

The future of cancer registries

Purchasers need to recognise how important they are for monitoring services

The abolition of regional health authorities raises questions about the future of the 12 regional cancer registries in England and Wales. Their survival will now depend on their ability to persuade district health authorities that they are essential for purchasing. This in turn will depend on how quickly they can acquaint purchasers with their role and function.

Cancer registration was introduced by clinicians in the 1930s to evaluate new treatments such as radium therapy. It has come to be identified with narrowly epidemiological aims, yet most registries hold a wealth of data that are vital for evaluating health care—for example, on treatment, tumour stage, place of treatment, consultant, and place of death. Although notification is voluntary, the registries achieve over 90% ascertainment for most cancers.¹ They contribute population data to the national cancer registration system at the Office of Population Censuses and Surveys, which in turn publishes annual statistics on incidence and mortality and, all too infrequently, survival.²

Most district purchasers use registry data only to monitor trends in incidence and mortality and to ensure that these accord with targets set out in the *Health of the Nation*. This is because many are ignorant about what registries can do; they know that many clinicians doubt the accuracy of registry data, and they may perceive that a registry duplicates data that they already collect. Since 1993 NHS acute hospital providers have had to make a return on each patient with cancer as part of the common dataset for cancer registration (NHS EL(92)95).

As part of their job of monitoring services purchasers also have available the minimum contract dataset which NHS hospital providers are obliged to collect. But, unlike the common dataset for returns to cancer registries, the minimum dataset is linked to consultant episodes of care and not individual patients, so patients' progress through different spells of treatment and care over time cannot be monitored. Outcome measures cannot be derived from the minimum dataset. The data that purchasers need most—relating the care of individual patients to a population in order to monitor trends in incidence (need) and care across populations—can be provided only by cancer registries. If purchasers are to evaluate health services and compare their residents' experience of health care with the experience of residents of other districts, survival statistics are necessary. Such statistics depend on having an accurate

date of diagnosis and date of death. A strict chronological sequence of clinical events must be used to define the diagnosis, and the staff of cancer registries are trained to apply such a hierarchy rigorously.

The Office of Population Censuses and Surveys automatically forwards all death certificates that mention cancer to the relevant cancer registry, which either initiates and traces a registration or updates an existing registration. The death certificate is an integral part of case ascertainment and ensuring completeness of data on incidence. The advantage of the registry handling death certificate returns is that through its links with both NHS and non-NHS providers and general practitioners its clerks can retrospectively retrieve data on cases missed across large geographical areas with relative ease. This is clearly important for ascertainment and completeness of data. District purchasers currently do not have the skill to update case records from death certificate returns; indeed, this is a major problem for the reliability of local registers for diseases other than cancer.

The main advantage of cancer registries analysing survival is that problems of patient selection can be eliminated. Despite attempts by many clinicians and health services researchers to prove the need for specialisation and for centres that treat large numbers of patients with cancer, the case for these is still at best based on clinical consensus and inconclusive research evidence. Attempts to compare treatment centres or clinicians' performance are always open to complaints of bias in case mix in the selection of patients. Data from cancer registries can be used to overcome this problem by providing statistics on survival for district of residence. Problems of patient selection also disappear if purchasers repeat these analyses for their residents by treatment centre. For the main cancers, such as those of the breast and colon, some 80% of a purchaser's patients receive treatment in their local treatment centre. By analysis of stage and survival on the basis of the 80% of purchasers' residents attending, say, treatment centre X biases in patient selection can be eliminated and treatment centres compared by purchaser's population. Furthermore, the numbers will be big enough to allow districts to look at trends in treatment and staging patterns for each treatment centre.

Ironically, one major threat to registries is from clinicians, especially those who have audited their caseloads

against what the registry says they have done. They dismiss many registry data as inaccurate. But the quality of the data held by the registry mirrors the quality of data held in the clinical notes. Two large case note studies of breast and colorectal cancer sampled from the Thames cancer registry showed that data on staging were missing for 51% of patients with breast cancer and 46% of those with colorectal cancer.¹⁴ The London Implementation Group's review of cancer services was hampered by lack of high quality information on where patients received treatment and the volume of treatment given.

The clinical response to these problems has been to use clinical audit to set up alternative and duplicate data systems. Many of these stand alone systems are not capable of comparisons between clinicians let alone across districts or providers, although more recently there have been signs of more sophisticated developments.¹ Typically, these clinical audit systems do not guarantee the quality of their data and do not link with cancer registries or other routine data systems; their data are not standardised; they are owned and used by clinicians rather than purchasers; and they have no population focus⁶; they also cannot capture patients not receiving care within the NHS acute sector. Population based comparisons of treatment are as important as comparisons of survival. Without these data purchasers will not know how many of their residents clinicians might expect to treat, at what stage they will present, and what treatments they might expect to receive. The purchaser cannot evaluate whether care is reaching all groups within their population or plan for services.

Clinicians should be encouraged to pursue clinical audit, but their audits of care should be capable of complementing a population focus and of integrating with cancer registries and routine hospital data systems.

The Expert Advisory Group on Cancer has recently published a policy framework for the commissioning of cancer services.⁷ It expects that most district hospitals will become cancer units and that tertiary care will be provided by cancer centres. Its message is clearly that there will be a move towards subspecialisation and more integrated cancer care. But the document fails to quantify the populations to be served and the volume and range of services and support required. Again, cancer registries could help answer these questions. But for them to do so purchasers will need to ensure that registries are properly resourced to develop the population perspective that purchasers need to support them in their task.

ALLYSON POLLOCK

Consultant in public health medicine

Merton, Sutton and Wandsworth Health Authority,
London SW17 7DJ

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