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Coronary and cerebrovascular population-based registers in Europe: are morbidity indicators comparable?

Results from the EUROCISS Project

On behalf of THE EUROCISS WORKING GROUP *

Background: The EUROCISS Project (European Cardiovascular Indicators Surveillance Set), as part of the Health Monitoring Programme financed by the European Commission, has been implemented to develop health indicators and recommendations for the monitoring of cardiovascular diseases (CVDs). Morbidity data are rarely available in the different countries and when available, they are very rarely comparable. The aims of this paper are to list the existing population-based registers of acute myocardial infarction (AMI) and stroke in Europe, describe their methodology, and discuss their comparability. **Methods:** using a questionnaire a comprehensive and updated picture on available sources of information, data, indicators, and methods were collected for population-based registers. The information requested generally included: the studied disease; the scope of the study (geographical area, temporal duration, age range, population); adopted methodologies (case definition, ICD coding for mortality and hospital discharge records, linkage and validation methods); morbidity indicators (attack rate, incidence, prevalence, case fatality rate). **Results:** Belgium, Denmark, Finland, France, Germany, Italy, Norway, Spain, and Sweden have ongoing population-based registers for AMI. Denmark, Finland, France, Germany, Italy, Norway, and Sweden have ongoing population-based registers for stroke. Selection procedures of events, differences in age range, different validation procedures and methods make the results from these registers difficult to compare. **Conclusions:** Population-based registers provide the best indicators for AMI and stroke, such as attack rate and case fatality. Registers cover large samples of the population, usually regions or large municipalities. The comparability of data across countries depends on standardization, case definition, completeness, proper linkage, common diagnostic criteria and validation procedures. Given the high burden of AMI and stroke, efforts are needed in implementing registers in all European countries.

Keywords: acute myocardial infarction, Health Monitoring Programme, morbidity, population-based register, stroke

The EUROCISS Project (European Cardiovascular Indicators Surveillance Set) started in 2000 thanks to a partnership of European Union (EU) countries to develop health indicators and recommendations for the monitoring of cardiovascular diseases (CVD). It is part of the Health Monitoring Programme financed by the European Commission.¹

The aims of the EUROCISS project are to identify, among existing data sets, the essential information required to objectively define morbidity indicators for CVD and to recommend standardized methods for future monitoring of CVD and data collection in the EU. This would permit cross-country comparisons to improve the prevention and control of CVD, to set public health priorities and determine appropriate actions.

For acute myocardial infarction (AMI) and stroke, CVDs of major interest, the most useful indicator is an attack rate, which considers first and recurrent events and is

* See *Appendix* for the composition of the EUROCISS Working Group

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based on a combination of mortality and morbidity data. Attack rates may be derived from population-based registers. National registers utilizing administrative data from hospital discharges and deaths have existed for many years in the Nordic countries.^{2–5}

Many countries of the EU have participated in the MONICA Project (Monitoring of Trends and Determinants in Cardiovascular Diseases), which was a multi-centre study involving formation of population-based registers. It produced valid and reliable information on fatal and non-fatal acute coronary and cerebrovascular events in different populations during the years 1985–1994.^{6,7} Attack rates produced by MONICA have been useful for cross-country comparisons of acute coronary and cerebrovascular trends in men and women. Information on mortality and morbidity was compiled using consistent methodology and validation techniques, applying standardized diagnostic criteria to identify events over time. The methodology, however, was very expensive, the population under surveillance was limited to persons aged 35–64 years and the selected areas were not necessarily representative of the whole country.⁸

Following the MONICA experience, other simplified surveillance systems were set up in some EU countries.^{9,10}

The purpose of EUROCISS has been to produce an inventory of different sources of information with available data on AMI and stroke in order to evaluate the best and most easily accessible indicators and to develop recommendations for assessing the burden of CVDs.

We quickly discovered that morbidity data are rarely available in the different countries and, when available, they are very rarely comparable. The aim of this paper is to list the existing population-based AMI and stroke registers in Europe and to describe their methodology in order to discuss their comparability.

MATERIALS AND METHODS

To obtain a comprehensive and updated picture on available CVD morbidity data, the partner countries of the project completed a questionnaire. The purpose of the questionnaire was to collect data necessary for making the inventory of the main sources of information, available data, indicators, and methods.

The questionnaire included five forms concerning the following main sources of information: population-based registers, hospital discharge records, surveys, longitudinal studies and GP-networks. The information requested in each form generally included:

- the diseases under study (ischaemic heart disease [IHD], AMI, stroke, heart failure [HF]);
- the scope of the study (geographical area, temporal duration, age range, population);
- adopted methodologies (case definition, ICD coding for mortality and hospital discharge records [HDR], linkage and validation methods);
- morbidity indicators (e.g. attack rate, incidence, prevalence, case fatality);

- data accessibility;
- available publications;
- partner comments.

We requested that the information provided be as accurate and detailed as possible. We were aware that each country might have developed different types of research and information sources, and thus partners were asked to choose those they judged the most complete and representative of their own country, in order to offer the best information at a national or regional level. In particular we asked to identify the ongoing population-based registers, which collected information on fatal and non-fatal events in and out of hospital.

Information derived from the completed questionnaires on AMI and stroke registers has been summarized. All of the information collected will constitute the basis for achieving the last aim of EUROCISS, the 'recommendations for the collection of comparable data for monitoring the CVD morbidity in the European Union'.

RESULTS

Acute myocardial infarction

Information on AMI registers is reported in *table 1*. Registers are available at regional level in Belgium,¹¹ Denmark,¹² Finland,^{2,10,13} France,¹⁴ Germany,¹⁵ Italy,^{16,17} Norway, Spain¹⁸ and Sweden.^{4,19}

Most of the registers started between the second half of the 1980s and the first half of the 1990s (Finland, France, Germany, Italy-MONICA, Spain and Sweden), while others are more recent (Belgium-Bruges, Italy and Norway). The ages covered range between 25 and 74 years or more. Many of these registers adopt simplified methodologies derived from the MONICA Project, using a record linkage of AMI from hospital discharge register and mortality and validating the suspected events by applying the MONICA diagnostic criteria.²⁰ In several

Table 1 Registers of AMI: population characteristics in each country

Country	Area coverage	Years	Age range (years)	Population mult 1000	Accessibility
Belgium Charleroi, Ghent	Regional	1983 →	25–69	230	School of Public Health, University of Ghent
Belgium Bruges	Regional	1998 →	25–74	151	University of Ghent
Northern Denmark	Regional	1977 →	All	493	Aarhus University
Finland	Regional	1991 →	35–100	232	KTL
France	Regional	1985 →	35–74	1,800	Min. Health
Germany	Regional	1985 →	25–74	400	GSF-KORA
Italy MONICA	Regional	1984–1993	25–64	1,000	MONICA–Brianza, Friuli
Italy	Regional	1996 →	35–74	3,360	Nat. Institute of Health
Norway	Regional	2000 →	15 →	58	Kirkenes Hospital
Spain	Regional	1985–1998	25–74	766	MONICA
Northern Sweden MONICA	Regional	1985 →	25–74	510	Nat. Board of Health and Welfare
Denmark	National	1978 →	All	5,368	Nat. Institute of Public Health
Finland	National	1991 →	All	5,000	KTL, Stakes
Sweden	National	1987 →	All	8,880	Nat. Board of Health and Welfare

registers troponine test data²¹ are currently collected in addition to MONICA criteria.

In Denmark,¹² Sweden^{22,23} and Finland²⁴ national AMI registers also have been compiled using a linkage of administrative records from national hospital discharge and death registers; they cover the entire population and all ages. In the Swedish national register, the events have been validated on a random sample of patients using diagnostic criteria recommended for use in Swedish hospitals.²³ In Denmark the national register has been validated by record linkage to the Danish MONICA register.²⁵

■ Mortality ICD codes

In the definition of AMI, countries use different sets of ICD (ICD-8, ICD-9 or ICD-10) codes from death certificates (table 2).

Denmark has never used ICD-9 but went directly from ICD-8 to ICD-10. Except Sweden, where only AMI is selected, all other countries include IHD; Finland, Germany and Norway add sudden non-violent death. In addition, Italy and Spain consider other causes of death, diabetes and hypertension, when one of the contributory causes of death is IHD.

■ HDR ICD codes

Selected diagnoses for the identification of suspected non-fatal events from hospital discharge records are as follows: AMI in Denmark and Sweden; AMI, other acute and subacute forms of ischaemic heart disease and angina pectoris in Finland; all IHD in Italy and Spain; IHD, HF and percutaneous transluminal coronary angioplasty (PTCA) in Norway; IHD, HF and coronary artery by pass grafting (CABG) in Belgium and Germany.

Linkage procedures between mortality and HDR are performed through the 'personal identification number' (ID) in Denmark, Finland, Norway and Sweden, and

through the name, date of birth and place of residence in Belgium, France, Germany, Italy and Spain.

Stroke

Registers are available in Finland,²⁶ France,^{27,28} Germany,^{29,30} Italy,³¹ Norway^{3,32} (Finnmark-MONICA) and Sweden (MONICA)^{33–36} at regional level. Available data from stroke registers are summarized in table 3. Stroke registers are less frequently found in EU countries than AMI registers. Stroke registers differ in the procedures used for the selection of suspected events, record linkage of mortality and HDR, and validation procedures.

In Denmark,¹² Finland^{26,37,38} and Sweden (Riks-Stroke),³⁹ there are also stroke registers based on the record linkage of administrative data from hospital discharge registers and deaths, which cover the entire population.

■ Mortality ICD codes

Table 4 summarizes the codes used for the selection of stroke. Finland, France, Germany and Norway select all cerebrovascular accidents (CVA); Italy includes CVA but does not include TIA; Sweden includes CVA but does not include TIA, other and ill defined cerebrovascular disease, and late effects of cerebrovascular disease.

■ HDR ICD codes

Finland, France, Germany, Norway and Sweden (MONICA) select all CVAs; Italy does not include TIA. Norwegian registers include hemorrhagic and ischaemic stroke separately.

All stroke registers of Nordic countries adopt the ID number for purposes of linkage; France, Germany and Italy link mortality and HDRs by name, date of birth and place of residence. Validation is based on the MONICA diagnostic criteria in Finland, Italy, Norway and Sweden

Table 2 Registers of AMI: case definition in each country. National data are presented in the lower part

Country	ICD version	Sources of information		Linkage mortality / HDR	Validation
		Mortality ICD codes ^a	HDR ICD codes ^a		
Belgium Charleroi, Ghent, Bruges	IX	410–414	410–414, PTCA, CAGB	Name, date of birth	MONICA, troponine
Northern Denmark	VIII, X	410	410	ID	–
Finland	X	410–414, 428, 798	410, 411, 413	ID	MONICA, troponine
France	X	410–414	410–414, 428	Name, date of birth	MONICA
Germany	X	410–414, 428, 798	410–414, 428, PTCA, CAGB	Name, date of birth	MONICA
Italy-MONICA, Italy	IX	410–414, 798, other	410–414	Name, date of birth	MONICA
Norway	X	410–414, 428, 798	410–414, 428, PTCA	ID	MONICA, troponine
Spain	IX	410–414, 428, 798, other	410–414	Name, date of birth	MONICA
Northern Sweden MONICA	IX, X	410	410	ID	MONICA
Denmark	VIII, X	410–414	410	ID	Recommended national diagnostic criteria and MONICA
Finland	X	410–414, 798	410, 411, 413	ID	Clinical diagnosis, troponine
Sweden	IX, X	410	410	ID	Recommended national diagnostic criteria

a: All codes are presented in the ICD-9 revision to facilitate the comparison.

(MONICA). Validation makes use of the CT-scan in France and Germany; in Germany health insurance data are also used for validation.

National registers of Nordic countries include all CVAs except the Swedish Riks-Stroke register, which include hemorrhagic and ischaemic stroke separately.

Selection procedures of suspected events, differences in age range, different validation procedures and methods make data from these registers difficult to compare.

DISCUSSION

Despite efforts to develop standardized CVD statistics in the EU, this goal remains to be achieved. The definition of disease differs from country to country, sometimes only slightly, sometimes more fundamentally, and varies over time.

Health status indicators represent a set of surveillance data properly adopted to assess the health status of the population. A standardized definition of disease is crucial for this process. Indicators can be used to set public health priorities and determine appropriate actions. Selection of indicators should be based on existing and comparable data sets for which regular monitoring is feasible. In-

dicators also need to be comprehensive, valid (sensitive and specific), standardized, and meet quality criteria.

On the basis of these considerations, population-based registers provide the best source of information for AMI and stroke data. In fact they are usually built taking into account mortality and hospital discharge data related to fatal and non-fatal events. They provide indicators such as attack rate and case fatality. Attack rate includes first and recurrent event and case fatality in and out of hospital. Incidence can be assessed if information on first event is available. If survival rates are available, prevalence can also be assessed.^{17,40} Registers often cover representative areas of the population, usually regions or large municipalities. National registers of AMI have been also compiled utilizing administrative data from hospital discharges and deaths; these registers are economical, include all age groups and collect large numbers of events. However, they are not planned for scientific research, data are not collected by standardized methods, and quality control procedures are limited.

The comparability of data across countries depends on standardization, case definition, completeness, proper linkage, common diagnostic criteria and validation

Table 3 Registers of stroke: population characteristics in each country

Country	Area coverage	Years	Age range (years)	Population mult 1000	Accessibility
Finland	Regional	1993–1997	25–99	232	KTL
France	Regional	1985 →	1 →	150	Dijon
Germany	Regional	1994 →	18 →	100	Erlangen University
Italy-MONICA	Regional	1984–1993	35–64	500	MONICA-Friuli
Italy	Regional	1996 →	35–74	3,360	ISS
Norway	Regional	1998 →	24–95+	58	Kirkenes hospital
Sweden MONICA	Regional	1985 →	25–75	322	Umea University
Denmark	National	1978 →	0 →	5,368	Nat. Institute of Public Health
Finland	National	1991 →	25–99	5,000	KTL, Stakes
Sweden Riks-Stroke	National	1995 →	1 →	8,880	Nat. Board of Health and Welfare

Table 4 Registers of stroke: case definition in each country. National data are presented in the lower part

Country	ICD version	Sources of information		Linkage mortality / HDR	Validation
		Mortality ICD codes ^a	HDR ICD codes ^a		
Finland	X	430–438	430–438	ID	MONICA
France	X	430–438	430–438	Name, date of birth	CT-Scan
Germany	X	430–438	430–438	Name, date of birth	CT-Scan, Health Insurance
Italy-MONICA, Italy	IX	430–434, 436–438	430–434, 436–438	Name, date of birth	MONICA
Norway	X	430–438	431, 434, 436	ID	MONICA
Sweden MONICA	IX, X	430–434, 436	430–438	ID	MONICA
Denmark	VIII, X	430–438	430–438	ID	–
Finland	X	430–438	430–438	ID	Clinical diagnosis, CT / MRI
Sweden Riks-Stroke	X	431, 434, 436	431, 434, 436	ID	Clinical diagnosis

a: All codes are presented in the ICD-9 revision to facilitate the comparison.

procedures. In particular data inaccuracy may represent a problem for stroke: 50% of 'new stroke diagnoses' are merely sequelae of an old stroke. This problem increases with age.^{3,33,34,37} A unique identification number for each subject would be very useful for linkage procedures between hospital discharge diagnosis and death certificate records.

The identification of events can be done by 'hot pursuit' or 'cold pursuit'. Hot pursuit means identifying case admissions to the hospital, usually within one or two days from the event onset, and acquiring relevant information by visiting the ward or interviewing the patient. Information bias is minimized by the 'hot pursuit' approach, as information is collected immediately after the event.^{8,41}

However, the process is expensive. 'Cold pursuit' implies the use of routine and delayed procedures, hospital discharge and death records. The process is easier and less expensive than hot pursuit; the number of cases studied is smaller because discharge diagnoses are more precise and specific than those on admission but there is the possibility of missing important information. Both methods are used to identify suspected events, which must be validated applying standardized criteria.

Several European countries have registers for AMI and stroke. The high cost of registers limits their implementation at a national level; therefore they should be established in representative areas of a country (regions, macro-areas, etc.). A simplified method, based on a record linkage of hospital discharge diagnoses and death certificates, with validation of a sample of events according to standardized diagnostic criteria, as adopted in many countries, might be suggested for those countries which do not have registers. This method uses sources of information and databases currently available in public health services, and aims to identify the number of fatal and non-fatal major coronary and cerebrovascular events; the positive predictive value, in such registers can be determined from comparisons with standardized validation systems such as MONICA.¹⁶ The possibility of linking routinely collected data may be improved through a unique identification number as in the Nordic countries. It is advisable for those countries that do not have registers to establish them following standardized procedures and using the experiences of the other countries. This would permit cross-country comparisons to improve the prevention and control of CVDs. The EUROCISS group has observed that no population data or registries are currently available in Europe on HF. Given the high burden of this form of CVD, further efforts to obtain information on HF are needed and the possibility of implementing registries needs to be considered.

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