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EDITORIAL

Can national cancer registration support clinical databases and clinical cancer research?

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Can national cancer registration support clinical databases and clinical cancer research?

The short answer is: Yes, it can. A longer version is: Yes, it can and if it cannot substantially help now, we will have to make sure that it can in the future.

In many countries and regions for decades there has been a mandatory registration of new and incident cancers. In many of these countries and regions there is also a rapidly growing interest in keeping clinical databases for clinical audit and research. The discussion about how to marry these two systems is growing, not least because both are time and resource demanding and it is important to get priorities right.

National cancer registration and clinical databases have different roles

National cancer registration is firmly rooted in public health and serves among other things to measure the occurrence of cancer in an entire population, to survey important changes that could alert us to new health risks, help in the planning of health services and be an important tool in etiological research.

Clinical databases are rooted in clinical epidemiology. They monitor for the purpose of audit and research what happens to a population that has been diagnosed with cancer in terms of diagnostic procedures and therapeutic interventions. Many clinical databases also capture outcomes on a more detailed level than the cancer registry, e.g. they monitor not only death but also time to and type of recurrence.

Even if a vast number of informative studies of important clinical aspects have been carried out using national cancer registration data (and certainly will continue to be researched), and clinical databases can under certain circumstances be used for etiological research, their two different basic roles should be maintained; they are both needed in our efforts to reduce and control the cancer burden. Sometimes clinicians are frustrated that the cancer registry cannot supply all the information they need. Sometimes public health officers are frustrated over the comparatively rapid change in variables and registration practices in the clinical databases. However, as this article aims to convey, these roles can be combined to increase the utility of both systems. And, moreover, in some aspects they already do meet naturally in their tasks, e.g. both systems are keenly interested in the stage at diagnosis being correctly registered and both are very useful in planning of services.

How can cancer registration support clinical databases?

Three of the basic characteristics of a national cancer registration are suited very well to help the clinical databases. National cancer registration aims for a very high completeness and to be truly population based. The mandatory registration in many countries is of great help here. Cancer registration aims for long-term consistency, since studies of trends is one key aspect of surveillance. Lastly, cancer registries in most countries deliver periodic official reports, often of very high quality.

Population-based system

For a centre of clinical excellence in a private insurance-based health care system to audit their own patient cohorts only is fine, although completeness of the registration in their known cohort would still be an issue. However, if that centre claims to be the prime,

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successful centre for a given base population, the backdrop of all the cancers in the population and also the outcome for those not treated at the centre both become important information. Furthermore, if the audit covers a wider infrastructure of large and small hospitals, outpatient clinics etc serving a defined population [exemplified in 1,2], knowing that the degree of population coverage of the clinical database is high becomes vital.

A clinical research question may also have a strong public health perspective, such as when the influence of socio-demographic factors on management and/or survival after a cancer diagnosis is studied, as exemplified by three Swedish studies [3–5]. In such situations, high population coverage is essential.

In some clinical settings – and probably more often than is appreciated – patient selection to a certain institution may be associated with patient and/or disease characteristics that introduce bias and confounding in a study of the impact of interventions, and sometimes even of the association between biomarkers and clinical outcome. In such situations, knowledge about the total population of cancer patients from which the selected series is drawn would also be highly informative.

A clinical researcher may want to use an interesting group of patients registered to a clinical database as cases in a case control study that utilises population controls. This can, for many study questions, be a powerful design. Such a study design will only be possible if the source population of the clinical database can be said to correspond reasonably well to the true population from which the controls are drawn. As examples, several analytical studies based on the National Prostate Cancer Register in Sweden (NPCR) would not have been possible without the population-based nature of NPCR [6–8].

Thus, in many situations a linkage of the data in clinical databases to the population-based system would help to recover population-based clinical databases.

Long-term nature

National cancer registration aims to be of a high quality over long periods of time to be able to measure trends reliably. When clinical databases are wanted to study trends for audit or research purposes, information about their completeness year on year is also important. For example, a claim that clinics adhere to guidelines better with time could easily be criticised if completeness were not reasonably stable over the time of study.

In some clinical studies individual follow-up over decades may not be feasible. If secondary cancers are important endpoints, the cancer registry can serve as an important source of information. With increasing survival after cancer treatments and use of more advanced radiotherapy and new cytotoxic drugs on successively widened indications, secondary cancers as long-term outcome tend to become more significant.

Reports

The periodic reports from the national cancer registration centres can alert a broad research community to important clinical issues. Classical examples are the rising incidence of malignant melanoma in many western countries, the seemingly deficient effect of cervical cancer screening in an older population and the notion that older women with breast cancer are undertreated. The latter has been substantiated in studies in clinical databases [9,10].

Reports from the cancer registry put the individual cancer studies in to a large public health context. They can inform about how successful the sum of advances in public health, epidemiology, prevention, basic science, early diagnosis, and clinical management have been in "the war against cancer". Owing to the "ecological fallacy" [11] problem, we need to be careful in interpreting effects of singular interventions, but the overall perspective may be thought provoking and challenging.

Does cancer registration benefit from collaboration with clinical databases?

It most certainly does. Health care professionals responsible for the care of the individual patient on site are usually involved directly in coding and registration to the clinical databases. In cancer registries, the coding often depends on a report that may not be checked by clinicians and there are limited resources for data clerks to check original records of ambiguous data items. So, if, e.g. stage information can be double checked between systems, the registration of stage would become more reliable.

In some settings the clinical databases are used in yearly reports, e.g. to the hospital administration. In such settings, the clinics are highly motivated to capture all activities, since quantity and quality may have implications for budget. Thus, clinical databases can alert the cancer registry to missing information, such as for patients at high age not diagnosed with a biopsy and not undergoing treatments specific for the cancer [12].

When studies of clinical problems have been done on cancer registry data, the investigators have generally tried to collaborate with clinical researchers. However, if a more long-term strategic alliance is formed between cancer registries and the clinical databases, we can expect a deeper and closer involvement of clinical researchers in registry studies, aiding biological and clinical interpretation of results. Likewise, through

such collaborations, cancer registries would strengthen demonstrations of their utility also in the clinical field, which would add to the justification of registration.

How can we improve?

It is likely that a close collaboration between cancer registries and the clinical databases would be supported by sharing at least some parts of the infrastructure for registration such as IT platforms, statistical support, a common understanding of the legal aspects of registration, etc.

Where there is an interest in a closer collaboration between the two registration forms, we can learn from the mistakes and the success stories. For instance, the Nordic countries are able to exchange experience and expertise on a broad scale.

Interested parties could make strategic plans to develop the link cancer registries – clinical databases – audit – research. The plans should then not only involve infrastructure and mutual use of resources, but also a set of major studies in clinical cancer epidemiology and clinical audit. The studies – besides informing on important clinical issues – could be used to define areas of strength and weakness and point out where we can strategically use resources (competence as well as equipment) to the best cost-effectiveness.

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