

Nordic cancer registration, a review of an invaluable source and example for surveillance, research and public health for more than 70 years

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ABSTRACT

Cancer registration has been with us for decades surveilling societies for cancer incidence, trends, mortality and survival. Data are used for health care planning but even more so for research in cancer treatment, outcome and prevention – *i.e.* overall cancer control. With the 70th anniversary of the Cancer Registry of Norway, this paper examines the impact and role of the registry in the past and today for cancer registration and affiliated research in the Nordic countries, as well as scientific peer reviewed productivity. The Nordic collaboration in cancer-registry-based research benefits from previous and actual ongoing activities in Norway. The Cancer Registry of Norway is a prominent independent organization under Oslo University Hospital Trust for registration and registry-based cancer epidemiology, with a multidisciplinary broad-based high quality professional staff. The research portfolio includes regular cancer registration, linkage to external data *e.g.* occupation, biobanks and clinical data conducting analysis with clear national, Nordic and international relevance. Various threats to the ownership of cancer registries and the derived epidemiology in past, such as organizational changes and loss of independence were avoided in Norway, but the interpretation of data protection following the GDPR today causes delays or may even block the Nordic cancer registry research.

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INTRODUCTION

20 years have passed, since Professor Lorentz M. Irgens on the 50th anniversary of the Cancer Registry of Norway, published his paper on challenges to registry-based epidemiology in post-modernized civilization (1). He thoughtfully walked us through from Adam and Eve to the birth of registration around 1000 BC (for tax purposes), the need for knowledge and the fear of losing integrity, the paradox between knowledge and wisdom, – to the evolution of registry-based epidemiology. Irgens highlighted the future need for epidemiological registries to be the instrument for research and surveillance, already for cancer foreseen in 1943 by the founder of the Danish Cancer Registry, Johannes Clemmesen (2,3). Registry epidemiology utilizes the ability to link registry data on individuals to other registries or data sources. This is essential also for long-term follow-up in the studies of exposures in the environment and development of disease, and not the least in quality assurance of health care services and public health, both important features of registry-based epidemiology (3). Epidemiology and perhaps more so registry-based is often as science rated of low value ignoring the enormous work collecting and quality assuring data, and the development and harmonization of definitions and methods employed. The ongoing Covid pandemic – developing much faster than any cancer – underpins the general need for better knowledge on how to collect, standardize, analyze and present data. During two years

of the Covid-19 pandemic, we have seen politicians, journalist, authorities and specialists in other medical fields violate even simple epidemiological terms and actions without knowledge on or respect for scientific evidence – of course in the name of the good for society. The voices and experience from the science – cancer-registry-based epidemiology – must now be included in the equation, both with respect to data collection (registration), definitions, harmonization and analysis.

THE NORDIC EXAMPLE IN CANCER REGISTRY COLLABORATION

Cancer registries in the Nordic countries has since the 1950s been forerunners in what Irgens (1) described as future needs in general for epidemiological registries, *e.g.* collaboration, record linkage, surveillance, *ad hoc* investigation on observed clusters, suspected exposures and quality assurance. Already in 1952–1955 the leaders of the cancer registries in Denmark, Norway, Finland and Iceland were in close contact and agreed on collaboration on registration issues and some harmonization. The Swedish cancer registry was included when established in 1958 (4). In 1965–1966, the cancer registries initiated a collaboration on registry-based research projects and annual meetings. This was in 1984 formalized as the Association of Nordic Cancer registries (ANCR). It changed the domestic surveillance centered on publication of annual statistics to larger collaborative projects including data from all of the Nordic region,

data linkages to external data sources, and scientific studies of relevance both to the clinical environment, cancer control and for occupational and public health. These activities coupled with high quality population data in the Nordic central statistical bureaus, data on an individual and identifiable basis (needed for linkage purposes) and development of databases on occupation, screening and biorepositories make the Nordic cancer registry collaboration an international stronghold in population-based cancer research (5). Optimal use and high data quality require knowledge, wisdom and collaboration from many professional groups. Eystein Glatre described in the editorial for the 50th anniversary of the Cancer Registry of Norway the cancer registry as a melting pot for professional cross-sectional fruitful collaboration both within and with external bodies (6). This is the case also for successful cancer registry organizations elsewhere, delivering the proof that the investment in high quality accurate and accessible data is key for progress in treatment and public health.

Well-known and brilliant statisticians have challenged the existence, investment in, and use of cancer registries advocating for use of mortality data (7). This was rebutted immediately (8) and further elaborated on in a simulations study on cancer survival (9). Indeed, mortality data exists world-wide – contrary to cancer incidence data, but for cancer, we know the accuracy of the diagnosis on death certificates is low, and even in developed societies as the Nordic only 80–90% are correct (10). Using a metaphor, we know the Vikings with success navigated the world in uncharted waters. We do not know how many were lost doing so, but who will today navigate without a chart, a compass and a GPS. This is what cancer registries provide for cancer in a modern world. If we rely solely on mortality, we record when the ship wrecked and sank, and we miss the learning of a successful sail reaching a safe harbor.

We usually consider the Nordic countries to be very similar in size, organization and social welfare including education and health care services. It is true we have more commonalities between the countries than differences, and we do have a long-standing Nordic collaboration between the governments exemplified by the Nordic Council of Ministers. Albeit based on the same ideas the cancer registries of the Nordic countries differ because of the small distinctions that do exist in the environments wherein they are established (11). Even so, agreement of the core data exists, enabling collaboration and data sharing whereby the statistical base increase to a population base in 2019 of 27.4 million people (12,13).

PUBLICATIONS AND PROJECT ON NORDIC CANCER REGISTRY DATA

With several decades of incidence data and follow-up the utilization of the joint Nordic data took off in the 1980s. One of the first publications to appear was the study of trends in incidence comparing data from the

five Nordic countries (14). Overall, the trends showed a slight increase in all countries while site-specific incidence varied notably, most for cancers of the thyroid and testis. Interestingly, the incidence trend of cervix cancer decreased 10 year later in Norway compared to the other countries, correlating to the delayed introduction of screening in Norway. At the same time, visualization of cancer incidence in atlases took off (15,16), first by administrative regions, later with smoothening techniques, likely inspired by Norway (15). A cancer atlas covering the entire Nordic Region using borders of administrative areas, was initiated in Denmark as a joint Nordic venture and published in 1988 (17). The visual display of cancer incidence was praised by many but also caused problems in interpretation. A headline in a Danish newspaper following publication of the National cancer map read: “All Danish men flee the city of Odense to avoid testis cancer” – as the dark red color in that area indicated a high incidence. A rare cancer and a color scale distribution from high to low gave rise to misinterpretation based on few cases not considering the population age distribution (university city) and the time needed from a carcinogenic exposure to development of cancer. Hence the smoothening technique avoiding visualization of administrative borders is now employed in cancer mapping (18). Following the mapping of cancer, it was proposed to publish tabular incidence data from the Nordic countries (19). This publication divided data for each country into the whole country, large cities and the rest of the country to present urban-rural differences. Further it presented trends in incidence, age-specific rates and main morphological entities by gender.

With the success of the joint publications and demonstrated harmonization of data, a large-scale joint project KIN (Kreftbildet i Norden / The Nordic cancer picture) was developed, under the leadership of the Cancer Registry of Norway and supported by the Nordic Council of Ministers. The KIN publications included site-by-site prediction of both cancer incidence and mortality from 1987 to 2012, where the mortality prediction was based on the observed survival rather than using the national mortality statistics (20,21). Cancer screening for cervical, breast and colorectal cancer and future effects on cancer mortality, gain and cost per life year gained were estimated (22). The last publication (1997) in the KIN project included estimation of avoidable cancers in the Nordic countries together and by country, applying preventable proportions based on the scientific literature on tobacco smoking, passive smoking, alcohol consumption, occupational risk factors, radon, manmade ionizing radiation, solar radiation, obesity, and HPV and H Pylori infection. The project considered prevention based on dietary interventions, but uncertainty around the risk estimates for diet was at the time too large to produce meaningful and trustworthy effects of preventive actions. Nevertheless, as much as 33% of all cancer cases in men and 20% in women could have been avoided in

the year 2000 given that all the validated risk factors had been eliminated when the evidence for an effect appeared in the scientific literature (23).

THE BIRTH OF A JOINT NORDIC CANCER DATABASE NORDCAN

With the increasing use of joint Nordic cancer data, and after time-consuming efforts in harmonizing the same data to meet the requirements of joint studies, the ANCR supported the launch of the NORDCAN database and data display project. It was developed in collaboration with the IARC in Lyon as a continuously updated common Nordic database on cancer incidence and mortality, first on floppy disks (1973-97 data), later as web-based (1970-99 data) including more analytical facilities (24,25). A paper describes the web-based tool together with a large series of 12 articles using NORDCAN on cancer survival in the Nordic countries (26). The web-based tool also incorporates predictions of cancer incidence and cancer mortality based on the NORDPRED model developed in Norway (27) and presented in conjunction with the world cancer Congress in Oslo 2002 (28). It predicts the future number and rates of cancer cases and cancer mortality due to demographic changes *i.e.* population size, aging and life expectancy and the proportion of changes due to other factors – potentially preventable. Initiated by the professional staff of the Danish Cancer registry, the NORDCAN project stayed with the Danish Cancer Society for more than 20 years. Changes in organization and loss of key professionals in cancer registration, continuation and hosting of the project moved to the present strongest cancer registry environment in the Nordic countries, the Cancer Registry of Norway. This coincided with the introduction of the GDPR (General Data Protection Regulation – EU) and change of IT platform by IARC, hosting the NORDCAN software. Under the Norwegian leadership and a grant from NCU (Nordic Cancer Union) the NORDCAN group representing each cancer registry in the Nordic region revised the data flow securing full anonymity of data subjects through a federated data analysis. The re-programmed visual display in the NORDCAN software by IARC reaches standards and user expectations in 2020, with fast speed, high flexibility and excellent export facilities (12). The software enables users, *i.e.* cancer registries, epidemiologists and authorities, to get results fast, useful for research and planning. The negative side of the system is that users take for granted that the service exists and do not acknowledge the time-consuming specialized work taking place behind the scenes in each cancer registry to obtain valid data. For researchers the speed of getting answers to questions raised in cancer may satisfy the curiosity that in the past lead to scientific publications of high value for cancer control. The benefit for science, however, is that a database harmonized for the entire Nordic population exists. This is important if external data collected on relatively rare

events, such as immunosuppression and transplant of organs, from the larger Nordic populations can be linked to the NORDCAN coded data in each of the cancer registries. The statistical strengths increase manifold, resulting in meaningful and trustworthy conclusions.

EPIDEMIOLOGY, PAST, PRESENT AND FUTURE WITH CANCER REGISTRIES

Descriptive epidemiology *i.e.* surveillance is evidently one of the central tasks for the cancer registry. However, even at the outset for cancer registries the founders planned analytical epidemiology, linking external data to the cancer data in search of risk factors (2). Occupational cancer epidemiologists use data on occupation history, with different exposure levels to suspected carcinogens, and create job-exposure matrices. The Cancer Registry of Norway has a long history in occupational cancer epidemiology. The Nordic collaboration in occupational epidemiology was highlighted at the 50th anniversary with results from a study based on census data where 31 cancer sites were studied for 52 occupational groups (29,30). As an update and extension, a joint Nordic study NOCCA (Nordic Occupational Cancer) was later launched, using 45 years of cancer registry data, 15 million people aged 30–64 years at four censuses 1970–1990, and more than 2 million cancer cases among these persons up to 2005 (31). These data are now freely available to the research community and is widely used (<https://astra.cancer.fi/NOCCA/>).

Another both present and future line of epidemiology introduced early in Norway is the use of biorepositories, more often called biobanks. The step into the future of biochemistry, serology, genetics, molecular biology and risk of cancer took off as early as 1973 when the Norwegian Cancer Society initiated and supported the Janus Serum Bank cohort, now holding serum from almost 320 000 blood donors (32,33). The Janus biobank contributed materially to Nordic and international co-operative studies during the first decades of the 21st century, such as the EU-funded CCPRB project (Cancer Control using Population-based Registries and Biobanks) (34) and the NBSBCCC initiative (Nordic Biological Specimen Bank cohorts as basis for studies of Cancer Causes and Control) (35). The present custodian of the Janus bank, the Cancer Registry of Norway has recently published details on what has been measured and found in numerous studies all recently quoted by Langseth et al. (33).

The Cancer Registry of Norway also took the initiative to include clinical cancer registries in the research institute, contrary to what was done in Denmark, where such databases have a steering committee from the multidisciplinary cancer groups and administration by the regions with other clinical databases (RKKP.dk). In Sweden cancer registration is federated to each of the 6 regions, also holding the clinical database recording INCA system

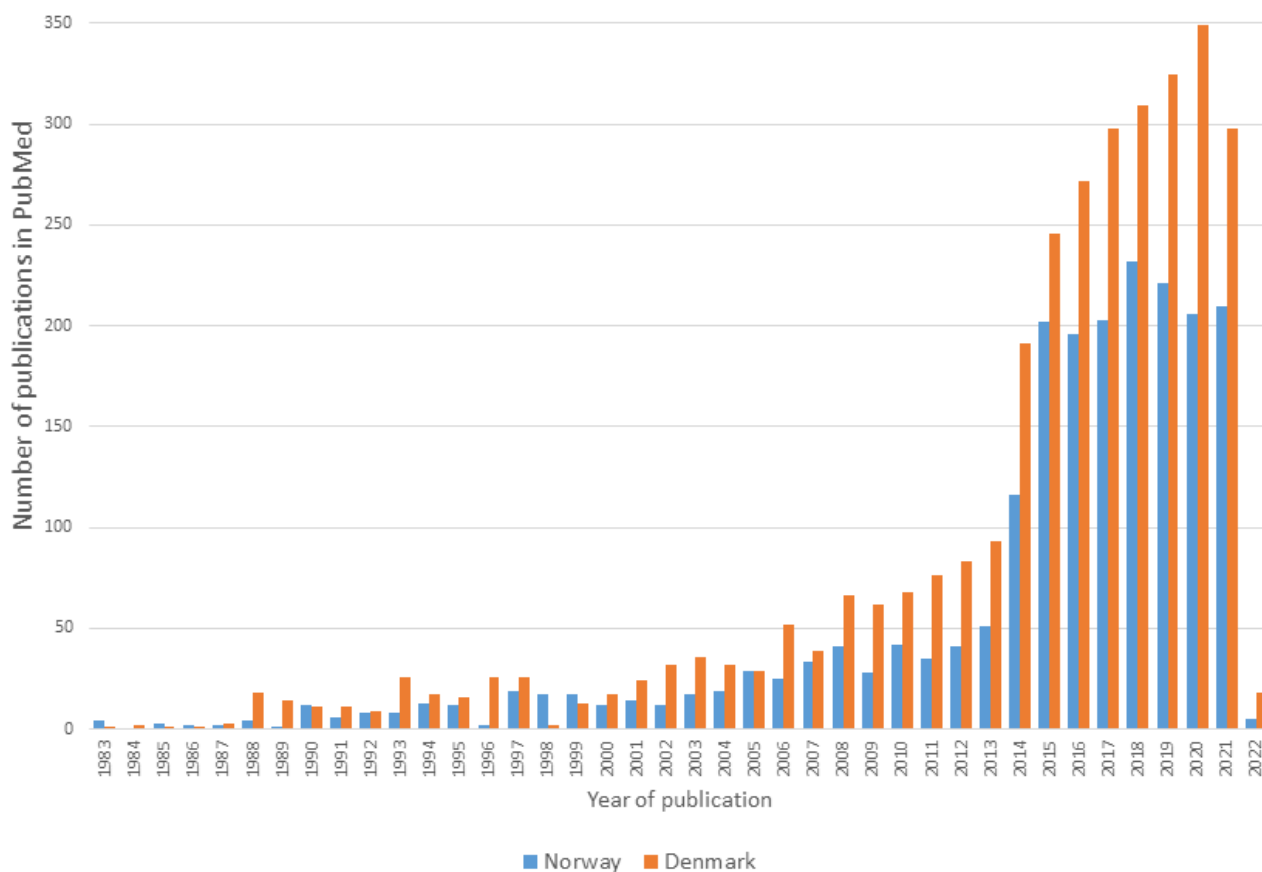


Figure 1. Annual number of publications cited in PubMed 1983-2022. PubMed search 07/01/2022, search terms “Cancer Register of Norway and epidemiology” and “Danish Cancer Society and epidemiology”.

(<https://cancercentrum.se/samverkan/vara-uppdrag/kunskapsstyrning/kvalitetsregister/om-inca/>). The number of clinical cancer databases established with the Cancer Registry of Norway, is now 11. A recent paper by Nilbert et al. gives a full description and status for clinical cancer registration in the Nordic countries as of today (36). Beyond doubt, subsequent research activities will both secure quality and progress in treatment for cancer. The combination of the clinical data and activities in early detection and screening impact treatment and health care with improved outcome, not only in survival but also in quality of life.

CURRENT AND FUTURE THREATS TO CANCER EPIDEMIOLOGY

Many research organizations, universities and authorities envy the access to cancer registry data and the productivity in terms of scientific output from cancer registries. Taking a look at the output of epidemiological papers from the Cancer Registry of Norway and the Danish Cancer Society Research Institute (previously holding the Danish Cancer Registry), it is interesting to see how productivity in peer reviewed publications takes off in the 1980s with an almost exponential growth after the turn of the century (Figure 1). The information stems from PubMed using the search terms “Cancer Registry of Norway and epidemiology” and “Danish

Cancer Society and epidemiology”. This shows it is possible to create epidemiological strongholds given you have access to data, finances and professionals. This also makes the organizations attractive and entails a risk for attempts to take over the cancer registration, with or without the research. Attempts in Norway was refuted some 20 years ago, but unfortunately happened in Denmark in 1996, where registration alone moved to the authorities. The research so far survived. Adopting only the registration part the authorities acknowledged, by a ministerial declaration, that research should continue with the Cancer Society Institute for cancer epidemiology without any hindrance by continuous provision of a copy of the updated cancer registry to the Cancer Society. Thereby Denmark so far maintained the essential link between data collection and research, which is so important for the quality and the interpretation of the data.

Another threat to progress in health and cancer control based on scientific evidence has arrived with the GDPR (General Data Protection Regulation). Ignoring that cancer registries have existed in 70 years or more in accordance with highest confidentiality and ethical standards, and without any reports of breaches or violation of confidential data on individuals the new legislation creates barriers – true or untrue for health science. Unclear definitions is obvious in relation to exemptions to informed consent, rights of data subjects,

sharing of data (necessary individual data) with laboratories or research organizations in other regions; to this adds missing clarity on data handling agreements, and on shared or transferred ownership. These uncertainties have paralyzed research organizations, and data protection authorities have not seen the need for some proportionality in the subject matter, so science-based progress is blocked. The irony of this is that the intension of the GDPR is to ease data sharing and flow within the European Union and to partners that adhere

to the same standards as defined in the GDPR. The overall result may well be a catastrophe long term, with unnecessary premature deaths due lack of progress in cancer treatment, care and control. We are concerned today of the death toll from Covid-19, and it seems that many legislative procedures are exempt in relation to curbing the pandemic. Cancer and other diseases kill many more people, so let this be the revelation to politicians, authorities and populations to facilitate research and harvest the improved results we all need.

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