

Use of Medical Databases in Clinical Epidemiology

Second edition

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Preface to second edition

In 2008, Department of Clinical Epidemiology launched a report for our researchers and international collaborators with the aim of providing an overview of the databases and registries most commonly used in Department of Clinical Epidemiology.

The first edition was a tremendous success and has already been printed in 500 samples. Therefore we have extended the first edition by including more descriptions of databases, adding references and revising the text. I would like to thank all the wonderful colleagues at Department of Clinical Epidemiology and our collaborators in the efforts to provide a second edition of this book. It is still our intention to regularly update the book and we will be happy to receive suggestions and feedback to continuously improve the book.

Henrik Toft Sørensen

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August 2009

Preface to first edition

Department of Clinical Epidemiology traces its roots to a clinical epidemiology research group founded, more than 20 years ago, at the Aalborg Hospital, where some of the first Danish clinical databases based on health care data were established and where the potential of using existing registries in clinical research was recognised. In 1991, the group established informal collaboration with epidemiologists from Boston University. In 1994, the group became affiliated with Aarhus University and Aarhus University Hospital. The first research registry was established at the end of 1995. It was the Pharmacoepidemiological Database from North Jutland Country. Since then, the group's activities have been steadily increasing in volume and scope.

With the establishment of the Department of Clinical Epidemiology, in 2000, the department gained access to a number of unique research databases founded at Aarhus University. By now, the department has created an extensive network of research databases that covers the four former counties of North Jutland, Viborg, Ringkjøbing and Aarhus. This means that health data of high quality – on the international scale – are available for a cohort of almost 1.8 million people. In 2007, the county was retired as Denmark's administrative unit, and the 15 former counties merged into 5 broad geographic regions. The department's collaboration with the aforementioned four counties is thus carried on with the current North Denmark Region and Central Denmark Region. In relation to the establishment of the National Indicator Project and the setting up of the Centre for Clinical Databases (see description on page 63), Department of Clinical Epidemiology has contributed to the construction of clinical cohorts, which are highly valuable for research purposes. In recent years, the department has reinforced its international significance by establishing collaboration with the Danish National Board of Health.

Over the years, many researchers have worked with the department's data and they have often requested an overview of the data sets maintained at Department of Clinical Epidemiology. The aim of the current publication is to provide such an overview in order to foster the research within clinical epidemiology and create an overview of data sources relevant for such research. This book was primarily developed for the Department of Clinical Epidemiology's own researchers and collaborators, which include an increasing number of international research institutions. The first edition of this book has been in high demand and the book will be updated at frequent intervals.

A number of people have assisted in constructing databases at the Department of Clinical Epidemiology and provided invaluable advice. I hereby express my sincere gratitude for their goodwill and cooperativeness. The people are: Tove Nilsson, Christian Lyhne, Hendrik Vilstrup, Per Østergaard Jensen, Jens Larsen Pedersen, Kenneth J. Rothmann, Jørn Olsen, John A. Baron, Peter Larsen, Ib Kjeldsen, Jørgen Nørskov Nielsen, Ole Østerballe, Birger Aaen Larsen, Paul Bartels, Leif Vestergaard Pedersen, Per Okkels, Per Christiansen, Jens Jørgen Jeppesen, Axel Brock, Ebba Nexø, Gunnar Lauge Nielsen, Flemming Hald Steffensen, Peer Fischer, Hans Jørgen Petersen, Henrik C. Schönheyder, Peter Funch-Jensen, Jørgen Lindhart, Niels Obel, Reinhold H. Jensen, and Karsten Nielsen. I also wish to thank the many researchers who have contributed their expertise to this report. Furthermore, I thank Ann Windfeldt Thorsen for her assistance in the early phases of the process and Vera Ehrenstein for undertaking the final proofreading of the manuscript. Last but not least, I want to thank the people who have written the registry and database descriptions for this report; a list of the authors is found at the beginning of the book. It is our intention to continuously update the book, and all contributions are welcome.

The book has been edited by Tina Christensen, Lars Pedersen, Hanne Kjeldahl Schlosser and Henrik Toft Sørensen.

The writing of this book has been supported by a grant from the Clinical Epidemiology Research Foundation.

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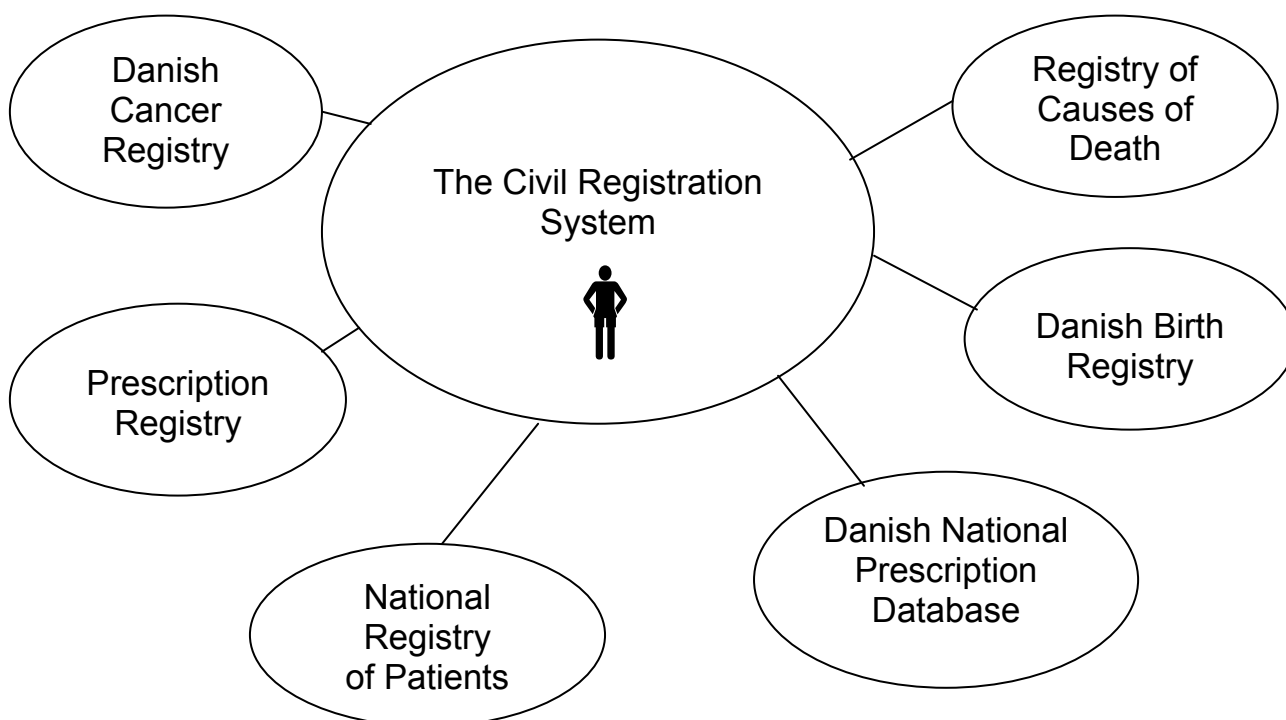
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Introduction to use of medical databases in clinical research

Henrik Toft Sørensen

The Nordic countries have established a number of disease and administrative registries over the course of many years. In Denmark, all births and deaths have been registered in church files since 1645, and in 1769, the first census was taken. The first disease registry – the Leprosy Registry – was initiated as early as 1856 in Norway. In the 19th century, registries of causes of death, tuberculosis and cancer (in Denmark in 1943) were added.

The establishment of the national population registry in 1924 and, in particular, of the Civil Registration System, in 1968, allowed for personal identification of remarkable quality and for the possibility of collecting information about the same person in several independent registries.



Please see page 5 for a description of the Danish Civil Registration System, which makes the entire Danish population a single cohort. The possibility of the individual-level record linkage is a distinctive feature of Nordic registries, setting them apart from those of other countries. In some contexts, the Nordic countries can be regarded as one cohort of 25 million people.

The costs and complexity often associated with primary data collection have led to use of existing registries and databases as an alternative data source for studies of many epidemiological and clinical questions. In general, medical databases available for clinical epidemiology research can be divided into three types:

- 1) Classical medical registries
- 2) Administrative databases
- 3) Clinical databases

Use of registry data in medical research offers many advantages by comparison with primary data collection. The main advantage is the fact that the registries already exist, effectively eliminating the need for data collection and sparing the associated effort, money, and time. As a result, the

overall costs of projects are reduced considerably, while data are used more efficiently. Other advantages of the use of medical databases include:

- 1) availability of data covering large study populations, contributing to high precision of risk estimates and enabling the study of rare exposures and outcomes
- 2) completeness of the registries with respect to capturing the people in the target population, thus reducing the risk of selection bias
- 3) routine accumulation of registry data independently of any research hypothesis, thus substantially reducing the types of bias that commonly influences primary data collection, e.g., differential recall, non-response, and effect on the diagnostic process of the attention caused by the research question
- 4) possibility of a long-term follow-up, which is particularly important whenever a health effect of an exposure becomes evident (or even suspected) many years after the exposure has acted, and existing registries often become a suitable and sometimes the only source for studying such associations

Still, originality and credibility, essential in all medical research, may not always be achievable by conducting studies based on registry data. Several limitations associated with using registries and medical databases are often ignored. Most important, data quality may be difficult to validate because data collection is not under the investigator's control; furthermore, the data required for a particular research question may not be collected at all.

The three key elements of a medical database

For an investigator wishing to use medical databases in clinical epidemiology, it is important to be aware of the advantages and disadvantages associated with this type of research. An important step is to understand the components of a medical database:

- 1) **The population.** Each database has a source population, comprised of the individuals whose medical experience its data represent. Many Danish medical databases are truly population-based. For example, the Civil Registration System (page 5) has a record for each person in the entire Danish population, enabling country-wide population-based studies.
- 2) **The medical event, diseases and other data.** All databases are abstracts in the sense that they only include selected data on events and other outcomes and contain only basic demographic information. In most healthcare databases, a numeric coding system is used to characterize the medical event or diagnoses covered. Coding systems used in databases may change over time, for example, as a result of better understanding of a particular condition necessitating a refined classification.
- 3) **The organisation of data collection and management.** In medical databases, many different individuals enter the data, introducing risk of substantial variation, error and missing data.

In the following sections we describe medical databases available for clinical epidemiology keeping in mind the three key elements describing a medical database.

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The Civil Registration System (CRS)

Aim:

The centralised Civil Registration System (CRS) was created in April, 1968. There were two main reasons for the establishment of the CRS:

- The ever-growing need for information about general personal data, especially addresses
- The need for a general identification of individuals, which could be used throughout the public administration. In particular, the need for collecting tax at source facilitated the establishment of the registration system

The purpose of the CRS is to administrate the personal identification number system and general personal data forwarded by the municipal registration offices to the CRS. Moreover, the CRS should supply personal data in a technically and/or economically suitable manner in compliance with the legislation governing registers and civil registration.

Population:

Persons who are born in Denmark or those who live or work in Denmark legally for a certain amount of time must register with the CRS.

Period:

The CRS encompasses persons who have lived in Denmark since April 2, 1968 and who have registered with the national registration offices. The registration began in Greenland on May 1, 1972, when the national registration act was extended to Greenland.

Data:

The CRS contains information about the personal civil registration number, name, address, marital status (including spouse), place of birth, citizenship, kinship (parents/children), declaration of incapacity, profession, membership of the Lutheran Church of Denmark, voting rights, municipal circumstances, registration notes and death. Changes regarding name, address, civil status and citizenship are updated without old data being deleted.

Record linkage:

Records in the civil registration system can be linked to all Danish registries containing civil registration numbers, e.g., the Danish Medical Birth Registry, the Danish National Registry of Patients, the Danish Psychiatric Central Registry, the Danish Cancer Registry, the Prescription Databases of the Central Denmark Region and the North Denmark Region, and the Danish Registry of Causes of Death.

Institution:

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Slotsholmsgade 10-12
1216 Copenhagen K
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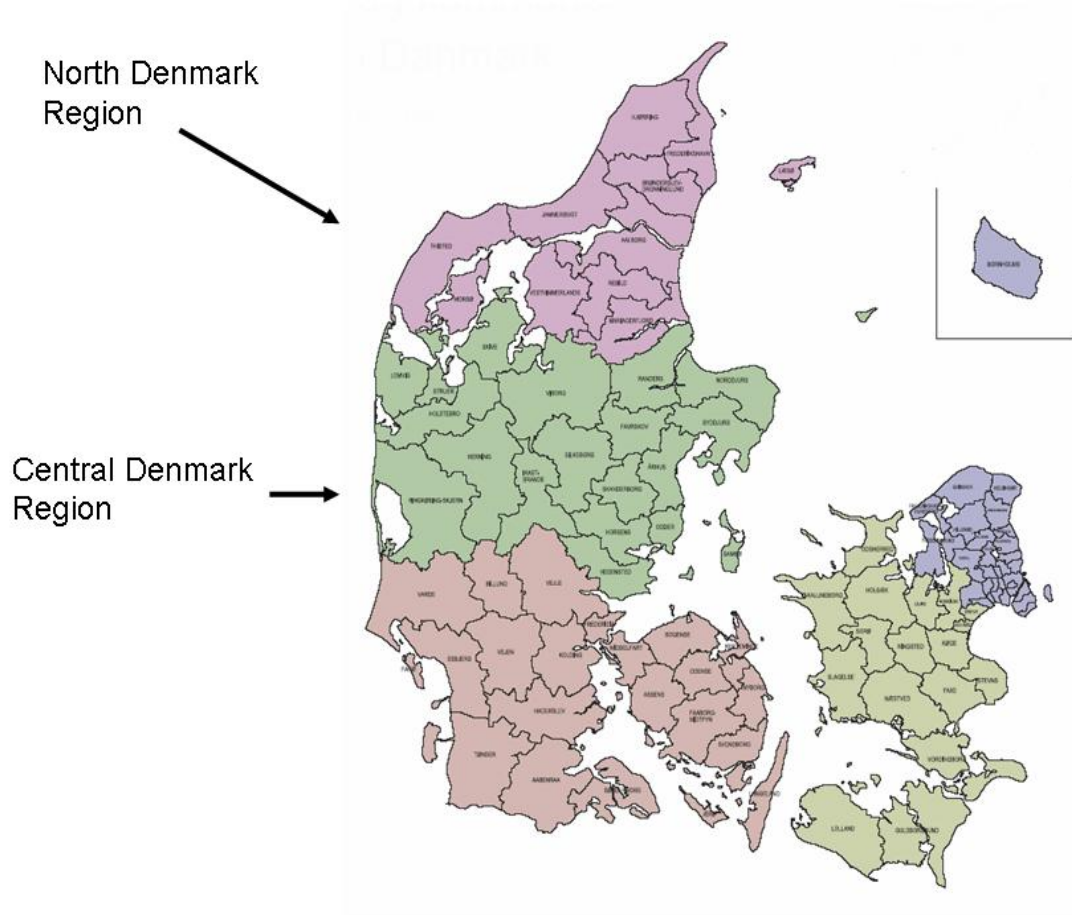
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Databases in Jutland, hosted by Department of Clinical Epidemiology



The Prescription Databases of the Central Denmark Region and the North Denmark Region

Aim:

Pharmacoepidemiological research for the study of longitudinal drug use, effectiveness and safety at the level of the individual.

Population:

All inhabitants of the former North Jutland, Aarhus, Ringkjøbing and Viborg counties (Since 2007: the Central Denmark Region and the North Denmark Region). In total, 1.8 million inhabitants (about 33% of the Danish population).

Period:

Former North Jutland County:	1989-2006 (complete coverage since February 1992)
Former Aarhus County:	1996-2006
Former Viborg County:	1998-2006
Former Ringkjøbing County:	1998-2006
North Denmark Region:	2007-
Central Denmark Region:	2007-

Data:

Community pharmacies collect data on all prescriptions filled by ambulatory patients and forward data on reimbursable medicines to their local regional Health Service section on a monthly basis. The main variables are: the civil registration number of the patient, name of the drug, ATC code, package identifier (enabling identification of brand, quantity and formulation of the drug), date of refill, code identifying the prescribing physician and code identifying the dispensing pharmacy.

Note: Over-the-counter medications such as low-dose aspirin or paracetamol are generally not registered in the databases unless the patient received individual reimbursement. Sedatives, hypnotics, oral contraceptives, and laxatives are not reimbursed generally and are thus not recorded in the databases. However, a chronic illness or a special need may qualify a patient for individual reimbursement by application. In these cases, prescriptions for medications that also are available over-the-counter, as well as prescriptions for sedatives, hypnotics, oral contraceptives and laxatives are recorded in the databases.

Record linkage:

The databases are merged into a single database and are linked to other Danish registries via civil registration numbers, e.g., the Danish Medical Birth Registry, the National Registry of Patients, the Danish Psychiatric Central Registry, the Danish Cancer Registry, the Civil Registration System and the Danish Registry of Causes of Death.

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The North Denmark Region Microbiological Bacteremia Research Database

Aim:

Data are collected with the following main purposes:

- 1) To enable complete surveillance of all episodes of bacteremia in a well-defined region in northern Denmark
- 2) To study risk factors and prognostic factors for bacteremia

Population:

All hospitalized patients with bacteremia in the former North Jutland County, Denmark (county population is approx. 500,000. The county is now part of the North Denmark Region).

Period:

From 1981 onwards.

Data:

Data include information on approx. 20,000 bacteremia episodes (~15,000 from 1992 onwards). Clinical and microbiological data are collected prospectively by medical doctors at the Department of Clinical Microbiology, Aalborg Hospital, Aarhus University Hospital. Main variables include: civil registration number, date and department of admission, a variable differentiating community- from hospital-acquired episodes (1992 onwards), focus (site) of infection (1992-), date of first positive blood culture, detection time in hours, microbiological species, antibiogram, and appropriateness of antimicrobial therapy (1992-). Since 1995, key data on *all* blood cultures (positive and negative) taken in North Jutland County are stored electronically.

Record linkage:

For individual projects, data can be linked to, among others, the Civil Registration System, the Danish National Registry of Patients, the Prescription Database of North Jutland County, the Danish Cancer Registry, the Intensive Care Database and the Danish Medical Birth Registry.

The database is maintained by the Department of Clinical Microbiology at Aalborg Hospital. A research version of the database including core variables is maintained at Department of Clinical Epidemiology.

Institution:

The research database is kept at:

Department of Clinical Epidemiology, Aarhus University Hospital
Olof Palmes Alle 43-45
8200 Aarhus N
Denmark

Selected key references:

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The Laboratory Information Systems (LABKA)

Aim:

Each of the former counties has its own laboratory information system (LABKA). The former counties affiliated with the Department of Clinical Epidemiology use either the LABKA system developed by CSC (Aarhus and North Jutland counties) or the system developed by B-data, which has later been taken over by WM-data (Ringkjøbing and Viborg counties). The databases were not designed for research purposes, but are part of the backbone of everyday clinical work. Hospital doctors order tests at a computer in their department, the orders are received electronically and carried out by the hospital bioanalysts, and the results are available online with no delay. Most general practitioners analyze C-reactive protein, haemoglobin, and blood sugar themselves, but all other laboratory tests will be analyzed in the hospital laboratories and will therefore also be recorded in the laboratory information systems.

Population:

All laboratory tests analyzed in hospital laboratories in the former Aarhus, North Jutland, Vejle, Ringkjøbing, and Viborg counties, i.e. all former counties, and current regions (i.e. the North Denmark Region and the Central Denmark Region) affiliated with Department of Clinical Epidemiology; therefore the data cover the population of these regions.

Period:

Data are updated at irregular intervals. The completeness of registration is not yet fully determined, particularly in the early years of registration. Presently, data from the former Aarhus County are considered complete from January 1, 1995 to December 31, 2006, as are data from the former North Jutland County from January 1, 1997 to March 31, 2005. Data from Ringkjøbing and Viborg counties are not yet available.

Data:

The data include the patient's civil registration number, the test name, the test's IUPAC-code (International Union for Pure and Applied Chemistry, see <http://www.iupac.org/> and http://www.labinfo.dk/English/ifcc_iupac_uk.asp) and/or a local analysis number, the result, the measurement unit, dates of ordering and carrying out the analysis, and a unique ID representing the hospital department or general practitioner who ordered the test.

Record linkage:

All necessary permissions have been granted. The Danish Data Protection Agency permits linking the laboratory test databases with the other databases available through the Department of Clinical Epidemiology.

The LABKA databases are hosted by several institutions, and it is presently unknown whether the transition from five counties to two regions will facilitate the acquisition of data. Department of Clinical Epidemiology has a research database with LABKA data.

Institution:

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Olof Palmes Alle 43-45
8200 Aarhus N
Denmark

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The Patient Administrative Systems (PAS)

Aim:

All regions (until 2007, counties) collect information on the activities of hospitals in order to handle resource management, and follow-up on activities, service goals and guarantees of treatment. This information is stored in the Patient Administrative Systems (PAS).

Population:

Residents of the Central Denmark Region and the North Denmark Region.

Period:

The hospitalizations have been registered since 1977. Visits to emergency units and outpatient hospital clinics have been registered since 1995.

Data:

All visits to non-psychiatric acute care hospitals in the two regions are covered. Administrative data registered include the patient's name, address, civil registration number, residence, and general practitioner. The recorded information also includes: dates of hospital admission and discharge, surgical procedures performed, and up to 20 discharge diagnoses, classified according to the International Classification of Diseases, 8th revision until December 31, 1993, and according to the 10th revision thereafter. Since 1995, similar data for outpatient clinic visits and emergency room visits have been registered. All coding of discharge diagnoses is done by the treating physician at the time of discharging a patient, whereas coding of surgical procedures is done by the surgeon in charge of the operation.

Record linkage:

The PAS of each region collects data to the National Registry of Patients. Thus, there is considerable overlap between the information accessible in the two registries.

Department of Clinical Epidemiology hosts a research database based on data from PAS of the former counties of North Jutland, Viborg, Ringkjøbing and Aarhus, covering approximately 1.8 million people. Since 2007, data are from the Central Denmark Region and the North Denmark Region, which together cover virtually the same population.

Institution:

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Selected key references:

Johnsen SP, Larsson H, Tarone RE, McLaughlin JK, Nørgård B, Friis S, Sørensen HT. Risk of hospitalization for myocardial infarction among users of rofecoxib, celecoxib, and other NSAIDs: a population-based case-control study. *Arch Intern Med.* 2005;165:978-984.

Thomsen RW, Riis A, Nørgaard M, Jacobsen J, Christensen S, McDonald CJ, Sørensen HT. Rising incidence and persistently high mortality of hospitalized pneumonia: 10-year population-based study in Denmark. *J Intern Med.* 2006;259:410-417.

The Aarhus University Intensive Care Database

Aim:

Data are collected with the following purposes:

- 1) To study incidence and risk factors for intensive care
- 2) To study predictors for short- and long-term morbidity and mortality following intensive care

Population:

All patients admitted to one of the three multi-disciplinary intensive care units of Aarhus University Hospital. Patients admitted to the ICUs for postoperative observation of less than 24 hours were not included. Data on approximately 25,000 intensive care unit admissions between 1999 and 2007 are currently available in the database; of these, 8,000 admissions included mechanical ventilation and 1,500 admissions included renal replacement therapy.

Period:

The database contains data on all post-1999 admissions and is updated annually.

Data:

Data are collected prospectively by intensive care physicians. The main variables include: civil registration number, date of hospital admission and discharge, department (medical/surgical), dates of admission and discharge to an intensive care unit, mechanical ventilation (no/yes – if yes: date of first and last day of ventilator), renal replacement therapy (no/yes – if yes: date of first and last day of renal replacement therapy).

Record linkage:

The cohort is linked to a number of clinical databases and administrative registries including: the Danish National Registry of Patients, the Civil Registration System, the Danish Psychiatric Central Registry, the Danish Registry on Regular Dialysis and Transplantation, the Danish Cancer Registry, the North Jutland Bacteraemia Database, the Prescription Databases of the North Denmark Region and the Central Denmark Region, and the Laboratory Information Systems.

Institution:

Department of Clinical Epidemiology, Aarhus University Hospital
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Selected key references:

Christensen S, Johansen MB, Thomsen RW, Pedersen L, Grijota M, Jensen R, Larsen KM, Larsson A, Tønnesen E, Sørensen HT. Preadmission statin use and one-year mortality among intensive care patients. Submitted.

Christensen S, Johansen MB, Pedersen L, Jensen R, Larsen KM, Larsson A, Tønnesen E, Sørensen HT. One-year mortality of alcoholic patients in intensive care. Submitted

Christensen S, Johansen MB, Christiansen CF, Jensen R, Lemeshow S, Sørensen HT. Comparison of Charlson Comorbidity Index with SAPS and APACHE Scores for prediction of mortality following intensive care. Submitted

The Western Denmark Heart Registry

Aim:

Data are collected with the following purposes:

- 1) To monitor and improve the quality of invasive heart procedures offered to patients in hospitals in western Denmark (South Denmark Region, Central Denmark Region, and North Denmark Region)
- 2) To enable clinical and health-service research on use of and outcomes following invasive heart procedures

Population:

Patients referred to invasive procedures, including coronary angiography, percutaneous coronary interventions (PCI) and cardiac valve and bypass surgery, at heart centres in Odense, Skejby and Aalborg and departments in Viborg, Herning, Vejle, Varde and Esbjerg. By May 2009, the registry contained data on 112,885 patients who have had coronary angiography at the centres, 48,104 patients treated with PCI and 24,665 patients who have been subject to cardiac valve or bypass surgery.

Period:

Registration of data began in 2000, but the database is not considered valid and complete until 2003.

Data:

For each procedure included in the registry, hospitals report administrative data, including civil registration number and dates of referral, admission, operation, and discharge. In addition, information regarding the actual procedure is reported, including possible complications. Finally, a number of demographic and clinical variables are reported, including age, gender, family history, the indication for intervention, number of affected vessels, euroSCORE, and smoking status. In total, approximately 200 variables are registered for each procedure.

Record linkage:

Data are linked to, among others, the Civil Registration System, the Danish National Registry of Patients, and the Prescription Databases of the Central Denmark Region and the North Denmark Region.

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Selected key references:

Jensen LO, Mæng M, Kaltoft A, Thayssen P, Hansen HHT, Bøttcher M, Lassen JF, Krussel LR, Rasmussen K, Hansen KN, Pedersen L, Johnsen SP, Sørensen HT, Thuesen L. Stent Thrombosis, Myocardial Infarction and Death following Drug-Eluting and Bare Metal Stent Coronary Interventions. *J Am Coll Cardiol*. 2007;50:463-470.

Mæng M, Jensen LO, Kaltoft A, Hansen HHT, Bøttcher M, Lassen JF, Thayssen P, Krusell LR, Rasmussen K, Pedersen L, Sørensen HT, Johnsen SP, Thuesen L. Stent thrombosis, myocardial infarction, and mortality following drug-eluting and bare-metal stent coronary interventions in Danish patients with diabetes mellitus. *Am J Cardiology*. 2008;102:165-172.

Jensen LO, Maeng M, Thayssen P, Kaltoft A, Tilsted HH, Lassen JF, Hansen KN, Krusell LR, Rasmussen K, Pedersen KE, Pedersen, Johnsen SP, Sørensen HT, Thuesen L. Clinical outcome

after primary percutaneous coronary intervention with drug-eluting and bare metal stents in patients with ST-segment elevation myocardial infarction. *Circ Cardiovasc Intervent.* 2008;1:176-184.

Jensen LO, Maeng M, Thayssen P, Kalsoft A, Tilsted HH, Lassen JF, Hansen KN; Bottcher M, Madsen M, Johnsen SP, Sørensen HT, Thuesen L. Long-term outcomes after percutaneous coronary intervention in patients with and without diabetes mellitus in Western Denmark. *Eur Heart J.* In press.

The Aarhus Endoscopy Registry

Aim:

The aim of the registry was to establish a research database including data from endoscopies performed at the Aarhus University Hospital, Aarhus County, Denmark.

Population:

All patients who had an endoscopy; esophagogastrosopy (GAS), endoscopic retrograde cholangiopancreatography (ERCP), and colonoscopy (COLO) in the former Aarhus County, Denmark.

Period:

Year	GAS, n	COLO, n	ERCP, n	Total, N
1975-1979	4,570	327	514	5,411
1980-1984	7,269	1,415	1,007	9,691
1985-1989	9,273	1,942	1,599	12,814
1990-1994	34,040	6,429	4,756	45,225
1995-1999	33,428	11,976	4,344	49,748
2000-2003	35,289	26,090	3,471	64,850
Total, N	123,869	48,179	15,691	187,739

Data:

Data are collected prospectively on all endoscopies performed at the hospitals in the former Aarhus County (hospitalized patients as well as outpatients). The registry comprises electronic information and paper records (including pathological diagnosis of biopsies taken and photo documentation of abnormalities) completed by the performing physician. The main variables in the electronic form are: the civil registration number, date of the procedure, hospital codes, and up to 30 diagnoses according to the International Classification of Diseases (ICD) system. The main variables in the paper records: the civil registration number, date of the procedure, description of the patient's symptoms and the procedure in text and by check lists. Data collection is still ongoing.

Record linkage:

For example, linkage to the nationwide population-based registries such as the Civil Registration System, the National Registry of Patients, Register of Medicinal Product Statistics, The Danish Cancer Registry, and the Danish Registry of Causes of Death.

Institution:

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8200 Aarhus N
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Selected key references:

Munk EM, Drewes AM, Gorst-Rasmussen A, Funch-Jensen P, Gregersen H, Nørgård B. Risk of gastrointestinal cancer in patients with unexplained chest/epigastric pain and normal upper endoscopy: A Danish 10-year follow-up study. *Dig Dis Sci.* 2007;52:1730-1737.

Munk EM, Drewes AM, Gorst-Rasmussen A, Gregersen H, Funch-Jensen P, Nørgård B. Risk of peptic ulcer, oesophagitis, pancreatitis, or gallstone in patients with unexplained chest/epigastric

pain and normal upper endoscopy: A 10-year Danish cohort study. *Aliment Pharmacol Ther.* 2007;25:1203-1210.

Munk EM, Nørgård B, Dethlefsen C, Gregersen H, Drewes AM, Funch-Jensen P, Sørensen HT. Unexplained chest/epigastric pain in patients with normal endoscopy as a predictor for ischemic heart disease and mortality: a Danish 10-year cohort study. *BMC Gastroenterol.* 2008;8:28.

The IN-hospital Medicine Database

Aim:

The primary aim of the database is to make it possible to study the association between various diseases and certain drugs, which are only dispensed at the hospital pharmacies. Previously, there has been no complete registration of drugs used at hospitals. The secondary aim is to establish a complete history of drug use for all residents in the former Aarhus County. This will be achieved by combining the IN-hospital Medicine Database with the Register of Medicinal Product Statistics.

Population:

Persons who have received drugs at a hospital in the former Aarhus County, Denmark.

Period:

From 1996 onwards. However, data are only complete from 2005 onwards.

Data:

Data are expected to come from three sources:

1. *The Electronic Patient File (EPJ)*: All drugs dispensed at hospitals in the former Aarhus County since the end of 2004 is registered in an EPJ-system. The data are entered by the nurses when handing out medicine to patients. These data are due to technical problems not yet available in the database.
2. *The Hospital Pharmacy at Aarhus University Hospital*: Certain drugs mixed and dispensed by the hospital pharmacy are registered as part of a pharmacy storage management system. The drugs registered include drugs used in treatment of cancer, sclerosis, HIV/AIDS and kidney failure. Drug data from this registry should, however, be validated thoroughly before use. Department of Clinical Epidemiology has a cooperation agreement with the hospital pharmacy.
3. *The Danish National Registry of Patients*: This can be used for research purposes. Despite an incomplete registration, some drugs can be found in this database. Here, it is possible to find older registrations not registered in the EPJ or drugs dispensed at other Danish hospitals. Drug data from this registry should be validated thoroughly before use. This registry also contains information of intoxications of medication, which is coded according to the ICD-10 classification system.

Record linkage:

Registration of civil registration numbers and delivery dates makes it possible to link the data to other databases.

Institution:

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Selected key references:

Flint C, Larsen H, Nielsen GL, Olsen J, Sørensen HT. Pregnancy outcome after suicide attempt by drug use: a Danish population-based study. *Acta Obstet Gynecol Scand.* 2002;81:516-522.

Qin P, Jepsen P, Nørgård B, Agerbo E, Mortensen PB, Vilstrup H, Sørensen HT. Hospital admission for non-fatal poisoning with weak analgesics and risk for subsequent suicide: a population study. *Psychol Med.* 2009;9:1-7.

Møller LR, Nielsen GL, Olsen ML, Thulstrup AM, Mortensen JT, Sørensen HT. Hospital discharges and 30-day case fatality for drug poisoning: a Danish population-based study from 1979 to 2002 with special emphasis on paracetamol. *Eur J Clin Pharmacol.* 2004;59:911-915.

National Registries, hosted and run by the National Board of Health

The Danish National Registry of Patients

Aim:

Data are collected with the following purposes:

- 1) To monitor the frequency of various diseases and treatments
- 2) To provide a sampling frame for longitudinal population-based and clinical research
- 3) To facilitate quality assurance in Danish healthcare services
- 4) To facilitate hospital physicians' access to patients' hospitalization history

Population:

All patients admitted to Danish somatic hospitals, emergency rooms, and outpatient clinics.

Period:

Admissions to hospitals are registered since 1977. Contacts to emergency rooms and outpatient clinics are registered since 1995.

Data:

Variables include, among others, administrative data, civil registration number, dates of admission and discharge, data on hospital and department, and diagnosis codes and surgical procedures. Some additional data can voluntarily be reported. The data are received from PAS (please see page 19). From 1977 to 1993, diagnosis codes were coded with reference to the 8th edition of the International Classification of Diseases (ICD-8); since 1994, they have been coded with reference to the 10th edition (ICD-10). The 9th edition (ICD-9) has never been used in Denmark. The diagnosis codes are registered at the time of discharge by the physician discharging the patient. From 1977 to 1995, procedure codes were coded with reference to a Danish classification of surgical procedures; since 1996, they have been coded with reference to a Danish version of the NOMESCO (Nordic Medico-Statistical Committee) Classification of Surgical Procedures. The procedure codes are registered immediately after surgery by the surgeon responsible for the procedure.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Smedby B, Schiøler G: Health classifications in the Nordic countries. Albertslund, Denmark: Schultz Information; 2006.
<http://nomesco-eng.nom-nos.dk/filer/publikationer/KlassifikationshistorieWeb.pdf>.

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Sørensen HT, Mellekjær L, Steffensen FH, Olsen JH, Nielsen GL. The risk of a diagnosis of cancer after primary deep venous thrombosis or pulmonary embolism. *N Engl J Med*. 1998;338:1169-1173.

Andersen TF, Madsen M, Jorgensen J, Mellekjær L, Olsen JH. The Danish National Hospital Register. A valuable source of data for modern health sciences. *Dan Med Bull*. 1999;46:263-268.

Sørensen HT, Mellekjær L, Olsen JH, Baron JA. Prognosis of cancers associated with venous thromboembolism. *N Engl J Med*. 2000;343:1846-1850.

Nørgård B, Fonager K, Sørensen HT, Olsen J. Birth outcomes of women with ulcerative colitis: a nationwide Danish cohort study. *Am J Gastroenterol*. 2000;95:3165-3170.

Sørensen HT, Mellekjær L, Skriver MV, Johnsen SP, Nørgård B, Olsen JH, Baron JA. Fever of unknown origin and cancer: a population-based study. *Lancet Oncol*. 2005;6:851-855.

Sørensen HT, Horvath-Puho E, Pedersen L, Baron JA, Prandoni P. Venous thromboembolism and subsequent hospitalization due to acute arterial cardiovascular events: a 20-year cohort study. *Lancet*. 2007;370:1773-1779.

The Danish Medical Birth Registry

Aim:

The registry has the following purposes:

- 1) To enable surveillance of the birth rate and other factors related to births in Denmark
- 2) To provide a basis for research in this field

Population:

Children born at home or in a hospital in Denmark.

Period:

From 1973 onwards.

Data:

The data are collected prospectively by midwives attending to birth. Each record includes civil registration numbers of the newborn and the mother. Data on newborns include gender, date of birth, multiplicity (singleton, twin, etc.), birth weight (grams) and length (cm), fetal presentation, gestational age (weeks), 1- and 5-minute Apgar scores (1978 onwards), mode of delivery, and birth presentation. Maternal variables include the number of previous stillbirths, live births (parity), age at delivery, marital status, smoking during pregnancy (1991 onwards), and citizenship. There is a code for home births and a code for the hospital where the birth occurred.

Coding of some variables has changed over the years, in particular, coding of fetal presentation has been expanded. Gestational age may be recorded in full completed weeks or in fractions of weeks. Documentation for this registry (in Danish) is available online from the National Board of Health.

Congenital malformations, delivery complications and maternal diseases tend to be under-reported in the MBR. These data can and should be drawn from the Danish National Registry of Patients. Availability of dates of hospital stay enables examination of episodes of maternal disease or fetal complications relevant to a given pregnancy.

Record linkage:

Data can be linked to any registry that uses civil registration number. Because maternal civil registration number is included in the baby's record, linkage to maternal records is also possible.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Kristensen J, Langhoff-Roos J, Skovgaard LT, Kristensen FB. Validation of the Danish Birth Registration. *J Clin Epidemiol.* 1996;49:893-897.

Sørensen HT, Sabroe S, Olsen J, Rothman KJ, Gillman MW, Fischer P. Birth weight and cognitive function in young adult life: historical cohort study. *BMJ.* 1997;315:401-403.

Knudsen LB, Olsen J. The Danish Medical Birth Registry. *Dan Med Bull.* 1998;45:320-323.

Nørgård B, Fonager K, Sørensen HT, Olsen J. Birth outcomes of women with celiac disease: a nationwide historical cohort study. *Am J Gastroenterol.* 1999;94:2435-2440.

Sørensen HT, Steffensen FH, Rothman KJ, Gillman MW, Fischer P, Sabroe S, Olsen J. Effect of home and hospital delivery on long-term cognitive function. *Epidemiology*. 2000;11:706-708.

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Mahon BE, Ehrenstein V, Nørgaard M, Pedersen L, Rothman KJ, Sørensen HT. Perinatal risk factors for hospitalization for pneumococcal disease in childhood: a population-based cohort study. *Pediatrics*. 2007;119:e804-812.

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Nørgaard M, Ehrenstein V, Mahon BE, et al: Febrile seizures and cognitive function in young adult life: a prevalence study among Danish conscripts. *J Pediatrics*. 2009;Jun 23. [Epub ahead of print]

Ehrenstein V, Rothman KJ, Pedersen L, Hatch EE, Sørensen HT. Pregnancy-associated hypertensive disorders and adult cognitive function among Danish conscripts. *Am J Epidemiol*. In press.

The Danish Cancer Registry

Aim:

Data on all Danish patients with incident cancers are registered with the following purposes:

- 1) To study the incidence and prevalence of cancer in Denmark
- 2) To plan and evaluate the facilities for diagnostic procedures and treatment of cancer in the public health service
- 3) To monitor the efficacy and performance of therapeutic measures against cancer (in the public health service)
- 4) To conduct cancer research

Population:

The registry records all incident cases of carcinoma, sarcoma, leukaemia, lymphoma, multiple myeloma, and mycosis fungoides in Denmark. In addition, the following tumour-like and benign lesions are recorded:

- 1) Papillomas of the urinary tract
- 2) Histologically benign tumours of the central nervous system and meninges
- 3) Carcinoma in situ and epithelial dysplasia diagnosed at biopsy or smear test of the cervix uteri.
- 4) Carcinoma in situ of the breast
- 5) Carcinoma in situ of the testicles
- 6) Benign tumours of intracranial glands (pinealomas, craniopharyngeomas, and pituitary gland tumours)
- 7) Carcinoid syndrome
- 8) Mola hydatidosa
- 9) Tumours of uncertain malignancy

Period:

From 1943 onwards.

Data:

Data are collected prospectively. Until 1987, reporting to the registry was voluntary and a small fee was paid for each notification form received. In 1987, reporting became mandatory for all medical doctors. During the period 1943-2003, registration was based on notification forms completed by hospital departments (including departments of pathology and forensic medicine) and practising physicians when a diagnosis of cancer was made clinically, at autopsy, or when changes were made to an initial cancer diagnosis. Manually recorded cases were supplemented by unreported cases identified by computerized links to the Danish National Registry of Patients and the Danish Registry of Causes of Death.

Since January 1, 2004, all notifications from hospital departments are reported electronically to the National Board of Health via the Danish National Registry of Patients, and since January 1, 2005, all practising physicians also report incident cases of cancer electronically to the National Board of Health. The information on diagnoses retrieved from hospitals and practising physicians are linked to the files of the National Pathology Register which holds information on all pathological examinations performed in Denmark since 2000. Furthermore, annual linkages are performed to the Danish Registry of Causes of Death.

During the period 1943-2003, tumours were classified according to a modified Danish version of the International Classification of Diseases, 7th revision (ICD-7). Since 1 January 1978, tumours have also been registered according to the topography and histology codes of the International Classification of Diseases for Oncology (ICD-O). From 1 January 2004, tumours are classified according to ICD-10. In addition, tumours diagnosed in the period 1978-2003 have been classified according to ICD-10 by conversion of the ICD-O codes.

Main variables: civil registration number, diagnosis (modified ICD-7 (1943-1977 (2003)), ICD-10 (1978-)), date of diagnosis, method of verification, extent of spread of the tumour at the time of diagnosis (local, regional, distant metastases, TNM from 2004), treatment given within four months of diagnosis (-2003), vital status (including date of death and migration), and topography and histology codes according to the first (ICD-O-1; 1978-2003) and third (ICD-O-3; 2004-) version of ICD-O.

Institution:

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2300 Copenhagen S
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Selected key references:

Sørensen HT, Møllekjær L, Steffensen FH, Olsen JH, Nielsen GL. The risk of a diagnosis of cancer after primary deep venous thrombosis or pulmonary embolism. *N Engl J Med.* 1998;338:1169-1173.

Sørensen HT, Møllekjær L, Olsen JH, Baron JA. Prognosis in patients with cancer associated with primary venous thromboembolism. *N Engl J Med.* 2000;25:1846-1850.

Jensen AR, Overgaard J, Storm HH. Validity of breast cancer in the Danish Cancer Registry. A study based on clinical records from one county in Denmark. *Eur J Cancer Prevent.* 2002;11:359-364.

Sørensen HT, Møllekjær L, Skriver MV, Johnsen SP, Nørgård B, Olsen JH, Baron JA. Fever of unknown origin and cancer: a population-based study. *Lancet Oncol.* 2005;6:851-855.

Langagergaard V, Gislum M, Skriver MV, Nørgård B, Lash TL, Rothman KJ, Sørensen HT. Birth outcome in women with breast cancer. *Br J Cancer* 2006;16:142-146.

Nørgaard M, Poulsen AH, Pedersen L, Gregersen H, Friis S, Ewertz M, Johnsen HE, Sørensen HT. Use of postmenopausal hormone replacement therapy and risk of non-Hodgkin's lymphoma: a Danish population-based cohort study. *Br J Cancer.* 2006;94:1339-1341.

The Danish Psychiatric Central Registry

Aim:

The registry has the following purposes:

- 1) To provide a research database
- 2) To enable long-term follow-up of psychiatric patients

Population:

All patients admitted to psychiatric hospitals and psychiatric wards in general hospitals in Denmark, the Faroe Islands, and Greenland. Since 1995, information on all psychiatric outpatient contacts has been included. The registry covers both adult and paediatric contacts.

Period:

The registry contains information dating from the 19th century to present. Paper-based systematic registration has been conducted since 1938. As of 1969, data on all psychiatric hospital admissions has been computerized. Since January 1, 1995, information about all outpatient contacts, including emergency room visits, has been included in addition to inpatient data.

Data:

In 1995, the Danish Psychiatric Central Registry became integrated into The Danish National Registry of Patients, and has, since then, received monthly updates from the latter. The National Board of Health is now responsible for data retrieval from the psychiatric departments. The registry covers the inpatient and outpatient facilities of the psychiatric health system, including community psychiatry. However, the activities in the social welfare systems and the educational system aimed at mentally ill people are not included.

The main variables are: civil registration number, marital status, admission and discharge dates (start and end date of a series of outpatient visits) and dates of outpatient treatment visits, manner of admission (voluntary or compulsory), all discharge diagnoses (ICD-8 until the end of 1993, and ICD-10 thereafter), municipality code, hospital code, authority referring the patient to treatment, the authority responsible for the patient after discharge, and, when applicable, date of death and cause of death.

Record linkage:

The registry can be linked to, e.g., the regional prescription databases, Register of Medicinal Product Statistics, the Danish Medical Birth Registry, the Danish National Registry of Patients, the Danish Cancer Registry, and the Civil Registration System.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Munk-Jørgensen P, Mortensen PB. The Danish Psychiatric Central Register. *Dan Med Bull.* 1997;44:82-84.

Jepsen P, Qin P, Nørgård B, Agerbo E, Mortensen PB, Vilstrup H, Sørensen HT. The association between admission for poisoning with paracetamol or other weak analgesics and subsequent admission for psychiatric disorder: a Danish nationwide case-control study. *Aliment Pharmacol Ther.* 2005;22:645-651.

Eaton WW, Byrne M, Ewald H, Mors O, Chen CY, Agerbo E, Mortensen PB. Association of schizophrenia and autoimmune diseases: linkage of Danish national registers. *Am J Psychiatry*. 2006;163:521-528.

Qin P, Jepsen P, Nørgård B, Agerbo E, Mortensen PB, Vilstrup H, Sørensen HT. Hospital admission for non-fatal poisoning with weak analgesics and risk for subsequent suicide: a population study. *Psychol Med*. 2009;9:1-7.

The Danish Registry of Causes of Death

Aim:

Data are collected with the purpose of supplying a basis for medical research, and are used for administrative purposes.

Population:

Residents of Denmark, The Faroe Islands, and Greenland.

Period:

Data have been collected since 1970 in Denmark and since 1983 from The Faroe Islands and Greenland. Until recently, data were only complete through 2001, but the registry is expected to be updated in 2008 to include complete data through 2006.

Data:

A death certificate must be filled for every Danish decedent. It is filled by the physician with the most accurate knowledge of the events that led to death. Thus, if the decedent was hospitalized at the time of death, the certificate is filled by a physician working in that hospital department; if the decedent was not hospitalized, it is filled by the decedent's general practitioner. The certificate contains information about the decedent's civil registration number, home address, occupation, time and place of death, a chain of one to four events that led to death, other diseases that may have contributed, the manner of death, and whether the decedent had been operated on. If an autopsy is performed, its findings are added to the death certificate by the pathologist conducting the autopsy.

Until 2007, the completed death certificate was mailed to the National Health Service where the supplied information on events that led to death, other diseases, and autopsy findings was interpreted and coded (with ICD-8 diagnosis codes through 1993 and with ICD-10 diagnosis codes from 1994 onwards) as one underlying cause of death and up to three additional immediate causes. These diagnosis codes were recorded in the Registry of Causes of Death along with the decedent's civil registration number, municipality of residence, marital status, age at death, manner of death (natural, accident, suicide, homicide, or unknown), place of death (own home, hospital, nursery home, or elsewhere (for accidental deaths, more details are recorded)), whether the decedent had recent surgery, and whether autopsy was conducted. If the death certificate had missing or incoherent information, the National Health Service would contact the physician who supplied it for corrections.

From 2007 onwards, data have been collected electronically, and so the data from the physicians who fill the death certificate enter the registry directly. It is currently unclear how this will affect the validity and completeness of the registry. The validity of the registry's data before 2007 is largely unknown, but one study found a low reproducibility of the events that led to death.

Record linkage:

Data are linked to the Danish Cancer Registry, the Danish National Registry of Patients and the Civil Registration System.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Gjersøe P, Andersen SE, Mølbak AG, Wulff HR, Thomsen OO. Reliability of death certificates. The reproducibility of the recorded causes of death in patients admitted to departments of internal medicine. *Ugeskr Laeger*. 1998;160:5030-5034. In Danish with English abstract.

Sørensen HT, Thulstrup AM, Mellekjar L, Jepsen P, Christensen E, Olsen JH, Vilstrup H. Long-term survival and cause-specific mortality in patients with cirrhosis of the liver: a nationwide cohort study in Denmark. *J Clin Epidemiol*. 2003;56:88-93.

de Luise C, Lanes SF, Jacobsen J, Pedersen L, Sørensen HT. Cardiovascular and respiratory hospitalizations and mortality among users of tiotropium in Denmark. *Eur J Epidemiol*. 2007;22:267-272.

The Danish "SCOR" database

In Danish: "Sundhedsstyrelsens Centrale Odontologiske Register" (the central dentistry registry of the National Board of Health)

Aim:

The aim of the database is to monitor the dental health among Danish children. According to the law of dental care for children, it is mandatory for dentists to report to the database for all Danish children at age 5, 7, 12, and 15. Each year, the National Board of Health publishes statistics based on the reporting. Separate statistics are available for each municipality and therefore many municipalities voluntarily report other age groups from 1 to 18 years in order to monitor dental health in age groups other than the mandatory ones.

Population:

All Danish children up to the age of 15.

Period:

The database was initiated in 1972. During the first year, children in first grade were reported and gradually additional age groups were included.

Data:

In each municipality, the child dental service invites the children in for dental examinations. At the examination either a pre-printed or an electronic form with the requested data is filled out and sent to the National Board of Health. The following data are reported: the civil registration number of the patient, data to identify the municipality, school and year in school, examination date, data on tooth type and eruption status, caries status of each tooth surface, data on gingival health, and malocclusion data. The form provides the option of reporting additional data of own choice, e.g., ethnicity, smoking, or BMI.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

The National Board of Health
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Denmark

Selected key references:

Helm S. Recording system for the Danish Child Dental Health Services. *Community Dent Oral Epidemiol.* 1973;1:3-8.

Poulsen S. Dental caries in Danish children and adolescents 1988-94. *Community Dent Oral Epidemiol.* 1996;24:282-285.

Poulsen S, Scheutz F. Dental caries in Danish children and adolescents 1988-1997. *Community Dent Health.* 1999;16:166-170.

Hansen I, Foldspang A, Poulsen S. Use of a national database for strategic management of municipal oral health services for Danish children and adolescents. *Community Dent Oral Epidemiol.* 2001;29:92-98.

Wogelius P, Poulsen S, Sørensen HT. Use of asthma-drugs and risk of dental caries among 5 to 7 year old Danish children: a cohort study. *Community Dent Health.* 2004;21:207-211.

Wogelius P, Dahllöf G, Gorst-Rasmussen A, Sørensen HT, Rosthøj S, Poulsen S. Dental caries among survivors of childhood cancer - a population-based observational study. *Pediatr Blood Cancer*. 2008;50:1221-1226.

The Primary Health Care Databases I

The National Health Insurance Service Registry (Sygesikringsregistret)

Aim:

Data are collected with the following purposes:

- 1) To administrate/reimburse health care services covered by the National Health Insurance (Den Offentlige Sygesikring) in the regions of Denmark
- 2) To provide a statistical basis for monitoring activities in the primary health care system for political and administrative use
- 3) To facilitate scientific investigations of public health

Population:

All permanent residents (more than three months) in Denmark.

Period:

The registry contains information on all services covered by the National Health Insurance since January 1, 1990.

Data:

The registry contains information on services provided by general practitioners, dentists, physiotherapists, chiropodists, chiropractors, psychologists and other specialists. As a prerequisite for reimbursement, the individual provider is responsible for registering any given health care service. The registry holds no data regarding health status or diagnoses. Influence of erroneous registrations, misclassifications, and possible fraud is considered to be extremely small, and the registry is known to have a high internal validity.

The registry contains information on:

1. Patient: civil registration number, age, gender, region of residence, municipality, number of teeth, etc.
2. Health provider: speciality, region of practice, practice number (ydernummer) (in cases of group practices, a single number may refer to several individual providers).
3. Health service: service code and service description of all: a) consultations, telephone consultations, and home visits, b) special diagnostic and therapeutic services (e.g. ECG and protoscopy), and c) other services (e.g. mother/child care, vaccinations, and collaboration services within social medicine). In addition, the time of service and size of fee covered by the National Health Insurance is registered.
4. Dates: week numbers and the year of service and reimbursement are kept and stored by The National Board of Health, but exact dates are only obtainable through CSC Computer Sciences Corporation.

Record linkage:

There are no links to other registries during formation of the National Health Insurance Service Registry. For more detailed information on the health provider, data may be linked to the Registry of Health Providers by means of the practice number.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Olivarius NF, Hollnagel H, Krasnik A, Pedersen PA, Thorsen H. The Danish National Health Service Register. A tool for primary health care research. *Dan Med Bull.* 1997;44:449-453.

Pedersen PA, Hollnagel H, Olivarius NF, Reusch S, Sørensen M, and Thorsen H. [Individual registration of children in the national health service. New possibilities for epidemiological research in primary health care]. *Ugeskr Laeger.* 1999;161:6351-6354. In Danish.

Vedsted P, Sørensen HT, Nielsen J, Olesen F. Variation in proportion of frequent attenders between Danish general practices. *Scand J Public Health.* 2004;32:188-193.

The In Vitro Fertilization Register

Aim:

Data are collected with the following purposes:

- 1) To enable surveillance of the in vitro fertilisation (IVF) treatment in Denmark
- 2) To contribute to research in relation to follow-up on maternal and infant health.

Population:

Danish women treated with IVF in both private and public IVF clinics in Denmark.

Period:

From 1994 onwards, statutory reporting of IVF techniques to the National Board of Health

Data:

It is obligatory for all clinics to report each treatment cycle to the registry. Data cover all treatments with IVF; intracytoplasmic sperm injection, frozen embryo replacement, and egg donations. The main variables are: reason for infertility, manner of fertilization and stimulation, number of eggs fertilized and placed into the woman's uterus, and whether fertilization resulted in a clinical pregnancy. Data on outcome of a clinical pregnancy are imported into the IVF Register from the Danish Medical Birth Registry (live birth, stillbirth) and from the National Patient Register (spontaneous abortion, induced abortion). For live-born children, data on civil registration number, date of birth, multiplicity of gestation (singleton, twin etc.), sex, birth weight, and five-minute Apgar score are obtained from the Danish Medical Birth Registry.

The IVF registry is updated annually.

Note. Data on assisted reproductive treatments other than in-vitro techniques, such as intrauterine insemination, are not reported to the National Board of Health at the time of writing. However, since 2001, intrauterine inseminations are reported to the Danish Fertility Society. Although reporting to the Danish Fertility Society is not mandatory, 35 clinics reporting intrauterine inseminations are thought to represent a large majority of the Danish treatment providers (Andersen & Erb, 2006).

Record linkage:

Records in the In Vitro Fertilization Registry are linked with the Danish Medical Birth Registry and the Danish National Registry of Patients.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Westergaard HB, Johansen AM, Erb K, Andersen AN. Danish National In-Vitro Fertilization Registry 1994 and 1995: a controlled study of births, malformations and cytogenetic findings. *Hum Reprod.* 1999;14:1896-1902.

Andersen AN, Westergaard HB, Olsen J. The Danish in vitro fertilisation (IVF) register. *Dan Med Bull.* 1999;46:357-360.

Westergaard HB, Johansen AM, Erb K, Andersen AN. Danish National IVF Registry 1994 and 1995. Treatment, pregnancy outcome and complications during pregnancy. *Acta Obstet Gynecol Scand.* 2000;79:384-389.

Pinborg A, Loft A, Schmidt L, Greisen G, Rasmussen S, Andersen AN. Neurological sequelae in twins born after assisted conception: a controlled national cohort study. *BMJ*. 2004;329:311.

Andersen AN, Erb K. Register data on Assisted Reproductive Technology (ART) in Europe including a detailed description of ART in Denmark. *Int J Androl*. 2006;29:12-16.

The Primary Health Care Databases II

Registry of Health Providers (Yderregistret)

Aim:

Data are collected with the following purposes:

- 1) To identify private health care providers in Denmark
- 2) To administrate/reimburse health care services covered by the National Health Insurance (Den Offentlige Sygesikring) in the regions of Denmark.

Population:

The registry covers the whole nation and comprises all health providers who perform businesses in accordance with the Law of National Health Insurance in Denmark.

Period:

The registry is complete from 1996 (lacks information on basic fees in 1995).

Data:

The registry contains detailed information on health care providers such as general practitioners, dentists, physiotherapists, chiroprodists, chiropractors, psychologists and other specialists (e.g., in anaesthetics, dermatology, rheumatology, neurosurgery, orthopaedic surgery, plastic surgery, psychiatry, paediatrics, ophthalmology, otology, laryngology). Providers are identified by a practice number (ydernummer) – a registration number within the health insurance system. Each number may refer to several providers, if, for example, two or three general practitioners have a medical practice partnership. In this case, it is not possible to obtain information about the individual doctor's activities in a practice, but only the partnership's activities as a whole can be examined.

The main variables are:

1. Provider: practice number, civil registration number(s), name, address, work telephone etc.
2. Provider person: civil registration number, name, gender, age, specialty etc.
3. Provider fees: basic fees, superannuation and other payments from the National Health Insurance (apart from the payment per provided service registered in The National Health Insurance Service Registry)
4. Number of patients per provider: the number of citizens insured in group 1 and group 6, respectively, is also reported.

Record linkage:

By means of the practice number, data can be linked to the National Health Insurance Service Registry.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Olivarius NF, Hollnagel H, Krasnik A, Pedersen PA, Thorsen H. The Danish National Health Service Register. A tool for primary health care research. *Dan Med Bull.* 1997;44:449-453.

Andersen M, Kragstrup J, Søndergaard J. How Conducting a Clinical Trial Affects Physicians' Guideline Adherence and Drug Preferences. *JAMA.* 2006;295:2759-2764.

The National Pathology Registry

Aim:

The aim of the registry is to provide data for analyses of utilization of resources in the Danish health care system. Furthermore, data from the registry are used in research and to measure the quality of diagnostics and treatment.

Population:

All individuals in Denmark who have had a histological examination of tissue, cell, or autopsy material.

Period:

January 1, 1997 onwards.

Data:

Data from histological examinations are reported by the pathologists, and with few exceptions all pathology departments in public hospitals have reported data since 1997. Since 2005, data reports have been mandatory for both privately and publicly employed pathologists. The following data are reported: the civil registration number of the patient, the municipality of residence, the referring department, the performing department, the date of the test, the histological specimens and procedures, and the histological diagnoses. The diagnoses primarily describe a specimen's topography and morphology, but a number of other features can also be described. All diagnoses are coded with reference to the international Systematized Nomenclature of Medicine (SNOMED).

Record linkage:

The National Pathology Registry is linked to the Danish Cancer Registry to secure the quality of the latter. Individual-level data can also be linked to several other registries through the civil registration number.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Jepsen P, Vilstrup H, Sørensen HT. Alcoholic cirrhosis in Denmark - population-based incidence, prevalence, and hospitalization rates between 1988 and 2005: a descriptive cohort study. *BMC Gastroenterol.* 2008;8:3.

Ettrup MS, Jensen AØ, Farkas DK, Engebjerg MC, Nørgaard M, Fryzek JP, Zhao S, Johansen P, Sørensen HT. Prevalence of bone marrow fibrosis in patients with adult chronic idiopathic thrombocytopenic purpura: A Danish nationwide study. In draft.

The Induced Abortion Registry

Aim:

Data are collected to maintain administrative statistics on legal, induced abortions among Danish women.

Population:

All female residents of Denmark undergoing a legal, induced abortion at a Danish hospital.

Period:

Since 1973 onwards.

Data:

The National Induced Abortion Registry has kept computerized records of all induced abortions performed since 1973. From 1973 to 1995, the physician responsible for the induced abortion reported data to the database on paper forms. From 1995 onwards, data have been extracted from the National Registry of Patients with diagnoses recorded according to the ICD-10 classification system. Surgical and medical procedures are coded separately. The type of drugs used for medical procedures (mifepristone, misoprostol, and other prostaglandin analogues) and their dosage are also recorded. The registry contains the following data: civil registration number of the patient, municipality of residence, variable to identify the hospital, dates of hospitalization, operation and discharge, gestational age at termination, indication and type of abortion procedure, and complications. From 1973 to 1995, civil status and parity (the number of previous live births and stillbirths) were also reported.

Record linkage:

Registry records can be linked to other databases.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Krebs L, Johansen AM, Helweg-Larsen K. [Reporting of induced abortions in 1994. A comparison between the data in the Registry of Legally Induced Abortions and the National Patient Registry] *Ugeskr Laeger*. 1997;159:1607-1611. In Danish.

Zhou W, Sørensen HT, Olsen J. Induced abortion and low birth weight in the following pregnancy. *Int J Epidemiol*. 2000;29:100-106.

Zhou W, Olsen J, Nielsen GL, Sabroe S. Risk of spontaneous abortion following induced abortion is only increased with short interpregnancy interval. *Obstet Gynaecol*. 2000;20:49-54.

Virk J, Zhang J, Olsen J. Medical abortion and the risk of subsequent adverse pregnancy outcomes. *N Engl J Med*. 2007;357:648-653.

The Registry of Congenital Abnormalities

Aim:

Data are collected to enable surveillance of congenital abnormalities and late (>12 week of gestation) miscarriages and to provide information for research in this field

Population:

Children born of women with a Danish civil registration number at a Danish hospital or at home.

Period:

From 1983 onwards.

Data:

From 1983 to 1994, data were based on manual registration forms. All doctors were obliged to report any congenital abnormality detected during the first year of life on special forms including a written description and a sketch of the congenital abnormality on a standardized drawing of a child. Late abortions and stillborns with visible congenital abnormalities were also included. The coding of diagnoses was designed specifically by the National Board of Health and was much more specific and detailed than in the International Classification of Diseases (ICD) system. From 1995 onwards, data have been reported electronically through the Danish National Registry of Patients according to the ICD-10 classification. The registry of congenital abnormalities contains information on stillborn and live born children and late miscarriages. The database contains supplementary information on the parents of the child, the delivery, the subtype of the congenital abnormality, and the chromosome anomaly.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Christensen K, Knudsen LB. Registration of congenital malformations in Denmark. *Dan Med Bull.* 1998;45:91-94.

Larsen H, Nielsen GL, Bendtsen J, Flint C, Olsen J, Sørensen HT. Predictive value and completeness of the registration of congenital abnormalities in three Danish population-based registries. *Scand J Public Health.* 2003;31:12-16.

The National Registry of Alcohol Treatment

Aim:

Data are collected with the following purposes:

- 1) To facilitate surveillance, evaluation, and future planning of alcohol treatment
- 2) To measure quality of diagnostics and treatment
- 3) To conduct research

Population:

Danish residents who follow treatment for alcohol abuse. The registry does not hold complete information on all people following treatment for alcohol abuse since such treatment is offered by both public and private institutions. It is mandatory to report to the registry for public institutions providing treatment, whereas registration is voluntary for private institutions.

Period:

Data have been collected since January 1, 2006.

Data:

The registry contains information on 1) the alcohol abuse (daily intake, kind of alcohol), 2) treatment during admission to hospital or outpatient treatment, 3) treatment programme, 4) social information (marital status, residence, children, education, job/unemployment).

Record linkage:

Through the civil registration number, data are linked to the National Board of Health's database on alcohol treatment.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

No information has been published yet, since the registry is still in the start-up phase.

The Registry of Drug Abusers Undergoing Treatment

Aim:

Data are collected with the following purposes:

- 1) To facilitate surveillance, evaluation, and future planning of treatment for drug abuse
- 2) To measure quality of diagnostics and treatment
- 3) To conduct research
- 4) To fulfil Denmark's international obligation to the European Monitoring Centre of Drugs and Drug Abusers (EMCDDA).

Population:

All drug abusers assigned to treatment by their municipality of residence.

Period:

Data have been collected since 1996.

Data:

The registry contains information on 1) the drug abuse (drugs taken, age at the first appearance with drug intake, risk behaviour (intravenous injection of drugs, sharing of instruments)), 2) treatment programme (type of treatment, institution, length of treatment), 3) social information (marital status, residence, children, education, job/unemployment).

Record linkage:

The drug abusers undergoing treatment are registered by their civil registration number. This number along with relevant information for the database is entered into a computerized reporting system in the National Board of Health's database of drug abusers undergoing treatment.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Not available.

The Danish National Diabetes Register

Aim:

Data are collected with the following purposes:

- 1) To monitor the occurrence of diabetes in the Danish population
- 2) To monitor the prognosis of diabetes by providing data on mortality and morbidity rates
- 3) To provide data for a system for continuous monitoring of quality of care
- 4) To be a resource for epidemiological research in the area of diabetes

Population:

Diabetic patients in Denmark.

Period:

From 1996 onwards.

Data:

The National Diabetes Register is based on data from the Danish National Registry of Patients, the National Health Insurance Service Registry, the Register of Medical Product Statistics, and the Civil Registration System. Individuals are classified as having diabetes if they are registered with at least one of the following criteria:

- A diagnosis of diabetes in the Danish National Registry of Patients, registered with one of the following codes: ICD-10: E10-14, H36.0, O24 (excluding O24.4), or ICD-8: 249, 250
- Chiropody for diabetic patients recorded in the National Health Insurance Service Registry
- Five blood glucose measurements within one year or two measurements per year in five consecutive years recorded in the National Health Insurance Service Registry.
- A second purchase of oral glucose-lowering drugs recorded in the Register of Medical Product Statistics within six months (except for women aged 20-39 years prescribed metformin alone).
- A second purchase of prescribed insulin recorded in the Register of Medical Product Statistics

Main variables include: civil registration number, gender, residence, date and cause of inclusion, date of death, as well as the fulfilment date for each of the inclusion criteria - if more than one.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Carstensen B, Kristensen JK, Ottosen P, Borch-Johnsen K. The Danish National Diabetes Register: trends in incidence, prevalence and mortality. *Diabetologia*. 2008;51:2187-2196

Kristensen JK, Drivsholm TB, Carstensen B, Steding-Jensen M, Green A. [Validation of methods to identify known diabetes on the basis of health registers]. *Ugeskr Laeger*. 2007;169:1687-1692. In Danish with English abstract.

The Conscription Registry

Aim:

The Danish National Board of Health keeps a copy of the nationwide conscription records, with the main purpose of making data available for research.

Population:

The population comprises Danish men reaching age 18 years, when they become draft-liable. (Women may volunteer to serve).

Period:

The National Board of Health has computerised data from 2006 onwards.

Data:

The registry contains data on men only. The mandatory evaluation to determine army fitness includes a health examination and intelligence testing. The main variables in the registry are civil registration number, date of evaluation, date of birth, years of education completed, occupation (if any), type of drivers' licence (if any), height, weight, hearing and visual acuity measured by standard methods, results of intelligence testing (using the Boerge Prien group intelligence test), a code indicating suitability for the army (fit, restricted fit, unfit), and, for men deemed restricted fit or unfit, a variable indicating the reason for restriction or rejection (in categories).

The registry is updated every six months.

Record linkage:

The data are linkable, via the conscripts' civil registration number, to individual-level birth, hospital, and demographic records in all other Danish registries. There may be more than one record per man in the Conscript Registry, as some men may be evaluated more than once.

Institution:

The National Board of Health
Islands Brygge 67
2300 Copenhagen S
Denmark

Selected key references:

Mortensen EL, Reinisch JM, Teasdale, TW. Intelligence as measured by the WAIS and a military draft board test. *Scand J Psychol.* 1989;30:315-318.

Other National Databases

The Integrated Database for Labour Market Research (IDA)

Aim:

The aim of this database is to create a basis for labour market research by linking all Danish citizens with Danish companies (both public and private organizations).

Population:

The database covers the entire population of Denmark, i.e., approximately 5.3 million citizens, and 230,000 companies.

Period:

The database contains annual data since 1980. Once a year (end of November), the employment status of every Danish citizen is registered in the database.

Data:

The data in IDA are based on other registries of Statistics Denmark, such as the Civil Registration System, the registry maintained by the tax authorities, and the registry that tracks unemployment (CRAM). IDA contains information on citizens, employment history, and companies. Information on the citizens includes their background characteristics (age, gender, etc.), family and marital relations, education, employment, unemployment, and income. For each citizen, the civil registration number is irreversibly replaced by a unique serial number. The registry contains variables for the type of employment, salary and ATP (a pension scheme), and changes in the employment. For the companies, the available data include background information (trade, ownership etc.), number of employees, the composition of the staff, and payroll.

Record linkage:

By means of the unique serial number provided by Statistics Denmark, data may be linked to other registries by Statistics Denmark.

Institution:

Statistics Denmark
Sejrøgade 11
2100 Copenhagen Ø
Denmark

Access to the data for scientific purposes is facilitated through Statistics Denmark. To obtain data, the research service unit at Statistics Denmark requests a project protocol, and will thereafter upload data onto UNIX-machines at Statistics Denmark. Access to the data occurs subsequently through an on-line system by use of a user-specific token (RSA SecureID-card) and passwords.

Selected key references:

Thomsen RW, Johnsen SP, Olesen AV, Mortensen JT, Bøggild H, Olsen J, Sørensen HT. Socioeconomic gradient in use of statins among Danish patients: population-based cross-sectional study. *Br J Clin Pharmacol*. 2005;60:534-542.

Horsdal HT, Johnsen SP, Søndergaard F, Rungby J. Type of preadmission glucose-lowering treatment and prognosis among patients hospitalised with myocardial infarction: a nationwide follow-up study. *Diabetologia*. 2008;51:567-574.

Horsdal HT, Olesen AV, Gasse C, Sørensen HT, Green RC, Johnsen SP. Use of statins and risk of hospitalization with dementia: A Danish population-based case-control study. *Alzheimer Dis Assoc Disord*. 2009;23:18-22.

<http://www.dst.dk/TilSalg/Forskningservice/Fsedatabaser/IDA.aspx>

The Danish Registry of Childhood Cancer (DBCR)

Aim:

The registry was established in 2003 by merging information in different local databases on childhood cancer. Data are collected with the following purposes:

- 1) To monitor the occurrence of childhood cancer
- 2) To improve and assure the quality of treatment of childhood cancer
- 3) To support and initiate clinical research in childhood cancer
- 4) To identify patients for further examination regarding occurrence of long-term damage due to illness and treatment

Population:

Children (younger than 19 years) who live in Denmark and have been diagnosed with cancer.

Period:

From 1985 onwards.

Data:

The registry is based on existing clinical databases: the child cancer database at Rigshospitalet, databases from children's wards in Odense, Aalborg and Aarhus, the Western Denmark brain tumour database, the ALL (acute lymphoblastic leukaemia) database of the Nordic Society of Paediatric and Haematology and Oncology, registries on Non-Hodgkin lymphoma and acute myeloid leukaemia, the Danish retinoblastoma database, the Danish neuroblastoma database and the Ole Raaschou-Nielsen brain tumour database. Information is also being retrieved from patient charts and discharge files. In addition, the registry contains information from the Danish Cancer Registry and the Civil Registration System.

Key variables include: name, civil registration number, age, gender, main and subgroup diagnoses, time of diagnosis, treatment, time of treatment, treatment results, and recurrence. The registry is regularly updated and contains an annual follow-up on patients and results of treatment. For children diagnosed before 2003, the registry only holds information on identity, hospital, diagnosis (type and date) and vital status.

Record linkage:

Each year, the registry is linked to the Civil Registration System in order to update the patients' vital status.

Institution:

DBCR
Department of Paediatrics A4
Skejby Sygehus
Brendstrupgaardvej 100
8200 Aarhus N
Denmark

Selected key references:

Not available.

The Register of Medicinal Product Statistics

Aim:

This database aims at providing complete statistics on the use and cost of drugs in the primary health care system and in the hospital sector in Denmark.

Population:

The entire population of Denmark (i.e. 5.3 million people).

Period:

The database was initiated in January, 1994 and is updated monthly. It is complete from 1995 onwards.

Data:

The statistics are based on reports submitted to the Register of Medical Product Statistics by pharmacies, hospital pharmacies and the Danish Serum Institute. However, only the reports from the pharmacies have individual-based information, as they contain data on all prescriptions for drugs dispensed from the Danish pharmacies. These data on prescription drugs are registered for each individual patient, and the civil registration number is irreversibly replaced by a unique serial number.

The main variables are: the unique serial number, age, sex, information on the dispensed drug (ATC-code, name, package size, formulation and quantity), date of transaction, county of residence of the presenter, the dispensing pharmacy, the prescriber of the drug, whether the drug was prescribed to a child, the pharmacy selling price, and other reimbursement variables. The indication for treatment and prescribed daily dose is not registered.

Record linkage:

By means of the patients' unique serial number, data may be linked to the other registries by Statistics Denmark.

Institution:

While the Danish Medicines Agency governs the Register of Medicinal Product Statistics, a complete copy is routinely transferred to Statistics Denmark. Access to the data for scientific purposes is facilitated through Statistics Denmark to all other major health registries.

Statistics Denmark
Sejrøgade 11
2100 Copenhagen Ø
Denmark

Selected key references:

<http://www.dst.dk/TilSalg/Forskningservice/Fsedatabaser/LMDB.aspx>

Rasmussen S. [Registries on health] Dansk Institut for Klinisk Epidemiologi, 1997;128. In Danish.

Nørgård B, Pedersen L, Christensen LA, Sørensen HT. Drug use in women with Crohn's disease and birth outcomes: a Danish nationwide cohort study. *Am J Gastroenterol.* 2007;102:1406-1413.

Horsdal HT, Johnsen SP, Søndergaard F, Rungby J. Type of preadmission glucose-lowering treatment and prognosis among patients hospitalised with myocardial infarction: a nationwide follow-up study. *Diabetologia.* 2008;51:567-574.

Pedersen L, Nørgaard M, Rothman KJ, Sørensen HT. Loratadine during pregnancy and hypospadias. *Epidemiology*. 2008;19:359-360.

Horsdal HT, Olesen AV, Gasse C, Sørensen HT, Green RC, Johnsen SP. Use of statins and risk of hospitalization with dementia: a Danish population-based case-control study. *Alzheimer Dis Assoc Disord*. 2009;23:18-22.

The Danish Multiple Sclerosis Registry (DMSR)

Aim:

Data are collected with the following purposes:

- 1) To enable surveillance of incidence of multiple sclerosis in Denmark
- 2) To provide data for research of the underlying causes and prognostic variables in multiple sclerosis
- 3) To monitor the effect of new treatments

Population:

Patients diagnosed with multiple sclerosis in all hospital departments of neurology in Denmark, including MS rehabilitation centres, departments of pathology and practicing neurologists. Included are patients diagnosed after 1921 and alive in 1948, and all patients diagnosed thereafter.

Period:

The DMSR was formally established in 1956, but registration began in 1949.

Data:

Data include information about date of birth, sex, date of diagnosis of multiple sclerosis, first clinical symptom and diagnostic category, among others. Since 1996, data on beta-interferon treatment for relapsing-remitting multiple sclerosis (RRMS) have been included in the database.

Record linkage:

Data from this registry are linked to the Civil Registration System, the Danish National Registry of Patients and the Danish Registry of Causes of Death. Data can also be linked to other Danish registries through the Civil Registration System.

Institution:

Rigshospitalet
Blegdamsvej 9
2100 Copenhagen Ø
Denmark.

Selected key references:

Koch-Henriksen N, Sørensen PS. The Danish National Project of interferon-beta treatment in relapsing-remitting multiple sclerosis. The Danish Multiple Sclerosis Group. *Mult Scler*. 2000;6:172-175.

Koch-Henriksen N, Rasmussen S, Stenager E, Madsen M. The Danish Multiple Sclerosis Registry. History, data collection and validity. *Dan Med Bull*. 2001;48:91-94.

Hansen T, Skytthe A, Stenager E, Petersen HC, Bronnum-Hansen H, Kyvik KO. Concordance for multiple sclerosis in Danish twins: an update of a nationwide study. *Mult Scler*. 2005;11:504-510.

Brønnum-Hansen H, Stenager E, Hansen T, Koch-Henriksen H. Survival and mortality rates among Danes with MS. *Int MS J*. 2006;13:66-71.

The Cerebral Palsy Registry

Aim:

Data are collected with the following purposes:

- 1) To estimate the birth prevalence of cerebral palsy (CP) in Denmark and to analyse changes over time
- 2) To relate changes in the birth prevalence of CP to pre- and perinatal conditions
- 3) To describe changes in the proportions of subtypes and severity of CP
- 4) To identify cases for specific sub-studies (risk factors, treatment, and social consequences)
- 5) To describe the need for social and health services for people with CP

Population:

Children born with congenital cerebral palsy with events occurring before 28 days of age.

Period:

The registry (established in 1968) includes children born in and with residence in the eastern part of Denmark (Funen and Zealand). From 2001 onwards, the registry covers all of Denmark. Collection of data is based on voluntary reports from a specific contact person in all paediatric departments in eastern Denmark. To complete registration, records of children born later than 1978 have been linked with the National Registry of Patients.

Data:

Variables include, among others: CP subtype, severity of motor handicap (ability to walk), orthopaedic operations, accompanying nervous system disease (mental retardation, epilepsy, and problems with hearing, vision, speech), demographic data on the child and mother, information on chronic maternal disease and complications in pregnancy, at birth, and in the neonatal period (gestational age, birth weight, mode of delivery, Apgar score, congenital malformations).

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

National Institute of Public Health
Øster Farimagsgade 5
1399 Copenhagen C
Denmark

Selected key references:

Topp M, Langhoff-Roos J, Uldall P. Validation of a cerebral palsy register. *J Clin Epidemiol.* 1997;50:1017-1023.

Uldall P, Michelsen SI, Topp M, Madsen M. The Danish Cerebral Palsy Registry. A registry on a specific impairment. *Dan Med Bull.* 2001;48:161-163.

White-Koning M, Arneaud C, Dickinson HO, Thyen U, Beckung E, Fauconnier J, McManus V, Michelsen SI, Parkes J, Parkinson K, Schirripa G, Colver A. Determinants of child-parent agreement in quality-of-life reports: A European study of children with cerebral palsy. *Pediatrics.* 2007;120:e804-814.

The Danish Renal Biopsy Register (DANYBIR)

Aim:

To accumulate computer-based comprehensive pathologic and clinical data concerning all renal biopsies performed in Denmark in order to:

- 1) Study the epidemiology of medical renal disease
- 2) Serve as a source for identifying patients with rare renal diseases

Population:

Patients who had a renal biopsy analysed at one of the four university hospital based departments of pathology which analyse more than 90% of all renal biopsies in Denmark.

Period:

From 1985 onwards.

Data:

Data are collected prospectively by pathologists simultaneously to the analysis of the renal biopsy. Main variables include: patients' civil registration number, pathology department, biopsy date, up to three clinical diagnoses (e.g., hypertension, nephrosis), renal function (normal, azotemia, uremia), up to four pathological diagnoses using the SNOMED classification, presence of immune deposition, and existence of electron microscopic analysis (but not the result). The register is updated annually. The annual number of biopsies has remained constant around 570 per year (200 from renal allografts).

Record linkage:

The register is routinely linked to the Civil Registration System, The National Registry of Patients, and the Danish Register for Patients on Chronic Dialysis. Linkage to the Cancer Registry and the Danish Registry of Causes of Death has also been carried out.

Institution:

Department of Nephrology B
Copenhagen University Hospital in Herlev
Herlev Ringvej 75
2730 Herlev
Denmark

Selected key references:

Heaf J. The Danish Renal Biopsy Register. *Kidney Int.* 2004;66:895-897.

The Danish Cytogenetic Central Register

Aim:

The registry has the following purposes:

- 1) To provide an overview of the cytogenetic service in Denmark, including trends in prenatal diagnosis
- 2) To gather data for use in pre- and postnatal genetic counselling
- 3) To avoid unnecessary repetition of chromosome examinations
- 4) To provide a basis for a better understanding of the nature of the chromosomal diseases, including type, prevalence, and potential risk factors

Population:

The registry contains information on persons undergoing cytogenetic examination in Denmark.

Period:

From 1960 onwards.

Data:

The register is based on reports from the cytogenetic laboratories in the entire country.

The variables include, among others:

1. *Patient variables*: civil registration number, karyotype, civil registration number of the mother, father, and proband (the first known family member affected by a given disorder), patient relationship to the proband, and date of death, if applicable.
2. *Postnatal variables*: group (abnormal, variant, normal), sex, karyotype group (syndromes/translocations etc.), cell type (blood/skin etc.), heredity (maternal/paternal).
3. *Prenatal variables*: cell type (AM/CVS), first day of last menstrual period of the mother, indication, karyotype group (syndromes/translocations etc.), group (abnormal, variant, normal), alpha-fetoprotein, ultrasound due to abnormality, multi-card code (more examinations of the same pregnancy, including twin and triplet pregnancies), gestational age, outcome of previous pregnancies, heredity (maternal/paternal), the karyotype of the foetus, result (of monogenic examination), abortion code (spontaneous/induced), indication for the abortion and date of abortion.
4. *Abortions/stillborn*: type (spontaneous, induced), karyotype, group (abnormal, variant, normal), sex, karyotype group (syndromes/translocations etc.), gestational age, cell type (blood/skin etc.), and heredity (maternal/paternal).

Record linkage:

Registration by the unique civil registration number enables linkage to other databases.

Institution:

The Danish Cytogenetic Central Register
Aarhus Hospital
Nørrebrogade 44, building 12
8000 Aarhus C
Denmark

Selected key references:

[The Danish Cytogenetic Central Register]. In Danish. Available at:
http://www.sundhed.dk/wps/portal/_s.155/1921?_ARTIKELGRUPPE_ID_=1044050606093228

Bojesen A, Juul S, Birkebæk NH, Gravholt CH. Morbidity in Klinefelter Syndrome: A Danish Register Study Based on Hospital Discharge Diagnoses. *J Clin Endocrinol Metab.* 2006;91:1254-1260.

Hasle H, Clemmensen IH, Mikkelsen M. [The incidence of cancer in patients with Down's Syndrome] *Ugeskr Laeger*. 2000;162:4535-4539. In Danish.

Clinical Databases

Centre for Clinical Databases (North)

Centre for Clinical Databases (North) is one of three Danish centres for clinical databases, which have been established in order to support the national clinical quality databases. The other two centres are Centre for Clinical Databases (East) and Centre for Clinical Databases (South), based in Glostrup and Odense, respectively.

Centre for Clinical Databases (North) provides health professional, epidemiological, biostatistical, IT-related and communication-related expertise in relation to development and running of clinical quality databases. The Centre is a section of Department of Clinical Epidemiology at Aarhus University Hospital, and it is affiliated with the health secretariat of the Central Denmark Region.

The requirements for the centres for clinical databases are determined by Danish Regions, which is an association of the five Danish administrative units called regions.

Clinical quality databases

A clinical quality database is a registry containing selected quantifiable indicators. Based on the individual patient's disease period, the indicators can help assess part of or the overall quality of the efforts by the healthcare system and the subsequent results. The collected data are used to monitor the quality of treatment in order to regularly evaluate the options for improving the quality level.

Quality indicators are defined as measurable variables that are applied in order to monitor and evaluate quality of treatment. The indicators thus facilitate monitoring of important elements of an entire disease period.

The clinical quality databases must comply with the following requirements before they can be implemented:

- They must be registered in accordance with the act on personal data.
- They must be approved by the National Board of Health as a clinical quality database, and thus they must be nationwide or cover one or more of the five regions. (For more information (in Danish) on the requirements, please see www.regioner.dk under "Service og Administration")

Databases that fulfil these requirements can apply for financial support from the Danish Regions' database pool.

The National Indicator Project

Some of the clinical quality databases of Centre for Clinical Databases (North) are part of the National Indicator Project (NIP). NIP was established within the Danish healthcare system in 2000. The purpose of NIP is to monitor the quality of care provided by the hospitals to groups of patients with specific medical conditions. The aim is to make patients, families, doctors, nurses and other healthcare professionals aware of the extent to which the completion and treatment outcomes correspond to the standards expected from a well-functioning healthcare service.

So far, focus is on the following eight conditions:

- Acute surgery - Centre for Clinical Databases (North)
- Stroke - Centre for Clinical Databases (North)
- Hip fractures - Centre for Clinical Databases (North)
- Chronic obstructive pulmonary disease - Centre for Clinical Databases (North)
- Diabetes - Centre for Clinical Databases (East)
- Heart failure - Centre for Clinical Databases (East)
- Schizophrenia - Centre for Clinical Databases (East)
- Lung cancer - Centre for Clinical Databases (South)

Nationwide reports on NIP results are published once a year. These annual reports, which are in Danish, are accessible on www.sundhed.dk. In addition, the individual hospitals receive quarterly reports on their respective patients. The results are examined by doctors, nurses and other health care professionals involved in treating patients. The objective is to identify areas with adequate treatment quality as well as areas with room for improvement.

NIP was initiated by a number of Danish institutions, including the Ministry of Internal Affairs, the Ministry of Health, the National Board of Health, the Centre for Evaluation and Assessment of Medical Technology, the Danish Association of Danish Regions, the five individual regions, the Danish Nursing Association, the Joint Danish Nursing Societies, the Danish Physiotherapists' Association, the Occupational Therapists' Association, the Danish Medical Association, and The Danish Medical Society.

NIP is managed by the Central Denmark Region.

More information on The Danish National Indicator Project is available at: www.nip.dk

The Danish Rheumatologic Database: DANBIO - DRD

Aim:

The registry has the following purposes:

- 1) To improve the quality of treatment of rheumatoid arthritis (RA) patients (and other rheumatologic diseases such as psoriatic arthritis and ankylosing spondylitis) who receive tumour-necrosis alpha blockers or other biologic or disease-modifying treatments by monitoring treatment efficacy and adverse events
- 2) To improve the quality of treatment of rheumatoid-arthritis patients with early disease
- 3) To provide an IT platform for clinical research in rheumatology

Population:

All adult RA patients with newly diagnosed disease and all patients who receive biologic treatment for a rheumatologic condition are registered at baseline and followed prospectively.

Period:

The registration of biologically treated patients began in October 2000. Registration of early RA began in January 2006, and registration of newly diagnosed RA in January 2008.

Data:

The registry is nationwide, with all 26 rheumatic departments in Denmark reporting to it. The coverage is more than 90%. The main variables registered are: civil registration number, name, age, gender, residence, hospital, diagnosis, year of symptoms' onset, year of diagnosis, previous disease-modifying anti-rheumatic drugs (DMARD), body weight and height.

Disease activity is monitored longitudinally (at least twice a year), and data are collected on: number of swollen and tender joints (0-28), serum C-reactive protein, pain score, patient global score, physician global score, health assessment questionnaire (HAQ), X-rays of hands, wrists and forefeet (at baseline and after 1 and 2 years).

Medical treatment is registered longitudinally (at least twice a year) includes: DMARD, biologic drug, use of analgesics, glucocorticoids. Adverse events are registered at each visit and are also reported to the Danish Medicines Agency.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

DANBIO
Hvidovre Hospital
Kettegård Alle 30
2650 Hvidovre
Denmark

Contact person: Consultant, PhD Merete Lund Hetland; e-mail: merete.hetland@dadlnet.dk; phone: +45 36322277 or Consultant Annette Hansen; e-mail: annette.hansen@danbio-online.dk

The registry is affiliated with Centre for Clinical Databases (East).

Selected key references:

Hetland ML, Unkerskov J, Ravn T, Friis M, Tarp U, Andersen LS, Petri A, Khan H, Stenver DI, Hansen A, Østergaard M. Routine database registration of biological therapy increases the report of adverse events twenty-fold in clinical practice. First results from the Danish Database (DANBIO). *Scand J Rheumatol*. 2005;34:40-44.

Hetland ML. DANBIO – a nationwide registry of biological therapies in Denmark. *Clin Exp Rheumatol*. 2005;23(5 Suppl 39):S205-207.

Hjardem E, Hetland ML, Østergaard M, Krogh NS, Kvien TK. Prescription practice of biological drugs in rheumatoid arthritis during the first three years of post-marketing use in Denmark and Norway: criteria are becoming less stringent. *Ann Rheum Dis*. 2005;64:1220-1223.

Østergaard M, Unkerskov J, Linde L, Krogh NS, Friis M, Ravn T, Ringsdal VS, Petri A, Andersen LS, Tarp U, Hansen A, Hjardem E, Hetland ML. Low remission rates but long drug survival in rheumatoid arthritis patients treated with infliximab or etanercept – results from the nationwide Danish "DANBIO" database. *Scand J Rheum*. 2007;36:151-154.

Hjardem E, Østergaard M, Pødenphant J, Tarp U, Andersen LS, Bing J, Peen E, Lindegaard HM, Ringsdal VS, Rødgaard A, Skøt J, Hansen A, Mogensen HH, Unkerskov J, Hetland ML. Do rheumatoid arthritis patients benefit from switching to a second biological drug in clinical practice? *Ann Rheum Dis*. 2007;66:1184-1189.

Hetland ML, Lindegaard HM, Hansen A, Pødenphant J, Unkerskov J, Ringsdal VS, Østergaard M, Tarp U. Do changes in prescription practice in patients with rheumatoid arthritis treated with biologics affect treatment response and adherence to therapy? Results from the nationwide DANBIO registry. *Ann Rheum Dis*. 2008;67:1023-1026.

Dreyer L, Mellekjær L, Hetland ML. [Cancer in arthritis patients after anti-tumour necrosis factor therapy] *Ugeskr Laeger*. 2009;171:506-511. In Danish with English abstract.

The Danish Colorectal Cancer Group (DCCG) Database

Aim:

The database was founded in 1994 by a subgroup of the Danish Surgical Society – the Danish Colorectal Cancer Group (DCCG), which is a multidisciplinary cancer group (now including radiologists, oncologists, surgeons and pathologists). Data are collected with the following purposes:

- 1) To unify procedures for diagnosis, treatment and follow-up on colorectal cancer
- 2) To improve and assure the quality of treatment of colorectal cancer
- 3) To reach the objectives for quality as described by the Danish Surgical Society and the National Board of Health
- 4) To support and initiate clinical colorectal cancer research

Population:

Patients with a first-time diagnosis of colorectal adenocarcinoma diagnosed or treated in surgical departments in Denmark. By the end of 2008, approximately 25,000 patients were registered in the database.

Period:

1994 to May 2001: patients with rectal cancer

May 2001 onwards: patients with colorectal cancer

Data:

Data are collected by all surgical departments and are prospectively entered into the registry. Data are retrieved through questionnaires filled in by the patients (height, weight, comorbidity, symptoms, alcohol and tobacco consumption, self perceived physical fitness, and general health), and the surgeons (diagnostics performed, staging, treatment, postoperative complications, planned follow-up). From 2005 onwards, reporting has been done via the Internet.

The completeness of data is validated monthly by linkage to the Danish National Registry of Patients. The completeness of patient registration has been close to 95% since 2002. All departments are notified of missing data and logical errors in the questionnaire responses.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

Danish Colorectal Cancer Group
Department of Surgery K
Bispebjerg Hospital
Bispebjerg Bakke 23
2400 Copenhagen NV
Denmark

Contact person: Head of department, MD, Henrik Harling, e-mail: hh06@bbh.regionh.dk; phone: +45 35312858.

The database is affiliated with Centre for Clinical Databases (East).

Selected key references:

Annual review 2006, DCCG.

http://www.kliniskedatabaser.dk/doks/432069700_AArsrapport_DCCG_2006.pdf

Bülow S, Christensen IJ, Harling H, Kronborg O, Fenger C, Nielsen HJ. Recurrence and survival after mesorectal excision for rectal cancer. A prospective study with matched historic controls. *Br J Surg*. 2003;90:974-980.

Nickelsen TN, Harling H, Kronborg O, Bülow s, Jørgensen T. [The completeness and quality of the Danish Colorectal Cancer clinical database on colorectal cancer]. *Ugeskr Laeger*. 2004;166:3092-3095. In Danish.

Harling H, Bülow S, Kronborg O, Møller LN, Jørgensen T. Danish Colorectal Cancer Group. Survival of rectal cancer patients in Denmark during 1994-99. *Colorectal Dis*. 2004;6:153-157.

Nickelsen TN. Treatment of colorectal cancer. Ph.D. Thesis. Glostrup University Hospital. Denmark, 2005.

Harling H, Bülow S, Møller LN, Jørgensen T. Danish Colorectal Cancer Group. Hospital volume and outcome of rectal cancer surgery in Denmark 1994-99. *Colorectal Dis*. 2005;7:90-95.

Iversen LH, Harling H, Laurberg S, Wille-Jørgensen P. Influence of caseload and surgical speciality on outcome following surgery for colorectal cancer: a review of evidence. Part 1: short-term outcome. *Colorectal Dis*. 2007;9:28-37.

Iversen LH, Harling H, Laurberg S, Wille-Jørgensen P. Danish Colorectal Cancer Group. Influence of caseload and surgical speciality on outcome following surgery for colorectal cancer: a review of evidence. Part 2: long-term outcome. *Colorectal Dis*. 2007;9:38-46.

Mathiesen TP, Willaing I, Freil M, Jørgensen T, Andreasen AH, Ladelund S, Harling H. How do patients with colorectal cancer perceive treatment and care compared with the treating health care professionals? *Med Care*. 2007;45:394-400.

Iversen LH, Bülow S, Christensen IJ, Laurberg S, Harling H on behalf of the Danish Colorectal Cancer Group. Postoperative medical complications are the main cause of early death after emergency surgery for colon cancer. A nationwide study. *Br J Surg*. 2008;95:1012-1019.

The Danish Hip Arthroplasty Registry (DHR)

Aim:

The aims of the registry are to examine and follow the epidemiology of total hip arthroplasty (THA) procedures including both primary operations and revisions in Denmark, and to facilitate continuous improvement of hip replacement surgery outcomes on both a national and a local level.

Population:

All patients subject to primary THAs, revisions and follow-up examinations in Denmark. The registry is population-based and nationwide. The number and distribution of cases in 1995-2004 are provided in the table below.

	1995-2005	2006	2007	Total	%
Type of surgery	N	N	N	N	
Primary	61,806	7,911	7,691	77,408	85.7
Revision	10,584	1,179	1,176	12,939	14.3
Total	72,390	9,090	8,867	90,347	100.0

Period:

The DHR was initiated January 1, 1995.

Data:

Data are collected prospectively by the operating surgeon before, during and after the surgery, using a standardized form. The registered preoperative data: civil registration number, laterality of the affected hip, primary diagnosis, hospital code and the Harris Hip Score. The perioperative data include: date of the surgery, use of antibiotic and antithrombotic prophylactic treatment, type of anaesthesia, prophylaxis against ectopic bone formation, duration of surgery, type of acetabular component and fixation, type of femoral component and fixation, and perioperative complications. In case of revision, defined as partial or total prosthesis replacement, or removal of the prosthesis, the following data are registered: cause of revision, extent of revision, and the number of earlier revisions. The postoperative data include: date of follow-up examination, postoperative complications, patient's own assessment of satisfaction with the surgery, and Harris Hip Score.

Record linkage:

The DHR is linked to a number of other registries including: the Danish National Registry of Patients, the Civil Registration System, the Prescription Databases of the Central Denmark Region and the North Denmark Region, the Danish Registry of Causes of Death, the Demographic Database and the Danish Transfusion Database.

Institution:

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Contact person: professor Søren Overgaard; e-mail:
soeren.overgaard@ouh.regionsyddanmark.dk; phone: +45 65413560

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Lucht U. The Danish Hip Arthroplasty Register. *Acta Orthop Scand.* 2000;71:433-439.

Pedersen AB, Johnsen SP, Overgaard S, Søballe K, Sørensen HT, Lucht U. Registration in the Danish Hip Arthroplasty Registry. Completeness of total hip arthroplasties and positive predictive value of registered diagnosis and postoperative complications. *Acta Orthop Scand.* 2004;75:434-441.

Pedersen AB, Johnsen SP, Overgaard S, Søballe K, Sørensen HT, Lucht U. Total hip arthroplasty in Denmark. Incidence of primary operations and revisions during 1996-2002 and estimated future demands. *Acta Orthop.* 2005;76:182-189.

Pedersen AB, Johnsen SP, Overgaard S, Søballe K, Sørensen HT, Lucht U. Regional variation in incidence of primary total hip arthroplasties and revisions in Denmark, 1996-2002. *Acta Orthop.* 2005;76:815-822.

Johnsen SP, Sørensen HR, Lucht U, Søballe K, Overgaard S, Pedersen AB. Patient-related predictors of implant failure after primary total hip replacement in the initial, short- and long-terms. A nationwide danish follow-up study including 36 984 patients. *J Bone Joint Surg Br.* 2006; 88:1303-1308.

Paulsen A, Pedersen AB, Johnsen SP, Riis A, Lucht U, Overgaard S. Effect of hydroxyapatite coating on risk for revision after primary total hip arthroplasty in younger patients. Findings from the Danish Hip Arthroplasty Registry. *Acta Orthop.* 2007;78:622-628.

Thillemann TM, Pedersen AB, Johnsen SP, Søballe K. Inferior outcome after intraoperative femoral fracture in total hip arthroplasty: outcome in 519 patients from the Danish Hip Arthroplasty Registry. *Acta Orthop.* 2008;79:327-334.

Thillemann TM, Pedersen AB, Johnsen SP, Søballe K. Implant survival after primary total hip arthroplasty due to childhood hip disorders: Results from the Danish Hip Arthroplasty Registry. *Acta Orthop.* 2008;79:769-776.

Pedersen AB, Mehnert F, Overgaard S, Møller B, og Johnsen SP. [Transfusion practice in relation to total hip arthroplasty in Danish orthopaedic surgery departments]. *Ugeskr Laeger.* 2009;171:973-978. In Danish.

Havelin LI, Fenstad AM, Salomonsson R, Mehnert F, Furnes O, Overgaard S, Pedersen AB, Herberts P, Kärrholm J, Garellick G. The Nordic Arthroplasty Register association. A unique collaboration of three national hip arthroplasty registries with 280,201 total hip replacements. *Acta Orthop.* 2009;Jan 1:1-9. [Epub ahead of print]

Thillemann T, Pedersen AB, Mehnert F, Johnsen SP, Søballe K. Association between diuretic use and the risk of implant failure after primary total hip arthroplasty. *Bone.* 2009. May 3. [Epub ahead of print]

Thillemann T, Pedersen AB, Mehnert F, Johnsen SP, Søballe K. Decreased risk for revision after primary total hip arthroplasty among statin users: A nationwide population-based nested case-control study. *JBJS (Am).* In press.

The Danish Knee Arthroplasty Registry (DKR)

Aim:

The Danish Knee Arthroplasty Registry is a population-based and nationwide clinical database. Since 2005, the DKR has been part of the Danish Common Orthopaedic Database. The objective of the registry is to examine the epidemiology of knee arthroplasty procedures in Denmark, and to facilitate continuous improvement of knee replacement surgery outcomes on both national and local levels. Knee arthroplasty quality improvement is measured by use of six quality indicators.

Population:

All patients subject to primary knee arthroplasties, revisions and follow-up examinations in Denmark in one of the 44 departments that perform this type of surgery, including private hospitals.

Period:

The DKR was initiated January 1, 1997.

Data:

Data are collected prospectively by the operating surgeon before, during and after the surgery, using a standardized form. The registered preoperative data are: the patient's civil registration number, the laterality of the affected hip, primary diagnosis, hospital code and knee score. The perioperative data include: date of the surgery, use of antibiotic and antithrombotic prophylactic treatment, type of anaesthesia, duration of surgery, type of tibia, femoral and patellar component and fixation, drainage, navigation and perioperative complications. In case of revision, the following data are registered: cause of revision, status before and after revision and the number of earlier revisions.

Record linkage:

The DKR can be linked to any of the other registries and clinical databases. So far, the DKR has been linked to the Danish National Registry of Patients and to the Civil Registration System.

Institution:

The Common Orthopaedic Database
Department of Clinical Epidemiology, Aarhus University Hospital
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Contact person: Consultant Anders Odgaard; E-mail: andeodga@rm.dk; phone: +45 89497430

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Not available.

The Danish Cruciate Ligament Register (DKKR)

Aim:

The Danish Cruciate Ligament Register (DKKR) is a population-based and nationwide clinical database. DKKR is part of the Danish Common Orthopaedic Database. The objective of the register is to examine the epidemiology of cruciate ligament procedures in Denmark, and to maintain and possibly improve the quality of cruciate ligament surgery. The quality is measured using five quality indicators.

Population:

All patients subject to primary cruciate ligament operations and revisions in Denmark in one of the 37 departments that perform this type of surgery, including private clinics.

Period:

The DKKR was initiated July 1, 2005.

Data:

Data are collected prospectively by the operating surgeon before, during and after the surgery, using a standardized form. The perioperative data include: surgery technique, use of implants, other injuries to the knee, and perioperative medical treatment. Data on results of treatment are collected at follow-up after one year. At this point, stability is also assessed. The patient's subjective functioning of the knee is evaluated by the self-assessment score systems KOOS and Tegner. The patients submit these data via the Internet before surgery and 1, 5 and 10 years after surgery.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases. So far, the DKKR has been linked to the Civil Registration System.

Institution:

The Common Orthopaedic Database
Department of Clinical Epidemiology, Aarhus University Hospital
Olof Palmes Alle 43-45
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Denmark

Contact person: Consultant Martin Lind; e-mail: martilin@rm.dk; phone: +45 89497465

The register is affiliated with Centre for Clinical Databases (North).

Selected key references:

Lind M, Mehnert F, Pedersen AB. The first results from the Danish ACL reconstruction registry. Epidemiologic and 2 year follow-up results from 5818 knee ligament reconstructions. *Knee Surg Sports Traumatol Arthrosc.* 2009;17:117-24.

The Danish Shoulder Alloplasty Registry (DSR)

Aim:

The Danish Shoulder Alloplasty Registry (DSR) is a nationwide clinical quality database. DSR has been part of the Danish Common Orthopaedic Database since 2005. The main aim of the DSR is to collect data to help improve treatment of patients undergoing shoulder alloplastics. The process identifies various risk parameters within patient categories, surgery methods, prosthesis components etc. Four indicators are used to assess the quality of the sequences.

Population:

All shoulder alloplastics carried out at one of the 29 Danish hospital wards performing this type of surgery.

Period:

The collection of data for the DSR began in 2004. The first year was a pilot period, with some wards reporting data voluntarily. As of January 1, 2005 all wards performing shoulder alloplastics were urged to report data to the database, and in a declaration of June 2006, the Danish National Board of Health ordered all hospitals, both private and public ones, to report to the approved clinical quality databases, including DSR.

Data:

Data are collected prospectively and contain variables regarding the patient and the surgery (gender, age, indicator, prosthesis brand etc.). Approximately one year after surgery, patients receive a follow-up questionnaire, consisting mainly of the WOOS score, which is a validated evaluation system designed specifically to evaluate outcome following shoulder alloplastic surgery. The WOOS score is a self-assessment instrument with 19 questions, whose answers correspond to VAS scores. Furthermore, aided by photos, patients rate their ability to lift the shoulder upward/forward and the overall shoulder functionality as a percentage compared with a normal shoulder (SSV score, Subjective Shoulder Value). Data are collected by an internet-based KMS (Klinisk Måle System – clinical measurement system) with direct linkage to the clinical wards via MedCom's Health data network.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases. So far, the DSR has been linked to the Danish Civil Registration System.

Institution:

The Common Orthopaedic Database
Department of Clinical Epidemiology, Aarhus University Hospital
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Contact person: Consultant John Jakobsen; e-mail: jj@artros.dk; phone: +45 96315555

The registry is affiliated with Centre for Clinical Databases (North).

Selected key references:

Not available.

The Danish National Indicator Project (NIP) – Hip Fractures

Aim:

To measure the quality of care provided by Danish hospitals to patients with hip fractures.

Population:

All patients with hip fracture admitted to any hospital in Denmark (ICD-10 codes S.72.0, S72.1, S72.2). Data include detailed information on more than 35,000 episodes of hip fracture. Each year between 6,000 and 7,000 new cases are registered.

Period:

2003 onwards.

Data:

Treatment quality process indicators and prognostic factors are collected actively (by patient interviews) and from medical records. Data include process indicators: early assessment of the patient's nutritional risk, systematic pain assessment during mobilization of the patient using a pain scale with documented validity, assessment of Activities of Daily Living before the fracture and again before discharge, and initiation of treatment to prevent future osteoporotic fractures. Individual prognostic factors include: alcohol intake, smoking habits, cohabitation, ASA score, and type/dislocation of fracture.

Record linkage:

Individual-level linkage with the Danish National Registry of Patients and the Civil Registration System is regularly done by Department of Clinical Epidemiology to assess risk of re-operation on the hip within two years, 30-day mortality, and underlying comorbidities (the Charlson index).

Institution:

The Central Denmark Region
NIP Secretariat
Olof Palmes Alle 15
8200 Aarhus N
Denmark

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Mainz J, Bartels P, Rhode P. Accountability and measurement in the Danish healthcare system. I Kazandjian VA. Accountability through measurement. A global healthcare imperative. *Am Soc Qual*. 2003;204-217.

Mainz J, Krog BR, Bjørnshave B, Bartels P. Nationwide continuous quality improvement using clinical indicators: The Danish National Indicator Project. *Int J Qual Health Care*. 2004;16:1-6.

The Danish National Indicator Project (NIP) - Stroke

Aim:

Data are collected in order to monitor and improve the quality of acute hospital care for patients with stroke.

Population:

All patients admitted to Danish hospitals with acute stroke. Reporting to NIP is mandatory for all hospitals and relevant clinical departments in Denmark treating patients with stroke. A total of 55,000 incidences of stroke were registered by the end of 2007. Each year approximately 12,000 new cases are registered.

Period:

Data have been collected since 2003.

Data:

Data on quality of care, according to fulfillment of specific quality of care criteria, and on patient characteristics is prospectively collected upon hospital admission by the staff taking care of the patients using a standardized registration form. The criteria included early admission to a stroke unit, early initiation of antiplatelet or anticoagulant therapy, early examination with CT/MRI scan, early assessment by a physiotherapist, an occupational therapist and of nutritional risk, early swallowing assessment and early carotid ultrasound or CT-angiography examination. Data on patient characteristics include age, sex, type (ischemic, hemorrhagic, undefined) and severity of stroke (according to Scandinavian Stroke Scale), comorbidity, marital status, housing, profession, alcohol intake and smoking habits.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

The Central Denmark Region
NIP Secretariat
Olof Palmes Alle 15
8200 Aarhus N
Denmark

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Mainz J, Bartels P, Rhode P. Accountability and measurement in the Danish healthcare system. I Kazandjian VA. Accountability through measurement. A global healthcare imperative. *Am Soc Qual.* 2003;204-217.

Palnum K, Petersen P, Sørensen HT, Ingeman A, Mainz J, Bartels P, Johnsen SP. Older patients with stroke in Denmark: Quality of care and short-term mortality. A nationwide follow-up study. *Age Ageing.* 2008;37:90-95.

Ingeman A, Pedersen L, Hundborg H, Petersen P, Zielke S, Mainz J, Bartels P, Johnsen SP. Quality of care and mortality among patients with stroke: a nationwide population-based follow-up study. *Med Care.* 2008;46:63-69.

Palnum KD, Andersen G, Ingemann A, Krog BR, Bartels P, Johnsen SP. Sex-related differences in quality of care and short-term mortality among patients with acute stroke in Denmark: a nationwide follow-up study. *Stroke.* 2009;40:1134-1139.

Svendsen ML, Ehlers LH, Andersen G, Johnsen SP. Quality of care and length of hospital stay among patients with stroke. *Med Care*. 2009;47:575-582.

The Danish National Indicator Project (NIP) - Schizophrenia

Aim:

To improve the quality of prevention, diagnostics, treatment and rehabilitation for patients with schizophrenia.

Population:

The population includes all patients with a Danish civil registration number who have been:

- diagnosed with schizophrenia (ICD-10 codes F20.00 – F20.99) (approximately 7,000 registrations in the NIP - Schizophrenia per year)
- discharged from a psychiatric ward or with a long-term hospitalization in a psychiatric ward in Denmark
- in contact with an outpatient clinic in Denmark after discharge from a psychiatric ward

Period:

Data have been collected since 2004.

Data:

The quality of treatment is measured by process indicators and standards which assess what the provider did for the patient and how well he or she did it. Main variables include: diagnostic process, contact, contact person, medication, side effects, family intervention, psychoeducation, planned outpatient treatment after discharge, and prevention of suicide. A registration form is used to collect data on the process indicators and standards from the medical records. This information is afterwards entered into a database.

Record linkage:

Registration of the civil registration number enables linkage to other databases.

Institution:

The Central Denmark Region
NIP Secretariat
Olof Palmes Alle 15
8200 Aarhus N
Denmark

The database is affiliated with Centre for Clinical Databases (East).

Selected key references:

Mainz J. Developing evidence-based clinical indicators: a state of the art methods primer. *Int J Qual Health Care*. 2003;15 Suppl 1:i5-11.

Mainz J, Krog BR, Bjørnshave B, Bartels P. Nationwide continuous quality improvement using clinical indicators: the Danish National Indicator Project. *Int J Qual Health Care*. 2004;16 Suppl 1:i45-50.

The Danish National Indicator Project (NIP) – Acute Abdominal Surgery

Aim:

To measure the quality of care provided by the hospitals in Denmark to patients with acute upper gastrointestinal bleeding (UGIB) or acute upper gastrointestinal perforation (UGIP).

Population:

All patients admitted to any hospital in Denmark with acute clinical symptoms of gastroscopically or surgically verified UGIB or UGIP. Data include detailed information on approximately 8,500 episodes of UGIB (~1,800 new cases per year) and approximately 2,000 episodes of UGIP (~400 new cases per year).

Period:

2003 onwards.

Data:

Treatment quality process indicators and prognostic factors are collected actively (by interview) and from medical records. Data for UGIB include: time-to-gastroscopy (hours), primary haemostasis, institution of medical anti-ulcer therapy, re-bleeding within 72 hours, gastroscopic treatment of re-bleeding, and necessity of open surgery (yes/no). Data for UGIP include: time-to-surgery (hours), timely withdrawal of post-operative antibiotics, institution of medical anti-ulcer therapy, and re-operation within 72 hours (yes/no). Data on prognostic factors for UGIB/UGIP include: smoking, use of alcohol, treatment with ulcer-related drugs, presence of chronic diseases, heart rate, blood pressure, ASA-score, height, weight, and type of bleeding/perforation.

Record linkage:

Linkage of each individual with the Civil Registration System is regularly done by Department of Clinical Epidemiology to assess mortality within 30 days.

Institution:

The Central Denmark Region
NIP Secretariat
Olof Palmes Alle 15
8200 Aarhus N
Denmark

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Mainz J. Defining clinical indicators for quality improvement. *Int J Qual Health Care*. 2003;15:523-530.

Mainz J, Bartels P, Rhode P. Accountability and measurement in the Danish healthcare system. I Kazandjian VA. Accountability through measurement. A global healthcare imperative. *Am Soc Qual*. 2003;204-217.

Mainz J, Krog BR, Bjørnshave B, Bartels P. Nationwide continuous quality improvement using clinical indicators: The Danish National Indicator Project. *Int J Qual Health Care*. 2004;16:1-6.

The Danish National Indicator Project (NIP) - Heart Failure

Aim:

To assess the quality of treatment, care and rehabilitation provided by Danish hospitals to patients with heart failure (HF). The quality is measured by a set of evidence based quality of care indicators.

Population:

All incident patients with systolic and non-systolic HF admitted to a cardiology unit or outpatient HF clinic in Denmark, are consecutively included in the NIP database.

The population includes patients aged 18 years or older, who meet one or more of the following criteria used by the European Society of Cardiology (ESC criteria):

- Typical symptoms of HF like shortness of breath at rest or during exertion and/or fatigue
- Signs of fluid retention such as pulmonary congestion or ankle swelling; and an objective evidence of an abnormality of the structure or the function of the heart at rest
- Response to treatment at HF: A clinical response to treatment alone is not sufficient for the diagnosis when it remains unclear after diagnostic investigations. Patients would be expected to show improvements in symptoms and signs in response to treatments from which a relatively fast symptomatic improvement could be anticipated (e.g., diuretic or vasodilator administration).

The database contains approximately 16,000 incident cases of HF patients in 2008.

Period:

Data have been collected since February 2003.

Data:

Data on quality of treatment and care, together with prognostic factors (age, sex, AMI, stroke, Chronic Obstructive Pulmonary Disease (COPD), diabetes, hypertension, serum-creatinine, 12 lead electrocardiogramme (ECG), heart rhythm, alcohol and smoking habits) are collected from medical records. Data are collected using a standardized registration form. 54 Danish cardiology wards, which treat HF patients, report to the NIP database.

Data include the following indicators:

- 1) Proportion of patients who undergo echocardiography
- 2) Proportion of patients who undergo New York Heart Association (NYHA) classification
- 3) Proportion of patients with reduced systolic function (ejection fraction below 40%) who were treated or tried treated with:
 - a) ACE-inhibitor/ATII-receptor antagonist (NYHA Class I-IV),
 - b) Beta blocker,
 - c) Aldosterone antagonist (NYHA Class III-IV) (ejection fraction below 35%)
- 4) Proportion of patients referred to individual exercise training at a physiotherapist (ejection fraction below 40%)
- 5) Proportion of patients who began a structured patient education (nutrition, physical training, detecting symptoms, understanding medical treatment, risk factors), (ejection fraction below 40%)
- 6) Proportion of patients who are readmitted
- 7) Proportion of patients who die after being admitted with HF.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

The Central Denmark Region
NIP Secretariat
Olof Palmes Alle 15
8200 Aarhus N
Denmark

The database is affiliated with Centre for Clinical Databases (East).

Selected key references:

Mainz J. Defining clinical indicators for quality improvement. *Int J Qual Health Care*. 2003;15:523-530.

Mainz J, Bartels P, Rhode P. Accountability and measurement in the Danish healthcare system. I Kazandjian VA. Accountability through measurement. A global healthcare imperative. *Am Soc Qual*. 2003;204-217.

Mainz J, Krog BR, Bjørnshave B, Bartels P. Nationwide continuous quality improvement using clinical indicators: The Danish National Indicator Project. *Int J Qual Health Care*. 2004;16:1-6.

The Danish National Indicator Project (NIP) – Chronic Obstructive Pulmonary Disease (COPD)

Aim:

To measure the quality of care provided by hospitals in Denmark to COPD patients who are seen in hospital outpatient clinics and to those who are admitted with a COPD exacerbation.

Population:

1. COPD outpatients: All patients seen at least once during a given calendar year in hospital outpatient clinics with a principal diagnosis of COPD (ICD-10 code J44). The registry contains approximately 12,000 of such COPD patients by Dec 31, 2008.
2. COPD inpatients: All patients experiencing an acute hospital admission with either a principal diagnosis of COPD (J44), or with a principal diagnosis of pneumonia (J13-18), non-specified lower respiratory tract infection (J22), or respiratory failure (J96) together with a secondary diagnosis of COPD (J44). The registry contains approximately 20,000 of such acute patient admissions with COPD exacerbation by Dec 31, 2008.

Period:

From January 1, 2008 onwards.

Data:

Data to calculate indicators of treatment quality are reported by the hospital departments and outpatient clinics to the Danish National Registry of Patients.

Data for COPD outpatients include: Forced Expiratory Volume in 1 Second (FEV₁, % of expected); body mass index (BMI); dyspnoea as measured on the Medical Research Council (MRC) Dyspnoea Scale; smoking status; counselling for smoking cessation; and pulmonary rehabilitation. Data for COPD inpatients include: proportion with non-invasive ventilation (NIV) therapy, proportion of all ventilated patients who received NIV therapy, and 30-day mortality after the date of hospital admission.

Record linkage:

Linkage of each COPD inpatient with the Danish National Registry of Patients and the Civil Registration System is regularly done by Department of Clinical Epidemiology to assess the outcome measure of 30-day mortality and confounding comorbidities.

Institution:

The Central Denmark Region
NIP Secretariat
Olof Palmes Alle 15
8200 Aarhus N
Denmark

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Mainz J. Defining and classifying clinical indicators for quality improvement. *Int J Qual Health Care*. 2003;15:523-530.

Mainz J, Krog BR, Bjørnshave B, Bartels P. Nationwide continuous quality improvement using clinical indicators: The Danish National Indicator Project. *Int J Qual Health Care*. 2004;16:1-6.

Mainz J. Developing evidence-based clinical indicators: A state of the art methods primer. *Int J Qual Health Care*. 2003;15:i5-i11.

The Danish Quality Database for Breast Cancer Screening

Aim:

To measure the quality of the Danish national screening programme for breast cancer.

Population:

All women (50-69 years old) invited to participate in the breast cancer screening programme. Screening is offered every second year to all Danish female residents in the defined age group.

Period:

Data have been collected since January 1, 2008.

Data:

Data are collected from the following existing data sources: local administrative invitation systems, the Danish National Registry of Patients, the Civil Registration System, and The National Pathology Registry.

To monitor the breast cancer screening programme, the following 11 indicators are used:

- Glandular dose (the average absorbed dose in the glandular tissue)
- Coverage (proportion of invited women that attend screening and proportion of target population that attend screening)
- Screening interval (proportion of women who are invited within the specified screening interval)
- Proportion of women recalled for further assessment (clinical mammography)
- Interval cancer
- Proportion of screen-detected cancers that are invasive
- Proportion of invasive screen-detected cancers that are node-negative
- Proportion of invasive screen-detected cancers that are ≤ 10 mm in size
- Benign to malignant open surgical biopsy ratio
- Proportion of women with invasive cancer who receive breast conserving surgery
- Time between screening and result provided

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

The Danish Quality Database for Breast Cancer Screening
Department of Mamma Surgery, Aalborg Hospital
Sdr. Skovvej 3
9000 Aalborg
Denmark

Contact person: Consultant Jens Peter Garne; e-mail: jpg@rn.dk; phone: +45 99321484

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Not available.

The Danish Quality Database for Cervical Cancer Screening

Aim:

To measure the quality of the Danish national screening programme for cervical cancer. Data are collected to ensure optimal diagnostics and treatment of cervical cancer nationwide. To achieve this purpose, the National Board of Health has produced uniform clinical guidelines for a cervical cancer screening programme that has been implemented all over Denmark.

Population:

All women who are between 23 and 64 years old are invited to enter the voluntary cervical cancer screening programme. Screening is offered to women between 23 and 50 years of age every third year and to women above 50 years of age every fifth year.

Period:

Data collection will begin in autumn 2009.

Data:

Data will be collected from the National Pathology Registry and the Danish Cancer Registry. In June 2008, the steering committee of the Danish Cervical Cancer Screening Database decided on nine quality indicators to monitor the quality of the cervical cancer screening programme:

- Capacity (women waiting for an invitation to participate in the screening programme and the number of samples analysed at each pathology department)
- Coverage (proportion of invited women who attend screening)
- Quality of the samples of cervical cytology (proportion of unsatisfied samples of cervical cytology within all samples of cervical cytology)
- Diagnostic quality (the sensitivity and specificity of diagnostic procedures)
- Reply (proportion of samples of cervical cytology for which the reply time exceeds ten weekdays)
- HPV-test
- Contribution ratio
- Follow-up (proportion of abnormal or unsatisfied samples of cervical cytology that are not followed)
- Proportion of women with invasive cancer

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

The Danish Quality Database for Cervical Cancer Screening
Hvidovre Hospital
Kettegård Alle 30
2650 Hvidovre
Denmark

Contact person: Consultant Carsten Rygaard, e-mail: carsten.rygaard@hvh.regionh.dk; phone: +45 36323048

The register is affiliated with Centre for Clinical Databases (North).

Selected key references:

Not available.

The Danish Hysterectomy Database

Aim:

To monitor and improve the quality of surgical procedures of benign hysterectomy in Denmark.

Population:

All women undergoing elective hysterectomy for benign disease in Denmark. By the end of 2008, nearly 20,000 hysterectomy surgical procedures were registered. Approximately 4,000 new cases of hysterectomy surgery are added each year.

Period:

October 1, 2003 onwards.

Data:

The registration consists of four parts:

- 1) baseline information about the patient's general health, lifestyle, intake of medication, and indication for surgery (registered before surgery)
- 2) information about the surgical procedure, complications during surgery (e.g. bleeding, lesion of organs, blood transfusion) prophylactic regimens, intake of medication during the surgery, and the surgeons' experience (registered immediately following surgery)
- 3) information about length of postoperative hospitalization, postoperative complications (e.g. bleeding, infection, lesion of organs), postoperative intake of medication, and reoperation (registered at discharge)
- 4) information on readmission to the hospital \leq 30 days postoperative (registered at discharge).

Record linkage:

Via the civil registration number, data are linked to the Danish National Registry of Patients, which registers primary admissions and readmissions.

Institution:

The Danish Hysterectomy Database
Department of Gynaecology, Obstetrics, and Paediatrics
Juliane Marie Centeret
2100 Copenhagen Ø
Denmark

Contact person: Clinical professor Bent Smedegaard Ottesen; e-mail:
bent.ottesen@rh.regionh.dk; phone: +45 35454769

The registry is affiliated with Centre for Clinical Databases (East).

Selected key references:

Møller C, Kehlet H, Utzon J, Ottesen B. [Hysterectomy in Denmark. An analysis of postoperative hospitalization, morbidity and readmission]. *Ugeskr Laeger*. 2002;164:4539-45. In Danish.

The Danish Breast Cancer Cooperative Group Register (DBCG)

Aim:

Data are collected in order to ensure optimal diagnostics and treatment of operable primary breast cancer on a nationwide basis. To achieve this purpose, the DBCG has worked out uniform country-wide guidelines. Subsequently, the surgical treatment as well as radiotherapy and systemic treatment has been developed further and evaluated by performing randomized trials.

Population:

Patients in Denmark with primary operable breast cancer and with initial stages of breast cancer (carcinoma in situ, CIS). By the end of 2007, the registry contained 75,000 cases of breast cancer. Each year, approximately 3,800 new cases of breast cancer are registered.

Period:

January 1, 1977 onwards.

Data:

Data are collected prospectively and sent from the participating departments of surgery, histopathology, oncology and radiotherapy on forms produced by the DBCG secretariat. The database holds information on primary surgical procedures, histopathology, adjuvant therapy and clinical follow-up. In addition, patient data are registered.

Main variables are: civil registration number, histological diagnosis, type of surgery, menopausal status, protocol allocation and randomization, information about adjuvant radiotherapy and adjuvant systemic treatment and side effects, status of recurrence.

Record linkage:

Through merging with the Civil Registration System, registration is supplemented with information on vital status and time of death on all registered patients. The data are also merged with the Danish Registry of Causes of Death. In addition, DBCG is responsible for The Registry of Hereditary Cancer of the Breast and the Ovaries. This registry is linked to the DBCG data and contains information about patients with hereditary predisposition for cancer of the breast and their relatives.

Institution:

DBCG Secretariat
Rigshospitalet 2501
Blegdamsvej 9
2100 Copenhagen Ø
Denmark

Contact person: Professor Peer Christiansen; e-mail: peechr@rm.dk; phone: +45 89497508

The registry is affiliated with Centre for Clinical Databases (North).

Selected key references:

Overgaard M, Hansen PS, Overgaard J, Rose C, Anderson M, Bach F, Kjær M, Gadeberg CC, Mouridsen HT, Jensen MB, Zedeler K for the Danish Breast Cancer Cooperative Group 82b Trial. Postoperative radiotherapy in high-risk premenopausal women with breast cancer who receive adjuvant chemotherapy. *N Engl J Med.* 1997;337:945-955.

Jensen AR, Ewertz M, Cold S, Storm HH, Overgaard J. Time trends and regional differences in registration, stage distribution, surgical management and survival of breast cancer in Denmark. *Eur J Cancer*. 2003;39:1783-1793.

Cold S, Düring M, Ewertz M, Knoop A, Møller S. Does timing of adjuvant chemotherapy influence the prognosis after early breast cancer? Results of the Danish Breast Cancer Cooperative Group (DBCG). *Br J Cancer*. 2005;93:627-632.

Hernandez RK, Sørensen HT, Pedersen L, Jacobsen J, Lash TL. Tamoxifen treatment and risk of deep venous thrombosis and pulmonary embolism: A Danish population-based cohort study. *Cancer*. 2009 Jun 30. [Epub ahead of print]

Hernandez RK, Sørensen HT, Jacobsen J, Pedersen L, Lash TL. Tamoxifen treatment in Danish breast cancer patients and 5-year risk of arterial atherosclerotic events: a null association. *Cancer Epidemiol Biomarkers Prev*. 2008;17:2509-2511.

Lash TL, Pedersen L, Cronin-Fenton D, Ahern TP, Rosenberg CL, Lunetta KL, Silliman RA, Hamilton-Dutoit S, Garne JP, Ewertz M, Sørensen HT. Tamoxifen's protection against breast cancer recurrence is not reduced by concurrent use of the SSRI citalopram. *Br J Cancer*. 2008;99:616-621.

Ahern TP, Pedersen L, Cronin-Fenton D, Sørensen HT, Lash TL. No increase in breast cancer recurrence with concurrent use of tamoxifen and some CYP2D6-inhibiting medications. *Cancer Epidemiol Biomarkers Prev*. 2009 Aug 18. [Epub ahead of print]

DBCG: the Danish Breast Cancer Cooperative Group Papers at the occasion of the 30-year anniversary meeting. *Acta Oncol*. 2008;47(4).

The Danish Registry on Regular Dialysis and Transplantation

Aim:

Data are collected with the following purposes:

- 1) To study changes in prevalence and incidence of end-stage renal disease (ESRD)
- 2) To study the prognosis of patients with ESRD
- 3) To study the incidence of renal transplantations and, among those undergoing transplantation, graft survival and mortality

Population:

All patients actively treated for ESRD in Denmark.

Period:

The registry was founded in 1990.

Data:

The registry contains data on more than 10,000 patients (by the end of 2005) with ESRD. Data input is made on identical software programmes in the four Danish nephrological centres. Once a year, data are sent to a central database. Here, all data are checked for errors, and appropriate corrections are made in cooperation with the reporting centres, thus providing high level of data completeness and validity.

The main variables include: civil registration number, nephrological centre, dialysis method, date of first dialysis, date of last dialysis if dialysis was stopped, measures of quality of dialysis (Kv/t), Hb(mmol/l), albumin (g/l), creatinine ($\mu\text{mol/l}$), renal diagnosis (results of renal biopsies), data on all Danish renal transplantations (living/cadaver donor, and if living, data on family relations and haplotypes), onset of graft function and creatinine ($\mu\text{mol/l}$) during follow-up, data on graft survival, data on cancer in patients with ESRD, cause of death of all deceased ESRD patients.

Record linkage:

The registry is annually linked to the Civil Registration System, The Danish Registry of Causes of Death and The Danish Cancer Registry. Since 1990, data from the Danish Registry on Regular Dialysis and Transplantation have been transferred to the European Renal-Dialysis and Transplantation Association (ERA-EDTA registry).

Institution:

The Danish Society of Nephrology
Department of Nephrology P
Rigshospitalet
Blegdamsvej 9
2100 Copenhagen Ø
Denmark

Contact person: Consultant, PhD Thomas Elung-Jensen; e-mail: secretary@nephrology.dk;
phone : +45 35453545

The registry is affiliated with Centre for Clinical Databases (South).

Selected key references:

Vestergaard P, Løkkegård H. Predicting future trends in number of patients on renal replacement therapy in Denmark. *Nephrol Dial Transplant*. 1997;12:2117-2123.

Vestergaard P. Dialysis and kidney transplant activity in Denmark between 1990 and 2004. Danish National Registry on Regular Dialysis and Transplantation. Report on Dialysis and

Transplantation in Denmark 2005. Available at:
<http://www.nephrology.dk/Publikationer/Landsregister/Landsregisteret.2004.pdf>

The Danish Transfusion Database (DTDB)

Aim:

The database is a national quality assurance database. Its aim is to visualize and describe the use of blood components in Denmark. The database was founded partly because of a high usage of blood components in Denmark compared with other western European countries.

Population:

All patients receiving blood transfusions in Denmark. The annual use of transfusions in Denmark includes approximately 350,000 erythrocyte transfusions, 110,000 platelet transfusions, and 57,000 portions of fresh frozen plasma.

Period:

Data are available from the former counties of Roskilde, Funen, North Jutland and Aarhus and the former Copenhagen Hospital Corporation (H:S) since 1997. Nationwide data are available from 2006.

Data:

The following data are registered for each hospitalized patient: civil registration number, number of blood components transfused, age, gender, diagnoses, treatment, haemoglobin concentration, platelet count, and level of coagulation factors.

Record linkage:

Data are collected through Danish blood bank registries, the National Registry of Patients and clinical-biochemical databases.

Institution:

DTDB
Department of Clinical Immunology
Odense University Hospital
Sdr. Boulevard 29
5000 Odense C
Denmark

Contact person: Consultant, PhD Kjell Titlestad; e-mail: dtdb@dtdb.dk; phone: +45 65413675

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

DTDB report 2007 (2005 and 2006 data). Danish Transfusion Data Base 2008.
Available at <http://www.dtdb.dk/publikationer.aspx>

Andreasen JJ, Riis A, Hjortdal VE, Jørgensen J, Sørensen HT, Johnsen SP. Effect of selective serotonin reuptake inhibitors on requirements of allogeneic red blood cell transfusion following coronary artery bypass surgery. *Am J Cardiovasc Drugs*. 2006;6:243-250.

Pedersen AB, Mehnert F, Overgaard S, Møller B, Johnsen SP. [Transfusion practice in total hip arthroplasty in Danish departments of orthopaedic surgery]. *Ugeskr Laeger*. 2009;171:973-977. In Danish.

The Danish Intensive Care Database

Aim:

The purpose of the database is to monitor the quality of care in Danish intensive care units (ICUs).

Population:

All patients admitted to ICUs in Denmark.

Period:

2005 onwards.

Data:

The database is updated four times a year. It is based on administrative data obtained from the Danish National Registry of Patients. Data on ICU patients are collected prospectively by ICU physicians and are entered into hospital information systems at discharge. From hospital information systems, the data are electronically transferred to the National Registry of Patients. Data include date of ICU admission, non-invasive mechanical ventilation (yes/no), invasive mechanical ventilation (yes/no), dialysis/renal replacement therapy in the ICU (yes/no), inotropic/vasopressor therapy (yes/no). The database contains data on approximately 30,000 annual admissions to ICU in Denmark. Approximately 4% of all ICU patients are treated with dialysis/renal replacement therapy and about 30% are treated with invasive mechanical ventilation.

Record linkage:

The database is linked to a number of registries including: the Danish National Registry of Patients (data on diagnosis, comorbidity and surgery), and the Civil Registration System (data on mortality). For the subgroup of patients admitted to ICUs in the former counties of Aarhus and North Jutland, the database has been linked to the LABKA laboratory database (data on all laboratory tests since 1997) and the Prescription Databases of the Central Denmark Region and the North Denmark Region (data on prescriptions redeemed since 1998).

Institution:

The Intensive Care Database
Department of Anaesthesia
Fredericia and Kolding Hospitals
Skovvangen 2-8
6000 Kolding

Contact person: Consultant Ebbe Rønholm; e-mail: ebbe.roenholm@fks.regionsyddanmark.dk; phone : +45 73362690.

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Not available.

The Danish Clinical Database of Carcinomas of the Esophagus, Cardia and Stomach (DECV)

Aim:

Guidelines from the Danish National Board of Health (2001) specify that only five centres in Denmark (in a close cooperation between surgical gastroenterologists and specialists of thoracic surgery) are responsible for the diagnostic process and treatment of patients with carcinomas of the esophagus, cardia and stomach. The database was established in 2003 to ensure uniform national guidelines for reporting on and treatment of patients with these cancer types. The database was initiated as a cooperation between the five treatment centres (Aarhus, Aalborg, Odense, Gentofte and Rigshospitalet) and surgical gastroenterologists, thorax surgeons, pathologists, oncologists and radiologists. Since January 1, 2008, there have been only four centres as Gentofte ceased to act as a centre.

Data are collected with the following purposes:

- 1) To unify procedures for diagnosis, treatment and follow-up on these types of cancer
- 2) To improve and assure the quality of treatment of these cancer types

Population:

Patients with a first-time diagnosis of carcinomas of the esophagus, cardia, and stomach, diagnosed and treated in one of five - now four - Danish treatment centres. By the end of 2008, approximately 3,800 patients with carcinomas of the esophagus (30%), cardia (45%) and stomach (25%) were registered. Approximately 700 new cases are added each year.

Period:

June 1, 2003 onwards.

Data:

The data are collected prospectively at the five treatment centres. Data are reported by participating surgeons and pathologists via the internet. The structure and contents of the database are extensive. For each patient and the current carcinoma type, forms on anamnesis, treatment (treatment intended to cure, palliative treatment or no treatment) and follow-up are reported.

Key variables include: civil registration number, hospital, date of referral and biopsy, information on type of surgery, non-surgical procedures, complications and patho-anatomic description. As of 2009, the database has been extended to include a section on oncology, containing information regarding non-surgical treatment.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

The DECV database
Department of Surgical Gastroenterology L
Aarhus Sygehus
Nørrebrogade 44
8000 Aarhus C
Denmark

Contact person: Consultant Lone Susanne Jensen; e-mail: lonsusje@rm.dk; phone: +45 89493879

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Not available.

The Danish Urological Cancer Group (DUCG) Database

Aim:

This database will be established during 2009 and will include four types of urological cancers: prostate, renal, testicular, and penile cancer.

Data will be collected with the following purposes:

- 1) To unify procedures for diagnosis, treatment and follow-up on each of the four urological cancers (prostate, renal, testicular, and penile cancer) in Denmark
- 2) To improve and assure the quality of treatment of prostate, renal, testicular, and penile cancer in Denmark
- 3) To monitor incidence and survival of prostate, renal, testicular, and penile cancer in Denmark
- 4) To support and initiate clinical urological cancer research

Population:

Patients in Denmark with prostate, renal, testicular or penile cancer.

Period:

October 1, 2009 onwards.

Data:

Data will be collected prospectively by the participating departments of surgery, histopathology, and oncology. Data are retrieved through the National Patient Registry and the National Pathology Registry but also through questionnaires filled in by the patients (height, weight, symptoms, alcohol and tobacco consumption, self-perceived physical fitness, and general health), and urologists or oncologists (diagnostics performed, staging, treatment).

Record linkage:

Through merging with the Civil Registration System, registration is supplemented with information on vital status and time of death on all registered patients.

Institution:

DUCG
Department of Urology
Aarhus University Hospital, Skejby
Brendstrupgaardsvej 100
8200 Aarhus N
Denmark

Contact person: MD, PhD, DMSc Michael Borre; e-mail: borre@ki.au.dk; phone : +45 89495566

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Not available.

The Danish Benign Prostatic Hyperplasia Database (ProsBase)

Aim:

Data in the ProsBase are collected to analyze and improve the quality of diagnosis and treatment among patients with benign prostatic hyperplasia (BPH) at departments of urology and urologic surgery nationwide.

Population:

Patients with BPH seen at Danish hospitals for diagnostic assessment, surgical treatment, and follow-up. In 2008, 42 public and private hospitals in Denmark performed surgical treatments for BPH; of these, 29 reported data to the ProsBase.

Data on approximately 10,000 patients with BPH are included at present (2009).

Period:

2004 onwards.

Data:

Data are collected prospectively using standardized registration forms filled out by the treating physician. Data are collected in three stages: Data concerning symptoms and diagnostic results at the time of first assessment, data concerning surgery, and data on complications at follow-up visits usually within six months after surgery.

In order to monitor the quality of BPH diagnosis and treatment, 12 quality criteria (% of patients fulfilling each criterion) are used: $\geq 70\%$ improvement of the DAN-PSS-1 (Danish Prostatic Symptom Score), $\geq 100\%$ improvement of urinary flow rate, satisfaction with treatment result, completed voiding diary at assessment, urine volume >150 ml at assessment, hospital length of stay ≥ 7 days, mortality 30 days after surgery, re-hospitalization due to post-surgical complications, revision surgery due to complications, treatment failure within six months, incontinence after surgical treatment, receiving more than two blood transfusions.

Record linkage:

Registration of the civil registration number enables linkage to other databases.

Institution:

The ProsBase Secretariat
Department of urologic surgery K
Aarhus University Hospital, Skejby
Brendstrupgårdsvej 100
8200 Aarhus N
Denmark

Contact persons:

- Chief physician Henning Olsen, MD; the ProsBase Secretariat; e-mail: h-olsen@dadlnet.dk; phone +45 8949 5920
- Associate professor Reimar W. Thomsen, MD, PhD, Center for Clinical Databases (North); e-mail: r.thomsen@rn.dk; phone: +45 9932 6404

The database is affiliated with Centre for Clinical Databases (North).

Selected key references:

Not available.

The Regional Clinical Database of Non-melanoma Skin Cancer

Aim:

Data are collected with the following purposes:

- 1) To monitor the treatment of non-melanoma skin cancer treated by dermatologists
- 2) To improve and assure the quality of treatment of non-melanoma skin cancer

Population:

All patients with non-melanoma skin cancer, mb. Bowen and keratoacanthoma diagnosed by dermatologists in private practice in the Central Denmark Region and by selected dermatologists in the North Denmark Region.

Period:

2009 onwards.

Data:

Data are collected prospectively and are reported by the dermatologist using an online registration system. Information on patient and tumour characteristics is recorded as well as choice of treatment. Evidence of recurrence, complications associated with treatment and cosmetic results are recorded at follow-up visits after 3 and 12 months.

Key variables include:

1. Patient characteristics: Civil registration number, previous skin cancers and skin type.
2. Tumor characteristics: cancer type, localization, size and recurrence of previous treated skin cancer. Choice of treatment.
3. Outcome variables: Evidence of recurrence, treatment-associated complications and cosmetic results evaluated by the dermatologist and by the patient.

Record linkage:

Data will be linked to the Civil Registration System and to the National Pathology Registry.

Institution:

The NMSC database
Department of Dermatology
Aarhus University Hospital
P.P. Ørumsgade 11
8000 Aarhus C
Denmark

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The registry is affiliated with Centre for Clinical Databases (North).

Selected key references:

Not available.

The Danish Database for Hepatitis B and C (DANHEP)

Aim:

Data are collected with the following purposes:

- 1) to study the demographic pattern, the morbidity and mortality, and the outcome of treatment as well as side effects for patients with chronic hepatitis B and C in Denmark
- 2) to provide an opportunity to do research. Blood samples are collected annually for research purposes

Population:

Patients, 16 years of age or older at date of referral, with chronic hepatitis B or C, who are followed by one of the 16 Danish specialized departments, which monitor and treat patients with chronic viral hepatitis in Denmark.

Period:

As of January 1, 2002: all prevalent cases, and from then on, all incident cases.

Data:

Data on patients in DANHEP include: date of initial registration in DANHEP, date of birth, gender, country of origin, date of last clinical observation, year of infection, route of infection, first positive anti-HCV and HCV-RNA assays, HCV genotype, all HCV-RNA measurements, human immunodeficiency virus (HIV)-status, HBsAg, HBe-Ag, HBV-DNA, ALT and alpha-phoetoprotein tests and date of death. The results of liver biopsies are registered as a modified METAVIR score. For patients treated for HBV or HCV infection, information on duration and type of treatment, side effects to treatment and treatment completion and outcome are registered. The database is updated online annually.

Record Linkage:

Presently, no permanent linkage, but linkage to other registries is possible, if permitted by the Danish Regions and the Danish Data Protection Registry.

Institution:

Department of Infectious Diseases
Copenhagen University Hospital, Hvidovre
Kettegaard Alle 30
2650 Hvidovre
Denmark

Selected key references:

Hansen N, Obel N, Christensen PB, Krarup HB, Laursen AL, Clausen MR, Lunding S, Møller A, Schlichting P, Kromann-Andersen H, Bukh J, Weis N and the DANHEP group. Predictors of antiviral treatment initiation in hepatitis C virus-infected patients: a Danish cohort study. *J Viral Hepatit*. 2009 Mar 27. [Epub ahead of print]

Hansen N, Cowan S, Christensen PB, Weis N. Reporting chronic hepatitis B and C in Denmark. Article in Danish. *Ugeskr Laeger*. 2008;170:1567-1570.

Christensen PB, Krarup HB, Møller A, Laursen AL, Kjær MS, Orholm M, Lindberg J, Grønbæk K, Kroman-Andersen H, Weis N and the DANHEP group. Liver biopsy performance and histological findings among patients with chronic viral hepatitis – a Danish database study. *Scand J Infect Dis*. 2007;39:245-249.

The Danish Vascular Registry

Aim:

Data are collected with the following purposes:

- 1) To ensure surveillance on all vascular procedures in Denmark (in relation to both the technological development and the implementation of new guidelines)
- 2) To facilitate quality improvement

Population:

All patients subject to primary vascular surgery/treatment carried out at one of the 11 Danish hospitals performing this type of surgery.

Period:

The Danish Vascular Registry was established in 1989 at Copenhagen University Hospital, Rigshospitalet. During the following years, it was expanded reaching coverage of the entire country in 1993. In 1996, a formal national registry was established.

Data:

Data are collected by all surgical departments and are prospectively entered into the registry. In 2002, the registry was centralised and since then reporting has been done through the internet. The registration consists of four target indicators and about 70 different clinical variables.

The four target indicators are:

- 1) Mortality after planned aorta aneurysm-surgery
- 2) Mortality after surgery of a ruptured aneurysm
- 3) Stroke rate after surgery on a. carotids
- 4) Mortality after surgery on a. carotids

The clinical variables include:

- a) Baseline information about lifestyle, comorbidities and indication for treatment (e.g., assessment of Activities of Daily Living, diabetes mellitus, cerebrovascular symptoms, hypertension, cardiac and/or pulmonary symptoms, smoking habits, alcohol intake, dialysis, dementia, cancer, immunosuppressive treatment, previous vascular surgery, biochemistry (haemoglobin, se-creatinine, total-cholesterol, HDL-cholesterol), BMI and indication of treatment).
- b) Information on surgical procedure and the surgeons' experience (e.g., all vascular surgery and/or treatment, type of prosthetic device, acute/elective surgery, ASA-score, type and duration of surgery, blood loss and type of anaesthesia)
- c) Information on postoperative hospitalization, complications and reoperations (e.g., bleeding, infections, time in intensive care unit, transfusions and cause of death)
- d) Follow-up (time of follow-up is individual)

Record linkage:

Registration of civil registration numbers enables linkage to other databases.

Institution:

Department of Cardiac Surgery
Gentofte Hospital
Niels Andersensvej 65
2900 Hellerup
Denmark

Selected key references:

Laustsen J, Jensen LP, Hansen AK. Accuracy of clinical data in a population based vascular registry. *Eur J Vasc Endovasc Surg.* 2004;27:216-219.

Andersen LV, Mortensen LS, Lindholt JS, Faergeman O, Henneberg EW, Frost L. Completeness and positive predictive value of registration of upper limb embolectomy in the Danish National Vascular Registry. *Clinical Epidemiology*. 2009:127-32.

Other Datasets

The Danish HIV Cohort Study (DHCS)

Aim:

Data are collected for research purposes to study:

- 1) Temporal changes in the demographic composition of the HIV population
- 2) The effects of antiretroviral therapy in general
- 3) Mortality and development of new AIDS-defining events
- 4) CD4+ cell count and plasma HIV RNA as surrogate endpoints for treatment success or failure

Population:

All clinics treating HIV-infected patients in Denmark participate in DHCS. Data from all patients seen in any of the clinics are collected from patient files and entered into the database. Treatment for HIV infection in Denmark is restricted to eight departments of infectious diseases.

Antiretroviral drugs are delivered free of charge directly from these clinics and cannot be bought from pharmacies.

Period:

As of January 1, 1995, all prevalent cases and all incident cases thereafter.

Data:

Baseline data collected are: date of birth, gender, origin, race, most likely mode and place of infection, time of HIV-1 and HIV-2 diagnosis, time of latest previous negative HIV antibody test, serological status regarding hepatitis B and C, cytomegalovirus, and toxoplasmosis. Regular updates are carried out once a year noting: antiretroviral treatment, prophylactic treatment for opportunistic infections, development of opportunistic infections and other AIDS-defining illnesses, myocardial infarction, diabetes, lipodystrophy, pregnancies and outcome of births, and laboratory values including plasma HIV-RNA, CD4+ cell count, and blood lipids.

Record linkage:

No permanent linkage, but linking to other registries is possible if permitted by the Danish Registry Board.

Institution:

Department of Infectious Diseases, Copenhagen University Hospital
Rigshospitalet
Blegdamsvej 9
2100 Copenhagen Ø
Denmark

Selected key references:

Jensen-Fangel S, Pedersen L, Pedersen C, Larsen CS, Tauris P, Møller A, Sørensen HT, Obel N. The effect of race/ethnicity on the outcome of highly active antiretroviral therapy for human immunodeficiency virus type 1-infected patients. *Clin Infect Dis*. 2002;35:1541-1548.

Jensen-Fangel S, Pedersen L, Pedersen C, Larsen CS, Tauris P, Møller A et al. Low mortality in HIV-infected patients starting HAART in advance of immunological deterioration: a comparison with the general population. *AIDS*. 2004;18:89-97.

Lohse N, Hansen AB, Jensen-Fangel S, Kronborg G, Kvinesdal B, Pedersen C, Larsen CS, Møller A, Willumsen L, Obel N. Demographics of HIV-1 infection in Denmark: results from the Danish HIV cohort study. *Scand J Infect Dis*. 2005;37:338-343.

Lohse N, Obel N, Kronborg G, Laursen A, Pedersen C, Larsen CS, Kvinesdal B, Sørensen HT, Gerstoft J. Declining risk of triple-class antiretroviral drug failure in Danish HIV-infected individuals. *AIDS*. 2005;19:815-822.

Lohse N, Kronborg G, Gerstoft J, Larsen CS, Pedersen G, Pedersen C, Sørensen HT, Obel N. Virological Control during the First 6-18 Months after Initiating HAART as a Predictor for Mortality, CD4+ Cell Increase, and Viral Suppression. *Clin Infect Dis*. 2006;42:136-144.

Weiss N, Lindhardt BØ, Kronborg G, Hansen AB, Laursen A, Christensen PB, Nielsen H, Møller A, Sørensen HT, Obel N. Impact of hepatitis C virus co-infection on response to HAART and outcome in HIV-Infected individuals: A nationwide cohort study. *Clin Infect Dis*. 2006;42:1481-1487.

Lohse N, Jørgensen LB, Kronborg G, Møller A, Kvinesdal B, Sørensen HT, Obel N, Gerstoft J. Genotypic drug resistance and long-term mortality in patients with triple-class antiretroviral drug failure. *Antivir Ther*. 2007;12:909-917.

Obel N, Thomsen HF, Kronborg G, Larsen CS, Hildebrandt PR, Sørensen HT, Gerstoft J. Ischemic heart disease in HIV-infected and HIV-uninfected individuals: a population-based cohort study. *Clin Infect Dis*. 2007;44:1625-1631.

Lohse N, Hansen ABE, Pedersen G, Kronborg G, Gerstoft J, Sørensen HT, Væth M, Obel N. Survival of Persons with and without HIV Infection in Denmark, 1995-2005. *Ann Intern Med*. 2007;146:87-95.

Hansen AB, Gerstoft J, Kronborg G, Pedersen C, Sørensen HT, Obel N. Mortality in siblings of patients coinfecting with HIV and hepatitis C virus. *J Infect Dis*. 2007;195:230-235.

The Danish National Birth Cohort (DNBC)

Aim:

Data are collected to provide information about the period from conception to early childhood and to examine how this period influences health conditions at later stages of life. Side effects of medications and infections are of special interest in the cohort.

Population:

Women coming to their general practitioner for the first pregnancy visit are invited to participate. The study has recruited approximately 100,000 women early in pregnancy, and continue follow-up for decades.

Period:

Data collection began in 1996, and was nationwide by 1999.

Data:

Data are collected by telephone interviews: twice during pregnancy, and when the child is 6 and 18 months old. In addition, blood samples are taken during pregnancy, and from the umbilical cord. Participants are asked to fill in a self-administered food frequency questionnaire halfway through their pregnancy. Key variables in interviews are, for mothers, age at conception, previous diseases, occupation, use of medications and duration of breast-feeding period; for children, apparent diseases at 6 and 18 months.

Record linkage:

The cohort is linked to the Danish National Registry of Patients and the Danish Medical Birth Registry.

Institution:

Danish Epidemiology Science Centre
Statens Serum Institut
Artillerivej 5
2300 Copenhagen S
Denmark

Selected key references:

Olsen J, Melbye M, Olsen SF, Sørensen TI, Aaby P, Andersen AM, Taxbol D, Hansen KD, Juhl M, Schow TB, Sørensen HT, Andresen J, Mortensen EL, Olesen AW, Sondergaard C. The Danish National Birth Cohort: its background, structure and aim. *Scand J Public Health*. 2001;29:300-307.

Basso O, Olsen J. Subfecundity and neonatal mortality: a longitudinal study within the Danish national birth cohort. *BMJ*. 2005;330:393-394.

Zhu JL, Basso O, Obel C, Bille C, Olsen J. Infertility, infertility treatment, and congenital malformations: Danish national birth cohort. *BMJ*. 2006;333:679.

Rebordosa C, Kogevinas M, Horváth-Puhó E, Nørgård B, Morales M, Czeizel AE, Vilstrup H, Sørensen HT, Olsen J. Use of acetaminophen during pregnancy and congenital abnormalities. *Am J Obstet Gynecol*. 2008;198:178.e1-7.

Rebordosa C, Kogevinas M, Sørensen HT, Olsen J. Paracetamol use during pregnancy and risk of wheezing and asthma in children: a birth cohort study. *Int J Epidemiol*. 2008;37:583-590.

Rebordosa C, Kogevinas M, Bech BH, Sørensen HT, Olsen J. Use of acetaminophen during pregnancy and risk of adverse pregnancy outcomes. *Int J Epidemiol.* 2009 Mar 30. [Epub ahead of print]

Pedersen L, Nørgaard M, Skriver MV, Olsen J, Sørensen HT. Prenatal exposure to loratadine in children with hypospadias: a nested case-control study within the Danish National Birth Cohort. *Am J Ther.* 2006;13:320-324.

The Soon Pregnant Cohort Study

Aim:

Data are collected with the following purposes:

- 1) To investigate risk factors for delayed fecundability and miscarriage
- 2) To test feasibility of using the Internet for recruitment and follow-up

Population:

The study includes more than 5,000 women with a Danish civil registration number who at the time of enrolment were:

- between 18 and 40 years old
- trying to become pregnant
- not using contraception
- not in fertility treatment

Period:

June 1, 2007 onwards.

Data:

Participants fill in web-based questionnaires every two months until they become pregnant or for one year. Information on the women's lifestyles is collected. The main variables are: civil registration number, education, menstruation and contraception history, information on previous pregnancies, weight, height, level of physical activity, intake of alcohol and caffeine, smoking habits and use of painkillers.

Record linkage:

The self-reported data will be linked to, e.g., the Danish Medical Birth Registry, The Civil Registration System, the Register of Medicinal Product Statistics and Statistics Denmark.

Institution:

Department of Clinical Epidemiology, Aarhus University Hospital
Olof Palmes Alle 43-45
8200 Aarhus N
Denmark

In collaboration with Department of Epidemiology, Boston University School of Public Health, US.

Selected key references:

Rothman KJ, Mikkelsen EM, Sørensen HT, Wise LA, Riis A, Hatch EE. Randomized Trial of Questionnaire Length. *Epidemiology*. 2009;20:154.

Mikkelsen EM, Hatch EE, Wise LA, Rothman KJ, Riis A, Sørensen HT. Cohort Profile: The Danish Web-based Pregnancy Planning Study--'Snart-Gravid'. *Int J Epidemiol*. 2009;38: 938-943.

Wise LA, Rothman KJ, Mikkelsen EM, Sørensen HT, Riis A, Hatch EE. An internet-based prospective study of body size and time-to-pregnancy. *Hum Reprod*. 2009. In press.

The Danish Newborn Screening Biobank (NBS-Biobank)

Aim:

Data are collected with the following purposes:

- 1) To offer all parents screening of their newborns for phenylketonuria (PKU), congenital hypothyroidism (CH) and toxoplasmosis in order to secure optimal management of these congenital disorders, including documentation, repeated testing, quality assurance, statistics and improvement of screening methods
- 2) To aid diagnostics later in infancy
- 3) To facilitate potential legal use of these data
- 4) To provide opportunity for research approved by the Scientific Ethical Committee System in Denmark, The Danish Data Protection Agency, and the NBS-Biobank Steering Committee.

Population:

All newborns in Denmark, Greenland and the Faroe Islands.

Period:

The registry contains dried blood spots obtained from 1982 onwards.

Data:

In Denmark, it is mandatory to offer all parents screening of their newborns for phenylketonuria (PKU), congenital hypothyroidism, and toxoplasmosis. The coverage of the programme is close to 100%, and it is carried out by analyses of dried blood spots taken by a heel prick five to seven days after birth. These routinely collected samples are stored in the biobank at -25°C . Storage of samples requires parents' consent and the parents may opt out of biobank storage at the time of blood sampling by marking the data card, or at a later stage. The number of samples stored per year is about 65,000. As of 2007, the biobank contains approximately 1.8 million samples.

Record linkage:

The dried blood spots are linked to the individual data forms (including civil registration number) by a unique sample number.

Institution:

Department of Clinical Biochemistry
Statens Serum Institut
Artillerivej 5
2300 Copenhagen S
Denmark

Selected key references:

Nørgaard-Pedersen B, Simonsen H. Biological specimen banks in neonatal screening. *Acta Paediatr Suppl.* 1999;88:106-109.

Nørgaard-Pedersen B, Hougaard DM. The Danish Newborn screening Biobank in Routine and Research. New revised Biobank regulations. 4th International DNA sampling Conference: In *Genomics and Public Health*. Ed. Knoppers BM. 2006.

Hollegaard MV, Sørensen KM, Petersen HK, Arnardottir MB, Nørgaard-Pedersen B, Thorsen P, Hougaard DM. Whole genome amplification and genetic analysis after extraction of proteins from dried blood spots. *Clin Chem.* 2007;53:1161-1162.

Nørgaard-Pedersen B, Hougaard DM. Storage policies and use of the Danish Newborn Screening Biobank. *J Inherit Metab Dis.* 2007;30:530-536.

The Gerda Frenzt Cohort (GFC)

Aim:

The cohort was initiated in order to determine the disease profile and the true disease burden (incidence) of non-melanoma skin cancers (NMSC). The task was undertaken due to incomplete registration of these cancers in the Danish Cancer Registry.

Population:

Patients with NMSC seen by Danish dermatologists or collaborating dermatopathologists.

Period:

From 1995 onwards.

Data:

Professor Gerda Frenzt initiated the nationwide cohort when she began to prospectively record NMSC patients in 1995. Two data sources were used to establish the cohort. The first source was patients seen at private or public outpatient dermatology clinics, for whom the following clinical data were available: tumour site, size and clinical diagnosis, availability of the histological review of a biopsy (yes/no), treatment type, and history of an NMSC. The second source comprised all patients with a histological review of suspected NMSCs sent from any other non-dermatology practitioner to a pathologist. These data also included biopsies diagnosed as NMSC, irrespective of the clinical diagnosis. Histological data on these tumours included the final histological diagnosis, the type of referring clinic and, if appropriate, details on the tumour's growth pattern, differentiation and excision borders. Both first primary NMSC and subsequent new primaries were included.

Record linkage:

Linkage between the two data sources is done by use of the civil registration number.

Institution:

Department of Clinical Epidemiology, Aarhus University Hospital
Olof Palmes Alle 43-45
8200 Aarhus N
Denmark

Selected key references:

Jensen AO, Olesen AB, Dethlefsen C, Sørensen HT. Ten year mortality in a cohort of non-melanoma skin cancer patients in Denmark. *J Invest Dermatol.* 2006;126:2539-2541.

Jensen AO, Olesen AB, Dethlefsen C, Sørensen HT. Do incident and new subsequent cases of non-melanoma skin cancer registered in a Danish prospective cohort study have different ten-year mortality? *Cancer Detect Prev.* 2007;31:352-358.

Jensen AO, Olesen AB, Dethlefsen C, Sørensen HT, Karagas MR. Chronic diseases requiring hospitalization and risk of non-melanoma skin cancers – A population based study from Denmark. *J Invest Dermatol.* 2008;128:926-31.

The DANVIR Cohort

Aim:

Data are collected for research purposes to study:

- 1) Mortality in patients infected with chronic viral hepatitis including independent predictors of mortality
- 2) The prevalence of chronic viral hepatitis in Denmark
- 3) The association between chronic viral hepatitis and cancer and cirrhosis
- 4) The impact of social risk factors on mortality in patients with chronic hepatitis

Population:

The DANVIR cohort study is a population-based prospective cohort consisting of all patients tested for hepatitis B virus (HBV) or hepatitis C virus (HCV) in 14 of the 18 Danish laboratories that perform these tests. The cohort is estimated to include more than 90% of all patients tested for HBV or HCV in Denmark.

Period:

Data has been collected once and includes data from the period January 1, 1995 to December 31, 2006. Updates are planned at intended intervals of three years.

Data:

Data collected for the cohort include results of HBV and HCV serology and virology with corresponding dates and site of testing. No further clinical data are collected.

Record linkage:

The DANVIR database is linked to the Civil Registration System, the Danish National Registry of Patients, the Danish Cancer Registry, the Danish Registry of Causes of Death, The Registry of Drug Users Undergoing Treatment and The Integrated Database for Labour Market Research.

Institution:

Department of Clinical Epidemiology, Aarhus University Hospital
Olof Palmes Alle 43-45
8200 Aarhus N
Denmark

Selected key references:

Omland LH, Jepsen P, Skinhoj P, Jørgensen HL, Münster A-MB, Bangsborg J, Fenger M, Sørensen HT, Obel N. The impact of HIV-1 co-infection on long-term mortality in patients with hepatitis C: a population-based cohort study. *HIV Med.* 2009;10:65-71.

Omland LH, Krarup H, Jepsen P, Georgsen J, Harritshøj LH, Riisom K, Jacobsen SEH, Schouenborg P, Christensen PB, Sørensen HT, Obel N. Mortality in patients with chronic versus cleared hepatitis C virus infection - a population based cohort study. In draft.

The North Jutland Conscript Dataset

Aim:

The data are collected to determine fitness of draft-liable Danish men for the mandatory army service.

Population:

All Danish men reaching draft age (17-19 years), born and residing in the geographically defined Fifth Conscription District, who present for mandatory evaluation for the army service.

Period:

The most complete data housed by the Department of Clinical Epidemiology are available on conscripts who were born between 1977 and 1983 and completed the draft board evaluation in 1995-2002. These records, comprising 22,000 men, were paper-based at the time of the draft, but were computerized by and are stored at the Department of Clinical Epidemiology.

Data:

The draft board evaluation consists of a health questionnaire, a physical examination, and an intelligence test. Exemption from the military service may be granted for health reasons, which include independently verified pre-existing serious medical condition (e.g., epilepsy, severe asthma, or mental retardation); serious medical condition discovered at the draft board physical examination (e.g., severe hearing or visual impairment); or inadequate performance on the group intelligence test. Results of all evaluations are recorded in the conscripts' files. Data include pre-existing serious diseases, coded using the International Classification of Diseases, 10th revision; occupation (if any); completed years of education; height; weight; hearing and visual acuity, measured using standard methods; results of the intelligence test (measured with the Boerge Prien intelligence test); and a code indicating suitability for the army (fit, conditionally fit, unfit).

Record linkage:

The data are linkable, via the civil registration number, to conscripts' birth, hospital, and demographic records in other Danish registries.

Institution:

Department of Clinical Epidemiology, Aarhus University Hospital
Olof Palmes Alle 43-45
8200 Aarhus N
Denmark

Selected key references:

Mortensen EL, Reinisch JM, Teasdale, TW. Intelligence as measured by the WAIS and a military draft board test. *Scand J Psychol.* 1989;30:315-318.

Sørensen HT, Sabroe S, Olsen J, Rothman KJ, Gillman MW, Fischer P. Birth weight and cognitive function in young adult life: historical cohort study. *BMJ.* 1997;315:401-403.

Sørensen HT, Steffensen FH, Olsen J, Sabroe S, Gillman MW, Fischer P, Rothman KJ. Long-term follow-up of cognitive outcome after breech presentation at birth. *Epidemiology.* 1999;10:554-556.

Steffensen FH, Sørensen HT, Gillman MW, Rothman KJ, Sabroe S, Fischer P, Olsen J. Low birth weight and preterm delivery as risk factors for asthma and atopic dermatitis in young adult males. *Epidemiology.* 2000;11:185-188.

Nielsen GL, Dethlefsen C, Sørensen HT, Pedersen JF, Molsted-Pedersen L. Cognitive function and army-rejection rate in young adult male offspring of women with diabetes: A Danish population-based cohort study. *Diabetes Care*. 2007;30:2827-2831.

Ehrenstein V, Pedersen L, Grijota M, Nielsen GL, Rothman KJ, Sørensen HT. Association of Apgar score at five minutes with long-term neurologic disability and cognitive function in a prevalence study of Danish conscripts. *BMC Pregnancy Childbirth*. 2009;9:14.

Nørgaard M, Ehrenstein V, Mahon BE, et al. Febrile seizures and cognitive function in young adult life: a prevalence study among Danish conscripts. *J Pediatrics*. 2009 Jun 23. [Epub ahead of print].

Ehrenstein V, Rothman KJ, Pedersen L, Hatch EE, Sørensen HT. Pregnancy-associated hypertensive disorders and adult cognitive function among Danish conscripts. *Am J Epidemiol*. In press.

The Danish Breast Cancer Recurrence Case Control Biobank

Aim:

To examine potential impact of polymorphisms in drug-metabolising enzymes and other genetic factors on the rates of breast cancer recurrence.

Population:

All women diagnosed with breast cancer between 1985 and 2001, and registered with the Danish Breast Cancer Cooperative Group (see page 85), with information on breast cancer recurrence. As a source of DNA for genotyping, all eligible subjects must have paraffin-embedded tumour blocks available (from pathology banks).

Period:

Data were collected from 1985 to 2001. Follow-up time from one year after the date of breast cancer diagnosis until the date of the first breast cancer recurrence, death from any cause, loss to follow-up (e.g., emigration), ten years of follow-up, or September 1, 2006.

Data:

Data in the DBCG are collected prospectively and sent from the participating departments of surgery, histopathology, oncology and radiotherapy on forms produced by the DBCG secretariat. The database holds information on primary surgical procedures, histopathology, adjuvant therapy and clinical follow-up. In addition, different patient data are registered.

Each study has collected archived paraffin-embedded breast tumour blocks for all patients. These blocks are used as a source of DNA.

Main variables: civil registration number, histological diagnosis, type of surgery, menopausal status, protocol allocation and randomization, oestrogen receptor status, receipt and duration of tamoxifen treatment, receipt and duration of chemotherapy treatment (specific agents), information about adjuvant radiotherapy and adjuvant systemic treatment and side effects, status of recurrence.

Record linkage:

Using patient civil registration numbers, the breast cancer recurrence dataset can be linked to a number of other Danish databases including the Civil Registration System (for information on vital status), the Danish Cancer Registry, the Register of Medicinal Product Statistics (for information on use of prescription drugs before, during and after breast cancer treatment, which may impact on rates of recurrence), and the Danish Pathology Registry (to facilitate retrieval of tissue specimens such as archived paraffin-embedded tumour blocks).

Institution:

Department of Clinical Epidemiology
Aarhus University Hospital
Olof Palmes Alle 43-45
8200 Aarhus N
Denmark

Selected key references:

Lash TL, Pedersen L, Cronin-Fenton DP, Ahern TP, Lunetta K, Rosenberg C, Silliman RA, Hamilton-Dutoit S, Garne JP, Ewertz M, Sørensen HT. Tamoxifen's protection against breast cancer recurrence is not reduced by concurrent use of the SSRI citalopram. *Br J Cancer*. 2008;99:616-621.

Ahern TP, Pedersen L, Cronin-Fenton D, Sørensen HT, Lash TL. No increase in breast cancer recurrence with concurrent use of tamoxifen and some CYP2D6-inhibiting medications. *Cancer Epidemiol Biomarkers Prev.* 2009 Aug 18. [Epub ahead of print].

The Registry of Patients with Chronic Immune Thrombocytopenic Purpura (ITP)

Aim:

Data are collected with the following purposes:

- 1) To describe the incidence of chronic ITP in the Danish adult population (age ≥ 18 years) between 1996 and 2007
- 2) To describe demographic characteristics, duration of disease, medical history, co-morbidities, complications, and concurrent medications and operative treatments among patients with chronic ITP between 1996 and 2007
- 3) To estimate the prevalence of bone marrow (BM) fibrosis with associated clinical symptoms (i.e., splenomegaly, hepatomegaly and thrombocytopenia), confirmed by findings in BM biopsies of patients with chronic ITP
- 4) To estimate the incidence of thrombotic/thromboembolic (TE) events in patients with chronic ITP

Population:

Using the Danish National Registry of Patients, all adult patients (aged ≥ 18 years) with a hospital diagnosis of ITP were identified as those with a hospital diagnosis of the 10th revision of the International Classification of Diseases (ICD-10) code D69.3 (i.e., purpura, idiopathic thrombocytopenic). The population was limited to patients with chronic ITP (lasting longer than six months) by including only those with two or more hospital diagnoses of ITP over a period of more than six months. Information from the chart reviews was used as confirmation, and the population was defined as ITP patients with a platelet count below $150 \times 10^9/L$ without an obvious cause (i.e., secondary ITP were excluded), lasting longer than six months. A total of 408 patients fulfilled the definition of chronic ITP.

Period:

January 1, 1996 to December 31, 2007

Data:

The registry contains information on the patients' civil registration number, date of initial ITP diagnosis, date of chronic ITP, presence of splenomegaly and/or hepatomegaly, platelet count at baseline (at initial ITP diagnosis), lowest ever platelet count during the entire follow-up, date of beginning and ending treatments (e.g., corticosteroids, splenectomy, anti-Rhesus-0 (anti-Rh₀(D)) immune globulins, and/or intravenous immunoglobins (IVIgs), chemotherapy, and Rituximab), date of platelet and red blood cell (RBC) transfusion, date of severe complications to chronic ITP (e.g., a major infection or bleeding episode requiring hospitalization), and remission date (i.e., the last hospital admission regarding chronic ITP according to the medical record).

For chronic ITP patients with an incident thrombotic/thromboembolic (TE) event (N=44) during follow-up, the following information is registered: date of TE event, type of TE event, presence of anti-phospholipid antibodies, haemoglobin count, leukocyte count and platelet count at TE date, type of chronic ITP treatment at TE date.

For chronic ITP patients, who had a bone marrow biopsy taken at initial ITP diagnosis (N=185), the amount of collagen and reticulin content was determined by use of an international scoring system.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

Department of Clinical Epidemiology, Aarhus University Hospital
Olof Palmes Alle 43-45
DK-8200 Aarhus N
Denmark

Selected key references:

Andersen TF, Madsen M, Jørgensen J, Mellemkjoer L, Olsen JH. The Danish National Hospital Register. A valuable source of data for modern health sciences. *Dan Med Bull.* 1999;46:263-268.

Klith Heden KE, Jensen AO, Farkas DK, Nørgaard M. Validity of a procedure to identify patients with chronic idiopathic thrombocytopenic purpura in the Danish National Registry of Patients. *Clin Epidemiol.* 2009;1:7-10.

Thiele J, Kvasnicka HM. Myelofibrosis--what's in a name? Consensus on definition and EUMNET grading. *Pathobiology.* 2007;74:89-96.

Frank L. Epidemiology. When an entire country is a cohort. *Science.* 2000;287:2398-2399.

Ettrup MS, Jensen AØ, Farkas DK, Engebjerg MC, Nørgaard M, Fryzek JP, Zhao S, Johansen P, Sørensen HT. Prevalence of bone marrow fibrosis in patients with adult chronic idiopathic thrombocytopenic purpura: A Danish nationwide study. In preparation.

Life after Breast Cancer

Aim:

The project follows women with breast cancer from before the diagnosis and three years after with repetitive registration of symptoms, quality of life and function. The aim is:

- 1) To find and describe determinants for the long term course of symptoms and health related quality of life
- 2) To find and describe determinants of return to work and ability to stay at the labour market

Population:

156 patients who were referred to mammography and diagnosed with breast cancer at the regional hospitals in Viborg and Randers. Included are women who were less than 65 years of age at inclusion.

Period:

Inclusion took place from September 2004 to December 2007 among women referred to mammography (not screening). Follow-up is carried out for two to three years and is still proceeding. 2027 women answered a baseline questionnaire received with the invitation for mammography. Both women diagnosed with breast cancer and a control group of women without breast cancer were then followed with questionnaires every third month.

Data:

Main variables include:

- Baseline questionnaire: demographic information, education, job and working conditions, physical symptoms, health-related quality of life and function (SF36), fatigue (MFI-20), anxiety and depression (HADS), sleep, psychological working environment, person-type, coping and hostility
- Follow-up questionnaires: physical symptoms, health-related quality of life and function (SF12), fatigue, anxiety and depression, sleep, and stress

The women could choose between internet reply or pen-and-paper reply.

Record linkage:

The Danish Cancer Registry, the Civil Registration System and DREAM (information on social benefits and other transfer income).

Institution:

Department of Occupational Health
Herning Regional Hospital
Gl. Landevej 61
7400 Herning
Denmark

Selected key references:

Kongsved SM, Basnov M, Holm-Christensen K, Hjollund NH. Response rate and completeness of questionnaires: a randomized study of Internet versus paper-and-pencil versions. *J Med Internet Res.* 2007;9(3):e25.

Nielsen NB, Zachariae R, Hjollund NH. Perceived risk prior to mammography as an independent predictor of breast cancer. *J Psychosom Res.* 2009;66:245-247.

Basnov MS, Kongsved SM, Bech P, Hjollund NH. Reliability of Short Form-36 in an Internet and a pen-and-paper version. *Inform Health Soc Care.* 2009;34:53-58.

Life with Heart Disease

Aim:

Data are collected with the following purposes:

- 1) To describe the long term course for patients with ischemic heart disease treated with PCI (percutaneous coronary intervention), with respect to self-reported health, fatigue, anxiety and depression, functioning, return to work, activities and social integration
- 2) To examine clinical, psychological, job- and society-related factors as predictors for persons with ischemic heart disease to stay on the labour market
- 3) To examine psychosocial factors of the medical prognosis including self reported stress, job-related stress and psychosocial job characteristics

Population:

1266 patients referred to PCI at Skejby University Hospital. The database includes patients less than 65 years of age at referral.

Period:

Inclusion took place from March 2006 to March 2008. Follow-up takes place every three months for two to three years and is still proceeding. Patients still alive one month after the procedure were first posed a short introductory questionnaire and if they accept to participate they were posed a baseline questionnaire followed by follow-up questionnaires every third month.

Data:

Main variables include:

- Introductory questionnaire: health related quality of life and function (SF12) and acceptance of participation.
- Baseline questionnaire: demographic information, education, job and working conditions, cardiac symptoms, health related quality of life and function (SF36), fatigue (MFI-20), anxiety and depression (HADS), sleep, psychological working environment, person-type, coping and hostility.
- Follow-up questionnaires: cardiac symptoms, health-related quality of life and function (SF12), fatigue, anxiety and depression, sleep and stress

The patients could choose between internet reply or pen-and-paper reply.

Record linkage:

The Western Denmark Heart Registry, the Civil Registration System and DREAM (information on social benefits and other transfer income).

Institution:

Department of Occupational Health
Herning Regional Hospital
Gl. Landevej 61
7400 Herning
Denmark

Selected key references:

Not available.

The Nordic Registry of Patients with Chronic Immune Thrombocytopenic Purpura (ITP)

Aim:

Data are collected with the following purposes:

- 1) To describe the incidence of chronic ITP among adults (age ≥ 18 years) in Denmark, Sweden, and Finland from 2009 onwards
- 2) To describe demographic characteristics, medical history, and comorbidity in chronic ITP patients
- 3) To describe course of the disease (platelet counts), therapy (splenectomy and medical treatment), and complications to therapy (thrombocytopenia, bleeding events, bone marrow fibrosis, malignancies, and thromboembolic events)

Population:

The registry includes all adult patients with chronic ITP in Denmark, Sweden and Finland. The respective national health registry systems of the three countries were used to identify patients with a hospital diagnosis of ITP or primary thrombocytopenia (diagnosis codes D69.3 and D69.4 in the 10th revision of the International Classification of Diseases, ICD-10). The diagnosis of primary chronic ITP was confirmed by a chart review: 1) platelet count below $150 \times 10^9/L$, 2) no other cause of thrombocytopenia, and 3) the disease duration lasted more than six months.

Period:

The registry includes all incident cases after January 1, 2009, and prevalent cases between January 1, 1996 and December 31, 2008, who were alive on January 1, 2009. The registry will be updated annually until 2020.

Data:

The registry contains information on the patients' civil registration number, date of initial ITP diagnosis, date of chronic ITP, medical history, and comorbidities. Data at the time of diagnosis (baseline) include, among others, initial platelet count and symptoms prior to diagnosis (bleeding episodes, infections). Medical records are reviewed once a year to obtain data on complications, treatment, and laboratory data. Data on complications include bleeding episodes, infections, and symptoms of thrombocytosis. Treatment data include date of any splenectomy, date of beginning and ending of medical treatments (e.g., corticosteroids, azathioprine, rituximab, romiplostim, chemotherapy and/or intravenous immunoglobins (IVIGs)), and date of platelet and red blood cell (RBC) transfusion. Laboratory data on platelet counts, haemoglobin and leukocytes are included during the entire follow-up period.

The registry also contains data on any bone marrow biopsies in the chronic ITP patients, including a description of the amount of collagen and reticulin content reported in accordance with an international scoring system. Data on malignancies and thromboembolic events are obtained from the national health registry systems.

Record linkage:

Registration of civil registration numbers makes it possible to link the data to other databases.

Institution:

Department of Clinical Epidemiology, Aarhus University Hospital
Olof Palmes Alle 43-45
8200 Aarhus N
Denmark

Selected key references:

Andersen TF, Madsen M, Jorgensen J, Mellemkjoer L, Olsen JH. The Danish National Hospital Register. A valuable source of data for modern health sciences. *Dan Med Bull.* 1999;46:263-268.

Heden KEK, Jensen AØ, Farkas DK, Nørgaard M. Validity of a procedure to identify patients with chronic idiopathic thrombocytopenic purpura in the Danish National Registry of Patients. *Clinical Epidemiology*. 2009;1;7–10.

Thiele J, Kvasnicka HM. Myelofibrosis--what's in a name? Consensus on definition and EUMNET grading. *Pathobiology*. 2007;74:89-96.

Frank L. Epidemiology. When an entire country is a cohort. *Science*. 2000;287:2398-2399.

Department of Clinical Epidemiology

Department of Clinical Epidemiology (DCE) is a research department at Aarhus University Hospital and the Institute of Clinical Medicine, Aarhus University. Researchers in the department use modern epidemiological methods to study the prognosis of patient populations. The department is engaged in a great variety of activities regarding research, counselling and improvement of the quality of care and treatment offered to patients within the Danish health care system. A great number of projects in the department are carried out in cooperation with international collaborators.

Research

DCE conducts free and independent research on a high international level. The department has a special obligation to strengthen and extend clinical epidemiological research within the health services of the Central Denmark Region and the North Denmark Region.

The services provided by DCE include:

- Clinical epidemiological consultancy
- Advice on data collection
- Data analysis
- Assistance in interpreting data
- Contract research
- Supervising clinical epidemiological research in the two regions
- Contributing to method development and the establishment of training in clinical epidemiology
- Ensuring the best possible use of health data in clinical epidemiological research and establishing a structure, which secures the use of research data
- Assisting with the development and running of registries and clinical databases
- Consultancy to the Central Denmark Region and the North Denmark Region in questions necessitating advanced clinical epidemiological knowledge
- Contributing to development, implementation and use of quality indicators

The department has a documentation function with the aim of securing, maintaining and promoting the use of regional registries for research purposes, among others, the prescription database, the birth registry, and the regional hospital information systems.

Informatics and Statistics

Statisticians at the department provide biostatistical advice/guidance to PhD students and employees at DCE and to persons affiliated with the health science environments in the North Denmark Region and the Central Denmark Region. The department offers assistance within the field of clinical epidemiology and experimental clinical research, i.e., experimental medicine, experimental surgery and other clinical trials. Primary methods include survival analyses and case-control studies, as well as analyses of trials within experimental research.

The department's biostatisticians teach biostatistics to PhD students at the Faculty of Health Sciences, Aarhus University and pre-graduate epidemiological and biostatistics courses at the Medical School, Aarhus University. In addition, the department's computer scientists and biostatisticians perform a variety of tasks within data management and statistical analyses, as well as prepare quarterly and annual reports for a number of clinical databases and research registries.

Quality Assessment

Department of Clinical Epidemiology assists in quality assurance partly through the clinical databases associated with Centre for Clinical Databases (North) and partly through specific projects like the surgery project, the regional and national cancer monitoring and analyses for nationwide campaigns like Operation Life.

For further information about DCE, please visit the department homepage at: www.kea.au.dk



Reports and PhD theses from Department of Clinical Epidemiology

1. Ane Marie Thulstrup: Mortality, infections and operative risk in patients with liver cirrhosis in Denmark. *Clinical epidemiological studies. 2000.*
2. Nana Thrane: Prescription of systemic antibiotics for Danish children. *2000.*
3. Charlotte Søndergaard: Follow-up studies of prenatal, perinatal and postnatal risk factors in infantile colic. *2001.*
4. Charlotte Olesen: Use of the North Jutland Prescription Database in epidemiological studies of drug use and drug safety during pregnancy. *2001.*
5. Yuan Wei: The impact of fetal growth on the subsequent risk of infectious disease and asthma in childhood. *2001.*
6. Gitte Pedersen: Bacteremia: treatment and prognosis. *2001.*
7. Henrik Gregersen: The prognosis of Danish patients with monoclonal gammopathy of undertermined significance: register-based studies. *2002.*
8. Bente Nørgård: Colitis ulcerosa, coeliaki og graviditet; en oversigt med speciel reference til forløb og sikkerhed af medicinsk behandling. *2002.*
9. Søren Paaske Johnsen: Risk factors for stroke with special reference to diet, Chlamydia pneumoniae, infection, and use of non-steroidal anti-inflammatory drugs. *2002.*
10. Elise Snitker Jensen: Seasonal variation of meningococcal disease and factors associated with its outcome. *2003.*
11. Andrea Floyd: Drug-associated acute pancreatitis. *Clinical epidemiological studies of selected drugs. 2004.*
12. Pia Wogelius: Aspects of dental health in children with asthma. *Epidemiological studies of dental anxiety and caries among children in North Jutland County, Denmark. 2004.*
13. Kort-og langtidsoverlevelse efter indlæggelse for udvalgte kræftsygdomme i Nordjyllands, Viborg og Århus amter 1985-2003. *2004.*
14. Reimar W. Thomsen: Diabetes mellitus and community-acquired bacteremia: risk and prognosis. *2004.*
15. Kronisk obstruktiv lungesygdom i Nordjyllands, Viborg og Århus amter 1994-2004. Forekomst og prognose. Et pilotprojekt. *2005.*
16. Lungebetændelse i Nordjyllands, Viborg og Århus amter 1994-2004. Forekomst og prognose. Et pilotprojekt. *2005.*
17. Kort- og langtidsoverlevelse efter indlæggelse for nyre-, bugspytkirtel- og leverkræft i Nordjyllands, Viborg, Ringkøbing og Århus amter 1985-2004. *2005.*

18. Kort- og langtidsoverlevelse efter indlæggelse for udvalgte kræftsygdomme i Nordjyllands, Viborg, Ringkøbing og Århus amter 1995-2005. 2005.
19. Mette Nørgaard: Haematological malignancies: Risk and prognosis. 2006.
20. Alma Becic Pedersen: Studies based on the Danish Hip Arthroplasty Registry. 2006.
Særtryk: Klinisk Epidemiologisk Afdeling - De første 5 år. 2006.
21. Blindtarmsbetændelse i Vejle, Ringkøbing, Viborg, Nordjyllands og Århus Amter. 2006.
22. Andre sygdommes betydning for overlevelse efter indlæggelse for seks kræftsygdomme i Nordjyllands, Viborg, Ringkøbing og Århus amter 1995-2005. 2006.
23. Ambulante besøg og indlæggelser for udvalgte kroniske sygdomme på somatiske hospitaler i Århus, Ringkøbing, Viborg, og Nordjyllands amter. 2006.
24. Ellen M. Mikkelsen: Impact of genetic counseling for hereditary breast and ovarian cancer disposition on psychosocial outcomes and risk perception: A population-based follow-up study. 2006.
25. Forbruget af lægemidler mod kroniske sygdomme i Århus, Viborg og Nordjyllands amter 2004-2005. 2006.
26. Tilbagelægning af kolostomi og ileostomi i Vejle, Ringkøbing, Viborg, Nordjyllands og Århus Amter. 2006.
27. Rune Erichsen: Time trend in incidence and prognosis of primary liver cancer and liver cancer of unknown origin in a Danish region, 1985-2004. 2007.
28. Vivian Langagergaard: Birth outcome in Danish women with breast cancer, cutaneous malignant melanoma, and Hodgkin's disease. 2007.
29. Cynthia de Luise: The relationship between chronic obstructive pulmonary disease, comorbidity and mortality following hip fracture. 2007.
30. Kirstine Kobberøe Søgaard: Risk of venous thromboembolism in patients with liver disease: A nationwide population-based case-control study. 2007.
31. Kort- og langtidsoverlevelse efter indlæggelse for udvalgte kræftsygdomme i Region Midtjylland og Region Nordjylland 1995-2006. 2007.
32. Mette Skytte Tetsche: Prognosis for ovarian cancer in Denmark 1980-2005: Studies of use of hospital discharge data to monitor and study prognosis and impact of comorbidity and venous thromboembolism on survival. 2007.
33. Estrid Muff Munk: Clinical epidemiological studies in patients with unexplained chest and/or epigastric pain. 2007.
34. Sygehuskontakter og lægemiddelforbrug for udvalgte kroniske sygdomme i Region Nordjylland. 2007

35. Vera Ehrenstein: Association of Apgar score and postterm delivery with neurologic morbidity: Cohort studies using data from Danish population registries. 2007.
36. Annette Østergaard Jensen: Chronic diseases and non-melanoma skin cancer. The impact on risk and prognosis. 2008.
37. Use of medical databases in clinical epidemiology. 2008.
38. Majken Karoline Jensen: Genetic variation related to high-density lipoprotein metabolism and risk of coronary heart disease. 2008.
39. Blodprop i hjertet - forekomst og prognose. En undersøgelse af førstegangsinlæggelser i Region Nordjylland og Region Midtjylland. 2008.
40. Asbestose og kræft i lungehinderne. Danmark 1977-2005. 2008.
41. Kort- og langtidsoverlevelse efter indlæggelse for udvalgte kræftsygdomme i Region Midtjylland og Region Nordjylland 1996-2007. 2008.
42. Akutte indlæggelsesforløb og skadestuebesøg på hospiter i Region Midtjylland og Region Nordjylland 2003-2007. Et pilotprojekt. 2009.
43. Peter Jepsen: Prognosis for Danish patients with liver cirrhosis. 2009.
44. Lars Pedersen: Use of Danish health registries to study drug-induced birth defects – A review with special reference to methodological issues and maternal use of non-steroidal anti-inflammatory drugs and Loratadine. 2009.
45. Steffen Christensen: Prognosis of Danish patients in intensive care. Clinical epidemiological studies on the impact of preadmission cardiovascular drug use on mortality. 2009.
46. Morten Schmidt: Use of selective cyclooxygenase-2 inhibitors and nonselective nonsteroidal antiinflammatory drugs and risk of cardiovascular events and death after intracoronary stenting. 2009.
47. Jette Bromman Kornum: Obesity, diabetes and hospitalization with pneumonia. 2009.
48. Theis Thilemann: Medication use and risk of revision after primary total hip arthroplasty. 2009.