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ORGANIZATION (WHO)**

Fifty-third plenary session
Geneva, 13-16 June 2005

**REPORT OF THE MAY 2004 JOINT UNECE/WHO/EUROSTAT MEETING ON THE
MEASUREMENT OF HEALTH STATUS**

Prepared by the ECE Secretariat

INTRODUCTION

1. The Joint UNECE/WHO/EUROSTAT Meeting on the Measurement of Health Status was held in Geneva from 24 to 26 May 2004. It was attended by representatives of Albania, Australia, Austria, Belgium, Bosnia and Herzegovina, Bulgaria, Canada, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, Iceland, Ireland, Italy, Latvia, Netherlands, New Zealand, Norway, Poland, Republic of Moldova, Romania, Slovak Republic, Slovenia, Spain, Switzerland, Turkey, United Kingdom and the United States of America. Representatives of the European Commission, OECD, ILO, UNFPA, the United Nations Economic and Social Commission for Western Asia (ESCWA) and invited experts from EuroReves¹ and Partnership for Health were also present.
2. A welcoming address was given by Mr. Heinrich Bruengger, Director of the Statistical Division of UNECE.
3. The provisional agenda was adopted.

¹ The European Arm of the International Network on Health Expectancy and the Disability Process (REVES).

4. Ms. Jennifer Madans (United States of America) was elected as Chairman.
5. The three keynote speeches of Session I focused on the national (USA speech), regional (EUROSTAT speech) and international (WHO speech) perspective of the measurement of health status.
6. The following substantive topics were considered in the sessions of the meeting on the basis of 26 invited and supporting papers:

Session II: A framework to conceptualize health.

Chair: UNECE.

Discussant: Howard Meltzer (Office for National Statistics, UK).

Presentations given by: Colin Mathers (WHO), Antoni Montserrat Moliner (DG SANCO), Sally Goodspeed (Australian Bureau of Statistics) and Somnath Chatterji (WHO).

Session III: The achievement of international comparable measures – a review of the work done to achieve international comparability

Chair: Marijke de Kleijn de Vrankrijker.

Discussant : Angela Me (UNECE).

Presentations given by : Jozsef Vitrai (Hungarian National Centre for Epidemiology), Jean Marie Berthelot (Statistics Canada) and Didier Dupre (EUROSTAT). 2 special interventions during the panel discussion were dedicated to the experiences of ILO and Bosnia and Herzegovina.

Session IV: The achievement of international comparable measures – strategies for ensuring international comparability

Chair: WHO.

Discussant: Goeke Bonsel (Amsterdam University).

Presentations given by: Arpo Aromaa (European HIS/HES Core Group), Somnath Chatterji (WHO), Marijke de Kleijn de Vrankrijker (Washington City Group) and Jean Marie Robine (EuroREVES)

Session V: The achievement of summary measures at population level

Chair: Marleen De Smedt.

Discussant : Michael Wolfson (Statistics Canada).

Presentations given by: Colin Mathers (WHO), Juergen Rehm (University of Zurich), Jacques Bonte (EUROSTAT).

Session VI: Implementation and co-ordination of health surveys in the region

Chair: Jennifer Madans.

Panelists: Goeke Bonsel, Howard Meltzer, Jean Marie Robine, Jozsef Vitrai, Michael Wolfson.

Paper presented by WHO.

7. All papers for the meeting were posted on the UNECE website:

<http://www.unece.org/stats/documents/2004.05.health.htm>

8. The conclusions reached by the participants during the discussion of the substantive items of the agenda will be presented in a separate report to be prepared after the meeting.

SUMMARY OF THE DISCUSSION

9. Participants at the meeting agreed that the aim of the meeting is to continue the process to achieve internationally comparable measurement of population health states within the framework of official statistics.

10. There was a broad consensus that there are a number of classes of indicators that need to be measured to provide a full statistical picture of population health, its determinants, and consequences (social demographic characteristics, proximal determinants and risk factors, health status, health interventions, participation, and well being). Indicators of population health status include: diseases and injuries, impairments, health states, and mortality risks.

11. The meeting focused on the development of common instruments to measure health states in its multiple dimensions. Minimum requirements for comparability in health state measurement include:

- conceptual clarity
- common set of domains/attributes
- comparable survey instruments: Translation of concepts and wording
- issues of pre and post harmonization (to be further discussed)
- survey design (sampling, survey execution, full coverage of the population, non-response, proxy interviews)
- common reference period
- reliability and validity

12. The meeting agreed that in order to achieve comparability there is need to work towards a new common instrument. Within the European Statistical System (ESS) important work has and is been done in order to arrive at comparable data on health and health related indicators in general and on a common methodology and instruments for surveys in particular. The operationalisation of these instruments by 2006 has started now and implementation is being overseen by a technical group with representatives of twenty eight countries. Any initiative at international level arising from this joint WHO/UNECE/Eurostat meeting will need to build on the work carried out within the ESS and other initiatives such as the joint United States and Canada survey, the Washington Group, and the World Health Survey.

13. In order to identify the core domains to be included in the survey module, to be tested in national survey programmes the following criteria should be considered:

- feasibility in health interview surveys (e.g. brevity, clarity, psychometrics)
- conceptually “important” and independent
- parsimonious set of domains describing most of variation in health states or valuations
- potential for x-population comparability
- clear series of levels within each domain
- capacity (not performance)
- aspects that are “within, on, or close to the skin” – i.e. excluding aspects that change with local social or environmental factors

- suitable for preference measurements
- link to the conceptual framework of the International Classification of Functioning Disabilities and Health (ICF).

14. There was a broad consensus on broad domains of "functioning" which should be included - physical, mental, and sensory. The next level of detail with reference to functioning is also reasonably clear (those domains for which it is clear that should be included are bolded, for others there is a need to examine the empirical evidence on how the domain should be defined, or whether it should make it into a core list):

- physical – **mobility**, dexterity or self care;
- cognition – memory and concentration;
- sensory – **seeing**, hearing;
- other important “feeling” domains for summary index – **pain/discomfort, affect/anxiety, vitality / fatigue, psychological functioning;**
- interpersonal relationships;
- social functioning.

15. Summary measures can provide useful way to report and compare health of populations. There is no need to agree on a summary measure at this point or its use in national reporting, as the main priority is to proceed with the work to develop a common instrument. Anyway, the creation of a standard measure as a future development should not be precluded, and a common survey instrument must allow for the measurement and application of health state preferences.

16. It was recommended that a Steering Group and a Working Group be established. The Working Group will work toward the development of a new common instrument and will coordinate with existing groups such as the Eurostat Group on HIS and the Washington Group. The following countries and international organizations volunteered to be members of the

- Steering Group: Canada, the USA, WHO, Eurostat, and ECE
- Working Group: Belgium, Canada, Estonia, Germany, Hungary, Italy, Norway, Spain, The Netherlands, United Kingdom, United States, ECE, Eurostat and WHO. Euro-Reves also volunteered to be part of the Group.

ADOPTION OF THE REPORT

17. The participants adopted the report of the meeting at its closing session.

ANNEX

SUMMARY OF THE MAIN CONCLUSIONS REACHED BY THE PARTICIPANTS DURING THE DISCUSSION

Session I: Keynote speeches

Documentation: Invited papers by the Unites States of America, WHO and Eurostat

Chair: Heinrich Bruengger, UNECE

1. The meeting agreed on need to work towards the development of common core measures of health status within the framework of official statistics to guarantee international comparability and to reach a consensus on the concept, measurement and reporting of health status. The work of other international key players in the same field will be taken in consideration when developing the common measurement instrument.
2. The first steps towards these objectives are the formulation of the concept of health status and the identification of a common framework with a clear understanding of the purpose of the measurement. Participants discussed the issue of subjective versus objective characteristics of health and the possibility of separating these two aspects when measuring health status. It was argued that in order to develop a set of core measures comparable across countries the focus should be on those aspects of health that are likely to produce comparable data.
3. The link between health, disability and quality of life was acknowledged and the concept of multi-dimensionality of health was highlighted. The use of ICF health domains was discussed as the reference framework for domain selection.
4. The work already in progress at European level and in the Washington group can provide an important contribution to the development of a common instrument for the measurement of health status.
5. There was an agreement that decisions taken on health status measurements are policy driven and that conceptual clarity is essential in the definitions in order to communicate with decision makers. Policy relevance is the starting point of the decision process even though basic measures are useful regardless of policy issues. The development of comparable measures within and among countries and throughout time should be the final purpose of the joint work.
6. The meeting agreed that the issue of cultural differences among countries is one of the main obstacles to the attainment of comparable measures. Health concepts and environments are different across people and societies and the same questions may be perceived in different ways. Literal translations do not guarantee the use of common underling concepts. However, the involvement of experts in each specific field in the translation process could minimize different interpretations.

7. The meeting was of the view that the initial focus of the work should be on countries with developed statistical systems and regular health surveys. The work undertaken by these countries can open the way to a wider use at international level. On the other hand, instruments defined at international level should be adaptable to regional and national needs.

Session II: A framework to conceptualize health: main conclusions

Documentation: Invited papers by WHO, the European Commission and Australia, supporting paper by New Zealand

Discussant: Howard Meltzer, UK

Chair: Angela Me, UNECE

8. During the discussion, meeting participants clearly agreed on the need for a strategy to measure health states. A consensus similar to the one achieved for the System of Health Accounts (SHA) needs to be found for Health Interview Surveys (HIS).

9. In order to measure health states, the necessity to agree more generally on a concept for the measurement of population health was high-lighted. There was a broad consensus on the need for a number of indicators to provide a full statistical picture of population health. It was also agreed that health needs to be defined via a multi-domain approach.

10. WHO already has defined such a multi-domain approach, and the meeting's discussion focused on the question of how to identify the important domains. WHO explained their criteria to identify the domains: (1) a domain should be one-dimensional and (2) the multiple domains together should explain most of the variation in health states (i.e. identification is an empirical question). In line with the discussant's summary, the meeting felt that there are quite some similarities in the various approaches and that an agreement on a number of health domains can be found.

11. It was considered important to agree on the focus of the health measurement – should it be on the individual or also on the factors outside the individual. It was concluded that it should be on measuring functions of individuals. This can be achieved through health interview surveys. Other health related measures that lie outside the individual (such as environmental factors but also participation) are considered to be valuable and necessary information but are different from a person's health. Also, they cannot completely be captured through surveys. In addition, environmental factors might change over time, and if it is not clearly distinguished between the health state of an individual and environmental factors, it will be difficult to monitor health state over time.

12. During the discussions, next to the agreed need for a multi-domain approach, a certain convergence of concepts such as illness status, functional status, subjective well-being and quality of life was observed. A coherent translation into national concepts was deemed to be feasible.

13. Policy makers are the main users of health statistics. Accordingly, they play an important role in shaping the “what to measure”. However, the importance of having measurements for the basic concepts of health was stressed, especially in the context of achieving internationally comparable measures and over-time comparisons. Statistical requirements such as quality and conceptualisation might differ from policy makers’ ever-changing needs. However, a stable set of measurements was deemed to be useful to inform and direct future policies. Although policies often have an environmental point of view and therefore are different in each cultural context, it was argued that basic concepts for measuring health should relate only to the person’s health.

14. Another issue discussed was the question of indicators vs. summary measures. As regards long lists of health indicators, concern was expressed that conclusions of information gained from such exercises are often not very clear. At the same time, the need for comprehensive measurement of health was expressed. Aiming at the measurement of the various underlying health issues rather than at indicators only was seen to be a good strategy. Having a set of harmonised domains would then allow the creation of summary measures if wanted. Summary measures as such were seen differently by participants. While some participants expressed their concern towards summary measures, WHO underlined its position that summary measures are needed in order to have a clear indication of a population’s health (for more details, see also the discussions during session IV and V).

15. A number of methodological questions were also touched. The question of response rates as well as survey coverage (i.e. coverage of the total population including institutionalised people) were mentioned as important issues of international comparability. In case agreement of an international measurement of health states is reached, the comparability with existing national time series has to be considered, i.e. whether to maintain two co-existing time series (for the national and international measures) or whether to opt for a break in series.

Session III: The achievement of international comparable measures– a review of the work done to achieve international comparability

Documentation: Invited papers by Hungary, Canada and Eurostat; supporting paper by Estonia, Italy, Romania and Spain

Discussant: Angela Me, UNECE

Chair: Marijke de Kleijin de Vrankrijker, The Netherlands

16. In trying to identify the health status domains to be included in a standard survey module, a discussion was dedicated to the semantic difference between ‘health status’ and ‘health states’. The definition of these two expressions needs to be clarified. It was noted however, that although there is a significant difference between the two concepts in English, other languages may not distinguish the two terms.

17. The meeting agreed to focus on capacity/functioning. This would eliminate the effect of different environments and would guarantee a more objective measure providing questions that are easier to pose and allowing better comparability at international level. In the process to reach

a consensus on some basic measures, various dimensions to be included in the measurement were discussed and the domains used in existing programmes and surveys such as the WHO World Health Survey, the Eurostat Health Interview Survey, the joint USA-Canada survey were reviewed and compared. Participants expressed support to domains related to the physical, cognition, and sensory functioning. Other domains related to psychological functioning, pain/discomfort, affect/anxiety, vitality/fatigue, interpersonal relationships and social functioning were also discussed for their relevance. Determinants of health status, risk factors, interventions are important and should be measured but kept separated from the measurement of health states.

18. Some participants pointed out the need to be more result oriented in order to anticipate the needs of decision makers. Decision makers' objectives may lead the selection of indicators, which in turn will drive the selection of domains. Therefore the selection of domains should also focus on the relevance of single domains for national needs.

19. The indicators selection process should take in consideration a number of minimum requirements to guarantee comparability. Among these requirements there are the use of the most parsimonious set of domains capable to explain/measure health status, a protocol for translation and explanation of concepts to be measured, , cognitive testing and the standardization of survey design (including a protocol for the use of different data collection instruments). Post-harmonization techniques were also discussed as a tool to calibrate response items and assure comparability. Suggestions were made for an instruction manual to come together with the standard survey module to include at least the translation of concepts in various languages.

20. Participants discussed the use of the self-perceived health single question. Even though such a question may be useful at a national level, it was generally recognized that it is based on perception and is dependent on cultural aspects, therefore not allowing cross-country comparability. Sometimes, even within the same country, individuals present different cut points and responses cannot be calibrated.

21. Quality of data is of importance when trying to assure comparability: strategies to minimise non-response, monitoring of fieldwork and use of proxy-responses should be taken in consideration. The issue of population coverage and representation was also discussed and the importance of including children, people with disabilities and the institutionalised population was addressed.

22. The decisions on the selection of domains to be measured and on the minimum requirements to guarantee comparability were deferred to Session VI.

Session IV: The achievement of international comparable measures - strategies for ensuring international comparability

Documentation: Invited papers by the European HIS/HES Group, Harvard University, the Washington Group, and Euroreves

Discussant: Goeke Bonsel, Amsterdam University

Chair: Bedirhan Ustun, WHO

23. The session focused on strategies to ensure comparability of self-reported health status. Three main approaches were presented and discussed: health examination surveys, anchoring vignettes, and concept-based translations.
24. Health examination methods add their own design and execution issues and hence additional sources of requirements to ensure comparability, eg. standardization of tests and test environment, and interviewer training should be considered. Existing health examination surveys in European countries were reviewed together with the comparative strengths and weaknesses of HIS and HES methods. The need to develop a coordinated plan by EU PHP, Eurostat and relevant experienced national bodies to improve the use and comparability of HES/HIS data in Europe was stressed. It was also argued that health examination techniques could usefully complement self-report for some domains.
25. The use of anchoring vignettes was presented by WHO as a powerful tool to increase the comparability of self-reported data. Empirical evidence of the lack of comparability arising from the use of unanchored response categories was reported even when question wording, meaning and administration are standardized. Data from the WHO Multicountry Survey Study showed that large differences in respondents' self-responses could be reduced after being adjusted using the responses from anchoring vignettes. A number of geographical comparisons of raw responses with those adjusted using anchoring vignettes were presented in a variety of domains. The meeting discussed the anchoring vignettes as a promising strategy to enhance the comparability of the results across population groups. However it also recognized that response category cut-point shift is a real problem that must be dealt using health in interview survey instruments.
26. The experience of ensuring cross-population comparability by providing translation guides for concepts was presented by EuroReves. It was argued that such a process ensures that the underlying concepts for each question are correctly preserved and therefore data comparability is improved. This is the approach used in the European Health Status Module (EHSM), which is now available in 5 languages with plans to extend to the new 20 EU languages. The domains included in this module are chronic morbidity, functional limitations, activity restriction, and perceived health. Differentiating functional limitations and activity restriction is central to the module.
27. The work of the Washington Group was presented as one of the processes leading to the development of a comparable measure. The Group uses the ICF as a framework and has given highest priority to the use of disability data for assessing equalization of opportunities. The group has focused on the development of a small set of general disability measures (to be used in censuses and surveys), but work is starting on the development of some more detailed measures.
28. Participants discussed the advantages and disadvantages of the three approaches to improve comparability, some argued that the selection of the domains could also improve comparability (some domains are more "comparable" than others) but others stated that domain choice is not a major issue. It was also argued that scientifically most comparability issues have been, or can be, resolved. Official statistics and health communities need to work more closely

and to build on and engage scientific work being carried out in academic institutions and clinical trials. The major difficulty is getting stakeholders to agree on a common process and to be sufficiently involved and motivated to make changes to existing procedures and to carry forward a process to improve international harmonization of population health measurement instruments.

29. There was an agreement on the need to pay more attention to response categories, their labelling and to the techniques for measuring conceptual distance of response categories. It was highlighted the use of numbers as response categories, the use of ranked labels, and of explicit response options. The use of post-survey rescaling techniques, with or without the use of data from anchoring vignettes was also discussed, although the point was made that all techniques to ensure comparability of unanchored response categories required some form of data collection at the time of interview. Post-survey techniques such as Item Response Theory (IRT) could not resolve the cut-point shift issue.

30. Issues of comparability relating to survey mode (CATI, personal interview, postal survey) were also discussed and the experience of the WHO Multicountry Survey Study was summarized. There were a number of countries where surveys with different modes were conducted in order to compare results and there were some significant differences in responses to health state questions.

Session V: The achievement of summary measures at population level

Documentation: Invited papers by WHO and EUROSTAT; supporting paper by Azerbaijan and Italy

Discussant: Michael Wolfson, Canada

Chair: Marleen De Smedt, Eurostat

31. The discussion on summary measures at population level focused on the following issues: concept clarification (i.e. 'what is a summary measure'), relevance at international level and quality of summary measures, and the research for a common approach to obtain comparable summary measures.

32. Once the core domains of health status to be measured are defined, a summary measure can be a parsimonious profile of an individual health status, a scoring function at individual level (implying the measurement at a specific point in time) or an aggregation function at population level (including the idea of measurement over time).

33. The meeting discussed the use of standard valuations to obtain stable measures across countries and over time. It was recognized that reliable valuations require the availability of very detailed data and different point of views were expressed on the relevance of developing measures based on standard valuations. What needs to be decided is whether valuations are necessary and if there are alternatives to them.

34. The possibility of using one or more summary measures was also examined and a proposal was advanced to define a family of summary measures instead. At the end of the

session the meeting reached the conclusion that it is too soon to agree on a summary measure and the main priority should be the development of a common instrument to measure health states. The possibility of developing and using summary measures in the future must not be precluded.

Session VI: Implementation and co-ordination of health surveys in the region

Documentation: Invited papers by WHO-ECE-EUROSTAT

Panelists: Goeke Bonsel (Amsterdam University), Howard Meltzer (UK), Jean Marie Robine (EuroReves), Jozsef Vitrai (Hungary), Michael Wolfson (Canada)

Chair: Jennifer Madans, USA

35. On behalf of WHO, ECE and Eurostat, Colin Mathers (WHO) prepared a paper (Working Paper 27) outlining a future agenda for development of a common survey module, and to coordinate the implementation of health surveys in the region. This working paper took into account comments and suggestions raised in plenary discussion the previous day and formed the basis of the panel and plenary discussion and the formulation of an agreed report on the outcomes of the meeting.

36. A broad consensus was reached that there are a number of classes of indicators that need to be measured to provide a full statistical picture of population health, its determinants, and consequences (social demographic characteristics, proximal determinants and risk factors, health status, health interventions, participation, and well being). Indicators of population health status include: diseases and injuries, impairments, health states, and mortality risks.

37. There was discussion that the distinction being made between health states and health status was difficult to translate into other languages, and also some discussion of replacing the term 'health states' by 'functioning' or 'functioning and feeling'. However, the use of the term functioning is also problematic because it has already been used in some conceptual schemes to distinguish body functioning (impairments) from activity limitations, both of which are included in the broader term 'health states'

38. The meeting focused on the development of common instruments to measure health states in its multiple dimensions and identified minimum requirements for comparability in health state measurement.

39. The meeting focused on the development of common instruments to measure health states in its multiple dimensions. Minimum requirements for comparability in health state measurement include:

- Conceptual clarity
- Common set of domains/attributes
- Comparable survey instruments: Translation of concepts and wording
- Issues of pre and post harmonization (to be further discussed)
- Survey design (sampling, survey execution, full coverage of the population, non-response, proxy interviews)

- Common reference period
- Reliability and validity

40. The meeting agreed that in order to achieve comparability there is the need to work towards a new common instrument. Within the European Statistical System (ESS) important work has and is been done in order to arrive at comparable data on health and health related indicators in general and on a common methodology and instruments for surveys in particular. The operationalisation of these instruments by 2006 has started now and implementation is being overseen by a technical group with representatives of twenty eight countries. Any initiative at international level arising from this joint WHO/UNECE/Eurostat meeting will need to build on the work carried out within the ESS and other initiatives such as the joint United States and Canada survey, the Washington Group, and the World Health Survey.

41. There was panel and general discussion on the criteria for choosing a set of core domains to be included in the proposed common survey module and there was a consensus on the following criteria:

- feasibility in health interview surveys (e.g. brevity, clarity, psychometrics)
- conceptually “important” and independent
- parsimonious set of domains describing most of variation in health states or valuations/preferences
- potential for x-population comparability
- clear series of levels within each domain
- capacity (not performance)
- aspects that are “within, on, or close to the skin” – i.e. excluding aspects that change with local social or environmental factors
- suitable for preference measurements
- link to the conceptual framework of the ICF

42. It was considered crucial that the common instrument be designed to allow in principle its use for measurement and application of health state preferences, whether or not individual users intended to report health state profiles or summary indexes. It was also agreed that an important criterion for choosing a parsimonious but comprehensive set of domains was to maximise the variance in health state preferences explained by the core set of domains.

43. Several participants emphasized the importance of linking to the conceptual framework of the ICF where a level of health in a domain is understood in terms of capacity, and also of using ICF classification for the identification and description of health domains.

44. There was a broad consensus on broad domains of "functioning" which should be included - physical, mental, and sensory. Participants agreed that the following core domains would certainly be included (mobility, cognition, seeing, pain/discomfort, affect/anxiety, vitality / fatigue) and that other core domains would almost certainly be drawn from set including dexterity or self care, hearing. There was less agreement on whether domains such as interpersonal relationships or social functioning should be considered for inclusion.

45. There were a range of views on the importance of reporting summary measures of population health. These can provide useful way to report and compare health of population and to link to evaluation activities. In discussion, it was generally agreed that there is no need to agree on a summary measure at this point or its use in national reporting, as the main priority is to proceed with the work to develop a common instrument.

46. There was then discussion of how to proceed after this meeting. Two key issues were to continue progress towards a common health state instrument, and to establish dialogue with the Washington Group to explore commonality of objectives and work. There was support for the establishment of a Working Group to work toward the development of a new common instrument and to coordinate with existing groups such as the Eurostat Group on HIS and the Washington Group. There was also agreement to establish a small Steering Group to coordinate the work of the Working Group and to plan for future joint meetings of WHO, EUROSTAT and UNECE. The following countries and international organizations volunteered to be members of the

- Steering Group: Canada, the USA, WHO, Eurostat, and ECE
- Working Group: Belgium, Canada, Estonia, Germany, Hungary, Italy, Norway, Spain, The Netherlands, United Kingdom, United States, ECE, Eurostat and WHO. Euro-Reves also volunteered to be part of the Group.
