

**METHODOLOGIES FOR PRODUCING EU-WIDE  
COMPARABLE DISEASE-SPECIFIC MORBIDITY DATA:  
DEVELOPMENT OF AN ELECTRONIC  
INVENTORY OF DATA SOURCES**

**FINAL REPORT - VS/1999/CVVF3-503**

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## Summary

The main aim of the project was to start to develop an electronic inventory of the main sources of morbidity data in the different Member States. This was achieved by creating a Microsoft Access database to serve as an encyclopaedia of available data sources. Maximum value was obtained by designing a database that could be easily updated in the future to include further countries, diseases, and providers of morbidity data. Hence, the production of an electronic inventory should be seen as the first phase of an ongoing programme of work. To achieve maximum value from the project, the inventory will need to be updated and enhanced regularly.

A steering group was assembled from experienced Public Health researchers in the participating countries. This panel helped to identify one main contact in each of the Member States for the diseases and providers to be included in the first version of the electronic inventory. The project team produced a questionnaire, with the help of the members of the steering group. This was piloted, revised and sent by post or e-mail to specialists in the Member States. The questionnaire asked about the compulsory nature and frequency of data collection for a particular disease or condition. It also enquired about data accessibility and relevant publications. Reminder letters were sent to encourage questionnaire completion. The information received was supplemented through further research carried out using the Internet and publications that provided information on sources of morbidity data. The information obtained through these processes was loaded into the database and a draft version circulated for comments to the members of the steering group and to over 70 interested parties working in the field of public health. Feedback received was either used to modify the design of the database or included in the study report as a recommendation for the future.

We have identified those areas where national and international systems have been devised in an aim to standardise data collection and analysis, for example, registration of births and mortality, congenital anomalies, cerebrovascular events, and cancer. Areas where morbidity data is lacking, or the information obtained by the study is incomplete, for example, respiratory diseases, are also visibly apparent. The study found that many Member States are making efforts to standardise and document procedures within their country for the collection and dissemination of morbidity data. This project could be seen as a way of encouraging Member States to update their own morbidity inventories and keep them up to date.

Key recommendations include using the Internet to make the database easily accessible to policy makers, Public Health officials and researchers within the European Union. Ongoing commitment and resources need to be set aside to ensure that the database is continually updated and thus retains its relevance as a reference tool. Inconsistencies in data entry and the obtaining of missing data need to be addressed. Existing participation at national level in the various international initiatives could be further researched and referenced accordingly.

## **1. Introduction**

The Treaty of the European Union created new responsibilities in Public Health for the European Community. Article 129 of the Treaty has general objectives for the Community to improve the level of human protection and also makes provisions for the types of Community action that should be undertaken to meet these objectives. Health care systems throughout the European Community are coming under increasing strain as a result of growing demands for health care, advances in medical technology, and greater patient expectations of health services. European Community policies must be targeted to supporting their Member States in their efforts to make health systems as effective and efficient as possible to improve and protect the health of their populations.

An important task for both the European Commission and Eurostat is to publish comparative information on the health of the populations of the Member States. However, this is not straightforward to do because of differences in the systems for collecting information on morbidity in the Member States. Hence, publishing comparative information on health requires an understanding of the different sources of morbidity data and their comparability, as well as information on how to access the data.

The aims of this project were to produce an electronic inventory of the sources of morbidity data available in Member States, which could:

- i) Identify sources of morbidity data that could be used to monitor the incidence and prevalence of specific diseases for the European Union's Action Programme on Health Monitoring in the field of Public Health.
- ii) Be updated regularly for the Commission by the Member States to ensure that the information contained in the inventory remained accurate.
- iii) Be made widely available, for example through the Internet, for use by policy makers, Public Health officials, and others with an interest in monitoring the health of the population, throughout the European Community.

The main reason for carrying out this project was that high quality, comparable data on health are essential for the planning, monitoring and assessment of European Community actions in the field of Public Health. This was stated in the Decision of the European Parliament and the Council on the 30<sup>th</sup> of June 1997. This project was designed to develop a strategy for providing the Committee of the Health Monitoring Programme with sources of morbidity data that could be used to help derive incidence and prevalence data for a range of diseases. This would allow disease-specific morbidity indicators to be monitored as part of the Action Programme on Health Monitoring in the field of Public Health. In addition, it would help provide data on the incidence and prevalence of specific diseases for Public Health Status Reports in Member States, which are essential for the annual European (Public) Health Status Report, and, if needed, for forecasting reports.

The project took forward recommendations arising from other work done in this field, for example, the work carried out by the UK Office for National Statistics, which examined some of the methodological issues involved in using data from a range of sources to produce European Union-wide estimates of the prevalence and incidence of specific diseases.<sup>1</sup> It also aimed to complement initiatives taken to produce comparable morbidity data from different countries. These include, for example, the development of common survey instruments by WHO Europe; inventories of survey items on disease-specific morbidity carried out by WHO

and the European Union Task Force on ‘Health and health-related survey data’; and research carried out in Italy on a harmonised morbidity indicators system. The project also aimed to build on efforts in Member States, such as by the Office for National Statistics in the UK and the National Institute of Public Health and the Environment (RIVM) in the Netherlands<sup>2</sup>, to compare data from different sources within one country; as well as by the Institute of Public Health (IPH) in Belgium and its electronic inventory of morbidity sources of information (Morbidat)<sup>3</sup>; the German morbidity sources of information (Gesundheits Bericht Erstattung)<sup>4</sup>; and an on-going Danish study which links survey data on disease with disease and disease-related registers.

All 15 Member States of the European Union and Norway were included in the study. Iceland was involved initially but unfortunately had to drop out of the study. If the project should be continued, it may well be possible to include Iceland at the next phase. All collaborating countries were asked to provide information for inclusion in the electronic inventory and some also contributed to the development of the inventory structure and the questionnaire. The findings of the project will be relevant to all European Union Member States, and in the longer term, to other European countries. Added value was derived from making the maximum use of already existing data, for example, from other Health Monitoring Projects. Furthermore, the electronic inventory of morbidity data sources lends itself to regular updating by the Member States for the Commission.

The report and the electronic inventory give an overview of different sources of morbidity data. However, the project did not cover information on data sources for general health status, health behaviour, health promotion or disability. The report and electronic inventory additionally try to provide information on the accuracy and quality of the data sources and therefore enable comparison of the data contained in those data sources within the different countries across the European Union. The report also makes suggestions for updating and extending the electronic inventory.

## **1.1 Aims and Objectives**

The specific aims of the project were:

- To develop an electronic database that can give information on the sources and comparability of morbidity data within the Member States of the European Union, and Norway.
- To structure the electronic database to allow it to be updated regularly, even after the end of this project.
- To be able to extend the database to meet future needs; for example, to increase the number of diseases covered.
- To raise awareness of the database among policy makers, Public Health professionals, and others involved in monitoring the health of the population, and to encourage its use.

## **1.2 Collaboration with other Health Monitoring Projects**

The project liaised with a number of international organisations, studies and other projects, as well as other Health Monitoring Projects funded by DG SANCO. We contacted and exchanged information with:

- 'EURO-MED-DATA' Project, Professor R Lagasse, Université Libré de Bruxelles, Belgium. The contact person from the 'Euro-Med-Data' Project for the 'Morbidity Data Sources' project was Dr Marc Jamouille, who is the researcher responsible for the collection of data from Primary Health Care in the European Union Member Countries. The project aims to develop an inventory of the medico-administrative data that is routinely collected in 18 European countries at the levels of primary and secondary health care and occupational medicine.
- European Study on 'Mental Health Indicators', Dr Jyrki Korkeila, Turku, Finland. The project aims to collect information on existing mental health indicators and tries to agree on harmonised definitions for European Mental Health Indicators.
- Health Surveys in the EU, Jaap van den Berg, Centraal Bureau voor de Statistiek, Netherlands. The project aims to generate a computerised database of methods and contents of existing and planned Health Interview Surveys (HIS), Health Examination Surveys (HES), and other population surveys with a significant health component in the Member States and EFTA countries. The project builds on an earlier study funded by the Commission ('Coverage of Health Topics by Surveys in the European Union', published 1998).
- EURODIAB, Professor Fuller, Royal Free & University College Medical School, London, United Kingdom. The aims of EURODIAB are to study the burden and determinants of the complications of diabetes and to contribute to the evidence base for the prevention and treatment of these complications. Eurodiab carries out large-scale epidemiological studies, clinical trials and smaller scale detailed studies of the pathophysiology of diabetic complications.
- 'Bone and Joint Decade 2000-2010' Project, Professor A. Woolf, Royal Cornwall Hospital, Truro, United Kingdom. The aim of the 'Bone and Joint Decade' Project is to improve the health-related quality of life for people with musculo-skeletal disorders throughout the world.
- Health Monitoring in Sentinel Practice Networks, Dr Douglas Fleming, Birmingham, United Kingdom. The project is concerned with health monitoring in sentinel practice networks in European Countries. It seeks to examine the capacity of networks to deliver information for health care planners, which is reliable and comparable between networks and between countries.
- European General Practice Research Workshop, Hanny Prick, University of Limburg, Department of General Practice, Netherlands. The 'European General Practice Research Workshop' carried out an inventory of General Practice Data in the EU- Member States in 1998.
- International Agency for Research on Cancer (IARC), Risto Sankila, Lyon, France. The aim of IARC is to co-ordinate and conduct research on the causes of human cancer, the mechanisms of carcinogenesis, and to develop scientific strategies for cancer control.
- European Network of Cancer Registries (ENCR), Mme Eva Démaret, Lyon, France. The aim of the ENCR is to improve the quality, comparability and availability of cancer

incidence data, and to create a basis for monitoring cancer incidence and mortality in the European Union.

- WHO-MONICA (MONitoring trends and determinants In Cardiovascular disease) project, MONICA Data Centre, National Public Health Institute, Helsinki, Finland. The WHO-MONICA project monitored trends in Coronary Heart Disease across 37 populations in 21 countries (including 29 populations in 16 European countries) from the early 1980s. However, the populations are not necessarily representative of the countries in which they are located.
- European Health Risk Monitoring (EHRM) Project, Professor Pekka, National Public Health Institute, Helsinki, Finland. The project aims to standardise national population risk factor surveys, based on the extensive experience in the MONICA and CINDI projects. The project will collect information on major chronic disease risk factors, etc. in order to serve and evaluate disease prevention and health promotion efforts.
- EuroSIDA study, Dr Lundgren, EuroSIDA Co-ordinating Centre, Department of Infectious Diseases, Hvidovre Hospital, Denmark. EuroSIDA was a prospective observational cohort study of 8 530 patients followed in 63 hospitals in 20 European countries that ran from 1994 until 1999. The main objective of the study is to assess the impact of antiretroviral drugs on the outcome of the general population of HIV-infected patients living in Europe.
- EUROCAT, London School of Hygiene and Tropical Medicine, London, UK. The EUROCAT network of congenital anomaly registers has been engaged in the surveillance of congenital anomalies since 1980, covering approximately 10% of all births in the participating countries.
- European Centre for the Epidemiological Monitoring of AIDS in Paris, France. The activities of the European Centre for the Epidemiological Monitoring of AIDS cover mainly HIV/AIDS surveillance in Europe, Tuberculosis surveillance in Europe and a monthly European communicable disease bulletin called “Eurosurveillance”.
- “Eurosurveillance”, Institut de Veille Sanitaire, France. “Eurosurveillance” is a European communicable diseases bulletin which aims to publish data from surveillance networks and results of outbreak investigations, compare national approaches to communicable disease prevention, and collate material of international interest from national bulletins.
- Euro Heart Survey, European Heart House, Sophia Antipolis, France. The Euro Heart Survey will provide systematic cardiovascular surveys, which will contribute to improved cardiovascular patient care in Europe.
- European Heart Network, 1 Place du Luxembourg, Brussels, Belgium. The European Heart Network links 28 national heart foundations and other non-governmental organisations committed to the prevention of cardiovascular disease, including coronary heart disease and stroke.
- The European Stroke Council, Lund, Sweden. The European Stroke Council is dedicated to furthering knowledge and promotes the prevention and treatment of stroke and cerebrovascular disorders.

## **2. Methods**

The project was carried out by the United Kingdom's Office for National Statistics. Some preliminary discussions about the project had already been held with Eurostat and collaborators in Belgium. The project team at the Office for National Statistics comprised Ms Petra Lehmann (Project Officer), Ms Eileen Watson (Project Officer) and Dr Azeem Majeed (Project Manager). The database was designed by Ms Caoimhe O'Sullivan from University College London. The project team was supported in its work by Mrs Joy Marshall, and Mr David Mountjoy. The project team was advised by a steering group with representatives from ten Member States, Norway and Eurostat (see Appendix 1 for details of membership of steering group).

The steering group first met in February 2000 to discuss the project and areas that it would need to focus upon. The comparability of data from different countries was viewed as an important issue, for example, where and how the data is collected; whether the data is representative; how often it is collected etc. The group agreed that the objective of creating an electronic inventory was to produce a tool that could be gradually completed and updated. The layout of the German (Gesundheits Bericht Erstattung) and the Belgian (Morbidity) databases were seen as good sources of information regarding structure and also regarding the choice of diseases included. It was agreed to use regional data and national data. Age-ranges for the data sources, for example, some surveys only include children, teenagers etc., would be included as applicable.

The steering group met again in September 2000 to discuss the initial design of the database. It was agreed to leave the database in English, to avoid having duplicate databases that would all need to be updated. Enhancements were suggested, for example, the inclusion of relevant websites and links in contact details, sub-dividing fields for greater clarity, for example, "Future Changes", "Publications", "Other morbidity data sources". The steering group also agreed that an application for funding would be submitted to enable the project to continue for another year to allow the database to be improved.

### **2.1 Data Collection Procedures**

With the help of the steering group, we identified one main contact in each of the 15 European Member Countries, and also in Norway (the contact in Iceland had to drop out of the study). As well as the United Kingdom, the project had close links with collaborators in nine other Member States, namely, Belgium, Denmark, Finland, France, Germany, Italy, Netherlands, Portugal, and Sweden. The collaborators from these nine countries and from the United Kingdom formed the steering group and attended two project meetings in London, in February 2000 and September 2000. During these meetings, the members of the steering group discussed issues surrounding data collection, data availability in the various countries, and the structure of the database and the final report.

We developed a questionnaire that was first sent out to the nine main collaborators and colleagues at the UK Office for National Statistics for comments. After this pilot, it was decided to split the questionnaire into smaller sub-questionnaires by specialty area. We requested from the main contact in each of the participating countries names and addresses of specialists in the following fields:

- Mortality and Births Registration
- Disease Registration
- Abortion Registration
- General Practice (Primary Care) Data
- Hospital Admissions Data
- Hospital Outpatients (Ambulatory Care) Data
- Surveys

and for the following diseases:

- Asthma
- Cancer
- Congenital Anomalies
- Communicable Diseases
- Coronary Heart Disease
- Diabetes
- Epilepsy
- Hypertension
- Mental Health Disorders (Psychiatric Disorders and Dementia)
- Musculo-Skeletal Disorders (e.g. Arthritis)
- Stroke

After receiving names and addresses of specialists for each country, we sent out the questionnaires either by post or by email. The number of specialists and their specialist area varied widely across the different participating countries, so that for some countries we had more than 20 names of specialists, whereas for other countries we had only one or two specialists' names and addresses. Altogether, we sent out over 130 questionnaires. Additionally, each specialist who had not replied to us by August 2000 was sent a reminder letter. Appendix 2 shows a breakdown by data source and country of the information received.

## **2.2 Database**

The electronic inventory was created using Microsoft Access 97. It is intended to serve as a reference tool and guide to the sources of morbidity data available in European Union Member States and Norway. It has been designed to be user-friendly with straightforward navigation from one section to the next. One of the most important aspects of the database design is its ability to be updated. Regular updates are essential to ensure that the data contained remains accurate and current. There is also a facility whereby the information contained can be extended to include new diseases, countries and providers.

Data obtained has been grouped under four different headings in the main menu: Contact Details, Data Availability, Diseases, Data Providers. Information can be accessed by clicking on drop down menus and selecting the relevant entry with a cursor. Countries, diseases and providers have been listed alphabetically for ease.

The database requires a PC capable of running Microsoft Access 97. Ideally, a PC with Microsoft Access 97 installed, a Pentium processor, 64MB of RAM, and either Microsoft Windows 98 or Microsoft Windows NT is needed to run the database.

### **3. Main Results**

The data obtained from the completed questionnaires was supplemented by information from the Internet, official reports, and articles in journals. However, work on the database is still not wholly complete.

The study found that the availability of data sources varies widely for the different providers and diseases. Some countries have more sophisticated procedures in place and are better able to link data from different sources. For those diseases and providers where data is generally or compulsorily collected, methods of dissemination are often similar. European-wide initiatives with standardised procedures for collection and analysis of data can be seen as an important step towards producing comparable data.

### **3.1 Organisations**

Table 1 summarises the findings on national statistical organisations.

All countries have established national organisations for the collection and analysis of routine morbidity data. These generally take the form of National Statistical Offices, Governmental Departments of Health, and National Public Health Institutes. They are responsible for the Registry of Births and Deaths, as well as for the production of health statistics. These organisations are the recognised central information points for the collection and dissemination of morbidity data, for example, cancer registration, national congenital anomaly system, general practice data, hospital episodes/admissions data, notification of communicable diseases. They are also often the repositories of national disease registers.

Many countries have also established special institutes within their departments of health to undertake and reference current epidemiological research into the field of Public Health and morbidity, for example, The National Institute of Public Health and the Environment (RIVM) in the Netherlands is responsible for the “Public Health Status and Forecasts”.<sup>5</sup> This report presents data on health, disease and health care. Its construction required participation from the different organisations responsible for morbidity data to ensure the scientific quality and utility of results. This collaboration between organisations on joint projects helps to increase uniformity of reporting and comparability of data.

The study found that many Member States are generally moving towards a comprehensive electronic inventory of morbidity data sources and information at national level. An increasing use of the Internet and websites allows this information to be easily and widely available to researchers and policy makers. Many websites are in the native language of the country but some also offer an English translation. The Institute of Health in France is working to develop a national website where French mortality and incidence data will be made available. STAKES, the National Research and Development Centre, in Finland, is setting up a similar system. Examples of other existing information systems are:

#### **i. Belgium**

The Scientific Institute of Public Health, has created Morbidat<sup>6</sup>: an overview of databases about morbidity and health related behaviours and the corresponding regulations. This information has been posted on the Internet and the Morbidat website forms a convenient “one-stop shop” for morbidity data in Belgium.

#### **ii. Germany**

Similarly, the Robert Koch-Institut is Germany’s central research and reference institute in the field of health. It is responsible for the surveillance of illnesses and relevant health risks in the German population, as well as for the derivation and reasoning behind initiatives undertaken to protect the health of the population. The Robert Koch-Institut also has an electronic inventory of morbidity data at its comprehensive “Gesundheits Bericht Erstattung” (Health Report) website.

### **iii. Sweden**

The Centre of Epidemiology is a part of the National Board of Health and Welfare. Its main responsibilities are to maintain epidemiological registers, e.g. The Medical Birth and Malformation Register, The Cause of Death Register, The Cancer Register; produce national public health and social reports; initiate and undertake research and development; and coordinate statistics within the health and social services sectors. The National Board of Health and Welfare began constructing a Swedish medical information database in 1993/94. The resulting MARS (Medical Access and Result System) database employs modern information technology to capture, systematise, and disseminate appropriate practices within the Swedish health services. The full text of the MARS system is available on the Internet, on CD-ROM, and, to some extent, as printed documents. Sweden now has over 40 national quality registries, documented in the report “National Health Care Quality Registries in Sweden 1999” (available at the National Board of Health and Welfare’s website or on the MARS CD-ROM of Registries).

**Table 1. National Statistical Organisations**

	Is data collected?	Is data collection compulsory?	Can data be used for national estimates?	Proportion of Births/deaths covered?	Use of personal ID no.
Austria	✓	✓	✓	100%	X
Belgium	✓	✓	✓	100%	X
Denmark	✓	✓	✓	100%	✓
Finland	✓	✓	✓	100%	✓
France	✓	✓	✓	100%	X
Germany	✓	✓	✓	100%	X
Greece	✓	✓	✓	100%	X
Italy	✓	✓	✓	99+%	✓ on death certificates
Ireland	✓	✓	✓	100%	X
Luxembourg	✓	✓	✓	100%	✓
Netherlands	✓	✓	✓	100%	X
Norway	✓	✓	✓	100%	✓
Portugal	✓	✓	✓	100%	X
Spain	✓	✓	✓	100%	X
Sweden	✓	✓	✓	100%	✓
UK	✓	✓	✓	100%	✓ on hospital admissions

Key: ✓ = yes

X = no

? = not known to the study

## **3.2 General Practice Data**

Comparison of general practice (primary care) data across the Member States is difficult because of the different definitions of primary care and differences in the health care system. For example, the United Kingdom's National Health Service has a clear divide between general practitioners (GPs) and specialists: general practitioners work exclusively in primary care and specialists work almost entirely in hospitals. Furthermore, general practitioners can not consult a specialist unless their general practitioner agrees this is necessary. In some other countries, this demarcation between primary care and specialist care is not as clear. For example, in Greece, many specialists work from community based offices and patients can see them without a referral from a general practitioner.

There is not uniform collection of general practice (primary care) data across the different countries. For example, some of the Member States focus instead on health service utilisation within hospitals and collect little information on primary care, e.g. Ireland. Countries that do collect general practice data often have different systems of primary care and data are therefore difficult to compare, e.g. there are no "generalist" doctors in Greece, and in Spain small private clinics specialise in some activities that are only carried out by hospitals in other countries. In some instances, report systems only exist for certain diagnoses. Additionally, access to records is often limited by data confidentiality restrictions.

General practice data are often collected via registration or via GP participation in disease-specific studies or surveys. The "Health Monitoring in Sentinel Practice Networks", co-ordinated by Dr Douglas Fleming at the RCGP Birmingham Research Unit and NIVEL (National Institute for Primary Care) in the Netherlands, is a European project, which is collating information on existing GP-based information systems in Europe. The project states as its aim that it seeks to examine the capacity of networks to deliver information for health care planners, which is reliable and comparable between networks and between countries. Information will be presented in the form of a database.

### *Registration*

When disease registration systems are present in general practice, they are generally computerised and report on all diseases that are presented by the patient to the participating general practice. The amount of information collected in a continuous registration system of this kind often has to be limited. Standardised forms and computerised databases are favoured over hand-written GP notes as they encourage a more harmonised data collection, thereby facilitating comparative analyses. Data collection is ongoing and results are published regularly (annually or bi-annually). With many systems, data collection is continuous for certain diseases and sporadic for others, depending on the health needs of the particular country. For example, in Italy, using general practice data, it is possible to derive national estimates of general practice data for diabetes. General practitioners in Belgium are also currently collecting data on diabetes. General practitioners in Portugal studied the incidence of diabetes from 1992 to 2000.

GP registration may be undertaken for varying reasons: to monitor morbidity and to measure the health needs of the population; for accounting purposes, for example, the register held by the National Association of General Practitioners in Germany holds data from 100% of all general practitioners who treat patients under its compulsory medical health insurance

scheme for workers; and to monitor and improve the efficiency of GP report systems, for example, in France the THALES database was set up by three physicians in 1990 to facilitate the use of computers in medical practice. It is now a representative network of 1200 general practitioners and specialists, holding records on over one million patients. The database provides the pharmaceutical industry or Government ministries with different types of survey data. One major advantage of this type of computerised registration is that it is possible to perform future surveys on a specific condition by adding this option to the software.

The General Practice Research Database (GPRD) in the United Kingdom was set up in 1987. The Office for National Statistics managed the database on behalf of the Department of Health from 1994 to 1999. Since April 1999, it has been managed by the Medicines Control Agency. The GPRD represents the largest source of continuous data on the overall health of the population in the United Kingdom. Contributing general practitioners are all members of the National Health Service. About 375 practices contributed data on 3.5 million patients in 1998 but the number of patients and participating general practices varies from year to year. There is also variation in the coverage between countries within the United Kingdom and in the coverage between English regions. General practitioners that contribute data to the database all follow agreed guidelines for the recording of morbidity information. With information on several million patients (currently round 3.5 million) and up to 12 years of longitudinal data, the General Practice Research Database is a unique data source for research into many aspects of morbidity, disease management and treatment. It therefore represents a source of valuable data for the identification of incidence and prevalence of major diseases, analysis of treatment patterns and outcomes for specific diseases.

Another example of a country that has a developed system of registration is the Netherlands. Its Continuous Morbidity Registration Nijmegen system (CMR) has collected data on all morbidity on a daily basis since 1971. An advantage of this type of longitudinal study is that changes in morbidity can be monitored, as figures for incidence and prevalence are available. The Registration Network Family Practices (RNH) database in Maastricht collects data on all diseases that are chronic (longer than 6 months), permanent, recurrent (3 or more recurrences in 6 months), or have a large impact on the patient. Registration is diagnosis-orientated rather than episode-orientated.

### *Studies/Surveys*

Disease-specific studies/surveys have been carried out by many Member States. In addition to their registration systems, the UK has also carried out a Morbidity Survey of GPs and the Netherlands (NIVEL) has undertaken two Dutch National Surveys on Morbidity in General Practice. Denmark carried out a 3 month survey in 1999 using ICPC coding to describe disease patterns in general practice, thereby enabling individual practitioners to compare practice patterns and management, exemplified by diabetic patients. In Spain, the Primary Health Care Spanish network (REAP) undertook a voluntary study in which GPs recorded the diagnoses in patients presenting in general practice surgeries between 1<sup>st</sup> May 1993 and 30<sup>th</sup> April 1994. Although the project was successful, the recording of data has not subsequently been continued and no similar recording has been carried out since. The National Health System in Spain is however planning a new information system for primary care. Confidence in the results obtained from sporadic and usually disease-specific pilot studies in Norway has led to plans for the implementation of a GP reporting system. Statistics Norway will be

responsible for collecting and processing data and distributing statistics from general practice. Plans for a similar system are also underway in Austria.

#### *Administrative Notification*

General practice sentinel networks generally report on incidence of communicable diseases. Notifications are sent ultimately to the Ministry of Health or a national institute responsible for communicable disease surveillance.

In summary, the advantages of GP registration are that it is not limited to one disease and can be adapted to examine the particular health requirements or specialties of the participating practices. Reports on diseases usually provide a medical diagnosis via the International Classification of Diseases (ICD) coding system, which enables comparisons between similar surveys in other countries. Providing the correct diagnosis is made, data are therefore generally accurate and can often be used to measure the incidence and prevalence of diseases, depending on the size of population covered by registration and the timescale involved. One major disadvantage is that coverage may be unrepresentative of patients or disease, e.g. in total, there are approximately 14 different network registration projects underway simultaneously in the Netherlands, varying in size, objectives and geography.

**Table 2. General Practice data**

	Is data collected?	Is data collection continuous	Can data be used for national estimates?	Proportion of Population covered?	Future changes?
Austria	✓	GP study	X	?	✓
Belgium	✓	✓	✓	1.4%	
Denmark	✓	GP study	X	6 GP practices only	
Finland	X	X	X	X	
France	✓	✓	✓	1 million patients	
Germany	✓	✓	✓	100%	
Greece	X	X	X	X	
Italy	✓	✓	✓	1 million patients	
Ireland	X	X	X	X	
Luxembourg					
Netherlands	✓	✓	X	14 projects	
Norway	✓	GP study	X	? – pilot studies only	✓
Portugal	✓	✓	?	3%	
Spain	✓	GP study	X	?	✓
Sweden	X	X	X	X	
UK	✓	✓	✓	2.6%	

Key: ✓ = yes  
 X = no  
 ? = not known to the study  
 blank = no data

### **3.3 Hospital Admissions Data**

All countries, with the exception of Luxembourg, collect hospital admissions data and just over 50% of Member States are also known to collect hospital outpatients' data. In Luxembourg, the Ministry of Health and the Directorate of Health are not yet in a position to deliver reliable data on hospitals. The Directorate of Health produced data on hospital admissions up to 1994, based on questionnaires which hospitals were asked to complete once a year. According to the new law on hospitals (1998), an inventory on hospital activities has to be made every year. A first data collection was carried out in 1999 (for 1998), provisional results only are available at present.

Data collection in all other countries is compulsory and is usually rated at between 90-100% complete, with the exception of Greece, which collects data on a sample (25%) of patients only. Admissions data is also collected through hospital surveys, for example, in Portugal, Greece, and Spain.

Generally a standard data set is collected on each patient admitted to, or discharged (e.g. Austria, Finland, Italy, Norway, and Sweden) from inpatient care. Often data-collection is episode-orientated and one data record therefore coincides with one patient (e.g. Germany, Ireland). If a patient receives in-patient treatment twice in one year, he or she will be counted twice in the statistics. In this case, records therefore facilitate analyses of hospital activity rather than the actual incidence of disease. Aggregate statistics are published annually and are usually available in publications or tables from National Statistical Offices or Health Departments. Routine publications tend to provide management information and administrative data, which enable national comparisons between hospitals, e.g. expenditure according to specialties and type of dependency, number of beds etc. Norway produces publications based on tables for diseases but with a focus on number of bed-days and development over time etc.

Some countries make greater use of hospital records than others. The Danish National Hospital Register<sup>7</sup> is one very good example of a national register that collects data according to a declared national standard and is able to handle and link information at the individual level, due to the use of a unique personal identification number (similar personal identifiers are also used by other Scandinavian countries). It was set up by the National Board of Health in Denmark in the late 1970s to monitor the demand for hospital treatment as well as to facilitate planning within the hospital sector, and to provide statistical data on its findings. Increasingly the Register is being used for the purpose of monitoring the occurrence of various diseases and treatments and for medical research as well as quality assurance in the hospital sector. Records are used to compile mandatory national registers, which are linked to other registers to add epidemiological information. In the UK, a unique personal identifier, the National Health Service number, is now collected on all hospital admissions. This number allocated to each individual should facilitate linkage of data on the same person across different data sets in the future. In Sweden, the information in the Hospital Discharge Register for 1987-1996 on whether a patient was discharged dead or alive, was compared with data of death in the Swedish Cause of Death Register and found to be 99.2% accurate.

Hospital admissions data may often be very accurate when used to measure hospital activity (for example, the number of admissions, lengths of hospital stay), but the accuracy of the diagnostic information is often questioned. In some countries, for example Norway, hospitals do not get funding to treat any patients that are not reported, so it is generally thought that

reporting is very reliable. France reports that hospital data will be extended to psychiatric and convalescence hospitals in the future. In Portugal, data on psychiatric patients are now being restructured.

A limitation for the purposes of this project is that information on hospital inpatients is often collected for management and administrative purposes rather than for measuring morbidity. In the cases of countries that have an episode-based system of data collection, records cannot be accurately used to assess incidence of disease as the same person may have received treatment on more than one occasion. Misdiagnosis of a condition will also result in inaccuracies of the data.

**Table 3. Hospital Admissions data**

	Is data collected?	Is data collection compulsory?	Can data be used for national estimates?	Proportion of admissions covered?	Future changes?
Austria	✓	✓	✓	100%	✓
Belgium	✓	✓	✓	?	
Denmark	✓	✓	✓	100%	
Finland	✓	✓	✓	100%	
France	✓	✓	✓	90%	✓
Germany	✓	✓	✓	100%	✓
Greece	✓	✓	✓	25%	
Italy	✓	✓	✓	98%	
Ireland	✓	✓	✓	95%	
Luxembourg	X	X	X	X	✓
Netherlands	✓	✓	✓	99%	
Norway	✓	✓	✓	100%	✓
Portugal	✓	✓	✓	100%	✓
Spain	✓	✓	✓	90-95%	✓
Sweden	✓	✓	✓	95%+	
UK	✓	✓	✓	100%	

Key: ✓ = yes  
X = no  
? = not known to the study  
blank = no data

### **3.4 Outpatient (Ambulatory Care) Data**

In many countries, outpatient data are not as widely collected as data for hospital admissions. Where information is collected, the basic unit of measurement is often an outpatient attendance. Hence, it is often not possible to calculate incidence and prevalence rates using outpatient data.

Denmark collects information on all outpatients within the framework of its National Hospital Register. Other countries have various restrictions to the data collected, for example Norway excludes some types of outpatient episodes; the UK does not include patients who attend a ward to receive treatment from nursing staff as opposed to a doctor; France only collects data on the 30% of patients attending hospital for acute care and excludes patients who visit a hospital to meet a doctor for other care. Hence, there are major issues about the comparability of data that need to be considered before the data from different countries can be compared.

In Austria, the introduction of outpatient registration is planned to take place within the next three years. Finland already collects voluntary data on 90% of outpatients but plans to also include the collection of morbidity data in the new model of outpatient statistics during the next five years. In Spain, a new information system is planned for public hospitals regarding outpatient care and plans are to provide specialised surgeries in hospitals.

Again publications in this area do not focus on diseases; but specialty, summarised by sector.

**Table 4. Outpatient data / Ambulatory Care**

	Is data collected?	Is data collection compulsory?	Can data be used for national estimates?	Proportion of Outpatients covered?	Future changes?
Austria	X	X	X	X	✓
Belgium	?	?	?	?	
Denmark	✓	✓	✓	100%	
Finland	✓	✓	✓	90%	✓
France	✓	X	✓	30%	✓
Germany	X	X	X	X	
Greece	X	X	X	X	
Italy	✓	✓	✓	98%	
Ireland	✓	✓	✓	100%	
Luxembourg	X	X	X	X	✓
Netherlands	✓	✓	✓	99%	
Norway	✓	✓	✓	100%	✓
Portugal	✓	✓	✓	100%	✓
Spain	X	X	X	X	
Sweden	X	X	X	X	
UK	✓	✓	✓	100%	

Key: ✓ = yes  
X = no  
? = not known to the study  
blank = no data

### **3.5 Diseases**

The information contained in the database with regard to diseases tends to have been provided by disease registers. Data collection is sparse for many conditions, for example musculo-skeletal disorders and respiratory diseases. For many conditions, we do not yet know whether data is collected or not. Further valuable data could possibly be obtained from sources such as hospital statistics or general practice data.

Morbidity data for many conditions are assembled by international initiatives. Some countries already participate in European projects that have been set up to collect and disseminate specified data using standardised methods of data collection and analysis. Wherever possible, resulting data are then subjected to comparisons with other participating countries. Examples are the WHO-MONICA cardiovascular research project and the EUROCAT network of reporting systems on congenital anomalies. Other projects make use of existing data collection systems within countries, taking into account as far as possible the diverse indicators used and differing levels of reliability. The output data is then “harmonised” in an attempt to calculate comparable estimates. An example is the WHO International Clearinghouse for Birth Defects Monitoring System.

Data collection by countries not participating in the aforementioned initiatives and for other conditions is generally routinely undertaken by registries and surveys. National and regional registries exist for certain diseases, namely cancer and congenital anomalies – also coronary heart disease to a lesser extent. Coverage for these diseases is broader as mortality rates are higher and trends in incidence have greater implications for healthcare provision. The purpose of the registries is generally to record incidence of a disease or condition, collecting data that are comparable between the participating regions. Prevalence of other conditions such as asthma or musculo-skeletal disorders tends to be via general practice surveys or health surveys.

### *Coronary heart disease*

Data on coronary heart disease is collected by all Member States. Most Member States, for example, Belgium, Denmark, Finland, France, Germany, Italy, Luxembourg, Spain, UK, have participated in the WHO-MONICA cardiovascular disease research project, which was established in the early 1980s to measure trends in cardiovascular mortality, coronary heart disease and cerebrovascular disease morbidity. Data registration was obligatory for coronary heart disease and optional for stroke, for example, Italy participated in data collection for both diseases. Ten-year data collection has now been completed and results are being published. However, although trends in mortality and morbidity can be monitored between the participating MONICA communities, the registers collect regional data only which does not always allow for the calculation of national estimates.

Data is also collected in other Member States via a variety of different sources. Sweden has a nation-wide Acute Myocardial Infarction (AMI) Register, established in 1996 by record linkage between the Hospital Discharge Register and the Cause of Death Register. The register comprises all persons with acute myocardial infarction reported to either register between 1987-1996. Within the Swedish MARS information system of quality registries, there are an additional eight further registers collecting data on other cardiac conditions, surgery and care. In Norway, the National Health Screening Service conducts regional screening for cardiovascular risk factors and publishes some statistics from these surveys. The general practice sentinel network in Portugal collected data during the period of 1990-1999. In Ireland, the report of the Cardiovascular Health Strategy Group (1999) recommended that a population-based Coronary Heart Disease and Stroke register should be established in a defined geographic area in Ireland. It also recommended a pilot study for the development of a hospital-based Coronary Care register.

**Table 5. Coronary Heart Disease**

	Is data collected?	Is data collection compulsory?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria						
Belgium	✓	✓	✓	✓	100%	
Denmark	✓	?	?	?	?	
Finland	✓	?	?	?	?	
France	✓	X	1985-1995 1996-1998	X	1.5 million inhabitants – 35-74 yrs	
Germany	✓	?	?	?	?	
Greece						
Italy	✓	✓	1984-1994  1998-2000	? results in press	1.5% of 25-64 year olds 12% of 35-74 year olds	
Ireland	X	X	X	X	X	✓
Luxembourg	✓	✓	✓	✓	100% aged 25-74	
Netherlands	✓	X	✓	X	?	
Norway	X	X	X	X	X	✓
Portugal	✓	?	X	?	?	
Spain	✓	?	?	?	?	
Sweden	✓	✓	✓	✓	100%	
UK	✓	X	✓	✓	2.6% of population via GPRD database	

Key: ✓ = yes  
 X = no  
 ? = not known to the study  
 blank = no data

## *Hypertension*

Surveys into incidence of hypertension have been carried out in Belgium and Portugal. Studies have also been carried out in Greece, notably The Didima Study and The Athens Study. In France, the THALES GP reporting network collects data on 120,000 patients with hypertension. Several of the Member States, namely Greece, Finland, the Netherlands and Italy, have also participated in the Seven Countries Study: Twenty-Year Stroke Mortality And Prediction (Inc Blood Pressure Changes As Predictors Of Future Mortality), which examined 12 cohorts of men aged 40-59 in the late 1950s or early 1960s for the measurement of some risk factors and then followed up for mortality and causes of death for 20 years.

**Table 6. Hypertension**

	Is data collected?	Is data collection compulsory?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria						
Belgium	✓	✓	X	X	?	
Denmark						
Finland	✓ - by epidemiological study only	?	?	?	?	
France	✓	✓	✓	?	120,000 patients – GP data	
Germany						
Greece	✓ - by epidemiological study only	X	X	?	?	
Italy	✓ - by epidemiological study only	X	X	X	X	
Ireland	X	X	X	X	X	✓
Luxembourg						
Netherlands	✓ - by epidemiological study only	X	✓	X	?	
Norway						
Portugal	✓	✓	X	?	?	
Spain						
Sweden						
UK	✓	X	✓	✓	2.6% of population via GPRD database	

Key: ✓ = yes  
 X = no  
 ? = not known to the study  
 blank = no data

## *Stroke*

Data on incidence of stroke has been obtained for nearly 40% of the Member States. Due to the differing levels of severity of this condition, treatment may be provided by a general practitioner or in a hospital; registration cannot therefore be deemed complete unless both services take part in the process.

Italy collected data on stroke between 1984 and 1994 as part of its collaboration in the MONICA project. A national stroke register is available in Sweden; however, although all departments and hospitals that provide care for stroke patients participate in the registration, this does not mean that all strokes are registered. Transient ischaemic attacks and subarachnoid haemorrhages are also not included at present. Other countries collect data via national or regional registers, for example, Belgium attempted to record 100% of incidents of stroke and transient ischaemic attacks in 1984, 1988-89, and 1998-99; Portugal's sentinel general practice network collected data on prevalence between 1990 and 1999; France has a local register in Dijon (150,000 inhabitants) which collected routine data on stroke for the period of 1985 to 1998.

**Table 7. Stroke**

	Is data collected?	Is data collection compulsory?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria						
Belgium	✓	?	?	✓	100%	
Denmark						
Finland	✓ - by epidemiological study only	?	?	?	?	
France	✓	X	1985-1998	X	150,000 inhabitants	
Germany						
Greece	✓ - by epidemiological study only	?	?	?	?	
Italy	✓ - by epidemiological study only	?	X	X	Different registrations	
Ireland	X	X	X	X	X	✓
Luxembourg						
Netherlands	✓ - by epidemiological study only	X	✓	X	?	
Norway						
Portugal	✓	?	X	?	1990-1999 GP study	
Spain						
Sweden	✓	✓	✓	✓	?	
UK	✓	X	✓	✓	2.6% of population via GPRD database	

Key: ✓ = yes

X = no

? = not known to the study

blank = no data

### *Musculo-skeletal Disorders*

Musculo-skeletal conditions are among the most common causes of severe long-term pain and physical impairment. For example, back pain is the second commonest cause of sick leave from work<sup>8</sup>. Hence, musculo-skeletal disorders impose a considerable burden on both the state and on health services. Despite this, musculo-skeletal conditions have traditionally been under-represented in registries and surveys. Data collection is not compulsory in most countries, but Sweden has a number of national registries, collecting data on hip fractures, hip replacement surgery, lumbar spine surgery, knee replacement, rheumatoid arthritis and spinal cord injuries. Regional registers exist in Italy, collecting data in Lazio and previously in Liguria.

The period 2000-2010 has been nominated “The Bone and Joint Decade – for Prevention and Treatment of Musculo-Skeletal Disorders” by the World Health Organisation (WHO). A global multi-disciplinary initiative, The Bone and Joint Monitor Project, has been launched (Co-ordinator: Professor A Woolf, Royal Cornwall Hospital in Truro, UK) to develop strategies to improve the quality of life for people with musculo-skeletal conditions. It aims to review and collate existing data, establish agreed outcome measures and the use of these in populations to collect data to compare and monitor outcomes.

**Table 8. Musculo-skeletal Disorders**

	Is data collected?	Is data collection compulsory?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria						
Belgium						
Denmark						
Finland						
France						
Germany						
Greece						
Italy	✓ via hospital admissions	✓	✓	✓ with caution	~3%	
Ireland	X	X	X	X	X	
Luxembourg						
Netherlands	✓	?	?	?	?	
Norway						
Portugal						
Spain						
Sweden	✓	X	✓	✓	65%-100% (varies by registry)	
UK						

Key: ✓ = yes  
 X = no  
 ? = not known to the study  
 blank = no data

### *Congenital Anomalies*

Reporting systems on this group of conditions are generally very good as compulsory hospital records of births provide almost complete coverage of births in many EU countries, and often include information about congenital anomalies. Some countries have a subdivision of their births register set aside for congenital anomalies (for example Norway), whereas others have developed independent registers, for example Denmark. In Greece, data are collected both regionally and nationally on cases that are reported in the monthly hospitalisation survey.

All of the Member States, with the exception of Greece, participate or have participated in the EUROCAT and ICBDMs networks of local registers. The EUROCAT Project is an European network of regional registries for the epidemiological surveillance of congenital anomalies in Europe. Local procedures are adjusted as far as possible so that data from the different registries can be validly pooled for analysis and surveillance. Members collect data regionally but in many cases it is possible to use this data to obtain national estimates.

The ICBDMs organisation represents more than 30 malformation monitoring programs world-wide. It promotes the exchange of routine information in the prevalence of congenital anomalies, collaborative epidemiological research and provides expert consultation and assistance for existing monitoring systems and establishment of new ones.

The advantage of these initiatives is that the standardised data collection and analysis of results aims to provide data that can be used for EU comparisons.

**Table 9. Congenital anomalies**

	Is data collected?	Is data collection compulsory?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria	✓	✓	✓	✓	100%	
Belgium	✓	✓ in Flemish community, also a voluntary Eurocat registration	✓	✓	100%	
Denmark	✓	✓	✓	✓	100%	
Finland	✓	✓	✓	✓	100%	
France	✓	X	✓	X	30%	
Germany	✓	X	?	?	?	
Greece	✓	X	✓	✓	?	
Italy	✓	✓	✓	✓	2-3%	✓
Ireland	✓	X	✓	X	70%	
Luxembourg	✓ - a former member of Eurocat	?	?	?	?	
Netherlands	✓	X	✓	✓	25%	
Norway	✓	✓	✓	✓	65%-100% depending on anomaly	✓
Portugal	✓	X	✓	✓	75%	
Spain	✓	X	✓	X	4000 cases	
Sweden	✓	✓	✓	✓	100%	
UK	✓	X	✓	✓	100%	

Key: ✓ = yes  
 X = no  
 ? = not known to the study  
 blank = no data

## *Diabetes*

Information was obtained from approximately 50% of Member States for data collection of this condition. A national diabetes register exists in Sweden, and in Italy several areas of the country are covered by registries for Type I diabetes. Other regions in Italy collect data locally for both Type I and II diabetes (e.g. Regione Piemonte); prevalence, age of diagnosis and treatment at onset can be calculated. A central co-ordinating office for data collection has now been established in Ancona. Data collection in other Member States is often limited to particular age ranges, e.g. The National Belgian Diabetes Register in Belgium collects data on all new cases of Types I and II diabetes in patients aged 40 years or under, France has four local registers which collect routine data on all patients aged 20 years or under, Luxembourg has an ongoing registration of Type I diabetes in patients 19 years and under. Routine data for diabetes has also been collected by GP studies in Denmark and Portugal.

Belgium and Luxembourg also provided the study with details of their collaboration in the EURODIAB study. This project aims to study the burden and determinants of the complications of diabetes and to contribute to the evidence base for the prevention and treatment of these complications.

**Table 10. Diabetes**

	Is data collected ?	Is data collection compulsory?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria						
Belgium	✓	✓	✓	✓	100% of under 40 year olds	
Denmark	✓	X	X	X	Pilot study with 14 GPs in 1999	
Finland						
France	✓	X	1988-1997	X	2.2 million inhabitants <20 years	
Germany						
Greece						
Italy	✓	X	✓	✓	Varies by register	
Ireland	X	X	X	X	X	
Luxembourg	✓	✓	✓ for under 19 year olds with Type I diabetes, also a prevalence study in 1991 for Types I and II	✓	100%	
Netherlands	✓	X	✓	?	?	
Norway						
Portugal	✓	X	X	X	?	
Spain						
Sweden	✓	✓	✓	✓	261 primary care units in 3 years	
UK	✓	X	✓	✓	2.6% of population via GPRD database	

Key: ✓ = yes

X = no

? = not known to the study

blank = no data

## *Communicable Diseases*

The “EU Inventory of the Means of Controlling Communicable Diseases”<sup>9</sup> has provided a description and analysis of the existing resources for the monitoring and control of diseases in the 15 Member States of the European Union, also Norway and Switzerland. The project aims to enhance collaboration and exchange of information. It will present recommendations to the European Commission to improve the monitoring and control of communicable diseases within the European Union. Results show that notification systems within the different countries are similar, although the organisation of resources for the monitoring and control of communicable diseases varies by individual Member State. The inventory reports that the number of diseases and pathogens subject to statutory notification varies greatly between countries; ranging from 22 in France to 80 in Finland, with a median of 40.

Surveillance systems for the monitoring and control of infectious diseases exist in all countries. Depending on the individual country, notifications may be made by general practitioners, clinics and laboratories. In Italy and Spain, all communicable diseases are subject to mandatory notification. Other countries, for example Ireland, have a current list of notifiable diseases; France also reports that HIV and Hepatitis B will be included on its list of notifiable diseases from 2001 onwards. The majority of countries have adopted standardised forms for collecting information. Some countries have established reference laboratories for notifiable diseases, for example Belgium has eight reference laboratories for HIV, AIDS and other sexually transmitted diseases; Greece has national reference centres for poliomyelitis, meningococcal disease, salmonella, cholera, viral haemorrhagic fever, and a Centre of Special Infections for HIV and hepatitis. National data are generally available in each country for tuberculosis. In the case of the Netherlands, data collection via registration using forms will be replaced in the future by a computerised registration system. Evaluation and validation may lead to changes in the contents of the surveillance system.

The “EU Inventory of the Means of Controlling Communicable Diseases” found that in most countries, a national institution is responsible for both validation and analysis of data. For example, in England, this task is carried out by the Public Health Laboratory Service. All countries report that an epidemiological bulletin is published at the national level, though the frequency of the publication varies: weekly in eight countries, monthly in nine, every two months in the Flemish Community, quarterly in Ireland, twice yearly in Italy.

**Table 11. Communicable Diseases**

	Is data collected?	Is data collection compulsory?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria	✓	✓	✓	✓	?	
Belgium	✓	✓	✓	✓	100%	
Denmark	✓	✓	✓	✓	Varies by disease	
Finland	✓	✓	✓	✓	80-100%	
France	✓	✓	✓	✓	Varies by disease	
Germany	✓	✓	✓	✓	~100% for compulsory notifiable diseases	
Greece	✓	✓	✓	✓	Varies by disease – 90%+ for high priority diseases	
Italy	✓	✓	✓	✓	~100% for compulsory notifiable diseases	
Ireland	✓	✓	✓	✓	~100%	
Luxembourg	✓	✓	✓	✓	?	
Netherlands	✓	✓	✓	✓	Varies by disease	✓
Norway	✓	✓	✓	✓	~ 90%	
Portugal	✓	✓	✓	✓	~100%	
Spain	✓	✓	✓	✓	Varies by disease	
Sweden	✓	✓	✓	✓	Varies by disease	
UK	✓	✓	✓	✓	~100%	

Key: ✓ = yes  
 X = no  
 ? = not known to the study  
 blank = no data

## *Cancer*

Collection of data on new cases of cancer in many countries is collected via a system of population-based registries. National data are usually available in most countries.

Notifications of cases are generally sent by general practitioners, hospitals clinicians and pathologists to the respective registries, e.g. in Greece data is collected nationally on all patients discharged from hospitals or who die in hospitals. Most countries use ICD coding to classify types of cancer although Greece, Belgium, Netherlands and Norway use the International Classification of Diseases for Oncology. Information in many countries can be linked to information on death to allow, for example, the calculation of cancer survival rates.

Registries in most countries passively receive notifications from the sources listed above. In Ireland, however, data collection is mainly active via eighteen nurses trained in cancer registration methods who are employed by the Registry with the title of Tumour Registration Officer (TRO). These Tumour Registration Officers are based in hospitals around the country. Each is responsible for gathering cancer data from a group of hospitals, and from other sources within a designated geographical area. Within their catchment areas, they liaise with hospital pathology and haematology laboratories, special clinics, hospital administrators and medical records staff, Hospital Inpatient Enquiry (HIPE) and casemix staff, and any other persons they consider to be a useful source of cancer registration data. They also maintain links with Public Health nurses, hospices and nursing homes in the community. Data is entered directly onto laptop computers by the Tumour Registration Officers.

The majority of countries are members of the International Association of Cancer Registries (IACR). This professional society was established in 1966 to foster the exchange of information between cancer registries internationally, so improving quality of data and comparability between registries. The ENCR (European Network of Cancer Registries) was established in 1989 within the framework of the Europe Against Cancer Programme. It is a joint project of the Association of Nordic Cancer Registries, the International Association of Cancer Registries, the IACR and the Latin Language Cancer Registry Association. Its activities include the promotion of continuous collaboration between cancer registries, the definition of data collection standards and a regular dissemination of information on incidence and mortality from cancer in the European Union. OECD Health Data also collects cancer data from national registries for most European Union countries and mentions the data source.

**Table 12. Cancer**

	Is data collected?	Is data collection compulsory?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria	✓	✓	✓	✓	100%	✓
Belgium	✓	✓	✓	✓	Varies by cancer	
Denmark	✓	✓	✓	✓	100%	✓
Finland	✓	✓	✓	✓	100%	
France	✓	✓	✓	✓	13% all ages, 30% for leukaemia in children	
Germany	✓	✓	✓	✓	90 to 95% in Saarland, less in other regions	✓
Greece	✓	✓	✓	✓	Less than 80%	
Italy	✓	✓	✓	✓	15%	
Ireland	✓	X	✓	✓	100%	
Luxembourg	✓	X	✓	✓	90%	✓
Netherlands	✓	✓	✓	✓	>95%	
Norway	✓	✓	✓	✓	100%	
Portugal	✓	✓	✓	?	85% for Central region	✓
Spain	✓	X	✓	✓	100% by 12 registers that cover 26% of population	
Sweden	✓	✓	✓	✓	95%+	
UK	✓	X	✓	✓	95%	

Key: ✓ = yes  
 X = no  
 ? = not known to the study  
 blank = no data

## *Asthma*

The study was only able to obtain limited data for asthma. Data for this condition is collected through prevalence studies or hospital admissions data as opposed to via incidence registers. Studies have been carried out by general practitioners in Belgium, Portugal and the UK. The Zutphen epidemiological study in the eastern Netherlands also collects data on this condition.

This is an important disease that is increasing in prevalence. Lack of data here may be addressed in the future if the study receives funding to continue.

**Table 12. Asthma**

	Is data collected?	Is data collection compulsory ?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria						
Belgium	✓	X	X	✓	?	
Denmark						
Finland						
France						
Germany						
Greece						
Italy	✓ via hospital admissions	✓	✓	✓	100% of hospital admissions	
Ireland	X	X	X	X	X	
Luxembourg						
Netherlands	✓	X	X	X	?	
Norway						
Portugal	✓	X	X	?	3% of population via GP sentinel network	
Spain						
Sweden						
UK	✓	X	✓	✓	2.6% of population via GPRD database	

Key: ✓ = yes  
X = no  
? = not known to the study  
blank = no data

## *Epilepsy*

The study received data about hospital admissions from Austria, Italy and Sweden. In Sweden, all units that offer epileptic surgery participate and therefore all patients who undergo preoperative epilepsy surgery investigations and/or operations will be registered. The registry has received grant funding since 1994. It is estimated that there are about 60 000 individuals with epilepsy in Sweden. More than 5 000 persons have more than 50 seizures a year despite medication and it is this group that are liable to be put forward for surgery. In Italy, there are no specific Public Health disease registers for epilepsy. However, *Episcreen* is a register that has been instituted by the Italian League against Epilepsy and sponsored by a pharmaceutical company. It is a multicentre longitudinal observational study and has been collecting data on epileptic patients. The patients included are however not representative of the real frequency of the disease. Specific epilepsy registers will be organised in the future in Lombardia in northern Italy, Tuscany in central Italy and Puglia in southern Italy. In Portugal, a prevalence study has been carried out by the GP sentinel network.

**Table 13. Epilepsy**

	Is data collected?	Is data collection compulsory?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria	✓	X	✓ via hosp admissions	✓ for hospital admissions	100% of hospital admissions	
Belgium						
Denmark						
Finland						
France						
Germany						
Greece						
Italy	✓	X	✓	X	?	
Ireland	X	X	X	X	X	
Luxembourg						
Netherlands	X	X	X	X	X	
Norway	X	X	X	X	X	
Portugal	✓	X	X	?	3% of population via GP sentinel network	
Spain						
Sweden	✓	✓	✓	✓	100% for preoperative epilepsy surgery	
UK						

Key: ✓ = yes  
X = no  
? = not known to the study  
blank = no data

## *Mental Health*

The Global Burden of Disease report, launched jointly by the World Bank and WHO, attributed a quarter of all morbidity to psychiatric illnesses. Major depression was ranked fifth as cause of disability. A two year action project to establish the indicators for mental health monitoring in Europe, co-ordinated by (Jyrki Korkeila) STAKES, The Finnish National Research and Development Monitoring Programme, started in the beginning of 1999 under the European Commission Health Monitoring Programme. Its main objectives are to collect information about existing relevant databases; propose a set of specified indicators for European mental health monitoring; establish unambiguous definitions for these indicators; give recommendations concerning data collection and assess the feasibility and usefulness of the indicators selected.

The study found that data collection seems to be limited to in-patients of psychiatric wards or hospitals. However, this group only accounts for a small percentage of the actual population living with some sort of mental health condition as hospital admission only usually occurs for more serious disorders, e.g. where the person's safety is in danger or the person is causing a threat to the safety of others. Also, many countries have experienced a shift from institutionalised care to outpatient, community-based care. However, Denmark and Portugal have national registers for internments in hospital due to mental health disorders, Belgium has a register which collects data from all mental healthcare centres on patients receiving treatment, the Netherlands also has three regional mental healthcare registers in Drenthe, Maastricht and Rotterdam. Two registries are currently being set up in Sweden, The National Quality Registry for Moods Disorders and The National Quality Registry for Eating Disorders. Both are still in the planning phase.

Mortality data also provide information about psychiatric disorders relating in suicide, alcohol-related diseases and drug-induced deaths.

**Table 14. Mental Health**

	Is data collected?	Is data collection compulsory?	Is data collection continuous ?	Can data be used for national estimates?	Proportion of Cases covered?	Future changes?
Austria	✓ for hospital discharges	✓	✓	✓	In 1996 = 4.3% of all hospital discharges	
Belgium	✓	✓	✓	✓	100%	
Denmark	✓	✓	✓	✓	100%	
Finland	✓	?	?	?	?	
France						
Germany						
Greece						
Italy						
Ireland						
Luxembourg						
Netherlands	✓	?	✓	X	?	✓
Norway						
Portugal	✓ for hospital internments	✓	✓	✓	100%	
Spain						
Sweden	Planning phases					✓
UK	✓	X	✓	✓	2.6% of population via GPRD database	

Key: ✓ = yes  
 X = no  
 ? = not known to the study  
 blank = no data

### *Research Projects*

Epidemiological and research projects also constitute an important source of data on diseases and conditions. In the Netherlands, the Department of Chronic Diseases and Epidemiology at the National Institute of Public Health has set up a research project in Zutphen, a rural town in the eastern part of the country. The study has registers for diabetes, coronary heart disease, hypertension, stroke and asthma. National estimates cannot be obtained from the Zutphen study as the sample is too small and all participants are men. Questionnaires, hospital discharge records and written information from GPs, are used as data sources. No special registries are used. The data are available in a computerised format but are not available on the Internet.

In the UK, a study was undertaken in 1998 to measure the prevalence of asthma symptoms in 27,500 schoolchildren in 93 schools across Britain.<sup>10</sup> There was little geographical variation in prevalence. Previous national studies also found little variation in the prevalence of asthma in 11 year olds and 5-17 year olds in Britain.<sup>11 12</sup>

### **3.6 Pregnancy Termination**

Pregnancy termination is illegal in Ireland except in circumstances where it is deemed necessary to save the mother's life. It is however legal in all of the other Member States. Notification on induced abortion is compulsory for all countries, but 100% reporting and data collection cannot be guaranteed in all Member States, for example in Portugal, only legal abortions which are carried out in hospitals are reported and this figure is not a true reflection of the real number; in France about 85% of all terminations are reported via form completion, some are not specified as a termination but as another surgical act. Changes planned for the next 2-3 years in France will see the phasing out of the notification by form. Hospital admissions data will be expanded to also include those terminations that are carried out under anaesthetic but do not require surgery. Hospital admissions data will be completed through a sample study to study the sociological determinants of pregnancy termination.

Although collection of data is compulsory in Belgium, it is not financed and reporting is thought to cover approximately 80% of cases. All other countries report ongoing 100% collection of routine data.

Data availability is heavily restricted due to the sensitivity of the subject matter. Tables of anonymous aggregate data are produced and access criteria varies from country to country. Hospital admissions data are also a valuable source of information on terminations carried out in hospital.

**Table 15. Pregnancy Terminations**

	Is data collected?	Is data collection compulsory?	Is data collection continuous?	Can data be used for national estimates?	Proportion of Terminations covered?	Future changes?
Austria	✓	?	?	?	?	
Belgium	✓	✓	✓	✓	80%	
Denmark	✓	✓	✓	✓	~100%	
Finland	✓	✓	✓	✓	100%	
France	✓	✓	✓	✓	85%	✓
Germany	✓	✓	✓	✓	?	
Greece	✓	?	?	?	?	
Italy	✓	✓	✓	✓	?	
Ireland	X	X	X	X	X	X
Luxembourg	?	?	?	?	?	
Netherlands	✓	?	✓	✓	100%	
Norway	✓	✓	✓	✓	~100%	
Portugal	✓	✓	✓	✓	100%	
Spain	✓	✓	✓	✓	100%	
Sweden	✓	✓	✓	✓	100%	
UK	✓	✓	✓	✓	100%	

Key: ✓ = yes  
 X = no  
 ? = not known to the study  
 blank = no data

### **3.7 Surveys**

General Health Surveys or Health Interview Surveys are carried out by most of the participating Member States. Their objective is to provide national data on health status and healthcare utilisation, evaluating health needs of population and the extent to which they are being met. Follow-up surveys are able to monitor changes over time.

Sample size is nationally representative and stratified, excluding institutionalised groups. The surveys usually consist of an interviewer-administered questionnaire and sometimes a health examination, e.g. Mini-Finland Health Survey 1977-1981. Results can be used to estimate prevalence of diseases. Comparability of data between the national health surveys is difficult to assess and depends on the health topics covered.

The National Hospitalisation Survey in Greece and the National Inpatients Survey in France also provide data on the healthcare utilisation of the hospitalised population. General Household Surveys also contain health components, e.g. Italy and UK. Other countries include health topics within their microcensus, e.g. Austria, Germany, Italy. The Survey of Living Conditions in Sweden contains a component covering long-term illnesses and their consequences, functional disorders, outpatient care, state of health and medical care, use of pharmaceutical products, dental condition and dental care. Austria and Spain have both undertaken a “Survey of Impairments, Disabilities and Handicaps”.

Surveys have additionally been carried out into the prevalence of specific conditions, e.g. diabetes prevalence in Belgium and Italy, and hypertension in Belgium.

This topic is the subject of another current health monitoring project: The Health Surveys in the European Union: HIS and HIS/HES Evaluations and Models, currently being undertaken by Statistics Netherlands and the University of Maastricht (co-ordinator: Jaap van den Berg). The project aims to improve comparability of data sets between Member States; improve indicator definitions, to be used in an EU indicator set; and improve availability of (comparable) data sets from Member States for use in the HIEMS system.

**Table 16. Surveys**

	General Health Survey	Health Interview Survey	Microcensus with health component	Additional surveys/studies with morbidity component
Austria	✓		✓	✓
Belgium		✓		✓
Denmark		✓		✓
Finland	✓			✓
France	✓			✓
Germany			✓	✓
Greece				✓
Italy	✓		✓	✓
Ireland	✓			✓
Luxembourg				?
Netherlands	✓			✓
Norway	✓			✓
Portugal				✓
Spain	✓			✓
Sweden				✓
UK	✓			✓

Key: ✓ = yes  
X = no  
? = not known to the study  
blank = no data

### **3.8 Publications**

The Annual Report of the Chief Medical Officer for England provides an example of a report which aims to provide an overview of the health status of the population. It includes information on mortality, morbidity and lifestyle factors.

Key health statistics are usually disseminated in publications available from the National Statistics Offices or Ministries of Health in the respective countries. They are generally published on an annual basis, but occasionally more frequently. Availability of these publications is sometimes restricted to local health authorities, research institutes or private sector purchasers; however many containing anonymous aggregate data are available to the general public through bookshops or on written request to the relevant department.

Registries, particularly in the case of cancer, often produce their own individual annual reports to summarise their activities and findings for the year. In France, the National Committee of Registers sets out the comprehensive situation and activities of all its registries in the Inserm Publication, Rapport d'activité 1996-1999 (Report of Activities).<sup>13</sup> The NOMESCO publication, Health Statistics in the Nordic Countries<sup>14</sup>, presents a range of general morbidity data for the Scandinavian countries. The use of IT is playing an ever-increasing role in disseminating statistical results and many organisations, for example the National Board of Health and Welfare in Sweden and Office for National Statistics in the United Kingdom have a range of publications and reports available at their websites. This trend towards greater availability of information on-line is likely to increase in the future. For example, market research carried out on behalf of the United Kingdom Office for National Statistics, suggests that 85% of customers approve of a proposal to replace "data-heavy" publications with web-only delivery of data.

### **3.9 Any other information**

#### *Personal Identification Number*

Many of the northern Member States, commonly in Scandinavia and also to a certain extent in other countries, for example Luxembourg, issue a personal identification number to each person at registration of birth. These identification numbers enable the linkage of data on the same person across different registers, and over periods of time. Information can therefore be cross-referenced and checked for accuracy against different disease registers, survey data, the Registry of Births and Deaths etc. In the United Kingdom, a unique patient identifier, the National Health Service (NHS) number is now being recorded on all hospital admissions. In the future, it may facilitate a linkage of health data relating to one individual. In Italy, a personal identification number issued for fiscal purposes has been requested on death certificates since 1997. The total number of certificates reporting this information is currently in the region of 70%. Where personal identifications do not exist, countries are often likely to hold regional rather than national registers.

#### *Death Registers*

“Cause of Death” info in death registers can play a role in estimating incidence of certain diseases, e.g. Sweden developed its Acute Myocardial Infarction Register in 1996 by record linkage between the Hospital Discharge Register and the Cause of Death Register. This is only the case for diseases associated with expected low recovery rates and high mortality, e.g. coronary heart disease, cancer.

#### **4. Discussion**

A starting point for achieving EU comparable morbidity data is to collate the existing data and methods of collection available in the different Member States. The overview of morbidity data sources recorded in the database identifies those areas where national and international systems have been implemented to ensure a standardised reporting and dissemination of data. It also highlights areas where information is lacking or incomplete. Although the database is not yet complete, it represents the first step towards achieving a definitive European Union-wide inventory of morbidity data. It will improve health indicator definitions by allowing other investigators to compare data sources available in the different Member States. This will allow them to determine which Member States an indicator can be produced for. Improved information on definitions of morbidity data in the Member States will be of benefit to the HIEMS system.

This project complements research currently being undertaken by other health monitoring projects, for example, the Euro-Med-Data - Clinical Information in Europe study, which aims to create an inventory of the medico-administrative data routinely collected in 18 countries at the levels of primary and secondary health care and occupational medicine; and the EUCOMP project which aims to set up a European system of standardised descriptions and comparisons of health care systems to form the basic foundation for routine data collection and comparative analysis of common EU healthcare statistics.

The study found that availability of data sources varies widely for the different conditions and providers. This is due to the different healthcare priorities within the Member States and the reasons for the data collection itself. Many countries have independent federal states and reporting even to a national level central organisation is more difficult to achieve. Data may be collected via different procedures and with different goals in mind, e.g. general practice registration. The collection of morbidity data is generally compulsory in some areas, for example, registration of births, cancer, communicable diseases and pregnancy termination.

European projects promote a standardised collection of data for other conditions, e.g. WHO-MONICA for coronary heart disease. The greatest variation in data exists for conditions and diseases where data collection is voluntary and may reflect a perceived lower priority in the nation's health needs, e.g. chronic illnesses not associated with high mortality and low recovery rates, such as asthma and epilepsy. Health budget restrictions in the different Member States may also play a role in the setting up of registries and financing of epidemiological studies. Current European projects, undertaken in conjunction with WHO, will set out standardised means of data collection for conditions where information held is currently somewhat sparse, e.g. musculo-skeletal disorders, mental health disorders.

Many data sources are difficult to compare due to the lack of a standardised definition for the provider, e.g. differences in the systems of primary care in the different countries. For example, the United Kingdom has a very clear divide between primary care and hospital care. General practitioners work in primary care, whereas specialists work almost entirely in hospitals. In other countries, this distinction is not so clear and many specialists work from community-based offices or clinics. The definition of primary care physicians also varies. In the UK, the primary care physicians (general practitioners) are generalists and see patients of all ages. In some countries, children's and women's problems are dealt with by paediatricians and gynaecologists respectively working in primary care. Standard questions on the questionnaire, particularly with regards to Hospital Admissions data and Hospital

Outpatients data, were therefore interpreted and answered in different ways in some instances. Many countries do not have defined systems for differentiating between these data sources; in some cases they overlap with primary care data. Also the different sizes of the Member States need to be taken into account when attempting to compare nationally representative figures. National figures may not always provide an accurate picture of significant differences between the regions within each member state. Even European projects, e.g. WHO-MONICA, have to be treated with a degree of caution, as figures are often regional rather than nationally representative.

However, there are also many similarities in sources of morbidity data and methods of data collection. Responsibility at national level is undertaken for dissemination of data by National Statistical Offices, Departments of Health, and National Public Health Institutes. There are recognised and standardised procedures for the registrations of births and deaths. Births registers often include sections on congenital anomalies. Hospital statistics include data on pregnancy terminations. All countries have implemented data collection procedures to monitor conditions associated with high mortality rates, for example, cancer, coronary heart disease. Health surveys are also widely used as a means of providing national data on health status and analysing the extent to which identified health needs are being met. Results can be used to highlight areas for further research, shape healthcare policies, or dictate further action. Use of ICD coding or other internationally recognised systems of classification in general practice and hospital records promotes comparability of these data between the different countries. In this way, data providers can be seen as moving towards a more standardised collation and exchange of information.

An increasing use of information technology and also the Internet in the dissemination of morbidity data promotes easier access to collection methods and results. Some countries are more advanced in this respect than others, e.g. the central institutes of health in Belgium, Germany, Sweden have all recognised the growing importance of the Internet as a means of documenting existing and future epidemiological research. Their websites feature electronic inventories of morbidity data. This wider availability of data may help to foster a more standardised approach to developing data sources and collection procedures, as Member States will find it easier to compare systems. The use of the personal identification number, widespread among Scandinavian countries and now also in use in the United Kingdom, Italy and Luxembourg, enables cross-referencing of data across different registers. The linkage of data on a particular individual enables a more accurate overview of health-related “episodes”.

## **5. Recommendations**

This project represents the first phase in the creation of an electronic inventory of EU-wide morbidity data sources. It is not complete and work should still be viewed as an ongoing process. The database was sent out for comments to interested parties working in the field of Public Health throughout Europe, including researchers involved in other health monitoring projects and those involved in complementary studies. Recipients were asked to provide feedback on the content and design of the morbidity information database. Comments made have been taken into account and suggestions are included here.

As this electronic inventory of morbidity data sources has been specifically created to serve as a reference tool and provide an overview of data availability, it should be made easily accessible to policy makers, public health officials and researchers. Use of the Internet should be made to reach as wide an audience as possible. With regard to the database itself, there is a pressing need to comprehensively and systematically update the information base regularly so that the implementation of the “future changes” mentioned in the current version are documented, amendments and enhancements are made, and new information is inputted. A process for seeking additions/revisions to the information base needs to be devised, and resources and an on-going commitment will be required. It may be possible to seek advice from organisations or projects already involved in such a procedure, for example, the OECD regularly updates its information bank of health data; the Inventory of the Means of Controlling Communicable Diseases in the European Union, Norway and Switzerland is also an electronic inventory in database format which requires updating.

One limitation of the study is inconsistencies in data entry. For example, in the case of information received regarding the proportion of cases with congenital anomalies reported in the individual Member States, most countries expressed this proportion as a percentage. However, Spain simply provided a figure of 4000 and Greece was unable to specify a percentage. The database has been limited to some extent by the varying types of information received from the different countries. One aim of a follow-up study should be to improve and standardise the information so that in time it will become more uniform. Attempts could also be made to obtain missing data; for example, certain areas could be highlighted for further research. When selecting those areas for consideration, highest priority should be given to those conditions not already covered by European Union and other international initiatives, such as EUROCAT, ICBDMS, the European Centre for the Epidemiological Monitoring of AIDS and OECD Health Data. Future collection of information might most usefully focus on the other important diseases that have been included, e.g. respiratory diseases, mental health disorders, musculo-skeletal disorders or neurological conditions.

With regard to collaboration in international initiatives, e.g. MONICA, EUROCAT, the study could obtain more comprehensive documentation on each Member State’s individual level of participation. More use could be made of existing international data sources, e.g. OECD health data includes congenital anomalies, communicable diseases, cancer. A reference section to set out what is available on an international level could be included in the database. The study also tended to focus on English-speaking articles and journals, which may have constituted a bias towards data availability in northern European countries.

The study tended to focus on registers as a source of morbidity data for diseases. Disease registers represent a valid and important source of data, which can be used to provide information on patterns and trends, and play an important role in research into the cause of

diseases. They aid the planning and monitoring of disease control strategies. However, the possibilities of obtaining further disease-specific morbidity data from hospital statistics and GP registration or studies could be explored in further depth.

Finally, it may also be possible to involve additional countries in the project; e.g. Iceland had to drop out of the initial study. The database has a function whereby new data providers and conditions can be added to the existing information. An application for funding to continue the study was submitted to DG Sanco by the Office for National Statistics in the UK. This application has now been provisionally approved, and the Office for National Statistics will therefore continue to work with experts in the Member States to expand and improve the electronic inventory.

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