In Pursuit of Internationally Comparable Measures of Health: Traveling with the Washington Group and Budapest Initiative

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Measuring health, functioning and disability
for international comparisons…

The Situation:
- Absence of internationally comparable measures
- Complexity of measuring health and disability
- No agreed upon definition or set of core measures
- No standards for producing the data

The Solution:
- A mechanism to identify the appropriate framework, define a set of core measures and identify ways of obtaining the needed data within the auspices of national statistical offices and international organizations – *The Washington Group, the Budapest Initiative, the ISWG-HS.*

The Washington Group on Disability Statistics (WG): Initial Objectives

- To guide the development of a small set of general disability measures suitable for censuses,

- To recommend one or more extended sets of items to measure disability in population surveys or supplements,

- To use the ICF model as a framework to assist in the development of the measures, and

- To address methodological issues associated with disability measurement.

The WG: 10 Years and Counting

- The WG has held 10 meetings to date in all regions of the world
  - Washington DC, Ottawa, Brussels, Bangkok, Rio de Janeiro, Kampala, Dublin, Manila, Dar el Salaam, Luxembourg
- NSO representatives from 116 countries have participated
- Current members include 109 NSOs, 7 international organizations, 6 DPOs, the UNSD and other U.N. affiliates
- Held two regional workshops: Africa and Latin America
- Participated in five other regional workshops
- Conducted cognitive testing of the short set questions in 15 countries, and the extended set in 15 countries
- On-going provision of technical assistance, methodological training and fostering of international cooperation

The Budapest Initiative (BI)

- May 2004: the Joint UNECE/WHO/Eurostat Meeting on the Measurement of Health Status
- October 2004: Steering Group and Task Force established by the Conference of European Statisticians
- Consensus reached:
  - A number of classes of measures are needed for full picture of population health
  - Focus on internationally accepted standard set of questions for assessing health state using modern sample surveys

The BI: Objectives

- The goal - to achieve internationally comparable measurement of population health states within the framework of official statistics.

- Focus <u>not</u> on providing a full statistical picture of population health, its determinants, and consequences.

- Focus is on the development of common instruments to measure health state in its multiple dimensions.
  - Health State is defined as functional ability across a range of domains.

WG-BI Similarities

Substantive overlap / Differing perspectives:
- Question domains include the same basic and complex activities
- Disability includes interaction with environment and civil rights perspective

Requirements for question sets:
- Minimize burden on national data collection
  - Parsimony in the number of indicators and measures; domains are succinct, clearly defined
  - Reasonable expectation of high quality responses from samples of the general public, demonstrated validity of measures
- International comparability, relevant at national and international level
  - Focus on aspects of health that are more likely to produce comparable data
  - Need for cross national cognitive and field testing
  - Questions must be simple, clear, easily translated into many languages
  - Amenable to multi-modes of collection

The WG Conceptual Model

The International Classification of Functioning, Disability and Health (ICF) selected as the conceptual model:

- Common point of reference
- Common vocabulary
- Highlights the environment, the physical, social and attitudinal context of disability
- Includes both activity and participation domains
- Does *not* provide an *operational* definition or a way to *measure* the concepts

Moved away from a medical definition, based on individual pathology/cause/condition, *towards* a concept based on the consequences of disease for *functional capacity* and *social participation*.
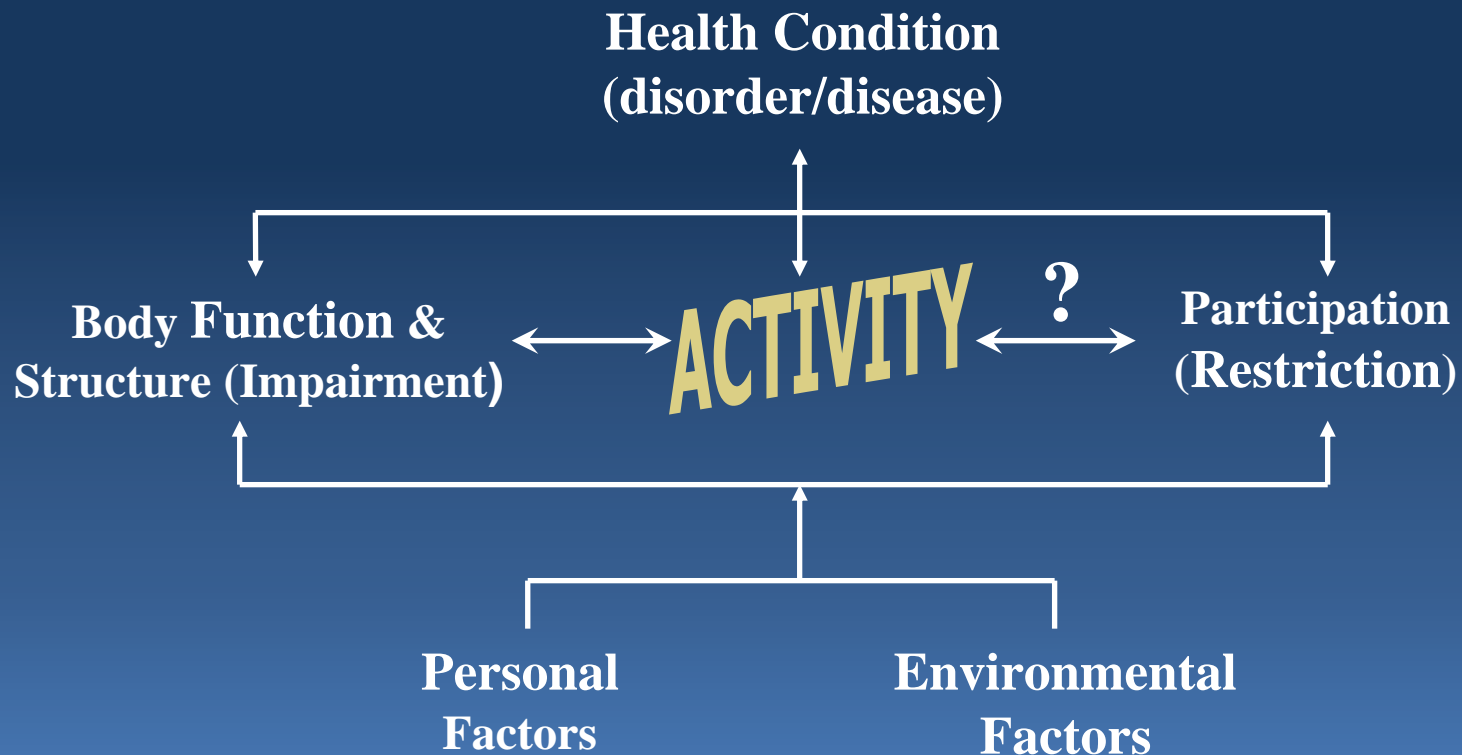
Moving from *Concept* to *Operational Definition*

The Definitional Paradox

- There is no single *operational* definition of disability.
- Different operational definitions lead to different estimates.
- The question you are trying to answer (**the purpose**) will determine which definition to use .
- Need to *understand the choices* that are being made when choosing a definition.

Decision: 'Equalization of Opportunity'

Locating Risk in the ICF Model

Health Condition (disorder/disease)

Body Function & Structure (Impairment) ← → ACTIVITY ← **?** → **Participation (Restriction)**

Personal Factors   **Environmental Factors**

WG Purpose:
Equalization of Opportunities

Seeks to identify all those *at greater risk* than the general population for limitations in participation.

Disability used as a *demographic*.

Employed (%)

Proportion (%)

90

60

30

0

Nondisabled   Disabled
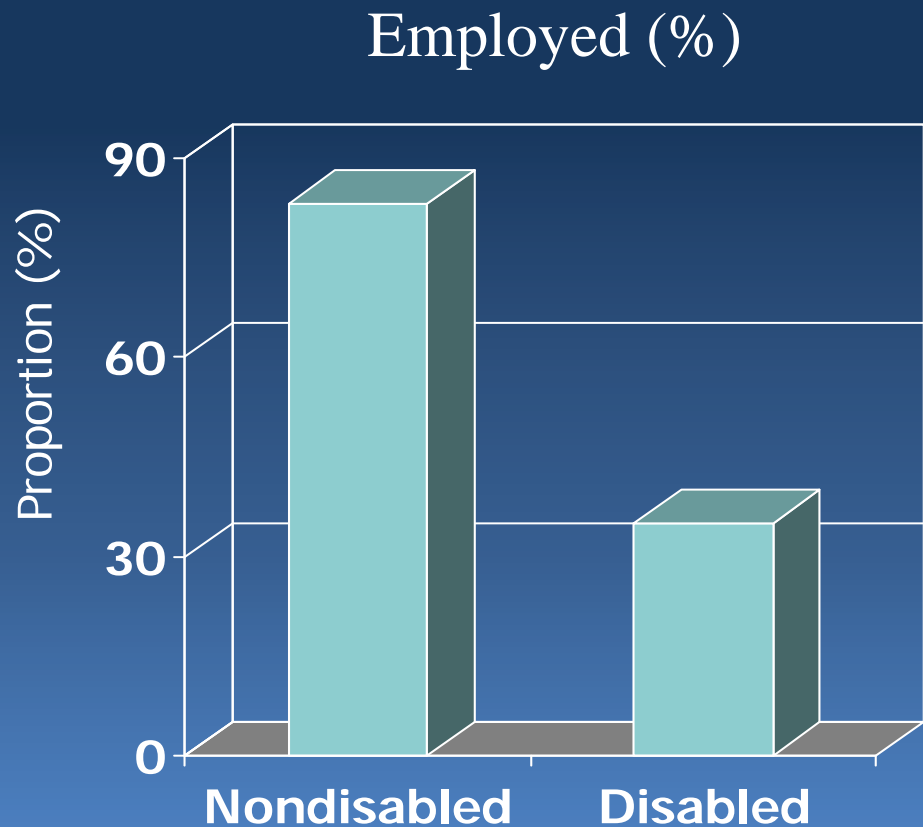
Possible Domains and Activities

Mobility
- Walking
- Climbing stairs
- Bending or stooping
- Reaching or lifting
- Using hands

Sensory
- Seeing
- Hearing

Communicating
- Understanding
- Speaking

Cognitive functions
- Learning
- Remembering
- Making decisions
- Concentrating

Emotional functioning
- Interpersonal interactions
- Psychological well-being

Other
- Affect
- Pain
- Fatigue
- Self care

WG Disability Short Set

1-5. How much difficulty do you have:

- seeing even if wearing glasses?
- hearing even if using a hearing aid?
- remembering or concentrating?
- walking or climbing stairs?
- with self-care, such as washing all over or dressing?

6.   Because of a physical, mental or health condition, how much difficulty do you have communicating, for example understanding or being understood by others?

a) No, no difficulty
b) Yes – some difficulty

c) Yes – a lot of difficulty
d) Cannot do at all

The WG Short Set To Date

Adopted in 2006 by the WG as an outcome of the 6th meeting held in Kampala, Uganda.

UN Principles and Recommendations for Population and Housing Censuses (2006) incorporates the approach taken by WG. (See: Section VI-8: Disability Characteristics pages 178-183, and Tabulations on Disability Characteristics pages 292-294; available online at: *http://unstats.un.org/unsd/demographic/sources/census/docs/P& R_Rev2.pdf*).

Incorporated into censuses throughout the world: Aruba, Bangladesh, China, Czech Republic, Fiji, Israel, Ivory Coast, Kazakhstan, Mexico, Mozambique, Netherlands, Oman, Palestine, Paraguay, Peru, Philippines, Poland, Rwanda, South Africa (2011), Sri Lanka, Uganda, Zimbabwe, with others planned…
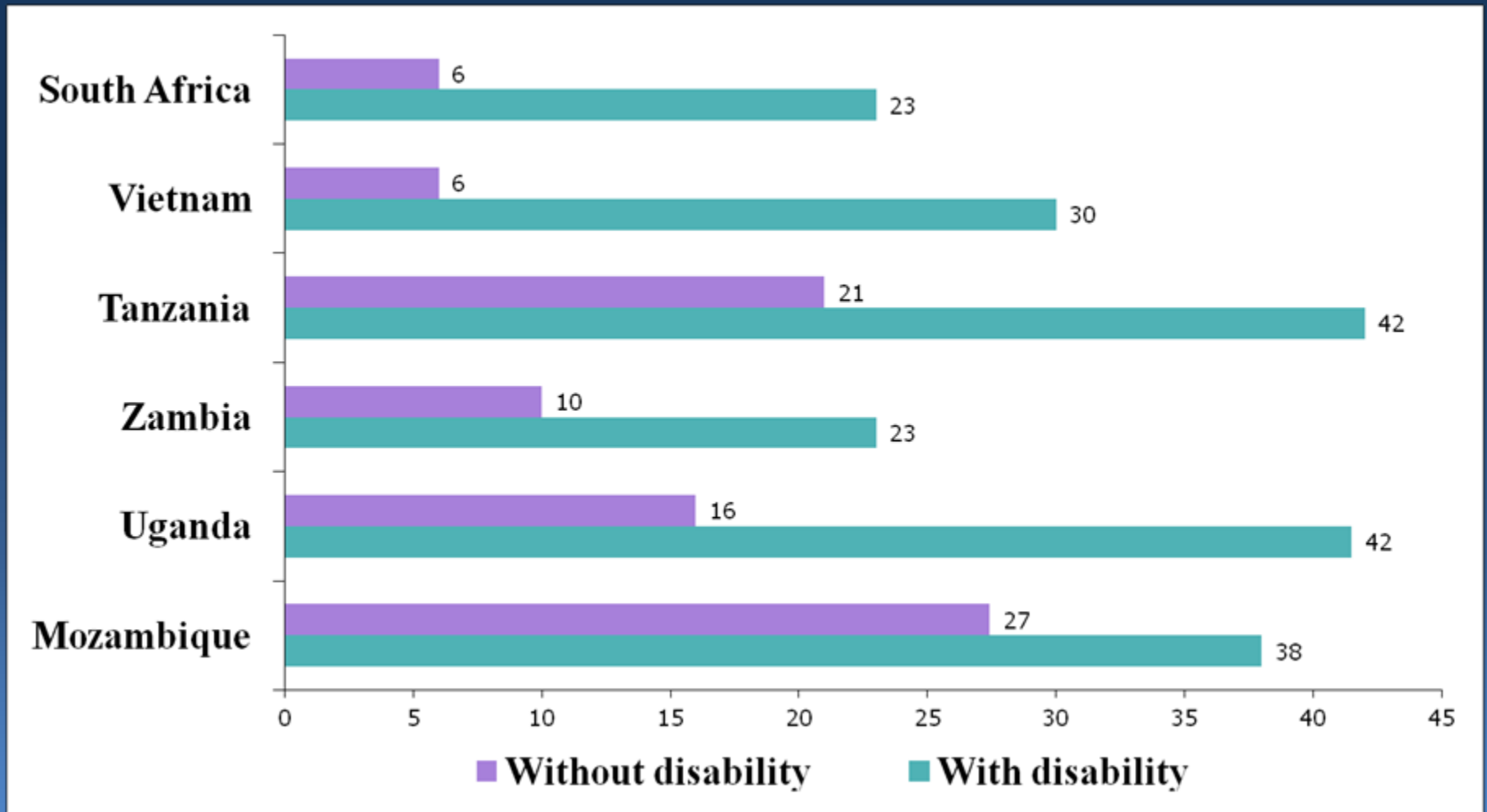
Using the WG Short Set to Monitor the UN Convention

UN Convention on the Rights of Persons with Disabilities (adopted Dec 2006, ratified May 2008): promote, protect and ensure the full enjoyment of human rights by persons with disabilities and ensure full equality under the law.

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;

Data 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.

Population Never Attending School, by Disability Status
(15 years of age and over)

Country	Without disability	With disability
South Africa	6	23
Vietnam	6	30
Tanzania	21	42
Zambia	10	23
Uganda	16	42
Mozambique	27	38

NOTE: Data are from national surveys collected between 2006 and 2008.

Extended Question Sets: The Next WG Product

Having successfully developed and tested the short set of questions for censuses, the WG moved on to extended sets.

A modular approach:
- Taken together will form a disability survey
- Modules can be used individually or grouped to meet the needs of the data collection
- Joint WG/BI question development

Work on Extended Measures

- Expands the number of domains covered, such as learning, affect, pain and fatigue (joint with BI).

- Goes into greater detail on the same 6 domains covered by the short set of questions (joint with BI) and adds topics age at onset and impact of the difficulty.

- Begins to construct the links between functioning in core domains without accommodation, functioning with accommodation, environment and participation.

- Initial sets have been cognitively and field tested— joint WB/BI question sets approved at joint Luxembourg meeting (2010).

Washington Group/Budapest Initiative/UNESCAP Activities and Workplan

Row	Questionnaire Topic/Type	Basic Activity Domains										Complex Activity Domains			
		Vision (1)	Hearing (1)	Mobility	Communi-cation	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			
Capacity	Extended Set Multiple Questions (1)					c			c	c	c	b			
Performance	Use of Assistive Devices Micro-E (2)											b			
Performance	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

The Next Sets

Continue development of questions on functioning in core domains

Develop extended sets of questions on the environment and child/youth functioning are in development.
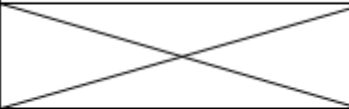
- Will be presented at the annual meeting of the WG in Bermuda in November 2011.

- A plan for further development and testing will also be presented.

Budapest Initiative: Health State

- Health State is defined as functional ability across a range of domains.
  - Functioning is a critical aspect of health.
  - Higher probability of being able to measure in an internationally comparable way.
- Overlaps WG extended sets

Budapest Initiative: Health State

- Health State measures functional ability as opposed to other aspects of health:
    - Determinants and risk factors
    - Disease states
    - Use of health care
    - Environment barriers and facilitators

- Functioning is measured in terms of 'capacity' not 'performance'
    - 'Within the skin'
    - Without the use of aids in a reasonable environment

Row	Questionnaire Topic/Type	Basic activity domain
		Anxiety
Capacity	Short Set Single Questions	(crossed out)
Capacity	**Extended Set Multiple Questions**	
Performance	**Use of Assistive Devices**	
Performance	Functioning with Assistance, Micro-E	
5	Age at Onset	
6	Cause	
7	Duration	
8	Impact	
9	Meso-Environment	
10	Macro-Environment	
	ICF Chapter Reference -	ICF-2

	Basic activity domains
Question topic	**Anxiety**
Use of AD/Micro-Environment	Do you take medication for these feelings?

Functioning: Extended questions	How often do you feel worried, nervous or anxious?
	    Daily, Weekly, Monthly, A few times a year, Never
	
	Thinking about the last time you felt worried, nervous or anxious,
	    how would you describe the level of these feelings?
	        A little, A lot, Somewhere in between a little and a lot
	            Would you say this was closer to a little, closer to a lot, or exactly in
	            the middle?

Probe:	Please tell me which of the following statements, if any, describe your feelings. 1. My feelings are caused by the type and amount of work I do. 2. Sometimes the feelings can be so intense that my chest hurts and I have trouble breathing. 3. These are positive feelings that help me to accomplish goals and be productive. 4. The feelings sometimes interfere with my life, and I wish that I did not have them. 5. If I had more money or a better job, I would not have these feelings. 6. Everybody has these feelings; they are a part of life and are normal. 7. I have been told by a medical professional that I have anxiety.

Anxiety Severity

		How often do you feel worried, nervous or anxious?				
		A few times a year	Monthly	Weekly	Daily	Total
Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?	A little	**1087**	**423**	**328**	**214**	**2052**
	In between	**179**	**126**	**161**	**104**	**570**
	A lot	**163**	**86**	**122**	**259**	**630**
	Total	**1429**	**635**	**611**	**577**	**3252**

Anxiety
Significant relationships with respondent location

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 yellow text. Positive associations shown in white text. **p<.05,*** p<.005				

Based on bivariate logistic regression models in each cell. Models run for cases NOT taking medication.

Final 7 Domains for BI Questions

- Vision
- Hearing
- Walking
- Cognition
- Affect
- Pain
- Fatigue

BI Health State Question Set

1. Do you wear glasses?
2. Do you have difficulty seeing, even when wearing glasses?

3. Do you use a hearing aid?
4. Do you have difficulty hearing even when using a hearing aid?
5. Do you have difficulty hearing what is said in a conversation with one other person in a quiet room?
6. Do you have difficulty hearing what is said in a conversation with one other person in a noisier room?

7. Do you have difficulty walking or climbing steps?
8. Do you use any equipment or receive help for getting around?
9. Do you use any of the following [list of aids]?
10. Do you have difficulty walking 100 meters on level ground?
11. Do you have difficulty walking half a km on level ground?
12. Do you have difficulty walking up or down 12 steps?

BI Health State Question Set

13. Do you have difficulty remembering or concentrating?

14. How often do you feel worried, nervous or anxious?
15. Do you take medication fro these feelings?
16. Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?

17. How often do you feel depressed?
18. Do you take medication for depression?
19. Thinking about the last time you felt depressed, how depressed did you feel?

BI Health State Question Set

20. In the past 3 months, how often did you have pain?
21. Thinking about the last time you had pain, how much pain did you have?

22. In the past 3 months, how often did you feel very tired or exhausted?
23. Thinking about the last time you felt very tired or exhausted, how long did it last?
24. Thinking about the last time you felt this way, how long did it last?

WG and BI Testing Protocol: Objectives

- Cross-cultural comparability
  - Do the survey questions work consistently across all countries and subgroups?
- Translation comparability
  - Do terms (both in the question and in the response set) have the same meaning across countries?
- Content Validity
  - Do respondents interpret questions consistently regardless of country, language, or demographic?
- Item reliability
  - Do respondents use the same thought processes to answer questions?
    - If not, then, why are there differences? What about the countries, languages or demographic subgroups generate different response processes?
    - How can we "fix" or manage these differences through question design?

WG and BI Testing Protocol: Methods

Purpose: To develop systematic comparable testing and analysis method.

- Joint and coordinated interviewing
  - Similar protocol
  - Similar sample
  - Understanding of differences (at a minimum)
- Joint and coordinated analysis
  - With interview data
  - Evidence based (as opposed to opinion)

WG and BI Testing Protocol: Lessons Learned

- Semi-structured cognitive interviews offers critical and unique insight into cross-national question performance
- Transparency is critical:
  - of data from interviews
  - of the process for drawing conclusions
- Data collection oversight
- Better data management

Standardized Testing Conducted

WG Testing To Date:

- 15 countries participating (13 funded via World Bank grant, 2 self-funded)
- Cognitive tests in 12 countries (Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Philippines, Uganda, Mexico, Tanzania, Vietnam)
- Field tests in 2 countries (Gambia, Vietnam)
- Combined cognitive/field test in 3 countries (Argentina, Brazil, Paraguay)

BI Testing: 2006; 7 domains

- 4 countries, 3 languages: Australia, Canada, Italy, U.S.
- Outcome: BI-M1 question set, submitted to Eurostat

BI Testing: 2007; 6 domains (not vision)

- BI-ESS collaborative test (7 countries, 6 languages): Bulgaria, Germany, Portugal, Spain, Switzerland, U.K, U.S.
- Improvements: Evidence-based methodology & systematic comparative analysis of patterns
- Analysis meeting in U.S. February 2008, all participants

Standardized Testing Conducted

WG/BI/UNESCAP Testing 2009:

- **Cognitive tests in 9 countries** (Canada, Fiji, Germany, Maldives, Sri Lanka, Philippines, Cambodia, United States, Vietnam)

- **Field tests in 6 countries** (Mongolia, Maldives, Sri Lanka, Philippines, Cambodia, Vietnam)

WG/BI European Testing 2010:

- **Cognitive tests in 7 countries** (France, Germany, Italy, Portugal, Spain, Switzerland, United States)

Q-Notes

- On-line data entry and analysis tool
  - Allows for continuous oversight
  - Facilitates quick but thorough analysis
- Designed around analysis principles

Summary Measures

- BI questions developed so that it will be possible to create summary measures, however creating the summary measures was not an Initiative objective.

- Efforts made to obtain variability in each domain.

- Methods need to be developed to combine information on all domains into a summary measure of health state.

Inter-Secretariat Working Group on Health Statistics

- October 2005 – meeting convened by WHO, with the UNSD, to 1) develop a coordinated and integrated agenda for the production of health statistics, and 2) agree on standard definitions, classifications, and methodologies in health statistics.

- The ISWG-HS has become a platform to share key international developments in health statistics, and to develop recommendations to the UNSC and all UN agencies.

- The ISWG-HS created a Framework on Health Statistics that has been submitted to the UN Statistical Commission.

Framework for Health Statistics: Objectives

- Clarify the content and hierarchical nature of health measures.

- Highlight the pressing need for general measures of population health.

- Identify an overall, coherent set of data collection systems.

- Identify areas where innovative approaches are needed.

- Institutionalize partnerships among the national statistical offices, ministries of health, and other constituencies within countries.

Thank You