Synopsis of talks

Sean McPhail - Current Registry Staging Data

This talk presents an overview of the staging data that currently exists at a national level. The process by which data collected at a local level is recorded by cancer registries and then combined into the National Cancer Data Repository (NCDR) is reviewed. Representation and recording of cancer stage within the NCDR is summarised. The most recent available data on the proportion of cases with a recorded stage within registries is presented. Definitions of the circumstances when a case can be considered to be staged are considered. The nature of the cohort of cases that makes up the denominator for this proportion is also examined. These cases are then examined by cancer type and the recording of staging meta-data (such as the TNM version used or the presence of neo-adjuvant treatment) is presented.

Brian Rous - Strategies for collecting staging data

The talk outlines how staging data may be collected by U.K. Cancer registries and highlights the strategies used by the Eastern Cancer Registry and Information Centre to improve the ascertainment of staging data. The role of the National Staging Panel for Registration in developing guidance and promoting a uniform approach to collecting stage data across the registries is discussed.

Malcolm Mason - TNM

The TNM staging classification has been in use for over 50 years, and has proved its worth. It is often forgotten that it is not, nor does it intend to be, a complete prognostic factor classification. Rather, it is a descriptor of one of the most important - maybe still THE most important - prognostic factor: extent of disease. The UICC TNM Core Group is tasked with providing, and updating, a system that is applicable worldwide, usable whether a cancer patient presents to an internationally acclaimed academic centre, or to a clinic in the developing world. The Core Group is supported by several 'Task Force' groups, which focus on the TNM Process, on Prognostic Factors more generally, and on other aspects, including an ongoing 'literature watch'. Additionally, the Core group has representatives of National Committees, which act as conduits for opinion from their respective countries, and in turn act as advocates for the UICC. The process for modifying the TNM classification is in constant evolution, and the next few years may well see some fundamental developments, that will link the Core Group more closely to the National Committees, and to healthcare professionals more generally. A number of countries have, as a performance metric for their cancer centres, a requirement for the collection and recording of TNM category, and it is timely for this to be considered in the UK as well.

Lynn Hirschowitz - Royal College of Pathologists’ Working Group on Cancer Services (WGCS): Cancer Datasets and Pathological Staging

WGCS: this falls under the aegis of the RCPath Professional Standards Unit (PSU), which is responsible for appointment of the Chair and WGCS members. There is PSU, UKACR and NCIN representation on the group and ex-officio membership from other professional pathology organisations. The WGCS works closely with the RCPath Publications section during the consultation phase of the datasets.
Role of the WGCS: to commission, review and publish succinct, evidence-based documents (cancer datasets) defining standards for reporting of common cancers, to ensure that histopathologists define pathological standards in the datasets and that College Fellows and stakeholders are involved in a consultation process to agree on the standards.

Cancer Datasets: these are commissioned in collaboration with subspecialty histopathology advisers. Authors are given guidelines for writing the datasets, which should include background, narrative advice and reporting proforma/s. Core and non-core data items must be evidence-based and include all information required for staging, prognosis and treatment of the specific cancer. The datasets are reviewed by the WGCS before RCPath fellows and stakeholders are consulted. Feedback from the consultation must be addressed before publication.

Cancer staging: the staging system to be used for each cancer type must be specified by the dataset authors and included as an appendix in the published documents. The staging recorded in the reporting proformas is regarded as provisional as final staging is contingent on MDT review. After consulting with subspecialty leads in histopathology, the WGCS published guidance on TNM7 implementation. The version of TNM used should be specified.

Recent developments: these include a WGCS survey of use, formats and coding for cancer datasets; a collaboration with US, Canadian and Australian Colleges to align core content of cancer datasets; a joint initiative with the NCIN pathology lead, Dr Tim Helliwell, for the RCPath to adopt the core data items as professional standards. The cancer dataset items have been proposed as KPIs. An audit of completeness of cancer dataset reporting has been suggested to HQIP.

Tim Helliwell - Staging of Head and Neck Cancers

This presentation will briefly review the complexities of TNM staging of head and neck cancers, recent data from the national audit (DAHNO) and the limitations of TNM for guiding effective management and predicting outcomes.

The anatomical complexities of the head and neck region are reflected in the need for TNM to include clinical, imaging and pathological data for accurate staging.

Registry data indicate that for England in 2006-8, staging data were available (from pathology reports) for 10.4% head and neck cancers. The 6th report from the DAHNO project provides a detailed analysis of the 6458 cases of cancers of the oral cavity pharynx, larynx and major salivary glands (95.7% of the number estimated from registry data). 94% patients had a care plan recorded and pre-treatment T and N staging were recorded in 79%. This is an improvement on previous years but falls below the 85% level of ambition. More than 50% of Networks record staging data in >80% patients but there is a wide range (34-99%) of completeness which is not related to number of patients registered with the audit. About 40% of head and neck cancers are treated primarily by surgery, and only 49% of patients with oral and laryngeal cancer had post-treatment stage recorded. Contributory factors to the variations in data completeness may include local enthusiasm and leadership, IT support for the MDT process and ease of data recording and transfer to the audit database. The publication of cancer outcome data should be a useful stimulus for MDTs to ensure accurate recording of staging data but MDT information systems need to be reviewed to ensure that all relevant data are captured.

The inherent limitations of TNM in predicting outcomes include the lack of important biological and pathological predictors of outcome, particularly for non-surgical treatments, the influence of lifestyle factors such as HPV infection, and the important contribution of co-morbidities and socio-economic deprivation to outcome.

The challenge for the future is how to retain a globally acceptable staging system for common communication while incorporating the other relevant information for patient management.
**Julia Newton-Bishop - Skin Tumour Staging**

Current staging is very poor for skin cancer, not least because skin cancer is extremely common and has been managed until comparatively recently by very large numbers of clinicians not working within teams. Approximately 1 in 3 people in the UK will develop a basal cell carcinoma. The mortality from non-melanoma skin cancer moreover is low so that cancer registration and staging has been a low priority in a system with poor IT support. National staging data for non-melanoma skin cancer are pretty much non-existent as a result. It is important to address this to compare the quality of care across the NHS and to manage costs of care as the aging population will result in increasing numbers of these cancers which must be managed effectively. It will not be possible to do this however without universal pathology reporting using RCPath data sets and the generation of histopathology reports with data fields downloaded directly to the registries.

Melanoma has an appreciable mortality and has a relatively flat age distribution curve so that young adults represent a reasonable proportion of affected individuals. The current staging requirements for cancer registries however are inadequate: the registries are required to collect Clark’s stage (which is a redundant measure) and Breslow thickness. Thickness is a useful predictor of outcome for primary tumours but is only one component of AJCC staging.

The first urgent step is therefore to move to AJCC staging of all melanomas, which will require pathology reporting of the essential components of the primary (thickness, mitotic rate, ulceration) and the collection of additional data at MDT (sentinel node biopsy status, present of distant metastases, LDH level).

**Paul Finan - Colorectal staging**

For such a common disease it is a cause astonishment that even a simple staging system for colorectal cancer has not been agreed at a national level. Dukes' classification has had several "modifications", some by Dukes himself! The TNM staging system was hailed as the way forward and yet there is no agreement as to the version that should be adopted. What is clear, as comparisons in outcomes are made internationally, is that we need to move to an agreed system that can be adopted throughout the UK and can be used for such comparisons. Information on distant metastatic disease is often missing and this is bourne out when one looks at the Registry returns that form the National Cancer Data Repository. The opportunity for change and the introduction of a uniform integrated clinico-pathological staging system is of the utmost importance and, if registration is to be devolved to individual MDTs, national guidance is essential. The short presentation will cover the problems that are currently experienced and hopefully stimulate a move to an agreed national staging system for colorectal cancer.

**Lars Holmberg - Recording Cancer Stage – Swedish Experience**

Law in Sweden mandates Cancer registration since 1958. A survey 1998 showed a completeness of 92% of the National Cancer Register (NCR). The law mandates that the organisation that provides care reports all new cases and thus provides an infrastructure for a complete reporting. Reporting stage of disease at diagnosis has only been mandatory since 2002. However, during the 1990s multidisciplinary groups for many cancer sites – and for all major sites – started clinical databases recording stage of disease and treatment. Since 2000 a growing number of groups have joined in, with now virtually all types of cancer covered. The completeness of the databases is constantly monitored against the NCR. Six regional oncological centres provides for both cancer registration and the collection of data for the clinical databases and the information about stage in the clinical databases can be fed directly to the NCR. The same IT platform supports all the clinical databases.
The clinical databases are used for quality assurance, administrative planning and research and are thus scrutinized in many ways, ensuring their validity. The process rests on several principles that underpin capture of complete and correct data:

- Registration mandated by law
- The law mandates that the organisation that provides care supports a complete registration
- Professional teams responsible for the patients’ care capture the stage information
- Professional teams constantly scrutinize the information
- The same infrastructure supports cancer registration and clinical databases

The weak points are: a less complete registration of older, frail patients or patients with advanced disease without histological verification and where no primary treatment is undertaken; a tendency to want to capture too much data which creates resistance to registration; for some cancer forms a relatively weak professional interest for feedback and research.

David Forman - International perspective

The routine collection of stage information by cancer registries is widely regarded as a critical process in building an understanding of the cancer burden within a population. Many registries capture some stage information and this has been usefully exploited to investigate the evolution of stage distribution within populations over time. However, there have rarely been systematic attempts to collate stage information across different international populations outside of specific studies (e.g. the EUROCARE high resolution studies) and even then, there have been few efforts to control the quality of stage information collected. A diversity of protocols are available for collection of stage information with no pre-defined standards. The approach generally has been to “take whatever has been provided” and, while this can be informative at some levels, it represents a crude standard of analysis. Recent attempts to improve this situation include module 1 of the International Cancer Benchmarking Programme (in high resource countries) and the IARC SurvCan project (mainly in low and medium resource countries). Examples from these projects and others will be used to demonstrate the strengths and weaknesses of these approaches and to initiate a discussion on strategies for moving forward.

Martin Crowe - Cancer Staging Tools

Cancer is a varied collection of diseases. The internationally recognised TNM staging system is different for each of over 50 malignancy types. It is hard to commit to memory and is often updated/ altered. Textbooks and manuals help professionals decide the correct TNM values and group stage, but these books may not be readily to hand when required, or might be out-of-date. For Radiologists to consistently give TNM stages in their reports they need a process that is quick and easy. They also need confidence that they are getting it right. A software programme can help here, provided it is simple, accurate and faster than using a book.

“StageCRAFT” has been created by myself (a Radiologist) specifically for this purpose. It will give a TNM and group stage in the following malignancies: bladder, cervix, colorectal, endometrium, lung, lymphoma, oesophagus, prostate and kidney. In addition, it provides helpful anatomic diagrams and key scan images. It will explain cervical lymph node levels and thoracic node stations. There are tables and calculators to assess adrenal nodule enhancement, risk of pathological fracture in bone metastases, and response to treatment (RECIST 1.1 or WHO criteria). There are also key hyperlinks for access to more in-depth information if required. The philosophy behind the programme is to make staging a quicker and more consistent process for Radiologists (and other professional groups). This started off as a personal project but I have made it available for others to use. Feedback from users has been overwhelmingly positive and it has now been downloaded in over 50 countries. StageCRAFT is being developed commercially, but is currently still available free at ...

www.tumourstager.com
**Trish Stokes - Cancer Outcomes and Services Dataset**

This talk will explain the purpose and scope of the Cancer Outcomes and Services Dataset which sets out the requirements for data collection for all cancer patients in the NHS in England. This is a partnership project between the National Cancer Intelligence Network and the NHS Information Centre (NHS IC) in collaboration with the NCIN Site Specific Clinical Reference Groups. There are currently a variety of cancer datasets in existence and the COSD project aims to define a single consistent dataset to support the current core business needs of the NHS. It will replace the current National Cancer Dataset and will include both the Cancer Registration dataset and additional site specific data items relevant to the different tumour types. It will be aligned with the other mandated national cancer datasets (Cancer Waits and Radiotherapy) and with the Systemic Anti Cancer Therapy dataset (SACT) which is currently being developed.

The dataset will provide information on incidence, mortality and survival and also service and outcomes. The intention is to collect data already used for patient management and clinical care and which should mostly be available from existing NHS electronic systems where possible such as PAS, pathology and MDT systems. These data will then be sent to the regional cancer registries who will link these and other multiple data sources at patient level using NHS number to complete the full dataset.

**Gill Lawrence - Breast cancer staging**

TNM staging is not widely used in the UK for the routine staging of breast cancers at pre- and post-operative multi-disciplinary team (MDT) meetings where treatment decisions are made. Pre-operative meetings use clinical imaging data (x-ray and MRI) to estimate the radiological size of the breast tumour and hence to decide whether to recommend breast conserving surgery or mastectomy to the patient. Ultrasound imaging together with needle biopsy or sentinel lymph node biopsy is also being used more frequently to identify nodal involvement prior to surgery. This pre-operative information is rarely translated into a documented clinical TNM stage. At post-operative MDMs, the UK Nottingham Prognostic Index (NPI) score and/or the US ‘Adjuvant on Line’ system are frequently used to make decisions about adjuvant therapy rather than TNM stage. Neo-adjuvant therapy is now being offered by many MDTs to shrink breast cancers prior to surgery or to test for positive tissue responses to chemotherapy or endocrine therapy. In this case information from the excision specimen cannot be used to provide a stage at diagnosis.

NPI values based on tumour size, nodal involvement and grade cannot be converted directly into a pathological TNM stage, but can be calculated from the information in the excision specimen report (provided that neo-adjuvant therapy has not been given). Most of the information required to derive the T and N components of the overall TNM stage for breast cancer is also included (tumour size and extent, nodal involvement), but reports rarely include the information on whether nodes are fixed or mobile that is required for TNM staging purposes. The information on distant metastatic spread required to derive the M component is rarely available in an excision report, and access to imaging data is required to obtain this information. However, whole body imaging is not recommended for patients with early breast cancer, so the information required to derive the M component for the TNM stage may not be available.

**Sally Vernon - Making assumptions**

One problem facing cancer registries aiming to improve their staging data is the question of partial stages. The WMCIU receives regular data flows from pathology labs, which commonly state the T stage of the tumour, often mention the N stage, but are unable to comment on the M stage, as the pathologist is only looking at the resected primary tumour. There is also a problem that it is more likely that oncology notes will comment on a positive feature (eg ‘the patient has positive metastases’) than on a negative feature (‘no metastases were found’)
The WMCIU's primary aim is to improve the quality of data collected, so that all parts of TNM stage are known. However, it is also important that the data already collected are used as fully as possible. In this talk we discuss making assumptions around missing staging information for certain tumours. For example, if we have information that the tumour was a T1 and the nodes were negative, and had no mention of metastases, would it be reasonable and evidence based to assume that the tumour was M0?

The WMCIU has used statistical regression to find the significant factors for predicting missing staging components for each cancer site. Tumours have been grouped by these factors, and for each group the assumptions tested – by looking at the cases where the missing staging component was known to see if the majority of these were negative or positive, and by looking at the survival curves for the unknown cases and comparing this with the known positives and known negatives. It is concluded that there are cases where assumptions can be made which are correct over 90% of the time. However, improving the data collection and reducing missing data remains the main way that staging data will be improved.

Andy Nordin - FIGO staging for Gynaecological Cancers

There is international support for the use of FIGO staging for gynaecological malignancies, which date back to 1961. In 2000 the International Gynecological Cancer Society collaborated with FIGO (International Federation Gynaecology and Obstetrics) to produce staging classifications and clinical practice guidelines. Full revision of the staging systems for carcinoma of the vulva, cervix and endometrium were produced and published in 2009 in collaboration with a new staging system for uterine sarcomas. Previously published staging systems for cancers of the vagina, fallopian tube, ovary and gestational trophoblastic neoplasia were republished but not revised.

The United Kingdom Gynaecological Oncology Community was caught by surprise by the publication of the revised vulva, cervix and endometrium staging systems in the International Journal of Gynecological and Obstetrics in 2009, and were unprepared for the changes that were required to data collection systems, clinical guidelines and patient information literature.

It is understood that the ovarian guidelines will be revised shortly and the NCIN Gynaecological Clinical Reference Group therefore contacted the Chairman of FIGO seeking clarification as to when this revision may be expected. Unfortunately we have not had a reply to this request to date. With the development of the National Cancer Data Set, the NCIN Clinical Reference Group, the British Association of Gynaecological Pathologists and the British Gynaecological Cancer Society consulted with its members and collaborated to clarify the future staging system requirements of the gynaecological oncology community. These organisations endorsed the use of FIGO staging, as the FIGO staging systems were clearly in routine clinical use throughout the United Kingdom and the maintenance of FIGO staging systems enabled ongoing international comparisons. Chairs of the three organisations published a letter to the editor of the International Journal of Gynecological Cancer in November 2010 endorsing the recommendations for the use of FIGO staging in the United Kingdom, with the addition of TNM staging for nodal status for early stage cervical cancer (which is not included in the FIGO staging system). The Clinical Reference Group of the NCIN co-ordinated the national introduction of the revised FIGO staging systems on the 1st January 2010.

FIGO staging systems are generally surgical in nature, based on surgical and histological findings. The principal exception is the cervical cancer staging system, because cervical cancers are frequently managed by chemoradiotherapy and even early stage cervical cancers can be treated with this methodology as effectively as they can be treated surgically. This creates a particular complication for Cancer Registries which seek to translate FIGO staging in to TNM staging. FIGO stage 1 cervical
cancer relates to a cervical cancer which appears clinically and on appropriate imaging to be confined to the cervix. However, should a patient undergo a radical hysterectomy procedure with lymphadenectomy, positive lymph nodes do not change the FIGO staging. We, therefore, have a situation where a FIGO stage 1B1 patient with negative nodes (T1 N0 M0) has the same FIGO staging as a patient with positive nodes (T1 N1 M0), the former with no need for adjuvant treatment and an 85% 5 year survival and the latter with the need for adjuvant chemoradiotherapy treatment and a 35 – 40% 5 year survival. For this reason, the British Gynaecology Oncology community considered that nodal status should be included in the National Cancer Data Set.

To accurately assign a FIGO stage, all relevant clinical information is required and this generally includes clinical findings, the histology of any diagnostic biopsy and also the pathology from any surgical resections and staging procedures, imaging including ultrasound, CT, MRI and possibly PET, and knowledge of the surgical/operative findings. The apparent stage may change on a number of occasions at various stages of the diagnostic and staging pathway and only the Gynaecological Oncology Multi-Disciplinary Team (MDT) is in a position to understand this process and accurately assign the definitive stage when all necessary information is available. It is, therefore, essential that the definitive FIGO stage for each patient is assigned by the MDT at the appropriate time and that this data is then uploaded to the Cancer Registries.

Considering every gynae cancer patient in the UK is discussed by a MDT and all cancer centres routinely assign FIGO staging, it is a great disappointment that centrally available staging data is poor for ovarian, uterine and vulval malignancies, generally confined to only two cancer registries (ECRIC and NYCRIS). Staging for cervix cancer is slightly better, but the analysis distributed to clinical teams to assist them in preparation of this current year’s Peer Review Clinical Lines of Enquiry shows great national variation, largely dependent on the local cancer registry. Clearly this is the next major challenge for the gynae oncology community and the cancer registries.

Steven Oliver - Staging haematological malignancies

The session will cover: an outline of the prognostic components of the proposed Cancer Outcomes and Services Dataset for haematological malignancies; information on the current completeness of staging for lymphomas in the merged English registry dataset; consideration of the level of staging achievable in a specialist haematological cancer registry and conclude with some questions to consider in taking forward the concept of a registry stage for lymphomas.

Michael D Peake - Lung cancer staging

1. Which tumour staging system is used? For lung cancer we are now committed to the UICC v7 of their TNM staging manual. Small Cell Lung Cancer (SCLC) had, until v7 of the UICC manual was published, been staged using the Veterans’ Association classification into ‘Limited’ and ‘Extensive’ disease. V7 proposed that SCLC should be staged in the same way as Non-Small Cell Lung Cancer using the TNM system and this has been accepted by UK professional bodies. For mesothelioma, there is no international consensus on staging and it is poorly recorded in the UK (and elsewhere).

2. How are the data collected? With the roll out of the National Lung Cancer Audit, data on Clinical Stage for lung cancer are now well collected, almost entirely by MDTs. This achieved with variable levels of support from MDT co-ordinators, audit staff, specialist nurses and clinicians. In 2009 the completeness for this data field was around 80%.

Pathological stage from surgical resection specimens is variably collected by MDT audit staff or direct from pathology reports seen by cancer registries.
3. Are there regional/local variations in how the data are collected? Instructions were issued (in England) to switch collection of TNM v7 (from v6) on 1.1.10. The software underpinning the NLCA was modified to allow collection of either v6 or v7 in 2010 and we are shortly to begin analysing the 2010 data so will soon be able to report on the regional and local variations in their usage.

4. Are there errors in interpretation? We believe that the quality of CT scan reporting is variable, with many scans being reported by general radiologists and there is anecdotal evidence of a tendency to over-stage in less expert settings. The standard of PET scan reporting and of the pathological stage in resection specimens we believe is very high. There is variable access to mediastinal staging across the country which probably means the quality of nodal stage is of variable accuracy.

5. Changes in the stage over the course of the diagnostic pathway. This is the major concern for the lung cancer community. All the NLCA thinking, data collection, reporting and analysis have been based on the Clinical Stage at the time of the MDT treatment decision. As progressively more investigations are carried out over time, the new evidence often changes the interpretation of stage and it must be clear in any data collection exercise precisely which ‘stage’ at which point in the care pathway is being recorded.