

EHRM

European Health Risk Monitoring

Final report

4 October 2002

Grand agreement number SI2.117134 (99CVF3-507) between the Commission of the European Community and National Public Health Institute (KTL), Finland.

Introduction

In 1997, the European Union launched a Programme of Community Action on Health Monitoring, with its objective to contribute to the establishment of a Community health monitoring system which makes it possible to:

- measure health status, trends and determinants throughout the Community;
- facilitate the planning, monitoring and evaluation of Community programmes and action; and
- provide Member States with appropriate health information to make comparisons and support their national health policies.

The objective of the actions in the first stage (Pillar A) of the Health Monitoring Programme (HMP) was to establish comparable Community health indicators by means of a critical review of existing health data and indicators, by developing methodologies for obtaining comparable health data and common indicators, and by developing appropriate methods for the collection of the progressively comparable health data needed for these indicators.

There is a major lack of reliable, standardized and co-ordinated monitoring system in the European Community area for the risk factors, related behaviours and determinants of major chronic diseases. Information on these is needed in order to serve and evaluate disease prevention and health promotion efforts in the countries and at European level. This gap cannot be filled by any routine statistical sources, but it calls for implementing carefully standardized population surveys. The European Health Risk Monitoring (EHRM) Project was established to contribute to the HMP by planning indicators and mechanisms for co-ordinated standardized risk factor surveys.

The major chronic diseases concerned were cardiovascular diseases, chronic obstructive pulmonary disease, cancers and diabetes. Mental health, accidents and environmental and occupational diseases are also major public health problems, but they were outside the scope of this Project. Furthermore, nutrition and physical activity were not be considered because they were being dealt with by other projects of the HMP.

To meet the objectives, four tasks were specified in the Project proposal:

1. analysing the experience so far;
2. carefully planning the indicators and recommendations for implementation, co-ordination and data management and processing the survey data;
3. analysing the existing data to be applied in the EU health monitoring database; and
4. training national centres to carry out the monitoring and to collaborate on reporting and use of the data for national and community needs.

The period of the Project contract was 24 months, starting on 01 December 1999, and it was extended by 7 months, to end on 30 June 2002.

Organization and activities of the Project

The project was coordinated and its documents drafted by a team at the National Public Health Institute (KTL), Helsinki, Finland. The team was assisted and other partners represented in the coordination by an international Steering Committee. Major expertise in the project came from the National Participating Centres in 20 European countries, the EU and WHO. The Project had Participating Centres in all EU Member States except Luxembourg, and in a number of other countries. Three of the National Participating Centres were adopted during the course of the Project, to represent the national health surveys in Germany, Norway and the UK. Near the end of the project period, contact was also made with relevant expertise in Luxembourg. The partner institutes and the National Principal Investigators are listed in Appendix 1.

The internet was used widely for the communication between the partners. In particular, all participants had access to up-to-date working drafts of the Project's documents through the World Wide Web, and could review and comment on them whenever needed.

The Steering Committee met twice, on 11-12 September 2000 in Helsinki (see Appendix 2) and 4-5 May 2001, also in Helsinki (see Appendix 3), and held one telephone conference, on 09 January 2001 (see Appendix 4).

The meeting of the National Principal Investigators was held on 9-10 February 2001 in Helsinki. The purpose of the meeting was to review and discuss on the work done for the Project by the time, and to plan and set the priorities for the work to bring the Project to its completion. The minutes of the meeting are given in the Appendix 5.

In the meetings of the EHRM Project, the participants expressed the need for a wider range surveys than covered by EHRM, including also nutrition, physical activity etc. As these areas were covered by other HMP projects the idea of a joint meeting with all HMP projects working on health survey issues started to develop. This resulted in a Workshop on "Health Surveys in Europe - Role of Surveys in Monitoring", which was organized jointly by the EHRM Project, Health Surveys in the EU: HIS and HIS/HES Evaluation and Models -Project and the European Commission to bring together experts from all areas of health surveys. The workshop was organized in Luxembourg on 13-14 May 2002.

The objectives of the Workshop were:

To discuss elements and structure of national health surveys comprising health interviews, health examinations or both. A comparison to the proposed indicator system (ECHI) was expected to reveal needs for development.

To produce proposals for the contents and implementation of national health surveys, which will be integrated into the final reports of the EHRM and HIS/HES projects. In addition, a document from the meeting will be produced, which will take into account, as far as possible, results from other projects. These issues will deal with e.g.

Health domains to be monitored and data for health indicators to be obtained by different types of surveys.

Structures of national health survey systems.

International comparability issues.

To facilitate the development of national health surveys through exchange of information and experiences.

To discuss the need for and form of future international collaboration.

To introduce participants to the HIS/HES database containing up-to-date information on European health interview surveys and complex HIS/HES surveys, and to discuss with them its future developments.

The report of the meeting is in Appendix 6 and its report is described below, in section "Deliverables".

The Project Leader attended six Project Co-ordinators' meetings of the Health Monitoring Programme, which facilitated synchronizing the Project with the other projects of the Programme. Project Leader and Co-ordinator visited WHO/NCD Surveillance unit in Geneva on 9-10 January 2002 to synchronize the Project with WHO's Steps initiative, which was being prepared to facilitate risk factor monitoring in the population globally. As EHRM and other projects of the Health Monitoring Programme were working on this in Europe, WHO would focus more on the developing countries and countries in transition. The Leader also attended an DG Sanco working group meeting preparing questions for the Autumn 2002 Eurobarometer in Luxembourg on 15 May 2002.

Three presentations of the Project and its early results were given in two international conferences:

Tolonen H for the European Health Risk Monitoring Project. Proposal to standardize chronic disease risk factors in Europe. 2nd international conference on Monitoring Health Behaviors - Towards global surveillance, Tuusula, Finland, October 1-3, 2001. (Oral presentation)

Kuulasmaa K, Tolonen H for the European Health Risk Monitoring Project. Proposal to standardize chronic disease risk factor surveys in Europe. Annual meeting of the European Public Health Association, Brussels, Belgium, 6-8 December 2001. (Poster and invited oral presentation)

Deliverables

The main results of the project came in the form of four documents, which are being published in the World Wide Web:

- Report from the workshop "Health surveys in Europe - role of surveys in monitoring", Luxembourg, 3-4 May 2002.
- Review of surveys for risk factors of major chronic diseases and comparability of the results.
- Recommendation for indicators, international collaboration, protocol and manual of operations for chronic disease risk factor surveys.
- Reporting the risk factor survey data.

Here is a brief summary of each of them:

Report from the workshop "Health surveys in Europe - role of surveys in monitoring", Luxembourg, 13-14 May 2002 (see Appendix 6)

Published in October 2002 in <http://www.ktl.fi/publications/ehrm/product4/report.htm>

Representatives from most HMP Projects dealing with surveys, the EUSTAT, DG SANCO, WHO/HQ and WHO/EURO participated the workshop. The objectives of the workshop were described above. The report gives brief introductions to the current HMP, the new HMP for years 2003-2008, summaries of the objectives and/or recommendations of the HMP projects which deal with surveys, and an overview of existing international health surveys. The document also includes brief reports of three working groups, on Comparability of survey data, Priorities for survey monitoring of health, disease, disability and determinants, and Types and frequencies of surveys needed.

The conclusions from the workshop were:

There is a clear need for relevant, valid and comparable health survey information in the European level. The existing information suffers from poor coverage of the most important health items, poor quality and comparability as well as from lack of coverage and accessibility.

To improve the situation, collaboration between countries, organizations and experts is needed. Improving national health interview and health examination surveys should be the main approach. Through EU supported collaboration, a core set of health indicators should be defined which would form the minimum set of information to be collected in each country. This set of indicators should be flexible and adapt changes over time if new health issues arise (e.g. biochemical indicators, genetic determinants). Countries are encouraged to extend their health surveys to other health indicators of their interest. The EU level collaboration should involve experts in the member states, DG Sanco, Eurostat and the forthcoming EU structure for health monitoring.

To get reliable and comparable information from selected health indicators, standardized measurement protocols and questionnaires need to be developed and validated. Special attention is needed for laboratory measurement standardization through establishment of European reference laboratories (for biochemical measurements such as blood lipids, biomarkers urinary tests, etc.).

Centralized training and quality control during and after the surveys is needed to support local survey organizers in countries to achieve reliable and comparable health information. This support is especially important for countries without earlier experience from health interview and examination surveys.

The agreed core set of data should be reported to a common European database accessible to the European health monitoring system and experts in the member countries. The forthcoming EU health monitoring structure should have a central role in compiling, analysing and distributing the data and information.

In the longer term, the feasibility of a European health survey/surveys should be examined taking into account the experiences gained from this collaboration of national surveys and health authorities.

Review of surveys for risk factors of major chronic diseases and comparability of the results (see Appendix 7)

- Prepared by Hanna Tolonen, Hermann Wolf, Dimitrije Jakovljevic, Kari Kuulasmaa and the European Health Risk Monitoring Project
- Published in October 2002 in <http://www.ktl.fi/publications/ehrm/product1/title.htm>

The document gives a critical review of previous risk factor surveys and assesses comparability of methods and indicators used for the reporting of survey results. The main emphasis is on the major cardiovascular risk factors, i.e. smoking, blood pressure, blood cholesterol and body weight, that are also relevant for other chronic diseases. In addition, the review focuses on a number of other factors that are considered important for population based risk factor surveys. These include HDL cholesterol, waist and hip circumferences, blood triglycerides, and blood glucose, relevant to the so called metabolic syndrome, as well as serum cotinine and expired air carbon monoxide, which are important for validating smoking questionnaire data and for assessing passive smoking.

Socio-economic factors, use of medications and alcohol, medical history, diet and physical activity, are all important for the interpretation of risk factor surveys, but they are topics for separate projects of the HMP.

The review aimed to have a good coverage of relatively recent European risk factor surveys that were either conducted in collaboration between several countries or aimed at providing nationally representative information. Considered were:

- WHO MONICA Project
- WHO-CINDI Programme
- The European Prospective Investigation into Cancer and Nutrition (EPIC)
- Risk factor monitoring in the Netherlands
- Risk factor monitoring in Germany
- National Health Surveys for England, Scotland and Northern Ireland
- National Cardiovascular Screening in Norway
- National Cardiovascular Screening in Italy

Also included was the National Health and Nutrition Examination Survey of the USA, a very large national survey that has documented extensive survey experience over many years.

At the end of each risk factor section there are discussion and conclusions on the comparability of the data and recommendations for future surveys based on the experience.

Recommendation for indicators, international collaboration, protocol and manual of operations for chronic disease risk factor surveys (see Appendix 8)

- Prepared by Hanna Tolonen, Kari Kuulasmaa, Tiina Laatikainen, Hermann Wolf and the European Health Risk Monitoring Project
 - Published in October 2002 in <http://www.ktl.fi/publications/ehrm/product2/title.htm>
- The recommendations of the document are largely based on findings and conclusions of the document "Review of surveys for risk factors of major chronic diseases and comparability of the results" (see above). The document consists of four parts:

Part I gives a list of recommended population indicators for chronic disease risk factors. The major chronic diseases concerned are cardiovascular diseases, chronic obstructive pulmonary disease, cancers and diabetes. Mental health, accidents and environmental and occupational diseases are also major public health problems, but are outside the scope of this Project. Only risk factors which can be measured through population surveys are considered. Some indicators related to prevention or treatments of chronic diseases are also proposed. The EHRM Project was in contact with other projects of the HMP to avoid overlap.

The indicators concern:

- Blood pressure and awareness and treatment of hypertension
- Blood lipids and awareness and treatment of high cholesterol
- Obesity
- Smoking
- Blood glucose
- Antiplatelet drugs
- Hormone replacement therapy

Sex, age, geographic area and socio-economic status are considered as breakdown variables for the indicators.

The indicators are divided into two categories: primary and secondary. Primary indicators should be included in every future survey to give basic information about the risk factors. Secondary indicators provide useful additional information about the risk factors and should be included in future surveys whenever feasible.

The proposal is closely related to the proposal for a comprehensive list of health indicators that has already been prepared by European Community Health Indicators (ECHI), another project of the HMP. For the indicators of chronic disease risk factors, the ECHI project asked the EHRM Project for advice. Therefore, most of the primary indicators proposed here have already been included in the ECHI proposal. The ECHI

Project stressed that flexibility is an important characteristic of their proposal as the interest in specific indicators may change with changing policy interests and scientific developments.

Part II deals with issues related to organizing the risk factor surveys on the national level. The definition of the target population, selection of sampling frame, procedures for sample selection, procedures for attaining a high response rate, general guidelines for organizing the survey measurements, the order of measurements as well as related legal and ethical issues are considered in this section.

Part III contains a protocol and operational guidelines for the individual measurements. Detailed instructions for the questionnaires to be used and for conducting the measurements needed for the indicators listed in Part I are given. Also, issues to be taken into account during the training of the measurers and interviewers, and quality control for each measurement/questionnaire items during and after the survey are considered. There also is a discussion about data management. At the end of the section, the formulae for deriving the indicators listed in Part I from the data described in the protocols and questionnaires in Part III are given.

The proposals were made with the knowledge that they are in conflict with some practices of previous national risk factor surveys. The primary aim was to focus on procedures that provide improved data quality. There may be good reasons - such as backward compatibility with previous surveys - that some national surveys will continue to adhere to their established procedures, rather than adopt the proposals of this document.

Part IV makes recommendations for organizing collaboration between countries in standardizing survey methods, quality control and reporting. Such collaboration will be crucial for the comparability of the results of the surveys. The main recommendation concerns a central facility for training, quality control and quality assessment. A centre with sufficient expertise should be established with the responsibility to facilitate the national surveys to follow the agreed standards of data collection. This would be done through:

- providing training material and procedures and organizing practical training seminars for persons responsible in training of the national survey teams. Such seminars should guarantee that the blood pressure measurements are done in exactly the same way in each country, the blood sampling is done in an appropriate way etc.
- coordinating external quality control and preparing guidelines for and monitoring of internal quality control. A specific part of this would be A European Laboratory Reference Centre, which should be established to provide secondary calibrators for the survey laboratories and external quality control. The Centre should collaborate with the Centres of Disease Control, which is responsible for the laboratory quality control for the surveys in the USA.
- assessment of the quality of the data obtained from each survey. The results would be discussed with the organizers of the surveys, and summaries reported to the central facility for reporting the indicators.
- preparation of the data for international reporting, as well as the preparation of the summary risk factor status statements in collaboration with the countries.

- coordinating a network of the organizers of national surveys for sharing experience and exchanging expertise in organizing surveys, data collection and reporting. The chronic disease risk factors considered in the EHRM Project define a sensible area of responsibility for such a centre, but also the inclusion of a wider set of indicators collected through population surveys, such as those on nutrition, physical activity and health should be considered.

The recommendation is in accordance with the conclusions of the workshop on Health surveys in Europe (see above).

Reporting the risk factor survey data (see Appendix 9)

Prepared by Hanna Tolonen, Markku Mähönen, Kari Kuulasmaa, Aulikki Nissinen for the European Health Risk Monitoring Project

[Available in http://www.ktl.fi/ehrm/documents/product3/title.htm](http://www.ktl.fi/ehrm/documents/product3/title.htm)

One of the tasks for the EHRM Project, specified in the project proposal, was analysing the existing data to be applied in the EU health monitoring database. An important part of such existing data was the international WHO MONICA data set, which was readily available in the EHRM coordinating centre. The European Commission had a separate activity ongoing for the technical implementation of the EU database through which the structured health information would be disseminated. The plan of the EHRM Project was to collaborate with the developers of the EU health monitoring database. When it became apparent that the technical development of the EU database will not reach the stage, were it could usefully collaborate with producers of the data, the task specified for the EHRM project was modified accordingly. The two parts of the modified task were (a) to apply the indicators suggested by the Project to the existing WHO MONICA data set to test that the suggested indicators are logical and their implementation works technically, and (b) to develop principles for the contents of the reports of the information.

The document "Reporting the risk factor survey data" deals with the principles of the contents of the routine reporting of the health monitoring information. It focuses on the ways of reporting the data for different target groups, and on the type of information that needs to accompany the actual data. It does not address the list of health issues that should be reported nor the technical aspects of reporting. The document gives the current view of the authors, based on their earlier experience in reporting and work with the users of such data. It was inspired by a number of recent conferences on health and health behaviour monitoring and the discussions in the HMP project coordinators' meeting. The focus of the document was largely determined by issues on which there was not necessarily a common understanding within the HMP.

Hypertension and related aspects, and data from the Finnish health risk monitoring were used in the examples.

The document identifies different user groups, in the EU-level and nationally, from the point of view of the level of detail of the information that should be reported, and a thus is complementary to the user-window discussion of the ECHI Project.

The document aims to give one point of view to the discussion on reporting. It is recognized that the reporting will, or at least should, be a dialogue between the

reporters and those who need the data, and therefore the forms and contents of reporting are expected to develop continually from year to year and for different uses of the data.

Other achievements of the Project

In addition to its publishable documents, the Project has created a network of experts and interest groups in risk factor surveys in all EU member states and many other European countries. The preparation of the Project proposal initiated within the networks formed by the WHO MONICA Project, which had conducted local and regional risk factor surveys in the 1980s and 1990s, and the WHO CINDI Programme, which also had conducted surveys and had need for reliable data in many European countries, but the network expanded to include many other countries and groups with valuable expertise. For example, all groups responsible for the existing national health examination surveys in Europe are involved.

The Project has an internet site at <http://www.ktl.fi/ehrm/>.

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