

Second meeting of the 2011/2012 Bureau
Geneva, 2-3 November 2011

For information

Item 4(a) of the Provisional
Agenda

**BUDAPEST INITIATIVE
SURVEY MODULE FOR MEASURING HEALTH STATE
(So-called "Budapest Initiative Mark 2" Question Set)**

Note prepared by the UNECE secretariat

I. INTRODUCTION AND RATIONALE FOR THE BUDAPEST INITIATIVE

1. The Budapest Initiative (BI), a joint effort of WHO, UNECE, Eurostat and a number of interested countries, has developed a short form questionnaire intended to provide the basis for comparable standardized information on population health focusing on health state. The questionnaire, the Budapest Initiative – Mark 2 (BI-M2), can be used to produce internationally comparable estimates of the measurement of health state. Developmental work and testing is continuing particularly to develop questions for domains (e.g., learning) that are not included in this set. The additional testing will also inform users of these questions about their measurement characteristics.

2. Underlying this questionnaire is a conceptual foundation which defines health state in terms of functioning in a core set of health domains. Health state is only one of a large number of classes of indicators that would be necessary to provide a full statistical picture of population health. Health state does not include determinants of health. This exclusion is essential from an analytical point of view and allows the strength of association between a determinant of health and health state to be assessed empirically. Correspondingly, health state is clearly distinguished from overall well-being and quality of life. While there is no doubt that health state is a major factor determining well-being, it is not the only one. It is also important to distinguish health state from physiological markers like blood pressure and cholesterol levels, and from clinically or bio-medically defined disease. Health state is essentially a rigorously structured but vernacular or plain language description of an individual's functional health status.

3. The BI-M2 addresses functional domains that met criteria related to relevance and feasibility as well as certain measurement characteristics. Relevance required each of the domains and their associated survey questions to be immediately seen as plausible and reasonable by ordinary individuals, to span the main aspects of health experienced by the population, to be seen as significant aspects of individuals' health and to draw on selected key ideas of the International Classification of Functioning, Disability and Health (ICF). Feasibility refers to a question set that is suitable for use in health interview surveys, has a consistent meaning in different social contexts, manifests a reasonable degree of heterogeneity within the population, and minimizes the number of domains on which questions need to be asked.

4. The domains also had to meet several measurement requirements. Domains should exhibit statistical independence which means that in most populations of interest, the levels of health on one domain are unlikely to be correlated with levels of health on another. While achieving complete statistical independence is not a feasible goal, the goal remains to minimize dependence and to focus on a set of domains that provide the most information on the population's health.

5. Structural independence between domains is also important and is distinct from statistical independence; it applies when an individual's level on one domain in no way pre-determines his or her level on the other domain.

6. Levels of functioning in each domain should also be graded in severity in an ordered fashion; and functioning should be measured within, on or near the skin. The latter criterion means that the domain refers to something that is intrinsic to the individual (equivalent to "capacity" in the International Classification of Functioning, Disability and Health). In other words, it is independent (to the extent possible) of external factors such as the physical or social environment. While aids like eyeglasses or pain medication can be considered to be essentially "within the skin", wheelchairs and wheelchair accessible public transport are not. This criterion generally implies two of the choices with regard to ICF concepts – specifically the focus on "functioning and disability" and not "contextual factors", and the focus on more elemental "activity" and not the more complex and typically socially mediated "participation". This criterion also greatly enhances the prospects for another criterion, cross-cultural comparability. Finally, functioning should be measured in a way that does not preclude preference measurement and the construction of summary measures of health.

7. Based on these criteria and the results of multiple rounds of cognitive and field testing, the following functional domains have been included in the BI-M2 questionnaire: vision, hearing, mobility (walking and climbing up or down stairs), cognition (remembering or concentrating), affect (anxiety and depression), pain and fatigue. Two additional domains have been developed and are included in the BI-M2 set as optional: communication and upper body.

8. The BI recommends that the BI-M2 be included in the 2014 European Health Interview Survey (EHIS) as a complete set or section. This would facilitate both international comparability on the individual domains and the computation of summary measures of health if there is interest in developing such a measure. We understand that some of the BI-M2 items are similar to those asked in the first round of the EHIS and that this may affect the placement of the BI-M2 questions.

Budapest Initiative – Mark 2
A Survey Module for Measuring Health State

(Proposal endorsed by the Joint UNECE/WHO/Eurostat Task Force on Measuring Health State,
at the joint Washington Group / Budapest Initiative Task Force Meeting,
3-5 November 2010, Luxembourg)

As for placement of the BI-M2 within the EHIS, the BI Steering Group emphasizes that the instrument needs to be treated as a complete set or package. This would facilitate both international comparability and the computation of summary measures of health.

Preamble to the BI-M2:

Interviewer read: "Now I am going to ask you some [further] questions about [your/his/her] general mental and physical health. These questions deal with [your/his/her] ability to do different daily activities, as well as with how [you have/he has/she has] been feeling. [Although some of these questions may seem similar to ones you have already answered, it is important that we ask them all.]"

VISION

VIS_1 [Do/Does] [you/he/she] wear glasses?

1. Yes
2. No
7. *Refused*
9. *Don't know*

VIS_2 [Do/Does] [you/he/she] have difficulty seeing, [*If VIS_1 = 1: even when wearing your glasses?*] Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

HEARING

HEAR_1 [Do/Does] [you/he/she] use a hearing aid?

1. Yes
2. No
7. *Refused*
9. *Don't know*

HEAR_2 [Do/Does] [you/he/she] have difficulty hearing, [*If HEAR_1 = 1*: even when using a hearing aid(s)]? Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

HEAR_3 [Do/Does] [you/he/she] have difficulty hearing what is said in a conversation with one other person in a quiet room [*If HEAR_1 = 1*: even when using your hearing aid(s)]? Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do (*Skip to next section.*)
7. *Refused*
9. *Don't know*

HEAR_4 [Do/Does] [you/he/she] have difficulty hearing what is said in a conversation with one other person in a noisier room [*If HEAR_1 = 1*: even when using your hearing aid(s)]? Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

MOBILITY

MOB_1 [Do/Does] [you/he/she] have difficulty walking or climbing steps? Would you say... *[Read response categories]*

- 1. No difficulty
- 2. Some difficulty
- 3. A lot of difficulty
- 4. Cannot do at all / Unable to do
- 7. *Refused*
- 9. *Don't know*

MOB_2 [Do/does] [you/he/she] use any equipment or receive help for getting around?

- 1. Yes
- 2. No *(Skip to MOB_4.)*
- 7. *Refused* *(Skip to MOB_4.)*
- 9. *Don't know* *(Skip to MOB_4.)*

MOB_3 [Do/does] [you/he/she] use any of the following?

Interviewer: Read the following list and record all affirmative responses:

		1. Yes	2. No	7. <i>Refused</i>	9 <i>Don't Know</i>
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):				

MOB_4 [Do/Does] [you/he/she] 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]? Would you say... *[Read response categories]*

- 1. No difficulty
- 2. Some difficulty
- 3. A lot of difficulty
- 4. Cannot do at all / Unable to do *(Skip to MOB_6.)*
- 7. *Refused*
- 9. *Don't know*

Note: Allow national equivalents for 100 metres.

MOB_5 [Do/Does] [you/he/she] 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]? Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

Note: Allow national equivalents for 500 metres.

MOB_6 [Do/Does] [you/he/she] have difficulty walking up or down 12 steps? Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

COGNITION

COG_1 [Do/Does] [you/he/she] have difficulty remembering or concentrating? Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

AFFECT (ANXIETY AND DEPRESSION)

Proxy respondents may be omitted from this section, at country's discretion.

Interviewer: If respondent asks whether they are to answer about their emotional states after taking mood-regulating medications, say: "Please answer according to whatever medication [you were/he was/she was] taking."

ANX_1 How often [do/does] [you/he/she] feel worried, nervous or anxious? Would you say... [*Read response categories*]

1. Daily
2. Weekly
3. Monthly
4. A few times a year
5. Never
7. *Refused*
9. *Don't know*

ANX_2 [Do/Does] [you/he/she] take medication for these feelings?

1. Yes
2. No (*If "Never" to ANX_1 and "No" to ANX_2, skip to DEP_1.*)
7. *Refused*
9. *Don't know*

ANX_3 Thinking about the last time [you/he/she] felt worried, nervous or anxious, how would [you/he/she] describe the level of these feelings? Would [you/he/she] say... [*Read response categories*]

1. A little
2. A lot
3. Somewhere in between a little and a lot
7. *Refused*
9. *Don't know*

DEP_1 How often [do/does] [you/he/she] feel depressed? Would [you/he/she] say... [*Read response categories*]

1. Daily
2. Weekly
3. Monthly
4. A few times a year
5. Never
7. *Refused*
9. *Don't know*

DEP_2 [Do/Does] [you/he/she] take medication for depression?

1. Yes
2. No (*If "Never" to DEP_1 and "No" to DEP_2, skip to next section.*)
7. *Refused*
9. *Don't know*

DEP_3 Thinking about the last time [you/he/she] felt depressed, how depressed did [you/he/she] feel? Would you say... [*Read response categories*]

1. A little
2. A lot
3. Somewhere in between a little and a lot
7. *Refused*
9. *Don't know*

PAIN

Proxy respondents may be omitted from this section, at country's discretion.

Interviewer: If respondent asks whether they are to answer about their pain when taking their medications, say: "Please answer according to whatever medication [you were/he was/she was] taking."

PAIN_1 In the past 3 months, how often did [you/he/she] have pain? Would you say...
[*Read response categories*]

1. Never (*If "Never" to PAIN_1, skip to next section.*)
2. Some days
3. Most days
4. Every day
7. *Refused*
9. *Don't know*

PAIN_2 Thinking about the last time [you/he/she] had pain, how much pain did
[you/he/she] have? Would you say... [*Read response categories*]

1. A little
2. A lot
3. Somewhere in between a little and a lot
7. *Refused*
9. *Don't know*

FATIGUE

Proxy respondents may be omitted from this section, at country's discretion.

TIRED_1 In the past 3 months, how often did [you/he/she] feel very tired or exhausted?
Would you say... [*Read response categories*]

1. Never (*If "Never" to TIRED_1, skip to next section.*)
2. Some days
3. Most days
4. Every day
7. *Refused*
9. *Don't know*

TIRED_2 Thinking about the last time [you/he/she] felt very tired or exhausted, how long did it last? Would you say... [*Read response categories*]

1. Some of the day
2. Most of the day
3. All of the day
7. *Refused*
9. *Don't know*

TIRED_3 Thinking about the last time [you/he/she] felt this way, how would you describe the level of tiredness? Would you say... [*Read response categories*]

1. A little
2. A lot
3. Somewhere in between a little and a lot
7. *Refused*
9. *Don't know*

COMMUNICATION

[NOTE: Communication questions were not originally included in the BI-M1 set. This domain has been adopted for inclusion by the Budapest Initiative Task Force members at the 3-5 November 2010 meeting. This section may be omitted, at country's discretion.]

COM_1 Using [your/his/her] usual (customary) language, [do/does] [you/he/she] have difficulty communicating, for example understanding or being understood? Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

UPPER BODY

[NOTE: Upper Body questions were not originally included in the BI-M1 set. This domain has been adopted for inclusion by the Budapest Initiative Task Force members at the 3-5 November 2010 meeting. This section may be omitted, at country's discretion.]

UB_1 [Do/Does] [you/he/she] have difficulty raising a 2 liter bottle of water or soda from waist to eye level? Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

UB_2

[Do/Does] [you/he/she] have difficulty using [your/his/her] hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles? Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
7. *Refused*
9. *Don't know*

Supporting Justification Budapest Initiative Question Set on Health State

Introduction

In developing survey questions to measure functioning and health state, 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 functioning 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.

In evaluating questions for both the Budapest Initiative (BI) and the Washington Group on Disability Statistics (WG), three large scale evaluation studies were conducted. The first study was an evaluation of the WG short set, a set of six disability questions intended for censuses. Fifteen countries took part in this study. They include: Argentina, Brazil, Congo, Egypt,

Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda and Vietnam. The results of this first evaluation have been published previously (available upon request). This document will primarily address the evaluation studies of the WG extended set and the BI health state set in two separate studies: the ESCAP and the Granada Group.

Methods

Granada Group

The Granada Group is an international coalition of survey methodologists whose primary interest is in developing best practice standards for cognitive interviewing studies, particularly for cross-cultural and multi-national surveys. In evaluating the WG and BI questions, members of the group conducted a total of 100 semi-structured, qualitative cognitive interviews. Interviews were conducted in Spain, Italy, Portugal, Germany, Switzerland, France and the United States. The specific objectives of the study 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.

ESCAP

The WG/ESCAP question evaluation project utilized a mixed method design. Like the Granada Group, cognitive interviewing was first conducted. 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. 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 100 standardized face-to-face 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 subgroup.

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.

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 or which required additional information. 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?*

Analyses of field test data were performed for each domain on the entire combined data set. The remainder of this document presents the major findings from both the ESCAP and Granada Group studies by domain. Full reporting of the ESCAP project is available on-line <http://www.unescap.org/stat/disability/analysis/index.asp>. The complete Granada Group report is due out in March. The recommendations in this document are based on these reports as well as discussions occurring at the joint Washington Group / Budapest Initiative Task Force Meeting, held 3-5 November 2010, in Luxembourg.

VISION

The vision domain covers a spectrum of seeing problems including dimensions of near and far vision, night blindness, and monocular vision.

Testing of the single WG short set question provided evidence that this question was able to capture all of these aspects of difficulty seeing. The glasses clause was included in this question because many seeing difficulties can be remedied with minimal interventions. This clause was, however, shown to be somewhat problematic. This was more evident in developing countries where the use of glasses (or corrective lenses) may be less common. However, given the chance of such problems occurring, countries are encouraged to test the clause and respective translations before fielding their surveys. Latitude in the use of the clause is accepted, considering countries' own cultural situation.

The WG and the BI developed and tested extended questions in order to gain more insight into some of the individual dimensions of vision, in particular near and far sightedness.

Analyses of the results of the testing in the six UNESCAP countries (these questions were not tested in Europe) indicated that responses to the extended questions were able to differentiate between near and far sightedness but taken together they were not able to improve upon the single question regarding severity.

Based on the results from the cognitive and field testing, the WG and BI recommended only the WG short set question for the vision domain, prefaced with a question on the use of glasses. Countries interested in differentiating between near vision and far vision problems are encouraged to include the extended set questions in their surveys in addition to the single question.

HEARING

Hearing difficulties include a range of problems that deal with some specific aspects of the hearing function: the perception of loudness and pitch, the discrimination of speech versus background noise, and the localization of sounds. Background noise is a detractor for hearing and this distraction becomes worse with increasing levels of hearing loss.

Testing of the single WG short set question provided evidence that this question was able to capture all of these aspects of hearing. Like the vision domain, a clause was included in this question that referenced the use of hearing aids. Also similar to the vision domain, this clause was shown to be somewhat problematic. However, unlike the vision domain where the use of eyeglasses may restore vision to normal function, hearing loss is not as easily rectified by the use of a hearing aid and the use of hearing aids is not as widespread. While in developed countries many hearing difficulties can be improved with the use of these aids, the problems with the use of this clause was more evident in developing countries where the use of hearing aids may be less common. However, given the chance of such problems occurring, countries are encouraged to test the hearing aid clause and respective translations before fielding their surveys. Latitude in the use of the clause is accepted, considering countries' own cultural situation.

The WG and the BI developed and tested several versions of extended hearing questions in order to develop a scale of severity for hearing problems. The questions used in the cognitive and field testing elicited two levels of difficulty in hearing – hearing in a quiet room (easier activity) and hearing in a noisy room (more difficult activity). The extent of the hearing problem for individuals who report difficulty hearing in a quiet room is likely to be moderate to severe, while many more people are likely to find hearing in a noise room difficult (mild difficulty hearing).

Analyses of results of the evidence provided from the testing in the six UNESCAP countries (these questions were not tested in Europe) indicated that responses to the extended questions were both able to discriminate individuals with hearing problems on a scale of severity.

Based on the results from the cognitive and field testing, the WG and BI recommended that the extended set of questions for the hearing domain include the WG short set question, prefaced with a question on the use of hearing aids, and followed by the questions that elicit difficulty hearing in a quiet room and a noisier room. A severity scale for the hearing domain could then be constructed.

MOBILITY

Mobility is a physical function that is an important determinant in an individual's ability to live independently. Movement-related difficulties are among the more prevalent difficulties or disabilities.

The Mobility domain is intended to capture movement difficulties associated with lower body functioning, specifically walking and climbing – and with respect to both capacity (without the use of personal assistance or assistive devices) and performance (with the use of personal assistance or assistive devices). The domain would capture difficulties in movement that are the

result of health conditions or impairments (i.e. spinal cord injuries, chronic diseases such as rheumatoid arthritis, as well as amputations and malformations), blindness or severe visual problems, and balance or vertigo.

The WG short set question is intended to cover both activities (walking and climbing) without the use of assistance in a single question. The WG and BI developed and tested an extended set of questions that would provide more information on the use of assistive technologies, extent of difficulties both with and without the use of assistive technologies, as well as differentiate between difficulties walking short distances (100 yards/meters) and longer distances (500 yards/meters) as an indication of severity.

The walking questions that specified two distances used in the UNESCAP field test (these questions were not tested in Europe) provide a useful severity scale. The question on climbing stairs adds an additional dimension. The questions also capture the impact of using assistive devices such as walkers and wheelchairs. The results do not, however, clarify the issue of what people are considering in relation to the use of handrails when climbing stairs.

Since the single WG short set question considers both walking and climbing, it was recommended that the extended questions differentiate between the two activities, and separate questions are included for walking and climbing without the use of assistive devices. The recommendation is also to use two walking questions, 100 and 500 yards/meters, so that a severity scale can be created. A parallel question battery with the use of assistive devices can be added if desired.

COGNITION

This domain covers multiple dimensions of cognition including memory, concentration, learning, and executive decision making. For the WG short set, an attempt was made to cover as many of these dimensions in a single question as possible. The WG extended set and the BI developed and tested questions for the some of the individual dimensions.

Several questions were developed and tested for the WG short set. The final version addresses only memory and concentration. It was not possible to include the other dimensions in a single question.

For all dimensions of cognition, cognitive testing showed that the questions elicited a wide range of themes. For example, in regard to memory, respondents reported very minor memory issues as well as more serious problems but the answer categories did not always discriminate along the severity domain in the same way. Asking about memory and concentration together in the short set reduced the reporting of very minor problems. Asking about both dimensions in the same question was not confusing to respondents. A follow up question tested by WG and BI showed that the majority of persons had memory problems or both types of problems as opposed to concentration alone.

Additional WG/BI questions on concentration (e.g., concentrating for 10 minutes) showed inconsistent response patterns. Respondents did not think of concentrating for 10 minutes as something they did and had difficulty responding.

Additional questions on memory varied in their ability to discriminate memory functioning. Asking about remembering important things still elicited responses of minor problems. Asking about remembering many things was more successful.

Several questions on learning were tested (separate questions for children and adults). The question for children used the example of learning to play a new game; the questions for adult used examples of learning to get to a new place and learning to use a cell phone. In all cases, respondents only answered about the examples and often the examples did not apply. Further question development is needed for learning and for executive decision making.

After consideration of all the test results, the WG and BI recommended to keep the single question only: Do you have difficulty remembering or concentrating?

AFFECT

The purpose of the affect domain is to capture psychological and mood-related problems that impinge upon daily living. In previous testing, such as testing the short set questions, attempts were made to use one question. However, because respondents reported a range of experiences (from trivial to severe), it was determined that multiple questions were required to adequately measure this domain. The intent of these questions is to place respondents along a severity continuum comprised of various dimensions of anxiety and depression (i.e. frequency, intensity, and consistency). In combination with the subsequent medication question, the first question (how often do you feel worried, nervous or anxious?) was also intended to serve as a screener question, routing respondents with no reported anxiety or use of medication to the set of depression questions. The depression questions replicate the general structure of the anxiety questions.

Analysis of cognitive interviews for both projects revealed that the construct captured by the anxiety questions included, for the most part, aspects of the intended concept, 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 a positive characteristic. These respondents appeared to interpret the question as asking about being excited, energetic or looking forward to the future.

In 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.

To determine the prevalence of the interpretive patterns, the ESCAP field test included two additional sets of follow-up questions. (see Appendix for probe questions). Table 1 presents respondents' characterization of their reported feelings by the frequency of those feelings for anxiety. Note that respondents could answer yes to the multiple dimensions and, therefore, there is overlap.

Table 1.

Percentage reporting various descriptions of anxiety by frequency of anxiety

Description of feelings	Frequency of anxiety			
	Few times a year	Monthly	Weekly	Daily
Response error				
Positive**	53.1	49.1	55.2	47.4
Normal	81.1	79.3	80.0	76.5
Stress-related				
Work**	38.7	53.0	49.0	42.5
Economic**	46.7	57.2	59.5	58.4
Impairment, limitation, pathology				
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	25.0

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

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 completely 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.

As was learned through analysis of the cognitive interviews, respondents appeared to experience and relate their feelings of anxiousness both in terms of frequency and intensity. Duration did not add significantly to the dimensions. Table 2 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 1 provides an even clearer picture of this relationship.

Table 2.
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

Bivariate logistic regression models were run to understand respondents' characterizations in each of the cells in the joint distribution. Table 3 shows the significant relationships for respondents who do not take medication.

Table 3.
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**	Positive** Chest hurts***	Chest hurts*** Interfere***	Positive*** Chest hurts***

	Normal** Chest hurts*** Interfere** Clinical***	Interfere** Clinical*** Limited***	Clinical*** Limited***	Interfere*** Clinical*** Limited***
Note. Negative associations shown in red text. Positive associations shown in black text. **p<.05,*** p<.005				

Table 4 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. 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 the upper left corner. 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 in the lower right corner. Moreover these variables are the most prominent when you get the highest level of the frequency and intensity variables.

Similar to anxiety, respondents' characterization of their depressed feelings (see Appendix) was also examined. Table 4 illustrates the percentage of respondents who endorsed the various characterizations by how they answered the frequency question.

Table 4.
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 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.

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. Table 5 shows the significant relationships for respondents who do not take medication.

Results for both affect question sets suggest that, by coupling the intensity and frequency variables, severity can be determined. Because respondents report a range of experiences for anxiety and depression, it is necessary to be able discriminate more severe cases from the less severe. Therefore, the WG/BI recommends the extended use of both frequency and intensity as well as the medication variables in the measurement of anxiety and depression.

Table 5.
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				

PAIN AND FATIGUE

While most of the functions included as measures in the WG and BI instruments fall discretely into a core domain of functioning, such as physical, sensory, psychological or cognitive functioning, pain and fatigue are unique. Neither is contained within a single domain. They are symptoms, rather than specific health diagnoses or diseases, and can be related to any of the aforementioned domains. In the framework of the domains selected to measure health state, both pain and fatigue are very relevant as they can impede the ability to function thereby limiting social participation.

Both pain and fatigue are difficult symptoms to measure. They 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. Both are also products of culture and condition. However, it is the subjective experience of pain and fatigue that determines the consequences for the person and his or her ability to participate.

When considering how to ask questions about pain and fatigue in order to accurately assess their presence and to capture information about burden, a number of approaches have been

considered. Conveying the concept of interest to the respondent and accurately capturing a range of experiences with pain or fatigue require more than a simple approach. For example, 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.

Testing and Results for Pain

Several approaches to the development of questions on pain have been explored. Initial approaches focused on a single question asking if a respondent has pain. This approach presented some challenges as the goal was to convey atypical pain, rather than less serious experiences or infrequent experiences. Thus a variety of words to describe the pain were used over the course of the tests, including “pain or discomfort” “physical pain” “physical discomfort”, “recurrent pain” and “frequent pain.” The evidence from these efforts demonstrated that the meaning of the words “recurrent” and “frequent” is not consistently interpreted by respondents. The use of the qualifiers did not focus respondents’ attention away from common pain experiences either.

“Discomfort” also generated a greater variety of experiences that were not in scope for the type of pain desired. The reporting of type of pain when no such qualifier was used, however, was found to be quite consistent across tests. 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. Thus, the use of “physical” was seen as unnecessary and the use of “frequent” was dropped in favor of a different approach to capturing frequency.

Based on the results from this first approach, none of these single questions appeared to capture the pain of most interest for this set, nor did they capture a range of information about the pain. Thus, 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.

A second approach focused on developing questions to ascertain information on the multiple dimensions of pain: frequency, duration and intensity. Questions asking about each of these were developed and have performed well across test rounds. In particular, test results demonstrated that the data captured with the frequency in the past three months and intensity (when “last time” is specified) questions were easier for respondents to answer and produced data more in scope with that desired.

Table 6 examines descriptions of pain (see Appendix) 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 responses that frequency is “some days” and intensity is “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. Similar findings are found for a parallel analysis of frequency by duration.

Using the data produced by the frequency-intensity-duration questions, analyses were conducted to explore whether the three dimensions of pain can be combined to provide a meaningful, yet succinct, measure of pain. The findings demonstrated that not any one of the three dimensions exceed the other two in terms of importance for pain. Nor are the three perfectly correlated, although there is a moderate relationship between duration and intensity.

Table 6.
Significant relationships with respondent location based on bivariate logistic regression models in each cell – frequency and intensity of pain

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

A summary pain measure was created using the three-way frequency presented in Table 7. 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 7 shows one option for where those cutoffs could be set. Low is coded in green, middle in black, and high in red.

A final decision was made to drop the duration question from the recommended BI-Mark 2 set. This decision was based in part on the basis of the data showing that regardless of test site, age, and sex, most respondents chose the lowest duration category available, “some of the day”, with few reporting in other options. This decision was also based on the correlation of duration and intensity (and some evidence that duration was a more difficult concept to report when the experience of pain was very frequent).

Asking about the use of medicinal aides was included to provide valuable information on understanding pain experiences. Unfortunately, the use and types of medicines reported vary in ways that do not provide clear evidence of how the data should be interpreted. In particular, the kinds of medicines reported showed great variation, often out of scope types of remedies. After consideration, the decision was made to exclude a question asking about the use and types of medicines for pain.

Table 7.

Crosstabulations of pain frequency, duration and intensity in field test interviews

Intensity			Pain Frequency (part of day)				Total
			Never	Some	Most	Every	
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
-------	-----------	------------	------------	------------	------------

Testing and Results for Fatigue

Like pain, many of the initial cognitive testing results suggested that a single question approach for eliciting information on fatigue is not suitable. Thus, an approach incorporating frequency, intensity and duration was used similar to that adopted for pain.

Tables 8 and 9 examine descriptions of fatigue (see Appendix) as predictors of frequency and intensity and frequency and duration, respectively. Note that in the top left corner cell of each table, descriptions include indications of fatigue relating to “sleep”, “health”, and “impact on daily activity” are all negatively associated with responses that frequency is “some days” and intensity is “a little” or duration is “some of the day”. Yet, most of these same descriptions are positively associated with responses that frequency is “every day” and intensity is “a lot” or duration is ‘all of the day’ in the lower right corner. The less frequent fatigue is and the less intense or of shorter duration that it is during the last experience, the more likely that work is indicated as a source of the fatigue.

Table 8:
Descriptions of fatigue, by frequency and intensity in field test interviews

Intensity	Frequency		
	Some days	Most days	Every day
A little	Work** Sleep** Health** Other** Impact**		Impact†
Closer to a little	Work* Health* Impact†	Other†	
In between	Work* Sleep** Health**	Health** Impact**	Health† Other* Impact**
Closer to a lot	Sleep* Health** Impact*	Health* Impact**	Health** Impact**
A lot	Work† Health** Impact**	Work† Health** Impact**	Work* Health** Other** Impact**

Note. Negative associations shown in red text. Positive associations shown in black text.
†<.10, *p<.05, **p<.005

Table 9.

Descriptions of fatigue, by frequency and duration in field test interviews

Duration	Frequency		
	Some days	Most days	Every day
Some of the day	Work* Sleep** Health** Other** Impact**	Impact*	Health*
Most of the day	Work** Sleep* Health** Impact**	Health** Impact**	Health** Other† Impact**
All of the day	Health* Impact*	Work* Health** Other* Impact**	Health** Other** Impact**

Note. Negative associations shown in red text. Positive associations shown in black text.
 †<.10, *p<.05, **p<.005

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. The findings demonstrate that not any one of the three dimensions duplicates any of the others so each seems to be adding something to our information about fatigue. Since that is the case, combining data on these dimensions into a single scale would be analytically useful and so the recommendation is to retain the three questions. However, as there is a moderate relationship between duration and intensity, additional analyses are underway to evaluate if all three measures are required.

A summary fatigue measure was created using the three-way frequency. A review of the data 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 10 shows one option for where those cutoffs could be set. Low is coded in green, middle in black, and high in red.

Table 10.
Crosstabulation for fatigue frequency, duration and intensity in field test interviews

Intensity			Tired 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
	Total		1,637	110	76	1,823
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
	Total		98	10	10	118
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
	Total		300	71	27	398
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
	Total		79	28	18	125
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
	Total		249	143	106	498

OPTIONAL DOMAINS

For the purposes of the WG, question set development has occurred in domains extending beyond those of primary interest to the BI work. These additional domains include: upper body functioning, self care, cognition and communication. At the 3-5 November 2010 joint Budapest Initiative - Washington Group meeting, BI Task Force members agreed to include in the final BI-M2 question set two domains from these additional WG domains – upper body functioning and communication. These domains are included in the BI-M2 as optional and may be included in the set at the country's discretion.

UPPER BODY

This domain covers various aspects of functioning of the upper body. The domain was not included in the WG short set but was considered as part of the self care question. However, the domain is important in relation to employment and the International Labor Organization requested that questions be developed in this area. Questions were developed to cover the dimensions of lifting ability and dexterity.

Building on an existing question that measured the ability to lift a water jug, the challenge was to find a universally understood substitute for water jug. Adapting the question to refer to a 2-litre bottle of water or Coca-cola was successful in cognitive testing. These references were found to be ubiquitous and a question about lifting the bottle from waist to eye level was interpreted the same way across countries and cultures.

A second question was also developed about dexterity or the ability to use hands and fingers. This question uses examples of picking up small objects, for example, a button or pencil, or opening or closing containers or bottles. While there was some evidence that a small group of respondents interpreted the activity referenced in the question to be picking up the object from the floor (and thus involving lower body functioning), the majority of respondents did not. Moreover, the activity is primarily interpreted correctly - as a "use of fingers" or "use of hand(s)" activity.

The recommendation is to retain both questions in the Upper Body domain.

COMMUNICATION

The purpose of the communication domain is to capture difficulties surrounding both expressive and receptive communication. Successful receptive language requires adequate hearing, or seeing for sign language use, followed by the ability to process the phonology, grammar and semantics of the message ending with the cognitive processing of the message.

Communication difficulties can stem from such problems as aphasia and or dysarthria 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, cognitive problems and hearing loss.

Results from both cognitive interviewing studies suggest that the short set question captures a broad range of communication-related problems across UNESCAP and European countries.

Those types of problems include:

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

2. 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.
3. Hearing-related problems that prevent respondents from being able to clearly hear what others are saying, and
4. 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.

While the first three elements (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 types of difficulties were prefaced with a question on the use of hearing aids learning or affect-related problems, while others were less likely due to health-related problems. One problematic interpretation did emerge across the countries; 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. Results from the ESCAP field test confirm that this particular pattern did occur across countries, though at significantly different rates (see Table 11 below). Note that respondents could answer yes to the multiple dimensions and, therefore, there is overlap.

Table 11.

Percent reporting various reasons for communication problems by country

Description of feelings	Sri						All Countries
	Kazakhstan	Cambodia	Lanka	Maldives	Mongolia	Philippines	
Shy**	59.8%	46.8%	22.4%	34.4%	62.4%	41.8%	46.7%
Mouth**	33.3	55.3	20.7	14.1	58.8	20.0	34.6
Language**	43.7	29.8	3.5	23.4	45.9	23.6	30.6
Fast**	20.7	34.0	17.2	35.9	36.5	36.4	29.8
Hear	34.5	44.7	32.8	18.8	38.8	36.4	34.1

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

Because of the different rates across countries, it is hypothesized that the language pattern is related to the translation. Therefore, it is recommended that countries consider this when performing translations of the questions. Additionally, a revised version of the question (Do you have difficulty communicating, for example understanding or being understood when speaking with someone in the same language?) is currently being tested in the ESCAP region.

Appendix 1
Probe Questions Used for Affect, Pain and Fatigue Domains

ANXIETY

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.
 - 1. Yes
 - 2. No
 - 7. Refused
 - 9. Don't know
- 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.

DEPRESSION

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

- A. My feelings are caused by the death of a loved one.
 - 1. Yes
 - 3. No
 - 7. Refused
 - 9. Don't know
- 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.

PAIN

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

A. It is constantly present.

- 1. Yes
- 2. No
- 7. Refused
- 9. Don't know

B. Sometimes I'm in a lot of pain and sometimes it's not so bad.

C. Sometimes it is unbearable and excruciating.

D. When I get my mind on other things, I am not aware of the pain.

E. Medication can take my pain away completely.

F. My pain is because of work.

G. My pain is because of exercise.

FATIGUE

Is your tiredness the result of any of the following?

A. Too much work or exercise?

- 1. Yes
- 2. No
- 7. Refused
- 9. Don't know

B. Not getting enough sleep?

C. A physical or health-related problem?

D. Something else? (specify:) _____

Appendix 2
Question Set Comparison
(BI-Mark 1 / EHIS / BI-Mark 2 / Washington Group Short Set)

VISION		
BI - Mark 1 Question Set	EHIS Questions	BI – Mark 2 Question Set
<p>WG Short Set Question: Do you have difficulty seeing, even if wearing glasses? 1) No, no difficulty 2) Yes, some difficulty 3) Yes, a lot of difficulty 4) Cannot do at all</p>		
<p>VIS_1 [Do/Does] [you/he/she] wear glasses or contact lenses?</p> <p>1) Yes (<i>Mention aids when asking VIS-2 and VIS-3</i>) 2) No 3) Don't Know 4) Refused</p>	<p>PL.1 Do you wear glasses or contact lenses?</p> <p>1) Yes 2) No 3) I'm blind or cannot see at all</p>	<p>VIS_1 [Do/Does] [you/he/she] wear glasses?</p> <p>1) Yes 2) No 7) Don't Know 9) Refused</p>
<p>VIS_2 How much difficulty [do/does] [you/he/she] have in clearly seeing someone's face across a room? (<i>If VIS_1 = yes</i>) ... when using your glasses or contact lenses?</p> <p>1) No difficulty 2) A little difficulty 3) A lot of difficulty 4) Unable 5) Don't Know 6) Refused</p>	<p>Interviewer read: "Please answer the following questions according to your normal use of glasses or contact lenses".</p> <p>PL.3 Can you see the face of someone 4 metres away (across a road)?</p> <p>1) Yes, with no difficulty 2) With some difficulty 3) With a lot of difficulty 4) Not at all</p>	<p>VIS_2 [Do/Does] [you/he/she] have difficulty seeing [<i>if VIS_1 = 1: even when wearing your glasses</i>]? Would you say... [<i>Read response categories</i>]</p> <p>1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all/unable 7) Don't know 9) Refused</p>
<p>VIS_3 How much difficulty [do/does] [you/he/she] have clearly seeing printed text in a newspaper? (<i>If VIS_1 = yes</i>) ... when using your glasses or contact lenses?</p> <p>1) No difficulty 2) A little difficulty 3) A lot of difficulty 4) Unable 5) Don't Know 6) Refused</p>	<p>PL.2 Can you see newspaper print?</p> <p>1) Yes, with no difficulty 2) With some difficulty 3) With a lot of difficulty 4) Not at all</p>	

HEARING		
BI - Mark 1 Question Set	EHIS Questions	BI – Mark 2 Question Set
<p>WG Short Set Question: Do you have difficulty hearing, even if using a hearing aid? 1) No, no difficulty 2) Yes, some difficulty 3) Yes, a lot of difficulty 4) Cannot do at all</p>		
<p>HEAR_1 [Do/Does] [you/he/she] wear a hearing aid?</p> <p>1) Yes (<i>Mention aids when reading HEAR-2 and HEAR-3</i>) 2) No 3) Don't Know 4) Refused</p>	<p>PL.4 Do you wear a hearing aid?</p> <p>1) Yes 2) No 3) I am profoundly deaf</p>	<p>HEAR_1 [Do/Does] [you/he/she] use a hearing aid?</p> <p>1) Yes 2) No 7) Refused 9) Don't know</p>
<p>HEAR_2 How much difficulty [do/does] [you/he/she] have hearing what is said in a conversation with one other person in a noisy room where there are several other conversations going on? (<i>If HEAR_1 = yes</i>) ... when using your hearing aid?</p> <p>1) No difficulty (<i>skip to WALK_1</i>) 2) A little difficulty 3) A lot of difficulty 4) Unable 5) Don't Know 6) Refused</p>	<p>PL.5 Can you hear what is said in a conversation with several people?</p> <p>1) Yes, with no difficulty 2) With some difficulty 3) With a lot of difficulty</p>	<p>HEAR_2 [Do/Does] [you/he/she] have difficulty hearing, [<i>if HEAR_1 = 1: even when using a hearing aid(s)</i>]? Would you say... [<i>Read response categories</i>]</p> <p>1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all / Unable to do 7) Refused 9) Don't know</p>
<p>HEAR_3 How much difficulty [do/does] [you/he/she] have hearing what is said in a conversation with one other person in a quiet room (<i>If HEAR_1 = yes</i>) ... when using your hearing aid?</p> <p>1) No difficulty 2) A little difficulty 3) A lot of difficulty 4) Unable 5) Don't Know 6) Refused</p>	<p>NONE</p>	<p>HEAR_3 [Do/Does] [you/he/she] have difficulty hearing what is said in a conversation with one other person in a quiet room [<i>if HEAR_1 = 1: even when using your hearing aid(s)</i>]? Would you say... [<i>Read response categories</i>]</p> <p>1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all / Unable to do (<i>Skip to next section.</i>) 7) Refused 9) Don't know</p>
		<p>HEAR_4 [Do/Does] [you/he/she] have difficulty hearing what is said in a conversation with one other person in a noisier room [<i>if HEAR_1 = 1: even when using your hearing aid(s)</i>]? Would you say... [<i>Read response categories</i>]</p> <p>1) No difficulty</p>

		2) Some difficulty 3) A lot of difficulty 4) Cannot do at all / Unable to do 7) Refused 9) Don't know
--	--	---

MOBILITY

BI - Mark 1 Question Set	EHIS Questions	BI – Mark 2 Question Set
-------------------------------------	---------------------------	-------------------------------------

WG Short Set Question: Do you have difficulty walking or climbing steps?
 1) No, no difficulty 2) Yes, some difficulty 3) Yes, a lot of difficulty 4) Cannot do at all

<p>WALK_1 [Do/Does] [you/he/she] use any aids or equipment for walking or moving around?</p> <p>1) Yes (<i>Go WALK-1b</i>) 2) No (<i>Go to WALK -2</i>) 3) Don't Know (<i>Go to WALK -2</i>) 4) Refused (<i>Go to WALK -2</i>)</p>	<p>NONE</p>	<p>MOB_1 [Do/Does] [you/he/she] have difficulty walking or climbing steps? Would you say... [<i>Read response categories</i>]</p> <p>1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all / Unable to do 7) Refused 9) Don't know</p>
--	-------------	---

<p>WALK_1b Which of the following types of aids or equipment [do/does] [you/he/she] use?</p> <p>a. Cane or walking stick? 1. yes 2. no b. walker (or Zimmer frame)? 1. yes 2. no c. crutches? 1. yes 2. no d. wheelchair? 1. yes 2. no e. someone's assistance? 1. yes 2. no f. other (specify: _____)</p>	<p>NONE</p>	<p>MOB_2 Do you use any equipment or receive help for getting around?</p> <p>1) Yes 2) No (<i>Skip to MOB_4.</i>) 7) Refused (<i>Skip to MOB_4.</i>) 9) Don't know (<i>Skip to MOB_4.</i>)</p>
--	-------------	--

<p>WALK_2 How much difficulty [do/does] [you/he/she] have walking 500 metres on level ground that would be about _____ (<i>insert country-specific example</i>)? (<i>if yes to WALK_1</i>) ... without using [your/his/her] _____ [<i>mention the aid from WALK_1b</i>]?</p> <p>1) No difficulty (<i>skip to WALK_4</i>) 2) A little difficulty 3) A lot of difficulty 4) Unable 5) Don't Know 6) Refused</p>	<p>PL.6 Can you walk 500 metres on a flat terrain without a stick or other walking aid or assistance?</p> <p>1) Yes, with no difficulty 2) With some difficulty 3) With a lot of difficulty 4) Not at all</p>	<p>MOB_3 Do you use any of the following? [<i>Interviewer: Read the following list and record all affirmative responses:</i>]</p> <p>A. Cane or walking stick? B. Walker? C. Crutches? D. Wheelchair? E. Artificial limb (leg/foot)? F. Someone's assistance? G. Other (please specify: _____)</p> <p>1. Yes 2. No [For each A-G]</p>
---	---	--

<p>WALK_3 How much difficulty [do/does] [you/he/she] have walking 100 metres on level ground that would be about _____ (<i>insert country-specific example</i>)? (<i>if yes to WALK_1</i>) ... without</p>	<p>NONE</p>	<p>MOB_4 [Do/Does] [you/he/she] have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the</p>
---	-------------	--

<p>using [your/his/her] _____ [<i>mention the aid from WALK_1b</i>]?</p> <p>1) No difficulty 2) A little difficulty 3) A lot of difficulty 4) Unable 5) Don't Know 6) Refused</p>		<p>use of your aid]? Would you say... [<i>Read response categories</i>]</p> <p>1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all / Unable to do (<i>Skip to MOB_6.</i>) 7) Refused 9) Don't know</p> <p><i>NOTE: Allow national equivalents for 100 metres.</i></p>
<p>WALK_4 How much difficulty [do/does] [you/he/she] have walking up and down a flight of stairs, (<i>if yes to WALK_1</i>) without using [your/his/her] [your/his/her] _____ [<i>mention the aid from WALK_1b</i>]?</p> <p>1) No difficulty 2) A little difficulty 3) A lot of difficulty 4) Unable</p>	<p>PL.7 Can you walk up and down a flight of stairs without a stick, other walking aid, assistance or using the banister?</p> <p>Yes, with no difficulty With some difficulty With a lot of difficulty not at all</p>	<p>MOB_5 [Do/Does] [you/he/she] 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]? Would you say... [<i>Read response categories</i>]</p> <p>1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all / Unable to do 7) Refused 9) Don't know</p> <p><i>NOTE: Allow national equivalents for 500 metres.</i></p>
		<p>MOB_6 [Do/Does] [you/he/she] have difficulty walking up or down 12 steps? Would you say... [<i>Read response categories</i>]</p> <p>1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all/unable to do 7) Refused 9) Don't know</p>

PAIN		
BI - Mark 1 Question Set	EHIS Questions	BI – Mark 2 Question Set
WG Short Set Question: None		
<p>PAIN_1 Overall, during the past week, how much physical pain or physical discomfort did you have?</p> <p>1) None at all 2) A little 3) Moderate 4) A lot 5) Extreme 6) Don't Know 7) Refused</p>	<p>SF.1 Overall during the past four weeks, how much physical pain or physical discomfort did you have?</p> <p>1) None 2) Mild 3) Moderate 4) Severe 5) Extreme</p>	<p><i>NOTE: Proxy respondents may be omitted from this section at country's discretion.</i></p> <p><i>Interviewer: If respondent asks whether they are to answer about their pain when taking their medications, say: "Please answer according to whatever medication you were taking."</i></p> <p>PAIN_1 In the past 3 months, how often did [you/he/she] have pain? Would you say...[Read response categories]</p> <p>1) Never (If "Never" to PAIN_1, skip to next section.) 2) Some days 3) Most days 4) Every day 7) Refused 9) Don't know</p>
		<p>PAIN_2 Thinking about the last time [you/he/she] had pain, how much pain did [you/he/she] have? Would you say...[Read response categories]</p> <p>1) A little 2) A lot 3) Somewhere in between a little and a lot 7) Refused 9) Don't know</p>

FATIGUE		
BI - Mark 1 Question Set	EHIS Questions	BI – Mark 2 Question Set
WG Short Set Question: None		
<p>The following question was tested prior to the BI-M1, however it was not accepted for inclusion in the BI-M1:</p> <p>Overall during the past four weeks, how much of a problem did you have with feeling tired or fatigued?</p>	NONE	<p><i>NOTE: Proxy respondents may be omitted from this section at country's discretion.</i></p> <p>TIRED_1 In the past 3 months, how often did [you/he/she] feel very tired or exhausted? Would you say...<i>[Read response categories]</i></p> <p>1) Never <i>(If "Never" to TIRED_1, skip to next section.)</i> 2) Some days 3) Most days 4) Every day 7) Refused 9) Don't know</p>
		<p>TIRED_2 Thinking about the last time [you/he/she] felt very tired or exhausted, how long did it last? Would you say...<i>[Read response categories]</i></p> <p>1) Some of the day 2) Most of the day 3) All of the day 7) Refused 9) Don't know</p>
		<p>TIRED_3 Thinking about the last time [you/he/she] felt this way, how would you describe the level of tiredness? Would you say...<i>[Read response categories]</i></p> <p>1) A little 2) A lot 3) Somewhere in between a little and a lot 7) Refused 9) Don't know</p>

COGNITION		
BI - Mark 1 Question Set	EHIS Questions	BI – Mark 2 Question Set
WG Short Set Question: Do you have difficulty remembering or concentrating? 1) No, no difficulty 2) Yes, some difficulty 3) Yes, a lot of difficulty 4) Cannot do at all		
COG_1 How much difficulty [do/does] you have remembering important things? 1) No difficulty 2) A little difficulty 3) A lot of difficulty 4) Unable 5) Don't Know 6) Refused	NONE	COG_1 [Do/does] [you/he/she] have difficulty remembering or concentrating? Would you say...[Read response categories] 1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all/Unable to do 7) Refused 9) Don't know

AFFECT (ANXIETY AND DEPRESSION)		
BI - Mark 1 Question Set	EHIS Questions	BI – Mark 2 Question Set
WG Short Set Question: None		
AFF_1 Overall, during the past week, how worried, nervous, or anxious did you [he/she] feel? 1) Not at all 2) Slightly 3) Moderately 4) A lot 5) Extremely 6) Don't Know 7) Refused	NONE	<i>NOTE: Proxy respondents may be omitted from this section at country's discretion.</i> <i>Interviewer: If respondent asks whether they are to answer about their emotional states after taking mood-regulating medications, say: "Please answer according to whatever medication you were taking."</i> ANX_1 How often [do/does] [you/he/she] feel worried, nervous or anxious? Would you say...[Read response categories] 1) Daily 2) Weekly 3) Monthly 4) A few times a year 5) Never 7) Refused 9) Don't know

<p>AFF_2 Overall, during the past week, how sad, low, or depressed did you [he/she] feel?</p> <p>1) Not at all 2) Slightly 3) Moderately 4) A lot 5) Extremely 6) Don't Know 7) Refused</p>		<p>ANX_2 [Do/does] [you/he/she] take medication for these feelings?</p> <p>1) Yes 2) No (<i>If "Never" to ANX_1 and "No" to ANX_2, skip to DEP_1.</i>) 7) Refused 9) Don't know</p>
		<p>ANX_3 Thinking about the last time [you/he/she] felt worried, nervous or anxious, how would [you/he/she] describe the level of these feelings? Would you say...<i>[Read response categories]</i></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>NONE</p>	<p>DEP_1 How often do [you/he/she] feel depressed? Would you say...<i>[Read response categories]</i></p> <p>1) Daily 2) Weekly 3) Monthly 4) A few times a year 5) Never 7) Refused 9) Don't know</p>
		<p>DEP_2 [Do/does] [you/he/she] take medication for depression?</p> <p>1) Yes 2) No (<i>If "Never" to DEP_1 and "No" to DEP_2, skip to next section.</i>) 7) Refused 9) Don't know</p>
		<p>DEP_3 Thinking about the last time [you/he/she] felt depressed, how depressed did you feel? Would you say...<i>[Read response categories]</i></p> <p>1) A little 2) A lot 3) Somewhere in between a little</p>

		and a lot 7) Refused 9) Don't know
--	--	--

COMMUNICATION

NOTE: Communication questions were not originally included in the BI-M1 set. This domain has been adopted for inclusion by the Budapest Initiative Task Force members at the 3-5 November 2010 meeting. This section may be omitted, at country's discretion.

BI - Mark 1 Question Set	EHIS Questions	BI – Mark 2 Question Set
<p>WG Short Set Question: Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood? 1) No, no difficulty 2) Yes, some difficulty 3) Yes, a lot of difficulty 4) Cannot do at all</p>		
		<p>COM_1 Using [your/his/her] usual (customary) language, do [you/he/she] have difficulty communicating, for example understanding or being understood?</p> <p>1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all / Unable to do 7) Refused 9) Don't know</p>

UPPER BODY

NOTE: Upper Body questions were not originally included in the BI-M1 set. This domain has been adopted for inclusion by the Budapest Initiative Task Force members at the 3-5 November 2010 meeting. This section may be omitted, at country's discretion.

BI - Mark 1 Question Set	EHIS Questions	BI – Mark 2 Question Set
WG Short Set Question: None		
		<p>UB_1 [Do/Does] [you/he/she] have difficulty raising a 2 liter bottle of water or soda from waist to eye level? Would you say... [<i>Read response categories</i>]</p> <p>1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all / Unable to do 7) Refused 9) Don't know</p>
		<p>UB_2 [Do/Does] [you/he/she] have difficulty using [your/his/her] hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles? Would you say... [<i>Read response categories</i>]</p> <p>1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all / Unable to do 7) Refused 9) Don't know</p>

* * * * *