## STATISTICAL COMMISSION and ECONOMIC COMMISSION FOR EUROPE

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### CONFERENCE OF EUROPEAN STATISTICIANS

Approved

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<u>Item 3f of the Provisional</u> Agenda

# REVISED TERMS OF REFERENCE OF UNECE/WHO/EUROSTAT STEERING GROUP AND TASK FORCE ON MEASURING HEALTH STATUS

#### Note prepared by the UNECE secretariat

#### I. BACKGROUND

- 1. The May 2004 Joint UNECE/WHO/Eurostat meeting on the Measurement of Health Status (Document CES/2004/46, available on the UNECE website at <a href="http://www.unece.org/stats/documents/ces/2004/46.e.pdf">http://www.unece.org/stats/documents/ces/2004/46.e.pdf</a>) under the auspices of the Conference of European Statisticians (CES) focused on the need for internationally comparable measurement of population health status within the framework of official statistics.
- 2. In order to achieve internationally comparable measurement of health status of population, it is necessary to develop common instruments to measure health status in its multiple dimensions. This will eventually facilitate the collection of internationally comparable information on health status as part of a regular data collection exercise in each country.
- 3. At this meeting, it was also proposed that the future CES work on health statistics be 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. Similarities in objectives and work of other international groups (the Eurostat Group on the Health Interview Survey (HIS) and the Washington Group on Disability Statistics (WG)) are to be explored and taken into consideration when developing common measurement instruments.
- 4. Against this background, the Joint UNECE/WHO/Eurostat Steering Group and Task Force on Measuring Health Status were established by the CES Bureau in October 2004.
- 5. During the November 2005 Joint UNECE/WHO/Eurostat Meeting on Measurement of Health Status held in Budapest, it was recommended, both for easy reference and identity purposes, to label the current UNECE/WHO/Eurostat work on health as the Budapest Initiative (BI). From this meeting onward, the joint UNECE/WHO/Eurostat work of on measuring health status has been referred to as the Budapest Initiative (BI).
- 6. The main purpose of the Budapest Initiative was 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 objectives of the Task Force and Steering Group were defined as follows:

- (a) A **Task Force** to work towards the development of a new common instrument and to coordinate with existing groups such as the Eurostat Group on HIS and the WG. The Task Force would be responsible for anlyzing existing survey data on multidimensional domains in order to identify the domains and the methods that prove to maximise the validity and the comparability of the instruments;
- (b) A **Steering Group** to coordinate the work of the Task Force and to plan for future joint meetings of WHO, Eurostat and UNECE.

#### II. ACCOMPLISHMENTS TO DATE

- 7. Since its inception, the Task Force has completed the following work:
- (a) Developed a conceptual framework defining the concepts of health status and health state;
  - (b) Decided on a set of criteria for selecting the functional domains to be included;
- (c) Selected seven domains, developed a set of questions to measure the selected domains and prepared a testing protocol to evaluate the questions.

Three Working Papers documenting each of these areas of accomplishment have been written and are available online at <a href="http://www.unece.org/stats/documents/2005.11.health.htm">http://www.unece.org/stats/documents/2005.11.health.htm</a>.

- 8. Work on the development and testing of questions to measure health state has been undertaken since this time. The Round 1 cognitive testing of the proposed question set was conducted in November December 2006 in four countries: Australia, Canada, Italy and the United States. Cognitive testing included all seven domains and results were reviewed at the January 2007 Task Force meeting. (http://www.unece.org/stats/documents/ece/ces/2007/6.e.pdf)
- 9. At the January 2007 meeting, the Task Force finalized and approved a survey module to be used to produce internationally comparable estimates of the measurement of health state for the next three to four years (referred to as the Budapest Initiative Mark 1 (BI-M1) module).
- 10. In February 2007, the CES Bureau welcomed, with appreciation, the finalization of the survey module on health state (B1-M1). It was noted that, as previously agreed, the survey module was to be delivered to Eurostat by end of February 2007 to allow EU countries to include it in their forthcoming health interview surveys. The 2007 CES plenary session endorsed the module. The CES Bureau noted that the BI will continue to work toward a refinement of the survey instrument for the next two to three years.
- 11. As a result, the Group has been exploring ways to improve the BI-M1 by using alternative ways of phrasing questions in the module, as well as further investigating issues that emerged through the first round of cognitive testing. Since then, the new questions have been further developed and tested. Round 2 of cognitive testing of the modified BI-

M1 was conducted in November 2007 – January 2008. This testing, which included six domains (except the domain Hearing), was performed jointly with a Cross-Cultural Cognitive Testing Workgroup and included test questions proposed for the European Social Survey. The following seven countries participated: Bulgaria, Germany, Portugal, Spain, Switzerland, United Kingdom and the United States.

- 12. Round 3 of the development and testing of questions took place in collaboration with the WG and UNESCAP United Nations Development Account Project on Improvement of Disability Statistics. Cognitive testing of the question set (which also included questions developed by the WG) was conducted January 2009 March 2009 in nine countries: Cambodia, Canada, Fiji, Kazakhstan, Maldives, Mongolia, Philippines, South Africa, Sri Lanka, and the United States. In addition, a field test component was incorporated into the development process and was conducted June 2009 August 2009. Five countries conducted interviews as part of the field test: Cambodia, Kazakhstan, Maldives, Sri Lanka and Philippines. These tests have included evaluation of all seven domains and question variations, and have contributed to the further development of the questions set. The work is expected to result in the establishment and approval of BI-Mark 2 (BI-M2) in 2010/2011.
- 13. Throughout this process, it is clear that the goal of producing internationally comparable health data in future can only be achieved if the BI group continues to be coordinated jointly by UNECE, WHO and Eurostat and that it also interacts with the WG, which reports to the United Nations Statistical Commission. Collaboration between international agencies, and particularly with EU member states through Eurostat, is essential for comparative analysis across the UNECE region and also globally.

# III. JOINT UNECE/WHO/EUROSTAT STEERING GROUP ON THE MEASUREMENT OF HEALTH STATUS

#### A. Purpose of the Steering Group

- 14. To continue information sharing and the development of common standards across the UNECE region, it is proposed to extend for another four years (until October 2013) the terms of reference for the UNECE/WHO/Eurostat Steering Group on the Measurement of Health Status. The Steering Group will coordinate the last stage of the Task Force's work and will then provide a venue for the continued development of measures of health status. The role of the Steering Group would be as follows:
  - To create opportunities to share experiences in the measurement of health status among stakeholders in the UNECE region (United Nations, WHO, Eurostat, OECD) through work sessions and meetings,
  - To liaise with the Washington Group and the United Nations Intersecretariat Working Group on Health Statistics to ensure common strategies for health and disability survey data collection,
  - To oversee the work of the BI Task Force and provide necessary guidance with specific focus on monitoring the adoption and implementation of the BI-M2 question set,
  - To facilitate the development and dissemination of methodological guidelines,

- To develop a work plan for the joint analysis of data generated by the BI question set, and
- To suggest areas where targeted work groups should be established to address priority issues in the measurement of health status.

#### B. Membership

- 15. The Steering Group currently includes representatives from Canada, Hungary, the United States (Chair), Eurostat, WHO, and UNECE.
- 16. The composition of the Steering Group may change after the Work Session on Measurement of Health Status that will take place in 20-22 January 2010.

#### C. Timetable

17. The mandate for the Steering Group covers the period from October 2009 until October 2013.

### D. Outputs

18. The Steering Group will submit a progress report to the CES Bureau at its October 2010 meeting. This report will include the results of the January 2010 work session and describe the demands for future activities in this field.

## IV. JOINT UNECE/WHO/EUROSTAT TASK FORCE ON MEASUREMENT OF HEALTH STATUS (BUDAPEST INITIATIVE)

### A. Purpose of the Task Force

- 19. To finalise the work associated with BI-M2, it is proposed to extend until 31 December 2010 the terms of reference for the UNECE/WHO/Eurostat Task Force on the Measurement of Health Status, to be referred to as the Budapest Initiative. The role of the Task Force would be as follows:
- (a) To evaluate the results of BI-M1 data collection and work toward the refinement and finalisation of the agreed on question set;
- (b) To carry out further development and testing of BI-M2 for finalization and approval in collaboration with the WG, health-related Eurostat projects and UNESCAP United Nations Development Account Project on Improvement of Disability Statistics;
- (c) To take into account the preliminary findings of ESCAP Disability Module testing in the finalization of BI-M2;
- (d) To provide a final BI-M2 question set, along with evidence from cognitive and field testing to justify changes between the BI-M1 and BI-M2 questionnaire versions, to Eurostat for the second round of the EHIS by December 2010. In the preparation of the EHIS questionnaire for the second round, Eurostat will consult its main users from the European Commission regarding any additions or changes to the questionnaire recommended by the BI;

- (e) To document the work of the BI for future reference, such as lessons learned and testing methodology;
- (f) To disseminate BI materials through a website, including the results of testing and guidelines for the translation protocol.

## B. Membership

- 20. The Task Force currently includes representatives from Australia, Belgium, Canada, Denmark, Estonia, Hungary, Italy, Norway, Spain, United Kingdom, United States (Chair), Eurostat, WHO, and UNECE.
- 21. The composition of the Task Force may change after the Work Session on Measurement of Health Status that will take place in 20-22 January 2010.

#### C. Timetable

22. The mandate of the Task Force will cover the period from October 2009 to December 2010.

#### D. Outputs

23. By December 2010, the Task Force will submit to the CES Bureau, through the Steering Group, a final report on its accomplishments and a proposal for follow-up work, if any.

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