Cancer registries – future development and uses in Britain
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Summary
Cancer registries are a vital source of information on cancer epidemiology and cancer services. Their role has changed dramatically over the past 15 years. A number of factors will affect their future role, including health service changes, information technology, development of clinical datasets and greater demand for both health service and public information. The potential of cancer registration needs to be realized by clinicians and health authorities: how they can use the data, its limitations, and how they can support and influence it through this period of change. A strategic direction is needed so that cancer registries develop into a dynamic, interactive source of knowledge for the twenty-first century.

Keywords: cancer, registry, information

Introduction
Cancer registries face major dilemmas. The expectations on them have changed and they are challenged by a number of competing priorities. A review of cancer registries is currently under way and a national advisory committee will shortly consider different organizational models. What should their future role be? The aim of this paper is to stimulate debate by discussing some of the challenges facing cancer registries.

The paper arises from one of the first collaborative research studies between cancer registries in the United Kingdom to use treatment and survival outcome data, and was undertaken by the first author.1 The research investigated the incidence, management, treatment and survival of patients with head and neck cancers in four cancer registry areas of the United Kingdom. That study, by an external researcher working with cancer registries, highlighted the wealth of information within cancer registries as well as some of the issues that they face. The present paper is not a systematic analysis of all cancer areas and does not attempt to quantify the issues, but aims to raise some issues for debate.

Changing roles
Cancer registries have been collecting and publishing population-based information on cancer registration and survival for many years, some since 1947. They have a vital role in cancer epidemiology and a developing role in health service monitoring and research. Many cancer registries have changed their names to cancer intelligence units or cancer surveillance units to reflect changes in their roles. In this paper the term cancer registry will be used to cover all of these units. The importance of cancer registries has been confirmed in the expert advisory group report on cancer services in 1995, the Calman–Hine report.2 For decades cancer registries have published information on the numbers of cases, incidence and survival of cancers. The Calman–Hine report2 led to a flood of requests for management and treatment information from both district health authorities and trusts. Patient flows and geographical information systems gained increasing importance. Cancer registries were considered neutral in the purchaser–provider split but the information that they possessed on hospital and clinician caseload and outcomes was politically explosive.

Cancer registries have traditionally been regionally based. Constant changing of health district and regional boundaries makes longitudinal studies and analysis of trends very difficult. Districts that change from one cancer registry to another may find that their new cancer registry collects different information compared with their previous cancer registry, or presents it in a different way. Registries in Southern England are responding to this by standardizing their outputs to allow districts to examine trends more easily. Continuity of registry information needs to be ensured whatever the future configuration of National Health Service (NHS) management structures.

Cancer registration
Cancer registries are a rich source of population-based information on cancer incidence, management, treatment and outcomes. However, there are problems of comparability because of large differences in the completeness of these data from one
registry to another. Each cancer registry is autonomous, being commissioned regionally, and each collects different information. A common minimum dataset, which includes registration and death details, has been agreed and used since 1993. Although this dataset fulfils the national requirements of the Office for National Statistics it cannot answer many of the management and treatment questions posed to cancer registries by trusts, health authorities and researchers.

Most registries hold more information than the common minimum dataset. Additional data may include demographic factors such as deprivation and ethnic status, tumour details such as stage and histological grade, and treatment details such as the type of treatment given, the hospital and surgeon of treatment, and referral pathways. The data vary between registries. For example, during the 10 year period of the head and neck cancer study (1984–1993), the West of Scotland registry (now part of the Scottish Cancer Intelligence Unit) had data on the main hospital of treatment but not the consultant or specialty. In contrast, the West Midlands registry had details of the consultant and specialty of treatment, but had information on the hospital of treatment in only half of cases. Comparative studies are hampered by differences in the data items collected. A balance needs to be struck between autonomy and comparability.

Not only do the data items vary between registries but also the definitions of data items differ between registries and within registries over time. For example, treatment data in Thames are actively collected for the first 6 months after diagnosis, but only for the first 9 weeks in Yorkshire. This affects comparisons of treatment: 16 per cent of head and neck cancer patients in Thames (diagnosed 1984–1993) received chemotherapy compared with 4 per cent in Yorkshire. How much of this difference was real or was due to chemotherapy not being recorded? If a district or region wants to find out whether its pattern of cancer care is similar to that in the rest of the country then these differences between registries need to be overcome. A larger standardized core dataset that includes precise definitions and code lists is needed. These definitions need to be compatible with those in clinical oncology datasets. A subcommittee of the National Advisory Committee on Cancer Registration (AKCCCR) is addressing some of the dataset issues.

Cancer registries can contribute to evidence-based health care. They can provide evidence on the management and outcomes of patients treated in different ways and have been instrumental in showing a link between specialization and outcomes for breast cancer. Randomized controlled trials for the treatment of head and neck cancers are difficult because of the relatively small numbers of cases and the large number of clinicians and hospitals treating them. A population-based observational study (of head and neck cancers) was able to show differences in survival by treatment when controlled for prognostic factors.

Death and second primary cancers are the only outcome measures routinely collected by cancer registries. There is no information on disease-free survival, tumour recurrence, functional status or quality of life. In head and neck cancers survival has not improved significantly on a population basis in the Western world over the last 40 years despite advances in treatments. For these cancers more sensitive outcome measures than survival are needed to measure improvements in care.

**Does the dataset need refining?**

What data should cancer registries collect? The data in this retrospective study were 3–13 years old at the start of the study so any current datasets need to be robust enough to meet the needs of the cancer registry users of 2010 and beyond. A balance needs to be found between the comprehensiveness and the quality, completeness and timeliness of data. A large dataset and poorly defined data items both make it difficult to ensure both quality and completeness. Some registries have responded to this by collecting only the minimum dataset, relying on separate studies to answer the health service questions. Other registries have responded to the health service demands by expanding their datasets. Health authorities and trusts need to take an active part with cancer registries in planning datasets to meet their future information needs.

A number of site-specific national audit databases have been developed. Much of the cancer registry dataset can be collected as a subset within audit datasets. The major difficulties in comparing audit results between hospitals to date have been comparability and data quality. Cancer registries have expertise in setting up and managing databases and in quality assurance systems. They are a source of expertise and advice, and their skills could be disseminated to trusts for use in audit databases.

Information technology is revolutionizing the registration of cancers, with more cancers being registered electronically rather than manually from patient notes. This information exchange opens up possibilities for developing integrated data systems between clinician, trust and cancer registry. For example, in Scotland the cancer registry is permanently linked with hospital discharge and death records systems. Yet cancer registration was not initially mentioned in the NHS information strategy. To be fully exploited cancer registries need to become an integral part of the NHS.

**Data quality – a joint responsibility**

Data quality and completeness are major issues in cancer registry studies. Two examples are given here. The proportion of death certificate only (DCO) registrations (where the only information is from death certificates) in the head and neck cancer study ranged from 1 to 12 per cent between registries and varied over time. The proportion of DCO registrations not only affects the representativeness of the data but also may bias the survival rates, as they are excluded from survival analysis.
In the study the registry with highest DCO rate (Thames) also appeared to have better survival.

Some of the minimum dataset and many of the additional data items in the head and neck cancer study were incomplete. For example, TNM stage is considered the most important prognostic factor in head and neck cancers.\textsuperscript{10–12} Any comparison of outcomes between hospitals needs to be adjusted for stage. Although registries have begun to collect TNM stage for some cancer sites (breast, cervix, colorectal and melanoma) other sites have no staging information. In the head and neck study only one registry collected TNM stage and that was only 20 per cent complete. Specific audit projects have considered stage in comparisons of outcomes\textsuperscript{13} but it is not routinely available in cancer registry data.

Data quality is only as good as the clinical information provided by hospitals and clinical notes. A traceback exercise in Thames found that only 18 per cent of patient clinical notes had a tumour stage recorded.\textsuperscript{14} Data completeness is highly dependent on the co-operation between trusts and registries. The new requirement for trusts to have a service level agreement with their cancer registry\textsuperscript{15} may help completeness of data.

**Access to data and release of information**

Who should have access to cancer registry information and in what form? Cancer registries traditionally have published reports and provided summary tables in paper form. They are increasingly providing the results of such analyses in electronic form on disk\textsuperscript{16,17} and on the Internet.\textsuperscript{18,19} The United Kingdom Association of Cancer Registries has agreed a confidentiality and data release policy. Requests for information inevitably involve time and resources for cancer registries. Should health authorities have access to anonymized patient-based data for their own district to undertake their own analysis? With training and support from cancer registries this could help health authorities to explore and understand the data more fully and make better use of it. Alternatively, it could be argued that the expertise in techniques and interpretation needed to make sense of the statistics would be better concentrated in cancer intelligence units. A strong link between registries and commissioners of care is needed.

What is the role of cancer registries in informing the public? Cancer registry reports have been available to the public, and the media have picked up international comparisons of cancer outcomes. With the advent of league tables for schools and shortly for hospitals the public expectation for information and accountability is unlikely to go away. Many people within cancer registries are concerned to ensure that any public information is both valid and reliable and is not misinterpreted. Data credibility is an issue that is likely to become increasingly important for cancer registries and clinicians. Clinicians may be encouraged to alter practice only in the light of detailed, prospectively collected data in which they have confidence.

**Conclusions**

Cancer registries provide valuable information for clinicians and health commissioners but much of the information is underused. Three important and urgent steps will help this: an expanded minimum dataset; greater co-operation between trusts and cancer registries to improve data quality; and easier access to data within appropriate ethical guidelines.

What do clinicians, primary care groups and health authorities want and expect from cancer registries? Registries face competing demands of data completeness and quality, providing epidemiological information, providing health services information, responding to information requests, providing information for research and undertaking original research. Clinicians and commissioners of health care need to recognize the potential of cancer registries and join in the debate on what their future role should be.

**References**


18 [http://cbl.leeds.ac.uk/~ycr/registry/yrerhime.htm](http://cbl.leeds.ac.uk/~ycr/registry/yrerhime.htm)


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