



Cardiovascular Indicators
Surveillance Set

Grant Agreement n.2003118

Project leader: Simona Giampaoli

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EXECUTIVE SUMMARY

I. TECHNICAL INFORMATION

1. <u>AREA OF ACTIVITIES / WORKING PARTY / TASK FORCE:</u> Health Monitoring Programme Working Party Morbidity and Mortality / Task Force on Major and Chronic Diseases	
2. <u>FULL NAME OF PROJECT:</u> European Cardiovascular Indicators Surveillance Set, Phase II	
3. <u>ACRONYM:</u> EUROCISS II	
3. <u>START DATE OF THE PROJECT:</u> 01.05.2004	
4. <u>DURATION OF THE PROJECT:</u> 43 months	
5. <u>PROJECT LEADER / ORGANISATION</u> (include contact address): Simona Giampaoli National Institute of Health Centre for Epidemiology, Surveillance and Health Promotion Unit of Cerebro and Cardiovascular Disease Epidemiology Viale Regina Elena 299 00161 Rome, Italy Tel: +39 06 4990 4231 Fax: +39 06 4990 4230 E-mail: simona.giampaoli@iss.it	
6. <u>PROJECT NUMBER:</u> EUROCISS Phase II (2004-2007): <u>Agreement n. 2003118</u>	
7. <u>SANCO REPRESENTATIVE:</u> Antoni Moliner Montserrat; Jaroslaw Waligora	
8. <u>COUNTRIES INVOLVED</u>	
<u>MEMBER STATES:</u> A (Austria) B (Belgium) CZ (the Czech Republic)	<u>EFTA/EEA COUNTRIES:</u> (IS) Iceland (NO) Norway

D (Germany) DK (Denmark) E (Spain) EL (Greece) F (France) FIN (Finland) HU (Hungary) I (Italy) IRL (Ireland) L (Luxembourg) NL (Netherlands) P (Portugal) PL (Poland) UK (United Kingdom)	OTHERS: European Heart Network
9. REPORT STATUS: FINAL (14 February 2008)	

II. CONTENT RELATED INFORMATION

10. CONTEXT/INTRODUCTION (limit 250 words):

Cardiovascular disease (CVD) is the leading cause of death and hospitalization in both genders in nearly all countries of Europe, thus representing a substantial public health burden.

CVD clinically manifests itself in middle life and older age, after many years of exposure to unhealthy lifestyles (unhealthy diet, physical inactivity, and smoking habit) and risk factors (high blood pressure, high cholesterolemia, diabetes, obesity).

Given the pressing need to implement comprehensive strategies to address this growing epidemic, surveillance remains the primary tool to evaluate the burden and trend of disease.

The magnitude of the CVD burden contrasts with the usual paucity and poor quality of data available on incidence and prevalence of CVD beyond mortality, on distribution of risk factors and prevalence of high risk conditions, other than rigorous but limited studies carried out in certain areas. In addition, the prevalence of complications following acute events is steadily increasing, mainly due to an increase in survival rate.

The development and implementation of effective surveillance systems for CVD produce reliable and comparable indicators, thus enabling health professionals and policy makers to trace differences within and between countries, to study trends and to make better decisions on planning and evaluation of prevention programs, healthcare delivery,

resource allocation, and research.

The European Cardiovascular Indicators Surveillance Set (EUROCISS) Project was launched in 2000 by a partnership of EU countries with the aim of developing health indicators and recommendations for monitoring the distribution and impact of CVD in Europe in order to facilitate cross-country comparisons and improve CVD prevention and control.

The first aims were to prioritize CVD of greatest interest in public health and identify specific indicators for assessing mortality and morbidity in CVD. The indicators were selected after an in-depth discussion among experts on the basis of the available data. Some indicators can be produced in a short time, while others need a long period of time to be processed and validated. Attack rate/incidence, case fatality and prevalence were suggested for inclusion in the European Community Health Indicators Monitoring (ECHIM) short list (<http://www.echim.org/>).

11. KEYWORDS (use maximum 5 MeSH terms):

Cardiovascular disease, stroke, surveillance, population-based register, HIS/HES.

12. AIM AND OBJECTIVES OF THE PROJECT:

The objectives of the second phase of EUROCISS Project (2004-2007) were:

- to complete the technical and scientific work begun during the first phase of EUROCISS project and necessary to finalize the list of indicators and the standardized procedures and methods of data collection that assist Member States (MS) in producing reliable, valid and comparable data;*
- to prepare the Manual of Operations for the implementation of surveillance systems for the collection and validation of indicators, in particular of population-based registers of Acute Myocardial Infarction/Acute Coronary Syndrome (AMI/ACS);*
- to prepare the Manual of Operations for the implementation of surveillance systems for the collection and validation of indicators, in particular of population-based registers of stroke;*
- to prepare the Manual of Operations for the implementation of CVD Surveys for collecting standardised indicators, in particular for prevalence of ischaemic heart diseases (IHD), heart failure (HF), cerebrovascular accidents (CVA) and other CVD, and to*

identify a minimum set of questions and exams to be included in the Health Interview Survey/Health Examination Survey (HIS/HES) for evaluating the prevalence of CVD at European level;

- to develop knowledge, tools and expertise among MS for CVD surveillance and prevention.

13. SPECIFIC CONTRIBUTION(S) TO THE EU HEALTH INFORMATION AND KNOWLEDGE SYSTEM:

Please indicate whether your project has contributed to (multiple areas can be indicated):

[x] Development of new indicators

A list of recommended indicators for CVD surveillance was proposed to improve the knowledge on cardiovascular disease and contribute to the promotion of health and prevention throughout the European Union.

Some indicators are based on available data and can be produced over a relatively short period of time (short-term implementation indicators). Others need a longer period of time to be implemented and require the training of a dedicated team of epidemiologists to support their development (long-term implementation indicators).

Short-term recommended indicators for AMI/ACS include mortality and hospital discharge rates; long-term indicators include incidence/attack rates and case fatality. Also prevalence is recommended for the surveillance of IHD and other CVD.

Recommended indicators for stroke include mortality, hospital discharge rate, incidence/attack rate, case fatality and prevalence.

Incidence/attack rate, case fatality of acute events and prevalence of chronic conditions were recommended for inclusion in the ECHIM short list as they provide important information on morbidity, mortality, disability and survival rate; incidence/attack rate and case fatality are drawn from routine databases and are processed after being pooled and validated. Incidence is particularly relevant in the case of acute events and useful for etiological research objectives; attack rate -- which includes fatal and non-fatal, new and recurrent events occurring in and out of hospital -- is important for disease surveillance, distribution and trend. Incidence/attack rate are collected through population-based registers. Prevalence is important in the case of chronic conditions and can be assessed through a set of questions and exams to

include in HIS/HES.

All these indicators, if used in combination, are able to provide an exhaustive picture of the disease and useful information supporting policy decision makers in planning and evaluating primary and secondary prevention actions.

[x] Revision of existing indicators:

No revision of mortality and hospital discharge records (HDR) was made but it was suggested to use these routine data to build new indicators. This is particularly important for acute coronary events (heart attack) given that today the proportion of events unable to reach hospital is still very high (about 30-40% considering MONICA Project data (MONItoring of trends and determinants in CARdiovascular diseases). Mortality records give information on fatal events, whereas hospital discharge records on non fatal events only. Therefore, if these sources, after being properly linked and validated, are used in combination, they are able to provide an exhaustive picture of the disease and standardized indicators (attack rate/incidence, case fatality). Thanks to advancements in therapy for acute phase of events, survival rate has increased and frequency of complications evolving into chronic conditions has greatly changed. Therefore, the availability of indicators such as incidence/attack rate and prevalence is essential to delineate the complete picture of the disease in the different countries and monitor disease trend over time.

[x] Development of European Health Interview Survey related products:

[x] Questions

The EUROCISS Project recommends to include in the HIS a minimum set of questions together with a longer and more detailed module to be administered periodically in order to assess the prevalence of IHD, old myocardial infarction (MI), HF, Intermittent Claudication (IC), Angina Pectoris (AP), stroke. The minimum set of questions includes: condition diagnosed by a doctor, medicines use, diagnostic and therapeutic procedures performed, family history, presence of diabetes, hypertension, hypercholesterolemia.

☐ Modules

☒ Guidelines/recommendations:

Manual of Operations for the implementation of CVD Survey: it is a simple guide to performing a population survey

☐ Other. Please describe shortly:

☒ Development of European Health Examination Survey related products:

☒ Examinations

The minimum set of exams for risk factors measurement includes: arterial blood pressure, anthropometric measurements (height, weight, and waist circumference), lipid and glucose blood assay. Some instrumental examinations such as Electrocardiogram (ECG) and Ankle/Brachial Index (ABI) are strongly recommended to assess IHD and atherosclerosis, provided that resources are available.

☒ Guidelines/recommendations:

Manual of Operations for the implementation of CVD Survey: it is a simple guide to performing a population survey

☐ Other. Please describe shortly:

☒ Activities related to the operation of registers. Please describe shortly:

It is not important that population-based registers cover the whole national territory, it is important that they cover representative areas of the country.

Population-based registers can be implemented if the following conditions are met:

- *availability of mortality and hospital discharge records for the age range 35-74 years and, particularly for stroke, up to 84 years of age. The age range 25-34, where few events occur, and the age range 85+, for which diagnostic*

information tends to be less reliable due to the existence of comorbidities, are excluded;

- possibility to perform record linkage (by PIN or by name, date of birth, sex and place of residence);*
- population big enough to produce 300 total events per year in the age range 45-74 years in order to assess trends (2% per year);*
- epidemiologic team interested in the development and improvement of surveillance systems of CVD for data processing and event validation.*

Given the still very high out of hospital case fatality of CVD, population-based registers are very important as they allow to evaluate fatal and non-fatal (first and recurrent) events occurring in and out of hospital (see EUROCISS Manuals of Operations in Appendix I).

[] Activities related to international coding systems. Please describe shortly:

[] Setting up / supporting international expert networks

[x] Making inventory of existing data sources:

During the first months of activity of the 2nd phase, a questionnaire was developed in order to collect data necessary for making the inventory of the main sources of information, available data, validation procedures and methods. In particular, partners were asked to identify the existing population-based registers with specific information on definition of events and to specify if any CVD survey was conducted in their country. Reported data referred to the year 2006.

The inventory helped partners describe appropriate procedures and methods for preparing the Manuals of Operations of population-based registers of AMI/ACS and Stroke and of CVD Surveys.

Data on sources of information in the different countries are available on the Project website (<http://www.cuore.iss.it/eurociss/progetto/progetto.asp>)

[] Collecting new data

Where can the data be found?

☒ Linking data sources

Record linkage of mortality and hospital discharge records and event validation represent the minimum requirement to implement a population-based registrar.

☐ Developement of international guidelines/recommendations for areas not mentioned above. Please describe shortly:

☐ Other. Please describe shortly:

14. DELIVERABLES/OUTCOMES:

The most important achievement of the EUROCISS Project has been the development of the Manuals of Operations for the implementation of population-based registers of AMI/ACS, stroke and of CVD surveys.

These Manuals of Operations are the result of a long and fruitful cooperation among many experts, such as epidemiologists, statisticians, cardiologists and public health professionals. These manuals represent a general guide to processing routine data, such as mortality and hospital discharge records, in order to build and validate attack/incidence rate, case fatality, prevalence for the surveillance of CVD. More specifically, they represent a valid scientific support for investigators, health professionals and staff interested in current data collection and analysis and working in National Institutes of Health, National Institute of Statistics, Local Sanitary Units, and other academic and public health institutions operating at both regional and national levels. These Manuals of Operations may support also policy makers in their public health decision processes.

The Manuals of Operations of AMI/ACS and Stroke population-based registers provide simple and comparable tools to support and stimulate implementation of population-based registers in those countries which lack them but collect routine data such as mortality and hospital discharge records. They recommend to start from a minimum data set and follow a step-wise procedure based on standardized data collection, appropriate record linkage and validation method, thus providing a standardized model for producing estimates of attack/incidence rate and case fatality.

The Manual of Operations of CVD Survey provides a general guide and updated methods for the surveillance of CVD and represents a useful tool to estimate the prevalence of

chronic CVD. Population surveys are important as they further supplement the information collected from registers with additional details on socio-demographic characteristics, risk factors, physical/biological measurements and chronic conditions.

Attack/incidence rate, case fatality of acute events and prevalence of chronic conditions are recommended for inclusion in the ECHIM short list.

Another achievement of the EUROCISS Project phase II has been the development of the project WEB SITE (<http://www.cuore.iss.it/eurociss/en/progetto/progetto.asp>) established within the page of the Progetto CUORE of the Italian Institute of Health (ISS) and Ministry of Health, which financed 40% of the EUROCISS Project. The website provides a detailed and interactive description of the Project and of recommended indicators.

A FORUM for discussion, accessible exclusively by EUROCISS partners, was created to facilitate discussion among project partners.

15. CONCLUSIONS / KEY HEALTH MESSAGES / ADDED VALUE FOR REACHING GOAL OF EU PUBLIC HEALTH PROGRAMME (limit 250 words);

CVD is responsible for a great deal of hospitalization and death. Many sources of information must be integrated to obtain a comprehensive picture of the disease. Clinical events may be acute or chronic and vary in their severity; hospitalization may be for the first occurrence of a disease or for treatment of further episodes or sequelae and complications. Validation of data thus becomes essential and the ability to temporally link events in time is of great potential interest. Following the experience of the Nordic countries, it is therefore also recommended that all medical and death records across Europe adopt a personal identification number (PIN), which would allow an easier and more accurate record linkage among the different sources of information.

In summary, the project added value by:

- proposing a stepwise procedure for the implementation of acute events indicators such as attack/incidence rate and case fatality (ECHIM recommended indicators) through population-based registers of AMI and Stroke;
- identifying a minimum set of questions to be included in the HIS for evaluating the prevalence (ECHIM recommended indicator) of chronic CVD at European level;
- identifying a minimum set of exams to be included in the HES for evaluating the prevalence of chronic CVD at European level;

- *creating a network of experts from each country to support the monitoring of CVD across Europe;*
- *creating a network of experts from each country to assess feasibility of comparison among countries and study CVD trend;*
- *establishing the basis for an improved future regulation in public health policies concerning the surveillance of CVD throughout European countries.*

The application of the recommended standard methodology in all countries will result in the availability of reliable, valid and therefore comparable data on CVD morbidity at the European level and will facilitate implementation of preventive actions.

16. DISSEMINATION OF RESULTS:

a) has a link with the EU Health Portal been established?

Yes

(http://ec.europa.eu/health/ph_projects/2003/action1/action1_2003_10_en.htm)

b) activities carried out so far:

One of the main tasks of the partners, throughout the duration of the Project, was to participate in national and international meetings related to public health and CVD prevention, contributing with their input to the dissemination of the Project results and giving further visibility to the Community approach.

The results of the EUROCISS Project were presented:

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

- at the Helsingborg Consensus Conference 'European Stroke Strategies (Helsingborg, Sweden March 22-24, 2006): "The EUROCISS Project: recommended indicators for monitoring stroke in Europe";
- at the EUROPREVENT Congress (Athens, Greece 10-13 May 2006): "EUROCISS: recommendations for coronary event surveillance in Europe"; "The EUROCISS Project: development of standardized measure for monitoring Coronary Heart Disease in Europe";
- 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";
- at the ESC Congress/World Congress of Cardiology 2006 (Barcelona, Spain, 2-6 September 2006): "Population-based Registers in Europe: results from EUROCISS Project";
- at the EUROPREVENT Congress (Madrid, Spain, 19-21 April 2007). Four presentations within a Specialist symposium entitled: "The EUROCISS Project: Recommendations for cardiovascular surveillance in Europe": 1) How to make routine data comparable across Europe; 2) Population-based AMI registers; 3) CVD Surveys; 4) Population-based stroke registers;
- at the ESC Congress 2007 (Wien, Austria, 1-5 September 2007): "Results and recommendation from EUROCISS-AMI"; "Results and recommendation from EUROCISS-Stroke";
- at the 15th European Conference on Public Health (EUPHA, Helsinki, Finland 11-13 October 2007) within the Symposium of the TFMCD: "The EUROCISS Project: recommendations for myocardial infarction and stroke population-based registers implementation".

The Manuals of Operations were reviewed by external experts: Prof. Shanti Mendis from WHO reviewed the Manual of Operations of population-based register of AMI/ACS; Prof. Birgitta Stegmayr from Umea University (Sweden) reviewed the Manual of Operations of population-based register of stroke; and Prof. Maurizio Trevisan from The Health Sciences System of the Nevada System of Higher Education in Las Vegas (USA) reviewed the Manual of Operations of CVD Survey.

The three Manuals were published on behalf of the EUROCISS Working Group in

November 2007 as Supplement in the European Journal of Cardiovascular Prevention and Rehabilitation, Vol 14 (Suppl 3): S1-S61.

(visit the Journal website www.jcardiovascularrisk.com/)

c) further plans:

The Manuals of Operations represent the starting point for implementing a pilot phase in those countries lacking CVD surveillance systems but willing to implement them in order to monitor disease trend over time and build valid and standardized indicators which are comparable with those already existing in other countries.

17. ACTIVITIES UNDERTAKEN TO GUARANTEE SUSTAINABILITY OF PROJECT OUTCOMES (limit 150 words):

Population-based registers can be implemented if the following conditions are met:

- *availability of mortality and hospital discharge records for the age range 35-74 years and, particularly for stroke, up to 84 years of age, if possible. The age range 25-34, where few events occur, and the age range 85+, for which diagnostic information tends to be less reliable due to the existence of comorbidities, were excluded;*
- *possibility to perform record linkage (by PIN or by name, date of birth, sex and place of residence);*
- *population big enough to produce 300 total events per year in the age range 45-74 years in order to assess trends;*
- *epidemiologic team interested in the development and improvement of surveillance systems of CVD.*

Given the still very high CVD out of hospital case fatality, population-based registers are very important as they allow to evaluate fatal and non-fatal (first and recurrent) events occurring in and out of hospital.

CVD surveillance systems can be further implemented including:

- *a minimum set of questions for HIS;*

- a minimum set of examinations for HES (blood pressure, anthropometric measurements, laboratory tests, ECG).

18. NEEDS FOR FUTURE POLICY DEVELOPMENT IDENTIFIED: (limit 250 words):

The Project selected indicators and established standardized methodologies for routine data collection and processing procedures necessary for CVD surveillance, assessment of disease burden and trend.

The succeeding step would be the implementation of the pilot phase in some countries under the coordination of a central body and the support of experts involved in CVD population-based registers. The minimum requirement is the involvement of geographical administrative areas lacking surveillance systems with populations big enough to provide stable estimates and available reliable routine data, such as mortality and hospital discharge records. A team of trained epidemiologists which fully dedicate to record linkage and validation procedures should be also available.

Also the implementation of questions and exams to include in HIS/HES for assessing CVD trend and distribution is feasible.

ABBREVIATIONS

ABI = Ankle Brachial Index
ACC= American College of Cardiology
ACS = Acute Coronary Syndrome
AHA = American Heart Association
AMI = Acute Myocardial Infarction
AP = Angina Pectoris
BCS= British Cardiac Society
CABG = Coronary artery bypass grafting
CSF = Cerebrospinal Fluid
CK-MB = Creatine-Kinase
CT-Scan= Computed Tomography – Scan
CVA = Cerebrovascular Accidents
CVD = CardioVascular Disease
ECHIM = European Community Health Indicators Monitoring
ECG = Electrocardiogram
ESC= European Society of Cardiology
EU = European Union
EUROCISS = European Cardiovascular Indicators Surveillance Set
EUROSTAT = Statistical Office of the European Communities
GP = General Practitioner
HDR = Hospital Discharge Records
HES = Health Examination Surveys
HF = Heart Failure
HIS = Health Interview Surveys
HMP = Health Monitoring Programme
IC = Intermittent Claudication
ICD = International Classification of Diseases
ICPC = International Classification for Primary Care
IHD = Ischaemic Heart Disease
ISS = Istituto Superiore di Sanità
LSHTM = London School of Hygiene and Tropical Medicine
MI = Myocardial Infarction
MONICA = Monitoring trends and determinants of Cardiovascular diseases
MRI = Magnetic Resonance Imaging
MS = Member States
PCI = Percutaneous Coronary Intervention
PIN= Personal Identification Number
PPV= Positive Predictive Value
PTCA = Percutaneous Transluminal Coronary Angioplasty
QoL = Quality of Life
TIA = Transient Ischaemic Attack
WHO = World Health Organization