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

Information for health for Europe
An overview

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

Introduction

1. During recent years health has become an increasingly important issue on the political agenda in most countries and also internationally. At country level, many new developments have taken place. In the health services sector *per se* these have included health care reforms and cost containment, together with a renewed call for equity and improving the quality and outcome of care. More generally, in many countries the public's concern for its health has led all sectors to recognize the importance of taking into consideration the impact of their policies on the health of the population. There is now also greater acceptance that health should be viewed as an asset and not only a cost. Together, these developments have resulted in more and more countries formulating **Health** policies (as opposed to Health Care policies) and updating them based on regular monitoring and evaluations. Collectively, countries have formulated and updated the European "Health for All" policy every 7 years since 1984, and monitor and evaluate progress towards it every 3 years. The last evaluation was in 1997 and the "Health for All policy for the 21st Century - Health 21" is to be finalized in 1998.

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2. All these policy developments require appropriate information support to ensure accurate analysis and assessment of the health situation, identification of directions for action, subsequent monitoring of outcomes and of the efficacy of policies and health care interventions. Therefore, the need for health and health-related (i.e. covering all sectors that impact on health) information, that enables the right policy choices and actions to be made for health, is today more important than ever before. It is, however, essential to recognize that in the field of health there are, in general, no absolute standards of health outcomes against which actions can be judged; even bench marks or guidelines are best deduced through comparisons between countries, regions, health care institutions etc. This means that firstly, the information collected (contents) should be relevant to today's and tomorrow's needs of the policy and decision-makers and health service managers and practitioners. Secondly, and perhaps most importantly, the information should be made accessible to them and their advisory teams in a user-friendly manner that facilitates international, national and sub-national comparisons. This requires a partnership for health between those who collect and provide statistics both amongst themselves and with those who use them.

Situation Analysis

3. Unfortunately, even in a region as advanced as Europe and in other developed countries, the health information systems in many countries are still lagging behind these needs and expectations. The traditional model of such systems serving central levels mainly for control, rather than as a service to other levels, is more common across Europe than it should be. Furthermore, some of the institute(s) traditionally responsible for health statistics still see their primary goal as the collection and publication (as voluminous non-user friendly annuals) of statistics *per se*. Also, although health information systems by their nature tend to be less flexible to rapid change, it is unfortunate that this and national traditions and past developments have led to their coverage at times being limited to health care services (mainly on process and input statistics) and mortality. In some countries this has, at best, resulted in other institutions starting to specialize in the collection of those health and health-related statistics that were traditionally not collected. At its worst, it has resulted in the dismantling of the traditional but functioning systems with increased fragmentation and at times unhealthy and wasteful competitiveness and duplication.

4. So today, in too many developed countries, information on health, in its broadest sense, requires the user to access more than one institute in the country (usually at least two) as there is no one place (physical or virtual) from which this can be obtained. For this and many other reasons, although in developed countries a lot of statistics are collected and produced, a large part of these routinely collected statistics are actually never used because most potential users do not have easy access to them or do not even know about their existence.

5. The situation at international level in Europe, perhaps not surprisingly, is similar to and reflects that at country level. However, the recognition of the importance of health issues for other sectors and agencies provides the opportunity to make powerful alliances for health. The international organizations and the European Commission now have a more active and broader role in the field of health than has hereto been the case. Under these circumstances and given the importance of information, it is inevitable that each organization will wish to maintain an international information base relevant and appropriate to its extended role and mandate (both in terms of content and Member States). The challenge facing the international community and information counterparts in Member States is how best to harness this new opportunity and to create a partnership for health information that shares both the work to be done and the fruits of this labour.

6. Most of these problems and issues were reviewed and discussed during the "Information for Health for Europe" joint EU/UNICEF/WHO meeting which took place in Copenhagen, 6 - 8 October 1994. This was the first Region-wide meeting on the Provision and Use of Health Information and brought together for the first time in recent decades the key national health information providers and users from all the 50 WHO Member States of the European Region. Also present at the meeting were representatives of the European Commission and a number of international organizations active in the health field. There was general consensus and recognition of the above-mentioned main problems of health information systems and needs for better co-ordination and collaboration at both country and international levels. The crucial role of telematics and how the current rapid advances in informatics can be best utilized in the future were also presented as a vision for the future.

Progress to date

7. Since then, substantial progress has already been made. Some countries have implemented or extended their existing initiatives (individually or as part of international, for example joint WHO/EU projects) to develop country-wide health databases. These are now providing user-friendly access and feedback of comparative health and health-related information to decision-makers, managers and health practitioners at national and sub-national levels. Some countries are also using or planning to use such country-wide databases as the prime source for reporting health data to international agencies. Most countries have also started to implement in earnest the tenth revision of the International Classification of Diseases (ICD-10). Renewed calls for health outcome measures, at times from the general public, has focussed attention again on the efficacy of treatments - on the need for "evidence-based medicine".

8. At the international level, UNICEF and UNFPA continue to bring attention to the health needs of the women, children and future generations of Eastern Europeans and the World Bank has rapidly expanded its work programme in response to the considerable health development needs of these countries. The European Commission has started implementation of the Health Monitoring programme which has imbedded in it the principles of building on existing

expertise and working with international organizations. To complement this effort, the Leadership Exchange Programme (LEGS) of EUROSTAT has started a cooperative framework utilizing the expertise of national statistical offices. This is an important step in the further development of the European Union Statistical System that enables a group of Member States to bring their resources to strengthen the joint efforts of Member States and EUROSTAT in developing a statistical domain.

9. OECD and ECE remain the "health bridge" between the developed countries of Europe and those in other continents providing comparative analysis through their publications. The *OECD Health Data* has considerably strengthened its financial focus and expanded to match its increased membership. Initiatives taken by the Council of Europe have greatly enhanced developments in the area of health and ethics and WHO has played a role in this and also in the other mentioned initiatives.

10. The primary role of WHO/EURO remains, however, that of formulating a Europe-wide health policy. This provides an agenda for action with European-specific health targets based on the Global Health for All (HFA) principles and policy, adopted by the World Health Assembly. The European policy, with its targets and principles, also provides the framework for countries to adapt it to their needs and to collectively monitor and evaluate progress towards it so that they can learn from each other's successes and failures. In the area of health information, the European HFA policy provides the *raison d'être* and foundation for the selection of the HFA indicators. It is these HFA indicators, as approved by the European Member States, that are reported on and fed back in the form of a user-friendly data presentation system - *the HFA database* - to enable Member States to pinpoint areas for public health action.

11. The telematic vision for the future, which was presented at the first Region-wide meeting, is also approaching reality in the area of health information. The European Commission has, for the 15 EU Member States, extended its Telematic programme for the Interchange of Data between Administrations (IDA) to health statistics. WHO has, with the support of the 4th Framework R & D programme of the EU, also started the development of a European Public Health Information Network for Eastern Europe (EUPHIN- EAST), initially for 23 countries, covering mortality and the HFA Indicators. It is the stated aim of both networks that they will interconnect to create one European Public Health Information Network - EUPHIN.

12. This substantial progress has been made, to a large extent as a cooperative and collaborative effort between countries, international organizations and the European Commission. This statutory Sixth joint WHO/ECE meeting on Health Statistics now provides a forum and another opportunity for Member States to review progress and discuss the problems and issues of health information systems in Europe. A number of the relevant international organizations and the European Commission will also be present at this meeting. This extended participation is a unique opportunity to also explore

and exchange ideas on how the existing national and international collaboration and cooperation can meet not only the needs of the individual projects *per se*, but at the same time those of Member States, including common definitions and effective international data collection and exchange. Attention also needs to be drawn to the important areas for which data of acceptable quality are mostly still not available in many parts of Europe (e.g. health accounting and quality of care and outcomes). It is in the interest of Member States, the European Commission and all the relevant international organizations that the current collaborative efforts continue so that we can ensure that all our efforts are directed towards tackling these important gaps rather than duplicating efforts and existing expertise.

The way forward

13. The task facing all of us must be to put health information high on the agenda. We can do this by ourselves, making greater, more effective and visible use of the information we collect; by broadening its coverage through mutually beneficial and cost-effective partnerships and by stimulating greater use of information by policy and decision-makers. This means strengthening health information systems at country level and sharing and feedback of comparative information internationally, nationally and sub-nationally.

14. As the papers presented to this meeting show, this requires two pre-requisites at country level:

- A national integrated health database (physical or virtual) that provides a single readily accessible source (bringing together a variety of data on indicators of health and areas related to health) for use at national and sub-national level. (Session 1 --Paper 2).
- Identification of a national minimum set of core indicators with a user-friendly, menu-driven system for the non-expert (policy makers, managers, practitioners) user (Session 1 - Paper 3).

Interlinked with the above, must be efforts to ensure expertise and training in the use of information for improved policy- and decision-making. However, without the above pre-requisites, such efforts cannot realize their full potential.

15. One or other of the above prerequisites or elements of them are being implemented internationally (e.g. the WHO HFA database system, OECD Health Data, the UNICEF MONEE database) and in many countries in Europe and elsewhere (as described in Paper 3). In such developments, issues relating to coordination, collaboration and avoidance of duplication arise both at national and international level. However, at international level such issues are more visible and recently there have been increasing demands from Member States for greater coordination and collaboration between the international agencies and the European Commission. These are discussed further in Paper 4 - session 1.

16. It is expected that countries will present, in Rome, some of their experiences including the problems faced in the sustained use of such systems for action. All such systems have the power of comparisons as a fundamental underlying principle to compare relevant data between countries, regions, hospitals, health practitioners and specific groups of populations. As the information age unfolds, the rapid developments in IT should be harnessed to facilitate ready and quick access to comparative information. Some examples will be presented during the session on IT.

17. IT can also serve as a solution to avoid many of the above-mentioned issues of coordination, collaboration and avoidance of duplication. However, IT is not and cannot be a panacea for underlying problems. Furthermore, IT should be viewed as a tool and not as the end-product. Nor, should the issue be one of which piece of software to use (be it the WHO HFA database system or some other).

18. Our firm goal must be to develop and maintain health information systems that provide feedback of comparative information. Such systems can, and do, enable areas for public action to be pinpointed and as the world moves to greater decentralization, it will enable local managers and practitioners for the first time to view the performance of their districts, hospitals, clinics and practices in a national and international perspective and that of their peers. It is the motivation derived from such comparisons, coupled with accountability, that will enable information to play its rightful role in improving the health of Europe.

Conclusions

19. Sound, relevant and comparative information is an essential basis for knowledge and considered action and its importance for improving health and health outcomes is now well recognized. The advantages of **comparative** information at all levels of the health service (nationally or internationally) are rapidly creating an impetus for sharing relevant information to add to the pool of knowledge for improved action, be it for health policy formulation, planning, management or monitoring and evaluation. Rapid advances in telematics can now facilitate ready and quick access to comparative information.

20. The challenge is to create partnerships at national and international level to extend on a systematic basis the sharing of:

- knowledge
- actions
- experience of actions

at international, national and sub-national level so that there is "a practice-oriented exchange of experience" leading to a continuous improvement in the delivery of care to patients and the health of the population - thereby contributing to the achievement of the goals of Health for All.