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**PROBLEMS ASSOCIATED WITH THE LACK OF COORDINATION IN NATIONAL AND
INTERNETIONAL HEALTH STATISTICS**

Submitted by the WHO Regional Office for Europe,
Unit of Epidemiology, Statistics and Health Information

Note by the ECE secretariat: At the request of the WHO Regional office for Europe, the secretariat is making the paper that is presented in the Annex to this note available at the plenary session as an additional aid to the Conference's in-depth review of health statistics at the plenary session. The paper presented in the Annex was originally issued as a paper (CES/AC.36/1998/7) for the ECE/WHO-Europe Meeting on Health, Statistics, which was held in Rome from 14-16 October, 1998 (see the report of the meeting, CES/AC.36/1998/3).

Annex

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**STATISTICAL COMMISSION and
ECONOMIC COMMISSION FOR EUROPE**

**WORLD HEALTH ORGANIZATION
REGIONAL OFFICE FOR EUROPE**

CONFERENCE OF EUROPEAN STATISTICIANS

Joint ECE-WHO Meeting on Health Statistics
(Rome, Italy, 14-16 October 1998)

SESSION I: Problems associated with the lack of coordination in national and international health statistics

**Collaboration and coordination in health information
and health statistics in the WHO European Region**

Invited paper submitted by the WHO Regional Office for Europe,
Unit of Epidemiology, Statistics and Health Information

Introduction

1. At the request of the Member States of the WHO European Region and following a number of discussions during the Regional Committees for Europe of the World Health Organization and specific Resolutions (e.g. EUR/RC43/R8 and EUR/RC43/Conf.Doc./3), the Regional Office has been trying to improve its collaboration and coordination in health information and health statistics in Europe. The aim of this effort has been to reach consensus on broad principles and specific cooperative and collaborative actions between Member States and between the International Organizations and the European Commission (EC) Services active in the field.

2. The ultimate goal is to develop a consistent and coherent health information system in Europe that is based on a collaborative effort that:

– avoids duplicate reporting by Member States to international agencies and the EC;

1 Throughout this document WHO specifically refers to the Regional Office for Europe of the World Health Organization.

- shares the work between the international agencies and the EC services involved in collating health information from Member States;
- consolidates and builds on existing international expertise in collection/collation;
- enables exchange of the information once collated between the various organizations;
- ensures feedback of the results for use by Member States for Public Health action.

3. This paper starts by simply listing some of the collaborative projects and work that has been undertaken jointly between WHO and the international agencies and the European Commission over the last five years. It then discusses the general issue of problems of uncoordinated reporting to international agencies, as perceived by WHO. Suggestions and options to avoid such problems and duplication of reporting are presented (partly based on informal meetings with OECD and EUROSTAT). The third section lists some of the concrete plans for 1998 and 1999 and ends by giving a vision for the future that we hope will be realized by the start of the 21st Century.

Progress to date

A. Bilateral

4. Up to now, the main bilateral efforts of WHO have been with the OECD and the EC, including mutual membership and participation in the main meetings and on the steering groups and task forces of each agency. In addition, OECD and WHO have informal agreements for mutual exchange of data of common interest and attempts are also being made to harmonize definitions of common indicators. In the case of WHO and the EC, joint efforts have been structured around a number of collaborative projects, for example (see also final section of this paper - Plans for 1998-1999) the development of:

- (i) A database of internationally used health indicators;
- (ii) Compatible telecommunication infrastructures for data exchange and reporting by Member States;
- (iii) Common Instruments for Health Interview Surveys in Europe;
- (iv) Highlights on Health for the EU countries and the report on the state of health in the European Community
- (v) WHO have also supported and contributed to the development of the Commission's programme on health monitoring (1997/2002).

5. Bilateral efforts, specifically in the area of health information, between WHO and UNICEF and the World Bank, have been mainly:

- general provision and exchange of data of mutual interest;
- specific data exchange for particular projects;
- participation in major meetings of the individual organizations.

B Multilateral

6. The major multilateral effort was on the occasion of the joint EU/UNICEF/WHO meeting on "Information for Health for Europe" (Copenhagen, 4-8 October 1994). This was the first region-wide meeting of the main providers and users of health information from each of the 50 Member States of Europe.

There were two representatives from each Member State and also from the EC, UNICEF, WB and OECD and the recommendations included the starting of a process of collaboration between the international agencies.

Reporting of health statistics to international agencies

A. The problem

7. The collection and collation of data for health policy analysis and health planning in an international perspective is chronically under-funded compared to other social and economic fields such as education, research and development, tourism, agriculture, general macroeconomic and financial, and industry statistics. There is growing consensus that this state of affairs is in sharp contrast to the importance of health as a field of social policy. It is ironic that in spite of this fact, or because of it, in recent times, the problem of duplicate reporting of the same data to different international organizations has been quite often raised on various occasions. Lack of coordination between international agencies which are active in health data collection was usually given as the reason for the problem of duplication. Requests to countries from different international agencies to provide the same or similar data, particularly when different agency-specific definitions for the same data items are applied, can certainly create problems and put an unnecessary burden on countries. On the other hand, the degree of such duplication and its effect on countries is not properly estimated in quantitative terms.

Attempts by the OECD to formally quantify and identify duplication with WHO, EUROSTAT and other organizations have yielded few examples of genuine double work, the duplication listed being mainly that at the reporting stage.

8. Nevertheless, along with any real or potential unnecessary additional burden on countries, duplicate reporting can and does result in different values for the same statistics or indicators. This is especially the case if more than one information source in a country is approached by the various agencies requesting their "national" data for international use. Such

discrepancies can and do cause serious difficulties for users of international data.

9. Furthermore, the common practice of exchanging unstandardized data (e.g. number of doctors, hospital beds) with or without heavy "metadata" systems for describing national sources and differences in national definitions used, needs now to be replaced by standardized data collection. As pioneering attempts, such exchange served a very useful purpose at the time. As pointed out by the OECD, even with investment into descriptive systems of "footnotes" or "metadata", such exchanges are of limited value for the majority of data users who are typically non-specialists in health statistics and more interested in numbers than footnotes. Problems created by such use are put at the door of quality and non-comparability of international data.

10. Potentially, the above two issues can lead to less or even non-use of international comparisons. This can only serve to deprive policy makers and managers of a very important source of comparative information that can and does help countries identify areas for action and learn from each other's successes and failures. Therefore, further improvement of international data collection, dissemination and use, must take place. However, a number of prerequisites are needed which require joint action both at country and international levels.

B. Prerequisites

11. Prerequisites for improved data collections for health policy are common frameworks and definitions for data collections. This comprises the selection of aspects of health and health care to be covered, a shared view of what constitutes health and the role of factors influencing it, and statistical standards for measurement tools and classifications. While there is an emerging consensus about underlying views on health and the role of health policy (WHO: HFA targets, OECD: implicit model of the production of health), there is less common consensus about measurement tools and still pressing demand for common classifications and definitions to be agreed upon internationally.

Examples are:

- Standards for measuring health care resources (human resources, technology) and their usage by type of resource, target group and purpose of health programme;
- Agreements on a family of outcomes measures and how best to collect them;
- A general framework for reporting on the organization and functioning of health care systems and health care reform as background for data analysis.

12. The approach to the development of international standards for frameworks and definitions must be flexible. In Europe most countries have invested

heavily in data collection systems that are based on national standards albeit in some cases historical and not compatible with other countries. In these circumstances, it is unlikely that countries will agree to any "international" standard that will require major changes to their national systems.

13. No international standards, definitions or frameworks should be developed without the ongoing and committed input of countries. The way forward is to have a three-pronged approach, all of which require close collaboration and cooperation between the international agencies and countries. In those cases where all countries have well established national systems, and where the infrastructures of the systems are inherently different (e.g. health care data), there should be "international" common classifications rather than standards. In these cases, the national data are "transformed" (what is known statistically as post-ante harmonization) by the countries to conform to the common classification. This approach has been tried and tested and shown to work during the EU/WHO ENSCARE Statistics Pilot Project (1992-1994).

14. In those cases where countries are still at an embryonic stage at national level (e.g. in the case of health outcomes and efficacy of interventions), there is a strong case for a longer term and sustained approach to develop international standards similar to the ICD. The approach adopted by the WHO/EURO Quality of Care Programme has already shown the value of involving the European and national medical associations in the process. Through consensus conferences to agree on the data items for reporting and associated definitions, and the collection of data and feedback of comparative indicators, major steps have been taken to identify differences in efficacy of medical interventions and health outcomes in the areas of diabetes, obstetrics, mental health and stroke (this approach will be presented as part of the session on health outcomes).

15. In between these two extremes is the example of the area of health interview surveys, where some countries carry these out but most don't. Even the majority of countries that carry out such surveys tend to do them every 3 to 5 years and therefore, are more flexible to considering changes to their "established" questionnaires. The WHO led Health Interview Survey Project (EUROHIS) started jointly with Statistics Netherlands in 1987, and now funded by the EC BIOMED2 programme for the next 3 years, provides an approach that enables countries to gradually move to an "international standard" framework for national reporting.

C. Options for routine collection of international data

16. There are likely to be a range of options but from a conceptual point of view the two solutions at the opposite ends of the range are:

The first extreme option

17. For each specific group or set of health statistics (e.g. finance, health status, demography, health services) only one particular international agency collects data from countries, cleans and harmonizes it and then shares it with all the other agencies and users who may need it.

18. Advantages of the first option:

- (i) The data is standardized and usually of a high quality due to the specific expertise and experience of the responsible agency and its direct contacts with the appropriate data providers in the countries.
- (ii) Data are reported only once to a particular agency (or group of them if joint questionnaire is used), i.e. no duplication or extra burden.

19. Disadvantages of the first option:

- (i) Given the relatively large number of agencies active in health in Europe, it is inevitable that there are differences in their needs for health data. Furthermore, there is rapidly changing demand on each agency for various and new types of health data. This diversity also means differences in requirements for the related collection methods and use. Under these circumstances it may be unrealistic to reach agreement on a strict division of health data collection amongst all active agencies. On the other hand, some kind of "natural" division of labour between major international agencies is already in place due to their specialization e.g. OECD is the key player in the field of health expenditure, WHO is the main source of detailed mortality data and FAO is the only source of comparable food production/consumption data. Further specification of this division and perhaps some more detailed and clear agreement between these agencies to share data may be helpful. Perhaps the main directions for better work and data sharing could be formulated and agreed.
- (ii) Receipt of data via secondary sources (e.g. through a "collector-agency") usually causes significant delays which cannot always be accepted by the end-users.
- (iii) Different agencies/users may need the same data in different formats and disaggregation. It means that the "collection agency" has to collect data in a most disaggregated form, which can then be aggregated according to the needs of other agencies and the end user. This requires appropriate permanent staff and resources which can be difficult for the respective "collector" agencies to justify since these extra requirements are not primarily for their own needs, and given that the health information sections of international agencies

and EUROSTAT are chronically underfunded compared to other sectors.

The second extreme option

20. International agencies continue to collect any data they may need directly from countries but countries have established a single depository of internationally (and nationally) collected and used health related data - national integrated health database (see paper 2). Data from these databases could be downloaded by any agencies or users themselves via telecommunication networks without any additional burden on the country. Countries should only ensure the regular maintenance and updating of their national databases. This is the approach tested by the EU/WHO ENSCARE Statistics Pilot in 1992-1994 and currently being implemented by the EU-IDA (HIEMS) and EUPHIN projects.

21. Advantages of the second option:

- (i) Significantly improved access to and use of health data both internationally and nationally.
- (ii) Time lag between the release of data in countries and access to these data by any user is reduced to the minimum.
- (iii) No duplication in reporting and there is only a single national source of data, i.e. no different values for the same data.

22. Disadvantages of the second option:

- (i) All countries should establish and maintain national health databases or integrate physically or virtually existing ones. This will require some administrative decisions, effort and resources.
- (ii) National health databases should be compatible in terms of content (at least a common standard set of data items which presently are reported to various international agencies) and the way of access to them to make automatic downloading of data possible. This requires a much better cooperation of the different sectors in the countries (present compartmentalization of data) and certain international coordination to ensure at least minimal level of compatibility of databases and access to them between countries.

The way forward

23. It is very likely that in reality the way forward is in between those two extremes, perhaps closer to the side of an "International Virtual database". In any case, improvement in availability, quality and use of health data at international level can happen only if the same improvements

take place at country level. National databases providing significantly better access to the data is an essential pre-condition to the progress at country and international level.

24. The main directions of work to ensure progress in better coordination and use of international health statistics, are perhaps the following:

- (i) mapping of duplications in health statistics collected by different international agencies and agreement on common definitions, at least for key health indicators (international agencies with the help of national data providers);
- (ii) international agencies should be encouraged to use, as much as possible, data already collected by other specialized agencies;
- (iii) establishment of a common international list of basic health statistics, integrating the presently collected and/or used indicators, by different international agencies, would be an indispensable tool for facilitating the implementation of the above two points;
- (iv) establishment and continuous maintenance of national integrated health statistical databases in each country as an essential step towards the improvement of access to and use of health data and their quality and comparability, both nationally and internationally. These databases should be easily accessible by international and national users, both for the professionals and the general public.

Plans for 1998 - 1999

A. The process for international agreement

25. The regular statutory joint ECE/WHO meeting in Rome, Italy (14-16 October 1998) provides another opportunity to continue the above process. The WB, UNICEF, UNFPA, OECD, the Council of Europe and the EC services have been approached regarding their own participation in the process and the meeting, and also support for the participation of the countries of eastern Europe. The response has been extremely positive in both respects and informal pre-meetings have been held between OECD, EUROSTAT and WHO and WB, UNICEF, and WHO, prior to the pan-European meeting.

B. The technical instruments for collaboration

26. In parallel, and in cooperation with the EC, an International Compendium of Health Indicators (ICHI) used by international agencies and the EC is being developed. The ICHI compendium is a structured database of internationally used health statistics and indicators containing for each indicator:

- (i) The title (where the title used by international agencies and the EC differs, a generic title is used).
- (ii) The definitions used (where these differ, the actual definitions used by the respective international agencies and the EC are recorded).
- (iii) The specific identification code (if any) used by each agency.
- (iv) The prime or basic source of the data used to calculate each indicator (this could be either reporting by Member States or a secondary international source, e.g. UN Statistical Office, UNESCO, FAO, etc).

27. The ICHI compendium is being developed both as a hard copy and as an interactive computerised database with a search facility. This compendium is intended to assist:

- (i) Member States in consistent reporting to different international agencies and the EC by identifying the differences in definitions (where they exist).
- (ii) The process of harmonising the definitions for common indicators currently used by international agencies and the EC.
- (iii) Reaching agreement on common sources for the data and mutual interchange of the data amongst international agencies and the EC.
- (iv) Users of international databases and statistics in identifying international sources for particular indicators.

28. The first version (draft) of the ICHI compendium is based on health indicators used by WHO, OECD and EUROSTAT². The OECD specially provided an advance copy of its "metadata" to enable this first version to be compiled. It has already proved useful to the new Member States of OECD, such as Poland, Hungary and the Czech Republic, to enable them to identify the

² EUROSTAT indicators are as per those provided to the "Working Party on Community Health Data and Indicators", Ministry of Health, Denmark, October 1994.

differences in definitions used by OECD and WHO. This identification has simplified their task of more accurate reporting to both agencies.

29. The ICHI compendium (version 1) will be available as a conference room document and will be further developed in cooperation and collaboration with other international agencies to include their health-related indicators. It will also be further developed to include the prime/basic source of the data used to calculate all indicators.

C. The infrastructure of collaboration

30. Both the EC and WHO/EURO are developing mutually compatible telecommunication networks for the exchange and reporting of health data and indicators. The EC is developing their Health Monitoring network (HIEMS) as part of the EC Interchange of Data between Administrations (IDA) programme. WHO/EURO is developing a European Public Health Information Network for Eastern Europe (EUPHIN-EAST), with the support of the EC's INCO-COPERNICUS programme and the EC's Health Telematics programme. The development of both the above networks is being coordinated through joint memberships of the project development team and are both based on the joint WHO/EC ENS CARE Statistics project (1992-1994). Both networks have as their stated aim to interconnect so that there is one European Public Health Information Network (EUPHIN) which can be accessed by all Member States and used by all international agencies in the field of health. This is the vision for the 21st Century that can be realized if we all invest and work for it.