NHS

The Information Centre
for health and social care

National Oesophago-Gastric Cancer Audit

An audit of the care received by people with Oesophago-Gastric Cancer in England and Wales

First Annual Report 2008

Prepared in partnership with:

The Royal College *of* Surgeons *of* England

British Society of Gastroenterology

AUGIS
ASSOCIATION OF
UPPER GASTROINTESTINAL SURGEONS
OF GREAT BRITAIN AND IRELAND

National Oesophago-Gastric Cancer Audit

An audit of the care received by people with Oesophago-Gastric Cancer in England and Wales

First Annual Report 2008

This report was prepared by:

Clinical Effectiveness Unit, The Royal College of Surgeons of England
Tom Palser, Research fellow
David Cromwell, Lecturer in health services research
Jan van der Meulen, Director of CEU

The Association of Upper GI Surgeons (AUGIS)
Richard Hardwick, Consultant Surgeon

The British Society of Gastroenterology (BSG)
Stuart Riley, Consultant Gastroenterologist

The NHS Information Centre for health and social care
Kimberley Greenaway, Project Manager,
National Clinical Audit Support Programme (NCASP)
Steve Dean, Senior Project Manager,
National Clinical Audit Support Programme (NCASP)

National Oesophago-Gastric Cancer Audit

A national audit examining the process and outcomes of treatment for all oesophago-gastric cancer patients in England and Wales.

This is the first annual report from the National Oesophago-Gastric Cancer Audit. The report presents the results of work undertaken by the audit in its first year, which included a pre-audit qualitative study, an analysis of routine data sources and an organisational audit.

The overall aim of the audit is to examine the quality of care given to patients with oesophago-gastric (O-G) cancer, and thereby help services to improve. The audit will evaluate the process of care and the outcomes of treatment for all O-G cancer patients, both curative and palliative.

Electronic copies of the National Oesophago-Gastric Cancer Audit report can be downloaded from the improving patient care section of our website.

Printed copies of this report can be ordered through our Contact Centre, quoting document reference 28010208.

Contents

Acknowledgements

The National Oesophago-Gastric Cancer Audit is commissioned and sponsored by the Healthcare Commission.

The following groups have provided valuable support for the audit:

- The Clinical Reference Group, chaired by Nick Black
- Jane Blazeby for her input into the design of the quality of life and patient experience study
- The Thames Cancer Registry, acting on behalf of the UK Association of Cancer Registries, who produced the linked HES – Registry dataset for the audit. We would particularly like to acknowledge Henrik Moller, Karen Linklater, Chris Carrigan and David Forman
- The Cancer Network Information System Cymru (CANISC) team and Informing Health who contributed on behalf of Wales. We would particularly like to acknowledge Tom Crosby and Jeff Stamatakis
- Cancer Action Team, Cancer Services Collaborative 'Improvement Partnership' and the Cancer Services Peer Review (CQUINs) team. We would particularly like to acknowledge Bill Allum.

We would like to thank the User Acceptance and Pilot participants for the significant early work carried out before the national rollout of the audit infrastructure, and the support of the Cancer Networks who encourage and support participation, and the individual users for their data contributions.

We would also like to thank the interviewees of the qualitative study.

The National Oesophago-Gastric Cancer Audit Project Team consists of:

- Richard Hardwick, AUGIS
- Stuart Riley, BSG
- Kimberley Greenaway and Steve Dean, NCASP
- David Cromwell, Tom Palser and Jan van der Meulen, CEU.

The Project Team is supported by a Clinical Reference Group and Project Board (see Appendix 1 for details).

The audit is supported by the NCASP Helpdesk and Ronnie Brar and Marion Standing of the NCASP development team, who provide support and technical infrastructure.

Foreword

We are delighted to see this first annual report of the National Oesophago-Gastric Cancer Audit. The audit provides a unique opportunity for services caring for patients with oesophago-gastric cancer to review their practice and we are pleased to see the positive response to the audit so far. We hope that this will continue. It is only with the support of all the health professionals and trusts that the audit will succeed.

The audit is planned to run for 3 years. Although there is still much to do, the work undertaken already identifies various improvements in patient care that have followed the substantial transformation of oesophago-gastric cancer services in England and Wales over the last decade. We are pleased to see that most trusts are meeting various standards highlighted as being characteristic of a quality service. This is particularly so in relation to quick diagnosis and staging. However, the results of the audit also highlight areas in which further improvements are required.

The next stage of the audit will examine the extent to which these differences influence the pattern of patient care. In order to gain a true national picture, it is vital that all trusts providing oesophago-gastric cancer care participate in the prospective audit and submit data on all of their oesophago-gastric patients.

National Cancer Audits can be a major driver for improvements in clinical practice and patient outcomes but a pre-requisite is a high level of participation, data completeness and case ascertainment. We strongly urge all English and Welsh trusts who have yet to start participating in this stage of the audit to begin doing so soon.

Finally, we would also like to thank all of those trusts who are already actively participating and encourage them to continue submitting information to the audit.

KR Palmer
BSG President

M Rees
AUGIS President

Kelvin Palmer

KR Palmer
BSG President

M Rees
AUGIS President

Executive Summary

The National Oesophago-Gastric Cancer Audit began on 1 October 2006. It was established to investigate whether the care received by patients with oesophago-gastric (O-G) cancer is consistent with recommended practice and assess where improvements can be made. It will examine:

- the degree to which variation in treatment is affecting patient outcomes
- how patients view their experience of care, and
- how patients rate their quality of life following treatment.

The last decade has seen a substantial transformation of O-G cancer services in England and Wales. In brief, Department of Health policies and recent clinical practice guidelines have contained the following key recommendations:

- Cancer Networks should be established as new regional models for providing integrated cancer care
- within each Network, specialist surgical teams should be established at appropriate cancer centres
- all O-G cancer patients should be managed by multi-disciplinary teams (MDTs). In addition, the care of all patients should be discussed with the specialist MDT at a cancer centre
- patients should have access to computed tomography (CT) scanning, endoscopic ultrasound (EUS) and laparoscopy for rapid staging
- palliative care should be an integral part of patient management and patients should have access to specialist palliative interventions when required.

The work undertaken by the audit so far suggests that services are increasingly providing care in line with these recommendations. 30 English and 3 Welsh Cancer Networks have been established. Within these, MDTs have been formed and surgical services are being centralised into 44 English and 3 Welsh O-G cancer centres. Nonetheless, the audit has found variation in the delivery of services to patients and has identified various areas requiring further improvement.

Analysis of existing data sources

Information from the English Cancer Registries and Hospital Episodes Statistics was combined to produce a single database that described the characteristics of O-G cancer patients and their treatments. Information was available for 107,524 patients diagnosed between 1998 and 2005. In summary, over this period:

- the annual number of patients diagnosed with gastric cancer fell from 6,195 to 4,680. The number of patients diagnosed with oesophageal cancer rose from 5,671 to 6,375. This increase was caused by a rise in the number of oesophageal adenocarcinomas
- the proportion of patients surviving for one year after diagnosis increased from 30 per cent to 37 per cent
- the proportion of patients undergoing a surgical resection fell from 28 per cent to 20 per cent
- in 2005, the proportion of surgical resections performed in the 44 English O-G cancer centres was 65 per cent
- in response to recent clinical evidence, the proportion of oesophageal cancer patients undergoing chemotherapy or radiotherapy prior to a surgical resection rose from 8 per cent to 51 per cent.

Organisational Audit

Cancer Networks and NHS trusts were surveyed to investigate issues of service organisation and access to care. Responses were received from all 30 English Cancer Networks and 1 of the 3 Welsh Cancer Networks as well as 132 (73 per cent) of the NHS trusts in England and Wales. Among the responding services:

- the process of centralisation of surgery was complete in only 19 of the 31 responding networks. The networks identified 17 trusts that were not O-G cancer centres that were still performing surgical resections
- in the trusts performing surgical resections, over 62 per cent of the surgical teams consisted of 1 or 2 surgeons, being fewer than the recommended 3 minimum

- all 31 Cancer Networks reported good access to the recommended staging investigations (CT scans, endoscopic ultrasound and laparoscopy)

- all 31 Cancer Networks provided access to stent insertion and argon beam coagulation, but only 17 networks provided access to laser ablation therapy and brachytherapy. Two networks could not provide access to endoscopic palliative therapy within 2 weeks of the decision to treat.

In relation to the functioning of multi-disciplinary teams:

- all 132 NHS trusts reported using MDT meetings for treatment planning

- only 16 of the 31 Cancer Networks discussed all patients at specialist MDT meetings

- palliative care team involvement was poor. No member of the palliative care team routinely attended the MDT meeting at 10 of the responding cancer centres (36 per cent) and 26 of the other responding trusts (28 per cent)

- clinical nurse specialists are available at most NHS trusts. Ten local units (11 per cent) reported having no nurse specialist

- nutritional assessment by a dietician is available for all patients at only 54 per cent of all NHS trusts; 26 per cent of responding cancer centres had no dietician support for their surgical inpatients

- administrative support for MDTs is poor, with a data clerk being employed at only 38 per cent of the responding centres and 29 per cent of the other responding trusts.

Patient and Stakeholder interviews

The audit interviewed 15 patients and health professionals to provide insights into the strengths and weaknesses of the current system that could not be gained with quantitative data. The responses highlighted a number of issues:

- diagnostic and staging investigations had improved treatment planning and better patient selection for curative care had probably caused the fall in surgical resection rates

- there was concern expressed about a shortage of histopathologists

- clinical nurse specialists play a fundamental role in providing patient-centred care, particularly in coordinating treatment. The role is threatened because of their limited recognition outside the O-G cancer team and an increasing administrative workload

- there was too little integration of palliative care clinicians and nutritional support in MDTs. Better integration would provide a more holistic care and better symptom control

- specialist MDTs were not involved in the management of all patients, which could affect the quality of care received by palliative patients.

In summary, it is clear that services have made considerable improvements in the diagnosis, staging and treatment of O-G cancer. Nonetheless, there is still variation between Cancer Networks, and the extent to which these different practices produce variation in patient outcomes will be examined in the prospective audit. It is therefore essential that all eligible trusts should participate in the National Oesophago-gastric Cancer Audit and submit data on the process and outcomes of their patients to the audit.

Recommendations

- Cancer Networks should complete the centralisation of surgery as soon as possible and ensure that there are sufficient surgeons in each cancer centre to provide comprehensive cover.
- Networks should provide a full range of palliative therapies and these should be consistently available within 2 weeks of the decision to treat.
- Trusts should ensure that palliative care teams are sufficiently well-resourced to allow attendance at MDT meetings and their involvement at an early stage of a patient's care.
- All patients with O-G cancer should be discussed with the specialist MDT at the cancer centre.
- Trusts should ensure that patients have sufficient access to clinical nurse specialists.
- Dietician access should be improved so that all patients have access to specialist nutritional support when required.
- Trusts should ensure that there is sufficient administrative support to facilitate routine data collection and clinical audit.

1 Introduction

1.1 The treatment of oesophago-gastric cancer

Each year, in England and Wales, approximately 13,500 people are diagnosed with either oesophageal or gastric (stomach) cancer, making it the fifth most common type of malignancy.[1,2] The risk of developing either cancer increases with age, with only a small proportion of tumours occurring in people under 40 years. The median age of diagnosis is 72 years.[3] Both types of cancer are also more prevalent in men than women.

In common with many other western countries, there has been a change in the pattern of oesophago-gastric (O-G) cancer in England and Wales. The incidence of gastric cancer has been falling, while the incidence of oesophageal cancer has increased slightly. In addition, there has been an increase in the incidence of tumours at the gastro-oesophageal junction. The most recent figures for England show that:[4]

- The age-standardised[i] incidence rate of stomach cancer in men decreased from 19.5 per 100,000 in 1996 to 13.8 in 2005, while the corresponding female rates decreased from 7.5 to 5.3.
- The age-standardised incidence rate of oesophageal cancer in men rose from 12.5 per 100,000 in 1996 to 14.0 in 2005, while the corresponding female rates rose from 5.4 to 5.6.

Similar changes have been reported for Wales.[2]

The prognosis for many patients diagnosed with O-G cancer is poor, with overall 5-year survival rates in England and Wales being approximately 7 per cent and 13 per cent for oesophageal and gastric cancer, respectively.[4] As with other cancers, patients diagnosed at an early stage typically have better rates of survival, partly because the treatment options available depend upon how advanced the disease has become. Only people diagnosed with localised disease are suitable for treatment with curative intent. Currently, between 20 and 25 per cent of patients receive curative therapies. The majority of patients require palliative care.

Establishing the disease stage, and consequently options for treatment, requires patients to undergo a number of investigations. Standard investigations currently include computed tomography (CT) scanning, endoscopic ultrasound (EUS) and staging laparoscopy.[5] CT scans are recommended to determine the presence of metastatic disease. EUS and laparoscopy are recommended for patients found to have no metastatic disease and who are candidates for curative therapy. It is recommended that Magnetic Resonance Imaging (MRI) is reserved for patients who cannot undergo a CT scan or require further imaging after EUS or laparoscopy.[5] In addition, it is becoming accepted that positron emission tomography (PET/PET-CT) can be beneficial for selecting patients for curative treatment.

The surgical removal (resection) of the malignant tumour remains the principal curative treatment. Recent clinical trials have shown that, for patients with operable oesophageal cancer, combining surgery with preoperative (neoadjuvant) chemotherapy can improve rates of 5-year survival.[5] The benefit of combining surgery with neoadjuvant chemo-radiotherapy, and of combining surgery with postoperative (adjuvant) chemotherapy or radiotherapy, is less clear and these are recommended only when given within a clinical trial.[5] Patients with locally advanced disease may also receive chemotherapy or radiotherapy with the aim of down-sizing the tumour to improve the chance of removing it completely.

Many O-G cancer patients with potentially curable disease are unfit for surgery due to coexisting conditions or frail health. A proportion of patients will also decline surgery. In these situations radiotherapy, either alone or combined with chemotherapy, may sometimes become a curative treatment option for patients with oesophageal cancer but not for patients with gastric cancer.

Patients unsuitable for curative treatment may be offered various types of palliative care. The principal goal of care is to achieve the best quality of life for patients and their families by alleviating pain and other symptoms as well as providing psychological and social support. This may involve different

---

[i] Directly age-standardised using the European Standard Population.

invasive treatments, including chemotherapy, surgery and various endoscopic and radiological palliative therapies. For example, dysphagia (difficulty swallowing) is a common presenting symptom for oesophageal cancer and can cause much physical and psychological distress. Palliative techniques that aim to reduce the degree to which the tumour obstructs the oesophagus include stenting, argon beam coagulation, laser therapy, photodynamic therapy, and brachytherapy. Consequently, it is recommended that patients' requiring these invasive treatments have their care managed and coordinated within multi-disciplinary teams.[7]

1.2 Service organisation and policy in England and Wales

There has been a major reorganisation of cancer services in England and Wales over the last decade, being initially stimulated by the Calman – Hine report in 1995.[8] In England, this was followed by the establishment of the Cancer Peer Review programme in 1998 and the Cancer Services Collaborative Improvement Programme in 1999. In Wales, cancer services were the subject of a thorough review (the Cameron Report),[9] and this has led to the development of cancer site specific standards, as well as an information framework for Cancer Services. The Welsh Assembly Government published its plan for a 'Cancer Information Framework' in 2000 and emphasised the importance of audit.[10]

For NHS services in England, the 'Improving Outcomes Guidance' for O-G cancer was published in 2001[7] and provided guidance on how services were to be organised. The recommendations were built upon two main principles. The first was that curative services should be centralised into specialist cancer centres. The second was that clinicians from different specialties, hospitals and professional backgrounds should work together as a coordinated multi-disciplinary team (MDT). In addition, it was recommended that the care of all patients should be discussed with the specialist MDT at each cancer centres, even if the patient was unsuitable for curative surgery because of metastatic disease or extensive co-morbidity.

Cancer Networks were established to provide this integrated model of care. Each network contained one or more cancer centres to provide curative surgical treatment and specialist radiology, oncology and palliative services to all patients living in the area. Diagnostic services and most palliative services continued to be provided by individual NHS trusts (units) within the network areas. There are currently 30 networks in England and 3 in Wales.

Another key aspect of health policy has been to establish specific cancer waiting time targets.[11] Currently, these are:

1. a maximum 2 week wait from an urgent GP referral for suspected cancer to the date first seen by a specialist for all patients

2. a maximum 1 month (31 day) wait from diagnosis to first treatment for all cancers

3. a maximum 2 month (62 day) wait from urgent GP referral to first treatment for all cancers.

The majority of O-G cancer patients will be urgent GP referrals and so will be part of the 'fast-track' system to which the 2-week and 62 day targets apply.

1.3 Clinical guidelines

Various clinical guidelines on the management of oesophageal and gastric cancer have been produced in the United Kingdom, partly in response to advances in diagnostic and therapeutic technologies, and partly due to the greater need for a multi-disciplinary approach to care. In 2002, a guideline was jointly published by the Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland (AUGIS), the British Society of Gastroenterology (BSG) and the British Association of Surgical Oncology.[12] More recently, the Scottish Intercollegiate Guideline Network (SIGN) published its guideline on the management of oesophageal and gastric cancer.[5] Both cover diagnosis, staging, curative and palliative treatment, and are largely similar in their recommendations.

Two guidelines published by the National Institute for Health and Clinical Excellence (NICE) have provided guidance for the investigation of suspected upper gastrointestinal cancer: Referral Guidelines for Suspected Cancer[13] and Management of Dyspepsia in Adults in Primary Care.[14]

They recommend urgent referral for investigation if a person presents with any "alarm" symptoms (e.g. dysphagia, persistent vomiting, weight loss or gastro-intestinal blood loss). People aged 55 years or older with unexplained and persistent recent-onset dyspepsia (indigestion) should also be referred for urgent endoscopy.

1.4 Previous audits on O-G cancer care in the United Kingdom

There have been several audits of O-G cancer care in the United Kingdom, all of which have highlighted various aspects of care that required improving. Many studies have focussed on surgical treatment because curative resection surgery is associated with significant postoperative mortality and morbidity. Postoperative mortality is typically around 12 per cent, with risk being associated with tumour stage and site, as well as the patient's general health and fitness.[15]

A prospective audit in Wales enrolled 916 patients who presented with O-G cancer during 1 year[16]. In total, 33 per cent of these patients had a surgical resection. However, 10 per cent of patients underwent an 'open and shut' operation[ii] which, coupled with the limited use of laparoscopy, suggested that selection for curative surgery could have been better. The audit also reported higher postoperative mortality after gastric surgery among surgeons with small caseloads. A similar relationship between surgical volume and postoperative mortality was reported by Bachmann et al in their study of 1,512 patients with O-G cancer in South-West England.[17] However, such a relationship was not found by the Scottish Audit of Gastric and Oesophageal Cancer (SAGOC), the largest of the previous audits, capturing data on 3,293 patients with O-G cancer diagnosed in Scotland between July 1997 and July 1999.[3]

An interesting finding from SAGOC was the considerable regional variation in the investigation and management of O-G cancer patients. Like the Welsh Audit, it reported differences in the investigations used to select patients for a curative resection but it also reported considerable regional variation in the use of endoscopic palliative procedures.

Finally, an audit in Northern Ireland using Cancer Registry data highlighted how the treatment of O-G cancer has been evolving.[18] It reported an increased use of chemotherapy and radiotherapy between 1994 and 2001, and a corresponding decrease in surgery. It also reported improved survival among patients who had surgery and chemotherapy compared to surgery only, results that are consistent with the findings of clinical trials on the effectiveness of combined treatments.[6]

[ii] This can occur when patients are planned to undergo curative surgery but, during the operation, it is found that the tumour cannot be removed..

2 The National Oesophago-Gastric Cancer Audit

2.1 Background to the audit

The management of oesophago-gastric cancer is complex and it is unclear to what degree patients are managed optimally during the normal process of care. The re-organisation of services over the last decade is likely to mean that the care received by O-G cancer patients varies between different parts of England and Wales. Moreover, there is currently a lack of information on:

1. the degree to which variation in treatment is affecting patient outcomes
2. how patients view their experience of receiving care, and
3. how patients rate their quality of life following treatment.

This audit was established to investigate whether the care received by oesophago-gastric cancer patients is consistent with recommended practice and to identify areas where improvements can be made. It was instigated by the Healthcare Commission and is 1 of 5 National Cancer Audits being undertaken in England and Wales.

2.2 Aims and objectives of the audit

The overall aim of the audit is to measure the quality of care received by patients with oesophago-gastric (O-G) cancer in England and Wales. It will answer audit questions related to:

1. the timescale of the process of care
2. the determinants of treatment and outcomes
3. the proportion of patients treated palliatively and its determinants
4. the short-term outcomes of surgical treatment
5. the survival and health status of patients at 1 year after diagnosis
6. patient quality of life and patient experience with care.

2.3 Design of the audit

This audit is a collaboration between:

- The Association of Upper GI Surgeons (AUGIS)
- The British Society of Gastroenterology (BSG)
- The National Clinical Audit Support Programme (NCASP) of The NHS Information Centre for health and social care
- The Clinical Effectiveness Unit of The Royal College of Surgeons of England.

The audit began in October 2006 and will run for 3 years.

The main component of the audit is a prospective audit of the process and outcomes of care among patients diagnosed with O-G cancer. All patients in England and Wales diagnosed with invasive epithelial cancer of the oesophagus or stomach between 1 October 2007 and 31 December 2008 are eligible for inclusion. The audit will not include non-epithelial tumours (e.g. gastrointestinal stromal tumours or lymphomas) and high-grade dysplasia.

The prospective audit will collect information on the diagnosis, staging, and planned treatment of all patients. The collection of additional information will depend upon the treatment subsequently received by patients, and will cover:

- curative and palliative surgery
- postoperative pathology for patients undergoing curative surgery
- curative and palliative oncological treatment (chemotherapy / radiotherapy)
- endoscopic palliative therapy.

The dataset for the National Oesophago-Gastric Cancer Audit was developed by the project team with input from the Clinical Reference Group. A description of the dataset is contained in Appendix 2.

The assessment of patient quality of life and experience with care is another component of the audit that is closely related to the prospective audit. All hospitals are eligible to participate but, due to the additional burden that the administration of the questionnaires will place on staff, it is expected to be undertaken in 10 to 15 cancer centres and their associated units. It will include patients diagnosed between 1 April and 31 December 2008.

The audit consists of three other components, namely:

1. an analysis of data from the Hospital Episodes Statistics (HES) and Cancer Registries to provide a retrospective picture of activity and outcomes
2. a qualitative study based on semi-structured interviews with patients and health professionals to identify important issues affecting the diagnosis and treatment of patients
3. an organisational audit to describe the characteristics of healthcare services in England and Wales, to examine aspects of care that the qualitative study flagged as important but which could not be included in the prospective audit.

2.4 Annual reports

Each year, the audit will publish an annual report describing its findings. This first annual report covers the work undertaken since October 2006. Specifically, it describes the development and analysis of the linked Hospital Episode Statistics / Cancer Registries dataset, the results of the qualitative study and the organisational audit, and the preparation for the prospective audit.

In the second annual report, we will describe the process of care using the results of the prospective audit. The analysis of the patient data will answer audit questions related to disease staging and co-morbidity of patients, the timescales for diagnostic and therapeutic procedures, and how therapeutic and palliative management decisions are associated with patient characteristics.

In the third annual report, we will describe the longer-term outcomes of care. The analysis of the patient data will answer questions related to variation in outcomes after surgery, chemotherapy responses, patient survival, and quality of life. It will also include the results of the patient experience survey.

3 Patterns of treatment and outcomes between 1997 and 2005

3.1 Creation of a Registry-HES linked dataset

The audit collaborated with Thames Cancer Registry, as lead Registry for the UK Association of Cancer Registries, to produce a dataset that linked Registry data to the Hospital Episode Statistics (HES) database. Thames Cancer Registry coordinated the collation of data from the individual Cancer Registry datasets into a complete England dataset. Data were extracted for calendar years between 1996 and 2005, the latest data that were available. An extract of the HES database was then obtained for all episodes relating to patients resident within England with a ICD10 diagnostic code of C15 (oesophagus) or C16 (stomach). The data were supplied for the period April 1997 to March 2006. Combining these two data sources produced a dataset that contained 6 month treatment histories of all patients diagnosed between calendar years 1998 and 2005.

Records in these two datasets were linked using a hierarchical approach. This process involved matching patient records using various combinations of NHS number, sex, date of birth, date of death and postcode. There were 107,524 O-G cancer patients recorded in the Registry dataset, and information on inpatient treatments was found in HES for just over 90 per cent of these patients. The proportion of links that included the NHS number (the most reliable linking variable) increased from 70 per cent in 1998 to 87 per cent in 2005.

The summary of patient characteristics described in this chapter is derived from Registry data. The analysis of the patterns of patient care is based on the combination of Registry and HES data. The analysis was restricted to care that was delivered within six months of the date of diagnosis, thereby matching the timeframe for data collection specified for Registry data.

3.2 Patient characteristics

Between April 1997 and March 2006, there were 48,593 patients (45 per cent) diagnosed with oesophageal cancer, and 58,931 patients (55 per cent) diagnosed with gastric cancer. More men than women were diagnosed with O-G cancer (68,245 men compared to 39,279 women, a ratio of 1.7:1) and, on average, men were slightly younger than women at the time of diagnosis (70.5 years v 75.0 years, respectively).

There was a yearly decrease in the total number of patients diagnosed, which was due to a marked decrease in the incidence of gastric cancer **(see Table 1)**. The number of patients with oesophageal cancer increased each year.

Table 1:
Number of patients diagnosed with either oesophageal or gastric cancer between 1998 and 2005

Year of diagnosis	Oesophageal cancer	(%)	Gastric cancer	(%)	Total
1998	5,671	41%	8,208	59%	13,879
1999	5,820	43%	7,868	57%	13,688
2000	6,004	43%	7,945	57%	13,949
2001	6,110	45%	7,481	55%	13,591
2002	6,140	45%	7,365	55%	13,505
2003	6,268	48%	6,915	52%	13,183
2004	6,205	48%	6,710	52%	12,915
2005	6,375	50%	6,439	50%	12,814

The change in oesophageal cancer was caused by an increase in the number of patients with oesophageal adenocarcinomas. In 1998, these made up 18 per cent of all O-G cancers; in 2005, the figure had risen to 26 per cent. The incidence of other oesophageal tumours (predominantly squamous cell carcinomas) remained fairly constant, with around 3,000 cases per year and corresponding to 23-24 per cent of all O-G cancers.

Among patients with a known tumour site, around 90 per cent of the oesophageal adenocarcinomas were located in the lower oesophagus. Because stomach cancers are predominantly adenocarcinomas, lower oesophageal adenocarcinomas and stomach tumours at the junction with the oesophagus (ie. the cardia) are increasingly treated as a distinct category of oesophago-gastric cancer and are commonly referred to as gastric-oesophageal junctional (GOJ) tumours. Unfortunately, in Cancer Registry data, the identification of GOJ tumours is hampered by the limitations of the ICD10 classification and because a sizeable proportion of patients have an ICD10 diagnosis code that does not include a specific tumour site (e.g. upper, middle, lower oesophagus).[19] In this dataset, the tumour site was unspecified in approximately 45 per cent of patients with oesophageal cancer (C15.9) and 30 per cent of patients with gastric cancer (C16.9).

In this following analysis, GOJ tumours were defined as oesophageal adenocarcinomas in the lower third (C15.3 or .6) or in an unspecified site (C15.9) and gastric tumours at the cardia (C16.0). The overall proportion of stomach cancers that were located at the cardia was 29 per cent, and did not change greatly between 1998 and 2005. The demographic characteristics of patients with O-G cancer are summarised in **Table 2**.

Table 2:
Average age of men and women with the various types of O-G cancer

	Cancer type	**No. of patients**	**Average age (years)**	**Interquartile range**	
				25th percentile	**75th percentile**
Male	Oesophageal	12,842	70	62	79
	G-O Junction	28,968	69	61	77
	Gastric	26,435	73	67	80
Female	Oesophageal	13,262	75	68	84
	G-O Junction	8,669	74	67	83
	Gastric	17,348	76	69	84

3.3 Patterns of patient care

Between 1998 and 2005, there were various changes in the pattern of care received by patients with O-G cancer. The proportion of patients coded as receiving either chemotherapy or radiotherapy almost doubled between 1998 and 2005, rising from 18 per cent to 34 per cent. The increase occurred both among patients undergoing a surgical resection (curative surgery) and those who received palliative care. In contrast, the proportion of patients undergoing a surgical resection fell from 28 per cent to 20 per cent. This is likely to reflect improved staging procedures and better patient selection. The proportion of patients undergoing either an oesophageal or gastric resection fell for each type of cancer **(see Table 3)**.

Table 3:
Proportion of patients undergoing curative (resection) surgery by year of diagnosis

Year	No. (%) of patients having resection		% of patients having resection by type of cancer		
			Oesophageal	Junctional	Gastric
1998	3,836	(28%)	14%	33%	31%
1999	3,687	(27%)	15%	31%	31%
2000	3,505	(25%)	13%	28%	30%
2001	3,310	(24%)	13%	28%	28%
2002	3,152	(23%)	11%	26%	28%
2003	3,027	(23%)	12%	27%	26%
2004	2,722	(21%)	11%	24%	25%
2005	2,521	(20%)	10%	24%	23%

One of the significant advances in care among O-G cancer patients has been the growing clinical evidence on the effectiveness of giving chemotherapy (and chemo-radiotherapy) to oesophageal and junctional patients prior to curative surgery. **Table 4** describes the change in use of oncological therapy among patients undergoing a surgical resection. Although the table groups chemotherapy and radiotherapy, the majority of patients received chemotherapy in combination with a resection procedure. There has been a change among patients with oesophageal or junctional cancers, with roughly half now receiving oncological therapy prior to surgery. Given that some chemotherapy will be provided on an outpatient basis, these proportions may be underestimates.

Another important aspect of surgical care has been the policy to centralise curative surgery in specialist O-G cancer centres. There are currently 44 cancer centres within the English Cancer Networks, and in 2005, these performed 65 per cent of all O-G cancer resections. Prior to 2002, before these trusts had been designated as O-G cancer centres, they performed 48 per cent of the surgical resections.

Table 4:
Change in use of chemotherapy (C) / radiotherapy (R) among patients undergoing a surgical resection (curative surgery)

	1998	1999	2000	2001	2002	2003	2004	2005
Oesophageal cancer								
Surgery only	77%	78%	67%	57%	57%	49%	45%	44%
C/R then Surgery	8%	9%	22%	38%	36%	43%	51%	48%
Surgery then C/R	15%	13%	11%	5%	6%	7%	4%	8%
Junctional cancer								
Surgery only	84%	85%	72%	61%	59%	52%	48%	42%
C/R then Surgery	6%	4%	18%	31%	34%	43%	48%	51%
Surgery then C/R	10%	11%	9%	8%	6%	6%	5%	7%
Gastric cancer								
Surgery only	91%	92%	89%	88%	89%	85%	86%	82%
C/R then Surgery	1%	1%	2%	2%	2%	3%	4%	8%
Surgery then C/R	8%	7%	9%	9%	9%	13%	10%	9%

Among those patients who did not undergo curative surgery, a sizeable proportion did not receive any inpatient or day case palliative therapy within the first 6 months after diagnosis. In 1998, the proportions were 44 per cent, 39 per cent and 81 per cent for patients with oesophageal, junctional and gastric cancer, respectively. Despite the recent advances in invasive palliative care, the proportion of patients not receiving any treatment was still sizeable in 2005, being 40 per cent, 35 per cent and 72 per cent for the same patient groups.

Table 5 summarises the proportion of these "palliative" patients[iii] undergoing endoscopic and radiological palliative therapy (ERPT), palliative (bypass) surgery or oncological therapy within the first six months after diagnosis. The proportion of patients receiving chemotherapy and radiotherapy increased across all patient groups. As expected, ERPT was predominantly used among patients with oesophageal or junctional cancers. The rates fell slightly overall but these aggregate figures conceal changes in the types of therapies used. In particular, for oesophageal cancer, the proportion of patients having a stent increased from 16 per cent to 24 per cent between 1998 and 2005. In contrast, the proportion of patients undergoing only a dilation procedure decreased from 15 per cent to 8 per cent over the same period. A similar pattern occurred in patients with junctional cancers. Both changes are consistent with recommended practice.[5]

[iii] Not all patients will be palliative as the group includes the small proportion of patients that received oncological treatments with curative intent.
Some patients receive more than one type of therapy and so the sum of the proportions does not equal the proportion of patients receiving any treatment.

Table 5:
Change in use of oncological treatments, endoscopic and radiological palliative therapy (ERPT) and palliative (bypass) surgery among patients who did not undergo a surgical resection

	1998	1999	2000	2001	2002	2003	2004	2005
Oesophageal cancer								
Oncology	29%	27%	30%	31%	32%	35%	37%	35%
ERPT	35%	38%	35%	35%	34%	34%	34%	33%
Surgery	10%	11%	9%	10%	10%	10%	9%	10%
Junctional cancer								
Oncology	26%	29%	34%	37%	37%	41%	40%	42%
ERPT	38%	39%	36%	34%	33%	32%	32%	30%
Surgery	13%	12%	10%	10%	10%	10%	10%	10%
Gastric cancer								
Oncology	10%	11%	13%	15%	18%	18%	19%	20%
ERPT	4%	4%	4%	5%	5%	5%	5%	6%
Surgery	7%	8%	8%	8%	7%	6%	6%	5%

3.4 Proportion of patients surviving 1 year after diagnosis

Table 6 gives the proportion of patients with O-G cancer who survived at least 1 year, grouped by their year of diagnosis. Overall, the proportion increased from 30 per cent to 37 per cent, and an increasing trend was also seen for patients with each typeof cancer. All increases were statistically significant (Chi-square test for trend, $p<0.01$). While these figures are not standardised for age and sex, they are consistent with pattern of improving duration of survival reported elsewhere.[20]

Table 6:
Proportion of patients surviving 1-year after diagnosis, grouped by year of diagnosis*

	1998	1999	2000	2001	2002	2003	2004	2005
Oesophageal	23%	24%	27%	28%	29%	28%	28%	31%
GOJ	33%	34%	35%	48%	39%	42%	40%	43%
Gastric	30%	32%	32%	32%	35%	33%	33%	35%

---

* Derived for patients whose basis of diagnosis was not a death certificate or whose date of diagnosis was not the same as their date of death. The analysis included 101,452 of the 107,524 patients (94 per cent)

3.5 Limitations of the analysis

The above analysis is limited by various aspects of the data. First, the proportion of patients allocated to the junctional cancer group is likely to be an underestimate. Its identification relies on patients having the site of the tumour specified in the 4-digit ICD10 diagnosis code. A high proportion of patients have the site of the oesophageal or gastric tumour entered as "unspecified".

Second, the figures for the use of chemotherapy and radiotherapy need to be interpreted with caution. HES data only capture oncology treatments that were performed on patients admitted as a day case or inpatient. As some treatment is delivered on an outpatient basis, the proportion of patients receiving care is likely to be underestimated. In addition, the figures will be influenced if trusts change from delivering oncological treatments from an outpatient to a day case / inpatient setting and vice versa. The figures may also be influenced by improvements in the coding of treatments over time. Nonetheless, it is unlikely that these factors account for the observed increase in chemotherapy use before resection surgery in oesophageal and junctional cancer patients, given the size of the change, and given that these factors would be expected to affect all types of cancer equally.

Third, the figures for the use of endoscopic and radiological palliative therapies also miss any treatments performed on an outpatient basis. The timing of these treatments is also conditional on the progression of the disease, and when symptoms become severe. Not all patients will require these therapies within the first 6 months after diagnosis. The figures should not be interpreted as the proportion of patients who will ever undergo these therapies.

4 The challenges of delivering high quality care for oesophago-gastric cancer: a qualitative study

The audit undertook a qualitative study of patients and health care professionals to identify the important components of the care process and where there might be opportunities to improve the quality of care. The specific objectives were:

- to define the characteristics of quality health care for O-G cancer patients, and

- to identify the strengths and weaknesses of the current system.

The information obtained from the study was also used in the design of the prospective and organisational audit to ensure that the issues raised as a concern were covered by the other audit components.

The study used a series of semi-structured telephone interviews with a selected sample of individuals who had experience and knowledge of the O-G cancer care in England and Wales. The interviews were conducted over a 3 month period in 2007. The sampling frame was devised to ensure representation from patient and professional groups, and to give a range of views. In total, the sample contained 15 representatives and consisted of:

- 2 patients
- 3 gastroenterologists
- 2 nurse specialists
- 1 oncologist
- 2 palliative medicine consultants
- 2 radiologists
- 3 surgeons

4.1 Characteristics of high-quality care for O-G cancer patients

An analysis of the interviews highlighted six characteristics of high-quality health care:

i **Early diagnosis**

ii **A rapid and efficient staging process**

iii **A centralised service run by a multi-disciplinary team**

iv **Patient-centred care and the role of clinical nurse specialists**

v **Good communication between health care professionals**

vi **NHS Policy, resources and the delivery of cancer services.**

Each of these themes will now be briefly discussed.

i Early diagnosis

Most interviewees emphasised the ability to make an early diagnosis as being an essential characteristic of high quality care. Currently, many patients are diagnosed with advanced cancer and their only treatment option is palliative care. An interviewee stated that “we have got to get the patient at a point in their illness where we really think we can do something about (the cancer)”.

The main barriers that prevent early diagnosis were identified as:

1. *delayed presentation by the patient.* It was felt that many patients sought medical care only after many months of symptoms, thereby delaying diagnosis. This was linked to poor public awareness of oesophago-gastric cancer but it was recognised to be partly due to the nature of the symptoms. One interviewee said “nearly all of us during any week will have some form of upper GI symptom… and people take these things very lightly because they’re so used to them”.

2. *delayed referral by general practitioners*. Several interviewees felt that general practitioners (GPs) differ in how long they monitor patients’ symptoms before referral and how they respond to “alarm” symptoms. The variation was thought to increase the risk of delayed referral, particularly for younger patients. Several interviewees related this issue to imprecise guidance about referral criteria. For example, NICE guidelines refer to persistent dyspepsia but this was regarded as ambiguous.

3. *referral to an inappropriate department*. Interviewees commented on the potential for patients with dysphagia (difficulty swallowing) to be referred to ENT outpatients department rather than to fast-track endoscopy units. When this

occurred, the use of less than optimum diagnostic tests (e.g. barium swallow) could result in delayed diagnosis.

Improving public awareness of the disease and its early symptoms was regarded as a pre-requisite to improving the disease's outcome: it was suggested that "a public awareness campaign of the significance of dysphagia would be money well spent". The concerns about delayed and inappropriate referral also highlighted the need for continuing GP education.

ii A rapid and efficient staging process

Interviewees repeatedly emphasised:

1. the importance of an efficient staging process
2. that the staging process had improved significantly over the last decade, with most patients now having quick access to the required investigations.

The benefit of a quick staging process was described by one of the interviewed patients as helping to allay the fear caused by not knowing how advanced the cancer was.

Two issues of concern were raised:

1. there is a shortage of specialist histopathologists which resulted in diagnostic delays for patients not referred by the fast-track route.
2. it was thought that younger patients who required more complex imaging sometimes took longer to stage than was desirable.

iii a centralised service run by a multi-disciplinary team

Another characteristic of a quality service was identified as a centralised, specialist service run by multi-disciplinary teams. Both patients and health care professionals felt that having staff with experience of O-G cancer improved outcomes. The interviewees emphasised the importance of all disciplines represented in the team being experienced and not just those in specialist cancer centres. One radiologist stated that care had improved "because we see it (O-G cancer) all the time and are making the decisions in conjunction with other specialties".

Interviewees identified four weaknesses with current multi-disciplinary teams. These were:

1. *poor integration of palliative care clinicians*. Their greater involvement was seen as promoting a more holistic approach and was likely to improve the control of patient's symptoms.
2. *poor integration of nutritional support*. It was felt that the importance of ensuring good nutrition for O-G cancer patients was not widely appreciated and that access to specialist dietetics was variable around England and Wales.
3. *too little investment* in supporting the new MDT structures.
4. *specialist MDTs were not involved in the management of all patients*. Several interviewees thought that not all patients were discussed with a member of the specialist MDT, with the consequence that the management of some palliative patients was suboptimal. One interviewee also stated that some patients offered palliative care from unit MDTs were, after seeking a second opinion, considered to be candidates for curative surgery by the specialist MDT.

Interviewees complained that the centralisation process had not been accompanied by adequate investment. Several issues were also raised in relation to the consequences of centralisation for a patient's experience of care:

1. *Insufficient infrastructure*. Interviewees thought that some services had limited parking facilities and poor transport links, and that this adversely affected access and was a potential source of dissatisfaction.
2. *Patients unclear of reason for centralisation*. Not all patients appreciated that the inconvenience of travelling greater distances had to be balanced against the better clinical care offered by centralised services. This was regarded as another potential source of dissatisfaction.

It was suggested that the reasons for the centralisation of services needed wider communication to the population as a whole.

iv Patient-centred care and the role of clinical nurse specialists

A recurrent theme among interviewees was the importance of patient-centred care in a high-quality service. Services need to be responsive to the individual needs of the patient, which involved managing physical problems and caring for a patient's psychological health. One interviewee said that doctors must be able "to recognise how people are managing and identify those that will need more input".

Various components were highlighted as constituting patient-centred care:

1 *clinical nurse specialists* were identified as playing a fundamental role in providing patient-centred care, particularly in providing information and coordinating treatment. They were described as "the total pillar in the system". An interviewee stated that "it's that sort of personal link in a very frightening experience; that's what makes the difference".

2 *good communication*. It was necessary to provide patients and their carers with detailed information about their treatment and disease. One patient said that "it made a big difference to (my family) because they always knew what was happening". The support provided by former patients through patient associations was also regarded as important.

3 l*ong-term follow up* of patients in a specialist setting. This gives patients access to clinicians with the skills required to manage their symptoms. One interviewee felt that few GPs would be sufficiently "skilled or aware of the issues to look for such as continuing problems with swallowing and nutrition and pain".

Several interviewees raised concerns related to the role of clinical nurse specialists:

1 *contributions went unrecognised*. It has been "a role which has been grossly underestimated and over-abused".

2 *lack of administrative support*, which led to nurse specialists doing too much paperwork and wasting their skills.

The combination of poor recognition and lack of administrative support was thought likely to lead eventually to an increasing number of nurse specialists leaving the workforce, and make it difficult for services to find replacements.

v Good communication between health care professionals

The importance of good communication between different units and teams was consistently highlighted by interviewees. Communication had been improved by the creation of the multi-disciplinary teams and the local designation of roles between units and cancer centres within the Cancer Networks. Again, the clinical nurse specialist was identified as playing a vital role in facilitating communication.

Most interviewees discussed how poor communication led to delays in treatment which could result in poorer patient outcomes. These problems can occur anywhere along the care pathway, but the slow transfer of radiological imaging between the units and the centres was a particular concern.

vi NHS policy, resources and the delivery of cancer services

Overall, interviewees thought that the investment in O-G cancer services since the NHS Cancer Plan had improved outcomes for patients. Most interviewees noted in particular how investment in radiology and endoscopy services has greatly improved the quality and efficiency of diagnosis and staging.

Almost all interviewees mentioned issues related to having adequate resources to maintain a high quality service. There was a shared sense of a lack of redundancy (spare capacity) in the system, and several interviewees were concerned that this had the potential to increase adverse events. Concerns were also raised about how the re-organisation process had been managed, with one interviewee commenting that "we never know from one year to the next what the local arrangement is going to be". Specific concerns related to the centralisation process not being accompanied by adequate investment in the required infrastructure, with the new MDT structures in particular receiving too little support.

5 The organisation of oesophago-gastric cancer services in England and Wales: an organisational audit

A survey was undertaken to identify the location and characteristics of NHS acute trusts involved in the care of patients with oesophago-gastric cancer. It also allowed the audit to assess issues raised as important in the qualitative study but which could not be included in the prospective audit. The objectives of the survey were:

1. to assess whether levels of access to the diagnostic investigations met the standards recommended by recent guidelines
2. to describe the provision of curative surgery, oncological and palliative interventions and assess whether it met published standards
3. to assess how trusts had implemented aspects of multi-disciplinary teams and patient-centred care.

The survey used two questionnaires. The first focussed on the structure of the Cancer Networks and contained questions about the availability of staging investigations, the organisation of surgical treatment, and access to endoscopic palliative therapy and oncology treatment. The second questionnaire focussed on services within individual NHS trusts and contained questions about MDT meetings, palliative care, nutritional support, specialist nurse provision and the availability of patient information. Both questionnaires were devised with reference to recommendations about the management of oesophago-gastric cancer contained in:

- the Improving Outcomes Guidance published in 2001 by DH[7]
- the clinical guideline published in 2002 by AUGIS, BSG and BASO[12]
- the National Cancer Manual published in 2004 by DH,[21] and
- the clinical guideline published in 2006 by the Scottish Intercollegiate Guidelines Network (SIGN)[5].

A list of networks and all NHS acute trusts involved in the treatment of O-G cancer was prepared from various sources. The network questionnaires were sent to the Cancer Network O-G cancer lead clinician, while the trust questionnaires were sent to the Trust O-G cancer lead clinician. The questionnaires were distributed in September 2007 and non-responders were followed up by email and telephone.

Responses were received from all 30 of the Cancer Networks in England and 1 of the 3 Cancer Networks in Wales. Questionnaires were returned from 126 (75 per cent) of the 168 NHS trusts in England and 6 (43 per cent) of the 14 NHS trusts in Wales.

5.1 Network characteristics

The structure within the Cancer Networks is still evolving. At the time of the audit, the centralisation process was not yet complete in 12 of the 31 Cancer Networks. In four of these networks, the proposed changes involve centralising the work of one remaining unit but in seven networks, major restructuring remains to be completed.

Availability of staging investigations within Cancer Networks

Guidelines on staging recommend the use of three principal investigations: CT scans, endoscopic ultrasound (EUS) and staging laparoscopy. The availability and use of the principal investigations within the Cancer Networks are described in **Table 7**. Almost all networks reported that CT scans were performed on all patients. There is greater variation in whether EUS and laparoscopy are used on all or selected patients. The use of these investigations on selected patients is consistent with the guidelines that recommend them for patients who are candidates for curative therapy. That few networks have a policy of using EUS in patients with gastric cancer and staging laparoscopy in patients with oesophageal cancer is consistent with expected clinical practice and is unlikely to indicate difficulties in access. Networks indicated that patients were selected on clinical grounds rather than geographical proximity.

Table 7:
Reported availability of staging investigations in Cancer Networks

Investigation		**Patients on whom the investigation is performed (number of networks = 31)**			
	Tumour site	**In all patients**	**In selected patients**	**None**	**Missing values**
CT scan	Oesophageal	29 (94%)	2 (6%)		
	Junctional	29 (94%)	2 (6%)		
	Gastric	29 (94%)	2 (6%)		
Endoscopic Ultrasound	Oesophageal	18 (58%)	13 (42%)		
	Junctional	17 (55%)	14 (45%)		
	Gastric	3 (10%)	23 (74%)	5 (16%)	
Staging Laparoscopy	Oesophageal	2 (7%)	25 (83%)	3 (10%)	1
	Junctional	12 (40%)	18 (60%)		1
	Gastric	20 (67%)	10 (33%)		1

Access to Surgical Services

Due to the specialist skills required to perform surgical resections, it is recommended that O-G cancer surgery is centralised [7]. A high-level of consultant commitment is required to manage postoperative care, and it is recommended that surgical teams contain at least 3 specialist consultant surgeons [21].

There were 63 trusts identified by the Cancer Networks as performing surgery. Of these, 46 corresponded to designated specialist cancer centres. The other 17 were local units which still performed some resections.

All of the centres and 9 local units performed both oesophageal and gastric surgery; the 8 remaining units only performed gastric surgery. There was a variable number of surgeons reported as operating within each trust **(see Table 8).** The surgical teams contained 143 upper GI surgeons and 13 thoracic surgeons. The thoracic surgeons were employed at 9 trusts.

Among the responding trusts, 22 (48 per cent) of the centres and all local units had teams containing fewer than 3 surgeons, and so did not meet the recommended minimum.

Table 8:
Number of surgeons within surgical teams at trusts performing surgery

	Number of surgeons per trust				
	1	**2**	**3**	**4**	**5**
Cancer centres (n = 46)	0 (0%)	22 (48%)	15 (33%)	3 (7%)	6 (13%)
Local units (n = 17)	9 (53%)	8 (47%)			

Table 9:
Availability of Endoluminal Palliative Therapy within each Cancer Network

Modality of Therapy	**Available**	**Not available**
Stent insertion	31 (100%)	0
Laser ablation therapy	17 (55%)	14 (45%)
Argon beam coagulation	30 (97%)	1 (3%)
Photodynamic therapy	10 (32%)	21 (68%)
Brachytherapy	17 (55%)	14 (45%)

Access to endoluminal and oncological therapy

It is recommended that oesophageal stenting and either laser or photodynamic therapy should be available for the treatment of obstructive oesophageal symptoms and tumour overgrowth.[12,5] In addition, because the selection of particular techniques depends on patients' individual characteristics, it is recommended that patients should have access to a range of therapies.[5]

Cancer Networks are generally providing access to a range of techniques in accordance with these standards, although there is some variation **(see Table 9)**. The availability of laser therapy and brachytherapy is limited, with only 17 Cancer Networks providing either form of care. No standard exists regarding the provision of brachytherapy. However, the SIGN guideline noted brachytherapy to be superior to stenting alone if patients live longer than 140 days.[5]

Only two Cancer Networks reported being unable to provide access to endoscopic palliative therapy within two weeks of the decision to treat. In one network, this delay was attributed to a lack of specialist endoscopist time, while the other attributed it to "generally poor communication".

In terms of access to oncology treatment within 2 weeks of the decision to treat:

- 3 of the 31 Cancer Networks (10 per cent) reported difficulty for chemotherapy,
- 5 of the 31 networks (16 per cent) reported difficulty for radiotherapy.

There was no distinction between palliative and curative patients in terms of which patients suffered delays.

Table 10
Issues reported and discussed at the MDT meeting

Issues discussed	**Trusts (n = 128*)**	**%**
Treatment planning	128	100%
Changes to a previous treatment plan	121	95%
Results of curative surgery (inc pathology)	100	78%
Results of curative oncological therapy	77	60%

5.2 Trust characteristics

Multi-disciplinary teams

The Improving Outcomes Guidance recommends that the specialist oesophago-gastric cancer team should be involved in the management of all patients, even if formal referral is not appropriate because of metastatic disease or extensive co-morbidity.[7] Among the responding Cancer Networks, 16 reported discussing all patients at the specialist MDT meeting, while the remaining 15 reported only reviewing patients requiring specialist input. The issues that trusts reported discussing at the MDT meetings are shown in **Table 10.**

It is recommended that palliative care teams for O-G cancer patients consist of (as a minimum) a palliative medicine consultant and a specialist nurse, and that a representative from this team attend the weekly multi-disciplinary team meetings.[7,14] The majority of trusts (84 per cent) reported having both a palliative care consultant and a palliative nurse specialist but there was some variation **(Table 11)**. Notably, 3 of the responding centres reported not having a palliative care consultant. No member of the palliative care team routinely attended the MDT meeting at 10 of the 39 cancer centres (26 per cent) and 26 of the 93 local units (28 per cent).

Table 11
Consultant and nurse specialist membership of palliative care teams

Palliative care team	**Centres (n = 39)**	**Units (n = 93)**
Consultant and nurse specialist	34 (87%)	77 (83%)
Consultant only	3 (8%)	5 (5%)
Nurse specialist only	2 (5%)	11 (12%)

---

* 4 trusts had missing values.

Table 12
Types of patient who have access to a dietician for specialist nutritional advice

Types of O-G cancer patient	Centres (n = 39)	Units (n = 93)
Surgical inpatients	29 (74%)	55 (59%)
All other O-G cancer inpatients	35 (90%)	79 (85%)
Outpatients	33 (85%)	73 (78%)
No specialist support available	0	5 (5%)

It is recommended that all patients with oesophageal or gastric cancer have access to a registered dietician if needed and are assessed for nutritional risk using a validated screening tool.[7,5] Access to specialist nutritional support is provided for both inpatients and outpatients at 68 of the 132 trusts (54 per cent) and the degree of access is variable overall **(Table 12)**. In particular, 5 per cent of local units do not have access to a dietician any O-G cancer patients, and 26 per cent of cancer centres have no dietician support for their surgical inpatients.

An MDT coordinator was employed within the MDT in 125 of the 132 trusts (97 per cent). However, while 72 per cent of trusts used an IT system to manage their clinical data, only 15 centres (38 per cent) and 27 units (29 per cent) had data clerks to support routine data collection.

Patient-centred care

It is recommended that all patients with oesophageal or gastric cancer have access to a clinical nurse specialist.[7,21,5] They play a critical role in coordinating patient care and it is recommended that they act as the central contact point, both for the team and for patients.[7] The number of specialist nurses at each trust was found to vary across the country. The majority have at least 1 or 2 part-time nurses and 23 trusts (17 per cent) have either 2 or 3 full-time nurse specialists. There were more nurses in larger trusts, with cancer centres being significantly more likely to have at least 1 full-time or 2-part time nurse specialists. However, 10 units (11 per cent) reported having no clinical nurse specialists.

The importance of providing information to patients was widely accepted. Some form of written material was provided by 124 trusts (94 per cent). The material typically contained information on the disease, the diagnostic process, and the options for treatment, although information about nutrition and patient support groups was also provided by 111 trusts (84 per cent) and 109 trusts (83 per cent), respectively.

5.3 Findings of the Cancer Action Team Peer Review

Between 2004 and 2007, the Cancer Action Team undertook a peer-review exercise to assess the degree to which English NHS trusts were meeting the O-G cancer measures specified in the National Cancer Manual.[21] The evaluation covered some of the areas included in the audit questionnaire but it was based on a combination of self-reported data and visits to the trusts.

The peer-review exercise reported that MDTs were established in all Cancer Networks but that the attendance by the core team was variable. All core members attended at least two-thirds of the MDT meetings at only 23 per cent of units and 37 per cent of cancer centres. Unfortunately, figures were not available specifically for palliative care team attendance at MDT meetings but this was also identified as a problematic area. The peer-review exercise also reported that MDTs had made limited progress in implementing routine audit and collecting the minimum dataset. This is consistent with our finding of limited administrative support.

Action Plans were found to have been agreed in 74 per cent of Cancer Networks at the time of peer-review, and the process of centralisation was ongoing. At the time of peer-review, the proportion of surgical teams containing at least three surgeons was found to be 38 per cent. The audit results show a slight improvement in this area but performance is still poor.

The peer-review exercise found that there were a total of 176 filled clinical nurse specialist posts, of which 112 were employed in units and 64 were employed in centres. Peer-review found that 17 per cent of units did not have nurse specialist posts, a figure higher than reported to this audit. It is unclear whether overall provision has improved or whether units included in their audit questionnaire response nurse specialists attending their clinics although their formal post was at a cancer centre. Peer review found one centre-based O-G cancer team without a nurse specialist.

The average number of nurse specialist posts was 0.85 for units, and problems were found at 31 per cent of units with workload intensity and providing cover for illness / leave. For centres, the figures were 1.4 posts and 14 per cent respectively.

Finally, written patient information was provided at 70 per cent of units and 88 per cent of centres. The audit results may suggest improvement in this area.

6 Discussion

There has been a substantial transformation of oesophago-gastric cancer services in England and Wales over the last decade. It has been due in part to changes in the incidence of the disease but it has also been driven by changes in the clinical evidence underpinning treatment decisions as well as changes in the organisation of services. In particular, key recommendations have been that:

- all O-G cancer patients should be managed by multi-disciplinary teams
- Cancer Networks should be established as new regional models for providing integrated cancer care
- within each Cancer Network, specialist surgical teams should be established at appropriate cancer centres
- patients should have access to computed tomography (CT) scan, endoscopic ultrasound (EUS) and staging laparoscopy for rapid staging
- palliative care should be an integral part of patient management and patients should have access to specialist palliative interventions when required.

The work undertaken so far by the audit suggests that the transformation of services has improved the care received by patients. Moreover, there has been a steady rise in survival rates during this period.[20] Nonetheless, the process of reorganisation is still ongoing and there are various areas in which further work is required.

A centralised service run by a multi-disciplinary team

The stakeholders were in broad agreement that a core requirement for a quality O-G cancer service was a multi-disciplinary team led approach with centralised, specialist services. Implementing this system was viewed as having produced substantial improvements in care, not least because of the expertise accumulated by health professionals being routinely involved in the care of O-G cancer patients.

The reorganisation process is not yet complete in the 33 Cancer Networks in England and Wales. In particular, 12 of the 31 networks who responded to the organisational audit still had to complete the centralisation of specialist surgery. In addition to the 47 known cancer centres, 17 trusts were identified as still performing curative surgery. It is not clear what proportion of curative surgery is currently being performed outside the cancer centres. The analysis of Registry-HES data found that the cancer centres undertook 65 per cent of surgical resections in 2005. The proportion may now be higher but these figures suggest that progress is still required in this area.

The organisational audit also suggests that the size of the surgical teams needs reviewing in many networks. In 62 per cent of the responding units, surgical teams were reported to consist of 1 or 2 upper GI surgeons, which is less than the minimum recommendation of 3.[21] The small surgical teams were not limited to those trusts not designated as cancer centres.

There appeared to be good access to endoscopic and radiological palliative therapies overall. All 31 responding networks were able to provide stent insertion and argon beam coagulation, but only 17 networks provided laser ablation therapy and brachytherapy. Two networks could not provide access to endoscopic palliative therapy within 2 weeks of the decision to treat.

All NHS trusts have established multi-disciplinary teams which meet regularly to plan the treatments of patients. It is recommended that the care plan of every patient is discussed with a member of the specialist O-G cancer MDT.[7] Although it is not a requirement that this discussion takes place at an MDT meeting, 16 of the 31 networks who responded to the organisational audit reported that all patients were discussed at the specialist MDT meetings. However, some interviewed stakeholders commented that, in their experience, not all patients were being discussed with the specialist MDT in different locations. This was a concern because it might affect the quality of symptom control for palliative care patients.

The organisational audit identified several issues related to the functioning of MDTs that require improvement. In particular, there needs to be better integration of palliative care team members and dieticians. A high proportion of O-G cancer patients receive palliative care and it is important to ensure patients maintain an adequate nutritional intake. Among respondents to the organisational audit, no member of the palliative care team routinely attends the MDT meeting at 10 of the cancer centres (36 per cent) and 26 of the local units (28 per cent). In addition, dieticians are involved in the assessing the nutrition needs of all patients at only 54 per cent of responding trusts. Finally, administrative support for the MDT is poor, with only 38 per cent of the responding centres and 29 per cent of the responding units having a data clerk.

A rapid and efficient staging process

Recent clinical guidelines and policy guidance for O-G cancer services in England and Wales have emphasised the importance of establishing the stage of a patient's cancer accurately and rapidly. Respondents to the organisational audit reported that, overall, patients had good access to the recommended staging investigations. Moreover, the generally high level of compliance among trusts with the cancer waiting times policy for fast-track referrals[22] suggests that networks have established rapid processes for patients. The interviewed stakeholders supported this view, although there was a concern about the availability of histopathologists.

There was variation in the staging policies adopted within the Cancer Network, notably in relation to which patients underwent endoscopic ultrasound and laparoscopy. It is not clear to what extent these different policies produce variation between regions within England and Wales, and whether this is related to differences in selected treatment options and outcomes. This will be examined in the prospective audit.

Patient-centred care and the role of the clinical nurse specialist

The stakeholders emphasised that patient-centred care was a core requirement for O-G cancer services, and stressed the need to support patients and provide clear information. They also identified the clinical nurse specialist as being fundamental to its provision because of their unique coordinating role and because they provide a single point of contact for the patient.

Among respondents to the organisational audit, patient-centred care was a widely supported principle. Almost all trusts reported providing various types of patient information and there was widespread use of clinical nurse specialists. There was variation in the number employed in individual trusts but whether this signifies limited access in some regions is unclear. Nonetheless, it is of concern that ten local units reported having no nurse specialist. Moreover, the comments from the stakeholders suggest that the importance of the nurse specialist was not always appreciated outside the O-G cancer MDT. This is despite the IOG recognising their crucial role in coordinating patient care and recommending that the clinical nurse specialist act as the central point of contact for both the team and patients.[7] Trusts should also ensure that the effectiveness of nurse specialists is not compromised by insufficient support.

Final comments

The stakeholder interviews raised various other issues. First, it was noted that, by the time patients diagnosed with O-G cancer first present with their symptoms, many will already have advanced disease. This fact means that even if treatment services were perfect, many patients would not be suitable for treatment with curative intent. Stakeholders suggested three strategies to increase the proportion of patients who present with the disease in an early stage:

1 educate patients so they are able to identify the warning symptoms,

2 clarify the referral guidance, and

3 educate general practitioners about appropriate referral pathways.

Second, a corollary to establishing a health service organised into cancer centres and local units is the need for good communication between health care professionals. The stakeholders noted that problems could occur anywhere along the care pathway (diagnosis, staging or treatment) and, if they did, would result in delays. The work undertaken for the first annual report did not allow this issue to be assessed directly. However, the time between referral and the start of treatment will be examined during the prospective audit.

Finally, stakeholders raised concerns about the levels of funding available for the ongoing process of reorganisation, especially in regions where this process is far from complete. Two areas in particular were highlighted as requiring more investment. The first was the new MDT structures. The second was the centralisation of surgery. It was suggested that commissioners should review whether these issues are being given sufficient priority.

7 Conclusion

Various clinical guidelines and government policies have established clear standards for oesophago-gastric cancer services in England and Wales. These documents set out a model of care that is built around the idea of networked specialist services and multi-disciplinary teams providing patient-centred care. This model has been widely accepted. Moreover, there is a general view that the process of diagnosis and staging has been improved considerably and that most patients have access to an appropriate range of curative and palliative treatments.

Against this generally positive assessment must be balanced several issues of concern. In particular, the process of centralisation of surgery is not complete and the provision of specialist palliative care support is limited in some areas. There is still variation between networks on staging practices, the functioning of MDT meetings, as well as access to endoscopic palliative therapies, clinical nurse specialists, and nutritional support. The extent to which these differences influence patterns of care and outcomes will be explored in the next stage of this audit.

Recommendations

- Cancer Networks should complete the centralisation of surgery as soon as possible and ensure that there are sufficient surgeons in each cancer centre to provide comprehensive cover.
- Networks should provide a full range of palliative therapies and these should be consistently available within 2 weeks of the decision to treat.
- Trusts should ensure that palliative care teams are sufficiently well-resourced to allow attendance at MDT meetings and their involvement at an early stage of a patient’s care.
- All patients with O-G cancer should be discussed with the specialist MDT at the cancer centre.
- Trusts should ensure that patients have sufficient access to clinical nurse specialists.
- Dietician access should be improved so that all patients have access to specialist nutritional support when required.
- Trusts should ensure that there is sufficient administrative support to facilitate routine data collection and clinical audit.

Appendix

Appendix 1:

Project Board and Clinical Reference Group

Members of Clinical Reference Group

Mike Hallisey	Consultant Surgeon Birmingham	Association of Cancer Surgeons
Geoff Clark	Consultant Surgeon	Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland
Stuart Cairns	Consultant Gastroenterologist	British Society of Gastroenterologists
Martin Richardson	Consultant Surgeon	Cancer Networks
Phil Hill	Information Strategy Lead	Department of Health, Cancer Policy Unit
Helen Laing	Clinical Audit Commissioning Manager	Healthcare Commission
Nick Black (chair)	Professor of Health Services Research,	London School of Hygiene and Tropical Medicine
Bill Allum	National O-G Cancer Lead (joint)	National Cancer Action Team
Chris Carrigan	National Co-ordinator for Cancer Registration	National Cancer Action Team
David Kirby OBE	Chairman	Oesophageal Patients Association
Andrea Burgess	Specialist Nurse	Royal College of Nursing
Suzanne Ball	Nurse Specialist for Surgery	Royal College of Nursing
Geraint Williams	Professor of Histopathology	Royal College of Pathologists
David Breen	Consultant Radiologist	Royal College of Radiologists
Sam Ahmedzai	Professor of Supportive Care Medicine	Palliative Care Representative
Jane Blazeby	Professor of Surgery	University of Bristol
Tom Crosby	Consultant Clinical Oncologist	Cancer Services Co-ordinating Group

Members of Project Board

Martin Old	Board Executive	National Clinical Audit Support Programme, The NHS Information Centre for health and social care
Helen Laing	Commissioner	Healthcare Commission
Mike Griffin	President	Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland
Mark Denyer	Chair of the BSG Audit and Clinical Services Committees	British Society of Gastroenterologist

---

* excludes project team members.

Appendix 2:

The dataset for the prospective audit

The dataset for the prospective audit consists for four components.

- **Part 1** (patient details, tumour and planned treatment) concerns newly diagnosed patients and contains data items related to their diagnosis, stage and treatment intent.
- **Part 2** (surgery) concerns patients who undergo either curative or palliative surgery and contains data items on the surgical treatment and pathology results (resections only).
- **Part 3** (oncology) concerns patients who undergo oncological treatment and contains data items on neoadjuvant, adjuvant, definitive and palliative treatments.
- **Part 4** (endoscopic therapy) concerns patients who undergo endoscopic therapeutic procedures.

Patients will only have one treatment record for surgery and endoscopic therapeutic procedures. Patients will generally only have one oncology record. However, two oncology records will be created if the patient undergoes both neoadjuvant and adjuvant therapy (oncology before and after surgery). Not all items will be relevant to each patient.

The data items in the audit dataset have been presented as they might look on data collection forms. A technical description of the dataset can be obtained from the audit website.

National Oesophago-Gastric Cancer Audit
New Patient Registration datasheet – Page 1

Part 1

Patient Details:

Surname:	Forename:
NHS Number:	Postcode:
Sex: Male ☐ Female ☐ Not specified ☐	Date of birth:

Initial Referral and Diagnosis Data

Source of referral:	GP ☐	Hospital consultant ☐	Emergency administration ☐	Not known ☐
Priority of referral (GP referral only):		Urgent ☐	Non-urgent / other referral source ☐	

Date of first referral to local oesophago-gastric team for investigation:

Date of diagnosis:

Local cancer unit where cancer was diagnosed:

Diagnosis – Site

Oesophagus:	Upper ⅓ ☐	Middle ⅓ ☐	Lower ⅓ ☐	***NB: cervical oesophageal tumours are not included in this audit***

Gastro-Oesophageal Junction (adenocarcinomas only) Siewert classification:

	1 ☐	2 ☐	3 ☐	
Stomach:	Fundus ☐	Body ☐	Antrum ☐	Pylorus ☐

Diagnosis – Histology

Adenocarcinoma	☐	Squamous cell carcinoma	☐
Adenosquamous carcinoma	☐	Small-cell carcinoma	☐
Undifferentiated carcinoma	☐	Other epithelial carcinoma	☐

Unspecified malignant neoplasm (histology not done) ☐

NB: Non-epithelial tumours (GIST, sarcomas or melanomas) are NOT included in this audit

Staging Investigations (please tick all that apply)

CT scan	☐	PET / PET – CT scan	☐
Endoscopic ultrasound (EUS)	☐	EUS Fine needle aspiration	☐
Staging laparoscopy	☐	Other investigation	☐

Pre - Treatment Stage

T:	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	x ☐
N:	0 ☐	1 ☐	2 ☐	3 ☐		x ☐
M:	0 ☐	1 ☐	M1a ☐	M1b ☐		x ☐

National Oesophago-Gastric Cancer Audit
New Patient Registration datasheet – Page 2

Part 1

ECOG (WHO) Performance Status

0 ☐ Carries out all normal activity without restriction	3 ☐ Limited self care, confined to bed or chair for >50% waking hours
1 ☐ Restricted but walks/does light work	4 ☐ Fully disabled, confined to bed/chair
2 ☐ Walks, full self care but no work. Up and about >50% of the time	5 ☐ Not recorded

Comorbidities (please tick all that are appropriate)

Chronic renal impairment	☐	Liver failure or cirrhosis	☐	Diabetes	☐
Cerebro/periph vascular	☐	Other epithelial carcinoma	☐	Mental illness	☐
Other significant condition	☐	Barrett's oesophagus	☐		

Treatment Plan

Date final care plan agreed:

Treatment intent:

Curative:	☐
Palliative anti-cancer treatment:	☐ (ie. surgery, oncological treatment, endoscopic palliation)
Palliative supportive care:	☐ (ie. non-specific symptomatic treatments, inpatient or outpatient)

Details of treatment

Curative modality:		**Palliative modality:**	
Surgery only	☐	Palliative surgery	☐
Chemotherapy and surgery (any combination)	☐	Palliative oncology (unspecified)	☐
Chemo-radiotherapy and surgery (any combination)	☐	Photodynamic therapy	☐
(Definitive) Radiotherapy only	☐	Endoscopic palliation therapy (unspecified)	☐
Definitive chemo-radiotherapy	☐		
Endoscopic mucosal resection	☐		

Reason for palliative treatment (please tick all that are appropriate):

Patient declined treatment	☐	Unfit: poor performance status	☐
Unfit: significant co-morbidity	☐	Unfit: advanced stage cancer	☐
Not known	☐		

National Oesophago-Gastric Cancer Audit
Postoperative Datasheet – Page 1

Part 2

Patient Details (for patient identification only)

Surname:	Forename:
NHS Number:	Date of birth:

Admission and Surgical Details (Main procedure only)

Hospital name:	Patient's lead surgeon (GMC no.):
Date of admission:	Date of operation:

Pre-operative intent of surgery: Palliative ☐ Curative ☐ Not known ☐

Priority of surgery (NCEPOD): Immediate (1) ☐ Urgent (2) ☐ Expedited (3) ☐ Elective (4) ☐

Fitness for Surgery: ASA grade 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

Lung function: FEV1% predicted % FEV1% predicted %

Procedure

Oesophageal		**Gastric**			
– Oesophagectomy		Gastrectomy:			
Left thoraco-abdominal approach	☐	Total	☐	Extended total	☐
2 – Phase (Ivor-Lewis)	☐	Proximal	☐	Distal	☐
3 – Phase (McKeown)	☐	Completion	☐	Merendino	☐
Transhiatal	☐	Wedge/localised gastric resection	☐		
Thoracotomy (Open and Shut)	☐	Bypass procedure/Jejunostomy only	☐		
		Laparotomy (Open and Shut)	☐		

Surgical Access (thoracic) – the approach used for the thoracic phase of the operation (if applicable)

Open operation ☐ Thoracoscopic converted to open ☐ Thoracoscopic completed ☐ Not applicable ☐

Surgical Access (abdominal) – the approach used for the abdominal phase of the operation

Open operation ☐ Laparoscopic converted to open ☐ Laparoscopic completed ☐

Feeding Adjunct: Spleen ☐ Parenteral feeding ☐ Other ☐ None ☐

Other Organ removed

Liver ☐ Pancreas ☐ Colon ☐

Spleen ☐ Other ☐

Nodal Dissection

Oesophagectomy:	None ☐	1 – field ☐	2 – field ☐	3 – field ☐
Gastrectomy:	D0 ☐ (peri-gut resection)	D1 ☐	D2 ☐	D3 ☐

National Oesophago-Gastric Cancer Audit
Postoperative Datasheet – Page 2

Part 2

Postoperative complications and course (please tick all that apply)

Anastomotic leak	☐	**Respiratory:**	Pneumonia	☐
Chyle leak	☐		ARDS	☐
Haemorrhage	☐		Pulmonary embolism	☐
Cardiac complication	☐		Pleural effusion	☐
Acute renal failure	☐		Wound infection	☐
Unplanned return to theatre?	Yes ☐	No ☐		
Death in hospital?	Yes ☐	No ☐		
Date of discharge or death:				

Postoperative Pathology and Staging

Site

Oesophagus:	Upper ⅓ ☐	Middle ⅓ ☐	Lower ⅓ ☐	***NB: cervical oesophageal tumours are not included in this audit***

Gastro-Oesophageal Junction (adenocarcinomas only) Siewert classification:

	1 ☐	2 ☐	3 ☐	
Stomach:	Fundus ☐	Body ☐	Antrum ☐	Pylorus ☐

Histology:

Adenocarcinoma	☐	Squamous cell carcinoma	☐
Adenosquamous carcinoma	☐	Small-cell carcinoma	☐
Undifferentiated carcinoma	☐	Other epithelial carcinoma	☐

Unspecified malignant neoplasm (histology not done) ☐

NB: Non-epithelial tumours (GIST, sarcomas or melanomas) are NOT included in this audit

Proximal resection margin involved?	Yes ☐	No ☐	Unknown ☐	
Distal resection margin involved?	Yes ☐	No ☐	Unknown ☐	
Circumferential resection margin involved? (<1mm)	Yes ☐	No ☐	Unknown ☐	N/A ☐

Number of lymph nodes examined:

Number of lymph nodes positive:

Post operative staging:

T:	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	x ☐
N:	0 ☐	1 ☐	2 ☐	3 ☐		x ☐
M:	0 ☐	1 ☐	M1a ☐	M1b ☐		x ☐

History of neo-adjuvant therapy	Yes ☐	No ☐

National Oesophago-Gastric Cancer Audit
Chemotherapy / Radiotherapy Datasheet

Part 3

Patient Details (for patient identification only)	
Surname:	Forename:
NHS Number:	Date of birth:

Hospital of treatment
Hospital where oncology treatment took place

Treatment Details				
Treatment intent:	Neoadjuvant ☐	Adjuvant ☐	Curative ☐	Palliative ☐
Intended treatment modality:	Chemotherapy ☐	Radiotherapy ☐	Chemo-radiotherapy ☐	

Chemotherapy details (if applicable)	
Date first cycle started:	
No. cycles prescribed:	
No. cycles prescribed:	
Chemotherapy treatment protocol:	
OEO2 ☐	MAGIC / STO 2 ☐
MacDonald ☐	Other ☐

Outcome of treatment:

Treatment completed as prescribed ☐

Reason if incomplete

Patient died ☐

Acute chemotherapy toxicity ☐

Technical or organisational problems ☐

Patient choice (stopped / interrupted treatment) ☐

Not known ☐

Radiotherapy details (if applicable)
Date first fraction started:
Total dose prescribed:
No. fractions prescribed:
Total actual dose given
Actual no. fractions given:

Outcome of treatment:

Treatment completed as prescribed ☐

Reason if incomplete

Patient died ☐

Acute chemotherapy toxicity ☐

Technical or organisational problems ☐

Patient choice (stopped / interrupted treatment) ☐

Not known ☐

National Oesophago-Gastric Cancer Audit Endoscopic / Radiological Palliative Therapy Datasheet – Procedure Details

Part 3

Please fill in this datasheet for every patient with oesophago-gastric cancer on the occasion of their FIRST PALLIATIVE endoscopic / radiological therapeutic intervention.

Patient Details (for patient identification only)	
Surname:	Forename:
NHS Number:	Date of birth:

Treatment Details
Hospital name:
GMC code of responsible consultant:
Date of endoscopic / radiological procedure:

Dysphagia Rating Scale	
0 ☐ No dysphagia	3 ☐ Able to consume liquids only
1 ☐ Able to eat solids	4 ☐ Complete dysphagia
2 ☐ Able to eat semi-solids only	5 ☐ Not known

Type of procedure (please tick all that apply)

Insertion of stent	☐	Laser therapy	☐	Argon beam coagulation	☐
Photodynamic therapy	☐	Gastrostomy	☐	Brachytherapy	☐
Dilatation	☐ *(Tick dilatation if it was the only procedure* _or_ *if required to facilitate treatment)*				
Other	☐				

Is this procedure part of a planned course of multiple interventions? Yes ☐ No ☐ Not known ☐

Anaesthesia: Sedation ☐ Local anaesthetic spray ☐ General anaesthesia ☐
Sedation and local anaesthetic spray combined ☐ Not known ☐

Grade of endoscopist: Consultant ☐ Assoc. specialist/Staff grade ☐ Registrar ☐
Senior House Officer ☐ Nurse specialist ☐ Other clinician ☐

Details of stent procedure, if inserted:

Type of stent: Plastic ☐ Metal: covered ☐ Metal: uncovered ☐ Metal: Anti-reflux ☐ Not known ☐

Method of stent placement: Fluoroscopic control ☐ Endoscopic control ☐ Fluoroscopic and Endoscopic ☐ Not known ☐

Stent crosses gastro-oesophageal junction? Yes ☐ No ☐ Unknown ☐

Did the stent deploy successfully? Yes ☐ No ☐ Unknown ☐

National Oesophago-Gastric Cancer Audit
Endoscopic / Radiological Palliative Therapy Datasheet – Outcomes at 3 months

Part 4

Use this datasheet to collect the details of complications and any subsequent palliative endoscopic/ radiological therapeutic procedures that occur 3 months after the initial palliative intervention.

Patient Details (for patient identification only)	
Surname:	Forename:
NHS Number:	Date of birth:
Hospital name:	
Date of INITIAL PALLIATIVE endoscopic/radiological therapeutic procedure:	

Additional planned endoscopic/radiological palliation that occurred with 3 months of the initial procedure

Number of additional planned treatments:

Type of procedure (please tick all that apply)

Insertion of stent	☐	Laser therapy	☐	Argon beam coagulation	☐
Photodynamic therapy	☐	Gastrostomy	☐	Brachytherapy	☐
Dilatation	☐	*(Tick dilatation if it was the only procedure or if required to facilitate treatment)*			
Other	☐				

Is this procedure part of a planned course of multiple interventions? Yes ☐ No ☐ Not known ☐

Complications of palliative endoscopic/radiological interventions and failure to control local disease (Please tick all that apply)

Aspiration	☐	Perforation	☐
Haemorrhage	☐	Stent migration	☐
Bolus obstruction	☐	Tumour overgrowth	☐
Death in hospital (ie patient did not leave hospital between first procedure and death	☐	Other	☐

Additional unplanned endoscopic/radiological palliation procedures (due to complications of endoscopic/radiological palliation and/or tumour progression)

Number of additional unplanned interventions:

Type of additional unplanned intervention(s) (please tick all that apply)

Stent insertion/replacement	☐	Laser therapy	☐	Argon beam coagulation	☐
Photodynamic therapy	☐	Gastrostomy	☐	Brachytherapy	☐
Dilatation	☐	*(Tick dilatation if it was the only procedure or if required to facilitate treatment)*			
Other	☐				

Appendix 3:

Respondents to the Organisational Audit

All English Cancer Networks and the South East Wales Cancer Network returned the Network level organisational audit.

The English and Welsh NHS trusts that returned the Trust-level organisational audit were (excludes one unknown English NHS trust):

- Aintree University Hospitals NHS Foundation Trust
- Airedale NHS Trust
- Ashford and St Peter's Hospitals NHS Trust
- Barking, Havering and Redbridge Hospitals NHS Trusts
- Barts and The London NHS Trust
- Bedford Hospital NHS Trust
- Blackpool, Fylde and Wyre Hospitals NHS Trust
- Bolton Hospitals NHS Trust
- Bradford Teaching Hospitals NHS Foundation Trust
- Brighton and Sussex University Hospitals NHS Trust
- Bro Morgannwg NHS Trust
- Bromley Hospitals NHS Trust
- Buckinghamshire Hospitals NHS Trust
- Burton Hospitals NHS Trust
- Calderdale and Huddersfield NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust
- Central Manchester and Manchester Children's University Hospitals NHS Trust
- Chelsea and Westminster Hospital NHS Foundation Trust
- Chesterfield Royal Hospital NHS Foundation Trust
- Christie Hospital NHS Foundation Trust
- City Hospitals Sunderland NHS Foundation Trust
- Clatterbridge Centre for Oncology NHS Foundation Trust
- Dartford and Gravesham NHS Trust
- Derby Hospitals NHS Foundation Trust
- Doncaster and Bassetlaw Hospitals NHS Foundation Trust
- Dorset County Hospital NHS Foundation Trust
- Ealing Hospital NHS Trust
- East Kent Hospitals NHS Trust
- East Lancashire Hospitals NHS Trust
- East and North Hertfordshire NHS Trust
- Essex Rivers Healthcare NHS Trust
- Frimley Park Hospital NHS Foundation Trust
- Gateshead Health NHS Foundation Trust
- George Eliot Hospital NHS Trust
- Gloucestershire Hospitals NHS Foundation Trust
- Guys and St Thomas NHS Foundation Trust
- Harrogate and District NHS Foundation Trust
- Heart of England NHS Foundation Trust
- Heatherwood and Wrexham Park Hospitals NHS Foundation Trust
- Hereford Hospitals NHS Trust
- Homerton University Hospital NHS Foundation Trust
- Hull And East Yorkshire Hospitals NHS Trust

- Imperial College Healthcare NHS Trust
- Ipswich Hospital NHS Trust
- Isle of Wight Healthcare NHS Trust
- James Paget University Hospitals NHS Foundation Trust
- Kettering General Hospital NHS Trust
- Lancashire Teaching Hospitals NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust
- Maidstone and Tunbridge Wells NHS Trust
- Mayday Healthcare NHS Trust
- Mid Staffordshire General Hospitals NHS Trust
- Mid Yorkshire Hospitals NHS Trust
- Milton Keynes General Hospital NHS Trust
- Gwent Healthcare NHS Trust
- Newham University Hospital NHS Trust
- Norfolk and Norwich University Hospital NHS Trust
- North Bristol NHS Trust
- North Cheshire Hospitals NHS Trust
- North Cumbria Acute Hospitals NHS Trust
- North Hampshire Hospitals NHS Trust
- North Middlesex University Hospital NHS Trust
- North Tees and Hartlepool NHS Trust
- Northampton General Hospital NHS Trust
- Northern Devon Healthcare NHS Trust
- Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
- Northumbria Health Care NHS Foundation Trust
- Nottingham University Hospitals NHS Trust
- Oxford Radcliffe Hospitals NHS Trust
- Pennine Acute Hospitals NHS Trust
- Plymouth Hospitals NHS Trust
- Poole Hospital NHS Trust
- Queen Elizabeth Hospital NHS Trust
- Queen Mary’s Sidcup NHS Trust
- Royal Berkshire And Battle Hospitals NHS Trust
- Royal Bournemouth And Christchurch Hospitals NHS Foundation Trust
- Royal Cornwall Hospitals NHS Trust
- Royal Devon and Exeter NHS Foundation Trust
- Pontypridd and Rhondda NHS Trust
- Royal Liverpool and Broadgreen University Hospitals NHS Trust
- Royal Surrey County Hospital NHS Trust
- Royal United Hospital Bath NHS Trust
- Dudley Group of Hospitals NHS Trust
- Salford Royal Hospitals NHS Trust
- Salisbury NHS Foundation Trust
- Scarborough and North East Yorkshire Health Care NHS Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- Shrewsbury and Telford Hospital NHS Trust
- South Devon Healthcare NHS Foundation Trust
- South Tees Hospitals NHS Trust

- South Tyneside NHS Foundation Trust
- South Warwickshire General Hospitals NHS Trust
- Southampton University Hospitals NHS Trust
- Southport and Ormskirk Hospital NHS Trust
- St George's Healthcare NHS Trust
- Stockport NHS Foundation Trust
- Surrey and Sussex Healthcare NHS Trust
- Swansea NHS Trust
- Swindon and Malborough NHS Trust
- Tameside and Glossop Acute Services NHS Trust
- Taunton and Somerset NHS Trust
- The Mid Cheshire Hospitals NHS Trust
- The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust
- The Princess Alexandra Hospital NHS Trust
- The Rotherham NHS Foundation Trust
- The Royal Marsden NHS Foundation Trust
- The Royal Wolverhampton Hospitals NHS Trust
- Trafford Healthcare NHS Trust
- United Bristol Healthcare NHS Trust
- United Lincolnshire Hospital NHS Trust
- University Hospital Birmingham NHS Foundation Trust
- Cardiff and Vale NHS Trust
- University Hospital of North Staffordshire NHS Trust
- University Hospitals Coventry and Warwickshire NHS Trust
- University Hospitals of Leicester NHS Trust
- University Hospitals of Morecambe Bay NHS Trust
- Walsall Hospitals NHS Trust
- West Hertfordshire NHS Trust
- West Middlesex University Hospital NHS Trust
- West Suffolk Hospitals NHS Trust
- Weston Area Health NHS Trust
- Whipps Cross University Hospital NHS Trust
- Winchester and Eastleigh Healthcare NHS Trust
- Wirral University Teaching Hospital NHS Foundation Trust
- Worcestershire Acute Hospitals NHS Trust
- Worthing and Southlands Hospitals NHS Trust
- North East Wales NHS Trust
- Wrightington, Wigan and Leigh NHS Trust
- South Manchester University Hospitals NHS Trust
- Yeovil District Hospital NHS Foundation Trust
- York Hospitals NHS Foundation Trust

Glossary

Adjuvant treatment – An additional therapy (e.g. chemotherapy or radiotherapy) provided to improve the effectiveness of the primary treatment (e.g. surgery). This may aim to reduce the chance of local recurrence of the cancer or to improve the patient's overall chance of survival.

Ablation – a palliative technique (performed by laser or argon beam coagulation) that aims to reduce symptoms by destroying the surface of the tumour, thereby shrinking it in size.

AUGIS – Association of Upper GI Surgeons

BSG – British Society of Gastroenterologists

BASO – British Association of Surgical Oncology

Brachytherapy – Brachytherapy is a palliative treatment that involves inserting radioactive beads into the tumour. The radiation from these beads then slowly shrinks the tumour over time.

Cancer Registry – The Cancer Registries (Eight in England, and one each for Wales, Scotland and Northern Ireland) collect, analyse and report data on cancers in their area, and submit a standard dataset on these registrations to the Office for National Statistics.

Chemotherapy – Drug therapy used to treat cancer. It may be used alone, or in conjunction with other types of treatment (e.g. surgery or radiotherapy).

CRG – The audit's Clinical Reference Group is comprised of representatives of the key stakeholders in oesophago-gastric cancer care. They advise the Project Team on particular aspects of the project and provide input from the wider clinical and patient community.

CEU – The Clinical Effectiveness Unit is an academic collaboration between The Royal College of Surgeons of England and the London School of Hygiene and Tropical Medicine, and undertakes national surgical audit and research. It is one of the key stakeholders leading the audit.

Clinical Nurse Specialists (CNS) – These are experienced, senior nurses who have undergone specialist training. They play an essential role in improving communication with a cancer patient, being a first point of contact for the patient and coordinating the patient's treatment.

CT scan – An imaging modality that uses X-ray radiation to build up a 3-dimensional image of the body. It is used to detect distant abnormalities (such as metastases) but has a limited resolution, so is less useful for detecting smaller abnormalities (such as in lymph nodes).

Curative care – This is where the aim of the treatment is to cure the patient of the disease. It is not possible to do this in many patients with O-G cancer and is dependent on how far the disease has spread and the patient's general health and physical condition.

Dysphagia – A symptom where the patient experiences difficulty swallowing. They often complain that the food sticks in their throat. It is the commonest presenting symptom of oesophageal cancer

Endoscopy – An investigation whereby a telescopic camera is used to examine the inside of the digestive tract. It can be used to guide treatments such as stents (see below).

Endoscopic ultrasound (EUS) – An investigation that uses an ultrasound probe on the end of a telescope. It is used to determine how deep into the surrounding tissues a cancer has invaded and to what extent it has spread to local lymph nodes.

Endoscopic palliative therapies – These are treatments that aim to relieve symptoms, such as vomiting or swallowing difficulties, by using a telescopic camera to guide instruments that can relieve the blockage. Examples include stents, laser therapy and brachytherapy.

Fast-track referral – This is a referral mechanism used by General Practitioners (GPs) when they suspect the patient may have cancer. It ensures that the patient will be seen faster than would otherwise be the case.

Gastric – an adjective used to describe something that is related to or involves the stomach, e.g. gastric cancer is another way of saying stomach cancer.

Healthcare Commission – The Healthcare Commission is the independent watchdog for healthcare in England. They aim to promote improvement in the services provided by the NHS and independent healthcare organisations.

HES – Hospital Episode Statistics is a database which contains data on all in-patients treated within NHS Trusts in England. This includes details of admissions, diagnoses and those treatments undergone.

ICD10 – International Statistical Classification of Diseases and Related Health Problems 10th Revision

The NHS Information Centre – The NHS Information Centre is a special health authority that provides facts and figures to help the NHS and social services run effectively. The National Clinical Audit Support Programme (NCASP) is one of its key components.

Laparoscopy – This is often called "keyhole surgery" and involves inserting a small camera into the belly through a small cut, so as to either guide the operation or to look at the surface of the abdominal organs and so accurately stage the disease.

Laser therapy – This is a technique that uses a laser to destroy the surface of the tumour and thereby relieve any blockage. It is a palliative technique only.

Lymph nodes – Lymph nodes are small oval bits of tissue that form part of the immune system. They are distributed throughout the body and are usually the first place to which cancers spread.

Metastases – Metastases are deposits of cancer that occur when the cancer has spread from the place in which it started to other parts of the body. These are commonly called secondary cancers. Disease in which this has occurred is known as metastatic disease.

MDT – The multi-disciplinary team is a group of professionals from diverse specialties that works to optimise diagnosis and treatment throughout the patient pathway.

NCASP – The National Clinical Audit Support Programme is part of the NHS Information Centre for Health and Social Care, and manages a number of national clinical audits in the areas of cancer, diabetes and heart disease. It is one of the key stakeholders leading the audit.

Neo-adjuvant chemotherapy – Chemotherapy given before another treatment, usually surgery. This is usually given to reduce the size, grade or stage of the cancer and therefore improve the effectiveness of the surgery performed.

Neoplasm – A neoplasm or tumour is an abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Neoplasms may be benign (not cancerous), or malignant (cancerous).

NICE – The National Institute of Health and Clinical Excellence is an independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

Oesophagus – The portion of the digestive tract that carries food from the bottom of the throat to the top of the stomach. It is also known as the gullet or the foodpipe.

Oncology – The branch of medicine which deals with the non-surgical treatment of cancer, such as chemotherapy and radiotherapy.

ONS – The Office for National Statistics (ONS) is the government department responsible for collecting and publishing official statistics about the UK's society and economy. This includes cancer registration data.

Pathology – The branch of medicine that deals with tissue specimens under a microscope to determine the type of disease and how far a cancer has spread within the specimen (i.e. whether a tumour has spread to the edges of the specimen or lymph nodes).

Palliative care – Palliative care is the care given to patients whose disease cannot be cured. It aims to improve quality of life rather than extend survival and concentrates on relieving physical and psychological distress.

PEDW – Patient Episode Database Wales contains data on all in-patients treated within NHS Trusts in Wales. This includes details of admissions, diagnoses and those treatments undergone.

PET – A new imaging technique that detects cancer spread or metastases by looking at how fast radioactive sugar molecules are used by different parts of the body. Cancer cells use sugar at a very high rate so show up brightly on this test.

Radiology – The branch of medicine that involves the use of imaging techniques (such as X-rays, CT Scans and PET scans) to diagnose and stage clinical problems.

Radiotherapy – A treatment that uses radiation to kill tumour cells and so shrink the tumour. In most cases, it is a palliative treatment but it can be used together with surgery or chemotherapy in a small number of patients as part of an attempt at cure.

RCS – The Royal College of Surgeons of England is an independent professional body committed to enabling surgeons to achieve and maintain the highest standards of surgical practice and patient care. As part of this it supports audit and the evaluation of clinical effectiveness for surgery.

Stage – The extent to which the primary tumour has spread; the higher the stage, the more extensive the disease.

Staging – The process by which the stage (or extent of spread) of the tumour is determined through the use of various investigations.

Stent – A device used to alleviate swallowing difficulties or vomiting in patients with incurable O-G cancer. It is a collapsible tube that is inserted into the area of narrowing (under either endoscopic or radiological control) that then expands and relieves the blockage.

Surgical resection – An operation whose aim is to completely remove the tumour

STATA 9.2 – A statistical analysis software package used in our analyses.

Ultrasound – An imaging modality that uses high frequency sound waves to create an image of tissues or organs in the body.

References

1 Office for National Statistics. Cancer Statistics registrations: Registrations of cancer diagnosed in 2005, England. Series MB1 no.36.
Available from: http://www.statistics.gov.uk/downloads/theme_health/MB1_36/MB1_No36_2005.pdf

2 Welsh Cancer Intelligence and Surveillance Unit (WCISU). Cancer Incidence in Wales 2002-2006. WCISU ANNUAL PUBLICATION No. SA8/013.
Available from: http://www.wales.nhs.uk/sites3/Documents/242/incpub2006_31Jan08.pdf

3 Scottish Audit of Gastro-Oesophageal Cancer Steering Group. Scottish Audit of Gastro-oesophageal Cancer: Report 1997-2000. Edinburgh: Information and Statistics Division, NHS Scotland, 2002.

4 Office for National Statistics. Mortality Statistics: cause. Review of the Registrar General on deaths by cause, sex and age, in England and Wales, in 2005 (series DH2 No 32).
Available from: http://www.statistics.gov.uk/downloads/theme_health/Dh2_32/DH2_No32_2005.pdf

5 Scottish Intercollegiate Guidelines Network (SIGN). SIGN 87 - Management of oesophageal and gastric cancer. A national clinical guideline. Edinburgh: 2006.

6 Malthaner RA, Collin S, Fenlon D. Preoperative chemotherapy for resectable thoracic esophageal cancer. Cochrane Database Syst Rev. 2006; 19(3):CD001556

7 Department of Health. Guidance on Commissioning Cancer Services: Improving Outcomes in Upper Gastro-Intestinal Cancers: The Manual. London: Department of Health, 2001.

8 Department of Health / Welsh Office. A Policy Framework for Commissioning Cancer Services (Calman-Hine Report). London: Department of Health, 1995.

9 NHS Wales. Cancer Services in Wales. Vol.1. A Report by the Cancer Services Expert Group (Cameron Report). Cardiff: Welsh Office, 1996.

10 Griffiths J. Cancer Services Information Framework. Cardiff: Welsh Assembly, 2000.

11 Department of Health. The NHS Cancer Plan: A plan for investment, a plan for reform. London: Department of Health, 2000.

12 Allum WH, Griffin SM, Watson A, Colin-Jones D. Guidelines for the management of oesophageal and gastric cancer. Gut 2002; 50(Suppl 5): v1-23.

13 National Institute for Health and Clinical Excellence. Clinical Guideline 27: Referral guidelines for suspected cancer. June 2005.
Available from: http://www.nice.org.uk/nicemedia/pdf/cg027niceguideline.pdf

14 National Institute for Health and Clinical Excellence. Clinical Guideline 17: Managing dyspesia in adults in primary care. August 2004.
Available from: http://www.nice.org.uk/nicemedia/pdf/CG017NICEguideline.pdf

15 McCulloch P, Ward J, Tekkis P for the ASCOT group of surgeons on behalf of the British Oesophago-Gastric Cancer Group. Mortality and morbidity in gastro-oeosophago cancer surgery: initial results of ASCOT multicentre prospective cohort study. BMJ 2003; 327:1192-7.

16 Pye JK, Crumplin MK, Charles J, Kerwat R, Foster ME, Biffin A. One-year survey of carcinoma of the oesophagus and stomach in Wales. Br J Surg. 2001; 88: 278-85.

17 Bachmann MO, Alderson D, Edwards D, Wotton S, Bedford C, Peters TJ, Harvey IM. Cohort study in South and West England of the influence of specialization on the management and outcome of patients with oesophageal and gastric cancers. Br J Surg. 2002; 89: 914-22.

18 Cronin-Fenton DP, Sharp L, Carsin AE, Comber H. Patterns of care and effects on mortality for cancers of the oesophagus and gastric cardia: a population-based study. Eur J Cancer. 2007; 43(3): 565-75.

19 Newnham A, Quinn MJ, Babb P, Kang JY, Majeed A. Trends in oesophageal and gastric cancer incidence, mortality and survival in England and Wales 1971-1998/1999. Aliment Pharmacol Ther 2003; 17: 655-64.

20 Cancer Research UK 2007. UK Oesophageal and Stomach Cancer Statistics. Cancer Research UK “Cancerstats” website (Statistical Information Team).
Available from: http://info.cancerresearchuk.org/cancerstats/?a=5441. Accessed February 2008.

21 Department of Health. The National Cancer Manual: Upper GI specific measures. London: Department of Health, 2004.

22 Department of Health. Cancer Reform Strategy. London: Department of Health, 2007

The NHS Information Centre for health and social care is working to make information more relevant and accessible to the public, regulators, health and social care professionals and policy makers, leading to improvements in knowledge and efficiency.

It is an NHS special health authority that collects, analyses and distributes data to reduce the burden on frontline staff, releasing more time for direct care.

Electronic copies of the National Oesophago-Gastric Cancer Audit report can be downloaded from the improving patient care section of our website.

Printed copies of this report can be ordered through our Contact Centre, quoting document reference 28010208.

Need to know more?

☎ **0845 300 6016**

www.ic.nhs.uk

✉ **enquiries@ic.nhs.uk**

The NHS Information Centre for health and social care
1 Trevelyan Square
Boar Lane
Leeds
LS1 6AE

Ref: 28010208