

INTRODUCTION AND OVERVIEW OF DANISH REGISTERS

Introduction to Danish (nationwide) registers on health and social issues: Structure, access, legislation, and archiving

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Abstract

Danish registers contain information on many important health and social issues. Because all Danish citizens have a unique personal identification number, linkage at the individual level between these nationwide registers and other data sources is possible and feasible. In this paper we briefly introduce selected Danish registers and the data structure and requirements for getting access to data at Statistics Denmark, which is the main provider of register data. We introduce the Danish Data Archive and briefly present the Act on Processing of Personal Data, which is the legal foundation for analyses of register-based data in Denmark.

Key Words: *Health, registers, morbidity, mortality, social issues*

Introduction

The Nordic countries have a long history of collecting information on births, deaths, immigration and emigration, disease incidence, and social conditions. High-quality data covering the whole population during long periods of time is therefore available. For example, information on causes of death has been collected since 1875 in Denmark [1], information on compulsory schooling and continuing education are available for cohorts born after 1945 [2], information on twins are available for cohorts born after 1870 [3], and cancer incidence has been registered for the whole country since 1943 [4].

Using a unique personal identification number assigned to all persons with a permanent residence in Denmark (CPR-number), it is possible to link data from one or more registers or from other sources with register-based information at an individual level [5]. It is also possible to link husband with wife and parents with children. Additionally, each Danish firm has a unique identification number, which makes link

between firm and employees possible [6]. Thus, the access to information on important exposures, confounders as education, income, and ethnicity and various health-related outcomes offers great possibilities for doing epidemiological research on, for example, the association and causal network between disease incidence, mortality, social issues, occupational exposures, clinical indicators, and rehabilitation.

It is important to underscore that almost all Danish research registers are byproducts of already existing administrative registers. When using registers, the researcher has to understand in detail how the data has been generated and needs to understand obvious confidentiality restrictions for many types of data relevant for research on health and social issues.

In this paper we will give a brief introduction to Danish registers with a short presentation of selected registers containing information on health and social issues. We also introduce the data structure and requirements for getting access to data at Statistics Denmark, which is an important provider of

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(Accepted 19 January 2011)

register data. We introduce the Danish Data Archive and, finally, we briefly present the Act on Processing of Personal Data, which is the legal foundation for analyses of register-based data in Denmark.

Examples of Danish registers containing social- and health-related information

In Denmark information on many issues are stored in registers ranging from disease incidence, e.g. the psychiatric disease incidence from the Danish Psychiatric Central Research Register [7] over nationwide clinical databases [8] to information on social and economic issues, e.g. information on

income and income transfers [9]. In Table I, examples of important Danish registers with information on health-related issues and clinical quality databases are given.

The disease registers offer information on hospital admissions, contact with the primary health care, and prescription drugs and constitute the basis of studies on prevalence, incidence, survival, and rehabilitation for specific diseases, e.g. cancers, psychiatric and infectious diseases (Table I). A group of registers include information on treatment and follow-up for specific disease groups, e.g. several malignant diseases, invasive heart procedures, and hysterectomies [8] (Table I). These clinical databases include information on diagnostic, treatment, and follow-up on all patients with the specific disease.

Table I. Examples of Danish registers on health-related issues and clinical quality databases.

Danish register	Content	Start year of registration	Data administrator
The Register of Causes of Death	Information on causes of death based upon the death certificates	1875	National Board of Health ^a
The National Patient Register	Information on diagnoses and operations performed at a hospital	1977	National Board of Health ^a
The National Health Service Register	Data from health contractors in primary health care about providers, health services and citizens receiving treatment	1990	National Board of Health
The National Prescription Registry	Information on dispensed prescription drugs	1994	Danish Medicines Agency ^a
The Danish Cancer Registry	Information on incidence of all malignant diseases	1943	National Board of Health
The Psychiatric Central Research Register	Information on all psychiatric patients treated at a hospital	1970	Centre for Psychiatric Research
The National Diabetes Register	Information on persons with diabetes diagnosis	1995	National Board of Health
The Multiple Sclerosis Registry	Information on incidence of all patients with multiple sclerosis.	1949	National Institute of Public Health
The Cytogenetic Register	Information on persons who have undergone prenatal chromosomal diagnostic procedures	1968	Århus Universitetshospital
The Pathology Register	Information on patient, pathology and workload data; the register is updated daily	1997	National Board of Health
The Breast Cancer Cooperative Group	Detailed information on diagnostic, treatment and follow-up of breast cancer patients	1977	Rigshospitalet, Copenhagen University Hospital
The Danish Heart Register	Detailed information on selected invasive procedures within cardiology (coronary angiography, percutaneous coronary intervention) and thoracic surgery (coronary artery bypass grafting and heart valve surgery)	2000	National Institute of Public Health
The Colorectal Cancer Database	Detailed information on diagnostic, treatment and follow-up on all Danish colorectal cancer patients	2001	Competence Center for National Clinical Databases, East
The Hysterectomy Database	Detailed information on diagnostic, treatment and follow-up on all Danish women who undergo hysterectomy	2004	Competence Center for National Clinical Databases, East

Further examples of clinical quality databases can be found at www.kliniskedatabaser.dk.

^aStatistics Denmark has an updated copy of the register for research linkage.

Information on several social issues is available including information on education, income, transfer payments, labour market affiliation, and housing conditions (Table II). For many registers, annual information is available during several decades.

Many of the health-related registers are handled by the National Board of Health, Denmark and the social registers are exclusively handled by Statistics Denmark. Copies of important health-related registers, e.g. the Danish National Patient Register [10] or the Danish National Prescription Registry [11], can also be accessed through Statistics Denmark (see Table I).

Data at Statistics Denmark

Statistics Denmark has a huge data quantity at its disposal for its production of official statistics (e.g. the registers in Table II) and Statistics Denmark offers easy access to their data for research projects. One simple access channel is through Statistikbanken (www.statistikbanken.dk), which offers data free of charge. This database gives an impression of the quantity and variety of data. Since the database is directly accessible, one guiding principle is that individuals and firms cannot be identified, i.e. data is at an aggregate level.

When doing register-based research, it is often necessary to have access to data on individual level, e.g. to have access to data for each person or firm which forms part of a research project. Statistics Denmark offers remote access to all individual level data that is necessary to carry out a serious research

project. According to the Act on Processing of Personal Data, working with individual level data is required to guarantee confidentiality and preserve full anonymity for the data subjects in every respect. The provisions for processing of personal data for statistical and scientific purposes are laid down in this Act and in the sets of conditions which are made applicable to scientific projects (see section below).

For this reason, individual level data from Statistics Denmark is not delivered to any external firm, institution, or person. Instead, datasets and linkages between datasets constructed at Statistics Denmark are stored at Statistics Denmark. Researchers employed at specific authorised environments can establish remote online access to these datasets stored at Statistics Denmark. This access method is also used if an external dataset, e.g. a survey, a cohort study, or an external register, is linked with datasets at Statistics Denmark. Then all data are stored at Statistics Denmark and the researcher gets online access to the linked dataset.

Although researcher may get access to rather detailed individual level data, they are only allowed to publish statistical analyses and results at an aggregate level where no single person or enterprise may be identified.

For security reasons, only researchers employed at authorised research institutions can get access to individual level data at Statistics Denmark. And only permanent research institutions with a responsible leader and several researchers can be authorised. Statistics Denmark does not authorise foreign research institutions, but foreign researchers may get access to relevant data if they are affiliated to an

Table II. Examples of Danish registers on economic and social issues.

Danish register	Content	Start year of registration	Data administrator
The Student Register	Grade-level information on compulsory schooling (primary and lower secondary education), upper secondary education and vocational education	1974	Statistics Denmark
The Population's Education Register	Information on individuals' highest completed education	1981	Statistics Denmark
The Employment Classification Module (AKM)	Information on attachment to the labour market at a given moment or throughout the year	1976	Statistics Denmark
The Integrated Database for Labour Market Research	Information on persons and establishments and their relation	1981	Statistics Denmark
The Income Statistics Register	Includes anyone who is economically active in Denmark. Variables describing wages, entrepreneurial income, taxes, public transfer payments, public pensions, capital income, private pension contributions and payouts, home ownership and fortunes	1970	Statistics Denmark
The Building and Housing Register	Information on ownership, type of housing, rental terms, living area, number of rooms, condition concerning bathroom, kitchen and toilet, and year of construction	1880/1981	Statistics Denmark

authorised Danish research institution. In this case, foreign researchers will get remote access to data at Statistics Denmark, directly from their own workplaces wherever they work or live.

Danish Data Archive

The Danish Data Archive (Dansk Data Arkiv; <http://samfund.dda.dk/default-en.asp>) is the national institution dedicated to the acquisition, preservation, and dissemination of (primarily quantitative) data created by researchers from social science, health science, and history. The registers described in this supplementum are in general not obliged to be deleted at a specific time, because of their administrative and continued use.

The Danish Data Archive is primarily used by researchers and students wanting access to data created by Danish researchers or data about Denmark for new analytical research purposes. The Act on Processing of Personal Data stipulates that data collected may not be kept in a form which makes it possible to identify the data subject for a longer period than is necessary for the purposes for which the data are processed. Accordingly, data must be destroyed or made anonymous when the statistical analyses are finished or the scientific project concluded. The Act, however, allows that data may be archived under the rules laid down in the legislation on archives. Data containing personal identifiers may therefore be transferred to the Danish Data Archive and stored there. At the Danish Data Archive, data and the personal identifiers are stored separately and access to this data is conditional upon authorisation by the Danish Data Protection Agency (Datatilsynet).

The Act on Processing of Personal Data

The rules regulating the processing of personal data in electronic and manual registers are laid down in The Act on Processing of Personal Data (Act No. 429 of 31 May 2000 with amendments), which can be found at <http://www.datatilsynet.dk/english>. We will here present key aspects of the rules; further information is available online or by contacting the Danish Data Protection Agency.

In general, personal data may only be collected for specific, explicit, and legitimate purposes and further processing must not be incompatible with these purposes. Processing which takes place exclusively for historical, statistical or scientific purposes shall not, however, be considered incompatible with the

purposes for which the data were originally collected, and may consequently take place.

Furthermore, data which are to be processed must be adequate to, relevant for, and not go beyond the purposes for which they are processed. Also, necessary checks must be made to ensure that no inaccurate or misleading data are processed. And finally, the data collected may not be kept in a form which makes it possible to identify the data subject for a longer period than is necessary for the purposes for which the data are processed. These basic rules also apply to data processing for scientific and statistical purposes.

Special provisions for statistical or scientific studies

As a general rule, no processing of personal data may take place which relates to racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, or of data concerning health or sex life, criminal offences, serious social problems, or other purely private matters. The processing of these kinds of data is permitted only if the data subject has given his or hers explicit consent or if the processing is done in accordance with one of the special exceptions stipulated by the law.

In addition to this, the Act on Processing of Personal Data contains an extraordinary provision for the processing of these kinds of data. According to this, these data may be processed without consent from the data subject where the processing takes place for the sole purpose of carrying out statistical or scientific studies of significant public importance and where such processing is necessary in order to carry out these studies. These data may not subsequently be processed for other than statistical or scientific purposes and may only be disclosed to a third party with prior authorisation from the Danish Data Protection Agency. The Agency may lay down specific conditions concerning the disclosure. It is an absolute requirement that the publication of statistical or scientific results may never reveal the identity of individuals or otherwise compromise data subjects.

Finally, the law stipulates that any private controller (the person or company legally responsible for the processing of data) must obtain the authorisation of the Danish Data Protection Agency prior to any processing of personal data of the above-mentioned kind. When processing is carried out for a public administration (research institutions, statistical offices, university hospitals, etc.) the opinion of the Agency must always be obtained.

As a general rule, the data subject has right of access to data pertaining the data subject itself. This right, however, does not apply where data are

processed solely for scientific or statistic purposes. Nevertheless, the data subject is entitled to file an objection to the processing of data concerning him or her. Such an objection may be filed either with the data controller or the Danish Data Protection Agency.

It is worthwhile mentioning that the Act on Processing of Personal Data does not apply to anonymous data. Anonymous data are defined as data which can no longer be traced back to an identifiable person or persons.

Regional ethics committees

According to Danish law, all research projects in Denmark involving any kind of human tissue, cells, etc. need permission from a regional ethics committee. This rule also applies to surveys and register-based research projects containing human biological material. Register-based projects not including human biological material are not obliged to be accepted by an ethical committee. It should be noted, however, that researchers using register-based data are not allowed to contact the registered individuals in order to get supplementary information through postal questionnaire or to get biological tissue.

Conclusion

Danish registers contain information on many important health and social issues. Because all Danish citizens have a unique personal identification number, linkage between these nationwide registers and other data sources is possible and feasible. These registers offer great possibilities for doing nationwide epidemiological studies. However, when conducting register-based research it is important to understand

how the data has been generated and at all times follow the obvious confidentiality restrictions for all kinds of personal data.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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