The Budapest Initiative*: Measuring Population Health Status in Surveys and Censuses

* The Joint UNECE/WHO/Eurostat Task Force on Measurement of Health Status

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Measuring health status
for international comparisons…

The Situation:
- Absence of internationally comparable measure
- Life expectancy does not reflect the health of the living
- Complexity of measuring health
- No agreed upon a set of core health measures or standards for producing the data

The Solution:
- A mechanism to define a set of core measures and identify ways of obtaining the needed data within the framework of national official statistics

The Budapest Initiative: Summary of the Work to Date

- May 2004 (Geneva)
  - Joint UNECE/WHO/Eurostat Meeting on the Measurement of Health Status
  - Recommended creation of a Task Force (TF): The Joint UNECE/WHO/Eurostat Task Force on Measuring Health Status
- October 2004 (Geneva)
  - The Conference of European Statisticians approves the TF
- November 2005 (Budapest)
  - First meeting of the TF, now also called The Budapest Initiative (BI)
- January 2007 (Geneva)
  - Second TF meeting
  - Review first round of cognitive testing
  - Agreement on content for BI-M1
  - Questionnaire subsequently provided to EC/Eurostat

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Consensus reached in Geneva, 2005:

- A number of classes of measures are needed to provide a full statistical picture of population health

- Focus on the development of an internationally accepted standard set of questions for assessing <u>health state</u> using modern sample surveys
  - The measures could be used to develop a core set of health indicators for use at the local, national and international levels

- Coordinate with existing activities, e.g., EHIS

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Requirements for question set:

- 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
- Relevant at national and international level
- Demonstrated validity of measures

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Requirements for question set (continued):

- International Comparability
  - Criteria for selecting items included 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 and clear, and easily translated into many languages
  - Amenable to multi-modes of collection

Why Health State?
What is Health State?

Why:

- To satisfy the requirements of the question set.
- Need to focus on one aspect of health.

What:

- 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
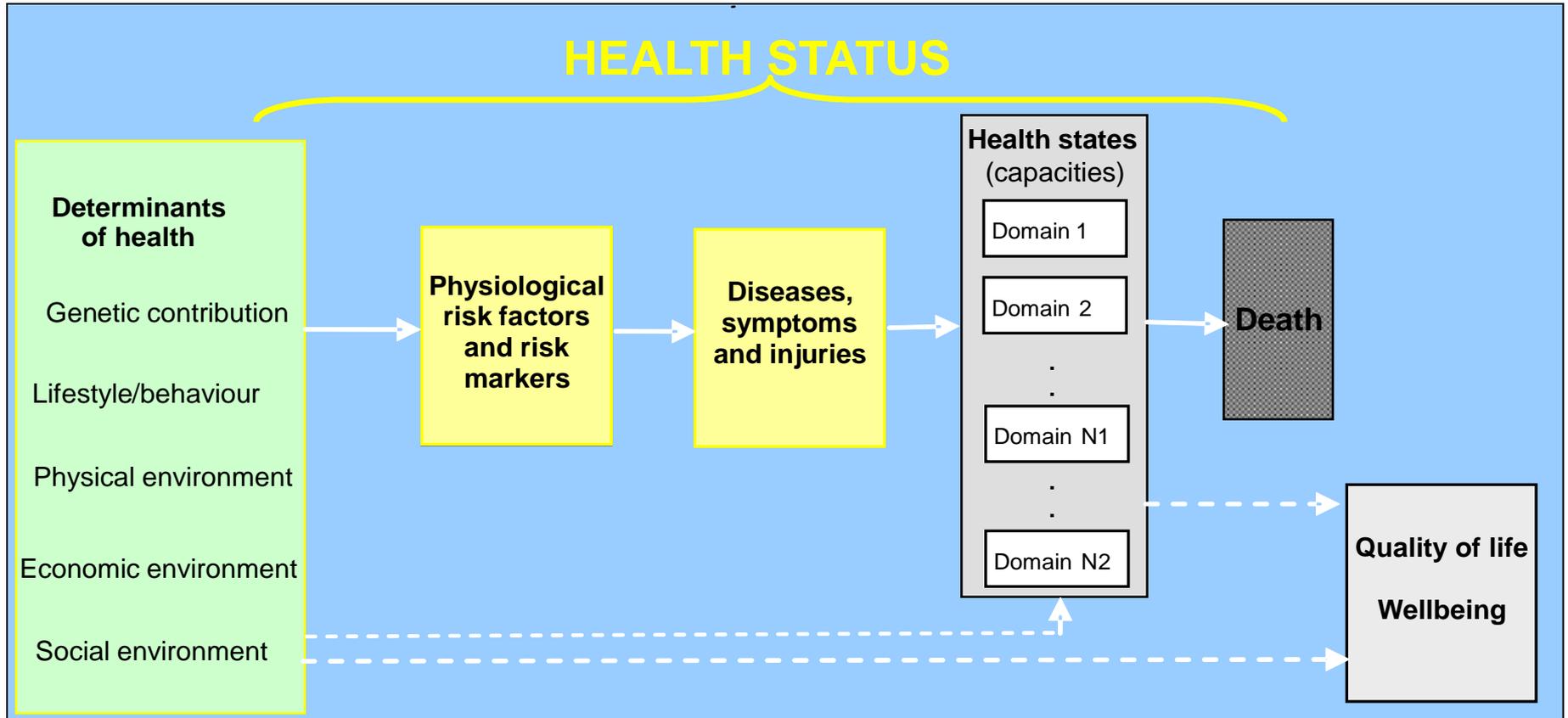
What is Health State?

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

Health Status and Health States

Health State: an individual's levels of functioning within a set of health domains.

BI Tasks

- Determine criteria for selection of domains
- Identify domains
- Determine criteria for selection of items
- Identify or develop items
- Test question set

Final List of Recommended Domains

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

Conceptual and Logistic Issues for Item Construction

- Number of questions per domain
- Duration of the recall period
- Dealing with assistive devices and medications
- Item wording and response categories
  - Positive vs. negative wording
  - 4- vs. 5-category response sets
- Summary/preference health measures

The BI-M1 Question Set: Vision

- Do you wear glasses or contact lenses?

- How much difficulty do you have in clearly seeing someone's face across a room? [when using your glasses or contact lenses?]

- How much difficulty do you have clearly seeing printed text in a newspaper? [when using your glasses or contact lenses?]

  - No difficulty
  - A little difficulty
  - A lot of difficulty
  - Unable

The BI-M1 Question Set: Hearing

- Do you wear a hearing aid?

- How much difficulty do you have hearing what is said in a conversation with one other person in a noisy room where there are several other conversations going on? [when using your hearing aid?]

- How much difficulty do you have hearing what is said in a conversation with one other person in a quiet room? [when using your hearing aid?]

  - No difficulty
  - A little difficulty
  - A lot of difficulty
  - Unable

The BI-M1 Question Set: Walking

- Do you use any aids or equipment for walking or moving around?

- Which of the following types of equipment or aids do you use?

  - Cane or walking stick
  - Walker
  - Crutches
  - Wheelchair
  - Someone's assistance
  - Other (*specify*)

The BI-M1 Question Set: Walking, continued

- How much difficulty do you have walking 500 metres on level ground, that would be about *(insert country-specific example)*? [without using your aid(s)?

- How much difficulty do you have walking 100 metres on level ground, that would be about *(insert country-specific example)*? [without using your aid(s)?]

- How much difficulty do you have walking up and down a flight of stairs? [without using your ?]

    - No difficulty
    - A little difficulty
    - A lot of difficulty
    - Unable

The BI-M1 Question Set: Pain

- Overall, during the past week, how much physical pain or physical discomfort did you have?

  - None at all
  - A little
  - Moderate
  - A lot
  - Extreme

The BI-M1 Question Set: Cognition

- How much difficulty do you have remembering important things?

    - No difficulty
    - A little difficulty
    - A lot of difficulty
    - Unable

The BI-M1 Question Set: Affect

- Overall, during the past week, how worried, nervous, or anxious did you feel?

    Note: Translators should use culturally appropriate terms to convey the spectrum of mood. Note that 'nervous' may have special meaning in English that will have to be interpreted carefully in other languages.

- Overall, during the past week, how sad, low, or depressed did you feel?

    Note: Translators should use culturally appropriate terms to convey the spectrum of mood.

    - Not at all
    - Slightly
    - Moderately
    - A lot
    - Extremely

Testing Challenges

- How to determine success
  - In national context
  - But especially in international context
- Countries have own methods for conducting and documenting cognitive tests
- In order to combine results across sites, needed a structured test protocol
- Many of questions had been tested before
  - Focus on cross-national comparability
  - Specific issues to be addressed

Testing Challenges

- Analysis of test results need to be coordinated
  - Systematic analysis plan for all sites
  - Systematic way to record and summarize data
- Goal is transparency in all aspects of the test
  - Especially in transforming test data into evidence

BI Accomplishments To Date

- Developed a cognitive test protocol to evaluate questions

- Evaluated the results of tests conducted in 4 member countries

- Finalized and adopted the survey module: BI-M1

- Provided BI-M1 to EC/Eurostat for use in the EHIS

Next Steps…

- Develop BI-M2 question set
    - Revised questions for domains not included in BI-M1
    - Investigate of impact of different number of response categories
    - Investigate alternative question structure
- Finalize second round testing protocol for the BI-M2
- Conduct second round testing (via CSDI)
- Full cognitive testing reports completed