4. ACTIVITIES (2004-2007)

A general overview of all the activities performed during the second phase of the EUROCISS II Project follows:

4.1 INVENTORY OF POPULATION-BASED REGISTERS AND CVD SURVEYS

The questionnaire produced during the first phase of the Project helped partners identify available indicators to recommend for data collection of CVD in Europe.
During the first months of activity an updated and more detailed version of the first 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 fatal and non-fatal events occurred in and out of hospital and to specify if any CVD survey was conducted in their country.
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.

AMI/ACS and Stroke Registers

Partners soon realized that the existing registers in Europe include different populations and adopt different data collection procedures: some registers are based on the direct identification and validation of event as in the MONItoring of trends and determinants in CArdiovascular diseases (MONICA) study, others are based on administrative data with or without record linkage, some are national and some regional. Different age groups are covered and the degree of validation of the diagnostic information varies. These population-based registers are used for different purposes and have different strengths and limitations.

Starting from the data provided by each partner with the questionnaire, a short overview of existing AMI/ACS and stroke registers (population-based and hospital-based) was developed and is provided below. Data from questionnaire refer to the year 2006, therefore information here reported refer to that time frame. In addition, information on countries sources of information are reported as they were provided by partners and are further summarized into Tables 1, 1A, 2, 2A, 3, 4, 4A, 5, 5A, 6.

AUSTRIA

The *Osterrich Infarktregister* is an hospital-based register started in 1990 and covering about 1.6 million of men and women of all ages. Fatal and non-fatal suspected AMI/ACS events are identified from hospital discharge diagnoses, International Classification of Disease (ICD) -10 I20-I22 codes (ICD-9 410, 413), Percutaneous Transluminal Coronary Angioplasty (PTCA) and Coronary Artery Bypass Grafting (CABG).

The *Austrian Stroke Registry*, a nationwide stroke register, was prospectively performed on 15 stroke units from August 1998 to December 2000. The aim was to document the quality performance of Austrian stroke units, focusing on rapid admissions, ready availability of investigations and therapies performed. Outcome measures were Barthel scale, Rankin score and percentages of complications. The register prospectively included 2313 patients with ischaemic stroke or with primary intracerebral haemorrhage admitted to an Austrian stroke unit within 24 hours after onset of symptoms. The overall stroke-unit mortality was about 6.8% and mortality at 3 months was 12.9%. The outcome at 3 months showed a modified Rankin Scale score of 0 or 1 in 47% of patients, denoting none or mild impairment.

No *AMI/ACS and Stroke population-based registers* exist in this country.

BELGIUM

The *MONICA Ghent/Charleroi* recruited two Belgian populations, Charleroi and Ghent.
Population under surveillance were residents ages 25-69 years of 15 municipalities, centred on the city of Charleroi and residents of the town of Ghent. Total population in 1991 was 206,000 in Charleroi and 230,000 in Ghent. Coronary-event registration for MONICA database lasted from 1983 to 1992. It is continuing in both populations and it was extended to the region of Bruges.

Presently, there are three regional *AMI/ACS Population-based Registers in Belgium (data accessibility: University of Ghent and School of Public Health):*
1) With the support of the Flemish government the *AMI Register Ghent* restarted on January 1th 1996. From January 1th 1998 onwards the target population (about 145,000) was extended to the age range 74 years; it is financially secured until 2009; the latest annual report covers the attack rates from 2003.
2) The *AMI Register Bruges* started in 1999 at the request of the Flemish government to have a register in a rural area of Flanders; this register covers the district of Bruges, not only the city; the population in the district is approximately 250,000 men and women ages 25-74 years. This register is also secured until 2009 and the latest report is based on 2003 data.
3) The *AMI Register Charleroi* was launched in 1983 in 15 municipalities centred on the city of Charleroi; the population under surveillance was about 100,000 men and women ages 25-69 years.
In the three registers fatal and non-fatal suspected events were collected by *cold pursuit* method and identified through a deterministic record linkage of mortality data and hospital discharge records (HDR). The following ICD codes were used for the selection of events: ICD-10: I20-I25, I50, R96, I46.1 (ICD-9: 410-414, 428, 798-799) in mortality records, and ICD-10: I20-I25, I50 (ICD-9: 410-414, 428), PTCA and CABG in HDR. Further medical information was obtained from patient's family doctor, or doctor who had certified death, or emergency team who attended acute event.
All the suspected events were validated using MONICA diagnostic criteria. There is a close and good collaboration with the population registers in the cities and towns, with all hospitals, with all primary care physicians, with the Public Health administration of the Flemish government regarding death certification.

No *Stroke population-based register* exists in this country.

CZECH REPUBLIC

Czech-MONICA and MONICA-linked Projects are the only source of data on the prevalence of different cardiovascular risk factors in the population of this country.
Population under surveillance was residents ages 25-64 of the six districts representing the middle, south, east and west of Bohemia. Total population in 1991 was 631,000. Coronary-event registration lasted from 1984 to1993 and used cold pursuit method.

No *AMI/ACS and Stroke population-based registers* exist in this country.

DENMARK

The *DANMONICA* study was population-based and consisted of all citizens ages 25-74 years living in 11 municipalities around Glostrup County Hospital in the western suburbs of Copenhagen. Total population in 1991 was 326,000. Coronary-event registration lasted from 1982 to 1991.
All cases of possible heart attack were identified retrospectively (cold pursuit) based mainly on relevant ICD diagnoses on death certificates and hospital discharge reports and somewhat on reports from general practitioners and nursing homes.

The *DANMONICA* population-based stroke register recorded stroke events until 1991. The main sources of information for the registration of stroke events in the DAN-MONICA stroke register were admission diagnoses to the hospitals and wards of health centers; hospital discharge diagnoses and diagnoses from death certificates were also checked routinely. The register used *cold pursuit* method.

The national *Danish AMI Register (data accessibility National Institute of Public Health www.ktl.fi/cvdr)* goes back to 1978 and was based on administrative data (Hospital Discharge Register and the Causes of Death Register). It aims to identify Myocardial Infarction (MI) events in the entire population of about 5 million men and women, all ages included. Fatal and non-fatal suspected events are identified through a record linkage of mortality data and HDR obtained by Personal Identification Number (PIN). The following ICD codes are used for the selection of events: ICD-10: I20-I25, R96, R98, I46.1 (ICD-8: 410-414, 798) in mortality records, and ICD-10: I20.0, I21, I22 (ICD-8: 410, 411), PTCA and CABG in HDR.
The register has been validated in a sample of cases from the DANMONICA area. In the validation study register data were compared with MONICA data by record linkage. The validation includes the period 1982-1991 when the MONICA study was running.

FINLAND

The *FINMONICA* study was population-based and covered persons ages 25-64 years whose official residence was in the *FINMONICA* study areas: North Karelia and Kuopio provinces in Eastern Finland and Turku/Loimaa area in South-Western Finland. The total population in 1991 was 174,000 in North Karelia, 257,000 in Kuopio and 200,000 in Turku. Coronary and stroke event registration lasted from 1983 to 1992 in North Karelia, Kuopio and Turku. Turku registered stroke at all ages, others registered stroke up to ages 74.
The Register used hot pursuit method. This was done by specially trained study nurses who checked the emergency departments every morning for possible acute events. In addition, hospital discharge lists containing diagnoses for IHD (ICD-9 codes 410-414) were reviewed regularly to catch all events suspected of having an AMI/ACS.

The national *Finnish Cardiovascular Diseases Register (SYVE - data accessibility: National Institute of P. Health www.ktl.fi/cvdr)* started in 1991 and is based on administrative data (Hospital discharge register and the Causes of Death Register). The whole Finnish population is under surveillance (about 5.2 million of men and women of all ages).

Fatal and non-fatal suspected cardiovascular events (AMI/ACS and Stroke) are identified through a record linkage of mortality data and HDR obtained by PIN. The following ICD are used for the selection of AMI/ACS events: ICD-10: I20-I25, I50, R96, I46.1 (ICD-9: 410-414, 428, 798, 799) in mortality records, and ICD-10: I20-25, I50 (ICD-9: 410-414, 428), PTCA and CABG in HDR. To select stroke events the following ICD are used: ICD-9 430-438; ICD-10: I 60-I69, G45
The register has been validated comparing administrative data with diagnoses in the FINAMI Register (regional AMI register validated according to MONICA diagnostic criteria) and using troponin test (European Society of Cardiology - ESC/American College of Cardiology – ACC criteria). The registration ended in 2004.

The *FINSTROKE Register (data accessibility: National Institute of P. Health www.ktl.fi/cvdr)* was implemented from 1993 to 1997 in the Kuopio area and Turku. The register area was reduced in Kuopio to consist of the cities of Kuopio, Varkaus, and Iisalmi, as well as three small rural areas with a combined population of 196,000 inhabitants (93,000 men, 103,000 women) ages 35-85 over. Fatal and non-fatal events were collected by *cold pursuit* method and identified through a record linkage of mortality and hospital discharge records obtained by PIN. In either source of information, the following ICD codes were used for the selection of events: ICD-10: I 60-I62, I64, G45. The register was validated using MONICA procedures and methods of validation.

FRANCE

The geographical areas, about one million inhabitants, involved in *MONICA Lille, MONICA Strasbourg*, and *MONICA Toulouse* were the Urban Community of Lille (Lille) and two French districts: Bas-Rhin (Strasbourg), Haute-Garonne (Toulouse) respectively. Coronary-event registration for the age range 25-64 lasted from 1985 to 1994 in Lille, from 1985-1993 in Strasbourg and Toulouse.
Morbidity data were systematically collected by the investigators (hot and cold pursuit, according to the type of hospital) in the public and private hospitals of the area, in the emergency departments as well as in cardiologists' private practices when necessary. General Practitioners were mainly interviewed during the search for further information on causes of death.

AMI/ACS Population-based Registers in France (data accessibility: INSERM U780). Since 1997 the three French centres have decided to use a simplified registration procedure (*hot* and *cold pursuit*) with regard to the MONICA protocol and to take into account the clinician's diagnosis written on the discharge letter. For fatal events, the validation procedures continue to follow the MONICA protocol. The use of the simplified procedure has permitted to enlarge the recorded age-range up to 74 years (ages: 35-74). However, for hospitalised events, a double registration with the MONICA protocol is performed each year during 15 days to maintain the comparability of the trends over time.
The following ICD codes are used for the selection of events: ICD-10: I20-I25, R96, I46.1 (ICD-9: 410-414, 798-799) in mortality records, and ICD-10: I20-I25, I50 (ICD-9: 410-414, 428) in HDR.
All the suspected events are validated using MONICA diagnostic criteria. Linkage of register data with routine mortality and HDR is currently under study to produce new indicators: fatal and non-fatal suspected events are collected by cold pursuit method and identified through a deterministic record linkage of mortality data and HDR.
Furthermore, a survey is currently being performed (2006-2007) in these three areas to assess the incidence of unstable angina in the 35-74 age group (both genders).

The *Dijon Stroke Register (data accessibility: Dijon University Hospital)* is a population-based register launched in 1985. Population under surveillance was the whole inhabitants of the city, about 150,000 (80,000 women and 70,000 men) covering all ages, from the 6 months age to the oldest people.
Fatal and non-fatal events are collected by hot pursuit method and identified through a record linkage of mortality, hospital discharge records from public and private hospitals and General Practitioners' (GP) records (n=250), imaging records obtained by deterministic linkage (first name, last name, date of birth, place of birth, death certificate). Both in mortality and hospital discharge records, the following ICD codes were used for the selection of events: ICD-10: I 60-I69, G45, G46, I72.0

All events are validated using symptoms, surgical or pharmacological treatment, neurologists examinations, Computed Tomography-Scan (CT-Scan), Magnetic Resonance Imaging (MRI) , Carotid Doppler, autopsy, death certificates and MONICA procedures and methods of validation.

GERMANY

MONICA Augsburg consisted in 1991 of about 575,000 men and women ages 25-74 years, residents of the cities of Augsburg and the less urban ones Landkreis Augsburg and Landkreis Aichach-Friedberg. Coronary-event registration of residents lasted from 1985 to 1995 and used hot pursuit method.
MONICA Bremen consisted in 1991 of about 552,000 men and women ages 25-69 years residents of the city of Bremen in two sub-populations: Bremen North and West and Bremen city, South and East. Coronary-event registration lasted from 1985 to 1992.
In the *MONICA East Germany* the total population under surveillance was the residents of the three districts of Erfurt, Chemniz and Zwickau ages 25-74, about 612,000 in 1991. Coronary-event registration lasted from 1984 to 1993.

MONICA/KORA Augsburg Registry of coronary events (data accessibility: National Institute of Staistics.; GSF; Official German health report via internet www.gbe-bund.de) started in 1985 with MONICA Project and included about 407,000 men and women ages 35-74 (25-74 in 2002).
Fatal and non-fatal suspected events were collected by *hot pursuit* method and identified through a record linkage of mortality data and HDR obtained by deterministic linkage (fist name, last name, date of birth, sex). The following ICD are used for the selection of events: ICD-10: I20-I25, I50, R96, I46.1 (ICD-9: 410-414, 428, 798, 799) in mortality records, and ICD-10: I21, I22, I24 (ICD-9: 410, 411), PTCA and CABG in HDR.
The register is validated using MONICA diagnostic criteria and troponin test (ESC/ACC criteria) since 2001.

The *Erlangen Stroke Project (ESPro - data accessibility: University of Erlangen)* is a community-based register located in Bavaria in Southeast Germany and established in 1994. The population under surveillance was the all residents of the Community of Erlangen, about 100,000 inhabitants (49,000 men and 51,000 women) ages 18 years and over. Fatal and non-fatal events were collected by hot pursuit method and identified through a record linkage of mortality, hospital admission and discharge records, GPs' records, relevant hospital wards, nursing homes, emergency services and death certificates. The linkage is obtained by deterministic linkage (fist name, last name, date of birth). Both in mortality and HDR, the following ICD codes are used for the selection of events: ICD-10: I 60-I69, G45. All events are validated using symptoms, surgical or pharmacological treatment, neurologist examinations, CT-Scan, MRI. The register is still running.

The *German Stroke Registers Study Group (ADSR)* investigated predictors for in-hospital mortality and attributable risks of death after ischaemic stroke in a pooled analysis of large German stroke registers. The ADSR is a network of regional stroke registers, combining data from 104 academic and community hospitals throughout Germany. A total of 13 440 ischaemic stroke patients admitted to hospitals between January 1, 2000, and December 31, 2000, were analyzed. The impact of patients' demographic and clinical characteristics, their comorbid conditions, and the treating hospital expertise in stroke care on in-hospital mortality was analyzed.

GREECE

There are *Hospital Discharge Registers* in several institutions. These registers allow the estimation of incidence densities of clinical outcomes and their predictors, but cannot by used to calculate incidence. As an example, the Cardiology Unit of the University of Athens Medical School (Hippokrateion Hospital) has undertaken the GREECS (GREEk aCs) study, based on several hospital-based registers covering men and women of all ages from 2003 to 2004. Suspected events were collected by the hot pursuit method and identified through medical records covering medical history, clinical examination and laboratory results of the patients with symptoms and signs consistent with AMI. These events were validated using Electrocardiogram (ECG), troponin test and enzymes. The ICD-10 coding system was used for recording fatal events and hospital discharge diagnoses.

The *Arcadia Stroke Register (data accessibility: Alexandra Hospital, University of Athens)* is a regional population-based register established from 1993 to 1995 in the Arcadia province at the southern part of Greece. The permanent resident population under surveillance in 1991 ages 20 years and over consisted of 41,864 men and 38,910 women, for a total of 80,774 inhabitants.
Fatal and non-fatal events were collected by the cold pursuit method and identified through GPs' records, medical records from health centres, HDR and death certificates. Both in mortality and hospital discharge records, the ICD-9 codes: 430-438 were used for the selection of events.
All events were validated by reviewing the symptoms, the surgical or pharmacological treatment, neurological examinations, neuroimaging (CT-scan, MRI, Carotid Doppler) and autopsy, if performed.

The *Athens Stroke Registry* (data accessibility: Alexandra Hospital, University of Athens) is a hospital-based study which started in 1992 collecting data on hospitalized patients ages 18 and over. Fatal and non-fatal events were collected by the hot pursuit method and identified through medical records based on history, clinical examination and laboratory results of the patients with symptoms and signs consistent with stroke. Both in mortality and hospital discharge records, ICD codes were used for the selection of events: ICD-9: 430-438 and ICD-9 CM code 38.12 (carotid endoarterectomy). All events are validated by examining the symptomatology of the patient, the surgical or pharmacological treatment administered, neurological examinations, neuroimaging and vascular studies (CT-scan, MRI, Carotid Doppler) and autopsy, if performed.

No *AMI/ACS and Stroke population-based registers* exist in this country.

HUNGARY

The *Centre for Healthcare Information, National Health Insurance Fund, Department of Financial Informatics (data accessibility: GYÓGYINFOK)* is not a "Register" in classical sense but a hospital and out-patient care based information system which primarily aims to provide data for financing purposes to the National Health Insurance Fund. The database contains information about that part of the population which utilizes in- or out-patient health services. On legal basis all hospital and out-patient clinics have to report monthly performance figures to the Centre for Healthcare Information, National health Insurance Fund, Department of Financial Informatics. It started in 1996 and covers about 10 million of men and women of all ages.
AMI/ACS suspected events are identified from hospital discharge diagnoses: ICD-10 codes I20-I25, I50 (ICD-9 410-414, 428) PTCA, CABG. Events are not validated.
Suspected stroke events are collected by cold pursuit method and identified from hospital discharge diagnoses: ICD-10 codes I60-I69, ICD-9 CM code 38.12 (carotid endoarterectomy). Events are not validated.

The *General Practitioners' Morbidity Sentinel Stations Program (data accessibility: National School of Public Health, Faculty of Public Health, University of Debrecen)* is a joint initiative of the Hungarian School of Public Health and the National Public Health Service created in 1998 based on a network of sentinel stations based in primary care facilities in 4 (8 from 2004) Hungarian counties. A total of 148 general practitioners participate, providing care for 7.6% (264,022 people) of the population of all ages and sex. Suspected events are identified linking mortality data and HDR using a unique identifier which is a combination of a special personal code identifying the patient registered in a GP practice and the identification code of the practice itself. ICD selected codes are: ICD-10 codes I20-I22, I25 (ICD-9 410, 412, 413, 414), both for mortality and hospital discharge diagnoses. Suspected events are validated using ECG, symptoms, enzymes and, if performed, autopsy.
The following ICD codes are used for the selection of stroke events: ICD-10 I60-I62, I64, I63 both for mortality and hospital discharge diagnoses. Suspected events are collected by cold pursuit method and validated using symptoms, neurologist examinations, MRI, Carotid Doppler, autopsy.

No *AMI/ACS and Stroke population-based registers* exist in this country.

ICELAND

The *Iceland-MONICA* covered residents ages 25-74 years. The total population in 1991 was 258,000. Coronary-event registration lasted from 1981 to 1994 and used cold pursuit method.

The *MONICA Coronary Event Registration (data accessibility: National Institute of Public Health; Icelandic Heart Association)* is based on administrative data (Hospital discharge register and the Causes of Death Register). The whole Icelandic population of men and women ages 25-74 years is still today under surveillance (about 295,000 persons in 2001). Coronary-event registration was initiated in 1981. Fatal and non-fatal suspected events are identified through a record linkage of mortality data and HDR obtained by PIN and deterministic linkage (first name, last name and birth date). The following ICD codes are used for the selection of events: ICD-10: I20-I25, I50, R96, I46.1 (ICD-9: 410-414, 428, 798, 799) in mortality records, and ICD-10: I21-25 (ICD-9: 410-412, 414).
Each individual case is validated according to MONICA diagnostic criteria.

No *Stroke population-based register* exists in this country.

ITALY

MONICA Brianza. Population under surveillance was residents ages 25-64 of 73 municipalities in Brianza, Lombardy, Northern Italy, between Milan and the Swiss border. The total population in 1991 was 850,000. Coronary-event registration lasted from 1985 to 1994.
MONICA Friuli. Population under surveillance was residents ages 25-64 of 3 provinces of the Friuli-Venezia Giulia region of North-East Italy, bordering Austria and Slovenia. The total population in 1991 was 940,000, including many elderly people. Coronary and stroke event registration lasted from 1984 to 1993.
In both areas, the procedures for notifying the events involved the systematic collection of death certificates and the review of hospital discharge diagnoses following *cold pursuit* methodology suggested by MONICA.

The *National Register of Coronary Events (data accessibility: National Institute of Public Health www.cuore.iss.it)* started in 1998 to monitor both fatal and non fatal coronary events in the general population. Event registration and validation are periodically repeated (1998-99; 2003; 2004-5). The Register was implemented in seven representative geographical areas in the North, Centre and South of the country: the region of Friuli-Venezia Giulia, the area of Brianza, the towns of Naples and Rome, the municipalities of Florence, Modena and Caltanissetta. The covered population is about 3.6 million of men and women ages 35-74 years.
Fatal and non fatal suspected events are identified through deterministic record linkage of mortality data and HDR. To identify current non fatal events, all those cases having codes of ischaemic heart disease (ICD-9 410–414) as underlying or as any of the secondary discharge diagnoses were extracted from the hospital discharge records database. To identify current nonfatal events, all those cases having codes of ischaemic heart disease (ICD-10 I20-I25; ICD-9 410–414) as underlying or as any of the secondary discharge diagnoses were extracted from the hospital discharge records database. To identify current fatal events, all death certificates reporting ischaemic heart disease (ICD-10 I20-I25; ICD-9 410–414) or sudden death (ICD-10 R96; ICD-9 798) or other ill-defined and unknown causes of morbidity and mortality (ICD-10 R98-R99; ICD-9 799) as underlying cause of death, or diabetes (ICD-10 E10-E11; ICD-9 250), hypertensive disease (ICD-10 I11-I13; ICD-9 401–404), other forms of heart disease (ICD-10 I30-I51; ICD-9 420-429), atherosclerosis (ICD-10 I70-I77; ICD-9 440-447) followed by ischaemic heart disease (ICD-10 I20-I25; ICD-9 410–414) were taken into account.
In each area a sample of 1000 suspected coronary events is validated using MONICA diagnostic criteria. The results from validation are used to assess the positive predictive values (PPV) of single codes of hospital discharge and cause of death. The estimation of coronary events occurrence is obtained by applying the PPV to current events generated from record-linkage procedure.

The *National Register of Cerebrovascular Events (data accessibility: National Institute of Public Health www.cuore.iss.it)* is a population-based register which started in 1998 following the experience of the MONICA project. It was implemented in eight areas (the same areas of coronary register plus Veneto Region) of the

country for monitoring about 4.5 million people among men and women ages 35-74 years old. Event registration is repeated periodically (1998-99; 2003; 2004-5).
Fatal and non-fatal events are identified through record linkage of mortality and hospital discharge records (name, date of birth). To identify current nonfatal events, all those cases having codes of cerebrovascular accidents (ICD-10 I60-I69; ICD-9 430–434, 436–438) or hemiplegia (ICD-10 G81; ICD-9 342) as underlying or as any of the secondary discharge diagnoses were extracted from the hospital discharge records database. To identify current fatal events, all death certificates reporting cerebrovascular accident (ICD-10 I60-I69; ICD-9 430–434, 436–438) or hemiplegia (ICD-10 G81; ICD-9 342) as underlying cause of death, or diabetes (ICD-10 E10-E11; ICD-9 250), hypertensive disease (ICD-10 I11-I13; ICD-9 401–404), arrhythmia (ICD-10 I46-I49; ICD-9 427), atherosclerosis (ICD-10 I70; ICD-9 440) followed by cerebrovascular accidents (ICD-10 I60-I69; ICD-9 430–434, 436–438) were taken into account. In each area a sample of 1000 suspected events is validated using MONICA diagnostic criteria to assess the PPV of single codes of hospital discharge and cause of death. Estimates of stroke events occurrence is obtained by applying the PPV to current events generated from record linkage procedure.

THE NETHERLANDS

The *CMR Nijmegen (data accessibility: Prismant www.prismant.nl)* is the oldest GPs' Register of morbidity in the Netherlands. It was created in 1971 and involved 4 general practices, providing care for approximately 12,000 men and women ages 35-85 and over. The National Institute of Public Health and the Environment (RIVM) combined the data from this GP register with those of 3 other regional GP registers to obtain an estimate of the national incidence of CVD. Each register had its own criteria and representativeness.

No *AMI/ACS and Stroke population-based registers* exist in this country.

NORWAY

The *CVD Register (data accessibility: Contact Health Region West www.helse-vest.no/sw7877.asp)* contains information on CVD and diabetes diagnoses and procedure codes related to CVD based on administrative data (Hospital discharge register and the Causes of Death Register). All CVD and diabetes diagnoses are included. In addition circulatory organ diagnoses related to pregnancy, birth and congenital malformations of the circulatory system are included.
Data from 1972 throughout 2001 are available on file. Data for 2002 – 2006 will be included in 2007.
The register covers 3 counties. The population under surveillance is about 1 million men and women of all ages. The total population of Norway is 4.6 millions. Fatal and non-fatal events are identified through record linkage. The following ICD codes are used for selection of AMI events: ICD-10: I21, I22, ICD-9: 410 in mortality records, and ICD-10: I21, I22, ICD-9: 410, PTCA and CABG in HDR. For ACS events ICD-9:411 and ICD-10:I20.0 are also included.
The 'CVD Register' has not yet been used for stroke surveillance but any ICD-9 and ICD-10 codes within Circulatory system diseases can be selected for stroke events. The following ICD codes can be used for the selection of events: ICD-9: 430-438 (ICD-10: I60-I69) in both mortality and hospital discharge records; in addition, ICD-9 CM code 38.12 (carotid endoarterectomy) is considered in HDR.
Until now this register is not population-based as persons that die from a CVD or diabetes are not included if they die outside hospital without previous registration with CVD in Health Region West. These persons are not registered in the Hospital discharge register. From the autumn 2006 such persons will be included, also retrospectively.
This register has no regular validation procedure. A project of controlling the diagnoses with codes in the National hospital discharge register has been performed. Two validation projects for AMI are ongoing in 2006 comparing the diagnoses with clinical data for the years 1995 and 2002, respectively. These validation projects include patients with AMI or elevated troponine/Creatine Kinase -MB (CK-MB) levels.

POLAND

Historical data are available from the *POL-MONICA Project*. Population-based registers of MI and Ischaemic Heart Disease Deaths were carried out from 1984 to 1993 in one rural province (Tarnobrzeg Voivodship) and from 1984 to 1994 in Warsaw capital (two districts). Population under surveillance ages 35-64 was 190,000 in Tarnobrzeg Voivodship and 190,000 in Warsaw.
Fatal and non-fatal coronary suspected events were collected by cold pursuit method and identified using mortality data and hospital discharge diagnoses. The following ICD-9 codes were used for the selection of events: 410-414, 428, 798-799 in mortality, and 410-413 in hospital discharge diagnoses. All the suspected events were validated using MONICA diagnostic criteria.
Regional population-based register for Stroke events was based on data from the POL-MONICA Project (Polish part of The WHO-MONICA Project), collected by cold pursuit method from 1984 to 1994 and available for one urban population of two districts of Warsaw. Mortality and hospital discharge were the main sources of information and in both cases the selection of events were made using ICD-9 codes 430-438 in mortality and in hospital discharge records.

The *Hospital Discharge Register of ACS (data accessibility: Silesian Centre for Heart Disease)* is carried out by the National Health Found in 535 hospitals. The project is coordinated by the Silesian Centre for Heart Disease. All hospitals have in their structure one of the following units: 1) Department of Cardiology/ Intensive Cardiac Care Unit, 2) Department of Internal Diseases, 3) Emergency Unit, 4) Intensive Care Unit/Intensive Therapy Unit, 5) Department of Cardiosurgery. Also involved are hospitals that include neither of the above but hospitalize at least 10 patients with acute coronary care syndromes per year. Data on all patients with discharge diagnosis codes as I20,0 or I21.0-9 or R57 are collected in the standard format and submitted in the electronic version to the Voivodship (provincial) Unit of the National Health Found and then transferred to the central registry in the Silesian Heart Disease Centre. The project was initiated in 2003 in the frames of National Program for Prevention and Treatment of Cardiovascular Disease (POLKARD 2003-2005). Patient's record includes data on hospitalisation, medical diagnosis, symptoms, ECG, complications, CVD risk factors and treatment.

The National Institute of Hygiene *(data accessibility: National Institute of Hygiene, Warsaw)* collects data on all discharged patients in a standard format. Patient's record includes: date of birth, sex, date of admission, outcome of hospitalization, date of discharge/date of death, up to six diagnoses (ICD-10 codes), underlying, direct and secondary causes of death (ICD-10 codes) and up to six medical procedures (Codes of the II Edition of International Classification of Medical Procedures). The estimated coverage is 80%.

No *AMI/ACS and Stroke population-based register*s exist in this country.

PORTUGAL

The Portuguese Society of Cardiology has hospital-based registers of ACS obtained on a voluntary basis from 2002 but not related to any range of the population.

No *AMI/ACS and Stroke population-based registers* exist in this country.

SPAIN

Historical data are available from the *MONICA-Catalonia* project, a regional AMI population-based register, launched in 1985 as part of the WHO-MONICA Project. About 480,000 men and women ages 25-74 years and residents in the geographical and administrative area of Catalonia near the city of Barcelona, in north-eastern Spain were under surveillance. Coronary-event registration lasted from 1985 to 1998 and used *cold pursuit* method.

A population based *AMI register (REGICOR)* in men and women 35 to 74 in three counties contiguous to the MONICA- Catalonia area exists since the late 80's.

The *IBERICA* register *(data accessibility: Municipal Institute of Medical Research)* is a pool of different hospital-based registers which started in 1997 and lasted for one year. It covered geographical areas of 7 regions and included about 4 million men and women ages 35-74. Suspected events were identified from hospital discharge diagnoses and ambulance services: ICD-9 410-414 in hospital discharge diagnosis. Suspected events were validated using ECG, enzymes and symptoms. Although suspected IHD deaths were also registered, fatal and non-fatal cases attended outside hospitals involved in the project are missing

No *Stroke population-based register* exists in this country.

SWEDEN

The *GOT-MONICA* included the residents ages 25-64 of the city of Goteborg (Gothenbourg), in the south-west of Sweden. The total population in 1991 was 433,000. Coronary-event registration lasted from 1984 to 1994 and used cold pursuit method.

The *Northern Sweden MONICA* study included the residents of two Swedish counties in northern Sweden (Norrbotten and Vasterbotten). The total population under surveillance in 1991 was 518,000 for the age range 25-64 years. Coronary-event registration lasted from 1985 to 1995 and used cold pursuit method.

The *Hjärfinfarktstatistinen (AMI Statistics - National Board of Health and Welfare www.sos.se)* started in 1987 and is based on administrative data (Hospital discharge register and the Causes of Death Register). The whole Swedish population was under surveillance (about 9 million of men and women of all ages).
Fatal and non-fatal suspected events are identified through a record linkage of mortality data and HDR obtained by PIN. In either sources of information the following ICD codes are used for the selection of events: ICD-10: I21, I22 (ICD-9: 410). The register is validated using ECG, symptoms, enzymes, and eventually autopsy; troponin test (ESC/ACC criteria) is also used. A retrospective review of records and a linkage to MONICA and WHO registers are performed.

The *Northern Sweden former MONICA Cerebrovascular Accidents (CVA) Register* continues the MONICA experience started in 1985 and is still running. The population under surveillance includes about 160,000 men and 162,000 women for the age range 35-74 years. Fatal and non-fatal suspected events are collected by cold pursuit method and identified through a record linkage of mortality data and HDR obtained by PIN. In either sources of information, the following ICD codes were used for the selection of events: ICD-10 codes I60-I69, G45, G46, for HDR; I60-I69 and R96-99 for mortality. The register follows the MONICA procedures and methods and events are validated according to MONICA criteria.

The *Riks-Stroke*, the Swedish national quality register on stroke care, evaluates stroke units in routine clinical care. Basic patient characteristics, process indicators and outcome variables are recorded in all 85 hospitals admitting acute stroke patients. A 3-month follow-up is included. There are wide variations between hospitals in the proportion of patients admitted to a stroke unit, in secondary prevention and in the proportion of patients in institutional care at 3 months. Even after adjustment for available prognostic indicators, case fatality is lower and functional outcome is better in patients treated in stroke units than in patients treated in general wards.

UNITED KINGDOM

MONICA Belfast included the residents ages 25-64 of Belfast city and the Castlereagh, North Down and Ards health districts in Counties Antrim and Down. The total population in 1991 was 477,000. Coronary-event registration lasted from 1983 to 1993 and used *hot pursuit* method.

Scottish MONICA included the residents ages 25-64 of Glasgow city, north of the River Clyde. The total population in 1991 was 392,000. Coronary-event registration lasted from 1985 to 1994 and used *hot pursuit* method.

No *AMI/ACS population-based register* exists in this country.

The *South London Stroke Register (SLSR - data accessibility: http://www.kcl-phs.org.uk/stroke/research/SLSR.htm)* which started in 1995, is an ongoing population based stroke register recording first stroke in patients of all age groups. By using 12 referral sources cases of stroke are identified in a defined area corresponding to 22 wards of Lambeth, Southwark, and Lewisham Health Commission. The total population is 234,533 men and women. Hospital surveillance of admissions for stroke includes two teaching hospitals within and three outside the study area. Community surveillance of stroke includes patients under the care of all general practitioners within and on the borders of the study area.
The notification sources are accident and emergency records; hospital wards; brain imaging requests; death certificates; coroner's records; general practitioners; hospital medical staff; community therapists; bereavement officers; hospital based stroke registries; general practice computer records; and "miscellaneous" including notification by patients or relatives of patients.
Patients are examined within 48 hours of referral to the register when possible. Subsequently, patients are followed up at 3 months by a register team field worker and then yearly by postal questionnaire. Death certificates with ICD-9 codes 430 to 434 and 436 are validated according to clinical registration criteria. The Office for National Statistics notified the registry of any patients who had died.
Methods used to ensure complete ascertainment of cases included personal visits to all general practitioners before the project started and 1 year later, and regular communication by telephone, posters, and quarterly newsletters. Use of a weekly stroke clinic or domiciliary visit by the study team are also available to general practitioners.

TABLE 1. NATIONAL POPULATION-BASED AMI/ACS REGISTERS: POPULATION CHARACTERISTICS

Country	First year available	Last year available	Ongoing registration	Age range	Population (x 1000)		Access data
					Men	Women	
Denmark	1978	2001	yes	all	2677	2734	NIPH
Finland	1991	2003	yes	all	2600	2600	NIPH
Iceland	1981	2002	yes	25 to 74	170		NIPH; Icelandic Heart Association
Sweden	1987	2001	yes	all	4545	4466	NBHW

NBHW, National Board of Health and Welfare; NIPH, National Institute of Public Health

TABLE 1A. NATIONAL POPULATION-BASED AMI/ACS REGISTERS: CASE DEFINITION

Country	ICD version	Mortality ICD codes *	HDR ICD codes *	Linkage mortality / HDR	Validation
Denmark	VIII, X	410-414	410	PIN	Recommended national diagnostic criteria and MONICA
Finland	X	410-414, 798	410, 411, 413	PIN	Clinical diagnosis, troponine
Iceland	VIII, IX, X	410-414, 428, 798, 799	410-412, 414, PTCA, CABG	PIN/name and date of birth	ECG, enzymes, symptoms, MONICA, autopsy
Sweden	IX, X	410	410	PIN	Recommended national diagnostic criteria

CABG, Coronary Bypass Grafting; ECG, Electrocardiogram; MONICA, MONItoring of trends and determinants in CArdiovascular diseases; PIN, Personal Identification Number; PTCA, Percuteneous Coronary Angioplasty

*all codes are presented in the ICD-9 revision to facilitate the comparison

TABLE 2. REGIONAL POPULATION-BASED AMI/ACS REGISTERS: POPULATION CHARACTERISTICS

Country	Area coverage	First year available	Last year available	Ongoing registration	Age range	Population (x 1000)		Access data
						Men	Women	
Belgium	Charleroi	1983	2003	yes	25 to 69	50	50	School of Public Health
Belgium	Ghent	1983	2003	yes	25 to 74	71	71	University of Ghent
Belgium	Bruges	1999	2003	yes	25 to 74	75	75	University of Ghent
Denmark	Northern Jutland	1978	2001	yes	all	247	247	Aarhus University
Finland		1993	2002	yes	35-85	90	103	NIPH
France	Lille, Strasbourg, Toulouse	1985	2004	yes	25 to 64 (until '96) 35 to 74 (from '97)	752	767	INSERM U780
Germany	Ausburg	1985	2002	yes	25 to 74	203	204	National Institute of Statistics
Italy	7 areas	1998	2003	yes	35 to 74	1300	1400	National Institute of Health
Norway		1972	2002	yes	all	1000		Health Region West
Spain	5 MONICA counties	1985	1998	no	25 to 74	234	246	Institute of Health Studies
Sweden	Northern Sweden	1985	2005	yes	35 to 74	160	162	MONICA

INSERM, Institut National de la Sante et de la Recherche Medicale ; MONICA, MONItoring of trends and determinants in CArdiovascular diseases ; NIPH, National Institute of Public Health

TABLE 2A. REGIONAL POPULATION-BASED AMI/ACS REGISTERS: CASE DEFINITION

		Sources of information			
Country	**ICD version**	**Mortality ICD codes** *	**HDR ICD codes** *	**Linkage mortality / HDR**	**Validation**
Belgium Charleroi, Ghent, Bruges	IX, X	410-414, 428, 798, 799	410-414, 428, PTCA, CAGB	name, date of birth	ECG, enzymes, symptoms, MONICA
Northern Denmark	VIII, X	410	410	PIN	No validation
Finland	X	410, 411, 428, 798, 799	410, 411, PTCA, CABG	PIN	MONICA, troponine
France	IX, X	410-414, 428, 798, 799, others	410-414, 428	name, date of birth	MONICA
Germany	X	410-414, 798, 799	410, 411, PTCA, CABG	name, date of birth	MONICA, troponine
Italy	IX	410-414, 798, 799, other	410-414	name, date of birth	MONICA
Norway	X	410	410, PTCA, CABG	PIN	no validation
Spain	IX	410-414, 428, 798, 799, other	410-414	name, date of birth	MONICA
Northern Sweden MONICA	X	410, 411	410	PIN	MONICA

CABG, Coronary Bypass Grafting; ECG, Electrocardiogram; MONICA, MONItoring of trends and determinants in CArdiovascular diseases; PIN, Personal Identification Number; PTCA, Percuteneous Coronary Angioplasty

*all codes are presented in the ICD-9 revision to facilitate the comparison

TABLE 3. EXAMPLES OF HEALTHCARE SERVICES-BASED AMI/ACS REGISTERS IN COUNTRIES PARTICIPATING IN THE EUROCISS PROJECT

Country	Area Coverage	1st Year	Age range	Population (x 1000)		Access data
				Men	Women	
Austria	National	1990	all	1,600		Austrian Health Foundation
Greece	Regional	2003	all	NA		Hippokrrateion Hospital, University of Athens Medical School
Hungary	National	1996	all	4800	5300	The Centre for Health Information, National Health Insurance Fund, Department of Financial Informatics
Hungary (GP)	Regional	1998	all	125	139	School of Public Health, University of Debrecen
The Netherlands (GP)	Regional	1971	all	12		NIPH - University Nijmegen
Poland	National	2003	all	NA		Silesian Centre for Heart Disease
Spain (IBERICA)	Several provinces	NA	35 to 74	NA		Municipal Institute of Medical Research

NIPH, National Institute of Public Health; NA, not available

TABLE 4. NATIONAL POPULATION-BASED STROKE REGISTERS

Country	Starting year	Last year available	Ongoing experience	Age range	Target population (x 1,000)		Access data
					Men	Women	
Denmark	1978	2001	yes	35 to 85+	2677	2734	NIPH
Finland	1991	2003	yes	35 to 85+	2600	2600	NIPH
Sweden	1994	2006	yes	all	4589	4523	NBHW

NIPH, National Institute of Public Health; NBHW, National Board of Health and Welfare

TABLE 4A. NATIONAL POPULATION-BASED STROKE REGISTERS: CASE DEFINITION

Country	ICD version	Mortality ICD codes*	HDR ICD codes*	Linkage mortality / HDR	Validation
Denmark	VIII, X	430-438	430-438	PIN	-
Finland	X	430-438	430-438	PIN	MONICA CT-Scan
Sweden	X	430-434, 436-438	430-438	PIN	WHO Clinical criteria in sub-

CT-Scan, Comouted Tomography-Scan; MONICA, MONItoring of trends and determinants in CArdiovascular diseases; PIN, Personal Identification Number; WHO, World Health Organization

*all codes are presented in the ICD-9 revision to facilitate the comparison

TABLE 5. REGIONAL POPULATION-BASED STROKE REGISTERS

Country	Area coverage	Starting Year	Last year available	Ongoing experience	Age range	Target population (x 1,000)		Access data
						Men	Women	
Finland		1993	1997		35 to 85+	93	103	NIPH
France	Dijon	1985	2004	yes	6 months→	69	81	CHU Dijon
Germany	Erlangen	1994		yes	18+	49	51	University of Erlangen
Italy	8 areas (North, Centre and South Italy)	1998	2003	yes (every 5 yrs)	35 to 74	2400	2600	National Institute of Health
Norway	3 counties	1972	2002	yes	all	1000		Health Region West
Sweden	Northern Sweden	1985	ongoing	yes	25 to 74	160	162	Umeå University Hospital

NIPH, National Institute of Public Health; CHU, Centre Hospitalier Universitaire

TABLE 5A. REGIONAL POPULATION-BASED STROKE REGISTERS: CASE DEFINITION

Country	*ICD version*	*Mortality ICD codes**	*HDR ICD codes**	*Linkage mortality / HDR*	*Validation*
Regional Registers					
Finland	X	430-432, 435, 436	430-432, 435, 436	ID	MONICA
France	X	430-438, 442.81	430-438, 442.81	PIN, date of birth	WHO Clinical criteria CT-Scan or MRI
Germany	X	430-438	430-438	name, date of birth	CT-Scan, Health Insurance
Greece	IX	430-438	430-438	name, date of birth	CT-Scan
Italy	IX	430-434, 436-438	430-434, 436-438	name, date of birth	MONICA
Norway	X	430-438	430-438	PIN	-
Northern Sweden	X	430-438, 798, 799	430-438	PIN	MONICA

CT-Scan, Comouted Tomography-Scan; MONICA, MONItoring of trends and determinants in CArdiovascular diseases; MRI, Magnetic Resonance Imaging; PIN, Perosnal Identification Number; WHO, World Health Organization

*all codes are presented in the ICD-9 revision to facilitate the comparison

TABLE 6. EXAMPLES OF HEALTHCARE SERVICES-BASED STROKE REGISTERS IN COUNTRIES PARTICIPATING IN THE EUROCISS PROJECT

Country	Area Coverage	1st Year	Age range	Access data
Greece (Athens)	Regional	1992	18+	Alexandra Hospital, University of Athens
Greece (Arcadia)	Regional	1993	20+	Alexandra Hospital, University of Athens
Hungary (HDR)	National	1996	all ages	The Centre for Health Information, National Health Insurance Fund, Department of Financial Informatics
Hungary (GP)	Regional	1998	all ages	School of Public Health, University of Debrecen
Poland	Selected hospitals	2001	all ages	Institute of Psychiatry and Neurology Warsaw
Sweden (Riks-Stroke)	all hospitals (85)	1995	all ages	Department of Internal Medicine, Norrland Umeå University Hospital

GP, General Practitioner; HDR, Hospital Discharge Records

Health Interview and Health Examination Surveys

Here below an overview of HIS/HES performed in partner countries follows. The data here presented derive from the questionnaire filled in by each partner country and refer to the period 2005-2006. Therefore the information are reported as they were provided by partners and are further summarized into Tables 7 and 8.

BELGIUM

Within the *MONICA Project*, three regional surveys were conducted on individuals ages 25-64 years in: 1985-87, 1987-90 (1988-90 Ghent), 1990-93 (1990-92 Ghent). The total sample size in each population survey was about 1200 and the response rate was 50%. The surveys were self-reported questionnaires for IHD and AMI; physical examination was also included.

An *HIS* is periodically conducted every 4 years (first year: 1997; last year: 2004).
The sample size was about 6,000 men and 6,000 women ages 35-85 years and over. The Survey included a specific question on AMI and Percutaneous Coronary intervention (PCI). Collected data are computerized and the last year available is 2001. They are not used to calculate national estimates of IHD prevalence. The response rate was about 60 %.

CZECH REPUBLIC

Within the *MONICA Project*, population surveys were conducted in 1985, 1988, 1992, 1997/98 and 2000/1 on individuals ages 25-64 years. The total sample size was 2573 in 1985, 2769 in 1988, 2353 in 1992, 2087 in 1997/8 and 2078 in 2000/1. The response rate was 83% in 1985, 87% in 1988, 75% in 1992, 65% in 1997/8 and 62% in 2000/1. The assessed diseases in all surveys were: AMI, hypertension, and dyslipidemia. Blood pressure and cholesterol levels were also measured.

An *HIS* is conducted every 3 years (first year: 1993; last year: 2002). Data are available for men and women ages 15 years and over, grouped by 5 years. The total sample size was 1600 in 1993, 3396 in 1996, 2476 in 1999 and 2476 in 2002. The response rate was 60-70% in 1993, 60-70% in 1996, 68,2% in 1999 and 70,7% in 2002.
The *HIS* included a face to face questionnaire and the assessed diseases were hypertension, cerebrovascular diseases and all IHD. Collected data are computerized and the last year available is 2002. They are used to calculate national estimates of IHD prevalence.

DENMARK

Within the *MONICA Project*, population surveys were conducted in 1982-84, 1988, 1992 on individuals ages 25-64 years. The total sample size in each population survey was about 1200.

The *Danish HIS Program* started in 1987 and afterwards has collected data in 1994, 1997, 2000 and 2005. The overall purpose of the survey is to describe the status and trends in health and morbidity in the adult population and in the factors that influence health status, including health behaviour and health habits, lifestyles, environmental and occupational health risks and health resources. The results are used in national, regional and municipal health planning and monitoring as well as in research and analysis.
Design, data collection methods and response rates are shown in the table below:

	1987, 1994, 2000	2005
Sample size	6,000 - 22,500 adult Danish citizens	21,832 adult Danish citizens
Method of data collection	Personal interview + self-administered questionnaire	Personal interview + self-administered questionnaire
Carrying through	3 rounds	1 round
Personal interview	Paper and pencil	CAPI
Response rate	79.9% - 78.0% - 74.2%	66,7%

The Survey includes specific questions on MI/angina pectoris (AP) and high blood pressure. Further a question about longstanding illness, from which all heart diseases can be identified. Collected data are computerized and the last year available is 2005. They are used to calculate national estimates of IHD prevalence.

The *Copenhagen City Heart Study* is an *HES* which started in 1976. The first period of data collection ended in 1978 and the survey was subsequently performed in the years: 1981-83; 1991-93 and 2001-03.
The target population included about 9,300 men and 10,300 women ages 20 years and over. The Survey collected data on AMI, AP, Intermittent Claudication (IC) and Stroke, using the Questionnaire of the London School of Hygiene and Tropical Medicine (LSHTM) for effort angina, AMI and IC. Methods of data collection included also physical examination and ECG codified by Minnesota code.
Collected data are computerized and the last year available is 2000. They are not used to calculate national estimates of IHD prevalence.

FINLAND

FINRISK is an *HES* which started in 1972 and has been performed every 5 years until 2007. In 1982, 1987 and 1992 the FINRISK surveys were also part of the *WHO MONICA Project*. The sample sizes have varied between 6000 and 12000 individuals. The response rates have varied from over 90% to 65%. In 2002, 10000 individuals were examined. The HES collected data on AMI, HF, AP, Stroke, CABG, PTCA and all IHD using a questionnaire. Physical examination was also performed. Collected data are computerized and the last year available is 2002.

Adult Health Behaviour Survey (AVTK) is an *HIS* which has been performed annually for 26 years, from 1978 to 2004. In 2003, the sample size was 5000 individuals ages 15-64 and the response rate was 67%. The Survey included a specific question on AMI, HF and AP. Collected data are computerized and the last year available is 2004. They are not used to calculate national estimates of IHD prevalence.

Health 2000 is a national *HES* which started in 1972 and was performed every 15 years until 2002.
In 2000, the population sample was 8028 individuals ages 30 and over and the response rate was 89%. The Survey collected data on AMI, HF, AP, IC, Stroke, CABG, PTCA and all IHD using a questionnaire. Methods of data collection included also physical examination and ECG coded according to the Minnesota code. Collected data are computerized and the last year available is 2002. They are used to calculate national estimates of IHD prevalence.

FRANCE

Within the *MONICA Project*, population surveys were conducted in 1986-89 and 1995/96 in MONICA Lille; in 1985-87 and 1996-97 in MONICA Strasbourg; in 1985-87, 1988-91 and 1994-96 in MONICA Toulouse. Eligible people were individuals ages 25-64 years. The total sample size in each population survey was about 1,200. Participation rates varied from 47 % (in Strasbourg) to 76 % (in Lille) for men and from 50 % (in

Strasbourg) to 76 % (in Lille) for women. These surveys are conducted to study the trends of cardiovascular risk factors. The methods of data collection were standardized questionnaires on personal data (mainly risk factors: physical activity, tobacco smoking, hypertension, hypercholesterolemia and self reported diabetes), clinical measurements (weight, height, blood pressure) and biological measurements (lipids-including total and HDL cholesterol- blood glucose level). At present, a third survey is being performed in the same areas (2005-2006; ages: 25-74 years; sample sizes: about 1, 600 per area with ECG in Toulouse area).

A national representative *HES* (*ENNS*) is currently being conducted (2006-2007) focused on nutrition and nutritional state (including cardiovascular risk factors). The sample size is about 4,000 adults (18-74 years) and 2,000 children. The methods of data collection also include standardized questionnaires (nutrition, physical activity, tobacco smoking, hypertension, hypercholesterolemia, diabetes), clinical measurements (height, weight, waist and hip circumferences, blood pressure) and biological measurements (total cholesterol, HDL cholesterol, triglycerides, blood glucose level, creatinine levels, etc.).

A national *HIS* started in 1960 and was performed every 10 years (*EDS-INSEE*). The last one was performed in 2002-2003. The target population was the non institutionalized population of Metropolitan France and the sample size was about 41,000 of all ages (20,000 men and 21,000 women). The household response rate was 78 % for the first interview and 68 % for the third one (this survey includes three interviews; there were two months between the first and the third). All assessed diseases were coded (ICD-10). Medication used was reported. This survey includes SF-36 Quality of Life (QoL) and functional health status questionnaires (ADL, IADL). Collected data were computerized and can be used to calculate national estimates of IHD, MI prevalence, etc.

Another national *HIS* is being performed every two years (*ESPS- IRDES*). The last one was performed in 2006. The target population was the whole non institutionalized population of Metropolitan France and the sample size was about 22,000 (participation rate 70 %) in 2004. Assessed cardiovascular diseases were: hypertension, AP, MI, stroke and heart failure. In addition, interview data could be matched with health insurance reimbursement data. Collected data were computerized and can be used to calculate IHD prevalence (ESPS 2006 is currently being carried out).

GERMANY

Within the *MONICA Augsburg*, a CVD survey was carried out in 1984/85, 1989/90 and 1994/95. It referred to cardiovascular risk factors and to IHD, AMI and CVA. In 1984/85 the number of people examined and/or interviewed in the study was 4,022 (2,023 men and 1,999 women) in the age range 25-64 years. The response rate was 79% (2nd MONICA survey 77%; 3rd MONICA survey 75%). Methods of data collection included self-reported questionnaires, physical examination and interview (LSHTM for AP, self-reported previous AMI, and stroke). Except for the survey carried out in 1994/95, automated ECG was collected, but has not been codified by Minnesota code yet. Blood samples were taken, cholesterol and HDL-cholesterol was analyzed. Anthropometric measurements were performed.

KORA Ausburg Survey 2000 (HES) was carried out in 1999 to 2001 in the same area and study population as in MONICA; MONICA procedures were used. It refers to AP, IC and previous AMI and stroke in population ages 25-74 years. Target population is men and women ages 25-64 in the first survey, and up to 74 in the other 3 surveys; all data are computerized. Collected data were not used to calculate national estimates of IHD prevalence. The interview included LSHTM for AP and IC, self-reported AMI, and stroke. The examination included blood sampling and ECG. The response rate was 67%. A follow-up examination of the survey 1994/95 was carried out in 2004/2005 (including LSHTM for AP an IC, echocardiography, Ankle Brachial Index –ABI-). A follow-up examination of the KORA Survey 2000 is ongoing including carotid ultrasonography, measurement of endothelial dysfunction, ECG, and ABI.

The Study of Health in Pomerania (SHIP) was carried out from 1997 to 2001 and referred to a variety of chronic diseases and included previous AMI and stroke, AP and IC. The target population examined and/or interviewed

in the study was 4,310 (2,117 men an 2,193 women) in the age range 20-79 years. The response rate was 69%. Methods of data collection were based on self-reported questionnaires of LSHTM for AP and IC, self-rated AMI, stroke and of procedures as CABG and catheterization. ECG was collected and codified by Minnesota code. Anthropometric measurements were carried out. Physical examinations included carotid ultrasonography, and echocardiography. Systolic and diastolic dysfunction, left ventricular hypertrophy, aortic valve sclerosis were examined. A follow-up examination of the population is ongoing. Collected data are not used to calculate national estimates of IHD prevalence.

The National HIS and HES is based on interview and examination and was expected to be performed every 5-6 years. It covers the age range of 18 to 79 years. The last survey started in 1997 and ended in 1999 and the target population was men and women aged 18-79 years. The response rate was 62%. The Survey included questions on AMI, HF, AP, IC and Stroke, based on a physicians' interview. Blood samples were taken to analyze cholesterol and HDL-cholesterol. Non-fasting trigycerides and glucose were analyzed. Anthropometric measurements were performed. Collected data are computerized and are used to calculate national estimates of IHD prevalence. Data are available as public use file. Every year, since 2002 on a regular basis, telephone interviews are carried out. Questions on previous AMI, stroke, and on AP are included. Data in the Telephone interview of 2002/2003 is available as public use file.

GREECE

National surveys focusing on assessing CVD rates are not performed in the country, though there are several regional surveys, such as the Attica study.

At the national level, the *EPIC-Greece* cohort is the Greek component of the European Prospective Investigation into Cancer and nutrition (EPIC). The aims of EPIC are the elucidation of the role of biological, dietary, lifestyle and environmental factors in the aetiology of chronic diseases. Cancer studies are jointly published by the EPIC consortium, while investigations, such as for cardiovascular diseases, are also undertaken by individual countries.

EPIC-Greece is considered an *HES*, but it is not a permanent system of data collection. Although the sample is not strictly representative, it covers all major regions of Greece and, with certain assumptions, allows estimation of CVD incidence (incidence rate, mortality rate).

Specifically, the baseline data were collected from 1994 to 1999 and follow-up data is performed every 3-4 years which continues today with losses to follow-up less than 5%. The study population is 11,954 adult men and 16,618 adult women. As concerning CVD, volunteers are asked for the presence or absence of the following diseases, as well as for possible risk factors: AMI, ACS, HF, AP, IC, Stroke, CABG, PTCA and all IHD. Further methods of data collection are based on questionnaire and physical examination. Collected data are computerized and the last year available is 2005. Detailed individual validation of cardiovascular cases began in 2005, by reviewing hospital records.

HUNGARY

The National HIS was conducted in 2000 and in 2003 and included 7,000 non-institutionalized men and women ages 18 years and over. In 2003 sample size was 5032 and the response rate was 81%. Diseases of interest were AMI and Stroke, detected through a self-reported questionnaire. Collected data are computerized and the last year available is 2003. National prevalence estimates are available only for AMI and Stroke.

Unknown Morbidity Survey is an *HES* performed in 2001 and lasting 6 months. The target population was 3,735 men and 4,737 women ages 55-64 years. The primary aim of the Unknown Morbidity Survey was to measure the magnitude of unknown cases in two regions (Western and Eastern of Hungary in case of hypertension, diabetes mellitus and chronic liver disease and cirrhosis). Within the framework of the survey, physical examination and laboratory tests had been carried out for establishing diagnoses based on WHO criteria. Collected data were computerized. With newly identified cases, updated prevalence estimates were calculated.

ICELAND

Within the *MONICA Project*, population surveys were conducted in 1983, 1988/89, 1993/94 on individuals ages 25-64 years. The total sample size in each population survey was about 1200.

The *Reykjavic Study* is an *HES* which started in 1967 and is performed continuously. The target population is 30,000 men and women of all ages. The survey collected data on AMI, ACS, HF, AP, IC, stroke and PCI using a questionnaire. Methods of data collection included physical examination and ECG codified by Minnesota code. Collected data are computerized and the last year available is 2005. These data are used to calculate national estimates of IHD prevalence.

ITALY

Within the *MONICA Project*, population surveys were conducted in 1986/87, 1989/90 and 1993/94 in Italy-Brianza and in 1986, 1989 and 1994 in Italy-Friuli. Eligible people were individuals ages 25-64 years. The total sample size in each population survey was 1200.

The Italian HIS: Health condition and the use of health services is a national survey called "Indagine sulle famiglie", performed every 3-4 years and covering all ages. The survey was first performed in 1980, then in 1983, in 1986/87, 1990/91 and 1999/2000. Main diseases assessed were: IHD, AMI, CVA. It consisted of interview, promoted by ISTAT, the Italian National Institute of Statistic. The study was based on a random probability sample of the whole country (180,000 individuals in 1999/2000). Chronic diseases were assessed through a 28 items questionnaire. The response rate in 1999/2000 was about 80%. Collected data are computerized and are used to calculate national estimates of IHD prevalence.

The *Osservatorio Epidemiologico Cardiovascolare (OEC)* is a cardiovascular *HES* which was conducted from 1998 to 2002 on about 10,000 men and women ages 35-74 who were homogeneously spread throughout the Italian territory. The occurrence of AP, IC and old MI was assessed using questionnaires set by the LSHTM, or else through positive anamnesis for bypass or angioplasty surgery. The presence of alterations, such as atrial fibrillation and left ventricular hypertrophy, was decoded using Minnesota code. For the prevalence of cerebrovascular events (stroke or Transient Ischaemic Attack, TIA) the LSHTM questionnaire, validated through clinical records, was used. The prevalence rate of the different diseases in 35-74 years age group is available on the website www.cuore.iss.it. Collected data are computerized and the last year available is 2002.
Next *OEC* is planned for the year 2008.

THE NETHERLANDS

The *POLS survey* is an *HIS*, collecting data at the national level since 1997. These data are continuously collected in representative samples of the population, through self-reported information. The target population is about 5,000 men and 5,000 women per year, all ages. The survey includes a specific question on AMI, ACS, AP and stroke. Collected data are computerized and the last year available is 2004. The response rate is 60%. The data are used to calculate national estimates of IHD prevalence.

Being a *HES*, the *Regenboog project* assesses prevalence of previous MI and stroke, including not only self-reported data, but also a physical examination (weight, height, blood pressure, total and HDL cholesterol). This project started in 1998 and stopped in 2001, collecting data continuously. During 1998-2001, 19,500 participants were interviewed (HIS), with 28% of these undergoing a physical examination at the health centre (HES). The target population over the whole period was for the HES 2,700 men and 2,700 women aged 12 years and older. Collected data were computerized and the last year available is 2001. The data were not used to calculate national estimates if IHD prevalence.

The Rotterdam Study (ERGO) is a *HIS-HES* survey/cohort study. Baseline data collection was performed from October 1990 to July 1993. Since then all participants have been re-examined every 2-3 years. All inhabitants of

Ommoord a suburb of Rotterdam, who were 55 years or older were invited to participate in the study. Out of 10,275 subjects, 7983 agreed to participate (3,105 men and 4,878 women). In 2002, 3011 participants 55 years and older were added to the cohort. In 2005, all inhabitants of Ommoord aged 45 years and older were added to the cohort. Morbidity and mortality is registered through general practitioners practises. Events are coded according to the International Classification for Primary Care (ICPC) and ICD-10 using clinical information obtained from the general practitioner and HDR. IHD, AMI, HF and Cerebrovascular Disease were examined by self reported questionnaire. Standardized physical examination was carried out, including measurement of weight and height (to evaluate the presence of HF the presence of ankle oedema and pulmonary crepitions or rhonchi was also verified); ECG was recorded to assess the presence of atrial fibrillation and left ventricular hypertrophy; Echocardiogramm was use too. Collected data are computerized and the last year avaible is 2005. Response rate in 1991 was 78%.

The Doetinchem Cohort Study started as a *HES*, with a baseline examination during 1987-1991. A population based sample from inhabitants of Doetinchem, a town in the eastern part of the Netherlands, aged 20-59 years was drawn. Response rate was about 60%. Participants are being re-examined at five year intervals, the fourth round now taking place (2003-2007), with respondents being 36-75 years of age. Questionnaires and physical examination are performed (weight, height, waist and hip circumference, blood pressure, ankle-arm index, total and HDL cholesterol, non-fasting glucose). Response rates at re-examination are 75-80%, and the cohort consists of about 5000 men and women. Self-reported AMI and stroke is collected, and linkage is established with HDR, vital statistics and the national mortality register. Data are not used to provide national estimates.

NORWAY

Health surveys started in 1968 and were repeated in 1975, 1985 and 1995. Since 1998 living condition surveys are performed every year with variable main topics, including health every 3 year (1998, 2002 and 2005). These surveys involve representative samples from a population of 3,400 million men and women which are more than 16 years old and are resident in the national territory, excluding persons living in institutions. In 1998 sample size was 7,125 ages 16+ and the response rate was 72%. In 2005 all 10, 000 were selected: 303 had died, emigrated or were living in institutions. Thus, 9697 persons were interviewed and 6766 responded (70%).
The surveys include a self-report of prevalent diseases. CVD are to be specified and coded by ICD-10, thus including any reported diagnoses as MI, ACS, HF, AP, stroke, CABG, PTCA and all IHD. The surveys include a question on the impact of the reported disease on functional capacity and quality of life. In the last period (1998, 2002, 2005) the questions on health were presented together with ”non-health” issues on ”living conditions”, but the way to collect information on diseases was the same.
Collected data are computerized and the last year available is 2002. They are not used to calculate national estimates of IHD prevalence.

HES have been performed in several counties from 1974 to 2000-3. All these surveys have assessed prevalence of MI, AP and stroke by self-reports, and performed physical examination on weight, height, blood pressure, total cholesterol and (non-fasting) triglycerides. The Rose questionnaire (short form) on effort AP has been included. Since 1994 all surveys included also measurement of waist and hip circumferences, (non-fasting) glucose and HDL- cholesterol. The age groups have varied from 35-49, 20 +, 40-42 and included subjects aged 30-, 40-, 45-, 60- and 75 years (2000-2003). The numbers of attendees have varied from more than 100,000 to 5,000 and the attendance rate varied from about 90% to 46%.

The *North-Trøndelag Health Survey* has been performed in 1984-86 and in 1995-97, and data are computerized and available. This survey is ongoing (2006-2008) and involves more than 100, 000 inhabitants aged 20+. The data are being computerized and will be available.

POLAND

Within the *MONICA Project*, population surveys were conducted in 1983/84, 1987/88, 1992/93 in POL-MONICA Krakow and in 1984, 1988, 1993 in POL-MONICA Warsaw. Eligible people were individuals ages 35-64 years. In both sites the total sample size was 2400 in the first and 1200 in the second and third surveys. The response rate was 70-80%. Methods of data collection included standard questionnaires for AMI, IC, AP and Stroke, physical examination, BP measurement, blood lipids determinations and ECG (Minnesota codes).

The *Poland HIS* was a national system of data collection conducted in 1996 and 2004 on men and women of all ages (household survey). The survey included a specific question on all IHD. Collected data are computerized and the last year available is 2004. They are used to calculate national estimates of IHD prevalence. Target population was total population of Poland.

Multi-centre examination of health of Polish population *(Project WOBASZ)* was carried out in 2004-2005 in the frames of the National Program for Prevention and Treatment of Cardiovascular Disease (POLKARD 2003-2005). The sample studied was 19,200 men and women selected from total population of Poland ages 20-74 years (26,360 men and women). Average participation rate was 74% in men and 79% in women. Methods of data collection included standard questionnaires, physical examination, blood pressure measurement and blood lipids. CVD risk factors measured included: demographic characteristics, smoking, social status, social support, depression, physical activity, assessment of diet, blood pressure and blood pressure lowering treatment, blood lipids and lipid lowering treatment, body height and weight, waist circumference, blood glucose, blood homocysteine (sub-sample and C-reactive protein).

PORTUGAL

The Inquérito Nacional de Saude was an *HIS* conducted from 1987 to 1998/99 and performed every 5 years. The last survey was performed during the two year period 2004-2005 and available data are expected for the beginning of 2007. The target population was 48,606 men and women ages 35-74 years and over grouped by 10 years. The response rate was 80,5%. On the whole, the percentage of refusal was only 1,5-2,0%. Data on AMI and stroke were collected by means of face-to face interviews conducted on a probability sample of households selected by the National Statistical Institute and using previously elaborated questionnaires. Collected data are computerized and the last year available is 1998.

SPAIN

Within the *MONICA Project*, the *Catalonia Survey* is an *HES* carried out in 1986-88, 1990-92, 1994-96 and included personal interviewed questionnaires, physical measurements, fasting blood sampling and biological determinations. IHD, previous MI, and stroke were included and the data collection methods were based on LSHTM standard questionnaires for MI, IC, AP and Stroke as well as doctor diagnosed questions and on resting ECG coded by the Minnesota code.
The target population was 1.100.000 persons from Central Catalonia and the metropolitanean area of Barcelona. The original sample size was 3,500-4,500 individuals in each survey (final size 8,990 between the 3 surveys): ages 25-64 years and beyond. The response rate was 74%.

The Encuesta nacional de salud de España is an *HIS* which started in 1987; and repeated in 1995, 1997 and 2003. The target population was 40 million men and women, covering the following age ranges: 0-4, 5-15, 16-24, 25-44, 45-64, 75 and over. The Encuesta nacional de salud de España included a specific question on heart disease and arterial hypertension. Collected data are computerized and the last year available is 2003. Data were not used to calculate national estimates of IHD prevalence.
Some Spanish regions (Comunidades Autònomas) and a few cities carry out their own non-homogeneous mainly HIS-type of surveys on an occasional basis, as the health system in Spain is decentralized.

SWEDEN

Within the *MONICA Project*, population surveys were conducted in 1985/86, 1990/91, 1994/96 in Gothenbourg and in 1986, 1990, 1994 in Northern Sweden. Eligible people were individuals ages 25-64 years. Since then similar surveys have been conducted in Northern Sweden also in 1999 and 2004 on 2000-2500 individuals. The response rate was 80-86%. The contents of the surveys and the methods of data collection followed basically the MONICA study protocol and the surveys included HIS and HES.

UNITED KINGDOM

Within the *MONICA Project*, population surveys were conducted in 1983/84, 1986/87 and 1991/92 in Belfast and in 1986, (1989*), 1992 and 1995 in Glasgow. Eligible people were individuals ages 25-64 years. The total sample size in each population survey was 1200.

Health Survey for England (HSE) is a *HIS/HES* which aims to assess morbidity for AMI, ACS, HF, AP and Stroke. The first year of HSE data collection was 1994 and surveys are performed every year, covering the age range 16-85+ years for adults. Children are also included (age 2-15). Sample size of population depends on survey year and focus of survey question (for HSE 2003 the target population was 13,680). The response rate varies (in HSE 1998 was 63%, in HSE 2000 was 44%).

The survey included specific question on doctor diagnosed AMI, ACS, HF, AP and stroke. Collected data are computerized and made available to researchers immediately after the report is published (around 12 months after completion of data collection). They are not used to calculate national estimates of IHD prevalence.

Scottish Health Survey (SHS) is an *HES* which collects data every 4-5 years since 1994. Age ranges included are 16-84 for adults and 2-15 for children. Since 2001 children under 2 were also included. In 1995 the target population was 7932 individuals and the response rate was 42%. In 1998 the target population was 15332 individuals and the response rate was 54%.The survey included a specific question on AMI, ACS, HF, AP and Stroke. Collected data were computerized and the last year available is 2003. Also physical examination was carried out. Collected data are not used to calculate national estimates of IHD prevalence.

TABLE 7. HES SURVEYS - DISEASE: ALL ISCHAEMIC HEART DISEASE

COUNTRY	Time period covered by surveys	Periodicity	Age range	Population recruited x 1000	Methods of data collection (last survey)			
					LSHTM	Other quest	Exam	ECG
Denmark 1 Copenhagen City Heart Study	1976-2003	performed in: 1976-78; 81-83; 91-93, 2001-03	20+	20	√	-	√	√
Denmark 2 Surveys at the Research Centre for Prevention and Health in Copenhagen	1964-2005	seven cohorts out of 11 examined 2 or more times	35-85+	41	√	√	√	√
Finland FINRISK/Health 2000	1972-2002	every 5 yrs (FINRISK); every 15 yrs (Health 2000)	30+ (Health 2000)	8 (Health 2000) 10 (FINRISK 2002)	-	√	√	√[a]
France (ENNS)	2006-2007	every 5 yrs	3-74	6	-	-	√[b]	-
France (MONICA)	1986-2006	every 10 yrs	35-64 35-74 (2006/2007)	5	-	√	√[b]	√ only in Toulouse
Germany	1997-1999	every 5-6 yrs	18-79	7	-	√	√	-
Greece	1994-2006	every 3-4yrs	Adult population	29	-	√	√	-
Hungary	2001	only once	55-64	8	-	√	√	-
Iceland	1967-2005	continuously	All together	30	-	√	√	√
Italy	1998-2002	performed once Next in 2007	35-74	10	√	√	√	√
The Netherlands	1998-2001	continuously	12+	5	-	√	√	-
Norway 1	1974-2003	discontinuously	30,40,45,60,75	35	√	√	√[b]	-
Norway 2	1984-86 - 1995-97	next in 2006-8	20+	80	-	√	√[b]	-
Poland	2004-2005	performed once	20-74	19	√	√	√	-
Spain (MONICA)	1986-96	every 4 yrs	25-64	1	√	-	-	√
Northern Sweden	1985-2004	every 5 yrs	25-64	2				
UK	1994-2006	every year	16+	14	-	√	√	-

ECG, Electrocardiogram; LHSTM, London School of Hygiene and Tropical Medicine; a) only for Health 2000; b) risk factor

TABLE 8. HIS SURVEYS - DISEASE: ALL ISCHAEMIC HEART DISEASE

COUNTRY	Time period covered by surveys	Periodicity	Age range	Population interviewed x 1000	Questions included (last year)
Belgium	1997-2004	every 4 yrs	35-85+/all together	12	AMI, Percutaneous Coronary Intervention (PCI)
Czech Republic	1993-2002	every 3 yrs	15+, 5 yrs ranges	25	Stroke, IHD, hypertension
Denmark	1987-2005	Performed in 1987, 91, 94, 97, 2000, 2005	15+	22	AP and all heart diseases
Finland	1978-2004	every year	15-64 (in 2003)	5	AMI, AP, HF
France (ESPS)	1988-2006	every 2 yrs	all	22	Hypertension, AMI, AP, HF, Stroke, Arteritis
Germany	1997-1999	5-6 yrs	18-79	7	AMI, AP, HF, IC, Stroke
Hungary	2000-2003	every 3 yrs	18+	7	AMI, stroke
Italy	1999-2000	every 5 years	20-79	14	AMI, Stroke
The Netherlands	1997-ongoing	continuously	0+	10	AMI, ACS, AP, Stroke
Norway	1968-2005	every 3 year	16+	3	all CVD (ICD-X Q20-28)
Poland	1996 and 2004	Performed twice	All ages	26	IHD
Portugal	1987-1998/99	every 5 yrs	35-75+/all together	49	AMI, Stroke
Spain	1987-2003	Performed in 1987, 95, 97, 2003	0-4, 5-74 (10-year grp), 75+	40	IHD, Hypertension
UK	1994-2004	every year	16+	14	AMI, ACS, HF, AP, Stroke

AMI, Acute Myocardial Infarction; ACS, Acute Coronary Syndrome; AP, angina pectoris; CVD, Cardiovascular disease; ESPS, Health Care and Health Insurance Survey; IC, intermittent claudication; IHD, ischaemic heart disease; PCI, percutaneous coronary intervention; HF, heart failure;

4.2 WEB SITE

The EUROCISS Project web site (http://www.cuore.iss.it/eurociss/progetto/progetto.asp) was established within the page of the Italian Progetto CUORE (http://www.cuore.iss.it) of the Italian Institute of Health (ISS), which financed 40% of the EUROCISS Project (Fig 1).

The EUROCISS website (available in both Italian and English versions) gives a detailed and interactive description of the Project and includes the following sections (Fig 2):

- summary of the first and second phases of the Project;
- presentation of the health status indicators, determinants of health and health systems indicators which are reported and described in detail; they are identified for assessing the populations' health status and implementing preventive actions. They are divided into: already available indicators, those to be implemented in the short term and those recommended for long term implementation. Tables summarizing those recommended indicators are available for AMI, ACS, IHD, CVA, HF, other forms of heart disease;
- presentation of databases available at European level (World Health Organization - WHO; EUROSTAT; MONICA);
- a map illustrating the European countries participating in the Project is available. By clicking on each country, it is possible to access tables summarizing available data sources on CVD by single country;
- project results dissemination;
- a list of all partners with their personal information (name of institution, address, phone, fax, e-mail address);
- a **FORUM** (Fig 3) for discussion created to facilitate discussion among project partners. This internal 'working page' could be accessed exclusively by EUROCISS partners through a password.

All partners greatly contributed to its development and updating.

FIGURE 1. CUORE WEBSITE HOME PAGE

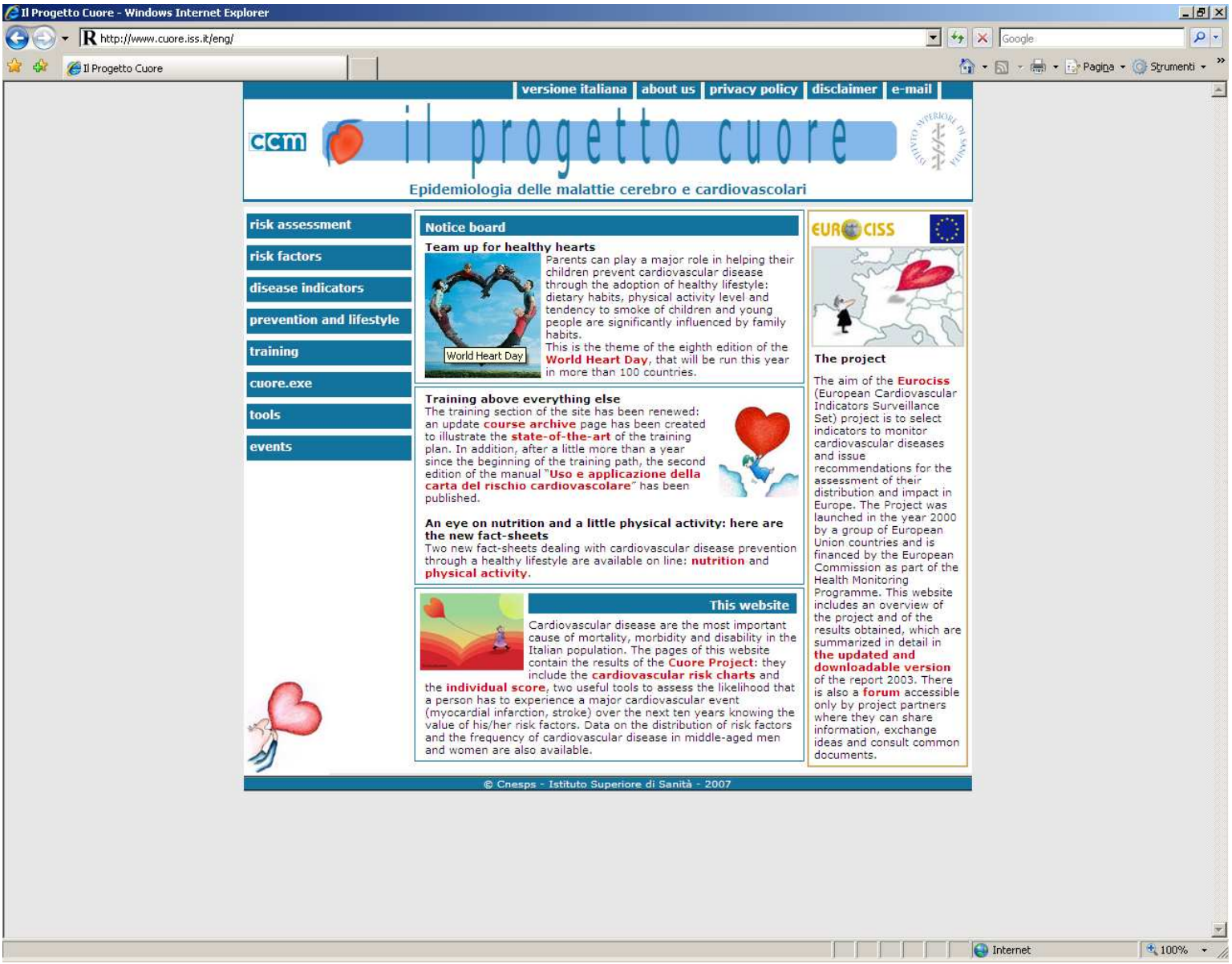


FIGURE 2. EUROCISS WEBSITE HOME PAGE

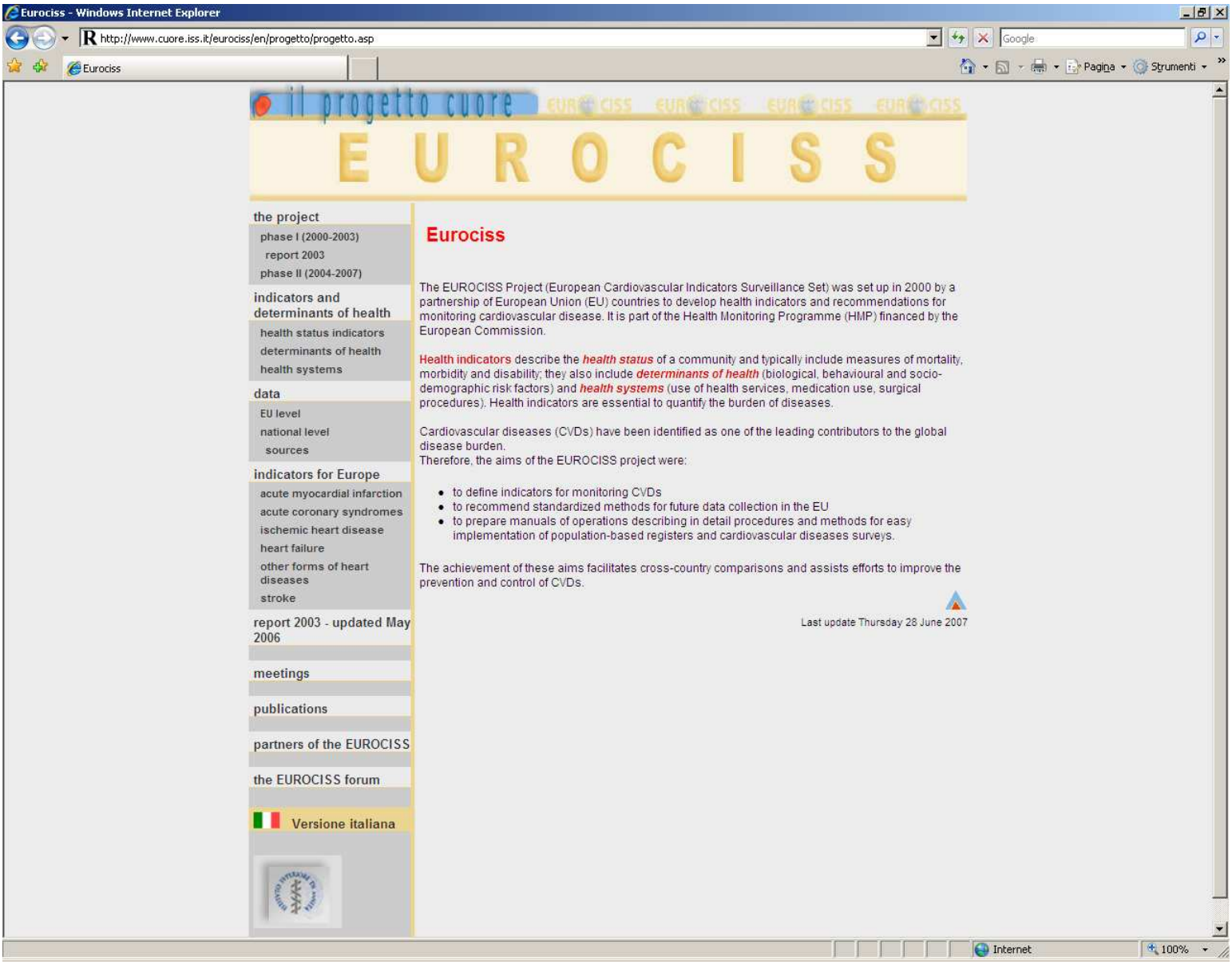
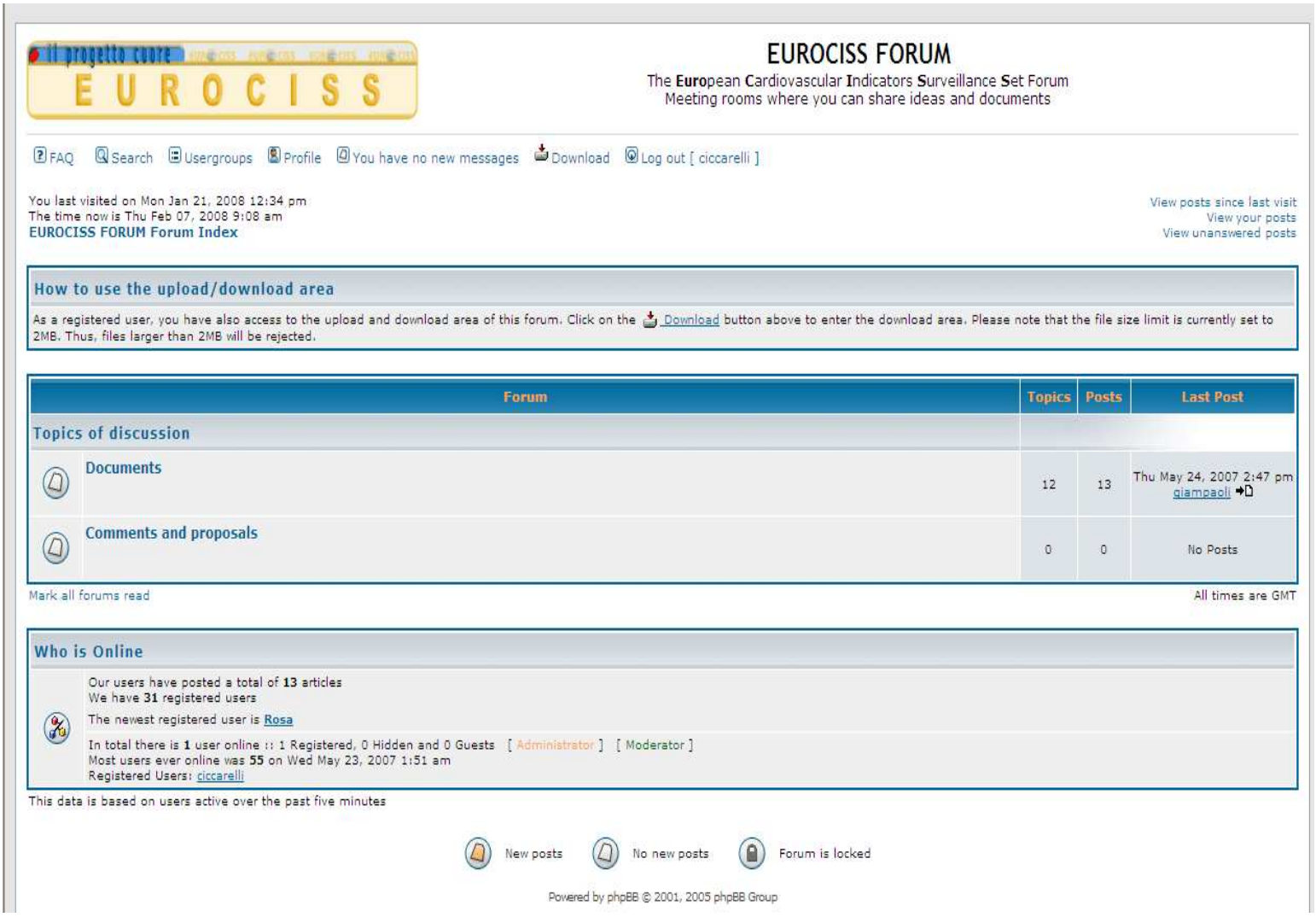


FIGURE 3. THE WEBSITE FORUM



4.3. MANUALS OF OPERATIONS

4.3.1 Background

The main objective and outcome of the 2nd phase of the EUROCISS Project (2004-2007) was to prepare the Manuals of Operations for the implementation of population-based registers of AMI/ACS and stroke in order to produce estimates of incidence/attack rate and case fatality, and of CVD surveys to assess prevalence.

These Manuals of Operations are the result of a long and fruitful cooperation among many experts involved in the EUROCISS Project, such as epidemiologists, statisticians, cardiologists and public health professionals, who aimed to produce a general guide for the surveillance of CVD to investigators, health professionals, policy makers and staff interested in current data collection and analysis. More specifically, they represent a valid scientific support for all those 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.

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 an efficient implementation of a population-based register.

A substantial number of sudden deaths (about 30% in middle age adults) still occurs out of hospital. Therefore, a population-based register is the best data source for the surveillance of AMI/ACS and stroke morbidity and mortality as it considers both fatal and non-fatal events occurring in-and out-of hospital, thus providing estimates of key indicators such as attack/incidence rate and case fatality. These indicators are included in the ECHIM short list proposed by the ECHIM project (www.echim.org) for improving comparable data collection at the European level.

Data extracted from mortality and hospital discharge records represent the minimum required to achieve a population-based register and are now available in most European countries thanks to the continuing process of computerization. To provide disease trends estimate, a population-based register should monitor a population able to produce a minimum of 300 total events (fatal and non-fatal, men and women together) per year in the age range 45-74 years. The minimum of 300 total events has been established to detect a decrease by 2% in attack rate per year.

Attack rates of acute coronary and cerebrovascular events are in themselves not sufficient to describe the impact of CVD on the population. The demographic changes in Europe with the increasing proportion of older people and the advancements in treatment have resulted in an increasing prevalence of chronic forms of IHD. Because of their frequency and cost there is a need to monitor the occurrence of both acute and chronic forms of the disease.

The EUROCISS Project has therefore produced the Manual of Operations of CVD Survey which provides a general guide and updated standardized methods for the surveillance of CVD and represents a useful tool to estimate CVD prevalence. This core indicator is also recommended by the EUROCISS Project for inclusion in the ECHIM short list. Population surveys are important as they further supplement the information collected from population-based registers with additional details on socio-demographic characteristics, risk factors, physical/biological measurements and chronic conditions.

While population-based registers are particularly useful for those events with a sudden onset requiring hospitalization, population screenings are the best surveillance system for complications of acute events, such as heart failure and arrhythmias, whose onset is not known and which do not require hospitalization.

4.3.2 Writing Groups

To develop the three Manuals of Operations mentioned above, the EUROCISS members were divided into three ***Writing Groups***: the Writing Group of the Manual of Operations of AMI/ACS population-based registers, the Writing Group of the Manual of Operations of Stroke population-based registers and the Writing Group of the Manual of Operations of CVD Surveys. Partners were grouped according to their expertise and each Writing Group was coordinated by a member of the Steering Committee.

The writing group of the Manual of Operations of Register of AMI/ACS was made of eight members: M Madsen (coordinator); V Gudnason.; A Pajak; L Palmieri; E C Rocha; V Salomaa; S Sans; K Steinbach; D Vanuzzo.

The writing group of the Manual of Operations of Register of Stroke is made of four members: S Giampaoli (coordinator); N Hammar; R Adany; C De Peretti.

The writing group of the Manual of Operations of CVD Surveys is made of six members:

P. Primatesta (coordinator); S Allender; P Ciccarelli; A Doring; S Graff-Iversen; J Holub; S Panico; A Trichopoulou; WMM Verschuren.

4.3.3 Essential Bibliography

Before starting the drawing up of the Manuals of Operations, a search for relevant papers published in medical journals from 1996 to 2005 was performed using MEDLINE and OVID databases.
The articles of interest in the field of AMI/ACS, Stroke and CVD Surveys were selected by each Writing Group according to previously defined criteria.
The following key words were used in order to select the most appropriate articles for preparing the Manual of Operations of AMI/ACS population-based registers: MI, coronary heart disease, epidemiological studies, hospital records, medical record linkage, validation studies, diagnostic criteria.

As for the Manual of Operations of stroke population-based registers, the following key words were used in order to select the most appropriate articles: disability, stroke classification, haemorrhagic stroke, ischaemic stroke, neuroimaging technology, MONICA classification, epidemiological studies.

As for Manual of Operations of Cardiovascular Surveys, the following key words were used in order to select the most appropriate articles: questionnaire, health status, health survey, epidemiologic investigation, angina, cardiovascular diseases, chest pain, mortality, self-rated health, validation, quality of life, symptoms, treatment, physical limitations, functional capacity.

The final list of selected articles represents the bibliography of each Manual of Operations.

4.3.4 Developing the Manuals of Operations for population-based registers: discussion issues

The three Manuals of Operations are the result of a long and fruitful cooperation among EUROCISS members. The majority of work was performed through the website Forum, the Partners meetings, the Steering Committee meetings and some meetings held in Rome between the three coordinators of the Writing Groups, which were responsible for the final elaboration of the Manuals.
For reasons of clarity and simplicity, the Manuals do not report all topics addressed by members and the various steps behind the elaboration; therefore, here below the most important and long debated issues are presented.

It was unanimously decided to give a similar structure to the ***Manuals of Operations of AMI and Stroke population-based registers***, and the following issues were basically discussed:

a. purpose
b. organization and content

c. how to summarize available data from countries
d. how to select population under surveillance
e. sources of information to be considered
f. data collection methods to be recommended
g. diagnostic criteria for event validation
h. how to evaluate quality control
i. validation procedures
j. cost-utility considerations
k. ethical issue

In particular, issues (d) and (g) required longer debate due to the fact that at the beginning there was quite a diversity of opinions among the Partners.

4.3.5 Population size

The issue (d) concerns the minimum number of events to suggest in order to set the population size under surveillance and monitor trends with the same degree of precision in the different registers (AMI/ACS and Stroke).

Starting from the procedure reported in the original MONICA Protocol, the change in incidence trend in 10 years was fixed at 10% and 20% for total events (1% and 2% per annum) in persons aged 45-74 years as the basis for statistical power calculation.

It was agreed to include, when possible, the oldest age range 75-84 (particularly for stroke as most events occur in this age range), so that a sufficient number of events could be produced also for women. Including, when possible, also the youngest age group 35-44 might be useful for comparison with previous registers, although the number of events in this age group is always quite small. Here below the procedures followed for calculating the population size to monitor for assessing incidence trends are described in detail:

> When planning a surveillance program, it is important to consider the population size needed to obtain reasonably precise estimates. In this context, it would be necessary to take into account the most basic comparisons of rates. In general, this would concern evaluations of changes in rates over time and of population differences in rates. Two different approaches to determine the required population size are presented below, the first based on a hypothesis testing

approach and the other on a confidence interval approach. The calculations are illustrated by a worked example.

Hypothesis testing approach

Under the hypothesis of a given annual percent change in the attack rate, this approach allows to calculate the necessary population size based on a Poisson probability function where the minimal number of events to be registered per year is given by the following relation:

Number of events per year = X / k =

$= 2 / k^3 *[(\Phi^{-1} (1- \alpha/2) + \Phi^{-1} (1-\beta)) / (t / 100)]^2$

where

X = indicates the number of events over k years;

α = significance level; $1-\beta$ = statistical power;

t = indicates the attack rate percent change per year;

Φ^{-1} = is the inverse of the Poisson probability distribution [http://en.wikipedia.org/wiki/Poisson_distribution].

For example, for an 80% probability ($1-\beta$) of detecting a 2% change in event rate per year over 5 years significant at the 5% level (α, two tailed test), the annual number of events needed is approximately 300:

Number of events per year = X / k =

$= 2 / 5^3 *[(1.96 + 0.84) / (2 / 100)]^2 = 314$

To give an example, the table 5 shows the numbers of events to be collected per year for an 80% probability of detecting a 2% or 1% change in attack rate per year over 10 years, significant at the 5% level (two tailed test), for men and women ages 45-74, for Coronary and Cerebrovascular events separately. In the table, to give an example, population sizes estimated for a low CVD incidence country (Italy) and a high CVD incidence country (Finland) are given. Coronary and Cerebrovascular attack rates used for the calculations derive from the Italian Progetto CUORE [URL http://www.cuore.iss.it/], and the Finnish National Cardiovascular Disease Register [Laatikainen T, et al. National Cardiovascular Disease Register, statistical database. URL http://www.ktl.fi/cvdr/].

In table 5, the column 'Events' shows the number of events to be collected per year to satisfy the chosen parameters; the two columns beside indicate the country specific crude attack rates used for estimating the minimal numbers; the next column shows the number of men and women to be taken under surveillance in the country specific population, calculated on the basis

of events to be collected and country specific attack rates; following, the required total population size based on the number of men and women respectively, using the European standard population structure is reported; the last column shows the correspondent total population size to monitor after 10 years, under the assumption of a constant decrease, in order to maintain statistical power.

Confidence interval width approach

An alternative approach to the hypothesis testing for estimating the population size to monitor is based on the confidence interval width: the requirement could be to have a confidence interval that is not too wide. Given that the purpose of the surveillance is to estimate attack rate and change in attack rate over time rather than testing a predefined hypothesis, this approach might be appealing. It is mainly based on the balance between two competing parameters: the confidence level and the interval width. If the confidence level is increased, the interval width will also increase, which means less information about the true rate. Given the confidence level and the interval width, it is possible to determine the related minimal population size. In a large population or for incidence rates not too small, the Poisson probability distribution can be approximated by the Normal distribution; in this case, estimation of the minimal population size (N) can be calculated using the following relation:

$N >= (2z_{\alpha/2})^2 \, p(1-p) / w^2$

where

p = attack rate estimate;

$p(1-p) = \sigma$ = standard deviation estimate;

α = significance level; in this context a factor specified by the confidence level, e.g. $\alpha=0.05/2$ would correspond to a 95% confidence interval;

z = refers to the use of the standard Normal distribution for deriving probabilities;

w = the chosen absolute interval width.

For example, in a large population with an attack rate of 44.1 / 10,000, given the significance level of 5% (α, two tailed test), and an absolute interval width of 20% of the attack rate, the minimal population size needed is approximately 87,000:

$N>= (2*1.96)^2 *0.00441*(1-0.00441) / (0.00441*20/100)^2 >= 86,727$

Estimating the population size needed for monitoring time trends in event rates is important and the results may limit the number of possible areas able to produce stable trend estimates. What matters is the annual number of events, and not the population size; in high attack rate

countries, smaller populations can be studied and in low attack rate areas larger ones would be needed. The limitations of using less than ideal sizes of populations for study could be reduced by:

i) accepting a higher threshold for the annual rate of change than those used in the example of 2% per year. This would be relevant to areas with low but rapid rates;

ii) increasing alpha and beta to lower the sample size. This would lower the power below 80% and/or increase α , the significance level, from 5% to 10%;

iii) pooling:

(a) results from age groups down to 25 (small effect on numbers);

(b) results from the age groups beyond 74 (large effect);

(c) combining data from both sexes (moderate effect);

(d) combining data from two or more geographically separate areas within one country establish trends, while studying them separately for other purposes;

(e) combining data within collaborative projects for centres in different countries, matched for certain characteristics such as initial event rates, risk factor trends, socio-economic characteristics, or health services.

While pooling data will increase numbers, it may conceal important information.

It is recommended that the minimum period of observation is one complete calendar year because of possible seasonal variations.

TABLE 5 Minimal size of low and high risk population under surveillance required for fatal and nonfatal coronary and stroke events, ages 45-74 years

Attack Rate percent variation (t %)	Events	Attack rate (x 10,000) Men	Attack rate (x 10,000) Women	Male and Female population required according to gender specific attack rates: Male population	Male and Female population required according to gender specific attack rates: Female population	Total population required using EU standard population structure: Total pop based on MEN	Total population required using EU standard population structure: Total pop based on WOMEN	Total population required after 10 years under the assumption of continuous attack rate decrease: Total pop based on MEN	Total population required after 10 years under the assumption of continuous attack rate decrease: Total pop based on WOMEN
2%									
Total Coronary Events Attack rates									
Italy	314	44.1	12.8	71,192	245,277	444,948	1,532,984	544,563	1,876,191
Finland	314	272.7	116.9	11,512	26,846	71,948	167,789	88,056	205,354
Total Cerebrovascular Accidents Attack rates									
Italy	314	33.5	20.3	93,718	154,658	585,737	966,611	716,873	1,183,017
Finland	314	112.0	61.2	28,044	51,317	175,276	320,730	214,517	392,536
1%									
Total Coronary Events Attack rates									
Italy	1256	44.1	12.8	284,767	981,110	1,779,791	6,131,937	1,967,964	6,780,251
Finland	1256	272.7	116.9	46,047	107,385	287,794	671,157	318,222	742,116
Total Cerebrovascular Accidents Attack rates									
Italy	1256	33.5	20.3	374,872	618,631	2,342,949	3,866,443	2,590,663	4,275,232
Finland	1256	112.0	61.2	112,177	205,267	701,104	1,282,921	775,229	1,418,560

4.3.6 Diagnostic criteria of AMI/ACS

The selection of **diagnostic criteria** for the validation of AMI/ACS was another complex issue which required debate.

After discussion, a general agreement was reached on the diagnostic criteria to recommend in the Manual for the validation of a sample of fatal and non fatal events in order to evaluate the PPV of codes selected for the definition of event.

The MONICA diagnostic criteria, based on symptoms, enzymes, ECG and, if possible, autopsy are highly recommended as they can be applied also for validating sudden deaths occurring outside hospital. The ESC/ACC diagnostic criteria, the American Heart Association (AHA) criteria and the British Cardiac Society (BCS) diagnostic criteria are also reported below.

A complete overview of the diagnostic criteria of AMI/ACS is available on the EUROCISS website http://www.cuore.iss.it/eurociss/en/progetto/progetto.asp

MONICA Criteria (1983-84)

The MONICA core study is concerned with coronary events and with two characteristics of the events, apart from their diagnostic category, which are whether they are (a) first or recurrent, and (b) fatal or non-fatal. Each episode must have a defined duration. In the MONICA core study a period of 28 days is used to establish the case-fatality and to distinguish two events from each other.

MONICA Algorithm

The MONICA algorithm classified the event according to location and duration of symptoms, evolution of injury current through ECG findings, variation within 72 hours of cardiac enzyme values and history of IHD, and, if performed, necropsy interpretation in fatal cases, to assign each event to one of the following

MONICA diagnostic categories.

a) *Definite AMI*: definite ECG; probable ECG with abnormal enzymes and symptoms which are typical, atypical; ischaemic or uncodable ECG or ECG not available, with abnormal enzymes and typical symptoms; fatal cases with definite findings in autopsy - recent acute MI or recent coronary occlusion.

b) *Possible AMI*: non-fatal events with typical symptoms whose ECG and enzyme results do not place them in the category 'definite' and in whom there is no good evidence for another diagnosis of the attack; fatal events where there is no evidence for another cause of death clinically or at autopsy, with symptoms typical, atypical or inadequately described, or without typical, atypical or inadequately described symptoms but with evidence of chronic IHD at necropsy, or with a good history of chronic IHD.

c) *Ischaemic cardiac arrest with successful resuscitation:* spontaneous cardiac arrest not provoked by medical intervention or gross physical insult, from presumed primary ventricular fibrillation secondary to IHD in the absence of significant valvular disease or cardiomyopathy.

d) *Insufficient data (unclassifiable):* fatal events with no autopsy, no history of typical, atypical or inadequately described symptoms, no previous history of chronic IHD and no other cause of death.

For a more complete overview of MONICA criteria consult the following publication**:** *World Health Organization: WHO Monica Project: MONICA manual. Part IV: Event Registration.* *http://www.ktl.fi/publications/monica/manual/part4/iv-2.htm#s1-1*

WHO Criteria (1971)

World Health Organization criteria for AMI

1. Definite ECG or

2. Symptoms typical or atypical or inadequately described, together with probable ECG or abnormal enzymes or

3. Symptoms typical with abnormal enzymes with ischaemic or non-codable ECG or ECG not available or
4. Fatal case, whether sudden or not, with naked eye appearance of fresh MI, recent coronary occlusion found at necropsy, or both

For a more complete overview of WHO criteria consult the following publication**:** *'Myocardial infarction community registers : results of a WHO international collaborative study coordinated by the Regional Office for Europe. Copenhagen : Regional Office for Europe, World Health Organization, 1976'*

ESC/ACC Criteria (2000)

Criteria for definition of acute, evolving or recent myocardial infarction

Either one of the following criteria satisfies the diagnosis for an acute, evolving or recent MI:

(1) Typical rise and gradual fall (troponin) or more rapid rise and fall (CK-MB) of biochemical markers of myocardial necrosis with at least one of the following:

(a) ischaemic symptoms;

(b) development of pathologic Q waves on the ECG;

(c) ECG changes indicative of ischemia (ST segment elevation or depression); or

(d) coronary artery intervention (e.g., coronary angioplasty).

(2) Pathologic findings of an acute MI.

Criteria for established MI

Any one of the following criteria satisfies the diagnosis for established MI:

(1) Development of new pathologic Q waves on serial ECGs. The patient may or may not remember previous symptoms. Biochemical markers of

myocardial necrosis may have normalized, depending on the length of time that has passed since the infarct developed.
(2) Pathologic findings of a healed or healing MI.

For a more complete overview of ESC/ACC criteria consult the following publication**:** *The Joint European Society of Cardiology/American College of Cardiology Committee. Myocardial infarction redefined. A consensus document of The Joint European Society of Cardiology/American College of Cardiology Committee for the Redefinition of Myocardial Infarction. Eur Heart J 2000; 21: 1502-1513.*

American Heart Association Criteria (2003)

Case definitions for Acute Coronary Heart Disease in Epidemiology and Clinical Research Studies

Classification of AMI

	Biomarker Findings							
	Cardiac Symptoms or Signs Present				***Cardiac Symptoms or Signs Absent***			
ECG Findings	Diagnostic	Equivocal	Missing	Normal	Diagnostic	Equivocal	Missing	Normal
Evolvine diagnostic	Definite	Definite	Definite	Definite	Definite	Definite	Definite	Definite
Positive	Definite	Probable	Probable	No	Definite	Probable	Possible	No
Non specific	Definite	Possible	No	No	Definite*	Possible	No	No
Normal or other ECG findings	Definite	Possible	No	No	Definite*	No	No	No

Classification of case is at highest level allowed by combinations of 3 characteristics (cardiac signs and symptoms, ECG findings, biomarkers).
*In absence of diagnostic troponin, downgrade to possible.

Definitions of IHD

The definition of a IHD case depends on symptoms, signs, biomarkers, and ECG and/or autopsy findings. These data may vary in quantity, quality, and timing. On the basis of the extent and diagnostic quality of data, definite, probable, and possible cases of fatal and nonfatal AMI, procedure-related events, and AP are defined. The recommendations emphasize biomarkers in a setting in which signs, symptoms, and/or ECG findings suggest acute ischemia.

For a more complete overview of AHA criteria consult the following publication: *Luepker VR, Apple FS, Chistenson RH, Crow RS, Fortmann SP, Goff D, Goldberg RJ, Hand MM, Jaffe AS, Julian DG, Levy D, Manolio T, Mendis S, Mensah G, Pająk A, Prineas R, Reddy S, Roger V, Rosamond WO, Shahar E, Sharrett R, Sorlie P, Tunsall-Pedoe H. Case definitions for acute coronary heart disease in epidemiology and clinical research studies. Circulation 2003; 108: 2543-2549.*

Nomenclature for AMI/ACS proposed by British Cardiac Society (2004)

The clinical and cardiac marker manifestations are determined by the volume of myocardium affected and the severity of ischaemia. Despite the similarities in disease mechanism the time course and severity of cardiac complications vary substantially across the spectrum of ACS. Similarly, treatment patterns differ.

BCS proposes that the spectrum of ACS should be subdivided as follows:

ACS with unstable angina

ACS with myocyte necrosis

ACS with clinical AMI.

SPECTRUM OF ACUTE CORONARY SYNDROME (ACS)

	Markers	ECG	Pathology
ACS with unstable angina	Troponin (TnT) and creatine-kinase (CK-MB) undetectable	ST or T non- elevation or transient ST elevation or normal	Partial coronary occlusion (plaque disruption, intra-coronary thrombus, micro-emboli)
ACS with myocite necrosis	TnT elevation, < 1.0 ng/ml	ST o T elevation or transient ST elevation or normal	Partial coronary occlusion (plaque disruption, intra-coronary thrombus, micro-emboli), more extended than that provoked by angina
ACS with clinical myocardial infarction	TnT elevation, > 1.0 ng/ml +/- CK-MB elevation	ST elevation or ST non-elevation or T inversion: may evolve Q waves	Complete coronary occlusion (plaque disruption, intra-coronary thrombus, micro-emboli)

BCS recommends that the term ‘‘unstable angina’’ should be reserved for patients with a clinical syndrome, but with undetectable troponin or CK-MB markers.

Unstable angina requires supporting evidence of coronary disease (abnormal ECG or prior documented coronary disease).

The term ‘‘ACS with myocyte necrosis’’ should be reserved for patients with a typical clinical syndrome plus an increased troponin concentration below the diagnostic threshold (that is, troponin T < 1.0 ng/ml or AccuTnI < 0.5 ng/ml)

The term ‘‘clinical MI’’ should be reserved for patients in the context of a typical clinical syndrome and a marker increase above the diagnostic threshold.

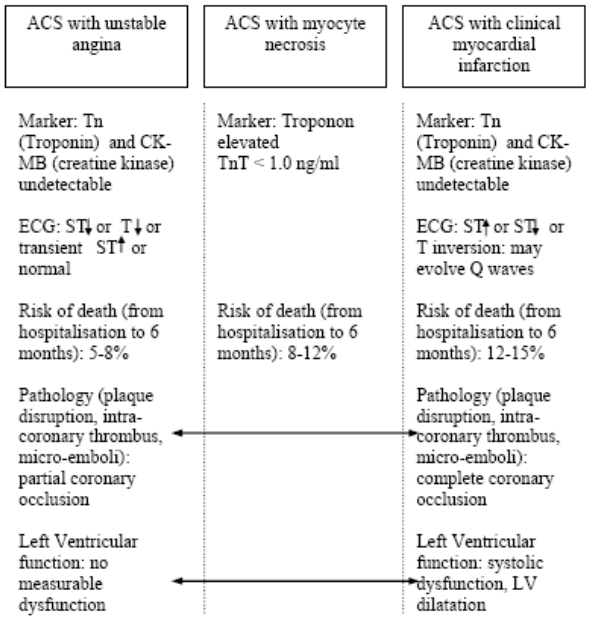
BCS proposes that the threshold for defining clinical AMI be set at 1.0 ng/ml for troponin T or 0.5 ng/ml for AccuTnI (or equivalent threshold with other troponin I methods).

Therefore, BCS recommends that in the context of a typical ACS clinical MI should be diagnosed when the maximum troponin T increase is > 1.0 ng/ml or AccuTnI > 0.5 ng/ml (and/or new Q waves develop on the ECG).

Individual laboratories that use other troponin I assays will need to estimate an equivalent troponin I concentration.

It is well recognised that the myocardium can be damaged after PCI and cardiac markers may increase in up to a third of patients. It is important to bear in mind, just as with spontaneous MI, that cardiac enzyme release after PCI should be integrated with clinical, angiographic, and ECG data to assess prognosis properly. Troponin concentrations should not be considered in isolation. BSC recommends systematic measurement of troponins after PCI (> 6 hours) as part of quality control standards.

The figure reported below describes the spectrum of acute coronary syndrome.



For a more complete overview of BCS criteria consult the following publication: *Fox KAA, Birkhead J, Wilcox R, Knight C, Barth J. British Cardiac Society Working Group on the definition of myocardial infarction. Heart 2004; 90: 603-609.*

4.3.7 Diagnostic Criteria of Stroke

For the population-based register of stroke, it is recommended to validate a sample of fatal and non fatal events in order to evaluate the PPV of codes selected for the definition of event.

In particular, the MONICA diagnostic criteria are recommended.

A complete overview of the diagnostic criteria of stroke is available on the EUROCISS website http://www.cuore.iss.it/eurociss/en/progetto/progetto.asp

MONICA definition

Stroke is defined as rapidly developed clinical signs of focal (or global) disturbance of cerebral function lasting more than 24 hours (except in cases of sudden death or if the development of symptoms is interrupted by a surgical intervention), with no apparent cause other than a vascular origin: it includes patients presenting clinical signs and symptoms suggestive of subarachnoid haemorrhage, intracerebral haemorrhage or cerebral ischaemic necrosis. Global clinical signs are accepted only in cases of subarachnoid haemorrhage or in patients with deep coma. Brain lesions detected by CT-scan but not accompanied by acute focal signs are not accepted as stroke, nor are extradural and subdural haemorrhages. This definition does not include TIA or stroke events in cases of blood disease (e.g. leukemia, polycythaemia vera), brain tumour or brain metastases. Secondary stroke caused by trauma should also be excluded.

The diagnostic classification follows:

(1) Definite focal signs

• unilateral or bilateral motor impairment (including dyscoordination)

• unilateral or bilateral sensory impairment

• aphasis/dysphasis (non-fluent speech)

• hemianopia (half-sided impairment of visual fields)

• diplopia

• forced gaze (conjugate deviation)
• dysphagia of acute onset
• apraxia of acute onset
• ataxia of acute onset
• perception deficit of acute onset.

(2) Not acceptable as sole evidence of focal dysfunction

Although strokes can present in the following way, these signs are not specific and cannot therefore be accepted as definite evidence for stroke.

• dizziness, vertigo
• localized headache
• blurred vision of both eyes
• dysarthria (slurred speech)
• impaired cognitive function (including confusion)
• impaired consciousness
• seizures

On the basis of the background information, each event may be classified into:

Definite stroke

Not stroke

Insufficient data

Insufficient data should be mainly used for fatal cases, especially for cases of sudden death without necropsy.

Cerebrovascular lesions discovered at autopsy are considered for diagnostic category.

All patients having insufficient supporting evidence of stroke, but for whom the diagnosis of stroke cannot be entirely excluded, should be classified as insufficient data, e.g. cases with no necropsy, no documented history of focal

neurologic deficits and no other diagnosis**.** Living patients can be classified into this category if:

• it is impossible to say whether the symptoms were from stroke or from some other disease, e.g. epilepsy, or

• patients with symptoms and clinical findings otherwise typical for a stroke but the duration remaining uncertain.

Subtype definition

Cases identified as 'definite stroke' were classified into stroke subtypes.

The MONICA subtype definition of stroke has to be confirmed by CT-Scan, examination or autopsy.

Subarachnoid Haemorrhage ICD-8 or ICD-9 430 or ICD-10 I60

Symptoms:

Abrupt onset of severe headache or unconsciousness or both. Signs of meningeal irritation (stiff neck, Kernig and Brudzinski signs). Focal neurological deficits are usually not present.

Findings:

At least one of the following must be present additional to typical symptoms.

1. Necropsy - recent subarachnoid haemorrhage and an aneurysm or arteriovenous malformation

2. CT-scan - blood in the Fissura Sylvii or between the frontal lobes or in the basal cistern or in cerebral ventricles

3. CerebroSpinal Fluid (CSF) (liquor) bloody (>2,000 rbc per cm^3) and an aneurysm or an arteriovenous malformation found on angiography

4. CSF (liquor) bloody (>2,000 rbc per cm^3) and xanthochromic and the possibility of intra-cerebral haemorrhage excluded by necropsy or CT-examination

Intracerebral haemorrhage ICD-8 or ICD-9 431 or ICD-10 I61

Symptoms:

Usually sudden onset during activities. Often rapidly developing coma, but small haemorrhage presents no consciousness disturbance.

Findings:

CSF often, but not always bloody or xanthochromic. Often severe hypertension present. Haemorrhage must be confirmed by necropsy or by CT-examination.

Brain infarction due to occlusion of precerebral arteries ICD-8 432 or ICD-9 433 or ICD-10 I65

Symptoms:

May vary.

Findings:

The occlusion must be confirmed by angiography or ultrasound or necropsy.

Brain infarction due to cerebral thrombosis ICD-8 433 or ICD-9 434 or ICD-10 I66

Symptoms:

No severe headache, if at all. Onset acute, sometimes during sleep. Often gradual progression of focal neurologic deficits. Usually, no, or only slight, disturbance of consciousness. TIA can often be detected in history. Often other symptoms of atherosclerosis (IHD, peripheral arterial disease) or underlying diseases (hypertension, diabetes).

Findings:

Brain infarction in the necropsy or in the CT-examination and no evidence for an embolic origin.

OR

CT-scan of satisfactory quality shows no recent brain lesion although clinical criteria of stroke are fulfilled.

Embolic brain infarction ICD-8 434 or ICD-9 434 or ICD-10 I66

Symptoms:

Abrupt onset, usually completion of the neurologic deficits within a few minutes. Disturbance of consciousness absent or only slight at the onset.

Findings:

As in brain infarction due to cerebral thrombosis, but in addition a source of the embolus must be detectable. The most common origins are:

- arhythmia (atrial flutter and fibrillation)
- valvular heart disease (mitral)
- recent AMI (within previous 3 months).

Remarks

If it is impossible to assign to a definite stroke event one of these sub-categories, the subcategory 'Acute, but ill-defined cerebrovascular disease' should be recorded (ICD code 436). If the clinical criteria for a stroke are fulfilled but a CT-Scan (of satisfactory technical quality) fails to reveal a brain lesion of recent origin, the patient has in all probability suffered an ischaemic stroke. In this case, type of stroke should be coded as 434 (infarction).

For a more complete overview of MONICA criteria consult the following publication: *World Health Organization: WHO Monica Project: MONICA manual. Part IV: Event Registration.* *http://www.ktl.fi/publications/monica/manual/part4/iv-2.htm#s1-1*

WHO criteria

The recommended WHO stroke definition is a focal (or at times global) disturbance of cerebral function, lasting more than 24 hours (or leading to death) with no apparent cause other than that of vascular origin. Transient episodes of cerebral ischemia were excluded by definition. Cerebrovascular lesions discovered at autopsy without having shown clinical manifestations in

life were not registered as stroke. A careful review of the patient's history is required to differentiate a previous stroke from previous Transient Ischaemic Attack (TIA), as the two episodes may be misclassified.

This definition is normally used in longitudinal studies. When possible, incidence studies should register TIA because mild strokes are often misdiagnosed as TIA.

For a more complete overview of WHO criteria consult the following publication: *Hatano S on behalf of the participants in the WHO Collaborative Study on the Control of Stroke in the Community. Experience from a multicentre stroke register; a preliminary report. Bull World Health Organ 1976; 54: 541-553.*

4.3.8 How to collect data

Mortality and HDR data file fields provide the necessary information to identify current events and allow record linkage. To give an example, here below standard forms for collection of mortality and HDR are reported. Basic information needed for record linkage include: PIN (or name and surname), place and date of birth, sex, residence; for the death certificate, place and date of death, underlying and secondary causes of death; for hospital discharge diagnosis, date of admission, date of discharge, underlying and other causes of discharge.

The 28-day survival period is the only basis for the assessment of fatal and non-fatal events: if the patient is alive after 28 days from disease onset, the event is defined as non-fatal; if the patient dies after 28 days from disease onset, the first event is defined as non-fatal, the second one as fatal but ischaemic heart disease is reported as underlying cause of death in the death certificate. If the death occurs within 28 days from disease onset, the first and unique event is defined as fatal.

Record linkage between mortality and hospital discharge records may be subject to reporting bias (e.g: errors in recording PIN or anagraphical data).

MORTALITY			
Field	**Type of data**	**Size**	**Description**
PIN (if available)	Text	10-11	Unique id number
Family name	Text	50	
First name	Text	50	
Date of birth	Date/hour	dd/mm/yyyy	
Place of birth	Text	6	Place of birth code
Sex	Text	1	men; women
Residence	Text	6	Residence code
Date of death	Date/hour	dd/mm/yyyy	
Place of death	Text	6	Place of death code
Died in	Text	1	home; private or public hospital; other
Underlying cause (main)	Text	4	Underlying (main) cause of death code
First cause	Text	4	First cause of death code
Intermediate cause	Text	4	Intermediate cause of death code
Final cause	Text	4	Final cause of death code

HOSPITAL DISCHARGE RECORDS			
Field	**Type of data**	**Size**	**Description**
PIN (if available)	Text	10-11	Unique id number
Family name	Text	50	
First name	Text	50	
Hospital code	Text	6	
Hospital discharge record	Text	8	
Admission date	Date/hour	dd/mm/yyyy	
Fiscal or sanitary code	Text	16	Fiscal or sanitary code
Sex	Text	1	1=men; 2=women
Place of birth	Text	6	Place of birth code
Date of birth	Date/hour	dd/mm/yyyy	
Residence	Text	6	Residence code
Types of admission	Text	1	ordinary; urgent; mandatory
Discharge date	Date/hour	dd/mm/yyyy	
Discharge modality	Text	1	ordinary; voluntary; transfer to other structure; died
Underlying (main) discharge diagnosis code	Text	4	Underlying (main) discharge diagnosis code
Secondary discharge diagnosis code	Text	4	Secondary discharge diagnosis code
Secondary discharge diagnosis code	Text	4	Secondary discharge diagnosis code
Discharge diagnosis code	Text	4	Secondary discharge diagnosis code

4.3.9 Developing the Manuals of Operations for CVD Surveys: discussion issues

Discussion mainly focused on the content of the Manual, in particular on the following issues:

a. minimum Set of questions for HIS (questions on disease, risk factors, use of medication and general questions on age, sex, education, occupation, ethnicity, self-reported health);
b**.** minimum Set of examinations for HES *(*height, weight, waist, hip, blood pressure, blood sampling - no fasting -, total and HDL cholesterol);
c. extra examination for HES (ECG, ECHO-cardiography, ABI, blood sample);
d. characteristics of population under surveillance: age-range; inclusion of institutionalized people subject to available resources; minority ethnic groups to be included; people younger than 35 to be excluded; socio-economic characteristics; ethnic origin and migration level;
e. population sampling: random national samples; boost of group of interest (e.g. ethnic groups, regional groups…..);
f. response rate: study of non-respondents; weight for non-respondents;
g. quality control: validation of questionnaires; validation of measurements (intra- and inter-observer variability); observer specific missing checks.

As for issues a) and b), priorities on a minimum set of examinations and questions to include should be based on public health criteria, starting from a basic set of questions/examinations and building up layers of complexity on the basis of user needs and available resources. A stepwise approach was proposed and is reported below:

Level of recommendation	Health Examination Survey (HES)	Health Interview Survey (HIS)
Minimum data collection	• Height • Weight • Blood pressure • Waist circumference • Non-fasting blood sample (Total cholesterol, HDL cholesterol, glucose)	• Age • Gender • Ethnicity • Social class indicator (income, education, occupation) • Smoking • Angina questions • Previous MI questions • Previous stroke questions • Diabetes • Medication use
Minimum + 1	The above plus • Fasting blood sample (e.g. for glucose) • ECG • Ankle/ brachial index • Clinical examination for HF	The above plus • Physical activity • Diet • Alcohol • Heart Failure questions • Rose questionnaire
Minimum + 2	The above plus • Echocardiography	The above plus • Family history • Quality of life • Use of health services
Minimum + 3	The above plus • Ultrasound of peripheral arteries • Other items pertaining to research question	The above plus • PAD questions • Parity • Other items pertaining to research questions

The debate mainly focused on the importance of validating HIS to get the disease prevalence and on the cost of implementation of HES, which need EU financial support since they are very much expensive and if performed only on sub-samples they might not be representative of whole population.

It was also stressed the importance of placing EUROCISS Surveys within the context of EU HIS/HES surveys to be aware of what is going on in Europe and contribute to CVD surveillance.

It was also suggested:

- to add obesity and diabetes to the list of risk factors since they are increasing throughout Europe;
- to perform fasting blood sampling at least in a sub-sample;
- to add disability to the list of questions;
- to perform HES at least in a sub-sample.