

We need to talk about head and neck cancer datasets

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Currently, for cancer registration purposes, many registries send registration clerks out, or employ hospital records staff, to read clinical notes and code the cancer registration data. If this information could be captured and transferred electronically this could reduce the cost of data collection. Many types of software can now read data written using a different piece of software. Improved communication between software could support audit, research and cancer registration.

If clinical databases contained the data which cancer registries are required to collect then these could be queried to gather data either for cancer registration or for cancer registry data verification purposes. The registries could act as external verifiers of data in the audit dataset. External verification of data would reduce the possibility of bias in outcomes of audit and research.

You might expect there to be wide agreement on data to be collected by cancer registries and clinical datasets. Your expectation would be wrong and datasets for use in head and neck cancer work are rapidly proliferating. Two datasets have recently been developed for use by oral and maxillo-facial surgeons and a third by the British Association of Head and Neck Oncologists. It is likely that many of the 35 new cancer centres will each develop their own distinct dataset for local use. These datasets are being independently designed for local users dealing with problems and issues they have identified.

These datasets can only act as cancer registration data sources if they contain the correct data items. These items to be compared should be the same. Ideally, the definitions used to generate the data should be identical and agreed following discussion. If there is little consultation regarding the data needs of others (ie cancer registries) either now or in the future, then opportunities to work together to mutual benefit will be lost.

Many different people may need to use

the data on a cancer database, so it is vital that anyone developing a database consults widely with local cancer registries, local colleagues and other parties who might need to query the database at some point in the future. Software compatibility is a relatively minor issue. Ignoring for now the data protection registration issues, the most important issues are identification of the data items that a dataset is to contain (making allowances for future requirements) and definitions for each item.

It is my belief that any clinical or audit dataset which collects data on cancers or cancer treatment should have fields for collection of cancer registration information. Currently the minimum dataset for cancer registration for England (similar information is collected in Wales, Scotland and Northern Ireland) specifies: record type; registration identity number; patient's name; patient's previous surname; patient's address; patient's post code; sex; NHS number; marital status; incidence date; site of primary tumour; date of birth; type of growth (from pathology report); behaviour of growth (from pathology report); multiple tumour indicator; date of death; basis of diagnosis; death certificate only indicator; side (right/left); treatment indicator (surgery, radiotherapy, chemotherapy, other); stage (currently breast and cervix only); and grade (currently breast and cervix only).

Optional data includes: ethnic origin; country of birth; patient's occupation; patient's employment status; patient's industry; head of household's occupation; head of household's employment status; head of household's industry; and registration from screening.

Most registries collect many data items above and beyond these. Many cancer registries, however find it difficult to collect some of the minimum dataset items (eg treatment indicator) because these data are not available from their main data sources (typically pathology reports and death certificate data) and they do not have the physical resources to address other current data sources (ie clinical notes). It is time to reconsider the national minimum dataset. If agreement could be reached upon the data items to be collected by cancer registries in

future this would help to define a common core of all clinical datasets.

The accreditation of cancer centres is ongoing and creating pressure to change now. The accreditation process offers a unique opportunity to improve cancer registration data collection. New datasets are under development now. These could be used to provide cancer registration data in addition to performing their primary function if they contained the correct data items.

In England, with the abolition of the regional health authorities, the purchasing of cancer registration was devolved to district health authorities. The districts pay for the service. The NHS trusts are the data sources. The cancer registries collect the information. The Office of National Statistics are supplied with the minimum dataset. The districts also purchase cancer care from the trusts. Many districts include in trust contracts the requirement that staging data be provided to the cancer registry. The purchasers could go further with cancer centres and require that all items in the cancer registration minimum dataset be included in any dataset used in a cancer centres to manage, monitor or audit clinical care. The cancer accreditation process affords an opportunity to set standards on data to be collected in future. We have a golden opportunity to reconsider the data collected for cancer registration purposes.

We need an urgent reconsideration of data to be collected nationally by cancer registries in future. All datasets under development should include this data core. In the absence of an agreement on this core those developing clinical audit datasets should consult widely on data to be included for cancer registration purposes.

This opportunity to influence the datasets under development will not last long. There is now the opportunity to consider expansion of the cancer registration national minimum dataset currently in use; this is being considered by a working group of the national Advisory Committee on Cancer Registration. But the least we can do is use the cancer accreditation process to ensure that all cancer registries have electronic access to the data they currently struggle to collect.

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