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Nordic Cancer Registries – an overview of their procedures and data comparability

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Abstract

Background. The Nordic Cancer Registries are among the oldest population-based registries in the world, with more than 60 years of complete coverage of what is now a combined population of 26 million. However, despite being the source of a substantial number of studies, there is no published paper comparing the different registries. We therefore conducted a systematic review to identify similarities and dissimilarities of the Nordic Cancer Registries which could possibly explain some of the differences in cancer incidence rates across these countries.

Method. We here describe and compare the core characteristics of each of the Nordic Cancer Registries: (i) data sources; (ii) registered disease entities and deviations from IARC multiple cancer coding rules; (iii) variables and related coding systems. Major changes over time are described and discussed.

Results. All Nordic Cancer Registries represent a high quality standard in terms of completeness and accuracy of the registered data.

Conclusions. Even though the information in the Nordic Cancer Registries in general can be considered more similar than any other collection of data from five different countries, there are numerous differences in registration routines, classification systems and inclusion of some tumours. These differences are important to be aware of when comparing time trends in the Nordic countries.

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Introduction

The cancer registries in the Nordic countries, Denmark, Finland, Iceland, Norway and Sweden operate in similar demographic settings. The Nordic cancer registries are all based on total populations, each having its unique personal identity code (PIC) system. The total population of these five countries now exceeds 26 million, and more than 100,000 new cancer cases are registered every year.

Notification of cancer is mandatory in all Nordic countries, and a high degree of comparability and validity has been documented in the practices of the registries. Similar issues were addressed in a 16-page questionnaire survey conducted in 2000 by the Association of the Nordic Cancer Registries (ANCR) and the Danish Cancer Society. The results were published in a 262-page document [1]. Close to 100% completeness of incident solid malignancies have been reported in each of the registries [2-8]. Data from each of the five Nordic registries have been presented in *Cancer Incidence in Five Continents* (CI5) – a compendium of cancer incidence data from registries evaluated to have high quality data – from Volume I, covering the years 1958-1962 [9], through to Volume X, covering the years 2003-2007 [10].

A history of close contact between the Nordic cancer registries has ensured many similarities with data often being used for the purpose of comparative and multicentre Nordic studies. Despite the similarities, a number of differences in cancer registration practices exists, but these are rarely discussed when rates are compared. These differences will in particular affect studies that compare the relative survival of cancer patients. Comparability issues could also explain some of the observed temporal trends in cancer incidence, and projections of future cancer burden.

The aim of this article is to describe the cancer registration systems in the Nordic countries in a systematic fashion, and provide documentation on the similarities and dissimilarities of the Nordic cancer registries. We also explain why the numbers of cancer cases published in national cancer statistics are not always identical with those published in NORDCAN (ancr.nu), the joint Nordic cancer statistics database [11,12].

Materials and Methods

For this paper, characteristics of the Nordic cancer registries were systematically described by experts from each of the five Nordic cancer registries on the following aspects.

1) Data sources of the cancer registry;

2) Registered disease entities (including precancerous lesions etc.); coding rules and deviations

from them, such as multiple cancer coding rules by the International Agency for Research on Cancer (IARC) and the International Association of the Cancer Registries (IACR);

3) Variables available in the permanent cancer registry database or easily available from other data sources via record linkage; coding nomenclatures related to these variables.

A set of questions was drafted by the first author (EP) and finalised in collaboration of all authors. The answers were filled in a template by best national experts of registration procedures and coding practices and synthesised in discussions between the fists author (EP) via email discussions and in face-to-face meetings.

This paper describes cancer registration practices as of April 2017, with documentation of major changes in the history of the cancer registration in each country. Examples are illustrated as graphs produced with NORDCAN graphical tools (ancr.nu).

The numbers of cases registered were calculated by each Nordic cancer registry for the period 2009-2013 and then compared with the respective numbers shown in NORDCAN version 7.3 released in July 2016 [11]. All Figures in this paper except Figure 9 are made with the NORDCAN graphical tool.

Results

All Nordic cancer registries are nationwide and population-based and have a long history. The Danish Cancer Registry is the oldest, founded in 1942. The Cancer Registries in Finland and Norway were founded in 1952, Iceland in 1954, and Sweden in 1958 (Table 1). We do not describe cancer registries of the Faroe Islands and Greenland in detail, although data from these regions are now accessible via NORDCAN. The Cancer Registry in the Faroe Islands was functional during some periods since the 1960s and was re-established in 1994 [13]. Cancer data from Greenland were coded and stored by the Danish Cancer Registry from 1943 until 2013. In 2014 Greenland took over the coding responsibility.

The completeness of data on incident cancers is considered to be very high already from the founding of the Cancer Registry in each of the Nordic countries (Table 1). For Sweden, however, data from the very first years are often not shown in the tabulations, e.g., the time trends in NORDCAN start from year 1960 [11]. The Finnish Cancer Registry also includes information on cases diagnosed in 1930-1952 in individuals who died from cancer or developed a new primary cancer after 1 January 1953. The Icelandic Cancer Registry also includes countrywide information on breast cancers diagnosed in 1911-1954, comprehensive data that were collected for a doctoral thesis [14]. The completeness of the information for such early years is not known.

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Notifications of cancer are centrally handled in all Nordic countries except Sweden, where six regional registries collect the notifications and perform checks before data are sent to the office of the National Cancer Registry at the National Board of Health and Welfare.

Table 1 and Web Table 1 list administrative information, such as contact addresses, links to instructions on data requests and permissions for access of data. Additionally, values for commonly used indicators for cancer registry quality, proportion of death certificate only (DCO) cases, and microscopically verified cases in 2009-2013 (range 93% to 98%) are presented in Table 1. In Web tables, we also provide links to more complete documents on data quality.

Data sources

Information on cancer stems from multiple sources, including hospitals, institutions with hospital beds, primary care physicians, pathology and cytology laboratories, and death certificates. Additional data items for cancer cases already known to the Cancer Registry may be obtained by record linkage with administrative health/disease registries (e.g. pathology registries, inpatient hospital registries, cause-of-death registry).

In all Nordic countries, cancer notifications have been received from public hospitals from the outset (Table 2). In Iceland, clinicians in private practice report only prostate cancers, while in the other countries they report all malignancies. Cancer notifications from dentists are received only in Denmark and Finland. This should not create incomparability in the cancer statistics, because dentists are supposed to refer people with suspicious lesions to hospitals.

Currently, all countries receive notifications from pathology laboratories/departments. Since 2004, the information in the Danish Cancer Registry has been based on data retrieved by record linkage to the National Patient Register, the National Register for Pathology, and the National Cause of Death Register, supplemented with notifications from general practice [15].

Sweden is the only Nordic country with no legal basis to routinely use cancer information from the death certificate notifications (DCN) to supplement the national cancer registry. This information is important, as it adds primarily cases with poor prognosis following trace back of DCNs to validate the diagnosis and retrieve information on date of diagnosis. Once identified and verified from another source, these cases become death certificate initiated (DCI).

Non-inclusion of information from death certificate sources in Sweden reduces the completeness of registration, particularly for poorly investigated cases without histology, which if included would lower the proportion of morphologically verified cases (MV), which is 98% in Sweden. A very high MV% – higher than might reasonably be expected – suggests over-reliance on pathology laboratories as the source of diagnosis and deficiencies in case-finding from other source.

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Due to the missing death certificate source, incident cases are incompletely registered in Sweden. The number of missing cases was estimated at 4% of all cases in 1978 [2]. According to the national cancer statistics of Sweden, there were more than 2600 death certificates stating cancer as cause of death in 2014 with no corresponding records in the cancer registry; if 2000 of those were verifiable and thus registrable cancers, this would mean about a 4% addition to the number of new cancers ([16], pages 122-3). Hence, the proportion of missing cancer cases in the Swedish Cancer Registry seems to be stable over calendar time, and it is also similar to the proportion of DCI cancers in Iceland (4.4%) [7]. When comparing with data from the Swedish Cause of Death Register and Patient Register, the largest underreporting to the Swedish Cancer Registry is observed for cancers commonly diagnosed in advanced stages, such as cancers of the pancreas, gallbladder, lung, oesophagus or liver, while the effect on the completeness of breast cancer registrations, for example, is small. A research project to assess the impact on cancer incidence and survival because of the non-inclusion of DCI cases in the Swedish Cancer Registry is ongoing. Preliminary results based on record linkage to the Swedish Patient Register to validate DCNs and retrieve a date of diagnosis suggest that age adjusted 1-year relative survival may be overestimated by 2-3 percentage points for lung cancer, a malignancy often diagnosed at advanced stage, while the effect on breast cancer survival was negligible.

In 1978, the under-registration in Sweden for leukaemia was as high as 18% [2], but may be smaller now (see trend slopes in Figure 1). A large proportion of of the malignancies detected in the Cause of Death Register only - and not registered in the Cancer Register - has not been diagnosed or treated in hospital. This proportion is likely to be particularly high in the elderly with malignancies with a poor prognosis, such as pancreatic cancer. However, similar patterns (a declining incidence in the oldest age groups) are also clearly evident in the other Nordic countries most likely reflecting factors related to diagnostic activity in non-hospitalised persons (Figure 2).

Cancers registered

The lists of disease entities registered by the Nordic Cancer Registries are so similar in all countries that the total cancer incidence summed in the “All sites” category in NORDCAN can be considered directly comparable between the countries (Table 3). Only three exceptions violating the comparability are worth noticing (www.ancr.nu front page, link *The NORDCAN database*):

(i) Basal cell carcinomas are not registered in all cancer registries, or the registration may be incomplete. Thus, both NORDCAN and national cancer statistics follow the tradition of excluding basal cell carcinomas from their statistics on “all sites”. Before 1978, data from Denmark do not separate basal cell and other skin cancers (Figure 3).

(ii) The incidence of urothelial tumours is not comparable over time between the Nordic countries due to varying coding practices (Figure 4). From the early days of cancer

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registration in Denmark, it was decided to include urothelial tumours from grade 1-4, unknown grade and "papilloma" in the bladder in the incidence figures because all of them would develop into invasive cancers if not treated. In the 1980s an attempt was made to record change in grade, but realising that changes occurred from high grades to low grades and vice versa in the same patient, demonstrating the random variation based on the biopsies taken, it was decided to keep the coding unchanged. Even if part of the high incidence in Denmark is explained by differing coding practices, it is of note that mortality rates for bladder cancer in Denmark are also higher than in the other Nordic countries.

(iii) In NORDCAN, pituitary gland tumours are included in the category of brain and central nervous system (even if they are tumours of the endocrine system). These tumours include benign tumours and make up almost 10% of that category in all countries except Finland, where only malignant cases are registered.

Factors such as changes in information sources and/or different diagnostic practices like cancer screening will affect incidence. The steep increase in the incidence of prostate cancer after introduction of the PSA screening test in the early 1990s (and in Denmark about 10 years later) is a good example of this effect. In Denmark, another marked change in the incidence of prostate cancer was observed from 2004, partly reflecting the inclusion of pathology register information (Figure 5). Excessive testing with ultrasound that started in the 1990s created a spatio-temporal cluster of thyroid cancer incidence around the city of Oulu in Finland (Figure 6).

Because of variations in the starting year, target ages, coverage and participation proportion, the organised screening programs cause incomparability in trends for cervical, breast and colorectal cancer between the Nordic countries. A countrywide organised cervical cancer screening program started first in Finland and Iceland in the mid1960s and latest in Norway in 1995. The effects can be seen in the trends of cervical cancer incidence (Figure 7). Organised nationwide mammography screening among women aged 50-59 years (50-69 years since 2007) started first in Finland in 1986 and latest in 2007-9 in Denmark (two counties in the 1990s, comprising 20% of population), causing major increases in the incidence rates (Figure 8). In Denmark, invitation to colorectal cancer screening for ages 50-74 years started in 2014, and increased incidence can already be seen. Details of Nordic cancer screenings have been published elsewhere [17-19].

Multiple cancers in the same organ

Table 3 lists the number of cases included in the Nordic cancer registries, but not reported as primary cancers in NORDCAN. The main reason for different numbers of invasive malignancies between NORDCAN and each of the Nordic registries can be explained by national deviations from the IARC/IACR multiple cancer coding rules [20]. NORDCAN strictly follows the IARC/IACR rules and only counts the first malignancy in the organ or organ group and broad

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morphology category [20]. The national cancer registries, instead, do not follow the mechanistic IARC/IACR rules, but evaluate if each cancer should be regarded as a new primary cancer. This is reflected in differences between nationally published cancer statistics and NORDCAN.

The national coding rules differ between countries in how to count multiple tumours in the same organ. This is especially the case for paired organs (lung, breast, kidney), but also for skin, colon, and urinary tract system. E.g., in the Swedish cancer statistics, there were 20% more breast cancer cases during the period 2009-2013 than in the NORDCAN statistics (Table 3). While Iceland and Norway follow the IARC/IACR rules and only count the first breast cancer in their official national reporting, there are about 8% additional cases of breast cancer diagnosed in 2009-2013 in their national cancer registry databases.

For colon and rectum cancer (ICD-O topographies C18-C20), Norway and Finland count each tumour with a different two-digit topography or different morphology groups within a two-digit topography as separate cancers. Denmark counts each tumour with a different ICD-O topography code as a separate cancer. Some of the multiple tumour coding rules have changed over the years, which further complicates this issue described in detail in the report of the earlier survey in 2000 ([1], Table 5 in appendix 3).

The Swedish Cancer Registry includes all incident tumours, meaning that if several tumours are detected at the same time, all tumours will be registered as separate entities regardless whether they share the same morphology or not. Therefore, there are, e.g., much more multiple squamous cell skin cancers in the Swedish Cancer Registry than in the other Nordic registries (Table 3). Whether a tumour is a new disease entity, and thus reportable, or a recurrence of an earlier diagnosed cancer is subject to the clinician's evaluation in Sweden. The Swedish national statistics report incidence of registered tumours but also give numbers of affected individuals for major cancer forms.

Basal cell cancer

B*asal cell carcinoma* (BCC) of the skin has been registered with varying practices in the Nordic countries (Figure 9). Due to its more benign nature, BCC is traditionally not included in the official national cancer statistics and is not included in NORDCAN.

In Denmark, the coding used before 1978 does not make it possible to separate BCC from other non-melanoma skin cancer. The new Danish registration system incorporated in 2004 has doubled the BCC incidence, partly due to inclusion of cases only identified from the Pathology Register. Only one BCC per person is registered. If a new registration is received, then the last digit of the topography code of the first BCC is changed to indicate that this person has multiple BCCs.

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The Cancer Registry of Norway started BCC registration in 1971, but there was a major drop in registration during 1983-1992 followed by a period of stabile registration in 1993-2007. The first BCC for each patient was registered as a separate entity, and all subsequent ones combined as a "second BCC", regardless of how many there were. The Cancer Registry of Norway still receives pathology reports on BCC, but since 2008 no information about BCC has been registered in the official national statistics, but is stored in a separate file from which it is possible to count the number of persons having a BCC-report within a year. In Iceland, systematic registration of BCC started in 1981, but it is not included in the national statistics. An average of about two BCC cases has been registered per BCC patient.

From 2004, BCC cases in Sweden have been registered in a separate file. In the initial years of registration, quite a large proportion of BCCs may have been erroneously counted as first BCCs, since the actual first BCCs were diagnosed before 2004. The best estimate of current BCC incidence rate seems to be about 100/100,000. The Finnish Cancer Registry has registered BCC since 1953 but with varying coding rules. Currently, the first case is coded, and further notifications are stored. The markedly lower rate in Finland compared to other Nordic countries suggests that the Finnish Cancer Registry does not get information on all BCC cases.

Premalignant and borderline diseases

For a variety of purposes, Nordic cancer registries have collected information on premalignant and borderline diagnoses that are not counted as actual cancers and therefore not included in the official national cancer statistics.

Ovarian borderline tumours are registered in all Nordic countries but not included in the national statistics. Historically, these practices have varied. In Denmark, borderline ovarian tumours have been registered since 1978, but are not reported in routine statistics.

Registration of *precancerous lesions of cervix uteri* is common in the Nordic cancer registries, because such information is needed for evaluation of the efficacy of screening programmes aiming at the prevention of invasive cervical cancer. The terminology and list of reportable lesions has, however, varied between the countries and over the years. In Finland, it was first compulsory to report cervical squamous cell carcinoma *in situ* lesions (compulsory since 1961). Registration of "dysplasia gravis" started around 1988, and "cervical intraepithelial neoplasia (CIN) III" around 1991 (for more details, see Finnish Cancer Registry 2009, page 7). In Norway, the current list of registered lesions includes, e.g., ASCUS, low- and high-grade squamous intraepithelial lesions (LSIL, HSIL); for details, see [21]. The number of LSIL jumped from almost zero before 2005 first to about 3,000 a year in 2005-2008, then to about 8,000 in 2009 and finally gradually to almost 15,000 in 2015. Such jumps are related to added transfers of information from the files of the screening program to the main database. In Denmark, there is a separate registry for moderate and heavy dysplasia, dysplasia without specification, and cervical carcinoma in situ. Reporting of light dysplasia has no longer been required after 1 January 2014. Cervical

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carcinomas in situ have been registered in the Swedish cancer registry since 1958, while HSIL, which also include CIN II lesions of the cervix, are included since 2015.

In organs other than cervix, information on *in situ tumours* can be registered in the Nordic cancer registries, and their numbers may be presented in official cancer statistics (Table 3). Finland, e.g., includes in situ carcinomas in all sites except for the skin, but the annual statistics only include intraductal (i.e. *in situ)* carcinomas of the breasts as a separate non-cancer category and in situ carcinoma of the urinary tract as part of invasive cases. Registration of skin melanoma *in situ* started in Finland in 2015. In Denmark and Norway, *in situ* cancers of the urinary tract are also registered and included in the national statistics. *In situ* cancers of the breast and some other sites are registered in the Norwegian database, but not included in the national statistics. I*n situ* cancers of the skin and colon/rectum are no longer registered. In Iceland, *in situ* cancers of breast and skin are registered, but not included in the national statistics. Sweden has registered carcinoma *in situ* lesions in all anatomical sites from the beginning of cancer registration but not reported them in their routine statistics for the years before 2013.Transition from a premalignant lesion to invasive cancer (malignant) is registered differently in the Nordic countries. In Denmark and Norway, the pre-invasive and invasive lesions will be registered as two separate entities if the difference in dates of diagnoses is more than 4 months. An exception to this principle is the registration of bladder cancer, where only the first tumour is registered even in a case when a diagnosis of invasive tumour would be done after an *in situ* tumour. In Finland - the general coding principle before 2017 was that if the time difference between the premalignant and malignant lesion was shorter than one year, then only one cancer was registered with the behaviour code of the invasive tumour and date of diagnosis of the premalignant one. Since 2017, there is no time limit and the pre-invasive case is registered separately from the invasive one (if diagnosed before the invasive cancer). In Iceland, this time limit is two months for skin cancer; for other cancers it is evaluated individually for each case whether the premalignant and malignant phase are considered as one event or two separate events. In Sweden, all phases of cancer transition are registered as separate entities. The practice of sometimes using the date of diagnosis of a premalignant tumour as the date of invasive tumour in the same organ causes a slight immortal bias in the survival estimate.

Variables collected

The variables collected in the databases of the Nordic cancer registries are summarised in Tables 4-5. The electronic versions of the same tables (link to the table on ANCR pages) also provide links to the nomenclatures used for coding these variables.

Data on patients

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In the Nordic countries, all residents are issued a unique personal identity code (PIC) at birth or time of permanent residency. PICs were introduced in Sweden in 1947, Norway 1964, Iceland 1965, Finland 1967, and in Denmark in 1968. PICs are used for every contact in the health system and also as key identifiers in each of the Nordic cancer registries. They thus represent a reliable tool when linking information on individuals across registries, including follow-up for death or emigration. Before introduction of PICs, the key identifiers for a person were name, sex and date of birth. Now, information on sex and date of birth are included in the PIC (except for Iceland where sex is not included), and the name is only needed if there is an error in the PIC reported to the cancer registry.

Cancer registries are updated with dates of death from the population registration system and the national cause-of-death registry at least once a year. Date of emigration is also important as an end-of-follow-up information in numerous routine tabulations (incidence, prevalence, mortality, survival), and it is directly available in all Nordic cancer registry databases except the Danish one. Information on immigration can be received via record linkage to the national population registries (Table 4).

The causes of death of patients are received from the national cause-of-death registries in all Nordic cancer registries. The Swedish Cancer Registry only receives information on the underlying cause of death, and the Icelandic Registry only on causes of death with cancer diagnoses. Differently from the other cancer registries, the Finnish Cancer Registry re-evaluates cancer deaths together with incidence data from the registry. This leads to some differences between the official cause of death and the FCR mortality statistics, especially in entities with common metastatic sites such as liver, lung or brain.

Data on residence have been available down to the level of municipality for all Nordic cancer patients since 1971. The Swedish and Norwegian cancer registries can classify cases by even smaller administrative regions, and in Finland, the map coordinates of residence can be linked to cancer patients diagnosed in 1981 and later.

Data on ethnicity are not available in any of the Nordic cancer registries, but country of birth is available in the Finnish, Icelandic and Swedish Cancer Registries. The numbers of foreign-born inhabitants range from about 6% in Finland to more than 17% in Sweden, with an average of 11%. The vast majority of inhabitants in the Nordic countries are Nordic-born, but in recent decades an increasing part of immigrants are from Eastern Europe, Asia and Africa. Data from the cancer registries can be linked to data on immigration from the population registries, as was recently done in Norway [22].

Collection of other demographic data such as occupation, educational level, language (mother tongue), and number of children were attempted in the early years of cancer registration in the Nordic countries, but the quality of the data was so poor that it was deemed not useful. If needed, such data can be obtained from the national population registries or census data from the

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statistical bureaus, as was done e.g. in the Nordic Occupational Cancer (NOCCA) study [23] or in the Danish CANULI project [24]. The Finnish Cancer Registry can now use the socio-demographic data on education and occupation in routine statistics and internal research as agreed in 2014 with Statistics Finland.

Data on cancers

Key variables needed for production of routine incidence statistics

Most of the routine statistics on cancer incidence can be estimated if information is available on date of diagnosis, topography, morphology and behaviour (benign, in situ or invasive/malignant) of the tumour. These variables are therefore the main focus of all Nordic cancer registries and have always been collected and precisely coded. For some cancer types, the morphology code adds essential information, but collection of that information has not occurred or been consistent in all countries throughout the registries´ history. In Denmark, there were only certain broad morphology categories for some primary sites coded in the cancer registry records of the earlier years. Before 2004, notifications (except autopsies) in Denmark were not received directly from the pathologists, but the morphological information was a transcript of the pathological report provided by the clinician. From 2004 it has been included automatically.

All Nordic cancer registries currently provide ICD-O-3 codes for topography, behaviour and morphology. The older cancer cases may, however, have been originally coded according to earlier versions of the ICD and various nomenclatures for morphology, and then subsequently bulk-translated using an algorithm to match old codes with the best-fitting current codes. To use Finland as an example: until 2007, the morphology was coded according to a slightly modified version of the old Manual of Tumor Nomenclature Coding (MOTNAC) [25] which only had 75 code values. These codes were converted in 2007 to the morphology codes of ICD-O-3 with hundreds of alternative code values. This conversion could not be 100% precise. Therefore, detailed assessment of the incidence of several specific morphologies can only be started from 2007. If necessary, it is possible to re-code the old cases according to current nomenclature from the free-text diagnoses of the pathology reports stored in the cancer registry database. Unexpected changes in trends of incidence rates should therefore be checked against changes in classification systems.

With the introduction of ICD-O-3 in 2000, new entities of haematological malignancies were added. Most substantial was the conversion of myeloproliferative diseases (for example polycythaemia vera) and myelodysplastic syndromes to malignant from being of unknown behaviour. The comparability of data on these malignancies is dependent on when the registration of these new cancer entities started in each of the Nordic countries, and what is the coverage of registrations in each country. For example, in Finland the coverage is notably lower than for solid

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cancers [26]. Thus, for earlier years especially, comparability of data on these entities between countries is lower than for solid cancers.

Data useful for survival statistics – disease stage

Precise and comparable information on tumour stage is important, especially in Nordic comparisons of survival of cancer patients. Unfortunately, not all countries have had access to complete data, and the coding of disease stage has varied over time and between countries. Cancer registries of Norway and Finland have from the beginning of cancer registration recorded a broad staging variable (localised – regional – distant - unknown) that is quite similar in both countries. In recent years, all Nordic cancer registries have been trying to improve the completeness and accuracy of TNM information, but further improvement is needed. Still in the 2010s in Finland, information on some part of TNM was only available for a maximum of 50% of newly diagnosed cancer patient depending on the primary site. The NORDCAN group is now working on a project to look more thoroughly at TNM for all Nordic cancer registries with a separate publication later on this work.

Information on metastases at diagnosis has been collected by the Icelandic Cancer Registry since 1995 for colorectal cancer, since 1998 for prostate cancer and since 2010 for breast cancer and skin melanoma. This is done concomitantly with registration of the TNM stage, by special registrars who search for the information in electronic patient records. None of the Nordic cancer registries has collected complete information on later metastases cancer recurrence.

Data on cancer treatment – routine data and quality registries

With regard to treatment, the Norwegian and Finnish cancer registries have asked for information on the first-line treatment given (or planned) for the first year after diagnosis. However, the completeness of even such limited information is far from perfect, mainly because the treating units – often several different units per patient – are not highly motivated to report. Since 2017, the Finnish Cancer Registry collects treatment data based on the Nordic Classification of Surgical Procedures (NCSP) codes. Iceland has collected information on the treatment of prostate cancer patients since 1999, while Denmark stopped collection of treatment information in 2004 (because it is available from the Hospital Discharge Registry). The national Swedish Cancer Registry never collected information on treatment. One possible way of retrieving treatment information would be to search information from the national hospital registries. This source covers all cancer types, but the information is generally restricted to date and code of surgery. More detailed information for selected cancer types and restricted time periods may be obtained from diagnose specific quality registers.

The Cancer Registry of Norway collects more detailed information on cancer treatment in nine *quality registries*, the oldest one covering childhood cancer patients from 1985 onwards (Web Table 6). One main purpose of these registries is to provide data on whether cancer treatment is given

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according to national guidelines. Similar quality registries with extended data have been operating in other countries but have not been controlled by the cancer registries.

In Sweden, more than 25 clinical cancer registries are in operation. Launched regionally on a small scale in the early 1990s for the purpose of quality assessment of cancer care, these databases now have national coverage and share a common platform (INCA – information network for cancer) since 2008. Compared to the Swedish Cancer Registry, the resolution is considerably higher with information available on diagnostics, tumour characteristics and treatment with a completeness usually exceeding 95% compared to the mandatory reporting to the cancer registry (Web Table 7). The clinical cancer registries are administered by the network of Regional Cancer Centres and are extensively used for quality assessment and research.

In Denmark, 22 clinical cancer groups exist, most of them with quality registries (www.DMCG.dk). The oldest one started in 1976 with the aim to ensure optimal diagnostic procedures and treatment for breast cancer patients. The quality registers for breast and for lung cancer were used for validating the new procedure for constructing the Danish Cancer Registry.

The Icelandic Cancer Registry has been the only institution in Iceland that has registered clinical variables in a standardised way. A limited number of variables for cancers of the colon, rectum, breast and cervix plus melanoma have been registered prospectively since 2010. However, the University Hospital of Reykjavik is preparing to implement population-based quality registration in co-operation with the ICR, similar to the Swedish INCA system.

In Finland, there are currently no clinical cancer registries with national coverage and systematic information exchange with the Finnish Cancer Registry. National decisions as to what should be collected are still missing but will be initiated with collaboration together with five regional cancer centres starting their work in 2017.

Discussion

Data sources

The data sources in all Nordic cancer registries are similar, and therefore the cancer data are overall comparable. In Sweden, however, information from death certificates has traditionally not been used as an additional routine source for the cancer registry. At present, there are legal obstacles to disseminate death certificate data as a basis for trace-back. Because of this, the proportion of non-registered cancer cases in Sweden is about 4 percentage units higher than in the other Nordic countries. The lack of DCI cases in Sweden has to be considered when comparing cancer survival between Sweden and the other Nordic countries and also when assessing the data quality by the M/I proportion. It also has some effect on incidence rates of cancer types that more

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often than others are identified from death certificates, such as chronic leukaemia or cancers of the lung and pancreas in the elderly [7].

Another issue that may have an effect on comparability of data from different regions and different time periods is the reporting activity. In Finland, e.g., the number of clinical cancer notifications – the majority of which are still completed manually - has decreased during recent years, which means that the completeness of cancer registration is more dependent on information received from pathology laboratories and death certificates. Fortunately, reporting from these two sources to the cancer registry is semi-automatic and not dependent on individual persons sending notifications. The earlier practice in Finland was to send out questionnaires to the treating hospitals identified from the laboratory notifications or death certificates if the clinical notification was missing, but – due to the change in the entire reporting system since 2017 – this practice was discontinued for cancers diagnosed after 2012. Thus, the quality (e.g. more DCO-cases) of the Finnish Cancer Registry data is temporally lower for the most recent diagnostic years [8].

Registered disease entities

Registration of subsequent primary tumours in patients with one tumour has been an important tool in numerous studies of shared risk factors of cancers (e.g., [27]) and late effects related to treatment of the first malignancy (e.g., [28]). In special instances, it would be important to assess the risk of second primary tumours in the same organ, e.g. in the study on risk of new breast cancer among women who took hormonal therapy after their first breast cancer [29]. For such cases, it is important that the Nordic cancer registries continue to register all malignancies of the same organ groups. Because new primary cancers in same organs also require treatment resources, they are counted as separate malignancies in national cancer statistics in Denmark, Finland and Sweden. For international comparison, though, it is recommended to use numbers calculated according to the IARC/IACR rules for reporting cancer incidence, because the national rules for multiple cancer coding have varied over the several decades of cancer registration, and they still vary between countries.

Registration of non-malignant disease entities has been useful in numerous studies. As an example, borderline ovarian tumours have been studied as part of clustering of different cancer types in same families [30], and precancerous lesions of cervical cancer have been an important outcome in studies of the effects of cervical cancer screening or HPV vaccines [31-34]. For the latter type of research, it would also be useful to have information on the low-grade lesions, but for the time being only the Cancer Registry of Norway can offer such information for recent years.

Registration of BCC of the skin has been controversial. According to the ICD-O coding system, BCC should be counted as a malignant tumour with the behaviour code 3, but most cancer registries in the world do not register it. In the Nordic countries, there have been different policies

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as to the registration of BCC, and therefore it is impossible to produce comparable time trends for overall cancer incidence that would include BCC. The current policy in registration of BCC cases is to collect data on BCC cases from electronic sources, but store them in a separate data base and do much less extensive manual coding and quality assurance operations compared to the data in the main cancer registry data base.

Registered variables

Completeness and accuracy are high for the key variables needed for production of standard incidence statistics, i.e., for the main output of the cancer registries. The changes in ICD versions do not cause such jumps in time series of cancer incidence in any Nordic countries that may be seen in the official time series of cancer mortality.

However, there is also a demand for more extensive data details than those needed for basic incidence tabulations. All Nordic cancer registries can provide data to external researchers for epidemiological studies. In addition, the cancer registries in Finland, Iceland and Norway are themselves active research institutes for epidemiological research; own active use of cancer data is considered an important tool in quality assurance [35]. Until 1997, the Danish Cancer Registry was hosted by the Danish Cancer Society where researchers also actively used the registry for research. After cancer registration was moved to the National Board of Health in 1997 (now the National Danish Health Data Authority), the Danish Cancer Society Research Centre each year receives a copy of the file for research purposes. In Sweden, many epidemiological research projects originate from the Regional Cancer Centres where the initial recording of reported cases takes place.

In more detailed studies of cancer, variables such as the morphologic type of the tumours, markers, stage, and treatment are often useful, and there is ongoing activity to improve the content of these in the Nordic cancer registries.

A joint vision in the Nordic countries is that the health care system should provide an efficient and equitable health care service to all residents, irrespective of socioeconomic position, ethnicity, and place of residence. Therefore, there are increasing demands to have such characteristics available in the cancer registries. There is a long tradition of linking the cancer patient file with census variables for research purposes (e.g., [23,24,36-38]). Such record linkages have required separate permissions. Since 2014, the Finnish Cancer Registry has the right to obtain – as an annual routine – population census data on occupation, education and socioeconomic position from Statistics Finland for all cancer patients and use them in its routine tabulations (but not give out for external research purposes). Therefore, it will be possible to produce routine incidence statistics stratified by these factors and follow development in equity cancer incidence, survival and mortality.

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Because of the increasing size of immigrant populations, it has become important to be able to stratify cancer incidence statistics according to migrant status. For that reason, the variables related to migration need to be easily accessible. Because the cancer patterns of some immigrant populations are very different from those of the Nordic populations, the increasing proportion of residents born abroad complicates the interpretation of time trends. Because the percentage of the foreign-born also varies between countries – currently from 6% in Finland to 17% in Sweden – it has an effect on the comparability of cancer incidence rates among the inborn populations between the countries.

Data on residence have been available on the level of municipality for all Nordic cancer patients since 1971. This has made it possible to produce statistics for smaller regions as well as small-area-based maps (such as Figure 6; for graphical method see [39]) and map animations on cancer incidence [40] and mortality [41]. Due to changes in municipal size and number, an alternative system has been developed for creating small-area regions on the basis of map coordinates (e.g., [42,43]). This is especially useful in creating longer regional time series when the borders of larger areas change over time.

Conclusion

The Nordic Cancer Registries are among the oldest population-based registries in the world, with more than 60 years of complete coverage of what is now a combined population of 26 million. The long history causes challenges in time series: the diagnostic methods, medical terminology, and classification nomenclatures have changed over time. Still, all Nordic Cancer Registries represent a high-quality standard in terms of completeness and accuracy of the registered data throughout their existence. Even though the information in the Nordic Cancer Registries can be considered more similar than any other collection of data from five different countries, there are some details that need to be understood in comparative studies of specific cancer entities.

So when can NORDCAN data be used, and when does a researcher need to use national data? For a more general overview of cancer trends in the Nordic countries, we think the differences between the countries are so small and many of them are dealt with the IARC check rules that it is clearly beneficial to start with NORDCAN data. To completely understand epidemiologic trends of one cancer, the differences in registration, screening and coding pointed out here, should be taken into account. For that purpose, we recommend that a researcher uses the national statistics supplemented with other national data (e.g. treatment details, spreading).

Recent international comparisons of cancer incidence and outcomes have highlighted the potential impact of differences in registration practices, and the need to increase comparability

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between cancer registry operations [44,45]. This overview is part of our efforts to increase such comparability between our registries.

This article describes the cancer registration systems in the Nordic countries – as they are in 2017 – in a systematic way that is believed to be useful when Nordic cancer studies are planned and carried out. However, there are continuous developments in the cancer registration processes, data contents and other issues. Therefore, the tables describing data sources, cancer entities registered, code nomenclatures, variables collected and principles on how to get access to cancer registry data (web Tables in this article) will be made available on the pages of the Association of the Nordic Cancer Registries (ancr.nu) and updated whenever there are changes to these issues in any of the Nordic cancer registries. The same tables will also be linked to the web pages of NORDCAN and of the Nordic Cancer Registries. Vigilant work to keep up the comparability is essential – otherwise the quality will decline.

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Table 1. Nordic cancer registries, administrative facts and quality issues. For questions on how to contact the Cancer Registry; how to apply information from the Cancer Registry (with links to forms and instructions); links to documents on data protection principles and to publications on data quality; please see the more detailed web version of this table.

Variable	Denmark	Finland	Iceland	Norway	Sweden
Official name	The Danish Cancer Registry	Cancer Society of Finland, Finnish Cancer Registry – Institute for Statistical and Epidemiological Cancer Research	The Icelandic Cancer Registry, the Icelandic Cancer Society	Cancer Registry of Norway. Institute of Population-based Cancer Research	Swedish Cancer Registry, the Swedish National Board of Health and Welfare
Founded	1942	1952	1954	1952	1958
Earliest/first complete year of cancer registration	1943/1943	1930/1953	1911/1955	1952/1953	1958
Percentage of death certificate only (DCO) cases (NORDCAN data 2009-2013)	0.3%	1.2% in 2009-2011 (tracing of DCI data for 2012+ delayed)	0.3%	1.1%	–
Percentage of microscopically verified (MV) cases (NORDCAN data 2009-2013)	95%	93%	95%	94%	98%

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Table 2. Data sources of the Nordic cancer registries (routine data collection).

	Denmark	Finland	Iceland	Norway	Sweden
Public hospitals	Yes (received automatically from Danish Patient Register 2004+)	Yes (automatic reporting from some hospital registers since late 1980s, still mostly manual)	Registrars have direct access to electronic medical records for completing registration and information on stage	Yes (manual reporting, mostly electronically)	Yes
Private clinicians	Yes	Yes	Yes, only for prostate cancer, manual reported on paper	Yes (manual reporting, mostly on paper)	Yes
Dentists	Yes	Yes	No	No	No
Inpatient registry	Yes	No[1]	2000+ (automatic reporting)	1998+ (in- and outpatients)	No
Laboratories, pathological reports	Yes (for cases coded 2004+)	Yes (automatic reporting from almost all laboratories since late 1980s)	Yes (automatic reporting)	Yes (automatic reporting, both paper and electronically)	Yes
Laboratories, haematological reports	No	Yes	Yes (automatic reporting)	No (only samples sent to pathological laboratories)	Yes
Laboratories, cytological reports	No	Yes	Yes (automatic reporting)	Yes (automatic reporting, both paper and electronically)	Yes
Death certificates	Yes	Yes (automatic reporting from Statistics Finland 1981+)	Yes (automatic reporting from Statistics Iceland until 2009 and from Directorate of Health 2010+)	Yes (automatic reporting, data file and picture files of death certificates)	No
Radiotherapy data (from all machines)	No	No	No	1997+[2]	No

[1] Since 2015 the hospital discharge data has been available for cross linkage with the Cancer Registry from year 1996 and can be used to complement possibly missing cases and to confirm DCI-cases.

[2] Data items: region being treated; diagnosis (ICD-10); intention of treatment; date for start of treatment; number of days for treatment; date for end of treatment; total dose; total number of fractions.

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Table 3. Numbers of cancers and other disease entities collected by the Nordic cancer registries, 2009-2013.

Disease / disease group	Number of registered cases in 2009-2013				
	Denmark	Finland	Iceland	Norway	Sweden
1. NORDCAN cancer entities (NORDCAN 7.3; Engholm et al. 2016)	186,141	150,441	7,360	146,007	272,658
Disease entities registered in the national registries but not included in NORDCAN tabulations[1]					
2. Cancers registered in the national registries, but not included in NORDCAN					
2.1 Multiple cancers in same organ group[2]	1,823	2,089	[147]	[4,309]	24,714
2.1.1 Breast	555	1,261	[81]	[1,240]	6,983
2.1.2 Skin, melanoma	0	106	0	[687]	1181
2.1.3 Skin, non-melanoma, excluding basal cell carcinoma	0	576	0	[165]	7,846
2.1.4 Colon	390	31	[21]	[814]	1,728
2.1.5 Bladder etc.	749	91	[26]	[423]	820
2.2 Polycythaemia vera	678	376	[14]	[349]	793
2.3 Skin, basal cell carcinoma	58,208	40,866	[1,671]	[40,606]	208,985
2.4 Other excluded categories	2608	43	0	89	
3. Premalignant or borderline diseases registered in the national registries but not included in NORDCAN					
3.1 Ovary, borderline cancer	[880]	767	[39]	[788]	810
3.2 Cervix uteri, precancerous lesions / in situ	26,835/2,648	5,872	[25]	[60,674]	14,568 (CIN III)
3.3 In situ cancers, excluding cervix uteri	2,516 (only breast)	2,732 (only breast) [423]	[618] [breast:100; melanoma: 96; other skin: 422]	[23,699]	[20,872]
3.4 Other	363			16	
4. Other registrations	0	[636]	[23]	[305]	

[1] The numbers in brackets indicate that these numbers are not shown in the national routine statistics publication.

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[2] See IARC/IACR multiple coding rules, organ grouping in multiple coding (http://www.iacr.com.fr/images/doc/MPrules_july2004.pdf)

Table 4. Variables on cancer **patients** registered by the Nordic cancer registries.

Variable	Denmark	Finland	Iceland	Norway	Sweden
Personal identity code (PIC)	For persons resident 1968+	For persons resident 1967+	For persons resident 1 Dec 1965+	For persons resident 1964+	Yes
Date of birth	Yes	Yes	Yes	Yes	Yes
Sex	Yes	Yes	Yes	Yes	Yes
Municipality of residence	1968+	Yes	Yes	1971+	Yes
Occupation	Until 2003	Yes	No	No	No
Education	No	Yes	No	No	No
Socio-economic position	No	Yes	No	No	No
Date of immigration	No	Yes	No	2015+	Yes
Country of origin	No	No	No	No	No
Country of birth	No	Yes	Yes	No	Yes
Date of emigration	Yes	Yes	No	Yes	Yes
Vital status	Yes	Yes	Yes	Yes	Yes
Date of death	Yes	Yes	Yes	Yes	Yes
Underlying cause of death	No	Yes	Yes (only for those who die from cancer)	Yes	Yes
Other causes of death	No	Yes	2003+ (only if the cause is cancer)	Yes	No
Incidental Autopsy	Yes	Yes	Yes	Yes (only for medical autopsies)	Yes

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Table 5. Variables related to each **cancer** registered by the Nordic cancer registries.

Yellow background: This information is not directly available (in a qualitatively accurate manner) but may be derived with a modest extra effort

Variable	Denmark	Finland	Iceland	Norway	Sweden
Date of diagnosis	Before 2004 only month and year	Before 2014 only month and year	Yes	Yes	Yes
Topography / primary site	Yes as ICD-10	Yes	Yes	Yes	Yes
Morphology / histology	Yes	Yes.	Yes	Yes	Yes, with limitations before 1993
Behaviour / malignancy	Yes	Yes	Yes	Yes	Yes
Method of confirmation	Yes	Yes	Yes	Yes	Yes
Stage at diagnosis	Before 2004	Yes	No	Yes	No
TNM	2004+	Incomplete	2010+ for selected sites	1993+ for selected sites; incomplete	2004+
Later metastases, recurrences	No	No	No	No	No
Treatment	Before 2004 (2004+ available via linkage to the Hospital Discharge Registry)	Yes, not complete	1999+, only for prostate cancer	Yes	No
Symptoms	No	No	No	Until 2011, incomplete; for melanomas, symptoms are still registered	No
Other	More detailed information may be available from the registries of 22 clinical cancer groups (www.DMCG.dk)	Code for evaluating cancer mortality (died of this cancer; died of other causes).		More detailed information available from 9 quality registries of the Cancer Registry 1985+ (Web Table 6)	More detailed information available from >25 clinical INCA registries (Web Table 7)

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WEB TABLES.

Details that are now in footnotes will be hidden behind the links.

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Web Table 1. Nordic cancer registries, administrative facts and quality issues.

Variable	Denmark	Finland	Iceland	Norway	Sweden
Official name	The Danish Cancer Registry	Cancer Society of Finland, Finnish Cancer Registry – Institute for Statistical and Epidemiological Cancer Research	The Icelandic Cancer Registry, the Icelandic Cancer Society	Cancer Registry of Norway, Institute of Population-based Cancer Research	Swedish Cancer Registry, the Swedish National Board of Health and Welfare
Founded	1942	1952	1954	1952	1958
Earliest year of registered cancer diagnosis	1943	1930 (previous malignancies for persons with cancer diagnosed 1953+; diagnoses of patients died from cancer 1953+)	1955 (breast cancer incidence also for 1911-1954, based on study by Snaedal 1965)	1952	1958
First year of incidence registration considered complete	1943	1953	1955	1953	1958
Link to web page	http://sundhedsdatastyrelsen.dk/da/registre-og-services/om-de-nationale-sundhedsregistre/sygedomme-laegemidler-og-behandlinger/cancerregisteret	www.cancerregistry.fi	www.krabbameinsskra.is	www.kreftregisteret.no	http://www.socialstyrelsen.se/register/halsodataregister/cancerregistret

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How to contact the Cancer Registry?	Email to cancerregisteret@sundhedsdata.dk	Email to kirjaamo@cancer.fi	skra@krabb.is	kreftregisteret@kreftregisteret.no	Email to cancerregistret@socialstyrelsen.se
How to apply information from the cancer registry (with link to forms and instructions)?	Contact the Researcher service at the Danish Health Data Authority, email: forskerservice@sundhedsdata.dk.	Send a form (https://www.cancer.fi/@Bin/119098415/Tietopyynt%C3%B6+sy%C3%B6p%C3%A4rekisterille2015eng061015.pdf) to kirjaamo@cancer.fi	Send a form (http://www.krabbameinsskra.is/index.jsp?id=eydublod) Contact person: gudridur@krabb.is	Send a form (https://www.kreftregisteret.no/Registrene/Datautlevering/Soknadsskjema/). Contact datautlevering@kreftregisteret.no for information	Send a Form (http://www.socialstyrelsen.se/register/bestalladatastatistik/bestallaindividuppgifterforforskningsandamal)
Links to documents on data protection principles. Survey 2000 (http://www.ancr.nu/cancer-data/cancer-registry-survey/): basic rules for confidentiality in Appendix 2	Information about data protection and privacy at the Danish Health: http://sundhedsdatastyrelsen.dk/da/borger-og-offentlighed/sikkerhed-om-dine-data			Information about data protection and privacy: https://www.kreftregisteret.no/Generelt/Om-Kreftregisteret/Personvern/	Information about data protection legislation. (http://www.socialstyrelsen.se/register/bestalladatastatistik/bestallaindividuppgifterforforskningsandamal/omsekretessen)
Publications on data quality	Storm et al. 1997 (link to pdf received from Hans Storm); Gjerstorff 2011	Teppo et al. 1994 (link to pdf received from Acta Oncol); Leinonen et al. 2017 (partly describing an exceptional period)	Sigurdardottir et al. 2012 (http://www.tandfonline.com/doi/pdf/10.3109/0284186X.2012.698751?needAccess=true)	Larsen et al., 2009 (https://ac.els-cdn.com/S0959804908008691/1-s2.0-S0959804908008691-main.pdf?_tid=7da7688c-c14a-11e7-95ce-00000aab0f6b&acdnat=1509791314_7728dc91a6c7c73d60dc1952dbc1cb3e)	Barlow et al. 2009 (http://www.socialstyrelsen.se/register/halsodataregister/cancerregistret/Documents/Artikel-Swedish-cancer-registry-2009.pdf)
Percentage of death certificate only (DCO) cases (NORDCAN data 2009-2013)	0.3%	1.2% in 2009-2011 (tracing of DCI data for 2012+ delayed)	0.3%	1.1%	0
Percentage of microscopically verified (MV) cases (NORDCAN data 2009-2013)	95%	93%	95%	94%	98%

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Web Table 2. Data sources of the Nordic cancer registries (routine data collection).

	Denmark	Finland	Iceland	Norway	Sweden
Public hospitals	Yes (received automatically from Danish Patient Register 2004+)	Yes (automatic reporting from some hospital registers since late 1980s, still mostly manual)	Registrars have direct access to electronic medical records for completing registration and information on stage	Yes (manual reporting, mostly electronically)	Yes
Private clinicians	Yes	Yes	Yes, only for prostate cancer, manual reported on paper	Yes (manual reporting, mostly on paper)	Yes
Dentists	Yes	Yes	No	No	No
Inpatient registry	Yes	No[1]	2000+ (automatic reporting)	1998+ (in- and outpatients)	No
Laboratories, pathological reports	Yes (for cases coded 2004+)	Yes (automatic reporting from almost all laboratories since late 1980s)	Yes (automatic reporting)	Yes (automatic reporting, both paper and electronically)	Yes
Laboratories, haematological reports	No	Yes	Yes (automatic reporting)	No (only samples sent to pathological laboratories)	Yes
Laboratories, cytological reports	No	Yes	Yes (automatic reporting)	Yes (automatic reporting, both paper and electronically)	Yes
Death certificates	Yes	Yes (automatic reporting from Statistics Finland 1981+)	Yes (automatic reporting from Statistics Iceland until 2009 and from Directorate of Health 2010+)	Yes (automatic reporting, data file and picture files of death certificates)	No
Radiotherapy data (from all machines)	No	No	No	1997+[2]	No

[1] Trial use 1985-1988: after validation process 965 cancers added. Since 2015 the hospital discharge data 1996+ have been available for cross linkage with the Cancer Registry and can be used to complement possibly missing cases and to confirm DCI-cases.

[2] Data items: region where treated; diagnosis (ICD-10); intention of treatment; date for start of treatment; number of days for treatment; date for end of treatment; total dose; total number of fractions.

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Web Table 3. Numbers of cancers and other disease entities collected by the Nordic cancer registries, 2009-2013. The percentages *in Italics* indicate the difference between the national routine statistics publications and NORDCAN.

Disease / disease group	Number of registered cases in 2009-2013				
	Denmark	Finland	Iceland	Norway	Sweden
1. NORDCAN cancer entities* (NORDCAN 7.3; Engholm et al. 2016)	186,141	150,441	7,360	146,007	272,658
Additional cancers / disease entities registered but not included in NORDCAN tabulations					
2. Cancers registered in the national registries, but not included in NORDCAN					
2.1 Multiple cancers in same organ group**	1,823	2,089	[147]	[4,309]	24,714
2.1.1 Breast (addition to the NORDCAN count)	555 (2.2%)	1,261 (5.6%)	[81] (7.7%)	[1,240] (8.3%)	6,983 (19.9%)
2.1.2 Skin, melanoma	0 (if there is a second skin melanoma, the topography code of the first skin melanoma is changed to C43.8 "multiple locations")	106 (1.7%)	0 (only the first case is registered)	[687] (8.3%)	1,181 (8.0%)
2.1.3 Skin, non-melanoma, excluding basal cell carcinoma	0 (if there is a second non-melanoma skin cancer, the topography code of the first non-melanoma is changed to C44.8 "multiple locations")	576 (7.8%)	0 (only the first case is registered)	[165] (2.2%)	7,846 (38.9%)
2.1.4 Colon	390 (2.8%)	31 (0.3%)	[21] (4.2%)	[814] (6.2%)	1,728 (8.8%)
2.1.5 Bladder etc. (ICD-10: C65-68+D09.0-1+ D30.1-9+D41.1-9)	749 (7.6%)	91 (1.6%) (includes in situ and PUNLMP cases)	[26] (6.9%)	[423] (6.2%)	820 (6.1%)
2.2 Polycythaemia vera (to be included in NORDCAN cancer entities in Fall 2017)	678	376	[14]	[349]	793
2.3 Skin, basal cell carcinoma	58,208	40,866	[1,671]	[40,606] (not stored in the actual Cancer Registry data base)	208,985

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Disease / disease group	Number of registered cases in 2009-2013				
	Denmark	Finland	Iceland	Norway	Sweden
2.4 Other excluded categories	Myelodysplastic syndrome: 1,264; Other not specified tumours in lymphatic and and haematopoietic tissue: 1,344 (In NORDCAN edition in Fall 2017 there will be new categories for these cancer entities.	43	0	89	
3. Premalignant or borderline diseases registered in the national registries but not included in NORDCAN					
3.1 Ovary, borderline cancer	[880]	767	[39]	[788] + [318 other premalignant ovarian tumours]	810
3.2 Cervix uteri, precancerous lesions / in situ	26,835/2,648	5,872	[25]	[60,674]	14,568 (CIN III)
3.3 In situ cancers, excluding cervix uteri	2,516 (only breast)	2,732 (only breast) [423, excluding breast and bladder; registered for all organs except skin]	[618] [breast:100, melanoma: 96, other skin: 422]	[23,699]	[20,872]
3.4 Mola and neoplasma placenta	363			16	
4. Other registrations					
4.1 Cancers of persons living abroad	0	[567]	[23]	[305]	0
4.2 Preregistered possible cancers, waiting for additional data to confirm the diagnosis	0	[69]	0	0	0

* Taken from NORDCAN 7.3 (Engholm et al. 2016). National exceptions from strictly comparable joint Nordic registration principle: see http://www-dep.iarc.fr/NORDCAN/english/frame.asp?o=database.

** See IARC/IACR multiple coding rules, organ grouping in multiple coding (http://www.iacr.com.fr/images/doc/MPrules_july2004.pdf)

Web Table 4. Variables on cancer **patients** registered by the Nordic cancer registries.

Yellow background: This information is not directly available (in a qualitatively accurate manner) but may be derived from other sources with a modest extra effort.

Variable	Denmark	Finland	Iceland	Norway	Sweden
Personal identity code (PIC)	Available for persons alive and living in DK from 1968 (checked with PR)	Available for persons not died before 1967 (checked with PR); before that homemade PICs.	Available for persons not died before 1 Dec 1965+ (before that homemade PICs)	Available for persons alive from 1964. The Cancer Registry gets monthly updates from the population register. Only cancer cases for persons registered in the population register are included. Notifications for persons without a valid birth number/ PIC are saved in a queue, and checked against PR for a few years before they are deleted if no match can be found.	Yes (checked with PR)
Date of birth	Yes	Yes	Yes	Yes	Yes
Sex	Yes	Yes	Yes	Yes	Yes
Place of residence (unit)	Yes (1968+: municipality registered in PR at date of cancer diagnosis; 1968-2006: county; 2007+: region)	Yes (municipality in the beginning of year of cancer diagnosis searched from PR). Plan to use coordinate-based place of residence information, with residential history.	Yes (1955+: municipality; 2016+: postal code)	Yes (municipality of residence January 1st the year of diagnosis, incomplete before 1971). Since 1990 also "grunnkrets" (smaller unit than municipality).	Yes (county, municipality, parish)

Variable	Denmark	Finland	Iceland	Norway	Sweden
Occupation	Available until 2003. Can be retrieved from SO.	Yes (from SO for patients who participated population census 1975 or later)	No	No. Information was collected in cancer notification but with incomplete reporting, so registration ended in 2011/2012. Information on occupation can be linked from Statistics Norway for specific research projects after research approval.	No
Education	No. Can be retrieved from SO.	Yes (from SO for patients who participated population census 1975 or later)	No	No. Information on education can be linked from SN for specific research projects after research approval.	No (Received via record linkage with SO when needed)
Socio-economic position	No. Can be retrieved from SO.	Yes (from SO for patients who participated population census 1975 or later)	No	No. Information on income can be linked from SN for specific research projects after research approval.	No (Received via record linkage with SO when needed)
Date of immigration	No (available from PR if needed)	Yes (from PR for patients not died before 1967)	No	Yes, from 2015	Yes
Country of origin	No (available from PR if needed)	No (available from PR if urgently needed)	No	No (could be obtained from linkage with SO or PR, but there are strict restrictions for access)	No
Country of birth	No (available from PR if needed)	Yes (from PR for patients not died before 1967)	Yes	No (could be obtained from linkage with SO or the population register, but there are strict restrictions for access to this parameter)	Yes
Date of emigration	Yes	Yes (from PR for patients not died before 1967)	No	Yes	Yes
Vital status	Yes (for each registered person it is checked that he exists in the PR alive, emigrated of died)	Yes (for each registered person it is checked that he exists in the PR alive, emigrated of died)	Yes (for each registered person it is checked that he exists in the PR alive or dead)	Yes. Monthly updates from PR allow updated status for persons who are alive and living in Norway, emigrated or dead.	Yes (date of death/migration from SO)
Date of death	Yes	Yes (from SO)	Yes	Yes (both from PR and from the Cause of Death Registry at National Health Institute)	Yes

Variable	Denmark	Finland	Iceland	Norway	Sweden
Underlying cause of death	No (available from Death Cause Registry at National Health Data Authority).	Yes (from SO)	Yes (but only for those who die from cancer)	Yes (from the Cause of Death Registry)	Yes (from the Swedish Cause of Death Register at the National Board of Health and Welfare)
Other causes of death	No (available from DCR and Pathology Registry at National Health Data Authority)	Yes (from SO)	Yes (from 2003) but only if the cause is cancer	Yes (from the Cause of Death Registry)	No (available from the cause of death registry at the National Board of Health and Welfare)
Autopsy	Included in macro verification variable	Yes	Yes	Yes for medical autopsies, not for forensic autopsies	Yes

External linked sources:
PR: Population Register
SO: Statistical Office (Statistics Denmark/Finland/Iceland/Norway/Sweden)

Web Table 5. Variables related to each **cancer** registered by the Nordic cancer registries.

Yellow background: This information is not directly available (in a qualitatively accurate manner) but may be derived with a modest extra effort.

Variable	Denmark	Finland	Iceland	Norway	Sweden
Date of diagnosis	1943-2003 only month and year.	Before 2014 only month and year[F1]	Day-month-year	Day-month-year	Day-month-year
Topography / primary site	1943-1977: ICD-7, modified. 1978 - 2003; ICD-O-3, based on conversion of ICD-O-1 and ICD-O-2. From 2004; ICD-O-3	ICD-O-3 (for most cancers diagnosed before 2007 the ICD-O-3 code was translated from ICD-7 via a conversion matrix; translated codes do not always offer as detailed cancer categories as the ICD-O-3 nomenclature would allow)	1955-1979: ICD-7; 1980 - 1982: ICD-9; 1983- 1989: ICD-O-1; 1990-2002: ICD-O-2; 2003+: ICD-O-3. All codes have been converted to ICD-10 for purposes of reporting and communication.	ICD-0-3 (In addition localization of ICD7: More detailed site of the neoplasm, e.g.. extralymphatic localization, extragonadal germ cell tumours	1958+: ICD7, 1987+: ICD9, 1993+: ICD-O-2, 2005+: ICD-O-3
Morphology / histology	1943-1977: ICD-7, modified. 1978 - 2003; ICD-O-3, based on conversion of ICD-O-1 and ICD-O-2. 2004+; ICD-O-3	ICD-O-3 (plus some newer ICD-O codes not in ICD-O-3 and previously some self-made additional codes for registered disease entities that are not in ICD-O-3). For most cancers diagnosed before 2007 the ICD-O-3 code was translated from MOTNAC via a conversion matrix; translated codes do not always offer as detailed cancer categories as the ICD-O-3 nomenclature would allow.	1955-1979: ICD-7; 1980 - 1982: ICD-9; 1983- 1989: ICD-O-1; 1990-2002: ICD-O-2; 2003+: ICD-O-3. All codes have been converted to ICD-10 for purposes of reporting and communication.	ICD-0-3 (plus some additional self-made codes)	1958+: C24.1*, 1993+: ICD-O-2, 2005+:ICD-O-3 *WHO Histological classification of neoplasms (WHO/HS/CANC/24.1), Geneva 1956
Behaviour / malignancy	1943-1977, ICD-7. 1978+: ICD-O-3	ICD-O-3: 0 Benign; 1 Semimalignant (Borderline malignancy, Low malignant potential, Uncertain malignant potential); 2 Carcinoma in situ (Intraepithelial; Noninfiltrating; Noninvasive); 3 Malignant	ICD-O-3: 0 Benign; 1 Semimalignant (Borderline malignancy, Low malignant potential, Uncertain malignant potential); 2 Carcinoma in situ (Intraepithelial; Noninfiltrating; Noninvasive); 3 Malignant	ICD-O-3 0 Benign 1 Uncertain whether benign or malignant Borderline malignancy Low malignant potential 2 Carcinoma in situ Intraepithelial Non-infiltrating Non-invasive 3 Malignant, primary site	0' Benign; '1' Semimalignant (Borderline malignancy, Low malignant potential, Uncertain malignant potential); '2' Carcinoma in situ (Intraepithelial; Noninfiltrating; Noninvasive); '3' Malignant

Variable	Denmark	Finland	Iceland	Norway	Sweden
Method of confirmation	Self-made code[D1]	Self-made code[FI3]	ENCR recommendations, Vol.1 (2003) https://www.iarc.fr/en/publications/pdfs-online/treport-pub/treport-pub40/IARC_Technical_Report_No40_0.pdf	Self-made code[N1]	'5' Autopsy, microscopical; '3'Histology from primary tumour; '5' Cytology; '8' Laboratory finding; '7' Autopsy, macroscopical; '6' Surgery; '2' X-Ray; '1' Clinical;
Stage at diagnosis	Before 2004, self-made codes (localised, regional, metastasis, unknown, Dukes). 2004+ TNM and Ann Arbor	Self-made code: 0 Unknown; 1 Localized; 2 Metastases in regional lymph nodes only; 3 Metastases further than in regional lymph nodes or tumour invades adjacent tissues; 4 Non-localized, unspecified. In 2012 two additions to the code: 5 Locally advanced, tumour invades adjacent tissues; 6 Distant metastasis	No (see TNM↓)	Self-made code[N2]; detailed UICC staging for breast cancer (1953/1986 -->), cervical cancer (1953/1991 -->), ovarian cancer (2002 -->) and lymphomas (1953/1993 -->)	No (see TNM↓)
TNM	Since 2004	No[F1] (Since 2017 TNM is coded as a combination of clinical and laboratory notifications. Information is incomplete.)	TNM stage according UICC (AJCC) , 7th edition, for following sites since 2010: Colon-Rectum, Breast, Melanoma, Prostate and Cervix (Figo). Previous years available for those sites along Thyroid.	Yes. Clinical TNM has been registered when reported, but information is incomplete. Pathologic TNM is only registered for the following cancer sites: Rectal cancer: from 1993 Breast cancer: from 1986 Prostate cancer: from 2003 Colorectal cancer: from 2007 Lung cancer: from 2013	Since 2004
Later Metastases, recurrences	No (can be studied with linkage to the National Patient Discharge Registry, validity not perfect)	No[F1] (can be studied with linkage to the national Care Register, validity not perfect)	No (can be obtained with considerable work, co-operating with clinicians).	No (can be studied with linkage to the national Patient Register). Metastases with confirmed histology are available. Several quality registries now ask for clinical information about recurrence, but the completeness is still not good.	No

Variable	Denmark	Finland	Iceland	Norway	Sweden
Treatment	Available before 2004 (2004+ can be studied through linkage to the National Discharge Registry)	Treatment started during the first year after diagnosis: self-made coding system[T2]. From 2016-2017 onwards NCSP-codes. The completeness of this information is so low and has decreased over the years, i.e., it can only be utilised for specific purposes with caution.	Only for prostate cancer since the year 1999; first treatment within 6 months from diagnosis.	Treatment started during the first year after diagnosis; self-made codes[N3]	No (can be studied with linkage to the national Patient Register)
Symptoms	No	No (Date of first symptoms was asked in cancer notification from the hospitals but it was so incomplete that it is has not been used lately. It is possible to identify cancers diagnosed in organised screening via record linkage with Mass Screening Registry.)	No	Information was collected in cancer notifications but with incomplete reporting; registration ended in 2011/2012. For melanomas, symptoms are still registered. There are also some questions about "reason for diagnostics" in some of the other quality registries. This variable might contain some information about symptoms.	No
Other	More detailed information may be available from the registries of 22 clinical cancer groups (www.DMCG.dk)	Code for evaluating cancer mortality (died of this cancer; died of other causes).		More detailed information available from quality registries: Childhood cancers 1985+, Rectal cancer 1993-2006, Ovarian cancers 2002+, Prostate cancer 2004+ Colorectal cancer 2007+ Melanoma 2008+, Breast cancer 2009+, Lymphoma and lymphoid leukaemia 2011+, Lung cancer 2013+ Oesophagus and stomach 2015+	More detailed information available from >25 clinical INCA registries (Web Table 7)

Specifications:

Variable	Denmark	Finland	Iceland	Norway	Sweden

[F1] More detailed information can be derived from the database which includes all information received on the cancer notifications (mainly free text).

[F2] Finland - coding of treatment (incomplete data; can be better studied with linkage to the National Care Register)

Surgical treatment

0 no treatment
1, 4, 7 Radical
2, 5, 8 Palliative
3, 6, A Not known whether radical or palliative
9 Not known whether treated
NB: Codes 1, 2, 3 indicate treatment within 4 months of diagnosis. Codes 4, 5, 6 indicate treatment starting more than 4 months after diagnosis. Codes 7, 8, A indicate that we do not know when the treatment started.

Radiotherapy

Codes as for surgical treatment

Cytostatic drug treatment

0 no treatment
1 treatment within 4 months of diagnosis
4 treatment starting more than 4 months after diagnosis
7 not known when treatment started
9 not known whether treated

Hormone treatment

Codes as for cytostatic drug treatment

Other treatment

Codes as for cytostatic drug treatment

[FI3] Finland, method of confirmation from 2017 onwards

7	Histological examination from primary tumour
8	Histological examination from autopsy specimens
6	Histological examination of metastasis
5	Cytological
4	Specific tumour markers
2	Clinical, including imaging diagnostics
1	Clinical
0	Death certificate only
9	Unknown
10	Flow cytometry

Variable	Denmark	Finland	Iceland	Norway	Sweden
12 Moleculargenetic analysis 13 Immunophenotyping For cancers coded before 2017, selected in order of following reliability: 4 Histology from primary tumour 5 Autopsy, microscopical 7 Histology from metastasis 6 Cytology 9 Laboratory finding 8 Autopsy, macroscopical 2 Surgery 3 X-Ray 1 Clinical 0 Unknown Before 2014 histology from autopsy was considered as most reliable method.					

N1 Norway - Method of confirmation

00 Clinical examination without additional examinations outside a hospital
10 Clinical examination without additional examinations in a hospital
20 Imaging diagnostics (x-ray, Ultrasound, CT, MR)
22 Clinical notification about cytological examination
29 PSA test
30 Biochemical examination, electrophoresis
31 Endoscopic examination
32 Cytological examination of primary tumour
33 Blood smear
34 Bone marrow smear
35 Examination of spinal fluid
36 Cytological examination of metastasis
37 Cytological examination of local recurrence
38 Cytological examination with immunephenotyping, cytogenetics etc.
39 Cytological examination, uncertain if taken from primary tumour or metastasis
40 Surgical intervention without morphological examination
41 Autopsy without histological examination
46 Hormone receptor analysis
47 Moleculargenetic analysis, PCR
57 Histological examination of local recurrence
60 Histological examination of metastasis
(68) Not coded - Histological examination of metastasis AND autopsy. Automatically given from a combination of basis 60 and 80/82
70 Histological examination of primary tumour
(71) Not coded - Automatically given from a combination of DS 5 and Basis 32, 33, 34, 35, 39, 70, 74, 75, 76
72 Clinical notification about histological examination
74 Histological examination with electron microscope (ultrastructural diagnostics)
75 Histological examination with immunephenotyping, flow-cytometri
76 Histological examination with cytogenetics, molecullargenetic examination
(78) Not coded - Histological examination of primary tumour AND autopsy. Automatically given from a combination of basis 70 and 68/80/82.
79 Histological examination, uncertain if taken from primary tumour or metastasis
80 Autopsy with histological examination
81 Casual finding at autopsy with histological examination
82 Partial autopsy
83 Clinical notification about autopsy
98 Biopsy without any tumour
90 Death certificate
99 Unknown basis of diagnostics
Increasing priority: 71, 47, 46, 45, 99, 98, 90, 00, 10, 20, 30, 29, 31, 40, 83, 41, 82, 80, 22, 36, 39, 37, 32, 38, 72, 60, 79, 57, 70, 68, 78, 74, 75, 76, 81.

N2 Norway - Stage at diagnosis

0 No metastasis
1 or A Metastasis to regional lymph nodes
2 or B Metastasis to distant lymph nodes
3 or B Metastasis to organ in the same part of the body as the primary tumour
4 or B Metastasis to organ in another part of the body than the primary tumour
5 or D Microscopic growth into neighbouring tissue
6 or D Macroscopic growth into neighbouring tissue
7 Metastasis found, but uncertain where primary tumour is located
8 or D Microscopically infiltrating tumour
9 Unknown metastasis

Web Table 6. Clinical Cancer Registries with national coverage, operated by the Norwegian Cancer Registry (May 2017).

Cancer type	National registration		Status
	Data from	National funding	
Operating (May 2017)			
Childhood cancer	1985	2013	Collecting additional clinical data
Prostate cancer	2004	2009	Collecting additional clinical data (from 2004) and pathology data (from 2009)
Colorectal cancer	2007	2009	Collecting additional clinical and pathology data
Skin melanoma	2008	2013	Collecting additional clinical and pathology data
Breast cancer	2009	2013	Collecting additional clinical and pathology data
Lymphomas and lymphoid leukaemias	2011	2013	Collecting additional clinical data
Ovarian cancer*	2012	2013	Collecting additional clinical and pathology data
Lung cancer	2013	2013	Collecting additional clinical and pathology data
Oesophagus and stomach cancer	2015	**	Collecting additional clinical data
Planned			
Haematological cancer		**	Additional parameters for clinical and pathology data established – not collecting data yet
Central nervous system cancer		**	Additional parameters for clinical and pathology data established – not collecting data yet
Testicular cancer		**	Additional parameters for clinical and pathology data established – not collecting data yet
Sarcoma		**	Additional parameters for clinical and pathology data established – not collecting data yet
Bladder and urinary tract cancer		***	Planning additional parameters

* Will be extended to include all gynaecological cancers. Cervix uteri is the first additional site, hopefully in 2018.

** Applied for national funding, but the establishment of new quality registries is currently stopped in order to evaluate the existing registries and discuss a better model of funding.

*** Not yet applied for funding.

Web Table 7. Swedish Clinical Cancer Registries with national coverage on information network for cancer (INCA) platform (April 2017).

Cancer site	National registration		Coordinating Cancer Centre[1]
	From	On INCA platform from	
Breast	2008	2008	Stockholm Gotland
Cervix/vagina[2]	2011	2011	West
Endometrium[2]	2010	2010	West
Central nervous system	1999	2009	North
Head and neck[3]	2008	2008	North
Pituitary gland	1991	2012	Stockholm Gotland
Colon	2007	2008	North
Leukaemia, acute[4]	2007	2007	South
Leukaemia, chronic lymphatic	2000	2007	Stockholm Gotland
Leukaemia, chronic myeloid	2002	2007	Uppsala Örebro
Lung	2008	2008	Uppsala Örebro
Liver/gallbladder	2008	2008	West
Lymphoma	2000	2007	South
Melanoma of the skin	2003	2009	South East
Multiple myeloma	2008	2008	West
Myelodysplastic neoplasms	2009	2009	Uppsala Örebro
Myeloproliferative neoplasms	2008	2008	Stockholm Gotland
Kidney	2005	2009	Stockholm Gotland
Oesophagus/stomach	2006	2007	North
Ovary[2]	2007	2008	West
Pancreas	2010	2010	South East
Penis	2000	2009	Uppsala Örebro
Prostate	1998	2007	Uppsala Örebro
Rectum	1995	2007	North
Testis	2009	2009	South
Thyroid	2013	2013	West
Urinary bladder	1997	2008	South
Vulva	2012	2012	West

[1] National responsibilities for coordination (general support, update, statistical output) of registers are shared between Regional Cancer Centres.

[2] Part of the clinical cancer register of Gynecological Oncology.

[3] From 2008 part of the clinical cancer register for head and neck cancer.

[4] Different set of variables for acute lymphatic and acute myeloid/unknown leukaemia.

Figure 1. Time trends of incidence of leukaemia in men in four Nordic countries. Five-year floating averages of age-standardised rates (World) 1943-2104. In 1978, 18% of leukaemia cases were missing from the Swedish Cancer Registry (Mattsson 1984); the proportion now may be smaller.

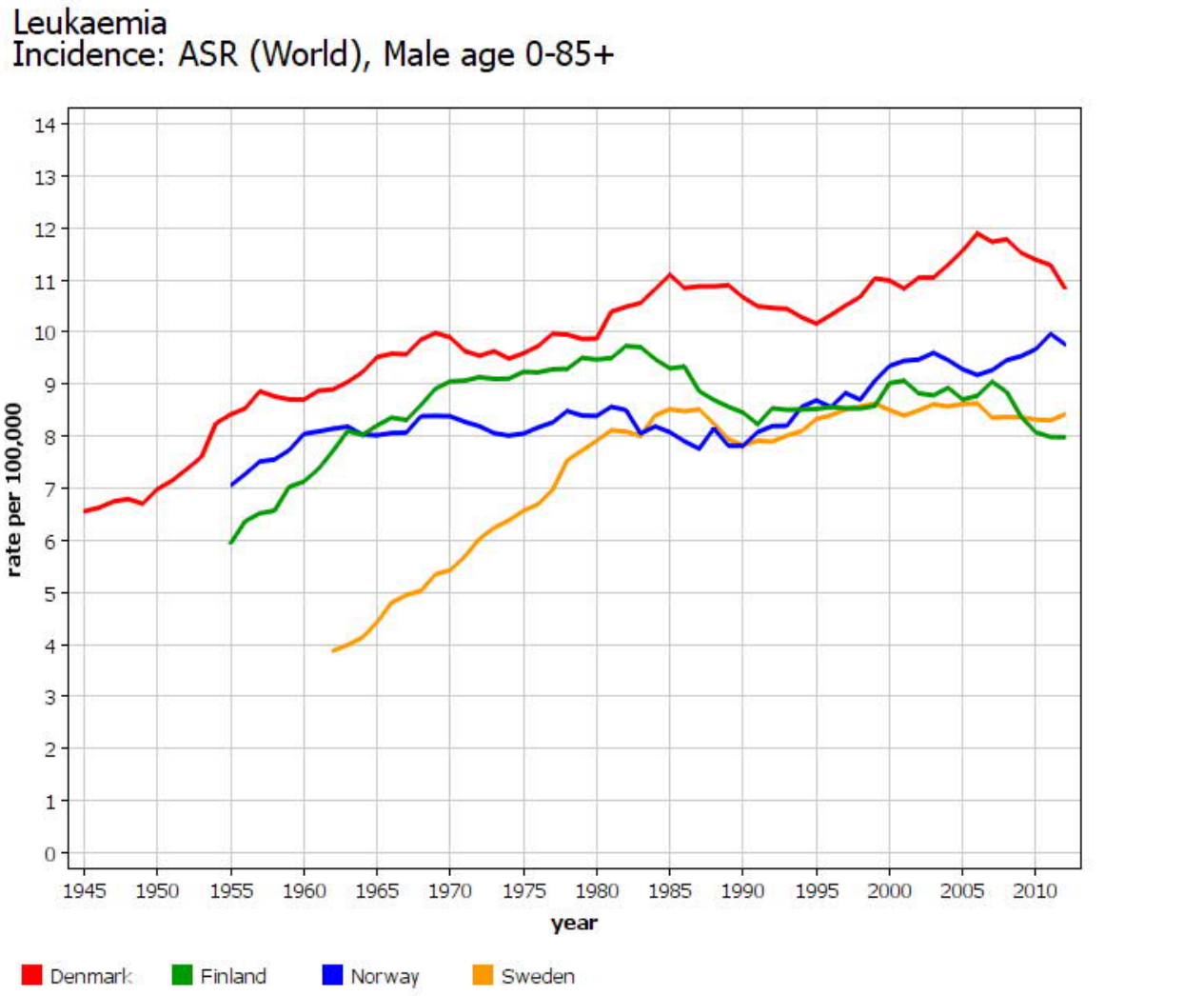


Figure 2. Incidence of pancreatic cancer in men in in the Nordic countries in 2009-2013, by age. The proportion of malignancies detected via the Cause of Death Register is particularly high for cancers not diagnosed or treated in hospital, e.g., cancers with a poor prognosis in the elderly such as pancreatic cancer.

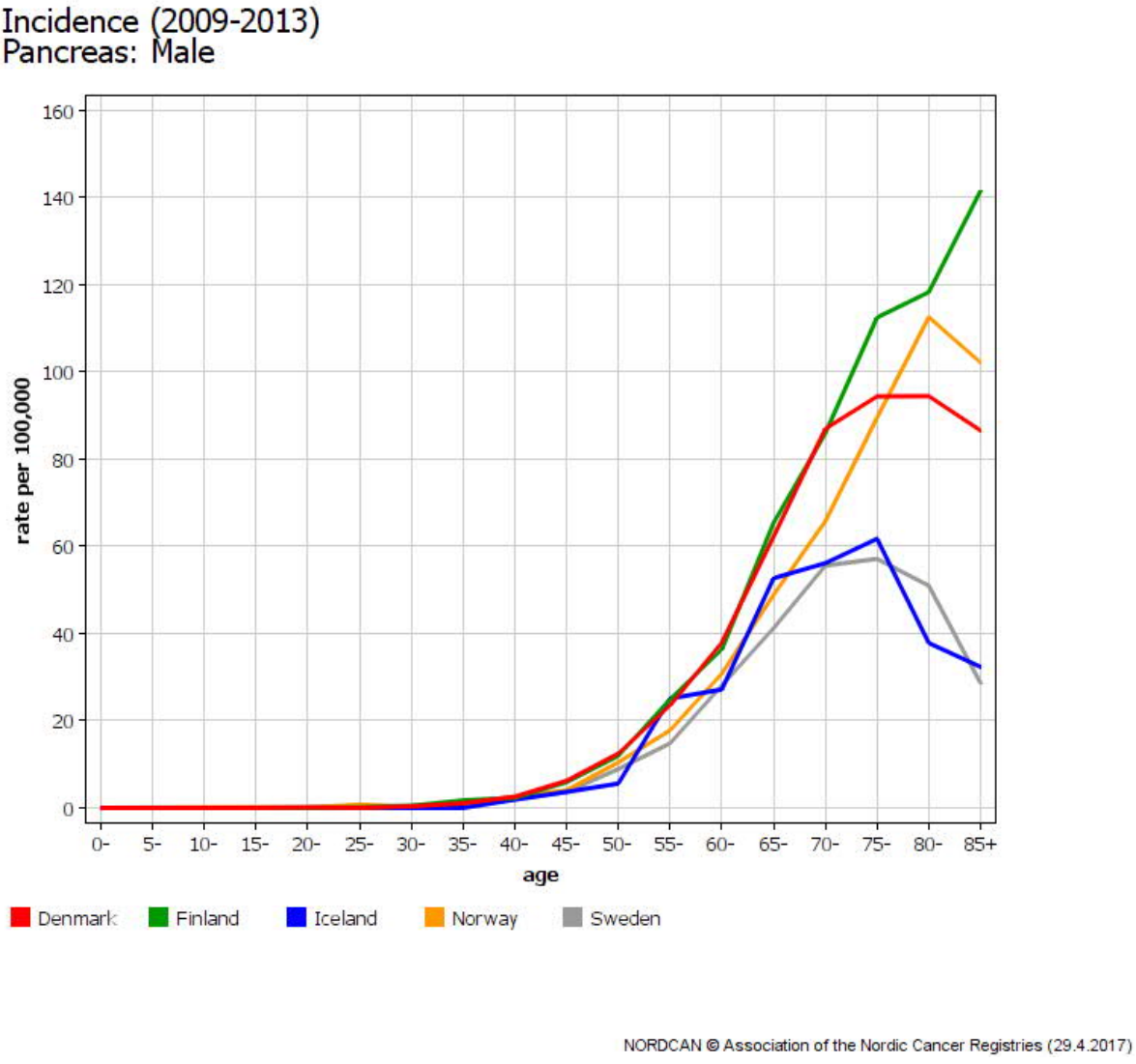


Figure 3. Time trends of incidence of non-melanoma skin cancer in men in the Nordic countries as reported by NORDCAN. Age-standardised rates (World) 1943-2014. Before 1978, Danish Cancer Registry could not separate basal cell carcinoma from the other non-melanoma skin cancers.

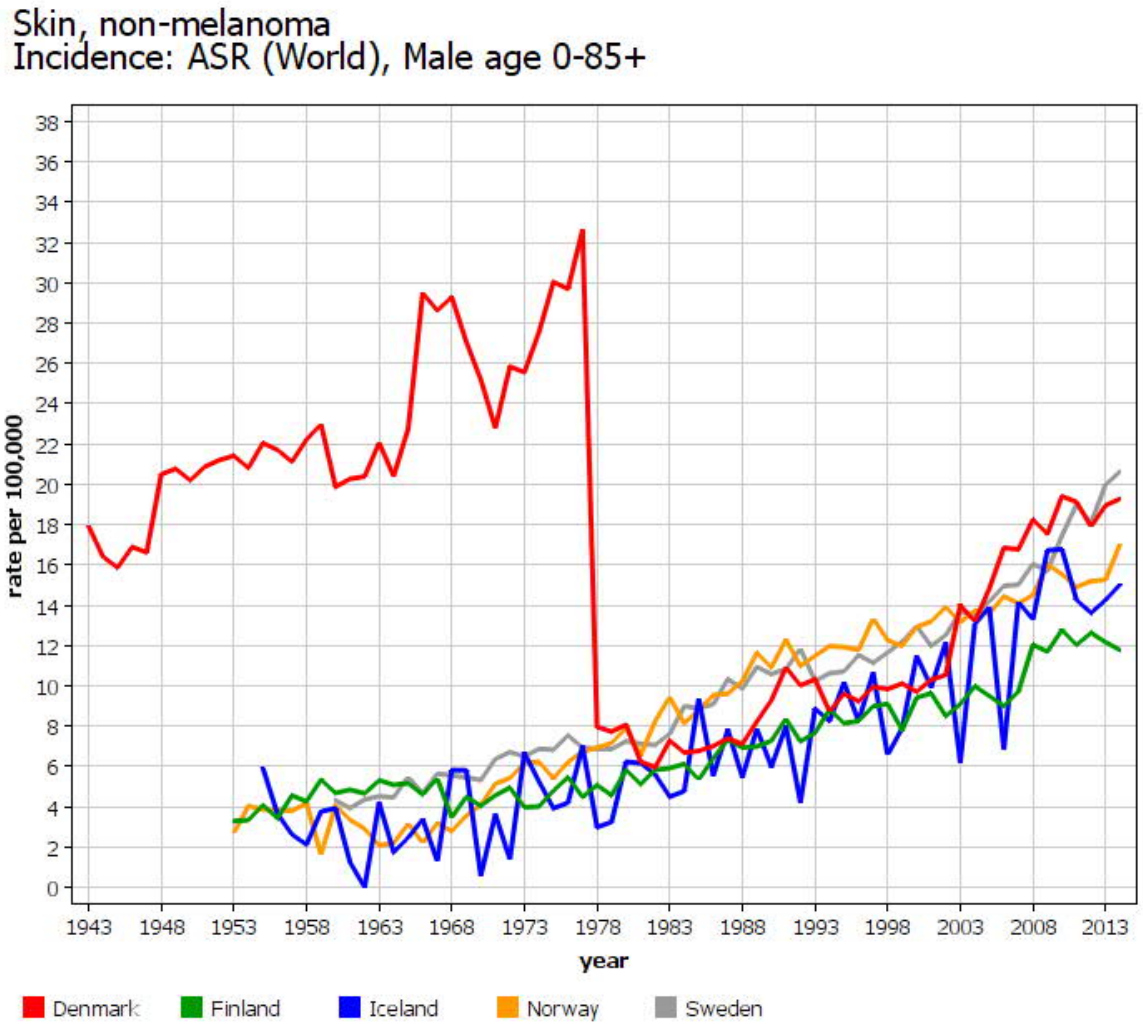


Figure 4. Time trends of incidence of bladder cancer in men in the Nordic countries. Five-year floating averages of age-standardised rates (World) 1943-2014. Part of the differences is explained by registration: Denmark has more often than the others included urothelial tumours of grades 1-4, unknown grade and "papilloma" in the bladder in the incidence.

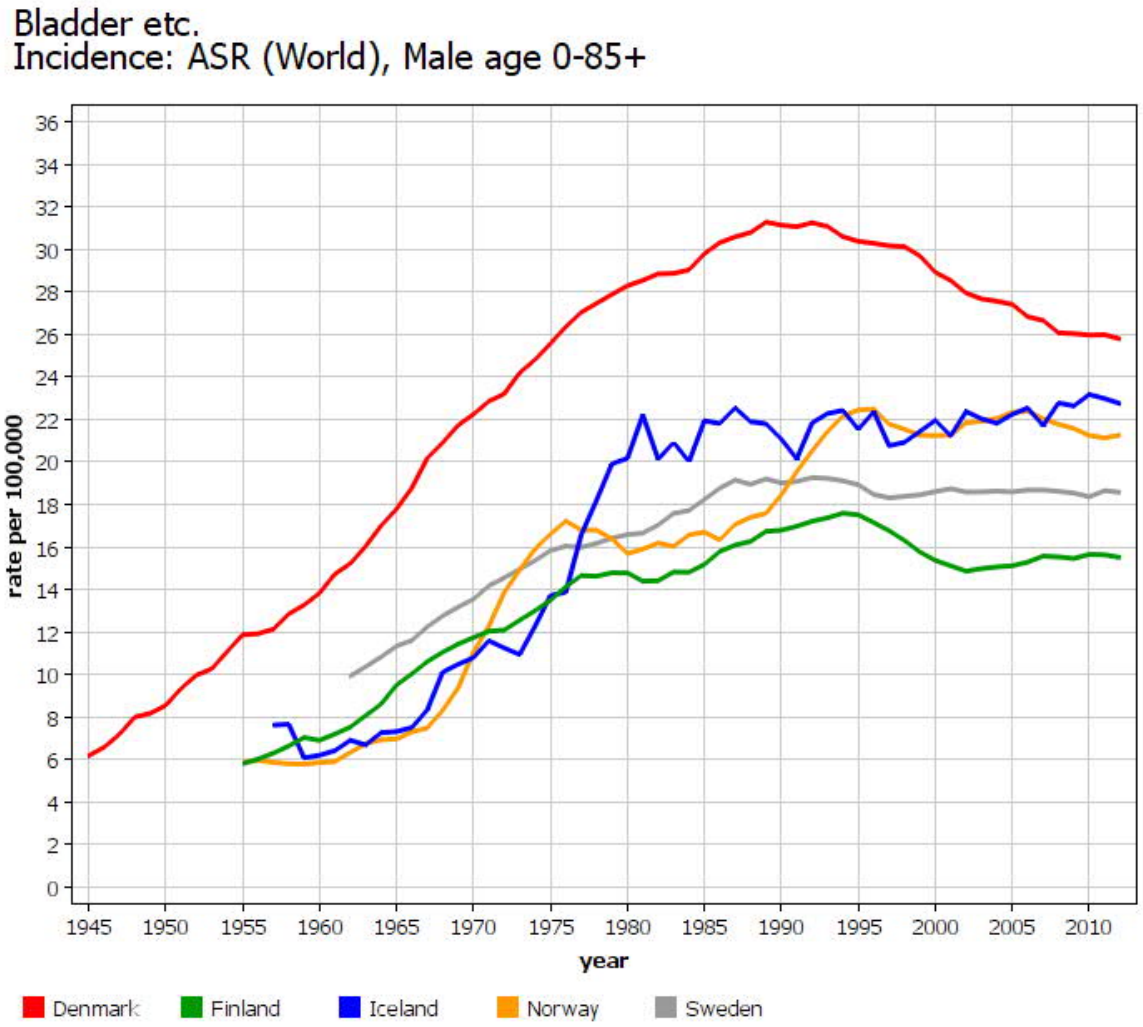
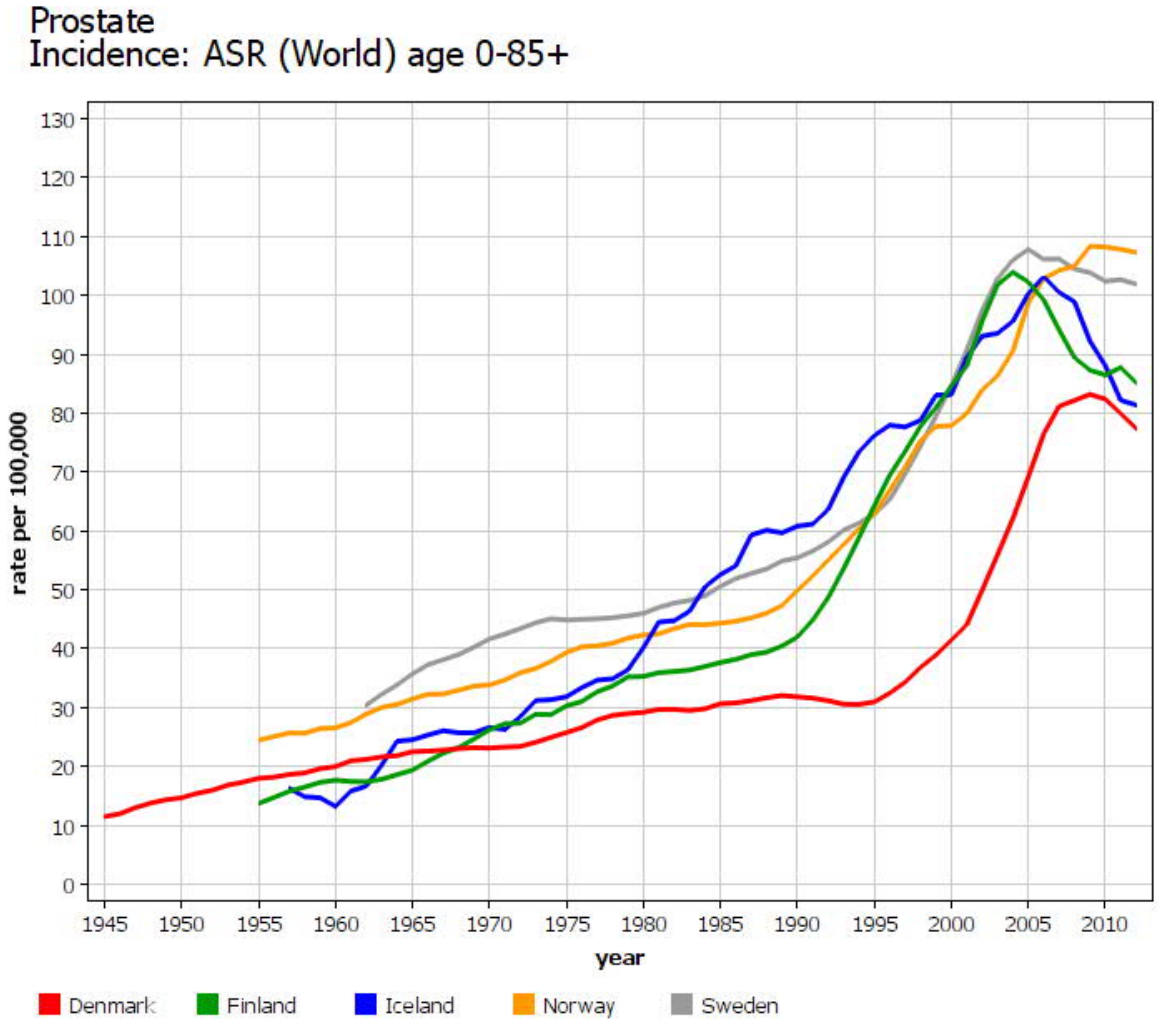


Figure 5. Time trends of incidence of prostate cancer in the Nordic countries. Age-standardised rates (World) 1943-2014. There was a steep increase in the incidence after global introduction of the PSA screening test in the early 1990s in all Nordic countries but in Denmark. In Denmark, the increase in incidence after 2004 partly reflects inclusion of pathology register information.



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Figure 6. Geographical variation of incidence of thyroid cancer among women in the Nordic countries in 2004-2010 (Patama & Pukkala 2016). The red area in mid Finland is consequence of excessive testing with ultrasound.

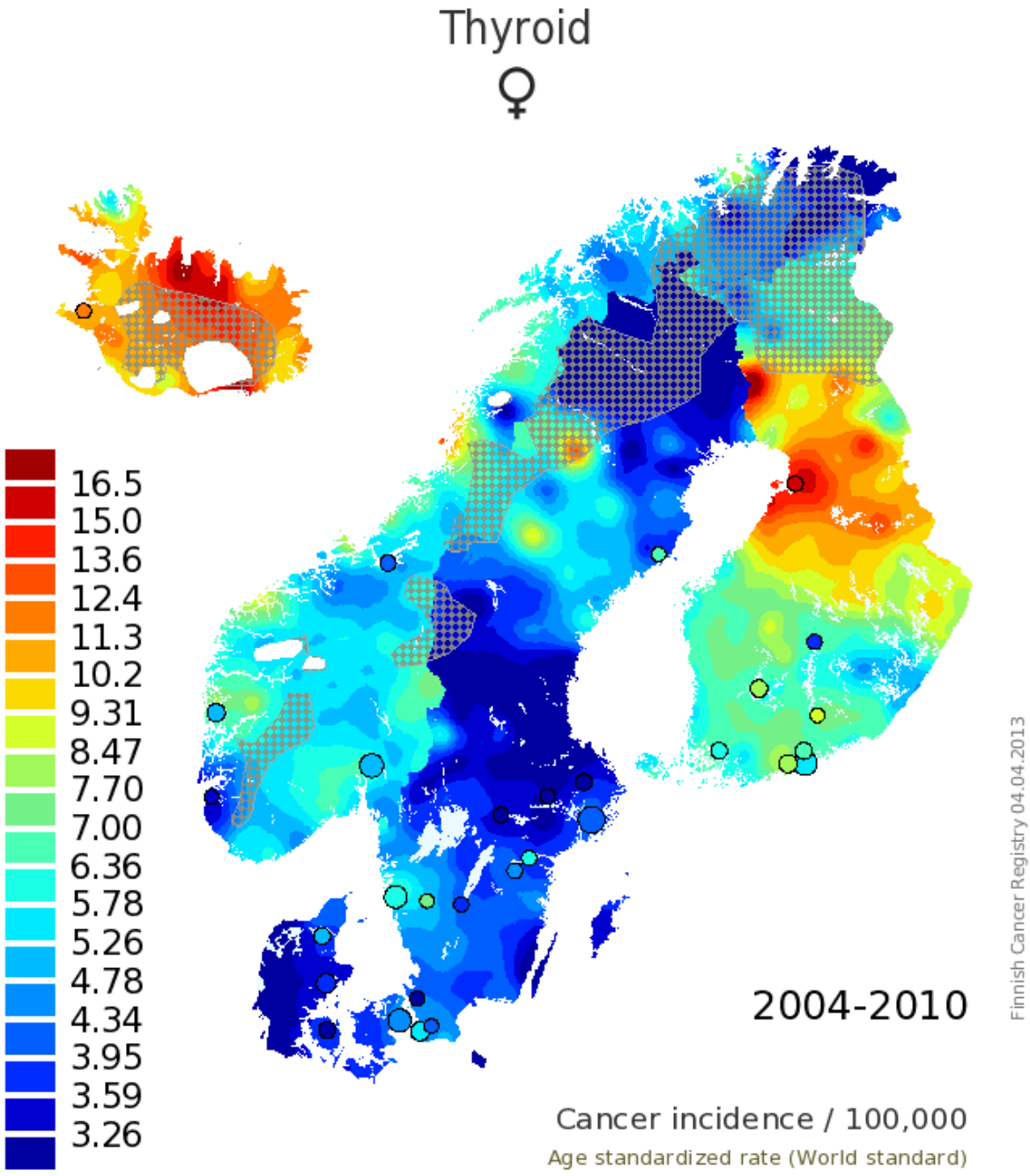
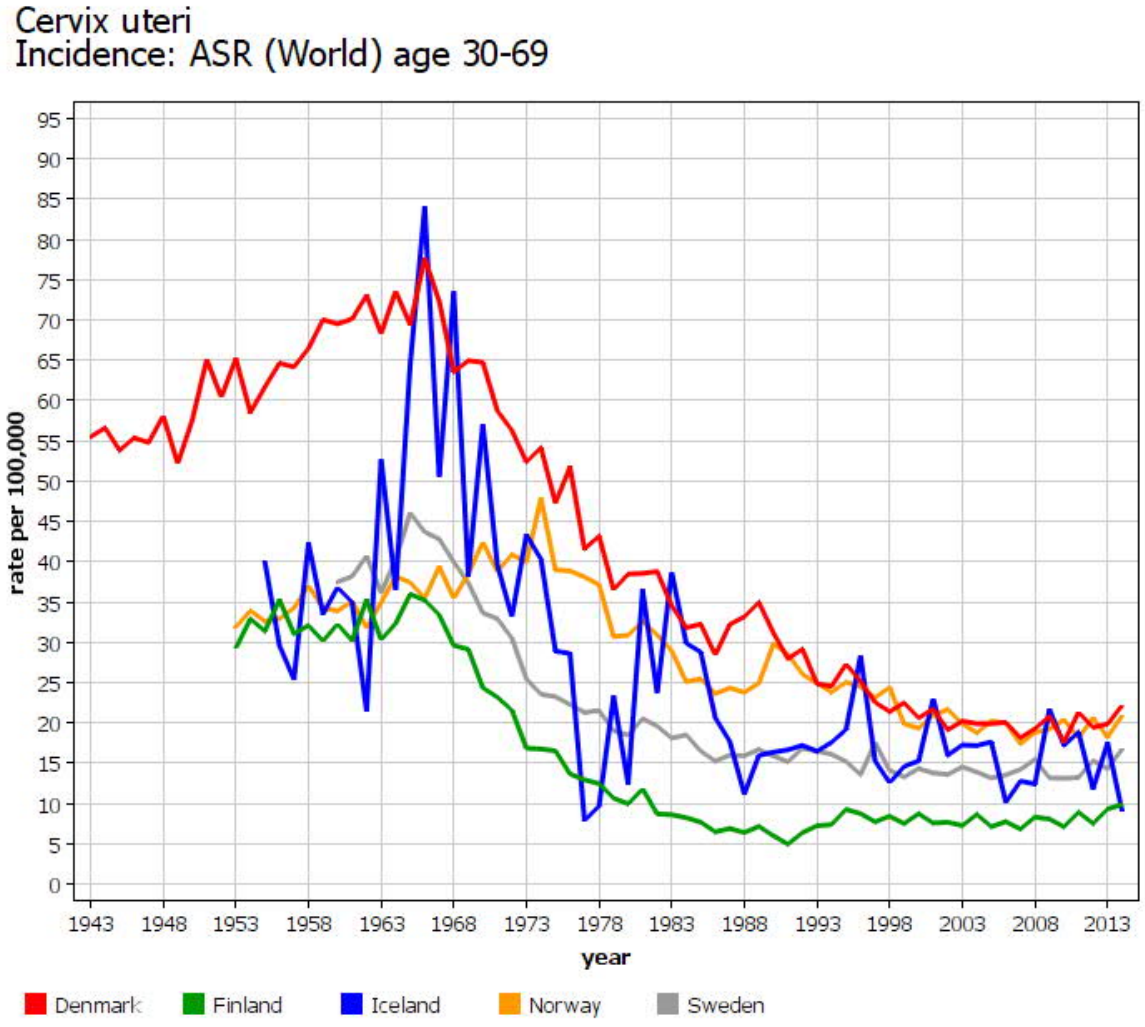
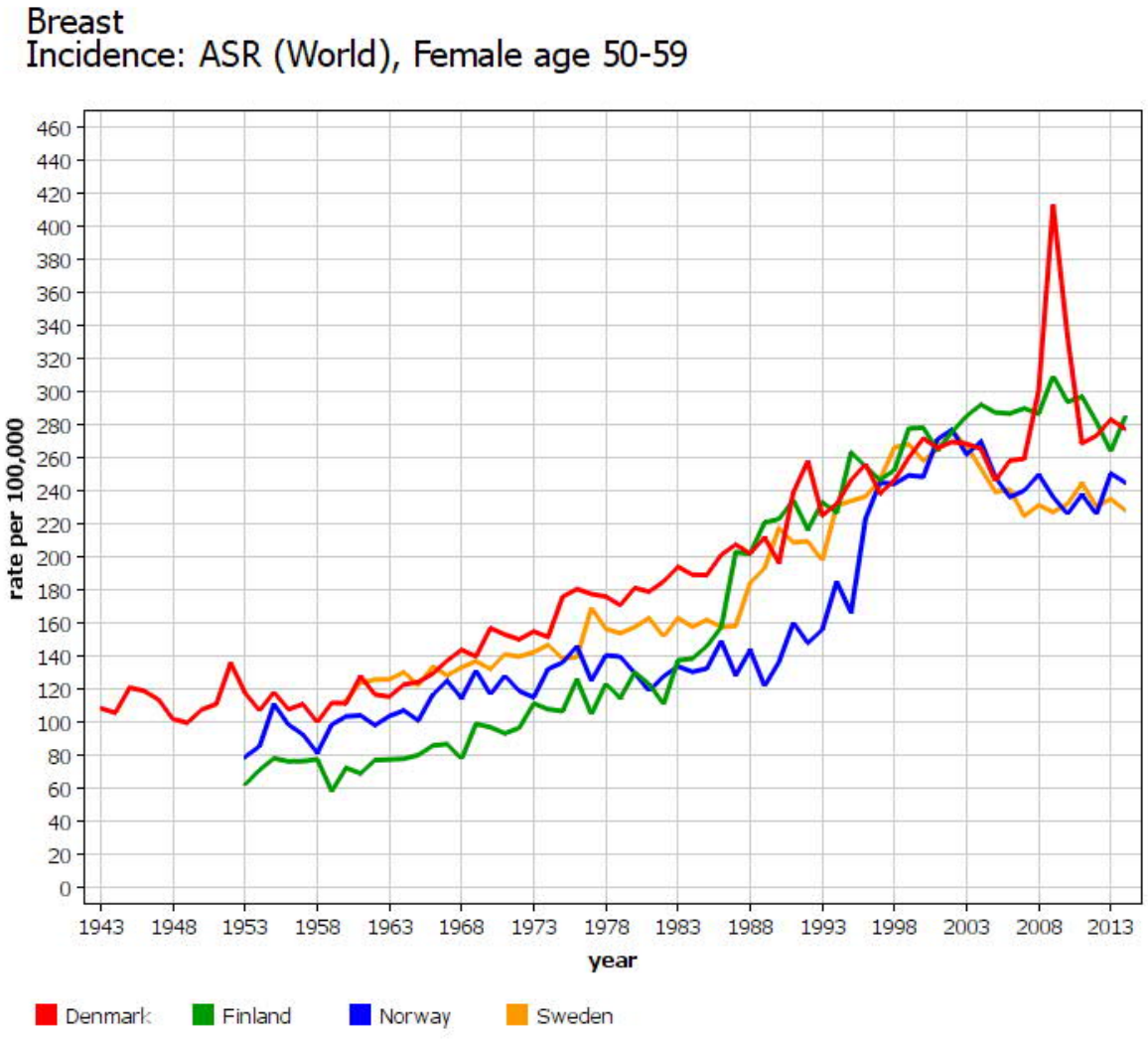


Figure 7. Time trends of cervical cancer in the Nordic countries in the screened age categories 30-69 years. Truncated age-standardised rates (World) 1943-2014. The downward trend in incidence started at different times depending on the start of national organised cervical cancer screening program.



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Figure 8. Time trends of female breast cancer in age 50-59 years in four Nordic countries. Truncated age-standardised rates (World) 1943-2014. Start of countrywide organised mammography screening varied from 1986 (Finland) to 2007-9 (Denmark); this caused major increases in the incidence rates of the screened age category.



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Figure 9. Time trends of incidence of basal cell carcinoma (BCC) among men in the Nordic countries in 1953-2015. Age-standardised rates (World), only the first BCC counted for each person. Registration practices of BCC – which has normally not been counted as true cancer in the routine statistics – have varied between countries and time periods.

