



Dr Tim Helliwell

## Cancer pathology datasets – once and for all

**C**ancer datasets have been with us for more than 10 years now, and keep on developing. They've driven up quality and standardized diagnoses. More work needs to be done to make sure they are implemented not just by pathologists themselves but by their hospital computer systems. Here Tim Helliwell and Gill Lawrence explain.



Gill Lawrence

The series entitled 'Standards and datasets for histopathology reporting on cancers' started life as documents to support the NICE Improving Outcomes Guidance publications on breast cancer (1996) and colorectal cancer (1997). The College's Working Group on Cancer Services was formed in 1998 under the chairmanship of Professor John Sloane who was succeeded by Professor Geraint Williams. Each of these leaders did much to establish the authority of the datasets in British pathology practice. In 2009, as the Working Group starts its second decade as the commissioning group for the cancer pathology datasets and Tim Helliwell completes his term of office as the chair of the Working Group, it is timely to consider the past, present and possible future purposes of the collection of cancer pathology data in a standardised form.

### Datasets – why and how are they produced?

The cancer dataset publications aim to:

- achieve consistent terminology and content in histopathology reporting to facilitate liaison in multidisciplinary teams (MDTs) and collaboration between cancer units and centres
- aid patient management and treatment by providing the histopathological information necessary to assist clinical decision-making by the MDT
- provide accurate prognostic information for the patient and clinician
- create a common database for clinical audit and effectiveness and to provide feedback to clinicians with regard to their quality of treatment
- provide accurate data for cancer registration to facilitate epidemiological monitoring and the detection of changing patterns of disease
- create a database for research and entry into clinical trials.

To achieve these aims, the College has commissioned a series of succinct, evidence-based documents which define the minimum standards for reporting resection specimens of common cancers. These are written by experienced pathologists and are subject to broad consultation before publication. The term 'minimum'

was dropped from the titles of the datasets in 2005 as they define much more than a minimum standard of practice, incorporating both core data that are essential for patient management and prognosis, and non-core data that illuminate the pathological description of a case and provide a mechanism to accumulate additional information for audit or research and which may inform future pathology practice.

More than 30 datasets covering the common and some less common cancers will have been published, some in more than one edition, by the end of 2009. The datasets seek to combine a simple list of data items with sufficient text to establish the basis in published evidence for the inclusion of the data items, and guidance on how specimens should be handled in the laboratory and how microscopic appearances should be evaluated in order to ensure that the data are recorded reliably. The provision of a proforma that incorporates a formatted list of core data items is intended to be an *aide memoire* to help pathologists to include all the key data in their reports. Synoptic reports provide more of the basic information that is used to describe cancers, as a means to derive the core data items in particular circumstances. Audits of the completeness of reporting are a regular feature of most pathological meetings and provide a relatively painless way to introduce trainee pathologists to both audit and the information content of the datasets.

### The quality agenda

As the impact of the cancer datasets on diagnostic histopathology has increased, the College has recognised the need to ensure that consistently high standards of content and publication are achieved. Governance of the commissioning process through the Cancer Services Working Group, working with the Professional Standards Unit and Publications Department in the College, has proved to be an effective and efficient process. To validate the governance processes, the College has recently adopted the use of an assessment tool for the production of clinical guidelines that has been produced by the

AGREE Collaboration ([www.agreecollaboration.org](http://www.agreecollaboration.org)). The retrospective use of this assessment tool on published datasets identified the need to encourage authors to provide some additional information on how evidence has been acquired and assessed, and to document more formally some of the College activities, such as recording potential conflicts of interest. The provision of additional information will now be monitored prospectively. It is interesting to note that NICE is currently consulting on the use of the AGREE standards for clinical guidance that will be published in the NHS Evidence project.

### Laboratory information management systems

In recent years, the limitations of the paper-based proforma have become more apparent and many laboratories have adapted the core data items in the College datasets for use with their own laboratory information management systems (LIMS). Commercial companies have also sought to use the datasets to inform the content of, and to support, their diagnostic reporting products.<sup>1</sup> The College licenses software companies for the use of the textual content of the datasets to ensure that the dataset information is used appropriately. The College does not license the list of data items, nor does it directly endorse any commercial product.

Many benefits follow the capture of data in a structured format (to complement traditional text reports), as this not only makes reports easier to produce in a consistent format and with fewer errors, but also encourages the wider use of the vast amount of information that is captured and generated in pathology departments. The automatic capture of core cancer data in a structured database removes much of the burden of data acquisition for audit, and provides a relatively simple means of transferring data between organisations. In 2001 (updated in 2006), the College published a set of requirements for computerised cancer pathology reporting,<sup>2</sup> which specify *inter alia* that:

- histopathology computer systems should be compatible with associated laboratory management systems, local clinical database systems, and hospital patient administration and information systems
- systems should allow for direct entry of patient pathology reporting data items using proformas or templates with pick-lists with defined choices (as specified in the cancer datasets)
- recording and retrieval of coded information according to SNOMED and ICD-10 must be included, and derived fields should be calculated from entered data wherever possible (e.g. final pTNM stage)

- it must be possible to generate in electronic and printed format full text reports and synoptic reports containing the College dataset from the same data/text entry using the templates, and synoptic report contents should be in a format that is automatically transferable to a standalone relational database
- systems should allow intelligent interrogation of databases for laboratory data/workload analysis and the generation of report lists for use by MDTs, audit and research
- systems should allow the downloading of anonymous data for audit. For certain key data items (e.g. tumour and dysplasia grading, positivity of clinical cytology, incidence of common diagnoses), there should be automatic audit and benchmarking between pathologists
- systems should allow core data items and/or reports to be captured and transmitted electronically in a secure, confidential form using agreed protocols to local clinical management systems, cancer networks and regional cancer registries.

Eight years on, it is disappointing that, to our knowledge, there are still no pathology LIMS available in the UK that support fully the coded reporting of all the College datasets, let alone meet the College's minimum requirements for computerised cancer pathology reporting.

### Drivers for change

Some recent national developments provide an opportunity to address issues around the collection and sharing of cancer pathology data. The 2007/08 NHS Standard Contract for Acute Services<sup>3</sup> set outlines timescales by which all NHS providers of cancer-related services should ensure that the full Cancer Registration Dataset is provided in electronic format to their local cancer registry, with electronic extracts from pathology systems having been required by 31 July 2008. The Review of the National Cancer Dataset by the Information Standards Board<sup>4</sup> recognised (section 10.1) that: *'one of the most critical hurdles to overcome is facilitating the generation of electronic pathology reporting as a primary process to replace the retrospective interpretation of text reports currently carried out widely within cancer registries. ... This must result in improved and consistent systems with agreed coding definitions and standards to support pathologists in delivering consistent coded pathology reports nationally'*. The National Cancer Intelligence Network (NCIN) ([www.ncin.org.uk](http://www.ncin.org.uk)), which was established in 2008 as part of the Cancer Reform Strategy,<sup>5</sup> is working with the College and others to review the content of the national cancer dataset, and is funding a project designed to improve the flow of electronic pathology data to cancer registries by defining system requirements in the context of the National Pathol-

ogy IT Strategy.<sup>6</sup> The NCIN review of the content of the national dataset will feed into the annual review process for the College's cancer pathology datasets to ensure that there is a single process for defining, validating and implementing core pathology data. Finally, the *Report of the Second Phase of the Review of NHS Pathology Services in England*<sup>7</sup> and the Department of Health's response<sup>7</sup> recommend that all pathology services should not only be accredited (with UKAS and/or CPA) but also be registered by the Care Quality Commission. If, in the future, accreditation were to include a requirement for laboratories to consult with Cancer Registries (as one of the users of the pathology service) to determine their need for structured data of a defined quality, then there may be an additional lever for change.

The inadequacies of current LIMS (for cellular pathology reporting) will not surprise cellular pathologists who should also welcome the national recognition that LIMS systems are generally inadequate in their ability to support the efficient sharing of cancer pathology data. A national lead, through the NCIN working with the College, will support current local initiatives to implement software solutions to structured data collection as part of the normal diagnostic reporting process. This should help to promote timely and effective diagnostic reporting and will undoubtedly facilitate the sharing of data with MDT management systems. The use of can-

cer pathology data, e.g. tumour type and stage, is important in stratifying the clinical outcomes for cancer services; this will be of increasing importance when clinical outcome data are made available by Trusts as a measure of service quality to guide patient choice.

It is important that cellular pathologists, who are the primary source of core cancer pathology data, ensure that data items are accurately recorded and coded and are aware of their wider potential use. Laboratory managers and pathologists need to engage users of pathology data outside the laboratories in discussions about how effectively data are shared and about how data quality (core diagnostic data, SNOMED codes) is audited so that the highest possible quality of service is delivered. A structured approach to data collection, which complements the more traditional descriptive reporting of cancer specimens, will ensure that pathologists are able to collect this important information once and make it available to a wide range of users for the benefit of all.

**Dr Tim Helliwell**

**Reader in Pathology, University of Liverpool and  
Chair of RCPATH Cancer Services Working Group**

**Gill Lawrence**

**Director, West Midlands Cancer Intelligence Unit**

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**Datasets and Tissue Pathways are available on the College website:**

[www.rcpath.org/index.asp?PageID=254](http://www.rcpath.org/index.asp?PageID=254)