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

**Strengthening National Health Information Systems
The concept of national integrated statistical health database**

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

The Problem

1. The difficulties in accessing statistical data in a user-friendly form are among the main reasons for the low use of already collected information and therefore insufficient functioning of the national health information systems in general. The underlying problem is that the importance of data accessibility in a user-friendly way is underestimated. Routinely collected data are usually controlled and used by data producers in most countries. Due to lack of dialogue between data producers and users, a large part of these data remain in the databases of the producers, normally not accessible or even known to most users. Increased use of data would also improve feedback to data producers and as a consequence, would improve data quality and availability. Presently, yearbooks on health statistics and, in some cases, public health reports, are often the only way for ordinary users in health services to get access to data. If data are needed in a different form, in practice it means that a special request for data retrieval/grouping/analysis has to be made to the statistical department or other relevant institutions. Such efforts are often not considered worthwhile by the users. It is even more difficult if data from different sectors (Ministries) are needed, e.g.

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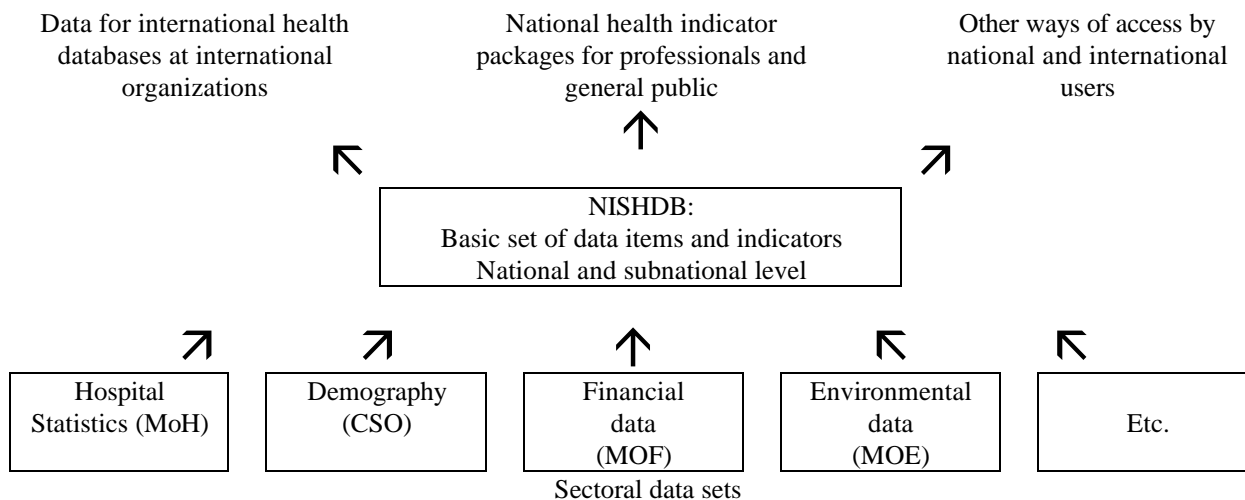
health, finances, environment, etc.

2. One of the usual excuses to limit direct access to statistical data is the perception that the data are of low quality and that the definitions and measurement techniques are not standard. This is true in many cases but it is also true that the bad quality of data is often over-estimated, without any proof that this is the case. Due to insufficient use of data, there is no feedback from users, which would stimulate improvements in data quality. In other words, a vicious circle is in place. This problem has to be better understood both by the data producers and the users and certain compromises have to be made. Producers should pay more attention to the detailed documentation of the definitions, registration and measurement techniques and practices, possible biases, etc. Users should accept, at least temporarily, that there is no guarantee that the data are fully reliable and comparable. The above, combined with user-friendly access to information, creates essential conditions to improve and widen the use of data. It should also gradually build an "information culture", i.e. practices to back-up any decision with thorough assessment of available information.

Suggested Solution

3. A way to overcome these problems is to establish a national integrated statistical health database (NISHDB) on health and health-related statistics, gathering most important statistical data in one place and giving national and international users user-friendly and flexible access to it. Technical solutions on how this database is organized and maintained may vary between countries depending on the level of development, available resources and ambitions. However, taking into account currently available information technology and telecommunication means, the establishment of NISHDB should not create great technical difficulties in most, if not all countries of Europe. It is more a matter for administrative decision by national health authorities and, in practice, depends on readiness and willingness of national health statistics producers to switch to modern ways of data dissemination and use and to share it with other sectors and users.

National Integrated Database on health and health-related statistics



4. It is important to point out that many countries actually have a kind of NISHDB. In general, however, these are data producer-oriented databases. Such databases are normally located at national health information institutions and are used by data producers to prepare the yearbook on health statistics or specific reports. Without reorganizing databases, the simplest way to make the information accessible for a wider range of users is via a user-oriented interface. The WHO Health for All (HFA) or national Health Service Indicator (HSI) like packages based on a user-friendly data presentation system, could serve as such an interface in the first instance. HFA/HSI indicators can be calculated from raw data items and updated packages distributed regularly on diskettes or via telecommunication networks. The second step would be to give the users access to the raw data in order to calculate user-specific indicators. A number of countries have already started to implement these steps.

Content of NISHDB

5. One of the issues faced by developers of NISHDB which requires certain compromises is the content of the NISHDB. The data has to be as detailed as possible in order to serve more users and to be used for a variety of purposes. On the other hand, the very large amount of disaggregated data makes the whole database complex and difficult to handle. Therefore, a certain optimal balance in NISHDB content should be found to satisfy most user needs and be manageable and cost-effective at the same time.

6. The NISHDB should normally cover the following broad areas with regard to content:

- Demography and vital statistics;
- Health status:
 - mortality
 - morbidity
 - disability
- Life styles;
- Environment;
- Health services:
 - resources
 - utilization including hospital and out-patient statistics
 - costs and funding.
- Basic social and economic data (living conditions).

Each data item normally gives a value for one year but some indicators, e.g. incidence of notifiable diseases may require a shorter reporting period, quarterly or monthly. Each data item contains a value corresponding to at least the total for the whole country and, whenever possible, also disaggregated by administrative or health regions of a country.

7. Technically, it may be more convenient to organize NISHDB by the origin and/or structure of data rather than by content. For example, hospital statistics and population survey data may be used to estimate the same indicator but the data source and structure is completely different. The following blocks of data, with similar origin and structure, may be provisionally identified as the main components of the NISHDB:

- Population by age groups, sex, urban and rural; births, migration, natural increase, marriages, divorces.
- Mortality by age group, sex, cause of death (e.g. in standard WHO format).
- Hospital discharge/admission data: number of discharges, length of stay, destination of discharge by diagnosis, age, sex; operations performed.
- Routine reporting on resources, manpower and utilization of in-patient care: number of beds, physicians, nurses, etc; admissions/discharges, length of stay by speciality.
- Routine reporting on resources, manpower and utilization of out-patient care: number of physicians, nurses, number of contacts/visits by type, age,

diagnosis and speciality; estimates of the incidence and prevalence by diagnosis.

- Routine notification data on infectious diseases: cases of diagnosis, age and sex.
- Immunization coverage and other preventive activities.
- Data on costs, including pharmaceuticals, insurance data.
- Dental care: resources and utilization.
- Laboratory data: resources and procedures performed.
- Environmental data: levels of pollutants in air, water, food, etc.
- Data of population surveys: sample size, incidence/prevalence of selected diseases, smoking, alcohol consumption, nutrition, disability, patient satisfaction estimates, perceived health, etc.
- Basic socio-economic indicators: unemployment, education, social class, inflation, income, housing, etc.

8. Although the content of the NISHDB may vary between countries, reflecting different needs and traditions, nevertheless, certain data items should be tagged, indicating that these are part of an internationally agreed common set of data items based on standard definitions. Where definitions required differ, this will also enable countries to more easily document and adjust the reported items to those requested. Some countries have started to maintain such a common integrated list of indicators (framework) with indication of which indicators are to be internationally reported to the various organizations. This will greatly facilitate the co-ordination and consistent reporting of data and simultaneously help users to contact the appropriate sectoral database. Furthermore, this can be an impetus to create a common international minimum set of health indicators, to facilitate harmonization of definitions and reduction of unnecessary duplication in data collection, whilst drawing attention to the important areas for which data of acceptable quality are mostly still not available (e.g. health accounting and quality of care and outcomes) across Europe.

Conclusions

9. The creation of an NISHDB at national or international level is an essential pre-requisite for greater accessibility and use of health information for policy and decision-making. Greater accessibility and use will also provide feedback on quality and enable providers of statistical information to correct discrepancies. Such a joint effort between the providers and users of data and a partnership between the various providers of data from different sectors will not only bring mutual benefits but also serve to ensure that the right areas for action to improve health are targeted. The creation of NISHDBs have also proved to be extremely beneficial and cost-effective and have greatly facilitated the task of countries in reporting to international organizations.