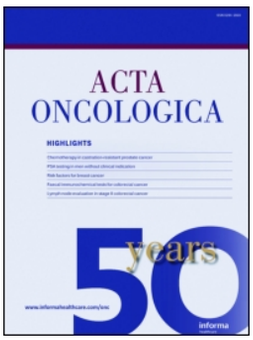

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# Data may save lives – cancer epidemiology needed to guide public health and clinical progress

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EDITORIAL

# Data may save lives – cancer epidemiology needed to guide public health and clinical progress

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The Nordic countries are privileged in many ways. We have well-functioning democracies, orderly societies, freedom of speech, and civil rights embedded in the constitutions. In general and confirmed by surveys, the populations enjoy and respect the privileges. Compared to most other countries, we have low socioeconomic differences, low unemployment rates, high living standards, long life expectancies, and economies that by BNP per capita are in the top 25 countries in the world. Equal rights and opportunities, a working environment built on negotiation and dialogue, free public education from basic school to universities, world-class health services, have over the years received attention as the Nordic model, albeit with high taxes. In order to run this complex machinery in a balanced way, a prerequisite is monitoring of the population – a task that in the 1960s was made easier by the introduction of the unique identification numbers in all Nordic countries. We monitor citizens from cradle to grave based on societal trust, regulations, and safety measures. The registries constitute separate 'silos' each with their specific purposes such as work environment, pension schemes and other financial activities, taxation, housing, driver's licenses, use of health services, etc. For cancer, the monitoring began as early as in the 1940s–50s with a Cancer Registry in each country [1]. Over the years, it became easier to link the various 'silos' as development and access to modern IT improved, with better and more correct linkages of data using the unique ID and with developments in legislation, which takes new possibilities and methods into account.

Linking 'silos' to health data gives us insight in exposures to risk factors be it factors improving or damaging our health, and enables us to evaluate outcome of preventive interventions, screening, and treatments illustrated by public health and clinical epidemiology. The ongoing Covid-19 pandemic, has underlined the need for basic knowledge in methods in public health epidemiology. Calculating and comparing risks requires basic skills in epidemiologic methods. The need to have comprehensive, representative, and valid data to get proportions right, and skills in forecasting risks based on solid and transparent methods is obvious. Further, communicating results to the public in a correct and understandable way is paramount.

In cancer monitoring, we have nourished many researchers and clinicians by the meticulous work of cancer registrars and faithful health care professionals reporting to the registries or clinical databases. We often fail to recognize and praise the importance of this work. They provide the corrected, harmonized, and analyzed data we otherwise should spend month or years to obtain. Among the examples, are the NORDCAN program [2], annual electronic accessible results, and clinical outcomes from clinical databases, made available after hours of work to secure correct proportions of e.g., cancer burden, outcome of clinical interventions, treatment, and prevention. As a metaphor, one can say the monitoring provides the chart and the compass to navigate the health ship to a better future. We need to improve the maps, correct the course to stay in safe waters, and consider the risks of skipping such efforts due to budget cuts in health care.

The Nordic Cancer registries are prime examples of what it takes over several decades to build and maintain a valid and comprehensive monitoring system. The development and maintenance of the work initiated in the 1940s and 1950s by a small group of medical trained visionary researchers with a view to combating cancer [1]. They saw the need for comprehensive harmonized monitoring with a large population base to get a solid foundation for cancer research and results of relevance to the public health and health care system. Although emperors of their own national registry, all labeled the world best, the founders of the Nordic cancer registries saw the need for comparing cancer rates between countries (bench marking) and to find factors explaining the differences. To do so, they agreed on standardized definitions and practices. They also formed the Association of Nordic Cancer Registries (ANCR) and the collaboration have over the years accelerated in number of relevant publications in cancer and epidemiological methods e.g., incidence, survival, prevalence, forecasting, mapping, occupational cancer, risk factor analysis and show the way worldwide in this discipline. The development of NORDCAN [2] and the mapping of cancer registry procedures to better understand differences and the use of data for research [3] and joint publications on incidence, survival, forecasting, mapping, occupational cancer, screening, avoidable cancers in the

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1990s published by APMIS and Acta [4–8] is today part of the regular portfolio of the ANCR activities. So is the ANCR/NCU collaboration on running a summer school in cancer epidemiology to secure new blood to population-based cancer epidemiology in the new scenario of personalized medicine, link to tissue banks, and the human genome.

Around the registry activities, strong research environments in epidemiology developed demonstrating the need for close integration with both the monitoring activities, the clinic, and the research to obtain the high standard of the Nordic publications in cancer epidemiology be it on the entire populations or specific cancer cohorts, single cancer sites, occupations, socioeconomic standards, etc.

In this issue of Acta Oncologica dedicated to cancer epidemiology, we find some recent examples on the use and power of continuous monitoring by population-based cancer registries. The paper assessing quality by linkage to independent data sources [9], benchmarking cancer survival in Finnish hospitals [10], and the expansion to develop clinical cancer registries [11] with a future view to modern individual targeted treatment based e.g., activated genes, etc., are noteworthy. In other words precision medicine or personalized oncology, a move from the helicopter view by descriptive epidemiology to data focused on the individual patient. The paper revisiting population based Nordic survival for nine major cancers expanding follow-up to 2016 confirm narrowing of the survival deficit earlier seen for Danish patients [12]. The paper both underline the need for regular benchmarking of Nordic cancer survival and calls for more precise treatment details to understand the observed trends in survival.

The paper by Trewin et al. [13] demonstrates the possibility of creating and studying breast cancer risk by stage in a cohort of young women. They extracted over 1 million young Norwegian women from the population file and stratified by socioeconomic status based on education and income before reaching screening ages. Linking these women to the national cancer registry and adjusting for interactions between stage, age, calendar period, and immigration history, the overall finding based on the stage of the breast cancer is an increasing in breast cancer risk in young ages unrelated to opportunistic screening in higher SES women compared to lower SES women.

Another paper by Hjerkind et al. [14] defined immigrants and non-immigrants in Norway based on place of birth and did an internal comparison on cancer incidence. They in general found a lower cancer incidence in immigrants, but for those with origin in Asia, a higher liver cancer and those in Eastern Europe and neighboring Nordic countries a higher lung cancer incidence than among Norwegian born. Studies on migrants have in the past supported several hypotheses about risk factors for cancers amongst these, dietary and smoking habits, and change in the same by 2 and 3rd generation immigrants. Migrants studies have also arisen ethical concerns e.g., stigmatization and due to this many countries do not allow recording of race or country of birth. Not doing so and being unable to study incidence patterns by immigration on the other hand may have the unwarranted effect that targeted prevention activities, information, education, and advice as part of a public health strategy simply is not happening with severe consequences for the immigrant families.

The paper by Nilbert et al. [11] Points the way forward for clinical cancer registries and raises a number of important issues as was seen in the 1950s when population-based general cancer registration was launched. An interesting point is the birth of clinical cancer registries most often initiated by surgeons, interested in their performance based on simple and few indicators. The fact that dedication comes from one or a few persons in one discipline is also the Achilles heel for a continuous dedicated high-quality monitoring. We often see the dedication vanish when the dedicated initiator in his or her career move to other responsibilities. Sustainability is a problem – alongside finances for building a base for research and progress in treatment. Another complication and barrier are the variables – the indicators collected. It is often said 'the more the merrier' but here prudence is more important. The more variables collected the less quality and effort to keep a high quality will be the case. It is thus important data are collected at the root and only variables that have clinical consequence hence documented in the hospital record system is put on file. More general variables are collected by linkage to e.g., general cancer registries or administrative systems. It is scary reading to realize that for breast cancer Denmark and Norway collect 10 indicators whereas in Sweden 35 are collected. The advice to involve multidisciplinary teams (MTD) in definition of variables and decision on what to collect and to adhere to privacy legislation by collection of few (but essential) variables is worth remembering – especially when the view is to precision or personalized medicine.

One point only alluded to very briefly is the legislation on collecting and sharing individual data for research – and the restriction imposed on presenting even tabular data with few cases. It is about time the consequences of hampered possibilities for epidemiologic research get high on the agenda. The consequences refraining from research and thus progress in cancer treatment and care due to perceived or real problems with the new privacy regulation urgently needs attention. In the GDPR preambles, it is suggested that pseudonymisation is a fair way to secure individual privacy. This is, however, not accepted as a sufficient measure by the Nordic Data Protection Agencies and even within EU demands a cumbersome and administrative heavy burden with uncertainty in collaborations on roles and requirements as data processor or data owner. This virtually stops sharing of data, but for sure to International organizations e.g., WHO and research institutes in third countries. It creates a barrier for epidemiologic research with negative effects on and the possibilities to collect and share individual-level data needed e.g., precision medicine. There is a need for international collaboration to get sufficient statistical strength i.e., trustworthy results. Statistically low powered studies will have weak conclusions and in turn consequences for future patients where treatment choices build on the research results. It is about time we introduce proportionality related to the risk of

pseudonymized data sharing between registers in secure IT environments and the hypothetical risk of violating the privacy of an individual. The basis for the patient-doctor relation is an oath of secrecy, now legally supported by the GDPR. The GDPR introduced a requirement for assessing the risk and harm for the individual if there is privacy breach. These points to who can possibly benefit from the knowledge on the data subjects health data by breaking the privacy shield? More attention directed toward this, than hypothetical breaches in the research and clinical setting may create much-needed balance between research-based progress in health and privacy.

## Disclosure statement

No potential conflict of interest was by reported the author(s).

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