

## Appendix J

# The United Kingdom Association of Cancer Registries

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In the early 1990s, the cancer registration system in the UK was subject to rapid change. With the development of information technology, the pace of change in registration practice quickened, and increasing demands for accurate and timely information were made on the cancer registration system. Changes in the organisation of the health service and in the methods of health care delivery contributed to an increased interest from various authorities and scientists. There were new uses which could and should be made of registration data, such as medical audit and quality assurance of health care, as well as the routine uses which have been made of these data in the past, such as estimation of incidence and evaluation of survival and mortality.

There was widespread awareness both of the need to improve the quality and completeness of cancer registration data, and of the opportunities to do so through the use of information technology. Together with the increased interest from external bodies in using the data, this led to the creation of several groups bringing together cancer registry staff and personnel from the Office for Population Censuses and Surveys (OPCS, as it then was) to discuss and resolve matters of common interest.

The longest standing of these was the *Cancer Registries' Consultative Group* (CRCG) which concerned itself essentially with issues of data collection, including coding and data quality. It had representation from all cancer registries, and its members were for the most part registry managers and others closely involved in the day-to-day business of data collection. The *Cancer Surveillance Group* (CSG) was set up in 1989 to meet a perceived need for a forum bringing together those with an interest in the use of cancer data. It had a loose, open and informal membership and structure. Its members included epidemiologists and statisticians, as well as other registry staff. The *Cancer Registries' Information Technology Group* (CRITG) brought together technical experts from the various registries. Education and training was another area of activity thought to be of such importance that it could justify the establishment of

another group. There was, however, no forum which brought together registry directors on a regular basis. There was a danger, therefore, with so many different perspectives and forums in which different points of view could be expressed, that the cancer registries might fail to speak with a united voice when, for example, making representations or giving advice to government. With no coherent framework of organisation, there would be a strong possibility of duplication of effort and inadequate communication between the various groups.

It was therefore proposed that a United Kingdom Association of Cancer Registries be established. Following preliminary meetings at which almost all of the UK registries were represented, the Association was brought into being on 2nd April 1992 in Cardiff.

The Association has a federal structure. All affiliated population-based cancer registries in England, the Welsh Cancer Intelligence and Surveillance Unit, ONS, the Information and Statistics Division of the NHS in Scotland and the Northern Ireland Cancer Registry are full members with their representative, usually the director, having a vote on the Executive Committee. Associate (non-voting) members currently (2005) comprise the National Cancer Registry of Ireland, the Childhood Cancer Research Group in Oxford, the CRUK Paediatric and Familial Cancer Research Group in Manchester, the Northern Region Children and Young Persons Malignant Disease Registry in Newcastle, the West Midlands Regional Children's Tumour Registry in Birmingham, the Yorkshire Specialist Register of Cancer in Children and Young People in Leeds, and the charities Cancer Research UK and Marie Curie Cancer Care. Some years after the formation of the UKACR, a Quality Assurance group was set up to standardise the methodology for, and report on, various registry performance indicators included in the national core contract<sup>1,2</sup> such as timeliness and the percentage of registrations made solely from a death certificate. A Training Group and a Coding and Classification Group were established to oversee and co-ordinate the implementation of developments in those particular aspects of cancer registries' work. And a Clinical Effectiveness Group took forward issues relating to the registries' expanding role in clinical audit and performance monitoring on cancer. The Chairs of the various sub-groups, were invited, as appropriate, to attend Executive Committee meetings as observers.

In 2003, the structure of the UKACR's sub-groups was reorganised. Three new sub-groups were established, chaired by a registry director, and with new terms of reference and some decision-making powers delegated from the Executive Committee. The Registration Sub-group, which effectively replaced the CRCG, has the former Coding and Classification

Group and the Quality Assurance Group reporting to it. The other two groups are the Information, Communications and Technology Sub-group; and the Analysis Sub-group.

The current (2005) officers are: Chair – Professor D Forman, Director of Information and Research at the Northern and Yorkshire Cancer Registry and Information Service; Vice Chair – Dr D Brewster, Director of the Scottish Cancer Registry; and Treasurer – Mrs S Reynolds, of the Welsh Cancer Intelligence and Surveillance Unit. It was agreed that ONS was the most appropriate body to provide secretariat facilities; Dr MJ Quinn (Director of the National Cancer Intelligence Centre) was nominated by ONS to be the Association's Executive Secretary.

The UKACR provides:

- a focus for national initiatives in cancer registration;
- a coherent voice for representation of cancer registries in the United Kingdom;
- a channel for liaison between registries and for agreeing policy on matters connected with cancer registration;
- a framework to facilitate the operation of special interest groups and regional registries; and
- a means of stimulating the development of cancer registration, of information procedures and practices, and of research based on cancer registry data.

The UKACR represents the views of its members to government and other bodies operating at national level on issues concerned with data quality, the definition of information requirements, and the development of health information systems where these have implications for cancer registration, in particular where matters of overall policy are concerned. The Association was represented on the former National Advisory Committee on Cancer Registration and is currently represented on the Cancer Registration Advisory Group (CRAG). The establishment of such close links is very important given the intimate ties many regional registries have with NHS information systems, and the potential importance of cancer registration to NHS functions such as medical audit and contracting.

The UKACR has, through consensus, examined and improved coding and classification issues; agreed the complex interface document for transmission of data to and from ONS; developed performance indicators; produced a training manual and cancer-specific training packs for registry staff; developed guidelines for the release of data, including for the rapidly expanding field of genetic counselling; developed guidelines for standardisation of reported results; and established a forum for sharing the latest epidemiological research. Consensus may

be slower to achieve than coercion, but may in practice be stronger and more valuable as there is often a better chance that an agreed procedure will actually be followed. Even near consensus requires those disagreeing to continually justify their minority position.

## References

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2. Winyard G. EL(96)7: *Core contract for purchasing cancer registration* (letter). Leeds: NHS Executive, 1998.

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