Cancer registration: its uses in research, and confidentiality in the EC

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Cancer registration in England and Wales was begun in 1929 by the Radium Commission. The work was transferred to the General Register Office in 1947 and thence to its successor, the Office of Population Censuses and Surveys (OPCS). National coverage, though not 100% registration, was achieved in 1962. Meanwhile a parallel system was established in Scotland, covering the whole country by 1959. The National Cancer Registry in England and Wales is the largest population-based registry in the world, containing over five million case records; though it is inevitable that some cancers will escape registration, studies of selected groups indicate a high degree of completeness of ascertainment.1 2

In December 1992 a meeting was organised in Oxford by the Society for Social Medicine (UK) in association with the UK Association of Cancer Registries and the Cancer Surveillance Group to discuss current and forthcoming developments in the cancer registration system and uses of the data in research. Most of the topics discussed below were covered in the presentations and discussion at that meeting.

The use of cancer data in descriptive and aetiological studies
Cancer registries are uniquely able to provide information on the overall burden of cancer in their territory among both the population as a whole and subgroups defined by sex and age. Population projections can be combined with projections of cancer incidence to obtain estimates of the future burden of cancer. A wide variety of descriptive studies of incidence can be carried out. Time trends can be investigated in relation to both the period of diagnosis and birth cohort. Analyses of geographical variations in incidence range from comparisons between regions or counties of the country to searches for small area clusters; these studies are greatly facilitated by the British postcode system which allows individual addresses to be automatically assigned to previously defined areas as small as census enumeration districts. Ecological studies of cancer risk and socioeconomic variables can be performed by assigning measures defined by combinations of census variables, such as the Carstairs deprivation score,3 to geographical areas.

Since 1971 copies of all cancer registrations in England, Wales and Scotland have been sent to Southport and Edinburgh to be linked with the National Health Service Central Registers (NHSCR). Cancer risk in cohorts of individuals with, for example, a common occupation, birthplace, or past medical history, can then be studied by flagging the cohorts at NHSCR. Linkage of cancer registrations to the census and other OPCS data sets occurs in the Longitudinal Study, a cohort study of a 1% sample of the population of England and Wales, enabling cancer incidence to be studied in relation to many individual characteristics.4

Most cancer registries have abandoned active follow up of patients because of the pressure on resources caused by increasing numbers of survivors. Passive follow up operates in England and Wales via the NHSCR, which receives copies of all death certificates, and in Scotland by direct matching with computerised death certificate files, but survival analyses are dependent on the completeness of follow up from these systems.

Evaluating services and health care
In addition to descriptive and aetiological studies, cancer registration data are increasingly used in evaluation of services and investigations of equity in health care.

Registries contribute both to evaluation of the effectiveness of screening for cancer and to quality assurance of current screening programmes. Effectiveness can be measured by case-control studies or randomised controlled trials, or by comparing trends in mortality (or in the incidence of invasive cancer if screening aims to detect and remove pre-invasive lesions). Linkage of cancer registry data with screening histories provides information on cancers in non-attenders, interval cancers, and cancers in subjects with suspicious screening results which were not adequately followed up.

Treatment patterns and outcomes
Treatment patterns and outcomes can be studied on a population basis using cancer registry data. In Scotland this has been done by linking individual cancer registrations, hospital discharges, and deaths; by incorporating Carstairs deprivation scores in the analysis, survival rates can be analysed with respect to the socioeconomic status of the area of residence. Survival in relation to individual social status has been analysed using...
data from the Longitudinal Study in England and Wales. Equity in health care and outcome for cancer patients in Britain has not been systematically monitored, but cancer registries could have a central role in monitoring changes in access to care, treatment and outcomes which may result from the introduction of the internal market in the National Health Service. Descriptive studies of variations in treatment or survival between districts within a region can identify areas which, for example, have unusually low or high survival rates and the causes of these patterns can then be investigated in more detail. Several studies of survival in relation to type of hospital and entry to clinical trials have been carried out both for childhood cancers and for some adult cancers.7 8 The Medical Audit Group is considering the use of cancer registry data for future studies.

International variations

International variations in survival can also indicate corresponding variations in the effectiveness of health care, though there could be many other reasons for differences in survival between countries. For instance, the apparently higher survival rates from the SEER Program in the United States compared with Britain may be due to greater ability to trace deaths in Britain through NHSCR and other means, systematic differences in the probability of registration for live and dead cases, or differences in histopathological criteria for malignancy.

National cancer registration scheme

Following the most recent review of the national UK cancer registration scheme, a national steering committee was established and the core data set extended. The present registration system at the OPCS will be shut down in September 1993, by which time the annual reference volume for 1989 should be published. The OPCS is redeveloping over 20 very large computer systems to a modern database environment. One of these is for cancer registration, which will be person-based in contrast to the current-tumour-based system; full results for cancers diagnosed in 1990 are to be published from this system in 1995. Linkage of cancers at NHSCR, which has recently introduced a computer system to replace manual working, will continue. Another major change is that cancer registration, which has been conducted on a voluntary basis in Britain since its inception, will soon become mandatory, with obligations on hospitals and other provider units to supply a “minimum data set for cancer registration” to the regional registries and on registries to send the data to OPCS. A new method of improving the completeness of ascertainment and accuracy of diagnostic data which is now under study in several regions is computerised linkage of the cancer registry with pathology databases.

Association of Cancer Registries

The population-based cancer registries in Britain represent a resource of unquestionable value for research into many aspects of cancer, which is likely to remain a major public health problem for many years, particularly as a result of the ageing of the population. The government White Paper Health of the Nation stresses the use of cancer registration to monitor progress towards several of its targets.9 Nevertheless, especially in times of financial stringency, it is important to promote greater awareness of cancer registries and the data that they contain. Partly with this in mind, the UK Association of Cancer Registries was formed in 1992. The Association is addressing the need to find more ways to make still better use of registry data by preparing a guide to registries and their data for clinicians and research workers. There is also a need for improved training both in research and in dissemination skills which might be met through regional schools of public health.

Cancer registries themselves are carrying out more research using their own data but this activity is limited by resources. According to a recent survey by the European Network of Cancer Registries, those in the UK have only 0·6 whole time equivalent staff in epidemiology, medicine, computing, or scientific work per million population covered, compared with over 5 in some European countries and a European Community average of 2.

Confidentiality and the EC

The greatest threat to cancer registration, however, arises from the issue of confidentiality. The need to safeguard the confidentiality of the personal data contained in cancer registries has always been conscientiously observed. Registries in Britain are registered under the Data Protection Act and have their own internal guidelines on data security and the release of identifiable data to bona fide researchers. Much of what was already standard procedure has recently been formalised in a published code of practice.10 There is no recorded instance of a breach of privacy by a cancer registry in respect of a registered patient. Nevertheless, cancer registration and much other epidemiological activity could be abruptly terminated if the European Community draft directive on confidentiality of personal data were ever to become law.11 This directive was originally developed with the intention of regulating commercial, administrative, and governmental organisations. Unless modified by appropriate exemptions for research, it would place on registries a duty to obtain permission from patients before registering them which would be always impracticable and sometimes impossible—for example, if they have already died—and would create restrictions on the use of the information which would render the collection of data virtually pointless. This is particularly ironic since a substantial amount of work being carried out under the European Commission’s “Europe Against Cancer” programme depends on uses of records which the directive would render illegal.

The possible consequences when the working practices of registries become a matter of political concern are illustrated by the fate of cancer registration in the former German Democratic Republic (GDR). Destruction of records relating to two million cancers registered over 36 years has been averted for the time being, but, under legal
provisions introduced at the end of 1992, cases of cancer may be reported by treating physicians only if the patient’s consent has been obtained. Although registration of newly diagnosed cases has ceased, the degree of completeness of ascertainment is much lower than before. The present special law is valid only in the region of the former GDR and expires at the end of 1994. A new law is planned for 1995, to cover the whole of Germany. If virtually complete registration is not allowed to resume, major opportunities will have been lost for studying the effects of socioeconomic and environmental change on incidence rates and the impact of reorganisation of health services on patterns of care and survival.

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