



SECOND CORE GROUP MEETING HEALTH SURVEYS IN THE EU: HIS AND HIS/HES EVALUATIONS AND MODELS

27-28 October 1999

Scientific Institute of Public Health – Louis Pasteur J. Wytsmanstreet 14 Brussels

DRAFT MINUTES OF THE MEETING



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PARTICIPANTS

Arpo Aromaa (Chairman second day, Finland); Ms. Paola Baroncini (Italy); Jaap van den Berg (Chairman first day, Netherlands); Jacques Bonte (Eurostat); Ms. Vittoria Buratta (Italy); Ms. Emmanuelle Cambois (on behalf of Jean-Marie Robine, France); Branko van Eijk (Netherlands); Gino Farchi (Italy); Ms. Päivikki Koponen (Finland); Carlos Matias Dias (Portugal); Herman van Oyen (Belgium); Ms. Paola Primatesta (United Kingdom); Ms. Susana Sans (Spain); Jaap Seidell (Netherlands); Jean Tafforeau (Belgium). Observers: Stefaan Demarest (Belgium); Ms. Lucie Viet (Netherlands)

See annex 1 for more details on the participants.

OPENING

Mr. Van den Berg opens the meeting by welcoming the participants on behalf of Statistics Netherlands and KTL Finland. Statistics Netherlands and KTL jointly have prepared this meeting. He extends words of thankfulness to Mr. Tafforeau of the Institute of Public Health who arranged a lot of practical matters like the conference room and the hotel. He specially welcomes Ms. Susana Sans who will present the experiences on the standardisation of methods and quality control in the MONICA project.

1. EXPERIENCES ON THE STANDARDISATION OF METHODS AND QUALITY CONTROL IN THE MONICA PROJECT BY DR. SUSANA SANS

In order to advance the comparability of data, standardisation and quality control have been major points of interest in the MONICA study. The experiences in this field are interesting especially with regard to the HES part of our project, because we also are faced with the problem of the comparability of the data from health examinations. For this reason Dr. Susana Sans from the Institute of Health Studies in Barcelona was invited.

First Ms. Sans gives attention to the aims of the MONICA project. The primary objective of the project is monitoring trends and determinants of cardiovascular disease and to assess the extent to which these trends are related to known risk factors, living habits, health care and socio-economic factors. These features are measured simultaneously by centres in different countries.

The data collection of the MONICA study is complete now. It contained several data components: official statistics (e.g. mortality), coronary and stroke event registration, and risk factor surveys (HIS/HES). 28 countries and 46 centres have been involved in the project. The project is led by the Council of Principal Investigators and a Steering Committee. The project Management Centre in WHO is responsible for the co-ordination of the centres.

In the experience of Ms. Sans, the organisation and implementation of a large-scale study like the MONICA project require considerable effort. In order to obtain the desired results the objectives have to be well defined and a clear definition of variables is absolutely necessary. An adequate organisation is essential, i.e. a competent and powerful Steering Group, as well as competent local teams.

A quality control system is vital for obtaining comparable results. In the project a manual of operations was used to secure a good standard. Also training and workshops were provided to among others the employees who performed the examinations.

From the successes and failures of the quality and comparability of the data from the MONICA study, one can learn that there are a number of key factors which determine the degree of success in large-scale projects. A long-term vision of usefulness of outcomes is necessary. This motivates and stimulates commitment to the project. There has to be a continuous surveillance of quality and feedback concerning quality issues to the centres. Finally, personal features like teamwork capacity, tolerance and patience have to be mentioned. These are also playing an important role in the results of the study.

Following the presentation the Core Group discusses the difficulties involved in making HIS/HES comparable in the different countries. It is concluded that for valid comparisons of physical measurements, for instance blood pressure, quality assessment methods must be developed and applied.

2. SUMMARY ON SOME PRELIMINARY RESULTS OF HIS/HES INVENTORY QUESTIONNAIRES

HES:

Ms. Koponen gives an overview of the results of the inventory of the Health Examination Surveys up until now. For a limited number of countries a contact person has not yet been appointed. This concerns Greece, Liechtenstein, Luxembourg and Norway. The expectations are that in short time for (almost) all countries a contact person will be appointed. By the end of September questionnaires were mailed to the contact persons. Only a few countries have responded yet.

HIS:

Mr. Van Eijk states that almost half of the 32 contact persons for HIS have responded until now. The mailing with the questionnaire was posted early September. So this is a rather slow response. A reminder will be sent soon. Much time has been spent on developing the database programme. The results of the questionnaires received so far are already included in the database. This will be shown later this afternoon. The survey questionnaires have not yet been included, except from the Belgian Survey.

3. DEMONSTRATION OF THE HIS/HES DATABASE UNDER CONSTRUCTION

Mr. Van Eijk says that a lot of work still must be done. Therefore the demonstration will be a first impression. The idea is to use the comments of the Core Group members for further development of the programme. The interface is not user-friendly at the moment, because a menu is not yet realised. This is one of the last steps in the development.

From the point of view of users, the database consists mainly of two parts. First there is a module containing the data regarding the methodological aspects which we asked for in our HIS questionnaire.

The methodological aspects of HES are not yet implemented. These differ from the HIS methodology to such an extent that a separate module must be developed. This will resemble the HIS module. Only the survey questionnaires from the Belgian Health Interview Survey are included for this demonstration. We are still searching for the most efficient way of filling the database.

An important part of the database is the system with which the questions on certain topics can be found. The database provides several ways of searching. One important method is searching by topic. To realise this, an adequate topic list must be developed. A provisional version is included at the moment. The system is built in such a manner that the topic list can be changed very easily. In fact this is one of the reasons for choosing a database management system: making changes in parts of the database is very easy without disturbing other parts. A second reason is that the interface can be made user-friendly. Especially MS-Access has very advanced possibilities for creating forms. This is one of the reasons why we have chosen for this programme.

After the demonstration the Core Group discusses some characteristics of the database. Also suggestions are made for the further development.

Regarding the topic list (with which questions can be searched), attention is called to the terminology. It can be quite confusing if it is not clear what is meant by the term 'topic'. Does this differ from 'item'

or even 'indicator'? More specific the so-called area of 'personal factors' should be renamed to 'biological risk factors'.

At least some of the Core Group members have a need for gaining insight in not only if a recommended instrument is used in a survey, but also which questions belong to this instrument. Mr. Van Eijk notices that in principle it will be possible to make a module providing this information. However, this requires extra work, which should be considered later during the second phase of the project.

It is not clear at first sight what is meant by 'section' on the questions form. Mr Van Eijk explains that this is the title of a certain part of a questionnaire. It is a name attributed by the author of the questionnaire. He will try to elucidate this field on the form.

It is asked whether it would be possible to create a field for additional remarks with each question in order to give the opportunity of making notes. The reference period of a question can be important. For instance the number of visits to a physician in the last two weeks, as opposed to three months in another survey. More thought will be given to how to include this information.

4. DISCUSSION ON THE ROLE OF HIS/HES IN HEALTH MONITORING

Mr. Aromaa says that HIS, HES and HIS/HES combinations have a central role in health monitoring. This importance must also be seen against the background of health monitoring developments in the European Union. National and international health monitoring should be undertaken to (1) measure health status, trends and determinants, (2) facilitate the planning, monitoring and evaluation of health policy, programmes and actions, (3) identify new priority areas for public health and (4) to obtain comparative information about health to support national health policies.

A recent report has examined the organisation of health monitoring to provide an optimal organisational alternative for the implementation of European Community health monitoring in the short and medium term and in the long-term. Health monitoring is understood to comprise (1) the definition of health information needs, (2) information gathering, (3) analysis and interpretation and (4) information dissemination. Central products of a capacity for health monitoring are policy relevant health reports and information. There is a need for the capability for health monitoring to be permanently enhanced in the European Community.

The European Community health monitoring capacity should be organised in a way, which ensures that it has the public health and scientific competence needed to meet its objectives, that it is acceptable to Member States and European Institutions, is able to be objective which requires scientific and professional independence and is cost-effective. Central co-ordination and leadership of health monitoring should be combined with networking to focal points in all Member States and intense collaboration with the relevant organisations in the European Union and at the international level. Close involvement of the Commission, in particular DG V and Eurostat, as well as strengthening the Commission's public health expertise are needed regardless of how health monitoring is organised.

The report evaluated four main alternatives for the organisation of health monitoring, which are all based on a core capacity and extensive networking. The long-term goal should be the creation of a new European body for health monitoring (a 'Health Observatory'). The new body should have close links with a suitable expert institute such as a strong national public health institute and would work in close collaboration with networks of focal points in the Member States. However, setting up the new EU body requires major new resources and will take a number of years.

Therefore, as an immediate solution the Commission should take steps to set up a European Community health monitoring capacity, which during the current Health Monitoring Programme comprises a consortium of 3 - 4 national public health institutes (or comparable organisations) of Member States.

According to Mr. Aromaa measurement of dimensions of health and of services and benefits contain various aspects (psychobiological, perceived, social and use of benefits and services). Some of these aspects can best be measured by HIS/HES. Methods used to measure the different phases of the health-disease continuum are presented in Table 1 (Annex 3). Table 2 (Annex 4) illustrates the suitability of HIS/HES and registers to obtain information for Health Monitoring purposes.

It is concluded that further clarification of the role of HIS/HES for Health Monitoring purposes is needed.

5. PROGRESS OF THE PROJECT

At the meeting the interim-report is handed out. Mr. Van den Berg explains the arrangement of the interim-report. The first part consists of an overview of the project. The second part is the report on the first Core Group meeting. The third part is the HIS questionnaire and the accompanying letter. The fourth part is the HES questionnaire for countries with a HES (there is also a separate questionnaire for countries without a HES), together with the accompanying letter.

As we can see from the interim-report the project started somewhat later than was planned in the project outline. Therefore we have some delay when comparing the actual status of the project with the original timetable. Nevertheless we expect to organise the plenary meeting in May/June 2000. We also expect to present the final report in time.

After the first Core Group meeting most of the activities at Statistics Netherlands concerned the development of a questionnaire for the renewed inventory of HIS, which has been sent off in the first week of September. Other activities of Statistics Netherlands concerned the development of the database. Also some time was spent on the topic list. Because of the importance of the topic list for searching the database, more time will be needed to improve this list. This will be discussed under next agenda item.

At KTL Finland most of the activities since June concerned the literature review on HES. A draft report on HES in each EU and EFTA Member State was written. Questionnaires for the inventory of HES and the accompanying request letters were developed, and mailed by the end of September. Further KTL Finland worked on finding the right contact persons for each Member State concerned. Most countries have appointed these contact persons (1-3 persons in each country) now.

6. DISCUSSION ON THE TOPIC LIST

HIS TOPIC LIST

Referring to the paper Mr. Van Eijk explains that the HIS topic list will be used to categorise the questions of Health Interview Surveys. Yesterday it was explained that the topic list is important in order to select questions in the database for comparison with regard to the wording.

The underlying concept of the topic list is 'influences on health': the areas (such as: health status [as measured by surveys], the use of facilities, lifestyle factors etc.) can be seen as factors influencing health. P. Kramers (RIVM, The Netherlands) uses a similar concept to develop a list of indicators. But there are some alternatives. Yesterday Mr. Seidell suggested a classification with a distinction between determinants and consequences of health or for health status a distinction between ICD diagnoses and symptoms. Also yesterday, Mr. Aromaa presented a concept of 'phases in the health continuum'. Perhaps this could be used for further development of the topic list. To the opinion of Mr. Van Eijk it is very important to develop the topic list in a consistent way and to be careful not to use many different concepts, because this will probably cause confusion with the user and will also cause problems with classifying the questions.

In the discussion a number of suggestions are made. Classification in terms of ethnicity can be a problem: perhaps an alternative should be found. A breakdown of health status in determinants, perceived/subjective health, objective health and consequences of disease is desirable. Injuries may be added as a category. 'Prevention and health promotion' should be identified as a main topic including 'vaccination and screening'. One could consider including a topic on informal care networks or alternative medicine/care. The name of the area 'use of health care facilities' should be 'use of health care or other facilities'.

Suggestions also are made for the database programme. We should consider creating an option for saving a chosen selection. Maybe it would be convenient if the user could create a personal keyword e.g. in a separate field.

HES TOPIC LIST

Ms. Koponen explains that the HES topic list will be used to categorise measurements and assessments of Health Examination Surveys. There is, of course, a difference between the topic lists for HES and HIS. Because the topic list for HIS concerns self-reported health as opposed to the topic list for HES, which concerns objective health, renaming the topics of HIS would be appropriate.

The participants ask several questions on the content of the items, among which the functional health status. It is asked whether information on the methods is gathered, for instance who performs the examinations, where the examination is carried out and the costs. This information is gathered by means of the literature study and/or the questionnaire.

Mr. Bonte realises that HES is a new domain. In his opinion we therefore should concentrate on the main issues. At this stage it is advisable to concentrate on generalities instead of specific methodological aspects of individual study items. With regard to the topic list he also suggests to justify the choices made concerning the level of detail.

The Core Group also suggests to have a look at the time investment involved with the health examinations. It can be of interest to know whether an examination took several hours, because in this way we easily can gain a global insight in the character of the survey and to a certain extent also the costs.

7. CREATING THE NETWORKS TO DEVELOP AND STANDARDISE HIS AND HES IN EUROPE

Ms. Koponen states that for HES in some countries a contact person has not yet been appointed. Further effort will be made to obtain contact persons from every country. For the purpose of this meeting at KTL a list of HES in the EU/EFTA Member states has been made. This list is examined. This leads among others to a suggestion for a person to get in touch with in Greece.

Mr. Aromaa says that KTL will be working on the network until the end of this year. One of the things still to be done is making a short list of tasks for the members of the network.

8. DISCUSSION ON THE DEVELOPMENT OF HIS/HES METHODS AND PLANS FOR THE FUTURE COLLABORATION.

The draft project proposal for the second phase "Health surveys in the EU: evaluation and development of internationally comparable HIS/HES methods" is under consideration. Mr. Aromaa presents a summary of the proposal.

During the current phase 1 of the project a review and general level evaluation is being carried out. The draft proposal concerns, in short, a second phase which is aimed at selecting, developing and

recommending comparable measurement of major public health problems. The methods comprise: an extended analysis of the HIS/HES studies included in the database of phase 1; consultation of experts (from previous multicentre HIS/HES studies, as well as subject matter experts); field application and evaluation of recommended methods.

Mr. Van den Berg adds that regarding HIS in a second phase further improvement of and updating of the database should be a point of interest. It is evident that the object of the database is to extend the insight in the differences of the HIS in the EU and the implications of those differences for the data retrieved from the surveys. This information then can be used to make the surveys comparable e.g. by making proposals for developing new common instruments and by recommendations concerning the co-ordination of the methodology of the surveys.

The Core Group members make a number of suggestions. One should be careful not to duplicate work already done in other projects. However, for HIS/HES combinations there is little risk for duplication. A continuous update of the database must be one of the major activities. It should be considered to develop a minimum set of common variables for HIS and HES. Finally, step-by-step harmonisation of a limited number of variables at a time was felt to be a good approach.

It is agreed that the work has to be divided some more over the countries. The participants all would like to contribute. Perhaps a model like in EUROHIS is appropriate. KTL Finland and Statistics Netherlands will make a new version of the proposal for the second phase taking into account the suggestions by the Core Group members.

9. PLANS FOR THE PLENARY MEETING ON HIS/HES IN MAY-JUNE 2000: HOW TO CREATE A CONSENSUS ABOUT THE RECOMMENDATIONS AND FUTURE PLANS?

Mr. Van den Berg describes in outline what Statistics Netherlands and KTL at the moment have in mind for the plenary meeting next year. First of all the participants will be informed on the results of the project. An analysis will be given of the results from the inventory. Also the database will be demonstrated. We intend to provide a number of laptops so the participants can actually try out the database. Of course the participants will be given the opportunity to give their comments on the project results and state their ideas on harmonisation of HIS and HIS/HES. A proposal for the second phase of the project will be presented. One of the proposals may be to continuously update the HIS/HES database and create an infrastructure needed for this purpose.

An important topic will be of course the participation in the networks for HIS and HIS/HES. For HES the willingness of participation in pilots will also be examined. The idea is to split up the participants in subgroups. Each subgroup will be asked to evaluate the current instruments used on a certain topic. Topics to be chosen may be e.g. health status, use of services, determinants or certain HES-components. The database may be used in these sessions. We expect the subgroups to report their conclusions to the plenary meeting. The plenary meeting then can draw conclusions regarding the relevance of the topic for further development in the second phase of the project. The general objective of the plenary should be achieving an agreement on future efforts for the co-ordination of HIS and HIS/HES.

CLOSING

Mr. Aromaa closes the meeting by expressing his thanks to all participants for their valuable contributions and in particular Mr. Tafforeau for hosting this meeting.

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AGENDA FOR THE SECOND MEETING OF THE CORE GROUP 27-28 OCTOBER 1999

Wednesday 27 October 1999, starting at 13.00h

Welcome, coffee, sandwich

Opening

- 1. Presentation of an international multicentre HIS/HES survey: experiences on the standardisation of methods and quality control
- 2. Summary on some preliminary results of HIS/HES inventory questionnaires
- 3. Demonstration of the HIS/HES database under construction (first impression)
- 4. Discussion on the role of HIS/HES in Health Monitoring in the European Union

Thursday 28 October, closing at 16.00h

- 5. The progress of the project
- 6. Discussion on the topic list, i.e. the list used to categorise the questions of Health Interview Surveys, and the measurements and assessments of Health Examination Surveys
- 7. Creating the networks to develop and standardise HIS and HES in Europe
- 8. Discussion on the development of HIS/HES methods and plans for the future collaboration. Outline for the project: "Evaluation and development of internationally comparable HIS/HES methods"
- 9. Plans for the plenary meeting on HIS/HES in May-June 2000: How to create a consensus about the recommendations and future plans?

Closing

Table 1. Methods used to measure the different phases of the health-disease continuum

| PHASES OF HEALTH/DISEASE CONTINUUM | | HEALTH EXAMINATION SURVEYS | | | | | |
|--|-----|----------------------------|--------------|-------|--------------|----------------|------|
| | HIS | Qs | Measurements | Tests | Observations | Clinical exams | REGS |
| HEALTH | + | + | + | + | + | + | - |
| RISK ENVIRONMENT | + | - | (-) | - | - | - | (+) |
| RISK BEHAVIOUR | + | + | + | - | (+) | (+) | - |
| RISK FACTORS | (+) | (-) | + | - | - | - | - |
| PRE-CLIN. DISEASE | - | (+) | + | + | + | (+) | - |
| PRE-DG. (symptomatic) DISEASE | (+) | + | + | + | + | + | - |
| DIAGNOSED DISEASE | + | + | + | + | + | + | (+) |
| IMPAIRMENT, DISABILITY | + | + | + | + | + | + | (+) |
| HANDICAP | + | + | + | + | + | + | + |
| DEATH | - | - | - | - | - | - | - |

Table 2. The role of HIS and HES in obtaining information for health monitoring

| | HIS | HES | REGs |
|---|-------------|---------------|---------------|
| POPULATION | + | (+) | + |
| LIVING CONDITIONS | + | (+) | + |
| BEHAVIOUR/LIFESTYLE | + | + | - |
| RISK FACTORS | (-) | + | - |
| GENERAL HEALTH STATUS Perceived health Mortality, life-expectancy Healthy / disability-free life-expectancy | + - + | (+) - + | - + + |
| HEALTH STATUS, SPECIFIC Cause-specific mortality Diseases, disorders Impairments, disabilities, handicaps | (+) + | - + + | + (+) + |
| PREVENTION AND HEALTH PROMOTION | + | (+) | + |
| HEALTH AND SOCIAL SERVICES | + | (+) | + |

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