which difficulties should be counted as disability ('in scope') and which should not ('out of scope'), the fact remains that functioning in the domain of cognition (as for all domains of functioning) is on a continuum from full functioning to full disability. These probes are an attempt to find out where this cutoff could be situated based on reasonably clear guidelines related to the pattern of responses to these probes. Figure 3 sets out the pattern of responses to the probes with red bars indicating 'out of scope' responses, green 'in scope' responses yellow as 'in between' responses.

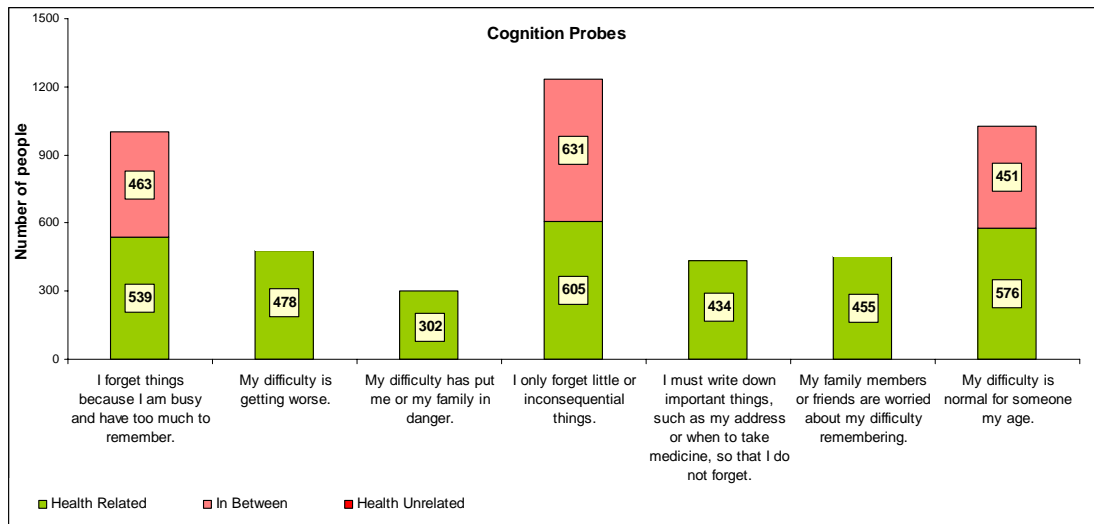
Thus, how respondents described their memory difficulty using the P\_COG\_3 statements will help determine response category thresholds (within the cognition domain) to support future data users. For example, how respondents stating 'some difficulty' to COG\_SS are treated statistically, can be decided based on whom this group contains: those reporting memory difficulties due to common day-to-day issues (more on the functioning end of the continuum) or those with associated possible health reasons (more on the disability end of the continuum).

The entirely green columns in figure 3 represent statements in scope of what the main question is trying to address. The columns containing red and green segments represent respondents who gave both 'in scope' and 'out of scope' descriptions of their difficulty remembering. The green segment represents those people who also responded 'yes' to at least one in scope probe statement while the red represents those who did not. Similarly for the yellow and green, where yellow represents the 'in between' probes and green where a respondent responded to both 'in scope' and 'in between' probes.

Figure 3 shows that respondents were most likely to identify their difficulty remembering with the two statements that are 'out of scope' (P\_COG\_3 a and b), in addition to the one 'in-between' (P\_COG\_3 g). It also shows that a large number of individuals, who confirmed an 'in scope' reason, also stated one 'out of scope' one. This is logical as someone with severe remembering and intellectual challenges (which, for example, could 'put his or her family at risk' or 'needs to write down important things as to not forget them'), might quite as well also forget irrelevant and day-to-day things.

Figure 3: Which of the following statements, if any, describe your difficulty remembering?





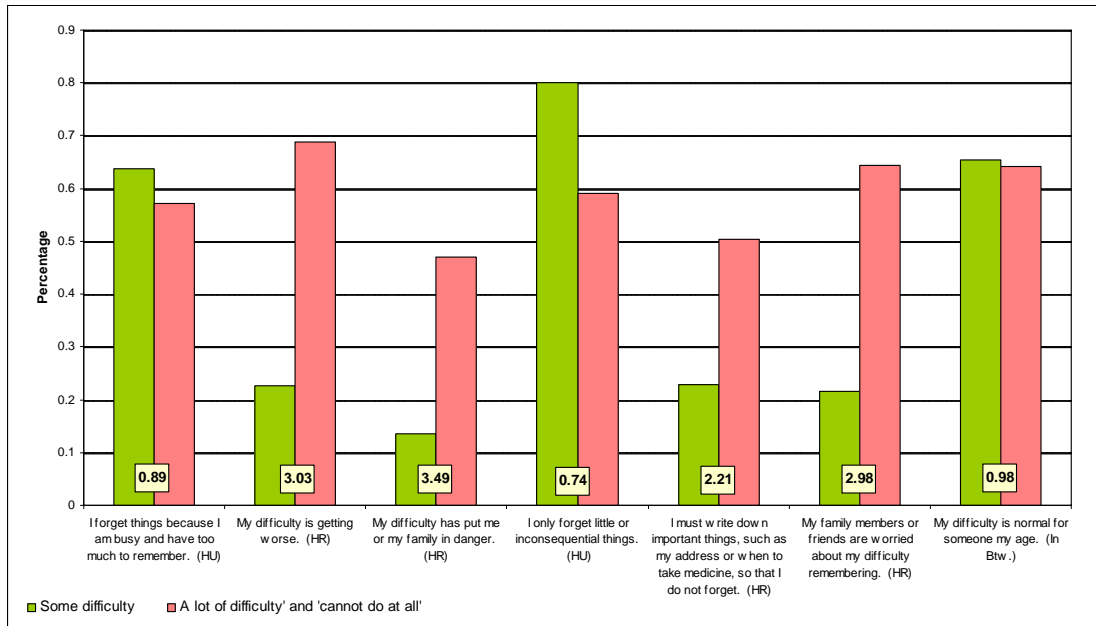
Further analysis of P\_COG\_3 (see table 11) shows that the greater the intensity of the memory difficulty, the more likely that an 'in scope' reason will be endorsed. Of all people with a memory difficulty, nearly half (48 percent or 840 people) identified with at least one of the four 'in scope' related probes. When analysed by severity of the remembering difficulty, the results show that 85 percent of those who reported their memory difficulty as severe (ie. either 'a lot of difficulty' or 'cannot do at all') reported an 'in scope' reason compare to only 41 percent of those reporting 'some difficulty' only.

Table 11 - Respondents who answered positively to at least one in scope probe, by difficulty level

Do you have difficulty remembering or concentrating?	Difficulty level	Persons	Persons describing their difficulty using at least one in scope reason	
			Number	Percent
	Some	1498	612	41%
	A lot' or 'Cannot do'	269	228	85%
	Total	1767	840	48%

Figure 4 shows that respondents with severe memory difficulties were two to nearly four times more likely to respond positively to any 'in scope' probes compared those people with only 'some' memory difficulty.

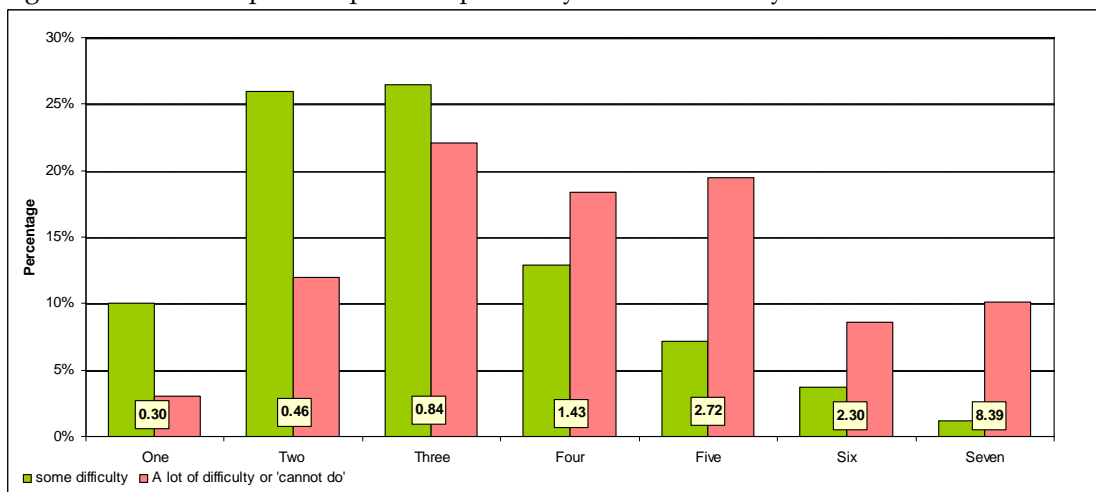
Figure 4: Proportion of 'Yes' responses to Cognition probes, by difficulty level



In line with results presented above, for the two probes that are 'out of scope', the percentage reporting 'some difficulty' is higher than that for those in the severe remembering difficulties categories. This is also the case for the 'in-between' response option of 'my difficulty is normal for someone my age'. In contrast, the response category 'my difficulty has put me or my family in danger' is almost four times more likely to be endorsed by someone with a severe memory difficulty, than by someone with a less severe one. Similarly, the likelihood of people with severe memory difficulty stating either 'my difficulty is getting worse' or 'my family members or friends are worried about my difficulty remembering', was three times higher than those with only 'some difficulty'.

Figure 5 further illustrates the link between the degree of a respondent's memory difficulty and the likelihood of it being 'in scope'. As one would expect, respondents with only 'some difficulty' remembering and concentrating endorsed less probes in P\_COG\_3 than did those respondents with 'a lot of difficulty' or 'cannot do at all'. The latter group was far more likely to respond positively to five, six, or all seven probes.

Figure 5: Number of positive probe responses by level of difficulty



## Difficulties in concentrating

Question COG\_4 asked about difficulty concentrating or 10 minutes. The results for this question are mixed. Firstly, for those who answer positively to ‘concentrating only’ or both ‘remembering and concentrating’, the degree to which they find it difficult to concentrate varies clearly. Of those having only difficulty concentrating, 80 percent have ‘a little difficulty’ doing so. In contrast, those respondents who answer positively to having both difficulties – remembering and concentrating – are more likely to have either ‘a lot of difficulty’ concentrating for 10 minutes (27 percent) or ‘somewhere in-between a little and a lot’ (18 percent). The more severe the concentration difficulty (COG\_4) the more likely a person is to have both concentrating and remembering difficulties.

Table 12: Difficulty concentrating

		How much difficulty do you have concentrating for 10 minutes?			
		A little	A lot	Somewhere in-between	Total
Do you have difficulty remembering, concentrating or both?	Only concentrating	117 80%	9 6%	20 14%	146
	Both remembering and concentrating	260 55%	129 27%	88 18%	477

Further information is needed to observe how successful this question is in measuring concentration as the cognitive test results were inconclusive. In order to do so, a set of behavioural probes was included to observe whether the respondent has any particular difficulties in understanding and making sense of this question (COG\_4). These questions answered by the interviewer based on the reactions and inquiries of the respondent to the referred question. The behavioural probes included were the following:

*Interviewer: Complete BC\_1a, BC\_1b and BC\_1c by yourself and then continue with respondent question COG\_4.*

*BC\_3a Did the respondent need you to repeat any part of question COG\_4?*  
*1. Yes*  
*2. No*

*BC\_3b Did the respondent have any difficulty using the response options?*  
*1. Yes*  
*2. No*

*BC\_3c Did the respondent ask for clarification or qualify their answer?*  
*1. Yes*  
*2. No*

Nearly a quarter (23 percent) of respondents required the interviewer to repeat the question, indicating some had some problem understanding it. This contrasts with only four percent of respondents who asked interviewers to repeat the questions on hearing in both a quiet and noisier room (the two other behavioural probes included in the question set). Moreover, 14 percent had a problem using the response categories. This is probably due to the fact that while ‘a little’ and ‘a lot’ were response categories included in previous questions, the category ‘somewhere in-between a little and a lot’ is introduced for the first time in this question.

Finally, 15 percent of those answering COG\_4 asked interviewers specifically for clarification or to qualify this question, supporting the results of BC\_3a. Linking this to the cognitive test results, these probes suggest that the notion of concentrating is confusing and possibly too abstract and/or that the phrase ‘for 10 minutes’ is problematic. Overall, therefore, the questions remains problematic in its present form. Further testing through a cognitive testing exercise is required to obtain more information on how respondents understand this question.

### Cognition and the impact of difficulties on daily activities

COG\_7 asks respondents about the impact of their difficulty on their everyday activities. It is expected that the degree of impact should be directly related to the degree of difficulty in remembering and concentrating. As for the probes in P\_COG\_3, the degree of impact can be used to determine the cutoff point between ‘in scope’ and ‘out of scope’ and thus provide suitable category response thresholds for data users. For this purpose, the relationship between impact and intensity is of most interest.

Table 13 shows that 96 percent of respondents (1,424) with only ‘some difficulty’ remembering or concentrating reported no impact (‘not at all’) on their daily activities (46 percent) or only ‘a little’ (50 percent). Conversely, the more severe the difficulty (‘a lot of difficulty’ and ‘cannot do at all’) the more severe the impact on daily activities. This strong relationship adds merit to the health-based findings of the probe. It shows, the more severe the difficulty, the more likely it will limit daily activities either ‘a lot’ or ‘completely’.

Table 13: COG\_SS by limitation on daily activities (percentages)

		How much does difficulty limit your ability to carry out daily activities?				Total number of persons
		Not at all	A little	A lot	Completely	
<b>Difficulty remembering or concentrating</b>	Some	46	50	4	0	1,481
	A lot	14	40	43	2	248
	Cannot do	7	14	29	50	14
	<i>Total</i>	41	48	9	1	1,745

Collectively, the separate findings of P\_COG\_3 and COG\_7 seem to point to ‘some difficulty’ on COG\_SS being largely interpreted by respondents to refer to mild and insignificant problems. The findings show these respondents are not likely to be ‘in scope’ of what should be counted as disability.

The 687 (46 percent) respondents answering that they have ‘some cognition difficulty’ and this does not affect them ‘at all’ should most likely be counted as ‘false positives,’ who are forgetting mundane or not so important things. The 135 respondents reporting ‘a lot of difficulty’ remembering but with no or only ‘a little’ impact on their daily activities are less clearly but possibly also false positives. The latter respondents could be at risk of more severe difficulties at a later stage.

### Conclusions and recommendations for cognition domain

The principal conclusion of this chapter is that the vast majority of respondents report having difficulties remembering only, or both remembering and concentrating. Very few report only difficulty concentrating. These results seem to confirm that, firstly, the main question, COG\_SS, is not functioning as a double-barreled question despite its double-barreled structure, and, secondly, as the degree of difficulty reported in COG\_SS increases so

the reporting of joint remembering and concentrating difficulties increase. These findings justify keeping both concepts in one single question as suggested by the WG short question set.

The cognitive and pilot tests indicate a wide and mixed range of examples of the types of difficulties remembering. Nevertheless, an extensive analysis of the cognitive data, as well as of all field test questions – including the probes – lead to the conclusion that the threshold between ‘in scope’ and ‘out of scope’ responses can be delineated with reasonable confidence. Those respondents reporting only ‘some difficulty’ on COG\_SS are most likely to be false positives and ‘out of scope’, while those reporting ‘a lot of difficulty’ and ‘cannot do at all’ are most likely to be true positives.

This conclusion is arrived from the analysis of Probe P\_COG\_3 in combination with other variables of frequency of forgetting (COG\_2) and the number of things forgotten. Moreover, a patent relationship exists between the severity of a respondent’s difficulty remembering, and the likelihood they will cite an ‘in scope’ health reason for their difficulty, given that 90 percent of people reporting a severe difficulty provided a health reason for their difficulty.

The findings are consistent across both tests – the cognitive and field testing. The relationship between the level of difficulty remembering and concentrating (COG\_SS), the frequency of forgetting (COG\_2) and number of things forgotten (COG\_3) is close. Analysis of these questions and their intrinsic correlation actually leads to ask whether both COG\_2 and COG\_3 are necessary in a question set. Based on findings highlighted through figure 2 and table 8, it would be highly recommendable to drop COG\_2 by giving the number of forgotten items recognized in COG\_3 a higher importance.

In the cognitive test, responses to the question on concentrating varied by a range of factors relating to the task at hand. Most respondents focused on the time clause of ‘10 minutes’. Unfortunately little information is available in both the cognitive and the pilot tests to allow for concrete recommendations on this question and further testing is required. Nevertheless, sufficient data is available to advise that time should not be included as part of such a question in future testing, and a more detailed understanding of respondents’ interpretation of the word ‘concentration’ would be highly beneficial.

Based on these results we suggest including the following questions for the cognition domain in a question set for surveys:

1. Do you have difficulty remembering or concentrating?

1) no difficulty

*If ‘No difficulty’, skip Cognition domain*

2) some difficulty

3) a lot of difficulty

4) Cannot do at all/ unable to do

2. Do you have difficulty remembering a few things, a lot of things, or almost everything?

1) A few things

2) A lot of things

3) Almost everything

A further question asking a series of probes as possible explanations for the respondents' difficulties could be added, similar to P\_COG\_3. These would need to be developed and tested before being recommended.

## Upper Body chapter

### Introduction

'Upper Body' is a concept which embraces a number of ICF components, domains and constructs. Impairment in upper body structure or function can occur in any mix of shoulder, upper arm, lower arm, wrist or hand as well as back, and/or torso. Activity limitations or participation restrictions can occur in a range of areas as a result.

Causes of upper body difficulties can be varied: from birth, or later in life through accident, disease or injury, or in later life through degeneration of body structure/function.

Due to this complexity the concept was not specifically included in the WG short question set as a single question, but was flagged as important for further research and development for potential inclusion in an expanded question set. However, the question on self care (UB\_SS) is included in the Washington Group Short Set as the 5<sup>th</sup> question. The rationale for its inclusion in the short set was that it reflected difficulties primarily in upper body movements and secondarily to more cognitive difficulties, such as in choosing the appropriate clothes for the occasion and weather conditions.

### Upper Body and the ICF

The objective of the domain is to identify individuals who report upper body difficulties. Representative aspects were selected for inclusion in testing for the WG extended set. These were: d430 'lifting and carrying objects', a combination of d440 and d445 'fine hand use' and 'hand and arm use' respectively, and Chapter 5 'self care'.

### Cognitive testing

The aim of the cognitive testing was to assess whether questions on self care, lifting and hand and finger use would elicit appropriate and comparable cross country and cross culture responses for the 'upper body' construct, whether respondents were able to easily understand the questions and concepts, and whether the resultant data could be meaningfully interpreted.

#### Box 1: The questions included in the cognitive interview protocol for Upper Body

Questions	Response Options
SS6a Do you have difficulty with self care, such as washing all over or dressing?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do
SS6b Do you have difficulty raising a 2 litre jug of water from waist to eye level?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do

6.1 Do you use any aids or equipment or receive help with lifting?	1) yes 2) no  <i>If <b>No</b>, go to 6.4 – hands and fingers question.</i>
6.2 <b>If Yes:</b> What types of aids, equipment or assistance do you use?	Specify all: _____
6.3 <b>Only if use aids:</b> Do you have difficulty raising a 2 litre jug of water from waist to eye level even when using your aid?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do
11.1ai How old were you when the difficulty lifting began?	_____ age in years
12.1i Is your difficulty lifting due to a health problem or something else?	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty lifting limit your ability to carry out daily activities?	1) yes 2) no
13.2bi Does your difficulty lifting limit your ability to carry out other activities that are not part of your day-to-day life?	1) yes 2) no
6.4 Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do  <i>If <b>No</b>, go to <u>next section</u>.</i>
6.5 Do you use any aids or equipment or receive help when using your hands or fingers?	1) yes 2) no  <i>If <b>Yes</b>, read aid-in <u>next question</u>.</i>
6.6 What type of aids, equipment or assistance do you use?	
11.1ai How old were you when the difficulty using your hands or fingers began?	_____ age in years
12.1i Is your difficulty using your hands or fingers due to a health problem or something else?	1) Due to a health problem 2) Something else _____
13.1i Does your difficulty using your hands or fingers limit your ability to carry out daily activities?	1) yes 2) no
13.2bi Does your difficulty using your hands or fingers limit your ability to carry out other activities that are not part of your day-to-day life?	1) yes 2) no

The questions were firstly analysed according to individual country responses as shown in Tables 1 and 2.



Do you have difficulty with self care, such as washing all over or dressing?						
	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Skipped: not asked	Total persons
Cambodia	16	0	1	0	1	18
Canada	10	6	0	0	1	17
Kazakhstan	14	3	0	0	3	20
Maldives	14	4	0	1	1	20
Mongolia	11	5	4	0	0	20
Philippines	2	0	0	0	18	20
South Africa	6	0	0	1	0	7
Sri Lanka	4	1	1	0	10	16
United States	15	4	0	0	0	19
<b>Total</b>	<b>92</b>	<b>23</b>	<b>6</b>	<b>2</b>	<b>34</b>	<b>157</b>
Percentage	59%	15%	4%	1%	22%	100%

Of the 157 respondents for the cognitive testing, 123 answered this question – due to the length of the interviews not all respondents were asked all domains. Some 59 percent reported ‘no difficulty’, 15 percent ‘some difficulty’, 6 percent ‘a lot of difficulty’, and 1 percent (2 people) could not undertake self-care tasks at all. Interestingly Mongolia had the highest rate of ‘a lot of difficulty’ responses (20 percent), whereas Cambodia had only 6percent with any level of difficulty reported at all.

Do you have difficulty raising a 2 litre jug of water from waist to eye level?						
	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Skipped: not asked	Total Persons
Cambodia	16	1	0	0	1	18
Canada	13	1	1	1	1	17
Kazakhstan	16	2	0	0	2	20
Maldives	14	1	4	1	0	20
Mongolia	15	2	3	0	0	20
Philippines	13	5	1	1	0	20
South Africa	6	0	0	1	0	7
Sri Lanka	2	1	1	1	11	16
United States	14	5	0	0	0	19
<b>Total</b>	<b>109</b>	<b>18</b>	<b>10</b>	<b>5</b>	<b>15</b>	<b>157</b>
Percentage	69	11	6	3	10	100

More respondents answered this question (142). Of those respondents answering, slightly fewer reported difficulties with lifting compared to selfcare (23percent vs 25percent), however lifting difficulties were reported at higher rates in the more severe categories.

### Conclusions from cognitive testing

The cognitive testing indicated some specific areas of concern. These were:

1. For the lifting question (SS6b) most respondents considered lifting from waist to eye level, with some considering lifting and drinking from a soda bottle. A few respondents with knee or back problems thought of lifting an item from the floor , stating that they would have some difficulty with this. Respondents described the

context of their responses, such as “I would need to use both hands” or “I could do it with my one arm”.

2. The use of ‘a 2-litre jug of water’ in the question wording appeared to work well, particularly where respondents considered a 2-litre soda bottle. For those respondents not thinking of a 2-litre soda bottle there was some evidence that respondents did not really know the capacity/weight generating potential error in responses.

For assistive devices

1. The lifting aid question was not always connected to the previous jug question, with respondents not always interpreting the question as asking about an aid to lift an object equivalent to a 2-litre jug of water.
2. There were varied ideas of what to count as an aid. Responses mainly referred to assistance from other people (this was referred to in the question), as well as to using a grabber to reach things from a shelf, and having their body lifted from bed to wheelchair.
3. Where ‘assistance from others’ was considered in question 6.1, this caused confusion in question 6.3 as it would be someone else doing the task, and where aids for reaching objects above eye level were considered, then these aids would not be relevant for 6.3. Similarly ‘assistive lifting’ would not be seen as relevant for 6.3.

For ‘using hands and fingers’:

1. For question 6.4, interpretations varied. Primarily seen as ‘use of fingers’ as intended, but there was evidence that ‘picking things of the floor’ was considered by some respondents. Others commented that they could pick up objects but could not open lids, and others reported difficulty due to vision problems – not being able to see an object to pick it up.
2. There was evidence that respondents accounted for their condition when responding e.g. being able to do the task with their only hand.

There was found to be no difference in the phenomena captured in the ‘daily’ and ‘non-daily’ questions (131i & 132bi).

Taking the respondents interpretation of health and non-health problems would screen out many people who would be considered as having a health problem in terms of ICD and ICF.

### Revisions of questions

- The aids questions were dropped.
- A specific reference to a ‘2-litre jug of water or soda’ was included.
- The question on health problems was dropped.
- Probe questions were added to identify how respondents arrived at their answers for UB\_1 (SS6b in the cognitive test) and for UB\_2 (6.4 in the cognitive test).
- The question on non-daily activities was dropped
- A question on types of activity restrictions was added – consistent with the other domains.

## Field test

### Box 2: Field test questions on upper body:

Questions	Response Options
UB_SS Do you have difficulty with self care, such as washing all over or dressing?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>
UB_1 Do you have difficulty raising a 2 litre jug of water or soda from waist to eye level?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>
P_UB_1 Can you tell me how you arrived at your answer? Why did you answer [ <i>Interviewer: fill in respondent's answer to UB_1</i> ]?	Interviewer: Record answer: _____ _____
UB_2 Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>
P_UB_2 In answering this last question, were you thinking about bending down to pick up an object from the floor, picking up an object from a table, or something else?	1) From the floor 2) From a table 3) something else (please specify): 7) <i>Refused</i> 9) <i>Don't know</i>
UB_3 How old were you when the difficulty lifting or using your hands and fingers began?	_____ age in years 777) <i>Refused</i> 999) <i>Don't know</i>
UB_4 How much does your difficulty using your hands and fingers limit your ability to carry out daily activities?	1) Not at all 2) A little 3) A lot 4) Completely 7) <i>Refused</i> 9) <i>Don't know</i>

## Field test results

Three key questions were included in the field test and Tables 3, 4 & 5 contain the difficulty ratings reported for each question by country.

Sri Lanka's data indicate a higher rate of difficulty with selfcare (12 percent) than other countries (3-6 percent) in the field test – particularly 'some difficulty', and Maldives and Philippines have a slightly lower rate (2-3 percent), again in the 'some difficulty' category. It

is to be noted that a similar pattern of distribution occurs for 'lifting' and 'hand and finger' use, and that this pattern of distribution between countries also occurs across many of the other domain areas included in the testing. Whether this reflects some real differences, translation issues, respondent differences or other reasons has still to be explored.

The field test did identify respondents with a range of difficulties in all three areas, with some differences apparent between countries in the reported levels. Sri Lanka consistently had the highest levels of reported difficulty (12 percent for selfcare, 9 percent for lifting (same as Cambodia) and 14 percent for hand and finger use) in comparison to other countries which were generally 2 to 8 percentage points lower. The area of difficulty most varying was 'some' indicating variance in response at the lower levels of severity.

Table 3: Responses to UB\_SS by country

		Kazakhstan	Cambodia	Maldives	Sri Lanka	Mongolia	Philippines	All countries
		(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Do you have difficulty with self care, such as washing all over or bathing?</b>	No	96	94	98	88	95	97	95
	Some	3	4	1	9	3	2	4
	A lot	1	1	1	1	1	0	1
	Cannot do	0	1	0	1	0	0	0
	Refused	0	0	0	0	0	0	0
	Don't know	0	0	0	0	0	1	0

Maldives had only 2% with reported self care difficulty, compared to 6% with difficulties lifting and 3% with hand and finger use.

Table 4- Responses to UB\_1 by country

		Kazakhstan	Cambodia	Maldives	Sri Lanka	Mongolia	Philippines	All countries
		(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Do you have difficulty raising a 2 litre bottle of water or soda from waist to eye level?</b>	No	94	91	94	91	93	96	93
	Some	4	6	3	6	4	3	4
	A lot	2	2	2	2	2	1	2
	Cannot do	1	1	0	1	1	0	1
	Refused	0	0	0	0	0	0	0
	Don't know	0	0	0	1	1	0	0

Table 5 - Responses to UB\_2

		Kazakhstan	Cambodia	Maldives	Sri Lanka	Mongolia	Philippines	All countries
		(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?</b>	No difficulty	94	94	97	86	94	95	93
	Some difficulty	5	4	2	11	4	3	5
	A lot of difficulty	1	2	1	3	2	1	1
	Cannot do at all	0	0	0	1	0	0	0
	Refused	0	0	0	0	0	0	0
	Don't know	0	0	0	0	0	0	0

Presence of difficulty and severity of difficulty with upper body movement may have some correlation with gender and/or age. Table 6 data indicate only marginal gender differences, possibly more correlated with gender age differences in the sample. However, there is a marked correlation between increasing levels of difficulty and increasing age – from 1 percent difficulty in the 18-30 age group thru to 41 percent with difficulty (23 percent with 'a lot' or 'cannot do at all') in the over 70 years age group.

Table 6 - UB\_SS by age and sex

		sex		age groups						
		Male	Female	<18	18-30	31-40	41-50	51-60	61-70	>70
		(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Difficulty with selfcare, such as washing all over or bathing	No	96	94	95	99	97	94	87	83	59
	Some	3	4	3	1	2	4	9	10	18
	A lot	1	1	1			2	2	7	15
	Cannot do	1	0	1	0	0	0	0	1	8
	Refused	0	0	0	0	0	0	0	0	0
	Don't know	0	0	0	0	0	0	1	0	0

It is of interest whether there are common responses between the lifting and self care responses. As presented in Table 7 in the green diagonal cells 94 percent of respondents had corresponding answers to both questions, and a further 4 percent had responses which did not differ widely (yellow cells). Only 2 percent responded quite differently to the two questions (red cells) with more of these people having a greater reported difficulty with lifting than with self care.

Table 7: Difficulty lifting by difficulty with selfcare

		Do you have difficulty with selfcare?							Total
		No	Some	A lot	Cannot do	Refused	Don't know		
Do you have Difficulty with raising a 2 litre bottle of water or soda?	No	5,786	83	8	3	0	0	5,880	
	Some	128	120	12	2	0	0	262	
	A lot	47	30	33	2	0	0	112	
	Cannot do	7	5	9	17	0	4	38	
	Refused	1	0	0	0	0	0	1	
	Don't know	14	0	1	0	0	1	16	
	<b>Total</b>	<b>5,983</b>	<b>238</b>	<b>63</b>	<b>24</b>	<b>0</b>	<b>1</b>	<b>6,309</b>	

Table 8: Where respondent was considering picking an object up from, by country

	Kazakhstan	Cambodia	Maldives	Sri Lanka	Mongolia	Philippines	All countries
From the floor	807	249	139	250	395	891	2731
From a table	171	163	10	227	643	94	1308
Something else	21	592	211	531	141	32	1528
Refused	0	1	0	0	7	0	8
Don't know	1	3	2	3	36	38	83
From the floor (%)	81	25	38	25	32	84	48
From a table (%)	17	16	3	22	53	9	23
Something else (%)	2	59	58	53	12	3	27
Refused (%)	0	0	0	0	1	0	0
Don't know (%)	0	0	1	0	3	4	1

After respondents were asked UB\_2 '...difficulty using your hands and fingers, such as picking up small objects....', they were asked whether they were considering picking up an object from the floor, from a table, or from somewhere else. Table 8 indicates the marked differences in conceptualisation between field test countries, with Philippines and Kazakhstan both having over 80 percent thinking of 'from the floor'. Mongolia was the only country where the majority (53 percent) considered 'from a table'. The main differences related to 'something else' and examination of the written responses indicated that the bulk of these responses were for people considering both locations, or 'from anywhere'.

Table 9: Overall level of upper body difficulty by age at onset\*

		<18	18-30	31-40	41-50	51-60	61-70	>70	Don't know	Total
<b>Overall level of upper body difficulty</b>	No difficulty	5	0	0	0	0	0	0	0	5
	Some difficulty	72	30	67	102	84	40	19	14	428
	A lot of difficulty	24	13	19	35	26	37	10	4	168
	Cannot do	12	1	1	7	5	5	13	3	47
	Don't know	0	0	0	0	0	0	0	1	1
<b>Total</b>		<b>113</b>	<b>44</b>	<b>87</b>	<b>144</b>	<b>115</b>	<b>82</b>	<b>42</b>	<b>22</b>	<b>649</b>

\* age of onset only asked of respondents with some level of reported upper body difficulty

There were 113 respondents with a reported age of onset of under 18yrs, which would encompass conditions/difficulties from birth, through the early development years to teenage years. This group had the highest proportion of 'cannot do' responses (11 percent), with the exception of those aged over 70 years (31 percent).

There appears to be an increase in rate of onset in the 41-50 age group, possibly reflecting the start of age related conditions, work related issues or other unspecified reasons.

Table 10 Limitation in daily activities by upper body difficulty

		Do you have difficulty with self care, such as washing all over or dressing?	
		Some difficulty	A lot of difficulty/ Cannot do at all
		(%)	(%)
<b>Limitation in daily activities</b>	Not at all	24	8
	A little	59	34
	A lot	14	41
	Completely	1	16
	Refused	0	1
	Don't Know	1	0
<b>Total persons</b>		<b>234</b>	<b>80</b>

Table 10 demonstrates the relationship between upper body difficulty and limitation in daily activities. More than four in five (83 percent) respondents who reported 'some difficulty' to the first upper body question (UB\_SS) reported that they were 'not at all' or 'a little' limited in their daily activities. In contrast, more than half of respondents (57%) who answered 'a lot of difficulty' or 'cannot do at all' reported that they are 'a lot' or 'completely' limited in their daily activities.

## Conclusions and recommendations

The three tasks of self care, lifting and hand and finger use do not identify the same populations (although there are significant overlaps) nor are they mutually exclusive. There is no single question which stands out for recommendation for 'upper body', although self care does perhaps identify a more consistent and 'severe' population.

There needs to be further exploration of the lifting question in terms of where respondents are considering lifting from, and how they are considering lifting in an effort to further standardise the concept and responses.

Until further testing can be undertaken all three questions could be considered useful for inclusion where space permits in an extended question set, with the opportunity arising with further data to explore options for a combined scaled response output category for upper body.

The proposed question set is:

1. Do you have difficulty with self care, such as washing all over or dressing?
2. Do you have difficulty raising a 2 litre jug of water or soda from waist to eye level?
3. Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?

## Learning chapter

### Introduction

Learning and applying knowledge or acquiring skills are considered among the basic activities itemised in the ICF. As a basic activity domain, learning was not included among the short set of questions adopted by the Washington Group on Disability Statistics. It was, however, considered an important domain for inclusion in the extended set of questions. Discussions on the development of questions for the learning domain focused on the age dependency of learning: learning among children and learning among adults.

The objective of the domain was to develop a single question (one for adults and one for children) that would identify individuals who may experience difficulty in the aspect of learning that involves the application of knowledge.

### Learning and the ICF

‘Learning and applying knowledge’ comprises Chapter 1 of the ICF activities and participation domain. The domain is divided into ‘purposeful sensory experience (d110-d129)’, ‘Basic learning (d130-d159)’, and ‘applying knowledge (d160-d179)’. ‘Following instructions’ also sits within chapter 2 ‘general tasks and demands’.

### Cognitive testing

Questions developed for cognitive testing are listed in Box 1.

#### Box 1: Questions included in the cognitive interview protocol for Learning

Questions	Response Options
7.1 Do you have difficulty understanding and using information like following directions to get to a new place?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do
7.2 Do you have difficulty learning new things such as the rules for a new game?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do
7.3 How much difficulty did you have in analyzing and finding solutions to problems in day-to-day life?	1) None 2) Mild 3) Moderate 4) Sever 5) extreme/Unable to do
11.1ai How old were you when the difficulty understanding and using information began?	_____ age in years
12.1i Is your difficulty understanding and using information due to a health problem or something else?	1) yes 2) no



## Learning findings:

An assessment of the findings that resulted from the cognitive testing of the learning questions includes an interpretation of the process of respondent comprehension, retrieval, judgment and response. The testing was designed to gain an understanding of the respondents' judgment processes and response patterns to the questions, specifically through their interpretation of the question (comprehension), and their determination of what they deemed relevant information (retrieval).

1. The first question involves some interpretation by the respondent. *Understanding and using information like following directions to get to a new place* is a complex question that includes several actions: understanding and using information, following directions, and getting to a new place.

A review of responses to the question revealed that responses focused on the third (last) action: getting to or finding a new place. This, in turn, involves varied interpretations, such as following directions, using a map, reading street signs, and needing assistance to walk or use various modes of transportation. Of the 124 respondents, the majority (73percent) replied no difficulty and some went on to explain that they used aids (maps, GPS, or MapQuest) to assist them. Some respondents, however, never go to new places and responded to the question either 'no difficulty' or 'can't do at all'. Twenty three percent of respondents reported at least some difficulty and most often referred to unfamiliar places, the fear of getting lost and difficulty concentrating on instructions. In a few instances respondents indicated other difficulties like vision (blindness or difficulty reading street signs) or mobility (needing assistance to get around) that affected their ability to learn and follow directions.

Among the valid interpretations that respondents offered to the question on using information were: thinking & logic skills at work, school work, directions for household chores, and following directions in general.

2. *Learning new things such as the rules for a new game* was primarily seen as asking about learning a new game, which involves the level of difficulty of the game, and the ability to understand directions written or spoken (in the respondents own language or a foreign language). Among those who responded to the question (n=52), 50 percent claimed 'no difficulty' and 42percent had at least 'some difficulty'. A few respondents (5) claimed that they never play games, and their answers ranged from 'no difficulty', 'don't know', 'can't do at all' or they provided no answer at all. A respondent who claimed not to have time to play games offered the example of cooking meals as an alternative. In a few instances (4), respondents mentioned other difficulties like vision ("because of sight") that impeded their ability to learn a new game; and two respondents mentioned their age ("she is old and no longer able...") as the reason for their difficulty (one responded 'cannot do at all' and the other chose not to respond).

Interpretations of this question included putting furniture together, learning how to feed livestock, cooking (following a recipe), dancing, schoolwork, and life in general.

3. Responses to the question on *analyzing and finding solutions to problems in day to day life* (n=41) elicited interpretations that included examples of daily problems like family issues, work issues, money problems, interpersonal relations, neighborhood crime and even being able to do puzzles. The myriad

responses to this question reflect the imprecision of the ‘problems in day to day life’ clause; and they do not necessarily capture the aspects of learning that we would want or expect through ‘analyzing and finding solutions’.

Of the 41 responses to this question, 46 percent reported ‘no difficulty’ and 46 percent reported at least mild difficulty. Some respondents (3) had difficulty understanding the question; in particular some had difficulty with the word ‘analyze’. This raises the issue of potential problems related to the effects of socio-economic status on the ability to interpret/ understand the question.

### Conclusions from cognitive testing and revisions of questions for learning

In summary, cognitive findings on the learning questions indicated that these were not getting at general learning but were being interpreted as asking about the specific example – issues of playing games and or being able to follow instructions.

Based on these findings it was decided to:

- simplify the child focus question deleting *new things like* and focusing only on *the rules for a new game*;
- add *a new cell phone* to adult question in an attempt to get the respondents to focus on learning rather than the specific example. In addition, a probe question was added as a follow up to this question to learn more about how respondents were responding; and
- drop the third question on *analyzing and finding solutions to problems in day-to-day life*.

### Box 2: The field test questions on learning

Questions	Response Options
Learn_1 Do you have difficulty learning the rules for a new game?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>
Learn_2 Do you have difficulty understanding and following instructions for example, to use a new cell phone or to get to a new place?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do 7) <i>Refused</i> 9) <i>Don't know</i>
P_Learn_2 Can you tell me how you arrived at your answer? Why did you answer [ <i>Interviewer: fill in respondent's answer to Learn_2</i> ]?	_____
Learn_3 How old were you when the difficulty understanding and using information began?	_____ age in years 777) <i>Refused</i> 999) <i>Don't know</i>
Learn_4 How much does your difficulty [learning/understanding and using information] limit your ability to carry out daily activities?	1) Not at all 2) A little 3) A lot

	4) Completely 7) Refused 9) Don't know
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### Field test results:

All respondents, all ages were asked the question: *Do you have difficulty learning the rules for a new game?*

Table 1 illustrates how respondents answered the question. Over three quarters responded no difficulty, about 15 percent responded some difficulty and about 6 percent had a lot of difficulty or could not do it at all.

**Table 1: Difficulty Learning the Rules for a new**

	Frequency	Percent
No difficulty	4890	77.5
Some difficulty	932	14.8
A lot of difficulty	238	3.8
Cannot do at all	132	2.1
Refused	20	0.3
Don't know	97	1.5
<b>Total</b>	<b>6309</b>	<b>100</b>

Some variation by country was observed. (See Table 2) Cambodia had fewer respondents reporting 'no difficulty' and more on each of the other categories of difficulty: 'some, a lot and cannot do it at all'. Sri Lanka on the other hand had slightly more respondents with 'no difficulty' and slightly fewer on the other categories of difficulty. This finding from Cambodia is consistent with reports in other domains about difficulties because of lack of education.

**Table 2: Difficulty Learning the Rules for a new game by Country - all respondents**

		Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
		(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Do you have difficulty learning the rules for a new game?</b>	no	81	54	87	81	76	84	77
	some	15	28	5	12	18	11	15
	a lot	2	10	2	4	2	3	4
	cannot do	2	7	2	1	1	1	2
	refused	0	0	1	0	0	0	0
	don't know	0	2	1	3	3	0	2
Total		100	100	100	100	100	100	100
Total persons		1000	1008	1000	1013	1222	1066	6309

By gender, female respondents appear to have somewhat more difficulty, at each level of difficulty, than males at learning the rules for a new game (Table 3).

Table 3: Difficulty Learning the Rules for a new game by Gender – all respondents

		Male	Female	Total
		(%)	(%)	(%)
<b>Do you have difficulty Learning the Rules for a new game?</b>	No	83	74	78
	Some	12	17	15
	A lot	3	5	4
	Cannot do	2	3	2
	Refused	1	0	0
	Don't know	1	2	2
<b>Total Persons</b>		<b>2448</b>	<b>3861</b>	<b>6309</b>

There was some indication from the cognitive interviews that the playing of games was age dependent; i.e. that older respondents either had not played games in a long time or were no longer able to play games. This observation was born out in the analysis of the field test data, which demonstrated a clear trend, appear with difficulty (at each level) increasing with increasing age (Table 4).

Table 4: Difficulty Learning the Rules for a new game by Age Group – all respondents

		<17	18-30	31-40	41-50	51-60	61-70	71+	Total
		(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Do you have any difficulty learning the rules for a new game?</b>	No	87	86	79	76	66	56	31	76
	Some	10	12	16	16	22	21	23	15
	A lot	2	1	3	5	5	11	19	4
	Cannot do	1	1	1	1	4	6	18	2
	Refused	0	0	0	1	1	1	3	0
	Don't know	1	0	1	2	2	6	7	2
<b>Total persons</b>		<b>1475</b>	<b>1478</b>	<b>1004</b>	<b>1008</b>	<b>738</b>	<b>395</b>	<b>211</b>	<b>6309</b>

Only respondents 17 years of age and over were asked the question: ‘Do you have difficulty understanding and following instructions for example, to use a new cell phone or to get to a new place?’ Twenty-two percent of respondents (1391) were under 17 years of age, and these are excluded from analyses of this question.

Table 5 illustrates how respondents answered the question. Almost three quarters (73 percent) responded ‘no difficulty’, about 17 percent responded ‘some difficulty’ and about 9 percent had ‘a lot of difficulty’ or ‘could not do it at all’.

Table 5: Difficulty Understanding and Following Instructions  
- respondents 17 years of age or older

	Frequency	Percent	Valid Percent
no difficulty	3590	56.9	73
some difficulty	843	13.4	17.1
a lot of difficulty	292	4.6	5.9
cannot do at all	152	2.4	3.1
refused	6	0.1	0.1
don't know	35	0.6	0.7
Total	4918	78	100
Missing:<17 years	1391	22	
<b>Total</b>	<b>6309</b>	<b>100</b>	

By country, it again appears that Cambodian respondents less often report 'no difficulty' understanding and following instructions to use a new cell phone or to get to a new place, and more often report difficulty at each level. Mongolian respondents display a similar though less prominent pattern of responses. Again, Sri Lankan respondents more often report 'no difficulty' and appear to have less difficulty than other respondents in understanding and following instructions (Table 6).

Table 6: Difficulty Understanding and Following Instructions by Country - respondents 17 years of age or older

	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
no difficulty	76	46	86	82	66	81	73
some difficulty	17	27	6	11	27	13	17
a lot of difficulty	3	16	4	4	5	5	6
cannot do at all	3	10	3	1	1	1	3
refused	0	0	1	0	0	0	0
don't know	0	1	1	2	1	0	1
<b>Total persons</b>	<b>822</b>	<b>759</b>	<b>753</b>	<b>814</b>	<b>933</b>	<b>837</b>	<b>4918</b>

Similar gender and age patterns were observed for responses to this question as were observed on the previous question that asked about learning the rules for a new game. Females more often report difficulty understanding and following instructions to use a new cell phone or get to a new place than their male counterparts; and difficulty at each level appears to increase with age (Table 7).

Table 7: Difficulty Understanding and Following Instructions by Gender – respondents 17 years of age or older

	Male	Female	Total
	(%)	(%)	(%)
no difficulty	86	69	73
some difficulty	13	20	17
a lot of difficulty	4	7	6
cannot do at all	2	4	3
refused	0	0	0
don't know	0	1	1
<b>Total Persons</b>	<b>1809</b>	<b>3109</b>	<b>4918</b>

Table 8: Difficulty understanding and following instructions by Age group

		<17	18-30	31-40	41-50	51-60	61-70	71+	Total
		(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Do you have any difficulty understanding and following instructions?</b>	No	94	85	80	74	60	51	30	73
	Some	6	12	15	17	25	26	24	17
	A lot	0	2	3	6	8	15	23	6
	Cannot do	0	1	1	2	5	6	22	3
	Refused	0	0	0	0	0	0	1	0
	Don't know	0	0	1	1	2	2	1	1
<b>Total persons</b>		<b>84</b>	<b>1478</b>	<b>1004</b>	<b>1008</b>	<b>738</b>	<b>395</b>	<b>211</b>	<b>4918</b>

Given the similar patterns between the two questions, it was decided to determine whether, or to what degree, the two questions (rules for a new game and understanding and following instructions) were capturing the same difficulties. A cross tabulation of the two questions produced the results depicted in Table 9.

Table 9: Learn\_1 by Learn\_2 (respondents 17 years of age or older)

		Do you have difficulty learning rules for a new game?							Total
		no difficulty	some difficulty	a lot of difficulty	cannot do at all	refused	don't know		
<b>Do you ave difficulty understanding and following Instructions?</b>	no	3412	111	16	2	10	39	3590	
	some	209	574	28	8	0	24	843	
	a lot	35	84	158	8	0	7	292	
	cannot do	15	18	14	100	1	4	152	
	refused	0	0	0	0	6	0	6	
	don't know	15	2	0	1	3	14	35	
<b>Total</b>		<b>3686</b>	<b>789</b>	<b>216</b>	<b>119</b>	<b>20</b>	<b>88</b>	<b>4918</b>	

Table 9 illustrates considerable overlap between the two questions. Among those who responded to the questions (excluding refused or don't know: See Table 10 below), 88.6 percent (of 4792) were in full agreement (green in the table), and an additional 7.2 percent reasonable agreement (yellow). The off-diagonals (red) however represent 4.2 percent of respondents who have considerable difficulty on one of the domain activities but not the other.

Table 10: Learning the Rules for a New Game with Difficulty Understanding and Following Instructions - (respondents 17 years of age or older)

		Do you have difficulty learning rules for a new game?				Total	N
		no difficulty	some difficulty	a lot of difficulty	cannot do at all		
<b>Do you have difficulty understanding and following instructions?</b>	no difficulty	71.20%	2.30%	0.30%	0.00%	73.90%	3541
	some difficulty	4.4	12	0.6	0.2	17.1	819
	a lot of difficulty	0.7	1.8	3.3	0.2	5.9	285
	cannot do	0.3	0.4	0.3	2.1	3.1	147
	Percentage	76.6	16.4	4.5	2.5	100	
Total persons		3671	787	216	118		4792

The free-text responses to the probe question: ‘Can you tell me how you arrived at your answer?’ [to the question on understanding and following instructions] were reviewed to determine whether they were “within scope” or not. That is, whether the respondents’ reasoning and judgment was compatible with the purpose of the question. About 29 percent of the responses were determined to be “within scope”. These respondents referred in their judgment to activities that included specifically following instructions or activities that required one to follow instructions, such as sewing or following a recipe. Others in this category made reference to their ability to understand in terms of memory or cleverness. Nineteen percent of responses were deemed to be “out of scope”. These individuals referenced their age, language problems, familiarity with the item, their education, or responses that were invalid in terms of the question posed (e.g. “fond of going places”, “I grew up in poverty”, “I don’t have a cell phone”).

A few questions were of indeterminable scope, deemed “questionable” and these amounted to 1.3 percent of responses. These individuals referenced physical difficulties other than those that might be related to learning alone; such as vision, hearing, dizziness and other chronic conditions.

One half of the respondents (50.3 percent) were not classified under any of these three categories. These individuals gave responses that could not be coded or responses that were mere affirmations of the question being probed.

The “scope” determination of responses to the probe question was analyzed by various background and socio-demographic variables: country of respondent, gender, age income category and main activity of respondent. These are depicted in Tables 11 and 12 below.

Scope	Sex		Age						
	Male	Female	<=17	18-30	31-40	41-50	51-60	61-70	71+
Out of scope	17	20.5	17.5	14.5	14.6	18.4	22.4	30.2	46.6
Questionable	1.5	1.2	1.3	0.5	1.1	1	1.6	4.1	3.4
In scope	30.1	28.7	33.8	33.2	33.5	28	25.5	21.6	11.5
Unclassified	51.4	49.6	47.5	51.8	50.8	52.6	50.5	44.2	38.5
Total	100	100	100	100	100	100	100	100	100
Total persons	-1789	-3067	-80	-1460	-992	-993	-729	-394	-208
	$\chi^2=8.8, 3 \text{ df}, p<0.05$		$\chi^2=236.0, 18 \text{ df}, p<0.001$						

Scope	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
Out of scope	13.8	36.6	15.7	12.6	16.6	20.9	19.2
Questionable	0.6	1.5	1.3	0.1	2.4	1.8	1.3
In scope	16.4	23.6	31.2	59.1	11.5	37.5	29.2
Unclassified	69.2	38.3	51.8	28.2	69.6	39.8	50.3
Total persons	821	759	747	762	933	834	4856
	$\chi^2=829.0, 15 \text{ df}, p<0.001$						

From tables 11 and 12, it seems that respondents provide answers to the probe question that are within scope fairly consistently by gender although there is a slight tendency for women to provide more 'out of scope' and less 'in scope' responses. 'In scope' responses decrease with age. There is considerably more variation however, by country, and this may reflect, among other things, issues related to either cultural differences in the interpretation of the probe questions or translation problems or both.

The correspondence between the two learning questions – Rules for a New Game and Understanding and Following Instructions – was re-examined by whether the response to the latter question was 'In' or 'Out of scope' (as defined above).

A comparison of Tables 13 and 14 indicate that agreement is greater among those who provide a response that is determined to be within scope (93 percent - green Table 13) compared to those out of scope (79 percent - green Table 14).



		rules for a new game				Total	N
		no difficulty	some difficulty	a lot of difficulty	cannot do at all		
		(%)	(%)	(%)	(%)	(%)	(%)
<b>Do you have difficulty understanding and following Instructions?</b>	no difficulty	84.1	2.6	0.6	0.1	87.3	-1213
	some difficulty	2.4	6.6	0.3	0.1	9.4	-130
	a lot of difficulty	0.2	0.9	1.4	0.1	2.5	-36
	cannot do at all	0.0	0.1	0.1	0.6	0.7	-10
Total percent		86.7	10.2	2.4	0.8	100	
<b>Total persons</b>		<b>1204</b>	<b>141</b>	<b>33</b>	<b>11</b>		<b>1389</b>

		rules for a new game				Total	N
		no difficulty	some difficulty	a lot of difficulty	cannot do at all		
		(%)	(%)	(%)	(%)	(%)	(%)
<b>Do you have difficulty understanding and following Instructions?</b>	no difficulty	42.1	2.4	0.4	0.1	45.1	401
	some difficulty	7.1	2.2	1.1	0.2	30.4	271
	a lot of difficulty	2.4	4.6	8.8	0.1	15.8	141
	cannot do at all	0.9	0.4	0.9	6.4	8.7	77
Total percent		52.5	29.4	11.2	6.9	100	
<b>Total persons</b>		<b>467</b>	<b>262</b>	<b>100</b>	<b>61</b>		<b>890</b>

Finally, expressed difficulty in daily activities was assessed by difficulty learning, based on most difficulty in either of the two questions: Rules for a New Game and Understanding and Following Instructions).

The wording of the question on daily activities was as follows:

*How much does your difficulty [learning / understanding and using information] limit your ability to carry out daily activities?*

The cross tabulation (Table 15) demonstrates considerable correspondence between the two constructs. Ninety-eight percent of those who report 'some difficulty' learning also report 'a little' or 'no difficulty' in their daily activities. Combining the columns 'a lot of difficulty' and 'cannot do it at all', 36 percent of those with either a lot of difficulty or who were unable to learn at all reported 'a little' difficulty in daily activities (yellow in the table below) and an additional 31 percent reported 'a lot' or 'complete' difficulty with daily activities (total 67 percent).

Examining the off-diagonals (red, by column), only 2.2 percent of those who reported 'some difficulty' learning also reported 'a lot' or 'complete' difficulty with daily activities; while almost a third (33.1 percent) of those reporting 'a lot of difficulty' or who 'cannot do at all' also reported 'no difficulty' with daily activities.

Since the daily activity question was asked directly with reference to the difficulty learning, these off-diagonal results are interesting. On the one hand there seems to be a small proportion of respondents (2.2 percent) who have daily activity difficulties due to learning problems that are not captured by the two questions included here (these may represent false negative responses or reflect difficulties in daily activities due to problems in other domains); while a larger proportion (32.2 percent) have ‘substantial’ learning difficulties that do not result in limitations in daily activities. These may not necessarily be false positives – but it is possible that they represent an environment that is accommodating to the extent that difficulties learning are not restricting an individual’s daily activities.

Table 15: Difficulty learning by Difficulty in daily activities – all respondents with some reported difficulty learning

		Difficulty learning				
		Some difficulty	A lot of difficulty	Cannot do at all	Total	Total persons
		(%)	(%)	(%)	(%)	(%)
<b>How much does your difficulty limit your daily activities?</b>	not at all	52.7	32.3	34.8	45.8	646
	a little	45.1	41.3	25	41.8	590
	a lot	2.1	24.6	17.1	9.1	129
	completely	0.1	1.8	23.2	3.2	45
<b>Total persons</b>		912	334	164		1410

## Conclusions and recommendations

The variation in responses by the country provides evidence that learning is culturally dependent and that more work needs to be undertaken to develop questions that are more cross-culturally and cross-nationally relevant and at the same time easy to understand and interpret. The learning questions tested here provided some insight into different aspects of learning: learning the rules for a new game and understanding and following instructions; however, many respondents were unable to provide adequate rationale for their choice of response. This would seem to indicate that the questions were complex and involved multiple tasks that may have confused the respondent or caused them to focus on only one aspect of the question without responding to the learning concept of interest (such as getting to a new place rather than understanding and following instructions).

The finding that the two questions captured different aspects of learning would seem to indicate that an extended set for the learning domain should include multiple questions. In particular, attention should be given to the age dependency with respect to learning. Many respondents expressed the fact that they do not learn new games because of their age.

These questions do not appear to adequately capture learning difficulties in the population that might be indicative of disability; and as a result, cannot be recommended in their tested form. More research, development and testing is required for the ‘learning’ concept.

## Affect (Anxiety and Depression) chapter

### Introduction

Affect is the domain of functioning dealing with emotional functions including depression and anxiety. These two domains are important to measure as they provide some indications of emotional or psychiatric disability. Depression and anxiety are common occurrences in most people's lives. However, of interest for this domain is to find a way of capturing difficulties people have because of depression and anxiety that goes beyond what is considered normal or most common. The aim is to measure depression and anxiety that creates significant problems for individuals. The domain of affect is similar to that of cognition where there is a continuum from full functioning to full disability and a meaningful cutoff point needs to be found to separate what is considered to be significant difficulty (and counted as being 'in scope') from common feelings that are less severe and more transient in nature ('our of scope').

The WG short Set did not include any questions for this domain as it is was deemed very difficult (if not impossible) to measure anxiety and depression using a single question. Rather than create a measure that is unclear as to what is being measured and most likely introduces a significant number of false positives, the decision was made to exclude this domain from the WG Short Set and develop it within the extended set.

### Affect and the ICF

The domain of affect is covered in Chapter One on Mental Functions within the Body Functions classification of the ICF. The sub domain b152 refers to emotional functioning and includes within it feeling and affective components of mental functions.

### Cognitive testing

The set of anxiety questions included in the cognitive interviews are presented in Box 1. As a set, the intent of the questions is to place respondents along a severity continuum comprised of various dimensions of anxiety (i.e. frequency, intensity, and consistency). In combination with the subsequent medication question, the first question (frequency) also serves as a screener question, routing respondents with no reported anxiety or use of medication into the set of depression questions. The depression questions (also in Box 1) replicate the general structure of the anxiety questions. The primary difference between the two sets is found in the intensity question. Instead of providing vague quantifiers (mild, moderate, severe) as response categories, the depression question lays out an explicit ranked order for respondents: 'a little', 'a lot', or 'somewhere in between a little and a lot'. Respondents answering 'somewhere in between a little and a lot' are then asked to further clarify their answer: 'closer to a little, closer to a lot, or exactly in the middle'.

### Box 1: Questions included in the cognitive interview protocol for Anxiety and Depression

Questions	Response Options
8.1a How often do you feel worried, nervous or anxious? Daily, Weekly, Monthly, A few times a year, or Never?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/unable to do
8.2 Do you take medication for anxiety?	1) Yes 2) No
8.3 Thinking about the last time you felt anxious, how would you describe the level of anxiety? Mild, moderate or severe?	1) Mild 2) Moderate 3) Severe
8.4 Thinking about the last time you felt anxious, was the anxiety worse than usual, better than usual, or about the same as usual?	1) Worse than usual 2) About the same as usual 3) Better than usual
11.1ai How old were you when the anxiety began?	_____ age in years
12.1i Is your anxiety due to a health problem or something else?	1) Due to a health problem 2) Something else: _____
13.1i Does your anxiety limit your ability to carry out daily activities?	1) Yes 2) No
13.2bi Does your anxiety limit your ability to carry out other activities that are not part of your day-to-day life?	1) Yes 2) No
8.5 How often do you feel depressed? Daily, weekly, monthly, a few times a year, or never?	1) Daily 2) Weekly 3) Monthly 4) A few times a year 5) Never  <i>If Never, go to next section.</i>
8.6 Do you take medication for depression?	1) Yes 2) No
8.7 Thinking about the last time you felt depressed, how depressed did you feel, a little, a lot, or somewhere in between a little and a lot?	1) A little 2) A lot 3) Somewhere in between a little and a lot
8.7b If somewhere in between: Would you say the depression was closer to a little, closer to a lot, or exactly in the middle?	1) Closer to a little 2) Closer to a lot 3) Exactly in the middle
8.8 Thinking about the last time you felt depressed, was the depression worse than usual, better than usual, or about the same as usual?	1) Worse than usual 2) About the same as usual 3) Better than usual
11.1ai How old were you when the depression began?	_____ age in years
12.1i Is your depression due to a health problem or something else?	1) Due to a health problem 2) Something else: _____
13.1i Does your depression limit your ability to carry out daily activities?	1) Yes 2) No
13.2bi Does your depression limit your ability to carry out other activities that are not part of your day-to-day life?	1) Yes 2) No

Investigation into the performance of the questions addresses: 1) how well the questions tapped into the intended constructs of anxiety and depression; 2) whether the three dimensions (frequency, intensity and consistency) were able to be reported by and relevant to respondents' experience; and 3) how well the three questions, when used together, could locate respondents on a severity continuum. Additionally, it was hoped that analysis of the cognitive interviews would shed insight into designing the response category structure for the intensity question. Specifically, the questions were whether articulating the ranked order provided clarification (as opposed to generating confusion) and whether it improved the accuracy of responses. Finally, as with all of the domains, examining the questions' performance across countries indicates the extent of comparability in the measures across different language groups and socio-cultural regions.

## Cognitive Interview Findings

Of the 108 cognitive interview respondents who answered the first anxiety question, 19 percent reported never having these feelings. None of these respondents reported use of medication and, therefore, skipped the remainder of the anxiety questions and were routed to the set of depression questions. Table 1 presents responses to the three anxiety questions.

Table 1: Level of Anxiety frequency, intensity and consistency

Frequency		Intensity		Consistency	
Never	18.5% (20)	Mild	40.5% (45)	Same as usual	62.2% (69)
Few times/year	30.5% (33)	Moderate	36.9% (41)	Better than usual	7.2% (8)
Monthly	18.5% (20)	Severe	17.1% (19)	Worse than usual	23.4% (26)
Weekly	22.2% (24)	Missing/Other	5.4% (6)	Missing/Other	7.2% (8)
Daily	28.7% (31)				

A little more than 30 percent of respondents reported having such feelings 'only a few times a year'. However, 19 percent reported having 'monthly' occurrences, 22 percent having 'weekly', and almost 29 percent having 'daily' feelings of anxiety. Of those reporting the presence of worried, nervous or anxious feelings, the majority reported 'mild' (41 percent) or 'moderate' (27 percent) intensity, with only 17 percent reporting 'severe' feelings. Finally, a full 62 percent responded that the level of intensity was the 'same as usual', 23 percent as being 'worse than usual', and only 7 percent reporting it being 'better than usual'.

Nearly twice as many respondents reported 'never' feeling depressed compared to anxiety (37 percent compared to 19 percent). None of these respondents, as in the anxiety set, reported use of medication and were routed out of the affect domain to the next domain entirely. Table 2 presents responses to the three depression dimension questions.

Table 2: Depression frequency, intensity and consistency

Frequency		Intensity		Consistency	
Never	37.2% (45)	Little	42.1% (32)	Same as usual	56.5% (43)
Few times/year	31.4% (38)	Closer to Little	10.5% (8)	Better than usual	11.8% (9)
Monthly	9.3% (13)	Exactly Middle	19.7% (15)	Worse than usual	23.7% (18)
Weekly	11.6% (14)	Closer to A lot	3.9% (3)	Missing/Other	7.9% (6)
Daily	9% (11)	A lot	22.7% (17)		
		Missing/Other	1.3% (1)		

A little more than 30 percent of respondents reported feeling depressed only ‘a few times a year’. The remaining 30 percent of respondents who reported feeling depressed were spread relatively equally across the ‘monthly’, ‘weekly’ and ‘daily’ categories. Furthermore, of those reporting feeling depressed, the majority reported having only ‘a little’ (42 percent) or ‘closer to little’ (11 percent) depression, with almost 20 percent reporting ‘exactly in the middle’. The remaining respondents reported having either ‘a lot’ (23 percent) or ‘in the middle, but closer to a lot’ (4 percent). Finally, and similarly to the anxiety questions, 57 percent responded that the level of depression was the ‘same as usual’, 24 percent ‘worse than usual’, and only 8 percent as ‘better than usual’.

Out of all of the respondents, only 15 reported taking medication for anxiety. In many of these cases, there is no information to determine what respondents were actually counting as anxiety medication and, therefore, impossible to determine the validity of these answers. However, the cases that do provide descriptions reveal some potential problems. For example, one South African respondent answered ‘yes’ to taking medication, but it was later revealed that the medication was for blood pressure and diabetes, and not specifically for anxiety. In another case, a respondent from Canada was not certain whether she should answer ‘yes’ (although she ultimately did) because she was not certain whether her Prozac was intended to treat her anxiety or her depression. Contrastingly, a United States respondent, who answered positively to all of the anxiety questions and who, in great detail described having regular panic attacks and being treated by a psychiatrist for anxiety, answered ‘no’ to the medication question stating that her Zoloft was treating her depression, not her anxiety.

The description in the narratives about use of medication for depression is even less detailed than that for anxiety medication. In total, only 12 respondents reported using medication for depression, and 7 of those 12 respondents also reported using medication for anxiety. It also appears from examination of the narratives that those respondents are indeed referring to the same medication for both the anxiety and depression medication questions. For example, one Mongolian respondents reported using ‘calmant’ for both questions; and the same South African respondent quoted above also answered ‘yes’ to using depression medication, again citing her blood pressure and diabetes medication.

Regarding the anxiety questions (specifically, the first frequency question), examination of the narratives indicates that a handful of respondents experienced some response difficulty: they either asked for the question to be repeated, needed additional time to consider their response, or were unable to provide an answer. Because of the limited amount of detail in the narratives, it is difficult to determine the exact nature of the problem. It is also possible that more respondents experienced this difficulty, but this was not documented in the narratives. There were a few cases, however, where the difficulty

appears to stem from the three words – ‘worried, nervous, and anxious’ – which were sometimes interpreted differently by respondents making it difficult for respondents to provide one summary answer.

There appeared to be fewer difficulties associated with the depression questions, although, again, it may be that the difficulties were simply not documented. Unlike the anxiety set, however, there was no indication that a respondent needed the question to be repeated or was unable to provide an answer. By far, the most common theme among respondent comments was that they did not see a difference between this depression question and the previous set of anxiety questions. In one case from Sri Lanka, the respondent considered the questions to be the same so would not provide answers to the set of depression questions. In fact, over 40 percent of the respondents who reported experiencing some depression and anxiety gave the exact same answer to the two questions, suggesting that they may have been thinking about the same kinds of feelings. These findings highlight the close relationship between anxiety and depression further confirmed by the fact that the same medication is often used to treat either or both together.

In considering the construct captured by the anxiety questions, respondents considered a range of feelings and experiences that they recognized as anxiety – or rather, what they believed the question was asking in terms of ‘worried, nervous or anxious’. For the most part, the feelings and experiences considered by respondents can be seen as various aspects of the intended concept of anxiety, though ranging in severity. These aspects include:

- 1) Clinical anxiety, whereby respondents described being diagnosed by a medical professional.
- 2) Elements of depression, whereby respondents spoke about being overly sad, wanting to stay in bed or being unable to perform daily activities, and
- 3) Stress-related worry, which respondents connected to work (e.g. heavy workloads, deadlines, and performances), family or relationship problems, crime, or concerns about their economic future and physical well-being.

One problematic theme, however, was that a handful of respondents spoke about their anxiety as being a positive characteristic. These respondents, it appears, interpreted the question as asking about being excited, energetic or looking forward to the future. For example, one US narrative states:

*‘Well it depends on what it is I got to do. Because I kind of get like hyped up when I know I’ve got to get something done by a certain time. I put the pressure on me to get it done by that certain deadline. That’s just me.’ I asked him what he meant by hyped up and he stated ‘I get like an adrenaline rush. I make myself get it done quick but when- ever I’m doing it in a quick way I’m often doing it in a safe, productive way to where I don’t get myself hurt or anybody else hurt.’ I asked him if he feels nervous or worried when this is happening and he said ‘no, just calm, relaxed, just know what I need to get done.’ He described what he was feeling as an energy boost, but not worried or nervous. I asked him about the last time this happened, he described going to school, and making sure he got there on time.*

This particular interpretation was clearly used by a small minority of respondents and was only found in the United States and Canada. It is possible, however, that this interpretation did exist in other regions,

but was not sufficiently detailed in the narratives. The field test is important to determine the extent of this pattern and whether it exists in particular subgroups.

With regard to the construct captured by the depression questions, respondents considered a similar range of feelings and experiences. Specifically, respondents described being diagnosed by a medical professional for clinical depression as well as the same kind of stress-related worries as they did in the anxiety questions. The primary difference in constructs between these two question sets is that depression did not contain the positive, excited theme. Instead, the depression set contained a theme of grief, whereby respondents spoke about their sadness or lack of enthusiasm related to the loss of a loved one.

In terms of examining how and why respondents came to choose their answer, there is little to no information in the narratives to inform our understanding of these processes. With regards to the intensity questions, there was some evidence that the vague quantifiers, as they were used in the anxiety response categories, were problematic. The narrative for a Sri Lankan respondent, for example, notes that 'she said it is difficult to answer as she does not know the meaning of mild, moderate or severe.' The narrative of one South African respondent notes that the respondent did not understand the question, though it is not clear whether the confusion is in regard to the meaning of the response categories or the concept of intensity as it applied to anxiety. Additionally, the narrative of a Canadian respondent noted that the respondent had to compromise when responding to the question: 'I chose moderate, but it is really in between moderate and severe.'

These types of problems did not exist for the depression intensity question, although, again, it is possible that problems were simply not documented. However, for this question, there were no reports of respondents being unable to answer because they did not understand the meanings of the response categories. Additionally, there were no reports of confusion related to the explicit order ranking in the response categories. The narrative for a Sri Lankan respondent does note, however, that while the respondent answered 'somewhere in between,' she was unable to answer the follow up question: it was 'difficult for her to distinguish' between 'closer to a little, closer to a lot or exactly in the middle.'

Regarding the consistency questions, the most often cited problem was that respondents were unable to provide a reasonable or accurate answer because either they could not determine what was meant by 'usual' or because the concept did not relate to their experience. Some respondents, for example, explained that their anxiety or depression does not occur episodically and, therefore, could not think in terms of 'the last time.' Additionally, one respondent from the US had difficulty answering because he does not get depressed often and, therefore, has no standard for usual. Another respondent from Canada also noted a dilemma with the concept: 'What is usual? ...last 5 years...last 20 years...usual for this decade, I guess.' In some cases it appeared that respondents were not fully considering or weighing out their answers. In fact, of the 67 respondents who answered this question for both depression and anxiety, two thirds (67 percent) gave the exact same answer in both with almost half of the respondents answering 'the same as usual' for both questions—suggesting that when respondents are answering the question, they might simply be satisfying the interviewer rather than providing a considered response.



## Conclusions from Cognitive testing and proposed revisions for the field test

Findings from analysis of the cognitive interviews informed several decisions regarding the revision of questions as well as to generate hypotheses about the questions' performance that would be further investigated in the field test. The revised questions are presented in Box 2 and Box 3. Regarding the changes to the questions, the consistency question was dropped because it did not appear that many respondents experienced their anxiety or depression in this manner making it difficult for them to report on this experience. Additionally, since there was no evidence of difficulty with the ranked order of response categories in the intensity question, but some evidence of problems with the vague quantifiers, it was decided that both intensity questions (ANX\_3, ANX\_4; DEP\_3, DEP\_4) would contain the explicit response categories (a little, a lot and somewhere in between a little and a lot). Finally, the medication questions (ANX\_2, DEP\_2) were revised to specify 'medication for these feelings' in the hopes that respondents would not include medication for other conditions such as blood pressure or diabetes.

Because of the lack of information in the cognitive interviews, it was also decided that that the field test would be used to fill in those gaps of knowledge. In particular, the field test would be used to determine the existence and prevalence of the various patterns of interpretation used by respondents to answer the questions. To this end, probe questions (P\_ANX\_4A - P\_ANX\_4G; (P\_DEP\_4A - P\_DEP\_4F) were generated from the interpretive patterns identified in the cognitive interviews. These probes would help to determine whether or not and how much the 'out of scope' 'positive' theme for anxiety posed a problem as well as to determine the measures' comparability across language and socio-cultural groups. As in the other domains, questions about age of onset and limitation in daily activities (ANX\_6, P\_ANX\_6A - P\_ANX\_6I; DEP\_6, P\_DEP\_6A-P\_DEP\_6I) were also included.

## Field testing

Boxes 2 and 3 present the revised questions for anxiety and depression taking into account the analysis of the cognitive testing interviews.

### Box 2: The field test questions on learning

Questions	Response Options
ANX_1 How often do you feel worried, nervous or anxious?	1) Daily 2) Weekly 3) Monthly 4) A few times a year 5) Never 6) <i>Refused</i> 7) <i>Don't know</i>
ANX_2 Do you take medication for these feelings?	1) Yes 2) No 7). <i>Refused</i> 9) <i>Don't know</i>

	<i>If "never" to ANX_1 and "No" to ANX_2, skip to DEP_1.</i>
ANX_3 Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?	1) A little 2) A lot 3) Somewhere in between a little and a lot 7) <i>Refused</i> 9) <i>Don't know</i>  <i>If "Somewhere in between a little and a lot" to ANX_3, continue with ANX_4. Otherwise, skip to P_ANX_4.</i>
ANX_4 Would you say this was closer to a little, closer to a lot, or exactly in the middle?	1) Closer to a little 2) Closer to a lot 3) Exactly in the middle 7) <i>Refused</i> 9) <i>Don't know</i>
P_ANX_4 Please tell me which of the following statements, if any, describe your feelings.	a) My feelings are caused by the type and amount of work I do. b) Sometimes the feelings can be so intense that my chest hurts and I have trouble breathing. c) These are positive feelings that help me to accomplish goals and be productive. d) The feelings sometimes interfere with my life, and I wish that I did not have them. e) If I had more money or a better job, I would not have these feelings. f) Everybody has these feelings; they are a part of life and are normal. g) I have been told by a medical professional that I have anxiety.  <i>Each category above has response options of:</i> 1) Yes 2) No 7) <i>Refused</i> 9) <i>Don't know</i>
ANX_5 How old were you when these feelings began?	____ Age in years 7. <i>Refused</i> 9. <i>Don't know</i>
ANX_6 How much do these feelings limit your ability to carry out daily activities?	1. Not at all 2. A little 3. A lot 4. Completely 7. <i>Refused</i> 9. <i>Don't know</i>

### Box 3: Depression field test questions

Questions	Response Options
DEP_1 How often do you feel depressed?	1) Daily 2) Weekly 3) Monthly 4) A few times a year

	<p>5) Never 7) <i>Refused</i> 9) <i>Don't know</i></p>
<p>DEP_2 Do you take medication for depression?</p>	<p>1) Yes 2) No 7) <i>Refused</i> 9) <i>Don't know</i></p> <p><i>IF "Never" to DEP_1 and "No" to DEP_2, skip to Section J Pain.</i></p>
<p>DEP_3 Thinking about the last time you felt depressed, how depressed did you feel?</p>	<p>1) A little 2) A lot 3) Somewhere in between a little and a lot 7) <i>Refused</i> 9) <i>Don't know</i></p> <p><i>If "Somewhere in between a little and a lot" to DEP_3, continue with DEP_4. Otherwise, skip to P_DEP_4.</i></p>
<p>DEP_4 Would you say this was closer to a little, closer to a lot, or exactly in the middle?</p>	<p>1) Closer to a little 2) Closer to a lot 3) Exactly in the middle 7) <i>Refused</i> 9) <i>Don't know</i></p>
<p>P_DEP_4 Please tell me which of the following statements, if any, describe your feelings.</p>	<p>a) My feelings are caused by the death of a loved one. b) Sometimes the feelings can be so intense that I cannot get out of bed. c) The feelings sometimes interfere with my life, and I wish I did not have them. d) If I had more money or a better job, I would not have these feelings. e) Everybody has these feelings; they are part of life and normal. f) I have been told by a medical professional that I have depression.</p>
<p>DEP_5 How old were you when the depression began?</p>	<p>_____ Age in years 7. <i>Refused</i> 9. <i>Don't know</i></p>
<p>DEP_6 How much does your depression limit your ability to carry out daily activities?</p>	<p>How much does your depression limit your ability to carry out daily activities?</p> <p>1. Not at all 2. A little 3. A lot 4. Completely 7. <i>Refused</i> 9. <i>Don't know</i></p>

## Field Test Findings for Anxiety

Respondents first reported how frequently they feel worried, nervous or anxious. Overall, nearly half of the respondents (47 percent) in the field test reported that they ‘never’ experienced these feelings. One in four reported experiencing the feelings ‘a few times a year’, and one in ten ‘monthly’. Nearly one in five (19 percent) respondents reported that they feel worried, nervous or anxious either ‘weekly’ or ‘daily’.

Table 3 demonstrates that the frequency reported varies significantly by country. For example, 30.9 percent of respondents in Kazakhstan and 26 percent from Mongolia reported that they experience the feelings ‘weekly’ or ‘daily’ compared to only about 10 percent of respondents from Sri Lanka and the Philippines reporting the anxiety ‘weekly’ or ‘daily’. In fact, 78.4 percent of respondents from Sri Lanka reported that they ‘never’ experienced worry, nervousness or anxiety.

Table 3. Frequency of anxiety by country.

Frequency	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Never	31.9	39.7	78.4	46.6	35.4	54.3	47.3
Few times a year	22.9	28.7	7.5	27.3	25.6	25.3	23
Monthly	13.6	14.5	2.7	5.7	12.8	10.8	10.1
Weekly	17.6	9.2	2.1	9	12.4	7.7	9.7
Daily	13.3	7.4	8.1	11	13.6	1.7	9.3
Refused	0.2	0	0.1	0.1	0.1	0	0.1
Don't know	0.5	0.5	1.1	0.4	0.3	0.2	0.5
Total persons	1000	1008	1000	1013	1222	1066	6309

Table 4 illustrates that there are also demographic differences in the reports of frequency. First, women experience the feelings more frequently than men. Specifically, men are more likely than women to report that they ‘never’ experience worry, nervousness or anxiety. Women are almost twice as likely as men to report that they experience the feelings ‘daily’ (11.3 percent versus 6.0 percent). Additionally, the feelings tend to increase with age. The percentage of respondents reporting that they ‘never’ experience worry, nervousness or anxiety generally decreases with age. The percentage reporting that they experience the feelings ‘daily’ increases with age.

Table 4. Frequency of anxiety by sex and age.

Frequency	Sex		Age						
	Male	Female	<18	18-30	31-40	41-50	51-60	61-70	>70
	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Never	56.9	41.2	75.7	43.8	39.8	37.7	30.2	38.2	32.7
Few times a year	20.2	24.8	13.8	27.2	26.8	25	24.7	23	24.6
Monthly	8.2	11.3	3.6	10.6	12.5	12	15.3	10.9	12.3
Weekly	8.1	10.8	3.5	11.4	10.5	12.3	13.7	11.4	9
Daily	6	11.3	3	6.6	9.9	12.2	15.3	16.5	19.9
Refused	0	0.1	0	0.1	0	0.2	0.3	0	0
Don't know	0.5	0.5	0.5	0.3	0.6	0.6	0.5	0	1.4
Total persons	2448	3861	1475	1478	1004	1008	738	395	211

Interestingly, Table 5 demonstrates that the intensity of anxiety appears to increase with frequency. The table shows that the percentage of respondents, who felt ‘a lot’ of worry, nervousness, or anxiety, increases with the frequency of anxiety and the largest increase occurs between the ‘weekly’ and ‘daily’ categories.

Table 5 Intensity of anxiety by frequency of anxiety.

Frequency	Few times a year	Monthly	Weekly	Daily
	(%)	(%)	(%)	(%)
A little	76.1	66.6	53.7	37.1
Closer to a little	2.5	3.9	4.4	2.1
In between	8.5	13.4	15.6	10.2
Closer to a lot	1.5	2.5	6.4	5.7
A lot	11.4	13.5	20	44.9
Total persons	1429	635	611	577

The intensity of anxiety reported by country is shown in Table 6. Overall, almost one in five (19.2 percent) respondents reported that they experienced ‘a lot’ of anxiety the last time they had these feelings.

Table 6. Intensity of anxiety by country.

	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
A little	64	62.7	54.4	39.4	65.6	83.5	62.4
Closer to a little	4.9	2	2	1.7	4.3	1.4	3
In between	10.2	18.6	6.4	15.1	6.8	6.8	11
Closer to a lot	6.7	2.2	2	1.1	5.1	0.4	3.3
A lot	12.9	14.1	34.8	40.9	16.9	7.2	19.2
Refused	0.2	0	0	0	0.3	0	0.1
Don't know	1.2	0.5	0.5	1.9	1	0.6	1
Total persons	675	603	204	536	785	486	3289

The intensity of anxiety reported varies significantly by country. One third (34.8 percent) of respondents from Sri Lanka and 40.9 percent of respondents from Maldives described the level of these feelings as ‘a lot’. The level of these feelings is much lower in the other countries. No more than 16.9 percent in any of the remaining countries and only 7.2 percent in Philippines described the level of their feelings as ‘a lot’.

As discussed earlier, the field test included two additional sets of follow-up questions to better determine the construct captured by the measures as well as to determine the impact of that construct on respondents’ lives. Table 7 presents respondents’ characterization of their reported feelings by the frequency of those feelings.

Table 7. Percentage reporting various descriptions of anxiety by frequency of anxiety.

Description of feelings	Few times a year	Monthly	Weekly	Daily
<i>Response error</i>				
Positive	53.1	49.1	55.2	47.4
Normal	81.1	79.3	80	76.5
<i>Stress-related</i>				
Work	38.7	53	49	42.5
Economic	46.7	57.2	59.5	58.4
<i>Impairment, limitation, pathology</i>				
Chest hurts	31.9	40.9	42.2	59.4
Interfere	49.5	56.9	61.7	79.5
Clinical	11.6	14.6	20.4	25

The characterizations can be roughly divided into three groupings. The first grouping describes feelings of anxiety that are more or less normative or even have a positive effect. One might be concerned about response error if a respondent were to base their response solely on these considerations. There is some variation across the distribution of the frequency variable for these considerations; however, no clear patterns emerge.

The second grouping of statements has to do with stress-related factors that may cause anxiety. The percentage reporting that their feelings are due to the type and amount of work that they do is highest for respondents who experience anxious feelings either 'monthly' or 'weekly'. The percentage reporting that they would not have these feelings if they had more money or a better job is lowest for those who report experiencing the feelings 'a few times a year'.

The third grouping of statements refers to more severe types of anxiety. These statements refer to impairments, limitations or clinical diagnoses related to anxiety. The clear trend is for the percentage agreeing with these descriptions to increase with the frequency of anxiety.

Table 8 presents the reporting of these descriptions by country. The table reveals considerable variation by country in the percentage answering positively to the statements.

Table 8. Percent reporting various descriptions of anxiety by country.

Description of feelings	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
<i>Response error</i>							
Positive	50.3	47.8	12.6	51.7	82.5	32.4	53.0
Normal	81.5	71.3	75.4	86.7	85.7	81.2	81.1
<i>Stress-related</i>							
Work	34.1	63.6	25.1	34.8	54.7	37.3	44.5
Economic	49.4	67.4	51.3	32.6	69.4	42.7	53.9
<i>Impairment, limitation, pathology</i>							
Chest hurts	21.4	72.3	30.9	37	50.6	20.3	40.6
Interfere	52.2	65	85.4	54.8	72.8	33.5	59.1
Clinical	11.8	16.8	3	28.4	18.6	11.5	16.5

Of note is that Mongolia had a high number of respondents who endorsed the ‘positive’ notion of anxiety while very few from Sri Lanka endorsed this description. All countries had a high number of respondents who endorsed the description of the feelings being normal. Anxiety for economic reasons, work and described as ‘my chest hurts’ was highest for Cambodia and Mongolia. The Maldives had the highest rate for diagnosed anxiety and Sri Lanka the lowest.

Table 9 shows that respondents report the impact of anxiety to be ‘completely’ most often for Sri Lankan respondents followed by Cambodian respondents. ‘A little impact’ on daily activities is noted most often by respondents from Mongolia and Cambodia.

Table 9. Amount that anxiety limits the respondents’ ability to carry out daily activities by country.

Limitation in daily activities	Kazakhstan (%)	Cambodia (%)	Sri Lanka (%)	Maldives (%)	Mongolia (%)	Philippines (%)	All Countries (%)
Not at all	60.7	36.8	51	56.5	41.4	71.6	52.1
A little	32.9	51.7	35.3	32.6	54.3	23.5	40.2
A lot	5.2	8.8	9.8	10.6	3.7	2.7	6.3
Completely	0.4	1.8	2.9	0.2	0.6	0.6	0.9
Refused	0.2	0	0.5	0	0	0	0.1
Don’t know	0.6	0.8	0.5	0	0	0.2	0.3
Other missing	0	0	0	0	0	1.4	0.2
Total persons	675	603	204	536	785	486	3289

As was learned through analysis of the cognitive interviews, respondents appeared to experience and relate their feelings of anxiety both in terms of frequency and intensity. Table 10 shows the joint distribution of the anxiety frequency and intensity questions. Intuitively, the seriousness of anxiety would be lowest in the upper left corner of the table and increase as one moves towards the lower right corner of the table. In addition, the correlation between these variables (polychoric correlation = .42) demonstrates, as expected, that the intensity of anxiety increases with frequency. Consequently, it does appear that a composite of the two variables can provide a multi-dimensional continuum for depicting severity of anxiety. However, this correlation is far from perfect, so by understanding the ways in which respondents characterized their feelings within each of the cells in Table 10 provides an even clearer picture of this relationship.

Table 10. Joint distribution of anxiety frequency and intensity.

	A few times a year	Monthly	Weekly	Daily	DK/REF
A little	1087	423	328	214	1
Closer to a little	35	25	27	12	0
In between	122	85	95	59	0
Closer to a lot	22	16	39	33	0
A lot	163	86	122	259	0
DK/REF	22	3	3	7	1

Note. Polychoric correlation = .42

Table 11 depicts the results of bivariate logistic regression models that were run to understand respondents’ characterizations in each of the cells. The dependent variable in each model was whether or not the respondent was located in the cell. The respondent was scored 0 if they were not located in

the cell of interest and 1 if they were located in the cell of interest. The independent variables in the models included the seven descriptions of depression from Table 7 and Table 8 (all scored 1 if the respondent selected the description; 0 if they did not). Models were also run using the limitation in daily activities variable as the independent variable (scored 1 = a little limited to 4 = completely limited).

Table 11. Significant relationships with respondent location based on bivariate logistic regression models in each cell (Models run for cases NOT taking medication).

Intensity	Frequency			
	A few times a year	Monthly	Weekly	Daily
A little	Work*** Chest hurts*** Interfere*** Economic*** Clinical*** Limited***	Clinical** Limited*** Work*** Economic**	Chest hurts*** Interfere*** Work***	Normal*** Interfere*** Limited**
Closer to a little			Economic**	
In between	Normal**	Positive** Work*** Limited**	Chest hurts*** Limited***	Interfere*** Economic** Limited***
Closer to a lot	Interfere**		Interfere** Economic*** Limited***	Chest hurts** Limited**
A lot	Work*** Economic** Normal** Chest hurts*** Interfere** Clinical***	Positive** Chest hurts*** Interfere** Clinical*** Limited***	Chest hurts*** Interfere*** Clinical*** Limited***	Positive*** Chest hurts*** Interfere*** Clinical*** Limited***

Note. Negative associations shown in red text. Positive associations shown in black  
 \*\*p<.05,\*\*\* p<.005

Table 11 illustrates how the characterizations of anxiety are associated with being located in each cell in the joint distribution of frequency and intensity. The table shows the results for cases that do not take medication that may help reduce their levels of anxiety. Several observations can be made from this table. First, the upper left corner of the table shows that anxiety described as being related to work, chest pains, interference with life, economic issues, clinical diagnoses, and limitation in daily activities decrease the likelihood of selecting the lowest levels of frequency and intensity. In contrast, anxiety described as being related to chest pains, interference with daily life, clinical diagnoses, and limitation in daily activities generally increase the likelihood of responding at the higher levels of the frequency and intensity variables. Moreover these variables are the most prominent when you get the highest level of the frequency and intensity variables. Finally, anxiety related to work or economic issues emerge in a variety of different places in Table 11.



## Field test findings for Depression

Table 12 illustrates how frequently respondents experience feelings of depression by country. Three in five (61.2 percent) respondents reported that they ‘never’ feel depressed. One in five reported that they feel depressed ‘a few times a year’. Another 6.9 percent reported that they feel depressed ‘monthly’. Less than one in ten (9.8 percent) respondents reported that they feel depressed ‘weekly’ or ‘daily’.

Table 12. Frequency of depression by country.

Frequency	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Never	68.4	46.6	87.3	58.3	46.8	62.7	61.2
Few times a year	22.2	26.9	6.8	22.3	27.4	23.9	21.8
Monthly	5	13.9	1.5	4.3	10.7	5.3	6.9
Weekly	2.5	5.9	0.7	7.4	10.2	5.6	5.6
Daily	1.5	6.7	2.8	7.1	4.8	2.3	4.2
Refused	0	0	0.1	0.1	0	0	0
Don't know	0.4	0.1	0.8	0.4	0.1	0.3	0.3
Total persons	1000	1008	1000	1013	1222	1066	6309

The frequency of depression varies by country. Almost nine in ten (87.3 percent) respondents from Sri Lanka reported that they ‘never’ feel depressed. Nearly seven in ten (68.4 percent) respondents from Kazakhstan and slightly more than six in ten (62.7 percent) respondents from the Philippines reported that they ‘never’ feel depressed. Depression is experienced most frequently in Cambodia and Mongolia where more than one in four respondents reported that they feel depressed ‘monthly’ or more often. Slightly less than one in five (18.8 percent) reported they feel depressed ‘monthly’ or more often in Maldives.

The frequency of depression also varies by sex and age. As shown in Table 13, approximately 12.2 percent of men reported feeling depressed ‘monthly’ or more often. In comparison, almost one in five (19.6 percent) women reported feeling depressed ‘monthly’ or more often. Additionally, depression generally appears to increase with age. Only 5.9 percent of respondents under the age of 18 feel depressed ‘monthly’ or more often. Less than one in five respondents between the ages of 18 and 50 reported that they feel depressed ‘monthly’ or more often. Approximately one in four respondents between the ages of 51 and 70 and one in three respondents over 70 reported that they feel depressed ‘monthly’ or more often.

Table 13. Frequency of depression by sex and age.

Frequency	Sex		Age						
	Male	Female	<18	18-30	31-40	41-50	51-60	61-70	>70
	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Never	69.8	55.7	84.3	55.4	54.1	56.6	51.5	52.7	45.0
Few times a year	17.6	24.5	9.6	27.1	26.9	24.4	25.2	22.5	20.9
Monthly	5.4	7.9	2	7.4	8.4	8.5	9.2	8.6	11.9
Weekly	4.3	6.4	2.6	7	6.1	5.4	6.2	8.1	7.6
Daily	2.5	5.3	1.3	2.9	4.1	4.5	7.6	7.9	13.7
Refused	0	0	0	0.1	0	0.1	0	0	0
Don't know	0.4	0.3	0.2	0.1	0.5	0.6	0.3	0.3	1
Total persons	2448	3861	1475	1478	1004	1008	738	395	211

Table 14 demonstrates that approximately a quarter of respondents (24.9 percent) who reported experiencing depression also reported that they experienced ‘a lot’ of depression the last time they felt depressed.

Table 14. Intensity of depression by frequency of depression.

Frequency	Few times a year	Monthly	Weekly	Daily	Overall
	(%)	(%)	(%)	(%)	(%)
A little	65.5	57.3	46.3	24.1	56.7
Closer to a little	4.3	4.4	3.7	1.9	4
In between	10.6	15.8	15.7	9.5	12.2
Closer to a lot	2.1	5.5	4.9	3.1	3.2
A lot	17.5	17	29.4	61.5	23.9
Total persons	1364	436	350	262	2412

There is a significant positive correlation between the frequency and intensity of depression. Approximately seventeen percent of respondents who experience depression ‘a few times a year’ or ‘monthly’ reported ‘a lot’ of depression the last time they experienced it. In contrast, nearly three in ten (29.4 percent) who reported experiencing depression ‘weekly’ and more than six in ten (61.5 percent) respondents who reported experiencing depression ‘daily’ also reported that they experienced ‘a lot’ of depression the last time they experienced it.

As shown in Table 15, the reported intensity levels of depression also vary by country. Nearly one half (48.9 percent) of respondents from the Maldives who experienced depression reported that they felt ‘a lot’ of depression the last time they felt depressed. Almost four in ten (39.8 percent) respondents from Sri Lanka and one in four (26.9 percent) respondents from Kazakhstan who reported experiencing depression reported the same. Respondents from Cambodia, Mongolia, and the Philippines reported the lowest levels of depression.

Table 15. Intensity of depression by country.

	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
A little	34.0	66.7	45.8	32.9	65.9	71.8	56.3
Closer to a little	8.3	2.2	0.9	3.1	5.1	2.8	4
In between	22.1	15.6	11	13.7	6.8	6.8	12.1
Closer to a lot	7.7	1.5	0.9	0.5	5.9	1.3	3.2
A lot	26.9	13.8	39.8	48.9	15.9	16.6	23.8
Refused	0.3	0	0	0	0	0.5	0.1
Don’t know	0.6	0.2	1.7	1	0.6	0.3	0.6
Total persons	312	537	118	417	650	397	2431

As was done with anxiety, respondents' characterization of their depressed feelings was also examined. Table 16 illustrates the percentage of respondents who endorsed the various characterizations by how they answered the frequency question.

Table 16. Percentage reporting various descriptions of depression by frequency of depression.

Description of feelings	Few times a year	Monthly	Weekly	Daily
	(%)	(%)	(%)	(%)
Normal	81.2	80.3	79.2	73.5
Death	48.2	52.8	49.3	47.4
Economic**	45.1	56.7	55.3	59.5
Intense**	14.7	21.8	31.6	42.4
Interfere**	49.2	65.1	67.5	71.6
Clinical**	12.4	15.1	19.9	35.2

\*\*Denotes significant differences ( $p < .05$ ) across levels of frequency.

There was very little variation in the percentage of respondents that describe their depression as being due to feelings that are 'normal' or 'caused by the death of a loved one' across the frequency categories. However, the percentage endorsing the other descriptions varies significantly across the frequency categories. Most notably the percentage who reports that 'Sometimes the feelings can be so intense that I cannot get out of bed' or 'I have been told by a medical professional that I have depression' increases with the frequency of depression.

Table 17 shows the percentage of respondents who endorsed these descriptions within each country. As with anxiety, the percentage endorsing the descriptions varied significantly across the countries. Overall, approximately eight in ten (79.8 percent) describe their depression as 'normal'. Almost six in ten (57.1 percent) respondents report that their depression interferes with their daily life. Approximately one half describe their depression as being due to the death of a loved one or economic problems. Slightly more than one in five (21.5 percent) report that 'Sometimes the feelings can be so intense that I cannot get out of bed'. Clinical diagnoses are reported by only 16.5 percent of respondents.

Table 17. Percent reporting various descriptions of depression by country.

Description of feelings	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Normal	74.0	76.7	83.1	86.3	83.1	75.6	79.8
Death	35.3	58.9	70.3	42.5	52.8	41.6	49.1
Economic	38.1	68.7	55.9	26.4	62.9	37.5	50.3
Intense	18	18.1	11	24.5	35.2	6.3	21.5
Interfere	61.5	67	83.1	54.4	65.1	22.4	57.1
Clinical	11.2	16.6	5.9	28.5	18.6	7.6	16.5

As with anxiety, the frequency and intensity variables for depression were examined together. The joint distribution of the two questions is shown below in Table 19. The findings show that the relationship

between intensity and frequency is not simple for depression. For example, ‘a lot’ of depression is most frequently reported by respondents who experience this only ‘a few times a year’. This is congruent with the understanding of disability as being an episodic phenomenon for many people, being intense but not constant necessarily. The people who reported ‘a lot’ of depression ‘weekly’ and ‘daily’ are more likely to be people who experience continuous depression. This would make it important to ask about both frequency and intensity of depression to make sure both of these types of depression are captured by the measures.

Table 18. Amount that depression limits the respondents’ ability to carry out daily activities by country.

Limitation in daily activities	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Not at all	46.8	35.9	56.8	48.9	42.3	65.7	47.1
A little	38.1	50.3	26.3	41	52.5	26.2	42.6
A lot	11.9	10.8	13.6	9.8	4.6	5.5	8.4
Completely	2.6	2.6	2.5	0	0.5	0.8	1.3
Refused	0.3	0	0	0	0	0	0
Don’t know	0.3	0.4	0.9	0	0.2	0	0.3
Other missing	0	0	0	0.2	0	1.8	0.2
Total persons	312	537	118	417	650	397	2431

Finally, as with the anxiety questions, bivariate logistic regression models that were run to understand respondents’ characterizations in each of the cells in the joint distribution shown in Table 19. The dependent variable in each model was whether or not the respondent was located in the cell. The respondent was scored 0 if they were not located in the cell of interest and 1 if they were located in the cell of interest. The independent variables in the models included the seven descriptions of depression from Table 16 and Table 17. These variables were scored 0 if the respondent did not endorse the description and 1 if the respondent endorsed the description. We also ran models with the limitation in daily activities variable as the independent variable (scored 1 = a little limited; 4 = completely limited). Table 20 shows the significant relationships for respondents who do not take medication.

Table 19. Joint distribution of depression frequency and intensity.

	A few times a year				
	Monthly	Weekly	Daily	DK/REF	
A little	893	250	162	63	0
Closer to a little	58	19	13	5	0
In between	145	69	55	25	0
Closer to a lot	29	24	17	8	0
A lot	239	74	103	161	0
DK/REF	11	0	1	2	1

Note. Polychoric correlation = .38

Table 20. Significant relationships with respondent location based on bivariate logistic regression models in each cell (Models run for cases NOT taking medication).

Intensity	Frequency			
	A few times a year	Monthly	Weekly	Daily
A little	Death** Intense*** Interfere*** Clinical*** Limited***	Clinical***	Intense**	Death** Intense** Economic**
Closer to a little	Interfere**			
In between	Limited**	Death** Economic** Limited***	Interfere*** Limited***	Interfere** Limited**
Closer to a lot		Interfere** Economic** Limited**	Intense**	
A lot	Economic*** Death*** Interfere**	Intense*** Interfere*** Clinical*** Limited***	Death** Intense*** Interfere*** Clinical*** Limited***	Intense*** Interfere*** Clinical*** Limited***
Note. Negative associations shown in red text. Positive associations shown in black text. **p<.05,*** p<.005				

## Relationship between anxiety and depression

The final set of analyses for the affect section examines the relationship between the anxiety and depression measures. As discussed earlier, analysis of the cognitive interviews suggests that there could be a fair amount of overlap in the two measures. It would be important, therefore, to examine the relationship in order to determine the utility of including both measures. A summative score based on frequency and intensity was created in order to facilitate these analyses. Respondents were scored from 0 (never) to 4 (daily) on the frequency variable and 1 (a little) to 5 (a lot) on the intensity variable. A single score for each respondent was created by summing these two variables. This process was conducted for both anxiety and depression.

Table 21 illustrates the distributions of the anxiety and depression variables. The left panel of the table illustrates that respondents are more likely to experience anxiety than depression. The mean scores for each variable indicate that on average respondents experience higher levels of anxiety than depression. The right panel of Table 21 illustrates the distributions of the anxiety and depression scores among the respondents who experience anxiety or depression. The distribution of scores is fairly similar among these two subsets of respondents. In addition, the mean scores are much closer once those who do not experience anxiety or depression are excluded.

Table 21. Distribution of anxiety and depression scores.

Score	Distribution for all respondents		Distribution for respondents who experience anxiety or depression	
	Anxiety	Depression	Anxiety	Depression
	(%)	(%)	(%)	(%)
0	47.7	61.4		
2	17.5	14.3	33.4	37.1
3	7.4	5	14	12.7
4	7.7	5.2	14.6	13.5
5	5.6	2.8	10.8	7.2
6	4.6	5.2	8.8	13.4
7	3	1.9	5.7	4.9
8	2.5	1.8	4.8	4.6
9	4.1	2.6	8	6.6
Total persons	6189	6189	3254	2410
Mean	2.21	1.6	4.24	4.13

The joint distribution of the anxiety and depression scores is shown in Table 22. The table collapses neighboring scores together for presentation purposes. There is a fairly high correlation ( $r=.62$ ) between the two variables as one might expect. Agreement as measured by Kappa is moderate at .52. Almost two thirds (65 percent) of the respondents reside in the diagonal of Table 22. That is, they have equivalent or nearly equivalent scores on anxiety and depression. Slightly more than one quarter (26 percent) of respondents have higher anxiety scores than depression scores. A large proportion of these cases derive from respondents who reported 'never' experiencing depression, but experience at least some level of anxiety. Slightly less than one in ten (9 percent) respondents have higher depression scores than anxiety scores.

Table 22. Joint distribution of anxiety and depression scores.

Anxiety score	Depression score			
	0	2-3	4-6	7-9
0	2690	153	84	26
2-3	618	709	181	27
4-6	381	267	378	82
7-9	110	63	171	249

Pearson Correlation = .62, Weighted Kappa = .52

## Conclusions and recommendations on affect domain

The cognitive and field testing findings confirm the close relationship between anxiety and depression. The findings show that anxiety is experienced more often than depression and that some experiences of anxiety have positive connotations whereas the experience of depression is always negative. There are country differences which could be investigated further to determine if these are real differences or more a function of translation issues and cultural features. Of note is that Sri Lankan respondents were the least likely to experience both anxiety and depression despite being a country with a very high rate of suicide and a recent protracted period of civil war.

The use of a range of questions (frequency and intensity) together with the responses on the probes allow for a good description of the continuum of functioning to disability for this domain. For anxiety the relationship between intensity and frequency seems to be clear and positive with increasing intensity being correlated with increasing frequency. This relationship is not as simple for depression where low frequency (few times a year) is most highly correlated with high intensity (a lot of depression). However, higher frequency (weekly and daily) are also correlated with high levels of intensity (a lot). This confirms the possibility of depression being intense but episodic.

The relationship between age and sex and anxiety and depression is that women are more likely to report difficulties with both anxiety and depression than men and younger respondents are least likely to report these feelings. For depression, the increase in the number of respondents with depression is strong from age of 18 years and least in the younger respondents. For anxiety there is a more steady increase in difficulties with increasing age than seen for depression.

Both anxiety and depression questions included the use of probes. These seem to work well for the probes that ask about a clinical diagnosis for both anxiety and depression, interference with life for anxiety, and for depression the probe on intense feeling that prevents a person getting out of bed. For these probes there was a consistent relationship where a 'yes' for the probe indicated increased frequency of the feeling. The other probes did not clearly differentiate between frequency of depression or anxiety.

## Recommendations for extended set of questions for Affect domain

Given the findings described above, the suggested questions to be used in the extended set are as follows where the questions on frequency and intensity are retained as are the probes that show a good correlation with frequency of anxiety and depression.

### **Anxiety:**

1. How often do you feel worried, nervous or anxious?
2. Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?
3. Please tell me which of the following statements if any describe your feelings:
  - Sometimes the feelings can be so intense that my chest hurts and I have trouble breathing
  - The feelings sometimes interfere with my life, and I wish that I did not have them

- I have been told by a medical professional that I have anxiety
4. How much do these feelings limit your ability to carry out daily activities?

**Depression:**

5. How often do you feel depressed?
6. Thinking about the last time you felt depressed, how depressed did you feel?
7. Please tell me which of the following statements, if any, describe your feelings.
  - Sometimes the feelings can be so intense that I cannot get out of bed
  - I have been told by a medical professional that I have depression
8. How much do these feelings limit your ability to carry out daily activities?

Of note, however, is the need for further testing of these questions. For example:

- the cognitive testing highlighted the confusion caused by the three words in the first question for anxiety – worry, nervous or anxious. A variation of the question using only the term ‘anxious’ should be tested in comparison to using the three terms.
- The probes should be further tested cognitively and see whether counting only ‘yes’ responses to these probes as being ‘in scope’ would provide a good measure of the prevalence of anxiety and depression.
- Further analysis should aim to set out a clear analytical strategy for calculating ‘in scope’ vs ‘out of scope’ responses and hence statistics.



## Pain chapter

### Introduction

While most of the functions included as measures in the Washington Group and Budapest Initiative instruments fall discretely into a core domain of functioning, such as physical, sensory, psychological or cognitive functioning, pain is unique. Pain is not contained within a single domain. It is a symptom, rather than a specific health diagnosis or disease, and can be related to any of the aforementioned domains.

### Pain and the ICF

Pain is discussed in Chapter 2 of the WHO's International Classification of Functioning, Disability and Health, "Sensory Functions and Pain". The chapter covers the functions of the senses such as seeing, hearing, and tasting, and also the sensation of pain (b280-b289) defined as an unpleasant feeling indicating potential or actual damage to a body structure. Inclusions listed are sensations of generalized or localized pain, in one or more body part, pain in a dermatome, stabbing pain, burning pain, dull pain, aching pain; impairments such as myalgia, analgesia and hyperalgesia. Thus, while pain is a multidimension concept, related to any number of the core domains of functioning, it is important to note that the focus in the ICF and in the question set here is on physical or bodily pain, rather than psychological or emotional pain.

### Conceptual Issues

Pain is a difficult symptom to measure. It cannot be measured directly, but must be judged by the individual's response, which is subjective and influenced by a number of factors including sex, age, education, and other personal factors. It is also a product of culture and condition. However, it is the subjective experience of pain that determines the consequences for the person and his or her ability to participate.

When considering how to ask questions about pain in order to accurately assess its presence and to capture information about burden, a number of approaches have been considered. For this question set in particular, conveying the concept of interest to the respondent (for example, pain versus discomfort, and physical pain versus psychological pain) and accurately capturing a range of experiences with pain requires more than a simple approach. Asking respondents if they have pain, or where it is located, does not sufficiently capture the desired dimensions, nor does it account for the burden of pain.

In previous rounds of testing, a number of dimensions have been identified as important including asking respondents about the frequency, duration and intensity of their pain. In addition, asking about the use of medicinal aides has also provided valuable information on understanding pain and is considered important when constructing questions on pain. The set of questions on pain included in the protocols tested in 2009 were intended to capture all of these essential elements, provide information on the validity and reliability of the information captured by the questions, and to further provide some

evidence that information on pain collected by the set can be combined to form a scale or summary measure of the experience of pain.

## Cognitive Test

The following question set on pain (Box 1) was included in the interview protocol for the 2009 round of cognitive testing in the ESCAP region. The set asks about having frequent pain, use of medication, duration, intensity, consistency, age at onset and whether the pain has any impact on daily and other activities. Note that unlike in other domains, there is no single “short set” question for pain as the multiple rounds of testing for pain have demonstrated that a single question is not feasible.

### Box 1. Pain questions administered in the cognitive test interviews.

Questions	Response Options
9.1 Do you have frequent pain?	1) Yes 2) No
9.2 Do you use medication for pain?	1) Yes 2) No  <i>If “No” to both 9.1 and 9.2, skip to next section. If “Yes” to 9.1 continue with 9.3.</i>
9.3 In the past 3 months, how often did you have pain? Some days, most days or every day?	1) Some days 2) Most days 3) Every day
9.4 Thinking about the last time you had pain, how long did the pain last? Some of the day, most of the day or all of the day?	1) Some of the day 2) Most of the day 3) All of the day
9.5a Thinking about the last time you had pain, how much pain did you have, a little, a lot, or somewhere in between a little and a lot?	1) A little 2) A lot 3) Somewhere in between a little and a lot  <i>If “Somewhere in between” to 9.5a, continue with 9.5b. Otherwise, skip to 9.6.</i>
9.5b Would you say the amount of pain was closer to a little, closer to a lot, or exactly in the middle?	1) Closer to a little 2) Closer to a lot 3) Exactly in the middle
9.6 Thinking about the last time you had pain, was the pain worse than usual, better than usual, or about the same as usual?	1) Worse than usual 2) About the same as usual 3) Better than usual
9.7 How would you describe your pain?	
9.8 How old were you when the pain began?	_____ age in years
9.9 Is your pain due to a health problem of something else?	1) Due to a health problem 2) Something else: _____
9.10 Does your pain limit your ability to carry out daily activities?	1) Yes 2) No

9.11 Does your pain limit your ability to carry out other activities that are not part of your day-to-day life?	1) Yes 2) No
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## Reporting of Pain

From the outset of testing pain questions, it has been clear that whether respondents report pain and what they are reporting as pain varies. The data from this round of cognitive testing also illustrates the variation among respondents in the reporting of pain. These variations appear to be related to a number of factors, including how the respondent interprets ‘frequent’. More information on this is provided below. Respondents’ reports of pain vary by whether or not the cause of the pain is believed to warrant the report. For example, firstly, self-inflicted pain or pain that results from overwork is discounted by some, but not all, respondents; secondly, depending on whether their pain is a frequent experience or ‘usual’ or typical experience for them, as well as whether they believe the question is asking about ‘usual pain’; lastly, the results show differences in reports associated with respondents’ beliefs that their pain is ‘intense’ enough to report. For example, the experience of discomfort is reported by some respondents as pain, but not by others.

## Interpretation of ‘Frequent’ and Frequency of Pain

Previous versions of the initial pain question have demonstrated that asking, ‘Do you have pain?’ captures a wide range of experiences, including discomfort and fatigue for example, which are out of scope for our purposes. The current version of the question inserted the word ‘frequent’ as an attempt to capture pain experienced above a relatively low or common threshold. The word ‘chronic’ was considered and seen to be a medical term not universally understood. Hence ‘frequent’ was chosen. Ultimately, the goal was to try to avoid capturing the occasional, routine experience of pain that lasts only for a short period of time and is easily resolved by medication.

The cognitive test provided some evidence that respondents vary in their interpretations of ‘frequent’ in the initial pain question. Some respondents asked immediately what was meant by this word. Others asked if ‘frequent’ was different from ‘chronic’ or ‘constant pain’. When respondents were asked by interviewers how they interpreted ‘frequent’, various interpretations were reported including: constant, every day, every week, and every time it rains.

## Type of Pain

Many different types of pain were reported in the cognitive test. The majority of reports of pain were based on physical pain. Among the responses recorded were long-term injury; injuries without specification of duration; disease-related pain such as liver disease, osteochondrosis and scoliosis; muscular pain and soreness. Only two respondents mentioned emotional pain when probed about their pain. Furthermore, the sites of the pain experienced covered nearly every part of the body, including the head, neck, eyes, teeth, back, arms, knees, feet, etc.

## Pain Medication

The question on pain medication was included in the set to provide some information on the degree of pain experienced, as well as to assess accommodation (and functioning with or without the accommodation). This is based on the assumption that, in most cases, the greater the pain experienced

the greater the likelihood an individual will use pain medication. It was also included as a way to interpret (during data analysis) the information provided in the frequency, duration and intensity questions. It was not included as a way to filter out those respondents who report experiencing pain, but for whom medication alleviates the burden of that experience. Everyone who reports pain in the initial question receives the follow up questions, regardless of their answer to the pain medication question.

Responses to 'Do you use medication for pain?' depend greatly on the interpretations of, and emphasis placed on, the term 'use' and 'for pain'. For some respondents, some medicines did not qualify as pain-relievers, for example those items typically associated with complimentary or alternative medicines. For others, medicine included water therapy, supplements, patches, exercise, and calcium, to name a few. For some respondents, it is the form of the medicine that dictated its report. Ointments and non-prescription drugs did not qualify for some respondents; for others these items along with tablets, prescription drugs, and other more traditional type drugs were counted as medicines. Many respondents were unsure of what medicines should be included and asked the interviewer for clarification.

### **Duration, Intensity and Consistency of Pain**

The cognitive test did not capture as much information as desired about these important dimensions of pain. In general, respondents answered the test questions, but the majority were either unable to answer, or due to time constraints were not asked, the probe questions which provide valuable interpretative information.

Some information was provided that was used to inform the field test, however. First, there is some evidence that respondents have difficulty estimating how long their pain lasts. Part of the evidence highlights the difficulties in accurately pinpointing the onset of the pain and the end of the pain experience. Some respondents chose varying metrics by which to estimate the length of time of their pain. For example, if the pain lasted a couple of hours or for an afternoon, they asked if that means 'some of the day' or 'most of the day'? Others were unsure of what metric to use at all. Clearly the response categories were problematic and did not correspond well to how most respondents measured the duration of their pain. Further, the phrase 'the last time' was not always included as part of the response process. When probed, some respondents had not limited their answer to just their last experience of pain.

In contrast, the response categories 'a little', 'a lot' and 'somewhere in between' seemed easy for most respondents, and respondents appear to have little difficulty with the follow up question for those that answered 'somewhere in between a little and a lot', although most responses still fall at the extremes or exactly in the middle.

Question 9.6 asks respondents to rate their last episode of pain as 'worse', 'better' or 'about the same as usual'. While little information was obtained during the probes, it is evident from the data collected that this question was especially difficult for those who do not experience pain in discrete periods. For

these individuals common verbatim responses to probes included, the pain is ‘always similar’, ‘always there’, ‘constant’ and ‘consistent’.

### **Cognitive Test Conclusions**

Several important findings emerged from the cognitive test of the pain question set.

1. Whether pain is reported or not by respondents varies. The variation occurs by respondents’ interpretation of ‘frequent’ as a qualifier of the pain, by cause, by frequency, and by intensity of the pain experience. Whether these variations occur as a result of socio-cultural differences, or are influenced by age, sex, education and other demographic factors is unknown. Clearly, the finding strongly supports the idea that pain must be measured along multiple dimensions in order to adequately and accurately capture the full experience of pain.
2. There is some evidence that the meaning of the word ‘frequent’ is not consistently interpreted by respondents. Thus, the initial pain question alone may not serve as a reliable screening question for the remainder of the set.
3. One consistent finding concerns the type of pain. When pain is reported, it is predominantly physical pain associated with a specific part of the body and the result of an injury or acute or chronic condition.
4. The use and types, of medicines reported vary in ways that do not provide clear evidence of how the data should be interpreted, although medication remains an important accommodation for pain and should not necessarily be excluded based on differences in type or frequency of use. Moreover, without asking about pain with and then again without medication, it is unclear whether we are ascertaining pain with or without accommodation.
5. Finally, information about the frequency, duration and intensity of pain is important but is also highly subjective and heavily influenced by whether the pain experience is episodic or continuous. Thus, many of the findings suggest quite a bit of interpretative variability.

### **Field Test**

As a result of the cognitive test findings, several changes were made to the pain question set for implementation in the ESCAP field test as set out in Box 2. In particular, an additional, second screener question was added and the pain medication and consistency questions were eliminated from this round. All of the remaining questions were unchanged for the field test, with the expectation that the field test would fill some of the data gaps from the cognitive test.

**Box 2. Pain questions administered in the field test interviews.**

Questions	Response Options
PAIN_1 Do you have frequent pain?	1) Yes 2) No
PAIN_2 In the past 3 months, how often did you have pain? Never, some days, most days or every day?	1) Never 2) Some days 3) Most days 4) Every day  <i>If “No” to PAIN_1 and “Never” to PAIN_2, skip to next section.</i>
PAIN_3 Thinking about the last time you had pain, how long did the pain last? Some of the day, most of the day or all of the day?	1) Some of the day 2) Most of the day 3) All of the day
PAIN_4 Thinking about the last time you had pain, how much pain did you have, a little, a lot, or somewhere in between a little and a lot?	1) A little 2) A lot 3) Somewhere in between a little and a lot  <i>If “Somewhere in between a little and a lot” to PAIN_4, continue with PAIN_5. Otherwise, skip to P_PAIN_5</i>
PAIN_5 Would you say the amount of pain was closer to a little, closer to a lot, or exactly in the middle?	1) Closer to a little 2) Closer to a lot 3) Exactly in the middle
P_PAIN_5 Please tell me which of the following statements, if any, describe your pain.	A) It is constantly present. B) Sometimes I’m in a lot of pain and sometimes it’s not so bad. C) Sometimes it’s unbearable and excruciating. D) When I get my mind on other things, I am not aware of it. E) Medication can take my pain away completely. F) My pain is because of work. G) My pain is because of exercise.
PAIN_6 How old were you when the pain began?	_____ age in years
PAIN_7 How much does your pain limit your ability to carry out daily activities?	1) Not at all 2) A little 3) A lot 4) Completely

**Reporting of Pain and Frequency of Pain**

Data from a total of 6,309 interviews are available for the evaluation of the pain question set. Tables 1 and 2 provide an overview of responses to the initial two pain questions, which were administered to all respondents. Forty percent of all respondents reported having frequent pain. The majority did not have frequent pain. Just over half of the sample (53 percent) indicated never having pain in the past three

months. One-third reported pain some days, and another 14 percent reported experiencing pain most days or every day (7.6 and 6.8 percent, respectively).

Table 1. Responses to initial pain question, 'Do you have frequent pain?'

<b>Have frequent pain?</b>	<b>Total persons</b>	<b>Percent</b>
Yes	2,534	40.2
No	3,763	59.6
Refused	3	0
Don't know	9	0.1
<b>Total</b>	<b>6,309</b>	<b>100</b>

Table 2. Responses to frequency pain question, 'In the past 3 months, how often did you have pain?'

<b>How often have pain?</b>	<b>Total persons</b>	<b>Percent</b>
Never	3,311	52.5
Some days	2,069	32.8
Most days	481	7.6
Every day	429	6.8
Refused	5	0.1
Don't know	14	0.2
<b>Total</b>	<b>6,309</b>	<b>100</b>

Table 3 shows how these 6,309 respondents answered both the first pain question and the next question on how often the pain was experienced in the past three months. Among those reporting having pain in the initial question, the majority (63 percent) indicate having pain on 'some days', 18 percent report pain on 'most days' and 17 percent report experiencing pain 'every day'. Conversely, among those initially indicating not having frequent pain, very few report 'most days' or 'every day'. Most report 'never' having pain in the past three months and 13 percent indicated 'some days' in the past three months. The results suggest good fit between the two questions with consistency across the two sets of responses.

Table 3. Responses to have frequent pain, by how often have pain

How often have pain?	Have frequent pain?	
	Yes	No
	(%)	(%)
Never	1.9	86.7
Some days	63	12.5
Most days	18.3	0.5
Every day	16.6	0.2
Refused	0.1	0
Don't know	0.1	0.1
Total persons	2,534	3,763

### Reporting of Pain and Frequency of Pain within National Populations

Table 4 indicates the distribution of those reporting having frequent pain in the various countries surveyed during the field test. On average, 40 percent of all respondents indicated that they experience frequent pain. Kazakhstan and Cambodia come close to the average. Sri Lanka's population shows a lower proportion indicating frequent pain, while among those in the Maldives frequent pain is a much more common occurrence – nearly 55 percent of the population.

Table 4. Responses to have frequent pain by country.

Pain	Kazakhsta	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Yes	39.4	47.3	28.3	54.9	34.4	37.9	40.2
No	60.3	52.7	71.1	44.9	65.5	62.1	59.6
Refused	0.1	0	0	0	0	0	0
Don't know	0.2	0	0.1	0	0.1	0	0.1
Total persons	1,000	1,008	1,000	1,013	1,222	1,066	6,309

Table 5 shows that the frequency of pain reported varies by country and does so in patterns similar to those exhibited in Table 4. When asked how frequently they experience pain, 52.5 of all respondents indicated they 'never' experience pain, somewhat less than the 59.6 percent who indicated they do not have frequent pain. Approximately 14.4 percent experience pain 'weekly' or 'every day'.

More than two-thirds (68.8 percent) of respondents in Sri Lanka reported that they 'never' experience pain compared to only 41.8 percent in the Maldives. However, at the same time, almost 10 percent of persons in Sri Lanka experience pain 'every day' but only 3 percent of persons in the Philippines have 'daily' pain and 3.4 percent have pain 'most days'. These findings for Sri Lanka are similar to those for fatigue (see Fatigue chapter). The suggestion is that Sri Lankans do not report pain (or fatigue) much but when they do they report quite severe pain (or fatigue).



Table 5. Responses to how often have pain in past three months by country

	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All
Frequency	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Never	47.8	49.5	68.8	41.8	51.8	55.3	52.5
Some days	38.8	35.6	16	35.7	32.2	38.2	32.8
Most days	7.4	5.4	4.7	11.7	12.4	3.4	7.6
Everyday	5.1	9.5	9.9	10.6	3.6	3	6.8
Refused	0.3	0	0	0.2	0	0	0.1
Dont know	0.6	0	0.6	0	0.1	0.1	0.2
Total persons	1,000	1,008	1,000	1,013	1,222	1,066	6,309

While most countries appear to have similar patterns of reporting on frequent pain and frequency of experiencing pain, there are some clear differences. Whether the differences in reporting are due to very real differences in pain experiences, or to socio-cultural variations (such as in the case of Sri Lanka and/or Maldives) is not clear. Moreover, it is possible that translation issues may have an impact on the responses.

### Reporting of Pain and Frequency by Sex and Age

Table 6 shows the distribution of responses from all countries to the initial pain question (PAIN\_1), by sex and age group. Overall women were more likely to report that they experience frequent pain (44.2 percent) compared to men (33.8 percent). Increasing age is particularly associated with experiencing pain with approximately 80 percent of persons aged 71 and over indicating frequent pain. At ages 41-50, at least half of persons report frequent pain and the proportion increases for each ten year age span beyond age 50.

Table 6. Responses to have frequent pain, by sex and age in field test interviews.

Pain	Sex		Age						
	Male	Female	< 18	18-30	31-40	41-50	51-60	61-70	71 +
	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Yes	33.8	44.2	15.7	34.6	44.4	50	56.9	63.8	80.1
No	66	55.6	84.1	65.3	55.5	49.5	43	35.9	19.9
Refused	0	0.1	0	0	0	0.2	0	0.3	0
Don't know	0.1	0.2	0.2	0.1	0.1	0.3	0.1	0	0
Total persons	2,448	3,861	1,475	1,478	1,004	1,008	738	395	211

Table 7 illustrates the demographic differences in the frequency of pain reflected from the initial question. First, women experience pain more frequently than men. This is particularly true at the extreme ends of the scale. Specifically, men are more likely than women to report that they 'never' experience pain (60.3 percent versus 47.6 percent). Women are more likely to report experiencing pain 'most days' or 'every day' compared with men. Additionally, the frequency of pain noticeably increases with age. The proportion experiencing pain 'every day' increases from a low of 1.2 percent among persons age 17 or under to more than 20 times that amount for those age 71 or over. More than a

quarter of all persons age 71 years and over report experiencing pain every day. The more frequent experience of pain is particularly noticeable after age 41.

Table 7. Responses to frequency of pain in past three months, by sex and age in field test interviews.

Pain	Sex		Age						
	Male	Female	< 18	18-30	31-40	41-50	51-60	61-70	71 +
	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Never	60.3	47.6	79.5	58.5	47.2	41.6	32	26.6	19
Some days	29	35.2	16.7	33.1	38	37.9	42.5	44.6	37.4
Most days	5.5	9	2.3	5.6	7.8	11.2	12.7	11.4	16.1
Everyday	4.9	8	1.2	2.7	6.8	8.8	12.1	17.2	27.5
Refused	0.2	0	0	0.1	0	0.1	0.3	0.3	0
Don't Know	0.2	0.2	0.3	0.1	0.2	0.4	0.4	0	0
Total persons	2,448	3,861	1,475	1,478	1,004	1,008	738	395	211

In conclusion, it is evident from the combined national data that more women than men report experiencing frequent pain. The pattern of reporting by sex is similar when asking men and women how often they experience pain. While most men and women report experiencing pain ‘never’ or only on ‘some days’, the gender gap is most apparent for ‘most days’ and ‘every day’. Furthermore, as age increases, so does the reporting of any pain and of frequent pain.

### Duration and Intensity of Pain

Duration and intensity are also important dimensions in the experience of pain and thus were included in the field test questions. These questions were administered as follow up questions and were not asked of respondents who reported ‘no’ to having frequent pain and ‘never’ to pain in the past three months. Again, the function of these two initial questions was to eliminate those who had inconsequential or infrequent pain. Thus, all individuals who received the duration and intensity questions had reported having pain at least on ‘some days’ in the past three months.

### Duration of Pain

Tables 8 and 9 show responses to the initial two pain questions by duration. Table 8 demonstrates once again that most respondents, regardless of whether they have frequent pain or not, indicate that the pain lasted ‘some of the day’. That is, most chose the shortest duration represented in the response set. The majority of those who do not have frequent pain (76 percent) chose ‘some of the day’. Of those who do report having frequent pain, 58 percent say their last episode lasted ‘some of the day’ and nearly 40 percent had pain that lasted ‘most’ or ‘all of the day’.

Table 8. Responses for duration of pain by 'have frequent pain' (PAIN\_1)

How long did pain last?	Have frequent pain?		Total
	Yes	No	
	(%)	(%)	
Some of the day	58	76.3	60.8
Most of the day	19.5	8.6	17.7
All of the day	22	12.9	20.4
Refused	0	0.6	0.2
Don't know	0.5	1.6	0.9
Total persons	2,528	498	3,036

As frequency of pain increases, so too does duration, as shown in Table 9. Those who report 'never' having pain in the past three months, or having it on 'some days', tend to report pain that lasts 'some of the day'. On the other hand, those who had pain 'most days' or on 'every day' tended to have pain lasting 'most' or 'all of the day' on their last episode. Thus the dichotomy at the extreme ends of pain ('some' versus 'most' or 'all') that was evident for frequency appears to continue when examining duration.

Table 9. Responses for duration of pain by how often feel pain (PAIN\_2)

How long?	How often have frequent pain (in days)					
	Never	Some days	Most days	Everyday	Refused	Dont know
	(%)	(%)	(%)	(%)	(%)	(%)
Some of the day	68.3	74.7	30.4	29.4	20	9.1
Most of the day	12.2	11.5	37.6	26.8	0	0
All of the day	14.6	13.1	32	43.6	0	0
Refused	0	0	0	0	60	18.2
Dont know	4.9	0.7	0	0.2	20	72.7
Total persons	41	2,069	481	429	5	11

The results for duration of pain are shown by surveyed country in Table 10. Overall, most respondents experience pain for only 'some' part of the day (60.8 percent). One-fifth of those surveyed indicated their last experience of pain lasted 'all of the day'. Those in the Philippines in particular experience pain for only 'some of the day' (82.3 percent) while those in Sri Lanka, Mongolia and, particularly, the Maldives are more likely to experience pain 'all day' on days they have pain (26.5, 24.3 and 33.3 percent respectively).

Table 10. Responses to duration of pain by country

	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All
<b>How long?</b>	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Some of the day	60.7	73	52.6	42.8	55.7	82.3	60.8
Most of the day	18.9	19.9	19.4	22.7	18.3	6	17.7
All of the day	18.9	7.1	26.5	33.3	24.3	11.2	20.4
Refused	0.6	0	0	0.3	0.2	0	0.2
Dont know	1	0	1.6	0.8	1.5	0.4	0.9
Total persons	524	518	310	607	596	481	3,036

Among those with pain, the duration of pain also varies by sex and age, but not as dramatically as the differences between those with pain and without pain. As shown in Table 11, men are somewhat less likely than women to describe the duration of their pain as taking place ‘all day’. However this difference is small and men and women respond in similar proportions to ‘most of the day’ and ‘all’ of the day.

More than half of all respondents, of all ages, indicate that their last experience of pain lasted ‘some of the day’. As seen with frequency of pain, there is an increase in the duration of pain with age. Nearly 27 percent of those 71 years of age and over report their last pain episode lasting all of the day, while just over 19 percent of 18-30 year olds report ‘all day’ pain. Among the oldest age groups, nearly half report ‘most of the day’ or ‘all day’ pain. This increase in pain reporting with increasing age is in line with the increase in chronic diseases such as various forms of arthritis which have pain as one of the main symptoms, This provides some face validity for the results obtained in the field testing.

Table 11. Responses for duration pain by sex and age

	Sex		Age						
	Male	Female	< 18	18-30	31-40	41-50	51-60	61-70	71 +
<b>How long?</b>	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Some of the day	62.7	59.9	73.9	65.6	61.4	57.1	57.1	56	50.3
Most of the day	17.9	17.6	12.1	14.4	18.8	18.8	19.1	22.3	21.1
All of the day	18.1	21.5	13.4	19.4	18.5	22.4	22.9	21.3	26.9
Refused	0.2	0.2	0	0	0	0.3	0.6	0.3	0
Dont know	1.1	0.7	0.7	0.6	1.3	1.3	0.4	0	1.8
Total persons	990	2,046	307	625	542	597	503	291	171

### Intensity of Pain

Tables 12 and 13 show responses to the first two pain questions on frequency (PAIN\_1 and PAIN\_2) by intensity – the amount of pain experienced during the last episode. Among those who do not report frequent pain, the majority indicate having ‘a little’ pain the last time (nearly 71 percent). However, among those who do have frequent pain, the intensity is reported as ‘a little’ (46 percent) or ‘a lot’ (33 percent). More than half of all respondents reporting pain on ‘most’ or ‘every day’ also report they

were in ‘a lot’ of pain during their last episode. Conversely most of the respondents who ‘never’ have frequent pain or have it only ‘on some days’ report the intensity of their last pain episode as ‘a little’.

Table 12. Responses for duration of pain by have frequent pain (PAIN\_1)

How much pain	Have frequent pain		Total
	Yes	No	
	(%)	(%)	(%)
A little	46.1	70.8	50.1
Closer to a little	3.2	4	3.4
In between	13.5	5	12
Closer to a lot	4.4	4.4	4.4
A lot	32.6	14.3	29.5
Refused	0	0	0.2
Don't know	0.2	1.4	0.6
Total persons	2,525	497	3,032

Table 13. Responses for duration of pain by frequency of pain (PAIN\_2)

How much pain	How often have frequent pain					
	Never	Some days	Most days	Everyday	Refused	Dont know
	(%)	(%)	(%)	(%)	(%)	(%)
A little	58.5	60.8	22.5	29.7	0	27.3
Closer to a little	0	3.7	4.4	0.9	0	0
In between	2.4	11.5	15	12.6	20	0
Closer to a lot	2.4	3.8	7.7	4	0	0
A lot	34.1	19.9	50.3	52.8	0	0
Refused	0	0	0	0	40	0
Don't know	2.4	0.3	0.2	0	40	72.7
Total persons	41	2,066	481	428	5	11

The results for intensity of pain are shown by surveyed country in Table 14. Overall, half of the respondents experienced ‘a little’ pain during their last episode (50.1 percent). One-third of those surveyed indicated they were in ‘a lot’ of pain during their last experience (29.5 percent). Those in the Philippines in particular report intensity as mostly ‘a little’ (81.2 percent) while those in Mongolia, Sri Lanka and particularly the Maldives are more likely to have experienced ‘a lot’ of pain (30.7, 33.9 and 58.6 percent respectively).

Table 14. Responses to intensity of pain (the last time) in national populations in field test interviews.

	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All
<b>How much pain</b>	(%)	(%)	(%)	(%)	(%)	(%)	(%)
A little	41	59.8	56.5	22.1	49.7	81.2	50.1
Closer to a little	7.6	1.7	1.3	0.8	4.5	3.5	3.4
In between	17.2	15.9	5.5	16.7	6.9	7.1	12
Closer to a lot	10.5	2.7	1.3	1.2	7.7	1.5	4.4
A lot	22.5	19.9	33.9	58.6	30.7	6.3	29.5
Refused	0	0	0	0.3	0	0	0.1
Don't know	1.1	0	1.6	0.3	0.5	0.4	0.6
Total persons	524	517	310	606	596	479	3,032

Table 15. Responses to how much pain (the last time by age and sex)

	Sex		Age						
	Male	Female	< 18	18-30	31-40	41-50	51-60	61-70	71 +
<b>How long?</b>	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
A little	51.6	49.3	56.9	51.9	52.9	48.1	48.9	46	39.4
Closer to a little	4.7	2.7	5.2	2.7	4.8	2.7	3.6	1.7	2.4
In between	14.4	10.9	11.1	13.6	12.2	11.1	11.5	12	12.4
Closer to a lot	3.5	4.8	2	3.4	4.3	5.4	5.8	5.5	3.5
A lot	25	31.7	24.2	28	24.8	32.2	29.4	34.4	41.8
Refused	0.1	0	0	0	0	0.2	0	0.3	0
Don't know	0.8	0.5	0.7	0.3	1.1	0.5	0.8	0	0.6
Total persons	989	2,043	306	624	541	597	503	291	170

Among those with pain, the intensity of pain also varies by sex and age. As shown in Table 15, men are less likely than women to describe the intensity of their last pain episode as 'a lot' (25.0 versus 31.7 percent). However, as was the case with duration, men and women respond in similar proportions to 'a little' pain and there is only a small difference among those reporting their experience as 'in between a little and a lot'. Similarly, intensity increases with age as well with larger differences appearing among those 61 years of age and over.

### Descriptions and Impact of Pain

The field test included two probe questions in the Pain section intended to capture more information from respondents on a) the construct that the pain questions are capturing using a series of probe questions, and b) the impact of the experience of pain for individuals.

### Descriptions of Pain

The first probe question (see Box 2, P\_PAIN\_5) asks respondents to indicate which of a list of statements describe their pain. Respondents were able to choose all statements that applied. The list includes descriptions which would provide more information about their pain, although exactly how those statements would fall on a continuum of characterizing pain was unknown. Statements such as 'It is

constantly present’, ‘Sometimes it is unbearable and excruciating’, and ‘Sometimes I’m in a lot of pain and sometimes it’s not so bad’ suggest a degree of pain that exceeds levels experienced by those who chose statements such as ‘When I get my mind on other things, I am not aware of the pain’ and ‘Medication can take my pain away completely’. Statements such as ‘My pain is because of work’ and ‘My pain is because of exercise’ are not as clearly interpreted given that the nature of work and exercise are variable and individuals vary in their assessments, but do represent the source of pain as being outside of the body. In order to examine the relationships more closely, Table 16 shows the percent of respondents choosing the different statements by frequency, country, age and sex.

The statements most frequently chosen include ‘Sometimes it is unbearable and excruciating’ (75.5 percent of all respondents) and ‘Medication can take my pain away completely’ (56.7 percent). ‘My pain is because of exercise’ was reported least often (8.2 percent). Just over a third of the sample described their pain as ‘constantly present’ (38.2 percent) or as ‘Sometimes I’m in a lot of pain and sometimes it’s not so bad’ (37.6 percent). Those who do not report having frequent pain are more likely to indicate that medication takes their pain away completely, whereas those who do report frequent pain are more likely to indicate their pain is constant, unbearable or variable.

Table 16. Frequency of pain (PAIN\_2) by descriptions of pain

Descriptions	How often have frequent pain (in days)			
	Never (%)	Some days (%)	Most days (%)	Everyday (%)
Constant	17.1	25.6	59.7	78.1
Unbearable	65.9	70.8	86.5	87.9
Variable	26.8	28.4	60.9	58.3
Not aware	51.2	49.4	47.8	50.6
Medication	53.7	60.4	50.7	46.6
Work	41.5	44.1	35.6	41.7
Exercise	2.4	8.3	7.1	9.8
Total persons	41	2,065	481	429

One of the more noticeable findings is that exercise and work are not often cited as reasons for pain in most countries, although in Cambodia and Kazakhstan almost two-thirds of respondents indicate their pain is due to work (Table 17). Three-quarters of the sample say their pain varies (sometimes a lot and sometimes not so bad) and more than half indicate that medicine can take their pain away.

Table 17. Descriptions of pain by country

Description	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Constant	22.5	75.1	29.7	28.4	45	24.9	38.2
Unbearable	27.1	41.5	41.6	49.3	49.7	12.6	37.6
Variable	72.5	60.6	86.5	88.4	85.1	59.1	75.5
Not aware	46.4	49.8	36.8	61.1	40.3	56.6	49.3
Medication	67.2	45.6	62.6	48.3	55.7	65.4	56.7
Work	29.4	60.8	37.1	29.4	36.9	62.3	42.2
Exercise	20.6	6.9	1.6	5.3	4	9.2	8.2
Total persons	524	518	310	606	596	477	3,031

Table 18. Descriptions of pain, by sex and age

How long?	Sex		Age						
	Male	Female	< 18	18-30	31-40	41-50	51-60	61-70	71 +
	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Constant	34	40.2	19.6	27.4	33.2	42.1	48.2	51.7	60.8
Unbearable	71.8	77.2	75.8	76.6	74.5	74.2	76.5	74.8	76
Variable	32.1	40.3	31	37.3	31.5	41.1	37.8	44.5	45.6
Not aware	49	49.5	43.8	56.4	52.6	47.8	47.6	42.4	45
Medication	56.9	56.6	53.6	51.6	56.6	57.6	62	63.1	52
Work	48.5	39.1	15.4	44.1	48.9	50.3	46.4	38.3	28.1
Exercise	11.4	6.7	10.5	5.9	5.9	9.9	10.6	7.2	8.8
Total persons	985	2,046	306	624	542	596	502	290	171

Examining these descriptions by sex and age also reveals a few noteworthy patterns. In general, men describe their pain as caused by work or exercise more than women. Women chose 'constant, sometimes unbearable or excruciating, and variable' to describe their pain more often than men. Both were equally likely to indicate that medicine can take away the pain, or that when their mind is on other things they are unaware of the pain. The general pattern remains, women and older persons appear to choose descriptions that indicate their pain is more difficult to manage.

### Impact of Pain

Respondents were asked how much their pain limits their ability to carry out daily activities. This question was added to the set to ascertain the degree to which pain limits participation in daily activities and beyond. Table 19 presents the responses on the impact of pain by country and Table 20 by sex and age.

Table 19 shows the impact of pain by country surveyed. Most respondents across the countries indicated that their pain limits their daily activities 'a little' or 'not at all'. Only the Philippines have a very different pattern, with more than two-thirds of respondents indicating no activity impact from pain. Again, it is difficult to understand whether culture, translation or other issues are causing these



differences. Table 20 provides limitation information by sex and age. Gender differences are minor. Fewer women than men indicate being ‘not at all’ limited or only ‘a little’ limited by pain, however the differences are small and the majority of both men and women have significant impacts on their daily activities. Patterns by age support earlier findings – the older the respondent, the less likelihood of pain having no impact on daily activities. In fact, more than 40 percent of all respondents indicate being ‘a lot’ or ‘completely’ limited in their daily activities as a result of pain.

Table 19. Impact of pain on daily activities, by country

Limited in activities	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All
	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Not at all	33.8	30.9	36.1	44.8	30.5	62.3	39.6
A little	52.9	51.9	44.2	35.6	55.7	33.5	45.9
A lot	11.3	14.1	14.8	17.6	11.7	2.7	12.1
Completely	1.5	2.9	3.5	1.3	1.7	0.8	1.8
Refused	0.4	0	0.3	0.5	0	0	0.2
Don't know	0.2	0.2	1	0	0.3	0.4	0.3
Total persons	524	518	310	603	594	472	3,013

Table 20. Impact of pain, by sex and age

How long?	Sex		Age						
	Male	Female	< 18	18-30	31-40	41-50	51-60	61-70	71 +
	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Not at all	41	38.9	49	46	44.3	42.1	32	28.6	16.4
A little	46.6	45.5	42.5	45.5	45	44.1	50.3	50	42.1
A lot	9.2	13.6	6.2	7.4	9.1	11.7	15.5	17.9	31.6
Completely	2.3	1.6	1.3	0.6	1.1	1.5	2	2.8	8.8
Refused	0.3	0.1	0.3	0.2	0	0.2	0	0.7	0.6
Dont know	0.6	0.2	0.3	0.2	0	0	0	0	0
Total persons	985	2,044	306	624	540	596	503	290	171

Table 21 presents findings from the frequency of pain in relation to the impact on daily activities. A clear relationship exists between frequency and impact. Those reporting pain on ‘most days’ or ‘every day’ are more likely to be limited ‘a lot’ or ‘completely’ than those who had no pain or pain on ‘some days’ in the past three months.

Table 21. Responses for impact of pain on daily activities, by frequency of pain (PAIN\_2)

Limited in activities	How often have frequent pain			
	Never	Some days	Most days	Everyday
	(%)	(%)	(%)	(%)
Not at all	56.1	46	21.4	27.6
A little	39	47	50.9	36.4
A lot	2.4	5.9	24.7	29.4
Completely	0	0.7	2.9	6.3
Refused	0	0.1	0	0.2
Don't know	2.4	0.3	0	0
Total Persons	41	2,064	481	428

### Multiple Dimensions of Pain: The Interplay of Frequency, Duration and Intensity

In previous tests of pain questions, the findings have suggested that a short set question on pain does not adequately capture the multiple dimensions of pain. Subsequently, and in this round of testing, a three-pronged approach that asks frequency, duration and intensity was hypothesized to be a better means to fully capture pain and reduce false positive data. How these three dimensions are related to one another and whether they can be combined to provide a meaningful, yet succinct, measure of pain is explored in this section.

An initial set of analyses was conducted to explore consistency in the types of pain reported and the responses to these three pain dimensions. Tables 22, 23 and 24 use data from respondents' descriptions of pain, combined with frequency, duration and intensity to explore if characterizations of pain are intuitively related to the three dimensions. That is, are the ways in which people describe their pain consistent with their answers regarding the frequency, duration and intensity of their pain experiences? These tables are based on a series of logistic regressions predicting the likelihood of a respondent being in a given cell of the table. For example, one set of models predict the probability of a respondent being in duration cell 'some of the day' and intensity cell 'a little', with the independent variables being the series of descriptions respondents may use to describe their pain. Values of zero were assigned to descriptions not chosen; a value of one meant that the respondent chose that description for his or her pain.

Table 22 examines descriptions of pain as predictors of frequency and intensity. Note in the top left corner cell that descriptions indicating pain as 'constantly present', 'sometimes in a lot of pain and sometimes not so bad', 'sometimes it is unbearable and excruciating' and indications that the pain limits daily activities are all negatively associated with frequency responses of 'some days' and intensity of 'a little'. Yet, these same descriptions are positively associated with responses that frequency is 'every day' and intensity is 'a lot' in the lower right corner. The less frequent pain is and the less intense the

last experience, the more likely medication resolves the pain and work and exercise are indicated as sources of the pain.

Table 22. Descriptions of pain, by frequency and intensity

Intensity	Frequency		
	Some days	Most days	Every day
A little	Constant** Sometimes bad** Unbearable** Impact** Medication** Work**	Constant** Unbearable*	Constant**
Closer to a little	Constant* Sometimes bad* Unbearable** Impact*		
In between	Sometimes bad* Constant* Unbearable*	Constant** Impact** Medication**	Constant** Sometimes bad** Exercise*
Closer to a lot	Constant** Sometimes bad** Work*	Constant* Sometimes bad* Unbearable** Impact** Other things* Work*	Constant** Impact*
A lot	Constant** Sometimes bad** Unbearable** Impact** Work** Exercise*	Constant** Sometimes bad** Unbearable** Impact** Medication* Work**	Constant** Sometimes bad** Unbearable** Impact** Medication**
Note. Negative associations shown in red text. Positive associations shown in black text. *p<.05, **p<.005			

Similarly, in Table 23 the models examine frequency and duration. Generally the pattern of the extreme corner cells is the same. The higher the frequency of pain and the longer the duration of the last episode, the more likely the pain is to be described as ‘constant, sometimes bad, unbearable’, and limiting in daily activities. Finally, Table 24 shows the combination of duration and intensity with generally similar relationships as have been demonstrated in Tables 22 and 23. One additional finding across all three tables is that relative absence of exercise reported as a source of pain and the

description ‘when I get my mind on other things, I am not aware of the pain’. This suggests that these characterizations may be less applicable for those that experience frequent pain.

Table 23. Descriptions of pain, by frequency and duration

Duration	Frequency		
	Some days	Most days	Every day
Some of the day	Constant** Sometimes bad** Unbearable** Impact** Medication** Work**	Constant** Sometimes bad* Work*	Constant** Sometimes bad*
Most of the day	Sometimes bad**	Constant** Sometimes bad** Unbearable** Impact**	Constant** Sometimes bad** Unbearable** Impact** Medication*
All of the day	Constant** Sometimes bad** Unbearable**	Constant** Sometimes bad** Unbearable** Impact** Medication* Work*	Constant** Sometimes bad** Unbearable** Impact** Medication**
Note. Negative associations shown in red text. Positive associations shown in black *p<.05, **p<.005			

Table 25 provides statistical correlations among the three dimensions of pain. All of the correlations are statistically significant. However, none of the coefficients exceeds 0.5. This may indicate that the three dimensions of pain are not totally independent, yet are measuring slightly different aspects of the pain experience. Results presented above also reinforce the moderate relationship seen in this table between the intensity and duration dimensions. These interpretations are consistent with earlier findings, and are also demonstrated in the three-way frequency provided in Table 26.

Table 24. Descriptions of pain, by duration and intensity

Intensity	Duration		
	Some of the day	Most of the day	All of the day
A little	Constant** Sometimes bad** Unbearable** Impact** Medication** Work**	Sometimes bad* Unbearable**	Constant**
Closer to a little	Exercise* Unbearable* Impact*		
In between	Sometimes bad* Unbearable*	Constant** Impact** Medication**	Sometimes bad* Other things*
Closer to a lot	Constant* Sometimes bad**	Other things** Unbearable* Impact*	Constant* Sometimes bad* Unbearable** Impact**
A lot	Sometimes bad** Unbearable** Impact* Work**	Constant** Sometimes bad** Unbearable** Impact**	Constant** Sometimes bad** Unbearable** Impact** Medication**
Note. Negative associations shown in red text. Positive associations shown in black text. *p<.05, **p<.005			

Table 25. Correlations for pain frequency, duration and intensity

		Frequency	Duration	Intensity
Frequency	Pearson Correlation	1	.376**	.317**
	Sig. (2-tailed)		0	0
	N	2,997	2,997	2,997
Duration	Pearson Correlation	.376**	1	.483**
	Sig. (2-tailed)	0		0
	N	2,997	2,997	2,997
Intensity	Pearson Correlation	.317**	.483**	1
	Sig. (2-tailed)	0	0	
	N	2,997	2,997	2,997

\*\* . Correlation is significant at the 0.01 level (2-tailed).

Table 26. Correlations for pain frequency, duration and intensity

		Pain Frequency				Total	
		Never	Some of the day	Most of the day	Everyday		
Intensity	Duration						
A little	Duration	Some of the day	22	1,098	67	61	1,248
		Most of the day	2	77	24	28	131
		All of the day	0	76	17	37	130
Total			24	1,251	108	126	1,509
Closer to a little	Duration	Some of the day	0	66	11	2	79
		Most of the day	0	3	8	1	12
		All of the day	0	8	2	1	11
Total			0	77	21	4	102
In between	Duration	Some of the day	1	166	25	19	211
		Most of the day	0	31	34	27	92
		All of the day	0	39	13	8	60
Total			1	236	72	54	363
Closer to a lot	Duration	Some of the day	1	45	14	4	64
		Most of the day	0	19	13	3	35
		All of the day	0	14	10	10	34
Total			1	78	37	17	133
A lot	Duration	Some of the day	4	167	29	40	240
		Most of the day	3	107	101	56	267
		All of the day	6	135	112	130	383
Total			13	409	242	226	890

Table 26 displays some very small cell sizes. However, noticeable patterns are familiar ones. For example, most respondents report duration of their last pain episode as 'some of the day'. Not until intensity reaches 'closer to a lot' or 'a lot' are there larger cell sizes in the 'most of the day' and 'all of the day' duration responses. There is also the familiar dichotomy displayed with intensity – most respondents reported intensity at the extremes of 'a little' (n=1,509) or 'a lot' (n=890).

### Pain Summary Measure

In this final section, analyses are presented that explore whether the three dimensions of pain can be combined to provide a meaningful, yet succinct, measure of pain. The findings thus far demonstrate that not any one of the three dimensions exceed the other two in terms of importance for pain. Each is different. Nor are the three perfectly correlated, although there is a moderate relationship between duration and intensity. In sum, it appears that frequency, duration and intensity each measure similar, though slightly different, aspects of pain. However, combining data on these dimensions into a single scale would be analytically useful.

A summary pain measure was created using the three-way frequency presented in Table 26. A review of the data in that table suggests that cutoffs could be made to create a categorical scale in which frequency, duration and intensity were combined to form a summary pain variable with three levels: low, middle, high. Table 27 shows where those cutoffs were created. Low is coded in green, middle in black, and high in red.

Table 27. Correlations for pain frequency, duration and intensity

			Pain Frequency				Total
			Never	Some days	Most days	Everyday	
<b>Intensity</b>	A little	Duration					
		Some of the day	22	1,098	67	61	1,248
		Most of the day	2	77	24	28	131
	All of the day	0	76	17	37	130	
Total		24	1,251	108	126	1,509	
Closer to a little	Duration	Some of the day	0	66	11	2	79
		Most of the day	0	3	8	1	12
		All of the day	0	8	2	1	11
	Total		0	77	21	4	102
In between	Duration	Some of the day	1	166	25	19	211
		Most of the day	0	31	34	27	92
		All of the day	0	39	13	8	60
	Total		1	236	72	54	363
Closer to a lot	Duration	Some of the day	1	45	14	4	64
		Most of the day	0	19	13	3	35
		All of the day	0	14	10	10	34
	Total		1	78	37	17	133
A lot	Duration	Some of the day	4	167	29	40	240
		Most of the day	3	107	101	56	267
		All of the day	6	135	112	130	383
	Total		13	409	242	226	890

## Field Test Conclusions

A number of findings from the data produced by the field test are informative and will be useful as the question set on pain continues to develop.

### 1. Frequency

The majority of respondents report that they do not have frequent pain (60 percent). When asked about the frequency of pain in the last 3 months, more than half of all respondents indicate 'never' and

another one-third report pain on 'some days'. More women than men report frequent pain, and report higher frequency of experiencing pain. Reporting of pain also increases with age.

## 2. Screener Questions

In the cognitive tests, the initial question asking whether one has frequent pain was not sufficient for screening purposes. In the field test, the combination of this initial question and the frequency in the past three months question seems to work better, with each playing a specific role. The value of the first question appears to be that it focused respondents' attention on the construct of interest, that is 'frequent pain'. Regardless of the varied interpretations of the word 'frequent' the data do show that the first question correlates well with the second question on frequency. This second question does not mention 'frequent' but because it follows the initial question, this is implied. One finding seems clear, those who report 'no' to the initial question or 'never' to the second do answer across all response options in the subsequent duration and intensity questions. Important information on some of the sample's pain experience would be missed by excluding these individuals. However, the exact nature of this information and the explanations for these patterns of responses requires more exploration.

## 3. Duration

Most respondents, regardless of whether they have frequent pain or not, indicate that their pain lasted 'some of the day'. Across countries, gender and age groups, most respondents reported the lowest duration of pain (i.e. 'some of the day'). As frequency of pain increases, so too does duration. Those who had pain on 'most days' or on 'every day' tend to have pain lasting 'most' or 'all of the day' on their last episode. With greater frequency and longer duration of pain, reporting discrete episodes of pain seems to become difficult. Differences in duration of pain were not found across gender, although duration does increase with age.

## 4. Intensity

Across all analyses involving intensity, a dichotomy of responses occurred. Most respondents reported either 'a little' or 'a lot' when asked how much pain they had during their last episode. Recall that the cognitive data show that respondents tend to weigh whether to report pain depending on the intensity of their pain experiences. Reporting in the extremes of the response set for intensity may be based on a similar response strategy to this cognitive test finding. Alternately respondents may simply find it difficult to characterize the intensity of their pain within the fine details represented by 'closer to a little', 'in the middle' and 'closer to a lot'. A final hypothesis may involve pain medication. It is at these extremes in intensity where medication may be either not taken (in the case of 'a little' pain not warranting the use of medication) or may not be effective (in the case of 'a lot' of pain). The dichotomy pattern exists in the country-specific data as well. Men and women differ in their reporting of intensity only in the 'a lot' response where more women than men report this level of intensity. As with frequency and duration, intensity increases with age, with larger increases at the oldest age groups.



## 5. Impact

The majority of respondents, regardless of the frequency, duration or intensity of their pain indicate that pain does not limit their daily activities. In fact across all of the dimensions of pain, few respondents indicate being limited in daily activities either 'a lot' or 'completely'. Gender differences are minor and the older the respondent, the less likely their pain has 'little' or 'no' impact on daily activities.

## 6. Cross-Country Variation

While most countries appear to have similar patterns in reports of having frequent pain and frequency of experiencing pain, clearly there are differences. Whether the differences in reporting are due to very real differences in pain experiences, or whether the differences in reporting are due to socio-cultural variations is not clear from the current data. However, previous research on asking pain questions does reveal that cultural differences have an impact on responses. Moreover, it is possible that translation issues may be affecting the responses. Given this, more exploration of data collected across different cultural, linguistic and geographical contexts will be needed to understand and characterize the kinds of differences that may be expected.

## 7. Gender Differences

Differences were observed in the data reported by men and women to the initial pain question (PAIN\_1) and the second question on frequency of pain (PAIN\_2). Subsequently, however, few differences by gender were found across the other dimensions of pain and the impact on daily activities. This suggests that while women are more likely than men to have frequent pain, and women experience pain more frequently, the quality of these experiences as measured by duration and intensity are not significantly different.

## 8. Summary Pain Measure

The analyses herein provided a demonstration of one way to construct a summary pain measure from the three different questions capturing frequency, duration and intensity of pain. The cutoffs chosen in this example may or may not differ across different samples of test data. Continuing to examine appropriate cutoff placement in future tests of these questions will provide the necessary evidence to support the decisions made here. However, the measure created here does demonstrate some construct validity as illustrated when examining this measure with responses to the limitation of activity question or the descriptions respondents chose to describe their pain.

## Recommendations for pain questions

Given the above findings it is recommended that the following questions be retained in the pain extended set and that a clear analytical procedure be set out for creating the summary measure of pain:

1. Do you have frequent pain?
2. In the past 3 months, how often did you have pain? Never, some days, most days or every day?

3. Thinking about the last time you had pain, how long did the pain last? Some of the day, most of the day or all of the day?
4. Thinking about the last time you had pain, how much pain did you have, a little, a lot, or somewhere in between a little and a lot?

## Fatigue chapter

### Introduction

Fatigue in the context of the Washington Group's extended set of questions for measuring disability is considered temporary or extended weariness or exhaustion that manifests itself physically, mentally, or through the senses or any combination of those. Though fatigue is a symptom rather than a basic action domain (such as walking, listening, learning or remembering), it is one which can strongly influence those actions and, like pain, can be more prominent in the respondent's mind as the relevant cause of the problems with basic actions. So, for example when asked about walking or standing the respondent who experiences exhaustion or fatigue may highlight that fact rather than any difficulty actually walking or standing. As such fatigue becomes an important intervening factor in understanding difficulties in other domains of functioning. Of interest is to determine whether people report both difficulties with fatigue as well as its impact on other domains (e.g. difficulty walking or remembering and concentrating) or only the fatigue and not its impact on these other domains.

Fatigue is a feature of life and has become more prominent with the identification of medical conditions such as chronic fatigue syndrome and fibromyalgia.

### Fatigue and the ICF

Fatigue is classified under body functions in the ICF. The subdomains under which it is described include exercise tolerance functions, covering respiratory and cardiovascular functions and fatiguability, and vigour (the opposite of fatigue) under mental functions in the domain of energy and drive functions. It is defined as the general mental functions of physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a persistent manner. Fatigue as used in these extended questions is neither limited to exercise tolerance or vigour, but is more broadly conceived as combining aspects of both mental and physical functioning.

### Cognitive Test on Fatigue Questions

#### Box 1: Questions on fatigue used in the cognitive testing

Questions	Response Options
10.1a Do you have frequent feelings of being tired?	1) Yes 2) No  <i>If No, go to next section.</i>
10.2 In the past 3 months, how often did you feel tired? Some days, most days, or every day?	1) Some days 2) Most days 3) Every day
10.3 Thinking about the last time you felt tired, how long did the tiredness last? Some of the day, most of the day, or all of the day?	1) Some of the day 2) Most of the day 3) All of the day

10.4 Thinking about the last time you felt tired, how would you describe the level of tiredness? Mild, moderate or severe?	1) Mild 2) Moderate 3) Severe
10.5 Thinking about the last time you felt tired, was the tiredness worse than usual, better than usual, or about the same as usual?	1) Worse than usual 2) About the same as usual 3) Better than usual
11.1ai How old were you when the tiredness began?	_____ age in years
12.1i Is your tiredness due to a health problem or something else?	1) Due to a health problem 2) Something else: _____
13.1i Does your tiredness limit your ability to carry out daily activities?	1) Yes 2) No
13.2bi Does your tiredness limit your ability to carry out other activities that are not part of your day-to-day life?	1) Yes 2) No

The purpose of asking questions about fatigue was to identify people who experience fatigue and determine the relationship between fatigue and other basic activities. Frequently an individual does not find that their performance of any one or more of the basic activities, represented in the short set of questions, is limiting; but rather that their functioning is generally restricted because of overwhelming fatigue or possibly pain. This is particularly true among persons with chronic conditions, such as cancer, diabetes, heart disease, HIV/AIDS and mental health problems (e.g. depression) that are chronic conditions for which fatigue is an important symptom that influences functioning.

The narratives from the cognitive testing interviews provided many explanations for the nature, frequency and intensity of tiredness reported by the respondents. Some respondents described their tiredness as a result of a lot of physical activity or lack of sleep (such as having a new baby). Others provided more health related explanations including pain or the side effect of medication, while some explained the tiredness as being a seasonal or a usual occurrence.

Some respondents asked for clarification in an effort to differentiate usual tiredness from tiredness associated with other factors. In all, the results of the cognitive testing were not definitive. Some small changes were made to the field test questions, but additional questions were also included in the field test in order to get a better understanding of the interpretation of the fatigue questions. Questions 6 and 7 below were added to try to interpret how the respondents were understanding the intent of the questions. In question 3 the reply categories were changed since respondents to the cognitive questions appeared to have difficulty applying the categories 'mild', and 'moderate' and 'severe' to the experience of fatigue.

## Field Test Questions for Fatigue

### Box 2: Questions on fatigue for the field testing

Questions	Response Options
<p>TIRED_1 In the past 3 months, how often did you feel very tired or exhausted?</p>	<p>1) Never 2) Some Days 3) Most Days 4) Everyday 7) Refused 9) Don't know</p> <p><i>If "Never" to TIRED_1, skip to Section L : Needs for Assistance, Health Conditions and Impairments.</i></p>
<p>TIRED_2 Thinking about the last time you felt very tired or exhausted, how long did it last?</p>	<p>1) Some of the day 2) Most days 3) Every day</p>
<p>TIRED_3 Thinking about the last time you felt this way, how would you describe the level of tiredness?</p>	<p>1) A little 2) A lot 3) Somewhere in between a little and a lot 7) Refused 9) Don't know</p> <p><i>If "Somewhere in between a little and a lot" to TIRED_3, continue with TIRED_4. Otherwise, skip to P_TIRED_4.</i></p>
<p>TIRED_4 Would you say it was closer to a little, closer to a lot, or exactly in the middle?</p>	<p>Would you say it was closer to a little, closer to a lot, or exactly in the middle? 1) Closer to a little 2) Closer to a lot 3) Exactly in the middle 7) Refused 9) Don't know</p>
<p>P_TIRED_4 Is your tiredness the result of any of the following?</p>	<p>a) Too much work or exercise? b) Not getting enough sleep? c) A physical or health-related problem? d) Something else? (please specify): _____</p> <p><i>Each category above has response options of:</i></p> <p>1) Yes 2) No 7) Refused 8) Not applicable 9) Don't know</p>
<p>TIRED_5 How old were you when the tiredness began?</p>	<p>_____ Age in years 777. Refused 999. Don't know</p>
<p>TIRED_6 How much does your tiredness limit your ability to carry out daily activities?</p>	<p>1. Not at all 2. A little 3. A lot 4. Completely 7. Refused</p>

## Indications of Fatigue within National Populations

Based on the answers to how frequently the individual experiences fatigue we can get some idea about the experience of fatigue from the various populations included in the field test. The important decision in calculating that estimate is choosing a cut point between those considered not to experience frequent fatigue and those with at least some frequency of fatigue. We have included everyone who indicates some frequency of experiencing fatigue, either 'some days', 'most days' or 'every day', into one category of 'yes'. On average, 47 percent of populations within the testing countries indicated that they experience fatigue with some frequency. Table 1 indicates the distribution of those with fatigue in the various countries surveyed. Kazakhstan and Cambodia are higher than the average, 63.4 percent and 59 percent respectively, while Sri Lanka's population shows a much lower proportion indicating fatigue on a somewhat regular basis (11.3 percent). In the Maldives fatigue is also a less common occurrence with 34.5 percent of the population reporting fatigue. At least some fatigue is reported by more than half of the populations in the other countries surveyed. Overall women were more likely to report that they experience fatigue (50.1 percent) compared to men (42.6 percent) (data shown in table 3). Age is particularly associated with experiencing fatigue with approximately 61 percent of persons aged over 70 years indicating some frequency of fatigue. At ages 18-30 years at least half of persons report fatigue and the proportion increases for each ten year age span beyond 30 years with those over 50 years old having similar proportions to those over 70 years old.

		Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
		(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Acknowledge Some Level of Fatigue</b>	Yes	63	59	11	35	54	59	47
	No	37	41	88	65	46	41	53
	Refused	0	0	0	0	0	0	0
	Don't know	0	0	1	0	0	0	0
	<b>Total persons</b>	<b>1000</b>	<b>1008</b>	<b>1000</b>	<b>1013</b>	<b>1222</b>	<b>1066</b>	<b>6309</b>

## Actual Frequency of Fatigue

The actual frequency that fatigue is experienced is shown in table 2. On average 52.5 percent responded that they 'never' experience fatigue. Most persons who report some frequency of fatigue in the past three months indicate that they experienced fatigue on 'some days' (37.7 percent). That average conceals the fact that persons in Kazakhstan, Cambodia, Mongolia and the Philippines are reporting fatigue on 'some days' at a level around 50 percent while respondents in Sri Lanka and the Maldives are reporting fatigue on 'some days' at a much lower proportion (6.9 percent and 26.8 percent respectively). Overall approximately 9.6 percent experience fatigue 'most days' or 'every day'.

Table 2 shows the frequency of fatigue reported as it varies by country. For example, more than three-quarters (88.0 percent) of respondents in Sri Lanka reported that they 'never' experience fatigue while only 36.5 percent in Kazakhstan reported 'never' experiencing fatigue. At the same time, 12 percent of

persons in Kazakhstan experience fatigue ‘most days’ or ‘every day’ and 11 percent of persons in Mongolia. While countries vary widely in their reporting (and hence probably their interpretation) of fatigue on ‘some days’ and ‘most days’, there is much less variation in the reporting of fatigue ‘every day’ except for Cambodia.

Table 2. Frequency of Fatigue by country.

		Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All countries
		(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Frequency of Fatigue</b>	Never	37	41	88	65	46	41	53
	Some days	51	48	7	27	43	49	38
	Most days	9	5	1	4	7	7	6
	Every day	3	6	3	4	4	4	4
	Refused	0	0	0	0	0	0	0
	Don't know	0	0	1	0	0	0	0
<b>Total persons</b>		<b>1000</b>	<b>1008</b>	<b>1000</b>	<b>1013</b>	<b>1222</b>	<b>1066</b>	<b>6309</b>

Table 3 illustrates the demographic differences in the frequency of fatigue reflected from the initial question. First, women experience fatigue more frequently than men. This is particularly true at the extreme ends of the scale. Specifically, men are more likely than women to report that they ‘never’ experience fatigue while women are somewhat more likely than men to report fatigue on ‘most days’ or ‘every day’ (11.1 percent compared to 8.7 percent). Additionally, the frequency of experiencing fatigue noticeably increases with age. The proportion experiencing fatigue ‘every day’ increases from a low of 0.3 percent among persons 17 years or younger to 13.3 percent for those age 70 or over. The more frequent experience of fatigue is particularly noticeable after age 50 when compared to those younger.

Table 3. Frequency of Fatigue by sex and age.

		Sex		Age						
		Male	Female	<18	18-30	31-40	41-50	51-60	61-70	>70
		(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Frequency of Fatigue</b>	Never	57	50	81	51	46	42	36	37	38
	Some days	34	40	18	43	44	45	48	43	32
	Most days	6	6	1	4	6	7	10	11	15
	Every day	3	4	0	2	4	5	6	9	13
	Refused	0	0	0	0	0	0	0	0	0
	Don't know	0	0	0	0	0	0	0	0	2
<b>Total persons</b>		<b>2448</b>	<b>3861</b>	<b>1475</b>	<b>1478</b>	<b>1004</b>	<b>1008</b>	<b>738</b>	<b>395</b>	<b>211</b>

### Duration and Intensity – Measures of Severity

The duration and intensity of the fatigue are also factors that can represent severity in the experience of fatigue, and questions on these aspects were included in the field test. There was also interest in exploring the relationship of the severity of the fatigue with the frequency of its occurrence. The following analysis examines the respondent’s experiences of the intensity and duration of the fatigue and explores the relationship of those two indicators of severity.

### Duration of Fatigue

The follow-up questions were asked of respondents who reported experiencing fatigue at least ‘some days’. The duration of fatigue reported is shown in Table 4. Overall, respondents experience fatigue for only ‘some of the day’ (74.0 percent). Those in the Philippines in particular experience fatigue for only

some of the day (84.3 percent) while those in Sri Lanka, Mongolia and the Maldives are more likely to experience the fatigue ‘all day’ on days they have fatigue (17.6 percent, 17.0 percent and 14.3 percent). Although the Sri Lanka respondents are less likely than the others to report frequent experiences of fatigue, those that do experience it for ‘most’ or ‘all of the day’. This may indicate that temporary fatigue that occurs less frequently is not considered worthy of reporting for the Sri Lankan population.

		Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
		(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Duration of Fatigue</b>	Some of the	72	80	58	67	68	84	74
	Most of the	17	15	19	14	18	7	14
	All of the day	11	4	18	17	14	9	11
	Refused	0	0	0	1	0	0	0
	Don't know	1	0	5	1	0	0	1
<b>N</b>		524	518	310	607	596	481	3036

Among those with fatigue, the duration of the fatigue varies very little by sex but more noticeably by age. As shown in Table 5, men are equally likely as women to describe the duration of their fatigue as lasting ‘all day’ (11.0 percent and 11.1 percent). However the effect of age on duration of fatigue is quite consistent - as age increases the duration of the fatigue increases. As age increases the likelihood that the fatigue will last ‘most’ or ‘all of the day’ increases by each additional decade while the probability that it will last only ‘some of the day’ declines. Among those less than age 18 only 8.7 percent indicate the fatigue lasts ‘most of the day’ and 5.6 percent that it lasts ‘all day’ compared to persons 70 and over who are more than twice as likely to indicate the fatigue lasts ‘most’ or ‘all day’ (21.4 percent and 19.1 percent).

		Sex		Age						
		Male	Female	<18	18-30	31-40	41-50	51-60	61-70	>70
		(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Duration of Fatigue</b>	Some of the	75	73	84	80	75	73	70	65	58
	Most of the	13	15	9	12	12	15	16	23	21
	All of the day	11	11	6	7	13	12	14	12	19
	Refused	0	0	0	0	0	0	0	0	0
	Don't know	1	1	2	1	1	1	0	0	2
<b>Total persons</b>		<b>990</b>	<b>2046</b>	<b>307</b>	<b>625</b>	<b>542</b>	<b>597</b>	<b>503</b>	<b>291</b>	<b>171</b>

### Intensity of Fatigue

A second follow-up question focused on the intensity of the fatigue. In addition to the questions about how long the fatigue lasted, respondents were asked the level of the fatigue they felt the last time they experienced fatigue. This was interpreted as the intensity and was recorded with a non-quantitative five-point scale ranging from ‘a little’ to ‘a lot’. Table 6 records the distribution of those answers for the various countries involved in the field test and shows that overall almost one third of persons (61.6 percent) who had reported fatigue indicated that the level of that fatigue was generally low (‘a little’ on the answer categories). Approximately 17 percent did indicate ‘a lot’ of fatigue the last time they experienced fatigue. However in Sri Lanka and the Maldives the proportion reporting ‘a lot’ of fatigue was almost double the average. This probably indicates again that the intensity of fatigue question is



picking up those with serious problems with fatigue but not those with lesser problems. The respondents in the Philippines stand out as reporting the lowest levels of intensity of fatigue.

		Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	All Countries
		(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Intensity of Fatigue</b>	A little	44	69	67	44	60	83	62
	Closer to a	8	2	1	2	6	3	4
	In between	24	13	4	24	7	6	13
	Closer to a lot	7	2	2	0	8	1	4
	A lot	17	15	27	30	19	7	17
	Refused/DK	1	1	8	1	0	0	1
<b>Total persons</b>		<b>635</b>	<b>597</b>	<b>120</b>	<b>353</b>	<b>658</b>	<b>631</b>	<b>2994</b>

There is very little difference between men and women in the intensity of fatigue experienced. Men are slightly more likely to report 'a little fatigue' (63.6 percent) compared to women (60.6 percent), while women are slightly more likely to report 'a lot of fatigue' (17.5 percent) compared to men (15.4 percent). The relationship of the intensity of the fatigue and age is more obvious. As age increases so reported intensity of fatigue increases for 'a lot of fatigue', with more than a quarter of persons 70 years and older compared to only 7.7 percent of 0 – 17 years olds. Starting at age 50 fatigue appears to be more intense, however those aged 51-60 years report intensity fatigue 'between a little and a lot' (17 percent) while by age 70 years reporting the intensity has moved from 'in between a little and a lot' to 'a lot of fatigue' (28.1 percent).

		Sex		Age						
		Male	Female	<18	18-30	31-40	41-50	51-60	61-70	>70
		(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
<b>Intensity of Fatigue</b>	A little	64	61	76	69	67	56	53	49	52
	Closer to a	5	4	4	4	4	5	4	2	4
	In between	13	14	10	13	11	14	17	16	13
	Closer to a lot	3	5	3	3	4	5	4	10	3
	A lot	15	18	8	11	14	20	24	23	28
	Refused/DK	1	1	1	1	1	1	0	2	2
<b>Total Persons</b>		<b>1038</b>	<b>1932</b>	<b>388</b>	<b>726</b>	<b>546</b>	<b>583</b>	<b>471</b>	<b>249</b>	<b>131</b>

### Relationship between Intensity, Duration and Frequency of Fatigue

Table 8 shows the relationship of duration of fatigue with the intensity of fatigue. Among those who report some frequency of fatigue, the relationship between the duration of that fatigue and intensity is dominated by those who report fatigue for 'some of the day' and intensity that is 'a little' (73.5 percent). Those who report fatigue for 'most' or 'all of the day' also are more likely to report 'a lot' of fatigue (36.3 percent and 33.7 percent respectively). The rest of the table does not have a clear pattern and only weakly supports the idea that duration and intensity have a strong relationship rather than that they are just two dimensions of fatigue. While the relationship seems to fall on the diagonal and indicates a dichotomous break, there are still those who have the fatigue for a greater proportion of the day but the intensity of that fatigue is low ('a little'). Fatigue is an individual experience and we cannot assume

necessarily that having ‘a little’ fatigue for ‘all’ or ‘most of the day’ is any less or more detrimental than having ‘a lot of fatigue’ for only ‘some of the day’. It depends on the person and their activities.

		Duration of Fatigue					
		Some of the day	Most of the day	All of the day	Refused	Don't Know	Total
		(%)	(%)	(%)	(%)	(%)	(%)
Intensity of Fatigue	A Little	74	27	25	0	33	61
	Closer to a little	4	6	2	0	0	4
	In between	12	20	12	0	0	13
	Closer to a lot	2	10	9	0	0	4
	A lot	8	36	34	0	0	17
	Refused/DK	0	1	1	100	67	1
<b>Total persons</b>		<b>2216</b>	<b>427</b>	<b>330</b>	<b>2</b>	<b>18</b>	<b>2993</b>

The relationship of the frequency of fatigue with the intensity or the duration of that feeling are examined in the next two tables. In table 9 we see that most respondents indicate that their fatigue only occurs on ‘some days’ and is for only ‘some part of the day’ (82 percent). For those who experience fatigue ‘every day’ the distribution of that fatigue over ‘some’, ‘most’ or ‘all of the day’ is relatively uniform. Persons who have fatigue ‘everyday’ are as likely to have it for only ‘some of the day’ as ‘all of the day’ (38.5 percent and 38.9 percent respectively). The relationship between frequency and duration of fatigue suggests that for two-thirds of respondents who report fatigue, (cell N = 1962) the fatigue is neither a regular occurrence nor does it last for more than part of the day. The correlation of the two measures (.379) also indicates a weak relationship of increasing fatigue frequency with increasing duration of the fatigue.

		Frequency of Fatigue					
		Some days	Most days	Every day	Refused	Don't Know	Total
		(%)	(%)	(%)	(%)	(%)	(%)
Duration of Fatigue	Some of the	83	44	39	0	17	74
	Most of the	11	33	23	0	0	14
	All the day	7	23	39	0	0	11
	Refused	0	0	0	100	0	0
	Don't know	0	1	1	0	83	1
<b>Total persons</b>		<b>2376</b>	<b>364</b>	<b>239</b>	<b>2</b>	<b>12</b>	<b>2993</b>

Table 10 shows the relationship between the frequency of experiencing fatigue and the intensity of that fatigue. Once again the bulk of the respondents, approximately 55 percent, fall into the cell indicating that they only experience ‘a little’ fatigue on ‘some days’, that is, infrequent and low levels of fatigue. The additional categories of response for intensity of the fatigue account for the remaining responses. However there are indications of association of intensity with the frequency of the fatigue. This is noted for those reporting ‘a lot of fatigue’ on ‘most days’ (39.3 percent) and ‘every day’ (44.4 percent). The

correlation between the two variables was .348 indicating that there is a less than perfect association of increasing intensity with increasing frequency of fatigue. (See table 14 for the correlations).

		Frequency of Fatigue					
		Some days	Most days	Every day	Refused	Don't Know	Total
		(%)	(%)	(%)	(%)	(%)	(%)
Intensity of Fatigue	A Little	69	30	32	0	17	61
	Closer to a little	4	3	4	0	0	4
	In between	13	20	11	0	0	13
	Closer to a lot	3	8	8	0	0	4
	A lot	11	39	44	0	0	17
	Refused/DK	0	1	1	100	67	1
<b>Total persons</b>		<b>2376</b>	<b>364</b>	<b>239</b>	<b>3</b>	<b>12</b>	<b>2994</b>

### Multiple Dimensions of Fatigue: The Interplay of Frequency, Duration and Intensity

In addition to the questions asked about frequency, duration and intensity of fatigue, a series of probes were asked about limitations in activity that may have been experienced and some possible causes of the feelings of fatigue. In table 11 we used regression models to depict the significant causes associated with each combination of answers to the intensity and duration questions. The variables are labeled *Work*, *Sleep*, *Health*, *Other* and *Impact*. *Work* refers to working or exercising too much. *Sleep* refers to not getting enough sleep. *Health* refers to a physical or health related problem. *Other* allows the respondent to give some other cause. The last variable, *Impact* refers to whether the respondent, in general, feels unable to do or limited in doing their daily activities. The significant negative patterns are shown in red and the significant positive patterns are shown in black. The results show that neither *sleep*, *health*, or *other* are seen as causing the lower levels of the combined duration and intensity of fatigue (upper left hand corner of table) and the only element associated with that combination is overwork or exercise. Additionally, *Impact*, the effect of the fatigue on daily activities, is significantly absent. At the same time the combination of duration and intensity represented in the lower right hand corner of the table ('a lot of fatigue', 'all day') is associated with *health* and *other* factors and does *impact* on daily activities. Earlier (see table 2) it was established that experiencing fatigue 'every day' showed least variation across countries and this same frequency category ('every day') is closely associated with high duration and frequency as shown in tables 9 and 10.

Table 11: Descriptions of fatigue, by duration and intensity in field test interviews

Intensity	Duration		
	Some of the day	Most of the day	All of the day
A little	Work**	Work†	Health†
	Sleep**	Health**	Impact*
	Health**		
	Other**		
	Impact**		
Closer to a little	Work†		
	Impact†		
In between	Work*	Work*	Health†
	Sleep*	Health**	Other†
	Health**	Impact**	Impact**
Closer to a lot	Work†	Sleep†	Sleep*
	Health**	Impact†	Health**
	Impact**		Other**
A lot			Impact**
	Work†	Work†	Work†
	Health**	Sleep*	Health**
	Impact**	Health**	Other**
		Impact**	Impact**

Note. Negative associations shown in red text. Positive associations shown in black text.

†<.10, \*p<.05, \*\*p<.005

Looking at the combinations of frequency with intensity and duration in Tables 12 and 13, we find the same patterns of relationship with cause and impact as with the combination of duration and intensity of fatigue. Overwork or exercise is associated with the lower levels of intensity/frequency, while health and other is associated with greater levels of intensity/frequency and at that greater level there is a clear impact on daily activities.

Table 12: Descriptions of fatigue, by frequency and intensity in field test interviews

Intensity	Frequency		
	Some days	Most days	Everyday
A little	Work**		Impact†
	Sleep**		
	Health**		
	Other**		
Closer to a little	Impact**		
	Work*	Other†	
	Health*		
	Impact†		
In between	Work*	Health**	Health†
	Sleep**	Impact**	Other*
	Health**		Impact**
Closer to a lot	Sleep*	Health*	Health**
	Health**	Impact**	Impact**
	Impact*		
A lot	Work†	Work†	Work*
	Health**	Health**	Health**
	Impact**	Impact**	Other**
			Impact**

Note. Negative associations shown in red text. Positive associations shown in black text.

†<.10, \*p<.05, \*\*p<.005

Table 13: Descriptions of fatigue, by frequency and duration in field test interviews

Duration	Frequency		
	Some days	Most days	Everyday
Some of the day	Work*	Impact*	Health*
	Sleep**		
	Health**		
	Other**		
Most of the day	Impact**		
	Work**	Health**	Health**
	Sleep*	Impact**	Other†
	Health**		Impact**
All of the day	Impact**		
	Health*	Work*	Health**
	Impact*	Health**	Other**
		Other*	Impact**
		Impact**	

Note. Negative associations shown in red text. Positive associations shown in black text.

†<.10, \*p<.05, \*\*p<.005

Table 14 provides statistical correlations among the three dimensions of fatigue. All of the correlations are statistically significant. However, none of the coefficients exceeds 0.5. This may indicate that the three dimensions of fatigue are not totally independent, yet are measuring slightly different aspects of the fatigue experience. Results presented above also reinforce the moderate relationship seen in this table between the intensity and duration dimensions. These interpretations are consistent with earlier findings, and are also demonstrated in the three-way frequency provided in Table 15a.

Table 14. Correlations for fatigue frequency, duration and intensity in field test interviews.

		Frequency	Duration	Intensity
Frequency	Pearson Correlation	1	.379**	.348**
	Sig. (2-tailed)		0	0
	N	2,962	2,962	2,962
Duration	Pearson Correlation	.379**	1	.467**
	Sig. (2-tailed)	0		0
	N	2,962	2,962	2,962
Intensity	Pearson Correlation	.348**	.467**	1
	Sig. (2-tailed)	0	0	
	N	2,962	2,962	2,962

\*\* Correlation is significant at the 0.01 level (2-tailed).

Table 15a displays some very small cell sizes. However, noticeable patterns are now familiar. For example, most respondents report duration of their last fatigue episode as 'some of the day'. Not until intensity reaches 'closer to a lot' or 'a lot' are there larger cell sizes in the 'most of the day' and 'all of

the day' duration responses. There is also the familiar dichotomy displayed with intensity – most respondents reported intensity at the extremes of 'a little' (n=1,626) or 'a lot' (n=498).

Table 15a. Crossfrequencies for fatigue frequency, duration and intensity in field test interviews.

Intensity		Fatigue Frequency			Total	
		Some Days	Most days	Every day		
A little	Duration	Some of the day	1,498	79	49	1,626
		Most of the day	82	22	11	115
		All of the day	57	9	16	82
	<b>Total</b>	<b>1,637</b>	<b>110</b>	<b>76</b>	<b>1,823</b>	
Closer to a little	Duration	Some of the day	72	7	6	85
		Most of the day	20	3	3	26
		All of the day	6	0	1	7
	<b>Total</b>	<b>98</b>	<b>10</b>	<b>10</b>	<b>118</b>	
In between	Duration	Some of the day	223	34	13	270
		Most of the day	56	27	4	87
		All of the day	21	10	10	41
	<b>Total</b>	<b>300</b>	<b>71</b>	<b>27</b>	<b>398</b>	
Closer to a lot	Duration	Some of the day	39	8	7	54
		Most of the day	21	14	7	42
		All of the day	19	6	4	29
	<b>Total</b>	<b>79</b>	<b>28</b>	<b>18</b>	<b>125</b>	
A lot	Duration	Some of the day	127	32	16	175
		Most of the day	71	55	29	155
		All of the day	51	56	61	168
	<b>Total</b>	<b>249</b>	<b>143</b>	<b>106</b>	<b>498</b>	

### Fatigue Summary Measure

In this final section, analyses are presented that explore whether the three questions on the dimensions of fatigue are duplicative or if they add additional information about the symptom in a complementary manner. The findings thus far demonstrate that not any one of the three dimensions duplicates any of the others. Each is different and seems to be adding something to our information about fatigue. While there is a moderate relationship between duration and intensity based on the correlation matrix it appears that frequency, duration and intensity each measure somewhat different aspects of fatigue. Which is most important to capture is not necessarily a consideration since the circumstances of the individual and their interpretation of their fatigue is what would predict the importance. Since that is the case, combining data on these dimensions into a single scale would be analytically useful. It will provide evidence that what we might not be capturing with one question is captured through the other two, and more importantly by combining responses on all three aspects.

A summary fatigue measure was created using the three-way frequency presented in Table 15a. A review of the data in that table suggests that cutoffs could be made to create a categorical scale in

which frequency, duration and intensity were combined to form a summary fatigue variable with three levels: low, middle, high. Table 15b shows where those cutoffs were created. A low level of fatigue is coded in green, middle level of fatigue in black, and high level of fatigue in red.

Table 15b. Crossfrequencies for fatigue frequency, duration and intensity in field test interviews.

			Fatigue Frequency			Total
			Some Days	Most days	Every day	
A little	Duration	Some of the day	1,498	79	49	1,626
		Most of the day	82	22	11	115
		All of the day	57	9	16	82
	<b>Total</b>		<b>1,637</b>	<b>110</b>	<b>76</b>	<b>1,823</b>
Closer to a little	Duration	Some of the day	72	7	6	85
		Most of the day	20	3	3	26
		All of the day	6	0	1	7
	<b>Total</b>		<b>98</b>	<b>10</b>	<b>10</b>	<b>118</b>
In between	Duration	Some of the day	223	34	13	270
		Most of the day	56	27	4	87
		All of the day	21	10	10	41
	<b>Total</b>		<b>300</b>	<b>71</b>	<b>27</b>	<b>398</b>
Closer to a lot	Duration	Some of the day	39	8	7	54
		Most of the day	21	14	7	42
		All of the day	19	6	4	29
	<b>Total</b>		<b>79</b>	<b>28</b>	<b>18</b>	<b>125</b>
A lot	Duration	Some of the day	127	32	16	175
		Most of the day	71	55	29	155
		All of the day	51	56	61	168
	<b>Total</b>		<b>249</b>	<b>143</b>	<b>106</b>	<b>498</b>

Table 16. Distribution of Fatigue measure summarizing frequency, duration and intensity based on field test interviews.

Summary fatigue measure	N	Percent
Low	1,895	64
Middle	491	16.6
High	576	19.4
<b>Total</b>	<b>2,962</b>	<b>100</b>

The summary measure allows us to look at the relationship of the combined frequency, duration and intensity measures with the causes and impact more directly. The distribution of fatigue related problems as measured by the questions are distributed as would be expected; that is, among persons who indicate some level of frequency of fatigue about two-thirds have responded in the lowest levels of frequency, duration or intensity. About 17 percent indicate somewhat more serious problems and another approximate 19 percent report the greatest levels of fatigue. Since we expect that the fatigue



we are trying to understand, that associated with chronic conditions and aging, is quite severe, the results have good face validity.

## Conclusions and recommendations

A number of findings from the data produced by the cognitive and field test are informative and will be useful as the question set on fatigue continues to develop.

### 1. Introductory statement or screener question

In the cognitive tests, the initial question asking whether one has frequent feelings of being tired, the connection between 'tiredness' and 'fatigue' were not made and then the question was dropped in the field test. A first question of that nature or a statement to explain the concept appears to focus respondents' attention on the construct of interest; that is 'experiences of fatigue, exhaustion or extreme tiredness'. This should be considered in the next round of testing of these questions.

### 2. Multidimensionality of fatigue

Most respondents seemed to be able to respond to questions of frequency, duration and intensity of whatever they conceptualized in their heads as fatigue. Since there was no indication that any of the three components were duplicating another, developing the three elements would seem to be appropriate for effectively capturing this concept of fatigue.

### 3. Cross National responses

There was a very strong pattern of differences across the six countries that tested these questions. Further exploration of translation problems or cultural norms about fatigue should be explored more thoroughly to identify the causes of these differences. However, for the most frequent occurrence of fatigue these variations were almost non-existent except for Cambodia.

### 4. Age differences

The strong relationship between age and reports of fatigue among the older population indicate that perhaps further cognitive testing among that population will help improve our understanding of these measures.

### 5. Multidimensional measure

The combination of the three measures into a combined measure that acts as expected in predicting the impact of fatigue on daily activities, suggests that the multiple dimensions we are capturing are contributing to the concept of fatigue. Improving the probes to get more information will help with the next round of testing.

While the results are not as clearly evident as we would like, another set of testing, taking into account the lessons learned here, should produce a useable measure of fatigue. Fatigue is an important element in understanding the nature of the factors that contribute to disability. Lack of energy or exhaustion,

which can result from any number of conditions or treatments, can create problems with activities that are not otherwise captured by standard questions, such as difficulties walking, self care and so on. However, as demonstrated here, fatigue is a complicated process which is made up of the frequency with which it occurs, the duration and the intensity with which it is felt. So many elements make it difficult to capture in a small set of survey questions, even when those questions provide a range of answers. In addition, as this test indicates, there are widely varying responses shown across countries which may be an indication of either different cultural conceptualizations of what fatigue is, or whether one can admit to such a problem. Or it may reflect a translation issue where terminology associated with the concept has not been well translated to the language. It is therefore important to keep the fatigue concept alive in the extended measurement development process, but that these results need to be further analyzed to locate the problems or that the questions need to be changed or adopted to provide a more robust representation of the concept.

#### **Possible extended set (to be tested further)**

1. In the past 3 months, how often did you feel very tired or exhausted?
2. Thinking about the last time you felt very tired or exhausted, how long did it last
3. Thinking about the last time you felt this way, how would you describe the level of tiredness
4. Would you say it was closer to a little, closer to a lot, or exactly in the middle

## Conclusion and way forward

The purpose of this WG/ESCAP project was to develop and test the performance of an extended set of disability questions that could be used in surveys (health surveys or disability components in other surveys) to provide information on the disability status of a population. This extended set of questions goes beyond the WG short set (WG SS) of six questions that was developed, and adopted in 2006, for use on censuses. The extended set includes more functional domains and more detail on each domain. The additional domains include learning, upper body mobility (as an extension of self care), affect (anxiety and depression), pain and fatigue. Furthermore, for each domain multiple questions, where appropriate, were added to provide a more detailed and nuanced measurement of disability and functioning.

There was also a second purpose or component to this project. That was to further develop and refine a methodology for the development of survey questions. The work presented here represents a large step in furthering question development research. This was accomplished in several stages:

1. In 2007 and 2008 Washington Group meetings, the strategy and content of an extended set of questions were discussed and a proposed set developed for testing. The matrix (see Introduction chapter) was created as a framework for the development of the question set. The ESCAP project was established as the main testing process for these questions with further testing initiated in Europe (the Granada Group) as part of the Budapest Initiative.
2. The first stage of testing was cognitive testing of the question set to determine how the questions were interpreted and understood. Issues of translation were also covered at this stage. Nine countries (six in the Asia-Pacific region: Maldives, Mongolia, Sri Lanka, Philippines, Cambodia, Kazakhstan; together with USA, Canada and South Africa) contributed cognitive interviews for this section.
3. Results of the cognitive testing of the questions were analyzed in July 2009. This analysis led to the development of probe questions for use in the field testing.
4. Field testing took place in the 6 Asia-Pacific countries (Maldives, Mongolia, Sri Lanka, Philippines, Cambodia and Kazakhstan). The data collection for the field test took place between June and October 2009.
5. This report is the culmination of the analysis phase of the project.

The chapters on the individual domains in this report provide evidence on the performance of the Washington Group Extended set of questions. This chapter will attempt to synthesize the results and conclusions from the other sections of this report to provide an overview of the process and to suggest a way forward for both the further development of the questions as well as a tentative process on how to use these questions.

## Summary of Results

For certain domains the questions perform well. These include: vision, hearing, mobility (lower body – walking and climbing), cognition, upper body mobility and self care. (Please refer to the individual chapters for detailed results.)

Other domains provided less conclusive evidence that the questions performed as well as anticipated. The learning domain provided mixed and varied responses with no clear indication of how to accurately phrase these questions. Evidence would indicate that this domain is complex and difficult to measure in a self-report context.

The analysis of responses for the communication, affect, pain and fatigue domains confirms that it is not possible to ask a single question in the extended set. Measurement in these domains requires either multiple questions (e.g. frequency, duration and intensity for affect, pain and fatigue) and/or requires a series of probes to clarify the respondent's interpretation of the questions. Further testing of these domains and the probes is necessary.

Due to the complexity of these domains further testing should include the development of probe questions that may be used to differentiate responses that are deemed to be within the scope of the question from those that are out of scope (i.e. responses that do not fit the intention of the question).

Furthermore, it is recommended that an analytical strategy is developed that highlights how to approach the complex, multi-faceted domains and that may provide guidelines in analyzing and differentiating 'in scope' responses from those that are 'out of scope'.

## The way forward

The work of the WG/BI/ESCAP initiative represents important advancement in the understanding of question development and more specifically, in the development of an extended set of disability questions for use in surveys. Rather than representing a conclusion, this report should be viewed as an important step in the process. Valuable information was gathered that supports the development of extended questions and gaps were identified that indicate where further research needs to be focused. And just as importantly, valuable expertise has been cultivated internationally in the area of question development research through the training of individuals in 6 Southeast Asian countries.

The way forward includes further development and testing of the questions and probes, developing a simple and clear analytical strategy for those more complex domains, and furthering our understanding of disability measurement and the performance of the Short and Extended sets of questions.

### 1. Further development and testing of questions and the probes

Cognitive testing of a somewhat reduced extended set of questions is currently under way as part of the Budapest Initiative in the development of a set of measures for the determination of health states. Six European countries are participating (from February 2010) in these activities of the Granada Group (Germany, Italy, Spain, Portugal, France and Switzerland).

Also a second round of cognitive testing will be conducted in the Asia-Pacific region involving five of the six original countries.

## **2. Developing an analytical strategy**

The WG/BI/ESCAP initiative has been challenged to develop a methodology that would analyze the more complex domains (affect, pain and fatigue) that require multiple questions to determine the extent of functional limitations. In order to achieve this goal, further analysis of the data and testing of various algorithms will be carried out by the WG to determine the best possible analytic approach for each domain.

## **3. Use of the data**

As set out in the introduction, the identification of people with and without disability is only the start of the full measurement of disability in a population. The definition and measurement of functional (or disability) status in a population will, coupled with the collection of information (on for example employment, education, access to health care and other services and social participation), pave the way for assessments of the equalization of opportunities as specified in the UN Convention on the Rights of Persons with Disability and the Millennium Development Goals. The list of ‘companion variables’ above is not exhaustive; and, depending on availability, more survey data items can be included that would further highlight disparities between those with and those without disability.

Data collected using the extended set of disability questions provide the ability to:

- address single domains – in particular with respect to specific groups of people with disabilities (special interest groups)
- assess the impact of the micro-environment on functioning – analyzing capacity and performance – for those domains that collect information on the use of assistive technology/personal assistance
- assess the impact of functional limitations on different aspects of daily living.

In addition to the above points the data obtained using these measures provide other opportunities for ensuring that disability is visible and on the policy agenda in an integrated manner. Some of these opportunities are discussed briefly below.

### **a) Mainstreaming disability**

Gender mainstreaming has been an approach used in many surveys where the analysis considers responses in terms of gender differences: males versus females. This has been facilitated, in part, because of the relatively simple measure used for determining gender status. Similarly, disability status can be used for ensuring that differences in experiences of disabled versus non-disabled sectors of the population are assessed and better understood. One reason that disability status has not been addressed in an integrated and mainstreamed manner in the presentation of survey data and statistics has been the lack of adequate measures of disability used to determine disability status. The WG Short and Extended Sets of questions provides us with such a measure. There is now a need for these measures to be implemented internationally on censuses and surveys (either the short or extended set) to mainstream disability

measurement. A second requirement is the inclusion of these questions in surveys and analyses that directly address issues pertinent to disabled people, such as the accessibility of the built environment, provision of rehabilitation services, and equal access to employment and education.

b) Creating disability status variable

The use of the WG SS and/or the WG Extended Set of questions to obtain a measure of disability status requires that analysts consider carefully the definition of disability that is being operationalized. For example, people who report only 'some difficulty' doing one of the functional domains could be included in analyses of disability depending on the purpose of the measure. Because of the possibilities for several determinations of disability based on the sets of questions, it becomes imperative that adequate attention be given to the definition of disability that is being operationalized for the particular analysis that is being carried out.

c) Influencing policy development and monitoring

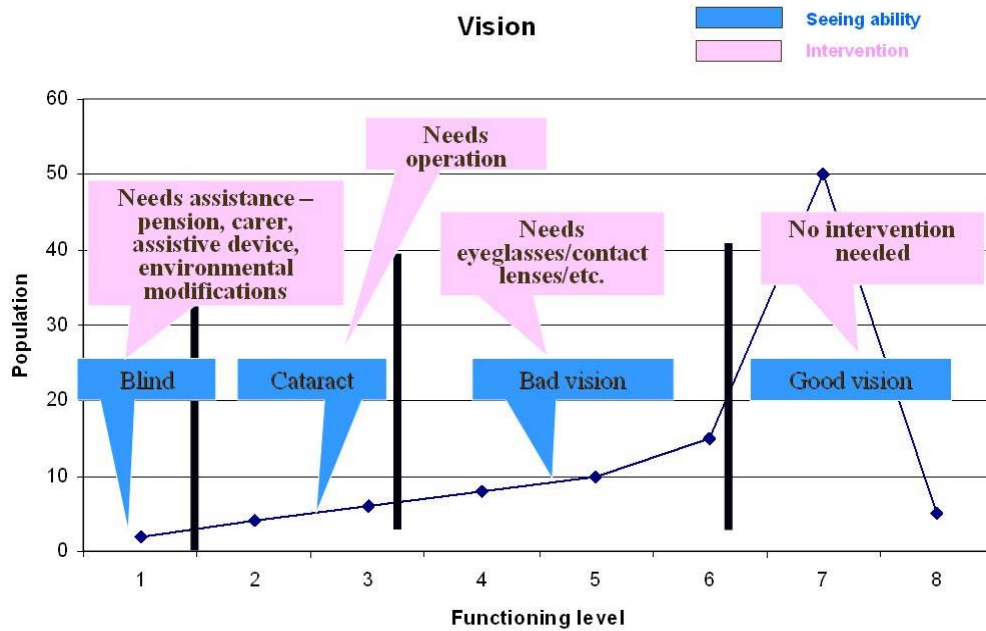
Evidence has shown that previous measures of disability that rely on a medical model approach and that reflect a simple dichotomy: Do you have a disability? With 'yes or no' response categories result in very low response rates. The approach to measuring disability using the WG short or extended set of questions will produce higher prevalence rates reflecting persons difficulties in functioning according to WHO's ICF approach. Unlike earlier measures that focused on people with severe disabilities, these measures include people with mild and moderate limitations.

There has thus been a tendency among policy makers to retreat in fear at the thought of having to manage a much larger number of disabled people in the population obtained using these new measures. It becomes increasingly important therefore that policy makers be well informed regarding what the disability measures are including – and for what purpose. This would include highlighting the different possible definitions of disability and how they should be used. For example, a social protection programme would consider only the more severe levels of difficulty as relevant for understanding the need for cash transfers as part of a social protection scheme. Public health specialists may be more interested in the people who have 'some difficulty' as these would be important sectors of the population to monitor to ensure that these mild difficulties do not progress to levels that are more severe (figure 1 is an example of this for vision). Another example would be the impact and effectiveness of providing antiretroviral therapy to people who are AIDS sick could be easily monitored in relation to functional status. Also, a shift in functional status from 'unable to do' to only having 'some difficulty', for example in walking and climbing stairs, would be a significant impact.

d) The issue of 'counting' people with disability is a contentious topic; yet many policy makers and disability activists are concerned with knowing, for example, 'how many blind people there are in the country'. The use of these disability measures is not inconsistent with such requests. The recommended measures of disability presented in this report allow for the explication of the full range of disability – from mild to severe – and provide for a more complete individual profile of functioning in several functional domains or in a single functional domain. This shift towards a

broader disability profile in a population has important implications for planning services as well as for ensuring human rights of recognition of individuals and their needs.

Figure 1 - Disability continuum



Source: Disability Statistics Training Manual (WHO/ESCAP)

#### 4. Monitoring the UN Convention on the Rights of Persons with Disabilities

Disability, as measured using the WG Short or Extended set of questions, can be applied to monitoring the UN Convention on the Rights of Persons with Disabilities and the Millennium Development Goals. It will become increasingly important for countries that have ratified the UN Convention to document their actions with respect to removing barriers to access/improving accessibility and eliminating disparities with respect to the rights of persons with disability.

Below are some guidelines developed by the Washington Group<sup>1</sup> for using these measures in monitoring the UN Convention.

Ratification and endorsement of the UN Convention on the Rights of Persons with Disability are the initial steps to establishing awareness and compliance at the national level. The United Nations has also requested that means be sought to develop a set of indicators intended to monitor the implementation of the Convention. This proposal falls within the scope of activities of the WG. The same tools (short set and extended questions) developed as measures of equalization of opportunity under the aegis of the WG would service equally to monitor the UN Convention.

<sup>1</sup> Standardized Approach to Monitoring the Convention – a document prepared by the Washington Group on Disability Statistics.

The WG short set of six questions, when incorporated in censuses or surveys, can provide baseline information that can fulfill the requirements for monitoring. During the present ESCAP exercise, efforts focused on expanding the short set by incorporating additional domains of functioning both in terms of basic actions (upper body, learning, affect, pain, and fatigue). In addition more detailed information is sought on the impact of environmental factors at all levels (micro, meso, and macro), as well as other allied information on age at onset, duration, impact and cause of basic action/complex activity limitations.

By standardizing these questions it will be possible to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources; comparable data that can be used to assess a country's compliance with the UN Convention and, over time, their improvement in meeting the requirements set out under the Convention. To this end, the current set of six questions can provide crucial information necessary to the task of monitoring the Convention.

We are proposing that the assessment of equalization of opportunity, employing general disability measures developed by the WG, is a suitable and meaningful approach to monitoring the UN Convention on the Rights of Persons with Disabilities. Equalization of opportunities was chosen as the guiding purpose in the development of the WG approach to measuring disability and it meets the criteria of relevance and feasibility of implementation internationally.

By coupling responses to questions that focus on one's ability to function in basic actions with information collected on the complex activity limitations, in particular access to employment and education, involvement in family and cultural life, it will be possible to assess the degree to which people with disabilities are afforded the same rights and access as people without disabilities.

In sum, to increase the availability of disability statistics at both the national and the international levels, it is important to continue advocating for the collection of data on disability and persist in the work on developing internationally comparable measurement tools. It is imperative to fully develop and adopt a unifying international approach for data collection through censuses and surveys, and to increase national political commitment and technical capacity to collect and disseminate better disability statistics.



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