Scandinavian Registers in Normal and Arthritic Populations

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Nationwide population-based longitudinal databases provide excellent resources for medical research. Each Scandinavian country, Sweden, Denmark, Finland, Norway, and Iceland has its own national databases, including a Population Registry, Cancer Registry, Cause of Death Registry, and Hospital Discharge Registry, among others. On a national level, each person has a unique identification code that is used in all registers and allows linking of the data between various registers. Extensive population studies have been conducted in these countries over the last 30 years to supplement registry data.

The population of Scandinavia is 24,280,000 and represents 6.4% of the European population and 0.4% of the world total population. It is almost entirely Caucasian, which may limit the generalizability of observations. Nevertheless, nationwide population-based databases are available only in Scandinavia. Furthermore, several national and local databases collect data on patients with arthritis.

Characteristics of the Registers

The initial basis for establishing population registers in Scandinavia was to collect taxes more effectively. Population registers in Scandinavia date back to the 16th Century in the former Sweden-Finland. In the 17th Century, a law was passed that all births, marriages, and deaths must be recorded. Genealogic information has been collected by Icelanders through the nation’s history of 11 centuries. Today, the population information system provides data for administrative authorities and for statistical and research purposes. Business enterprises and private citizens may obtain permission to select information. Continuous evaluations ensure the reliability of the data. Data collection, maintenance, and delivery are strictly controlled by laws, acts, and decrees.

Prescribed by Law

The registers are strictly regulated by law. The authority to develop and control the registration, maintenance, and delivery of information is granted to organizations that operate under the supervision of the government. These organizations are also responsible for the national information services concerning processing the data to be developed and tailored to meet the needs of the institutions and authorities that use the data.

Coverage and Reliability

The quality requirements of the registered data include extensive coverage and high reliability. The requirement about coverage is met when each unit that should be registered is entered in the register, and has an officially approved identifier. Information to be entered comes from the basic units, their representatives, or the authorities concerned and is properly rectified, if needed. Reliability studies are carried out at certain intervals to ensure reliability of the data.

Information is Versatile and Has Many Uses

Under the principle of accessibility, the information is available to users through information services. Registers are part of the infrastructure of the society. According to the principles that regulate the use of the data, authorities acquire the information they need directly from the information systems, and individuals do not need to submit data when requesting services. In fact, authorities have a statutory right to access the required information.

The System is Covered by Data Protection

Data protection is based on strict regulations of access to and delivery of data. The authorities that receive data
directly from the information services are predefined. All other organizations are required to request and then receive a permission to access the data, after careful review of the purpose for which the data will be used.

Privacy and the Registers
As described above, population registers in Scandinavia have been used for hundreds of years and are regarded as part of the infrastructure of the society. Registers that contain information on individuals’ health were established in order to recognize public health problems and to develop preventive strategies. Furthermore, the society assumes responsibility for an individual who develops an illness, providing access to medical care almost without cost, as well as benefits that include sick leave, rehabilitation, and a disability pension. The historical background and the society’s major role of being responsible for its members may have extricated Scandinavia from major concerns regarding privacy of personal health information, unlike in some countries where laws concerning the protection of privacy have made health information registers almost illegal.1-3

Scandinavian countries have enacted legislation for protection of personal data since the 1970s and 1980s. European Union directives concerning privacy are strict, but allow each member state to make exceptions for medical research. Overall, in Scandinavia, protection and improvement of public health appears to overcome the issue of protection of privacy, both in legislation and in public opinion.

Scandinavian Registers in Normal Populations
There are some differences between the registers in each country (Sweden, Denmark, Finland, and Norway) although the major aspects are similar. Historically, all data were collected on paper, which was called a “registry,” and these were eventually computerized as the technology became available. Therefore, the terms “registry” and “database” are now used interchangeably in the literature and, as well, in this article. On the national level, each person has a unique identification code that is used in all registers and allows the linking of data between various registers; computerized record linkage is precise.4 The primary features of the national databases are described below.

Population Registry
The Population Registry maintains a file on all citizens and foreigners living permanently in the country. The system’s basic unit is a person whose personal identifiers are a personal identification code, date of birth, and first and last name. Characteristics of each individual that are recorded include gender, native language, citizenship, address, marital status, membership of a religious group, and the status of a minor, guardian, or a dependant. The date of death also is recorded.

Information about births and deaths come to the registry from hospitals and health centers, while guardians and parishes provide information about given names. If someone moves, that person is responsible for notifying the registry about the new address, a duty of all citizens and permanent residents by law. Parishes or other authorities who officiate at weddings are required to provide information concerning marriages. Courts provide the necessary information about divorces and decisions on paternity, adoptive children, and guardianships. Information regarding decisions on citizenship is provided by immigration offices.

The purposes of the Population Registry include identification of a person, clarification of his or her status regarding personal and family law, and recognition of his or her legal capacity. The registry provides data for authorities who are responsible for elections, taxes, national defense, social and medical care, and national statistics. Interestingly, the acts and decrees state that providing data for scientific and medical research is one of the purposes of the population registry.

Cancer Registry
Cancer registers were created in most Scandinavian countries during the 1950s. Reporting became obligatory during the 1960s. The Cancer Registry collects data on all cancer cases in the population. The informants who submit data on cancer cases include all hospitals, physicians, and dentists, as well as pathological, cytological and hematological laboratories. Moreover, the registry performs an annual screening of all death certificates issued in the country, and, thus, records the death of patients with cancer from both cancer and noncancerous causes.

Cancers are classified in the database according to the International Classification of Diseases (ICD) codes, as outlined by the World Health Organization (WHO). The Cancer Registry, as all other national databases, is based on an individual’s personal identification codes. Completeness and accuracy of the cancer registration system is reported as high.5,6 Annual statistics on the occurrence of cancer provide the number of cases and incidence rates by gender, primary site, age, and healthcare district. In addition to routine cancer registration, cancer registers are engaged in epidemiological and statistical cancer research. Descriptive epidemiology includes analyses on cancer incidence trends and future predictions, spatial cancer studies, and studies on cancer risk by occupational groups and social classes.

Cause of Death Registry
Official statistics on death rates have been available since the early 1900s in Scandinavian countries. The Cause of Death Registry contains information on dates and causes of all deaths among residents according to the personal identification code. Cause of death is classified according to the ICD.

Hospital Discharge Registry
The Hospital Discharge Registry contains information on inpatient care according to the personal identification code.
For every hospital discharge, information on diagnoses and surgical procedures are recorded according to the ICD. The hospital code and the date of both admission and discharge also are recorded.

**Registers Concerning Benefits and Reimbursements in the Case of Diseases**

The government is responsible for sickness allowances and national pensions. If a person becomes temporarily unable to perform his or her regular job or another similar job because of an illness, he or she is entitled to a sickness allowance as compensation for lost income. This is payable to persons from 16 years of age until the official retirement age, which is 65 to 67 years, depending on the country, and can be awarded to both employed, self-employed, and involuntarily unemployed persons. Public disability pensions are managed under the same rules, and are granted to any person whose working capacity is judged to be permanently reduced by at least 50% due to illness, injury, or defect. The National Insurance Administration maintains a registry of all benefits and disability pensions awarded according to the personal identification code.

The Finnish Sickness Insurance Act provides for partly or entirely reimbursed medications for chronic conditions, including rheumatic diseases. The national sickness insurance scheme covers the entire population, i.e., permanent residents. To receive the reimbursement, the patient needs a comprehensive medical certificate from the treating rheumatologist. The certificate provides evidence that a patient has the disease and needs treatment. The certificate is then approved by an expert advisor on behalf of the sickness insurance scheme. The entitlement is usually life-long. Due to a reasonably high reimbursement coverage of 75% (90% until 1992) for disease-modifying antirheumatic drugs (DMARDs) and glucocorticoids for rheumatic diseases in Finland, it is very rare that eligible patients do not apply for this benefit. Nonsteroidal antiinflammatory drugs (NSAIDs) were covered until 1994. Therefore, the Medication Reimbursement Registry is an excellent nationwide means to identify all individuals who have been diagnosed with a chronic condition. This registry contains the codes of the conditions and the individuals’ personal identification codes; however, the code is the same for rheumatoid arthritis (RA) and other inflammatory arthritides. Therefore, information concerning RA, for example, cannot be obtained directly from the database; the certificates are needed to confirm the disease entity.

The Prescription Registry that covers all permanent residents of Finland comprises a record of all purchases of prescribed medications (regardless of the reimbursement level, which is higher for chronic conditions, as described above, and lower for other diseases). The registry includes codes of the medications, prescribing physicians, and the personal identification code. The registry does not include information on drugs sold over-the-counter. Comparison of registry data with wholesale figures indicate that 75% of prescription NSAID uses was included in the registry in 2000.

**Genealogy Databases**

The first inhabitants of Iceland settled the island more than 1000 years ago; however, the Icelandic population has been, historically, more than somewhat isolated. Government supported churches and public institutions have kept records of the population over the centuries, including church records, genealogy manuscripts, and censuses. In fact, population-based lists of almost all Icelanders who have lived at any given time are obtainable. All of these data have been stored in the Genealogy Database and include personal identification codes, identification of parents, gender, and the dates of birth and death relative to all presently living Icelanders (approximately 270,000) and most of their ancestors over the last few centuries, covering a total of more than 620,000 individuals. Furthermore, the genotypes of 25,000 Icelanders have been studied. Linking these data has documented that the accuracy of the data is high: the maternal connection is more than 99% correct, and false paternity and labeling error are less than 1.5%.

The Swedish Multi-Generation Registry contains information on Swedish residents who were born in 1932, or later and were alive in 1961, with links to data on their parents, siblings, and offspring. In 2000, the database included almost 11 million people.

**Arthritis Registers in Scandinavia**

Local and national registers have been established to collect data on patients with arthritis in the Scandinavian countries. In Denmark, the DANBIO (Danish Database for Biologic Therapies in Rheumatology) register was established, in 2000, to collect data on patients who are seen in Danish rheumatology practices and receiving biologic treatments. More recently, the DANBIO includes rheumatology patients, regardless of treatments.

In 1992, the Oslo Rheumatoid Arthritis Registry (ORAR) was established in Norway, with a goal to include all patients with RA residing in Oslo. Another Norwegian register was established, in 2000, to collect data on all prescriptions of DMARDs to patients with inflammatory arthropathies.

Several rheumatology registers have been established in Sweden, including inception cohorts TIRA (Therapies in Rheumatoid Arthritis), BARFOT (Better Antirheumatic Pharmacotherapy), and the Swedish Rheumatoid Arthritis Registry, which have merged to a large inception cohort database. Swedish registers that collect data on biologic treatments are ARTIS (Antirheumatic Therapies in Sweden), SSATG (Southern Sweden Antirheumatic Therapy Group), and STURE (Stockholm Tumor Necrosis Factor-alpha Follow-up Registry).

In Finland, inception cohorts and databases have been established in the Rheumatism Foundation Hospital in...
Heinola, Jyväskylä Central Hospital, and Helsinki University Hospital. Data on biologic treatments are collected in the National Register of Biological Treatment in Finland (ROB-FIN).

Summary

Nationwide population-based longitudinal databases provide excellent resources for medical research in Scandinavia, including the Population Registry, the Cancer Registry, the Cause of Death Registry, the Hospital Discharge Registry, and other registers, and are linked to each other by the personal identification code. The registers have long historical backgrounds and are strictly regulated by law. In addition, several national and local registers collect data on rheumatology patients in Scandinavian countries.

Acknowledgments


References