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EDITORIAL

Cancer registration in the era of modern oncology and GDPR

Giske Ursin[a,b,c]

[a]Cancer Registry of Norway, Oslo, Norway; [b]University of Oslo, Institute of Basic Medical Sciences, Oslo, Norway; [c]Department of Preventive Medicine, University of Southern California, Los Angeles, USA

The Nordic cancer registries are among the oldest cancer registries in the world. The Nordic health authorities showed resolve and vision by establishing nationwide cancer registries already in the middle of the twentieth century. Denmark's registry was founded in 1943, the Finnish and Norwegian in 1952, Iceland in 1954 and Sweden in 1958 [1]. Notably, the authorities understood early that reporting must be mandatory. Doctors and laboratories that diagnose or treat cancer were required to report details of each patient to the registry in their country. Mandatory reporting, multiple case sources, histological verification, manual verification and trace back from death registry records represent key aspects of a cancer registry. As a consequence, these registries have been found to be over 95% complete in validation studies [1].

So what role do cancer registries play today after more than six decades, in the era of modern oncology? Cancer registries across the world are important for monitoring cancer incidence, mortality and survival. International Agency for Research on Cancer provide data from countries across the world in a global database (https://gco.iarc.fr).

Results from the Nordic countries are displayed in the Nordic database NORDCAN [2], a collaboration between the five Nordic countries (http://www-dep.iarc.fr/NORDCAN/english/frame.asp). A recent study from Estonia is another example of a strong cancer registry with a long history [3]. Their registry is more than 40 years old, with cancer reporting going back even further, to 1968 (https://www.tai.ee/en/r-and-d/registers/estonian-cancer-registry).

The Estonian study shows that 5-year relative survival of lung cancer diagnosed at a localized stage is currently above 50% in men and 60% in Estonia [3]. This is a remarkable improvement over the past decades. Innos et al. report that this is similar to data seen in NORDCAN for the five Nordic countries. The improvement in Estonia is attributed to surgery of small resectable lesions. A similar improvement can be seen in Norwegian rates [4]. The Estonians report an increase in T1 tumors from 2010 to 2016 from 27% to 47%, possibly due to the occasional finding on a CT ordered for other purposes [3]. This is quite a substantial change. The number of cases diagnosed at an advanced stage in the Estonian data remains high, however. Similar results can be seen in Norway [4]. Although novel cancer treatments offer hope, we need to remain realistic. Among patients with locally advanced or metastatic disease, the phase Ib KEYNOTE-001 study recently reported 23.2% overall survival rates at 5-years and survival rates above 25% among those with a high PD-L1 score [5]. These results are impressive and good news, but we cannot rejoice over survival rates as low as 25%. We need additional oncologic improvements as discussed in a recent editorial in this journal [6].

So what role can cancer registries play in this modern oncologic era? Cancer registries could and should play a stronger role in assessing the effects of all cancer treatment. Clinical cancer registries have been established in many countries, often started by surgeons who wanted to assess the effects of various surgical treatments. These registries have provided the basis for much important clinical research. However, if these registries are to have as high quality as the 'mother registries', the main cancer registries, clinical reporting needs to not only be mandatory, but reporting should also be seamlessly incorporated into electronic patient records. This requires that physicians must record treatments in a structured way, using international standard terms, in the patient record. Further, clinical registries should use international standards to register such treatment data. For that to happen, we urgently need agreed-upon international standards for what should be reported to clinical registries. While International Agency for Research on Cancer has been key in standardizing cancer incidence across five continents for decades (http://ci5.iarc.fr/Default.aspx), we have no similar international standards in clinical cancer registration.

We do, however, desperately need clinical registry data. Perhaps this is most visible within oncology. Approval of new oncologic medications requires detailed cost–benefit analyses – which require – oncology data. Where possible, and where oncological treatment is already registered structured in hospital databases, these databases should be standardized, and reported directly and electronically to clinical cancer registries. Another obvious use of such clinical registries with complete medication data would be as a valuable resource to conduct phase IV studies.

The Nordic registries all have the possibility to link to prescription registries, where all out-patient medications are registered. The newer peroral cancer medications can be obtained from these registries. However, in-hospital provided

CONTACT Giske Ursin Giske.Ursin@kreftregisteret.no Cancer Registry of Norway, P.O. Box 5313, Majorstuen, Oslo 0304, Norway

medications have not been part of our prescription registries, and have not been reported automatically to cancer registries. As a consequence, none of the Nordic registries have complete data on in-hospital provided medications. Repairing this oversight is now a large ordeal as new systems have to be developed to communicate with ever-changing hospital IT systems. We need to look to England to see how this could be done. Public Health England has ensured that they get oncology information regularly [7]. Combined with cancer registration data, this provides valuable information to test the effect of medication provided in hospitals. Cancer registries need this information in order to be as complete as possible both on incident disease and on occurrence of metastatic disease.

Cancer registries are important for monitoring rates, and for representing a possible source of cancer cases for medical research. This dependency is bilateral, however. Research using cancer registry data represents an essential validation of cancer registry data. While some quality assurance can be done manually at the registries, the most important validation is the critical assessment from outside researchers. Jokela et al. found high completeness in the Finnish cancer registry on pediatric tumors [8]. Their work also increased the completeness of the registry, simply by them providing data on a few more previously missed cases. Such validation projects are essential, in particular for clinical registries that may have a shorter history, manual reporting, limited validation of data, or registries that lack direct linkage with the cancer registries. We must also keep in mind that analyses based on 'simpler solutions' than cancer registries, may not include all cases. Jokela et al. warn against possible incomplete, and biased results, if one were to uncritically use hospital discharge data [8].

So how has the EU General Data Protection Regulation (GDPR, https://gdpr-info.eu) affected cancer registration? A number of countries, including the Nordic ones, have specific regulation in place, that still mandates cancer registration without the patient's consent. Further, current legislation is not that different from the previous strict privacy regulations that cancer registries have been operating under. Thus, introduction of GDPR provided limited impact on day-to-day routine processing of health data. But there are some challenges that have become apparent over the past year. While GDPR was expected to make it easier to share personal data between European countries, there are no obvious mechanisms for transferring already collected health data from any source (not just registry data), to third countries outside of the European Economic Area (EEA), specifically to countries which have not obtained approval from the European Commission to receive and process such data. Similarly, there are no obvious mechanisms for transferring such data to international organizations such as the International Agency for Research on Cancer, which is part of the World Health Organization. Investigators and lawyers across Europe are struggling to find transfer mechanisms subject to appropriate safeguards using GDPR. The lack of appropriate mechanisms for sharing already collected data is hampering research, and an issue every country in the EEA should raise with the EU commission.

So why not anonymize the data? This is of course possible for aggregate or tabular cancer registry data. Such data can be published openly. However, for research containing data on an individual level, the combination of details often makes it impossible to anonymize the data. Such indirectly identifiable data are still considered personal data, and cannot be shared openly according to GDPR, unless the data subjects have provided explicit informed consent to do so. Thus, analyses of European health data must, until this has been solved, simply take place in Europe.

In conclusion, cancer registration remains essential for both cancer monitoring and cancer research. Use of cancer registry data in research studies is essential to ensure high data quality. Additional data on medication are crucial and underscore the importance of such registries. Finally, cancer registries operate smoothly under GDPR. However, research collaboration with researchers outside of Europe using health data has met obstacles under GDPR. This in particular had an impact on research collaboration with the USA.

We must urge the European Commission to find solutions to this problem as soon as possible.

Disclosure statement

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