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STATISTICAL COMMISSION and UN ECONOMIC COMMISSION FOR EUROPE

STATISTICAL OFFICE OF THE EUROPEAN COMMUNITIES (EUROSTAT)

CONFERENCE OF EUROPEAN STATISTICIANS

WORLD HEALTH ORGANIZATION (WHO)

Joint UNECE/WHO/Eurostat Meeting
on the Measurement of Health Status
(Geneva, 24-26 May 2004)

Session 6 – Invited paper

AGENDA FOR FUTURE WORK

For discussion in Session 6

Implementation and co-ordination of health surveys in the region

OBJECTIVES

1. The aim of this meeting is to initiate the process to achieve internationally comparable measurement of population health states within the framework of official statistics.
At the end of the meeting we should be able to give an answer to the following question:
Can we develop a common framework and the building blocks for measuring health states to be used in national surveys, and can this be the basis for international comparable data?

2. In this sixth and final session, panellists and participants will draw on the discussions of issues over the last three days to identify an agenda for the implementation and co-ordination of health surveys in the region. The agenda should particularly focus on:

1) The agreement on a common framework for health state/status measurement
2) The identification of the core health domains to be measured and the definition of a set of health status questions, which addresses the fundamental problem of comparability of self-reported health data.

The discussion on how to report to policy makers the measures derived from survey results.

1) CORE INDICATORS RELATING TO POPULATION HEALTH

3. 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. These may be classified as follows:

1. Sociodemographic indicators / distal determinants
   Age, sex, income, education, etc
2. Proximal determinants and risk factors
   Environmental and workplace exposures, behavioural and lifestyle risk factors, biological/physiological risk factors
3. Health status
   Global health question ("perceived" overall health)
   Diseases and injuries (+ impairments)
   Health state profile (Health state index)
   Mortality risks
4. Health interventions
   Service utilization, coverage, access, responsiveness etc
5. Participation and well-being
   Participation (handicap), subjective quality of life, wellbeing

4. Mortality statistics alone are generally recognized not to be sufficient indicators of population health status. Indicators of the incidence or prevalence of diseases and injuries provides additional information but are also not sufficient with mortality to measure population health status. Two populations may have the same prevalence of a given disease but very different severity distributions. In order to assess and compare the health of populations, and to evaluate interventions, it is necessary to have some means to summarize health status across the wide range injuries and disease categories.

5. There has thus been a widespread national and international focus on the measurement of health states in individuals and populations.

2) INDICATORS OF POPULATION HEALTH STATUS

6. Fundamental to the achievement of a common, consistent and comparable approach to the measurement of health status in populations is a common agreement on what should be measured.

Diseases and injuries
ICD categories, clinical definitions, HIS/HES,
self-report biases (lay, access, stigma etc)

Impairments
ICD/ICF, HIS/HES, Impairment-specific scales

Health states
ICF categories, capacity for functioning, multidimensional, parsimonious subset, self-report biases (unanchored responses)

Mortality risks (by age, sex, ICD cause)
Death registration, diagnosis and coding issues

- Global "perceived" health (global question)

7. Developments in conceptual definitions and operationalization of health state description and measurement over the last two to three decades have converged on a common framework in which:

- Health states are an intrinsic, multi-dimensional (or multi-domain) characteristic of individuals.
- Measurement of health states in populations refers to determining the levels of functioning of individuals on multiple domains (or dimensions , or attributes) of health in representative population samples
- Functioning within health domains is conceptually distinct from overall well-being or quality of life.
- Determinants of health status (pathologies, aetiologies, risk factors, encounters with health services, more distal socio-cultural health determinants) must be distinguished from health status.
- Health interventions must also be distinguished from health status.

8. This conceptualisation preserves the spirit of the WHO Constitution definition: rather than equating health with diseases or diagnostic categories, it recognizes a causal chain through which risk factors are determinants of diseases, and diseases in turn are determinants of health states.

9. Agreement on a common framework for the measurement of health status in official statistics will include:
- Agreement on the need to measure health states in multiple dimensions. These dimensions or domains should not include health determinants, interventions or service use.
- Agreement on a set of common core health domains (see below).
- Agreement on what is being measured in each domain.
- Agreement on one or at most two questions per domain.

3) MINIMUM REQUIREMENTS FOR COMPARABILITY IN HEALTH STATE MEASUREMENT

- Conceptual clarity
- Common set of domains/attributes
- Comparable survey instruments:
  Translation of concepts and wording
- Calibration of unanchored response categories
- Sample design, survey execution,institutionalized sample, proxy interviews etc

4) DEVELOPMENT OF A STANDARD HEALTH STATESURVEY MODULE

10. Once agreed on the common framework, the next objective is to identify which domains should be included in the survey module, to be tested in national survey programmes.

Criteria for “Core Domains” of Health State Profile

- feasibility in HIS (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-populational 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 also

11. There is an emerging consensus on broad domains of "functioning" which should be included - physical, mental, and sensory. The next level of detail re functioning also reasonably clear (those domains which it is clear should be included are bolded, 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
- mental – memory and concentration (**cognition**)
- sensory –**seeing**, hearing*

- other important "feeling" domains for summary index – **pain/discomfort, affect/anxiety, vitality / fatigue**
- Interpersonal relationships/social functioning ??

Points for discussion

- Further process to identify the key elements of a short health module? See proposal in following session.
- How do we address the problem of comparability of self-reported data?
  - What is the role of vignettes in achieving comparability?
  - Are there other tools to achieve comparability?
- What is the process that needs to be put in place in order to develop a common approach to comparability?
- What is the role of health examination surveys? Can they be the first line of calibration for some domains?
- What obstacles might be at national level to introduce the health status questions and techniques for improving comparability in national survey programmes?
- Are countries ready to adopt approaches that make self-report more comparable going beyond the use of common questions?

5) SUMMARY INDICATORS FOR REPORTING ON HEALTH STATUS

12. The simplest and most widely used method for producing population health statistics is to aggregate data on individuals in order to generate statistics such as the proportion of the population (or of a particular population sub-group) suffering from a given health problem or living in a particular health state, or the number of individuals who die from a particular cause during a specified interval. This approach rapidly becomes unwieldy when a number of problems or domains are being monitored and we want to make comparisons over time, across population groups, or before and after some health intervention.

13. While there is no requirement for national official statistics to include summary indicators or measures of population health, these provide the best known way to

1) provide overall summaries of health state/status to enable comparisons of groups or comparisons over time - for broad social accountability and evaluation of health policy

2) provide *de facto* basis for international standard QALY – key to intervention and health technology assessment, and the linking of information on cost-effectiveness to population health.

14. One potential set of summary indicators for reporting on health status is a set of prevalence distributions for the core domains of health. An alternative is to choose a single cutpoint on the scale for each domain and give a single prevalence (of incapacity in that domain above a certain level). Such an approach throws away considerable information unnecessarily.

15. A second alternative is to apply a scoring function (health state valuations or scoring function) to provide a severity-weighted prevalence or average health state valuation across all domains. Such a single number provides a way to compare the point-in-time health status of two populations, or of a single population over time.
As well as such summary measures of the point-in-time health status of a population, there is also interest in integrated measures that combine the health status of the living with mortality risks to provide a comprehensive picture of the levels of health in populations. Such summary measures of population health (SMPH) are measures that combine information on mortality and non-fatal health outcomes to represent population health in a single number. While such summary measures have many potential uses, there are two that are particularly important for public health policy: (1) comparisons of the average health levels in different populations or sub-groups, or in the same population over time; and (2) assessments of the relative contributions of different diseases, injuries and risk factors to overall population health. These two key uses may best be served by different forms of SMPH.

16. SMPH may provide a convenient and useful summary of the vast array of components of population health status. SMPH do not replace the more detailed reporting of data on specific aspects of health and mortality or on the specific causes of health problems; rather they supplement and give focus to these data with more comprehensive indicators that can much more easily be used to monitor trends and compare levels of health across populations.

Points for discussion

- Is there a need to reach an agreement on standard summary measures at this point in time, or can we proceed with the basic work to standardize a core health state instrument?
- Is it relevant to develop measurements that combine information on health status with mortality risks?
- What is the role of valuation in the construction of the summary indicators? Again, is there a need at this time to take further steps, or can this wait till the standard core health state module is agreed? Is this work that individual countries and research groups with a specific interest and motivation can undertake?

6) PROPOSED NEXT STEPS

17. On the basis of a general commitment to work together and assuming that:
- there is consensus on the approach to defining the basic domains;
- there is consensus on the need for a short series of internationally comparable health status interview survey questions;

two working groups composed by countries and international organizations could be established to prepare proposals to be discussed in future plenary meetings on the following two items:

1. Define criteria, identify domains, develop and pilot test a set of questions of a core health states module;
2. Identify whether work on health states module and the international work on disability statistics can be brought together.

Proposal 1.

18. Create small working group of motivated participants to agree on a core set of domains and a draft set of questions for testing

- Base selection on conceptual requirements / common ground in existing instruments / empirical evidence from Canada, WHO and other groups with relevant data
- Identify methods to address x-comparability
- Pilot test in surveys/ trials / small samples
- Present results and proposal to next meeting

19. Once a preliminary list of questions is developed, volunteer groups can be identified who agree to test / pilot the set of questions. In the course of developing these pilots they will work together to make the specific questions as comparable and as identical in meaning and psychometric properties across their populations as possible.

20. A steering group can be formed to coordinate the working groups and follow up with the work of other key players (such as Eurostat, WHO-Europe, the Washington Group on disability) that have already put in place similar health status modules.

Proposal 2.

21. Create small group to enter dialog with Washington City group

- Are the measurement objectives and stakeholders similar or not?
- Can health and disability be seen as a single measurement entity or with known relationships (domains, construct measured, chronicity etc)
- Is a common approach to x-population comparability feasible?

22. This second group could be another small group, an overlapping subgroup, or a steering group which can also coordinate the other working group and follow up with the work of other key players (such as Eurostat, WHO-Europe) that have already put in place similar health status modules.

23. The Secretariats (WHO, ECE and Eurostat) will prepare shortly after the meeting a work plan of activities that would lead to the next joint meeting where the results of the definition process will be reviewed. The date (possibly late 2005) and the venue of the meeting will also be decided.

24. If a broad consensus is reached (in one or two years time), the group will submit the agreed recommendations to the Conference of European Statisticians to hope for a stronger commitment of national statistical offices to implement the agreed approaches.

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