

9. Data availability

9.1 Databases available at a European level

9.1.a WHO statistical databases

WHO produces two main health databases: the Health for All Statistical Data Base (HFA-DB) and the WHO Mortality Data Base (HFA-MDB)⁵⁰

WHO HFA-DB database contains data on about 600 health indicators grouped into the following categories: demographic and socio-economic statistics, mortality-based indicators, morbidity, disability and hospital discharges, lifestyles, environment, health care resources, health care utilization and expenditure, maternal and child health. They allow a simple and user-friendly analysis of trends and international comparisons for a wide range of health statistics to support the formulation and monitoring of health policies at the national and international level.

The HFA-DB is used by the WHO for the routine analysis and assessment of the health situation in Europe; it provides easy and rapid access to a wide range of basic health statistics for the 51 (52 since 2004) MS of the WHO European Region (including countries of the former Soviet Union). It was developed by the WHO Regional Office for Europe in the mid-1980s to support the monitoring of health trends in the Region.

The data are either submitted by European MS to the Regional Office or collected from other international organizations or sources. The Regional Office continuously collects new data and issues updated versions of the database twice a year, generally in January and June. Data are presented in a user-friendly, graphical or tabular form.

There are two versions of the database:

- An **on-line** version, which allows rapid access to the data via the Internet⁵⁰; and
- An **off-line** version, which can be downloaded from the Regional Office Website⁵⁰.

For CVD morbidity, the HFA-DB provides the following indicators for each country:

- number of hospitalisations for *circulatory system diseases* (ICD-9 390-459);
- hospitalisation rates/100,000 for *circulatory system diseases*, *ischaemic heart disease* (ICD-9 410-414), and *cerebrovascular disease* (ICD-9 430-438) (tables 1a,1b,1c);
- *new cases of ischaemic heart disease* and *new cases of cerebrovascular disease*;
- *incidence of ischaemic heart disease/100,000* and *incidence of cerebrovascular disease/100,000*.

There is no regular data collection for incidence and ad hoc sources are used when available; therefore, availability of data for this indicator is very limited. Furthermore, this indicator cannot be

used for comparisons between countries and/or time periods on account of the great differences in national definitions and registration practices.

Not all morbidity indicators are available by sex or age groups. In particular, in the HFA-DB only a relatively small number of indicators are directly collected from each country.

Tables 1 a, b and c report, as an example, years of the first and last available data, and the sources of the indicators mentioned.

Limitations involving the use of the morbidity WHO-HFA database can be summarised as follows:

- definitions of morbidity indicators are lacking;
- morbidity data are not available by ICD code; they are grouped within the nosologic definition as *circulatory system diseases, ischaemic heart disease, and cerebrovascular disease*;
- morbidity data are not available by sex and age;
- morbidity data are not always available for the same calendar years.

Mortality data by leading causes and more detailed age-groupings are available in the off-line HFA-DB supplementary mortality database (HFA-MDB)⁵⁰. In June 2004, the HFA-MDB was improved and actually includes about 2500 mortality indicators by 67 causes of death, by age and sex; diseases of the circulatory system (ICD-9 390-459), Ischemic Heart Disease (ICD-9 410-414) and Cerebrovascular disease (ICD-9 430-438) are available as cardiovascular disease.

Overall, absolute number of deaths are available by sex and calendar year. Age-standardized death rate (SDR), calculated using the direct method and standard European population structure, are available for men and women separately, for all ages or grouped into 0-65, 65+, 25-64 years, or in the age ranges 0-14, 15-29, 30-44, 45-59, 60-74, 75+, 25-64 and for various calendar years. Along with mortality data, mid-year population by 5-year age range, sex and calendar year are available (being 0 and 85+ the first and the last age ranges). ICD version used by each country and calendar year is also available.

Mortality detailed basic underlying raw data files for the world WHO MS, together with the necessary instructions, file structures, code reference tables, etc., which can be used by institutions and organizations requiring access to this level of detail, are also available⁵¹

9.1.b EUROSTAT (The statistical office of the European communities)

EUROSTAT was established in 1953 to meet the requirements of the Coal and Steel Community. Over the years, its task has broadened and, when the European Community was founded in 1958, it became a Directorate General (DG) of the European Commission. EUROSTAT is the only provider of statistics at the European level; its key role is to provide statistics to other DGs and to the

Commission, and to other European Institutions in support of their role in defining, implementing and analysing Community policies.

EUROSTAT's main role is to process and publish comparable statistical information at the European level. Its efforts are directed towards a common statistical 'language' that embraces concepts, methods, structures and technical standards. EUROSTAT does not collect data: these are provided by the MS. EUROSTAT's role is to consolidate the data, ensuring comparability through the use of harmonised methodology.

Health statistics cover all 15 MS as well as Iceland, Norway and Switzerland. EUROSTAT integrates information from the most relevant data sources existing at international level: *OECD (Organisation for Economic Co-operation and Development)*, *WHO*, *FAO (Food and Agriculture Organisation)*, etc. Data are available from as far back as 1960 in some cases. Most EUROSTAT publications and data are available for a fee on the Internet⁵².

Information and tables about cardiovascular disease morbidity are included in the second edition of the publication *Key data on health 2002 – Data 1970–2001*. This second edition of Key Data on Health includes a comprehensive, consistent and internationally comparable set of health data and indicators, highlighted in New Programme of Community Action in the field of Public Health (2003-2008); this programme was adopted by the European Parliament and the Council on 23 of September 2002 in the framework for action in the field of public health. In this report Eurostat try to bring together information on a wide range of health topics from the most relevant data-sources available around the world: New Cronos of Eurostat, Ecosante from OECD, Health for All from WHO, FAO, International Agency for Cancer, Euro HIV, specific epidemiological studies, etc. Information on the Health Status of the population, the main Diseases as well as the statistical description of Health Care systems are at the core of this publication; however, Key Data on Health also addresses the issues of lifestyles (nutrition, smoking, drinking, physical activity, drug use), mortality (infant, causes of death) and health risks associated with environment, work, leisure and traffic. Key Data on Health covers the 15 EU MS, as well as Iceland, Norway, Liechtenstein and Switzerland. Tables and graphs provide, where possible, data from 1970 onwards disaggregated by gender and age. The publication is divided into six chapters: the first presents data on populations; the second focuses on lifestyle issues; the third describes health risks associated with the environment, working conditions, leisure time, and traffic; the fourth describes the health status of EU populations. For *Cardiovascular disease* Chapter four contains the table *Coronary event rates, coronary case fatalities, and annual changes; adults aged 35–64, by sex; years in 1980s and early 1990s* (graph. 4.7.29)⁵³, using data from the MONICA project. Chapter five presents a detailed picture of mortality, while the last chapter gives an overview of the health care system.

9.1.c *OECD*

The OECD provides the *OECD-Health Data 2006* (realised on the 6th June 2006), a unique software package consisting of an interactive database and query modules to provide a user-friendly tool for the comparative analysis of health systems within and among the 30 OECD Member countries. It is available for a fee on the Internet ⁵⁴ or in a CD-ROM version; this edition contains more than 1200 indicators across 30 countries up to 2004, with some time series as far back as 1960. Most data cover the 1980s and 1990s, many series continue up to 2003 or 2004, including selected preliminary data for 2005. The 1200 series cover Health status, Health care resources, Health care utilisation, Expenditure on health, Health care financing, Social protection, Pharmaceutical market, Non-medical determinants of health, Demographic references, Economic references. The list of all variables is downloadable from the following internet address ‘<http://www.oecd.org/dataoecd/43/5/36946481.pdf>’.

The OECD also provides a trial version of the *OECD Health Data 2006*, freely downloadable to evaluate the database and access the OECD Health Data 2006 software; the only restriction is the data coverage: 1990-1995 in the trial version instead of 1960-2005 in the database. Sources and Methods, software tools, map and chart modules are identical to the final release version of OECD Health Data 2006 (CD-ROM and online).

Data are gathered from different sources, mainly from public institutions such as Ministries of Health and Welfare, National Statistical Institutes, Research Institutes and hospital morbidity databases.

For cross-national comparisons of health care data, there are still important gaps with respect to international agreements on statistical methods. The same term can refer to very different things among the 30 OECD countries. Despite efforts to develop homogeneity, standardized health statistics is still a goal, not a reality. The statistics contained in *OECD Health Data 2006* reflect the situation at the time of release; they have been refined and improved year after year. The aim of the files and the accompanying sources and methods is to provide an objective working tool: the co-operation and, indeed, the criticism of the various national data providers and users will enable improvements in the future.

Under the Ageing-Related Disease Project, for the Study of Cross National Differences in the Treatment, Cost and Outcome of Ageing-Related Diseases, a final report with data on mortality, morbidity health system indicators and determinants of health is available on AMI, IHD and stroke⁵⁵.

9.1.d MONICA – Monitoring cardiovascular disease

The WHO MONICA (MONItoring trends and determinants of Cardiovascular disease) Project was developed to answer questions arising from the 1978 Bethesda Conference on the decline in CHD mortality.

MONICA aimed at measuring, within defined populations, 10-year trends of CHD and stroke, and their case fatality rates^{11,41,57,58}; trends in CVD risk factors¹³; and trends in acute coronary and stroke health care for men and women, 35 to 64 years of age¹². Indeed, MONICA has provided a unique opportunity for exploring the relationship between CVD morbidity and mortality²⁴.

Tables 2 and 3 list the EU countries involved in MONICA surveillance during the study^{58,59}.

Public access to MONICA data is available at the MONICA website⁶¹. The website provides quality assessment reports on coronary and stroke event registration and demographic data.

Fatal and non-fatal coronary events are reported as the total number of definite coronary events for each year, with separate totals for men and women, for the age range 35-64 years. The data are also presented as crude percentage of first, recurrent and indeterminate events from previous history⁵⁸.

Fatal and non-fatal stroke events are reported for each year, and separately for men and women, as the total number of definite strokes, stroke following a coronary event and non-classifiable because of insufficient data; for the age ranges 35-64 and 65-74 years, data are also presented as crude percentages of first and recurrent events⁵⁹.

9.2 Databases available at a national level and methodologies adopted

9.2.a Inventory

For the previously mentioned sources of information (HDR, surveys, registers, cohort longitudinal studies and GP networks), tables were developed to summarise the available data, providing a comprehensive overview and facilitating a comparison between countries.

To up-date the inventory of available data in countries participating to the first phase of the EUROCISS Project and in those participating for the first time at EUROCISS II, the original questionnaire was up-dated taking into account the discussions on recommended indicators arisen during the first phase: available indicators in the country, sources of information, ICD codes used (ICD VIII, ICD IX, ICD X), operational definitions used, whenever the data are available, references of calendar years, all information necessary towards a valid inventory.

The questionnaire prepared during the first months of activity of the Project II phase is more detailed than the one produced during the first phase, making the most of the results of the previous phase. In order to provide greater reliable information on CVD indicators, much more questions on validation and more complete data were included in the questionnaire. This gives all partners the possibility to meditate upon the already proposed indicators and to find the best way to develop

them in the future. The new questionnaire is divided into the following sections: AMI, ACS, IHD, HF, CVA, OFHD.

Before each section a table showing the recommended indicators (available, short-term, long-term) is provided.

At bottom of each section there are few lines dedicated to comments, where partners can indicate what they might consider useful and helpful for the comprehension of the methods adopted.

Table 4 reports information about HDR. In all countries HDR cover almost the entire population, both genders and all ages. National reimbursement systems based on DRG are applied in all countries except Austria, Belgium, Germany, The Netherlands and the UK. ICD-9 is used in Belgium, Italy, The Netherlands, Portugal and Spain. Linkage with mortality is possible for Denmark, Finland, The Netherlands, Sweden and the UK by different methods: ID in Denmark, Finland and Sweden; date of birth, sex and zip code in The Netherlands and UK. The *in-hospital case fatality* is computed in all partner countries except Belgium and Spain. In Finland the validation of HDR is implemented; in other countries validation is not performed (Austria, Belgium, Germany, Italy, The Netherlands, Norway) or has been performed by retrospective review on an *ad hoc* basis (Sweden and Denmark) or only in a sample of the population (France and Spain).

Data are generally accessible with previous written request of authorisation, through national health or statistical institutions.

Table 4a reports information about HDR in actual partner countries updated 2006.

Tables 5a and 5b provide the main surveys on CVD. HIS performed by national statistical institutes are included in **Table 5a**; they usually report generic questions on health conditions and use a self-reported questionnaire. Therefore, some conditions such as the prevalence of hypertension and diabetes could be underestimated.

Finland, Germany, Italy, The Netherlands, Portugal and Spain carry out CVD surveys periodically (**Table 5b**). All these include the LSHTM questionnaire for the evaluation of symptoms, medical examination and ECGs.

Information is available for 20-80 year-old men and women. The response rate is over 60% in all countries except in the MORGEN survey in The Netherlands (55%). The majority of CVD surveys adopt MONICA standard methodologies⁶¹; WHO standard methods are used in CARDIO 2000 (Greece) and ERGO (The Netherlands)^{34,35}. Data are accessible through national health or statistical institutions, universities and MONICA reference centres.

Table 5c and 5d provide the main HES and HIS on IHD in actual partner countries updated 2006.

Available information on cohort longitudinal studies is summarised in **Table 6**. These studies are performed in Belgium, Denmark, Finland, France, Germany, Italy, The Netherlands, Sweden and

the UK. Age ranges between 20 and 84 years. Cohort longitudinal studies are predominantly performed at the regional level. Most do not include HF. Denmark and the UK include HF as well as The Netherlands. Some started in the 80's (Belgium, Germany-KORA, Italy-Progetto CUORE, The Netherlands-Zutphen and Doetinchem), some in the 90's (France-PRIME, The Netherlands-ERGO, Sweden-Stockholm), and others more recently, in the year 2000 (Finland-HEALTH 2000 and Germany); the Finland FINMARK started in 1972 and the British Regional Heart Study in 1978. The data are accessible through national health institutes or universities.

GP networks provide data only in The Netherlands, Portugal and UK (*Table 7*).

EUROCISS Project II phase is particularly focused on population-based Registers and the new questionnaire is an useful mean to collect sources of information, methods to define events, record linkage procedures and validation techniques which contribute to give a picture of the health status of populations.

Table 8 reports information on AMI population-based registers collected through the first questionnaire (2003).

Table 8 a reports information on AMI population-based registers updated 2006.

Population-based registers are available at the regional level in Belgium, Denmark, Finland, France, Germany, Italy, Norway, Poland, Spain and Sweden. Most of the registers started between the second half of the 80s and the first half of the 90s (Finland, France, Germany, Spain and Sweden) within the MONICA Project framework. The others are more recent (Belgium-Bruges, Italy and Norway), nevertheless they adopt simplified methodologies derived from the MONICA Project . The Danish register goes back to 1978.

Age of persons included ranges between 25 and 74 years or more. Many of the population-based registers adopt simplified methodologies derived from the MONICA Project and validate the events applying the MONICA diagnostic criteria.

In Denmark, Iceland, Sweden, and Finland, national AMI registers are compiled using a linkage of administrative records from national hospital discharge and mortality registers; they cover the entire population and all ages.

Available data on stroke population-based registers collected through the first questionnaire (2003) are summarised in *Table 9*.

Table 9a reports information on stroke population-based registers updated 2006.

Out of 18 partner countries with available data, 5 participated in the MONICA stroke registration. Nine countries have regional stroke population-based registers, but only 2 have also a national stroke population-based register. Registers differ from each other in case definition -- ICD codes, record linkage (probabilistic, deterministic by personal ID or by first name, last name, date of birth),

and validation procedures (i.e. MRI, TAC, MONICA criteria) -- and population characteristics -- population size, age range (35-64, 35-74, all ages), and years covered. These differences make morbidity indicators difficult to compare.

9.2.b Main differences between registers

In different countries AMI and stroke population-based registers use different procedures for the selection of events. Record linkage of mortality and HDR and validation methods are reported in *Table 10*.

In the definition of AMI/ACS, countries use different ICD revisions (ICD-8, ICD-9 or ICD-10) to code death certificates (Table 2). Denmark never used ICD-9 but replaced ICD-8 with ICD-10. Denmark and Norway select only acute myocardial infarction (ICD-10: I21, I22), Sweden considers acute myocardial infarction (ICD-10 I21, I22) and other acute and subacute forms of ischaemic heart disease (ICD-10 I20.0), while all other countries include all ischaemic heart disease (ICD-9: 410-414; ICD-10: I20-I25); Belgium, Finland, France, Poland and Spain add also heart failure (ICD-9: 428; ICD-10: I50) and sudden non-violent death (ICD-9: 798,799; ICD-10: R96-R98). Germany and Italy add sudden non-violent death as well. In addition, Italy, Spain and France consider other causes of death. Italy, in particular, considers diabetes (ICD-9: 250), hypertension (ICD-9: 401-404), other forms of heart disease (ICD-9: 420-429) and disease of arterioles and capillaries (ICD-9: 440-447), when one of the contributory causes of death is ischaemic heart disease.

Selected diagnoses for the identification of suspected non-fatal events from hospital discharge records are as follows: acute myocardial infarction (ICD-10: I21, I22) in Denmark; acute myocardial infarction (ICD-10: I21, I22) and other acute and subacute forms of ischaemic heart disease (ICD-10: I20.0) in Finland, Germany and Sweden; all ischaemic heart disease (ICD-9: 410-414; ICD-10: I20-I25) in Belgium, France, Italy and Spain; Belgium and France add also heart failure (ICD-9: 428; ICD-10: I50); percutaneous transluminal coronary angioplasty (PTCA, ICD-9 CM 36.0) and coronary artery by pass grafting (CABG, ICD-9 CM 36.1) are selected in Belgium, Finland, Germany and Norway.

Linkage procedures between mortality and HDR are performed through the ID only in Denmark, Finland, Norway and Sweden. In Germany, Italy, Belgium, France and Spain events are identified through deterministic (first name, last name, date of birth) or probabilistic record linkage procedures since these countries do not have ID.

Validation of events can be realized on each single case or on a randomly selected sample. The validation of events is usually based on MONICA diagnostic criteria using an algorithm based on various combinations of symptoms, ECG changes, cardiac enzymes elevation, history of ischaemic

heart disease and, in fatal cases, autopsy findings. Some registers also adopt more sensitive and specific biomarkers of myocardial injury, such as creatine kinase MB mass (CK-MBm) and cardiac troponins (troponin T and troponin I) to recognize myocardial necrosis.

In the Swedish national register, the events are validated on a random sample of patients using diagnostic criteria recommended for use in Swedish hospitals. In Denmark the national register is validated through record linkage with the Danish MONICA register.

Table 11 summarises the codes used for the selection of stroke. Denmark, Finland (only national register), France, Germany, Greece, Norway and Sweden select all CVD for mortality and HDR.

All stroke registers adopt the personal ID number except for Italy and Germany which links mortality and HDR by name, birth date and place of residence. Validation is based on MONICA diagnostic criteria in all countries, except for Germany where validation takes use of health insurance data and CT-scans.