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REVIEW

Nordic Health Registry-Based Research: A Review of Health Care Systems and Key Registries

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Abstract: The Nordic countries are Denmark, Finland, Iceland, Norway, and Sweden and comprise a total population of approximately 27 million. The countries provide unique opportunities for joint health registry-based research in large populations with long and complete follow-up, facilitated by shared features, such as the tax-funded and public health care systems, the similar population-based registries, and the personal identity number as unique identifier of all citizens. In this review, we provide an introduction to the health care systems, key registries, and how to navigate the practical and ethical aspects of setting up such studies. For each country, we provide an overview of population statistics and health care expenditures, and describe the operational and administrative organization of the health care system. The Nordic registries provide population-based, routine, and prospective data on individuals lives and health with virtually complete follow-up and exact censoring information. We briefly describe the total population registries, birth registries, patient registries, cancer registries, prescription registries, and causes of death registries with a focus on period of coverage, selected key variables, and potential limitations. Lastly, we discuss some practical and legal perspectives. The potential of joint research is not fully exploited, mainly due to legal and practical difficulties in, for example, cross-border sharing of data. Future tasks include clear and transparent legal pathways and a framework by which practical aspects are facilitated.

Keywords: health care system, population characteristics, registries, epidemiology, Scandinavian and Nordic countries

Introduction

The Nordic countries are Denmark, Finland, Iceland, Norway, and Sweden and comprise a total population of approximately 27 million (Figure 1). All five countries have welfare state models with universal and tax-funded health care systems, population-based nationwide registries, and personal identity numbers that enable individual-level linkage of these registries. The similarities between and within the Nordic registries allow researchers to combine data from several countries into one study cohort. Combining these resources in Nordic health registry-based studies provides unique opportunities for research on large study populations with long and complete follow-up. Such studies may contribute to important research findings,[1–6] especially regarding rare exposures or outcomes. However, conducting such multinational studies requires in-depth understanding of the respective health care systems and registries, as well as some knowledge of practical and legal matters.

In this review, we provide an overview of all five health care systems, describe key registries, and provide guidance on how to navigate the practical and ethical aspects of setting up Nordic study collaborations.

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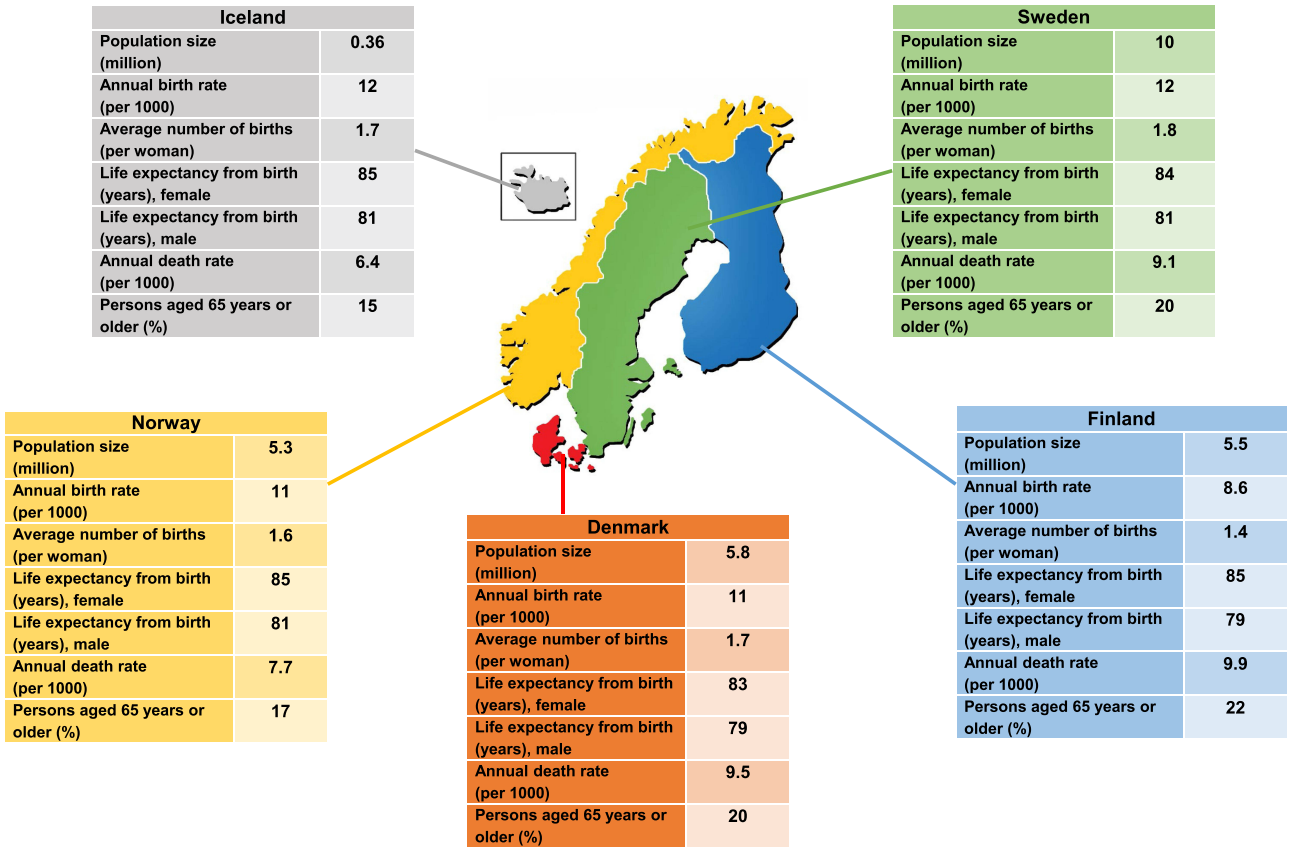


Figure 1 Population statistics for the five Nordic countries, 2018.
Notes: Data from the World Bank (2018).

The Health Care Systems

People in the Nordic countries have universal access to the health care systems, which are mainly publicly financed through taxes with minor private health care sectors and limited private medical insurance. Approximately 2–10% of total in-hospital beds are private depending on the country.[7–9] Moreover, private providers are often reimbursed by the public health insurance system according to economic contracts between the private and public sectors. Below we provide a brief description of each of the Nordic health care systems. More detailed information can be found elsewhere.[7–10–14]

The Danish Health Care System

Denmark is a country with approximately 5.8 million inhabitants and population statistics as shown in Figure 1.[15–18] In 2019, Denmark spent approximately 10% of its gross domestic product (GDP) on health care expenditures, corresponding to 5568 USD per capita (Figure 2).[19] Roughly 85% of all health care expenses are covered through taxes, including free access to general practitioners (GPs), hospitals, outpatient hospital specialist clinics, and partial reimbursement of prescribed medications. Patient copayments are ~15% and primarily consist of cost-sharing for medications, physiotherapy, and/or dental care.[7] Key health care spending is shown in Figure 2.[19,20]

Operational Organization

The Danish health care system is subdivided into primary and secondary health care sectors.[7] Primary health care includes services provided by the regions, such as GPs and private clinics (dentists, psychologists, physiotherapists, chiropractors, and private practicing specialist), as well as services provided by the municipalities, such as elderly care, primary disease prevention, and rehabilitation. The secondary health care sector comprises hospitals, including inpatient treatment, outpatient hospital clinics, and emergency care, as well as psychiatric hospital care.

GPs account for approximately 20% (n=4900) of the total Danish physician workforce and play a central role in the Danish health care system.[7] GPs are generalists trained to evaluate the need for referral to specialists. Their

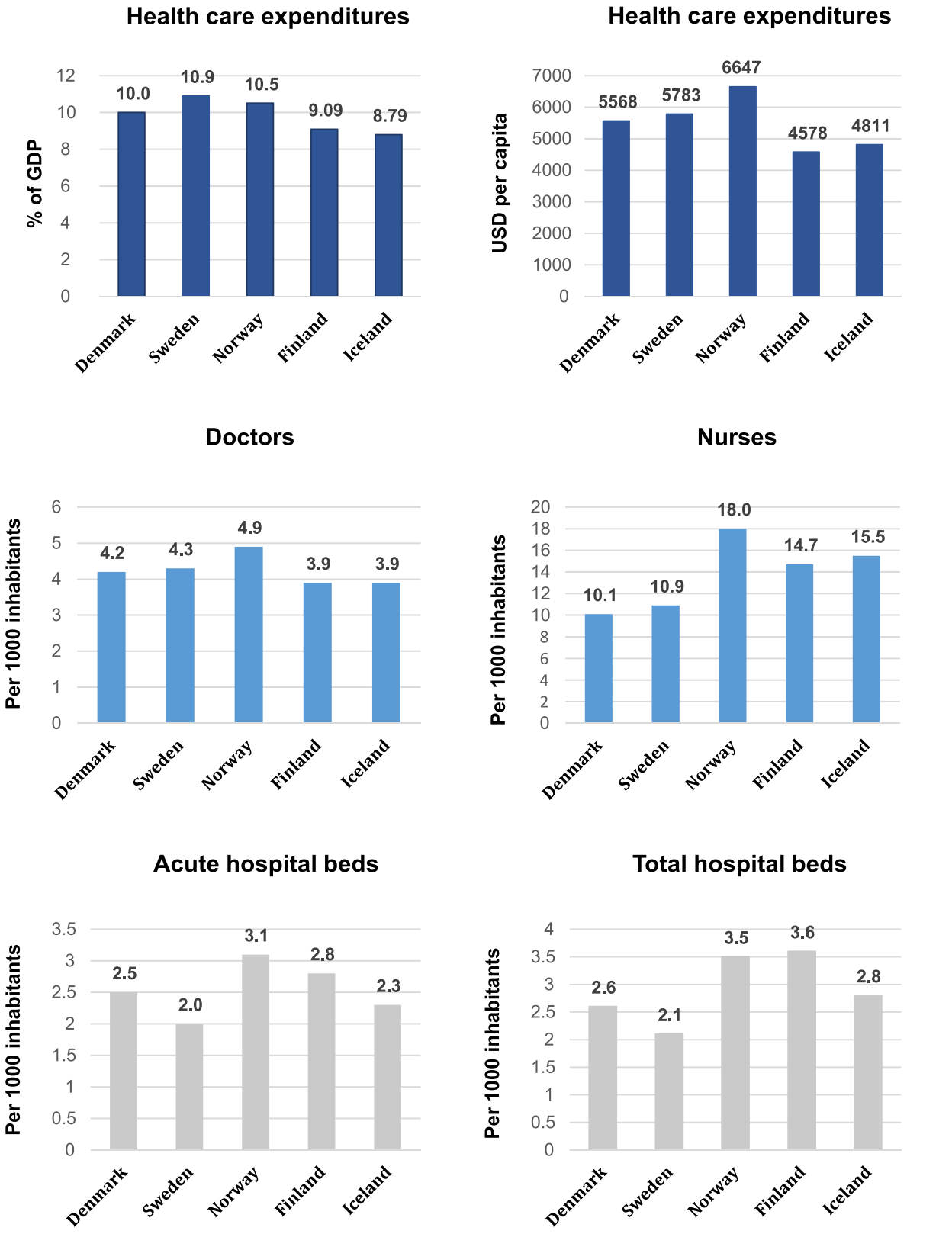


Figure 2 Key spending in the Nordic health care systems, 2018/2019 or latest available.
Notes: Data from OECD. GDP: gross domestic product. Total hospital beds include curative (or acute) care beds, rehabilitative care beds, long-term care beds and other beds in hospitals. The indicator is presented as a total and for curative care and psychiatric care.

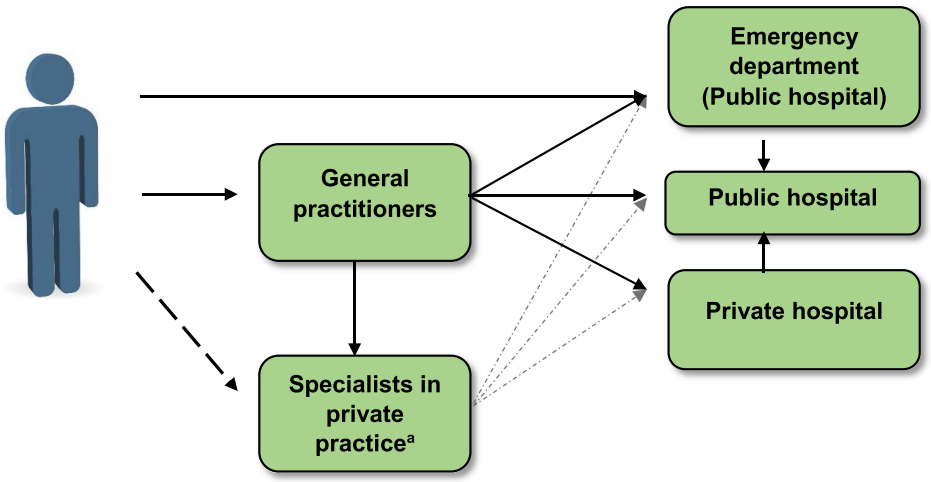


Figure 3 Overview of the operational organization of the Nordic health care systems.
Notes: [a]Includes physiotherapists, dentists, psychologists, and specialized medical doctors working in private practice as eg. dermatologists, otorhinolaryngologist, fertility treatment specialists, cardiologists and pulmonologists. Visits to dentist never require referral from general practitioners (GPs). Other specialists may be accessed with or without referral from GPs; however, patient co-payment is often larger without a referral. Some private clinics are reimbursed completely or partly by public funding and some rely solely on patient self-payment or private insurance. Specialized medical doctors in private practice can refer patients to hospitals if needed. In Sweden, it is also possible to self-refer to hospital specialists. Patients need to fill out an online form, and then a hospital specialist will decide whether to see the patient without a GP referral.

primary tasks are to treat ordinary health problems, perform regular checkups (eg, children and patients with chronic diseases), prescribe drugs and carry out vaccinations, refer patients to specialists when needed, and follow-up on patient health plans after hospital discharge. Except in emergencies, the GPs are the first point of contact and act as gatekeepers to the hospitals (Figure 3).[7] GPs further provide on-call services after daily opening hours and on weekends for acute services. In case of emergencies, patients may go directly or by referral to public hospital emergency departments (Figure 3). Private emergency care is not available in Denmark. In 2017, the average number of GP contacts per person was 8 and approximately 85% of all Danes had at least one contact with their GP.[21] Danish legislation ensures that diagnosis and treatment are provided within certain timeframes.[7]

Administrative Organization

The Danish health care system currently has three administrative levels: the national level (state), the regional level (5 regions), and the local level (98 municipalities).

National Level (State)

The government, headed by The Ministry of Health, defines the framework of the Danish health care system by legislation, national guidelines, and health care monitoring. Furthermore, they set the economic framework and obtain financial agreements between the national, regional, and municipal administrative levels.[7] The Ministry of Health operates through several authorities or agencies (Supplementary Table 1).[7] Though the overall health care policy is organized centrally, responsibility for the provision of health care is decentralized.

Regional Level

The five regions are responsible for GPs, hospitals, specialists in private practice, and specialized nursing homes (eg, psychiatric patients). The regions also administer the Danish Drug Reimbursement Plan. In Denmark, all GPs are private practitioners but work according to a collective economic agreement and are paid by the public health insurance system with no patient cost-sharing (with few exceptions). Most specialists in private practice are also self-employed but are reimbursed for provided services on a fee-for-service basis according to an economic agreement with the regions.[7] A few private specialists rely solely on patient self-payment or private medical insurance.

Local Level (Municipalities)

The municipalities are responsible for social services and some health care services, including primary disease prevention and health promotion, student health, child dental

care, ordinary home care and nursing homes, alcohol and drug abuse treatment, rehabilitation outside hospitals, and postnatal home visits.

The Swedish Health Care System

Sweden is a country with approximately 10 million inhabitants and population statistics as shown in Figure 1.[15–18] The Swedish health care system is almost free of charge, with minor visit fees at GPs, outpatient hospital clinics, or during in-hospital stays (Supplementary Table 2).[22] In 2019, Sweden spent 10.9% of their GDP on health care expenditures (5783 USD per capita) (Figure 2).[19] Tax incomes cover approximately 80% of the Swedish health care expenses, including services at GPs, hospitals, outpatient specialist clinics, and partial reimbursement of prescribed medications. Patient copayments are ~20% and include visit fees, as well as copayments for medications, physiotherapy, or dental care. Key health care spending is shown in Figure 2.[19,20]

Operational Organization

The operational organization of the Swedish health care system is subdivided into primary and secondary health care sectors. The primary health care sector includes GPs, psychologists, physiotherapists, some private practicing specialists, and rehabilitation. The secondary health care sector comprises hospitals, including inpatient and outpatient hospital clinics.[11]

In Sweden, citizens are free to choose their primary care providers. The GPs can be the first point of contact (Figure 3), but citizens also have the opportunity to consult or self-refer to specialists through "1177.se", a 24-hour internet/phone health care service. A large proportion of Swedish patients have their initial health care contact with this service before seeking care with a physical health care provider. Through 1177.se, patients fill out an online or paper form and a specialist then decides whether to see the patient without contact with a GP first.[23] Approximately 16% (n = 6000) of Swedish physicians work in the primary care setting,[24] and the average number of yearly GP visits per capita is 1.3.[25]

Administrative Organization

The Swedish health care system has three administrative levels: the national level (state), regional level (21 counties/regions), and local level (290 municipalities).[11]

National Level (State)

The state, through the Ministry of Health and Social Affairs, outlines the Swedish health care system by legislation, guidelines, and health care monitoring.[11] The Ministry of Health and Social Affairs acts through agencies (Supplementary Table 1).[11,26] Though health care policy is determined centrally, responsibility for providing health care is decentralized and lies within the counties/regions and municipalities.

Regional Level (Counties/Regions)

The Swedish counties/regions manage and operate the primary and secondary health care sectors. Primary care is provided by primary care units, approximately 42% of which are private but mostly still reimbursed by the public health insurance system.[27] To work as a private practitioner within the social security system, an agreement (including economic agreement) must be made with the County Council.[11] A number of private digital health care providers recently established themselves in Sweden. Their growth has been spurred, in part, by the COVID-19 pandemic.[26]

Local Level (Municipalities)

The Swedish municipalities are responsible for student health, nursing homes and home care, public health, disease prevention, and rehabilitation.[11]

The Norwegian Health Care System

Norway is a country with approximately 5.3 million inhabitants and population statistics as shown in Figure 1.[15–18] The Norwegian health care system is universal with almost free access, though some patient fees exist when visiting GPs or outpatient hospital clinics (Supplementary Table 2). In 2019, Norway spent 10.5% of their GDP on health care expenditures (6647 USD per capita) (Figure 2).[19] Tax incomes cover approximately 85% of all health care expenses, including access to GPs, hospitals, outpatient hospital clinics, and partial reimbursement of prescribed medications. Patient copayments are ~15% and are primarily copayments for GP or outpatient clinic visits, and medications, or dental care.[12] Key health care spending is shown in Figure 2.[19,20]

Operational Organization

The operational organization of the Norwegian health care system is divided into primary and secondary health care sectors. The primary health care sector includes GPs, psychologists, and physiotherapists among others. The secondary health care sector comprises hospitals, including inpatient care, outpatient hospital clinics, and psychiatric health care. GPs account for approximately 16% (n =

4900)[28] of the total Norwegian physician workforce and have similar tasks as described for Denmark. As in the other Nordic countries, patients need a referral from their GP to access specialized care (eg, hospital outpatient or inpatient care; Figure 3).[12] In 2019, the average number of GP visits (excluding telephone contacts) per person was 3, and 70% of all Norwegians had at least one contact with their GP.[29]

Norwegian legislation ensures free hospital choice, which allows patients to be referred for assessment, examination, or treatment by specialists at hospital or treatment centers of their choice, including public or private providers.

Administrative Organization

The Norwegian health care system is currently organized into three administrative levels: the national level (state), the regional level (4 regional health authorities), and the local level (356 municipalities). A few healthcare responsibilities (eg, dental care) are held by the counties.[12]

National Level (State)

The state (Ministry of Health and Care Services) determines the national health policy, decides on the allocation of funds within the health sector, and implements the national health policy. The Ministry of Health and Care Services acts through several subordinate institutions (Supplementary Table 1).[12,30] Furthermore, as the Ministry of Health and Care Services is the owner of the four regional health authorities, the ministry has somewhat direct responsibility for the delivery of hospital and specialist care.[12]

Regional Level (Health Authorities)

The four regional health authorities (including 20 hospital trusts) are responsible for the hospitals and specialist outpatient hospital clinics, including psychiatric, rehabilitation and alcohol and substance abuse treatment.[12]

Local Level (Municipalities)

The Norwegian municipalities are responsible for social services and all primary health care, including GPs, rehabilitation, and physiotherapy, as well as public health and preventive measures. The majority of GPs are self-employed, but they are embedded in the public system through contracts with the municipalities, and patient cost-sharing is very limited.[12]

The Finnish Health Care System

Finland is a country with approximately 5.5 million inhabitants and population statistics as shown in Figure 1.[15–18] The Finnish health care system is universal with almost free access, though some fees exist when visiting GPs, emergency rooms, outpatient clinics, or during inpatient hospital stays (Supplementary Table 2).[13] In 2019, Finland spent 9.1% of their GDP on health care expenditures (4578 USD per capita) (Figure 2).[19] Taxes cover approximately 75% of all health care expenses, including access to GPs, hospitals, outpatient hospital clinics, and partial reimbursement of prescribed medications. Patient copayments are ~20% and are primarily copayments for visits and procedure fees, medication costs, or dental care. Private insurance covers approximately 5% of health care expenses.[13] Key health care spending is shown in Figure 2.[19,20]

Operational Organization

The operational organization of the Finnish health care system is divided into primary, secondary, and tertiary healthcare. The primary health care sector includes GPs, dentists, psychologists, physiotherapists, some medical specialists, and rehabilitation. In addition, inpatient departments located in primary health centers are a specific feature of Finnish primary care. These inpatient hospital-type wards are staffed with nurses, GPs, or specialists in geriatrics. The secondary health care sector includes regional hospitals (inpatient and outpatient specialist clinics). The tertiary sector includes university hospitals. GPs account for ~40% (n = 7000) of the total Finnish physician workforce and have similar tasks as described for Denmark. Patients need a referral from their GP to access the hospitals (Figure 3).[13] In 2019, the average number of visits to health care center per person was 4.1, of which 1.1 was a GP visit. A total of 67% of all Finns had used public primary health care in 2019.[31]

Administrative Organization

The Finnish health care system is currently structured into three administrative levels: the national level (state), the regional level (20 hospital districts), and the local level (311 municipalities).[13] Finland has a decentralized health care system, meaning that responsibility for organizing, providing, and financing health care lies within the individual municipalities. A future task may be to implement a more centralized system.

National Level (State)

The state, headed by the Ministry of Social Affairs and Health, provides a framework for the Finnish health care system via health legislation.[13] The Ministry of Social Affairs and Health acts through several institutions and agencies (Supplementary Table 1).

Regional and Local Level (Municipalities)

The municipalities are responsible for organizing, providing, and financing primary care, as well as secondary and tertiary health care services through hospital districts. Due to the decentralized public administration, municipalities decide how the local services are provided, and differences may exist between the municipalities. Primary health care is provided at municipal health centers, where GPs are usually salaried employees of the municipalities. Yet, the lease of physicians from private firms has recently increased.[13] The country is further divided into 20 hospital districts (plus Åland Islands, an autonomous area with special legislation) that are responsible for the provision of municipal secondary health care services. Hospital districts are federations of municipalities, and each municipality must be a member of a hospital district. Each hospital district is financed and managed by the member municipalities.[13]

The Icelandic Health Care System

Iceland is a country with approximately 0.36 million inhabitants and population statistics as shown in Figure 1.[15–18] People in Iceland have almost free access to the health care system with some minor fees for visits to GPs, outpatient hospital clinics and emergency wards (Supplementary Table 2).[14] In 2019, Iceland spent 8.8% of their GDP on health care expenditures (4811 USD per capita) (Figure 2).[19] Tax incomes cover approximately 80% of the Icelandic health care expenses, including services at GPs, hospitals, outpatient specialist clinics, and partial reimbursement of prescribed medications. Patient copayments are ~20% and include visit fees and copayments for medications, physiotherapy, or dental care. Key health care spending is shown in Figure 2.[19,20]

Operational Organization

The Icelandic health care system is divided into primary, secondary, and tertiary health care sectors. The primary health care sector includes GPs and primary health care clinics. The secondary sector includes private practicing specialists and the tertiary health care sector includes hospitals, comprising inpatient and outpatient hospital treatments, as well as psychiatric hospital care.[32] From 1990–2017, Icelandic GPs had no gatekeeping role, but GP referrals have recently been re-implemented (Figure 3).[33] GPs account for approximately 17% of the total Icelandic physician workforce. In 2019, approximately 80% of the population had contact with GPs (including visits and telephone consultancy) and 74% of the population actually visited a primary care center/physician.[34]

Administrative Organization

The Icelandic health care system is highly state-centralized and divided into a national level (state) and a regional level (7 regions). Local level administration plays a very minor role in the system.[14]

National Level (State)

The state (the Ministry of Health) is responsible for health policy and the financing, planning, regulation, and delivery of both primary, secondary, and tertiary health care. The Ministry of Health acts through several agencies (Supplementary Table 1). Physicians working in public hospitals and in general practice receive salaries from the state (with some fee-for-service payments to GPs for out-of-hours work), as do other professionals (eg, nurses and midwives). Private practitioners, such as medical specialists who provide outpatient care outside of hospitals, physiotherapists, dentists, and psychologists are paid by the state on a fee-for-service basis.[14]

Regional Level

The country is divided into seven regions for healthcare organization purposes, but these regions have limited administrative authority.[14]

Future Aspects of the Nordic Health Care Systems

The Nordic countries face several challenges that may strain the existing health care systems in the future, not least from an economic perspective. Foremost among these challenges is the aging population, which has a high demand for healthcare. Simultaneously, the aging population fosters a decline in the workforce and tax payments that are needed to preserve the public health care systems. The proportion of individuals aged ≥65 years has increased substantially in the Nordic countries in recent years; between 1965 and 2019, the proportion of individuals aged ≥65 years has increased from ~11% to

20% in Denmark,[35] from 13% to 20% in Sweden,[36] from 12% to 17% in Norway,[37] from 8% to 22% in Finland,[38] and from 8% to 15% in Iceland.[39] With aging populations, the burden of diseases such as cardiovascular diseases, cancer, chronic obstructive pulmonary disease, osteoporosis, diabetes, and dementia increases, as does the burden of multi-morbidity.[40] In addition, elderly patients with multimorbidity require a substantial joint effort between hospital specialties, as well as between GPs, hospitals, rehabilitation, home care, and nursing homes. The increase in disease burden and multi-morbidity, together with an increase in drug utilization, strains the health care systems and economies. The proportion of migrants in the Nordic populations has increased over the past decades. While migrants typically promote a growing labor force and counteract the aging population, they can also influence health care utilization. It is documented that the health status of migrants differs from that of non-migrants.[41,42] Migrants may originate from countries without vaccination programs, with poor quality of primary prevention, diet options, and employment conditions as well as high level of trauma exposure and mental distress with the implications of disease development.[41,42] Further, language and cultural barriers or different health beliefs or attitudes may lead to miscommunication between patients and health care providers with the result of poor health care service and patient dissatisfaction as well as non-compliance. This potential problem is despite the fact that interpreter services are heavily applied. Last, new technologies, used for diagnostic or treatment purposes, as well as novel and effective but expensive drugs place additional pressure on health care economies. Though the advent of biological treatment has revolutionized the care of some patients, such as those with rheumatoid arthritis and inflammatory bowel disease, these treatments and some novel drugs against cancer and inborn errors of metabolism have high costs.[43] Therefore, prioritizing is becoming more important.

Over the past decades, the Nordic countries have faced a shift from inpatient care to outpatient and primary care, or even home-assisted care, in part to ease the strain on the health care systems, but also for the benefit of the patients. Between 2007 and 2018, the total number of hospital beds per 1000 inhabitants declined from 3.7 to 2.4 in Denmark, from 2.9 to 2.1 in Sweden, from 4.9 to 3.5 in Norway, from 6.7 to 3.6 in Finland, and from 4.1 to 2.9 in Iceland.[44] Moreover, digital healthcare is quickly growing in all the Nordic countries. However, despite these initiatives, health care expenditures have kept growing.[45]

Concluding Remarks

All five Nordic countries have welfare state models with tax-funded health care systems and minor private health care sectors. The operational organizations are to some extent similar in the countries, although differences do remain. A shared feature of all five Nordic countries is the GP gatekeeping role, meaning that patients need referral from GPs to access the hospitals . However, in Sweden, GP gatekeeping is only partial. The future challenges of the Nordic health care systems are the aging population, with an increasing demand for health care. Further, novel, effective but expensive technologies and treatments place additional pressure on the health care economies. Hence, prioritizing and individual-tailored treatments are important aspects of the future health care systems. Finally, all five health care systems deliver routinely collected data to a great amount of registries and databases.

The Personal Identity Number and Population-Based Registries

The Personal Identity Number

In each of the five Nordic countries, each resident is assigned a unique personal identity number upon birth or immigration, and the number follows each person their whole lifespan (except in under certain circumstances such as gender reassignment). The numbers are typically 10 or 11 digits long and encode the date of birth and sex, as well as a unique identifier. The overall purpose is administrative, and the number is generally used in all aspects of life, such as by authorities, the health care systems, schools and universities, banks and insurance companies, and when applying for jobs, among other examples.[46–48] The personal identity numbers were originally introduced to control and monitor tax payments and have existed since 1968 in Denmark,[46] 1964/1968 in Finland, 1964 in Norway, 1954 in Iceland (1987 in its current form),[49] and 1947 in Sweden.[47] From the perspective of registry-based research, these personal identity numbers are essential because they are key identifiers in all registries and databases, enabling easy, accurate, and unambiguous individual-level linkage of the registries. Therefore, these identifiers are essential for using the registries to their full potential (Figure 4).

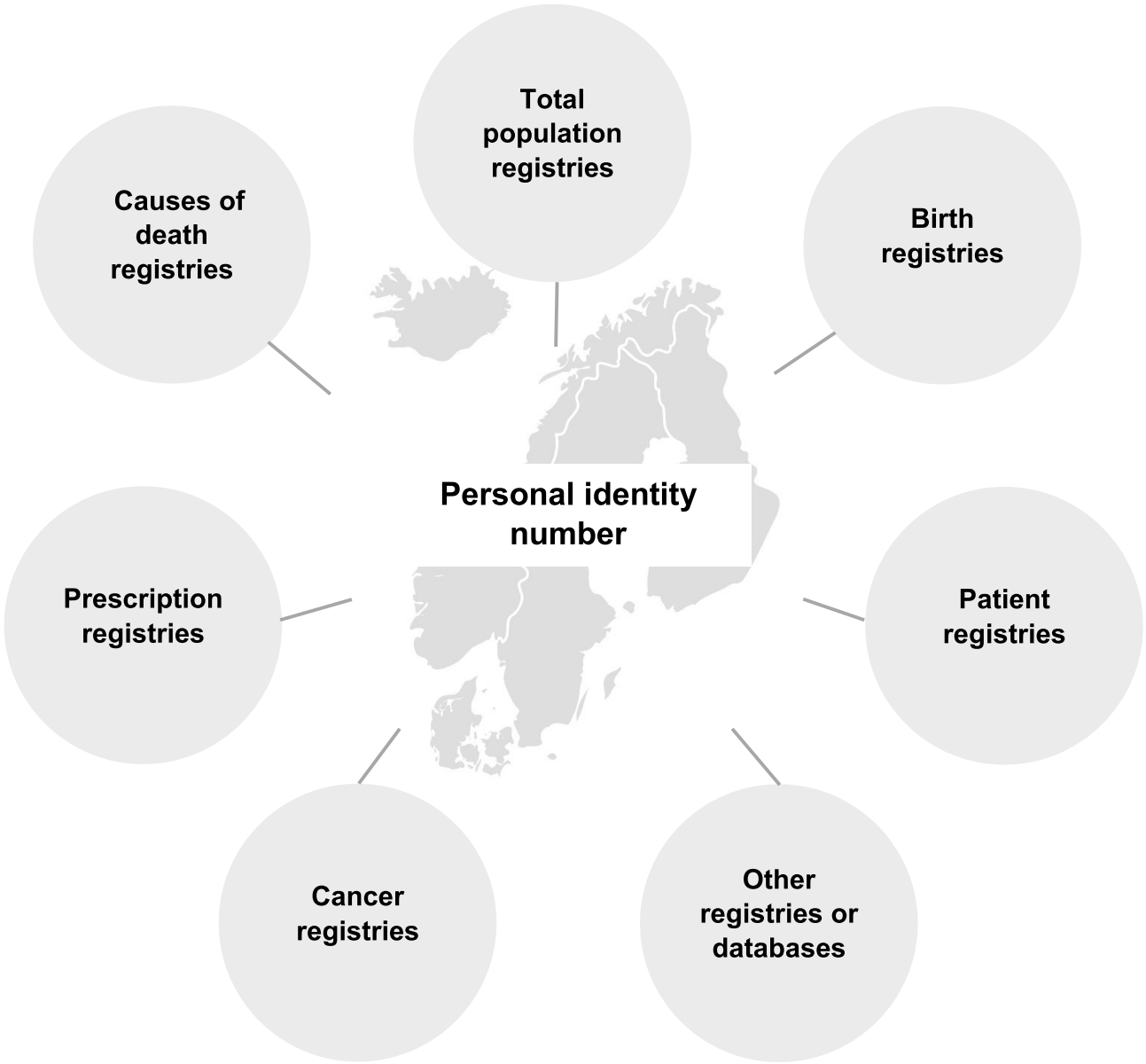


Figure 4 Combining Nordic registries by personal identity number.
Notes: Other registries and databases refer to registries containing socioeconomic data, the numerous disease or procedure registries, clinical quality databases/registries, surveys, researcher-initiated cohorts and biobanks.

Population-Based Registries

The Nordic registries provide population-based data that are routinely and prospectively collected on individuals lives and health. The registries have several advantages, but also potential disadvantages, described in overall terms below and in more detail in the subsequent sections on key registries.

Advantages

The Nordic registries are population-based with virtually complete follow-up and exact censoring information, reducing the risk of selection bias. Population-based registries share the feature of intended coverage of all members of the underlying source population with a given set of traits, exposures, or events, making selection bias less likely at study inclusion.[50] The term "coverage" denotes the proportion of all health care units that report to the registry. Although the coverage of a population-based registry may be incomplete, it is the intention that defines the term, in contrast to registries that rely on, for example, insurance or survey data. Importantly, population-based studies are not necessarily

free of selection bias. The collection of national registry data in the Nordic countries is further independent of the research question, which reduces the risk of certain types of bias (eg, recall bias). The large size of the registries provides an opportunity to study rare exposures or outcomes, increasing the precision of estimates. Furthermore, many of the registries offer the possibility for long-term follow-up. Lastly, as the data are already available in the registries, the time and cost spent on a typical registry-based study are probably less than that spent on studies using primary data collection.

Potential Disadvantages

The Nordic registries may also have potential disadvantages, mainly in the areas of data quality and data availability, and the validation of variables is important for the quality of registry-based research. The registries covered in this review are mainly administrative with the aim of health care surveillance, planning, and reimbursement.[7] When using registry data for research, one should therefore bear in mind the data quality in terms of validity and completeness. Validity denotes the extent to which a variable measures the intended event, trait, or exposure and is most often described in terms of the positive predictive value. The positive predictive value denotes the probability that a person has a condition or disease given that this person is recorded with the condition or disease. The validity of health information in registries may vary extensively. The completeness refers to the percentage of all eligible patients with a diagnosis in the target population who are recorded in the registry. Thus, completeness is related to sensitivity. Lastly, registries may directly lack information because data collection is predetermined and not controlled by the researcher. Data quality and availability obviously impact potential exposure and outcome misclassification, but may also affect a researcher's ability to control for confounding.

Although the Nordic registries were established at different points in time (Figure 5), they often share a similar overall structure. The number of registries and databases in each country are substantial, with more than 200 registries and databases in Denmark alone.[7] Below, we provide an overview of some of the key registries, with a focus on registries that are present in most of the countries and may be particularly useful when conducting registry-based studies. Despite the similarities within the Nordic registries, researchers should keep in mind that some differences do exist, including variable types and registration practices. In addition, the organization and structure of the health care systems affect the registration practices. Having experienced collaborators within each country is important in order to use and manage the registries correctly.

Key Registries

Below we describe the total population, birth, patient, cancer, prescription, and causes of death registries with a focus on period of coverage, selected key variables, and potential limitations. We have chosen to describe these specific registries, as they share similarities in context and structure between the countries and they are frequently used for research. In addition, each of the Nordic countries has various other registries, databases, and biobanks available for research. In the end of this section, we will briefly mention a selection of these.

The Total Population Registries

All Nordic countries maintain registries of their entire population with continuously updated information on the variables presented in Table 1.[46,51,52] The coverage periods of the registries are shown in Figure 5.[46,51,52]

These registries are intended for administrative purposes and, for example, form the basis for monitoring of population statistics, demographics, and development. In addition, they are also widely used for research and play a key role in almost all registry-based studies. The total population registries are important tools in epidemiological research and provide inimitable possibilities. These registries hold information on date of birth and death and allow for virtually complete follow-up and exact censoring information for an entire population. The registries may further be used for sampling general population comparison cohorts (cohort studies)[53] or controls (case-control studies),[54] identification of family members as eg siblings,[55] sampling of people for surveys,[56] or subsequent long-term follow-up in clinical trials.[57] Regarding case-control studies, the registries also permit risk-set sampling, so that estimated odds ratios provide unbiased estimates of incidence rate ratios, as well as back-calculation of incidence rate differences.[54,58–60] Lastly, non-response may introduce bias in studies using surveys. However, individual-level linkage of participants and non-participants to other registries using the total population registries allows the calculation of calibrated weights that can be utilized to diminish such bias in studies using survey data.-[61–63]

Birth Registries

Each Nordic country has a nationwide birth registry with complete coverage of live and stillbirths.[64–70] Abortions are not registered. The registries contain electronically

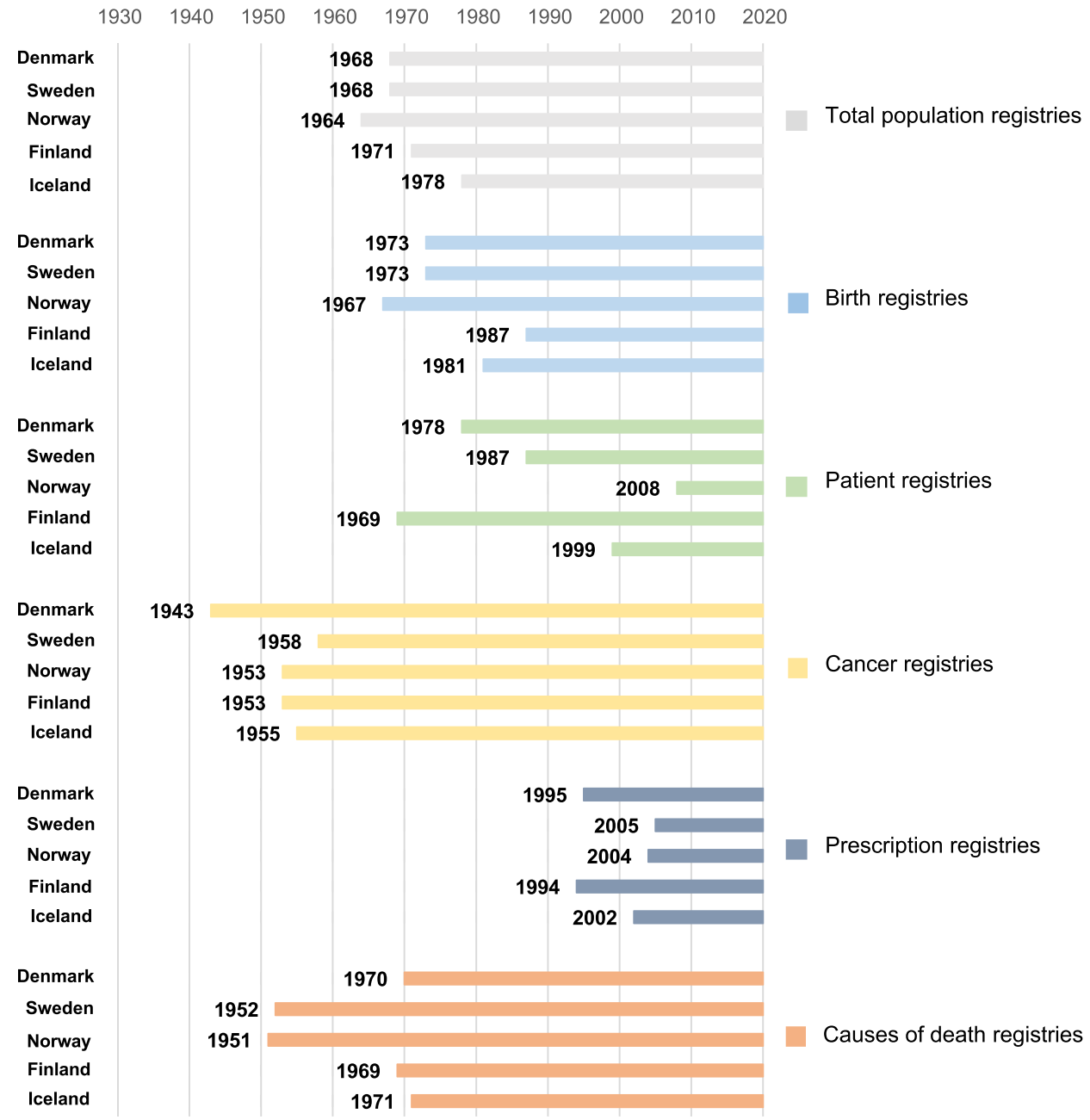


Figure 5 The time coverage of selected Nordic population-based registries.
Notes: Only the time for complete nationwide coverage is displayed. The Finnish Hospital Discharge Register has had nationwide coverage since 1967 but was limited by incomplete registration of the personal identity number in 1967-1968 and diagnoses in 1967-1970. The Icelandic Birth Registry was complete from 1972 but electronically since 1981.

submitted information on variables, such as the personal identity number of the live-born infant and parents, some infant and maternal characteristics, as well as information on the pregnancy and delivery. The Swedish and Norwegian registries further collect information on fertility treatments, their indications, and procedures.[67,69] The midwife or physician overseeing the delivery collects the data at the hospital, or at home in the case of planned home delivery. The coverage periods of the birth registries are shown in Figure 5.[65,67–70]

The contents of the Nordic birth registries are similar, and selected key variables are given in Table 2. Date of birth, sex, and kinship can be obtained from the total population registries as well.

Table 1 Key Variables in the Nordic Total Population Registries

Variables
Personal identity number
Sex
Date of birth
Country of birth
Name
Address, including date of address changes
Immigration and date
Emigration and date
Civil status, including changes in and personal identity number of spouse or registered partner
Kinship, including personal identity number of parents, siblings, and children
Date of death

Strengths and Limitations

An extensive validation of the Danish Medical Birth Register was performed in 2001, showing that most procedures, surgical codes, and diagnoses had high validity in terms of positive predictive values. However, some variables, such as pain relief procedures and uterine rupture, did not have high validity.[71] The Medical Birth Registry of Norway has undergone validation of a few selected variables.[72,73] A validation study of the 1991 Finnish Medical Birth Registry found good or acceptable validity for many variables.[74] Regarding diagnoses and procedures, check-box variables were generally more reliable than collection by specific codes.[74]

Patient Registries

The nationwide patient registries[75–78] are administrative and contain electronically submitted information from hospitals, including information on inpatient hospital care and, often, hospital-based outpatient care. The primary aim of these registries is monitoring of hospital and health service utilization to provide a tool for health care planning. The coverage periods of the patient registries are shown in Figure 5. The Danish National Patient Registry[75] was established in 1977 and reached complete nationwide coverage in 1978. From 1977 to 1994, it included only somatic inpatient care, but from 1995 onwards it included also somatic and psychiatric inpatient and outpatient care. From 1999, diagnostic examinations and treatments were included. The Swedish National Patient Register[76] was founded in 1964 but attained complete nationwide coverage in 1987. Initially, only somatic inpatient care was included. Psychiatric contacts were added from 1973, day surgeries were added from 1997, and outpatient contacts were included from 2001. The Norwegian Patient Registry[77] was founded in 1997. When established, the registry covered inpatients in somatic hospitals. Psychiatric hospital data for adults were included in 2001, whereas data from children were included in 2003. In 2009/2010, the registry was further expanded to include information from emergency departments. Importantly, before 2008, the registry did not include information on the personal identity number. The Finnish Hospital Discharge Register has had complete coverage since 1969 (including personal identity

Table 2 Selected Key Variables in the Nordic Birth Registries

Information Type	Variables
Basic information	The personal identity number of the infant
	The personal identity number of the mother
	The personal identity number of the father[a]
Delivery information	Date of birth
	Place of birth
	Presentation at birth (eg, cephalic, breech, or shoulder presentation)
	Method of delivery
	Delivery complications
	Procedures around delivery
Maternal characteristics	Age at birth
	Height, weight, body mass index[b]
	Smoking status[c]
	Parity
	Diagnoses[d] and complications during pregnancy or delivery
	Number of previous pregnancies and deliveries
Infant characteristics	Single or multiple birth
	Sex
	Gestational age at birth
	Birth weight
	Length
	Head circumference
	Live or stillborn[e]
	Health status of the child (Apgar score, infant diagnoses, and treatment)
	Congenital malformations at birth[f]

Notes: [a]Not in Sweden and Finland but can be obtained through linkage to the total population registries. [b]The coverage period of these variables varies considerably across the countries. [c]Sweden also record use of snuff. [d]Not recorded in the Danish Medical Birth Registry, but some diagnoses may be obtained through linkage to the Patient Registry. [e]Gestational age at which stillbirth is defined varies by country and calendar year. [f]More detailed information may be obtained in the registries of congenital anomalies or patient registries, depending on country. The birth registries of Norway and Sweden also contain information on fertility treatment procedures and indications.

Table 3 Selected Key Variables in the Nordic Patient Registries

Information Type	Variables
The patient	Personal identity number Area of residence
Hospital and department	Hospital code Department code/specialty
Admission	Admission date Discharge date Admission type (acute, non-acute, etc.) Patient contact type (eg, inpatient, outpatient) ICD diagnoses (primary and secondary/ additional codes) Surgical and medical procedure codes

Abbreviation: ICD, the International Statistical Classification of Diseases and Related Health Problems for coding diagnoses.

numbers), but was replaced in 1994 by the Finnish Care Register for Health Care.[78] The Hospital Discharge Register only included data on inpatient care, whereas the Care Register for Health Care also contains data on specialized outpatient care (since 1998) and day surgery (since 1994). The Icelandic Hospital Discharge Registry[79] has been nationwide since 1999. Until 2009, the registry included inpatient contacts only, but from 2010 onwards the registry also collected information on outpatient contacts.

Table 3 provides an overview of selected key variables in the Nordic patient registries.

The Nordic countries use different versions of the International Statistical Classification of Diseases and Related Health Problems (ICD) for coding diagnoses (Table 4).[80]

Since 1996/1997, a Nordic collaboration has defined surgical procedures in the Nordic Medico-Statistical Committee (NOMESCO), making the coding and selection of surgical procedures more homogenous between the countries. However, the NOMESCO Classification of Surgical Procedures (NCSP) has not been updated since 2011. Because the national versions have been updated with new codes, the classification cannot be used before mapping the old NCSP and its national versions.

The patient registries do not capture information from GPs, but separate registries exist with such information for Norway,[77] Finland,[81] Iceland,[82] Denmark,[83] and probably soon for Sweden. However, the level of details in these registries varies extensively.

Strengths and Limitations

The Danish, Swedish, and Norwegian patient registries have undergone extensive validation, though some work still persists, and findings indicate a high positive predictive value for many, but not all, diagnoses.[75–77] Furthermore, some diagnoses in the Finnish patient registry have been validated.[84] The completeness of the diagnoses (relative to the general population) are dependent on whether the condition requires hospitalization, as well as the diagnostic and coding practices. For example, completeness is high for conditions such as acute myocardial infarction or hip fractures, which require a hospital encounter,[75,76] whereas completeness is low for conditions such as hypertension, type 2 diabetes, asthma, or chronic obstructive pulmonary disease (COPD), which are often diagnosed and treated by GPs (ie, outside hospitals).[75,76] Under the latter circumstances, researchers may benefit from using algorithms based on, for example, prescription data to increase completeness. Information on lifestyle-related factors, such as smoking, alcohol drinking, or body mass index, is generally lacking or incompletely recorded. Clinical details, such as disease severity, are also absent. Such information may be captured in other

Table 4 Timeline for Use of the International Statistical Classification of Diseases and Related Health Problems (ICD) Coding Systems in the Patient Registries by Country

	ICD-7	ICD-8	ICD-9	ICD-10
Denmark	NA	1977–1993	NA	1994-
Sweden	1964–1967[a]	1968[a]-1986	1987–1996	1997[b]-
Norway	NA	NA	1997–1998	1999-
Finland	NA	1969–1986	1987–1995	1996-
Iceland	NA	NA	NA	1999-

Notes: [a]*Officially, the change to ICD-8 occurred in 1968, but in practice ICD-7 was used during 1968, and only in 1969 was ICD-8 used.* [b]*The Skåne region introduced ICD-10 in 1998.* Source: Health Classifications in the Nordic Countries (2006). Björn Smedby and Gunnar Schiøler. Responsible organization: Nordic Council of Ministers, NOMESCO-NOSOSCO. (http://norden.diva-portal.org/smash/get/diva2:970544/FULLTEXT01.pdf).
Abbreviation: NA, not applicable.

Table 5 Selected Key Variables in the Nordic Cancer Registries

Information Type	Variables
The patient	Personal identity number Date of birth Sex Place of residence (unit) Vital status Date of death
Tumor characteristics	Date of diagnosis Topography (primary site) Morphology/histology Tumor stage or grade[a] Method of confirmation Behavior (malignant, premalignant, and borderline behavior)

Note: [a]Classification system depends on country, calendar year, and cancer type.

databases, such as disease or procedure registries, clinical quality databases/registries, or surveys.

Cancer Registries

All of the Nordic countries have well-established cancer registries with data on incident malignancies and a few certain benign tumors.[85–91] Recurrence and subsequent metastases are not recorded. In contrast to the other registries described in this review, the cancer registries are not administrative, but were created mainly for research purposes. The cancer registries receive information from multiple sources, including hospitals, outpatient clinics, primary care physicians, pathology and cytology laboratories, and death certificates.[85] The coverage periods of the cancer registries are shown in Figure 5.[85–91] The cancer registries are used to monitor cancer incidence. The cancer registries of the Nordic countries have established an association and a partnership with the International Agency for Research on Cancer (IARC). As a result, IARC has developed NORDCAN 2.0, which is an interactive and analytical tool and database enabling the comparison of cancer statistics for the Nordic countries. Information from NORDCAN 2.0 includes estimates on incident cancer cases, cancer mortality, number of persons living with a cancer diagnosis (prevalence), and cancer survival, among others.[92]

Table 5 provides selected key variables in the Nordic cancer registries.

The Nordic countries have used different systems to code topography and morphology (for more details please see Pukkala et al[85]). Today, all countries use the International Classification of Diseases for Oncology, third edition (ICD-O-3) to code morphology. Denmark also uses ICD-10 codes (recoded from ICD-8 codes in 1978–1993) and Sweden ICD-7 codes to identify cancer diagnoses.

Table 6 Selected Key Variables in the Nordic Prescription Registries

Information Type	Variables
The patient	Personal identity number (or pseudonymized number) Sex Date of birth
The prescriber	Prescriber type (eg, GP, hospital physician, or private physician)
The pharmacy	Identifier Location of the pharmacy[a]
The drug	Date of dispensing Nordic article number (unique identifier) Anatomical Therapeutic Chemical classification (ATC) code Number of packages dispensed Number of tablets in one package Tablet strengths The defined daily dose (DDD) Formulation of the drug Drug reimbursement

Note: [a]Location not recorded in the Finnish prescription registry but can be linked.

Strengths and Limitations

Cancer reporting is mandatory in all Nordic countries, and all of the cancer registries include high quality data in terms of completeness and validity.[85,87,88,90] In addition, microscopic verification of the cancers is frequent (93–98%) in all countries.[85] The validity of the cancer registries is fortified by manual quality control routines and notifications from different data sources, which also secures high completeness.

Prescription Registries

Each Nordic country has a nationwide prescription registry containing electronically submitted information on prescriptions dispensed by pharmacies.[93–98] The registries are valuable data sources for drug utilization studies or pharmacoepidemiological research on the effectiveness or

safety of medical drugs. The coverage periods of the prescription registries are shown in Figure 5.[93–98]

Table 6 shows selected key variables in the Nordic prescription registries.

The Swedish, Norwegian, Finnish, and Icelandic registries contain information on prescribed daily dose, but only as free text, which renders the information difficult to utilize in research. The Danish registry does not capture information on prescription duration, but in many pharmacoepidemiological studies, prescription duration or the definition of treatment episodes are important information. For some medications, clinical input may be used to guide the duration of individual prescriptions (eg, assuming use of one defined daily dose or one tablet per day), or data-driven methods may be utilized, such as the parametric or reverse waiting time distribution.[99–102]

Currently, all registries contain information on both reimbursed and non-reimbursed medications. However, until 2017, the Finnish registry recorded information only on reimbursed medications.[93] Individual-level data on drug use in hospitals are not available in the prescription registries. Some medications, such as chemotherapeutics or immunotherapies, are typically registered in the patient registries by treatment or sometimes ATC codes. Individual-level information on drug use in nursing homes is available in Denmark, Sweden, and Iceland (in Iceland from 2007 onwards).[93] Furthermore, the majority of over-the-counter (OTC) medicines, such as non-steroidal anti-inflammatory drugs or paracetamol, are not captured except when prescribed to patients, typically in patients with chronic diseases for whom reimbursement is needed.

In addition to existing individual-level information, aggregated drug sale information is public and freely available in Denmark (www.medstat.dk),[103] Finland (www.fimea.fi/web/en/databases_and_registers/consumption-information),[104] Sweden (https://sdb.socialstyrelsen.se/if_lak/val.aspx),[105] and Norway (www.norpd.no).[106] In Denmark and Finland, aggregate statistics are available for community pharmacy-dispensed medication, drug use in hospitals, and OTC medicines, whereas Norwegian and Swedish statistics only provide information on community pharmacy-dispensed medication.

Strengths and Limitations

Completeness for drugs dispensed at community pharmacies and the validity of medication records is considered high because of legislation and other incentives (eg, financial) that motivate pharmacies to collect and send the data electronically to the registries.[93–95,97] Nevertheless, several limitations need to be considered. The lack of information on in-hospital drug use may create observation gaps or an unmeasurable exposure time during hospital stays. In addition, secondary non-adherence, defined as filling a prescription but not taking the drug, cannot be ruled out. However, primary non-adherence, defined as not filling a prescription, is not an issue, as the registries only have information on dispensed drugs. Many of the prescription registries lack information on treatment indication and the severity of the conditions being treated. Absence of this information makes it even more difficult to control for confounding by indication or disease severity. Several approaches can diminish confounding by indication or disease severity, including the new use active-comparator design[107] or the inclusion of proxies for disease severity, such as number of hospital contacts or prescriber type (GP vs hospital physician). Since 2004, The Danish National Prescription Registry has recorded a numerical code for the treatment indication. Physicians should always state the treatment indication on prescriptions, but some do so in free text, which is then not reported to the registry. In Norway, reimbursement codes may be used (ICD-10 or ICPC-2).

Table 7 Selected Key Variables in the Nordic Causes of Death Registries

Information Type	Variables
The person	Personal identity number Place of residence
The death	Date of death (or date of discovery if found dead) Manner of death (natural, accident, violence, suicide, uncertain) Underlying cause of death The immediate or direct cause of death[a] The contributing causes of death Place of death (private residence, nursing home, hospital) Autopsy performed (yes/no) Type of autopsy (clinical, medico-legal)
Physician issuing the death certificate	Hospital physician, GP, health officer, etc

Notes: [a]The Swedish Causes of Death Registry does not record immediate/direct cause of death directly. Nevertheless, this information can mostly be obtained by the position of the cause of death on the death certificate (the first line on the death certificate corresponds to the immediate/direct cause of death).

Causes of Death Registries

All Nordic countries have a long tradition of recording cause of death data, which are stored in nationwide administrative registries. These registries are used to estimate and inform on cause-specific mortality statistics. The coverage periods of the registries are shown in Figure 5.[108–111] Denmark holds the records of Danish citizens who died in Denmark, Greenland, or the Faroe Islands, whereas Finland, Sweden, and Norway also record whether citizens died abroad.

Table 7 shows selected key variables in the Nordic causes of death registries. Information on date of death can be obtained from the total population registries as well.

Causes of death are recorded using ICD codes (Supplementary Table 3).[80] In general, the death registries contain information on underlying (the World Health Organization definition), immediate, and contributing causes of death.

Strengths and Limitations

The quality of the causes of death registries is affected by several factors, including the quality with which the responsible physician certifies the death, autopsy rates (which are generally low and declining), and the processing of death certificates by responsible agencies. The completeness of the causes of death registries is considered high, but validity may vary and depend on age at death (less valid in elderly) and cause of death (eg, high validity for cancers but low validity for COPD).[108,109] Furthermore, the recording procedures may vary between the Nordic countries and may have also changed within each country over the years. Changes in recording procedures, shifts in the coding systems, new diagnostic techniques, the decline in autopsy rates, and altered priorities in the health care systems may all impact the reporting of cause-specific mortality. Therefore, cause-specific mortality trends over the years and between-country variations need to be interpreted carefully. Information on all-cause mortality is usually retrieved from the total population registries, and this information is regarded as precise and valid. For example, 93% of all deaths are recorded in the Swedish Total Population Register within 10 days, and the remaining 7% within 30 days.[51]

Other Registries and Databases

The Nordic countries have a great number of other registries, databases, surveys, and biobanks available for research.[7,112–117] Among these are registries containing socioeconomic data on educational level and achievements, income, labor market affiliation, housing, and social benefits.[116–123] Further, numerous disease and procedure registries[7,112,113,116,117,124] and clinical quality databases/registries[7,125,126] collect detailed clinical information on factors such as the disease of interest, disease severity and progression, drug treatment, diagnostic or treatment procedures, lifestyle factors, laboratory values, and other clinical characteristics relevant for the specific database. National or regional surveys may also contain valuable data, such as self-reported physical and mental health, social relations, lifestyle and other factors not recorded in the registries.[7,113,117,127–130] Lastly, researcher-initiated cohorts[7,117,128,131–139] or biobanks[7,128,131–145] are widely available.

Concluding Remarks

The unique personal identity number, assigned to all residents upon birth or immigration, makes the Nordic population a cohort that is followed its entire lifespan with exact date of death or censoring information. The wide range of population-based registries and databases as well as surveys and biobanks make the Nordic countries a goldmine for joint health registry-based research. The similarities between and within the Nordic registries allow researchers to combine data from several countries, providing opportunities for research in large study populations with long and complete follow-up. Data quality as well as potential dissimilarities in registration practice, variables, and underlying health care systems between the countries should be taken into account.

Examples of Nordic Health Registry-Based Research

Nordic research collaborations have contributed with important surveillance and clinical research. For example, cancer incidence,[146,147] survival,[147–151] prediction,[152] and risk factors[153] have been described and studied extensively using the Nordic registries. Findings of country-specific variations in eg cancer survival have already led to national improvement strategies and may also foster common surveillance and treatment guidelines in the future.[147] Examples of other findings include studies by Stephanson et al[1] and Kieler et al[2] (cohort studies of 1.6 million infants), which found no association between the use of selective serotonin reuptake inhibitors (SSRIs) during pregnancy and the risk of stillbirth, neonatal mortality, or post-neonatal mortality; however, an association with neonatal persistent pulmonary hypertension

Table 8 Country-Specific Overview of Permission Needed for Registry-Based Research and Where to Apply for Data

	Required Permissions	Where to Apply for Data
Denmark	Approval from the Danish Data Protection Agency; from a practical perspective this is done by reporting the study to local authorities with data responsibility (universities or regions) No ethical permission is needed	The Danish Health and Medicines Authority (www.sundhedsdatastyrelsen.dk) Statistics Denmark (www.dst.dk)
Sweden	Approval from the relevant governmental registry holder (Statistics Sweden and the National Board of Health and Welfare) Ethical permission is required from the Ethical Review Authority.	The National Board of Health and Welfare (www.socialstyrelsen.se) Statistics Sweden (www.scb.se)
Norway	Ethical permission is required from the regional ethical committee	Helsedata (www.helsedata.no) Statistics Norway (www.ssb.no)
Finland	Approval from the Health and Social Data Permit Authority (Findata) and/or Statistics Finland No ethical permission is needed	Findata (www.findata.fi) Statistics Finland (www.stat.fi)
Iceland	Approval from the National Bioethics Committee (including a review from the National Data Protection Agency) Approval from the relevant governmental registry holder	The Directorate of Health (www.landlaeknir.is) Statistics Iceland (www.statice.is)

was found with SSRI use in late pregnancy (adjusted odds ratio of 2.1 and absolute risk of 3 per 1000 vs 1.2 per 1000 in the background population). A study by Bateman et al[3] (cohort study of ~18,500 hypertensive pregnancies) found that maternal use of β-blockers in the first trimester of pregnancy was not associated with a large increase in the overall risk of malformations (adjusted relative risk 1.07, risk difference of 3.0 per 1000 infants) or the risk of cardiac malformations (adjusted relative risk 1.12, risk difference of 2.1 per 1000). A study by Daltveit et al[4] (case-control study including 62,295 cancer cases and 724,542 controls) reported an increased risk of cancer in individuals with birth defects. The odds ratio for cancer was 1.54 for individuals with non-chromosomal birth defects and 5.53 for those with chromosomal anomalies.[4] Two studies by Olén et al[5,6] (cohort studies of 1 million and ~500,000 individuals, respectively) assessed the risk of colorectal cancer and mortality from colorectal cancer in patients with ulcerative colitis (n = 100,000) and Crohn´s disease (n = 47,000) during modern treatment and surveillance paradigms compared to the general population. Patients with ulcerative colitis or Crohn´s disease were at increased risk of colorectal cancer and increased risk of dying from the cancer. These excess risks declined substantially over time (1969–2017), but surveillance programs may still have room for improvement.[5,6] Lastly, the SCAN-AED (Nordic register-based study of antiepileptic drugs in pregnancy) is a project that aims to investigate the association between in utero exposure to antiepileptic drugs and folic acid supplements, and later disease in the mother and child.[154]

Practical and Ethical Aspects

Combining Nordic registries can be challenging from both the practical and legal perspective.[155] Currently, organizations exist to facilitate Nordic collaboration research, including NordForsk. NordForsk was established in 2005 under the Nordic Council of Ministers and facilitates and funds Nordic research and infrastructure.[156] Different initiatives have also been created to ease cross-border data-sharing and transfer, including current and future platforms, such as NordMAN and Nordic Commons.[157,158] Yet, legal and practical aspects can still hamper the process. The NORDCAN collaboration has been successful in pooling and harmonizing data.[92]

Practical Aspects

To initiate joint Nordic research, the first step is to establish collaboration between experienced researchers within each country. The next step is to write a detailed protocol and analysis plan with a clear aim and description of the required variables. Variables are not always present in all country-specific registries and coding practices may also vary. In addition, permissions need to be obtained within each country. The timeline is often extensive for obtaining permission and retrieving data. An additional major barrier

is that Danish data cannot legally be transferred out of the country, and other countries need to provide their data to Statistics Denmark or the Danish Health and Medicines Authority. Other Nordic countries are increasingly moving towards specific remote access environments for secure data processing. Whether Nordic data can be gathered in such environments and on which principles is still unclear.

Ethical Aspects and Data Permissions

Researchers must obtain permission in each country. Necessary permissions and procedures vary between the Nordic countries[155,159] (for a detailed review see Ludvigsson et al[159]). Table 8 provides a country-specific overview of the permissions needed for registry-based research and information on where to apply for the data. A shared feature of legislation in all Nordic countries is that no informed patient consent is required for collection of large-scale data in the national registries reviewed in this paper.

Data Transfer Out of the Country

Currently, all data except Danish data may (theoretically) be transferred out of country. If Danish data are needed, two solutions may exist depending on the analytic strategy of the study. If an individual-level analytical approach is wanted, data from the other Nordic countries may be transferred to and stored at Danish servers. However, a legal barrier to this is the requirement that only (one) Danish researcher can be responsible for the data (ie data controller). This means that other countries must resign data responsibility, which can hamper or even stop the data transfer process. Another option is to choose a meta-analytic approach, storing and analyzing the data in their respective countries and combining the results in a pooled analysis.

In general, the data themselves are free of charge, but administrative handling and data processing are not. If the data are to be analyzed in a remote server, additional fees apply.

Future Directions

Joint Nordic data resources remain underutilized in health research, mainly due to legal and practical difficulties in cross-border sharing of data. To fully exploit Nordic joint research, these barriers must be overcome. Future tasks include clear and transparent legal pathways and a framework to ease practical aspects of data transfer and storage. Such tasks, likely, require a collaborative effort between the political administrative levels, organizations with interest in joint research as well as register owners and data processors.

Ethical Approval

Not needed.

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