7. **Sources of information**

Indicators are obtained using different sources of information. The most important for CVD are briefly described below.

7.1 **Hospital discharge records**

Hospital discharge records (HDR) give the number of hospitalisations by disease. Hospitalisation does not include less serious events. Problems arise when an acute event is followed by a period of rehabilitation or a transfer to other wards and the event could be counted more than once. Hospital discharge registers do not include emergency room records, seldom includes nursing homes and only in some instances private hospitals. Discharge diagnoses are rarely validated; validity may vary by case mix and total number of discharges. Hospital admission policies vary over time and place; the adoption of new diagnostic techniques, such as troponine for AMI/ACS, CT-scan and MRI for strokes, may cause major changes in event rates calculated from hospital discharge data.

In general, discharge records are more reliable than admission records. Hospital discharge data are available in most EU countries, but data may not be organised by age and sex.

*Diagnosis Related Groups (DRG)*

In some countries, hospital reimbursement is based on the DRG tariff system. The DRG system is based on equal-resources criteria and aggregates events in major diagnostic categories (MDC). Homogeneous groups of patients are defined as those requiring similar facilities, similar levels of organisation and diagnostic procedures. This system has been used in the United States for over 10 years, and is the basis for the prospective payment system of hospital stay for Medicare patients (elderly over 65 years). DRG may be useful in hospitals for acute events, but are not reliable for chronic diseases requiring a long hospital stay and rehabilitation. The DRG system takes into account the main hospital discharge diagnosis according to the MDC, complications, age and sex.

The main hospital discharge diagnosis is the condition identified for reimbursement of treatments and/or diagnostic procedures. Hence, information is synthesised and organised by economic objectives that could overestimate or underestimate seriousness, complications and co-morbidity; i.e. stroke units or specialist wards may selectively admit the most severe cases. For this reason, the use of the hospital discharge diagnosis may be misleading in countries applying the DRG tariff system. One of the advantages of the DRG tariff system, however, is its availability for the entire population of a country. This overcomes one of the drawbacks of hospital records, which is the difficulty of determining the population denominator by identifying the total country population as a reference.
Countries using the DRG system are Denmark, Finland, France, Italy, Norway, Portugal, Spain and Sweden. Countries where the DRG system will be implemented in the near future are Germany and the Netherlands.

7.2 Surveys

HIS may be part of a permanent system of data collection at the national level. They are usually repeated periodically; information is self-reported and may not be sufficient to assess CVD morbidity.

High costs of clinical examination make the HES difficult to carry out; they are usually based on a general broad health focus and conducted at the regional level. Only few HIS and HES use properly standardised and sensitive methods to assess CVD morbidity.

Ad hoc CVD surveys provide important information on risk factors and disease prevalence but are seldom representative of the whole country. They are usually conducted on adults and often exclude individuals older than 70 years. Their reliability greatly depends on the participation rate and methodologies adopted. If conducted in representative population samples, they may provide a reliable estimation of CVD prevalence. Standardised procedures and methods are available\textsuperscript{34,35} such as the questionnaires from the London School of Hygiene and Tropical Medicine (LSHTM), used to identify angina pectoris, myocardial infarction and intermittent claudication. These have been used for many years in population studies and are available in different languages. They may evaluate the presence of symptoms of great importance for the health system when evaluating the burden of disease because not only the acute manifestations of the diseases, for example, myocardial infarction, but also the symptoms, for example, chest pain, contribute to the use of health services and to health costs. ECG, read according to the Minnesota Code (the Minnesota Code changes qualitative diagnoses into quantitative results), blood pressure, weight, height, total and HDL-cholesterol are usually collected to assess cardiovascular disease and risk factors. Echocardiography is recommended to make a reliable diagnosis of heart failure.

7.3 Cohort longitudinal studies

Cohort longitudinal studies are usually very comprehensive: they enrol a large healthy population, measure risk factors and observe over a long period, commonly years, the development and evolution of the disease. Incidence of disease can be determined in groups that differ in exposure level. These studies are very expensive, therefore seldom used for studying rare diseases, for example, CHD in women. They are useful for both aetiologic and public health administrative purposes. Their validity greatly depends on the representativeness of the enrolled population and on the number of persons lost during the follow-up. Almost all countries of the European Union have ongoing longitudinal studies of CVD. They include relatively small samples of the population and
in general involve collecting and validating hospital discharge diagnoses and deaths of the enrolled cohort. Diagnostic criteria for the definition of CVD events are specific to each study. Diagnostic criteria are based on history, clinical examination, hospital records, blood tests, and autopsies in cases of death.

Cohort longitudinal studies have contributed to the understanding of the differences in incidence across countries, to the measurement of the importance of risk factors in the prediction of disease and to the establishment of causality.\textsuperscript{2-4, 14, 17-19, 36}

Other longitudinal studies are those following cohorts of patients enrolled through registers. These studies lack the information on risk factors at baseline; they are defined as long-term survival of population-based registers.

7.4 **GP networks**

In some countries networks of general practitioners (GPs) can be useful when dealing with conditions not necessarily requiring hospitalisation. They may provide an adequate coverage for prevalence of chronic conditions such as IHD or HF. In a few countries these networks are operative (e.g. The Netherlands and UK). Information on this source has been exhaustively covered by the Project Health Monitoring in Sentinel Practice Network\textsuperscript{37}. GPs networks may be affected by selection bias; usually not all GPs participate in studies but only volunteers. Data from GPs networks require validation.

7.5 **Registers based on administrative data**

In some countries registers are available, based on record linkage of mortality and hospital discharge records. These registers have existed for many years in a number of Nordic countries, where individuals are identified by a personal ID thus allowing record linkage of all information sources. These registers are economical, cover the whole country, all age groups and collect large numbers of events; they are limited because they are not planned for scientific research and data are not standardised. Changes in the ICD version or the introduction of new diagnostic criteria may have unpredictable effects. These registers can be used when carefully validated\textsuperscript{38-44}.

7.6 **Population-based registers**

Population-based registers are usually formed through the linkage of various sources of information (mortality data, hospital discharge and GP records) and the validation of suspected events. Registers cover large samples of population, usually entire municipalities. Case finding (in- and out-of-hospital events, in-hospital events which occurred out of the region, home treatment events) and validity depend on the health system, medical care and diagnostic criteria applied in the definition of events. Potential sources of bias are the following: incompleteness of hospital records, death
certificates and autopsy records; coding errors; inaccuracy and non-comparability of the diagnostic criteria and autopsy rate.

The accuracy of rates produced using registers is related to the completeness and quality control of the data collected for the numerator (death and hospital discharge registers) and the denominator (population). Completeness also involves tracing subjects treated outside hospitals (nursing homes, clinics). In order to have a valid population-based register, the register should also collect events that happen to the residents but occur outside the area of surveillance. Data inaccuracy may be a problem for stroke: 50% of “new stroke diagnoses” are merely sequelae of an old stroke. This problem increases with ageing. Deaths occurring within 28 days are considered to reflect the same event. A unique ID for each subject would be very useful in linkage procedures between hospital discharge diagnoses and death certificate data sets; alternatively, multiple variables (e.g. name, date of birth, sex, residence), deterministic or probabilistic methods can be used for record linkage. Figure 1 shows the data flow in a population-based register.

The identification of events can be obtained by hot pursuit or cold pursuit. Hot pursuit means identifying case admissions to hospital usually within one or two days from the event onset and acquiring relevant information by visiting the ward or interviewing the patient. Information bias is minimised by the hot pursuit approach as information is collected immediately after the event. The process is expensive. The method was used in the WHO European Office Myocardial Infarction Registers in 1970 and in the WHO MONICA project. Cold pursuit implies the use of routine and delayed procedures, hospital discharge and death records. The process is easier and less expensive than hot pursuit; the number of cases studied is smaller because discharge diagnoses are more precise and specific than those on admission, but there is a possibility of missing important information. Both methods are used to identify suspected events, which must be validated applying the criteria of the WHO community register, or the MONICA methodology, or the new criteria of the European Society of Cardiology (see paragraph 10.3).

Registers are the best and most feasible source of morbidity data at a population level; they provide key indicators such as attack rate and case fatality. Incidence can be assessed if information on first event is available. If survival rates are available, also prevalence can be assessed.

The high cost of registers limits their implementation at a national level; therefore, they should be established in representative areas of a country (regions, macro-areas, etc).

Several countries have registers for AMI/ACS (Belgium, Denmark, Finland, France, Germany, Iceland, Italy, Norway, Poland, Spain and Sweden), fewer have them for stroke (Denmark, Finland, France, Germany, Greece, Italy, Norway and Sweden). Most adopt simplified methods derived from the MONICA project, which involves record linkage of death, hospital discharge and autopsy;
almost all apply the MONICA diagnostic criteria for the validation of all suspected events, or on a random sample or periodically.