Measuring Quality in Cancer Services

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

July 2007

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# Measuring Quality in Cancer Services

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Executive Summary

This research has investigated population-level datasets in England to develop measures of quality in cancer services. We have assessed:

- their availability, statistical characteristics and presentation;
- perceptions of managers, patients and analysts for their use;
- their statistical inter-relationships.

Measuring Quality in Cancer Services (MQiCS) was proposed in response to a competitive call for research put forward by the Department of Health in 2003 as part of the Service Delivery and Organisation research programme. The study was led from UCL Epidemiology and Public Health, with collaborators within UCL (Departments of Mathematics and Psychology) and from London School of Hygiene (Cancer Survival Group) and Royal Holloway College (School of Management). The study was approved by the South East Regional Ethics Committee.

We reviewed literature in two fields: datasets for cancer services management; and organisational determinants of cancer outcomes.

The impacts of networks on cancer services have been previously investigated, but not the assessment of performance of cancer services. In health care, there is greater focus on the use of qualitative information and tacit knowledge, and less use of routinely available data for operational management and the factors that inhibit or facilitate the use of routinely available data.

Datasets

We identified six national datasets which describe aspects of cancer services:

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The Acute Hospital Portfolio, National Cancer Peer Review and Cancer Waiting Times datasets refer directly to hospital trusts, while for the other three we grouped at hospital trust level data from anonymised individuals. We investigated the four common cancers - breast, colo-rectal, lung and prostate (peer review standards were not available for prostate cancer).

The data were related approximately around 2000/1, and we had to match the changing NHS organisational structures over time and also group data according to the 34 cancer networks in England. For survival, data could only be analysed at cancer network level to accommodate the statistical requirements of age, sex and socio-economic group standardisation.
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The datasets were cleaned and **Limited Datasets**, providing national, network and local trust data, were distributed to each of the 34 cancer networks.

We also developed a range of graphical **presentations** for the datasets that enable comparisons.

**Perceptions of users**

To learn how managers at network level use cancer services quality data, we made initial group interviews with four cancer network management teams, and then structured telephone interviews with 68 managers from 29 networks. Respondents indicated that networks had few staff for information analysis, and rarely had an information strategy. They were focused on demands from the Department of Health to improve data collection, ensuring better data upwards rather than using data for their own management.

We also held two focus groups with patient representatives, including discussing questions of choice, and discussed our findings with national cancer information stakeholders. Five networks provided feedback after receiving the datasets, and the response suggested continued low interest in using these data for management at cancer network level.

**Data analysis**

The datasets showed ranges for both networks and hospital trusts, with statistically significant outliers - including for survival (at cancer network level). We compared the datasets using rank correlations. Analyses between datasets required many statistical tests. We used standard levels of statistical significance, but caution is needed in interpretation.

The large majority of associations were non-significant. However, both positive and negative findings were found.

- There were stronger correlations within hospitals for rankings between tumour types, and fewer associations between hospitals for the different measured dimensions. This suggested that hospital characteristics had greater impact on cancer services performance than differences in specialist care.

- One-year survival (at cancer network level) for colorectal and lung cancers was associated with total cancer standards score. Satisfaction (at hospital trust level) for breast, colorectal and prostate cancers, was associated in hospitals with fewer formal complaints. Some cancer standards for hospital cancer centres and units showed associations for breast cancer an inpatient measure of satisfaction, while tumour-specific team cancer standards for lung cancer showed associations with an outpatient measure.

- One year survival was not associated with total standards score for breast cancer, and five year survival was not associated with standards for any tumour type. Measures of waiting showed little association between each other, and GP referral waiting time measures were not
-associated with any expected positive performance. Hospitals with slower admissions of (all, general) patients through emergency departments had greater inpatient satisfaction with cancer care, for all tumour types. Staff variables showed few expected performance associations.

Conclusion

Existing routine datasets are of value both for local assessment of performance by cancer networks, and also for analysis to understand relationships and possible effects between structure, process and outcome at service level. Routinely available cancer data are an underused resource, and deserve further attention both for performance management and for health services research.
Section 1  Introduction

1.1  Cancer information at population level

Background

In 1995, the NHS published *Guidance for Purchasers and Providers of Cancer Services*, an Expert Advisory Group report to the Chief Medical Officers of England and Wales. Action on cancer services was partly stimulated by the professional interest of the then Chief Medical Officer in England, Dr Calman, formerly a professor of oncology. The aim of the action programme was to co-ordinate modalities of service (e.g. chemotherapy, radiotherapy) on a geographical basis, develop a hierarchy of cancer units and centres collaborating with each other, and improve treatment of rarer tumours in specialised centres.

From 1997 there was a change in government, a new Chief Medical Officer, and (subsequently) devolution of the NHS into separate services for England, Wales, Scotland, and Northern Ireland. In England, a Director of Cancer Services was appointed in 1999, with responsibilities both leading cancer policy within the Department of Health and also leading implementation of change within the NHS. A Cancer Plan was published in November 2000, the first of four disease-specific ‘national service frameworks’. In the same year, the government also decided to make substantial increases in NHS funding, and created new structures to direct service improvement from the Department of Health (the Modernisation Agency) with some freedom to allocate new funds and a particular focus on reducing waiting times for care.

The Cancer Plan for England therefore included both ways of improving clinical services through evidence-based treatment, and also new structures to promote service delivery. The new structures included a national NHS Cancer Action Team, with a greater focus on clinical services (for example, developing local specialist teams), and also the NHS Cancer Services Collaborative which was concerned with improving organisation at local level (for example, shorter waiting times).

Drawing on the existing designation of cancer centres and units, the Plan created 34 defined cancer networks across England (see Figure 1). These roughly corresponded to the decentralised boundaries of the Special Health Authorities (SHAs) at that time (however, SHAs were later reconfigured at regional level, and have lost the coterminosity). The cancer networks are designed to reflect patient referral ‘economies’, linking specialist facilities with associated hospitals across national transportation links, and reflecting the ‘hierarchy’ of co-operating cancer services initially foreseen by Calman, while cutting across other initiatives by government to make hospitals more independent, and indeed to compete with each other. The cancer networks...
were required to have a Board representing the collaborating hospitals, but were each established by local arrangements without central direction on their structures.

Fig 1  Map of cancer networks

At the time of the Research Call for the present study, therefore, cancer services in England were in the middle of substantial change. New developments were being funded across the country, including major investments in electronic patient information, new systems of guidance on clinical practice, and creation of private-sector entities to compete under regulation. The call sought for research to capture some of these issues through analysing national available datasets, some of which had been generated by the Cancer Plan, and which offered a national perspective on the state of the services.

In response to the research call, we put forward a proposal for a two-year study which would both report on the state of information use by the newly-created cancer networks, and also to make innovative analyses of the datasets on organisational issues. Our report is organised in the following way.

- Introduction: provides the setting and a brief description of the conduct of the study.
- Literature reviews: the literature addresses the two main areas of the study - literature on NHS information management, and an international
literature on explanatory factors for health service outcomes related to the data analyses of the research.

- Cancer networks information: we describe a pilot study with four cancer network teams, and the subsequent telephone survey of 29 cancer network teams which gained their views on the use of routine data for network level management.

- The datasets: the chapter describes the six datasets we worked with, their availability and characteristics, assessed using a standardised databank method.

- The limited dataset: we created a ‘limited dataset’, drawing together data items from the larger datasets, which has a range of dimensions for comparisons at network and hospital trust level, and analysis.

- Presentation: We briefly describe ways of presenting data to the networks.

- Analyses of the datasets: the six questions for data analysis posed in the research Call are addressed here.

- Cancer services statistics: a way forward: the chapter discusses themes from the study and the need to develop information support to cancer networks for their management role.

- Conclusion.

1.2 Background - research proposal

The study was commissioned by the Department of Health (DH) through its Research and Development Division’s Service Development and Organisation programme (SDO).

The call text was the result of consultation by SDO both within the DH (including the Cancer Services Team), the NHS (including the Director of Cancer Services and the Healthcare Commission), and external academic advisers. It calls for the analysis of data and comparisons for four common tumour types, and also for understanding of the organisational context of the data. As a result, our study had two complementary streams, concerned with use of information and analysis of the information.

The theoretical approaches used were multi-disciplinary. We looked to the fields of management research, organisational psychology and informatics for our study of use of information. We looked to epidemiology, clinical studies and health services research for our analyses of the datasets chosen.

1.3 Organisation of the study

The study was undertaken from April 2004 to October 2006. Consultations were held between the SDO and the DH sponsor department (the Director of Cancer Services) annually during the research, and there were more frequent contacts with NHS cancer networks and services. Referees were commissioned by the SDO and made comments on two occasions, from which the report was revised and approved in July 2007.
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We divided the study into two complementary teams, co-ordinated by Professor Mark McCarthy, and with Ms Marina Thomas appointed as (part-time) co-ordinator.

1 Dr Dawn Wilkinson undertook the information use side of the study, working with Professor Ewan Ferlie and Dr Rachael Addicott (Royal Holloway College, University of London) for organisational sociology and Professor Susan Michie (UCL Department of Behavioural Psychology,) for social psychology.

2 Mr Arturo González-Izquierdo (year 1) and Ms Preeti Datta (year 2) and Dr Artak Khachatryan (UCL Epidemiology and Public Health) undertook the data side, working with Mr Chris Sherlaw-Johnson (Department of Mathematics, UCL) and Professor Michel Coleman and Dr Bernard Rachet (Cancer Research UK Cancer Survival Unit, London School of Hygiene and Tropical Medicine).

We also held quarterly meetings with our Research Advisory Committee, including representatives from sponsor and stakeholder organisations and a patient representative.

There was a temporal sequence to the study. We needed to identify national datasets, assess and clean them, create organisation-specific data, and distribute them to networks, and then undertake analyses. At the same time, we wished to investigate how stakeholders saw these data for use, and this part of the study could be undertaken before datasets were distributed. This report describes the two streams of work, and their integration as recommendations for policy and further research in this field.
Section 2 Literature review

This Section is in two parts. First, we look at literature from the NHS on the use of information in cancer services management. Second, we examine international literature about the use of administrative databases to assess performance and outcome.

2.1 Using aggregate data for management

Our review revealed that there is relatively little literature on organisational management (in contrast to clinical management) in cancer services. We have divided the literature of relevance into three broad areas (although these were not mutually exclusive) and comment on the gaps in the literature.

1 Network models and cancer services.
2 Knowledge management and learning processes.
3 Using data in health and social care.

2.1.1 Networks and cancer services

The literature on network models and cancer services mapped the emergence of networks (as opposed to hierarchies or bureaucracies) as new models of management (e.g. Ferlie and Pettigrew, 1996). Organisation of health, and more specifically cancer, services were shown to be moving toward the ‘managed network’ form where the network is constructed and managed rather than naturally evolving out of professional and organisational relationships (e.g. Addicott, McGivern, & Ferlie, 2005a; Addicott, McGivern, & Ferlie, 2005b; Cropper, Hopper, & Spencer, 2002; Ferlie, Hawkins, & Kewell, 2002, Kunkler 2000). Studies documented the organisational realities of the managed network and partnership working within cancer services, and the impact these have had on processes such as learning and development (e.g. Addicott, et al., 2005a; Richardson, Sitzia, & Cotterell, 2005, Rimmer 2002).

2.1.2 Knowledge management / learning processes

The knowledge management and learning processes literature explored the ways in which different types of information are used within organisations and the processes by which information becomes usable knowledge (e.g. Argote, McEvily, & Reagans, 2003; Seely Brown, & Duguid, 2000). Network relationships and communities of practice that foster knowledge transfer are discussed as well as systemic barriers that might (and do) inhibit the transformation of information into innovation (e.g. Bate & Robert, 2002; Swan, Scarbrough, & Robertson, 2002). Examples of contrived and organic learning processes are explored in relation to another public service (i.e. the UK’s Beacon council scheme). The reasons for apparent shortcomings for
imposed learning strategies such as these are discussed in relation to organisational contexts and realities (e.g. Downe, Hartley & Rashman, 2004; Rashman, & Hartley, 2002).

2.1.3 Using data in health and social care

The literature on data use in health and social care covered a range of issues such as the availability of routinely collected information, the (somewhat missed) opportunities to use this information for management purposes, and the practicalities of doing so (e.g. Brittain, & Macdougall, 1995; Fuller-Love, & Cooper, 1996; Lakhani, Coles, Eayres, Spence, & Sanderson, 2005, Lilford 2004). Key issues on the use of performance indicators are discussed, as well as considerations in determining the quality and utility of such data (Black, 1999; Exworthy, Wilkinson, McColl, Moore, Roderick, Smith, & Gabbay, 2003; Lefkovitz, 2004; Powell, Davies, & Thomson, 2003). There is a strong focus in this literature on the use and impact of published performance data such as US score cards and NHS Star Ratings, both from the perspective of the service user and the service provider (e.g. Goddard, Mannion, & Smith, 2000; Mannion, & Davies, 2002; Mannion, Davies, & Marshall, 2005; Marshall, & Davies, 2001). Organisational and individual barriers to the use of different types of data and databases, including health risk surveillance data, social service performance data, published performance indicators in health care, and laboratory data, are identified (Bloom, Figgs, Baker, Dugbatey, Stanwyck, & Brownson, 2000; Carrilio, Packard, & Clapp, 2003; Mannion, & Goddard, 2001).

2.1.4 Commentary

While network processes and the impacts of introducing networks into cancer services have been discussed, the ways in which network teams co-ordinate and performance develop network services using the information routinely available to them has not been examined.

Knowledge management/learning process articles focus on various ways of learning and sharing knowledge, covering the impact of ‘hard data’ in combination with and complementary to other information sources. However, there is a heavy focus on qualitative and tacit knowledge, and while the importance of hard data is recognised, there is (apparently) little analysis of the ways in which hard data sources are disseminated and turned into meaningful information and then into action.

Studies on the use of routine data and information have tended to focus on the problems of health data and the consequences and issues of making performance data (such as NHS ‘star’ ratings) publicly available. There has not been a great deal of research on the day to day use of routinely available data for operational management and co-ordination of health care services, or on the organisational and individual factors that might inhibit or facilitate the use of aggregated management type data in health care.
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2.2 Administrative databases and determinants of cancer outcomes

The review of the literature was conducted using MEDLINE and EMBASE for articles on organisational determinants of cancer services published during 1985 - 2005. Searches used combinations of key words and Medical Subject Headings (MeSH) to identify the majority of included studies. In addition, review of citations and expert advice was carried out to detect studies/publications not found in the electronic databases. ‘Grey literature’ was also searched through Department of Health and key government agency websites, and hand searching of bibliographies in official publications. Descriptive, observational studies, reviews and discussion papers were the most commonly found and used. Studies on cancer patients were the main ones included, but key studies examining organisational determinants in relation to other pathologies have also been considered where there was a lack of evidence from the cancer literature.

This section of the literature review addresses the three fields.

1 Using administrative databases for research.
2 Patient factors affecting outcomes.
3 Organisational determinants of outcomes.

2.2.1 Using administrative databases for research

Administrative databases have recognised uses in characterising patients, clinicians, and institutions (Naylor, 2002). However, limitations in their use may include poor data quality; incomplete or inaccurate coding of diagnosis and procedures; missing data; inability to describe important dimensions, and complications of case mix (Iezzoni, 1997; Mark, 2001; Ray, 1997).

Validity and reliability

Administrative databases always contain routine demographic data. Additional clinical information in the UK includes diagnosis codes (usually ICD) and procedure codes, (categorised in the UK as OPCS-4). Hospitals in the US report procedures using ICD-9-CM codes, while physicians generally use codes from the American Medical Association’s CPT95 (Iezzoni, 1997). Only limited code systems are available for clinical data such as test results, clinical observations, units of measure, symptoms, or infectious organisms (American College of Pathology 1996; McDonald et al. 1997).

Many of the proposed indicators for performance evaluation/outcome management depend on accurate coding of secondary diagnoses, although this may vary widely (Iezzoni, 1997; McKee, 1997). The coding, recoding, and measurement of routine patient data in hospitals may be adequate for
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internal management but not for outcomes evaluation (Orchard, 1994). In the UK, the Hospital Episode Statistics (HES) data system contains up to eight diagnosis fields (one main diagnosis, one subsidiary diagnosis and six further diagnoses), and up to four operative procedures fields (one main and three secondary procedures) (Department of Health, 2000).

Yet clinical databases appear to be less complete than administrative ones. For example, Fine et al (2003), who assessed the quality and completeness of a database of clinical outcomes after cardiac surgery in the UK, concluded that the database was incomplete, with a mean of 25% of essential data elements missing, whereas only 1% were missing in the patient record. Similarly, data in the Manchester orthopaedic database, compared with Hospital Activity Analysis data, showed overall completeness of 62%, although the accuracy was 96% (Barrie & Marsh 1992).

Coding error is frequently listed as a limitation of studies using hospital discharge summary databases. Green & Wintfeld (1993) showed that substantial inter-hospital variations exist, particularly in the underreporting of co-morbidities and distinction between urgent and emergency admissions. They also reported a nine percent error rate in coding the principal diagnosis.

Quality of cancer registry data

The accuracy of cancer statistics depends on the completeness of case ascertainment by the registries and on the completeness and accuracy of the data sources from which registrations are made (Brewster, 1995). The main data sources for cancer registration are hospital notes and data on death certificates forwarded by the Office of National Statistics (ONS) to each registry on every person dying for whom cancer is mentioned. Death certificates also enable registries to identify cases not registered in life. For instance, at Thames Cancer Registry, approximately 50 percent of the cases identified by death certificate notifications will already be known (Pollock & Vickers 1994). For the remainder, the death certificate is used to initiate a new registration.

Those cases not traced by following up case notes at hospitals and treatment centres defined as death certificate only (DCO) registrations (Pollock & Vickers, 2000). A high proportion of DCOs may bias the calculation of incidence, survival and treatment rates through inadequate coding of tumour site or cause of death, and lack of information on the date of diagnosis. For the latter reason, they are excluded from the survival analysis.

Completeness of cancer registries relies heavily on completeness of clinical case notes (Brewster, 1995), particularly reports of tumour stage, treatment and diagnostic procedures. Observed discrepancies in important clinical indicators between cancer registry data and clinical notes requires cautious interpretation of results in studies which use the registry data.
2.2.2 Patient factors affecting outcomes

Prognosis can be affected by several non-medical factors such as socio-economic status (class), diet, smoking, physical activity, family support, genetic predisposition, and psychological status (Orchard, 1994).

**Age**

The literature shows that survival decreases with increasing age. For example, in the Eurocare study, the relative risk of dying for the oldest patients (75+) was 1.39 for rectal cancer and 1.54 for colon cancer compared with the youngest patients (15 to 44 years) (Gatta et al. 1998). There were similar findings in the study of cancer survival in England and Wales (Romanengo et al. 2002). Older patients have higher frequency of comorbidity, are more likely to present with advanced stage, undergo emergency surgery and have generally worse clinical outcomes (Irvin 1988; Tekkis et al. 2002b; Tekkis et al. 2002a).

**Stage of disease**

Differences in survival are clearly related to stage recorded at presentation (Jarrel & Carabasi 1996; Commission for Health Improvement / Audit Commission, 2001). For example, unadjusted five-year relative survival rates by Dukes’ stage may vary from 83% to 3% for colorectal cancer patients with the least and the most advanced stage, respectively (Cancer Research UK, 2004). Stage is probably closely related to the biological characteristics of the tumour.

**Social deprivation**

Several studies have reported that the survival of cancer patients was worse in lower socio-economic groups (Schrijvers et al. 1995; Monnet et al. 1993). Pollock et al (1998) have also shown that emergency admissions are more frequent in socially deprived areas. Auvinen (1992) considered that social class differences were due more to differences in stage of disease at diagnosis than to differences in treatment. In the recent study on trends and socio-economic inequalities in cancer survival in England and Wales, improvements in survival were greater for those living in affluent areas than those in deprived ones (Coleman et al. 2004). This trend persisted even after correction for the differences in overall mortality between these two groups.

**Comorbidity**

Comorbidities may be assessed by different methods, including medical records in electronic databases, medical charts, physical examination, personal interviews, and self-reports using written questionnaires (Gijsen et al. 2001). Studies show that cancer patients with comorbid conditions have worse survival than patients without comorbidity for tumour sites including head and neck (Hall et al. 2002; Piccirillo, 2000; Ribeiro, Kowalski, & Latorre, 2000); lung (Battafarano et al. 2002); breast (Satariano, 1992); prostate (Albertsen et al. 1996; Clemens et al. 1986), and colon (Yancik et al. 1998). The impact of comorbidity varied between cancer sites, and even within the
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site if considered by stage of disease or type of treatment received (Read et al. 2004).

However, while the impact of comorbidity has been addressed in clinical outcome studies (Yancik et al. 2001a), no studies were identified as to the impact of comorbidity on cancer registry relative survival estimates, which take into account background (non-cancer specific) mortality, and thus, to some extent, indirectly reflect the presence or absence of co-existing diseases or pathological conditions on population level.

2.2.3 Organisational determinants of outcomes

Along with patient factors, the outcome of care is also dependent on the quality of care received throughout the patient’s stay in hospital and the performance of a considerable number of health care professionals, all of whom are influenced by the environment in which they work, such as team co-ordination, communication, equipment and so on (Vincent et al. 2004; National Audit Office, 2004).

Staffing level

There is a general belief that increased staffing level may at least partly facilitate improvement of outcomes of care in clinical settings. The main reason for this is the speculation that it may affect the occurrence of errors, complications and other adverse events (Brown, 2001). In addition, staffing deficiencies may deprive patients of sufficient nursing or medical care and increase stress level among health care workers and lead to higher possibilities of mistakes.

A higher level of nurse staffing has been associated with lower postoperative complications (Cho et al. 2003; Kovner et al. 2002; Lichtig, Knauf, & Milholland, 1999); a lower incidence of adverse events (Unruh 2003), lower nosocomial infection rates (Fridkin et al. 1996), and higher patient satisfaction (Hall et al. 2003). Studies in the US and the UK, and a number of reviews of the literature (Curtin, 2003; Heinz, 2004; Lang et al., 2004; Lankshear, Sheldon, & Maynard, 2005) have demonstrated that the level of nurse staffing may affect patient and organisational outcomes, but the results were equivocal and vary by institution (Aiken, Smith, & Lake, 1994; Blegen, Goode, & Reed, 1998; Clarke, 2004; Hartz et al. 1989; Huston, 1996; Krakauer et al. 1992; Krapohl & Larson, 1996). Specifically for cancer, in a US study of bladder carcinoma patients, hospitals with a high registered nurse-to-patient ratio had a lower inpatient mortality risk among patients who underwent cystectomy, after adjustment for age, indicators of social status and comorbidity (Eltig et al. 2005). However, the authors did not account for tumour stage, which is the major indicator of disease severity for cancer patients and may affect the observed relationships.

Volume effect

The literature provides support for an association between higher volume and better outcome of care, in both cancer and non-cancer settings, such as paediatric cancer care (Hillner & Smith, 1998; Lin et al. 1998); breast cancer
surgery (Mikeljevic et al. 2003); prostate cancer surgery (Thorpe et al. 1994); and trauma centres (Nathens et al. 2001). The 'higher procedural volume, better outcome' relationship has an extensive literature in cardiovascular disease (Hannan et al. 1995; Hillner & Smith, 1998; Jollis & Romano, 2000; Magid et al. 2000; McGrath et al. 2000; Thiemann et al. 1999; Tu & Naylor, 1996).

However, studies use various definitions of 'volume' (quartiles; quintiles; some specific cut-off points; other approaches) and consider different aspects of it: volume of hospitals; volume of doctors; volume for specific conditions/diseases; volume for specific procedures or surgery. Usually the studies have combined hospitals with similar volumes into a small number of groups and then compared the rates of outcomes among the groups. Most studies considered in-hospital or 30-day mortality as the only measures of adverse outcome (Hannan, 1999). Longer-term outcomes and survival were investigated to lesser extent. Studies normally controlled for differences among 'volume' groups by adjusting for the severity of patients' conditions at admission. The level and methods of adjustments differ from study to study, which make comparisons between results difficult.

Most studies found positive associations between volume and outcomes only for high-risk conditions and complex surgical procedures (Begg et al. 1998; Birkmeyer et al. 2002; Finlayson, Goodney, & Birkmeyer, 2003; Halm, Lee, & Chassin, 2002; Hillner & Smith, 1998). A systematic review (1980 to 2000) on the relationship between hospital or physician volume and clinical outcomes by Halm, Lee & Chassin (2002) showed that the strongest associations with high volumes were found for more complex surgical procedures, like pancreatic resection and oesophagectomy (a median of 3.3 to 13 excess deaths per 100 cases were attributed to low volume). In addition, they showed that studies with more complete case-mix adjustment were less likely to report a positive effect of high volume on outcomes. Therefore, it is possible that differences in severity of patients’ condition between hospitals, and incomplete adjustment for case mix, may partly explain the observed associations between hospital volume and outcomes. There is also, of course, the possibility of publication bias towards positive associations.

Hospital volume is perhaps more important than individual surgeon’s volume in its effect on short-term outcomes, such as in-hospital mortality (Harmon et al. 1999) and two-year survival (Kee et al. 1999) for colorectal cancer. Particularly, medium-volume surgeons achieved results equivalent to high-volume surgeons when they operated in high- or medium-volume hospitals but not in low-volume hospitals (Harmon et al. 1999). On the other hand, the results of low-volume surgeons, although improved with increasing hospital volume, never equalled those of the high-volume surgeons.

**Specialisation**

Along with the volume-outcome studies, there is extensive literature about the impact of specialisation on outcome of care. In fact, some studies showed that specialist care was more important and beneficial than volume effect
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(Hilska et al. 2004; Woodman et al. 2003; Smith et al. 2003). For instance, according to one Finnish study, there were no significant differences in the rates of postoperative mortality, morbidity, and long-term overall survival between the volume groups (Hilska et al. 2004). However, the definition of ‘specialist care’ provided in studies has varied and included membership in professional site-specific associations (Smith et al. 2003; Prystowsky, Bordage, & Feinglass, 2002); surgical subspecialty (Porter et al. 1998; Hilska et al. 2004); broader certification in surgery (Prystowsky, Bordage, & Feinglass, 2002); or being treated at multi-disciplinary specialist units (Kingsmore, Hole, & Gillis, 2004). Some authors did not provide with the formal definitions employed (Gillis & Hole, 1996).

There is no systematic description of specialisation in the UK. While the literature, in general, discusses the effect of specialist care in terms of ‘specialist surgeon’, in the UK, the approach is on multidisciplinary teams - ‘specialist teams’, as opposed to the notion of ‘specialist surgeon’ prevailing in the literature. Fleissig et al. (2006) have recently reviewed literature on multidisciplinary teams in cancer. However, apart from clinical aspects, there were few studies dealing with organisation and functioning of MDTs (Blazeby et al. 2006; Jenkins, Fallowfield, & Poole 2001; Kelly et al. 2003; Whelan, Griffith, & Archer, 2006). Fleissig et al. (2006) conclude: ‘MDT working has been widely introduced around the UK for the provision of cancer care, but there is little evidence for its direct effect on the quality of patient care. The systems that assess the effectiveness of teams are not fully developed, and better methods to monitor performance, team working, and outcome are needed.’

Compliance with clinical guidelines and standards of care

Compliance with guidelines have been assessed in the literature mainly in terms of specific clinical interventions (Akeson et al. 2005; de Roos et al. 2005; Engel et al. 2005; Hebert-Croteau et al. 2004; Kapiteijn et al. 1998; Tilling, Wolfe, & Raju 1998). A review by Smith & Hillner (2001) described the impact of clinical practice guidelines on improvement in processes of care and outcomes in oncology. Improvements have been demonstrated in compliance with evidence-based guidelines or evidence-based medicine, and in short-term length of stay, complication rates, and financial outcomes. The data suggest that patient satisfaction can be maintained despite a shorter length of stay. However, there was a lack of comprehensive evidence on whether compliance with guidelines affects long-term outcomes, particularly survival. More recent reports have indicated links between treatment guidelines and long-term survival for breast (de Roos et al. 2005; Hebert-Croteau et al. 2004) and ovarian (Akeson et al. 2005; Tilling, Wolfe, & Raju, 1998) cancer patients.

In general, whereas most studies seem to suggest that compliance with guidelines is beneficial for cancer outcomes, this association has been less explored in relation to adherence to standards on organisation of services and care. Morris (2004) studied adherence to cancer services standards for colorectal cancer patients in 14 hospital teams in Yorkshire (UK). She concluded that a 25 percent increase in adherence was related to around an
eight percent reduction in the risk of death after one and two-year follow-up. The effect remained after adjustment for age, stage, socio-economic status and year of diagnosis. However, this association was not sustained in relation to breast and lung cancers. No study on the relationship between compliance with published Manual of Cancer Services Standards (NHS Executive 2000), as assessed by national peer-review in England, and outcomes, was identified.

Waiting time

There is inconclusive evidence in the literature on the impact of referral and treatment delays on survival for cancer patients. Studies used different types of treatment and various tumour types. Also, there were differences in the degree of case-mix adjustment and definitions of ‘waiting time’ used. A systematic review of the literature by Richards et al. (1999b) suggested that delays between the onset of symptoms and start of treatment for breast cancer patients were associated with a lower survival. However, the quality of reviewed studies and levels of adjustments for patients’ case-mix and other predictors of survival varied considerably, which made interpretations of these findings equivocal. In studies that controlled for stage, longer delay was no longer associated with shorter survival. Also, in another study of breast cancer patients, multivariate analyses indicated that the adverse impact of delay in presentation on survival was attributable to more advanced stage (Richards et al. 1999a). However, within individual stages, longer delays had no adverse impact on survival. Evidence for an association between age and delay by patients and providers for breast cancer patients was presented in a systematic review by Ramirez et al (1999).

On the other hand, a number of studies have described and discussed the so called phenomenon of ‘waiting time paradox’, when patients with shorter waiting times have worse outcomes or more advanced disease (Comber et al. 2005; Myrdal et al. 2004; Sainsbury, Johnston, & Haward, 1999). This association was only partially accounted for by interaction between stage and delay in a statistical model corrected for age (Crawford et al. 2002).

2.2.4 Summary of literature findings

Administrative data are used widely for research, monitoring and evaluation in health systems, and their limitations and opportunities have been described. There are questions on data completeness and reliability, but systematic routine collection of data, for example by cancer registries, can achieve standards that are acceptable for scientific analytic studies.

Tumour stage is the crucial individual level determinant of the outcome for cancer patients, but is poorly recorded by clinicians in routine practice. However, health services data are able to compare whole populations, including all stages together. Then, the literature indicates the importance of age, social deprivation, type of admission (emergency vs. elective), and co-morbidity as important correlates of survival and mortality of cancer patients. The use of cancer registry data to study the impact of clinical treatment on
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survival of cancer patients is limited due to the lack of comprehensive and high quality treatment data in registry datasets.

There is a literature on organisational determinants of outcomes. Several studies examined the effect of levels of nurse staffing, but there is little research on the impact of medical staffing, especially in cancer settings. The literature mainly supports the notion of ‘higher volume, better outcome’, particularly for high-risk conditions and complex surgical procedures. However, studies used various definitions of ‘volume’ and ‘specialisation’, and most studies considered short-term outcomes, particularly in-hospital or 30-day mortality. There is a recent literature on multidisciplinary teams, but with little evidence on outcomes.

One recent study reviewed the impact of self-reported adherence to cancer services standards, but no study had explored the impact on survival or other outcomes of adherence measured through the national cancer standards peer-review process. There is conflicting evidence in the literature on the impact of referral waiting times and delays in treatment and diagnosis on survival for cancer patients.
References


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diagnosed 1993-95 and followed up to 31 December 2000. London School of Hygiene and Tropical Medicine, London.


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Section 3 Cancer networks information

Before developing new information sets for cancer networks, we wished first to describe how they currently addressed statistical information. Cancer networks were established without a formal template or design - they were developed locally. There was no ‘guidance’ specifically to cancer networks on their use of statistical information. While developing Limited Datasets that would be sent to the cancer network teams, we sought to understand better their structures and activities in relation to routinely available information. We discussed this with the Cancer Action Team and the Department of Health Cancer Policy division, and decided on a two-stage process. First, to develop our understanding of the issues, we made contact with four teams indicated by the Cancer Action Team.

3.1 Team interviews

The network team interviews were undertaken with four contrasting cancer network teams in England. A semi-structured interview schedule (Appendix D) was developed for the face-to-face interviews, drawing from relevant literature and discussions with research team members in organisational sociology, health psychology, public health, and epidemiology, as well as a patient-representative. The questions addressed the use and impact of aggregate data, information roles and responsibilities, data use and dissemination strategies, and barriers and facilitators to using data. Nineteen interviews were conducted with network team members. The interviews were recorded, transcribed and independently analysed thematically by two researchers.

We looked at the use and dissemination of data as a form of knowledge creation and transfer, while trying to identify organisational (and other) factors which may act as barriers or facilitators to this process. The responses of members differed between teams, and between people with different roles in the teams. Our areas of interest were validated by the face-to-face interviews. The key findings were as follows.

- Due to nationally imposed targets, network teams were particularly concerned with the timely and accurate collection of waiting times data. Data collection was currently prioritised over data use.
- National aggregate data was less useful to the network teams than locally collected data and other information sources such as experiential knowledge and expert opinion.
- Data use was limited due to problems with accessibility to/of the data, lack of resources for interrogating data and transforming information into action, and perceived deficiencies in the data such as poor quality and lack of contextualisation.
- Use of data in the future could be enhanced through the provision of a central information source or compendium comprising all relevant cancer
services management data, funding for a full-time information/data officer at network team level, and quality assurance of the data combined with increased (clinician and network) ownership over the data collection and aggregation process.

- Organisational factors affected the extent of data use including the designation of network team roles and cross-over roles with outside bodies (such as the Strategic Health Authority or cancer registry), relationships within and beyond the networks (e.g. with data collection agencies, other networks, DH), strong management and network commitment to the use of data as a development tool, innovative approaches to data use and integration of different information sources (including quantitative and qualitative).

Despite limitations and restraints, network team members perceived value in using aggregate data to improve services and were striving to integrate the use of these data in strategic planning.

3.2 Telephone survey

On the basis of these findings, a structured telephone survey was undertaken. The questionnaire is shown in Appendix F.

We worked with the Cancer Action Team to contact the Board chairs and managers of each cancer network to inform them of the study. We asked networks to help with two aspects: to record the views of Network Management Team members on the provision and use of data; and for the research team to provide datasets for networks to use. In this discussion, it became evident that network structures differed considerably in size and composition. We compiled a description of the network board members, and the larger board structures and programmes.

We chose to focus on five respondents per network – the four ‘core’ network team roles including network manager, clinical lead, nurse lead, and service improvement lead as well as the information officer. While most networks had the four core team members, not all had a network level information or data officer. To develop our understanding of the views of networks on information, we chose two steps: first, to put open questions to selected members of four network teams through face-to-face interviews; second, to draw on this material to undertake telephone interviews with representatives from all the network teams.

Twenty-nine network teams participated in the survey, resulting in 68 individual responses from 26 Network Lead Managers/Directors, 18 Lead Clinicians/Clinical Directors, 18 Information/Data Leads, and six other roles (such as Service Improvement Leads, Development Managers, Sector Performance Manager, Macmillan Information Lead. Details of respondents are shown in Table 1.
## Table 1 Cancer Network Respondents to Telephone Survey

<table>
<thead>
<tr>
<th>Cancer Network</th>
<th>Network Manager</th>
<th>Clinical Lead</th>
<th>Lead Nurse</th>
<th>Service Improvement Lead</th>
<th>Information Officer</th>
</tr>
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</table>

i + performance manager and cancer information manager for one cancer centre in the network

ii + network business manager

iii + network development manager

iv + clinical information lead
3.3 Results

The results from the telephone surveys validated and extended many of the findings from the in-depth interviews:

3.3.1 Data use and recognition

Of our dataset, Cancer Waiting Times and Registry data were most recognised and most often used (Table 2). These data sources were ranked as most useful/important by the majority of participants and this reportedly related to current network priorities and national targets. In addition, 60 percent (41) participants reported using 24 other aggregate data sources.

The majority of participants indicated that aggregate data had been used to inform two current NHS processes - implementation of Improving Outcomes Guidance (IOG) and Service Improvement plans. Cancer registry data and Hospital Episodes Statistics were most frequently used for IOG while Cancer Waiting Times and Registry data were most frequently used for Service Improvement plans. Peer Review 2000/2001 data had been used by around half the participants to inform the current peer review process although many participants had not had access to the national peer review data.

Other uses of aggregate data included planning (e.g. through monitoring capacity and demand), providing supporting evidence, and setting the network picture in the national context. Specific uses included validating and checking other data (e.g. Cancer Registry and Cancer Waiting Times), and assessing treatment trends (e.g. using Hospital Episodes Statistics).
Table 2  Findings from telephone surveys of 68 network team members: awareness and use of aggregate data sources

<table>
<thead>
<tr>
<th>Data source</th>
<th>Overall N (%)</th>
<th>Lead Managers N (%)</th>
<th>Lead Clinicians N (%)</th>
<th>Info/Data Leads and Other N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Waiting Times Database</td>
<td>68 (100)</td>
<td>66 (97)</td>
<td>26 (100)</td>
<td>18 (100)</td>
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<tr>
<td>Cancer Registry</td>
<td>68 (100)</td>
<td>63 (93)</td>
<td>26 (100)</td>
<td>18 (100)</td>
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<tr>
<td>Hospital Episodes Statistics</td>
<td>67 (98)</td>
<td>45 (66)</td>
<td>25 (96)</td>
<td>18 (100)</td>
</tr>
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<td>Cancer Standards Peer Review 2000/2001</td>
<td>64 (94)</td>
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<td>Healthcare Commission Acute Hospital Portfolio</td>
<td>41 (60)</td>
<td>8 (12)</td>
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<td>12 (67)</td>
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<tr>
<td>Minimum Dataset for Palliative Care</td>
<td>49 (72)</td>
<td>19 (28)</td>
<td>18 (69)</td>
<td>11 (61)</td>
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<tr>
<td>National Cancer Patient Survey</td>
<td>56 (82)</td>
<td>40 (60)</td>
<td>25 (96)</td>
<td>14 (78)</td>
</tr>
</tbody>
</table>
3.3.2 Network team information strategies

The majority of participants (59 percent) indicated that their network team had some sort of information strategy usually focussing on data collection as well as use. However, not all team members were aware of the strategy. Several respondents noted that their information strategy was not formalised. Participants were more likely to use data ad hoc (37%) rather than either routinely (26%), or both routinely and ad hoc equally (34%). Lead Clinicians in particular, were most likely to say they used data only as and when they needed to. However, the frequency of data use depended largely on the data source in question, with Cancer Waiting Times data being looked at frequently. Other types of data were only used as and when needed, mainly due to lack of time, lack of routine provision of such data, and lack of formal mechanisms or understanding of how/when/why to use data routinely.

3.3.3 Provision of data to patients and carers

Most participants (75%) thought it was the network team’s responsibility to disseminate aggregate data to patient and carer user groups and 53% of participants said that their networks (but not necessarily the network team) had provided some aggregate data to patient and carer user groups in the past year with Cancer Waiting Times and Cancer Registry data cited most frequently.

The most frequently cited reasons for not having provided data to patients and carers were that: there were currently no means or forums to feed data back to user groups, or that the user groups were still developing and deciding their own priorities. Lead Managers were slightly more likely than other roles to say that they simply had not thought about it or got around to it, while Lead Clinicians and Information/Data more often said that service users had not asked for the data and/or would not want them anyway.

3.3.4 Issues of aggregate data

Participants were divided over whether current data enable them to measure quality of service. Clinicians were least likely to agree that data were useful in this way.

There was a general perception of the data quality being poor and a perceived lack of trust in the data. However, participants commented that trust in the data is improving. Most participants (particularly Lead Clinicians) thought that people in the Network worry about how aggregate data will be used. Particular worries were about how data are interpreted and whether they are contextualised.

Most participants (particularly Lead Clinicians) agreed that the relevance of some data is not clear. However, skill base may also be a pertinent reason. Participants did not think that Government priorities prevent them from using
data as they would like to and some commented that Government priorities may in fact help to strengthen and/or focus the use of some data. However, several participants noted that the current centrally driven focus on waiting times diverted attention away from other data sources (such as clinical) and other possible uses of data.

Participants were asked about being given a comparative set of cancer data that brought together data from various aggregate data sources. On the whole, respondents were positive, with the dataset being seen as potentially helpful to each role. Several participants said they would welcome it, and that there was interest in good quality comparative and aggregate data. However, there were concerns that clinicians would not trust the data, particularly if the data came from existing data sources, and that the dataset would potentially be time consuming. Participants emphasised the need to review data in context.

### 3.3.5 Information

The survey of cancer networks indicated that there was not a clear NHS cancer information strategy at network level. An Information Strategy had been published by the Department of Health at the same time as the Cancer Plan, but neither the Department of Health Cancer Group nor the Cancer Action Team drew our attention to this document, nor did cancer network team interviewees refer to it.

In contrast, during our development of the interviews, the Department of Health and the Cancer Action Team expressed some concern that the Networks had a high level of tasks, and would not find responding on information easy. The networks were heavily focused on information tasks directed by the political agenda of the Department of Health – especially ensuring waiting times data were correctly recorded. The networks acknowledged data from cancer registries, and also knew of cancer standards, cancer survey data and HES; they did not know much about Healthcare Commission dataset.

One limitation of this part of the study is that it doesn’t directly reflect the views of hospitals or primary care teams. There are about 170 trusts providing cancer treatment in England. Our study was not funded for a separate survey of this size; nor indeed is it clear whether hospitals could identify an individual respondent with specific responsibility for cancer information – especially as we were interested in integration of different sets of information. [We subsequently found that a commercial company, Ardentia, provided a ‘Cancer Information System’ to the NHS, but covering cancer registration only.]

The needs of primary care are different. Primary care staff are not strongly represented on cancer networks. Only some, perhaps half, of all patients with cancer are initially referred by a GP for investigation of cancer, as the diagnosis may also be made in the course of investigation for other diseases. Moreover, GPs are not usually part of the treatment regime, and patients continue in contact with hospital or hospital-outreach services for most of the
course of their disease. Thus, primary care is less frequently recorded in primary care patients than in secondary care patients, and there has been no special attention to cancer treatment in primary care. (By contrast, of course, cancer prevention through behavioural change and screening services have important links with primary care.)

### 3.3.6 Performance

We asked networks team members what they thought about aggregate data. While in practice they were required to focus on ensuring that hospitals provide waiting time data for the Department of Health, they did recognise in principle that wider information was relevant.

First, there was a commitment to supporting clinical audit data collection, including the developing systems of local and national clinical audit. Second, there was interest in receiving comparative data both across hospitals within the network, and for comparisons with other networks.

Network team respondents were concerned about ‘performance’ measures. Networks were against being held accountable for performance, especially for targets over which they have little influence, or which deflect from their priorities. On the other hand, Networks accept that data can contribute to performance review, for themselves and their partners, and can relate to managerial objectives.

### 3.4 The patient’s perspective

The service-user representative on our Advisory Board and member of our local Cancer Network Board provided advice on the patient’s perspective on cancer information. We recognised that information about cancer itself, or information on a patient’s particular disease, was outside the scope of our study: we were concerned with how patients, or their representatives (eg carers, patient groups), might access and use the data we had collected together.

In 2005, the Government published a White Paper, which describes new mechanisms to move control of the NHS from performance management to patient demand (ie as a ‘market’). Change will occur through responsiveness to customers rather than by central direction. This is ‘patient choice’. Part of the motivation for patient ‘choice’ has been to open health care to private providers as well as the ‘public sector’ (ie NHS Trusts), and also to reduce hospital costs by GPs taking on more of the treatment. Cancer services do not fall easily within this model, because:

1. treatment costs are higher and treatment is more complicated than, for example, ‘cold’ surgical treatment;
2. services and structures need to collaborate, rather than one independent service providing all the treatment;
3. there is little opportunity for GPs to provide more care as their knowledge base for specialist cancer care is low and their access to
appropriate investigations is limited. Anyway, most patients prefer a cancer specialist for cancer treatment.

We also undertook two focus groups to explore with patient representatives the potential use of comparative cancer data. These groups showed that patients would welcome access to more information on services at the start of their treatment and during it. It would empower them to ask more questions and to encourage quality of service provision. It is necessary, of course, to present the information in a meaningful way, and for it to be available at the right time within the ‘patient pathway’.

### 3.5 Commissioning

A third set of stakeholders, apart from providers and patients, is the administrative structure that manages provision and demand. In the NHS this is known as ‘commissioning’, and involves setting agreements and standards for service provision, as well as agreeing future funding streams so that investment can be efficiently supported.

In parallel with ‘patient choice’ is practice-led commissioning, by which GPs will hold funding for their patients’ choices. This commissioning needs to have comparative data. Because the NHS is trying to set common prices, GPs will be encouraged to make choices (in part) on grounds of quality (as well as other factors such as access and availability). The measures of quality investigated for the present study are a potential basis for commissioning.

### 3.6 Conclusion

The research gained systematic views of information users at cancer network level, using both team interviews and a telephone survey. Cancer networks teams’ perspectives on information were limited - network managers knew of some but not all the data, and did not have a perspective of using the data for performance managements of cancer services. Nor, we were told, did the NHS Cancer Team of the Department of Health - their emphasis on information at the time was in developing the electronic patient dataset.
Section 4 The datasets

The call for this research had listed several sources of cancer data that might be relevant for the study. This section describes the datasets briefly, indicates their availability and characteristics, and then reports on the datasets in detail using a standardised assessment instrument Directory of Clinical Databases (DoCDat).

4.1 Datasets included in the study

Six datasets forming the ‘Limited Dataset’ are described.

4.1.1 Acute Hospital Portfolio

Information about health services in England were collected by the Audit Commission from 2000/01, and have been continued thereafter annually by the Healthcare Commission. Each survey addresses a different aspect of health care provision, including financial, facilities, structural and personnel. National overview reports are available for each topic completed at [http://www.healthcarecommission.org.uk/(click on ‘information for healthcare providers/ reviewsandstudies/ servicereviews/ ahpmethodology.cfm’)](http://www.healthcarecommission.org.uk/(click on ‘information for healthcare providers/ reviewsandstudies/ servicereviews/ ahpmethodology.cfm’)) In the period 2000/02 relevant for our study, we chose four sets: medical staffing, medicines management, radiology, ward staffing. The 1999/2000 and 2000/2001 surveys were made on 188 NHS acute hospital trusts, and collected data in a wide range of dimensions. There were explicit rules for deciding how to record variables, and datasets were estimated as mostly >80% complete.

4.1.2 National Cancer Peer Review

Along with the NHS Cancer Plan for England, a Manual for Cancer Services Standards was published. Approximately 170 hospital cancer units and centres were asked to assess themselves against these standards, and were then visited by teams of health care professionals and managers with expertise in the day-to-day delivery of cancer care, and also patient representatives. The visits were organised by each of the 13 NHS regions, and data collected uniformly (except for one region, Trent, which had piloted a different instrument). The review teams assessed the presence or absence of over 180 variables grouped in 10 areas: patient centred care, multi-disciplinary teams (for breast, colo-rectal and lung cancers), diagnostic services, oncology, radiotherapy, chemotherapy, palliative care, training, communication, and organisation. Through the detailed recording methods, all variables were at least 95 percent complete. For the Limited Dataset, standards were selected in three areas.

1 Total compliance with cancer standards for each main topic (including three MDT-related cancer specific topics) - 12 variables.
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2 Compliance with 3 MDT-related set of variables (cancer-specific) grouped according to the sub-topics specified within the Manual. Only groupings for MDT standards for breast (11 variables), colorectal (10 variables) and lung (10 variables) cancers have been considered.

3 Compliance with chemotherapy-related standards grouped according to the sub-topics specified within the Manual – eight variables.

4.1.3 Hospital Episode Statistics
These data are collected routinely in all NHS hospitals and units, and record more than 12 million inpatient episodes per year. Data are held electronically by the NHS Health and Social Care Information Centre, a not-for-profit agency run by the National Health Service. Within a large dataset, in which episodes can be linked within-year (but not across years), data were available for patients with a cancer diagnosis and data on length of admission by hospital, operation and consultant specialty. Definitions of variables held are in the HES Data Dictionary. A review in DoCDat in 2002 indicated 99% coverage of admissions, but for the variable ‘mean and median length of stay’ in the Limited Dataset, missing data by diagnosis was: breast 9.3%; colorectal 5.7%; lung 13.3%; and prostate 6.5%.

4.1.4 Cancer Waiting Times
These data are collected by all NHS acute hospital trusts in England. For each trust, the data recorded are the percentage of GP urgent referrals achieving a waiting time ≤2 weeks (by tumour type – one month for some rarer cancers). However, measuring patients referred with a possible cancer diagnosis both includes non-cancer patients (wrong initial diagnosis) and excludes those identified by other routes (about half of all cancers). There are clear definitions and coding rules, but local completeness is unassessed, and data are missing for some trusts. The data are reported quarterly (http://www.performance/doh.gov.uk/cancerwaits/).

4.1.5 Cancer Survival
The nine regional cancer registries in England collect population-based data on incidence and mortality from cancer. A subset of the data collected by the regional cancer registries is collated centrally to provide national figures on cancer incidence and survival. Regional cancer registries receive notification of incident cancer cases from sources including hospital inpatient and outpatient systems; radiotherapy; pathology; GPs, coroners; and chest clinics. Linkage between cancer registration and death certificates is achieved through the NHS Central Registry, which notifies cancer registries of registered patients who die with any diagnosis, and all patients with a cancer diagnosis. Registries check hospital case-notes of patients, and are estimated to include above 90 percent of patients with date of diagnosis as well as date of death (both are needed to calculate survival). For a limited group of individual level variables, including tumour types and place of treatment, there is 95 percent completeness, but lower figures for cancer stage.
4.1.6 National Survey: Cancer Patients

This was a one-off survey of a sample of patients discharged from NHS acute hospitals in England. The survey was undertaken in 2001, with reports from patients with discharges July 1999 to June 2000. Sampling and surveying were undertaken by an independent organisation, and the data stored in the Economic and Social Research Council archive. The survey covered six cancers: breast; colorectal; lung; non-Hodgkin lymphoma; and ovary prostate. Response rates by trust were 60% to 80%, while variables have 5 to 19% missing data. The survey recalls patients’ perspectives on their process of care: access to care; waiting times; diagnostic process; first treatment; hospital environment; and outpatient experience. For the Limited Dataset, 564,36 patient responses were included.

4.2 Availability

We found four of the datasets listed by the research call to be of use for our study. In particular, we were alerted to the National Cancer Peer Review, for which the data were held by the Department of Health and had been sent to the cancer networks, but not otherwise published. We also drew upon two other datasets, including information on hospitals from the Healthcare Commission, and on patients in Hospital Episode Statistics. On the other hand, we did not find that the Cancer Services Collaborative held data in a form that was available to us; and we found that palliative care, reflecting the voluntary service nature, was not recorded systematically across the country.

We were able to access all the datasets eventually, but this took the best part of nine months. Agreement to access the cancer registry survival data from the Office of National Statistics was particularly lengthy. We were given three datasets at the level of individuals, but fully anonymised, so we were not able to link data by individuals. [Linkage of cancer registration with HES is, nevertheless, feasible and is subsequently being developed by the National Cancer Services Analysis Team and the cancer registries.]

We also investigated the Minimum Dataset, collected by the National Council for Palliative Care. While this is a systematic and well-characterised set of data, data is only collected voluntarily and the teams and hospice services do not cover the whole population. We chose to exclude it from our data analysis.

4.3 Characteristics

We reviewed the properties of national datasets using DocDat developed at the London School of Hygiene, to report the general characteristics and completeness of datasets.

- Range of data: The datasets ranged from single items (the waiting time) to complex sets (eg the Peer Standards). Data in the Acute Trust Portfolio needed to be selected from a larger set.

- Tumour types: Data were available for each of the study’s four tumour types, except for the Healthcare Commission’s Acute Trust Portfolio,
which is not collected by diagnosis, and the Cancer Services Peer Review did not include prostate cancer.

- Level: All the data were available at national, network and hospital levels. Analysis of relative survival was limited to networks because of the small numbers required for age-standardisation.

- Completeness: Cancer survival data completeness has been assessed regularly by the Office of National Statistics. Data items in the satisfaction survey were approximately 80 percent complete: we have used simple averages according to the response denominators. Data for the Acute Hospital Portfolio were only approximately 70 percent complete: we used data for individual trusts, but not at aggregate (network) level.

Three datasets (cancer registration/survival, HES, National Survey: Cancer Patients) are recorded for individual patients and three (Cancer Waiting Times, National Cancer Peer Review, Acute Hospital Portfolio) have data aggregated at hospital trust level. (Individual patient survival and hospital episodes cannot be routinely linked by the unique identifiers yet in England.) We could divide most of the datasets according to the four most common tumour types: breast, colo-rectal, lung and prostate cancers, which relate to the different natural survival patterns and different management requirements described in national Manual of Cancer Services.

The datasets varied in size. Hospital Episode Statistics record more than 12 million episodes each year and the Acute Hospital Portfolio collected over 100 items of data from more than 200 trusts over a year. In contrast, the Waiting Times survey concentrates only on this dimension for the same trusts. Only a few items were relevant from the large dataset within Hospital Episode Statistics, describing hospital activity. The Acute Hospital Portfolio provided an array of general characteristics: a subset was chosen which was more particularly related to cancer (although not separated by tumour type). The Peer Review data were treated as binary (compliant or not compliant with the standard), and were summed to give total scores. The National Survey: Cancer Patients satisfaction items had been chosen by an earlier factor analysis into nine themes, each represented by one lead question, while five independent questions for one theme were averaged.
4.4 The six datasets – DoCDat descriptions

4.4.1 Acute Hospital Portfolio - Data Quality Assessment

General aspects

Background information

The Acute Hospital Portfolio (AHP) is a collection of ongoing audit reviews (not cancer-specific) that are undertaken at acute and specialist trusts by Audit Commission / Healthcare Commission (AC/HC). They focus on key service areas or resources within the trust that are of concern to trust managers and patients.

The following national reviews have been published (or being undertaken) by AC/HC:

1. Accident and Emergency 2000/01; 2004/05
2. Admissions Management 2005/06
3. Bed Management 2002/03
4. Catering 2000/01
5. Day Surgery 2000/01; 2004/05
6. Diagnostic Services 2005/06
7. Facilities Management 2003/04
8. Information and Records 2003/04
9. Medical Staffing* 2001/02
10. Medicines Management* 2001/02; 2005/06
11. Operating Theatres 2002/03
12. Outpatients 2002/03
13. Pathology 2003/04
14. Procurement and Supply 2001/02
15. Radiology* 2001/02
16. Therapy and Dietetics 2003/04
17. Waiting for Elective Admission 2002/03
18. Ward Staffing* 2000/01; 2004/05

*These topics have been chosen for inclusion into the Cancer Networks Limited Dataset based on relevance and time period covered in relation to other datasets.

Source: Healthcare Commission

http://www.healthcarecommission.org.uk

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1 Based on Directory of Clinical Databases (DocDat) format (http://www.lshtm.ac.uk/docdat/page.php?t=index).
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and http://www.healthcarecommission.org.uk

Reference population:

Common circumstance that determines inclusion in the database: All NHS acute hospital Trusts are covered by the dataset.

Geographical area covered by the database: England and Wales.

Time period covered by the database: 2000/2001 - ongoing, depending on topic (see Background information).

Level of aggregation: NHS Trust or hospital site

Dataset

- Content

Number of individuals or episodes of care included in the database: The intention of the dataset is to include data on patients, staff, resources, services and activities of all NHS acute hospital Trusts in England and Wales and to reflect treatment of all patients in relevant financial years.

Data collection questionnaire: According to the Audit Commission, wherever possible, data were taken from routine national sources and standard definitions are applied. However, many areas of the portfolio are not covered by existing data, so the Audit Commission conducted national surveys for each topic at all relevant NHS acute hospital trusts in England and Wales by providing electronic forms for trusts to complete. In some cases specially written computer software was also provided to assist trusts.

Data collection forms for selected topics (medical staffing 2001/2002; medicines management 2001/2002; radiology 2001/2002; ward staffing 2000/2001) have not been published and are not available online.

Data collection forms/tools or questionnaires are available for more recently reviewed topics.

- Data linkage

Are nationally approved codes used for identifying the subject, clinician or institution? Nationally approved codes are used to identify each NHS Trust.

To which other databases is linkage routinely undertaken? None known

Outputs

- Analysis

Can ad hoc analyses be performed for health care providers?

- Locally ("the health care provider who collects the data locally is able to analyse their data even though their data are also sent to the centralised..."
database to be analysed with the data collected from other health care providers') – no.
- Centrally (Local health care providers can obtain ad hoc analyses of their own data from the central database custodian) – yes. Healthcare Commission provides CD version of audit review data to individual trusts. The CD uses Audit Commission’s software tool 'Compare'. Also, on-line query form is available for all AHP queries: http://www.healthcarecommission.org.uk

- Audit reports

How frequently are multi-centre audit reports produced? National overview reports are available for each topic completed. The intention is to audit the same topic each four years.

How frequently are provider-specific audit reports produced? Provider-specific reports for audited topics are produced each four years, as soon as audit reviews for these topics are completed (see previous item and Analysis).

Publications

- Bibliography

The Healthcare Commission provides no references to any studies that have used these data. However, national overview reports are available for each topic completed. The following article which was produced using AC/HC data has been identified:


Management

- Support for database

Is the database approved by any clinical or professional associations? No.

Who is involved in the management of the database? Doctors; statisticians; epidemiologists; IT specialists.

- Source of funding:
Acute Hospital Portfolio transferred from the Audit Commission to the Healthcare Commission on 1 April 2004 under the Health and Social Care (Community Health and Standards) Act 2003.

Data quality

- Coverage
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Extent to which the eligible population is representative of the country: All NHS acute hospital Trusts in England are covered by the dataset.

Completeness of recruitment of eligible population: All NHS acute hospital Trusts have been included.

- Variables included in the database:

There are numerous variables available in Acute Hospital Portfolio for each specific topic. Among them, the selected list of variables has been chosen for inclusion into the Cancer Networks Limited Dataset (see Appendix A for the list of variables). This selection has been made based on relevance and completeness and following discussions with a number of health care professionals and researchers associated with the ‘Measures of Quality for the Improvements of Cancer Services’ study.

Completeness of data (% variables at least 95% complete).

1. Medicines management (expenditures) – all variables (two) have more than 5% of missing data (9.2%).
2. Medical staffing – no variable has more than 5% missing data.
3. Radiology – three variables have between 5 and 19.9% of missing data. Two variables have more than 20% of missing data. In this topic, ‘missing’ also includes: - Trusts which do not provide radiology services.
4. Ward Staffing (statistics) – one variable has more than 5% of missing data (6.4%). (see Table 1)

<table>
<thead>
<tr>
<th>Topics</th>
<th>No. of variables</th>
<th>No. of Trusts or hospital sites</th>
<th>No. of missing variables divided by percentage range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicines Management</td>
<td>2</td>
<td>218</td>
<td>0 2 0 0 0 0</td>
</tr>
<tr>
<td>(expenditures)</td>
<td></td>
<td></td>
<td>0% - 4.9% 5% - 19.9% 20% - 39.9% 40% - 59.9% 60% - 79.9% 80% - 100%</td>
</tr>
<tr>
<td>Medical Staffing</td>
<td>6</td>
<td>193</td>
<td>0 0 0 0 0 0</td>
</tr>
<tr>
<td>Ward Staffing (statistics)</td>
<td>9</td>
<td>247</td>
<td>2 3 2 0 0 0</td>
</tr>
</tbody>
</table>

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Accuracy

Use of explicit definitions for variables: The definitions of most of variables are provided in national overview reports or published guides to indicators.

Use of explicit rules for deciding how variables are recorded: Data manuals (guide to indicators) are available for the following topics:
- medical staffing
  http://www.healthcarecommission.org.uk/assetRoot/04/00/25/48/04002548.pdf);
- medicines management
  (http://www.healthcarecommission.org.uk/assetRoot/04/00/25/50/04002550.pdf);
- radiology
  (http://www.healthcarecommission.org.uk/assetRoot/04/00/25/47/04002547.pdf)

No published data manual has been identified for ward staffing topic.

- Extent to which data are validated:

No published information has been identified as to whether data have been validated. Our internal analyses show some inconsistencies between datasets within the Acute Hospital Portfolio as well as between Acute Hospital Portfolio and external sources, namely HES and Hospital Activity Statistics.

4.4.2 National Cancer Peer Review - Data Quality Assessment2

General aspects

Background information

The Manual of Cancer Services Standards published by Department of Health in December 2000 sets out a number of quality measures (standards) in relation to the commissioning of cancer services.

At the beginning of 2001 every cancer unit and centre was intended to assess itself against these standards to measure own performance. This was then followed up with a peer review visit. The visits were carried out by teams of health care professionals and managers, all of whom are involved in the day-to-day delivery of cancer care, together with patient representatives. The main purpose of these peer review visits was to validate the self-assessment, so identifying where standards were or were not being met.

2 Based on Directory of Clinical Databases (DocDat) format (http://www.lshtm.ac.uk/docdat/page.php?t=index).
The standards look at the infrastructure and process of care rather than clinical outcomes.

The following 10 topics have been considered during peer review visits.

1. Patient-centred care.
2. Specialist multi-disciplinary teams (MDT).
3. Diagnostic services.
4. Provision of non-surgical oncology to cancer units.
5. Radiotherapy.
6. Chemotherapy.
7. Specialist palliative care services.
8. Education, training and continuing professional development.
10. Cancer services organisation and management.

Standards for specialist MDT are specified separately for breast, colorectal, lung and gynaecological cancers. No data are available for urological cancers since urology was not included in the 2001 programme.

A second round of peer review assessments is now in process, using the revised version of the Manual of Cancer Services Standards published by Department of Health in 2004.

**Source:** Cancer Action Team (by request), Department of Health, St Thomas’ Hospital, London (tel. 020 7960 5880).

**Reference population**

Common circumstance that determines inclusion in the database: All cancer units and centres.

Geographical area covered by the database: England.


Level of aggregation: Cancer units and centres in original dataset.

For the **Cancer Networks Limited Dataset** purposes, UCL research team transformed them into NHS Trust level.

**Dataset**

- Content

Number of individuals or episodes of care included in the database: The intention of the dataset is to include all cancer units and centres in England.

Data collection questionnaire: There is no questionnaire for this database.

- Data linkage
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Are nationally approved codes used for identifying the subject, clinician or institution? Cancer units and centres are identified by nationally approved organisational codes.

Available look-up table has been enhanced by UCL research team to link organisational codes to nationally approved NHS Trust codes.

To which other databases is linkage routinely undertaken? None known.

Outputs

• Analysis

Can ad hoc analyses be performed for health care providers?
  - Locally ('the health care provider who collects the data locally is able to analyse their data even though their data are also sent to the centralised database to be analysed with the data collected from other health care providers') – no.
  - Centrally (Local health care providers can obtain ad hoc analyses of their own data from the central database custodian) – yes.

• Audit reports

How frequently are multi-centre audit reports produced? National overview report³ (one-off) has been produced after 2001 peer review. Second round of peer review assessments is currently in process.

How frequently are provider-specific audit reports produced? It is assumed that final report (one-off) to the Trust, Strategic Health Authority and Cancer Network has been prepared by the peer review team chair and agreed with the Trust. However, no published information has been identified.

Publications

• Bibliography

No references have been identified to any studies that have used these data.

Professor Ellie Scrivens and colleagues conducted the evaluation of the whole process of 2001 peer review and published report⁴.

Management

• Support for database

Is the database approved by any clinical or professional associations? No.

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Who is involved in the management of the database? Doctors; statisticians; epidemiologists; IT specialists.

- **Source of funding**
  Department of Health, Cancer Action Team.

**Data quality**

- **Coverage**

  Extent to which the eligible population is representative of the country: Total population of country included.

  Completeness of recruitment of eligible population: Six regions used the final version of the cancer services standards (Manual of Cancer Services Standards, 2000). Eastern Region used the draft version and Trent used 'Trent Standards'. These are very similar to the final version of the standards but are not mappable one to one with the standards. Hence, the dataset includes individual standard data for each Trust in the six regions and summary data for Trent and Eastern regions.

- **Variables included in the database:**

  Variables represent cancer standards for each topic specified within the 'Manual of Cancer Services Standards' (Department of Health, 2001).

  For the Cancer Networks Limited Dataset purposes, individual standards have been grouped and presented according to the topics or subtopics specified within the Manual.

  Particularly, five main sets of variables are presented.

  - Total compliance with cancer standards for each main topic (including three MDT-related cancer specific topics) - 12 variables.
  
  - Compliance with three MDT-related set of variables (cancer-specific) grouped according to the sub-topics specified within the Manual. Only groupings for MDT standards for breast (11 variables), colorectal (10 variables) and lung (10 variables) cancers have been considered.
  
  - Compliance with chemotherapy-related standards grouped according to the sub-topics specified within the Manual – eight variables.

  See **Appendix A** for the variable list.

  Completeness of data (% variables at least 95% complete): Except for radiotherapy standards, all other variables at least 95% complete. Missing values for radiotherapy may imply no radiotherapy service at particular Trust.

**Accuracy**

Use of explicit definitions for variables: Clear definitions of all variable are available in the 'Manual of Cancer Services Standards' (Department of Health, 2001), accessible on-line at: www.dh.gov.uk
Use of explicit rules for deciding how variables are recorded: No published information (e.g. data manual) has been identified. However, the ‘Manual of Cancer Services Standards’ (Department of Health, 2001) sets out for each standard the information that would demonstrate that the standards have been complied with.

- Extent to which data are validated:

No published information has been identified as to whether data have been validated.

4.4.3 Hospital Episode Statistics - Data Quality Assessment

General aspects

Background information

The Hospital Episode Statistics database (HES) contains information on all admitted patients treated in NHS hospitals in England. Each record contains a variety of administrative, clinical and patient information describing the care and treatment a patient received while in hospital.

The data is captured from hospital patient administration systems, and HES now collects 12 million records per year from all hospital trusts in England.

HES publishes standard tables of analyses of NHS admitted patient care by diagnosis, operation, Healthcare Resource Group, consultant specialty, NHS Trust and Health Authority on their website. Users can also request specialised analyses to be performed on their behalf by the HES team.

HES is used by the NHS, Government and many other organisations and individuals who have an interest in health and health care administration.

Source: Department of Health


Reference population

Common circumstance that determines inclusion in the database: Inpatients and day cases admitted to NHS hospitals in England (including private cases), and NHS patients normally resident in England treated in the independent sector or abroad.

For the Cancer Networks Limited Dataset, only HES data for four cancer types (breast, colorectal, lung and prostate) has been included.

Geographical area covered by the database: England.

5 Based on Directory of Clinical Databases (DocDat) assessments (http://www.lshtm.ac.uk/docdat/records.php?t=records&id=HES).
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Time period covered by the database: April 1989 - ongoing. For presentation purposes, only 2002/2003 HES data has been included into the Cancer Network Limited Dataset.

Level of aggregation: Patient; NHS Trust.

Dataset

• Content

Number of individuals or episodes of care included in the database: The intention of the dataset is to include data on all in-patients at NHS Trusts in England.

Data collection questionnaire: There is no questionnaire for this database.

• Data linkage

Are nationally approved codes used for identifying the subject, clinician or institution? Nationally approved codes are used to identify each NHS Trust.

To which other databases is linkage routinely undertaken? None known.

Outputs

• Analysis

Can ad hoc analyses be performed for health care providers?

- Locally ("the health care provider who collects the data locally is able to analyse their data even though their data are also sent to the centralised database to be analysed with the data collected from other health care providers") – yes;

- Centrally (local health care providers can obtain ad hoc analyses of their own data from the central database custodian) – yes.

• Audit reports

How frequently are multi-centre audit reports produced? Never.

How frequently are provider-specific audit reports produced? Annually.

Publications

• Bibliography

There are numerous references identified to studies that have used HES data with regard to different pathologies and for different purposes.

Some of the main references are listed below:

1 Aylin P, Alves B, Cook A, Bennett J, Bottle A, Best N, Catena B, Elliott P. 1999. Analysis of Hospital Episode Statistics for the Bristol Royal Infirmary Inquiry. Division Primary Care & Population Health Sciences, Imperial College School of Medicine, St. Mary’s Campus. London: Crown Copyright.
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Management

- Support for database

Is the database approved by any clinical or professional associations? No

Who is involved in the management of the database? Doctors; statisticians; epidemiologists; IT specialists

- Source of funding

Department of Health.

Data quality

- Coverage

Extent to which the eligible population is representative of the country: Total population of country included (patients treated in NHS hospitals).

Completeness of recruitment of eligible population: The database includes more than 97 percent of the eligible population.

According to the DocDat, completeness (99 percent) was last determined in 2002 when national comparisons between Trusts had been conducted to identify those with poor completeness.

- Variables included in the database
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There are numerous variables in HES dataset reflecting patient and provider identifiers; administrative info; condition; intervention and outcome.

Taking into account completeness and relation to the variables in other national datasets presented, the following variables have been included in the Cancer Networks Limited Dataset: number of patients; in-hospital mortality; mean number of episodes per patient; mean and median length of stay; mean waiting time.

Completeness of data (% variables at least 95% complete): Except mean and median length of stay, all other variables included in the Cancer Networks Limited Dataset are complete.

The percentage of missing values for mean and median length of stay varies by cancer type.

- Breast cancer – 9.3%.
- Colorectal – 5.7%.
- Lung – 13.3%.
- Prostate – 6.5%.

On a national level, from 80% to 97% of variables are at least 95% complete in the HES dataset (National Data Quality Indicators, 2002).

Accuracy

Use of explicit definitions for variables: All or almost all variables (>97%) have clear definitions. Definitions of variables are available in HES Data Dictionary (http://www.performance.doh.gov.uk/hes/dictionary/index.html)

Use of explicit rules for deciding how variables are recorded: All or almost all variables (>97%) have clear rules on how to code them in the database (HES Data Dictionary).

- Extent to which data are validated

Range and consistency checks (continuous autocleaning followed by validation). There is no rigorous validation at source, however the NHS Information Authority conducts periodic external audits.
4.4.4 Cancer Waiting Times - Data Quality Assessment

General aspects

Background information

Cancer Waiting Times contain data on the waiting time of patients with suspected cancer and those subsequently diagnosed with cancer at NHS Trusts in England. Data are submitted quarterly by NHS Trusts.

Cancer Waiting Times Statistics monitors the following waiting time targets.

- ‘Two week wait’ from urgent GP referral to first outpatient appointment for all patients with suspected cancer.
- ‘One month wait’ from urgent GP referral to treatment for children’s cancers, testicular cancers and acute leukaemia.
- ‘One month wait’ from diagnosis to treatment for breast cancer.
- ‘Two month wait’ from GP referral to treatment for breast cancer.
- ‘One month wait’ from diagnosis to treatment for all cancers.
- ‘Two month wait’ from GP referral to treatment for all cancers.

However, Cancer Networks Limited Dataset includes data only for ‘two week wait’ target. The reason for that is that it is available for all four cancers presented (breast; lower gastrointestinal cancer; lung; urological cancers) and it was not until the quarter 4, 2004/2005 that Department of Health started monitoring ‘1 month wait’ and ‘2 month wait’ targets for all cancers, similar to breast cancer targets.

It is impossible to differentiate cancer sites under ‘lower gastrointestinal cancer’ and ‘urological cancers’ though it is assumed that they reasonably reflect waiting times for colorectal and prostate cancers, respectively.

Source: Department of Health

http://www.performance.doh.gov.uk/cancerwaits/

Reference population

Common circumstance that determines inclusion in the database: All urgent GP referrals of patients with suspected cancer seen by a specialist

Geographical area covered by the database: England.

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6 Based on Directory of Clinical Databases (DocDat) format (http://www.lshtm.ac.uk/docdat/page.php?t=index).
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Time period covered by the database: Data submitted quarterly, from the 1st quarter of 2001/2002 – ongoing.

Level of aggregation: Patients’ records are aggregated at NHS Trust level. Data are available also at Strategic Health Authority level.

Dataset

- Content

Number of individuals or episodes of care included in the database: The intention of the dataset is to include all urgent GP referrals of suspected cancer patients.

Data collection questionnaire: There is no questionnaire for this database.

- Data linkage

Are nationally approved codes used for identifying the subject, clinician or institution? Nationally approved codes are used to identify each NHS Trust.

To which other databases is linkage routinely undertaken? None known.

Outputs

- Analysis

Can ad hoc analyses be performed for health care providers?

- Locally (the health care provider who collects the data locally is able to analyse their data even though their data are also sent to the centralised database to be analysed with the data collected from other health care providers) – yes.

- Centrally (Local health care providers can obtain ad hoc analyses of their own data from the central database custodian) – yes.

- Audit reports

How frequently are multi-centre audit reports produced? The Department of Health issues statistical reports each quarter. The National Audit Office\(^7\) and Audit Commission\(^8\) have produced audit reports on accuracy and management of NHS waiting time statistics.

How frequently are provider-specific audit reports produced? No published information is identified.


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Publications

- Bibliography

No references have been identified to any studies that have used these data.

Management

- Support for database

Is the database approved by any clinical or professional associations? No.

Who is involved in the management of the database? Doctors; statisticians; epidemiologists; IT specialists.

- Source of funding:

The Department of Health.

Data quality

- Coverage

Extent to which the eligible population is representative of the country: All urgent GP referrals of patients with suspected cancer are included in the dataset. However, the dataset does not include cancer patients with non-urgent GP referrals and those admitted to the hospital without GP referral.

Completeness of recruitment of eligible population: Overall, 216 NHS Trusts have been included in the dataset. It is difficult to determine to what extent the recruitment of eligible population is complete, since it depends on reporting from each NHS Trust.

- Variables included in the database:

Total referrals seen during the quarter, and the number of patients whose waiting times are within specific time periods (days) of the decision to refer by their GP, are the main variables included in the dataset. There are also variables indicating cancer type, NHS Trust and Strategic Health Authority (Health Authority for 2001/2002). For the Cancer Networks Limited Dataset, quarterly data have been summed into annual data.

Completeness of data (% variables at least 95% complete): Data for some NHS Trusts are missing for some quarters.

Accuracy


Use of explicit rules for deciding how variables are recorded: All variables have clear rules on how to code them in the dataset (http://www.dh.gov.uk/assetRoot/04/01/90/66/04019066.xls and
Measuring Quality in Cancer Services

http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Cancer/CancerArticle/fs/en?CONTENT_ID=4001800&chk=dpRNWQ). (see also previous item)

- Extent to which data are validated:

No published information has been identified as to whether data have been validated.

4.4.5 Cancer Survival - Data Quality Assessment

General aspects

Background information

Cancer registration has been conducted in parts of the UK since 1929, with national coverage since 1962 (although ascertainment of all cancer cases was not 100 percent at this time). From 1971 patients were followed up through death certifications, allowing survival analyses to be performed. This assessment of data quality relates to data collected from 1971 onwards.

There are currently nine regional cancer registries in England and one in Wales that collect population-based data on the incidence, mortality and survival from cancer. A subset of the data collected by the regional cancer registries is collated centrally by the National Cancer Intelligence Centre at the Office for National Statistics (ONS), to provide national figures on cancer incidence and survival on a regular basis.

Regional cancer registries receive notification of incident cancer cases from a number of different sources. These include hospital inpatient and outpatient systems (PAS); radiotherapy; pathology; GPs, coroners; cytology; chest clinics etc.

Source: Office for National Statistics, National Cancer Minimum Dataset

Reference population

Common circumstance that determines inclusion in the database: Diagnosis of cancer.

Geographical area covered by the database: England and Wales.


Level of aggregation: Cancer Network.

---

9 Based on Directory of Clinical Databases (DocDat) assessments (http://www.lshtm.ac.uk/docdat/records.php?t=records&id=NCMDS).
Measuring Quality in Cancer Services

Dataset

• Content

Number of individuals or episodes of care included in the database: The intention of the dataset is to include data on all cancer patients in England and Wales.

Data collection questionnaire: There is no questionnaire for this database.

• Data linkage

Are nationally approved codes used for identifying the subject, clinician or institution? Nationally approved codes are used to identify each Cancer Network. Individual patients are separately identified within the system by unique codes so that separate data elements such as diagnosis and death can be accurately linked, but data that are released for analysis do not contain personal identifiers.

To which other databases is linkage routinely undertaken? The National Health Service Central Register

Outputs

• Analysis

Can ad hoc analyses be performed for health care providers?
- Locally ('the health care provider who collects the data locally is able to analyse their data even though their data are also sent to the centralised database to be analysed with the data collected from other health care providers') – yes.
- Centrally (Local health care providers can obtain ad hoc analyses of their own data from the central database custodian) – yes.

• Audit reports

How frequently are multi-centre audit reports produced? Never.
How frequently are provider-specific audit reports produced? Annually.

Publications

• Selected bibliography:


Measuring Quality in Cancer Services


Measuring Quality in Cancer Services

Management

• Support for database

Is the database approved by any clinical or professional associations? Yes – the UK Association of Cancer Registries.

Who is involved in the management of the database? Doctors; statisticians; epidemiologists; IT specialists.

• Source of funding:

Department of Health (The NHS funds the regional cancer registries and the Department of Health (DH) pays the ONS to process the data and to operate the National Cancer Registry).

Data quality

• Coverage

Extent to which the eligible population is representative of the country: Total population of country included.

Completeness of recruitment of eligible population: The database includes 90 to 97% of the eligible population.

Absolute levels of case ascertainment are very difficult to obtain as there is no truly independent source with which to compare. A number of methods to determine ascertainment are employed by the registries, including capture/recapture methods, a comparison of incidence to mortality ratios, and mathematical modeling. The level of ascertainment can be judged by the proportion of cases which are registered through death certificates, as this indicates that the patient was missed by the normal notification channels. The proportion of Death Certification Only (DCO) registrations varies by cancer site and register. Overall, it is around 5%, ranging from 0% to 12% between regional registries. In general, more aggressive cancers tend to have higher ascertainment rates. Ascertainment rates in the 1970s were lower, and improved in 1979 due to the introduction of ICD9 codes. The rapidity with which death certificate notifications reach the regional registries (3 to 10 days), compared with the difficulty of completing a standard cancer registration within six months, including the first courses of treatment, means that DCO levels tend to exaggerate the problems of completeness, even after success in tracing back such notifications to the hospital are taken into account.

• Variables included in the database:

The complete set of variables collected at national level for inclusion in the National Cancer Minimum Dataset is provided in Appendix B.
Measuring Quality in Cancer Services

Taking into account completeness and relation to the variables in other national datasets presented, the following variables have been included in the Cancer Networks Limited Dataset: cancer type; sex; survival period (years); number of cancer cases; relative survival (%) with 95% confidence interval. Relative survival estimates have been provided by the LSHTM part of the research team.

Completeness of data (% variables at least 95% complete):

All variables included in the Cancer Networks Limited Dataset are complete (there are no missing data).

At a national level, from 50% to 79% of variables are at least 95% complete in the National Cancer Minimum Dataset. Completeness is poor for stage and grade of tumours, major confounding factors and the patient’s ethnicity and NHS number.

Accuracy

Use of explicit definitions for variables: All or almost all variables (>97%) have clear definitions, either within the WHO’s International Classification of Diseases for Oncology or within other source documents agreed between the Department of Health and the UK Association of Cancer Registries.

Use of explicit rules for deciding how variables are recorded: All or almost all variables (>97%) have clear rules on how to code them in the database (see previous item).

- Extent to which data are validated:

Range and consistency check plus external validation using an alternative source.

Records have to pass a series of validation checks before they are allowed onto the register. A limit of 0.5% of records rejected is set, and the average number of actual rejections a year since 1971 is 0.4%. A record is entered onto the register if all key fields are complete and valid (status code 1). A record in which data in a non-essential field (such as occupation) is invalid can still be included on the register (status code 2). If a record contains invalid information in any of the key variables, it is assigned a status code of 3, and can only be entered onto the National Cancer Register once suitable amendments have been made and the record has passed the same set of quality controls as before. Records containing such errors are sent back to the regional cancer registries for validation with original records and the record has been corrected (or the apparently anomalous information has been confirmed as correct from the original clinical records) and the record has been re-submitted as appropriate. Regional registries are required to audit a sample of their cases, however in reality this is done sporadically and differently between registers. Proposals for a standard audit programme are currently being developed.
4.4.6 National Survey: Cancer Patients - Data Quality Assessment

General aspects

Background information

The National Survey: Cancer Patients was undertaken in 2000 to 2001 to assess the quality of care as seen by hospital patients with one of six types of cancer: breast; colorectal; lung; ovarian; prostate or non-Hodgkin's lymphoma.

The following areas have been considered during the survey:

- Access to care.
- Waiting times.
- The diagnosis.
- First treatment.
- The hospital environment.
- Outpatients’ experience.

The results of the survey are presented as scores which represent a percentage of patients whose answers indicate a problem with care at the NHS Trust. A score of 0.5% or below is indicated by ‘0’. Data for Trusts with fewer than 50 patients with a particular type of cancer, for a particular question, have been excluded from the tables presented at Department of Health website. An asterisk (*) indicates a base of 49 or below.


Reference population:

Common circumstance that determines inclusion in the database.

- The sample of patients was drawn from hospital administrative records of hospital episodes. It was limited to those who had been discharged between July 1999 and June 2000, having been diagnosed with one of six different types of cancer: breast; colorectal; lung; ovarian; prostate or non-Hodgkin's lymphoma.
- All NHS Trusts in England estimated to have 150 or more qualifying patients within the stated period, were asked to participate in the survey. There were 172 such Trusts; all of them participated.

---

10 Based on Directory of Clinical Databases (DocDat) format (http://www.lshtm.ac.uk/docdat/page.php?t=index).
Geographical area covered by the database: England.

Time period covered by the database: July 1999 to June 2000. Patients responded to the survey over 2000/2001 and were commenting on treatment they received between July 1999 and June 2000 – before the publication of the NHS Cancer Plan (September 2000).

Level of aggregation: NHS Trust and Cancer Network.

The number of Trusts for which data are available varied between cancer types (there were fewer patients for cancers with short survival).

- Breast cancer - 157 Trusts.
- Colorectal cancer - 143 Trusts.
- Prostate cancer - 89 Trusts.
- Lung cancer - 19 Trusts.

Dataset

- Content

Number of individuals or episodes of care included in the database: Total sample size (including all cancer types) – 653,37 drawn from 172 NHS Trusts, 34 Cancer Networks. Total sample size including only the four cancers (colorectal, lung, breast (female), prostate) – 565,21.

Data collection questionnaire: Questionnaire is available to access on-line at: http://www.dh.gov.uk/assetRoot/04/06/77/83/04067783.pdf

- Data linkage

Are nationally approved codes used for identifying the subject, clinician or institution? NHS Trusts are identified by name (within on-line dataset) and id (within SPSS file provided by Department of Health). Available look-up table has been enhanced by UCL research team to link id-s and names to nationally approved NHS Trust codes and cancer networks.

To which other databases is linkage routinely undertaken? None known.

Outputs

- Analysis

Can ad hock analyses be performed for health care providers?

- Locally ('the health care provider who collects the data locally is able to analyse their data even though their data are also sent to the centralised database to be analysed with the data collected from other health care providers') – no.

- Centrally (Local health care providers can obtain ad hoc analyses of their own data from the central database custodian) – yes. The Department of Health produced Trust-specific reports (one-off) and feed back results to each participating Trust.
Measuring Quality in Cancer Services

- Audit reports
  How frequently are multi-centre audit reports produced? Not applicable
  How frequently are provider-specific audit reports produced?
  Provider specific reports (one-off) have been issued at both NHS Trust and cancer network level (published: 08/07/2002; available on-line: http://www.dh.gov.uk

Publications

- Bibliography
  Department of Health provides no references to any studies that have used these data. However, the following national reports produced by the Department of Health are available to access on-line:


The following articles which were produced using National Cancer Patient Survey have been identified.


Management

- Support for database
  Is the database approved by any clinical or professional associations? No.
  Who is involved in the management of the database? Doctors; statisticians; epidemiologists; IT specialists.
  Source of funding:
  Department of Health (organisations involved: National Centre for Social Research (NatCen); Picker Institute Europe; Imperial College London).
Data quality

- Coverage

Extent to which the eligible population is representative of the country: There were approximately 200 NHS acute Trusts available for the survey. Table 4 shows the national response rates by tumour type.

Completeness of recruitment of eligible population: Overall, at the 172 Trusts included in the postal survey, a total of 123984 patients were selected across the six cancer types as eligible for the survey. There was a considerable variation in the numbers selected at each Trust. For the majority of Trusts however the selected sample was in the range 500 to 800 patients. Prior to mailing, the names of patients who were known to have died were removed from the sample. Relatively small numbers of selected patients were removed for other reasons (eg difficulties in matching NHS number to the NSTS files). In all, approximately one in four of selected names was removed, resulting in questionnaires being sent to 926,83 patients. Completed questionnaires were received back from 653,37 patients. This represented an overall response of 74 percent, after discounting returned mail, patients whose deaths had been reported after mailing and others who had been sent questionnaires but proved, in the event, to be ineligible. The response rates for patients with different types of cancer varied, as set out below\textsuperscript{11}.

\textsuperscript{11}http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/NationalSurveyOfNHSPatients/NationalSurveyCancer/NationalSurveyCancerArticle/fs/en?CONTENT_ID=4001299&chk=DIXnuW
Table 4  Response rates by tumour type

<table>
<thead>
<tr>
<th>Cancer type</th>
<th>Number of questionnaires returned</th>
<th>Response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast (including 145 males)</td>
<td>25 772</td>
<td>77%</td>
</tr>
<tr>
<td>Colorectal</td>
<td>15 891</td>
<td>74%</td>
</tr>
<tr>
<td>Lung</td>
<td>4 011</td>
<td>62%</td>
</tr>
<tr>
<td>Ovarian</td>
<td>3 067</td>
<td>74%</td>
</tr>
<tr>
<td>Prostate</td>
<td>10 992</td>
<td>71%</td>
</tr>
<tr>
<td>Non-Hodgkin's lymphoma</td>
<td>5 604</td>
<td>69%</td>
</tr>
</tbody>
</table>

The response rate varied between Trusts, from below 60% to over 80%.

These analyses were derived from the database restricted to 164 out of the 172 Trusts that participated in the survey. Response rate at the eight omitted Trusts was too low (below 60%) to provide statistically reliable information.

- Variables included in the database:

Most of the data represent coded responses to survey questions. There are also dates, Trusts of first appointment, treatment and most recent outpatient visit, details about the cancer diagnosis and some demographic information (age, sex, social class).

Out of 96 items (questions) available in the original questionnaire, 18 items have been included in the Cancer Networks Limited Dataset. This selection has been made based on the results of secondary analysis of the data (factor analysis) conducted by NatCen\textsuperscript{12}. Particularly, factor analyses suggested that apart from the ‘Recent outpatient visit: medical care’ theme (five questions), nine individual questions can be used to represent nine themes identified by factor analyses. In addition, there were four questions that did not fit into any themes. The list of these questions is provided in Appendix A.

Completeness of data (Table 5):

- Breast cancer: 16 variables in the dataset have more than 5% of missing data; 1 variable has 29.6% of missing values.
- Colorectal cancer: 17 variables have more than 5% missing data.

Measuring Quality in Cancer Services

- Lung cancer: 16 variables have between 5% and 19.9% of missing data; 1 variable has more than 20% of missing data.
- Prostate cancer – 17 variables have more than 5% of missing data.

<table>
<thead>
<tr>
<th>Type of Cancer</th>
<th>No. of variables</th>
<th>No. of Trusts</th>
<th>No. of missing variables divided by percentage range</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>0% - 4.9%</td>
</tr>
<tr>
<td>Breast</td>
<td>18</td>
<td>157</td>
<td>1</td>
</tr>
<tr>
<td>Colorectal</td>
<td>18</td>
<td>143</td>
<td>1</td>
</tr>
<tr>
<td>Lung</td>
<td>18</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Prostate</td>
<td>18</td>
<td>89</td>
<td>1</td>
</tr>
</tbody>
</table>

Accuracy

Use of explicit definitions for variables: Variables represent items of questionnaire.

Use of explicit rules for deciding how variables are recorded: Most variables (>88%) have clear rules on how to code them in the database.

- Extent to which data are validated:

No published information has been identified as to whether data have been validated.
Section 5  The limited dataset

An important objective of the study was to develop limited dataset from the routine national data sources and distribute it to the 34 cancer network teams in England. The purpose was to demonstrate that the datasets could be used in a reduced and efficient way, and to determine whether this was valued by cancer networks.

Our interview studies indicated that network managers were selective in their use of datasets. Typically, interest in data came from below, for example from clinicians, or from above, for example the Department of Health. Some of our datasets had been made available, in past years, to the networks in generic form, or were accessible on the internet. No dataset had been provided to networks before.

We cleaned the full datasets by statistical analysis, and reduced them to the ‘limited dataset’ by selecting variables out of numerous available. Factor analysis was initially tried with the Acute Hospital Portfolio, but yielded item groupings with little intuitive meaning: we therefore chose individual items in the dataset that reflected measures of health system performance identified in the literature review. For the Satisfaction Survey, the original questions had already been reduced to 10 that reflected different dimensions of the care episode. Further factors in the selection included completeness of the data, timeliness, and the analytic questions posed in the original research call.

We had particular concern to ensure that the data related to the same hospital trusts: these change over time in England, as a result of mergers and developments. We gained access to conversion codes from the Department of Health which fitted the various datasets, and formed a list which reflected the situation in 2001.

We produced the limited dataset in hard copy form for the Networks in June 2006. (We were able to discuss aspects of the networks’ perceptions of datasets at the Cancer Action Team meeting on 7 July 2005.) We sent the limited data, grouped by the six dataset sources, providing each network with average national data, data for their own network and data for their local trusts.

We provide below (Table 6 to 11) a dataset for a single anonymous “Network K”. The items chosen from the dataset are shown horizontally, and the letters refer to hospital trusts identified within the datasets. We also produced a composite summary set of data at
network level, which is available from the research team, and was the basis for the analyses subsequently undertaken. More time could refine, or extend these data items: this was an initial attempt to portray collectively the data available.
### Table 6  Network K - Acute Hospital Portfolio

#### Medical Staffing 2001/2002

<table>
<thead>
<tr>
<th>Indicators</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant WTE* per 1000 all admissions</td>
<td>2.12</td>
<td>5.45</td>
<td>2.04</td>
<td>n/a**</td>
<td>2.31</td>
<td>2.26</td>
<td>n/a</td>
</tr>
<tr>
<td>Anaesthetist Consultant WTE per 1000 surgical admissions</td>
<td>0.85</td>
<td>1.79</td>
<td>1.01</td>
<td>n/a</td>
<td>0.83</td>
<td>1.31</td>
<td>n/a</td>
</tr>
<tr>
<td>Medicine Consultant WTE per 1000 medicine admissions</td>
<td>2.11</td>
<td>1.79</td>
<td>1.60</td>
<td>n/a</td>
<td>1.37</td>
<td>2.34</td>
<td>n/a</td>
</tr>
<tr>
<td>Pathology Consultant WTE per 1000 all admissions</td>
<td>1.88</td>
<td>0.98</td>
<td>2.92</td>
<td>n/a</td>
<td>2.60</td>
<td>2.00</td>
<td>n/a</td>
</tr>
<tr>
<td>Radiology Consultant WTE per 1000 all admissions</td>
<td>2.04</td>
<td>0.34</td>
<td>2.46</td>
<td>n/a</td>
<td>2.49</td>
<td>2.17</td>
<td>n/a</td>
</tr>
<tr>
<td>Ratio of outpatients to all admissions</td>
<td>4.08</td>
<td>3.55</td>
<td>5.15</td>
<td>n/a</td>
<td>4.64</td>
<td>4.70</td>
<td>n/a</td>
</tr>
</tbody>
</table>

*Whole-time equivalent (WTE)

### Table 7  Network K - Acute Hospital Portfolio


<table>
<thead>
<tr>
<th>Indicators</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical nurse specialists (WTE) per 1000 FCE***</td>
<td>n/a</td>
<td>2.20</td>
<td>0.87</td>
<td>0.32</td>
<td>0.80</td>
<td>0.65</td>
<td>0.50</td>
</tr>
<tr>
<td>Standardised ward patient accidents per 100 available beds</td>
<td>n/a</td>
<td>202</td>
<td>59</td>
<td>26</td>
<td>115</td>
<td>66</td>
<td>119</td>
</tr>
<tr>
<td>All formal complaints per 1000 FCEs</td>
<td>n/a</td>
<td>9.92</td>
<td>12.86</td>
<td>9.16</td>
<td>9.98</td>
<td>8.16</td>
<td>4.86</td>
</tr>
</tbody>
</table>

***Finished consultant episode (FCE)

### Radiology 2001/2002

<table>
<thead>
<tr>
<th>Indicators</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waiting times* sympt. Mammography</td>
<td>5</td>
<td>n/a</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>n/a</td>
<td>2</td>
</tr>
<tr>
<td>Waiting times nuclear medicine</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>n/a</td>
<td>6</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Waiting times CT**</td>
<td>5</td>
<td>4</td>
<td>8</td>
<td>3</td>
<td>5</td>
<td>n/a</td>
<td>4</td>
</tr>
<tr>
<td>Waiting times MRI***</td>
<td>25</td>
<td>28</td>
<td>78</td>
<td>26</td>
<td>16</td>
<td>n/a</td>
<td>10</td>
</tr>
<tr>
<td>% exams unreported****</td>
<td>27</td>
<td>n/a</td>
<td>5</td>
<td>32</td>
<td>5</td>
<td>n/a</td>
<td>33</td>
</tr>
<tr>
<td>% exams reported by radiology staff</td>
<td>73</td>
<td>21</td>
<td>90</td>
<td>28</td>
<td>75</td>
<td>n/a</td>
<td>28</td>
</tr>
<tr>
<td>Inpatient exams per FCE</td>
<td>0.44</td>
<td>n/a</td>
<td>0.48</td>
<td>1.15</td>
<td>0.52</td>
<td>n/a</td>
<td>1.00</td>
</tr>
<tr>
<td>Outpatient exams per outpatient visit</td>
<td>0.25</td>
<td>n/a</td>
<td>0.23</td>
<td>1.23</td>
<td>0.29</td>
<td>n/a</td>
<td>1.33</td>
</tr>
<tr>
<td>Radiographers per 1000 FCE</td>
<td>0.71</td>
<td>n/a</td>
<td>0.71</td>
<td>1.24</td>
<td>0.73</td>
<td>n/a</td>
<td>1.48</td>
</tr>
</tbody>
</table>

*Average wait (median) in weeks

**Computed Tomography (CT)
**Measuring Quality in Cancer Services**

***Magnetic Resonance Imaging (MRI)***

****Percentage of examinations unreported or reported by referring clinicians without agreement with radiology department

**Medicines Expenditure 2001/2002**

<table>
<thead>
<tr>
<th>Indicators</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
</tr>
</thead>
<tbody>
<tr>
<td>BNF* Spend malignant disease (£000)</td>
<td>n/a*</td>
<td>472</td>
<td>1620</td>
<td>2507</td>
<td>469</td>
<td>297</td>
<td>1963</td>
</tr>
<tr>
<td>BNF* Spend malignant disease per FCE** (£)</td>
<td>n/a</td>
<td>21.59</td>
<td>40.38</td>
<td>28.60</td>
<td>10.67</td>
<td>8.46</td>
<td>32.44</td>
</tr>
</tbody>
</table>

*British National Formulary (BNF)*

---

**Table 8  Network K - Compliance with cancer standards: Peer Review 2001**

**Standards topic groups**

<table>
<thead>
<tr>
<th>Topic**</th>
<th>Total number of standards</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient centred care</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Breast cancer MDT***</td>
<td>39</td>
<td>26.5</td>
<td>25</td>
<td>22</td>
<td>19</td>
<td>27</td>
</tr>
<tr>
<td>Colorectal cancer MDT***</td>
<td>35</td>
<td>23</td>
<td>19</td>
<td>15</td>
<td>23</td>
<td>24</td>
</tr>
<tr>
<td>Lung cancer MDT***</td>
<td>36</td>
<td>14</td>
<td>25</td>
<td>24</td>
<td>18</td>
<td>22</td>
</tr>
<tr>
<td>Pathology</td>
<td>7</td>
<td>4</td>
<td>3</td>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Non-surgical oncology</td>
<td>5</td>
<td>1.5</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Radiotherapy****</td>
<td>60</td>
<td>0</td>
<td>45</td>
<td>52</td>
<td>0</td>
<td>59</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>45</td>
<td>21.5</td>
<td>30</td>
<td>33</td>
<td>37</td>
<td>34</td>
</tr>
<tr>
<td>Palliative care</td>
<td>11</td>
<td>8</td>
<td>6</td>
<td>11</td>
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<td>Communication</td>
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<td>Cancer units (centre)</td>
<td>15 (16)*****</td>
<td>7</td>
<td>10</td>
<td>0</td>
<td>12</td>
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</tr>
</tbody>
</table>

*includes also gynaecological cancers; prostate cancer was not included in 2001 peer review

**for full description of topics, see Attachment B (Table 1)

***Multi-disciplinary team (MDT)

****'0' for radiotherapy implies no radiotherapy service

*****15 standards were assessed for each cancer unit; 16 standards were assessed for each cancer centre

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**Measuring Quality in Cancer Services**

**Table 9  Network K – Compliance with cancer standards: Peer Review 2001**

**Compliance with breast cancer MDT*-related standards**

<table>
<thead>
<tr>
<th>Topic**</th>
<th>Total number of standards</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
</tr>
</thead>
<tbody>
<tr>
<td>MDT* structure</td>
<td>9</td>
<td>9</td>
<td>7</td>
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<td>6</td>
<td>7</td>
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<td>1</td>
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<td>3</td>
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<td>8</td>
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<td>8</td>
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<td>3</td>
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<td>1</td>
<td>1</td>
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<td>1</td>
</tr>
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*Multi-disciplinary team (MDT)*

**for full description of topics, see Attachment B (Table 2)**

**Table 10  Network K – Compliance with cancer standards: Peer Review 2001**

**Compliance with colo-rectal cancer MDT*-related standards**

<table>
<thead>
<tr>
<th>Topic**</th>
<th>Total no. standards</th>
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<td>5</td>
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<td>Patient centred care</td>
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<td>1</td>
<td>5</td>
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<td>Treatment</td>
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<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Clinical guidelines</td>
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<td>1</td>
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<td>1</td>
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<td>1</td>
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</table>

*Multi-disciplinary team (MDT)*
Measuring Quality in Cancer Services

Table 11  Network K - Compliance with cancer standards: Peer Review 2001
Compliance with lung-cancer MDT*-related lung cancer standards

<table>
<thead>
<tr>
<th>Topic**</th>
<th>Total no. of standards</th>
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<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
</tr>
</thead>
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<td>5</td>
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<td>2</td>
<td>4</td>
<td>3</td>
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<td>3</td>
</tr>
<tr>
<td>Operational policies</td>
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<td>4</td>
<td>7</td>
<td>7</td>
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<td>5</td>
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<tr>
<td>Patient-centred care</td>
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<td>4</td>
<td>2</td>
<td>1</td>
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<td>Treatment</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Clinical guidelines</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
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<td>0</td>
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<td>0</td>
<td>0</td>
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<td>0</td>
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<td>Clinical trials</td>
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<td>0</td>
<td>1</td>
<td>1</td>
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<td>1</td>
</tr>
</tbody>
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*Multi-disciplinary team (MDT)

**for full description of topics, see Attachment B (Table 2)

Table 12  Network K - Compliance with cancer standards: Peer Review 2001
Compliance with chemotherapy-related cancer standards

<table>
<thead>
<tr>
<th>Topic*</th>
<th>Total no. of standards</th>
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<th>B</th>
<th>C</th>
<th>D</th>
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<td>Policy</td>
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<td>1.5</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>2</td>
</tr>
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<td>Training</td>
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<td>1.5</td>
<td>2</td>
<td>4</td>
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<td>4</td>
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<tr>
<td>Guidelines/protocols</td>
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<td>8.5</td>
<td>10</td>
<td>9</td>
<td>13</td>
<td>11</td>
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<tr>
<td>Out of hours administration</td>
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<td>0.5</td>
<td>0</td>
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<td>1</td>
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<td>3.5</td>
<td>7</td>
<td>7</td>
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<td>7</td>
</tr>
<tr>
<td>Prescription/documentation</td>
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<td>3</td>
<td>4</td>
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</table>

*for full description of topics, see Attachment B (Table 3)
# Measuring Quality in Cancer Services

## Table 13  Network K  Hospital Episode Statistics 2002/2003

### Breast cancer

<table>
<thead>
<tr>
<th>Indicators</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>186</td>
<td>304</td>
<td>156</td>
<td>236</td>
<td>112</td>
<td>250</td>
</tr>
<tr>
<td>In-hospital mortality</td>
<td>7.5%</td>
<td>3.6%</td>
<td>3.2%</td>
<td>5.1%</td>
<td>5.4%</td>
<td>6.4%</td>
</tr>
<tr>
<td>Mean number of episodes per patient</td>
<td>1.1</td>
<td>4.6</td>
<td>1.6</td>
<td>3.6</td>
<td>4.4</td>
<td>3.3</td>
</tr>
<tr>
<td>Mean length of stay (days)</td>
<td>6.9</td>
<td>3.7</td>
<td>8.8</td>
<td>5.4</td>
<td>3.9</td>
<td>5.2</td>
</tr>
<tr>
<td>Median length of stay (days)</td>
<td>5</td>
<td>0</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Mean waiting time (days)*</td>
<td>13.9</td>
<td>19.3</td>
<td>13.4</td>
<td>13.6</td>
<td>12.9</td>
<td>12.6</td>
</tr>
</tbody>
</table>

*waiting time is defined as ‘the difference in days between the date on which it was decided to admit the patient and the admission date’

### Colorectal cancer

<table>
<thead>
<tr>
<th>Indicators</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>207</td>
<td>247</td>
<td>152</td>
<td>209</td>
<td>107</td>
<td>210</td>
</tr>
<tr>
<td>In-hospital mortality</td>
<td>13.5%</td>
<td>7.3%</td>
<td>9.9%</td>
<td>11.5%</td>
<td>16.8%</td>
<td>7.6%</td>
</tr>
<tr>
<td>Mean number of episodes per patient</td>
<td>1.2</td>
<td>6.1</td>
<td>1.6</td>
<td>6.5</td>
<td>5.1</td>
<td>3.4</td>
</tr>
<tr>
<td>Mean length of stay (days)</td>
<td>15.5</td>
<td>8.5</td>
<td>21.2</td>
<td>8.2</td>
<td>11.3</td>
<td>10.2</td>
</tr>
<tr>
<td>Median length of stay (days)</td>
<td>10</td>
<td>0</td>
<td>11</td>
<td>1</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Mean waiting time (days)*</td>
<td>40.2</td>
<td>15.0</td>
<td>20.2</td>
<td>24.3</td>
<td>9.3</td>
<td>15.4</td>
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</tbody>
</table>

*waiting time is defined as ‘the difference in days between the date on which it was decided to admit the patient and the admission date’

### Lung cancer

<table>
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<tr>
<th>Indicators</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
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<td>149</td>
<td>109</td>
<td>154</td>
<td>195</td>
<td>249</td>
</tr>
<tr>
<td>In-hospital mortality</td>
<td>32.4%</td>
<td>17.4%</td>
<td>13.8%</td>
<td>27.9%</td>
<td>19.5%</td>
<td>12.4%</td>
</tr>
<tr>
<td>Mean number of episodes per patient</td>
<td>1.1</td>
<td>2.2</td>
<td>1.3</td>
<td>2.1</td>
<td>2.8</td>
<td>2.3</td>
</tr>
<tr>
<td>Mean length of stay (days)</td>
<td>17.4</td>
<td>10.9</td>
<td>13.3</td>
<td>9.1</td>
<td>11.3</td>
<td>9.0</td>
</tr>
<tr>
<td>Median length of stay (days)</td>
<td>11</td>
<td>5</td>
<td>10</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Mean waiting time (days)*</td>
<td>9.6</td>
<td>18.6</td>
<td>9.5</td>
<td>5.8</td>
<td>10.6</td>
<td>12.2</td>
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*waiting time is defined as ‘the difference in days between the date on which it was decided to admit the patient and the admission date’
Measuring Quality in Cancer Services

Prostate cancer

<table>
<thead>
<tr>
<th>Indicators</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
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<td>Number of patients</td>
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<td>122</td>
<td>103</td>
<td>217</td>
<td>68</td>
<td>140</td>
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<tr>
<td>In-hospital mortality</td>
<td>14.4%</td>
<td>9.8%</td>
<td>9.7%</td>
<td>7.8%</td>
<td>11.8%</td>
<td>5.7%</td>
</tr>
<tr>
<td>Mean number of episodes per patient</td>
<td>1.1</td>
<td>2.0</td>
<td>1.2</td>
<td>1.4</td>
<td>1.3</td>
<td>2.9</td>
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<tr>
<td>Mean length of stay (days)</td>
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<td>10.0</td>
<td>5.1</td>
<td>11.2</td>
<td>6.9</td>
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<td>21.4</td>
<td>76.2</td>
<td>55.8</td>
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*waiting time is defined as 'the difference in days between the date on which it was decided to admit the patient and the admission date'
Table 14  Network K - Cancer Waiting Times

Percentage of urgent GP referrals seen within two weeks (numbers of referrals in brackets)

<table>
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<tr>
<th>Tumour</th>
<th>Year</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
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<tr>
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<td>99.3%</td>
<td>100%</td>
<td>94.5%</td>
<td>99.1%</td>
<td>99%</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>(432)</td>
<td>(111)</td>
<td>(55)</td>
<td>(231)</td>
<td>(300)</td>
<td>(59)</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>2002/3</td>
<td>93.5%</td>
<td>97.3%</td>
<td>99.4%</td>
<td>100%</td>
<td>87.0%</td>
<td>99.5%</td>
</tr>
<tr>
<td></td>
<td>(865)</td>
<td>(153)</td>
<td>(172)</td>
<td>(374)</td>
<td>(294)</td>
<td>(212)</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>2003/4</td>
<td>97.3%</td>
<td>99.0%</td>
<td>99.6%</td>
<td>99.7%</td>
<td>99.5%</td>
<td>99.2%</td>
</tr>
<tr>
<td></td>
<td>(831)</td>
<td>(213)</td>
<td>(331)</td>
<td>(423)</td>
<td>(223)</td>
<td>(259)</td>
<td></td>
</tr>
<tr>
<td>Breast 2002/3</td>
<td></td>
<td>93.5%</td>
<td>97.3%</td>
<td>99.0%</td>
<td>100%</td>
<td>87.0%</td>
<td>99.2%</td>
</tr>
<tr>
<td></td>
<td>(865)</td>
<td>(153)</td>
<td>(331)</td>
<td>(423)</td>
<td>(223)</td>
<td>(259)</td>
<td></td>
</tr>
<tr>
<td>Breast 2003/4</td>
<td></td>
<td>97.3%</td>
<td>99.0%</td>
<td>99.4%</td>
<td>100%</td>
<td>87.0%</td>
<td>99.5%</td>
</tr>
<tr>
<td></td>
<td>(831)</td>
<td>(213)</td>
<td>(331)</td>
<td>(423)</td>
<td>(223)</td>
<td>(259)</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>2001/2*</td>
<td>97.2%</td>
<td>97.5%</td>
<td>100%</td>
<td>97.1%</td>
<td>88.4%</td>
<td>100%</td>
</tr>
<tr>
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<td>(110)</td>
<td>(41)</td>
<td>(12)</td>
<td>(71)</td>
<td>(52)</td>
<td>(14)</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>2002/3</td>
<td>88.5%</td>
<td>98.1%</td>
<td>100%</td>
<td>100%</td>
<td>93.4%</td>
<td>100%</td>
</tr>
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<td>(59)</td>
<td>(61)</td>
<td>(47)</td>
<td>(69)</td>
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</tr>
<tr>
<td>Lung 2003/4</td>
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<td>100%</td>
<td>100%</td>
<td>97.6%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>(118)</td>
<td>(62)</td>
<td>(85)</td>
<td>(134)</td>
<td>(71)</td>
<td>(69)</td>
<td></td>
</tr>
<tr>
<td>Lower gastrointestinal**</td>
<td>2001/2*</td>
<td>98.1%</td>
<td>100%</td>
<td>97.8%</td>
<td>89.7%</td>
<td>94.6%</td>
<td>97.5%</td>
</tr>
<tr>
<td></td>
<td>(441)</td>
<td>(90)</td>
<td>(47)</td>
<td>(156)</td>
<td>(75)</td>
<td>(40)</td>
<td></td>
</tr>
<tr>
<td>Lower gastrointestinal**</td>
<td>2002/3</td>
<td>89.9%</td>
<td>98.1%</td>
<td>100%</td>
<td>87.3%</td>
<td>88.0%</td>
<td>97.3%</td>
</tr>
<tr>
<td></td>
<td>(525)</td>
<td>(110)</td>
<td>(122)</td>
<td>(197)</td>
<td>(201)</td>
<td>(114)</td>
<td></td>
</tr>
<tr>
<td>Lower gastrointestinal**</td>
<td>2003/4</td>
<td>100%</td>
<td>100%</td>
<td>98.3%</td>
<td>99.6%</td>
<td>97.7%</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>(441)</td>
<td>(157)</td>
<td>(186)</td>
<td>(271)</td>
<td>(177)</td>
<td>(184)</td>
<td></td>
</tr>
<tr>
<td>Urological***</td>
<td>2001/2*</td>
<td>96.2%</td>
<td>100%</td>
<td>80%</td>
<td>97.5%</td>
<td>77.2%</td>
<td>89.3%</td>
</tr>
<tr>
<td></td>
<td>(132)</td>
<td>(19)</td>
<td>(15)</td>
<td>(81)</td>
<td>(44)</td>
<td>(47)</td>
<td></td>
</tr>
<tr>
<td>Urological***</td>
<td>2002/3</td>
<td>82.8%</td>
<td>50.4%</td>
<td>96.8%</td>
<td>100%</td>
<td>80.4%</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>(181)</td>
<td>(105)</td>
<td>(32)</td>
<td>(222)</td>
<td>(82)</td>
<td>(86)</td>
<td></td>
</tr>
<tr>
<td>Urological***</td>
<td>2003/4</td>
<td>99%</td>
<td>97.5%</td>
<td>98.7%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>(200)</td>
<td>(80)</td>
<td>(80)</td>
<td>(268)</td>
<td>(90)</td>
<td>(92)</td>
<td></td>
</tr>
</tbody>
</table>

*data reflect only urgent referrals received within 24 hours

**ICD-10 codes C17-21 and C26: malignant neoplasms of small intestine; colon; rectosigmoid junction; rectum; anus and anal canal; other and ill-defined digestive organs

***ICD-10 codes C60-68: malignant neoplasms of penis; prostate; testis; other and unspecified genital organs; kidney; renal pelvis; ureter; bladder; other and unspecified urinary organs

****not available
(n/a)
# Measuring Quality in Cancer Services

## Table 15: Network K - Cancer Survival: 5-year relative survival

Age standardised relative survival estimates for patients diagnosed in 1996 to 2001 and followed-up till 2003

<table>
<thead>
<tr>
<th>Cancer</th>
<th>Sex</th>
<th>Cancer cases*</th>
<th>Survival period, years</th>
<th>Relative survival**, %</th>
<th>95% Confidence interval***</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>female</td>
<td>3671</td>
<td>one</td>
<td>80.2</td>
<td>79.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>five</td>
<td>67.2</td>
<td>64.7</td>
</tr>
<tr>
<td></td>
<td>male</td>
<td>1263</td>
<td>one</td>
<td>66.7</td>
<td>63.8</td>
</tr>
<tr>
<td></td>
<td>female</td>
<td>1196</td>
<td>one</td>
<td>71.8</td>
<td>69.1</td>
</tr>
<tr>
<td></td>
<td>all</td>
<td>2459</td>
<td>one</td>
<td>69.1</td>
<td>67.2</td>
</tr>
<tr>
<td></td>
<td>male</td>
<td>1263</td>
<td>five</td>
<td>41.4</td>
<td>37.7</td>
</tr>
<tr>
<td></td>
<td>female</td>
<td>1196</td>
<td>five</td>
<td>51.0</td>
<td>47.3</td>
</tr>
<tr>
<td></td>
<td>all</td>
<td>2459</td>
<td>five</td>
<td>46.5</td>
<td>43.9</td>
</tr>
<tr>
<td>Colorectal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>male</td>
<td>1749</td>
<td>one</td>
<td>25.9</td>
<td>23.8</td>
</tr>
<tr>
<td></td>
<td>female</td>
<td>1096</td>
<td>one</td>
<td>30.0</td>
<td>27.1</td>
</tr>
<tr>
<td></td>
<td>all</td>
<td>2845</td>
<td>one</td>
<td>27.4</td>
<td>25.7</td>
</tr>
<tr>
<td></td>
<td>male</td>
<td>1749</td>
<td>five</td>
<td>7.0</td>
<td>5.6</td>
</tr>
<tr>
<td></td>
<td>female</td>
<td>1096</td>
<td>five</td>
<td>7.4</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>all</td>
<td>2845</td>
<td>five</td>
<td>7.1</td>
<td>5.9</td>
</tr>
<tr>
<td>Lung</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>male</td>
<td>2248</td>
<td>one</td>
<td>91.4</td>
<td>89.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>five</td>
<td>74.2</td>
<td>70.7</td>
</tr>
</tbody>
</table>

*number of patients diagnosed with cancer

**Relative survival rate is the ratio of the observed survival in the study group to the survival expected if they were only subject to the general (all cause) mortality in a standard population (England and Wales). Relative survival may be interpreted as survival corrected for ‘background’ mortality.

***Lower and upper limits of 95% confidence interval for relative survival estimates
### Table 16 Network K - National Survey: Cancer Patients. Breast cancer: % respondents expressing a problem with each aspect of care*

<table>
<thead>
<tr>
<th>Question**</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enough nurses on duty (a3)</td>
<td>31.8%</td>
<td>35.6%</td>
<td>30.5%</td>
<td>25.9%</td>
<td>41.4%</td>
<td>18.5%</td>
</tr>
<tr>
<td>Date of first hospital visit ever cancelled or postponed (b1)</td>
<td>8.0%</td>
<td>1.2%</td>
<td>10.5%</td>
<td>3.8%</td>
<td>4.6%</td>
<td>7.6%</td>
</tr>
<tr>
<td>Treated with respect and dignity (b7)</td>
<td>31.4% (+)</td>
<td>34.6% (+)</td>
<td>36.6% (+)</td>
<td>30.2% (+)</td>
<td>34.8%</td>
<td>17.7%</td>
</tr>
<tr>
<td>Purpose of treatment discussed (b19)</td>
<td>14.9%</td>
<td>23.3%</td>
<td>13.3%</td>
<td>24.7% (+)</td>
<td>23.2%</td>
<td>15.1%</td>
</tr>
<tr>
<td>Consent form signed (b21)</td>
<td>3.2%</td>
<td>9.4%</td>
<td>3.3%</td>
<td>7.4%</td>
<td>4.7%</td>
<td>6.4%</td>
</tr>
<tr>
<td>Pain and discomfort (b24)</td>
<td>66.9%</td>
<td>57.5%</td>
<td>65.0%</td>
<td>76.1% (+)</td>
<td>76.1%</td>
<td>69.2%</td>
</tr>
<tr>
<td>Enough time spent explaining what would happen after discharge (c1)</td>
<td>16.0%</td>
<td>27.3%</td>
<td>30.5% (+)</td>
<td>20.3%</td>
<td>26.1%</td>
<td>16.6%</td>
</tr>
<tr>
<td>Written or printed information given (c2)</td>
<td>16.0%</td>
<td>20.7%</td>
<td>26.6%</td>
<td>28.3% (+)</td>
<td>16.6%</td>
<td>34.6% (+)</td>
</tr>
<tr>
<td>Waiting time from GP visit till first hospital appointment (d3)</td>
<td>23.0% (+)</td>
<td>26.6%</td>
<td>20.9%</td>
<td>3.1%</td>
<td>10.8%</td>
<td>25.0% (+)</td>
</tr>
<tr>
<td>Being told what was wrong (d10)</td>
<td>1.5%</td>
<td>4.3%</td>
<td>1.9%</td>
<td>2.1%</td>
<td>2.2%</td>
<td>2.7%</td>
</tr>
<tr>
<td>Time spent telling what was wrong (d15)</td>
<td>21.0%</td>
<td>12.7%</td>
<td>21.5%</td>
<td>29.1% (+)</td>
<td>22.7%</td>
<td>10.5%</td>
</tr>
<tr>
<td>Outpatient appointment ever cancelled or postponed by hospital (e4)</td>
<td>15.5%</td>
<td>7.1%</td>
<td>4.6%</td>
<td>5.8%</td>
<td>16.6%</td>
<td>11.4%</td>
</tr>
<tr>
<td>Waiting after appointment time to see a doctor (e6)</td>
<td>58.4% (+)</td>
<td>54.5% (+)</td>
<td>48.3% (+)</td>
<td>62.8% (+)</td>
<td>38.8%</td>
<td>48.2%</td>
</tr>
<tr>
<td>Time spent by doctor during appointment (e7)</td>
<td>41.2%</td>
<td>28.5%</td>
<td>32.2%</td>
<td>42.8%</td>
<td>41.6%</td>
<td>16.2% (-)</td>
</tr>
<tr>
<td>Whether time spent by doctor was enough (e8)</td>
<td>14.0%</td>
<td>8.9%</td>
<td>20.6% (+)</td>
<td>22.8%</td>
<td>13.8%</td>
<td>8.1%</td>
</tr>
<tr>
<td>Confidence and trust in doctor (e9)</td>
<td>8.7%</td>
<td>5.4%</td>
<td>11.1%</td>
<td>5.7%</td>
<td>0.0%</td>
<td>9.3%</td>
</tr>
<tr>
<td>Privacy (e11)</td>
<td>0.8%</td>
<td>0.0%</td>
<td>1.5%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>4.5% (+)</td>
</tr>
<tr>
<td>Treated with respect and dignity (e13)</td>
<td>0.0%</td>
<td>0.0%</td>
<td>3.1%</td>
<td>2.8%</td>
<td>0.0%</td>
<td>1.1%</td>
</tr>
</tbody>
</table>

* '+' for Trusts which have a significantly higher difference from national average (p<0.05)
* '-' for Trusts which have a significantly lower difference from national average (p<0.05)
* ** for full description of questions, see Attachment A
### Measuring Quality in Cancer Services

**Table 17 Network K - National Survey: Cancer Patients. Colorectal cancer: % respondents expressing a problem with each aspect of care***

<table>
<thead>
<tr>
<th>Question**</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enough nurses on duty (a3)</td>
<td>38.4% (+)</td>
<td>37.1% (+)</td>
<td>29.1% (+)</td>
<td>39.3% (+)</td>
<td>33.3%</td>
<td>26.9%</td>
</tr>
<tr>
<td>Date of first hospital visit ever cancelled or postponed (b1)</td>
<td>7.2%</td>
<td>9.7%</td>
<td>17.9% (+)</td>
<td>3.3%</td>
<td>0.0%</td>
<td>8.3%</td>
</tr>
<tr>
<td>Treated with respect and dignity (b7)</td>
<td>28.7% (+)</td>
<td>37.8% (+)</td>
<td>17.5%</td>
<td>27.8%</td>
<td>29.7%</td>
<td>28.5%</td>
</tr>
<tr>
<td>Purpose of treatment discussed (b19)</td>
<td>13.6%</td>
<td>26.2%</td>
<td>22.5%</td>
<td>22.5%</td>
<td>8.1%</td>
<td>11.1%</td>
</tr>
<tr>
<td>Consent form signed (b21)</td>
<td>2.9%</td>
<td>8.9%</td>
<td>7.6%</td>
<td>8.6%</td>
<td>2.8%</td>
<td>12.7%</td>
</tr>
<tr>
<td>Pain and discomfort (b24)</td>
<td>82.1% (+)</td>
<td>62.9%</td>
<td>67.5%</td>
<td>68.3%</td>
<td>75.6%</td>
<td>75.0%</td>
</tr>
<tr>
<td>Enough time spent explaining what would happen after discharge (c1)</td>
<td>11.1%</td>
<td>28.2%</td>
<td>33.3%</td>
<td>24.1%</td>
<td>14.7%</td>
<td>19.1%</td>
</tr>
<tr>
<td>Written or printed information given (c2)</td>
<td>36.6%</td>
<td>32.4%</td>
<td>47.5%</td>
<td>45.7% (+)</td>
<td>32.3%</td>
<td>40.4%</td>
</tr>
<tr>
<td>Waiting time from GP visit till first hospital appointment (d3)</td>
<td>38.7%</td>
<td>35.8%</td>
<td>27.5%</td>
<td>39.0%</td>
<td>48.3%</td>
<td>38.7%</td>
</tr>
<tr>
<td>Being told what was wrong (d10)</td>
<td>1.1%</td>
<td>0.0%</td>
<td>8.3%</td>
<td>2.1%</td>
<td>2.7%</td>
<td>5.0%</td>
</tr>
<tr>
<td>Time spent telling what was wrong (d15)</td>
<td>16.1%</td>
<td>14.5%</td>
<td>25.7%</td>
<td>32.6%</td>
<td>13.1%</td>
<td>32.5%</td>
</tr>
<tr>
<td>Outpatient appointment ever cancelled or postponed by hospital (e4)</td>
<td>7.5%</td>
<td>6.2%</td>
<td>9.4%</td>
<td>7.1%</td>
<td>13.7%</td>
<td>3.9%</td>
</tr>
<tr>
<td>Waiting after appointment time to see a doctor (e6)</td>
<td>49.3% (+)</td>
<td>46.6% (+)</td>
<td>46.8%</td>
<td>46.3%</td>
<td>37.9%</td>
<td>38.0%</td>
</tr>
<tr>
<td>Time spent by doctor during appointment (e7)</td>
<td>30.2%</td>
<td>23.3%</td>
<td>19.1%</td>
<td>34.1%</td>
<td>13.7%</td>
<td>24.0%</td>
</tr>
<tr>
<td>Whether time spent by doctor was enough (e8)</td>
<td>9.3%</td>
<td>10.0%</td>
<td>19.1% (+)</td>
<td>7.3%</td>
<td>10.3%</td>
<td>14.0%</td>
</tr>
<tr>
<td>Confidence and trust in doctor (e9)</td>
<td>6.5%</td>
<td>8.4%</td>
<td>8.5%</td>
<td>4.8%</td>
<td>3.4%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Privacy (e11)</td>
<td>2.5%</td>
<td>1.5%</td>
<td>0.0%</td>
<td>2.4%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Treated with respect and dignity (e13)</td>
<td>2.5%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>2.4%</td>
<td>0.0%</td>
<td>2.0%</td>
</tr>
<tr>
<td><strong>Number of patients responding to different questions (range)</strong></td>
<td>65 - 93</td>
<td>39 - 113</td>
<td>29 - 53</td>
<td>41 - 66</td>
<td>29 - 38</td>
<td>31 - 63</td>
</tr>
</tbody>
</table>

* '+-' for Trusts which have a significantly higher difference from national average (p<0.05)

** '-' for Trusts which have a significantly lower difference from national average (p<0.05)

***for full description of questions, see Attachment A

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Table 18  Network K - National Survey: Cancer Patients. Lung cancer: percentage respondents expressing a problem with each aspect of care*

<table>
<thead>
<tr>
<th>Question**</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enough nurses on duty (a3)</td>
<td>20.0%</td>
<td>40.0% (+)</td>
<td>25.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>17.1%</td>
</tr>
<tr>
<td>Date of first hospital visit ever cancelled or postponed (b1)</td>
<td>11.1%</td>
<td>0.0%</td>
<td>14.2%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Treated with respect and dignity (b7)</td>
<td>22.2%</td>
<td>34.6%</td>
<td>14.2%</td>
<td>20.0%</td>
<td>0.0%</td>
<td>16.0%</td>
</tr>
<tr>
<td>Purpose of treatment discussed (b19)</td>
<td>22.2%</td>
<td>33.3%</td>
<td>14.2%</td>
<td>16.6%</td>
<td>0.0%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Consent form signed (b21)</td>
<td>11.1%</td>
<td>7.4%</td>
<td>0.0%</td>
<td>16.6%</td>
<td>0.0%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Pain and discomfort (b24)</td>
<td>66.6%</td>
<td>55.5%</td>
<td>57.1%</td>
<td>83.3%</td>
<td>33.3%</td>
<td>56.0%</td>
</tr>
<tr>
<td>Enough time spent explaining what would happen after discharge (c1)</td>
<td>11.1%</td>
<td>37.0%</td>
<td>16.6%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>20.0%</td>
</tr>
<tr>
<td>Written or printed information given (c2)</td>
<td>66.6%</td>
<td>29.6%</td>
<td>66.6%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Waiting time from GP visit till first hospital appointment (d3)</td>
<td>22.7%</td>
<td>46.1%</td>
<td>20.0%</td>
<td>14.2%</td>
<td>33.3%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Being told what was wrong (d10)</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Time spent telling what was wrong (d15)</td>
<td>30.4%</td>
<td>30.7%</td>
<td>0.0%</td>
<td>42.8%</td>
<td>25.0%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Outpatient appointment ever cancelled or postponed by hospital (e4)</td>
<td>15.3%</td>
<td>8.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>11.1%</td>
</tr>
<tr>
<td>Waiting after appointment time to see a doctor (e6)</td>
<td>30.7%</td>
<td>47.8%</td>
<td>30.0%</td>
<td>0.0%</td>
<td>33.3%</td>
<td>55.5%</td>
</tr>
<tr>
<td>Time spent by doctor during appointment (e7)</td>
<td>53.8% (+)</td>
<td>13.0%</td>
<td>20.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>5.8%</td>
</tr>
<tr>
<td>Whether time spent by doctor was enough (e8)</td>
<td>15.3%</td>
<td>4.3%</td>
<td>10.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>5.8%</td>
</tr>
<tr>
<td>Confidence and trust in doctor (e9)</td>
<td>7.6%</td>
<td>4.3%</td>
<td>10.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>5.8%</td>
</tr>
<tr>
<td>Privacy (e11)</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Treated with respect and dignity (e13)</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Number of patients responding to different questions (range)</td>
<td>5 - 23</td>
<td>13 - 40</td>
<td>4 - 10</td>
<td>1 - 7</td>
<td>2 - 4</td>
<td>8 - 35</td>
</tr>
</tbody>
</table>

* '+' for Trusts which have a significantly higher difference from national average (p<0.05)

'-' for Trusts which have a significantly lower difference from national average (p<0.05)

**for full description of questions, see Attachment A
Table 19  Network K - National Survey: Cancer Patients  Prostrate cancer: percentage respondents expressing a problem with each aspect of care*

<table>
<thead>
<tr>
<th>Question**</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enough nurses on duty (a3)</td>
<td>20.6%</td>
<td>0.0%</td>
<td>27.5%</td>
<td>22.4%</td>
<td>21.0%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Date of first hospital visit ever cancelled or postponed (b1)</td>
<td>11.1%</td>
<td>7.6%</td>
<td>14.7%</td>
<td>11.2%</td>
<td>25.0%</td>
<td>26.9% (+)</td>
</tr>
<tr>
<td>Treated with respect and dignity (b7)</td>
<td>21.2%</td>
<td>46.1% (+)</td>
<td>36.3% (+)</td>
<td>20.3%</td>
<td>26.3%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Purpose of treatment discussed (b19)</td>
<td>17.0%</td>
<td>38.4%</td>
<td>29.4%</td>
<td>23.4%</td>
<td>26.3%</td>
<td>14.8%</td>
</tr>
<tr>
<td>Consent form signed (b21)</td>
<td>20.4%</td>
<td>15.3%</td>
<td>0.0%</td>
<td>25.3%</td>
<td>10.0%</td>
<td>15.3%</td>
</tr>
<tr>
<td>Pain and discomfort (b24)</td>
<td>59.5%</td>
<td>76.9%</td>
<td>81.8% (+)</td>
<td>65.0%</td>
<td>85.0% (+)</td>
<td>71.4%</td>
</tr>
<tr>
<td>Enough time explaining what would happen after discharge (c1)</td>
<td>18.6%</td>
<td>23.0%</td>
<td>36.3%</td>
<td>26.9%</td>
<td>36.8%</td>
<td>29.6%</td>
</tr>
<tr>
<td>Written or printed information given (c2)</td>
<td>36.3%</td>
<td>53.8%</td>
<td>48.4%</td>
<td>38.0%</td>
<td>36.8%</td>
<td>22.2%</td>
</tr>
<tr>
<td>Waiting time from GP visit till first hospital appointment (d3)</td>
<td>50.0%</td>
<td>50.0%</td>
<td>40.9%</td>
<td>61.7%</td>
<td>50.0%</td>
<td>55.0%</td>
</tr>
<tr>
<td>Being told what was wrong (d10)</td>
<td>1.8%</td>
<td>0.0%</td>
<td>6.6%</td>
<td>2.3%</td>
<td>5.8%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Time spent telling what was wrong (d15)</td>
<td>33.9%</td>
<td>66.6%</td>
<td>32.2%</td>
<td>29.5%</td>
<td>33.3%</td>
<td>26.0%</td>
</tr>
<tr>
<td>Outpatient appointment ever cancelled or postponed by hospital (e4)</td>
<td>26.8%</td>
<td>16.6%</td>
<td>10.0%</td>
<td>14.8%</td>
<td>30.0%</td>
<td>24.3%</td>
</tr>
<tr>
<td>Waiting after appointment time to see a doctor (e6)</td>
<td>43.9%</td>
<td>33.3%</td>
<td>51.7% (+)</td>
<td>43.4%</td>
<td>33.3%</td>
<td>39.0%</td>
</tr>
<tr>
<td>Time spent by doctor during appointment (e7)</td>
<td>26.1%</td>
<td>0.0%</td>
<td>27.5%</td>
<td>22.7%</td>
<td>22.2%</td>
<td>26.8%</td>
</tr>
<tr>
<td>Whether time spent by doctor was enough (e8)</td>
<td>4.7%</td>
<td>16.6%</td>
<td>20.6% (+)</td>
<td>0.0%</td>
<td>11.1%</td>
<td>7.3%</td>
</tr>
<tr>
<td>Confidence and trust in doctor (e9)</td>
<td>0.0%</td>
<td>0.0%</td>
<td>6.8%</td>
<td>0.0%</td>
<td>11.1%</td>
<td>7.3%</td>
</tr>
<tr>
<td>Privacy (e11)</td>
<td>0.0%</td>
<td>0.0%</td>
<td>6.8% (+)</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Treated with respect and dignity (e13)</td>
<td>0.0%</td>
<td>0.0%</td>
<td>3.4%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

Number of patients responding to different questions (range)

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>41 - 58</td>
<td>2 - 13</td>
<td>22 - 40</td>
<td>22 - 89</td>
<td>9 - 20</td>
<td>20 - 44</td>
</tr>
</tbody>
</table>

* '+' for Trusts which have a significantly higher difference from national average (p<0.05)

'-' for Trusts which have a significantly lower difference from national average (p<0.05)
Section 6 Presentation

The limited data set for cancer networks was distributed as tables. We recognise that presentation is a contributor to use, and we investigated appropriate visual methods for presentation. The research did not allow time to make visual presentations of data for each individual network, but we have collected together here some examples of methods of presentation.

Surveys represent the true populations in proportion to the sampling fraction. The variation of social phenomena has greater importance for statistical interpretation in smaller samples. We used funnel plots to demonstrate the relationship between statistical variations and sample size. We used ‘caterpillar’ plots to demonstrate the comparisons between different providers (network or hospital level). These methods help draw attention to the statistical uncertainty of a data value for a specific network or hospital.

However, a network or trust may wish itself to improve in comparison with its own previous values (regardless of the value in comparison with others) and for this control charts and spider diagrams can be useful.

6.1 Presenting data graphically

Table of presentations.

1  The graph compares satisfaction with waiting time related to different numbers of respondents.
2  Indicates the concept of values within a funnel plot: statistical significance of distance from the average depends on sample size.
3  A larger number of trusts, with more values, shows some that are statistical outliers.
4  Higher confidence limits (three standard deviations) can be used to identify the extent of deviation from the standard.
5  Higher numbers of respondents in networks (summing trust values); deviation from the average can be shown.
6  An alternative way is to use individual value confidence intervals. These can be grouped on the page to compare different parameters.
7  Again, for networks the confidence intervals are smaller.
Measuring Quality in Cancer Services

8 A difficulty for waiting time statistics is that values are close to the limit of 100 percent.

9 A spider plot allow different measures to be compared by Trusts or networks at the same time.

10 A control chart is useful for a single network or Trust to track values changing over time.
Figure 2 The graph compares satisfaction with waiting time related to different numbers of respondents.

Outcomes for Trusts within a single London Network

Proportion of patients expressing a problem with waiting time

London average
Figure 3 Indicates the concept of values within a funnel plot: statistical significance of distance from the average depends on sample size.

Assessing the importance of the observed differences
Assessing the importance of the observed differences

- Network Trusts
- Other London Trusts
Figure 5  Higher confidence limits (three standard deviations) can be used to identify the extent of deviation from the standard.

Selection of limits

![Graph showing selection of limits for Network Trusts and Other London Trusts.](Image)
Figure 6  Higher numbers of respondents in networks (summing trust values); deviation from the average can be shown

Outcomes for London Networks compared with England average
Figure 7 An alternative way is to use individual value confidence intervals

Expressing variation with error bars

Trusts in a single London Network and 95% confidence intervals

London average
Figure 8  These can be grouped on the page to compare different parameters

Trust variations across five survey questions

Proportion of patients expressing a problem with each aspect of care

- Not treated with respect and dignity
- Doctor did not discuss the purpose of treatment
- In pain or discomfort
- Waited too long
- Time spent explaining condition

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Figure 9  For networks the confidence intervals are smaller

Network variations

Proportion of patients expressing a problem with each aspect of care

Not treated with respect and dignity
Doctor did not discuss the purpose of treatment
In pain or discomfort
Waited too long
Time spent explaining condition
Figure 10  Relationship between survey responses and cancer waiting data

% referrals waiting less than 2 weeks: lower gastrointestinal cancer, 1st quarter 2001/2

A difficulty for waiting time statistics is that values are close to the limit of 100 percent.
Figure 11  A spider plot allow different measures to be compared by trusts or networks at the same time

Ranking of one network for breast cancer in five data sets

Five dimensions: 0 = most favourable, 10 = least favourable

Key
A: 1 year relative survival
B: Satisfaction survey ‘respect and dignity’
C: Compliance with cancer standards
D: % GP urgent referrals seen within 2 weeks
E: Inhospital mortality
Figure 12 A control chart is useful for a single network or trust to track values changing over time

Percentage GP urgent referrals for lung cancer seen within 2 weeks (single trust)

Moving average control chart
% urgent GP referrals seen within 2 weeks. Lung cancer.
Single NHS Trust

- % seen within 2 weeks
- Moving average
- Control limits for moving average

<table>
<thead>
<tr>
<th>Year</th>
<th>1st Qtr</th>
<th>2nd Qtr</th>
<th>3rd Qtr</th>
<th>4th Qtr</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001/2</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>2002/3</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>2003/4</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
</tbody>
</table>
Section 7 Analyses of the datasets

We set out here responses to the questions posed in the research call. Our analyses started by looking at individual datasets as frequencies, especially comparisons between trusts and networks, and by cancer type. In making comparisons between datasets, we have selected leading data items that appear relevant.

The analyses are exploratory, investigating possible associations. Such investigations have an underlying hypothesis of causal relationships, but the initial concern is to see if there is association, whether it occurs across more than one cancer type, and its strength. We were limited with the survival data to analyses only at network level, while the other data were available for hospital trusts.

In this approach, we have made hypotheses of association by comparing specific parameters. However, the fact of repeating tests on different parameters limits the uniqueness of the hypothesis. Thus, statistically 'significant' results need to be considered with due caution, whether the findings are in the expected direction or contrary.

The datasets relate to approximately the same period of 2000 to 2002. This is cross-sectional rather than with a temporal sequence, but was necessary because of the limitations on data available. However, health services are continuous and do not change dramatically from year to year: it is possible to consider causal relationships from cross-sectional data.

Spearman rank correlation test was used for bivariate analyses when both variables were continuous, and Pearson’s test when using the cancer standards (which are dichotomous). Kendall’s W test of concordance was used to compare multiple datasets.

7.1 Research call questions

7.1.1. Question 1: Which items are inter-related within surveys, and can simpler versions of the surveys be derived?

The datasets had each been separately developed by public agencies, and although there were some items that approached the same issues from different perspectives (see analyses in Question 2 below), there was no repetition of material between the datasets.
One of the datasets was a population survey, collecting responses from samples of individuals: this was the national cancer satisfaction survey, and by the time of our study the authors of the survey had themselves created a reduced version. Otherwise, the data included dimensions relevant for administrative purposes, and we chose relevant parts from them for the limited data set and the analyses.

- Acute Hospital Portfolio.
  From the 18 datasets available, we chose four (Medical Staffing, Medicines Management, Radiology, Ward Staffing) undertaken over the period 2000 to 2002, and reflecting general clinical aspects relevant to cancer care. We selected items within these through discussion, and used these in the subsequent analyses.

- National Cancer Peer Review
  The 10 areas and full list of standards have been shown earlier. The standards were chosen by professional decision, and therefore each regarded as important. We chose to use the total scores for Radiology and Chemotherapy, and the individual scores for Multidisciplinary Team (MDT) and Cancer Centre/Unit standards. We used these for cross-tabulations against outcomes (survival, satisfaction) to look for statistically predictive measures.

- Hospital Episode Statistics
  This major, continuous record of hospital activity is held centrally. We requested a sub-group of the full dataset, and used them independently for presentation and in the analyses.

- Cancer Waiting Times.
  For the years of our analysis, only ‘two week waits’ were available, and this was therefore a small dataset.

- Cancer Survival
  We were provided with data from the Office of National Statistics for England. Survival is estimated by linking date of diagnosis with date of death. Data for individuals was anonymised, and age, sex and socio-economic group were included in adjustment to calculate the relative survivals. We chose to use one and five year survival: probably one-
year survival reflects better the possible impact of initial hospital care, while five-year survival has traditionally been used in epidemiological studies as a measure of prognosis/successful outcome.

- National Survey: Cancer Patients (Table 20)

The original 2001 satisfaction survey had been reduced from 96 questions through factor analysis by its authors - see below - which reflect different dimensions of the patient pathway. We included the 18 items in the Limited Dataset. However, for the dataset analyses we chose to use two main in the table below: **B7**: ‘Respect and Dignity’ (‘Not treated with respect and dignity by doctor/nurse’ and **D15**: ‘Outpatient communication’ (‘Time spent on explaining condition on first visit’). Also, for the correlations with nursing we used **A3** ‘Insufficient nurses on duty’, for waiting time, we used **D3**: ‘Outpatient waiting’ (‘Over one month from visit to GP to hospital appointment’) and for comparison with the Acute Hospital Portfolio data we used **C1**: ‘Aftercare communication’ (‘Doctors didn’t spend enough time informing patients on aftercare’).
### Table 20 The list of questions included in the Cancer Networks Limited Dataset along with themes identified by factor analysis

<table>
<thead>
<tr>
<th>Theme identified by factor analysis</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to care – waiting times</td>
<td>D3 Over one month from visiting GP to hospital appointment</td>
</tr>
<tr>
<td>Explanation at first visit</td>
<td>D15 Time spent on explaining condition on first visit</td>
</tr>
<tr>
<td>Understanding of diagnosis and treatment</td>
<td>B19 Doctor did not discuss purpose of treatment with patient</td>
</tr>
<tr>
<td>First treatment: Respect, communication and involvement</td>
<td>B7 Not treated with respect and dignity by doctor/nurse</td>
</tr>
<tr>
<td>First treatment: Pain and discomfort</td>
<td>B24 In pain or discomfort during first visit</td>
</tr>
<tr>
<td>Hospital management</td>
<td>A3 Insufficient nurses on duty</td>
</tr>
<tr>
<td>Discharge co-ordination</td>
<td>C2 Patient not given printed information on care after discharge</td>
</tr>
<tr>
<td>Aftercare</td>
<td>C1 Doctors didn’t spend enough time informing patient on aftercare</td>
</tr>
<tr>
<td>Recent outpatient visit: medical care</td>
<td>E6 Waiting time to see doctor</td>
</tr>
<tr>
<td></td>
<td>E7 Time spent by doctors with patients</td>
</tr>
<tr>
<td></td>
<td>E8 Not enough time spent by doctors with patient</td>
</tr>
<tr>
<td></td>
<td>E9 No confidence and trust in outpatient doctor</td>
</tr>
<tr>
<td></td>
<td>E13 Not treated with respect and dignity as outpatient</td>
</tr>
<tr>
<td>Recent outpatient visit: privacy</td>
<td>E11 Lack of privacy when discussing condition/treatment</td>
</tr>
<tr>
<td>Four questions that did not fit into themes:</td>
<td>B1 Date of first appointment was cancelled/postponed by hospital</td>
</tr>
<tr>
<td></td>
<td>B21 Patient was not asked to sign a consent form</td>
</tr>
<tr>
<td></td>
<td>D10 Patient was not told of condition in person at first appointment</td>
</tr>
<tr>
<td></td>
<td>E4 Recent outpatient appointment was cancelled/postponed by hospital</td>
</tr>
</tbody>
</table>

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7.1.2 Question 2: Within a specific quality domain, do different surveys yield consistent findings e.g. do places that perform well in relation to one measure of access to care also perform well on other measures?

The datasets were chosen for their differences more than their similarities, reflecting dimensions of structure, process and outcome in services for four common cancers. There were no places where they directly recorded the same information, but some ‘quality domains’ were present in more than one dataset. We developed four domains - survival, staffing, waiting and hospital volume - for analysis using correlation statistics.

Survival (Table 21)

We measured the following data.
- Cancer registration: one and five-year relative survival.
- Satisfaction score: B7 ‘Respect and Dignity’.
- Referral waiting times.
- Hospital Episode Statistics: In-hospital mortality.

There were significant positive associations for one-year survival with the total MDT standards score for colorectal and lung cancers, but not for breast cancer (there were no prostate cancer standards). Only for lung cancer, was there a strongly significant positive association between five-year survival and ‘Respect and Dignity’ in the satisfaction survey, but also a negative association between five-year survival and in-hospital mortality. For breast and colorectal cancers, neither one nor five-year survival was associated with the ‘Respect and Dignity’ satisfaction measure, nor with referral waiting times.
Table 21  Rank correlations of survival with measures from other datasets at network level

<table>
<thead>
<tr>
<th>Combinations of variables</th>
<th>Breast cancer</th>
<th>Colorectal cancer</th>
<th>Lung cancer</th>
<th>Prostate cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of networks (range)</td>
<td>27-34</td>
<td>27-34</td>
<td>27-34</td>
<td>34</td>
</tr>
<tr>
<td>1 year relative survival % vs. 'respect and dignity'</td>
<td>0.27, p=0.18</td>
<td>0.14, p=0.42</td>
<td>0.28, p=0.11</td>
<td>0.07, p=0.71</td>
</tr>
<tr>
<td>1 year relative survival % vs. total MDT standards score</td>
<td>-0.10, p=0.61</td>
<td>0.41*, p=0.03</td>
<td>0.44*, p=0.02</td>
<td>-</td>
</tr>
<tr>
<td>1 year relative survival % vs. waiting times 2001/02</td>
<td>-0.26, p=0.14</td>
<td>-0.14, p=0.42</td>
<td>0.22, p=0.21</td>
<td>-0.13, p=0.47</td>
</tr>
<tr>
<td>1 year relative survival % vs. in-hospital mortality</td>
<td>0.19, p=0.29</td>
<td>-0.18, p=0.30</td>
<td>0.01, p=0.96</td>
<td>0.21, p=0.28</td>
</tr>
<tr>
<td>5 year relative survival % vs. 'respect and dignity'</td>
<td>0.05, p=0.77</td>
<td>-0.10, p=0.58</td>
<td>0.49**, p&lt;0.01</td>
<td>-0.01, p=0.94</td>
</tr>
<tr>
<td>5 year relative survival % vs. total MDT standards score</td>
<td>-0.23, p=0.24</td>
<td>0.32, p=0.10</td>
<td>0.14, p=0.50</td>
<td>-</td>
</tr>
<tr>
<td>5 year relative survival % vs. waiting times 2001/02</td>
<td>-0.008, p=0.97</td>
<td>-0.002, p=0.99</td>
<td>0.17, p=0.34</td>
<td>0.04, p=0.83</td>
</tr>
<tr>
<td>5 year relative survival % vs. in-hospital mortality</td>
<td>0.11, p=0.52</td>
<td>-0.24, p=0.18</td>
<td>-0.39*, p=0.02</td>
<td>0.27, p=0.12</td>
</tr>
</tbody>
</table>

Commentary: The analyses using survival were limited by availability only at the level of the 34 cancer networks – thus with less statistical power than the other datasets available by hospital. The association of colorectal and lung cancer one year survival with the total MDT standards score is of note, but the lack of association with breast cancer, or with five-year survival, suggests this association is not systematic. The lack of positive association between hospital survival and five-year survival (and negative values for lung cancer) may indicate that the impacts of the initial hospitalisation are shorter rather than longer-term, though there may be subsequent impacts in aftercare. (Although the literature describes ‘30-day mortality’, this is usually derived from hospital administrative statistics, without home
Measuring Quality in Cancer Services

deaths, and indicates only a 30-day cut-off point for the inpatient episode of care.)

Nursing (Tables 22, 23)
We measured the following data.
- Satisfaction survey A3: ‘Insufficient nurses on duty’.
- Standards: nurses registered for specialist course; nurse obtained specialist qualification; nurse obtained higher cancer qualification.
- Acute Hospital Portfolio: Nurse Whole Time Equivalents (WTE) per 10,000 annual attendances.

These measures were correlated three ways. Only prostate cancer showed an association, between the satisfaction measure and the hospital staffing levels measure - but it was an association in the ‘wrong’ direction.
Table 22  Correlations of nursing variables from three datasets: hospital
Trust level

<table>
<thead>
<tr>
<th></th>
<th>Breast cancer</th>
<th>Colorectal cancer</th>
<th>Lung cancer</th>
<th>Prostate cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Trusts (range)</td>
<td>93-145</td>
<td>95-145</td>
<td>95-145</td>
<td>145</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not always enough nurses on</td>
<td>0.08</td>
<td>0.03</td>
<td>-0.01</td>
<td>0.27**</td>
</tr>
<tr>
<td>duty vs. nurse WTE per 10,000</td>
<td>p=0.30</td>
<td>p=0.73</td>
<td>p=0.90</td>
<td>p=0.01</td>
</tr>
<tr>
<td>attendances</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not always enough nurses on</td>
<td>-0.01</td>
<td>-0.02</td>
<td>-0.005</td>
<td>-</td>
</tr>
<tr>
<td>duty vs. nurse qualifications</td>
<td>p=0.90</td>
<td>p=0.83</td>
<td>p=0.96</td>
<td></td>
</tr>
<tr>
<td>– registered ENB 237 course</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not always enough nurses on</td>
<td>0.01</td>
<td>0.12</td>
<td>-0.14</td>
<td>-</td>
</tr>
<tr>
<td>duty vs. nurse qualifications</td>
<td>p=0.99</td>
<td>p=0.23</td>
<td>p=0.14</td>
<td></td>
</tr>
<tr>
<td>– obtained ENB 237 course</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not always enough nurses on</td>
<td>-0.19</td>
<td>-0.04</td>
<td>-0.14</td>
<td>-</td>
</tr>
<tr>
<td>duty vs. nurse qualifications</td>
<td>p=0.07</td>
<td>p=0.73</td>
<td>p=0.19</td>
<td></td>
</tr>
<tr>
<td>– obtained ENB and/or cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>related nursing degree</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse WTE per 10,000 attendances vs.</td>
<td>-0.11</td>
<td>-0.05</td>
<td>0.06</td>
<td>-</td>
</tr>
<tr>
<td>nurse qualifications – registered ENB 237 course</td>
<td>p=0.28</td>
<td>p=0.60</td>
<td>p=0.55</td>
<td></td>
</tr>
<tr>
<td>Nurse WTE per 10,000 attendances vs.</td>
<td>0.02</td>
<td>-0.15</td>
<td>0.13</td>
<td>-</td>
</tr>
<tr>
<td>nurse qualifications – obtained ENB 237 course</td>
<td>p=0.82</td>
<td>p=0.13</td>
<td>p=0.18</td>
<td></td>
</tr>
<tr>
<td>Nurse qualifications – obtained ENB and/or cancer related nursing degree</td>
<td>-0.11</td>
<td>-0.12</td>
<td>0.15</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>p=0.30</td>
<td>p=0.23</td>
<td>p=0.14</td>
<td></td>
</tr>
</tbody>
</table>
Table 23  Correlations of nursing variables from three datasets: network level

<table>
<thead>
<tr>
<th></th>
<th>Breast cancer</th>
<th>Colorectal cancer</th>
<th>Lung cancer</th>
<th>Prostate cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Networks (range)</td>
<td>27-34</td>
<td>27-34</td>
<td>27-34</td>
<td>34</td>
</tr>
<tr>
<td>Not always enough nurses on duty vs. nurse WTE per 10,000 attendances</td>
<td>0.22 p=0.21</td>
<td>0.19 p=0.28</td>
<td>0.30 p=0.08</td>
<td>0.25 p=0.15</td>
</tr>
<tr>
<td>Not always enough nurses on duty vs. nurse qualifications – registered ENB 237 course</td>
<td>-0.13 p=0.54</td>
<td>-0.06 p=0.78</td>
<td>0.24 p=0.22</td>
<td>-</td>
</tr>
<tr>
<td>Not always enough nurses on duty vs. nurse qualifications – obtained ENB 237 course</td>
<td>0.14 p=0.49</td>
<td>0.20 p=0.32</td>
<td>-0.08 p=0.71</td>
<td>-</td>
</tr>
<tr>
<td>Not always enough nurses on duty vs. nurse qualifications – obtained ENB and/or cancer related nursing degree</td>
<td>-0.27 p=0.17</td>
<td>-0.33 p=0.09</td>
<td>-0.33 p=0.09</td>
<td>-</td>
</tr>
<tr>
<td>Nurse WTE per 10,000 attendances vs. nurse qualifications – registered ENB 237 course</td>
<td>0.32 p=0.11</td>
<td>-0.06 p=0.78</td>
<td>0.23 p=0.26</td>
<td>-</td>
</tr>
<tr>
<td>Nurse WTE per 10,000 attendances vs. nurse qualifications – obtained ENB 237 course</td>
<td>0.34 p=0.08</td>
<td>-0.7 p=0.73</td>
<td>0.13 p=0.53</td>
<td>-</td>
</tr>
<tr>
<td>Nurse qualifications – obtained ENB and/or cancer related nursing degree</td>
<td>-0.33 p=0.09</td>
<td>-0.29 p=0.14</td>
<td>-0.25 p=0.20</td>
<td>-</td>
</tr>
</tbody>
</table>

Commentary: While an association between the standards and the structural measures might not be expected, there should have potentially been an association between satisfaction perception of 'insufficient nurses on duty' and overall nurse staffing levels in the Acute Hospital Portfolio. The only association found (Table 26), for prostate cancer, was in the 'wrong' direction - higher rates of nurses were associated (strongly) with greater dissatisfaction on the 'nurses on duty' measure. However, the Acute Hospital Portfolio includes all hospital nurses, not just those present on the urological service, and there was not a direct measure of cancer service staffing levels available.

Waits

We measured the following data.

- GP referral waits 2001/2.
Measuring Quality in Cancer Services

- Satisfaction: D3 ‘Outpatient waiting’.
- Hospital Episode Statistics: Waiting time to admission.

GP referral waits showed no correlation with the >1-month wait measure of satisfaction for any cancer. However, for breast and colorectal cancers there were statistical associations between dissatisfaction from waits for hospital appointments and mean waiting times for admissions (Hospital Episode Statistics).

Table 24 Rank correlations of waiting times variables from three datasets: hospital trust level

<table>
<thead>
<tr>
<th></th>
<th>Breast cancer</th>
<th>Colorectal cancer</th>
<th>Lung cancer</th>
<th>Prostate cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Trusts (range)</td>
<td>146-149</td>
<td>149-150</td>
<td>142-148</td>
<td>149-149</td>
</tr>
<tr>
<td>Satisfaction: outpatient waiting vs. GP outpatient waiting times 2001/02</td>
<td>0.08</td>
<td>-0.14</td>
<td>-0.09</td>
<td>-0.06</td>
</tr>
</tbody>
</table>
p | 0.36 | 0.09 | 0.29 | 0.51 |
| Satisfaction: outpatient waiting vs. HES; Waiting time to admission | 0.17* | 0.25** | -0.04 | 0.13 |
p | 0.04 | <0.01 | 0.67 | 0.11 |
| GP outpatient waiting times 2001/02 vs. HES: waiting time to admission | -0.11 | -0.09 | 0.034 | -0.15 |
p | 0.20 | 0.27 | 0.69 | 0.07 |

Commentary: Lack of correlation for GP referrals with the other waiting measures may reflect different groups of patients: the GP referrals, patients ‘to be seen urgently’, will include a high proportion (appropriately) who are subsequently found not to have cancer, and not include patients diagnosed with cancer through other pathways. The hospital satisfaction sample asked patients to recall the period of time between GP consultation and hospital referral: this would include, for some patients, the period before the diagnosis was clear, while others may have had clinical pathways not through the GP.

The association between the satisfaction measure and hospital admissions would be expected - higher dissatisfaction associated with longer times to admission. However, this needs cautious interpretation since (as above) satisfaction is recalling the period before hospital in weeks, while the admission period is much shorter, a mean of six days. Nevertheless, these two measures together may give a better picture.
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of the efficiency of the ‘patient pathway’ to treatment than GP referral waiting times.

Volume (Table 25)

We measured the following data.

- Acute Hospital Portfolio: total annual attendances.
- Hospital Episode Statistics: number of patients treated per year.

There were significant associations (p<0.01) for all cancers for these data.

<table>
<thead>
<tr>
<th>Table 25 Rank correlations of ‘volume’ related measures from the Acute Hospital Portfolio and Hospital Episodes Statistics datasets.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Trusts</td>
</tr>
<tr>
<td>------------------</td>
</tr>
<tr>
<td>Total annual attendances (from AHP data) Vs. number of patients (from HES data)</td>
</tr>
</tbody>
</table>

Commentary: These two data probably represent the most similar measures in this analysis, and the significant correlations provide some validation of the statistical approach for all the cancers. The Acute Hospital Portfolio data are for all diseases, while the Hospital Episode Statistics in our analysis were for specific cancers. However, there should be a volume effect in both datasets.

7.1.3 Question 3: Within a specific tumour type, do [hospital] Trusts perform consistently well across a range of quality indicators?

No. Within specific tumour types, there were a few associations between the different datasets.

Variations by tumour type (Tables 26, 27)

We measured the following data.

- 1-year survival.
- Cancer standards: Total MDT score.
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- GP referral waiting times 2001/2.
- In-hospital mortality.
- Satisfaction: B7: ‘respect and dignity’

No associations between dataset variables were found for breast cancer. For colo-rectal cancer, there was a single association; Lung cancer showed associations in two areas: one-year survival associated with MDT standards, and standards associated with waiting time - and overall (Kendall’s W: 0.32, p=0.03). At hospital trust level analysis, the total MDT score of standards was strongly positively associated with GP referral waiting times, but there were no significant correlations overall.
Table 26  Rank correlations of combinations of measures from five datasets: Network level

<table>
<thead>
<tr>
<th>Combinations of variables</th>
<th>Breast cancer</th>
<th>Colorectal cancer</th>
<th>Lung cancer</th>
<th>Prostate cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Networks (range)</td>
<td>27-34</td>
<td>27-34</td>
<td>27-34</td>
<td>34</td>
</tr>
<tr>
<td>1 year relative survival % vs. 'respect and dignity'</td>
<td>0.27 p=0.12</td>
<td>0.14 p=0.42</td>
<td>0.28 p=0.11</td>
<td>0.07 p=0.71</td>
</tr>
<tr>
<td>1 year relative survival % vs total MDT Standards score</td>
<td>-0.10 p=0.62</td>
<td>0.41* p=0.03</td>
<td>0.44* p=0.02</td>
<td>-</td>
</tr>
<tr>
<td>1 year relative survival % vs. waiting times 2001/02</td>
<td>-0.26 p=0.15</td>
<td>-0.14 p=0.42</td>
<td>0.22 p=0.21</td>
<td>-0.13 p=0.47</td>
</tr>
<tr>
<td>1 year relative survival % vs. in-hospital mortality</td>
<td>0.20 p=0.27</td>
<td>-0.18 p=0.30</td>
<td>0.01 p=0.96</td>
<td>0.21 p=0.28</td>
</tr>
<tr>
<td>'Respect and dignity' vs. standards score</td>
<td>0.01 p=0.96</td>
<td>0.09 p=0.66</td>
<td>-0.03 p=0.87</td>
<td>-</td>
</tr>
<tr>
<td>'Respect and dignity' vs. waiting times 2001/02</td>
<td>-0.10 p=0.56</td>
<td>0.04 p=0.81</td>
<td>-0.12 p=0.51</td>
<td>-0.08 p=0.67</td>
</tr>
<tr>
<td>'Respect and dignity' vs. in-hospital mortality</td>
<td>0.24 p=0.18</td>
<td>0.04 p=0.84</td>
<td>-0.22 p=0.22</td>
<td>0.19 p=0.27</td>
</tr>
<tr>
<td>Standards score vs. waiting times 2001/02</td>
<td>0.20 p=0.32</td>
<td>0.18 p=0.37</td>
<td>0.48** p=0.01</td>
<td>-</td>
</tr>
<tr>
<td>Standards score vs. in-hospital mortality</td>
<td>-0.15 p=0.45</td>
<td>0.23 p=0.25</td>
<td>0.07 p=0.74</td>
<td>-</td>
</tr>
<tr>
<td>Waiting times 2001/02 vs. in-hospital mortality</td>
<td>-0.03 p=0.85</td>
<td>-0.08 p=0.66</td>
<td>-0.001 p=0.99</td>
<td>-0.21 p=0.25</td>
</tr>
<tr>
<td>Kendall’s W</td>
<td>0.25 p=0.17</td>
<td>0.27 p=0.11</td>
<td>0.32* p=0.03</td>
<td>0.25 p=0.44</td>
</tr>
</tbody>
</table>

Kendall’s W: measures the agreement of the five variables in ranking the 34 networks. p>0.05 = randomness in ranking.
Table 27 Rank correlations of combinations of measures from five datasets: hospital trust level

<table>
<thead>
<tr>
<th>Combinations of variables</th>
<th>Breast cancer</th>
<th>Colorectal cancer</th>
<th>Lung cancer</th>
<th>Prostate cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Trusts (range)</td>
<td>119-155</td>
<td>122-155</td>
<td>122-155</td>
<td>149-155</td>
</tr>
<tr>
<td>'Respect and dignity' vs. standards</td>
<td>-0.03, p=0.70</td>
<td>-0.005, p=0.95</td>
<td>0.059, p=0.52</td>
<td>-</td>
</tr>
<tr>
<td>'Respect and dignity' vs. waiting times 2001/02</td>
<td>-0.05, p=0.53</td>
<td>-0.02, p=0.84</td>
<td>0.014, p=0.86</td>
<td>-0.057, p=0.49</td>
</tr>
<tr>
<td>'Respect and dignity' vs. in-hospital mortality</td>
<td>0.09, p=0.27</td>
<td>0.09, p=0.25</td>
<td>-0.060, p=0.46</td>
<td>0.054, p=0.51</td>
</tr>
<tr>
<td>Total MDT score vs. waiting times 2001/02</td>
<td>0.27**, p&lt;0.01</td>
<td>0.27**, p&lt;0.01</td>
<td>0.17, p=0.06</td>
<td>-</td>
</tr>
<tr>
<td>Total MDT score vs. in-hospital mortality</td>
<td>-0.04, p=0.66</td>
<td>-0.08, p=0.38</td>
<td>-0.04, p=0.63</td>
<td>-</td>
</tr>
<tr>
<td>Waiting times vs. in-hospital mortality</td>
<td>-0.02, p=0.76</td>
<td>-0.04, p=0.66</td>
<td>-0.09, p=0.27</td>
<td>0.02, p=0.80</td>
</tr>
<tr>
<td>Kendall's W</td>
<td>0.27, p=0.27</td>
<td>0.282, p=0.16</td>
<td>0.28, p=0.21</td>
<td>0.34, p=0.43</td>
</tr>
</tbody>
</table>

Kendall’s W: measures the agreement of the 4 variables in ranking the Trusts. p>0.05 = randomness in ranking.

Commentary. The positive association for Total MDT standards and GP referral waits may indicate similarities for hospital administrative practice - hospitals achieving higher implementation of MDT standards would have been expected to have had shorter referral times.

7.1.1 Question 4: Do [hospital] Trusts perform consistently well across a range of tumour types?

Yes. Networks and hospitals perform similarly for breast, colo-rectal and prostate cancer, although less so for lung cancer.

In the tables (28, 29) it is evident that there are high correlations within a dataset across tumour types especially between breast, colorectal and prostate cancers, and less strongly for lung cancer (indeed absent at hospital trust level analysis). There is also less association for five-year survival compared with one-year.
Measuring Quality in Cancer Services

We measured the following data.

- 1-year and 5-year survival.
- Total MDT standards score.
- Satisfaction: B7: ‘Respect and dignity’.
- GP referral waiting times 2001/2.
- HES: in-hospital mortality.
Table 28  Rank correlations for combinations of tumour types for measures from five datasets: network level

<table>
<thead>
<tr>
<th>Combinations of tumour types</th>
<th>1 year relative survival %</th>
<th>5 year relative survival %</th>
<th>'Respect and dignity'</th>
<th>Total MDT standards score</th>
<th>Waiting times 2001/02</th>
<th>In-hospital mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer vs. Colorectal cancer</td>
<td>0.43** p=0.01</td>
<td>0.58** p&lt;0.01</td>
<td>0.73** p&lt;0.01</td>
<td>0.62** p&lt;0.01</td>
<td>0.33* p=0.05</td>
<td>0.60** p&lt;0.01</td>
</tr>
<tr>
<td>Breast cancer vs. Prostate cancer</td>
<td>0.51** p&lt;0.01</td>
<td>0.51** p&lt;0.01</td>
<td>0.49** p&lt;0.01</td>
<td>-</td>
<td>0.40* p=0.02</td>
<td>0.54** p&lt;0.01</td>
</tr>
<tr>
<td>Colorectal cancer vs. Prostate cancer</td>
<td>0.46** p&lt;0.01</td>
<td>0.19 p=0.29</td>
<td>0.49** p&lt;0.01</td>
<td>-</td>
<td>0.53** p&lt;0.01</td>
<td>0.47** p&lt;0.01</td>
</tr>
<tr>
<td>Breast cancer vs. Lung cancer</td>
<td>0.31 p=0.07</td>
<td>0.16 p=0.38</td>
<td>0.34* p=0.05</td>
<td>0.62** p&lt;0.01</td>
<td>0.35* p=0.04</td>
<td>0.39* p=0.03</td>
</tr>
<tr>
<td>Colorectal cancer vs. Lung cancer</td>
<td>0.36* p=0.04</td>
<td>0.30 p=0.09</td>
<td>0.37* p=0.03</td>
<td>0.51** p&lt;0.01</td>
<td>0.32 p=0.07</td>
<td>0.58** p&lt;0.01</td>
</tr>
<tr>
<td>Prostate cancer vs. Lung cancer</td>
<td>0.37* p=0.03</td>
<td>0.21 p=0.24</td>
<td>0.30 p=0.09</td>
<td>-</td>
<td>0.46** p&lt;0.01</td>
<td>0.45** p&lt;0.01</td>
</tr>
</tbody>
</table>

*Kendall’s W: measures the agreement of each variable by tumour type in ranking the 34 networks. Therefore, it measures the consistency at which each network ranked (performed) across each variable, by tumour type. p<0.05 = there is some consistency in ranking.
### Table 29: Rank correlations of combinations of tumour types for measures from four datasets: Hospital trust Level

<table>
<thead>
<tr>
<th>Combinations of tumour types</th>
<th>Satisfaction</th>
<th>'Respect and dignity'</th>
<th>Total MDT standards score</th>
<th>In-hospital mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer vs. Colorectal cancer</td>
<td>0.40**</td>
<td>0.46**</td>
<td>0.39**</td>
<td>0.21**</td>
</tr>
<tr>
<td></td>
<td>p&lt;0.01</td>
<td>p&lt;0.01</td>
<td>p&lt;0.01</td>
<td>p=0.01</td>
</tr>
<tr>
<td>Breast cancer vs. Prostate cancer</td>
<td>0.30**</td>
<td>-</td>
<td>0.35**</td>
<td>0.49**</td>
</tr>
<tr>
<td></td>
<td>p&lt;0.01</td>
<td></td>
<td>p&lt;0.01</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>Colorectal cancer vs. Prostate cancer</td>
<td>0.34**</td>
<td>-</td>
<td>0.45**</td>
<td>0.27**</td>
</tr>
<tr>
<td></td>
<td>p&lt;0.01</td>
<td></td>
<td>p&lt;0.01</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>Breast cancer vs. Lung cancer</td>
<td>0.09</td>
<td>0.44**</td>
<td>0.33**</td>
<td>0.35**</td>
</tr>
<tr>
<td></td>
<td>p=0.26</td>
<td>p&lt;0.01</td>
<td>p&lt;0.01</td>
<td>p=0.01</td>
</tr>
<tr>
<td>Colorectal cancer vs. Lung cancer</td>
<td>0.19*</td>
<td>0.37**</td>
<td>0.17*</td>
<td>0.37**</td>
</tr>
<tr>
<td></td>
<td>p=0.02</td>
<td>p&lt;0.01</td>
<td>p=0.04</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>Prostate cancer vs. Lung cancer</td>
<td>0.05</td>
<td>-</td>
<td>0.38**</td>
<td>0.44**</td>
</tr>
<tr>
<td></td>
<td>p=0.52</td>
<td></td>
<td>p&lt;0.01</td>
<td>p&lt;0.01</td>
</tr>
</tbody>
</table>

*K Kendall’s W: measures the agreement of each variable by tumour type in ranking the 34 networks. Therefore, it measures the consistency at which each network ranked (performed) across each variable, by tumour type. p<0.05 = there is some consistency in ranking.

Commentary

These tables suggest that there is a strong ‘hospital’ effect on all the datasets - hospitals perform similarly across different tumours.
7.1.5 Question 5: At a [hospital] Trust, do the issues raised by the Cancer Patient Survey correlate with those identified by qualitative (focus group) methods used by the Cancer Services Collaborative?

A: We were not able to gain information from the Cancer Services Collaborative, but we instead compared the Cancer Patient Survey with the Acute Hospital Portfolio and the Cancer Standards Peer Review. Although there were not statistical associations between the majority of indices, there were several suggestive associations which are explored below.

In comparing the Acute Hospital Portfolio measures with two measures of satisfaction related to the inpatient episode, there were associations for breast, colorectal and prostate cancers, although not for lung cancer (30, 31). For both measures, in general higher levels of formal complaints, and shorter waiting for emergency admissions, were associated with greater dissatisfaction. There were some other associations on throughput measures, but not for in-hospital waits. On staffing, the most notable association was with the ratio of medicine consultants to hospital admissions.
### Measuring Quality in Cancer Services

Table 30 Rank correlations between inpatient ‘Respect and dignity’ (from satisfaction survey) and measures from the Acute Hospital Portfolio dataset

<table>
<thead>
<tr>
<th>Domain</th>
<th>Variables</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Lung</th>
<th>Prostate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Number of hospital Trusts - range)</td>
<td>134-148</td>
<td>134-148</td>
<td>134-148</td>
<td>134-148</td>
</tr>
<tr>
<td><strong>Complaints</strong></td>
<td>Formal complaints rate</td>
<td>0.22**</td>
<td>0.21**</td>
<td>0.10</td>
<td>0.22**</td>
</tr>
<tr>
<td></td>
<td>p=0.01</td>
<td>p=0.01</td>
<td>p=0.25</td>
<td>p=0.01</td>
<td></td>
</tr>
<tr>
<td><strong>Throughput</strong></td>
<td>Total attendances / year</td>
<td>0.11</td>
<td>0.26**</td>
<td>0.02</td>
<td>0.19*</td>
</tr>
<tr>
<td></td>
<td>p=0.18</td>
<td>p&lt;0.01</td>
<td>p=0.78</td>
<td>p=0.03</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patients per bed</td>
<td>0.03</td>
<td>-0.05</td>
<td>-0.02</td>
<td>-0.02</td>
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<td>Ratio outpatients: admissions</td>
<td>0.23**</td>
<td>0.13</td>
<td>0.07</td>
<td>0.17</td>
</tr>
<tr>
<td></td>
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<td>p=0.14</td>
<td>p=0.40</td>
<td>p=0.06</td>
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</tr>
<tr>
<td><strong>Waiting times</strong></td>
<td>% emergency patients admitted under 4 hours</td>
<td>-0.26**</td>
<td>-0.35**</td>
<td>-0.10</td>
<td>-0.16</td>
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<td>0.04</td>
<td>0.01</td>
<td>-0.01</td>
</tr>
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<td><strong>Staffing</strong></td>
<td>Doctor WTE per 10,000 attendances</td>
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<td>-0.04</td>
<td>0.09</td>
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<tr>
<td></td>
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<td>0.16</td>
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<tr>
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<tr>
<td></td>
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<td>0.03</td>
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<td>All consultants rate per 1000 admission</td>
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<td>0.12</td>
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<td>p=0.43</td>
<td>p=0.15</td>
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</table>

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Table 31  Rank correlations between 'Aftercare: communication' (from satisfaction survey) and measures from the Acute Hospital Portfolio dataset

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<tr>
<th>Domain</th>
<th>Variables</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Lung</th>
<th>Prostate</th>
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<td>Complaints</td>
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<td>0.26**</td>
<td>0.11</td>
<td>0.23**</td>
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<td>p=0.18</td>
<td>p&lt;0.01</td>
<td></td>
</tr>
<tr>
<td>Throughput</td>
<td>Total attendances / year</td>
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<td>0.13</td>
<td>0.07</td>
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<tr>
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<td>p=0.03</td>
<td>p=0.12</td>
<td>p=0.43</td>
<td></td>
</tr>
<tr>
<td>Patients per bed</td>
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<td>-0.11</td>
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<td>0.08</td>
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<tr>
<td>Ratio outpatients: admissions</td>
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<td>0.17</td>
<td>0.08</td>
<td>0.13</td>
<td></td>
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<tr>
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<td>p=0.05</td>
<td>p=0.33</td>
<td>p=0.13</td>
<td></td>
</tr>
<tr>
<td>Waiting times</td>
<td>% emergency patients admitted under four hours</td>
<td>-0.17*</td>
<td>-0.28**</td>
<td>-0.15</td>
<td>-0.21*</td>
</tr>
<tr>
<td></td>
<td>p=0.04</td>
<td>p&lt;0.01</td>
<td>p=0.08</td>
<td>p=0.02</td>
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</tr>
<tr>
<td>Waiting for computer tomography</td>
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<td>0.05</td>
<td>0.11</td>
<td>-0.07</td>
<td></td>
</tr>
<tr>
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<td>p=0.59</td>
<td>p=0.19</td>
<td>p=0.41</td>
<td></td>
</tr>
<tr>
<td>Waiting for magnetic resonance imaging</td>
<td>-0.04</td>
<td>-0.03</td>
<td>-0.02</td>
<td>-0.08</td>
<td></td>
</tr>
<tr>
<td></td>
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<td>p=0.69</td>
<td>p=0.82</td>
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<td></td>
</tr>
<tr>
<td>Staffing</td>
<td>Doctor WTE per 10,000 attendances</td>
<td>0.10</td>
<td>0.08</td>
<td>0.02</td>
<td>0.15</td>
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<td></td>
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<td>p=0.36</td>
<td>p=0.83</td>
<td>p=0.07</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nurse WTE per 10,000 attendances</td>
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<td>0.06</td>
<td>0.05</td>
<td>0.21**</td>
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<tr>
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<td>p=0.47</td>
<td>p=0.54</td>
<td>p=0.01</td>
<td></td>
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<tr>
<td></td>
<td>Medicine consultants per 1000 admissions</td>
<td>0.08</td>
<td>0.19*</td>
<td>0.10</td>
<td>0.20*</td>
</tr>
<tr>
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<td>p=0.03</td>
<td>p=0.27</td>
<td>p=0.02</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anaesthetists consultants per 1000 admissions</td>
<td>0.002</td>
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<td>0.18*</td>
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<td>p=0.25</td>
<td>p=0.04</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pathology consultants per 1000 admissions</td>
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<td>0.08</td>
</tr>
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<td>p=0.07</td>
<td>p=0.35</td>
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</tr>
<tr>
<td></td>
<td>Radiology consultants per 1000 admissions</td>
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<td>0.08</td>
<td>0.10</td>
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<tr>
<td></td>
<td>p=0.97</td>
<td>p=0.21</td>
<td>p=0.34</td>
<td>p=0.25</td>
<td></td>
</tr>
<tr>
<td></td>
<td>All consultants rate per 1000 admissions</td>
<td>0.03</td>
<td>0.13</td>
<td>0.13</td>
<td>0.18*</td>
</tr>
<tr>
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<td>p=0.13</td>
<td>p=0.04</td>
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</tr>
</tbody>
</table>
Looking at associations between cancer standards for hospital cancer centres and units, and two measures of satisfaction, (B7, D15), Table 35, there were several associations, particularly across the domains of clinicians, nurses and managers, for breast cancer but not for colorectal and lung. For ‘Respect and Dignity’ these were all in the expected direction (implementation of standards associated with less dissatisfaction), but the outpatient communication measures were all unexpected - standards associated with greater dissatisfaction.
### Table 32 Associations between cancer standards for hospital cancer centres and units and two measures of satisfaction measures for patients with breast, colorectal and lung cancers.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Variables</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Lung</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>'Respect and dignity'</td>
<td>'After-care communication'</td>
<td>'Respect and dignity'</td>
</tr>
<tr>
<td>(Number of Trusts - range)</td>
<td></td>
<td>122</td>
<td>121</td>
<td>122</td>
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<tr>
<td>10.2/1 – Referral guidelines for cancer sites not covered by the unit MDT</td>
<td>-0.07</td>
<td>0.04</td>
<td>-0.16</td>
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<td>-0.20*</td>
<td>0.16</td>
<td>-0.07</td>
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<tr>
<td></td>
<td>10.2/3 - Written job description for the lead role</td>
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<td>0.27**</td>
<td>0.04</td>
</tr>
<tr>
<td></td>
<td>10.2/4 - Specification of time available and administrative support for the lead clinician</td>
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<td>0.26**</td>
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</tr>
<tr>
<td></td>
<td>10.2/5 - Regular review of time/support available to lead clinician</td>
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<td>0.14</td>
<td>0.08</td>
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<tr>
<td></td>
<td>10.2/6 - Lead clinician member of cancer unit group</td>
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<tr>
<td>Nurse</td>
<td>10.2/7 - Cancer services lead nurse for the cancer unit</td>
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<td>0.06</td>
<td>-0.07</td>
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<td>10.2/8 - Written job description for the lead nurse</td>
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<td>-0.06</td>
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</table>
### Measuring Quality in Cancer Services

<table>
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<tr>
<th>Group</th>
<th>Score</th>
<th>p-value</th>
<th>Score</th>
<th>p-value</th>
<th>Score</th>
<th>p-value</th>
<th>Score</th>
<th>p-value</th>
<th>Score</th>
<th>p-value</th>
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</thead>
<tbody>
<tr>
<td>10.2/11 - Named cancer unit group with membership</td>
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<td>0.14</td>
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<td>-0.020</td>
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<td>-0.009</td>
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<td>0.56</td>
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</table>

Looking at associations for selected cancer standards for *multi-disciplinary teams* with the same measures of satisfaction, Table [Table below] 36, there was a rather different picture. Breast cancer showed associations, but they were distributed across lower and higher dissatisfaction by the two measures; colorectal cancer again showed little associations; while lung cancer showed several associations of the standards with outpatient communication satisfaction.
## Table 33  Associations between Cancer Standards for multidisciplinary teams and two measures of patient satisfaction for patients with breast, colorectal and lung cancers

<table>
<thead>
<tr>
<th>Domain</th>
<th>Variable</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Lung</th>
</tr>
</thead>
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<td>0.18</td>
<td>0.02</td>
</tr>
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<td>0.18</td>
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<td>0.19</td>
<td>0.56</td>
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<td>Higher</td>
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## Measuring Quality in Cancer Services

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<tr>
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<th>-0.16 p=0.08</th>
<th>-0.04 p=0.66</th>
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<tbody>
<tr>
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<td>Referral guidelines for the cancer site</td>
<td>0.22* p=0.02</td>
<td>0.10 p=0.28</td>
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<td>-0.07 p=0.41</td>
<td>-0.04 p=0.64</td>
<td>-0.02 p=0.79</td>
</tr>
<tr>
<td>Data collection</td>
<td>Network-wide dataset</td>
<td>0.12 p=0.21</td>
<td>0.20* p=0.03</td>
<td>0.01 p=0.90</td>
<td>0.02 p=0.79</td>
<td>0.23** p&lt;0.01</td>
<td>0.01 p=0.87</td>
</tr>
<tr>
<td></td>
<td>Recording data for individual patients</td>
<td>0.20* p=0.04</td>
<td>0.004 p=0.97</td>
<td>0.10 p=0.33</td>
<td>0.05 p=0.61</td>
<td>0.24** p&lt;0.01</td>
<td>0.17 p=0.06</td>
</tr>
<tr>
<td>Treatment</td>
<td>Treatment planning decisions recorded</td>
<td>0.04 p=0.63</td>
<td>-0.009 p=0.92</td>
<td>0.12 p=0.19</td>
<td>0.08 p=0.38</td>
<td>-0.05 p=0.56</td>
<td>-0.003 p=0.98</td>
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<tr>
<td></td>
<td>Network wide clinical guidelines for cancer site</td>
<td>0.06 p=0.51</td>
<td>0.16 p=0.08</td>
<td>-0.04 p=0.67</td>
<td>-0.12 p=0.19</td>
<td>0.05 p=0.59</td>
<td>-0.06 p=0.55</td>
</tr>
<tr>
<td></td>
<td>List of agreed clinical trials</td>
<td>0.19 p=0.09</td>
<td>0.12 p=0.23</td>
<td>0.07 p=0.53</td>
<td>-0.005 p=0.53</td>
<td>0.02 p=0.83</td>
<td>-0.09 p=0.37</td>
</tr>
<tr>
<td>Other</td>
<td>Network wide audit</td>
<td>-0.11 p=0.28</td>
<td>0.04 p=0.68</td>
<td>-0.05 p=0.63</td>
<td>-0.02 p=0.87</td>
<td>0.12 p=0.23</td>
<td>0.02 p=0.86</td>
</tr>
<tr>
<td></td>
<td>MDT workload</td>
<td>-0.17 p=0.10</td>
<td>0.10 p=0.36</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**Commentary**

The tables shown here have multiple tests, and there must be caution in interpretation against false positive (and false negative) results. However, by tumour type, breast, colorectal and prostate cancer show some hospital level correlation between measures of satisfaction and of activity, while hospital level cancer standards are associated with satisfaction measures for breast cancer and tumour-specific team standards for lung cancer. These latter results may have some basis in clinical practice: breast cancer patients are usually admitted for surgery and most receive inpatient, while lung cancer patients (where treatment options are limited and surgery only suitable for a minority) more often attend outpatients for their symptomatic management, or day-care for radiotherapy. The greater dissatisfaction at hospitals with specialised breast surgery is unexplained.

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Section 8  Cancer services statistics: a way forward

8.1  Cancer information

The Department of Health Cancer Information Strategy (June 2000) recommended that

‘Monitoring of performance indicators which relate to the quality of cancer services delivery, including screening, should form part of the assessment of individual cancer services.

‘Health service managers and commissioners working at local (eg Primary Care Group/Trust, NHS Trust or Cancer Network), regional or national level will need information on the structure, process and outcome of cancer care in the area for which they are responsible. This will involve information about cancer services and aggregated information on activity and outcomes.’

Our study has shown:

• the Cancer Information Strategy issued at the start of the Cancer Plan has not yet been fully developed for service management at cancer network level;
• cancer data exist at network and trust level for structure, process and outcome, and by common tumour type;
• cancer network members do not currently use these data routinely, but would welcome more focus on them, and on using them;
• there are statistically significant differences and rankings between networks and hospital trusts which can be relevant for local decision-making and performance assessment by network and hospital managers, patients and health care commissioners (including GPs).

Implications

While the current programme of electronic collection of data for whole NHS, ‘Connecting for Health’, will provide data about clinical conditions and activities, it is not as wide-ranging in content as the datasets we have analysed. Its focus on individual records, even when aggregated as ‘Secondary User Statistics’, is complementary to other data on institutional level characteristics. It is institutional characteristics that the Cancer Plan is seeking to address (eg cancer standards, infrastructure investments) and there is no clear information system linking these.
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There has been growing recognition of the value of institutional assessments using multiple data sources. The Healthcare Commission has moved from ‘stars’ to a ‘scorecard’, with items reflecting different aspects that require attention or are monitored for direction of change. The use of existing data would be a cost-effective way of implementing the NHS cancer information strategy.

We recommend the following.

1. There should be a ‘Cancer Information System’ for NHS cancer services management that is drawn from existing data sources. Such a system is feasible for cancer, and necessary for the NHS, given the size of the service and importance to patients, and the direct management structure (Cancer Action Team and 34 Cancer Networks) created by the Cancer Plan.

2. The datasets should be updated and regularly presented to the NHS to ensure similar available comparisons in the future (Table 37). At present, there are no plans to repeat the survey of cancer patients, although this would appear to be data at the heart of concern for a ‘patient-centred’ service, and the Acute Hospital Portfolio surveys are also only occasional. A discussion on their use for cancer with the data owners could be helpful in promoting better cancer information.
**Table 34** Timing of datasets used in this study

<table>
<thead>
<tr>
<th>Dataset</th>
<th>First</th>
<th>Repeat</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute trust portfolio</td>
<td>Undertaken 2001</td>
<td>Healthcare commission repeats its surveys</td>
</tr>
<tr>
<td>National Cancer Peer Review</td>
<td>Undertaken 2001 to 3</td>
<td>Being repeated 2005 to 2007</td>
</tr>
<tr>
<td>Cancer Waiting Times</td>
<td>Quarterly since 2001</td>
<td>Continues, but new waiting times (62 days) coming because 15 days now insensitive</td>
</tr>
<tr>
<td>Hospital Episode Statistics</td>
<td>Annual</td>
<td></td>
</tr>
<tr>
<td>Cancer Survival</td>
<td>Annual</td>
<td></td>
</tr>
<tr>
<td>National Survey: Cancer Patients</td>
<td>Undertaken 2001</td>
<td>Repeat for smaller sample by National Audit Office in 2004 Could be repeated by Healthcare Commission</td>
</tr>
</tbody>
</table>

3 Including data on screening and prevention should be considered for expansion of the Cancer Information System. Cancer screening datasets are available (in certain age groups) for breast and cervical cancers, and in future for colo-rectal cancer. Data exist at Primary Care Trust level about services and population levels for behaviours including smoking, diet and sexual activity, which relate particularly to incidence of lung cancer, stomach cancer and cervical cancer. These datasets can be linked to data on age-standardised cancer incidence from cancer registration, with suitable ‘lags’ in time series to allow for delays in onset.

4 Investment. There has been considerable new expenditure through the NHS on cancer services since 2000. Analysis of PCT-level investment in cancer services is possible from the cancer services annual investments (http://tinyurl.com/7gxpa) or the national programme budget (http://tinyurl.com/le9ze). Changes in service expenditure could then be related at population level to changes in the datasets – for structures, process and outcome.

5 A commercial firm, **Ardentia**, has developed a ‘Cancer Information System’, using NHS data in association with the National Association of Cancer Registries. This includes only cancer registration datasets. We wrote a proposal to the Department of
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Health and NHS Cancer Action Team to expand this system to include the datasets and analyses developed here, and indeed to extend it to cover other existing datasets.

6 Cancer network information managers should be present in every cancer network, and the Cancer Action Team should develop a programme for analysis and use of datasets for performance management. Indeed, with abolition of the Strategic Health Authorities and development of devolved commissioning, there is greater than ever need for cancer networks to show their benefit by influencing the development of services on the basis of quality measures. Allocating NHS funds to ‘investments’ should be based on evidence of both need and benefit. A cancer information system should be able to demonstrate whether the current investments are beneficial.

8.2 Associations between quality measures in cancer services

It is accepted that the cross-sectional timing of the datasets in this study limits interpretation of causality. Nevertheless, since health systems change relatively slowly, cross-sectional data provide a reasonable starting point for exploring possible relationships in chronic disease control and health care, and the analyses we made of the datasets could address some initial hypotheses from the literature.

At a general level, we found high levels of association between datasets for different cancers (especially breast, colorectal and prostate cancers) within the same hospital, suggesting a ‘hospital’ effect on specific services. In contrast, there were fewer associations across datasets at cancer network and hospital levels.

We found that some hospital level characteristics are related to cancer quality indicators. Associations were found for the following dimensions.

- Survival (cancer network level): for colorectal and lung cancers, one-year survival at network level was associated with total cancer standards score.
- Satisfaction (hospital level): for breast, colorectal and prostate cancers, greater dissatisfaction, as measured by responses to being ‘treated with respect and dignity’ in hospital, was associated with more formal complaints; and there were some associations with levels of hospital consultants.
- Cancer standards: For hospital cancer centres and units cancer standards, there were associations for breast cancer with a
measure of inpatient ‘Respect and dignity’ satisfaction across the domains of clinicians, nurses and managers, for breast cancer. For tumour-specific team cancer standards, for lung cancer there were associations with a measure of outpatient ‘communication’ satisfaction.

On the other hand, for the majority of analyses there was a lack of association, or sometimes a negative relationship.

- Survival: One year survival was not associated with total standards score for breast cancer, and five year survival was not associated with standards for any tumour type.

- Waiting times: The different measures showed little association between each other. GP referral waiting time measures were not associated with any expected positive performance. A lower proportion of (all, general) patients admitted through emergency departments within hospitals was associated with less inpatient satisfaction, for all tumour types.

- Staff: Nursing variables showed few expected performance associations, and one significant association (for prostate cancer nursing) of greater dissatisfaction of availability of nurses in the ward in hospitals with overall higher nursing levels.

These findings reflect the lack of clear evidence in the literature. Studies using administrative data are liable to errors through generalisation, in comparison with focused clinical studies. However, more research is needed to elucidate the impacts of cancer services on clinical practice and outcomes. If the Cancer Plan is to be ‘evidence-based’, it needs to demonstrate a causal relationship between changes in resources and organisation (structure), patterns of practice (process) and health service outcomes.

### 8.3 Future research

We have sought to answer the specific questions set by the research call. However, further analysis of the existing datasets could be undertaken. Moreover, in the future with the advent of time-series data for outcomes, especially the repeat cancer standards data, further linked analyses would be valuable. Linking changes in hospital structures and processes over time with changing outcomes would both provide greater statistical power, and greater support for causal relationships. Adding further datasets, in prevention and screening, would also add to relevance for cancer management.

More research is needed using secondary data sources: both the research councils and disease charities should give more attention to this area of health services research, working with the NHS and the
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Department of Health, for patient benefit. This would be cost-effective, and relevant to national and local performance management.

8.4 Dissemination

We have undertaken an active programme of dissemination through the study.

We have held / will hold three presentation meetings with the SDO and the Director of Cancer Services.

In March 2005 we held a regional meeting bringing together local practitioners from the cancer network, including information and general managers, public health, primary care and clinicians, as well as the research team.

In May 2005 we gave a presentation at the SDO national research conference.

In July 2005 and July 2006 we addressed the quarterly national meeting of cancer networks.

In March 2006 we held a specialised meeting for key national stakeholders concerned with cancer information, including the ‘owners’ of the datasets we used, the DH, NHS and industrial sectors.

We presented results of the study in a workshop at the First national Health Services Research conference, London, June 2006, and as posters at the National Cancer Institute second annual conference in Birmingham, UK (November 2006), 15th European Public Health Association annual conference in Montreux, Switzerland (November 2006).

Following the end of the formal SDO contract, we have produced a series of papers.


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Work in relation to this study also contributed to the PhD Thesis by Artak Khachatryan: Use of routine data to investigate determinants of colorectal cancer survival in London. UCL Department of Epidemiology and Public Health, University College London, 2008.

8.5 Governance

This study was supported by funding from the Department of Health.

Regular quarterly meetings of the Advisory Group, including representatives of the Department of Health’s Cancer Action Team and Policy Unit, were held, and annually with the funding body (SDO). Minutes of these and other meetings undertaken for the study are available from the principle investigator.
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Ethical approval was given by the South East Regional Ethical Committee.

We are also grateful to our advisors and respondents in the study, and to staff at UCL in implementing the financial and contractual arrangements.
Section 9  Conclusion

Our study, funded by the UK Department of Health and undertaken at UCL, has examined the use of routine datasets for NHS management of cancer services in England.

We found relatively little academic literature describing the use of cancer information for management at the organisational level, in contrast to the considerable literature on cancer care itself. There is rather more literature on organisational determinants of cancer outcomes, but again, in contrast to treatment, less clarity of evidence in this area.

Six datasets were used in the study, of which five had data divided by cancer type for the four common tumours (breast, colo-rectal, lung and prostate), while the sixth was of hospital characteristics more generally. The datasets can be considered to describe dimensions of structure, process and outcome relevant to quality in patient care.

Our study surveyed members of cancer network management teams in England. Only half of the teams had cancer information leads, and most were dependent on their constituent hospitals to provide information expertise. Nevertheless, where there was a positive information policy, for example linked with data gained from the cancer registry or public health observatory, active management of cancer services at network level was possible. Lack of information policy was at odds with the Information Strategy of the NHS Cancer Plan. The strong need to demonstrate the effectiveness of the Cancer Plan, and the need for better commissioning of cancer services, argues for enhancement of information at the strategic level of cancer networks.

Our study also made analyses of the datasets, in response to the questions set in the research call, to explain relationships between different dimensions. We were able to contrast information at hospital and tumour specialty levels, and found support for the impact of hospital-level factors. The datasets themselves are of considerable relevance for cancer services performance management, since they reflect both provision and outcomes (satisfaction and survival) of services.

While we were able to use data from the national survey of cancer patients to assess satisfaction in this study, it was undertaken in 2001 and has not been repeated, so that continued data are not available. A second (but much smaller) repeat was made in 2004 by the National Audit Office, but only covering 44 hospitals. It would be welcome for the Healthcare Commission, which commissioned the first survey, and
the Department of Health to decide on repeating the survey, or making other arrangements to record experiences of care across the patients’ pathway.

The national peer review of standards in cancer units and centres has been repeated over the period 2004 to 2006, so that a second comparative ‘point’ is available. However, the data do not appear to be being used in a systematic research way, and this is a pity. There are many standards being recorded, but they are based on expert recommendations rather than science. Our study suggested that some of the standards were statistically associated with outcomes, and these findings deserve further attention through research. Perhaps most interesting would be to work with the current national clinical audits, to determined how hospital level factors (from the standards) compare with clinical practice (from the audits).

Our study was unusual in combining service objectives (developing a dataset for management) with statistical investigation of relationships between data to look for possible causal associations. Cancer data are unusual in having continuous recording of outcomes through cancer registration, and linking datasets is a cost-effective and intellectually relevant activity.

We made recommendations to the Department of Health for further development of these datasets for management purposes. A second area of considerable importance would be to use the national tumour-specific audits that are now being developed, which have patient-level clinical information that can be linked to organisational data for analysis of outcomes. Future research should be built on these important databases.
Appendices

Appendix A  Variables included in the Cancer Networks Limited Dataset

1. Medicine Management (expenditures):
   - BNF spend, malignant disease and immunosuppression (in £000)
   - BNF spend, malignant disease and immunosuppression, per FCE
     (in £)

2. Medical Staffing
   - Consultant WTE per 1000 admissions
   - Anaesthetist Consultant WTE per 1000 admissions
   - Medicine Consultant WTE per 1000 admissions
   - Pathology Consultant WTE per 1000 admissions
   - Radiology Consultant WTE per 1000 admissions
   - Ratio of outpatients to admissions

3. Radiology:
   - Waiting times, symptomatic mammography
   - Waiting times, nuclear medicine
   - Waiting times, CT
   - Waiting times, MRI
   - % exams unreported
   - % exams reported by radiologist
   - Inpatient exams per FCE
   - Outpatient exams per OP visit
   - Radiographers per 1000 FCE's

4. Ward Staffing (statistics):
   - Clinical nurse specialists (WTE) per 1000 FCE
   - Standardised ward patient accidents per 100 available beds
   - All formal complaints per 1000 FCEs
Appendix B  The list of variables included in the cancer networks limited dataset


Table 35  Total compliance with cancer standards for each main topic

<table>
<thead>
<tr>
<th>Variables</th>
<th>Corresponding topics/standards in the Manual</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Standards:</strong></td>
</tr>
<tr>
<td></td>
<td>1/1 Written guidelines for the centre or unit</td>
</tr>
<tr>
<td></td>
<td>1/2 Guidelines distributed to core members of MDTs</td>
</tr>
<tr>
<td></td>
<td>1/3 List of staff and hours/sessions available to offer support for cancer patients/carers</td>
</tr>
<tr>
<td></td>
<td>1/4 Assessment of staffing requirements</td>
</tr>
<tr>
<td></td>
<td>1/5 Requirement for additional staff proposed to the network management group</td>
</tr>
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<td>Breast cancer MDT</td>
<td>Topic 2. Breast Multi-disciplinary team.</td>
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<tr>
<td></td>
<td><strong>Standards:</strong></td>
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<td>2.2/1 Named Lead Clinician for the breast specialist MDT</td>
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<tr>
<td></td>
<td>2.2/2 Lead Clinician written responsibilities</td>
</tr>
<tr>
<td></td>
<td>2.2/3 Names of core members of MDT</td>
</tr>
<tr>
<td></td>
<td>2.2/4 Lead Histopathologist for the MDT</td>
</tr>
<tr>
<td></td>
<td>2.2/5 Histopathologist attendance at MDT</td>
</tr>
<tr>
<td></td>
<td>2.2/6 Consistency between histopathologists audit</td>
</tr>
<tr>
<td></td>
<td>2.2/7 Lead Imaging Consultant for the MDT</td>
</tr>
<tr>
<td></td>
<td>2.2/8 Lead Imaging Consultant attendance at MDT</td>
</tr>
<tr>
<td></td>
<td>2.2/9 Pre-operative core MDT members</td>
</tr>
<tr>
<td></td>
<td>2.2/10 MDT meetings – frequency and attendance records</td>
</tr>
<tr>
<td></td>
<td>2.2/11 Core members attendance at MDT</td>
</tr>
<tr>
<td></td>
<td>2.2/12 Cover arrangements for core members</td>
</tr>
<tr>
<td></td>
<td>2.2/13 Operational policy meetings</td>
</tr>
<tr>
<td></td>
<td>2.2/14 Operational policy – MDT review of new cancer patients</td>
</tr>
<tr>
<td></td>
<td>2.2/15 Written operational policy – communication of a patient’s diagnosis to their general practitioner</td>
</tr>
<tr>
<td></td>
<td>2.2/16 Implementation of the policy – timeliness of communication of a</td>
</tr>
</tbody>
</table>
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patient’s diagnosis to their general practitioner following diagnosis
2.2/17 Written operational policy – provision of information on the appropriateness and timeliness of urgent referrals
2.2/18 Designated breast surgeon sessions
2.2/19 Designated breast surgeon trained in accordance with BASO policy document
2.2/20 Breast care nurses work in breast care only
2.2/21 Breast care nurse specialist qualifications - registered on the ENB 237 course
2.2/22 Breast care nurses specialist qualifications - obtained the ENB 237 course
2.2/23 Breast care nurses specialist qualifications - obtained the ENB A11 and/or cancer related nursing degree
2.2/24 Core oncologist sessions
2.2/25 Written agreement describing referral guidelines – core team and clinical oncologist
2.2/26 Names of extended team members
2.2/27 Arrangements for access to MDT
2.2/28 Survey of patients experience undertaken/being undertaken
2.2/29 Survey results presented and discussed at MDT
2.2/30 Action taken as a result of the survey
2.2/31 Written information material available
2.2/32 Treatment planning decisions recorded
2.2/33 Network wide clinical guidelines for the cancer site
2.2/34 Referral guidelines for the cancer site
2.2/35 Network wide dataset for the cancer site
2.2/36 Recording of dataset for individual patients
2.2/37 Network wide audits
2.2/38 List of agreed clinical trials
2.2/39 MDT workload

Colorectal cancer MDT

| Standards: |
| 2.3/1 Named Lead Clinician for the colorectal specialist MDT |
| 2.3/2 Lead Clinician written responsibilities |
| 2.3/3 Names of core members of MDT |
| 2.3/4 Lead Histopathologist for the MDT |
| 2.3/5 Histopathologist attendance at MDT |
| 2.3/6 Consistency between histopathologists audit |
| 2.3/7 Lead Imaging Consultant for the MDT |
| 2.3/8 Lead Imaging Consultant attendance at MDT |
| 2.3/9 Pre-operative core MDT members |
| 2.3/10 MDT meetings – frequency and attendance records |
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<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td><strong>2.3/11</strong></td>
<td>Core members attendance at MDT</td>
</tr>
<tr>
<td><strong>2.3/12</strong></td>
<td>Cover arrangements for core members</td>
</tr>
<tr>
<td><strong>2.3/13</strong></td>
<td>Operational policy meetings</td>
</tr>
<tr>
<td><strong>2.3/14</strong></td>
<td>Operational policy – MDT review of new cancer patients</td>
</tr>
<tr>
<td><strong>2.3/15</strong></td>
<td>Written operational policy – communication of a patient’s diagnosis to their general practitioner</td>
</tr>
<tr>
<td><strong>2.3/16</strong></td>
<td>Implementation of the policy – timeliness of communication of a patient’s diagnosis to their general practitioner following diagnosis</td>
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<td><strong>2.3/17</strong></td>
<td>Written operational policy – provision of information on the appropriateness and timeliness of urgent referrals</td>
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<tr>
<td><strong>2.3/18</strong></td>
<td>Colorectal nurse specialist qualifications – registered ENB 237 course</td>
</tr>
<tr>
<td><strong>2.3/19</strong></td>
<td>Colorectal nurse specialist qualifications - obtained the ENB 237 course</td>
</tr>
<tr>
<td><strong>2.3/20</strong></td>
<td>Colorectal nurses specialist qualifications - obtained the ENB 216 and/or cancer related nursing degree</td>
</tr>
<tr>
<td><strong>2.3/21</strong></td>
<td>Written agreement describing referral guidelines – core team and clinical oncologist</td>
</tr>
<tr>
<td><strong>2.3/22</strong></td>
<td>Written operational policy for stabilising and treating emergency admissions</td>
</tr>
<tr>
<td><strong>2.3/23</strong></td>
<td>Names of extended team members</td>
</tr>
<tr>
<td><strong>2.3/24</strong></td>
<td>Arrangements for access to MDT</td>
</tr>
<tr>
<td><strong>2.3/25</strong></td>
<td>Survey of patients experience undertaken/being undertaken</td>
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<td><strong>2.3/26</strong></td>
<td>Survey results presented and discussed at MDT</td>
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<td>Action taken as a result of the survey</td>
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<tr>
<td><strong>2.3/28</strong></td>
<td>Written information material available</td>
</tr>
<tr>
<td><strong>2.3/29</strong></td>
<td>Treatment planning decisions recorded</td>
</tr>
<tr>
<td><strong>2.3/30</strong></td>
<td>Network wide clinical guidelines for the cancer site</td>
</tr>
<tr>
<td><strong>2.3/31</strong></td>
<td>Referral guidelines for the cancer site</td>
</tr>
<tr>
<td><strong>2.3/32</strong></td>
<td>Network wide dataset for the cancer site</td>
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<tr>
<td><strong>2.3/33</strong></td>
<td>Recording of dataset for individual patients</td>
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<tr>
<td><strong>2.3/34</strong></td>
<td>Network wide audits</td>
</tr>
<tr>
<td><strong>2.3/35</strong></td>
<td>List of agreed clinical trials</td>
</tr>
</tbody>
</table>

**Lung cancer MDT**

**Topic 2. Lung Multi-disciplinary team.**

**Standards:**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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<tr>
<td><strong>2.4/1</strong></td>
<td>Named Lead Clinician for the lung specialist MDT</td>
</tr>
<tr>
<td><strong>2.4/2</strong></td>
<td>Lead Clinician written responsibilities</td>
</tr>
<tr>
<td><strong>2.4/3</strong></td>
<td>Names of core members of MDT</td>
</tr>
<tr>
<td><strong>2.4/4</strong></td>
<td>Lead Histopathologist for the MDT</td>
</tr>
<tr>
<td><strong>2.4/5</strong></td>
<td>Histopathologist attendance at MDT</td>
</tr>
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<td><strong>2.4/6</strong></td>
<td>Consistency between histopathologists audit</td>
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<td><strong>2.4/7</strong></td>
<td>Lead Imaging Consultant for the MDT</td>
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<tr>
<td><strong>2.4/8</strong></td>
<td>Lead Imaging Consultant attendance at MDT</td>
</tr>
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<td><strong>2.4/9</strong></td>
<td>Pre-operative core MDT member</td>
</tr>
<tr>
<td><strong>2.4/10</strong></td>
<td>Designated cytologist as core member of MDT</td>
</tr>
<tr>
<td><strong>2.4/11</strong></td>
<td>MDT meetings – frequency and attendance records</td>
</tr>
</tbody>
</table>
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| 2.4/12 | Core members attendance at MDT           |
| 2.4/13 | Cover arrangements for core members     |
| 2.4/14 | Operational policy meetings             |
| 2.4/15 | Operational policy – MDT review of new cancer patients |
| 2.4/16 | Written operational policy – communication of a patient’s diagnosis to their general practitioner |
| 2.4/17 | Implementation of the policy – timeliness of communication of a patient’s diagnosis to their general practitioner following diagnosis |
| 2.4/18 | Written operational policy – provision of information on the appropriateness and timeliness of urgent referrals |
| 2.4/19 | Policy for referral for chest x-ray – MDT and PCTs |
| 2.4/20 | Lung nurse specialist qualifications – registered ENB 237 course |
| 2.4/21 | Lung nurse specialist qualifications – obtained the ENB 237 course |
| 2.4/22 | Lung nurse specialist qualifications – obtained the ENB 285 and/or cancer related nursing degree |
| 2.4/23 | Written agreement describing referral guidelines – core team and clinical oncologist |
| 2.4/24 | Names of extended team members           |
| 2.4/25 | Arrangements for access to MDT           |
| 2.4/26 | Survey of patients experience undertaken |
| 2.4/27 | Survey results presented and discussed at MDT |
| 2.4/28 | Action taken as a result of the survey   |
| 2.4/29 | Written information material available    |
| 2.4/30 | Treatment planning decisions recorded    |
| 2.4/31 | Network wide clinical guidelines for the cancer site |
| 2.4/32 | Referral guidelines for the cancer site  |
| 2.4/33 | Network wide dataset for the cancer site |
| 2.4/34 | Recording of dataset for individual patients |
| 2.4/35 | Network wide audits                      |
| 2.4/36 | List of agreed clinical trials           |

### Pathology

**Topic 3. Diagnostic services (pathology).**

**Standards:**
- 3.2/1 Pathology department conditional CPA Accreditation
- 3.2/2 Pathology department full CPA Accreditation
- 3.2/3 Referral guidelines for second opinion to histopathologist
- 3.2/4 Consistency of second opinion reporting audit
- 3.2/5 Minimum datasets – data items
- 3.2/6 Histopathology reporting proforma
- 3.2/7 Recording and storing data

### Non-surgical oncology

**Topic 4. Provision of non-surgical oncology to cancer units.**

**Standards:**
- 4/1 Non surgical oncology sessions

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| 4/2 | Non surgical oncology support |
| 4/3 | Oncologist sessions at the cancer centre |
| 4/4 | Oncologist attendance at meetings – network site specific, audit & educational |
| 4/5 | Oncologist sessions at the cancer unit |

### Radiotherapy

**Topic 5. Radiotherapy.**

**Standards:**

- 5/1 Head of radiotherapy service
- 5/2 Service level agreement – medical physics and radiotherapy
- 5/3 Defined lines of accountability
- 5/4 On call rota
- 5/5 Out of hours emergency procedures
- 5/6 Complement of radiotherapy department equipment
- 5/7 Complement of radiotherapy department facilities/equipment – brachytherapy with remote afterloading
- 5/8 Complement of radiotherapy department facilities/equipment – unsealed radioisotopes
- 5/9 Departmental equipment replacement programme
- 5/10 Number of consultant clinical oncologists
- 5/11 Staffing of equipment – RCR guidance & conformance to
- 5/12 Number of radiotherapy physicists – IPEM recommendations & conformance to
- 5/13 Written classification of radiotherapy treatment
- 5/14 Waiting time for treatment – urgent, within 48 hours
- 5/15 Waiting time for treatment – urgent, within 24 hours
- 5/16 Waiting time for treatment – palliative, within 2 weeks
- 5/17 Waiting time for treatment – palliative, within 48 hours
- 5/18 Waiting time for treatment – radical, within 4 weeks
- 5/19 Waiting time for treatment – radical, within 2 weeks
- 5/20 Overall treatment time
- 5/21 Documentation – access to & content
- 5/22 List and description of departmental techniques
- 5/23 Departmental group meetings to discuss treatment techniques
- 5/24 Frequency of group meetings
- 5/25 Frequency of access to CT scanner facilities
- 5/26 Written departmental procedure - Isodosimetry is calculated in treatment planning systems
- 5/27 Written departmental normalisation policy
- 5/28 Written departmental policy – doses to PTV and method of calculating them
- 5/29 Written departmental policy – CTV & the PTV
- 5/30 Written departmental policy – treatment planning parameters
- 5/31 List of personnel to check the accuracy of final treatment plans
### Measuring Quality in Cancer Services

| 5/32 | Written departmental policy – criteria to determine personnel on list |
| 5/33 | Systems for checking the monitor unit calculation |
| 5/34 | Authorisation of plans |
| 5/35 | Administration of radioactive isotopes by departmental staff |
| 5/36 | Checking of isotope activity prior to treatment |
| 5/37 | Imaging of catheters prior to treatment |
| 5/38 | Recording doses of intrauterine applications |
| 5/39 | Patient counselling and written information – patients receiving unsealed sources |
| 5/40 | Authorisation of prescriptions |
| 5/41 | Authorisation of palliative treatments |
| 5/42 | Content of treatment prescription sheets |
| 5/43 | Authorisation of treatment prescription sheets – treatments not according to departmental techniques |
| 5/44 | Labelling of treatment information/immobilisation aids with patient details |
| 5/45 | Departmental patient identification procedure |
| 5/46 | Password protected electronic treatment data |
| 5/47 | Required number of therapy radiographers in treatment unit during treatment |
| 5/48 | Agreed simulation or virtual simulation images prior to treatment |
| 5/49 | Portal imaging for radical treatments |
| 5/50 | Monitoring of patient progress according to local review policy |
| 5/51 | Availability of supplementary written information |
| 5/52 | Departmental quality management system |
| 5/53 | Internal quality audit programme |
| 5/54 | Implementation of internal audit programme & recommendations |
| 5/55 | External quality control programme |
| 5/56 | Comparison of quality control parameter with another radiotherapy department |
| 5/57 | Written departmental policy – indications for elective invivo-dosimetry |
| 5/58 | Written departmental policy of invivo-dosimetry – to confirm the accuracy of the treatment delivery process |
| 5/59 | Written procedure for incident reporting & review meetings |
| 5/60 | Departmental review against radiation protection legislation – recommendations and results available |
Table 35 (cont’d). Total compliance with cancer standards for each main topic (continued)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Corresponding topics/standards in the Manual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy</td>
<td>Topic 6. Chemotherapy.</td>
</tr>
<tr>
<td><strong>Standards:</strong></td>
<td></td>
</tr>
<tr>
<td>6/1</td>
<td>Head of service for chemotherapy</td>
</tr>
<tr>
<td>6/2</td>
<td>Administration of inpatient chemotherapy on wards</td>
</tr>
<tr>
<td>6/3</td>
<td>Administration of outpatient chemotherapy in outpatient areas</td>
</tr>
<tr>
<td>6/4</td>
<td>Use of out-patient chemotherapy areas</td>
</tr>
<tr>
<td>6/5</td>
<td>Policy documents &amp; equipment for management of emergencies in inpatient/outpatient chemotherapy areas</td>
</tr>
<tr>
<td>6/6</td>
<td>Storage and organisation of chemotherapy in inpatient/outpatient chemotherapy areas</td>
</tr>
<tr>
<td>6/7</td>
<td>Network drug &amp; therapeutics committee established</td>
</tr>
<tr>
<td>6/8</td>
<td>List of acceptable chemotherapy regimens for the network</td>
</tr>
<tr>
<td>6/9</td>
<td>Policy for use of regimens not on the agreed list</td>
</tr>
<tr>
<td>6/10</td>
<td>Administration of chemotherapy by qualified staff</td>
</tr>
<tr>
<td>6/11</td>
<td>In-house training course for the administration/prescription of chemotherapy</td>
</tr>
<tr>
<td>6/12</td>
<td>Training requirement – medical staff first starting to administer/prescribe chemotherapy</td>
</tr>
<tr>
<td>6/13</td>
<td>Training requirement – all medical staff in cancer related training posts</td>
</tr>
<tr>
<td>6/14</td>
<td>Written guidelines/protocols for the prevention and treatment of complications</td>
</tr>
<tr>
<td>6/15</td>
<td>Explicitness of guidelines/protocols – hospital specific, across hospitals</td>
</tr>
<tr>
<td>6/16</td>
<td>Content of guidelines/protocols</td>
</tr>
<tr>
<td>6/17</td>
<td>Explicitness of guidelines/protocols – solid tumours, haematological malignancy</td>
</tr>
<tr>
<td>6/18</td>
<td>Guidelines/protocols documented in a handbook/single document</td>
</tr>
<tr>
<td>6/19</td>
<td>Availability of guidelines/protocols for specific patient care</td>
</tr>
<tr>
<td>6/20</td>
<td>Guidelines/protocols for specific patient care common across the network</td>
</tr>
<tr>
<td>6/21</td>
<td>Guidelines/protocols agreed by the drug &amp; therapeutics committee or relevant body</td>
</tr>
<tr>
<td>6/22</td>
<td>Written guidelines/protocols for primary care practitioners – advice and management of symptoms relating to complications</td>
</tr>
<tr>
<td>6/23</td>
<td>Content of guidelines/protocols</td>
</tr>
<tr>
<td>6/24</td>
<td>Guidelines/protocols for primary care practitioners – regimen/drug specific antigens</td>
</tr>
<tr>
<td>6/25</td>
<td>Agreement of guidelines/protocols for primary care practitioners</td>
</tr>
<tr>
<td>6/26</td>
<td>Distribution of guidelines/protocols to primary care practitioners</td>
</tr>
<tr>
<td>6/27</td>
<td>Written guidelines for patients</td>
</tr>
<tr>
<td>6/28</td>
<td>Content of patient guidelines – symptom specific</td>
</tr>
<tr>
<td>6/29</td>
<td>Content of patient guidelines – other relevant information</td>
</tr>
</tbody>
</table>
### Measuring Quality in Cancer Services

<table>
<thead>
<tr>
<th>6/30</th>
<th>Agreement of patient guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/31</td>
<td>Availability of patient guidelines</td>
</tr>
<tr>
<td>6/32</td>
<td>Written policy for chemotherapy administered out of hours</td>
</tr>
<tr>
<td>6/33</td>
<td>Independent audit of pharmacy responsible for the preparation of chemotherapy</td>
</tr>
<tr>
<td>6/34</td>
<td>Designated pharmacist dealing with drug treatment specific to malignant disease</td>
</tr>
<tr>
<td>6/35</td>
<td>Role of the designated pharmacist</td>
</tr>
<tr>
<td>6/36</td>
<td>Membership of drug and therapeutics committee or relevant body</td>
</tr>
<tr>
<td>6/37</td>
<td>Network pharmacy group membership</td>
</tr>
<tr>
<td>6/38</td>
<td>Frequency of meeting of network pharmacy group</td>
</tr>
<tr>
<td>6/39</td>
<td>Designated pharmacist as member of group</td>
</tr>
<tr>
<td>6/40</td>
<td>Prescribing of first cycle of course of systemic chemotherapy</td>
</tr>
<tr>
<td>6/41</td>
<td>Pharmacy authorisation of cytotoxic chemotherapy prescriptions</td>
</tr>
<tr>
<td>6/42</td>
<td>Patient identification policy</td>
</tr>
<tr>
<td>6/43</td>
<td>Patient treatment record content - prior to the start of a course of chemotherapy</td>
</tr>
<tr>
<td>6/44</td>
<td>Patient treatment record content – prior to each cycle</td>
</tr>
<tr>
<td>6/45</td>
<td>Patient treatment record content – after the final cycle</td>
</tr>
</tbody>
</table>

### Palliative care

**Topic 7. Specialist palliative care services.**

#### Standards:

- **7/1** Palliative care Lead Clinician for each palliative care team
- **7/2** Palliative care Lead Clinician for the centre/unit
- **7/3** Membership of core palliative care MDT
- **7/4** Palliative care nurse specialist qualification – registered on ENB 285
- **7/5** Palliative care nurse specialist qualification – obtained the ENB 285
- **7/6** Palliative care nurse specialist qualification – working towards a palliative care related nursing degree
- **7/7** Membership of extended palliative care MDT
- **7/8** MDT meeting frequency
- **7/9** Operational policy meetings – frequency & purpose
- **7/10** 24 hour availability of team members
- **7/11** Information for the cancer services directory
### Table 35 (cont’d). Total compliance with cancer standards for each main topic (continued)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Corresponding topics/standards in the Manual</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td><strong>Topic 8.</strong> Education, training and continuous professional development.</td>
</tr>
<tr>
<td><strong>Standards:</strong></td>
<td></td>
</tr>
<tr>
<td>8/1</td>
<td>Training needs of MDT core members</td>
</tr>
<tr>
<td>8/2</td>
<td>Training needs of professionals in cancer care in centre/unit</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td><strong>Topic 9.</strong> Communication between primary, secondary and tertiary services.</td>
</tr>
<tr>
<td><strong>Standards:</strong></td>
<td></td>
</tr>
<tr>
<td>9/1</td>
<td>Cancer services directory</td>
</tr>
<tr>
<td>9/2</td>
<td>Content of cancer services directory</td>
</tr>
<tr>
<td>9/3</td>
<td>Distribution of directory</td>
</tr>
<tr>
<td><strong>Cancer units</strong></td>
<td><strong>Topic 10.</strong> Co-ordination and organisation of cancer units (centre).</td>
</tr>
<tr>
<td><strong>Standards for cancer units:</strong></td>
<td></td>
</tr>
<tr>
<td>10.2/1</td>
<td>Referral guidelines for cancer sites not covered by the unit MDT</td>
</tr>
<tr>
<td>10.2/2</td>
<td>Cancer services Lead Clinician for the cancer unit</td>
</tr>
<tr>
<td>10.2/3</td>
<td>Written job description for the lead nurse</td>
</tr>
<tr>
<td>10.2/4</td>
<td>Specification of time available and administrative support for the Lead Clinician</td>
</tr>
<tr>
<td>10.2/5</td>
<td>Regular review of time/support available to Lead Clinician</td>
</tr>
<tr>
<td>10.2/6</td>
<td>Lead clinician member of the cancer unit group</td>
</tr>
<tr>
<td>10.2/7</td>
<td>Cancer services lead nurse for the cancer unit</td>
</tr>
<tr>
<td>10.2/8</td>
<td>Written job description for the lead nurse</td>
</tr>
<tr>
<td>10.2/9</td>
<td>Cancer services lead manager for the cancer unit</td>
</tr>
<tr>
<td>10.2/10</td>
<td>Written job description for the lead manager</td>
</tr>
<tr>
<td>10.2/11</td>
<td>Named cancer unit group with membership</td>
</tr>
<tr>
<td>10.2/12</td>
<td>Terms of reference for the group</td>
</tr>
<tr>
<td>10.2/13</td>
<td>Primary care representation on the group</td>
</tr>
<tr>
<td>10.2/14</td>
<td>Named cancer site leads for each cancer site</td>
</tr>
<tr>
<td>10.2/15</td>
<td>Reporting requirements to the cancer registry</td>
</tr>
<tr>
<td><strong>Standards for cancer centres:</strong></td>
<td></td>
</tr>
<tr>
<td>10.3/1</td>
<td>List of tumour sites not being treated by network</td>
</tr>
<tr>
<td>10.3/2</td>
<td>Referral guidelines for sites not covered on the list</td>
</tr>
<tr>
<td>10.3/3</td>
<td>Cancer services Lead Clinician for the centre</td>
</tr>
<tr>
<td>10.3/4</td>
<td>Written job description for the Lead Clinician</td>
</tr>
<tr>
<td>10.3/5</td>
<td>Specification of time available and administrative support for the Lead Clinician</td>
</tr>
</tbody>
</table>
### Measuring Quality in Cancer Services

<table>
<thead>
<tr>
<th>Standard</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.3/6</td>
<td>Regular review of time/support available to Lead Clinician</td>
</tr>
<tr>
<td>10.3/7*</td>
<td>Lead clinician member of the cancer centre group</td>
</tr>
<tr>
<td>10.3/8</td>
<td>Cancer services lead nurse for the cancer centre</td>
</tr>
<tr>
<td>10.3/9</td>
<td>Written job description for the lead nurse</td>
</tr>
<tr>
<td>10.3/10</td>
<td>Cancer services lead manager for the cancer centre</td>
</tr>
<tr>
<td>10.3/11</td>
<td>Written job description for the lead manager</td>
</tr>
<tr>
<td>10.3/12</td>
<td>Named cancer centre group with membership</td>
</tr>
<tr>
<td>10.3/13</td>
<td>Terms of reference for the group</td>
</tr>
<tr>
<td>10.3/14*</td>
<td>Lead clinician member of the cancer centre group</td>
</tr>
<tr>
<td>10.3/15</td>
<td>Primary care representation on the group</td>
</tr>
<tr>
<td>10.3/16</td>
<td>Named cancer site leads for each cancer site</td>
</tr>
<tr>
<td>10.3/17</td>
<td>Reporting requirements to the cancer registry</td>
</tr>
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</table>

*Standards 10.3/7 and 10.3/14 are repeating (identical) in the Manual*
### Measuring Quality in Cancer Services

#### Table 36 Compliance with MDT-related standards:

<table>
<thead>
<tr>
<th>Breast cancer</th>
<th>Corresponding sub-topics in the manual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variables</td>
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</tr>
<tr>
<td>MDT structure</td>
<td>MDT structure. Number of compliant standards: standards 2.2/1 - 2.2/8, 2.2/26</td>
</tr>
<tr>
<td>MDT meetings</td>
<td>MDT meetings. Number of compliant standards: standards 2.2/9 - 2.2/12</td>
</tr>
<tr>
<td>Operational policies</td>
<td>Operational policies. Number of compliant standards: standards 2.2/23 - 2.2/25</td>
</tr>
<tr>
<td>Patient-centred care</td>
<td>Functions of the team providing patient centred care. Number of compliant standards: standards 2.2/27 - 2.2/31</td>
</tr>
<tr>
<td>Treatment</td>
<td>Treatment planning decision. Number of compliant standards: standard 2.2/32</td>
</tr>
<tr>
<td>Clinical guidelines</td>
<td>Clinical guidelines. Number of compliant standards: standard 2.2/33</td>
</tr>
<tr>
<td>Referral guidelines</td>
<td>Referral guidelines. Number of compliant standards: standard 2.2/34</td>
</tr>
<tr>
<td>Data collection</td>
<td>Data collection. Number of compliant standards: standards 2.2/35 - 2.2/36</td>
</tr>
<tr>
<td>Network audit</td>
<td>Network audit. Number of compliant standards: standard 2.2/37</td>
</tr>
<tr>
<td>Clinical trials</td>
<td>Participation in approved clinical trials. Number of compliant standards: standard 2.2/38</td>
</tr>
<tr>
<td>MDT workload</td>
<td>MDT workload. Number of compliant standards: standard 2.2/39</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Colorectal cancer</th>
<th>Corresponding sub-topics in the manual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variables</td>
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</tr>
<tr>
<td>MDT structure</td>
<td>MDT structure. Number of compliant standards: standards 2.3/1 - 2.3/8, 2.3/23</td>
</tr>
<tr>
<td>MDT meetings</td>
<td>MDT meetings. Number of compliant standards: standards 2.3/9 - 2.3/12</td>
</tr>
<tr>
<td>Operational policies</td>
<td>Operational policies. Number of compliant standards: standards 2.3/13 - 2.3/22</td>
</tr>
<tr>
<td>Patient-centred care</td>
<td>Functions of the team providing patient centred care. Number of compliant standards: standards 2.3/24 - 2.3/28</td>
</tr>
<tr>
<td>Treatment</td>
<td>Treatment planning decision. Number of compliant standards: standard 2.3/29</td>
</tr>
<tr>
<td>Clinical guidelines</td>
<td>Clinical guidelines. Number of compliant standards: standard 2.3/30</td>
</tr>
<tr>
<td>Referral guidelines</td>
<td>Referral guidelines. Number of compliant standards: standard 2.3/31</td>
</tr>
<tr>
<td>Data collection</td>
<td>Data collection. Number of compliant standards: standards 2.3/32 - 2.3/33</td>
</tr>
<tr>
<td>Network audit</td>
<td>Network audit. Number of compliant standards: standard 2.3/34</td>
</tr>
<tr>
<td>Clinical trials</td>
<td>Participation in approved clinical trials. Number of compliant standards: standard 2.3/35</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lung cancer</th>
<th>Corresponding sub-topics in the manual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variables</td>
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</tr>
<tr>
<td>MDT structure</td>
<td>MDT structure. Number of compliant standards: standards 2.4/1 - 2.4/8, 2.4/24</td>
</tr>
</tbody>
</table>
## Measuring Quality in Cancer Services

<table>
<thead>
<tr>
<th>MDT meetings</th>
<th>MDT meetings. Number of compliant standards: standards 2.4/9 - 2.4/13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Operational policies</td>
<td>Operational policies. Number of compliant standards: standards 2.4/14 - 2.4/23</td>
</tr>
<tr>
<td>Patient-centred care</td>
<td>Functions of the team providing patient centred care. Number of compliant standards: standards 2.4/25 - 2.4/29</td>
</tr>
<tr>
<td>Treatment</td>
<td>Treatment planning decision. Number of compliant standards: standard 2.4/30</td>
</tr>
<tr>
<td>Clinical guidelines</td>
<td>Clinical guidelines. Number of compliant standards: standard 2.4/31</td>
</tr>
<tr>
<td>Referral guidelines</td>
<td>Referral guidelines. Number of compliant standards: standard 2.4/32</td>
</tr>
<tr>
<td>Data collection</td>
<td>Data collection. Number of compliant standards: standards 2.4/33 - 2.4/34</td>
</tr>
<tr>
<td>Network audit</td>
<td>Network audit. Number of compliant standards: standard 2.4/35</td>
</tr>
<tr>
<td>Clinical trials</td>
<td>Participation in approved clinical trials. Number of compliant standards: standard 2.4/36</td>
</tr>
</tbody>
</table>
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**Table 37 Compliance with chemotherapy-related standards**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Corresponding sub-topics in the manual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Named head of service</td>
<td>Named head of service for chemotherapy. Number of compliant standards: standard 6/1</td>
</tr>
<tr>
<td>Facilities</td>
<td>Facilities. Number of compliant standards: standards 6/2 - 6/6</td>
</tr>
<tr>
<td>Policy</td>
<td>Policy relating to chemotherapy regimens. Number of compliant standards: standards 6/7 - 6/9</td>
</tr>
<tr>
<td>Training</td>
<td>Training in administration of chemotherapy. Number of compliant standards: standards 6/10 - 6/13</td>
</tr>
<tr>
<td>Out of hours administration</td>
<td>Out of hours administration of chemotherapy. Number of compliant standards: standards 6/32</td>
</tr>
<tr>
<td>Pharmaceutical aspects</td>
<td>Pharmaceutical aspects of the chemotherapy service. Number of compliant standards: standards 6/33 - 6/39</td>
</tr>
<tr>
<td>Prescription/documentation</td>
<td>Prescription and documentation of chemotherapy. Number of compliant standards: standards 6/40 - 6/45</td>
</tr>
</tbody>
</table>
Appendix C  Variables included in the National Cancer Minimum Dataset

Table 38  National Cancer Minimum Dataset list of variables

<table>
<thead>
<tr>
<th>Core</th>
<th>Optional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Record type (new registration, amendment, deletion)</td>
<td>Country of birth</td>
</tr>
<tr>
<td>Identity number (unique)</td>
<td>Ethnic origin*</td>
</tr>
<tr>
<td>Patient’s name</td>
<td>Patient’s occupation</td>
</tr>
<tr>
<td>Patient’s previous surname</td>
<td>Patient’s employment status</td>
</tr>
<tr>
<td>Patient’s address</td>
<td>Patient’s industry</td>
</tr>
<tr>
<td>Post code</td>
<td>Head of household’s occupation</td>
</tr>
<tr>
<td>Sex</td>
<td>Head of household’s employment status</td>
</tr>
<tr>
<td>NHS number</td>
<td>Head of household’s industry</td>
</tr>
<tr>
<td>Marital status</td>
<td>Registration from screening*</td>
</tr>
<tr>
<td>Date of birth</td>
<td></td>
</tr>
<tr>
<td>Date of death (if dead)</td>
<td></td>
</tr>
<tr>
<td>Incidence date</td>
<td></td>
</tr>
<tr>
<td>Site of primary growth</td>
<td></td>
</tr>
<tr>
<td>Type of growth</td>
<td></td>
</tr>
<tr>
<td>Behaviour of growth</td>
<td></td>
</tr>
<tr>
<td>Multiple tumour indicator</td>
<td></td>
</tr>
<tr>
<td>Basis of diagnosis*</td>
<td></td>
</tr>
<tr>
<td>Death certificate only indicator*</td>
<td></td>
</tr>
<tr>
<td>Side (laterality)*</td>
<td></td>
</tr>
<tr>
<td>Treatment(s) (indicators)*</td>
<td></td>
</tr>
<tr>
<td>Stage†</td>
<td></td>
</tr>
<tr>
<td>Grade†</td>
<td></td>
</tr>
</tbody>
</table>

* From 1993 only
† Some sites only (breast and cervix)

(There is no questionnaire for this data base as all data are collected electronically)
Appendix D  Pilot interview questions

Written by Dawn Wilkinson©, 2005

1.0 General

1. Can you briefly describe your role in the Cancer Network and a little bit about what you do?
2. How does the Network currently monitor and assess quality in their cancer service?
3. What to you constitutes good valid/reliable/useful measures of quality?

2.0 Theme A – Receptivity to information/Awareness of data

2.0 Does the network have any explicit or formal strategies for disseminating and using routinely available aggregate information?

Probes

E.g. as opposed to Trust specific information strategies.

2.0 What routinely available aggregate datasets about cancer are you aware of?

2.1 Which of these are you aware of (provide the list)

- Cancer registry data
- Cancer standards database
- Audit commission acute hospital portfolio
- Cancer waiting times statistics
- Hospital Episodes Statistics
- Minimum dataset for palliative care
- Patient survey data

2.4 Which of these do you use most?

Which parts of these datasets are most useful to you?

Probes

Which measures or indicators in these databases do you use and find useful? (e.g. survival etc) i.e. What do you need aggregate data for/how do you use it?

Which indicators or measures are not useful? (e.g. dates)

2.6 Does the Network have any data analysts?

Probes
Measuring Quality in Cancer Services

i.e. people whose role it is to collate and examine data provided to the Network

3.0 Theme B: Roles and responsibilities; reception and dissemination of data
3.1 Who, in the Network, originally gets given routinely available cancer data?
3.2 Whose responsibility is it to disseminate this type of data?

Probe

Individual or group, e.g. a cross Trust information strategy group.
3.3 Who is the routinely available data disseminated to?
3.4 What are the barriers to the dissemination of this data?

Probe

Problems communicating across Trusts, disciplines, roles, IT issues?
3.5 What factors do or could facilitate the dissemination of this data?
3.0 Theme B: Roles and responsibilities; using and acting upon the data
3.6 Which more reflects your engagement with aggregate data: does it come to you and you have to act on it, or, do you seek out aggregate data to enhance your work?

Probes

i.e. what is your involvement with routinely available aggregate data?
3.7 Where would you go to find this kind of data?
3.8 What are the barriers to using or acting upon routinely available aggregate data?

Probes

Problems with acceptance of the data/info, defensiveness, difficulties getting all parts of the Network to work together.
3.9 What does/could facilitate the use of routinely available cancer data?
3.10 Has routinely available aggregate data been broken down to meet the needs of specific MDTs – if so how?
3.11 Is routinely available aggregate data used for performance management purposes – if so what/how?
3.12 Is routinely available aggregate data used for benchmarking and comparisons with other Networks?
3.13 Do you see any issues or problems arising from the use of comparative data available across all the Networks?
Measuring Quality in Cancer Services

Probe

Anonymity of the Trusts and Networks for instance

4.0 Theme C: Impacts and outcomes

4.1 Can you describe the main big decisions you have to take for the Network in terms of improving Cancer Services.

Probe

So that we can get an idea of the types of aggregate information that might be useful to help inform policy and implement service changes:

- Financial
- Reconfiguration.

4.2 Can you think of any big decisions within the Network where routinely available aggregate data has played an important role – if so what?

4.3 In terms of measuring service impacts and outcomes what do you think are the information or data needs of the Cancer Network? (i.e. in terms of large scale population level data)

Probe

Do you have enough/the right information about processes, costs, activities (e.g. numbers of patients being treated), referral patterns etc.

4.4 If there were a set of indicators to help you make decisions for monitoring or improving cancer services what would they be?

(i.e. what kind of information would you want to get from aggregate data if you could have a dataset that told you anything you needed to know?)

4.5 How might this information help to monitor or improve outcomes?

4.6 How would you like to see routinely available information presented – i.e. to make it clearer, more useable, more readable?

If time....

Extra question: How has the CSC contribution affected the Network?

5.0 Specific questions in relation to the Cancer Patient Survey (2002) data

5.1 Are you aware of the findings from the National Survey of NHS Cancer Patients produced in 1999/2000 and published in 2002 (local [i.e. Trust level], Network or national level?)
5.2 Do you think that the data collected by the survey was too large or too small an amount – do you have any other comments about the survey data?

5.3 What findings from the study, if any, were used/acted upon?

5.4 What action was taken?

5.5 What impact did this action have?

5.6 Was there any information that identified problem areas, not used/acted upon – if not why not?

5.7 Are cancer patient/user group perceptions assessed in any other way (i.e. Are any other regular surveys carried out by service providers)?

5.8 What are your perspectives of what constitutes useful performance outcome measures particularly from the patient/users point of view?

I ask the following questions to the patient/user representative.

5.9 Are you aware of the findings from the National Survey of NHS Cancer Patients produced in 1999/2000 and published in 2002 (local [i.e. Trust level], Network or national level?)

5.10 What do you think about the survey – do you think the questions it asked were useful? Was it too short or too long? Do you have any general comments about the patient survey?

5.11 Were the findings from the study fed back to patient/user representatives?

5.12 Do you know what action was taken in the Network to act upon the findings from the study?

5.13 Do you know what impact this action had/is having?

5.14 Do you think that important findings from the study were not acted upon?

5.15 Are cancer patient/carers and user group perceptions assessed in any other way (i.e. Are any other regular surveys carried out by service providers to assess patient satisfaction, quality of life, important outcomes to patients?)

5.16 From your point of view what performance outcomes are important to patients and carers?

5.17 If another patient survey was conducted, what kinds of things would you like it to ask about?

6.0 Patient/user group involvement in comparative data
**Measuring Quality in Cancer Services**

6.1 Is comparative data (e.g. waiting times, survival, incidence, patient satisfaction etc for the Network and the Trusts) routinely fed back to user group?

6.2 If so, what kind of information is fed back to you and how is it fed back (e.g. are you given reports on waiting times – do you get given these reports at specific meetings or do you have to ask for them?)

6.3 Do you get to see how the Network, or Trusts within the Network, are performing in comparison to other Networks and Trusts around the country – if so, can you give any examples; if not – do you think patient/user representatives should be receiving this kind of information?

6.4 Are user groups involved in the dissemination of this kind of comparative data?

6.5 Are user groups involved in any decision making or action that results from this kind of comparative data?

6.6 Do you feel that users could be more involved in the decision making and action planning from this kind of information/data – if so how?

6.7 What types of waiting time outcomes (e.g. waits for initial appointments, waits once at the appointment, waits for radiography etc) are most important to patients and carers – could you explain why?

6.8 Do patients choose which hospitals/treatments to seek on the basis of comparative data (e.g. comparative survival rates, quality of life reports, waiting times – comparing one Network against another Network?)

6.9 Would patients/carers be interested in and able to use data about overall performance, comparative measures of quality, comparative measures of survival and waiting times (for example) regarding cancer services and Cancer Networks?

6.10 How would this data be best provided to patients and users?

6.11 Does the Cancer Network have a role to play in delivering this kind of data and information?
Appendix E  MQiCS Cancer Networks telephone questionnaire

Written by Dawn Wilkinson ©
Version Date: June 2005

Telephone survey baseline questions for the network management team manager

Survey date and time: ……./……/2005 …….am/pm

On behalf of Professor Mike Richards and the Cancer Action Team, we are undertaking a survey investigating the use and perception of routinely available data in Cancer Networks. The survey is being conducted as part of the SDO funded study ‘Measures of Quality for the Improvement of Cancer Services’. The study is supported by the Cancer Services Collaborative. A summary of the study is enclosed for your information.

You have been contacted by a member of the research team to arrange a mutually convenient date and time to complete the survey over the telephone. The agreed date and time are at the top of this sheet. To assist the survey process, the questionnaire has been enclosed for your information. Please have the questionnaire in front of you to read during the telephone survey.

If you have any questions, points or issues you wish to raise about the study, please feel free to contact us. The names and contact numbers of the Principal Investigator, Study Co-ordinator and Social Scientist can be found on the Study Summary.

We want to know your views on routinely available data at Trust and Network level. By routinely available, we mean data that are collected locally and then aggregated nationally, that allow you to compare the performance of your Trusts, and your Network, on measures of structure, process of care, and outcomes. We are NOT inquiring about your local data collection.
Measuring Quality in Cancer Services

We are interested in your views on the seven datasets listed below. You may or may not recognise these datasets.

1. Cancer Waiting Times
2. Cancer Registry
3. Hospital Episodes Statistics (HES)
5. Audit Commission Acute Hospital Portfolio
6. Minimum dataset for Palliative Care
7. National Patient Survey data

The first questions ask about two specific datasets: Cancer Waiting Times and Cancer Registry.

Q1. a) Are you aware of the Cancer Waiting Times dataset?
   Yes □ No □ [If you are not aware of this dataset then move on to Q5].

   b) Do you use the Cancer Waiting Times dataset?
   Regularly □ [go to Q3] Sometimes □ [go to Q3] Rarely □ [go to Q2] Never □ [go to Q2]

Q2. If you use this dataset rarely or never please indicate the main reason/s why [indicate all that apply by saying YES after the answer is read out – say NO if the answer does not apply]

   a) Do not know where to find the dataset □
   b) The dataset is difficult to access □
   c) The dataset is not user-friendly □
   d) The dataset is not relevant to my role □
   e) The quality of the data is poor □
   f) The data are out of date □
   g) Other – please specify
Measuring Quality in Cancer Services

[Now go to Q5]

Q3  Please indicate how you use this dataset [indicate all that apply by saying YES after the answer is read out – say NO if the answer does not apply]

a  To monitor the level, quality, or timeliness of data collection/capture  □

b  To assess or demonstrate progress towards specific local or national goals, targets, guidelines or initiatives (e.g. Cancer Plan, Improving Outcomes Guidance, Peer Review)  □

c  To benchmark or monitor performance in comparison to other Networks  □

d  To identify areas for service improvement initiatives  □

e  To assess population needs  □

f  To plan or allocate levels of staffing and/or other resources  □

g  To direct or inform the use of funding (i.e. informed investment)  □

h  To keep interested parties informed and updated (e.g. Board, SHA, Users)  □

i  To identify impacts of service improvement initiatives  □

j  Other, please specify
Measuring Quality in Cancer Services

Q4 How do you perceive the information in this dataset in terms of the following descriptions? [Please indicate on a scale of -3 to +3 for each description]

<table>
<thead>
<tr>
<th>Description</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficult to access</td>
<td></td>
</tr>
<tr>
<td>Unreliable and not robust</td>
<td></td>
</tr>
<tr>
<td>Distrusted by clinicians</td>
<td></td>
</tr>
<tr>
<td>Out of date</td>
<td></td>
</tr>
<tr>
<td>Duplication of other datasets</td>
<td></td>
</tr>
<tr>
<td>Meaningless measures</td>
<td></td>
</tr>
<tr>
<td>Difficult to interpret</td>
<td></td>
</tr>
<tr>
<td>Useless for monitoring performance</td>
<td></td>
</tr>
<tr>
<td>Unhelpful in my role</td>
<td></td>
</tr>
<tr>
<td>Easy to access</td>
<td>+3</td>
</tr>
<tr>
<td>Reliable and robust</td>
<td>+3</td>
</tr>
<tr>
<td>Trusted by clinicians</td>
<td>+3</td>
</tr>
<tr>
<td>Up to date</td>
<td>+3</td>
</tr>
<tr>
<td>Unique data</td>
<td>+3</td>
</tr>
<tr>
<td>Meaningful measures</td>
<td>+3</td>
</tr>
<tr>
<td>Easy to interpret</td>
<td>+3</td>
</tr>
<tr>
<td>Useful for monitoring performance</td>
<td>+3</td>
</tr>
<tr>
<td>Helpful in my role</td>
<td>+3</td>
</tr>
</tbody>
</table>

Q5  a) Are you aware of the Cancer Registry data?

Yes ☐ No ☐ [If you are not aware of this dataset then move on to Q9].

b) Do you use the Cancer Registry data?

Regularly ☐ Sometimes ☐ Rarely ☐ [go to Q6] Never ☐ [go to Q6]
Measuring Quality in Cancer Services

Q6 If you use this dataset rarely or never please indicate the main reason/s why [indicate all that apply by saying YES after the answer is read out – say NO if the answer does not apply]

a. Do not know where to find the dataset  

b. The dataset is difficult to access  

c. The dataset is not user-friendly  

d. The dataset is not relevant to my role  

e. The quality of the data is poor  

f. The data are out of date  

g. Other – please specify

[Now go to Q9]

Q7 Please indicate how you use this dataset [indicate all that apply by saying yes after the answer is read out – say no if the answer does not apply]

a. To monitor the level, quality, or timeliness of data collection/capture  

b. To assess or demonstrate progress towards specific local or national goals, targets, guidelines or initiatives (e.g. Cancer Plan, Improving Outcomes Guidance, Peer Review)  

c. To benchmark or monitor performance in comparison to other Networks  

d. To identify areas for service improvement initiatives  

e. To assess population needs  

f. To plan and or allocate levels of staffing and/or other resources  

g. To direct or inform the use of funding (i.e. informed investment)  

h. To keep interested parties informed and updated (e.g. Board, SHA, Users)  

i. To identify impacts of service improvement initiatives  

j. Other, please specify
**Measuring Quality in Cancer Services**

**Q8. How do you perceive the information in this dataset?** [Please indicate on a scale of -3 to +3 for each description]

<table>
<thead>
<tr>
<th>Description</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficult to access</td>
<td></td>
</tr>
<tr>
<td>Unreliable/not robust</td>
<td></td>
</tr>
<tr>
<td>Distrusted by clinicians</td>
<td></td>
</tr>
<tr>
<td>Out of date</td>
<td></td>
</tr>
<tr>
<td>Duplication of other datasets</td>
<td></td>
</tr>
<tr>
<td>Meaningless measures</td>
<td></td>
</tr>
<tr>
<td>Difficult to interpret</td>
<td></td>
</tr>
<tr>
<td>Useless for monitoring performance</td>
<td></td>
</tr>
<tr>
<td>Unhelpful in my role</td>
<td></td>
</tr>
</tbody>
</table>

Easy to access

Reliable/robust

Trusted by clinicians

Up to date

Unique data

Meaningful measures

Easy to interpret

Useful for monitoring performance

Helpful in my role

**Q9** We are also interested in whether you use other routinely available datasets. Please could you indicate whether you are aware of and if you use the following.

[as each dataset is read out, please say if you are aware of it, and if you use it]:

<table>
<thead>
<tr>
<th>Dataset</th>
<th>Aware of</th>
<th>Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hospital Episodes Statistics (HES)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Audit Commission Acute Hospital Portfolio</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Minimum dataset for Palliative Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. National Patient Survey data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Are there any others that you use? Please specify</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Q10. a) Do you currently use any of these datasets to monitor performance of the Cancer Network or measure quality of service?
   Yes ☐ [go to b] No ☐ [go to Q11]

b) If so, which ones [please specify the number/s of the dataset listed above]

Q11. Is routinely available data currently provided in any form to user-groups?
   Yes ☐ [go to b] No ☐ [go to Q12] Don’t know ☐ [go to Q13]

b) If so, which datasets are used to provide data? [Please specify from the list below by reading out the number/s of the relevant dataset/s]

1. Cancer Waiting Times
2. Cancer Registry
3. Hospital Episodes Statistics (HES)
5. Audit Commission Acute Hospital Portfolio
6. Minimum dataset for Palliative Care
7. National Patient Survey data
8. Other, please specify

[now go to Q13]

Q12. If no routinely available data is provided to user-groups, please indicate the reason/s why [indicate all that apply by saying YES after the answer is read out – say NO if the answer does not apply]

   a. The datasets are not relevant to user-groups ☐
   b. It is not summarised regularly ☐
   c. They would not be able to use the information ☐
   d. There is no means/forum to present this information to users or user-groups ☐
   e. Don’t know ☐
   f. Other, please specify ☐

Q13. Thinking about the Cancer Network generally, how strongly do you agree or disagree with the following statements?
**Measuring Quality in Cancer Services**

a) The routinely available datasets that currently exist enable me to assess the structure of this Network

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>N/A</th>
</tr>
</thead>
</table>

b) The routinely available datasets that currently exist enable me to assess the process of care in this Network

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>N/A</th>
</tr>
</thead>
</table>

c) The routinely available datasets that currently exist enable me to assess service outcomes

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>N/A</th>
</tr>
</thead>
</table>

d) Overall, the routinely available datasets that currently exist enable me to assess the quality of services provided by this Cancer Network

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>N/A</th>
</tr>
</thead>
</table>

Q14. In the last year, have you used or are you currently using routinely available data to inform Network Service Improvement Action/Work plans?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>N/A</th>
</tr>
</thead>
</table>

   [go to Q15]  [go to Q17]  [go to Q17]  [go to Q17]

**Q15. If so, which datasets have you used for this purpose? [Please specify from the list below by reading out the number/s of the relevant dataset/s]**

1. Cancer Waiting Times
2. Cancer Registry
3. Hospital Episodes Statistics (HES)
5. Audit Commission Acute Hospital Portfolio
6. Minimum dataset for Palliative Care
7. National Patient Survey data
8. Other, please specify
Measuring Quality in Cancer Services

Q16. In comparison to other factors (e.g. locally collected data, anecdotal information, expertise and specialist knowledge, internal politics, existing resources) how influential is/was the routinely available data in informing the Network Service Improvement Action/Work plans? [Please indicate on a scale of -3 (not at all influential) to +3 (very influential)]

-3 -2 -1 0 +1 +2 +3

Not at all influential [ ] [ ] [ ] [ ] [ ] [ ] Very influential [ ] [ ] [ ] [ ] [ ] [ ]

Q17. Have you used or are you currently using routinely available data to inform Improving Outcomes Guidance Action Plans?

Yes [ ] No [ ] Don’t know [ ] N/A [ ]

Q18. If so, which datasets have you used for this purpose? [Please specify from the list below by reading out the number/s of the relevant dataset/s]

1. Cancer Waiting Times [ ]
2. Cancer Registry [ ]
3. Hospital Episodes Statistics (HES) [ ]
5. Audit Commission Acute Hospital Portfolio [ ]
6. Minimum dataset for Palliative Care [ ]
7. National Patient Survey data [ ]
8. Other, please specify [ ]

Q19. In comparison to other factors (e.g. locally collected data, anecdotal information, expertise and specialist knowledge, internal politics, existing resources, local needs) how influential is/was the routinely available data in informing the Improving Outcomes Guidance Action Plans? [Please indicate on a scale of -3 (not at all influential) to +3 (very influential)]

-3 -2 -1 0 +1 +2 +3

Not at all influential [ ] [ ] [ ] [ ] [ ] [ ] Very influential [ ] [ ] [ ] [ ] [ ] [ ]

Q20. Has your Cancer Network started the 2004-2007 Peer Review Process?

Yes [ ] No [ ] Don’t know [ ]

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**Measuring Quality in Cancer Services**

Q21 Have you used or are you currently using data from the previous round of Peer Review (2000/2001) to inform the 2004-2007 Peer Review Process?

Yes □ No □ Don’t know □

Q22 How useful is it, or would it be, to be able to see and use comparative data from the last round of Peer Review (2000/2001)?

[Please indicate on a scale of -3 (useless) to +3 (useful)]

Useless

-3 -2 -1 0 +1 +2 +3

Useful

Q23. Other than improved data quality and better resources to input and analyse data, what are the current information/data needs of the Cancer Network in regards to measuring quality of service? [Please indicate the THREE most important needs by saying YES after the item is read out – say NO if it is not important]

- a Better/more equitable access to the datasets
- b Unified system/s that ‘talk to each other’
- c More knowledge of what is available and how to use it to monitor performance
- d More context to the data (e.g. how it has been collected, how it should be interpreted/evaluated, no.s of patients/cases used to produce the data etc)
- e More or better managerial data
- f More or better clinical data
- g Improved ability to analyse meaningful links between indicators (i.e. relationships between measures of structure, process and outcome)
- h Easier to interrogate the data (i.e. more user-friendly)
- i The ability to analyse or compare data at different levels/by different categories (National, population, geographical area, network, SHA, PCT, Trust, hospital, MDT, GP practice, clinician, patient, disease, stage of disease, treatment, etc.)
- j Other, please specify.
Measuring Quality in Cancer Services

Q24  Imagine that data from the seven following datasets
1  Cancer Waiting Times
2  Cancer Registry
3  Hospital Episodes Statistics (HES)
4  Cancer Standards – Peer Review 2000/2001
5  Audit Commission Acute Hospital Portfolio
6  Minimum dataset for Palliative Care
7  National Patient Survey data

are brought together to enable you to cross reference and compare different measures of service structure, process of care, and outcome. Using this combined dataset, each Network would be able to see the performance of individual Trusts and the overall performance of the Network. In addition the performance in one Network could be compared with the performance of any other across the country and the national average.

On a scale of -3 to +3 do you think this would be:

<table>
<thead>
<tr>
<th>-3</th>
<th>-2</th>
<th>-1</th>
<th>0</th>
<th>+1</th>
<th>+2</th>
<th>+3</th>
</tr>
</thead>
<tbody>
<tr>
<td>A bad idea</td>
<td>A good idea</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Useless for monitoring performance by Network  Useful for monitoring performance by Network

Distrusted by clinicians  Trusted by clinicians

Uninformative  Informative

Resented  Welcomed

Never used  Regularly used

Useless for monitoring performance by Trust  Useful for monitoring performance by Trust

Unhelpful in my role  Helpful in my role
Measuring Quality in Cancer Services

If possible please list three advantages/benefits of such a dataset
1
2
3

If possible please list three disadvantages/problems of such a dataset
1
2
3

Male/Female
Which Cancer Network do you work for?
What is your role title in the Cancer Network?
How long have you worked in this or another Cancer Network?
How long have you been in your current post?

Many thanks for taking part in this survey.
Appendix F  Telephone survey: baseline questions for the network management team lead clinician

Survey date and time: ......../....../2005  ........am/pm

On behalf of Professor Mike Richards and the Cancer Action Team, we are undertaking a survey investigating the use and perception of routinely available data in Cancer Networks. The survey is being conducted as part of the SDO funded study 'Measures of Quality for the Improvement of Cancer Services'. The study is supported by the Cancer Services Collaborative. A summary of the study is enclosed for your information.

You have been contacted by a member of the research team to arrange a mutually convenient date and time to complete the survey over the telephone. The agreed date and time are at the top of this sheet. To assist the survey process, the questionnaire has been enclosed for your information. Please have the questionnaire in front of you to read during the telephone survey.

If you have any questions, points or issues you wish to raise about the study, please feel free to contact us. The names and contact numbers of the Principal Investigator, Study Co-ordinator and Social Scientist can be found on the Study Summary.

We want to know your views on routinely available data at Trust and Network level. By routinely available, we mean data that are collected locally and then aggregated nationally, that allow you to compare the performance of your Trusts, and your Network, on measures of structure, process of care, and outcomes. We are NOT inquiring about your local data collection.

We are interested in your views on the seven datasets listed below. You may or may not recognise these datasets.

1  Cancer Waiting Times  
2  Cancer Registry  
3  Hospital Episodes Statistics (HES)  
4  Cancer Standards – Peer Review 2000/2001  
5  Audit Commission Acute Hospital Portfolio  
6  Minimum dataset for Palliative Care  
7  National Patient Survey data
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The first questions ask about two specific datasets: Cancer Waiting Times and Cancer Registry.

Q1. a) Are you aware of the Cancer Waiting Times dataset?

Yes ☐ No ☐ [If you are not aware of this dataset then move on to Q5].

b) Do you use the Cancer Waiting Times dataset?

Regularly ☐ [go to Q3] Sometimes ☐ [go to Q3] Rarely ☐ [go to Q2] Never ☐ [go to Q2]

Q2. If you use this dataset rarely or never please indicate the main reason/s why [indicate all that apply by saying YES after the answer is read out – say NO if the answer does not apply]

a) Do not know where to find the dataset ☐
b) The dataset is difficult to access ☐
c) The dataset is not user-friendly ☐
d) The dataset is not relevant to my role ☐
e) The quality of the data is poor ☐
f) The data are out of date ☐
g) Other – please specify [Now go to Q5]

Q3. Please indicate how you use this dataset [indicate all that apply by saying YES after the answer is read out – say NO if the answer does not apply]

a) To monitor the level, quality, or timeliness of data collection/capture ☐
b) To assess or demonstrate progress towards specific local or national goals, targets, guidelines or initiatives (e.g. Cancer Plan, Improving Outcomes Guidance, Peer Review) ☐
c) To benchmark or monitor performance in comparison to other Networks ☐
d) To identify areas for service improvement initiatives ☐
e) To assess population needs ☐
f) To plan or allocate levels of staffing and/or other resources ☐
g) To direct or inform the use of funding (i.e. informed investment) ☐
h) To keep interested parties informed and updated (e.g. Board, SHA, Users) ☐
i) To identify impacts of service improvement initiatives ☐

j) Other - please specify
Measuring Quality in Cancer Services

Q4 How do you perceive the information in this dataset in terms of the following descriptions? [Please indicate on a scale of -3 to +3 for each description]

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Difficult to access | Easy to access
Unreliable and not robust | Reliable and robust
Distrusted by clinicians | Trusted by clinicians
Out of date | Up to date
Duplication of other datasets | Unique data
Meaningless measures | Meaningful measures
Difficult to interpret | Easy to interpret
Useless for monitoring performance | Useful for monitoring performance
Unhelpful in my role | Helpful in my role

Q5 a) Are you aware of the Cancer Registry data?

Yes ☐ No ☐ [if you are not aware of this dataset then move on to Q9].

b) Do you use the Cancer Registry data?

Measuring Quality in Cancer Services

Q6 If you use this dataset rarely or never please indicate the main reason/s why [indicate all that apply by saying YES after the answer is read out – say NO if the answer does not apply]

- a Do not know where to find the dataset
- b The dataset is difficult to access
- c The dataset is not user-friendly
- d The dataset is not relevant to my role
- e The quality of the data is poor
- f The data are out of date
- g Other – please specify

[Now go to Q9]

Q7 Please indicate how you use this dataset [indicate all that apply by saying YES after the answer is read out – say NO if the answer does not apply]

- a To monitor the level, quality, or timeliness of data collection/capture
- b To assess or demonstrate progress towards specific local or national goals, targets, guidelines or initiatives (e.g. Cancer Plan, Improving Outcomes Guidance, Peer Review)
- c To benchmark or monitor performance in comparison to other Networks
- d To identify areas for service improvement initiatives
- e To assess population needs
- f To plan and or allocate levels of staffing and/or other resources
- g To direct or inform the use of funding (i.e. informed investment)
- h To keep interested parties informed and updated (e.g. Board, SHA, Users)
- i To identify impacts of service improvement initiatives
- j Other - please specify
**Measuring Quality in Cancer Services**

**Q8** How do you perceive the information in this dataset?  
[Please indicate on a scale of -3 to +3 for each description]

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**Q9** We are also interested in whether you use other routinely available datasets. Please could you indicate whether you are aware of and if you use the following [as each dataset is read out, please say if you are aware of it, and if you use it]:

<table>
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<th>Aware of</th>
<th>Use</th>
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1. Hospital Episodes Statistics (HES)  
3. Audit Commission Acute Hospital Portfolio  
4. Minimum dataset for Palliative Care  
5. National Patient Survey data  
6. Are there any other’s that you use? Please specify
Q10. a) Do you currently use any of these datasets to monitor performance of the Cancer Network or measure quality of service?  
Yes [go to b)]  No [go to Q11]  

b) If so, which ones? [Please specify the number/s of the dataset listed above]  

Q11. a) Within your clinical field, are any routinely available datasets used to monitor the performance of the MDTs? [Including all those routinely available datasets specified above as well as Waiting Times and Registry data]  
Yes [go to b)]  No [go to Q13]  Don’t know [go to Q13]  

b) If so, which ones? [Please specify from the list below by reading out the number/s of the relevant dataset/s]  
1. Cancer Waiting Times  
2. Cancer Registry  
3. Hospital Episodes Statistics (HES)  
5. Audit Commission Acute Hospital Portfolio  
6. Minimum dataset for Palliative Care  
7. National Patient Survey data  
8. Other, please specify  

Q12. How useful are routinely available data in monitoring the performance of MDTs? [Please indicate on a scale of -3 (useless) to +3 (useful)]  

Useless  

Q13. What variables, measures or indicators from routinely available datasets are or might be useful to MDTs (e.g. in your specialisation) for monitoring quality of service? [Please give up to three examples]  
1  
2  
3
Measuring Quality in Cancer Services

Q14. Thinking about the Cancer Network generally, how strongly do you agree or disagree with the following statements?

a) The routinely available datasets that currently exist enable me to assess the structure of this Network

Strongly □ Agree □ Neither agree □ nor disagree □ Disagree □ Strongly □ disagree □ N/A □

b) The routinely available datasets that currently exist enable me to assess the process of care in this Network

Strongly □ Agree □ Neither agree □ nor disagree □ Disagree □ Strongly □ disagree □ N/A □

c) The routinely available datasets that currently exist enable me to assess service outcomes

Strongly □ Agree □ Neither agree □ nor disagree □ Disagree □ Strongly □ disagree □ N/A □

d) Overall, the routinely available datasets that currently exist enable me to assess the quality of services provided by this Cancer Network

Strongly □ Agree □ Neither agree □ nor disagree □ Disagree □ Strongly □ disagree □ N/A □

Q15. In the last year, have you used or are you currently using routinely available data to inform Network Service Improvement Action/Work plans?

Yes □ [go to Q16] No □ [go to Q18] Don’t know □ [go to Q18] N/A □ [go to Q18]

Q16 If so, which datasets have you used for this purpose? [Please specify from the list below by reading out the number/s of the relevant dataset/s]

1 Cancer Waiting Times
2 Cancer Registry
3 Hospital Episodes Statistics (HES)
4 Cancer Standards – Peer Review 2000/2001
5 Audit Commission Acute Hospital Portfolio
6 Minimum dataset for Palliative Care
7 National Patient Survey data
8 Other, please specify
Measuring Quality in Cancer Services

Q17. In comparison to other factors (e.g. locally collected data, anecdotal information, expertise and specialist knowledge, internal politics, existing resources) how influential is/was the routinely available data in informing the Network Service Improvement Action/Work plans? [Please indicate on a scale of -3 (not at all influential) to +3 (very influential)]

-3  -2  -1  0  1  2  3

Not at all influential [ ] [ ] [ ] [ ] [ ] [ ] [ ] Very influential

Q18. Have you used or are you currently using routinely available data to inform Improving Outcomes Guidance Action Plans? Yes ☐ [go to Q19] No ☐ [go to Q21] Don’t know ☐ [go to Q21] N/A ☐ [go to Q21]

Q19. If so, which datasets have you used for this purpose? [Please specify from the list below by reading out the number/s of the relevant dataset/s]

1. Cancer Waiting Times
2. Cancer Registry
3. Hospital Episodes Statistics (HES)
5. Audit Commission Acute Hospital Portfolio
6. Minimum dataset for Palliative Care
7. National Patient Survey data
8. Other, please specify

Q20. In comparison to other factors (e.g. locally collected data, anecdotal information, expertise and specialist knowledge, internal politics, existing resources, local needs) how influential is/was the routinely available data in informing the Improving Outcomes Guidance Action Plans? [Please indicate on a scale of -3 (not at all influential) to +3 (very influential)]

-3  -2  -1  0  +1  +2  +3

Not at all influential [ ] [ ] [ ] [ ] [ ] [ ] [ ] Very influential

Measuring Quality in Cancer Services

Q22 Have you used or are you currently using data from the previous round of Peer Review (2000/2001) to inform the 2004-2007 Peer Review Process?

Yes ☐ No ☐ Don’t know ☐

Q23 How useful is it, or would it be, to be able to see and use comparative data from the last round of Peer Review (2000/2001)?

[Please indicate on a scale of -3 (useless) to +3 (useful)]

-3 -2 -1 0 +1 +2 +3

Useless _____________________________ Useful _____________________________

Q24 Other than improved data quality and better resources to input and analyse data, what are the current information/data needs of the Cancer Network in regards to measuring quality of service? [Please indicate the THREE most important needs by saying YES after the item is read out – say NO if it is not important]

a Better/more equitable access to the datasets ☐
b Unified system/s that ‘talk to each other’ ☐
c More knowledge of what is available and how to use it to monitor performance ☐
d More context to the data (e.g. how it has been collected, how it should be interpreted/evaluated, no.s of patients/cases used to produce the data etc) ☐
e More or better managerial data ☐
f More or better clinical data ☐
g Improved ability to analyse meaningful links between indicators (i.e. relationships between measures of structure, process and outcome) ☐
h Easier to interrogate the data (i.e. more user-friendly) ☐
i The ability to analyse or compare data at different levels/by different categories (National, population, geographical area, network, SHA, PCT, Trust, hospital, MDT, GP practice, clinician, patient, disease, stage of disease, treatment, etc.) ☐
j Other, please specify
### Measuring Quality in Cancer Services

Q25. Imagine that data from the seven following datasets are brought together to enable you to cross reference and compare different measures of service structure, process of care, and outcome. Using this combined dataset, each Network would be able to see the performance of individual Trusts and the overall performance of the Network. In addition the performance in one Network could be compared with the performance of any other across the country and the national average.

On a scale of -3 to +3 do you think this would be:

<table>
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<th>Score</th>
<th>A bad idea</th>
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<th>Useless for monitoring performance by Network</th>
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Measuring Quality in Cancer Services

If possible please list three advantages/benefits of such a dataset
1
2
3

If possible please list three disadvantages/problems of such a dataset
1
2
3

Male/Female
Which Cancer Network do you work for?
What is your role title in the Cancer Network?
What is your clinical specialisation?
How long have you worked in this or another Cancer Network?
How long have you been in your current post?

Many thanks for taking part in this survey.
This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.
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