Quality of Cancer Registration Data in Scotland

Overall, the quality of recent cancer registration data in Scotland appears to be high. It is evident from reviewing the literature in this field that relatively few other cancer registries undertake specific studies of data quality and publish their results. However, where such studies are available, the quality of Scottish cancer registration data does seem to compare favourably to that reported by other cancer registries.

The references to eight ‘in-house’ studies of Scottish cancer registration data quality are listed below. In addition, three studies of case ascertainment of specific tumour types in Scotland have been published since 1995. These studies were carried out independently of the Scottish Cancer Registry and provide mixed results. The first study was conducted in seven health districts in England and one health board in Scotland covering the period 1987-1989. Records from pigmented lesion clinics and pathology laboratories collected during the Cancer Research Campaign’s health education programme (the Mole Watcher study) to promote the early detection of cutaneous malignant melanoma were matched with cancer registry records. In England, 74% out of a total of 642 cases of invasive malignant melanoma (ICD-9 172) and 44% out of a total of 155 in situ melanomas (ICD-9 232) had been registered compared with 96% and 100%, respectively in Scotland. The relatively good performance in Scotland may reflect a close working relationship between the Scottish Cancer Registry and the Scottish Melanoma Group which runs a specialist tumour registry.

The second study aimed to assess the completeness and accuracy of registration of primary intracranial tumours in the Scottish Cancer Registry compared to a database assembled in the context of a detailed incidence study carried out in South-East Scotland during 1989-1990. Unfortunately, the cancer registry identified only 54% of cases, although the registry at that time did not attempt to collect information on ‘benign’ intracranial neoplasms which were included in the detailed incidence study. Nevertheless, only 84% of neuro-epithelial tumours were identified by the cancer registry. It has since transpired that, during the timeframe of the study, the South-East Scotland Regional Cancer Registry was not receiving neuropathology data from the regional neuro-oncology centre, a situation which has now been rectified. Now, ascertainment of potential cases is achieved in a more systematic fashion, making use of all readily available sources, where possible. However, it remains a challenge to identify all intracranial tumours diagnosed solely by imaging, especially benign ones.

The third study was designed to assess the completeness of ascertainment of non-melanoma skin cancers in Greater Glasgow during a single representative month in 1995. Cases were ascertained prospectively by dermatologists and retrospectively from pathology departments serving Greater Glasgow. These cases were then compared to the holdings of the West of Scotland Cancer Registry. The Registry was missing 31% of basal cell carcinomas and 44% of squamous cell carcinomas. At the same time, the study showed that dermatologists rarely treat clinically suspicious tumours without histological proof of the diagnosis. At first sight, given the dependence of diagnosis on pathological confirmation, the relatively poor ascertainment is somewhat surprising and at odds with our own estimates of ascertainment of basal cell and squamous cell carcinoma in Ayrshire & Arran during the year 1992. The results are unlikely to be representative of the whole of Scotland because, during the period of the study (March 1995), the former West of Scotland Regional Cancer Registry did not receive histopathology records from the majority of Glasgow hospitals. In contrast, the former regional cancer registries serving most of the east side of Scotland had all been receiving histopathology records routinely since at least 1990. Under-ascertainment in Glasgow, rather than a genuine difference in risk, probably explains largely why, for example, the published (world) age-standardised incidence rates per 100,000 of non-melanoma skin cancer in Lothian for the year 1995 were substantially higher than those in Greater Glasgow (Males: Lothian 88.4, Glasgow 55.0; Females: Lothian 60.7, Glasgow 41.9). Histopathology records from hospitals across Glasgow are now captured routinely.

Routine indicators of cancer registration data quality
Routine indicators of cancer registry data quality (and advice on their interpretation) can be found in the International Agency for Research on Cancer (IARC) monographs, *Cancer Incidence in Five Continents*, (available at: [http://www-dep.iarc.fr/](http://www-dep.iarc.fr/)). Data quality indicators for all of the registries in the UK are also available on the UK Association of Cancer Registries (UKACR) website ([http://www.ukacr.org/](http://www.ukacr.org/)).

**References**


