



ВСЕМИРНАЯ ОРГАНИЗАЦИЯ ЗДРАВООХРАНЕНИЯ  
ЕВРОПЕЙСКОЕ РЕГИОНАЛЬНОЕ БЮРО

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Planning Group on Information Systems  
for the Research Promotion and Development Programme

Copenhagen, 30 June - 1 July 1977



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REPORT

Introduction

A meeting of the Planning Group on Information Systems for the Research Promotion and Development Programme was held in Copenhagen on 30 June - 1 July 1977. The list of background documents, the list of participants and the agenda are given in Annexes IV, V and VI respectively.

The recommendations by the Executive Board and the World Health Assembly for an increased involvement of the regional offices in the development and coordination of biomedical and health services research led to the establishment of the European Advisory Committee for Medical Research (EACMR). The first meeting of this Committee was held in Copenhagen on 21-22 February 1977. During that meeting, the EACMR recommended, *inter alia*, the setting up of a Planning Group on Information Systems which would meet before October 1977 and report to the next EACMR meeting, due to be held on 25-26 October 1977.

The meeting of the Planning Group on Information Systems was opened by the Regional Director, Dr Leo A. Kaprio, who, underlining the purpose of the meeting and its task to advise the EACMR, emphasized that the scope of the information system for research promotion and development in the WHO European Region should not be overextended, and he also stressed the importance of relying as much as possible on the national information systems of the Member States of the Region.

Summary of the discussions

The participants recognized that the Regional Office's information system on health research would contribute to better cooperation in the field of medical research in the European Region. For instance, it would help to avoid unnecessary overlapping, thus resulting in a saving of funds and manpower. It would also be of great value in the evaluation of diagnostic methods by helping to identify those that were the most costly and, possibly, those that were least effective as well.

An earlier WHO pilot attempt in this field some ten years previously in a few selected countries (WHOBRIIS) had been halted because the requests for information sent to leading research institutes had either not been answered, or, when answers were received, they sometimes gave a false idea of the real situation. A renewed attempt in that direction would be unrealistic. While numerous information systems on basic medical research already existed, the situation was far from satisfactory with regard to health services research. The participants agreed that the collection of information should be limited to the priorities selected by the EACMR and to the Regional Office for Europe's major programmes, emphasis being placed on health services research, but controlled medical trials, including field trials and trials of diagnostic measures, would be incorporated.

It was stressed that the health research information system would not replace any existing system but could act as a clearing-house, providing information for those who required it.

The main users of the health research information system would be, at the government level, (a) those involved in funding, (b) those concerned with the coordination of ongoing research, (c) health administrators, (d) persons involved in health services research.

In the development of the system, different situations would have to be taken into account, such as the difference in information needs of countries using Medline/Medlars services and of those not using those services, together with the potential difference in the spectrum of information from the two above-mentioned types of countries which would be covered by the Regional Office. The different structures for the development of research in the various Member States and their implications for the information system would also have to be taken into consideration.

Two broad types of information were needed: (a) information which would enable an inventory to be compiled of institutions' research capacities, manpower, funding, etc., and (b) a description of the national medical research structure to be formulated, together with information on problems, programmes and projects. The information system should concentrate on planned and ongoing research rather than on results of completed research, as the latter were reported more or less satisfactorily in biomedical literature documentation systems. At the regional level, the health research information system would have two dimensions: (a) a country profile approach, and (b) a subject approach, e.g. health economics.

The work relating to medical research carried out so far by the Regional Office's Health Information Unit was described (see Annex I). WHO Headquarters' role was discussed and it was felt advisable for the Regional Office to obtain existing data on information systems and special-purpose information systems which might be of value in the field of medical research. The purpose of future activities was to ascertain, as a first step, the mechanisms involved in health research in each country.

A list of information which the group suggested might be gathered by the Regional Office is given in Annex II. A sample list of areas of study for a country review of medical research organization was distributed to participants (see Annex III).

It was considered advisable to develop contacts with scientific bodies from which up-to-date information on people involved in health research would be easily obtainable. In certain countries, e.g. France and the Federal Republic of Germany, there was no single health research information system as such, but information relating to different fields could be gathered from several bodies. For example, an information system on health economics had been developed in France, and cancer research information systems existed in the Scandinavian countries. The closest possible contact with the institutions concerned should be established.

The present research structure in Poland was described as an example of a system, based on a five-year planning cycle, with centralized information and funding responsibilities and decentralized implementation at different levels. In most countries of the European Region it was common for information to be collected from several sources in each country; such a situation again underlined the need, already indicated by the EACMR, for the existence in each country of a focal coordinating point (person or institution) which would also act as the official contact (counterpart) of the Regional Office at the national level. The participants agreed that the establishment of such focal coordinating points was desirable.

In connexion with the need not to overextend the area covered by the health research information system, it was agreed that in each research area the content of the technical information required would have to be further specified by the appropriate planning group according to the general guidelines laid down by the Planning Group on Information Systems. At a later stage, the latter group would meet to evaluate the progress of work and to advise on further steps or modifications. That would ensure that the health research information system would be concentrated on the priority areas defined by the EACMR and on the Regional Office's major programmes.

The ultimate aim of the information system was to achieve more concerted action in the field of health research in the WHO European Region. The usefulness of existing and potential research activities for the other regions, e.g. in the field of tropical diseases, would be an additional outcome.

There was a consensus among the participants regarding the usefulness of the closest possible cooperation between the Regional Office and the different types of health information system (or their equivalent) existing in the various countries or areas of the European Region. The Regional Office's information system would play a catalytic role and would promote cooperation and coordination, e.g. in research organized by different organizations, in the development of national information systems, in the improvement of quality control, etc.

Cooperation with and the use of national or international research information systems and more closely defined relations with international scientific associations and national and international research councils and institutions were recommended. The development of the health research information system, which had to rely on voluntary contributions, would of course depend on the funds eventually allotted. It was suggested that research institutes would provide information at their own cost; they would naturally wish to benefit from feedback and might be prepared to pay for such a service.

The problem of the languages to be used in the information system was discussed. It was agreed that, for financial and technical reasons, countries could supply information in one of the four working languages (English, French, German and Russian) and that the Regional Office would not provide a translation service but would deliver the information in its original version. It was suggested that, for reasons of accuracy, the official titles of projects might also be recorded in the original language as well as being provided in one of the working languages.

It was agreed that the present report would be sent in draft form to each participant for comments and would be submitted to the EACMR at its next meeting in October 1977.

It was expected that information would be obtained in the meantime from Headquarters both on methods and procedures existing in research information and documentation systems, and information on the special-purpose information subsystems relating to medical research.

#### Conclusion

The Planning Group wished to have the agreement and support of the EACMR on:

- (1) the principle of the coverage by the information system of the five priorities selected by the EACMR and the Regional Office in relation to its major programmes;
- (2) the emphasis on health services research;
- (3) the list of proposed basic information to be collected by its Regional Office for Europe (Annex II);
- (4) the suggested areas of study for a country review (Annex III);
- (5) the language policy as described in the above summary of discussions;
- (6) the recommendation that the most direct contacts possible be established with national institutions, associations and councils.

#### Annexes

- Annex I Information sources in the WHO Regional Office for Europe relevant to health research  
Annex II List of proposed basic information to be collected by the WHO Regional Office for Europe  
Annex III Suggested country review of the organization of medical research  
Annex IV List of background documents  
Annex V Agenda  
Annex VI List of participants

ANNEX I

INFORMATION SOURCES IN THE WHO REGIONAL  
OFFICE FOR EUROPE RELEVANT TO HEALTH RESEARCH

The Health Information Unit of the WHO Regional Office for Europe collects the following information which may assist in the further development and promotion of a health service research information subsystem. These activities started as part of those related to the general information service of the Office.

- Since 1974, the unit has kept a manual list of experts in the European Region on advisory panels. Names are also entered on the computer and can be retrieved by country and/or advisory panel.
- Since 1974 the unit has kept a list of WHO collaborating centres in the Region.
- Since 1974 the unit has kept a list of research agreements with institutions in the European Region.
- Since 1976 the unit has kept a list of centres and institutions which are collaborating with or may be involved in the programme of the Regional Office.
- Since 1977 the Regional Office has been registering all bilateral or multilateral agreements between European countries in the health field which come to its attention.
- In recent years, the Health Information Unit has stored information received concerning bibliographies of research projects, workers or institutions.

It also stores information it receives on automated medical and environmental literature retrieval systems and services.

- In 1975 the Office started to develop a short research profile for Member States of the European Region based on literature passing through the Health Information Unit. This profile contains information on research coordination and funding mechanisms, priority areas and criteria for selecting projects, list of sources on research projects, institutions and workers, etc.

LIST OF PROPOSED BASIC INFORMATION  
TO BE COLLECTED BY THE WHO REGIONAL OFFICE FOR EUROPE

1. Country summaries of systems for the organization and administration of health services and health research
2. File (possibly maintained on computer) of centrally-funded health service research projects in the priority fields indicated by the Regional Committee and the European Advisory Committee for Medical Research
3. Annotated list of sources of information (national, multinational and international) on projects, institutions, workers and priority problems in the field of health research
4. List of data communication networks that contain information on health research (possibly as a sublist of item 3.)
5. List of major institutes and services involved in research in selected fields and which may be used as national or multinational focal points for information in these fields
6. List of bilateral or multilateral health services research agreements
7. List of training institutions and facilities for medical research careers
8. Exchange of information on planned and ongoing randomized control trials in the health field, including the evaluation of diagnostic procedures
9. Development of interregional exchange of information on health services research

ANNEX III

SUGGESTED COUNTRY REVIEW OF THE  
ORGANIZATION OF MEDICAL RESEARCH

1. Main characteristics and general research policy and objectives  
General features, overall coordination, research plans (period covered, relation to general plans, purpose of plans), priorities, policy, legal basis
2. Organizational structure  
Main research administrative mechanism in relation to health services (organizational chart), level of responsibility and decision; list of main research bodies by type
3. Funding bodies and mechanisms  
Method and mechanism for funding, main funding agencies and area of research; research budget (public, private); allocation of research grant, research staff, fellowship, contract, etc.
4. Establishment of priorities and selection of projects  
Criteria and mechanism for establishing priorities; procedures for selecting applications
5. Research career and training  
Curriculum and research positions in medical and other faculties
6. International cooperation  
Participation in major international research programmes (e.g. CREST); major bilateral or multilateral health research agreements
7. Sources of information  
General, directories of research institutions, directories of research workers, research project list

LIST OF BACKGROUND DOCUMENTS

- A30/A/SR/11      Development and coordination of biomedical research, World Health  
A30/A/SR/12      Assembly, Provisional Summary Record, Committee A, 1977  
A30/A/SR/13
- ISD/76/13      Towards a new WHO information system, by Dr S.H. Mandil, Programme  
Manager, ISP, Joint IFIP/WHO Working Group on Health Data Banks, Prague,  
23-27 August 1976
- EURO 4914      Health information systems, report on a Conference, Copenhagen,  
18-22 June 1973
- EURO 4916      WHO information services in Europe, Report on a Working Group, Copenhagen,  
17-19 June 1974 (restricted)
- EUR/RC27/Tech.  
Disc./1      Information systems in the health services, document for twenty-seventh  
session of the Regional Committee for Europe, Munich, 1977 (restricted)

AGENDA

1. Opening
2. Needs for information on medical research in Europe
  - (a) Main uses and users
  - (b) Type of information required, e.g. on research projects, on institute/worker, on research management and planning (national priorities, funding mechanisms and bodies, etc.)
3. Scope and purpose of the medical research information system of the WHO Regional Office for Europe
  - (a) Value and limitations of existing information systems
  - (b) Role of the Regional Office's medical research information system
4. Coordination and integration with existing programmes
  - (a) The WHO information system programme
  - (b) Relationship with other WHO medical research information systems (Headquarters and other regions)
  - (c) Coordination with other international research information systems
    - (i) Medical research information systems
    - (ii) General information systems on research
  - (d) Coordination with national medical research information systems
5. Procedures and resources required:
  - (a) for data collection and interpretation
  - (b) for data storage
  - (c) for data retrieval, dissemination and feedback
6. Timetable (main milestones)
7. Conclusions

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