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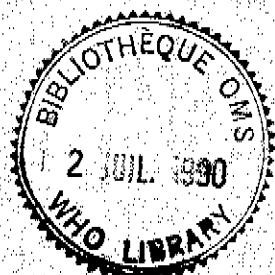
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HEALTH MONITORING SYSTEMS AND EPIDEMIOLOGY
AS A BASIS FOR HEALTH POLICY DECISIONS

Report on a WHO Symposium

Kiel

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TARGET 35

Health information systems

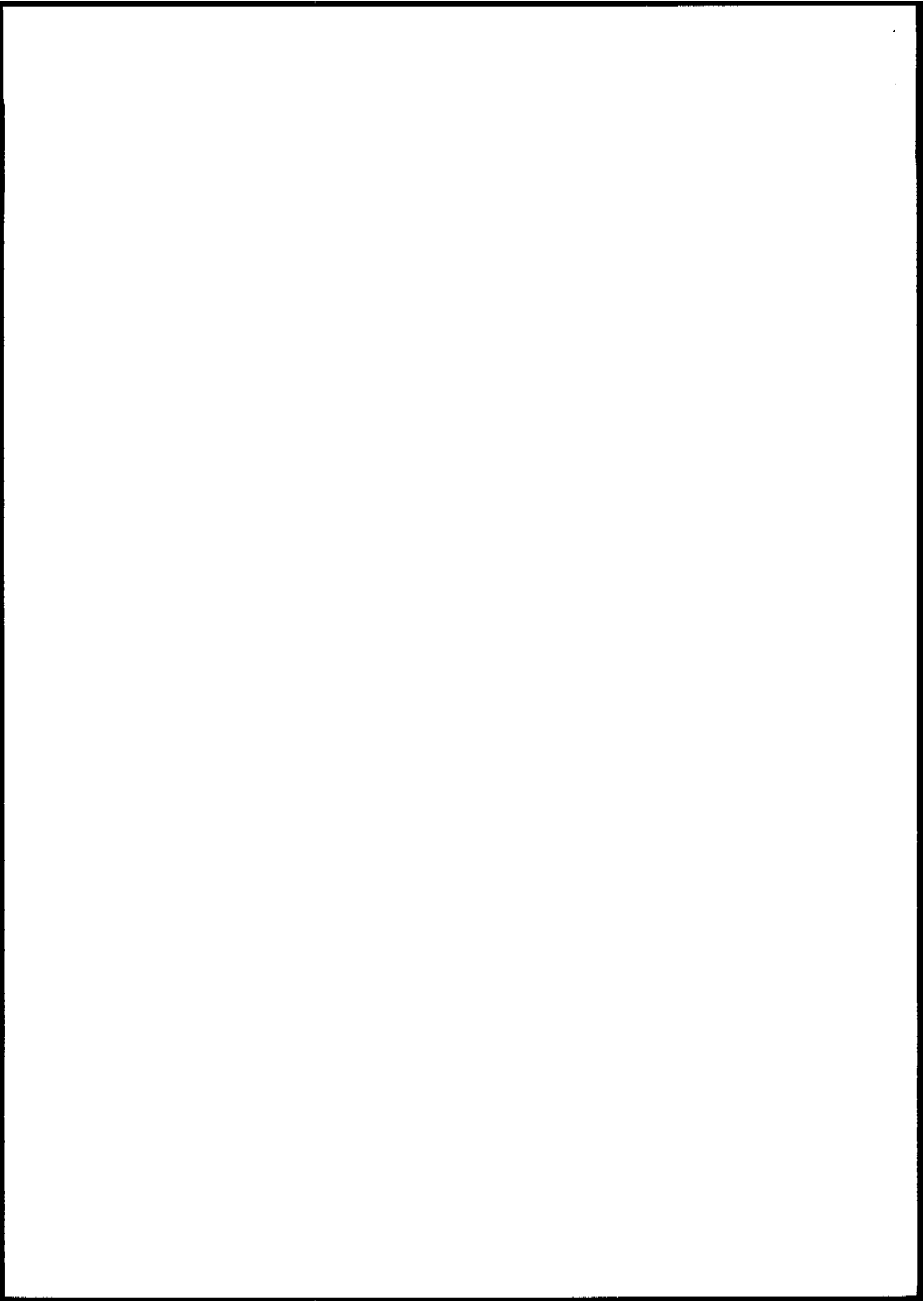
Before 1990, Member States should have health information systems capable of supporting their national strategies for health for all.

Index:

INFORMATION SYSTEMS
HEALTH
EPIDEMIOLOGY
HEALTH POLICY
EUROPEAN ECONOMIC COMMUNITY

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Introduction

Many countries in the European Region have implemented or are planning programmes for health monitoring. This development is closely related to the formulation of health policy objectives which, in part, have been or are being influenced by WHO's strategy for health for all (HFA) by the year 2000. At the same time a number of problems have arisen in connection with the establishment of monitoring systems geared to health policy.

The Symposium on Health Monitoring Systems and Epidemiology as a Basis for Health Policy Decisions was held in Kiel, Federal Republic of Germany, from 14 to 16 November 1989. It was organized by the WHO Regional Office for Europe in collaboration with the Institute for Health Systems Research, Kiel, and the Ministry for Youth, Family Affairs, Women and Health, Bonn. The meeting was opened by Dr Hans Stein of the Federal Ministry for Youth, Family Affairs, Women and Health on behalf of the Federal Minister, by Professor Meyerhoff of the Schleswig Holstein Ministry of Social Affairs on behalf of the Minister, by Professor Fritz Beske of the Institute for Health Systems Research, Kiel, and by Dr P. Owe Petersson on behalf of the WHO Regional Director for Europe.

The purpose of the Symposium was:

- to review health monitoring systems (existing or planned);
- to identify crucial aspects of these systems;
- to suggest ways of overcoming major problems;
- to encourage those concerned to consult each other in order to improve the contents and relevance of health monitoring systems.

A problem of terminology arose at the beginning of the meeting. The question was how the German term "Gesundheitsberichterstattung" could be related to the English term "health monitoring". While both terms imply continuity in keeping watch over a process of events, the German term may also be used to describe the outcome of this activity (i.e. a health report), while the English term refers to the observation and noting of events and their comparison with the results expected, a facet of monitoring not necessarily implied by the German term. In order to overcome these differences the participants agreed to use the terms "health-related data" and "health information system" instead of "health monitoring system", while keeping in mind the aspect of continuity.

General aspects of health monitoring in Europe

The monitoring of the HFA strategy stands out as a prominent example of a health monitoring activity at the international level. It has the specific aim of evaluating, in the light of predefined targets, changes in the health situation that are attributable to the HFA movement. This explicitly active approach to measuring change has the advantage of being an integral part of health policy implementation. As the concept of health adopted by WHO is so broad, the scope of monitoring necessarily includes: health policy; activities undertaken in order to reduce risk factors, improve health protection, strengthen the role of communities and make health services more

appropriate; increasing public awareness; reducing mortality, morbidity and disability; and information support and research. The HFA indicators are effective in areas of more traditional public health concern but are not yet a satisfactory tool for measurement in the fields of environment, lifestyles or perceived health status.

A good deal of the problems stem from the international character of the monitoring system, that is to say differences between countries in concepts, definitions, instruments of measurement and the availability of data. Nevertheless, WHO's demands for data have been welcomed by some countries, having spurred them to refine their existing health information systems. WHO and other international bodies may play a significant role in developing and promoting methods which permit international comparisons of health information.

Health information systems in countries will most probably have some country-specific features, but many aspects of such systems are common to the Member States as a whole. In many instances the relevant data are available but are neither prepared nor presented in a form suitable for use by decision-makers. Participants stated that health information would have more impact if it were related to health policy targets, presented for small areas and displayed so that it showed trends over time.

The following were identified as being major gaps in present health information systems:

- a lack of data on perceived health status, certain important and frequent diseases (e.g. allergies), disabilities, the incidence and prevalence of major chronic diseases, behavioural risk factors, exposure to physical and social risk factors and the outcome of the work of health services (impact of health policy);
- incompatibility between data components in a system;
- a lack of specific information on the characteristics of important population subgroups, such as the elderly, minorities, and particularly vulnerable individuals (e.g. children, pregnant women);
- a lack of analyses (including medical and social variables) other than mortality analyses;
- failure to feed back results to those concerned or to those who have provided data.

Discussing the first item on the list, the participants attempted to assess whether the data were available by region or by socioeconomic group. Small-area data are not usually available at these levels continuously. However, specific analyses, mostly of mortality data, are possible in some countries, as is demonstrated by analyses of avoidable mortality.

Surveys were mentioned as possible sources for the majority of the missing data components. However, most European countries lack a set of interrelated population-based surveys that are broad enough to cover the subjects mentioned and have been carried out at frequent enough intervals.

The participants felt that one of the obstacles to collecting and disseminating relevant health information was the lack or undersupply of well

trained epidemiologists, health statisticians, and experts in health information, which they attributed to the fact that health information as a career does not attract enough young people.

Reports from several European countries suggested that health monitoring systems are either set up or substantially improved in content when health service funds are distributed on the basis of health indicators. However, this happens in only a minority of countries, and even then not necessarily at all administrative levels.

The participants gave examples of health policies and discussed them in relation to the availability or otherwise of health information.

In the following examples of national-level health policies, health information was available as a basis for the policy decision:

- development of goals and priorities in health policy;
- introduction of lead-free petrol;
- campaign against malignant melanoma;
- reduction of accidents to children.

Information was also available for the following local-level policies:

- immunizations;
- anti-smoking campaigns;
- tuberculosis control activities;
- reduction of cardiovascular disease.

In some cases no health policy decision is taken at national level, even though health information is available, examples being:

- anti-smoking activities;
- reduction of low birth-weight infants;
- planning for the supply of physicians;
- financial disincentives to alcohol abuse and smoking.

The same may also hold true at local level, as in the following examples:

- fluoridation of drinking-water;
- reduction of abortions/unwanted pregnancies;
- reduction of speed limits for motor vehicles;
- planning for hospital beds.

On the other hand, action has sometimes been taken despite the fact that no health information was available on which to base the policy. National-level examples include:

- introduction of an information service to monitor the pollen count;
- activities relating to AIDS;
- cancer (specifically breast cancer) screening;
- manipulation of co-payment in order to reduce the cost of health services.

Local-level examples include:

- provision of special diets in kindergartens;
- mental health programmes;
- measurement of environmental pollution.

Needs of health policy-makers for health information

It was pointed out that modern health policy relies heavily on health information, but that administrators tend to use this information selectively, carefully avoiding anything unfavourable that might be attributed to a failure of health policy in the past. The participants felt, therefore, that it might be advisable for the major findings of a health information system to be made public, to guarantee full public awareness of all the facts.

On the question of who should be responsible for a country's health information system, it was pointed out that there could be a substantial duplication of health data storage and handling if the department of health developed one health information system for keeping its health policy up to date and the central statistical office developed another for general-purpose data. There are some convincing examples of health policy decisions based on information, but much useful health information remains unused.

The participants stressed that a health information system requires the support of decision-makers. Politicians can be expected to support it if they understand the political necessity for it and its usefulness for their own work, but the system's scientific merit alone will not be enough. Health may rank high as personal value but is not necessarily a public issue. In practice, many decisions are taken in the absence of information, or using information that is incomplete. One explanation put forward for this unsatisfactory relationship between health information and health policy decision-making was the fact that health information can be used to question the wisdom of political decisions. Its nonpartisan character is one of its merits, but health information may also create pressure, especially if broken down in such a way that it can be seen where the political responsibility lies for specific results.

Use of health information in health policy-making

One aspect of health policy is the development of policy objectives. Objectives may either be based on comparisons of concrete data (the empirical approach) or not (the theoretical approach). Both approaches have their advantages and in reality a policy objective may be based on a combination of the two. The empirical approach may be preferable in instances where health policy is not developed at the national level but rather emerges from decentralized negotiations between those supplying and those paying for services. Relevant and differentiated health indicators are a sine qua non for a health information system capable of supporting the development of policy objectives.

Epidemiological data are used in health policy mainly for two purposes: to formulate needs and goals, and to implement policies by means of the managerial process. In the first case, data are needed to answer questions about the distribution of health problems and about trends, about the resources required to effect desired changes, and about appropriate political goals. In the second case, the data are used to support the intersectoral and intrasectoral processes. A health policy matrix (summarizing the different risk factors for different health problems) can be developed for the intersectoral process, whereas in the intrasectoral process it is the indicators for resource allocation to geopolitical areas and the indicators for monitoring the outcome of care that are the centre of attention.

Experience shows that a number of health services indicators may be available at the national, regional and very small area levels. Such indicators are useful for highlighting variations and extremes that have policy implications, which in turn may help administrators to understand better the health needs of defined populations, to target services to identified needs, and to monitor the outcome of the services. Examples of indicator-based policy at the national level are heart disease campaigns, financing services for HIV/AIDS and screening for cancer; local-level examples are the reduction of perinatal and infant mortality, and the provision of antenatal care for residents of small areas. Surveys will be needed to augment the above service-based and demographic data by adding data on positive health and lifestyles.

Information for policy-makers should be presented in such a way that it attracts their attention. Traditional health information systems suffer from a lack of relevance and timeliness, and from the fact that decision-makers are not prepared to use the data. Improvements are necessary to make health-related information easier to use. It was suggested that the users' attitudes need to be changed and that information services should be developed to serve specific categories of user. One successful service consists of the selection, evaluation, analysis and synthesis of information gleaned from scientific journals and presented to health decision-makers on a regular basis in extremely condensed form. This type of excerpting service can also produce mini-reviews at short notice in response to very specific inquiries.

International comparisons of data and health indicators

The participants also discussed the methodological aspects of collecting, analysing and presenting data on equity in health care. An analysis of equity requires an input of data for subgroups of populations. This means that there must be not only uniform definitions of the outcome of treatment but also a minimum of agreement on the variables used to classify the subgroups. International comparisons of trends in variability are therefore much more data-dependent than the traditional international comparisons of parameters of location. Of various methods evaluated, only two turned out to be suitable for equity analyses: weighted squared deviation and Gini index. Using regionalized lung cancer mortality rates as an example, it was shown that analyses made on the basis of these methods would reduce the volume of data substantially - which is essential if policy-makers are to be interested in health information. It was felt that the European countries' data base is at present insufficient for Europe-wide analyses of equity, but that it could be worthwhile developing it for that purpose.

The participants pointed out that the traditional type of health information was much better for describing the situation than for making predictions. As prognoses are often required, however, it was suggested that mathematical modelling and expert system methods might be used to fill the gap and to help improve decision-making.

Ideas for developing a minimum basic data set of internationally comparable health indicators were discussed. The participants felt that such a set of quantitative and nonquantitative indicators could be useful for the advancement of health policy. It would be a challenge in terms of methodology and theory, requiring training, research and the efforts of schools of public health in many countries.

Conclusions

1. The health information system

A health information system is a changing entity consisting of data elements and an organizational structure which facilitates their utilization. The organizational structure enables the user of the system to condense, select, aggregate, extract or display data. The system should be flexible enough to receive new data items and to adapt to new methods of data structure and organization. A health information system should be able to provide information at local, regional or country levels and for other subsets of the population. It should enable users to extract and analyse data from various perspectives and in different contexts, thus providing information for many purposes. This depends on a database being available which allows the data to be used and interpreted in a number of ways by different interested groups.

2. The quality of health information, and methods for data analysis

Data in health information systems should gradually be improved so that they provide relevant information to the public, to politicians and to administrators. For that purpose data should have the following characteristics:

- full documentation of data contents, and of origin or secondary source;
- uniform definition of terms;
- relevant references, such as sizes of numerators and denominators, reference population, reference period;
- reference to population served and to providers of services;
- timeliness.

The following methodological requirements should be met:

- methods of data analysis should be appropriate;
- parameters of location (means, medians) and measures of variability should be provided;
- estimates of location and variability should be calculated on the basis of valid weighting procedures.

3. The content of a health information system

The major data items that a health information system should contain are:

- vital events;
- data on health status of the population;
- data on lifestyle and behavioural factors;
- data on self-help and self-support;

- data on health services utilization;
- data on health and social services resources;
- data on cost and financing;
- data on environmental factors; and
- data on factors directly or indirectly affecting the health of populations that stem from outside the health service system.

While specific data indicators were considered for each of these data components, no deliberate attempt was made to suggest specific indicators for country health information systems. However, it might be useful for a working group to decide on a minimum basic health-related data set for within-country and intercountry analyses.

4. Country indicator systems

Countries should be encouraged to develop databases containing the necessary data components at the smallest possible aggregation level (i.e. local area, ward, census district). Using the bottom-up approach, these data can be aggregated to form indicators at state and country levels. Excerpts from such indicator systems might also be useful to the Regional Office in the framework of the HFA evaluation exercises.

Experience from several countries shows that the development of a health information system does not necessarily follow the same pattern everywhere and does not occur according to a predesigned plan. Instead, it happens by discrete steps, each influenced by a multitude of factors, and the whole process seems to be rather country-specific.

5. Effectiveness of health information for the public

To be effective, information needs to have special characteristics and to be disseminated through the appropriate communication mechanisms. Effective information is characterized by its ability to highlight important items. In particular it should:

- point to problems that people are not yet aware of;
- be group-specific (e.g. information on work-related disability and mortality);
- be oriented to a local area or community;
- focus on health problems that are amenable to intervention;
- concentrate on striking differences or trends;
- help to create a health lobby.

6. Effectiveness of health information for health policy-makers

The requirements just listed also apply to information intended for decision-makers. Politicians and administrators may be particularly

interested in information that points to problems amenable to action (such as early intervention or cure). Health information will be most effective when presented to decision-makers with a special interest in health or who are qualified in that domain. Scientists should feel challenged to improve the training of administrators and decision-makers, in order to narrow the gap between the traditionally trained decision-maker on the one hand and powerful health information technology on the other.

Politicians prefer to act rather than react. This implies that information systems should be broad in terms of database contents and flexible in terms of methods and indicators, so that they can anticipate future demands for information and also supply information about new health problems on which attention might later focus. It may be necessary to streamline the information product and to develop marketing strategies for it.

7. Obstacles to the use of health information by the public or by decision-makers

Some of the problems which prevent decision-makers or the public from using information are:

- insufficient understanding on the part of scientists of the working reality of politicians;
- insufficient willingness on the part of scientists to present scientific results in lay terms;
- hesitancy on the part of scientists to present complex problems in simple, understandable language;
- lack of time or willingness to listen on the part of politicians;
- lack of involvement in health matters on the part of politicians;
- partial reluctance on the part of politicians to base decisions on information.

These obstacles might be overcome if the partners were to approach each other, that is to say if scientists would make relevant health information available at the right time and in an appropriate form, and if health administrators or politicians would make the attempt to listen to them.

Recommendations

1. Health targets

Each country should develop health targets in order to provide a framework for the development of a set of indicators adaptable to those targets. The indicators would provide a frame of reference for within-country policy evaluation.

2. Cooperation between health politicians/administrators and scientists working in health services research and epidemiology

Member States should establish working groups of health policy-makers and scientists. The aim of this cooperation would be to give each side a better

understanding of the other's responsibilities and perceptions. In particular, groups of this kind could help to define both the information requirements of politicians and the scientists' capacity to provide them with adequate information.

3. Database and infrastructure for a health information system

When a national health information system is developed, both a database and an infrastructure should be created. The system should be accessible to many users. Intensive use of databases is advantageous in at least two ways: first, it tends to improve data quality, and second, it helps to focus indicators on new policy questions. Furthermore, it should be possible to analyse the data from various perspectives and for different levels of management. In particular, governmental and nongovernmental organizations and scientists should be involved in data interpretation in order to guarantee a balanced view of the information.

4. Periodicity of country reports

Country reports on the health of the population should be prepared every three years, possibly drawing on reports from subregions within countries. The Regional Office might provide a framework for these reports by suggesting contents and procedures.

5. Coordination/collaboration between the Regional Office and international governmental and nongovernmental organizations

The Regional Office and the European Economic Community should intensify their efforts to collaborate in selected research areas. The European AIDS Centre in Paris and the investigation into avoidable deaths were cited as examples of major collaborative research activities.

6. Development of a minimum basic data set for the health service system

A minimum basic data set of standardized health service indicators should be developed systematically until it contains all the data components listed under Conclusion 3 above.

7. Inventory of data sources

The Regional Office should invite Member States to help draw up an inventory of health-related data sources. Ideally this inventory should contain information on the relevance of data components to specific topics, methodological details (such as numerators and denominators), source and modes of access. It could be useful to have information from a number of countries about the experience with classification and the appraisal of data sources.

Member States might also be encouraged to make data available to the Regional Office for analyses of equity. The participants made suggestions for classification (by region, age and sex), outcome variables and methods of data analysis.

8. European Health Survey

It might be worth examining the possibility of combining the Member States' efforts and inputs and carrying out a European Health Survey. The

work already in progress under the auspices of the EEC could perhaps be redesigned to allow more European countries to become involved in the preparations for such a survey.

The participants suggested that the survey instruments should be developed one by one, and that each module should be distributed to Member States immediately it is ready. Unified health survey procedures would take a long time to finalize, but this way of proceeding would permit countries to use the modules already completed for their own health surveys. A European Survey could be an especially good solution to the information needs of European countries.

9. Data use, data protection and data security

In some European countries it is difficult, or becoming progressively more difficult, to extract health services information. In particular, data collection agencies do not fully appreciate the information needs of health administrators, health services researchers and epidemiologists. However, as the needs of information users are often satisfied by impersonal (anonymous) data, the problem might be overcome by designing data forms that both respond to these needs and at the same time are compatible with the country's laws.

Annex 1

WORKING PAPERS^a

Working papers

- ICP/HST 123/6 Monitoring of HFA policy in the European Region of WHO, by Dr Anatoly Nossikov
- ICP/HST 123/7 Needs for health monitoring in the Federal Republic of Germany, by Dr Wilhelm Thiele
- ICP/HST 123/9 Role of health monitoring in updating national health policies, by Dr Peter Jozan
- ICP/HST 123/10 What does a health policy-maker expect from a health monitoring system? by Dr Hans Stein
- ICP/HST 123/11 Contribution of a health monitoring system to define health policy objectives, by Dr Joseph Georg Brecht
- ICP/HST 123/12 Presenting health information to the users, by Dr Finn Diderichsen
- ICP/HST 123/13 Information for the health policy-maker: a challenge for the information professional, by Professor Paul Weiss
- ICP/HST 123/14 Methodological aspects in the study of indicators on equity in health, by Mrs Elisabeth Schach
- ICP/HST 123/15 Problems in comparing monitoring results from different health systems, by Dr Juri M. Komarov
- ICP/HST 123/16 Possibilities to establish an internationally comparable minimum set of indicators for health policy, by Dr Horst Noack

^a Copies are available from the Epidemiology and Statistics unit, WHO Regional Office for Europe, 8 Scherfigsvej, DK-2100, Copenhagen O.

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