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Report of the work session of the Budapest Initiative on measuring health status (Geneva, 20-22 January 2010)

Note by the Secretariat

Summary

The Conference of European Statisticians' work programme 2010 includes organisation of the Budapest Initiative on measuring health status, which was held in Geneva, 20-22 January 2010 (see ECE/CES/2009/2/Add.1). Conference of European Statisticians' (CES) work on health statistics is directed towards developing common core measures of health status to guarantee international comparability and to reach a consensus on the concept, measurement and reporting of health status. Against this background, the Joint UNECE/WHO/Eurostat Steering Group and Task Force on Measuring Health Status, also known as the Budapest Initiative (BI), were established to develop a new common instrument to measure health status in its multiple dimensions which would be included in population surveys as a recommended set of questions.

The outcomes of the January 2010 meeting include a broad agreement on the questions to be adopted/revised based on cognitive/field tests results and a workplan for finalising the BI-Mark 2 question set.

I. Attendance

1. The work session of the Budapest Initiative (BI) on Measuring Health Status was held on 20-22 January 2010 in Geneva. It was attended by participants from Australia, Austria, Canada, Czech Republic, Denmark, Hungary, Israel, Italy, Poland, Russian Federation, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, United Kingdom and United States of America. Eurostat, World Health Organisation, United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), and Washington Group (WG) were also represented. The meeting was also attended by a representative from the Robert Koch Institute of Germany and an observer from the Catholic University of Milan.

2. Ms Jennifer Madans (USA), Chair of the BI Steering Group and Task Force, was elected as Chair of the meeting.

II. Organization of the meeting

3. At the opening session of the meeting welcoming remarks were delivered by UNECE, Eurostat and WHO. The Chair reviewed the objectives of the meeting and the agenda.

4. The following substantive topics were discussed at the meeting:

Session 1: A review of recent activities on measuring health status in the international arena;

Session 2: Sharing countries' experiences on measuring health status.

Session 3: Review of the BI-Mark 1 question set and cognitive and field test results.

Session 4: Steps towards development of BI-Mark 2.

Session 5: Development of workplan for the timely delivery of BI-Mark 2 into European Health Interview Survey.

Session 6: BI Steering Group and Task Force.

5. The discussion at the meeting was based on supporting papers and power point presentations. The papers and the presentations are available on the UNECE website[1].

III. Summary of the main topics discussed at the substantive sessions

A. Session 1: A review of recent activities on measuring health status in the international arena

6. UNECE highlighted that the UN Secretary General has identified Sustainable Development as a priority for the work of the United Nations, and that one of the main inputs to advance Sustainable Development is investing in human capital, including education and health. Within this framework, it is now the appropriate time and a window

[1] http://www.unece.org/stats/documents/2010.01.health.htm

of opportunity to work on improving health statistics, especially in developing common tools for internationally comparable measurements of health state.

7. The Chair of the BI reviewed the objectives, history and accomplishments of the group. A summary of how the question set was developed and tested was provided. The question set focuses on functioning capacities in a parsimonious set of domains. Information on health state should be collected using international standards within the framework of official statistics as part of national statistical systems.

8. WHO discussed that measuring health state is not about diseases or risk factors but it is about measuring individual and population levels of health and tracking this over time. It is now more important than in the past to measure the health state of the population as the focus of global health has shifted from diseases that kill to diseases that lead to disability. WHO has begun a process of developing standard survey modules that will include a module on health states as well. The work done by the BI will be one of the inputs into this process. The Study on Global Ageing and Adult Health is ongoing as is the work on the Global Burden of Disease.

9. Eurostat noted that, for the second wave of the European Health Interview Survey (EHIS) to be fielded in 2014, the questionnaire will be based on a thorough evaluation of the results of the first wave (2008) and will focus on information needed for policy purposes at EU level. It will not be possible to incorporate all the questions in all domains of the BI question set but the EHIS might be able to use some of the questions – especially ones that can replace the problematic questions identified in the EHIS first wave.

10. The concern of not having the opportunity to integrate all the questions in the BI-Mark 2 set into the EHIS was discussed and some recommendations were made. It was also noted that the BI-Mark 2 should be built on the existing BI-Mark 1 and the revisions to be made based on hard evidence from the testing outcomes rather than on expert opinions. A wide range of results from the field and cognitive testing, including the most recent 2009 round conducted by UNESCAP and the 2010 testing in European countries and the U.S., will be available before finalising the questions for BI-Mark 2.

11. The issue of how the health state measurement can be institutionalised within countries' national statistical systems was also discussed at the meeting. A number of possible mechanisms were suggested. The Health Metrics Network, the United Nations Statistical Commission, the Conference of European Statisticians (CES) and the Inter-Secretariat Working Group on Health Statistics were discussed as possible options.

B. Session 2: Sharing countries' experiences on measuring health status

12. The Austrian and Slovenian experiences on measuring health status were presented at the meeting.

13. UNECE presented findings from the pre-meeting survey questionnaire sent out to 65 countries, of which 34 countries responded.

C. Session 3: Review of the BI-Mark 1 question set and cognitive/field test results

14. UNESCAP presented an update of their work to improve disability measurement. It was confirmed that the UNESCAP Report on the Field and Cognitive Testing will be available by April 2010 and that it will be shared with BI Steering Group and Task Force members.

15. The Chair of the BI Steering Group and Task Force made a domain by domain presentation of the test results and the bases for why revisions were made to the BI-Mark 1 question set. It was clarified that the BI-Mark 1 consisted of the vision, hearing, mobility, affect, pain and cognition domains. The revised version of BI-Mark1 (which can be called BI-Mark 1.2) introduced the fatigue domain. These most recent changes were based primarily on the 2009 round of test results.

16. The question sets for some domains (vision, hearing and mobility) are close to final and may not need any major changes. However, changes are expected in other domains including anxiety and depression, pain, fatigue and cognition.

17. Issues discussed extensively included: the use of screener questions, "in-scope" and "out of scope" responses, questions on taking medication, differentiation between normal and chronic conditions, inclusion of performance test rather than survey type questions and the applicability of some questions for countries that use proxy respondents.

18. The broadly accepted norm of keeping the first question as is in the WG short question set and expanding with additional questions can be changed when needed.

19. When considering adding or deleting questions or domains, it will be vital to take into consideration the impact of doing so. The objective is to keep the question sets as short as possible since shorter question sets are more likely to be adopted.

20. A clarification of the difference between the work of the WG and the BI was raised. The Chair explained that (1) the WG includes all countries and the BI is primarily comprised of countries in the European region; (2) the BI-Mark 1 covers only 7 domains (vision, hearing, mobility, pain, cognition, affect and fatigue) whereas the WG work includes the additional domains of communication, learning, and upper body; (3) the WG is broader than the BI both in terms of objectives and scope of questions as the WG includes (a) performance as well as capacity, (b) understanding the barriers to full participation in life, and (c) areas to support the improvement of the impact of the environment on functioning; and (4) the BI focuses more on measuring health state rather than participation. BI's main aim is to expand the consistency of the health state measurement to the European community through the EHIS.

21. The meeting also emphasized the fact that, for consistency and comparability of measurement over time, once the BI questions are endorsed, changes to the questions should be avoided as much as possible.

D. Session 4: Initial step towards development of BI-Mark 2

22. A break out session dividing the participants into two groups was organized to encourage participation and discussion. The participants found this exercise very useful as they were able to discuss in detail the points that were not clear during the meeting presentation and discussion sessions.

23. Based on the discussions held in the plenary session of the individual group presentations, the meeting adopted some of the groups' concerns as essential points to be included in the meeting recommendations.

E. Session 5: Development of workplan for timely delivery of BI-Mark 2 into EHIS

24. Canada, as a non-European country, expressed interest in participating in the cognitive testing if the questionnaire set can be made available in time for their national

survey in the summer or fall of 2010. This can be done by replacing the survey screener questionnaires with the BI questions. Australia also will discuss with the relevant persons in Australian Bureau of Statistics the possibility of using the BI questions for the upcoming surveys.

25. The meeting participants expressed the need for a restricted website where all past and future documents relevant to the BI process can be posted and accessed by the BI team members only.

26. The meeting proposed, if possible, to make available a draft BI-Mark 2 question set for discussion and review at the Eurostat "Workshop on EHIS" which will discuss the content of EHIS and attended by all European National Statistics Agencies in Berlin in September of 2010.

F. Session 6: BI Steering Group and Task Force

27. The mandate of the Task Force ends in December 2010 after the final BI-Mark 2 question set is handed over to Eurostat, however the CES has extended the Steering Group's mandate to October 2013. Given that social and health statistics have come to the forefront of the CES agenda, the Bureau feels that there is a broader scope for the Steering Group to pursue work beyond the measurement of health state.

28. The next Steering Group and Task Force meeting was proposed to be held in conjunction with the WG meeting in Luxembourg (3-5 November 2010), with an extra half day for the Steering Group and Task Force members to meet and discuss the BI-Mark 2**.**

29. The meeting also recommended that the Chair of the Eurostat Core Group on Health Interview Surveys should be contacted and included in the future BI meetings.

IV. Meeting recommendations

30. The meeting recommended the following:

(a) General recommendation: to develop a mechanism to institutionalize Health State Measurement at the national level within the framework of official statistics and integrated into the national statistical systems;

(b) Eurostat EHIS**:** To build a strong partnership with Eurostat to further comparability of measures of health state in the UNECE region. This would include joint discussion with Eurostat about possibility of including the BI question set in the 2014 EHIS and also consider including questions developed by the WG or the BI in the 2012 Disability Survey;

(c) BI Mark 2**:**

i) To consider if the BI-Mark 2 should be used on a question-by-question basis or as a complete stand-alone set.

ii) To work for timely delivery of the BI-Mark 2 question set to meet the Eurostat deadlines. A firm proposal on questionnaire content should be available for review by Sept 2010. The final question set should be submitted to Eurostat by December 2010.

iii) To decide on whether BI-Mark 2 will have one or two recommended question sets. e.g. one short and one long. Under this scenario, the long list of

questions would include more domains. The short set might give priority to domains not currently in EHIS.

iv) To avoid changing questions adopted and endorsed by the BI in order to maintain consistency and effective comparability over time.

(d) Testing results:

i) To make a detailed documentation of the testing evidence that provided basis for change from the BI-Mark 1 to BI-Mark 2 and to share with countries.

ii) To share the UNESCAP report on the field and cognitive test results with the Budapest Initiative group when it becomes available.

iii) To carry out additional analysis (when possible) on how respondents score on the same questions in past

(e) On domains:

i) To consider rearranging the sequence of the domains (if Communication is included).

ii) To consider adding or deleting domains on the basis of prevalence, relationships with other domains and impact questions.

iii) *Vision, hearing and mobility*: To keep as it is unless there are contrary significant findings in the U.S. cognitive and field test results. Suggested the possibility of moving to one question in the vision domain. Field test data will be used to decide whether the two specific hearing questions provide a better scale than the single question.

iv) *Mobility:* As EHIS has questions on 500m and stairs, it would only be necessary to include the 100m question to have the surveys harmonized. To consider whether both 500m and 100m need to be retained based on the US survey data.

v) *Learning*: One of the more problematic domains. Additional work is needed if it is to be retained.

vi) *Cognition:* Consider incorporating a test-type question (as opposed to a survey-type question). Germany and Canada agreed to provide examples of existing practice.

vii) *Fatigue:* Considered one of the weaker domains in terms of robustness of test results. It is important to include the whole set of questions in the Round 4 of testing.

viii) *Pain and Affect*: Will be included in the Round 4 test and evaluated based on the test data.

(f) Future work:

i) BI Steering Group to plan the development of supporting materials for the surveys.

ii) Countries are invited to join the Steering Group and Task Force.

iii) BI Task force meeting to coincide with WG meeting in Luxembourg in Nov 2010.

V. Adoption of the meeting recommendations

31. The recommendations of the meeting were adopted during the closing session.