



**EU Public Health Outcome Research and Indicators Collection
EUPHORIC Project
Grant Agreement n° 2003134**

*A project funded by the European Commission,
Directorate General for "Health and Consumers"*

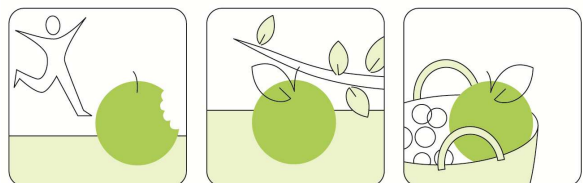
Deliverable N. 1

Survey: the first phase of the project

December 2008 E8 and E9 update

June 2008 Final editing and publication
on the website

April 2007 Submitted to EU Commission



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EUPHORIC Project

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Acknowledgements: The authors would like to thank Mascia Masciocchi for editing the report and Christina Heine and Caterina Genua for taking care of the linguistic revision.

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Introduction

At Community level, monitoring the health of the European population and the performance of the health care systems of Member States is a huge effort since it is difficult to acquire comparable information across countries.

The information needed “can effectively be summarized in the form of indicators”(…) that are “a concise definition of a concept meant to provide maximal information on an area of interest”(1).

Over the last few years the EU has focused its efforts on creating a European Health Monitoring System mostly based on the development of a common European list of indicators.

The ECHI (European Community Health Indicators) project has contributed to this enterprise by producing a list of indicators that should cover all aspects of public health.

Integrating the ECHI list with regard to the area of health care quality (positioned in the area of health care systems within the ECHI hierarchy), is one of the aims of the European Public Health Outcome Research and Indicators Collection project (EUPHORIC). Focusing on the field of outcome assessment, Euphoric proposes a list of 54 outcome indicators. However, the long-term aim of the EUPHORIC project is to elaborate protocols for data collection, harmonization and analysis of outcome indicators, by integrating the previous knowledge and experiences of the seven participating countries in the outcome research. Therefore a consortium of nine institutions has been established. Its vital role in the development of a joint effort is to provide a valuable source of information.

The project is structured in three phases: survey, pilot and dissemination of results.

This report illustrates the methods and the results of the survey phase and presents the nine participating institutions.

(1) Public Health Indicators For Europe: Context, selection, definition. Final Report By the ECHI Project, Phase II, June 20, 2005.

Background

In the last years, the Istituto Superiore di Sanità, (ISS, Italian National Institute of Health) has been involved in several projects concerning outcomes assessment.

In 2001, the Ministry of Health entrusted the ISS with the task of evaluating national health system quality, singling out and comparing the performances obtained by some pathology therapies. This first assessment will progressively be spread to other sectors with the aim of setting a bench mark for the various in-the-field centres working in the territory in order to detect the best ones.

A project was therefore launched, managed by the ISS in agreement with regional health authorities and professional associations, firstly on a voluntary basis and by self-certification. The project dealt with three fields that had shown to have a high impact on public health by focusing on a particular procedure for each field: Coronary Artery By-pass Graft (CABG) in cardiac surgery, hip replacement in orthopaedics, and transplantation. For each, pathology working groups were created in order to establish collection and evaluation methods that were discussed and shared by in-the-field professionals. Therefore, in early 2002 the ISS began two national prospective studies: the CABG Project (<http://bpac.iss.it>) and the EIPA Project (Esiti Interventi ArtroProtesi di Anca – Hip replacement outcomes) (<http://eipa.iss.it>).

The CABG project was coordinated by the National Centre for Epidemiology and was widespread at a national level involving all the Cardiac Surgery Units operating in Italy. The aims of the project were to describe observed and expected mortality rates 30 days after CABG intervention in each Cardiac Surgery Unit, being the last adjusted by the individual risk of patients, and to compare different risk-adjustment models. This study represented the first attempt to produce outcome indicators at the national level, to profile hospitals with respect to their performances, and to publicize a report card where providers can see their own results and compare them to the Italian average.

The EIPA Project was based on the voluntary participation of Orthopaedic Surgery Units with the aim to evaluate short term outcomes of hip arthroplasty (6 months after intervention). The endpoints were mortality, complications (for example, infections or subluxations), motor recovery, and patient satisfaction.

As for transplant activities, seven working groups were set up in November 2001, co-ordinated by the Italian National Transplant Centre. The groups focused on kidney, liver, heart, lung, pancreas transplantation, paediatric transplants, donor assessment and control systems. This work was aimed at promoting attention to quality in organ transplantation through the collection of outcome indicators. It directly involved in-the-field professionals and operating transplant centres in order to provide citizens with a transparency tool and encourage improvement in operating facilities (<http://www.ministerosalute.it/trapianti/trapianti.jsp>). The aims of the project were to compare the national result after one year from the transplant with international case histories, to describe the national activity, to evaluate national results, and to compare national results of the previous year. Results of activities were evaluated in terms of the survival rate (Kaplan-Meier estimator) of the organs and of the patients (adults and paediatrics) adjusted by the relative risk factor for each centre.

At the end of 2002, the Ministry of Health funded two other studies relevant to hip arthroplasty within the national research finalised program for the years 2002-2004, in which the ISS was involved as a partner. The first was coordinated by the Orthopaedic Institutes Rizzoli in Bologna and was aimed at implementing a hip register in five Italian regions and studying the feasibility to extend the data collection on a national basis. The second, coordinated by the Apulia region, was a multicentre study for outcome evaluation 12 months after intervention.

In 2004, the Italian Health Ministry funded a 3 year national project to redesign the organization of the National Informative Health System (NIHS): the “Mattoni” (Bricks) Project. In order to carry on specific activities within the NIHS, fifteen programs (Mattoni) have been identified. ISS has been given the responsibility of coordinating the OUTCOME MEASUREMENT program with the aim to identify and systematically apply valid, reliable and appropriate methodologies in order to define, measure and evaluate outcome indicators at national level. The program covers 2 main areas of interest: comparative outcome evaluation concerning health providers, representing the “supply” point of view; and comparative outcome evaluation concerning population, that is the “public health protection” point of view. In order to compare results from providers or populations by taking into account different case mixes, a “risk-adjusted” area of

activity has been also set up. The Outcome Measurement program has identified 45 indicators split in 7 areas of interest: cardiovascular diseases, cancer, infectious diseases, chronic diseases, orthopaedics, emergency diseases and miscellanea. Out of the 45, 32 were already calculated using the routinely collected data, while some others have started *ad hoc* clinical data collections.

As laid down by the National Health Plan 2003-2005, the final aim of these activities is to develop protocols to “ensure and monitor the quality of health care” in order to improve health status, lengthen life span and better the satisfaction degree of people and population, by evaluating quality through objective methods.

In this context and in order to share with Europe the acquired experience, in the Spring of 2003, ISS promoted among European partners the presentation of a proposal in the Public Health Program 2003-2008.

Project Partners

The coordinators wish to thank all the members of the EUPHORIC project group for their active participation throughout the project.

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Partners Presentation

The EUPHORIC Project, coordinated by the ISS (Italy), has involved seven European countries (Greece, Italy, Finland, Spain, Sweden, Austria, Bulgaria).

In this chapter the main beneficiary, the associated beneficiaries, the collaborating partner and the technological partner are presented.

Main Beneficiary

Istituto Superiore di Sanità (ISS, The Italian National Institute of Health)

The Italian National Institute of Health (www.iss.it) is the leading technical and scientific body of the Italian National Health System.

The Institute collaborates and consults with other institutions responsible for public health, including the Ministry of Health, regional health authorities, local health agencies and hospitals. It cooperates with those responsible for the design and implementation of health and scientific programmes at a local and a national level. It also plays a leading role in several major international research projects, ranging from cooperative research and development projects to humanitarian assistance.

Its activities include: research, clinical trials, control, documentation and training in public health. It also serves as a major national clearing-house for technical and scientific information on public health issues.

The Institute conducts scientific research in a wide variety of fields, from cutting-edge molecular and genetic research to population-based studies of risk factors for disease and disability. Research priorities are based on those set forth in the National Health Plan. It is also involved in several major clinical trials which are frequently conducted in cooperation with the National Institutes for Scientific Research and Care (IRCCS) network and hospitals.

The institute is organised in departments, national centres and technical–scientific services. One of the centres is the National Centre for Epidemiology, Surveillance and Health Promotion which is involved in developing and applying epidemiological and biostatistical methods to monitor and protect human health and to evaluate the quality of health services, and in monitoring the outcomes of hospital procedures. In fact, in order to compare and improve the quality of health services, the centre deals with outcome assessment studies. In the field of cardiovascular diseases for acute events, like the coronary artery by-pass graft, PTCA (angioplasty), myocardial infarction and stroke, the centre is involved in the study of risk adjustment models. Moreover, it conducts studies in the orthopaedic field, relating to the evaluation of hip arthroplasty outcomes and to the setting up of implant registers.

Data source for transplantation field derive from the Italian National Transplant Centre (CNT), a technical body within the ISS. It has a role of coordinating waiting list management; establishing shared standards and procedures for allocating organs, especially referring to emergency; establishing national requirements; defining protocols and guidelines for the activity of interregional and regional centres; and identifying the standards of testing quality and outcome of transplant facilities. It also fixes criteria for organ and tissue allocation and it defines technical parameters and criteria to be inserted in waiting lists.

Generally, the role of the centre is to monitor the situation of the transplant sector in Italy by keeping in contact with reference interregional and regional centres.

Associated Beneficiaries

1) University of Athens, School of Medicine, Department of Hygiene and Epidemiology

The Department of Hygiene and Epidemiology (DHE), School of Medicine, University of Athens is responsible for undergraduate and postgraduate programmes in Epidemiology and Methodology of Research, Biostatistics, Occupational and Preventive Medicine. Every year more than 400 medical students attend each of the courses and a lot of Doctoral Degrees are awarded.

The research activities of DHE are focused on the epidemiology and aetiology of cancer, coronary heart disease, infectious diseases and injuries, as related to lifestyle (e.g. dietary) and macro-environmental factors. The Department's involvement in nutrition research activities is extensive, as more than 200 scientific papers on the role of nutrition to health have been published. Studies have also been conducted pertaining to the identification of healthy dietary patterns and their influence on overall survival.

The Public Health Nutrition and Nutritional Epidemiology Unit (Unit) was created in the Department of Hygiene and Epidemiology a few years ago. Today, the Unit's scientific and technical personnel includes medical doctors, biologists, chemists, nutritionists, food technologists, health visitors, statisticians, computer experts and lab technicians, as well as research administrators. This department is successfully coordinating the EU supported DAFNE network of 24 European countries and is responsible for the maintenance and update of the DAFNE databank; is coordinating the Greek segment of the EPIC study and the EU funded EPIC-NAH project; is a core member of the EuroFIR NoE and is coordinating a series of national projects, particularly on the assessment and promotion of traditional foods.

Analytically, the Unit participates in the largest cohort investigation ever launched in Europe for the study of the associations between nutritional, biological factors and chronic diseases, the European Prospective Investigation into Cancer and nutrition study (EPIC). European countries participate under the coordination of the International Agency for Research on Cancer (IARC) of the World Health Organization. The Unit has recently successfully completed the EPIC-ELDERLY project, a nested-study to the EPIC project, which focused on studying the potential role of nutrition on the health and longevity of elderly people across Europe and started the coordination of a new project, which is considered a continuation of EPIC-elderly, the EPIC-Elderly Network on Ageing and Health (EPIC-Elderly NAH) project. The aim of EPIC-NAH project is to set up a health information and surveillance programme for reporting issues relevant to ageing and health, by establishing a central databank of standardised data including baseline information on socio-demographic, dietary, lifestyle, somatometric characteristics and self reported morbidity, as well as follow up data on any of the above mentioned parameters and cause specific mortality of elderly Europeans. The Unit also coordinates the effort for the development of a European database of comparable nutritional data, which was initiated in the context of the European Union, DAFNE (DATA Food NETWORKING) projects. DAFNE refers to a joint effort of European countries to compare the food habits of their populations and monitor overtime trends in food availability, through the creation of a non-static, regularly-updated food databank.

2) Genetics Research Institute ONLUS (GRI)

The Genetics Research Institute ONLUS (GRI) is a non-profit association located in Milan, Italy, constituted under Italian law in 1998. Its purpose is to perform scientific research and other efforts related to human genetics in connection with chronic diseases such as cancer. An important facet of GRI's mission is the study of the interaction between genetics and environmental factors as causative agents in disease. GRI sponsored several international educational events, such as educational workshops on "Health Effects of Non-Ionizing Radiation", and "Menopause and Osteoporosis", and the international course on molecular epidemiology.

The institute is involved in a variety of internationally and nationally funded projects. Some of the internationally funded projects relate to studies aimed at investigating the genotype susceptibility to the exposure to air pollution and to the low level of benzene in Europe. The nationally funded projects focus on the relationship between diet and cancer and on the role of hepatitis B and C viruses in the development of primary liver cancer.

Furthermore, the institute is a partner of three funded outcome studies: a study on cancer outcomes after solid organ transplant in Italy; a project on the health status of professional soccer players in Italy, in order to assess the incidence of cancer and amyotrophic lateral sclerosis (ALS); and APIKIDS, a pooled analysis of all the existing studies on outcomes in children born after assisted procedures.

3) Department of Epidemiology ASL RM E

The Department of Epidemiology Health Authority RM-E in Rome is a public health and research institution that has the responsibility for epidemiologic monitoring of the regional population (about five million inhabitants). The department has access to the regional information system for routine statistics (mortality and hospital discharges).

The department has worked for many years in the field of environmental exposure carrying out several epidemiologic studies on the effects of indoor and outdoor pollution on health. Occupational factors related to lung cancer have been studied with particular reference to silica exposure and urban air pollution. Several studies on respiratory disorders in childhood have been conducted, also in relation to residency in proximity of air pollution point sources.

The institution is currently participating, as coordinator or partner, in several European collaborative studies.

Since 2002, the department has run a heat/health watch warning system in the city of Rome, and has developed a framework of preventive strategies. In spring 2004, the department was nominated national reference centre for the implementation of heat/health watch warning systems in Italian cities by the National Civil Protection Agency.

The department has strong expertise in outcome research. It is currently collaborating with the Ministry of Health and the National Institute of Health in defining and applying appropriate and reliable methodologies to measure and evaluate health care outcomes. In particular, its current participation in the project “Mattoni – Misura dell’Outcome” of the Ministry of Health is aimed at:

- defining and implementing models, tools and indicators for measurement and evaluation of health care outcomes, to be used by policy makers and health care professionals, in the areas of cardiovascular, respiratory and gastrointestinal diseases, and caesarean section;
- developing risk adjustment models;
- producing methodologies for data record linkage.

Also, the Cochrane Group on Drugs and Alcohol operates within the Department of Epidemiology. It is one of the two Italian collaborative review groups of the Cochrane collaboration, an international non-profit and independent organization, dedicated to making up-to-date, accurate information about the effects of health care readily available worldwide. The collaborative review groups are composed of mostly health care professionals who prepare systematic reviews of health care interventions, with editorial teams overseeing the preparation and maintenance of the reviews, as well as the application of rigorous quality standards.

4) Centre for Health Economics at Stakes

STAKES is an independent, non-political institution financed by the Ministry of Social Affairs and Health. STAKES is a public professional centre and its clients are public and private decision-makers, professionals, specialists, administrators, service producers, research communities, researchers, students, media and citizens in Finland and abroad. STAKES has three highly integrated tasks: research, development and an information bank (social, welfare and health care statistics). This structure creates synergy between statisticians and experts in the field of social welfare and health care research. STAKES is not an administrative organization. It has no control or supervisory roles. The previous strict norms have given place to steering with information .

STAKES is organizationally divided into seven divisions led by the director general, and an international development collaboration unit at STAKES. The Centre for Health Economics (CHESS) was established at STAKES in September 2002. It belongs to the health service research division. CHESS undertakes highquality health economics research into healthpolicy-relevant issues. It also aims to promote co-ordination of Finnish health economics research and to increase the impact of research and interaction between researchers. CHESS is part of an international health economics network.

The most important research projects going on at CHESS are concerned with the evaluation of the productivity, outcomes and cost-effectiveness of health care and care for the elderly. Methods that are being developed are used for making comparisons between service providers, regions and population groups, and in related information systems. They are utilised in national and international benchmarking of social and health services. Studies conducted at CHESS seek to investigate why there are great differences between different countries, regions, service providers and population groups in the costs, outcomes, and availability of services.

5) The Institut Municipal d'Investigació Mèdica Foundation, Lipids & Cardiovascular Epidemiology Research Unit

The IMIM Foundation (www.imim.es) is a private non-profit entity created in 1992. The foundation's objectives focus on post-doctoral research and teaching activities in the field of biomedicine and health and life sciences and the promotion of such activities within the Institut Municipal d'Assistència Sanitària (IMAS).

The following are some of the functions of the IMIM Foundation: to manage and follow-through research projects and funding endeavours it supports, to promote high quality research, to ensure the ethical aspects of its research as well as the application of deontological principles, to disseminate research results, and to promote specialized teaching activities and the continuing education of professionals in the field of health sciences.

The IMIM Foundation is progressively becoming the entity in charge of managing the administration of research resources of IMAS, specially those related to the management of European projects, those related to extramural services, and those related to the funding of research projects and research networks that result from the cooperation with the Instituto de Salud Carlos III.

The IMIM Foundation is one of the main promoters of the Parc de Recerca Biomèdica de Barcelona (PRBB), and in conjunction with the Foundation for Research of the Universitat Pompeu Fabra and the Center for Genomic Regulation, actually constitutes the PRBB.

The Board (Patronat) is the highest governing body of the foundation and it includes representatives from the Institut Municipal d'Assistència Sanitària (IMAS), from the Department of Universities and Research, from the Generalitat de Catalunya, from the Universitat Pompeu Fabra (UPF), from the Universitat Autònoma de Barcelona (UAB), and staff from the Institut Municipal d'Investigació Mèdica (IMIM).

6) Department of Medical Epidemiology and Biostatistics, Karolinska Institutet

Karolinska Institutet is one of Europe's largest medical universities. It is also Sweden's largest centre for medical training and research, accounting for 30% of the medical training and 40 % of the medical academic research that is conducted nationwide. Ten of the research fields at Karolinska Institutet currently have the status of WHO collaborating centres. Research constitutes a major part of Karolinska Institutet's activities and covers all medicine, from public health and caring science to research into human genomics using advanced technological methods. More than 2,000 researchers are active at Karolinska Institutet, together with nearly 1,000 people who work in laboratories or with other support services. Several hundred researchers from all over the world come each year to work as guest researchers at Karolinska Institutet.

The Department of Medical Epidemiology and Biostatistics was formally established at Karolinska Institutet in March 1997 as the Department of Medical Epidemiology (MEP). A biostatistical group was recruited around 2000, and the name of the department was changed in 2002 to the Department of Medical Epidemiology and Biostatistics (MEB). The department currently has 160 employees, including 11 full professors and 12 associated professors who have multidisciplinary backgrounds from medicine, behavioural science to biostatistics. The department is one of the largest units for epidemiologic research in Europe with broad research programmes, including chronic disease epidemiology, infectious disease epidemiology, genetic epidemiology, and molecular epidemiology, etc. The department has extensive experience in using the Swedish registers in various research projects, including outcome research.

7) EFORT-EAR Innsbruck Medical University

The European Arthroplasty Register is a voluntary network of national arthroplasty registers in Europe. It is a major scientific activity of the European Federation of National Associations of Orthopaedics and Traumatology (EFORT, www.efort.org), and organised as a non-profit society (EFORT-EAR) located in Linz, Austria. The project was officially launched by EFORT in June 2002.

The central organization for the daily business and scientific activities is the EARoffice, located at the Orthopaedic Department of the Medical University, Innsbruck, Austria.

It is headed by the EARCoordinator, Dr. Gerold Labek, and includes a central staff of 7 persons.

The mission of EAR is to support the development of other national arthroplasty registers, to update data collection and evaluation, to standardize evaluation and reporting by aiming to increase the

comparability of national reports on supranational level, and to increase the scientific activities and quality control in arthroplasty based on register datasets.

EAR supports projects that develop updated technological solutions for data collection and evaluation and is active in developing central services for registers for common use to allow more economic procedures on national level and supranational common evaluations.

By 28 February 2006 EAR was centrally involved in the development of 9 national arthroplasty registers.

All national arthroplasty registers in continental Europe are member of EAR.

There are 13 national registers in 10 countries that collect data regularly.

The national orthopaedic societies of 8 countries have consented to start national arthroplasty registers in cooperation with EAR and based on the EAR guidelines. Some of them are at an advanced stage of organization and close to starting data collection.

EAR is in negotiation to set up a register or support national activities in a further 7 countries. EAR is in contact with the national joint registry in Great Britain concerning future cooperation. EAR is involved in activities regarding quality control in orthopaedic surgery.

EAR has established a user friendly website at the EFORTportal that includes all the worldwide homepages of arthroplasty registers, has developed a web-based communication structure and supports publication activities of arthroplasty registers worldwide.

EAR is member of the steering group of an international network of arthroplasty registers, the International Register Society, and provides the web-based communication infrastructure for the entire project.

Collaborating Partner

The National Center of Public Health Protection (Bulgaria) participates in this project as subcontractor, i.e. without receiving funding but with the same responsibility for sharing knowledge and data.

National Center of Public Health Protection

The National Center of Public Health Protection (NCPHP) was established on 1 January 2005 by uniting the former National Centre of Hygiene, Medical Ecology and Nutrition and the former National Center of Public Health. NCPHP plays an active role in the development and implementation of prevention, improvement of work and leisure conditions, mitigation of environmental pollution, health, safety of foods and commodities related to human health.

NCPHP is a health institution with research, expert consultative, methodological and training activities in the fields of public health protection, health risk assessment of hazardous impacts to the environment, risk factors related to behaviour and life style, health promotion, and integrated disease prevention. The major departments at NCPHP are: environmental protection, nutrition, occupational health, child and adolescent hygiene and health promotion.

NCPHP has the necessary facilities to perform the proposed analyses. NCPHP is accredited (ISO EN 17025) for testing chemical agents and preparations, biocides, pesticides, medications, foodstuffs, environmental compartments, cosmetic and toiletry products and is accredited for training PhD students. NCPHP is a collaborative centre of the World Health Organization.

The main area of interest and the present work in the departments “Environment - Health” and “Occupational Health” in the National Center of Public Health Protection, Bulgaria consist of organization and performance of epidemiological studies for risk assessment about the influence of different substances in the surrounding environment on human health. Risk management and risk reduction programs are implemented into practice aiming at improving the quality of life of the people.

Technological Partner

Consorzio Interuniversitario per le Applicazioni di Supercalcolo Per Università e Ricerca (CASPUR, Inter-University Consortium for the Application of Super-Computing for Universities and Research).

Established in Rome on June 5th 1992, the Consortium is a non-profit organization, financed by MIUR (Ministero dell'Istruzione, dell'Università e Ricerca – the Ministry for Education, Universities and Research) and by associated Universities.

Its purposes are:

- to manage a center capable of guarantee a high quality and high-powered processing service;
- to become a center of excellence available to the national university and research network and to MIUR, with the aim of spreading the culture of information and communication technology, along with promoting their applications;
- to promote the use of the most advanced information processing systems, to support public and private scientific and technological research;
- carrying out projects for other bodies, where their activity is necessary and useful to the Consortium's goals.
- developing research programs aiming at a more effective and innovative usage of information and communication technology, in collaboration with other organizations and enterprises.

The Consortium can enter into an agreement with Universities, CNR, ENEA, INFN, Scientific Academies, and with other public or private organizations and institutes, Foundations, Societies, national and international authorities working in areas related to the Consortium's activities.

At present the Consortium collaborates with the National Institute of Nuclear Physics (Istituto Nazionale di Fisica Nucleare - INFN), the Italian National Agency for New Technologies, Energy and the Environment (Ente per le Nuove Tecnologie, l'Energia e l'Ambiente - ENEA), the National Institute for Geophysics and Volcanology (Istituto Nazionale di Geofisica e Vulcanologia - INGV), and other university departments and institutions.

Source: <http://www.caspur.it/en/theconsortium/aboutus/>

Survey: the first phase of the project

Aims

The first phase of the project was aimed to define the tools and the operational conditions necessary to be used in the implementation of the the pilot, the second phase of the project.

Therefore aims of the first phase were:

- the definition of a list of outcome indicators;
- the collection of information from the participating countries about their internal organisation in terms of health care system as well as of the health data sources available for the selected outcome indicators;
- the design of a web site and the selection of the technological partner.

Methods

Developing a list of the outcome indicators

The definition of the indicators list was performed following several steps.

The starting point was the experience consolidated within the “Outcome measurement” research of the Italian Mattoni project, the project launched in 2003 by the Italian Ministry of Health in order to redesign the National Health System. (<http://www.ministerosalute.it/nsis/pgServizi.jsp?area=mattoni&language=italiano>). Aim of this research line was “to identify and experiment suitable methodologies to define, measure and evaluate outcomes”.

Therefore the methodological approach adopted in the Italian Outcome Mattoni Project was shared with all of the partners. It was decided to update and integrate the first results obtained in Italy taking into account the different contexts of the participating countries.

Through a deep analysis of international websites and documents concerning experimented collections of indicators, a set of nine areas of pathology were selected (cardiovascular disease and surgery; cancer; infectious disease; other chronic disease; orthopaedics; transplantation; emergency; neonatal/maternal; miscellanea). Inside each area, the outcome indicators adopted in European and Extra-European countries were identified. Besides, an analysis of the literature relevant to the selected areas was performed by all of the partners in order to amend and/or integrated the first indicators list (see Appendix 1).

Gathering information from participating countries: the questionnaire

To collect information from the participating countries a questionnaire consisting of 4 parts was drawn up.

The first part was aimed at gathering information from each participant country about the political-demographical situation and the health care systems organization. It was also aimed at assessing the current situation regarding the possibility of implementing the selected outcome indicators.

The second part requested each partner to provide detailed information about the source of data existing in their respective country for a list of diseases/procedures within the selected nine areas of interest. For each disease/procedure the followings were specified:

- Covered area, (national, regional, other);
- Electronic form (yes/no);
- Type of source of data;
- Linkage with other archives (e.g. Hospital Discharge, Mortality Records);
- Notes.

The participant were also requested to give a brief description of the method employed in filling in their respective questionnaire (see questionnaire description at the beginning of each Part 2)

The third part was aimed to estimate the future trend regarding the possibility of building up additional source of data in each country (databases or registers or others within two years after the beginning from the study).

The fourth part of the questionnaire aimed at assessing the current situation regarding the possibility of implementing the selected outcome indicators in each country by using “risk adjustment methods”. Therefore the indicator profile was specified as follow:

- source of data;
- outcome indicators number;
- crude /adjusted;
- adjusted by (age, gender comorbidities, others counfounding factors);
- age range;
- disaggregated by (gender, hospital, geographical area, national, other).

It should be pointed out that all the information gathered could not be exhaustive of the all existing sources of data at a local and at a national level.

The design of a web site and the selection of the technological partner

The aim of the website is to give full account of the project work and to facilitate the dissemination of results and the communication among the participants in the project. Furthermore the web will host a website application to browse the outcome indicators of the list.

The Inter-University Consortium for the Application of Super-Computing for Universities and Research (CASPUR) was selected by the main beneficiary as technological partner to build up the EUPHORIC web site and assist in the data management.

Results

As results of the survey the list of 54 outcome indicators and the questionnaires (Part 1, Part 2, Part 3, Part 4) filled in by each participant are presented in the following pages.

The EUPHORIC web site is accessible at: www.euphoric-project.eu

List of Indicators

Category	N.	Indicator	P (*)	T (*)	Numerator	Denominator
A. CARDIOVASCULAR DISEASE AND SURGERY	A 1	Emergency readmission to hospital following treatment for a stroke	*	*	The number of emergency admissions within 0-27 days (inclusive), previous discharge from hospital following treatment for a stroke (excluding psychiatric and obstetric readmission episodes).	The number of discharges following treatment for a stroke, excluding those where discharge is coded as death.
	A 2	Death within 30 days of admission to hospital with a stroke	*	*	The number of emergency admissions for patients with a primary diagnosis of stroke (ICD 10 codes I61-I64) on admission, where the patient dies in hospital and after discharge between 0-29 days (inclusive) of admission.	The number of emergency admissions for patients of all ages with a primary diagnosis on admission of stroke (ICD 10 codes I61-I64).
	A 3	In-hospital deaths following Coronary Artery Bypass Graft (CABG) operation	*	*	The number of ordinary admissions with CABG where the patient dies in hospital (before the discharge).	The number of ordinary hospital admissions with CABG.
	A 4	Death within 30 days of Coronary Artery Bypass Graft (CABG) operation	*	*	The number of ordinary admissions with CABG where the patient dies in hospital or after discharge, between 0-29 days (inclusive) after the first eligible procedure.	The number of ordinary hospital admissions where CABG was performed.
	A 5	In-hospital deaths following Percutaneous Transluminal Coronary Angioplasty (PTCA) operation	*	*	The number of ordinary admissions with PTCA where the patient dies in hospital (before the discharge).	The number of ordinary hospital admissions with PTCA.
	A 6	Death within 30 days of Percutaneous Transluminal Coronary Angioplasty (PTCA) operation	*	*	The number of ordinary admissions with PTCA where the patient dies between 0-29 days (inclusive) of the procedure, included deaths in hospital and after discharge.	The number of ordinary hospital admissions with PTCA.
	A 7	Death within 6 months of Percutaneous Transluminal Coronary Angioplasty (PTCA) operation	*	*	The number of ordinary admissions with PTCA where the patient dies between 0-6 months (inclusive) of the procedure, included deaths in hospital and after discharge.	The number of ordinary hospital admissions with PTCA.
	A 8	Death within 12 months of Percutaneous Transluminal Coronary Angioplasty (PTCA) operation	*	*	The number of ordinary admissions with PTCA where the patient dies between 0-12 months (inclusive) of the procedure, included deaths in hospital and after discharge.	The number of ordinary hospital admissions with PTCA.
	A 9	In-hospital deaths following admission to hospital with Acute Myocardial Infarction (AMI)			The number of emergency admissions for patients aged over 18 with a primary diagnosis of AMI on admission, where the patient dies in hospital (before the discharge).	The number of emergency admissions for patients aged over 18, with a primary diagnosis of AMI.
	A 10	Death within 30 days of admission to hospital with an Acute Myocardial Infarction (AMI)	*	*	The number of emergency admissions for patients aged over 18 with a primary diagnosis of AMI on admission, where the patient dies in hospital and after discharge between 0-29 days (inclusive) of admission.	The number of emergency admissions for patients aged over 18 with a primary diagnosis of AMI.
	A 11	Death within 30 days of admission to hospital with Congestive Heart Failure (CHF)	*	*	The number of emergency admissions for patients aged over 18 with a primary diagnosis of CHF on admission, where the patient dies in hospital and after discharge between 0-29 days (inclusive) of admission.	The number of emergency admissions for patients aged over 18 with a primary diagnosis of CHF.
	A 12	Hospital admission for Congestive Heart Failure (CHF)	*		The number of ordinary admission episodes for patients aged over 18 with a primary diagnosis of CHF.	Resident population aged over 18.
	A 13	In-hospital deaths and neurological complications following carotid stenting procedures			The number of ordinary admissions with carotid stenting where the patient dies or has neurological complication in hospital (before the discharge).	The number of ordinary hospital admissions with carotid stenting.
	A 14	Deaths and neurological complications within 30 days from carotid stenting procedures			The number of ordinary admissions with carotid stenting where the patient dies or has neurological complications in hospital and after discharge between 0-29 days (inclusive) of admission.	The number of ordinary hospital admissions with carotid stenting.

(*) P = Population; T = Trust

Category	N.	Indicator	P (*)	T (*)	Numerator	Denominator
B. CANCER	B 1	Breast cancer relative survival	*		The observed five year survival rate of patients diagnosed with breast cancer.	The expected survival rate among a population with the same age structure.
	B 2	Lung cancer relative survival	*		The observed five year survival rate of patients diagnosed with lung cancer.	The expected survival rate among a population with the same age structure.
	B 3	Colon cancer relative survival	*		The observed five year survival rate of patients diagnosed with colon cancer.	The expected survival rate among a population with the same age structure.
C. INFECTIOUS DISEASES	C 1	Emergency admissions to hospital of children with lower respiratory infections	*		The number of emergency admissions of children aged under 16 with lower respiratory tract infections. (Primary diagnosis – ICD 10 codes: J10.0, J11.0, J11.1,J12.-,J13,J14,J15.-,J16.-,J18.0,J18.1,J18.9,J21.-).	Resident population aged under 16.
	C 2	AIDS survival	*		The observed 1/2/5 year survival rate of patients diagnosed with AIDS.	The expected survival rate among a population with the same age structure.
	C 3	Death within 30 days of admission to hospital with pneumonia	*	*	The number of admissions for patients with a primary diagnosis of pneumonia where the patient dies in hospital and after discharge between 0-29 days (inclusive) of admission.	The number of admissions for patients of all ages with a primary diagnosis of pneumonia.
	C 4	Hospital admissions for paediatric gastroenteritis	*		The number of ordinary admission episodes for children aged under 18 diagnosed with paediatric gastroenteritis.	Resident population aged under 18.
	C 5	Hospital admissions for influenza	*		The number of ordinary admission episodes for patients diagnosed with influenza.	Resident population.
	C 6	Hospital admissions for tuberculosis	*		The number of ordinary admission episodes for patients diagnosed with tuberculosis.	Resident population.
D. OTHER CHRONIC DISEASES	D 1	Hospital admissions for uncontrolled diabetes	*		The number of ordinary admission episodes for patients aged over 18 diagnosed with uncontrolled diabetes.	Resident population aged over 18.
	D 2	Hospital admissions for short term complications of diabetes	*		The number of ordinary admission episodes for patients aged over 18 diagnosed with short term complications of diabetes.	Resident population aged over 18.
	D 3	Hospital admissions for long term complications of diabetes	*		The number of ordinary admission episodes for patients aged over 18 diagnosed with long term complications of diabetes.	Resident population aged over 18.
	D 4	Hospital admissions for lower extremity amputations in patients with diabetes	*		The number of ordinary admission episodes for lower extremity amputations in patients aged over 18 with diabetes.	Resident population aged over 18.
	D 5	Hospital admissions for adult asthma	*		Discharged patients aged over 18 and under 65 with ICD-9-CM principal diagnosis codes for asthma. Patients with any diagnosis code of cystic fibrosis and anomalies of the respiratory system, transferring from another institution, or Major Diagnostic Category (MDC) 14 (pregnancy, childbirth, and puerperium) are excluded.	Population aged over 18 and under 65 in a selected area or country.
	D 6	Hospital admissions for paediatric asthma	*		Discharged patients aged under 18 years with ICD-9-CM principal diagnosis codes for asthma. Patients with any diagnosis code of cystic fibrosis and anomalies of the respiratory system, transferring from another institution, or Major Diagnostic Category (MDC) 14 (pregnancy, childbirth, and puerperium) are excluded.	Population aged under 18 in a selected area or country.
	D 7	Hospital admissions for senile asthma	*		Discharged patients aged 65 years and older with principal diagnosis codes for asthma. Patients with any diagnosis code of cystic fibrosis and anomalies of the respiratory system, transferring from another institution, or Major Diagnostic Category (MDC) 14 (pregnancy, childbirth, and puerperium) are excluded.	Population aged 65 years and older in selected area or country.

(*) P = Population; T = Trust

Category	N.	Indicator	P (*)	T (*)	Numerator	Denominator
E. ORTHOPAEDICS	E 1	Emergency readmission to hospital following treatment for a fractured hip	*	*	The number of emergency admissions within 0-27 days (inclusive), previous discharge from hospital (excluding psychiatric and obstetric readmission episodes).	The number of discharges excluding those coded under mental health and obstetric specialities and those where discharge is coded as death.
	E 2	Death within 30 days of admission to hospital with a fractured hip	*	*	The number of emergency admissions for patients aged 65 years and over with a primary diagnosis on admission of fractured proximal femur (ICD 10 codes S72.0, S72.1 and S72.2) where the patient dies in hospital and after discharge between 0-29 days (inclusive) of admission.	The number of emergency admissions for patients aged 65 years and over with a primary diagnosis on admission of fractured proximal femur (ICD 10 codes S72.0, S72.1 and S72.2).
	E 3	In-hospital death following admission with a fractured hip			The number of emergency admissions for patients aged 65 years and over with a primary diagnosis on admission of fractured proximal femur (ICD 10 codes S72.0, S72.1 and S72.2) where the patient dies in hospital (before the discharge).	The number of emergency admissions for patients aged 65 years and over with a primary diagnosis on admission of fractured proximal femur (ICD 10 codes S72.0, S72.1 and S72.2).
	E 4	Returning home following hospital treatment for fractured hip		*	The number of emergency admissions for patients aged 65 years and over with a primary diagnosis on admission of fractured proximal femur (ICD 10 codes S72.0, S72.1 and S72.2 – see denominator data) where the patient is discharged to the pre-admission category of accommodation between 0 and 27 days (inclusive) of admission.	The number of emergency admissions for patients aged 65 years and over with a primary diagnosis on admission of fractured proximal femur (ICD 10 codes S72.0, S72.1 and S72.2). The denominator excludes admissions where the first episode has an admission source coded other than 19, 29, 30, 37, 38, 48, 50, 54, 65, 66, 69, 84, 85, 86, 88, 89.
	E 5	In-hospital waiting time for femur fracture surgery		*	The number of patients aged 65 and over admitted to the hospital with a diagnosis of upper femur fracture with surgery initiated within 48 hours.	The number of patients aged 65 and over admitted to the hospital with a diagnosis of upper femur fracture.
	E 6	Total hip replacement in-hospital mortality rate		*	The number of in-hospital deaths with a code of total hip replacement in any procedure field (ICD-9-CM procedure code: 81.51 total hip replacement).	All discharges with a procedure code of total hip replacement in any field (ICD-9-CM procedure code: 81.51 total hip replacement).
	E 7	Partial hip replacement in-hospital mortality rate		*	The number of in-hospital deaths with a code of partial hip replacement in any procedure field (ICD-9-CM procedure code: 81.52 partial hip replacement).	All discharges with a procedure code of partial hip replacement in any field (ICD-9-CM procedure code: 81.52 partial hip replacement).
	E 8	Revision rate			Number of revisions (= exchange or removal of at least a part of the implant) at follow-up period X.	Total number of primary implantations included in the evaluation sample.
	E 9	Revision burden rate			Number of revisions (= exchange or removal of at least a part of the implant) in a period.	Number of all operations (primary and revision).
F. TRANSPLANTATIONS	F 1	Medulla ossium graft relative survival	*	*	The five year survival rate of patients after the medulla ossium graft transplantation procedure.	The expected survival rate among a population with the same age structure.
	F 2	Liver transplantation relative survival	*	*	The five year survival rate of patients after the liver transplantation procedure.	The expected survival rate among a population with the same age structure.
	F 3	Heart transplantation relative survival	*	*	The five year survival rate of patients after the heart transplantation procedure.	The expected survival rate among a population with the same age structure.
	F 4	Lung transplantation relative survival	*	*	The five year survival rate of patients after the lung transplantation procedure.	The expected survival rate among a population with the same age structure.
	F 5	Kidney transplantation relative survival	*	*	The five year survival rate of patients after the kidney transplantation procedure.	The expected survival rate among a population with the same age structure.

(*) P = Population; T = Trust

Category	N.	Indicator	P (*)	T (*)	Numerator	Denominator
G. EMERGENCY	G 1	Emergency admission to hospital	*		The number of emergency admissions to hospital.	Population resident in a selected area or country.
	G 2	Emergency readmissions to hospital within 28 days	*	*	The number of emergency admissions within 0-27 days (inclusive), previous discharge from hospital. The readmission where the patient dies is included, but patients with any mention of a cancer diagnosis or chemotherapy for cancer, or Major Diagnostic Category (MDC) 14 (pregnancy, childbirth, and puerperium), or mental health specialties are excluded. Day cases are also excluded.	The number of discharges from every hospital. The following cases are excluded from the calculation of the denominator: - patients discharged as deceased;- day cases;- patients discharged with mention of mental health;- patients discharged with any mention of cancer or cancer related pathologies or treatment;- patients discharged with Major Diagnostic Category (MDC) 14 (pregnancy, childbirth, and puerperium).
	G 3	Emergency hospital admissions for alcohol related pathologies		*	The number of emergency admission episodes for patients with principal and secondary diagnosis for alcohol related pathologies (ICD9-CM 291;303;305.0;357.5;425.5;535.3).	Resident population.
H. NEONATAL/MATERNAL	H 1	Maternal mortality rate	*		The number of deaths of women while pregnant or within 42 days of termination of pregnancy.	Number of live births in year of analysis.
	H 2	Neonatal / Infant mortality rate	*		The number of children dying under 28 days / one year of age.	The number of live births.
	H 3	Perinatal mortality rate	*		The number of perinatal deaths. The perinatal period starts as the beginning of foetal viability (28 weeks gestation or 1,000g) and ends at the end of the 7 th day after delivery. Perinatal deaths are the sum of stillbirths plus early neonatal deaths.	The number of live or death births.
	H 4	Perinatal intensive care mortality rate		*	The number of perinatal deaths admitted in intensive care unit. The perinatal period starts as the beginning of foetal viability (28 weeks gestation or 1,000g) and ends at the end of the 7 th day after delivery. Perinatal deaths are the sum of stillbirths plus early neonatal deaths.	The number of live or death births.
	H 5	Percentage of births carried out by caesarean section	*	*	The number of births carried out by caesarean section.	The number of births.
I. MISCELLANEA	I 1	Death within 30 days of surgery (elective and non-elective admissions)	*	*	The number of discharges with elective/non-elective admission records where the patient dies between 0 - 29 days (inclusive) of the first procedure while hospitalized.	The number of discharges records with elective/non-elective admissions, where an eligible operative procedure was performed. Day cases are excluded.
	I 2	Hospital admissions for alcohol related pathologies		*	The number of ordinary admission episodes for patients with principal and secondary diagnosis for alcohol related pathologies (ICD9-CM 291; 303;305.0;357.5;425.5;535.3).	Resident population.

(*) P= Population; T=Trust

Questionnaires

ITALY

PART I

Political and demographical description

Italy is a parliamentary republic, administratively divided into 19 regions and 2 autonomous provinces.

The territory is 301,401 sq. km, and the population at the end of 2003 was 57.9 million, with an increasing proportion of elderly people. Subjects aged 65 years and older constituted about 18% of the population in 2003 (Council of Europe, 2003), and is expected to grow to 28% in 2030.

Currently, Italy has one of the lowest birth rates in Europe. The rate of natural increase in the population has dropped from 1.8 per 1,000 in 1980 to -0.45 per 1,000 in 2001, and then further to 0.7 per 1,000 in 2003. In contrast, the rate of net migration into the country has risen 30 times from 1980 to 2001. (World Health Organization Regional Office for Europe, 2004)

In 2000, the GINI index (a high index indicates the degree of income inequality in a country) was 36 for Italy, compared with 30.8 for Eur-A overall. From 1990 to 2000, almost 13% of Italy's population lived below the 50% median income level at some point, compared to about 9% for the Eur-A group (UNDP, 2004).

Overall unemployment in Italy was 8.7% in 2003 against 6.5% for the Eur-A (UNSD, 2004).

The National Health System

The NHS was set up in 1978 based on three fundamental principles: universality of assistance, equality of access and solidarity. Since 1978 there have been fundamental changes, some concerning the organizational structure of the NHS, and others the way patient services are provided.

One of the most important features of the new organizational structure is that regions are responsible for health services planning and organization in a situation of absolute autonomy within the framework of the three principles mentioned above.

NHS, funded nationally through general taxation, is organized in different public bodies which cooperate to provide healthcare for all citizens. These bodies work at a national, at a regional and a local level.

The bodies operating at national level are:

- the Ministry of Health (Ministero della Salute);
- the National Institute of Health (Istituto Superiore di Sanità, ISS);
- the National Institute of Occupational Safety and Prevention (Istituto Superiore per la Prevenzione e la Sicurezza del Lavoro, ISPESL);
- the Experimental Animal Prophylaxis Institutes (Istituti Zooprofilattici Sperimentali I.ZZ.SS.);
- the Regional Health Services Agency (Agenzia per Servizi Sanitari Regionali, ASSR).

The Ministry of Health, the central body of the NHS, is made up of four Departments and supported by the National Health Council (Consiglio Superiore di Sanità, CCS). It plays a prominent role in protecting human health, veterinary health, occupational health and food safety and health.

It is responsible for:

- ensuring access for all citizens to adequate health care;
- collaborating with regions in order to evaluate and guide improvements in care;
- taking action to correct health inequalities;
- developing plans to face serious health risks.

The National Institute of Health is the technical and scientific body of the National Health Service.

The National Institute of Occupational Safety and Prevention reports to the Ministry of Health regarding all aspects of occupational safety, health, and prevention.

The Agency for Regional Health Care Services offers strategies and support to help Italian regions and autonomous provinces in order to organize and manage the local health services in their area and makes sure they are performing well and using correctly the resources allocated.

The Experimental Animal Prophylaxis Institutes as NHS technical and operating bodies, have the important role of controlling animal health, quality of animal food, breeding, and making sure that the relation between human settlements, animals and environment is balanced.

The regional organization

The region governments have the important role of fulfilling the objectives of the National Health plan at a regional level. They are responsible for planning and organizing health care facilities and activities through the regional health departments. Moreover, they coordinate and control the local health units (see below) and public and private accredited hospital activity.

The local organization

Local health authorities (unità sanitarie locali, usl) are distributed throughout the country. Each local health unit, as an autonomous body of the NHS, organizes and plans the health care systems for specific areas so as to provide services in the community closer to where people live.

The 197 local health authorities ensure national health priorities (Livelli Essenziali di Assistenza, LEA) operating throughout 934 districts.

Public hospital trusts (aziende ospedaliere) which are large hospitals (often including more than one hospital), become “trusts” because of their peculiar characteristics, a status which gives them much more freedom in running their services. One hundred and two hospital trusts throughout the country are designed to provide wide-ranging services, assuring an effective use of available resources. These services include treatments where patients are admitted to hospital, day surgery which does not require an overnight hospital stay for the patient, as well as out-patient services where patients attend consultations and clinics.

The National Institutes for Scientific Research and Care

(Istituti di Ricovero e Cura a Carattere Scientifico IRCCS) have 32 structures (fifteen public and seventeen private) distributed all over the country. As autonomous national bodies, they conduct scientific research in biomedical fields as well as in the field of health services organization and management. They also provide treatments where patients are admitted to hospital as well as out patient services where patients attend consultations and clinics.

Private accredited providers, provide hospital care (inpatient- outpatient) diagnosis services. The conditions for obtaining accreditation are set at regional level.

Source:

Donatini A., Rico A, D'Ambrosio M. G., Lo Scalzo A, Orzella L., Cicchetti A., Profili S. *Health Care Systems in Transition 2001*. A. Rico, T.Cetan (Eds) *European Observatory on Health Care Systems*.

www.ministerosalute.it

<http://www.ispesl.it>

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www.iss.it

Health Data Collection

In Italy the most systematized data collection on health care at national level is represented by the hospital discharge abstract (“Scheda di Dimissione Ospedaliera” - SDO). Information on hospitalizations contained in SDOs is transmitted by all public and private hospitals to their own region and, from the region to the Ministry of Health every six months. Hospitals currently use ICD-9-CM (International Classification of Diseases-Clinical Modification, 9th Revision), Italian version 2002, to code diagnoses and procedures.

Since 1995 all hospital discharge forms have been compiled using a Hospital Information System (HIS). The data entered into the system include information such as demographics (tax code, gender, date and place of birth, place of residence, etc), admission and discharge dates, admission referral source, discharge status, principal diagnosis and up to five secondary diagnoses, up to six hospital procedures, ward(s), date(s) of in-hospital transfer, and a regional code corresponding to the admitting facility. Regions can gather, through the SDO, more information than those required from the Ministry of Health.

Since 1995 the SDO-DRG (Diagnosis Related Groups) system has been used to allocate funds to hospitals and to monitor quality of care and outcomes. The current DRGs in use is the 19th version. Information from SDOs is available on the website <http://www.ministerosalute.it>.

Data relative to the notification of infectious diseases and to the management and economic activities of the local health authorities are reported to the Ministry of Health from the LHAs and regions through specific information flows regulated by law. These data, also including the activities performed by facilities and practitioners that provide outpatient care in each LHA, are reported to the Ministry of Health on specific forms. They concern:

- pharmaceutical care covered by the National Health System;
- primary care provided by general practitioners and paediatricians;
- specialty ambulatory care;
- residential and semi-residential health care;
- rehabilitation health care;
- home care.

Since the specific forms do not contain information on the outpatient characteristics - i.e., on the form relative to ambulatory care, LHAs have to report only the number of procedures or visits supplied by speciality type - Italian regions have built their own information systems and data collection is very different among them.

For example, in the Lazio region, data from outpatient care are gathered by the Outpatient Care Information System (SIAS), the Emergency Information System (SIES), integrating the HIS which gathers detailed information from Emergency Departments of the region, and the Rehabilitation Assistance Information System (SIAR) which monitors rehabilitation activities provided to patients by accredited rehabilitation facilities.

In Italy drug expenditure control and monitoring adverse reactions of medicinal products is carried out by the Italian Medicines Agency (AIFA) through a national network of pharmacovigilance which connects pharmacovigilance contact persons in local health authorities, hospitals, research institutes, regional authorities and pharmaceutical companies.

Mortality data are registered in the Regional Registers of Deaths that include information on the deceased's personal characteristics as well as details of the death itself (causes of death are mostly codified using ICD-9 codes). Registers of Deaths are not present in all Italian regions. In these cases, information about residents' deaths is supplied by the Civil Status office of the municipality or by the local health authority.

In Italy several patient (disease-specific) registers exist but only some of them cover the whole Italian territory. Some of the most important Italian registers are: the national register of AIDS, the national register of rare diseases, the national register of twins, the national register of growth hormone users, the national and regional register of blood and plasma, the Italian Registry of Dialysis and Transplantation, the Italian Association of Cancer Registers, the Italian register of cystic fibrosis.

Finally, the National Statistical Institute (ISTAT) represents a fundamental source of information on citizens' health, particularly on the health status of the population, lifestyles, health risk factors, life expectancy, resources of the national health service (economic and instrumental) and their use by citizens. It also supplies data on mortality by gender, age group, place of residence and main causes.

PART 2

Questionnaire description

The questionnaire has been filled in on the basis of the available information for the ISS; therefore, it cannot be considered an exhaustive inventory of all the existing sources of data at local and national level.

In Italy, discharge records (SDO, Scheda di Dimissione Ospedaliera) are one of the main sources of information concerning health data (ref. bibl. DM 28th December, 1991, DM 26th July, 1993). They are collected to calculate the proper reimbursement to be paid by the National Health System (NHS) for each hospital (DRG, Diagnosis Related Groups DM 14 December 1994).

Every hospital fills in and sends to its own region a SDO record for each patient undergoing an admission; then, the Ministry of Health checks and puts together the data sets from each region into a national one.

The ICD9-CM has been adopted to code diagnoses and procedures for the SDO database. Decree legislation n. 380 of the Ministry of Health, made on the 27th of October, 2000 defines the SDO as “a synthetic and accurate representation of a medical record”. The condition which required the widest effort of workload and expenditure for the hospital, as identified at the discharge, is defined as the main diagnosis. Similarly, the main procedure is defined as the treatment closer related to the main diagnosis and which has implied the greatest allocation of healthcare resources.

The Ministry of Health keeps, handles, and utilises the SDO data set, but some public institutions can have this database at their own disposal only in particular cases and for specific purposes. During the Mattoni Project, led by the ISS and aimed at calculating a series of outcome indicators at a national level, the Ministry of Health provided the ISS with the SDO databases of the years 2001, 2002 and 2003 in order to achieve the aims of this study.

Moreover, clinical databases, fed with an active collection of data, are available for some pathologies and procedures listed in the questionnaire (i.e. surveillance systems on infectious diseases and research projects) as a multicentre study on coronary artery bypass graft surgery available at a national level.

The registers cited in the questionnaire concern: the area of cardiovascular diseases and surgery, with a regional population register for stroke in Friuli Venezia Giulia; cancer area, with regional and provincial registers which cover a geographical area that considers 20% of the Italian population; and orthopaedics area, with regional registers for hip replacement in three regions (Lombardia, Emilia Romagna, Puglia), whereas for knee replacement only in one region (Emilia Romagna).

Data source for the transplantations area is the Italian National Transplant Centre (CNT <http://www.trapianti.ministerosalute.it/>). Its data set includes the following organs: heart, liver, kidney, pancreas and lung.

Both the SDO and clinical records referred to in the questionnaire are available in electronic form.

It is important to note that the linkage between the SDO and other data sets, such as regional mortality registers (RENCAM, REgistro Nominativo delle CAuse di Morte) could be implemented, but at present it has been accomplished only in some regions.

ITALY

A. CARDIOVASCULAR DISEASES AND SURGERY

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
CABG procedures	X			X		2001	2003	Discharge records	Possible but not yet implemented	Indicator: A3
CABG procedures	X			X		2002	2004	Clinical records (active collection)	No	Indicator: A3 A4
PTCA procedures	X			X		2001	2003	Discharge records	Possible but not yet implemented	Indicator: A5
ACS – AMI	X			X		2001	2003	Discharge records	Possible but not yet implemented	Indicator: A9
ACS – AMI and Unstable angina										
ACS – Unstable angina										
STROKE	X			X		2001	2003	Discharge records	Possible but not yet implemented	Indicator: A1
STROKE		X		X		1995	2004	Population registry	Yes	Indicator: A1 A2 Only for Friuli Venezia giulia region
CAROTID ENDO-ARTERECTOMY procedures										
CAROTID STENTING procedures	X			X		2001	2003	Discharge records	Possible but not yet implemented	Indicator: A13

Legend: Nat, National; Reg, Regional; Other, please specify in the “Notes” column if covering Areas, Hospital(s), etc.

ITALY

B. CANCER

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
BREAST CANCER		X		X		1985	1985	Hospital discharge data	Survival registry	INDICATOR: B1 Data on incidence are collected in 19 representative areas of the country, covering 14 regions
CERVICAL CANCER		X		X		1985	1985	Hospital discharge data	Survival registry	Data on incidence are collected in 19 representative areas of the country, covering 14 regions
COLORECTAL CANCER		X		X		1985	1985	Hospital discharge data	Survival registry	INDICATOR: B3 Data on incidence are collected in 19 representative areas of the country, covering 14 regions
HAEMATOLOGICAL MALIGNANCIES		X		X		1985	1985	Hospital discharge data	Survival registry	Data on incidence are collected in 19 representative areas of the country, covering 14 regions
LUNG CANCER		X		X		1985	1985	Hospital discharge data	Survival registry	INDICATOR: B2 Data on incidence are collected in 19 representative areas of the country, covering 14 regions
MESOTHELIOMA		X		X		1993	Present	Population based, through Regional Operative Centers	No	National registry of mesothelioma
MESOTHELIOMA	X			X		1993	Present	Population based, through Regional Operative Centers	No	6 regions have local registries
OTHER TYPES OF CANCER (specify)										
ALL CANCER		X		X		1985	1985	Hospital discharge data	Survival registry	Data on incidence are collected in 19 representative areas of the country, covering 14 regions
CHILDHOOD HAEMATOLOGICAL MALIGNANCIES										
CHILDHOOD CANCERS		X				1990	Present	Hospital discharge data	Survival registry	Data on incidence are collected in 3 representative areas of the country

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

ITALY

C. INFECTIOUS DISEASES

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIV/AIDS								Registry	NO	AIDS national registry (RAIDS)
PNEUMONIA	X			X		2001	2003	Discharge records	Possible but not yet implemented	INDICATOR: C3
VACCINATION(*)								Surveillance system	NO	SPES Registry
INFLUENCE			X	X		1999	2000	Clinical records (Active Collection)	NO	INDICATOR: C5
INFLUENCE						2001	2003	Discharge records		
MENINGITIS (BACTERIAL)	X			X		1993	2004	Clinical records (Active Collection)	Possible but not yet implemented	FONTE: MINISTERO+ISS (SIMI)
MENINGITIS (BACTERIAL)	X			X		2001	2003	Discharge records		
HEPATITIS (*) (VIRAL)	X			X		1993	2004	Clinical records (Active Collection)	Possible but not yet implemented	FONTE: MINISTERO+ISS (SIMI)
HEPATITIS (*) (VIRAL)	X			X		2001	2003	Discharge records		
HEPATITIS (*) (ACUT)	X			X		1986	PRESENT	Clinical records (Active Collection)	NO	SEIEVA Project
MEASLES	X			X		1993	2004	Clinical records (Active Collection)	Possible but not yet implemented	
MEASLES	X			X		2001	2003	Discharge records		
RUBELLA	X			X		1993	2004	Clinical records (Active Collection)	Possible but not yet implemented	
RUBELLA	X			X		2001	2003	Discharge records		

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc

ITALY

D. OTHER CHRONIC DISEASES

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
DIABETES	X			X		2001	2003	Discharge records	Possible but not yet implemented	INDICATOR: D1 D2 D3 D4
RENAL DISEASE										
HYPERTENSION										
COPD										
ASTHMA	X			X		2001	2003	Discharge records	Possible but not yet implemented	INDICATOR: D5 D6 D7
MULTIPLE SCLEROSIS										
CROHN'S DISEASE										
CHRONIC RENAL FAILURE										

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

ITALY

E. ORTHOPAEDICS

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIP REPLACEMENT	X			X		2001	2003	Discharge records	Possible but not yet implemented	INDICATOR: E6 E7
HIP REPLACEMENT		X		X		2000	2005	CLINICAL RECORDS (Active Collection)	YES (MORTALITY REGISTRY)	INDICATOR: E6 E7
KNEE REPLACEMENT	X			X		2001	2003	Discharge records	Possible but not yet implemented	
KNEE REPLACEMENT		X		X		2000	2005	CLINICAL RECORDS (Active Collection)	YES (MORTALITY REGISTRY)	
ACCIDENTS-INJURIES										
FRACTURE OF PROXIMAL FEMUR	X			X		2001	2003	Discharge records	Possible but not yet implemented (Regional mortality registry if available)	INDICATOR: E1 E2 only where regional mortality registries are available E3 E4 E5
TRAUMA CARE										

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

ITALY

F. TRANSPLANTATIONS

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
LIVER	X			X		1995	2006	Active collection SIT (Sistema Informativo Trapianti)	Possible but not yet implemented	
KIDNEY								Active collection SIT (Sistema Informativo Trapianti)	Possible but not yet implemented	
HEART								Active collection SIT (Sistema Informativo Trapianti)	Possible but not yet implemented	
LUNG								Active collection SIT (Sistema Informativo Trapianti)	Possible but not yet implemented	
MEDULLA								Active collection SIT (Sistema Informativo Trapianti)	Possible but not yet implemented	

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

ITALY

G. EMERGENCY

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Emergency admission	X			X		2001	2003	Discharge records	Possible but not yet implemented	INDICATOR: G1 G2
Emergency admission for alcohol related pathologies						2001	2003	Discharge records	Possible but not yet implemented	INDICATOR: G3

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc

ITALY

H. NEONATAL/MATERNAL

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Vaginal births	X			X		2001	2003	Discharge records	Possible but not yet implemented	INDICATOR: H1
Caesarian births	X			X		2001	2003	Discharge records	Possible but not yet implemented	INDICATOR: H1, H5
Perinatal intensive care	X			X		2001	2003	Discharge records	Possible but not yet implemented	INDICATOR: H4

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

ITALY

I. MISCELLANEA

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Alcohol related pathologies										
Surgical procedures	X			X		2001	2003	Discharge records	Possible but not yet implemented	INDICATOR: II only where regional mortality registries are available

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

ITALY

PART 3.

Are there in Your Country activities related to Disease Registers or databases that could become effective in the next two years?

Yes !X! No !_!

If Yes:

Activity	Covered Area			Electronic forms		Starting in year	Source of data	Notes
	Nat	Reg	Other	Yes	Not			
Italian CABG Project 2	X			X		2006	Clinical Records (Active Collection)	MULTICENTRIC STUDY INDICATOR: A3 A4
IN-ACS OUTCOME	X			X		2005	Clinical Records (Active Collection)	MULTICENTRIC STUDY INDICATOR: A 11 A10 Death, re-AMI, heart failure at 30 days, 6 or 12 months
OSCAR FOR QUALITY "Outcome Survey on Coronary Angioplasty"	X			X		2005	Clinical Records (Active Collection)	MULTICENTRIC STUDY INDICATOR: A5 A6 A7 A8 MACE (death, myocardial infarction and new revascularizations) at 3, 6, 12 Months
RISC2 "Carotid Stenting procedures Registry"	X			X		2006	Clinical Records (Active Collection)	MULTICENTRIC STUDY INDICATOR: A13 A14
Fracture of Proximal femur Registry		X		X		2006	Clinical Records (Active Collection)	Regonal collection (Marche Region), planned in Regional Health Program data

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

ITALY

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

CABG, ACS-AMI, Coronary Angioplasty, Carotid Stenting procedures, Fracture of Proximal femur

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other
CLINICAL RECORDS (DB Italian CABG Project 1-2)	A3 A4		X	Confounding factors (age, gender, comorbidities, type of intervention,...)	15-99	X	X	X	X	
CLINICAL RECORDS (DB IN-ACS OUTCOME)	A 11 A10 MACE (Death, re-AMI, heart failure) at 30 days, 6 or 12 months		X	Confounding factors (age, gender, comorbidities, ...)	All	X	X	X	X	
CLINICAL RECORDS (DB OSCAR FOR QUALITY “Outcome Survey on Coronary Angioplasty”)	A5 A6 A7 A8 MACE (death, myocardial infarction and new revascularizations) at 3, 6, 12 Months		X	Confounding factors (age, gender, comorbidities, ...)	All	X	X	X	X	STEMI/NO-STEMI
CLINICAL RECORDS (DB RISC_2 “Carotid Stenting procedures Registry”)	A13 A14		X	Confounding factors (age, gender, comorbidities, type of plaque...)	All	X	X	X	X	medical speciality (surgeon, radiologist, ...)
CLINICAL RECORDS (DB of Fracture of Proximal femur Registry)	E5		X	Confounding factors (age, gender, ...)	All	X	X			

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify

GREECE

PART I

Political and Demographical Description

Greece is a parliamentary democracy with the Prime Minister elected through national elections and the President elected by the Parliament. Characterized by a mixed economy and a large public sector, Greece is slowly restructuring parts of its economy through privatization.

With almost 11,000,000 inhabitants (2001 national census), the country has received substantial immigration from neighbouring countries during the last decades that places additional burden on the health care system. The territory of the country is mountainous and with an abundance of islands which poses difficulties in accessing health care facilities for the whole of the population. The unemployment rate is around 10% and the total health expenditure (as percentage of the gross domestic product) is almost 9%. More than 15% of the population is over 65 years old; the demographic ageing is bound to challenge traditional systems in responding to the future long-term care needs of elderly people. Conventional life expectancy is around 75 for men and 80 for women, ranking Greece high on the list of countries with the highest life expectancy in Europe. Although infant and maternal mortality rates have dropped substantially during the last decades (perinatal mortality is one of the lowest in Europe, around 8/ 1,000 live births), there are still health problems related mainly to mortality from ischemic heart disease, cerebrovascular disease, and road accidents.

National Health System

Currently, the number of hospital beds is 477/100,000 inhabitants whereas the number of hospital doctors is 223/100,000 inhabitants (the number of total doctors is 434/100,000 inhabitants) and nursing care personnel is 400/100,000 inhabitants. Dentists are around 114/100,000 and pharmacists around 69/100,000 inhabitants. In 2001, 336 hospitals and health units were in operation: 145 of them were public and 191 were private. Hospital beds are at 500/100,000 inhabitants and hospital services are delivered mainly through public hospitals. During the two last decades, rural health centres have been established which permitted the decentralization of delivered health services and universal coverage of the rural population. Private sector hospitals are mainly in the capital of Greece, Athens. They are characterised by a modern infrastructure and high technology equipment, but they have higher costs compared to public hospitals.

The health care system in Greece is financed by a mix of taxed-based and insurance-based financing, sharing elements from both the Bismarck model (health care is funded by social insurance) and the Beveridge model (health care is funded by the state budget). The Ministry of Health exercises central control by regulating, among others, social insurance funds, the payment of hospitals, the number of the personnel employed in the hospitals and rural centres.

The national health insurance system is public, though optionally, a private form of insurance can be chosen. The founding stone of the Greek welfare system is the creation of IKA (Social Security Institution, 1934) which is a vast organization comprising hundreds of administrative centres and health units. All IKA members have access to a sufficient standard of health care as well as a pension upon their retirement. Subsequently, the implementation of OGA (Agricultural Insurance Organization) followed in 1961 which covers all the country's rural population. In order to reverse the degeneration of the old health care system as well as to restrain the expansion of private practices, the ESY (National Health System) was created during the eighties, comprising all public hospitals and rural health centres. Following restructure, ESY was divided into autonomous and independent regional branches called DYPE (Peripheral Health Systems) and professional hospital management was introduced for the better administration of the system. Each DYPE is a public entity, with a director appointed by the Minister of Health and Social Solidarity, which has the responsibility of the coordination of regional primary, secondary and tertiary health activities within the area. Out of a total of about 300 different social insurance organizations, about 40 provide coverage against the risk of illness to nearly all the Greek population. Membership of the insurance funds is compulsory for the employed population and its dependants and is based on occupation. All the above-mentioned insurance funds are administered as public entities and operate under extensive control by the central Government. Approximately 10% of the Greek population take out some voluntary health insurance by private insurance companies.

Concerning payment modality, medical personnel working in public hospitals, in rural centres, and in IKA polyclinics is paid on a salary basis. Private doctors, comprising also the ones that are contracted by the social insurance funds, are paid on a fee-for-service basis. Since 1992, 25% of the drugs have been paid by the patient. For certain diseases, the percentage is as low as 10% and persons with major chronic conditions are fully exempted.

Finally, concerning social care state-run social services, there are mother and child care centres and centres for disabled persons in operation. Many communities offer social services through centres for the elderly (KAPIs). These centres provide, among others, drug prescriptions and doctor and nurse visits.

References:

Health care systems in transition. Greece. World Health Organization. Regional Office for Europe. Copenhagen. 1996

Health for all database. WHO Regional Office for Europe. The European Health Report. 2002

Health Data Collection

The main source of information at a national or regional level concerning health indicators is the National Statistical Service of Greece (www.statistics.gr). On this site, there are data concerning the country's demographics (births, marriages, deaths, demographic projections) as well as morbidity (from the analysis of hospital discharge records) and mortality (from the analysis of mortality records).

Data derive from hospitals and each record represents one in-hospital episode.

The coding system used by the National Statistical Service of Greece is the ICD-9 system. The ICD-10 system for the coding of diseases will be implemented during the next few years.

Another national record keeping organization is the Hellenic Centre for Infectious Diseases Control (www.keel.org.gr) with available data even for diseases such as avian influenza and SARS.

Population-based registers, created through linkage of various sources of information, such as mortality data, hospital discharge and physician records, do not exist at a national level.

Nowadays, there is an effort to construct a more detailed national database for several diseases, especially cancer.

Patient registers, hospital discharge records and mortality records are confidential. Major hospitals have departments that, for research purposes, often keep detailed records regarding their patients; from these hospital or regional databases, analyses can be done concerning morbidity and mortality data.

PART 2

Questionnaire description

There are no population-based registers and databases of a national or regional level implemented by a national authority in Greece. In order to examine possible indicators, the inventory has been filled in mostly on the basis of available information from the National Statistical Service of Greece (www.statistics.gr). This service publishes morbidity and mortality data for all over Greece, as well as for different age groups, regions and gender. Morbidity data derive from a representative hospital sample and each record represents one in-hospital episode. The coding system used by the National Statistical Service of Greece is the ICD-9 system. The ICD-10 system for the coding of diseases will be implemented during the next few years.

Data source for the transplantations area is the Hellenic National Transplant Organization (www.eom.gr). Its data set comprises information for the following organs: heart, liver, kidney, pancreas, lung, bone marrow and corneal.

The Hellenic Centre for Infectious Disease Control publishes periodically statistics regarding infectious diseases (www.keelpno.gr). The statistics available for the last few years are for all infectious diseases, such as influenza, avian influenza, tuberculosis, HIV/AIDS, etc.

For cardiovascular diseases and procedures, apart from the available data published by the National Statistical Service of the country, there are some additional data found on the site www.onasseio.gr. On this site, the Onassis Cardiac Surgery Centre, a non-profit institution specializing in cardiovascular surgery, as well as in diagnostic and interventional cardiology, publishes statistical data about in-hospital cardiovascular mortality, as well as the absolute number of cases per year in various cardiovascular procedures, also per total number of patients.

Major hospitals have departments that, for research purposes, often keep detailed records regarding their patients; from these hospital or regional databases, analyses can be done concerning morbidity and mortality data, which are usually found in pubmed (www.ncbi.nlm.nih.gov/entrez/query.fcgi). In some diseases, only pubmed articles were retrieved, because there were no other data available. Thus, the limitation of the absence of national registers makes the Greek inventory not an exhaustive inventory of all existing sources of data at local and national level. As an example, the Arcadia Stroke Registry is a local registry where information can only be found in papers published in widely accepted peer-reviewed journals in the pubmed.

GREECE

A. CARDIOVASCULAR DISEASES AND SURGERY

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
CABG procedures										
PTCA procedures			X	X		2003	2003	Onassio Cardiosurgery Center (one of the biggest hospitals in Greece specialized in heart-surgery procedures) CLINICAL RECORDS	Possible but not yet implemented	Hospital INDICATOR: Number of cases per year and per total number of patients
ACS – AMI	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that because the ICD-9 is still implemented, it would be difficult to define cases of acute coronary syndromes
ACS – AMI and Unstable angina		X		X		2003	2004	“Hippokrateion hospital”- Cardiology Unit- University of Athens CLINICAL RECORDS	Possible but not yet implemented	INDICATORS: A3, A5, A9
ACS – Unstable angina	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that because the ICD-9 is still implemented, it would be difficult to define cases of acute coronary syndromes
STROKE	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
STROKE		X		X		1993	1995	POPULATION REGISTRY (The Arcadia Stroke Registry)	Possible but not yet implemented	INDICATORS: incidence of stroke, 28-day case fatality rate A1, A2 could also possibly be calculated after re-analysis of the data. Data are available only for the Arcadia region.
CAROTID ENDO-ARTERECTOMY procedures										
CAROTID STENTING procedures										

Legend: Nat, National; Reg, Regional; Other, please specify in the “Notes” column if covering Areas, Hospital(s), etc.

GREECE

B. CANCER (1/2)

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
BREAST CANCER	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
CERVICAL CANCER	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
COLORECTAL CANCER	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
HAEMATOLOGICAL MALIGNANCIES	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
LUNG CANCER	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
MESOTHELIOMA						1980	2002	National Statistical Service of Greece MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of deaths per year.

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

GREECE

B. CANCER (2/2)

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
ALL CANCER	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
CHILDHOOD HAEMATOLOGICAL MALIGNANCIES	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
CHILDHOOD HAEMATOLOGICAL MALIGNANCIES	X			X		Mid-80s	Present	Department of Epidemiology of Athens Medical School DISCHARGE RECORDS, CLINICAL RECORDS, MORTALITY RECORDS	Possible but not yet implemented	Here are some references of the articles of the Childhood Haematologists-Oncologists Group in Greece: Petridou E, Trichopoulos D, Kalapothaki V, et al. The risk profile of childhood leukaemia in Greece: a nationwide case-control study. Br J Cancer. 1997; 76(9): 1241-7. Petridou E, Skalkidou A, Dessypris N, Moustaki M, Mantzoros C, Spanos E, Trichopoulos D. Endogenous risk factors for childhood leukemia in relation to the IGF system (Greece). The Childhood Haematologists-Oncologists Group. Cancer Causes Control. 2000 Sep;11(8):765-71.
CHILDHOOD CANCERS	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

NOTE for Cancers: Oncologists in Greece have formed two groups, 1. the Hellenic Cooperative Oncology Group (HeCOG) and 2. the Hellenic Oncology Research Group (HORG). These groups have in their disposal big databases/registers of patients with different types of cancer.

Though these data are strictly confidential and they are not representative of Greece, they could provide data concerning the B1, B2, B3 categories mentioned (that is, data concerning breast cancer, lung cancer and colon cancer survival).

GREECE

C. INFECTIOUS DISEASES (1/3)

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIV/AIDS	X			X		1984	2003	National Statistical Service of Greece MORTALITY RECORDS, DISCHARGE RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented
HIV/AIDS	X			X		1984	2004	Hellenic Centre for Infectious Diseases Control (HCIDC) CLINICAL RECORDS	Possible but not yet implemented	INDICATORS: newly reported HIV infections per total cases, total and percentage of each transmission category, percentage of each gender among cases, newly diagnosed AIDS cases per total cases, cumulative number of AIDS cases, percentage of deaths among HIV/AIDS cases.
PNEUMONIA	X			X		1957	2003	National Statistical Service of Greece MORTALITY RECORDS DISCHARGE RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
VACCINATION										Not available. Some data for vaccination in Greece could be found in pub med articles, as: Frantzidou F, Diza E, Halkia D, Antoniadis A. A seroprevalence study of poliovirus antibody in the population of northern Greece. Clin Microbiol Infect. 2005 Jan;11(1):68-71. Van Damme P. Hepatitis B: vaccination programmes in Europe--an update. Vaccine. 2001 Mar 21;19(17-19):2375-9.
INFLUENCE	X			X		1998	2003	Hellenic Centre for Infectious Diseases Control (HCIDC) CLINICAL RECORDS	Possible but not yet implemented	Number of cases per year

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

GREECE

C. INFECTIOUS DISEASES (2/3)

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
INFLUENCE	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: C5, that is almost equal to the number of hospital discharges per year--- and number of deaths per year. Note that the ICD-9 is still implemented.
MENINGITIS	X			X		1998	2003	Hellenic Centre for Infectious Diseases Control (HCIDC) CLINICAL RECORDS	Possible but not yet implemented	INDICATORS: Number of cases per year for viral meningitis, bacterial meningitis, meningitis from unknown cause.
MENINGITIS	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
HEPATITIS	X			X		1998	2003	Hellenic Centre for Infectious Diseases Control (HCIDC) CLINICAL RECORDS	Possible but not yet implemented	INDICATORS: Number of cases per year for Hepatitis A, B, C and other types of hepatitis.
HEPATITIS	X					1957	2003	National Statistical Service of Greece	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
MEASLES	X			X		1998	2003	Hellenic Centre for Infectious Diseases Control (HCIDC) CLINICAL RECORDS	Possible but not yet implemented	INDICATORS: Number of cases per year for measles
MEASLES	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
RUBELLA	X			X		1998	2003	Hellenic Centre for Infectious Diseases Control (HCIDC) CLINICAL RECORDS	Possible but not yet implemented	INDICATORS: Number of cases per year for rubella.

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

GREECE

C. INFECTIOUS DISEASES (3/3)

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
RUBELLA	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year (hospital discharge rate and mortality rate). Note that the ICD-9 is still implemented.
TUBERCULOSIS	X			X		1998	2003	Hellenic Centre for Infectious Diseases Control (HCIDC) CLINICAL RECORDS	Possible but not yet implemented	INDICATORS: Number of cases per year for tuberculosis.
TUBERCULOSIS	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: C6, which is almost equal to the number of hospital discharges per year-----and number of deaths per year. Note that the ICD-9 is still implemented.

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

GREECE

D. OTHER CHRONIC DISEASES

	Covered Area			Electronic forms		Data years		Source of data*	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
DIABETES	X			X		1957	2003	DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
RENAL DISEASE	X			X		1957	2003	DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
HYPERTENSION	X			X		1957	2003	DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
BPCOD	X			X		1957	2003	DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
ASTHMA	X			X		1980	2003	MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: mortality rate. Note that the ICD-9 is still implemented.
CHRONIC RENAL FAILURE	X			X		1957	2003	DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
MULTIPLE SCLEROSIS	X			X		1957	2003	DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
CROHN'S DISEASE										Not available. Possibly, in ICD-9 crohn's disease could have been classified under the title: non-infectious enteritis and colitis

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

GREECE

E. ORTHOPAEDICS

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIP REPLACEMENT										Not available
KNEE REPLACEMENT										Not available
ACCIDENTS-INJURIES	X			X		1957	2003	National Statistical Service of Greece MORTALITY RECORDS, DISCHARGE RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
ACCIDENTS-INJURIES	X			X		1996	Present	Emergency Department Injury Surveillance System- Department of Epidemiology, Medical University of Athens	Possible but not yet implemented	Nationwide data that appear in articles in Pub med from this department are numerous, such as: Dedoukou X, Spyridopoulos T, Kedikoglou S, Alexe DM, Dessypris N, Petridou E. Incidence and risk factors of fall injuries among infants: a study in Greece. Arch Pediatr Adolesc Med 2004; 158(10); 1002-6 Petridou E, Kedikoglou S, Belechri M, Ntouvelis E, Dessypris N, Trichopoulos D. The mosaic of equestrian-related injuries in Greece. J Trauma 2004; 56: 643-7 1. Dessypris N, Petridou E, Skalkidis Y, Moustaki M, Koutselinis A, Trichopoulos D. Countrywide estimation of the burden of injuries in Greece: a limited resources approach. J Cancer Epidemiol Prev 2002; 7: 123-9
FRACTURE OF PROXIMAL FEMUR	X			X		1957	2003	National Statistical Service of Greece DISCHARGE RECORDS, MORTALITY RECORDS	Possible but not yet implemented	INDICATORS: Number of hospital discharges per year and number of deaths per year. Note that the ICD-9 is still implemented.
TRAUMA CARE										Not available

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

GREECE

F. TRANSPLANTATIONS

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
LIVER	X			X		1985	2002	Hellenic National Transplant Organization, Hellenic Republic Ministry of Health and Welfare CLINICAL RECORDS	Possible but not yet implemented	INDICATOR: cases per year There are also data for combined transplantations of kidney-liver and liver-pancreas
KIDNEY	X			X		1985	2002	Hellenic National Transplant Organization, Hellenic Republic Ministry of Health and Welfare CLINICAL RECORDS	Possible but not yet implemented	INDICATOR: cases per year There are data for transplantations from an alive or a dead donor. There are also data for combined transplantations of kidney-liver, kidney-pancreas
HEART	X			X		1985	2002	Hellenic National Transplant Organization, Hellenic Republic Ministry of Health and Welfare CLINICAL RECORDS	Possible but not yet implemented	INDICATOR: cases per year There are also data for combined heart-lung transplantation
LUNG	X			X		1985	2002	Hellenic National Transplant Organization, Hellenic Republic Ministry of Health and Welfare CLINICAL RECORDS	Possible but not yet implemented	INDICATOR: cases per year There are also data for combined heart-lung transplantation
MEDULLA	X			X		2001	2002	Hellenic National Transplant Organization, Hellenic Republic Ministry of Health and Welfare CLINICAL RECORDS	Possible but not yet implemented	INDICATOR: cases per year There are data concerning if there are autologous or allogenic and the rate of survival.

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

GREECE

G. EMERGENCY

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Emergency admission										Not available
Emergency admission for alcohol related pathologies										Not available

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

GREECE

H. NEONATAL/MATERNAL

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Vaginal births	X			X		1957	2003	National Statistical Service of Greece	Possible but not yet implemented	INDICATOR: cases/year
Caesarian births	X			X		1957	2003	National Statistical Service of Greece	Possible but not yet implemented	Data are under the title (ICD-9 coding): other direct obstetric causes
Perinatal intensive care										Not available

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

GREECE

I. MISCELLANEA

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Alcohol related pathologies										Not available
Surgical procedures										Not available

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

GREECE

PART 3.

Are there in Your Country activities related to Disease Registers or databases that could become effective in the next two years?

Yes No

Activity	Covered Area			Electronic forms		Starting in year	Source of data	Notes
	Nat	Reg	Other	Yes	Not			
GREEK CANCER REGISTRY	X			X		2006	Greek Ministry of Health and Welfare	
“HELIOS” STUDY	X			X		2005	CLINICAL RECORDS (Active Collection) by the Greek Cardiologic Society	MULTICENTRIC STUDY INDICATORS: A3 –A10

If Yes:

Legend: Nat, National; Reg, Regional; Other, please specify in the “Notes” column if covering Areas, Hospital(s), etc.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

PTCA procedures

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
CLINICAL RECORDS	Number of cases per year and per total number of patients	X			All ages		X			

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

ACS-AMI

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

ACS-AMI and unstable angina

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
CLINICAL RECORDS	A3	X						X		
CLINICAL RECORDS	A5	X						X		
CLINICAL RECORDS	A9	X						X		

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

ACS-unstable angina

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Stroke

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	
CLINICAL RECORDS	Incidence of stroke per 100000 person-years	X	X	Age, sex, type of stroke	All ages			X		
CLINICAL RECORDS	28-day case fatality of stroke		X	Type of stroke, sex	All ages			X		

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Breast cancer

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Cervical cancer

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Colorectal cancer

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Haematological malignancies

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages					

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Lung cancer

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Mesothelioma

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

All cancers

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Childhood haematological malignancies

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Childhood cancers

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

HIV/ AIDS

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	
CLINICAL RECORDS	Number of cases per year		X	Transmission, gender, deaths	All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Pneumonia

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Influenza

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year (almost equal to C5)	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	
CLINICAL RECORDS	Number of cases per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Meningitis

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	
CLINICAL RECORDS	Number of cases per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Hepatitis

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	
CLINICAL RECORDS	Number of cases per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Measles

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	
CLINICAL RECORDS	Number of cases per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Rubella

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	
CLINICAL RECORDS	Number of cases per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Tuberculosis

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year (almost equal to C6)	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	
CLINICAL RECORDS	Number of cases per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Diabetes

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Renal Disease

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Hypertension

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

BPCOD

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Asthma

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Chronic Renal Failure

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Multiple sclerosis

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Accidents/ Injuries

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Fracture of proximal femur

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
DISCHARGE RECORDS	Number of hospital discharges per year	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Transplantations

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
CLINICAL RECORDS	Cases per year (for transplantations of liver, kidney, heart, lung)	X			All ages				X	
MORTALITY RECORDS	Number of deaths per year (medulla transplantation)	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

GREECE

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

Vaginal births

Source of data	N Indicator	Crude/Adj		Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
CLINICAL RECORDS	Cases per year	X			All ages				X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

FINLAND

PART I

Political And Demographical Description

Finland is situated in northern Europe. It has a population of 5.2 million with 15 inhabitants per square kilometre. Finland has an 80-year old history of independence and Western democracy. Finland is a parliamentary republic with a multiparty political system. It has been a member of the European Union since 1995.

The Finnish administration system consists of three levels: state, province and municipality. However, the provinces are actually regional representatives of the central state government. Their administrators are appointed by the central government; they do not have any democratically elected organs. Finland is divided into five administrative provinces and the Åland Islands which have an autonomous status.

Power in Finland is vested in the people who are represented by deputies assembled in Parliament. Legislative power is exercised by Parliament, the President of the Republic having a minor role. The highest level of government of the state is the Council of State (Government) which consists of a Prime Minister and a requisite number of Ministers.

The head of the state is the President of the Republic who is elected for a period of six years. In practice, the President's power in political areas other than foreign policy is limited; but the power to accept laws and to appoint senior civil servants does incorporate the potential for acts of political significance.

The Parliament has a single chamber of 200 representatives, elected for a four-year term. Parliament has three main functions through which it represents the people and makes basic decisions on Finnish policy. It passes laws, it debates and approves the national budget and it supervises the way the country is governed.

Closest to the people are the self-governing municipalities which are all governed according to uniform national legislation. Many responsibilities, including primary education and the social and health services, are devolved at the level of the 432 municipalities. Municipalities levy a local income tax which is decided independently by each municipality. Municipalities also receive other tax revenues, subsidies paid by the state, and other revenues.

National Health System

In its institutional structure, financing, and goals, the Finnish health care system is closest to those of other Nordic countries and the UK, in that it covers the whole population and its services are mainly produced by the public sector and financed through general taxation. The Finnish health care system can be described as one of the most decentralised in the world. Even the smallest of the municipalities are responsible for arranging and taking financial responsibility for a whole range of "municipal health services". From an international perspective, another unique characteristic of the system is the existence of another public finance scheme (the National Health Insurance-NHI-scheme) that partly reimburses the same services as the first, but also services which are provided by the private sector. In addition to subsidising the use of specific private health services, the NHI scheme also finances occupational and student health services and outpatient medicines.

Municipally provided services include primary and specialist health care. Primary health care is mainly provided at health centres that are owned by municipalities or federations of municipalities. Preventive care for communicable and non-communicable diseases, ambulatory, medical and dental care, an increasing number of outpatient specialised services, and various public health programs (e.g. maternity and school health care) are provided by the health centres. They also provide occupational health services and services for specific patient groups, e.g. clinics for diabetes and hypertension clinics. Included with health centres are inpatient departments. The majority of patients in these departments are elderly and chronically ill, but in some municipalities health centres also provide short-term acute curative inpatient services. In addition to the inpatient departments of health centres, long-term care is provided at homes for the elderly that administratively come under municipal social services.

The local authorities are also responsible for organizing specialized medical care for residents of the municipality. To this end, the country is divided into 20 hospital districts (in addition, Åland forms its own hospital district). The largest hospital district in terms of population base has over 1.4 million inhabitants

while the smallest has over 65,000. Each municipality must belong to one hospital district. The number of members in a hospital district varies from six to 58.

Each hospital district has a central hospital and other units. Five of these are university hospitals offering more demanding forms of specialized medical care. Hospital districts provide specialised outpatient and inpatient care. Patients need a referral from their health centre doctor or any other licensed physician in order to get access to the outpatient or inpatient department in a specialized care hospital. In general, patients cannot choose the hospital where they will be treated. In practice, travelling distance limits the choice. Moreover, health centres have guidelines on where patients with certain symptoms and diagnoses should be sent. In hospitals, the possibilities for patients to choose their doctor depends on, for example, the organization of departments and the number of specialists.

The second public financing scheme, the NHI, covers its members (i.e., all Finnish residents including people who are not working) in the following fields: sickness allowances, maternity allowances, special care allowances, student health services, rehabilitation services, and medical expenses (drugs prescribed by a doctor, private-sector examinations and treatments performed or prescribed by a doctor or dentist, and transportation services). In addition, it partly reimburses employers for the costs of occupational health services.

There are only a few private hospitals that provide less than 5% of the hospital days in the country. Patients do not need any referral for these hospitals, and National Health Insurance reimburses part of the expenses to the patient. In addition, some municipalities and hospital districts purchase some specific services from private hospitals. However, this is not very common at the moment. There are also doctors' own private practices which provide specialized outpatient care.

Both primary health care physicians and hospital specialists may work in the private sector in addition to their work in the public sector. About one-third of all doctors (both general practitioners and specialists) have some kind of part-time private practice. In addition, about 10% of doctors work full time in private practice. In the private sector, patients are free to choose any private general practitioner or private specialist. Doctors in private practice can refer patients to public hospitals as doctors in health centres can.

Health Data Collection

The responsibility for national social welfare and health care statistics is divided in Finland between Statistics Finland and National Research and Development Centre for Welfare and Health (STAKES), both of which are official statistical authorities in this field. Statistics Finland collects and publishes the economic and manpower statistics and mortality records. STAKES's field of activity is the service structure of social welfare and health care: birth statistics, day care statistics, hospital statistics, income support and child allowances, etc. Most of this information comes from nation-wide client-patient registers based on individual personal identification numbers (PIN). This makes it possible to link different in-patient episodes and even different registers together.

STAKES collects data from the social welfare and health care institutions. Providers of health care services include hospital districts, primary health care institutions and 50 private care institutions. In the social services, service producers total about 1,800. It includes services for the elderly, services directed at alcohol and drug problems, services for disabled people, etc. There is also a large private sector that especially produces so-called half-open services, largely various kinds of service homes.

Discharge reports (Hilmo) are sent yearly to STAKES from care institutions. Before sending, they are scrutinised for technical errors at the institution. At STAKES, the data is analysed, checked and corrected both manually and with a computer program. A personal identifier is encrypted and the data is included into the relational database. This is used for reporting and research purposes.

The collection process has many phases and it depends on the capabilities of the data providers. At one end of the process, everything is done by filling in paper forms while at the other end of the process everything is done by information technology. The data collection technology may be integrated into commercial information systems. For smaller organizations, there is a product for collecting data. About 700 producers use this free product. This product includes classifications, definitions, rules, etc. and it also includes a reporting system. STAKES also collects individual data of special health conditions: births, congenital anomalies, abortions, sterilizations, cancer, and sight disabilities. Regarding social welfare, there is a special collection process for income support and child welfare.

One idea of data collection is to give automatic and quick feedback information (reports on paper) to the service producers and information senders. New information technology has made it possible to create intelligent and safe database access systems. As examples, there is SOTKANet information bank and hospital benchmarking data base which are available on the web.

The SOTKANet Indicator Bank is a new STAKES information service that offers key population welfare and health data from 1990 onwards on all Finnish municipalities, based on the current administrative division into municipalities. For instance, it allows the user to search for indicator data concerning different geographical areas in absolute numbers and percentages. Indicator descriptions provide information on data content, interpretations, data sources, years covered, and possible restrictions. The Current News section on the front page will offer summaries prepared by experts on interesting topics.

The hospital benchmarking project is a collaboration between STAKES and hospitals. It uses a patient level national register of discharges (for all somatic inpatient and outpatient admissions) and costs data. To measure output, a new measurement unit was developed. It is called the 'care episode'. An episode consists of all the admissions and outpatient visits for a patient due to one and the same illness. The indicators that are used to measure productivity can be viewed from two different viewpoints and at different levels: from the provider's viewpoint at the hospital level, speciality and patient group (DRG level), and from the regional viewpoint at hospital-district and municipality levels. This permits, for example, the comparison of productivity in different hospitals and disaggregated specialities to the comparison of episodes on each DRG group using indicators such as hospital admissions per episode, outpatient visits per episode, bed days per episode, and cost per episode.

PART 2.

Questionnaire description

The Finnish statistical system in health care relies increasingly on registers based on individual records with a unique personal identification number (PIN), and extraction of data from the patient/client information systems organised at local level. The questionnaire has been filled in on the basis of the available information included in the Finnish registers. The main source of data is the National Discharge Register. Using a PIN, it is possible to link different in-patient episodes and different registers (such as Finnish Death Register, Registers of Social Insurance Institution, and Finnish Cancer Registry) together.

The National Discharge Register includes all inpatient discharges. The new report system was implemented at the beginning of 1994 for institutional health care, and partially for out-patient (day) surgery. Questionnaires supplementing the basic report form have been used from 1994 onwards to collect data on patients with demanding cardiac conditions (demanding cardiac patients). Since 1998, the register has also included outpatient visits to public hospitals

The National Discharge Register includes the following information:

Provider of the service

1. Code
2. Code specifier

Information on the patient/client

3. Personal identification number
4. Municipality
5. Population responsibility area
6. Code of the patient living abroad
7. Type of service
8. Speciality

The treatment is described by the following:

9. Date of admission
10. Way of admission
11. From where the patient came to the institution
12. Code of the referring institution (if another institution)
13. Code specifier of the referring institution
14. Sent by/referral given by
15. Code of the institution from where the patient was sent
16. Code specifier of the institution from where the patient was sent
17. Date when put on to waiting list for treatment
18. Reason for treatment
19. Need for treatment at the beginning of treatment
20. Diagnoses (main and two secondary)
21. External cause of accident
22. Need of treatment when discharged
23. Surgical procedures
24. Decision of long-term care (yes/no)
25. Demanding cardiac patient (yes/no)
26. Psychiatry (yes/no)

27. Code for specialized hospital care
28. Number of holidays

Discharges described with the following information:

29. Date of discharge
30. How the patient's care is organized after discharge
31. Where the patient will be cared for after discharge
32. Code specifier of the institution after discharge

Additional information on demanding cardiac patients

1. Type of procedure
2. Nature of procedure
3. NYHA-assessment
4. The risk points in coronary arterial disease
5. Employment status before hospital admission
6. Primary result of procedure

Additional information concerning patients in adult, paediatric and juvenile psychiatric care

1. Way of arrival at psychiatric ward
2. Duration in days of hospital care against patients will
3. Sequence number of latest admission to psychiatric ward
4. GAS-assessment on admission and at the moment of census
5. Drug therapy
6. Unwilling admission and care procedures
7. Meetings with relatives or other close acquaintances

FINLAND

A. CARDIOVASCULAR DISEASES AND SURGERY

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
CABG procedures	X			X*		1987	At Present	National discharge register	Yes . Death register, Registers of National Health Insurance.	Special interest for research (Stakes/CHES)
PTCA procedures	X			X*		1995	At Present	National discharge register	Yes Death register, Registers of National Health Insurance.	Special interest for research (Stakes/CHES)
ACS – AMI	X			X* ¹		1987	At Present	National discharge register. In a special data base (Perfect project see under) hospital discharge data is linked with mortality register and registers in National Health insurance (see appendix 1)	Death register, Registers of National Health Insurance.	Special interest for research (Stakes/CHES). we have a ongoing research project since 1998
CONGESTIVE HEART FAILURE	X	X		X*		1987	At Present	National discharge register	Yes Death register, Registers of National Health Insurance.	
STROKE	X			X*		1987	At Present	National discharge register	Yes Causes of death register, Registers of National Health insurance.	Special interest for research (Stakes/CHES). we have a ongoing research project since 2004
CAROTID STENTING procedures	X			X		2004	At Present	National discharge register	Yes Causes of death register, Registers of National Health insurance.	We do not yet know how the procedure is reported in the register

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

* On line internet from 2001 to 2003

¹ A special data base at internet on one year follow up of AMI patients, their cost, use of services, medicines and mortality , available at internet since 1998

FINLAND

B. CANCER

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
BREAST CANCER	X			X		1956	At Present	finnish cancer registry http://www.cancerregistry.fi/eng/statistics.htm	yes death register, national discharge register , registers of national sickness insurance.	special interest for research (stakes/chess). we have a ongoing research project since 2004. however, there are other international projects (eurocare-2 ,eurochip-2)
LUNG CANCER	X			X		1956	At Present	finnish cancer registry http://www.cancerregistry.fi/eng/statistics.htm	yes death register and national discharge register.	there are other international projects (eurocare-2 ,eurochip-2)
COLON CANCER	X			X		1956	At Present	AS ABOVE	AS ABOVE	AS ABOVE

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

FINLAND

C. INFECTIOUS DISEASES

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
INFECTIOUS DISEASE	X			X		1987	At Present	National Discharge Register (includes all hospital inpatients)	Yes, such as Finnish Death register	Includes only patient with a hospital inpatient discharge
HIV/AIDS	X			X		1980	At Present	Infection disease register Based on data given by medical doctors and laboratory tests	Generally not, but may be possible with a specific permission	http://www3.ktl.fi/stat/

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc

FINLAND

D. OTHER CHRONIC DISEASES

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
OTHER CHRONIC DISEASES	X			X		1987	At Present	National Discharge Register (includes all hospital inpatients)	Yes, such as Finnish Death register	Includes only patient with a hospital inpatient discharge

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc

FINLAND

E. ORTHOPAEDICS

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
ORTHOPAEDICS	X			X		1987	At Present	National Discharge Register (includes hospital inpatients) all	Yes, such as Finnish Death register. Registers of National Health Insurance	Special interest for research (Stakes/CHESS). We have a ongoing research project since 2004

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc

FINLAND

F. TRANSPLANTATIONS

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
TRANSPLANTATIONS	X			X		1987	At Present	National Discharge Register (includes all hospital inpatients)	Yes, such as Finnish Death register	Includes only patient with a hospital inpatient discharge

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc

FINLAND

H. NEONATAL/MATERNAL

	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
NEONATAL/MATERNAL	X			X		1987	At Present	National Discharge Register and National Birth register	Yes, such as Finnish Death register	

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc

FINLAND

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

CARDIOVASCULAR DISEASES AND SURGERY

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
CABG procedures	National discharge register	A3 A4	X	X	Age, gender (from the year 1998) diabetes; endstage renal disease; chronic cardiac insufficiency; connective tissue disease ; chronic hypertension; chronic coronary heart disease; chronic arrhythmias; chronic neurological disease and previous stroke and AMI EuroScore (from the year 2004)	All ages	X	X	X	X	
PTCA procedures	National discharge register	A5 A6 A7 A8	X	X	Age, gender(from the year 1998) diabetes; endstage renal disease; chronic cardiac insufficiency; connective tissue disease ; chronic hypertension; chronic coronary heart disease; chronic arrhythmias; chronic neurological disease and previous stroke and AMI	All ages	X	X	X	X	
ACS – AMI	National discharge register. In a special data base (Perfect project see under) hospital discharge data is linked with mortality register and registers in National Health insurance (see appendix 1)	A9 A10	X	X	Age, gender diabetes; endstage renal disease; chronic cardiac insufficiency; connective tissue disease ; chronic hypertension; chronic coronary heart disease; chronic arrhythmias; chronic neurological disease and previous stroke and AMI	All ages	X	X	X	X	
CONGESTIVE HEART FAILURE	National discharge register	A11 A12	X	X	Age, gender	All ages	X	X	X	X	
STROKE	National discharge register	A1 A2	X	X	Age, gender . From the year 1998 similar co-morbidity as for AMI (see above)	All ages	X	X	X	X	
CAROTID STENTING procedures	National discharge register	A13 A14	X	X	Age, gender	All ages	X	X			

Legend: Adj, Adjusted; Gen,Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

FINLAND

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

CANCER

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
BREAST CANCER	Finnish Cancer Registry http://www.cancerregistry.fi/eng/statistics.htm	B1	X	X	AGE	ALL AGES		X	X	X	
LUNG CANCER	Finnish Cancer Registry http://www.cancerregistry.fi/eng/statistics.htm	B2	X	X	AGE,GENDER	ALL AGES	X	X	X	X	
COLON CANCER	AS ABOVE	B3	X	X	AGE,GENDER	ALL AGES	X	X	X	X	

Legend: Adj, Adjusted; Gen,Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

FINLAND

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

INFECTIOUS DISEASES

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
INFECTIOUS DISEASE	National Discharge Register (includes all hospital inpatients)	C1 C3 C4 C5 C6	X	X	Age, gender	All ages	X	X	X	X	
HIV/AIDS	Infection disease register Based on data given by medical doctors and laboratory tests	C2	X			All ages	X		X	X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

FINLAND

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

OTHER CHRONIC DISEASES

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other
National Discharge Register (includes all hospital inpatients)	D1									
	D2									
	D3									
	D4	X	X	Age, gender	All ages	X	X	X	X	
	D5									
	D6									
	D7									

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

FINLAND

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

ORTHOPAEDICS

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other
National Discharge Register (includes all hospital inpatients)	E1 E2 E3 E4 E5 E6 E7	X	X	Age, gender . From the year 1998 similar co-morbidity as for AMI (see above)	All ages	X	X	X	X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

FINLAND

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

TRANSPLANTATIONS

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other
National Discharge Register (includes all hospital inpatients)	F1 F2 F3 F4 F5	X	X	Age, gender	All ages	X	X	X	X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

FINLAND

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

NEONATAL/MATERNAL

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other
National Discharge Register and National Birth register	H1 H2 H3 H4 H5	X	X	Gestational age, gender, birth weight		X	X	X	X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

SPAIN

PART I

Political And Demographical Description

Spain is established as a social and democratic state, subject to the rule of law, and advocating as higher values: legal order, freedom, justice, equality and political pluralism. National sovereignty is vested in the Spanish people from whom emanate the powers of the state. The political form of the Spanish state is that of a parliamentary monarchy. The King is the head of state, the symbol of its unity and permanence. He arbitrates and moderates the regular working of the institutions, assumes the highest representation of the Spanish state in international relations, especially with those nations belonging to the same historic community, and performs the functions expressly conferred on him by the constitution and the law. As a result of this form of government, three powers are established: the legislative, the executive and the judiciary.

The Spanish Parliament, known as the Cortes Generales, represents the Spanish people and exercises state legislative power, approves its budgets, oversees the actions of the Government and has the other powers and jurisdictions assigned to it in the constitution.

The Government directs domestic and foreign policy, civil and military administration and the defence of the state. It exercises executive and statutory authority in accordance with the constitution and the law. The Government is headed by a Prime Minister, who is appointed by the King, following his investiture by the Congress of Deputies. He directs the action of the Government and co-ordinates the functions of the other members of the cabinet, without prejudice to powers, and direct responsibility of the latter in the discharge of their duties. The Government must leave office after a general election, in the event of a loss of parliamentary confidence, as provided for in the constitution, or on the resignation or death of the Prime Minister.

Justice emanates from the people and is administered on behalf of the King by the judges and magistrates of the judiciary. They are independent, irremovable, accountable and subject to the rule of law. The exercise of jurisdictional power in all kinds of trials, judgement and execution of judgement is the exclusive prerogative of the courts and tribunals specified by the law, according to rules of jurisdiction and procedure laid down therein.

Politics

(<http://www.sispain.org/english/politics/>)

Demographics

Population referring to January 2005 is 44,108,530. Spain's population density is lower than that of most European countries and in recent years rural populations have moved to cities.

According to the Spanish Government, there are 3.7 million legal foreign residents in Spain. Of these, around 500,000 are Moroccan and another half a million are Ecuadorian. More than 300,000 are Romanian, and 270,000 are Colombian. In 2005 alone, the immigrant population of Spain increased by 700,000 people. Spain has the highest immigration rate of the European Union.

Spain has no official religion. The constitution of 1978 abolished the Roman Catholic Church as the official state religion while recognizing the role it plays in Spanish society. More than 90% of the population are at least nominally Catholic.

Life expectancy at birth is high, 75.32 in males and 82.49 in females. The fertility rate is low, 1.31 children born/woman.

National Health System

Spain's health care system is tax-based, and during the past two decades the responsibility for health care has largely been devolved to Spain's 17 regions, and the autonomous communities. The National Health Survey of 1997 showed a population coverage of 99.8%, including the low-income and immigrant population. Private insurance companies provide complementary health care coverage and increasingly play

a role in covering services not included in the basic package and that are also designed to avoid waiting lists. In 2003, 18.7% of the population purchased private insurance policies.

The Ministry of Health and Consumer Affairs establishes norms that define the minimum standards and requirements for health care provision, has regulatory power, sets up information systems, and assures cooperation between national health authorities and the autonomous communities. The Ministry is also responsible for interterritorial and international health issues and publicizes comparative reports (benchmarking and highlighting best practices).

The autonomous communities decide how to organize or provide health services and implement the national legislation. The Interterritorial Council (Consejo Interterritorial del Sistema Nacional de Salud) is composed of representatives of the autonomous communities and the state administration and is in charge of promoting the cohesion of the health system. The role of municipalities is limited to complementary public health functions linked to hygiene and the environment.

(http://www.euro.who.int/eprise/main/who/progs/chhspa/system/20050131_1)

Health care financing and expenditure

The health care system is financed out of general taxation, such as value-added tax and income tax but also regionally raised taxes. The regions may modify the rate of taxation at the regional level up to a threshold fixed by the national government. Some autonomous communities also receive grants from the state. Private health care financing complements public financing with out-of-pocket payments to the public system (such as co-payments for pharmaceuticals) as well as the private sector (such as private outpatient care) and contributions to voluntary insurance.

Spain has one of the lowest levels of health expenditure in the Eur-A: in 2002, Spain was estimated to spend US\$1,646 in purchasing power parity per capita. Total health care expenditure amounted to 7.6% of GDP. In the same year, public expenditure was also relatively low, accounting for 71% of total health expenditure.

Hospital payment mechanisms vary among autonomous communities. Although there are experiments with hospital budgets, traditionally, hospital expenditures were retrospectively reimbursed with no prior negotiation and no formal evaluation. During the past two decades, the use of contract programmes with prospective financing of target activities increased, especially for private hospitals. Most physicians are employed by the public sector and receive fixed salaries.

Health care provision

Pursuant to the General Health Care Act (1986), primary health care (PHC) was given an independent, reinforced status. The first contact point of the population with the health system is the general practitioner who acts as a gatekeeper. The traditional system of PHC delivery consisted of a solo practitioner working part-time while the reformed model is based on a PHC team working full-time on a salaried basis. Coverage is rising with the reformed network and by 2001 was well above 90% in most autonomous communities. Despite the political focus on PHC, the health system is still centred on hospitals. In 2001, Spain had 4.0 hospital beds per 1,000 population; in 2002, an estimated 39% of the hospitals were publicly owned. Alongside the hospital system, there is an extensive network of outpatient ambulatory centres. In the reformed model of provision, members of the specialist teams in clinical departments rotate to cover outpatient care in ambulatory centres. Although waiting times have decreased, they are still considerable in public health care provision.

Most health staff has a status similar to that of civil servants. In 2000, the total number of doctors approached the Eur-A average with 3.2/1,000 population, an increase from 2.3 in 1990. The total number of nurses remained relatively low with 3.7/1,000 population in 2000.

Health indicators

Hospital indicators constitute a summary statistical operation that has been elaborated by the National Statistics Institute since 1984. Based on the 1995 statistic, the publication was modified as a consequence of the changes produced in the structure of specialised care in the national health system that joined the hospitals with the dependent specialities centres.

The aims of these indicators are:

- a) to establish a series of indicators that facilitates getting to know the different care levels and resources of health establishments by dealing with the different typology;
- b) to provide data that facilitate making a first approximation of comparative studies on the supply of resources in this sector in each autonomous community;
- c) to know care activity in each one of the medical and surgical specialities dealt with in the different types of establishment, and contrasting this both on a national level and within each autonomous community;
- d) to maintain a database that facilitates a study of the evolution over different periods of time in this sector.

This is an annual investigation where the health establishment constitutes the basic information unit on which the different variables in the study are measured. Health establishments are classified according to the functional dependence on public establishments: national health system, and defence forces, autonomous communities, town councils, municipalities and others; and non-public institutions: private non-profit (Red Cross, church), private profit, and autonomous private profit-making institutions; according to objectives in general, special short stay (medical-surgical, paediatric, maternal, maternal-paediatric and others); special long stay (geriatric and chronic and others), and psychiatric. For each type or combination of types, a series of indicator groups was subsequently elaborated.

Mortality

Currently, the statistic which reflects natural population movement is the deaths statistic, according to cause of death. This statistic is carried out according to criteria established by the WHO in the ICD.

In this classification, it is recommended that the cause of death that must be investigated and tabulated is the basic cause of death. This is defined as the disease or lesion that started the chain of pathological events. Specifically, this set or chain of diseases is what the death certifying doctor should supply in the statistical bulletin. Based on these causes, denominated by the WHO immediate, intermediate, fundamental and other processes, and by following international guidelines for the selection of the basic cause, the latter will be arrived at.

The data on the cause of death are covered in two models of statistical questionnaires: Statistical Death Bulletin (SDB) and Statistical Birth Bulletin (SBB). In the former, data on the deceased who lived more than 24 hours are covered, and in the latter, relatives of the deceased before 24 hours of life. The latter, although for statistical purposes are considered deceased, for legal purposes they are not counted as deceased but rather as aborted children.

The sections of the bulletins which cover the cause of death are different in both models. While in the SDB, 4 causes are described which conform with the chain of diseases that led to the death, in the SBB only two feature, a relative of the mother and another of the foetus. In the cases of deaths when the court intervenes, apart from the SDB, another questionnaire must be filled in by the courts of instruction where external circumstances that produced the lesions feature.

This statistic supplies information on the mortality dealing with the basic cause of death, its distribution by sex, age, residence and month of death. It also offers indicators that facilitate carrying out geographical comparisons, and measuring premature mortality; standardised rates of mortality, and potential years of lost life on an autonomous community level and large groups of causes of death.

Hospital indicators statistic (http://www.ine.es/en/metodologia/t15/t1530415_en.htm)

PART 2.

Questionnaire description

The questionnaire has been filled in on the basis of different sources of information. The most general and universal information is the hospital indicators statistics that constitute a summary statistical operation that has been elaborated at the National Statistics Institute since 1984 and is the National Administrative Register. (http://www.ine.es/en/metodologia/t15/t1530415_en.htm). Based on the 1995 statistics, the publication was modified as a consequence of the changes produced in the structure of specialised care in the national health system that joined the hospital with the dependent specialities centres. The aims of these indicators are:

- a) to establish a series of indicators that facilitates getting to know the different care levels and resources of health establishments by dealing with the different typology;
- b) to provide data that facilitate making a first approximation to comparative studies on the supply of resources in this sector in each autonomous community;
- c) to know care activity in each one of the medical and surgical specialities dealt with in the different types of establishment and contrasting this both on a national level and within each autonomous community;
- d) to maintain a database that facilitates a study of the evolution over different periods of time in this sector.

The second general and universal source of information is the National Mortality Register (http://www.ine.es/en/daco/daco42/sanitarias/notaecm_en.htm). This register is carried out according to criteria established by the WHO in the ICD. The register supplies information on mortality dealing with the basic cause of death, its distribution by sex, age, residence and month of death. It also offers indicators which facilitate carrying out geographical comparisons and measuring premature mortality: standardized rates of mortality and potential years of lost life, on an Autonomous Community level, and large groups of causes of death.

On the other hand, there are specific disease registers with some specific information, such as:

- Cancer of different location survival (EUROCare-3 Study) <http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm>
- AIDS National Registry <http://cne.isciii.es/htdocs/sida/sidavih.htm>
- Vaccination coverage http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm
- Spanish Liver Transplantation Register http://www.msc.es/Diseno/informacionProfesional/profesional_trasplantes.htm
- Spanish Kidney Transplantation Register http://www.senefro.org/modules/subsection/files/031112_informe_2001_definitivo.pdf?check_idfile=834
- Spanish Heart Transplantation Register http://www.revespcardiol.org/cgi-bin/wdbcgi.exe/cardio/mrevista_cardio.resumen?pident=13055340
- Other national or regional specific registers (acute coronary syndromes, ...).

SPAIN

A. CARDIOVASCULAR DISEASES AND SURGERY

	Covered Area			Electronic form		Data Years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
CABG procedures	X			X		2002	2002	National Administrative Register - CMBD		Elaborated data by DRG (Diagnosis Related Groups) in an Excel file
PTCA procedures	X			X		2001	2002	CMBD		Elaborated data by DRG (Diagnosis Related Groups) in an Excel file
ACS – AMI		X		X		1985	1994	MONICA-CATALONIA		Population based register in a region of Catalonia, covering a population of 600.000 inhabitants. http://www.ktl.fi/publications/monica/coredb/table9.htm
ACS – AMI		X			X	1997	1998	IBERICA Study		Population based register in 7 areas of Spain, covering a population of 8 million of inhabitants.
ACS – AMI		X			X	1990-		REGICOR Study		Ongoing population based register in Girona, a province in the North-East of Spain, covering a population of 550.000 inhabitants.
ACS – AMI	X				X	1994	1995	PRIAMHO I Study		Hospitalary register in a random sample of hospitals of Spain.
ACS – AMI		X			X	1999	1999	RISCI Study		Hospitalary register in a random sample of hospitals of Spain.
ACS – AMI	X				X	2000	2000	PRIAMHO II Study		Hospitalary register in a random sample of hospitals of Spain.
ACS – AMI			X		X		1995-	ARIAM Study		Hospitalary register in a sample of hospitals of Spain.
ACS – AMI		X			X		1994-	PRIMVAC Study		Hospitalary register in the hospitals of Valencia, a region of Spain.
ACS – AMI and Unstable angina		X			X	1992	1994	RESCATE Study		Hospitalary register in four hospitals of Catalonia.
ACS – Unstable angina		X			X		C 1995	PEPA Study		Hospitalary register in a sample of hospitals of Spain
STROKE										
CAROTID ENDOARTERECTOMY procedures										
CAROTID STENTING procedures										

Legend: Nat, National; Reg, Regional; Other, please specify in the “Notes” column if covering Areas, Hospital(s), etc.

SPAIN

B. CANCER

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
BREAST CANCER survival	X			X		1990	1994	EUROCARE-3 Study	EUROCARE-3 Study	http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm
CERVICAL CANCER survival	X			X		1990	1994	EUROCARE-3 Study	EUROCARE-3 Study	http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm
COLORECTAL CANCER survival	X			X		1990	1994	EUROCARE-3 Study	EUROCARE-3 Study	http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm
HAEMATOLOGICAL MALIGNANCIES	X			X		1990	1994	EUROCARE-3 Study	EUROCARE-3 Study	http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm
LUNG CANCER	X			X		1990	1994	EUROCARE-3 Study	EUROCARE-3 Study	http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm
MESOTHELIOMA	X			X		1990	1994	EUROCARE-3 Study	EUROCARE-3 Study	http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm
OTHER TYPES OF CANCER (Any localization)	X			X		1990	1994	EUROCARE-3 Study	EUROCARE-3 Study	http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm
CANCER	X			X		1990	1994	Population and hospitalary cancer registers EUROCARE-3 Study	Population and hospitalary cancer registers EUROCARE-3 Study	http://193.146.50.130/cancer/cancer1.htm http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm
CHILDHOOD HAEMATOLOGICAL MALIGNANCIES				X		1990	1994	EUROCARE-3 Study	EUROCARE-3 Study	http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm
CHILDHOOD CANCERS	X			X		1990	1994	EUROCARE-3 Study	EUROCARE-3 Study	http://www.todocancer.com/ESP/Fundacion+Cientifica/Estadistica+y+Epidemiologia/Supervivencia+en+Espana.htm

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

SPAIN

C. INFECTIOUS DISEASES

Activities	Covered Area			Available on-line		Data years		Source of data	Possibility to link with other registers	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIV/AIDS	X			X		1981	2001	AIDS National Registry		http://cne.isciii.es/htdocs/sida/sidavih.htm http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm
PNEUMONIA										Not available
VACCINATION	X			X		1992	2003	Vaccination coverage		http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm
DTP (DIFTERIA, TETANUS, WHOOPING COUGH)	X			X		1992	2003	Vaccination coverage		http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm
POLIOMYELITIS	X			X		1992	2003	Vaccination coverage		http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm
HIB (HAEMOPHILUS INFLUENZAE B)	X			X		1992	2003	Vaccination coverage		http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm
MENINGITIS (MENING. C) ^C	X			X		1992	2003	Vaccination coverage		http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm
HEPATITIS B	X			X		1992	2003	Vaccination coverage		http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm
MEASLES-RUBELLA-MUMPS	X			X		1992	2003	Vaccination coverage		http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm
HEPATITIS B	X			X		1992	2003	Vaccination coverage		http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm
INFLUENZA	X			X		1992	2003	Vaccination coverage > 64 Y		http://www.msc.es/Diseno/enfermedadesLesiones/enfermedades_transmisibles.htm

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

SPAIN

D.OTHER CHRONIC DISEASES

Activities	Covered Area			Available on-line		Data years		Source of data	Possibility to link with other registers	Notes
	Nat	Reg	Other	Yes	Not	From	To			
DIABETES	X						2003	National Administrative Register - CMBD		Number of hospital admissions for diabetes
RENAL DISEASE										Not available
HYPERTENSION										Not available
BPCOD										Not available
ASTHMA	X						2003	National Administrative Register - CMBD		Number of hospital admissions for bronchitis asthma
CHRONIC RENAL FAILURE	X						2003	National Administrative Register - CMBD		Number of hospital admissions for chronic renal failure
MULTIPLE SCLEROSIS										Not available
CROHN'S DISEASE										Not available
										Not available

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

SPAIN

E. ORTHOPAEDICS

Activities	Covered Area			Available on-line		Data years		Source of data	Possibility to link with other registers	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIP REPLACEMENT										Not available
KNEE REPLACEMENT										Not available
FRACTURED HIP	X			X		2003	2003	National Administrative Register - CMBD		Number of hospital admissions for fractured hip

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

SPAIN

F. TRANSPLANTATIONS

Activities	Covered Area			Available on-line		Data years		Source of data	Possibility to link with other registers	Notes
	Nat	Reg	Other	Yes	To	From	To			
LIVER	X			X		1984	2001	Spanish Liver Transplantation Register		http://www.msc.es/Diseno/informacionProfesional/profesional_trasplantes.htm
KIDNEY	X			X		1996	2002	Spanish Society of Nephrology Register		http://www.senefro.org/modules/subsection/files/031112_informe_2001_definitivo.pdf?check_idfile=834
HEART	X			X		1984	2002	Spanish Heart Transplantation Register		http://www.revespcardiol.org/cgi-bin/wdbcgi.exe/cardio/mrevista_cardio.resumen?pident=13055340
LUNG										Not available

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

SPAIN

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

CARDIOVASCULAR DISEASES AND SURGERY

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
CABG-procedure	National Administrative Register – CMBD	A3	X			All					
PTCA	National Administrative Register - CMBD	A5	X			All					
AMI	National Administrative Register - CMBD	A9	X			All					
AMI	Hospitalary registers	A9		X	Age, sex, cardiovascular risk factor, MI location, Killip, previous MI,	25-74 y	X	X	X		
AMI	Hospitalary registers	A10	X			All					
CONGESTIVE HEART FAILURE	National Administrative Register - CMBD	A12	X			All					
CONGESTIVE HEART FAILURE	National Administrative Register - CMBD	A11	X			All					

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

SPAIN

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology:

CANCER

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
BREAST CANCER	EUROCARE-3 Study	B1	X			All					
LUNG CANCER	EUROCARE-3 Study	B2	X			All					
COLON CANCER	EUROCARE-3 Study	B3	X			All					

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

SPAIN

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology

INFECTIOUS DISEASES

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
HIV	AIDS National Registry	C2	X			All	X				
PNEUMONIA	National Administrative Register - CMBD	C6	X			All					

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

SPAIN

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology

OTHER CHRONIC DISEASES

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
DIABETES	National Administrative Register - CMBD	D1	X			All	X				
ADULT ASTHMA	National Administrative Register - CMBD	D5	X			19- y					
PEDIATRIC ASTHMA	National Administrative Register - CMBD	D6	X			0-18 y					

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

SPAIN

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology

ORTHOPAEDICS

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
FRACTURED HIP	National Administrative Register - CMBD	E3	X								

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

SPAIN

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology

TRANSPLANTATIONS

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
LIVER	National registry	F2 (Liver) Number of liver transplants Survival (1 week, 1 month, 1 year)	X	X		All					
HEART	National registry	F3 (Heart) Number of heart transplants Survival (1 month, 1 year, 5 years)	X	X		All					
KIDNEY	National registry	F5 (Kidney) Number of kidney transplants Survival (1 month, 1 year)	X	X		All					Age

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

SPAIN

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology

EMERGENCY

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other

SPAIN

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology

NEONATAL / MATERNAL

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
NEONATAL / INFANT MORTALITY	National Statistical Data	H2 Neonatal, infant and perinatal mortality	X			All					
CESARIAN BIRTHS	National Administrative Register - CMBD	H5 Percentage of vaginal and cesarean births									

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

SPAIN

PART 4.

Detailed information concerning the selected indicators for Procedure/Pathology

MISCELLANEA

	Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
							Gen	Hos	Geo	Nat	Other
SURGICAL PROCEDURES	National Administrative Register - CMBD	II Number of hospitalary deaths/total admissions	X			All					

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

SWEDEN

PART I

Political and demographical description

Sweden, a constitutional monarchy, based on a parliamentary democracy, has a population of 8,882,792 (2000), almost exclusively Caucasian and Lutheran.

As of today, February 2006, the head of state is King Carl XVI Gustaf, and the Prime Minister of Sweden is Göran Persson (leader of the Social Democratic Party). The Swedish currency is the krona (SEK), equal to approximately EUR 0.11. Based on the world's oldest system of population records (since 1686), approximately 90% of the population resides on less than 30% of the area. More than 80% live in urban areas. Less than 5% of the working population is occupied within the agricultural sector. Sweden is one of the world's most prosperous and sophisticated industrial nations. Information technology (IT) and biomedicine are, among many, knowledge-intensive sectors in which Sweden has been among the global leaders for years. The wealth is unusually evenly distributed in Sweden: there is, for instance, no population stratum that for economic reasons cannot get access to the best medical services available. The average life expectancy at birth is 77.38 for men and 82.03 for women (2000); 1.53 million (17.2%) of the population are older than 64.

National Health System

With the exception of a small number of private practitioners who provide outpatient services, and a few very small private hospitals mainly devoted to minor surgery, the Swedish health care system is entirely public. It is organized by the county administrations under supervision by the National Board of Health and Welfare. Each county typically has 2-4 local hospitals and one county hospital that serves as a first instance referral centre and is capable of treating all but a few specialized cases. Basically, the catchment's areas of the hospitals are mutually exclusive. The counties are organized in 6 health care regions, each containing one academic referral hospital. Technical facilities and management practices are uniform throughout the country, and there is practically no variation in health care quality between the counties. Every patient is obliged to use the hospital with the catchment's area within which he/she resides (except for emergencies occurring outside the county). Thus, medical services are, in effect, population-based and referable to the county of residence.

All Swedish residents are covered by the mandatory social insurance, which reimburses the health care providers for all but a small part of the costs for both outpatient and inpatient care. Thus, Swedish health care is characterized by excellent availability, high and uniform quality throughout the country, and low cost for patients. The fees are kept low enough to permit all residents equal access to public health care. There are no restrictions or barriers neither for socio-economically unprivileged nor for ethnical minorities or women.

Health Data Collection

The population-based Inpatient Register

In 1964-1965, the National Board of Health and Welfare began collecting data on individual hospital discharges in the Inpatient Register. At discharge from hospitals, a specific form is completed for each patient without exception. These forms are computerized locally, and the data are first stored in administrative registers held at the hospitals and the county administrations until delivery once a year to the National Board of Health and Welfare. Each record represents one in-hospital episode. In addition to the NRN and some administrative information, including admission and discharge dates, hospital and department codes, it contains medical data such as up to 10 surgical codes (coded according to the Swedish Classification of Operations and Major Procedures), and 1-8 discharge diagnoses. The register has had nationwide coverage since 1987. Each year, the Inpatient Register includes approximately 1.7 million instances of hospital care.

The Swedish Cancer Register

A nation-wide cancer register has been in operation in Sweden since 1958. Both clinicians and pathologists/cytologists are required by law to notify the regional cancer register whenever a malignant condition is diagnosed (also autopsy). The notifications are checked extensively at the regional cancer registers. The national register is created annually at the National Board of Health and Welfare by merging data from the 6 regional cancer registers. In the register, all cancers are recorded with the coding system in current use along with a translation into ICD-7. There is a special code for benign tumors, which are also reported to the register. There is a code for the basis for diagnosis, and a special code to indicate if a tumor was first detected at autopsy. Histological confirmation of tumors has varied over time and with tumor site but is generally high and increasing with time. With respect to different histological cancer types, a special PAD coding and a SNOWMED classification have been in use since 1958.

The Causes of Death Register

The National Causes of Death Register is held by the National Board of Health and Welfare. Besides date of death, the Death Register also holds information on underlying and contributory causes of death based on the International Classification of Disease codes. For every deceased person, a death certificate must be issued before burial is permitted. The death certificates are filled in by the physicians or surgeons in charge of the patient during the last hospitalization, or, for those few who die outside hospitals, by a family physician or a specialist in forensic medicine.

The Register of Population Changes

The Register of Population Changes is held by Statistics Sweden. This register records all individuals who have emigrated from Sweden to another country.

In the above-mentioned registers, the 10-digit national registration numbers (NRNs) are always collected, and usually carefully checked. NRN was introduced in Sweden in 1947. All Swedish residents have unique NRNs that contain the date of birth and an additional 4 digits. The 9th digit can be used for gender identification. The 10th digit is a check sum that protects against incorrect data entries in computerized registers. The NRN is assigned to the individual immediately after birth or after immigration. The NRNs are used extensively, both by official authorities and by the health care system. NRNs will enable unambiguous linkages between different registers that will greatly facilitate follow-up of hospitalized patients after discharge.

PART 2

Questionnaire description

A well-developed information system is a necessity in a democratic society. The long tradition in Sweden of collecting information on health and social conditions of the population provides an excellent base for monitoring disease and social problems. A unique person identification number, i.e. national registration number, for every citizen enables linkage of exposure and outcome data from several decades. The existence of accurate epidemiological registers is a basic prerequisite for monitoring and analyzing health and social conditions in the population. The questionnaire has been filled in on the basis of the available information included in these registers. The main source of data is the Swedish Inpatient Register and the Swedish Cancer Register. Using the national registration numbers, it is possible to link the Inpatient Register and the Swedish Cancer Register to other registers such as Causes of Death Register, Medical Birth Register, et al.

There are four different types of information available in the Swedish Inpatient Register:

Data on the patient

- personal identification number
- sex
- age
- place of residence

Data on the hospital

- county council
- hospital
- department

Administrative data

- date of admission
- date of discharge
- length of stay
- acute/planned admission
- admitted from
- discharged to

Medical data

- main diagnosis
- secondary diagnoses
- external cause of injury and poisoning
- surgical procedures

There are three different types of information available in the Swedish Cancer Register

Data on the patient

- Personal identification number
- Sex
- Age
- Place of residence

Medical data

-Site of tumor

For the years 1987-1992 the tumors has primarily been coded in ICD-9 and from 1993-2004 in ICD-O/2. From 2005 the cases has been coded in ICD-O/3. For the whole period 1958-w the codes are available as ICD-7 codes.

-Histological type

For the period 1993-2004 according to ICD-O/2 and from 2005 in ICD-O/3. For the whole period 1958-w the codes are available as the old histology code (WHO/HS/CANC/24.1). Stage has been collected since 2004. Stage is not recorded for brain, cranial nerves, lymphoma and leukemia. Gynecological tumors are coded according to FIGO and the rest according to TNM (6th edition).

-Basis of diagnosis

-Date of diagnosis

-Reporting hospital and department

-Reporting pathology/cytology department

-Identification number for the tissue specimen.

SWEDEN

A. CARDIOVASCULAR DISEASES AND SURGERY

Activities	Covered Area			Electronic forms		Data years ²		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
CABG procedures	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	
PTCA procedures	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	
ACS – AMI	X			X		1965	2004	Inpatient Register (and Causes of death register for sudden MI death)	Causes of Death register Migration register	
ACS – AMI and Unstable angina						1965	2004	Inpatient Register	Causes of Death register Migration register	Unstable angina will not be completely registered in Inpatient Register
ACS – Unstable angina						1965	2004	Inpatient Register	Causes of Death register Migration register	Unstable angina will not be completely registered in Inpatient Register
STROKE	X			X		1965	2004	Inpatient Register (and Causes of death register for sudden stroke death)	Causes of Death register Migration register	
CAROTID ENDO- ARTERECTOMY procedures	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	
CAROTID STENTING procedures	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	

Legend: Nat, National; Reg, Regional; Other, please specify in the “Notes” column if covering Areas, Hospital(s), etc.

² From 1987 nationwide

SWEDEN

B. CANCER

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
BREAST CANCER Survival	X			X		1958	2004	National Register Cancer	Cause of Death Migration	
LUNG CANCER SURVIVAL	X			X		1958	2004	National Cancer Register	Cause of Death Migration	
COLON CANCER SURVIVAL	X			X		1958	2004	National Cancer Register	Cause of Death Migration	
HAEMATOLOGICAL MALIGNANCIES	X			X		1958	2004	National Register Cancer	Cause of Death Migration	
LUNG CANCER	X			X		1958	2004	National Register Cancer	Cause of Death Migration	
MESOTHELIOMA	X			X		1958	2004	National Register Cancer	Cause of Death Migration	
OTHER TYPES OF CANCER (specify)	X			X		1958	2004	National Register Cancer	Cause of Death Migration	(all other malignant cancers)
ALL CANCER	X			X		1958	2004	National Register Cancer	Cause of Death Migration	
CHILDHOOD HAEMATOLOGICAL MALIGNANCIES	X			X		1958	2004	National Register Cancer	Cause of Death Migration	
CHILDHOOD CANCERS	X			X		1958	2004	National Register Cancer	Cause of Death Migration	

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

SWEDEN

C. INFECTIOUS DISEASES

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIV/AIDS	X			X		Unclear	Unclear	Swedish Institute for Infectious Disease Control	Cause of Death Migration	Completeness unknown
PNEUMONIA								Not available		
VACCINATION (*)								Not available		
INFLUENZA								Not available		
MENINGITIS	X			X		1965	2004 From 1987 nationwide	Inpatient Register	Causes of Death register Migration register	
HEPATITIS(*)	X			X			unclear	Swedish Institute for Infectious Disease Control Inpatient Register	Causes of Death register Migration register	
MEASLES								Not available		
RUBELLA								Not available		

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc. (*) Please specify one type in each line. If necessary, add lines

SWEDEN

D. OTHER CHRONIC DISEASES

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
DIABETES								Inpatient register National diabetes register		Incomplete
RENAL DISEASE								Inpatient register		Incomplete
HYPERTENSION								Inpatient register		Incomplete
BPCOD								Inpatient register		Incomplete
ASTHMA								Inpatient register		Incomplete
CHRONIC RENAL FAILURE								Inpatient register		Incomplete
MULTIPLE SCLEROSIS								Inpatient register		Incomplete
CROHN'S DISEASE								Inpatient register		Incomplete

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

SWEDEN

E. ORTHOPAEDICS

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIP REPLACEMENT	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	
KNEE REPLACEMENT	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	
ACCIDENTS-INJURIES	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	
FRACTURE OF PROXIMAL FEMUR	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	
TRAUMA CARE	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

SWEDEN

F. TRANSPLANTATIONS

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
LIVER	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	
KIDNEY	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	
HEART	X			X		1965	2004	Inpatient Register	Causes of Death register Migration register	
LUNG						1965	2004	Inpatient Register	Causes of Death register Migration register	
MEDULLA						1965	2004	Inpatient Register	Causes of Death register Migration register	

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

SWEDEN

G. EMERGENCY

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Emergency admission										Not available
Emergency admission for alcohol related pathologies										Not available

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

SWEDEN

H. NEONATAL/MATERNAL

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Vaginal births	X			X		1973	2004	Medical register birth	Causes of Death register Migration register	
Caesarian births	X					1973	2004	Medical register birth	Causes of Death register Migration register	
Perinatal intensive care										Not available

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc

SWEDEN

I. MISCELLANEA

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Alcohol related pathologies										Not available
Surgical procedures										Major surgical procedures are registered in the Inpatient Register

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc

SWEDEN

PART 3

Are there in Your Country activities related to Disease Registers or databases that could become effective in the next two years?

Yes !_! No !_!

If Yes:

Activity	Covered Area	Electronic forms	Starting in year	Source of data	Notes

SWEDEN

PART 4

Detailed information concerning the selected indicators for Procedure/Pathology:

Source of data	N Indicator	Crude	Adj	Adjusted by	Age range	Disaggregated by				
						Gen	Hos	Geo	Nat	Other (specify)
Inpatient Register		X	X	Age, gender & comorbidities	All ages	X	X	X	X	
Cancer Register		X	X	Age, gender	All ages	X	X	X	X	

Legend: Adj, Adjusted; Gen, Gender; Hos, Hospital; Geo, Geographical Area; Nat, National; Other, please specify.

AUSTRIA

PART I.

Political And Demographical Description

Austria is a federal republic, 83,849 sq. km. in size, with 9 states (Bundesländer). The capital is Vienna with 1.55 million inhabitants, the largest county according to population. The others are Niederösterreich (1.54 million inhabitants), Oberösterreich (1.38 million), Steiermark (1.18 million), Tirol (0.67 million), Kärnten (0.60 million), Salzburg (0.51 million), Vorarlberg (0.35 million) and Burgenland (0.28 million inhabitants)

According to the 2001 Census, the entire population of Austria is 8,033,000.

About 7,322,000 people are Austrian citizens and 711,000 have other nationalities.

About 1,000,000 inhabitants are not born in Austria. The majority of immigrants are from the former Yugoslavia, Turkey and Germany.

Austria has a mixed presidential-parliamentary government and a federal system of executive organization. The President, which is elected by popular vote for a 6 year term, nominates the Prime Minister who heads the cabinet. The cabinet is responsible to the lower house of Parliament (Nationalrat) which is elected by popular vote according to proportional representation.

The upper house of Parliament represents the provinces according to the federal basic of the Constitution from 1929.

National Health System

The Austrian health system is organized in a federal way. The main duties concerning patient care and detailed decisions are done at the political level of the provinces. The national level is responsible for the coordination and general guidelines as well as regulatory affairs and quality control. Ninety-eight per cent of the population is covered by the National Public Health Insurance System. These funds are covered by the employees and employers based on regular levies. The public budget supports unemployed and/or poor people. The reimbursement for outpatient service by a physician is a mix of flat rate and reimbursement for specific services. At the moment, the organization of the reimbursement is modified by the introduction of a regular, nation-wide electronic procedure (e-card). The health service, which is covered by public grants, is defined in a catalogue. Additional service has to be paid by the patient or is partially covered by a public contribution.

About 1/3 of the population has additional private health insurance which guarantees free choice of the physician and a higher standard in service in the hospitals. According to the contracts, private health insurances cover additional treatments which are not included in the public health service catalogue.

The number of hospitals in Austria decreased from 1999 to 2003 from 325 to 272. The number of incharge beds decreased in the same period from 73,600 to 70,600. This represents 8.4 beds/1,000 inhabitants. The total number of physicians increased from 33,800 to 37,400. 18,025 were active in outpatient service, 6,221 were general practitioners and 11,804 were specialists of the various specializations. Of the 272 hospitals, 137 are covered by public budgets (Landesfondsfinanzierte Krankenanstalten) and represent 73% of the entire bed proportion. This sector presents the acute care in the Austrian medical system and includes the majority of the high level medical service. For these hospitals, national evaluations are available. The average costs per patient and day is €439. Additionally, of the 137 hospitals covered by public budgets, 27 hospitals operate as non-profit organizations. They represent 7.8% of the entire bed resources. In general, the non-profit sector in the Austrian health system is represented by 160 hospitals (=58.8%) and 78.1% of the entire bed capacity. The largest owner of hospitals is the provinces with 32.7% of the institutions, representing 52.3% of beds. Further owners are cities, religious communities, public and private health insurances and private persons. There is a large proportion of small hospitals, 61.4% of them have less than 200 beds, 40% less than 100 beds (=5.1% of the entire bed capacity). This sector includes institutions for rehabilitation and special care. Seventy-five hospitals have between 200 and 500 beds (= 31% of the bed capacity), 21 hospitals between 500 and 1,000 beds (=22.7% of the bed capacity). Including the 3 University Clinics in Vienna, Innsbruck and Graz, there are 9 hospitals with more than 1,000 beds (= 19.3% of the bed capacity).

In 2004, Austria spent €17 billion for health which represents 7.5% of the national gross income. 67.7% is covered by the national public health system. Austria's expenses for health services of 7.5% of the NGI is in the mid-range of the European Union. The average is 8.4% in the OECD countries. To compare the figures: the USA spends 14.4%, Switzerland 11.2%, Korea is on the lower end and spends 5.1%. Public health insurances are the most important structure in the administration and financing of the public health system. They are organized at the province level with a national coordination structure. Additional income to the health system is by the national budget and the private sector. The entire budget for public health insurances is €11.5 billion. From this budget, €3.2 billion are spent on hospital service, €2.9 billion for the outpatient physicians service, €2.4 billion for drugs and medical devices, €707 million for dental care and €454 million for mother and child care (incl. prevention and screening). The expenses for administration for public health insurances are €351 million (=3%).

References:

- 1) *National Health Report 2004 by the Austrian Ministry of Health and Consumer Protection (www.bmgf.gv.at)*
- 2) *Statistical Reports by the Austrian Public Institute for Statistics (www.statistik.at)*

Health Data Collection

Since EAR has started its cooperation with EUPHORIC delayed, this report has to be stated as preliminary. The data will be updated when necessary during the project.

In Austria, discharge records are a main source of information concerning health data. The documentation is based on the DGR-System and is the basis for reimbursement.

The discharge records are sent to the public health insurances. Every citizen has to be included in one public health insurance. Every region has its own independent public health insurance (Gebietskrankenkasse), which is connected to a national network including a central institution (Hauptverband der Sozialversicherungsträger), which has to coordinate and is responsible for central decisions. Some professional groups like public employees, farmers or railway employees are covered by insurance institutions.

ICD9 and IDC10 dominate as the basis for the diagnosis documentation. Main and additional diagnoses are documented. This documentation is the basis for reimbursement for single case and diagnosis base (MEL = Medizinische Einzelleistung). The reimbursement and value of the single position is in permanent reconstruction since this system is one of the main strategic instruments that guide the health system. The financial impact might have an effect on the documentation in the hospital departments. Software is frequently used to improve the financial result. This should be taken into consideration when these data are used for public health issues and quality control monitoring.

The screening and evaluation of discharge records and quality control issues are done by the Austrian Health Institute (ÖBIG). Public registers and the connection of different data sources are done predominantly in this institution at the national level. Additionally, there are some projects by local health care providers like TILAK in Tyrol. TILAK runs the local Tyrolean arthroplasty register, but also includes registers and a nationwide birth register. Scientific organizations run some more projects.

The presented report is based on a summary of information from these institutions, web based research and advices from the described network on other, smaller projects which have been asked for data or cooperation in the network.

Links to other databases like the mortality registers are possible by special permission due to privacy of data regulations, but this is not always possible for every case.

PART 2.

Questionnaire description

The technical report is a summary of information collected from a survey including the main institutions responsible for data collection for public health and quality control purposes.

These are the Austrian Health Institute (Österreichisches Bundesinstitut für Gesundheitswesen; ÖBIG; recently included in the basket organisation “Gesundheit Österreich GmbH”) and the “Institut für klinische Epidemiologie of TILAK”, the holding for health care providers in the Tyrol region.

Additionally, a survey of the scientific network and scientific societies has been done to identify projects with a scientific background that could also serve as a database for public health issues.

In depth analyses of the data sets could not be realised due to the delayed participation of EAR in the EUPHORIC Project, but the intention is to complete the report later.

AUSTRIA

A. CARDIOVASCULAR DISEASES AND SURGERY

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
CABG procedures	X			X		1997	At Present			
PTCA procedures	X			X				Biostatistik Innsbruck		
ACS – AMI										
ACS – AMI and Unstable angina										
ACS – Unstable angina										
STROKE		X		X		2005	2005	Stroke Unit Register (ÖBIG) Discharge Records		In Development, aim national, not completely implimented
CAROTID ENDO-ARTERECTOMY procedures										
CAROTID STENTING procedures										

Legend: Nat, National; Reg, Regional; Other, please specify in the “Notes” column if covering Areas, Hospital(s), etc.

AUSTRIA

B. CANCER

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
BREAST CANCER	X	X		X				Tumorregister Tirol		All projects are covering all types of cancer (www.iet.at)
CERVICAL CANCER	X	X		X				Tumorregister Tirol		Austria: Nationwide Register by "Statistik Austria", internationally not accepted Tyrol, Vorarlberg: regional coverage, internationally accepted, Salzburg, Carinthia: not validated yet
COLORECTAL CANCER	X	X		X				Tumorregister Tirol		
HAEMATOLOGICAL MALIGNANCIES	X	X		X				Tumorregister Tirol		
LUNG CANCER	X	X		X				Tumorregister Tirol Bronchus CA Reg. (ÖBIG)	Potentially possible, not implemented	In Development
MESOTHELIOMA										
OTHER TYPES OF CANCER (specify)										
ALL CANCER	X	X		X				Tumorregister Tirol		
CHILDHOOD HAEMATOLOGICAL MALIGNANCIES	X	X		X				Tumorregister Tirol		
CHILDHOOD CANCERS	X	X		X				Tumorregister Tirol		

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

AUSTRIA

C. INFECTIOUS DISEASES

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIV/AIDS		X								Single clinics, no links, in general more clinical surveillance studies
PNEUMONIA										
VACCINATION (*)										
INFLUENZA										
MENINGITIS										
HEPATITIS(*)										
MEASLES										
RUBELLA										

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

(*) Please specify one type in each line. If necessary, add lines

AUSTRIA

D. OTHER CHRONIC DISEASES

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
DIABETES		X		X				Diabetesregister (Institut für Epidemiologie der TILAK)		In development, aim in the innitial phase is to improve the hospital servive. For epidemiological and outcome issues the outpatient service would have to be included. It is scheduled, but not implimented
RENAL DISEASE	X			X				Österreichisches Dialyse- und Transplantationsregister (Austrian Nephrological Society)		
HYPERTENSION										
BPCOD										
ASTHMA										
CHRONIC RENAL FAILURE								Österreichisches Dialyse- und Transplantationsregister (Austrian Nephrological Society)		
MULTIPLE SCLEROSIS										
CROHN'S DISEASE										

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

AUSTRIA

E. ORTHOPAEDICS

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIP REPLACEMENT	X	X		X		2004	At Present	ÖBIG		
KNEE REPLACEMENT		X		X						Scheduled in the same organization than the THA Register
ACCIDENTS-INJURIES		X		X				Traumaregister (AUVA)		PROSA (Prospective Polytrauma Survey in Austria) In Development
FRACTURE OF PROXIMAL FEMUR		X		X				Traumaregister (AUVA)		
TRAUMA CARE		X		X				Traumaregister (AUVA)		

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

AUSTRIA

F. TRANSPLANTATIONS

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
LIVER										
KIDNEY	X							Österreichisches Dialyse- und Transplantationsregister (Austrian Nephrological Society)		
LUNG										
MEDULLA										

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

AUSTRIA

G. EMERGENCY

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Emergency admission										
Emergency admission for alcohol related pathologies										

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

AUSTRIA

H. NEONATAL/MATERNAL

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Vaginal births	X			X				Geburtenregister Österreich (Austrian Birth Register)		Approx. 70% coverage Only Tyrol complete coverage
Caesarian births	X			X				Geburtenregister Österreich		
Perinatal intensive care				X				Partial included in Birth Register (weight)		

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

AUSTRIA

I. MISCELLANEA

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Alcohol related pathologies										
Surgical procedures										
Stem Cells	X			X		1991	At Present	Austrian Stem Cell Transplant. Register (ASCTR)		
Herzschrittmacher	X					X		Austrian Society for Cardiology (Arbeitsgruppe für Rhythmologie)		
Discharge Records	X					1997	At Present	Discharge Records (MEL)		Nationwide for structure quality, but not for outcome quality assessment

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

AUSTRIA

PART 3.

Are there in Your Country activities related to Disease Registers or databases that could become effective in the next two years?

Yes No

If Yes:

Activity	Covered Area			Electronic forms		Starting in year	Source of data	Notes
	Nat	Reg	Other	Yes	Not			
Knee Arthroplasty	X			X	X		ÖBIG	ÖBIG, connected to THA
HEART							ÖBIG	
Pediatric cardiology	X				X		ÖBIG	

BULGARIA

PART I.

Political And Demographical Description

Official Name: Republic of Bulgaria

Area: 10,994 sq. km.

Major cities: Capital--Sofia (1.2 million). Others--Plovdiv (350,000), Varna (300,000).

Geography: Located on the Balkan Peninsula, Bulgaria extends from the western shore of the Black Sea to Yugoslavia in the west. In the north, the Danube River forms the greater part of Bulgaria's common boundary with Romania. Greece and European Turkey lie to the south and southeast of Bulgaria.

Terrain: Bulgaria is located in south central Europe. The terrain is varied, containing large mountainous areas, fertile valleys, plains and a coastline along the Black Sea.

People: Partly due to its mountainous terrain, Bulgaria's population density is one of the lowest in Eastern Europe, about 81 persons per sq km. About two-thirds of the people live in urban areas, compared to one-third in 1956. Sofia, the capital, is the largest city. Other major cities are Plovdiv, site of a major annual international trade fair, the Black Sea cities of Varna and Burgas, and Ruse on the Danube River. The principal religious organization is the Bulgarian Orthodox Church to which most Bulgarians belong. Other religions include Islam, Roman Catholicism, Protestantism, and Judaism.

Population (2003): 7,801,300.

Growth rate (2003): -5.7 (on the basis of 1,000 people).

Ethnic groups (2001): Bulgarian 83.94%, Turkish 9.42%, Roma 4.68%, and others.

Religions (2001): Bulgarian Orthodox 82.6%, Muslim 12.2%, Roman Catholic 0.6%, Protestant 0.5%, others.

Language: Bulgarian (official).

Health: Life expectancy (2002)--male 68.5; female 75.4. Infant mortality rate (2002)--13.3 deaths/1,000 live births.

History: The first Bulgarian state was recognized in 681 A.D. and was a mixture of Slavs and Bulgars. Several years later, the First Bulgarian Kingdom or the "Golden Age" emerged under Tsar Simeon I in 893-927. During this time, Bulgarian art and literature flourished. Also during the ninth century, Orthodox Christianity became the primary religion in Bulgaria and the Cyrillic alphabet was established. In 1018, Bulgaria fell under the authority of the Byzantine Empire. Byzantine rule was short-lived, however. By 1185, Bulgarians had broken free of Byzantine rule and, in 1202, they established the Second Bulgarian Kingdom. Ottoman domination of the Balkan Peninsula eventually affected Bulgaria in the late 14th century, and by 1396, Bulgaria had become part of the Ottoman Empire. Following the Russo-Turkish War (1877-78) and the Treaty of Berlin (1885), Bulgaria gained some autonomy under the Ottoman Empire, but complete independence was not recognized until 1908. The early-to-mid-1900s in Bulgaria was characterized by social and political unrest. Bulgaria participated in the First and Second Balkan Wars (1912 and 1913) and sided with the Central Powers and later the Axis Powers during the two World Wars. (Although allied with Germany during World War II, Bulgaria never declared war on Russia.)

Following the defeat of the Axis Powers, communism emerged as the dominant political force within Bulgaria. Former King Simeon II, who is currently Prime Minister, was forced into exile in 1946 and remained primarily in Madrid, Spain, until April 2001, when he returned to Bulgaria. (Note: Simeon assumed control of the throne in 1943 at the age of 6 following the death of his father Boris III.) By 1946, Bulgaria had become a satellite of the Soviet Union, remaining so throughout the Cold War period.

In 1989, Zhivkov relinquished control and democratic change began. The first multi-party elections since World War II were held in 1990. The ruling communist party changed its name to the Bulgarian Socialist Party and won the June 1990 elections. Following a period of social unrest and passage of a new constitution, the first fully democratic parliamentary elections were held in 1991 in which the United Democratic Front won. The first direct presidential elections were held the next year.

As Bulgaria emerged from the throes of communism, it experienced a period of social and economic unrest. With the help of the international community, former Prime Minister Ivan Kostov initiated a series of

economic reforms in 1997 that helped stabilize the country. Recent elections in 2001 ushered in a new Government and President, but the new leadership in Sofia remains committed to Euro-Atlantic integration, democratic reform, and development of a market-based economy.

Government: Bulgaria is a parliamentary republic. The unicameral National Assembly, or Narodno Subranie, consists of 240 deputies who are elected for 4-year terms through a system of proportional representation in 31 electoral regions. Party or coalition lists, rather than individual candidate names, appear on the ballots. A party or coalition must garner a minimum of 4% of the vote in order to enter Parliament. Parliament selects and dismisses Government Ministers, including the Prime Minister, exercises control over the Government, and sanctions deployment of troops abroad. It is responsible for enactment of laws, approval of the budget, scheduling of presidential elections, declaration of war, and ratification of international treaties and agreements.

Principal Government Officials

- President--Georgi Purvanov
- Prime Minister--Sergei Stanishev
- Deputy Prime Minister/Minister of Foreign Affairs--Ivailo Kalfin
- Deputy Prime Minister/Minister of Education--Daniel Vulchev
- Deputy Prime Minister/Minister of Disaster and Accidents--Emel Etem
- Minister of Defence--Vesselin Bliznakov
- Minister of Economy and Energy--Roumen Ovcharov
- Type: Parliamentary democracy.
- Constitution: Adopted July 12, 1991.
- Independence: 1908 (from the Ottoman Empire).
- Branches: Executive--President (chief of state), Prime Minister (head of Government), Council of Ministers (cabinet). Legislative--unicameral National Assembly or Narodno Subranie--240 seats. Members are elected by popular vote of party/coalition lists of candidates for 4-year terms. Judicial--three-tiered system.

More political information and statistics about Bulgaria:
<http://www.europeanforum.bot-consult.se/cup/bulgaria/>

National Health System

The population health state is a national priority and is ensured by the state through implementation of the following principles:

1. Equity in using health services;
2. Provision of accessible quality health care with priorities for children, pregnant women and mothers of young children;
3. Priority to health promotion and integrated disease prevention;
4. Prevention and reducing of the risk for human health from hazardous environmental factors;
5. Special health protection for children, pregnant women, mothers of young children, individuals;
6. with physical disabilities and mental disturbances;
7. State participation in funding activities related to human health protection.

The management of the national health policy is stipulated by the Health Law. Relevant chapters/articles:

1. The national health policy is managed and implemented by the Council of Ministers.
2. The Council of Ministers, after a proposal of the Minister of Health, approves the National Health Strategy further adopted by Parliament.
3. The Council of Ministers, after a proposal of the Minister of Health, approves national health programmes.

The national health strategy and national health programmes are based on an assessment of the health state and health needs of the population, health-demographic tendencies and resource capacities of the

National Healthcare System. The national health strategy and national health programmes are financed by the national budget as differentiated expenditures of the Ministry of Health and can be also supported by other financial sources.

The National Healthcare System incorporates hospital establishments as referred to in the Law for Health Establishments, health establishments as referred to in the same law, and Law for Drugs and Pharmacies for Humane Medicine, as well as, state, municipal and public bodies and institutions for the organization, management and control of activities on health protection and improvement.

Management bodies of the National Healthcare System

The Minister of Health manages the national healthcare system and controls the activities on:

1. protection of population health and state health control;
2. provision of urgent medical aid, transfusion haematology, stationary psychiatric
3. care, medico-social care for young children, transplantations and health information;
4. provision and sustainable development of health activities at health establishments;
5. medical expertise.

The Higher Medical Council is organized by the Minister of Health. It includes five representatives authorized by the Minister of Health, five representatives of the Bulgarian Union of Medical Doctors, three representatives of the Union of Dentists, three representatives of the Health Insurance Fund, one representative of the Bulgarian Health Care Professionals, one representative of the National Society of Municipalities, one representative of each higher medical university and one representative of the Bulgarian Red Cross. The Higher Medical Council is a consultative body that discusses and provides standpoints on:

1. priorities of the national health strategy;
2. ethic issues of medicine and biomedicine;
3. draft laws and draft regulations of the Council of Ministers in the field of health care and of the competency of the Minister of Health;
4. report of the Minister of Health as referred to in Art. 5 (2)
5. annual draft budget of healthcare;
6. research priorities in the field of medicine and dentistry.

The national health policy at regional level is implemented and organized by a regional healthcare centre and the Regional Inspectorate for Protection and Control of Public Health. The regional healthcare centres implement activities on the:

1. control of registrations and health wards on the territory of the region;
2. control of the compliance with medical standards, and organization for the quality assurance of the medical activities at health establishments;
3. implementation of IT in healthcare;
4. collection, registration, processing, storing, analysis and provision of health information for the needs of the national healthcare system;
5. planning, organization, management and control of medical expertise in the region;
6. planning and organization of health activities at different accidents and emergencies in the region;
7. checking of complaints and signals from the population related to health services;
8. coordination of the activities on the implementation of national and regional health programs.

PART 2

Questionnaire description

The questionnaire has been filled in on the basis of the available information in the database of the National Centre of Health Information; therefore, it can not be considered an exhaustive inventory of all the existing sources of data at local and national level.

In Bulgaria, discharge records are one of the main sources of information concerning health data and they are collected to calculate, for each hospital, the proper reimbursement to be paid by the National Health System through the National Health Insurance Bank (NHIB).

Every hospital fills in and sends to its own regional health insurance office a record for each patient undergoing an admission; then the data are transmitted to the NHIB. Next, the Ministry of Health checks and puts together the data sets from each region in a national one. A part of the information is gathered and analyzed by the National Centre of Health Information (NCHI).

ICD10 has been adopted to code diagnoses and procedures for the database. The condition, which has required the greatest workload and expenditure for the hospital, as identified at the discharge, is defined as the main diagnosis. Similarly, the main procedure is defined as the treatment more closely related to the main diagnosis and which has implied the greatest allocation of healthcare resources.

The database is kept and handled by the NHIB. Only in particular cases and for specific purposes, some public institutions can have this database at their own disposal. For example, clinical databases were developed by an active data collection available for some pathologies and procedures listed in the questionnaire, i.e. knee and hip transplantation.

The published data source for the health information indicators is: www.nchi.government.bg. Its data set includes the morbidity and mortality of diseases of different systems: infectious diseases, cardio-vascular system, ischaemic heart diseases, cerebrovascular diseases, malignant melanoma, chronic liver diseases, poisoning, and diabetes mellitus.

It is important to note that the linkage between clinical records and other data sets, such as regional mortality registers (in the NCHI data base), could be implemented, but at present it has not been fully realised. The database of the NHIB is not available to the public.

The NCHI data base is the administrative document, but it consists of only morbidity and mortality data according to sex and age without detailed hospital indicators.

BULGARIA

A. CARDIOVASCULAR DISEASES AND SURGERY

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
CABG procedures			X	X		2003	2005	DISCHARGE RECORDS	POSSIBLE BUT NOT YET IMPLEMENTED	INDICATOR: A3 National Insurance registry
CABG procedures						2003	2005			
PTCA procedures			X	X		2003	2005	DISCHARGE RECORDS	POSSIBLE BUT NOT YET IMPLEMENTED	INDICATOR: A5 National Insurance registry
ACS – AMI			X	X		2003	2005	DISCHARGE RECORDS	POSSIBLE BUT NOT YET IMPLEMENTED	INDICATOR: A9 National Insurance registry
ACS – AMI and Unstable angina										
ACS – Unstable angina										
STROKE			X	X		2003	2005	DISCHARGE RECORDS	NO	A2 National Insurance registry
CAROTID ENDO-ARTERECTOMY procedures										
CAROTID STENTING procedures			X	X		2003	2005	DISCHARGE RECORDS	No	National Insurance registry

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

BULGARIA

B. CANCER

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
BREAST CANCER	X			X		1992	At Present	Clinical records	Yes	
CERVICAL CANCER	X			X		1992	At Present	Clinical records	Yes	
COLORECTAL CANCER	X			X		1992	At Present	Clinical records	Yes	
HAEMATOLOGICAL MALIGNANCIES	X			X		1992	At Present	Clinical records	Yes	
LUNG CANCER	X			X		1992	At Present	Clinical records	Yes	
MESOTHELIOMA						1992	At Present			
OTHER TYPES OF CANCER (specify)						1992	At Present			
ALL CANCER	X			X		1992	At Present	Clinical records		
CHILDHOOD HAEMATOLOGICAL MALIGNANCIES										
CHILDHOOD CANCERS										

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

BULGARIA

C. INFECTIOUS DISEASES

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIV/AIDS										
PNEUMONIA										
VACCINATION (*)										
INFLUENZA	X			X		1980	At Present	Clinical records		
MENINGITIS	X			X		1980	At Present	Clinical records		
HEPATITIS(*)	X			X		1980	At Present	Clinical records		
MEASLES	X			X		1980				
RUBELLA	X			X		1980				
Tuberculosis	X			X		1980				

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc. (*) Please specify one type in each line. If necessary, add lines

BULGARIA

D. OTHER CHRONIC DISEASES

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
DIABETES			X	X		2003	2005	DISCHARGE RECORDS	No	D1, D2, D3, D4 National Insurance registry
RENAL DISEASE	X	X		2003	2005	X	X	DISCHARGE RECORDS	No	National Insurance registry
HYPERTENSION										
BPCOD										
ASTHMA										
CHRONIC RENAL FAILURE	X			X				National registry		
MULTIPLE SCLEROSIS	X			X				Population registry		
CROHN'S DISEASE										

Legend: Nat, National;Reg, Regional;Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

BULGARIA

E. ORTHOPAEDICS

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
HIP REPLACEMENT			X	X		2002	At Present	Clinical records	No	National registry Insurance
KNEE REPLACEMENT										
ACCIDENTS-INJURIES			X	X		2003	2005	DISCHARGE RECORDS		E3 National registry Insurance
FRACTURE OF PROXIMAL FEMUR										
TRAUMA CARE										

Legend: Nat, National;Reg, Regional;Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

BULGARIA

F. TRANSPLANTATIONS

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
LIVER										
KIDNEY										
HEART										
LUNG										
MEDULLA										

Legend: Nat, National;Reg, Regional;Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

BULGARIA

G. EMERGENCY

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Emergency admission		X		X		2003	2005	DISCHARGE RECORDS	No	G1
Emergency admission for alcohol related pathologies										

Legend: Nat, National;Reg, Regional;Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

BULGARIA

H. NEONATAL/MATERNAL

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Vaginal births			X	X		2003	2005	DISCHARGE RECORDS	No	H1, H2,
Caesarian births			X	X		2003	2005	DISCHARGE RECORDS	No	H3
Perinatal intensive care										

Legend: Nat, National;Reg, Regional;Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc.

BULGARIA

I. MISCELLANEA

Activities	Covered Area			Electronic forms		Data years		Source of data	Possibility to link with other registers (specify)	Notes
	Nat	Reg	Other	Yes	Not	From	To			
Alcohol related pathologies										
Surgical procedures										

Legend: Nat, National; Reg, Regional; Other, please specify in the "Notes" column if covering Areas, Hospital(s), etc

APPENDIX 1

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http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=services_cjrr_e
<http://ojrr.ca/ojrr/public/>
<http://www.aaos.org/wordhtml/bulletin/apr04/acdnws4.htm>
<http://www.outcomes-umassmed.org/GLORY/index.cfm>
<http://www.dmac.adelaide.edu.au/aoanjrr/aoanjrr.jsp>
<http://www.cdhb.govt.nz/NJR/>
<http://www.statistics.gr>
<http://www.eom.gr>
<http://www.keelpno.gr>
<http://www.onasseio.gr>
<http://www.registri-tumori.it/incidenza1998-2002/gruppi.html>
<http://www.registri-tumori.it/pubblicazione/pubbl.html> (period 1986-1997)
<http://www.encl.com.fr/europe95.htm>
<http://www-dep.iarc.fr/eucan/eucan.htm>

International web sites concerning collections of indicators

INSTITUTION	COUNTRY	WEBSITE	Date
Centre for Health Program Evaluation	AU	http://chpe.buseco.monash.edu.au/main.html	May 2005
Australian Health Outcomes Collaboration (AHOC) - Australia	AU	http://chsd.uow.edu.au/ahoc/	May 2005
Australian Council on Healthcare Standards (ACHS)	AU	http://www.achs.org.au	May 2005
Australasian Association for Quality in Health Care	AU	www.aaqhc.org.au	May 2005
Australia's national agency for health and welfare statistics	AU	www.aihw.gov.au/	May 2005
Australasian Cochrane Centre	AU	www.cochrane.org.au	May 2005
SPHERE Social and Public Health Economics Research Group	AU	www.curtin.edu.au/health/research/sphere	May 2005
Effective Healthcare Australia	AU	www.eha.usyd.edu.au	May 2005
Health Communication Network (HCN)	AU	www.hcn.net.au	May 2005
Commonwealth Department of Health and Ageing (Australia)	AU	www.health.gov.au	May 2005
LinkageWiz Record Linkage Software	AU	www.linkagewiz.com	May 2005
Centre for Clinical Effectiveness (Monash Institute of Health Services Research)	AU	www.med.monash.edu.au/healthservices/cce/	May 2005
Centre for Clinical Governance Research in Health	AU	www.med.unsw.edu.au/chmisr	May 2005
Western Australian Mental Health Information Development Plan	AU	www.mhidp.health.wa.gov.au	May 2005
National Centre for Epidemiology and Population Health	AU	www.nceph.anu.edu.au	May 2005
Australian Longitudinal Study on Women's Health	AU	www.newcastle.edu.au/centre/wha	May 2005
Medical Outcomes Trust	AU	www.outcomes-trust.org	May 2005
Centre for Health Services Research	AU	www.populationhealth.uwa.edu.au/welcome/research/chsr/chsr	May 2005
Canadian Institute for Health Information (CIHI)	CA	http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=pirc_indicators_outcomes_e	May 2005
Canadian Institute for Health Information (CIHI)	CA	http://www.cihi.ca/cihiweb/dispPage.jsp?cw_page=indicators_e	May 2005
Health Related Quality of Life Mapi Research Institute	FR	www.mapi-institute.com - for the linguistic validation of health outcomes and PRO instruments	May 2005
PROQOLID (Patient-Reported Outcome and Quality Of Life Instruments Database)	FR	www.proqolid.org	May 2005
Agency for Quality in Medicine (AQUMED)	DE	http://www.aeqz.de/qualitaetsindikatoren	May 2005
German Office for Quality Assurance	DE	http://www.bqs-qualitaetsindikatoren.de/	May 2005
Agency for Quality in Medicine (AQUMED)	DE	www.aqumed.de/	May 2005
New Zealand Health Technology Assessment Centre	NZ	http://nzhta.chmeds.ac.nz	May 2005
Ministry of Health, New Zeland	NZ	www.moh.govt.nz	May 2005

INSTITUTION	COUNTRY	WEBSITE	Date
National Centre for Health Outcomes Development (NCHOD)	UK	http://phi.uhce.ox.ac.uk	April 2005
Clinical Standards Board for Scotland (CSBS)	UK	http://www.clinicalstandards.org	May 2005
The International Centre for Mental Health Promotion	UK	www.charity.demon.co.uk	May 2005
Healthcare Commission NHS	UK	www.healthcarecommission.org.uk/homepage.cfm	April 2005
Clinical Indicators Support Team - NHS Scotland	UK	www.indicators.scot.nhs.uk/	April 2005
European Clearing Houses on Health Outcomes	UK	www.leeds.ac.uk/nuffield/infoservices/ECHHO/home.html	May 2005
National Confidential Enquiry into Patient Outcome and Death (NCEPOD)	UK	www.ncepod.org.uk/	April 2005
Statistics and performance indicators in healthcare, social services, complaints handling and waiting times	UK	www.performance.doh.gov.uk/	April 2005
Sheffield School of Health and Related Research ScHARR	UK	www.shef.ac.uk/uni/academic/R-Z/scharr/	May 2005
NHS Centre for Reviews and Dissemination (UK)	UK	www.york.ac.uk/inst/crd/ehcb.htm	April 2005
Agency for Health Care Research and Quality (AHRQ)	USA	http://www.ahrq.gov/chttoolbx/understn.htm	April 2005
Centers for Medicare & Medicaid Services (CMS)	USA	http://www.cms.hhs.gov/MedicaidSCHIPQualPrac/02_evidencebasedcard.asp#TopOfPage	May 2005
Commonwealth Fund	USA	http://www.cmf.org/topics/topics.htm?attrib_id=12010	May 2005
Joint Commission on Accreditation of Healthcare Organizations (JCAHO)	USA	http://www.jcaho.org	May 2005
National Committee for Quality Assurance (NCQA)	USA	http://www.ncqa.org	April 2005
The Association of Maryland Hospitals & Health Systems (MHA)	USA	http://www.qiproject.org	May 2005
National Quality Forum	USA	http://www.qualityforum.org/	May 2005
Agency for Health Care Research and Quality (AHRQ)	USA	http://www.qualityindicators.ahrq.gov	April 2005
Center for Healthcare Improvement (CHI)	USA	www.100tophospitals.com/	April 2005
Agency for Health Care Research and Quality (AHRQ)	USA	www.ahrq.gov	April 2005
Center for Disease Control and Prevention (CDC)	USA	www.cdc.gov/hrqol/methods.htm	May 2005
Foundation for Accountability	USA	www.facct.org	May 2005
National Guidelines Clearinghouse (AHCPR)	USA	www.guidelines.gov	May 2005
Pennsylvania Health Care Cost Containment Council	USA	www.phc4.org/	April 2005
Quality Metric	USA	www.qmetric.com	May 2005
OECD	Int	www.oecd.org/dataoecd/1/36/36262363.pdf	May 2005
World Health Organization	Int	www.who.int/en/	April 2005