

C11

A review of research-related information requests to a cancer registry over the past 5 years

M Keen

South West Public Health Observatory, Bristol, United Kingdom

Aim: The aim of this study was to examine the ways in which cancer registry data is used for research-related purposes. Cancer registries collect data for every cancer and neoplasm in the UK. Data collected includes cancer site, histology, and staging, together with information about hospitals attended and type of treatment. Registries also hold data on cause and date of death, which is supplied by the Office for National Statistics. This rich and comprehensive data source is mainly used by NHS organisations for planning and monitoring of cancer services.

Methods: A review of research-related information requests made to one UK cancer registry between 2001 and 2005 was performed. The registry had an electronic log of information requests which included details of the requesting organisation and the intended use of the data.

Results: The registry received around 200-300 ad hoc requests each year, of which 10-20 per year were research-related. Requestors included research organisations, university departments, doctors conducting research at their local hospitals, and medical and PhD students. There were three main types of information supplied: (1) information on whether a group of study subjects had developed cancer; (2) cause and date of deaths for studies involving long term follow-up of patients with cancer; and (3) information on cancer incidence to assist with planning study recruitment and feasibility. Ethical (Multi-centred Ethics Committee (MREC)/Patients Information Advisory Group (PIAG)) approval was required before data relating to individuals could be released, but general information on incidence and mortality was available to any requestors.

Conclusions: Cancer registry data is already being used to support researchers in a number of ways. Promotion of cancer registries will help more researchers to benefit from this useful data.