Grant Agreement n.2003118
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FINAL REPORT

UPDATED MAY 2006
1. Summary

Although cardiovascular disease (CVD) has been identified as one of the leading contributors to the global disease burden, the number of reliable indicators for monitoring CVD and for which data are available on a comparable basis across EU countries is currently limited. Therefore, the aims of the EUROCISS project were to define indicators for monitoring CVD and to recommend standardised methods for future data collection in the European Union (EU). The achievement of these aims will facilitate cross-country comparisons and will assist efforts to improve CVD prevention and control.

Specific project objectives included:

1. prioritise CVD of importance in public health;
2. identifying specific indicators for assessing morbidity;
3. developing recommendations for collection and harmonisation of data that can be easily applicable within member countries in order to obtain reliable and significant data for the periodic monitoring of CVD.

Objective 1 - prioritise CVD of importance in public health

In prioritising CVD of greatest interest, two criteria have been selected: high prevalence of disease, in terms of mortality, morbidity and disability; and the possibility of prevention, in terms of modifiable risk factors.

On the basis of these criteria, acute myocardial infarction/acute coronary syndromes, ischemic heart diseases, heart failure and cerebrovascular accidents are considered the most important CVD.

Objective 2 - Identifying specific indicators for assessing morbidity

Acute myocardial infarction/acute coronary syndromes (AMI/ACS)

Recommended indicators include mortality, hospital discharge rates, incidence/attack rates and case fatality. Only mortality and hospital discharge diagnoses are available for all countries. Information about incidence/attack rate and case fatality is available in some countries through population-based registers, usually implemented at the regional level. These registers are based on record linkage of mortality and hospital discharge diagnoses and apply some validation procedures.

Recently, sensitive serologic biomarkers have become available for the identification of very small myocardial infarctions that would not have been detected earlier. The application of new and more sensitive biomarkers criteria will potentially cause a rise in the myocardial infarction incidence and a fall in the case fatality rate.

Heart failure and Ischemic Heart Diseases

Heart failure is a frequent complication of myocardial infarction and hypertensive disease. Hospitalisation rates are not sufficient to evaluate the frequency of the disease, because heart failure
does not necessarily require routine hospitalisation. For this reason, the EUROCISS working group suggests review of GP medical records, health examination surveys or CVD surveys and the adoption of standardised criteria. If hospital discharge records are used, validation studies are recommended because heart failure can be found under other diagnoses.

Other indicators can be used as a proxy to measure the burden of the disease if integrated with other sources of information, e.g. national consumption of drugs used to treat heart failure and its complications. Among the recommended indicators, functional disability and quality of life are suggested in patients with HF.

Prevalence of ischemic heart diseases is assessed by surveys, but information on important clinical measures is often lacking.

Cerebrovascular accidents

Recommended indicators for cerebrovascular accidents include mortality, hospital discharge rate, incidence/attack rate, case fatality and prevalence. Mortality and hospital discharge diagnoses are available for all countries. Information about incidence/attack rate and case fatality of stroke is available in some countries through population-based registers; prevalence is assessed by CVD surveys, health interview surveys and health examination survey. Special surveys at 1 year follow-up of stroke patients are recommended to evaluate the functional disability and the quality of life.

Objective 3 - Developing recommendation for data collection

The list of the new recommended indicators is based on available data and can be generated over a relatively short period of time: these indicators are called short-term implementation indicators. Others, called long-term implementation indicators, need a longer period of time to be implemented; most of these indicators represent validated versions of the available and short-term indicators and require, for each country, the training of a dedicated team of epidemiologists to support their development.

Following the experience of many Northern European countries, it is also recommended that all medical and death records across Europe adopt a personal identification number, which would allow an easier and more accurate record linkage among the different sources of information.

The application of the recommended indicators, validated through standardised methodology in all countries will result in the availability of reliable, valid and therefore comparable data on CVD morbidity at the European level.

In the year 2004 the Project was re-funded and one of the main objective of the 2\textsuperscript{nd} phase is the preparation of the Manual of Operations for the implementation of population-based registers of acute myocardial infarction/acute coronary syndrome, stroke and of CVD surveys.
To this purpose, three Writing Groups have been formed in order to elaborate each Manual: the Writing group of the Manual of Operations of AMI/ACS Registers, the Writing group of the Manual of Operations of Stroke and the Writing group of the Manual of Operations of CVD Surveys.

Partners have been grouped according to their expertise. Each group is coordinated by a member of the Steering Committee who has the task to organize the activities of the members.

After an accurate bibliography revision (see Interim report 2005), the three Writing Groups have started the elaboration of the Manuals and they are still working on them.

The procedures described in the Manuals aim to be very simple. Starting from a minimum data set and following a step-wise procedure, a standardized model for the implementation of registers and surveys is provided.

A draft version of each Manual is enclosed to this Report.

Another achievement of the EUROCISS phase II has been the further development of the project WEB SITE (http://www.cuore.iss.it/eurociss/en/progetto/progetto.asp):
- under the section “Data at national level” tables summarising data about cardiovascular diseases by single country are now available in a more updated and completed version;
- a forum for discussion has been set up. This internal ‘working page’ can be accessed exclusively by EUROCISS partners through a password. Tables summarizing data from partner countries, draft Manuals of Operations, minutes of previous meetings and the Interim Report are among the most important documents available on the forum;
- a new page on the EUROCISS web site has been created to allow visitors to view all the past meetings where EUROCISS project had been presented;
- a list of future meetings can be found on the EUROCISS web site as well. This page contains the submitted proposals and abstracts and will be continually updated.

Being the web site the best and fastest way to spread information all over the world, all partners strongly contribute to its continuous development and updating.
2. **Organisation and Management**

The project is a collaborative effort of 18 different member states and the European Heart Network. Initially, twelve countries signed the agreement to participate (Austria, Belgium, Finland, France, Germany, Italy, The Netherlands, Norway, Portugal, Spain, Sweden, United Kingdom).

Two other countries (Denmark and Greece) joined the project later on. In the year 2004 four further countries (Czech Republic, Hungary, Iceland, Poland) were involved in the Project.

A questionnaire for the creation of an of the available information sources and indicators was prepared and sent to each partner country who returned it completed.

A list of possible indicators and recommendations was generated during the meetings open to all formal participants. Six meetings were organised during the **I phase** of EUROCISS project:

- Rome, 5-6 April 2001;
- Amalfi, 18-21 October 2001;
- Luxembourg, 7-8 March 2002;
- Taormina, 17-20 April 2002;
- Dresden, 28-30 November 2002;
- Varese, 8-10 April 2003.

During the **II phase** of the project, two Partners’ meetings were held:

- Rome, 11-12 October 2004
- Barcelona, 4-6 October 2005

The minutes of these meetings are reported in Appendix 1 and 3 respectively

At the beginning of the second phase, a **Steering Committee** was set up. It is constituted of 4 members (S Giampaoli, M Madsen, A. Pajak, P Primastata, S Sans) who will undertake to perform the following activities:

- support the coordinating centre in its main decisions;
- represent the project in all occasions;
- assure the involvement of all participating in supporting the objectives of the project;
- contribute to the coordination of working groups;
- plan the dissemination of final results;
- give its contribution to other EU projects;
Registers) which will be distributed to the three groups dedicated to the preparation of the same manuals.

- assist the writing groups in organizing the work, discussing and reviewing the Manuals of Operations (Manual of Operations of Cardiovascular Surveys; Manual of Operations of AMI/ACS; Manual of Operations of CVD Registers) in collaboration with the coordinating centre.

Up to now, the Steering Committee members met twice:

- on February 24-25, 2005 in Rome
- on May 11-13 in Athens, on the occasion of the EUROPREVENT meeting

The minutes of these meetings are reported in Appendix 2 and 4 respectively

The EUROCISS project was presented:

- at the European Society of Cardiology Working Group on Epidemiology and Prevention (Taormina, 17-20 April 2002) in the symposium Surveillance of Cardiovascular Diseases ‘The EUROCISS Project: the need for a common health currency in Europe’ (S. Giampaoli);

- at the tenth Annual Meeting of the European Public Health Association (Dresden, 28-30 November 2002): Workshop ‘Monitoring of Cardiovascular Diseases and Risk Factors: results from the EUROCISS Project’ proposed by the EUROCISS Research Group: ‘Monitoring of acute myocardial infarction and coronary heart disease’ (N. Hammar); ‘Monitoring of stroke and other cerebrovascular diseases’ (V. Salomaa); ‘Monitoring of cardiovascular risk factors’ (S. Sans); ‘Recommendations from the EUROCISS Project’ (S. Giampaoli);

- at the International Epidemiological association - European Epidemiology Federation (Toledo, 1-4 October 2003): Workshop ‘Monitoring of Cardiovascular Diseases and Risk Factors: results from the EUROCISS Project’ proposed by the EUROCISS Research Group: ‘Monitoring of acute myocardial infarction and coronary heart disease’ (N. Hammar); ‘Monitoring of stroke and other cerebrovascular diseases’ (V. Salomaa); ‘Monitoring of cardiovascular risk factors’ (S. Sans); ‘Recommendations from the EUROCISS Project’ (S. Giampaoli);

- at the 11th Annual Meeting of the European Public Health Association (Rome, 20-22 November 2003): Workshop ‘Monitoring of Cardiovascular Diseases: results from the EUROCISS Project’ proposed by the EUROCISS Research Group: “The burden of cardiovascular diseases in Europe” (S. Sans); “Recommended indicators for monitoring acute myocardial infarction and ischemic heart diseases” (N. Hammar); “Recommended indicators
for monitoring stroke and other cerebrovascular diseases” (S Petersen); “Recommended indicators for monitoring of heart failure and other forms of heart disease” (K Steinbach);

- at the Workshop “A Canadian Best Practices system for chronic disease prevention and control” (Toronto Ontario, Canada 10-11 March 2005);

- at the Sixth International Conference on Preventive Cardiology (Foz do Iguassu, Brazil, 21-25 May 2005): “European Cardiovascular Indicators Surveillance Set (EUROCISS): Recommendations for monitoring cardiovascular disease” (poster);

- at the ESC Congress 2005 (Stockholm, Sweden, 3-7 September 2005): “Population-based registers of Myocardial Infarction in Europe: results of the EUROCISS Project” (D. Vanuzzo);

- at the EUPHA 13th European Conference on Public Health (Graz, Austria, 10-12 November 2005): “The EUROCISS Project: development of cardiovascular morbidity indicators for the European Community” (S. Giampaoli); “Cardiovascular registers in Europe: results from EUROCISS Project” (S. Giampaoli);

- at the EUROPREVENT Congress (Athens, 10-13 may 2006): “EUROCISS: recommendations for coronary event surveillance in Europe” (S Giampaoli); “The EUROCISS Project: development of standardized measure for monitoring Coronaty Heart Disease in Europe” (M. Madsen);

- at the European Congress of Epidemiology (Utrecht, The Netherlands, 28 June-1 July 2006): “Population-based Registers for Myocardial Infarction in Europe: results from EUROCISS Project” (WM Monique Verschuren);

The following manuscripts have been published on behalf of the EUROCISS Working Group:

- Coronary and cerebrovascular population-based registers in Europe: are morbidity indicators comparable? Results of the EUROCISS Project (European J Public Health 2003;13, suppl3);

- “Population-Based Registers Of Acute Myocardial Infarction In Europe: Are Their Indicators Comparable?” (article to be submitted to European Journal of Cardiovascular Prevention and Rehabilitation)
The Project is coordinated by Simona Giampaoli, head of Unit of Epidemiology of Cerebro and Cardiovascular Diseases, National Centre for Epidemiology, Surveillance and Health Promotion.

She avails herself of the support of the following national officials: L.Palmieri, P.De Sanctis, C.Lo Noce, A.Giannelli, C.Donfrancesco, F.Dima.

Two full time researchers, P.Ciccarelli and V.Rebella are assigned to the activities of the Project and are paid by project funds.
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