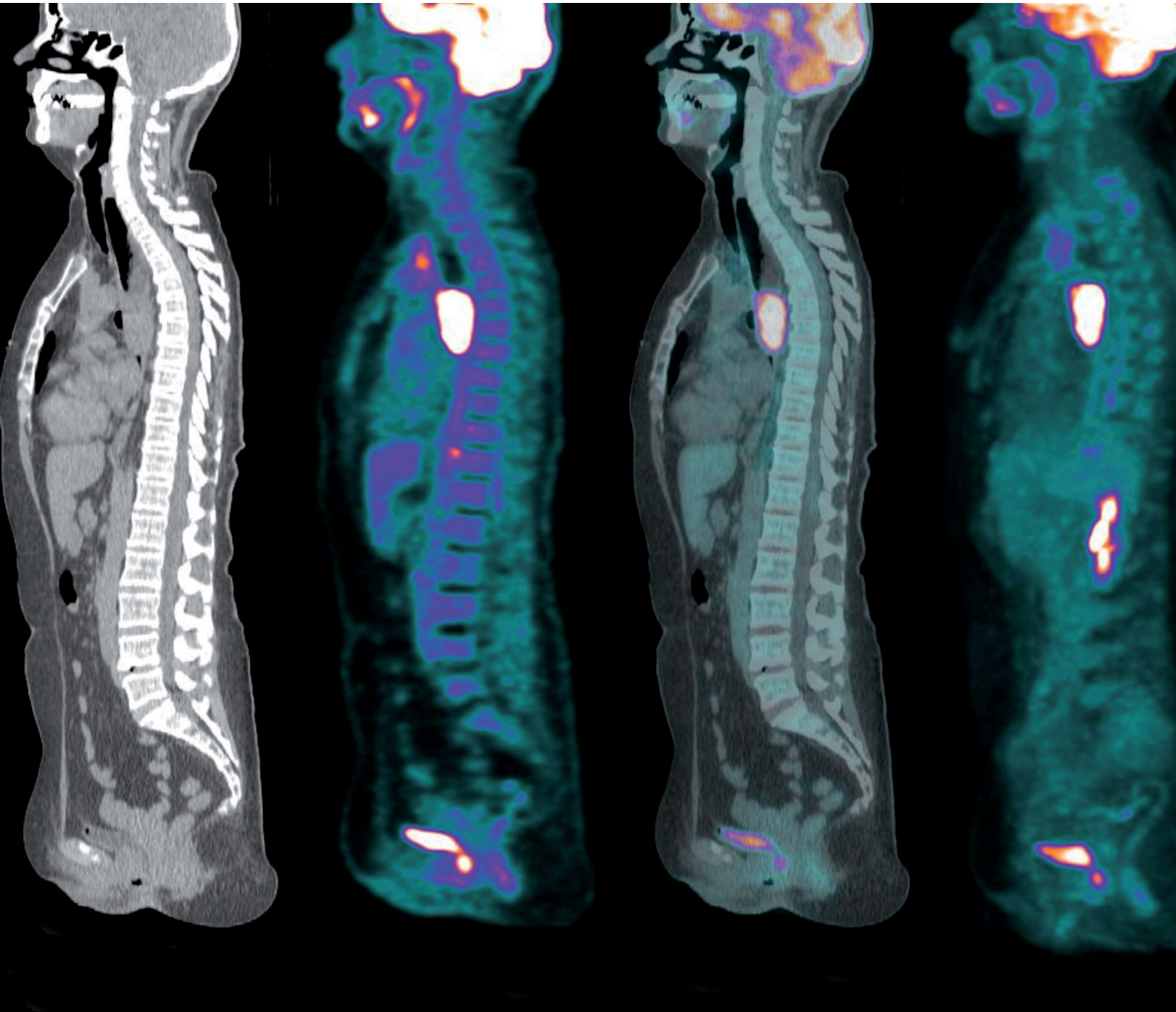
National Oesophago-Gastric Cancer Audit 2012



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The Association of Upper GI Surgeons is the speciality society that represents upper gastrointestinal surgeons. It is one of the key partners leading the Audit.

The British Society of Gastroenterology is the speciality society of gastroenterologists. It is one of the key partners leading the Audit.

The Royal College of Radiologists is the speciality society of radiologists. It is one of the key partners leading the Audit.

National Oesophago-Gastric Cancer Audit 2012

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

2012 Annual Report

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Acknowledgements

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Foreword

We are delighted to see results of the Second National Oesophago-Gastric Cancer Audit (NOGCA), a continuation of the First NOGCA that collected data from 2007 to 2009. Building on the success of previous phases, it provides a unique opportunity for those involved in delivering and improving oesophago-gastric cancer services.

This year's report focuses on the results of an organisational audit and on longer-term follow-up and in-depth analysis of data collected in the First NOGCA. The current audit has started collecting data on patients diagnosed after April 2011 but complete information on these patients was not available for this report. As of April 2012, the audit started to include data on patients diagnosed with high grade glandular dysplasia of the oesophagus. This will allow the audit to provide crucial feedback to trusts on the early detection and management of high grade dysplasia.

A number of results of this year's annual report are noteworthy.

The organisational audit highlights that the process of re-organizing cancer services has come to an end and patients have good access to key diagnostic services and therapeutic procedures. However, early detection and diagnosis remains a key issue. The Audit found substantial variability in diagnostic access routes and the biggest improvements in life expectancy are to be made through early diagnosis and prompt referral to specialist care.

Improvements are also required in appropriate planning of palliative care. There was variation in the use of palliative chemotherapy. Nonetheless, we are pleased to note the infrequent use of hospital services for the most severely ill patients in the last month of life.

This annual report once again demonstrates how useful national audit is. We strongly encourage all English Trusts and Welsh Health Boards to participate in this audit.

We would like to thank all those that have made this audit possible, by actively contributing and collecting data. Finally, in order to close the audit-cycle, we would also like to encourage all to read this report and utilise its findings to improve local practice.

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Executive Summary

This is the 2012 Annual Report of the Second National Oesophago-Gastric Cancer Audit (NOGCA). It builds on the procedures and findings of the First National Oesophago-Gastric Cancer Audit that began in October 2006. Both audits are part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP), and are commissioned by the Healthcare Quality Improvement Partnership (HQIP).

The second Audit began collecting prospective data on patients (aged 18 years or over) diagnosed with invasive epithelial cancer of the oesophagus, gastro-oesophageal junction (GOJ) or stomach on or after 1 April 2011. From 1 April 2012, the Audit also included patients diagnosed with oesophageal high grade glandular dysplasia (HGD). To allow this, a slightly revised data set was implemented.

The results presented in this report are based on an organisational survey of Cancer Networks and NHS organisations (trusts in England and boards in Wales), and further analysis of data from patients diagnosed in the First NOGCA. The further analysis addresses the following issues:

- Patterns of referral of oesophago-gastric cancer patients
- Long-term outcomes for patients receiving curative treatment
- Completion rates of palliative chemotherapy
- Hospital admissions of patients on a best supportive palliative care pathway

At the end of the First NOGCA in 2009, clinical data had been submitted by 152 (99%) of the 154 English NHS organisations that provided oesophago-gastric (O-G) cancer care. Data on patients treated in Wales was provided by NHS Wales from the Welsh Cancer Information System (CANISC) and covered all Health Boards in Wales. In total, data was submitted on over 17,000 patients.

Results of the Organisational Audit

We administered online questionnaires in February 2012 to clinical leads of Cancer Networks and NHS organisations providing care for oesophago-gastric cancer in England and Wales. At the time of the survey in 2012, there were 28 Cancer Networks in England and two in Wales. The network questionnaire focused on organisational policies of care, while the trust questionnaire examined operational procedures. Combined, the organisational audit assessed: referral criteria, organisation of the Multi-Disciplinary Team (MDT), diagnosis and management of patients with high grade dysplasia, access to medical oncology and endoscopic palliative services.

Valid responses were received from all Cancer Networks and from 137 of 151 NHS organisations (91% response rate).

Findings of the organisational audit suggest that progress has been made in the organisation of services for oesophago-gastric cancer over the last five years. The majority of networks and NHS organisations have access to key therapies and most trusts achieve the standard on the number of surgeons performing resections.

However, while most patients are now routinely discussed at MDT meetings, the inclusion of patients on a palliative care pathway requires further effort. Moreover, the inclusion of the palliative care team in MDT discussions is still low.

With regard to the treatment of HGD patients, all NHS organisations provide access to oesophageal resections. Other procedures relevant for the treatment of HGD were less widely available.

Further attention should focus on systematic referral of HGD patients to the MDT and procedures for diagnosis of high grade dysplasia patients.

Patterns of referral

Route of referral reflects early detection of symptoms and has implications for early diagnosis and curability of oesophago-gastric cancer. The proportion of patients planned to have curative treatment is considerably lower among patients diagnosed after an emergency admission compared to urgent GP referrals.

The Audit distinguished between three distinct diagnostic pathways:

- 66.3% of patients were referred by their general practitioner (GP).
- 16.4% were referred following emergency admission (eg, via Accident & Emergency department, or medical admissions unit).
- 17.3% were referred from another hospital consultant (patients referred to the O-G cancer centre by a hospital consultant from a non-emergency setting).

Among the GP referrals, 68.8% patients were labelled as urgent (suspected cancer) but the proportion was higher among patients with oesophageal tumours compared to those with stomach tumours (71.1% vs 62.6%, $p<0.001$).

There was substantial variation between Cancer Networks in the proportion of patients diagnosed via each pathway. In particular, there was significant variation between Cancer Networks in the proportion of patients diagnosed after emergency admission. The pathway to diagnosis is important for NHS services to examine.

Long-term outcomes for patients receiving curative treatment

The third annual report of the First NOGCA audit gave preliminary estimates for longer-term survival of O-G patients undergoing treatment with curative intent. Here we report descriptive estimates of 1, 2 and 3 year survival, stratified by tumour type.

- For oesophageal squamous cell tumours, the proportions of patients undergoing curative treatment who survived 1 and 3 years were 73% and 41%, respectively
- For oesophageal adenocarcinoma (including Siewert 1 and 2), the proportions of patients who survived 1 and 3 years were 78% and 46%, respectively
- For gastric tumours (includes Siewert 3), the proportions of patients who survived 1 and 3 years were 78% and 49%, respectively.

Although these results illustrate the comparatively poor prognosis for these cancers compared to other types of tumour (eg, breast cancer), these results are better than reported in older studies.

Completion rates of palliative chemotherapy

Palliative chemotherapy aims at reducing symptoms, improving quality of life and increasing life expectancy in oesophago-gastric cancer not suitable for curative treatment. The report examined completion rates of patients initiating palliative chemotherapy.

Among the 9,768 patients with a palliative treatment intent, 2,313 (23.7%) underwent palliative chemotherapy. This treatment was more commonly used amongst younger patients, and those with good performance status. Nonetheless, around 10% of patients aged 75 plus, or who had a performance status of 2 or worse also received palliative chemotherapy. A lower proportion of women than men received palliative chemotherapy (17.4% vs 27.1%, $p<0.001$).

The overall rate of treatment completion was 53%. The rate of completion fell as the age of patients increased. Rates of completion among patients also decreased as the performance status got worse, the number of comorbidities and level of deprivation increased. The amount of variation in completion rates across NHS trusts in England was substantial.

The results raise questions about appropriate patient selection and the benefit of palliative chemotherapy over best supportive care in patient groups less likely to complete therapy. Responding to this question may require a randomised-controlled trial (RCT).

Hospital admissions of patients on a best supportive palliative care pathway

Patients on best supportive care are in principle best managed in the community to receive care that relieves symptoms and pain. There is little known about the variation in use of hospital inpatient care amongst this group of patients. The report examines hospital admission patterns for patients receiving palliative best supportive care.

There were 8,449 patients in the linked Audit-Hospital Episode Statistics (HES) dataset with a palliative treatment intent. Of these 2,887 patients had a treatment plan of best supportive care.

Overall, 50% of patients receiving best supportive care were admitted to hospital between their diagnosis and their death. For a quarter of these patients, the admission was planned. Just over 40% of patients had one or more emergency admission, however, the proportion of patients that had an emergency admission in the last month of their life was only 6.75%.

The differences between planned and emergency admission rates for individual trusts were fairly large, but funnel plots revealed that this may be due to random fluctuations alone.

Recommendations

1. All patients diagnosed with oesophageal high grade dysplasia and oesophago-gastric cancer should be discussed within specialist MDT meetings. This should include patients on a palliative care pathway.
2. 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.
3. The diagnosis of oesophageal high grade dysplasia should be based on two independent assessments by pathologists with gastrointestinal interest.
4. Cancer Networks should have access to endoscopic therapies including endoscopic mucosal resection, stent insertion and ablation therapies, such as radiofrequency ablation or argon beam coagulation.
5. Standardized tools should be used more frequently in the nutritional assessment of oesophago-gastric cancer patients.
6. For patients referred for treatment, networks should know the proportion referred following an emergency hospital admission and, working with NHS commissioners and providers, develop strategies for reducing emergency admissions within the network.
7. Clinicians should carefully assess eligibility of patients for palliative chemotherapy, especially in those of older age and low performance status. This assessment should balance clinical considerations with patient choice.
8. In line with the Department of Health's End of Life Care Strategy, networks, trusts and commissioners should know the rate of emergency (re-)admissions of palliative care patients and develop strategies to offer improved support to patients and reduce emergency re-admissions.

1.Introduction

1.1 Background

Oesophago-gastric (O-G) cancer is the fifth most common malignancy (and fourth most common cause of cancer death) in the United Kingdom, affecting around 13,500 people each year [Cancer Research UK 2011; ONS 2010]. In common with many Western countries, the incidence is increasing, particularly adenocarcinomas of the lower oesophagus and gastro-oesophageal junction (GOJ) [Newham et al 2003]. The prognosis for most patients diagnosed with oesophago-gastric cancer remains poor, with overall 5-year survival rates in England and Wales being approximately 7% for oesophageal and 13% for gastric cancer.

The National Oesophago-gastric Cancer 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 commissioned by the Healthcare Quality Improvement Partnership (HQIP) and is one of four national cancer audits currently being undertaken in England and Wales.

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

1. whether clinical (pre-treatment) staging is performed to the standards specified in national clinical guidelines
2. whether decisions about planned curative or palliative treatments are supported by the necessary clinical data (staging, patient fitness, etc)
3. access to curative modalities for suitable patients, such as neoadjuvant chemotherapy prior to surgical resection
4. the use of oncological and endoscopic/radiological palliative services among palliative patients
5. outcomes of care for patients receiving curative and palliative therapies.

This is the 2012 Annual Report of the Second National-Oesophago-Gastric Cancer Audit (NOGCA). The first Audit was established in October 2006 and collected data on patients with O-G cancer between October 2007 and June 2009. The second Audit has restarted the collection of patient level data but insufficient time has elapsed for the results to be available on these patients. Consequently, in this report, we describe:

1. the results of an organisational audit on the characteristics of healthcare services in England and Wales
2. more detailed information about the patterns of care, and longer-term outcomes, using data collected in the first Audit.

An overview is also given on differences between the first and second Audits.

Service organisation for oesophago-gastric cancer care

Cancer services within England and Wales are organised into Cancer Networks, which provide an integrated model of care. For O-G cancer services, each network contains one or more specialist cancer centre that provides curative surgical treatment and specialist radiology, oncology and palliative services to all patients living in the area (see Figure 1.1). Diagnostic services and most palliative services continue to be provided by individual NHS organisations (units) within the network areas.

Figure 1.1
The Cancer Networks and Cancer Centres in England and Wales that existed on 1 April 2011

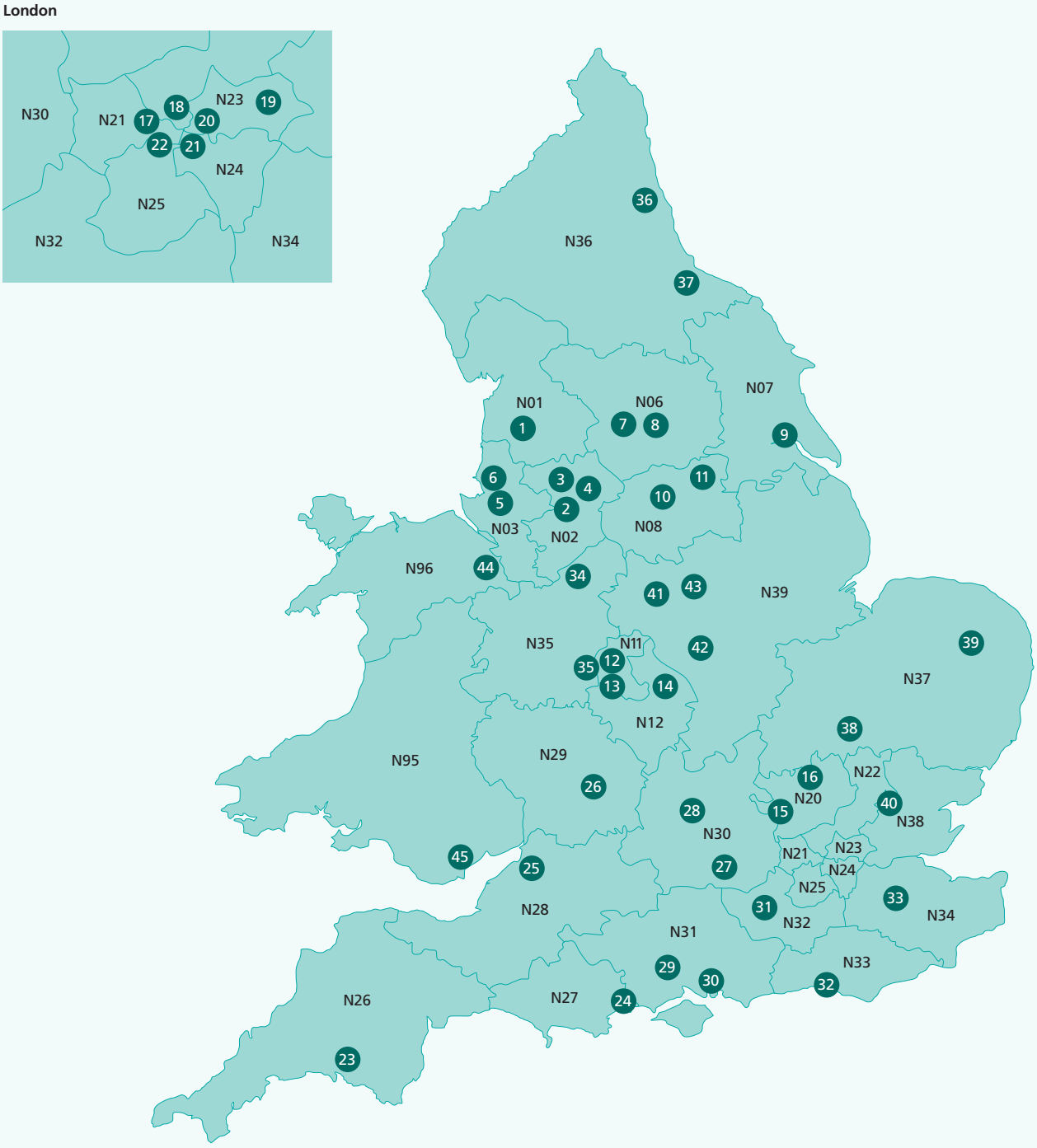
Cancer Centres

ID	Code	Name	ID	Code	Name
1	RXN	Lancashire Teaching Hospitals NHS Foundation Trust	24	RDZ	Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
2	RM2	University Hospital of South Manchester NHS Foundation Tust	25	RA7	University Hospitals Bristol NHS Foundation Trust
3	RM3	Salford Royal Hospitals NHS Foundation Trust	26	RTE	Gloucestershire Hospitals NHS Foundation Trust
4	RW3	Central Manchester and Manchester Children's Uni' Hospitals NHS Trust	27	RHW	Royal Berkshire NHS Foundation Trust
5	RBQ	The Cardiothoracic Centre – Liverpool NHS Trust	28	RTH	Oxford Radcliffe Hospitals NHS Trust
6	REM	Aintree University Hospitals NHS Foundation Trust	29	RHM	Southampton University Hospitals NHS Trust
7	RAE	Bradford Teaching Hospitals NHS Foundation Trust	30	RHU	Portsmouth Hospitals NHS Trust
8	RR8	Leeds Teaching Hospitals NHS Trust	31	RA2	Royal Surrey County Hospital NHS Trust
9	RWA	Hull and East Yorkshire Hospitals NHS Trust	32	RXH	Brighton and Sussex University Hospitals NHS Trust
10	RHQ	Sheffield Teaching Hospitals NHS Foundation Trust	33	RWF	Maidstone and Tunbridge Wells NHS Trust
11	RP5	Doncaster and Bassetlaw Hospitals NHS Foundation Trust	34	RJE	University Hospital of North Staffordshire NHS Trust
12	RR1	Heart of England NHS Foundation Trust	35	RNA	Dudley Group of Hospitals NHS Trust
13	RRK	University Hospital Birmingham NHS Foundation Trust	36	RTD	The Newcastle Upon Tyne Hospitals NHS Trust
14	RKB	University Hospitals Coventry and Warwickshire NHS Trust	37	RTR	South Tees Hospitals NHS Trust
15	RWG	West Hertfordshire Hospitals NHS Trust	38	RGT	Cambridge University Hospitals NHS Foundation Trust
16	RWH	East and North Hertfordshire NHS Trust	39	RM1	Norfolk and Norwich University Hospital NHS Trust
17	RYJ	Imperial College Healthcare NHS Trust	40	RQ8	Mid Essex Hospital Services NHS Trust
18	RRV	University College London Hospitals NHS Foundation Trust	41	RTG	Derby Hospitals NHS Foundation Trust
19	RF4	Barking, Havering and Redbridge Hospitals NHS Trust	42	RWE	University Hospitals of Leicester NHS Trust
20	RNJ	Barts and The London NHS Trust	43	RX1	Nottingham University Hospitals NHS Trust
21	RJ1	Guy's and St Thomas' NHS Foundation Trust	44	7A1	Wrexham Maelor Hospital
22	RPY	The Royal Marsden NHS Foundation Trust	45	7A4	University Hospital of Wales
23	RK9	Plymouth Hospitals NHS Trust			

Cancer Network

Code	Name	Code	Name
N01	Lancashire and South Cumbria	N27	Dorset
N02	Greater Manchester and Cheshire	N28	Avon, Somerset and Wiltshire
N03	Merseyside and Cheshire	N29	3 Counties
N06	Yorkshire	N30	Thames Valley
N07	Humber and Yorkshire Coast	N31	Central South Coast
N08	North Trent	N32	Surrey, West Sussex and Hampshire
N11	Pan Birmingham	N33	Sussex
N12	Arden	N34	Kent and Medway
N20	Mount Vernon	N35	Greater Midlands
N21	North West London	N36	North of England
N22	North London	N37	Anglia
N23	North East London	N38	Essex
N24	South East London	N39	East Midlands
N25	South West London	N95	South Wales
N26	Peninsula	N96	North Wales

Figure 1.1 (Continued)
The Cancer Networks and Cancer Centres in England and Wales that existed on 1 April 2011



There are currently 28 Cancer Networks in England and 2 in Wales. For data collected in this second Audit, we will be presenting results using these organisations, and the NHS organisations that were in existence on 1 April 2011.

At the start of the previous O-G Cancer Audit, there were 30 Cancer Networks in England and 3 in Wales, and we present the results of the analyses based on the first audit dataset using these areas. The change from 30 to 28 Cancer Networks in England occurred on 1 October 2008. Three Cancer Networks (Leicestershire, Northamptonshire and Rutland, Derby/Burton and Mid Trent) were combined to form East Midlands Cancer Network. Results for the NHS trusts derived from the first Audit dataset are presented for those trusts that were in existence on 1 April 2008.

1.2 The care pathway for oesophago-gastric cancer

Diagnosis and staging

Many of the symptoms and signs of O-G cancer are non-specific and are present in large numbers of individuals without cancer. Guidelines recommend that general practitioners (GPs) make an urgent referral for an endoscopy assessment only if patients present with "alarm symptoms" (eg, weight loss, vomiting, dysphagia) or have persistent dyspepsia and are over 55 years [SIGN 2006; NICE 2004].

Various policy initiatives have aimed to improve the diagnostic process. In 2001, English Cancer Networks were recommended to establish fast-track, open-access endoscopy services and agree local referral protocols between general practice and hospital diagnostic services [IOG 2001]. But, while the majority of patients diagnosed with O-G cancer in the UK are referred by their general practitioner, there are several other referral pathways to the hospital-based O-G cancer team. Some patients are referred following an emergency hospital admission for acute symptoms, while others are referred by another hospital consultant (in the non-emergency setting) who diagnoses or suspects the disease. This latter group includes patients with Barrett's metaplasia under routine surveillance endoscopy.

Establishing the disease stage, and consequently options for treatment, requires patients to undergo a number of investigations. Standard investigations currently include computed tomography (CT) scan, endoscopic ultrasound (EUS) and staging laparoscopy [SIGN 2006]. 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. In addition, it is becoming accepted that positron emission tomography (PET / PET-CT) can be beneficial for selecting patients for curative treatment and has now been accepted as routine for staging of oesophageal and gastro-oesophageal tumours.

Curative treatment

The surgical removal (resection) of the tumour remains the mainstay of curative treatment. Recent clinical trials have shown that for patients with locally advanced adenocarcinoma of the oesophagus, GOJ and stomach, combining surgery with peri-operative (neoadjuvant) chemotherapy can improve rates of 5-year survival [MRC Lancet 2002; Cunningham et al 2006]. The regimen for stomach cancer also includes three postoperative (adjuvant) cycles of chemotherapy [Cunningham et al 2006]. The role of chemo-radiotherapy as a potentially curative modality is more developed in the treatment of squamous cell carcinoma of the oesophagus [SIGN 2006].

Surgery for O-G cancer is a major undertaking. It is only suitable for patients who are relatively fit, and are found to have localised disease on staging investigations. In the late 1990s, reported 30-day postoperative mortality rates were around 12% for resection of the oesophagus and stomach [SAGOC 2002; McCulloch et al 2003; Jamieson et al 2004]. The level of risk associated with these procedures had improved by the end of the First National O-G Cancer Audit, with reported 30-day postoperative mortality rates of around 4% - 5%, respectively. Nonetheless, patients require six and nine months to regain their quality of life after this major surgery [Blazeby et al 2000].

Palliative treatment

For those patients who are not eligible for radical therapy, a range of palliative treatments exist. The principal aim of palliative care is to achieve the best quality of life for patients and their families by alleviating pain and controlling other symptoms as well as providing psychological and social support. Some oncological treatments may extend life by a short period but the primary aim is the relief of suffering. Palliative treatments essentially fall into two groups: oncological (chemotherapy, radiotherapy or a combination of the two) or endoscopic / radiological, including stenting, argon beam coagulation, laser therapy and brachytherapy. For patients with distal stomach cancers that are obstructing the passage of food out of the stomach, palliative surgery may be required to remove or bypass the obstruction.

2. The Second National Oesophago-Gastric Cancer Audit

2.1 Overview

The principal component of the second audit will be prospectively-collected, patient-level data on patients diagnosed with invasive epithelial oesophago-gastric cancer. This information will be combined with other available datasets to provide a rich description of the care process and minimise the burden of data collection on clinical staff.

From April 2012, the Audit will also include patients diagnosed with high grade glandular dysplasia of the oesophagus (HGD). It is preferable that these patients are referred to a cancer centre and discussed at the Multi-Disciplinary Team (MDT) meeting. It is not clear that this is happening consistently within England and Wales and an important objective in extending the Audit would be to evaluate whether the management of HGD within Cancer Networks meets these requirements. Another objective is to describe the types of treatments that HGD patients undergo and the outcomes associated with type of treatment. Patients with HGD increasingly have mucosal ablative therapies and/or photo-dynamic therapy but whether access to these treatments is uniform across Networks is unknown.

The other key component is an organisational audit of Cancer Networks and NHS organisations. This has been undertaken in the first year of the Audit to assess compliance against the organisational standards set out in the NHS Cancer Plan and the Improving Outcomes Guidance in Upper Gastro-Intestinal Cancer. This exercise was also part of the First NOGCA.

2.2 Prospective data collection on patients with oesophago-gastric cancer

Patients are eligible for inclusion in the prospective audit if they are diagnosed on or after 1 April 2011 with invasive epithelial cancer of the oesophagus, gastro-oesophageal junction (GOJ) or stomach (ICD10 codes C15 and C16), and are aged 18 years or over. Patients with endocrine tumours or gastro-intestinal stromal tumours (GISTs) are not included in the Audit due to the different behaviour and management of these tumours.

The inclusion criteria are currently restricted to patients diagnosed in an NHS hospital in England or Wales. The management of patients with O-G cancer takes place in the context of an NHS MDT meeting irrespective of whether they were diagnosed in the public or private sector, and the majority of patients in the Audit had received treatment in the NHS only. However, to achieve complete coverage, discussions have been held with independent sector organisations about the inclusion of private patients. These are currently ongoing.

In the first year of the second Audit, the prospectively collected data was based on the First NOGCA dataset. This had several advantages. First, NHS organisations were familiar with the data items, and had procedures in place to collect them. Second, NHS organisations who uploaded data to the Audit from their existing clinical software were able to use the same CSV export facility.

For subsequent years, the Audit will be moving to a slightly revised dataset. Changes to the dataset were made in response to comments from users and lessons learnt during the first audit. The changes included:

1. The removal of some data items because they were poorly completed or because we do not plan to report on them.
2. The inclusion of some new items to improve the capture of patient flows or to improve case-mix adjustment.
3. Provision to enter staging information using TNM version 6 or 7.
4. The revision of data item definitions to reflect changes in practice or to be consistent with data items in the proposed Cancer Outcomes and Services Dataset (COSD).

The greatest number of changes occurred among the data items on endoscopic / radiological palliative therapies. The items on the initial procedure remained largely unchanged. However, the audit is no longer requesting hospital staff to collect 3 month outcomes after the procedure. Instead, hospitals only need to report complications that occur before the patient is discharged.

The dataset was revised by the Project Team with support from the Clinical Reference Group, and other stakeholders. In particular, for England, there was cooperation between the Audit and the National Cancer Intelligence Network (NCIN) to ensure that the revised dataset and the new Cancer Outcomes and Services Dataset (COSD, version 0.5) were aligned as much as possible. Data items were defined to be consistent with:

- The Scottish Upper GI Cancer dataset (July 2005)
- The All Wales Oesophago-Gastric Cancer Minimum Reporting Requirements (v 2.0) including Core Reporting Items v5.0
- The Royal College of Pathologists Datasets for reporting oesophageal and gastric cancers
- The Royal College of Radiologists radiotherapy dataset (version 3.7).

A copy of the clinical datasheet and the data manual can be downloaded from the Audit website at: www.ic.nhs.uk/og

2.3 Audit of high grade glandular dysplasia of the oesophagus

From 1 April 2012, the Audit will include patients with high grade glandular dysplasia of the oesophagus (HGD). Patients are eligible for the audit if their first biopsy (after either an initial referral or as part of routine surveillance), performed during the audit period, identifies high grade glandular dysplasia of the oesophagus. Patients with squamous dysplasia are excluded from the audit.

The incidence of HGD in England and Wales is uncertain. Our initial estimate of the incidence in England and Wales is 1,350 per year, which corresponds to around 45 patients per Cancer Network per year. This is less than one-tenth of patients diagnosed with O-G cancer annually.

The audit questions about the management of HGD patients have been kept simple, partly because their management is complex and varied within hospitals in England and Wales.

The main questions are:

1. Has HGD been diagnosed on two separate sets of biopsies from two different endoscopies?
2. Has the patient been discussed in a Specialist MDT meeting?
3. What treatments were planned for the patient?
4. What were the post-treatment pathology results?
5. What are the short-term outcomes of oesophagectomy in patients diagnosed with HGD?

To answer these questions, a small dataset of 20 data items was designed. It captures information on diagnostic pathway, patient characteristics, treatment planning and delivery.

The full revised dataset is available in Appendix 7.
A copy of the clinical datasheet and the data manual can be downloaded from the Audit website at: www.ic.nhs.uk/og

2.4 Data collection procedures

Data can be submitted to the Audit in two ways. If data are already being collected on a local information system, the relevant data fields can be extracted and uploaded to the Audit's secure database via a "csv" file upload facility. Alternatively, data can be entered manually via a secure web-based data entry form. Hospital staff have access to a helpdesk during working hours to help with problems and answer questions about data submission.

The Audit data will be linked to several sources of routine data prior to analysis. We envisage linking the prospective dataset to:

- the Hospital Episode Statistics (HES) in England and Patient Episode Database Wales (PEDW) in Wales,
- Office for National Statistics (ONS) mortality data and
- Data from the case mix programme with the Intensive Care National Audit and Research Centre (ICNARC) dataset

National routine data collections for radiotherapy and chemotherapy services are currently being established by the National Cancer Intelligence Network (NCIN). We will link the Audit data to these sources as the data become available. The national data collection for radiotherapy will be available by summer 2012.

3. Results of the Organisational Audit

3.1 Rationale and methods

An organisational audit was undertaken to examine the structure of oesophago-gastric services within the Cancer Networks in England and Wales. It was also designed to assess organisational policies and procedures.

A similar audit was conducted in 2007 as part of the First National Oesophago-Gastric Cancer Audit. By repeating the process, the Audit aimed to identify where improvements had been made to service arrangements. The results from the first organisational audit are summarised in Box 3.1.

Box 3.1
Results for Organisational Audit in 2007 [Palser et al 2009]

Responses were received from all 30 English Cancer Networks and 1 of the 3 Welsh networks as well as 132 (73%) of the NHS organisations 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 14 NHS organisations that were not O-G cancer centres that were still performing surgical resections
- In the Cancer Centres performing surgical resection, 47% of the surgical teams consisted of only 2 surgeons, being fewer than the recommended 3 minimum.
- All 31 networks reported good access to the recommended staging investigations (CT scans, endoscopic ultrasound and laparoscopy)
- Waiting times of more than two weeks were observed for palliative chemotherapy in three networks and for palliative radiotherapy in five networks
- All 31 networks provided access to stent insertion and argon beam coagulation, but only 17 networks provided access to laser ablation therapy and brachytherapy.

In relation to the functioning of multi-disciplinary teams:

- All 132 NHS organisations reported using MDT meetings for treatment planning
- Only 16 of the 31 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%) and 26 of the other responding trusts (28%)
- Clinical nurse specialists were available at all Cancer Centres, but local units had fewer nurse specialists. Nine (10%) local units had none at all.
- Dietician support was available for all patients at only 54% of all NHS organisations; one quarter of cancer centres had no dietician support for their surgical inpatients.

Two online questionnaires were designed and administered to Cancer Networks and NHS organisations in England and Wales.

- The network questionnaire focused on organisational policies, defined as those documented governing principles that inform clinicians, define the scope of care, guide decision-making, and ensure consistency in implementation. Areas of assessment included are referral criteria, organisation of the MDT, diagnosis and management of high grade dysplasia, access to medical oncology and endoscopic palliative services.
- The NHS organisation questionnaire focused on 'operational procedures' and 'guidelines' at the level of trusts or health boards. Areas of assessment include organisation of Multi-Disciplinary Team, diagnosis and management of high grade dysplasia, informed patient consent, access to palliative care services, and service provision.

Where possible, survey questions were derived from the previous Audit to enable comparison. Additional questions were derived from guidelines on management of patients with oesophageal high grade glandular dysplasia and oesophago-gastric cancer. The draft questionnaires were piloted with clinicians involved in the care of oesophageal high grade glandular dysplasia and oesophago-gastric cancer patients.

A list of networks and all NHS acute health organisations involved in the treatment of HGD and oesophago-gastric cancer was prepared from sources at the Health and Social Care Information Centre. Links to the online questionnaires were sent to the Cancer Network O-G cancer lead clinician for the network survey and to trust/unit O-G cancer leads for the NHS organisation survey. These links were administered in February 2012 and non-responders were followed up by email and telephone.

3.2 Results

Questionnaires were returned from all Cancer Networks in England (N=28) and Wales (N=2). For the NHS organisation survey, valid responses to the survey were received from 137 of 151 NHS trusts (91%). For some items, the number of responses reported is lower than 30 and 137, respectively, because not all questions were completed in the returned questionnaires.

We report the results as the proportion of responding NHS organisations. Where appropriate we report differences between percentages of specialist centres and local units using the chi-squared test.

All p-values are two-sided and those lower than 0.05 were considered to indicate a statistically significant result. STATA was used for all statistical calculations.

Network level referral criteria and management policy

Current guidelines and measures of the National Cancer Peer Review Programme state that referral criteria of O-G cancer patients should be documented for the whole network and that all O-G cancer patients should be discussed at Multi-Disciplinary Team meetings. This should include patients with high grade dysplasia.

All but one network (97%) reported that referral criteria for O-G cancer patients were documented. This is in line with self-reported CQUINS data on measure 11-1A-205f (Network Agreed Referral Guidelines between teams), although the National Cancer Peer Review Programme reported only 71% compliance [National Cancer Peer Review Programme 2012].

Twenty-nine of the 30 networks (97%) reported having a policy to ensure that all oesophageal-gastric cancer patients are referred to and discussed at MDT meetings. This is in accordance with the National Cancer Peer Review Programme measure 11-2F-109 (Policy for All New Patients to be Reviewed by the Multi-Disciplinary Team) [The National Cancer Peer Review Programme 2012]. In addition, 90% of the networks reported that the policy covered patients with high grade dysplasia as well. Of the Cancer Networks, 23 (77%) had a specialist surveillance policy for patients with Barrett's oesophagus, and 26 of the 30 networks (87%) had a policy for the management of HGD.

Access to curative surgical services in specialist centres

In the reorganisation of O-G cancer services since 2001, a major component has been the centralisation of curative surgical services into specialist cancer centres. The National Cancer Manual recommended that surgical teams comprise at least three specialist consultant surgeons to manage surgery and postoperative care.

There were 37 responses from the 39 specialist cancer centres providing surgery for oesophageal and gastric resections that returned the organisational questionnaire.

There was a variable number of surgeons reported as operating within each NHS organisation (see Table 3.1), with only 2 trusts (5%) not meeting the minimum requirement of having at least three surgeons.

Table 3.1
Distribution of surgeons performing oesophago-gastric curative surgery among the specialist O-G cancer centres (37 responses)

	Number of surgeons					
	2	3	4	5	6	7+
Employed or visiting surgeons performing oesophageal or gastric resections at the trust	2 (5%)	13 (35%)	8 (22%)	7 (19%)	5 (14%)	2 (5%)

Access to oncology care and endoscopy procedures in Cancer Networks

It is recommended that patients should have access to a range of endoscopic/radiological palliative therapies because the selection of particular techniques depends on patients' individual characteristics. Among the various options, it is recommended that oesophageal stenting and either laser or photodynamic therapy should be available for the treatment of obstructive oesophageal symptoms [SIGN 2006; Allum et al. 2011].

All Cancer Networks provided access to stent insertion and the majority (86%) provide access to argon beam coagulation (Table 3.2). Brachytherapy and laser ablation could be performed in only about half of the Cancer Networks and is typically performed in the specialist centres.

Only eight specialist centres (29%) offered access to photodynamic therapy. Local units in general provided less access to these endoscopic procedures, except for stent insertion that is available through local centres and photodynamic therapy, which is available in none of the local centres.

Eleven networks (37%) reported that patients had difficulties in accessing oncological therapy within two weeks of the decision to treat. These difficulties applied to both patients receiving curative treatment and patients receiving palliative care, and did not differ between specialist centres and local units.

Table 3.2
Access to endoscopic procedures in Cancer Networks (28 responses)

	Access to endoscopic procedures in the Cancer Network (either at specialist or local centre)	
Procedure	**No**	**Yes**
Endoscopic stent insertion	0 (0%)	28 (100%)
Laser ablation	13 (46%)	15 (54%)
Photodynamic therapy	20 (71%)	8 (29%)
Argon beam coagulation	4 (14%)	24 (86%)
Brachytherapy	13 (46%)	15 (54%)

Organisation and management of patients with High Grade Dysplasia within NHS organisations

Respondents at NHS organisations were asked about the local mechanisms to ensure that patients with HGD are referred for discussion at MDT meetings. The most common mechanisms were:

- Referral by investigating clinician (n=30, 22%)
- Combination of referral by clinician and pathologist (n=16, 12%)
- Combination of referral by investigating clinician, pathologist and endoscopist (n=22, 16%).

There were 11 NHS organisations (8%) that reported having no specific mechanism. The remainder of NHS organisations (n=52, 42%) used a combination of pathologist, clinician, endoscopist or other mechanisms for the referral of patients with HGD.

Overall, 104 of responding NHS organisations (76%) reported having an agreed management protocol for patients with HGD. In terms of the local procedures for confirming a diagnosis of HGD,

- 105 NHS organisations (77%) reported that diagnosis was always confirmed by at least two pathologists with gastrointestinal interest
- 24 NHS organisations (18%) reported that diagnosis was confirmed by a pathologist with gastrointestinal interest and
- 5 NHS organisations (4%) stated the diagnosis was based on confirmation by a general pathologist.
- Responses from 3 organisations (2%) were missing.

Specialist centres were slightly more likely to follow the recommendations to base diagnosis of HGD on confirmation by at least two pathologists with gastrointestinal interest [BSG 2005; Allum et al 2011].

Table 3.3 describes the procedures for the treatment of patients with HGD reported to be available at the NHS trust or another hospital. Not all NHS organisations have, or require, access to each of these procedures. However, access to oesophagectomy, EMR and at least one of the thermal ablation therapies (argon beam coagulation, multipolar electrocautery, laser therapy, cryotherapy, radiofrequency ablation) is recommended.

Based on the organisational audit, 35 NHS organisations (26%) reported providing access to *all* these procedures, 26 NHS organisations (19%) provided access to argon plasma coagulation *and* radiofrequency ablation, and 3 (2%) report not having access to *any*. Others provided access to a combination of procedures.

Table 3.3
Therapeutic procedures available for patients with high grade dysplasia reported to be available at the trust or another hospital (Responses from 137 NHS organisations).

	Available at local NHS organisation or another hospital		If available, the procedure can be accessed at:	
Procedure	**No**	**Yes**	**Local NHS organisation**	**Another hospital**
Oesophagectomy	3 (2%)	134 (98%)	39 (29%)	95 (71%)
Endoscopic Mucosal Resection	4 (3%)	133 (97%)	58 (44%)	75 (56%)
Photodynamic therapy	37 (27%)	100 (73%)	8 (8%)	92 (92%)
Argon plasma coagulation	21 (15%)	116 (85%)	92 (79%)	24 (21%)
Multipolar electrocautery	81 (59%)	56 (41%)	27 (48%)	29 (52%)
Laser therapy	62 (45%)	75 (55%)	17 (23%)	58 (77%)
Cryotherapy	52 (72%)	39 (28%)	2 (5%)	37 (95%)
Radiofrequency ablation	26 (19%)	111 (81%)	25 (23%)	86 (77%)

Implementation of the MDT policy at trust level

It is recommended 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 [DH 2001].

Of the local units, 63 (72%) had combined MDT meetings with the specialist centre. In the 2007 organisational audit, only 44 (34%) had a combined meeting.

Regarding the type of patients discussed at the specialist centre MDT meetings (multiple responses to items were allowed):

- 129 NHS organisations (94%) include patients in need of curative treatment
- 137 NHS organisations (100%) include patients needing specialist tests
- 118 NHS organisations (86%) discuss patients in need of specialist input into palliation and
- 84 NHS organisations (61%) include patients that are on a best supportive care pathway
- 130 NHS organisations (95%) reported to include patients with HGD.

In principal, all O-G cancer patients should be included in the MDTs. However, this only occurs at 80 (58%) of the NHS organisations responding to the audit. Patients in need of either specialist or best supportive care are often not included. Excluding these two groups of patients, 91% of audited organisations include the remaining patient groups in the MDTs.

Inclusiveness was higher in specialist centres than in local units: 82% in specialist centres compared to 49% in local units reported that all patients, including those on a palliative care pathway, are included in MDT discussions.

When asked about the inclusion of private patients in MDT meetings, 74% of NHS organisations reported that these patients were mostly listed by their clinician. At 8% of NHS organisations, private patients are not listed at all, while another 7% of NHS trusts reported that private patients were not formally listed. Specialist centres were more likely to include private patients in MDT discussions than local units (p=0.017).

Access to nutritional support

It is recommended that all oesophago-gastric cancer patients should have access to dietician advice if needed and should be assessed for nutritional risk using a validated screening tool [SIGN 2006]. In general, three quarters of cancer centres reported providing access for surgical patients, non-curative O-G cancer patients and outpatients (Table 3.4). Access at the local units was more variable.

In both cancer centres and local units, nutritional assessment of oesophago-gastric cancer patients was made mostly by dietician assessment. Fewer NHS organisations used a formal nutritional assessment instrument. A quarter of NHS organisations combined dietician assessment with use of a standard tool.

Table 3.4
Dietician access and nutritional assessment in specialist centres and local units

	Specialist centres n=39 (%)	Local units n=98 (%)
Dietician access		
Surgical patients	33 (85%)	59 (60%)
All other O-G cancer patients	29 (74%)	84 (86%)
Outpatients	29 (74%)	74 (76%)
Nutritional assessment		
No formal assessment	3 (8%)	15 (15%)
Dietician assessment	26 (67%)	63 (64%)
Formal screening instrument	16 (41%)	38 (39%)

Provision of palliative care

All patients with oesophago-gastric cancer should have access to a palliative care team to manage the comprehensive patients needs. When asked about the constitution of the palliative care team:

- 92 NHS organisations (67%) reported that the palliative care team is constituted by both a consultant in palliative medicine and a specialist nurse in palliative care
- 21 NHS organisations (15%) report that the palliative team involves an additional staff member, such as a clinical nurse specialist or an oncologist, and
- 10 NHS organisations (7%) report that the team is constituted mainly around the input of the specialist nurse in palliative care.
- The remaining 14 NHS organisations (10%) constituted the team in other combinations of consultant, nurse or other staff.

The palliative care team should attend the MDT discussions to provide appropriate input to the care plan of the patient. In 56 NHS organisations (41%), it is the specialist nurse in palliative care that attends the MDT. In 23 organisations (17%) both consultant in palliative medicine and specialist palliative nurse attend the MDT meeting. However, in 26 organisations (19%), none of the palliative care team members routinely attend the MDT meeting.

An agreed protocol for managing patients whose treatment plan is best supportive care was available in 28 NHS organisations (21%).

In terms of approaches to care for people in the last days of life, the majority of NHS organisations had implemented some combination of end-of-life care, the most frequent one being the Liverpool care pathway (n=129, 94%), followed by NICE guidance on end of life care (n=68, 50%), the Gold Standards Framework (n=30, 22%) and Preferred Priorities for Care (n=28, 20%). Only 4 NHS organisations (3%) reported not having implemented any approach towards end-of-life care.

3.3 Discussion

The survey provides an overview of Cancer Network and NHS organisations compliance with the organisational policies and recommendations for access to key procedures that are expressed in policy documents and clinical practice guidelines.

When compared to the 2007 organisational audit, the overall structure of care has improved in several areas:

- The inclusion of different patient groups in MDT discussions has improved since the 2007 audit. Most patients are now discussed at the MDT although some palliative care patients are not routinely included, in particular those on a best supportive care pathway. This may have implications for palliative care planning. Issues concerning the inclusion of private patients in MDT and potential issues regarding access to the full patient chart merit further investigation.
- The recommended number of surgeons at specialist cancer centres was not attained by two NHS organisations compared to seven in the 2007 audit.
- There is no change from the 2007 survey in the networks reporting difficulties in accessing oncology services within the decision to treat. These responses need to be validated further.
- The involvement of palliative care teams in Multi-Disciplinary Team meetings is still poor.
- With regard to endoscopic procedures, there is good access to endoscopic stent insertion and argon beam coagulation. Access to brachytherapy is still restricted. Photodynamic therapy is performed in selected centres only.
- Dietician support has increased since 2007 but the use of standardized tools for nutritional assessment is still low. Nevertheless, the proportion of NHS organisations that formally assess nutritional status before treatment has increased significantly.

The current organisational audit examined the structure and procedures for patients with high grade dysplasia for the first time. Nearly all NHS organisations provided access to oesophageal resections for these patients, either at the trust or another hospital. Other procedures relevant for the treatment of HGD were less widely available. Referral and procedures for diagnosis of high grade dysplasia patients should be investigated further to make sure that all patients are appropriately referred to the MDT and have their biopsies confirmed by two pathologists with gastro-intestinal interest.

Finally, the audit also asked about end of life care. The majority of NHS organisations have implemented an approach to manage patients in the last days of their life with the most frequent one being the Liverpool Care Pathway.

4. Further analysis of data from First National Oesophago-Gastric Cancer Audit

4.1. Data collected during the first audit

Patients were eligible for inclusion in the first national audit if they were diagnosed between 1 October 2007 and 31 June 2009 with invasive epithelial cancer of the oesophagus, gastro-oesophageal junction (GOJ) or stomach (ICD10 codes C15 and C16), and were aged 18 years or over. At the end of the first Audit, clinical data had been submitted by 152 individual trusts (99%) of the 154 that provided O-G cancer care. This included all of the specialist cancer centres. Data on patients treated in Wales was provided by NHS Wales from the Welsh Cancer Information System (CANISC) and covered all 13 Welsh NHS organisations.

English NHS trusts submitted clinical information for 16,264 patients (71% of the 22,870 estimated total). Welsh NHS organisations submitted clinical information for 1,015 patients (98% of the 1037 registered patients) via CANISC.

The Audit received information on 3,803 curative surgical procedures and 3,630 courses of curative oncological therapy, 4,328 courses of palliative oncological therapy, and 3,249 endoscopic/radiological palliative therapies.

Of 17,279 patients enrolled in the Audit, approximately half of the patients had a tumour of the distal oesophagus or GOJ, while one in three patients had tumours located in the stomach (Table 4.1). The majority of the stomach tumours were located proximally (in the body or fundus). Approximately two thirds of the oesophageal tumours were adenocarcinomas, while most others were squamous cell carcinomas (28%). Almost all of the stomach cancers were adenocarcinomas (96%).

Table 4.1
Distribution of O-G cancer tumours across the various sites

Site	Sub-site	No. of patients	%sub-site of tumour site
Oesophagus	Upper third	673	8
	Middle third	2,209	25
	Lower third	5,944	67
G-O junction[1]	Siewert I	1,299	41
	Siewert II	860	27
	Siewert III	987	31
Stomach	Fundus	694	13
	Body	2,670	50
	Antrum	1,329	25
	Pylorus	614	12
Total		**17,279**	

[1] Tumours of the G-O junction are described using the 3 category Siewert classification [Siewert et al 1996]:
I. Adenocarcinoma of the distal oesophagus, the centre of which is within 2-5cm proximal to the anatomical cardia. It may infiltrate the gastro-oesophageal junction from above.
II. True junctional adenocarcinoma, the centre of which is within 2cm above or below of the anatomical cardia.
III. Subcardial gastric adenocarcinoma the centre of which is within the 5cm distal to the anatomical cardia. It may infiltrate the gastro-oesophageal junction from below.

The disease affected a broad range of patients. Their median age was 73 years but 10 per cent of patients were aged under 55 years. The cancer was more common in men than women, with two men being diagnosed for every one woman overall. There were differences in the age distributions between men and women among the oesophageal and junctional tumours but these were not apparent among patients with stomach tumours (Table 4.2).

A substantial proportion of the 17,279 patients were frail. Between 13% and 23% of patients in the different tumour groups having a performance status of 3 or more, indicating that they were confined to bed for more than 50% of the time. About 40% of patients had at least one comorbidity.

Table 4.2
Summary of patient characteristics by type of tumour

	Oesophageal SCC	Oesophageal ACA Upper / Mid	Oesophageal ACA Lower / SI	GOJ SII / SIII	Stomach
Number of patients					
Total	3,512	995	5,618	1,847	5,307
Women	1,803	322	1,133	420	1,989
Men	1,709	673	4,485	1,427	3,318
Ratio women to men	1:0.95	1:2.1	1:4.0	1:3.4	1:1.67
Median age (years)					
Women	74	78	75	73	76
Men	69	71	69	70	75
Performance status[1] >3 (%)	**18%**	**17%**	**13%**	**13%**	**23%**
Patients with >1 comorbidity (%)	**37%**	**40%**	**42%**	**38%**	**41%**

Key
SCC = squamous cell carcinomas;
ACA = adenocarcinoma;
SI, SII, SIII = Siewert I, II, III
[1] Eastern Cooperative Oncology Group (ECOG) score for performance status in cancer patients. 0 denotes perfect health and 4 a patient who is bed-bound, completely disabled and unable to carry out any self-care. Patients scoring 3 or more are capable of only limited self care, confined to bed or chair >50% of waking hours.

4.2. Statistical analysis of patient-level data

Rates are presented as percentages for O-G cancer patients, being typically grouped by their tumour characteristics or network of treatment. Averages and rates are presented with 95% confidence intervals (CI) using the Binomial Exact method.

Regional differences in England and Wales are shown using the 30 Cancer Networks that existed on 1 October 2007. To show differences between the geographical regions, their rates and 95% CI are plotted against the overall rate for England and Wales, with networks ordered according to the number of patients on whom data was submitted. English patients were allocated to the Cancer Network based on their NHS trust of treatment and not by region of residence.

Differences between the percentages of two groups were assessed using the chi-squared test. Where necessary, multiple logistic regression was used to adjust for potential confounders such as age and sex. To account for a lack of independence in the data of patients treated in the same NHS organisation, the standard errors of the regression coefficients were calculated using a clustered sandwich estimator. All p-values are two-sided and those lower than 0.05 were considered to indicate a statistically significant result. STATA was used for all statistical calculations.

In deriving adjusted rates for each NHS organisation, multiple logistic regression was used to model the relationship between the outcome and measures of patient risk (such as age, sex, tumour site, stage, comorbidities, performance status, ASA grade, neoadjuvant therapy). Separate regression models were developed for each outcome. These models were devised using information about strength of association between the outcome and the individual factors (assessed using a Wald test), the calibration of the model (using the Hosmer-Lemeshow goodness-of-fit test), and its power of discrimination (using the c-statistic / ROC curve) [Hosmer and Lemeshow 2000].

The logistic regression model was used to estimate the probability of each complication. The probabilities derived for patients treated at the same organisation were summed to give the predicted number of events. Risk-adjusted rates for each organisation were then produced by dividing the observed number of events with the predicted number and multiplying this ratio with the national rate.

The variation in adjusted rates among the NHS trusts was examined using a funnel plot [Spiegelhalter, 2005]. This plot tests whether the rate of any single NHS organisation differs significantly from the national rate. We used two funnel limits that indicate the ranges within which 95% (representing a difference of two standard deviations from the national rate) or 99.8% (representing a difference of three standard deviations) would be expected to fall if variation was due only to sampling error. The funnel plots use exact binomial limits which become narrower as the number of procedures performed increases. Following convention, we use the 99.8% limits to identify "outliers", as it is unlikely for an NHS organisation to fall beyond these limits solely because of random variation (a 1 in 500 chance).

5. Patient referral patterns

5.1. Rationale and method

An objective of the 2007 National Cancer Reform Strategy was to improve the early diagnosis of cancer [Richards 2009]. However, little is known about the relative contributions of patient delay, doctor delay and system delay on the care that patients with cancer receive and their outcomes.

In this chapter, we describe how patients diagnosed with O-G cancer in England were referred for diagnosis and treatment, and examine whether the patterns of referral were similar among Cancer Networks. Data from Welsh NHS organisations did not use all options for the source of referral data item and so were not included in this analysis. Preliminary results were published in the Audit's Second Annual Report [NOGCA 2009].

The Audit distinguished between three distinct diagnostic pathways: referral from a general practitioner (GP), referral after an emergency admission (eg, via Accident & Emergency department, or medical admissions unit), and an "other hospital referral" (patients referred to the O-G cancer centre by a hospital consultant from a non-emergency setting). GP referrals were further subdivided into urgent (for suspected cancer) and non-urgent.

We calculated the proportion of patients from the different diagnostic pathways for the 30 Cancer Networks that existed on 1 October 2007. Patients were grouped into networks by their NHS trust of diagnosis. Patients were also categorised as having either oesophageal (including junctional) or stomach tumours because differences in the distribution of patients across the diagnostic pathways were small across the various histological types and anatomical sub-sites of these tumours. Patients missing either source of referral or referral urgency were excluded.

We adjusted the network rates of referral for patient characteristics using (multinomial) logistic regression. An equivalent regression model was used to adjust the rates of urgent GP referrals for each network.

5.2. Results

Overall, 66.3% of patients were referred by their general practitioner, 16.4% were referred following an emergency hospital admission and 17.3% were referred from another hospital consultant.

The proportion of GP referrals was lower among patients with stomach tumours compared to oesophageal tumours (56.5 vs 70.7%, p<0.001). This was in part because a greater proportion of stomach cancers were diagnosed after an emergency admission (24.1% vs13.0%, p<0.001). Diagnosis after an emergency admission was also more common among patients as their performance status got worse.

Among the GP referrals, 68.8% patients were labelled as urgent (suspected cancer) but the proportion was higher among patients with oesophageal tumours compared to those with stomach tumours (71.1% vs 62.6%, p<0.001).

Variation in referral patterns between Cancer Networks

The proportion of patients diagnosed via the three referral pathways varied substantially between Cancer Networks, being greater than would be expected from random fluctuations alone:

- For GP referrals, the 10th and 90th percentiles of the network rates were 54.2% and 74.0%, respectively.
- For emergency admissions, the 10th and 90th percentiles of the network rates were 9.3% and 23.7%, respectively.
- For other hospital referrals, 80% of networks had rates between 7.7% and 24.6%.

The estimated case-ascertainment within the 30 networks was variable: it exceeded 70% for 12 networks, was between 45% and 70% for 13 networks and was under 45% for 5 networks. However, the level of variation was similar among the networks with high, medium or low case-ascertainment (see Figure 5.1).

Adjusting the network referral patterns for differences in the network's patient casemix did not greatly reduce the overall level of variation. Figures 5.2 and 5.3 show the adjusted proportion of patients diagnosed after an emergency admission for each network, and both highlight an over-dispersed pattern of variation among networks.

Figure 5.1
Proportion of patients diagnosed after GP referral for the 30 English Cancer Networks.
The networks are grouped by level of case-ascertainment and adjusted for patient characteristics.

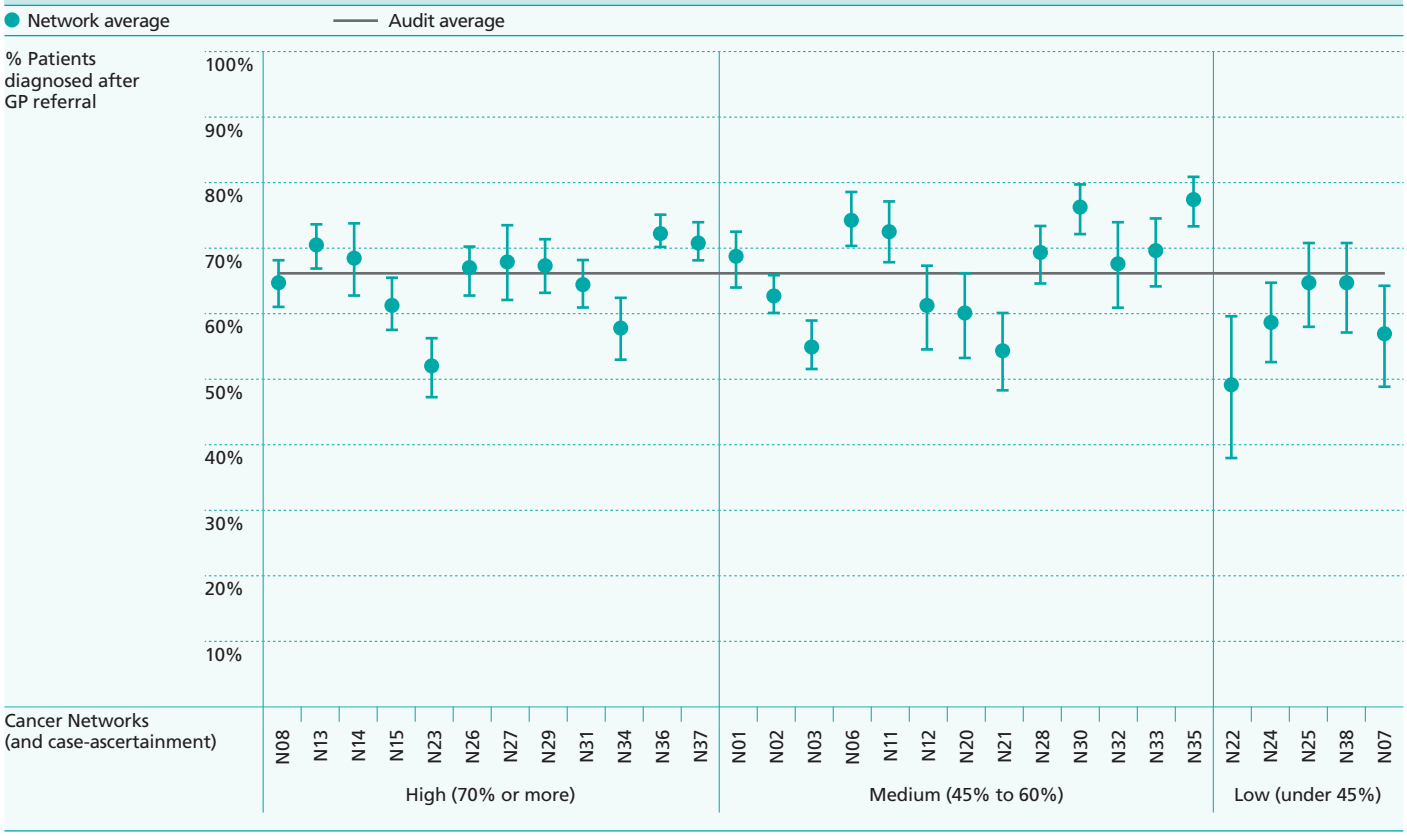


Figure 5.2
Proportion of patients diagnosed after an emergency admission by 30 English Cancer Networks, adjusted for patient characteristics

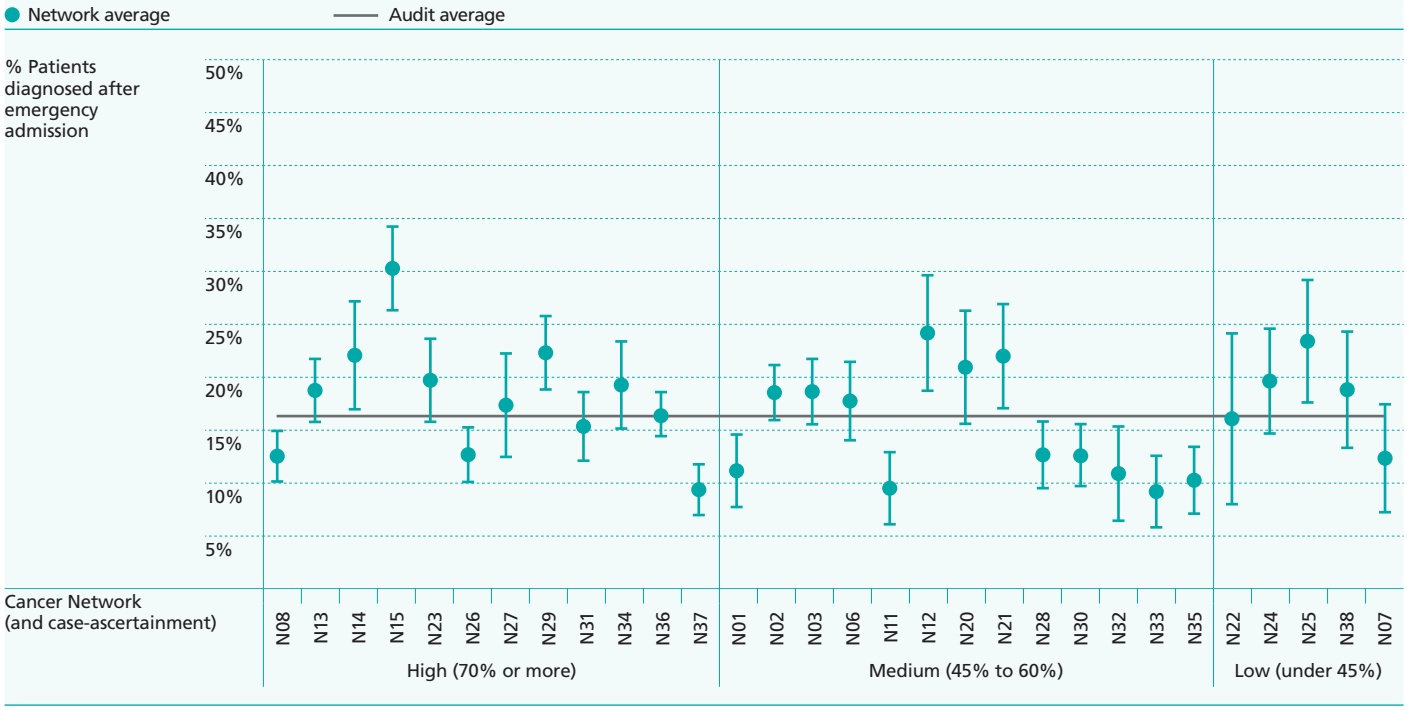
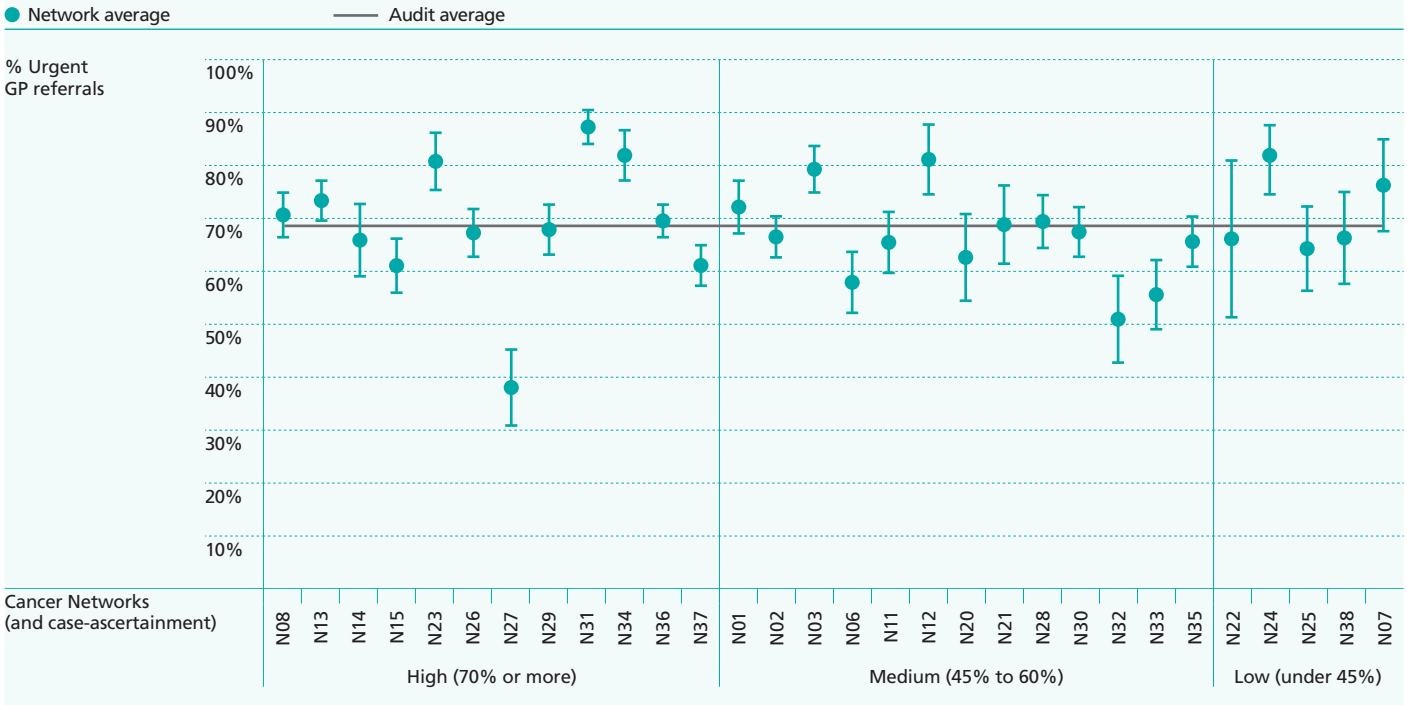


Figure 5.3
Proportion of GP referrals who were referred urgently prior to diagnosis with O-G cancer by 30 English Cancer Networks, adjusted for patient characteristics



5.3. Discussion

For patients diagnosed between October 2007 and June 2009, there was substantial variation between Cancer Networks in the proportion of patients diagnosed via each pathway. In particular, there was significant variation between Cancer Networks in the proportion of patients diagnosed after emergency admission.

The pathway to diagnosis is important for NHS services to examine. The proportion of patients planned to have curative treatment was considerably lower among patients diagnosed after an emergency admission (16%) compared to urgent GP referrals (36%). The lessons to be learnt from these Cancer Networks require investigation at a local level so that appropriate strategies can be devised.

6. Long-term outcomes for patients receiving curative care

6.1 Rationale and methods

In the last annual report of the First National O-G Cancer Audit, preliminary estimates were given for longer term survival among patients who underwent treatment with curative intent. For patients with oesophageal / junctional tumours, the proportion who survived 1 year was estimated to be 76.1%; for patients with gastric tumours, 78.0% of patients survived at least 1 year. Since that report, it has been possible to have longer term follow-up for these patients (median was 1369 days; minimum was 1039 days), and so improve the survival estimates. In this chapter, we therefore provide descriptive estimates of 1, 2 and 3 year survival for patients undergoing curative treatment.

Survival from the time of diagnosis was calculated using Kaplan-Meier estimates and did not take account of background mortality. The analysis was limited to patients with known treatment intent and the common treatment modalities given to patients with each type of tumour.

For patients with oesophageal squamous cell carcinoma, this included definitive chemo-radiation therapy, and surgery with or without neoadjuvant chemotherapy. For patients with oesophageal adenocarcinomas or gastric tumours, treatment modality corresponded to surgery with or without neoadjuvant chemotherapy.

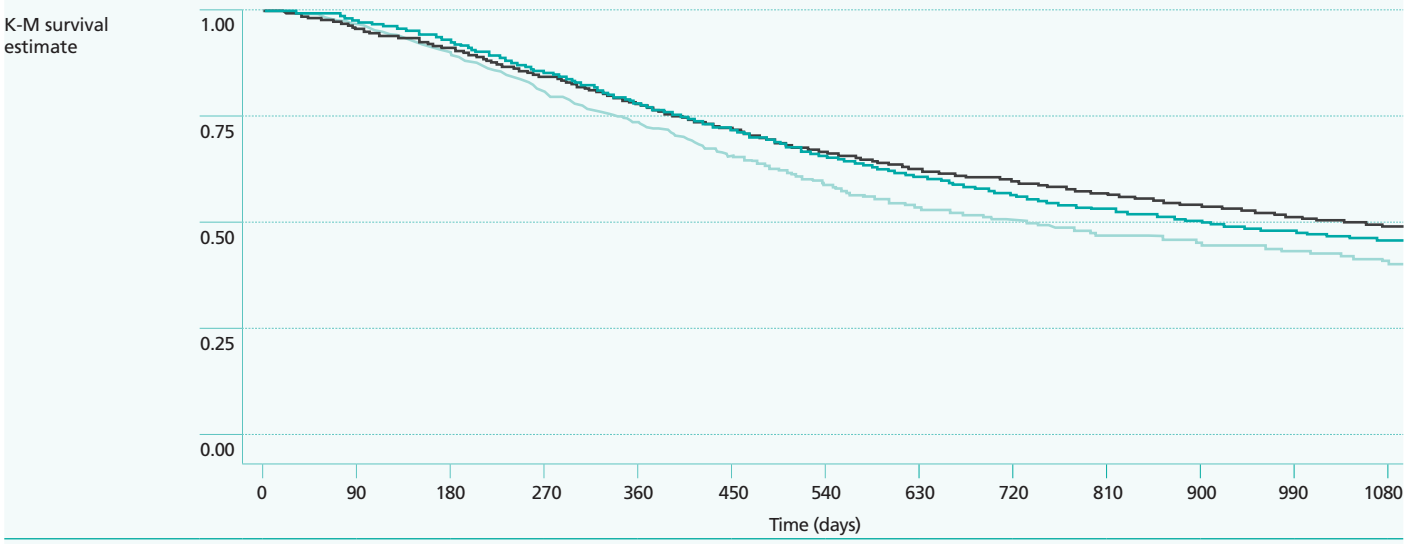
6.2 Results

Overall, around three-quarters of patients receiving treatment with curative intent survived at least 1 year from diagnosis. At two years, just over one-half of patients were still alive. The survival differences between the three groups were not large at one year, but at 2 and 3 years survival was slightly better for patients with stomach tumours compared to those with an oesophageal tumour (see Table 6.1 and Figure 6.1).

Table 6.1
Proportion of patients with curative treatment intent estimated to survive 1, 2 and 3 years from date of diagnosis (unadjusted Kaplan-Meier estimates)

	Survival estimate (95% Confidence Interval)		
Patients with curative treatment intent	**1 year**	**2 year**	**3 year**
Oesophageal Squamous Cell	73.1 (69.9-76.0)	50.7 (47.3-54.1)	41.3 (38.0-44.7)
Oesophageal adenocarcinoma (includes Siewert 1 and 2)	78.2 (76.4-79.8)	56.5 (54.4-58.5)	46.0 (43.9-48.0)
Gastric tumours (includes Siewert 3)	77.6 (75.7-79.5)	59.7 (57.4-61.9)	49.4 (47.1-51.2)

Figure 6.1
Unadjusted Kaplan-Meier survival estimates for patients with curative treatment intent, stratified by tumour type. Survival times estimated up to 1100 days after diagnosis (approx 3 years)



6.3 Discussion

Estimates of relative survival for patients with oesophago-gastric cancer are published by the Office for National Statistics (ONS), and are based on cancer registrations to ensure there is minimal selection bias. Among all patients, relative survival has increased in the last decade, although 5-year survival of patients with oesophageal and gastric cancer is 10% and 15% respectively [ONS 2010].

Survival figures are not available from ONS by treatment intent. These descriptive survival estimates for patients undergoing curative treatment show that the prognosis for these patients is far better than for patients overall and long-term follow-up of this cohort is important.

7. Completion of palliative chemotherapy

7.1. Rationale and methods

Only about 20-30% of patients are suitable for curative treatment and about three quarters of patients die within the year of diagnosis [Cancer Research UK 2011a; 2011b]. To prolong survival and improve quality of life, palliative chemotherapy is given to patients with locally advanced or metastatic cancer [SIGN 2006; Allum et al 2011].

In this chapter, the results of an analysis of palliative chemotherapy completion rates are described. A limitation of the current evidence is the lack of information on how different patient groups respond to palliative chemotherapy. Recent European Society for Medical Oncology (ESMO) guidelines for gastric patients recommend organ function, performance status and co-morbidities be considered, and age alone is not a contra-indication [Stahl et al 2010]. The ESMO guideline for oesophageal patients recommended palliative chemotherapy should be considered for patients with adenocarcinoma who have a good performance status [Okines et al 2010].

The study included all English patients with a palliative treatment intent that received palliative chemotherapy. Patients from Wales were excluded due to differences in coding treatment intent and modality. Information was collected on patient characteristics such as age, sex, deprivation index, tumour site, pre-treatment stage, pre-treatment histological diagnosis, performance status (ECOG score), and co-morbidities. We grouped site of cancer as oesophageal (oesophageal squamous cell carcinoma, upper or middle adenocarcinoma and lower or Siewert I adenocarcinoma) and gastric cancer (gastro-oesophageal junction Siewert II or III, and stomach).

The primary outcome was the rate of completion among patients receiving palliative chemotherapy. This was calculated across patients with various characteristics such as age, sex and tumour site.

7.2. Results

Among the 9,768 patients with a palliative treatment intent, 2,313 (23.7%) underwent palliative chemotherapy (Table 7.1). This treatment was more commonly used amongst younger patients and those with good performance status. Nonetheless, around 10% of patients aged 75 plus, or who had a performance status of 2 or worse also received palliative chemotherapy. A lower proportion of women than men received palliative chemotherapy (17.4% vs 27.1%, $p<0.001$).

Table 7.1
Patient selection for palliative chemotherapy among all patients with palliative treatment intent

	Patients (%) with palliative treatment intent:	Patients undergoing palliative chemotherapy:	
		Number	Rate (%)
All patients	**9,768**	**2313**	**23.7**
Age			
Under 55	670 (6.9)	344	51.3
55 to 64	1,344 (13.8)	626	46.6
65 to 74	2,437 (24.9)	853	35.0
75 and over	5,317 (54.4)	490	9.2
Gender			
Female	3,429 (35.1)	596	17.4
Male	6,339 (64.9)	1,717	27.1
Index of multiple deprivation			
1 (least)	1,806 (18.5)	502	27.8
2	1,832 (18.8)	471	25.7
3	2,016 (20.6)	490	24.3
4	1,967 (20.1)	400	20.3
5 (most)	2,147 (22.0)	450	21.0
Tumour			
Oesophagus	5,686 (58.2)	1,286	22.6
Stomach	4,082 (41.8)	1,027	25.2
Diagnosis (histology)			
Adenocarcinoma	7,411 (75.9)	1,884	25.4
Squamous cell	1,661 (17.0)	304	18.3
Other	696 (7.1)	125	18.0
Pre-treatment stage			
1 or 2	892 (9.1)	83	9.3
3	1,127 (11.5)	239	21.2
4	3,896 (39.9)	1,377	35.3
Missing	3,853 (39.5)	614	15.9
ECOG/WHO Performance status			
0 no restrictions	1,413 (14.5)	622	44.0
1 restricted in strenuous activities	1,835 (18.8)	620	33.8
2 unable to work or worse	3,474 (35.6)	326	9.4
Missing	3,046 (31.2)	745	24.5
Co-morbidities			
None	5,317 (54.4)	1,551	29.2
1	2,638 (27.0)	542	20.5
2 or more	1,813 (18.6)	220	12.1

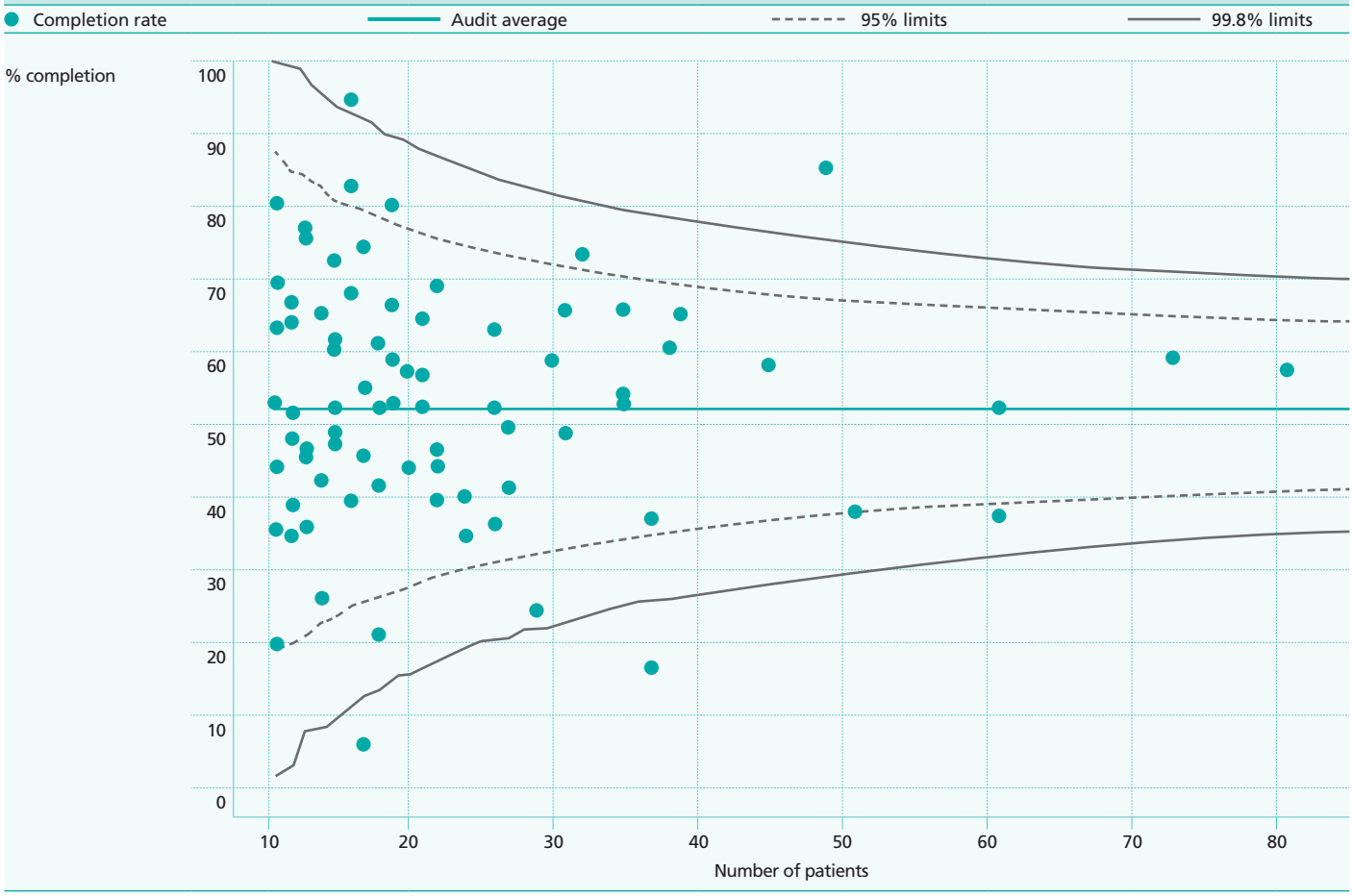
Table 7.2 presents the relationship between patient characteristics and the proportion of patients completing palliative chemotherapy. The rate of completion fell as the age of patients increased. Rates of completion among patients also decreased as the performance status got worse, and the number of comorbidities increased. It did not differ between men and women, or between oesophageal or gastric tumours.

Table 7.2
Relationship between patient characteristics and completion of chemotherapy

	No. (%) of patients with known outcome		Patients who completed treatment		p-value
	Number	Rate (%)	Number	Rate (%)	
All patients	**1741**	**100**	**917**	**52.7**	
Age					
Under 55	268	15.4	160	59.7	<0.001
55 to 64	479	28.0	273	57.0	
65 to 74	634	36.4	325	51.3	
75 and over	360	20.7	159	44.2	
Index of multiple deprivation					
1 (least)	393	22.6	229	58.3	<0.001
2	363	20.9	203	55.9	
3	357	20.5	183	51.3	
4	311	17.7	158	50.8	
5 (most)	315	18.2	144	45.7	
ECOG/WHO Performance status					
0 no restrictions	497	28.6	297	59.8	<0.001
1 restricted in strenuous activities	524	30.1	278	53.1	
2 unable to work or worse	271	15.6	86	31.7	
Missing	449	25.8	n/a	n/a	

Figure 7.1 shows the variation between the adjusted completion rates of NHS trusts. The rates were risk-adjusted for patient age, performance status and level of deprivation. There is substantial variation among all trusts but this is mostly within the range expected from random fluctuations below.

Figure 7.1
Adjusted rate of completion of palliative chemotherapy for English NHS trusts at which treatment was given.



7.3. Discussion

The overall rate of treatment completion was 53%. Higher completion rates were obtained in patients that are younger, had a higher performance status and were from less deprived groups.

Information on the drug regimen for chemotherapy was not available for this study, but assuming that the treatment selected was the most appropriate for the patient, it would seem that a substantial proportion of patients are not completing palliative chemotherapy.

Medical decision-making regarding palliative chemotherapy is complex and involves balancing clinical assessment, patient preferences and the probability of treatment completion. Palliative chemotherapy may prolong survival but there are alternative therapies for improving symptom control and quality of life. The observation that only half of patients complete their chemotherapy may reflect an overly optimistic assessment of patients' ability to benefit from treatment, or a preference of treatment over best supportive care among patients despite poor prognostic factors. It may also highlight a lack of adequate institutional and social support services.

We observed substantial variation in the adjusted rates of completion between NHS trusts. There are likely to be various sources of this variation including:

1. differences in the proportion of patients who received palliative chemotherapy and who had a treatment record for this submitted to the Audit
2. differences in the level of missing data on whether or not a patient completed their palliative chemotherapy
3. residual confounding due to inadequate risk adjustment for patient characteristics
4. differences in patient preferences for chemotherapy.

Due to the likely influence of data quality as a source of variation between trusts, those NHS trusts with unusually high or low rates of treatment completion should not be viewed as "outliers" in terms of clinical performance. Instead, these results should be interpreted as highlighting the need for improving the quality of data on this important patient outcome.

8. Hospital admissions of palliative care patients on a best supportive care pathway

8.1. Rationale and methods

The Department of Health 'End of Life Care Strategy' (2008) aims to improve access to palliative care services where the patients most need it [DH 2008]. The strategy proposes an end-of-life care pathway emphasizing open communication about end of life, appropriate care planning, coordination and delivering high quality services in all locations, care in the last days of life and, relevant for family members, care after death. A high proportion of patients are admitted to hospital, typically for care related to disease progression and the development of new co-morbidities [Grim et al 2010]. Appropriate community services or proper palliative care planning by a multi-disciplinary team of palliative care specialists may reduce admission rates near end-of-life [Nelson et al 2011; Fromme et al 2006].

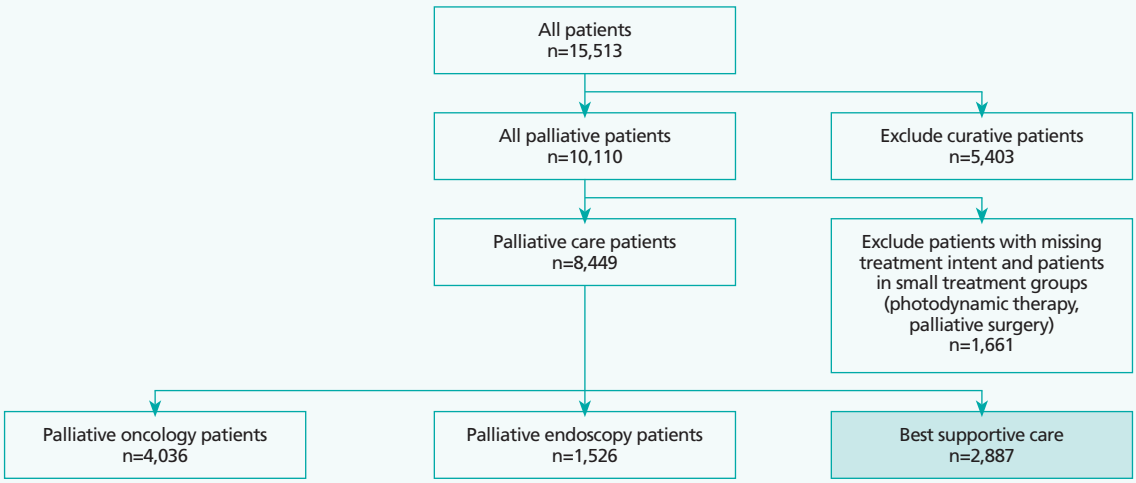
Patients on best supportive care are in principle best managed in the community to receive care that relieves symptoms and pain. There is little known about the variation in use of hospital inpatient care amongst this group of patients. In this chapter, we examine hospital admission patterns for patients receiving palliative best supportive care.

We included patients diagnosed with oesophago-gastric cancer in the period of the first NOGCA in England. For each patient, we identified date and mode of treatment intent and covariates such as age, sex, performance status, deprivation and comorbidities. The NOGCA dataset was linked to Hospital Episode Statistics based on an algorithm using age, sex, date of birth and postcode and identified the method of hospital admission (planned and emergency) between date of treatment intent and death for each patient.

8.2. Results

There were 8,449 patients in the linked Audit-HES dataset with a palliative treatment intent. Of these 2,887 patients had a treatment plan of best supportive care (see Figure 8.1).

Figure 8.1
Summary of patient selection for the analysis of hospital admissions among patients receiving best supportive care in England



Overall, 50% of patients receiving best supportive care were admitted to hospital between their diagnosis and their death (Table 8.1). For a quarter of these patients, the admission was planned. However, just over 40% (1,188) of patients had one or more emergency admissions.

Table 8.1
Planned hospital admissions of patients on a best supportive care pathway

Number of admissions	% of patients with ANY admission	% of patients with PLANNED admissions	% of patients with EMERGENCY admissions
None	50.0	76.7	58.9
1	22.6	13.1	25.1
2	12.2	4.6	9.4
3	6.2	1.9	3.6
4	2.9	0.9	1.7
5	1.8	0.8	0.6
6	1.3	0.5	0.5
7	0.7	0.3	0.0
8 or more	2.4	1.4	0.3
No. of patients	**2,887**	**2,887**	**2,887**

The planned and emergency admission rates for each English NHS trust are shown in figures 8.2 and 8.3, respectively. The differences between individual trusts are fairly large, but the funnel plots reveal that this may be due to random fluctuations alone.

Figure 8.2
Adjusted admission rates by trust for *planned admissions* of patients on a best supportive care pathway

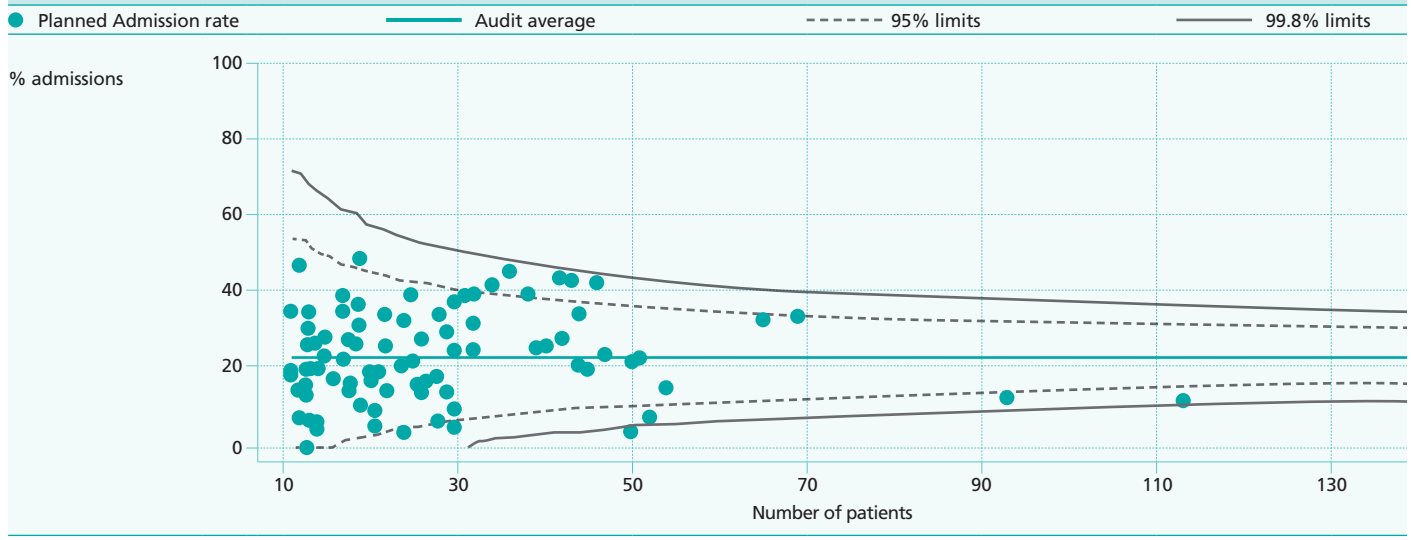
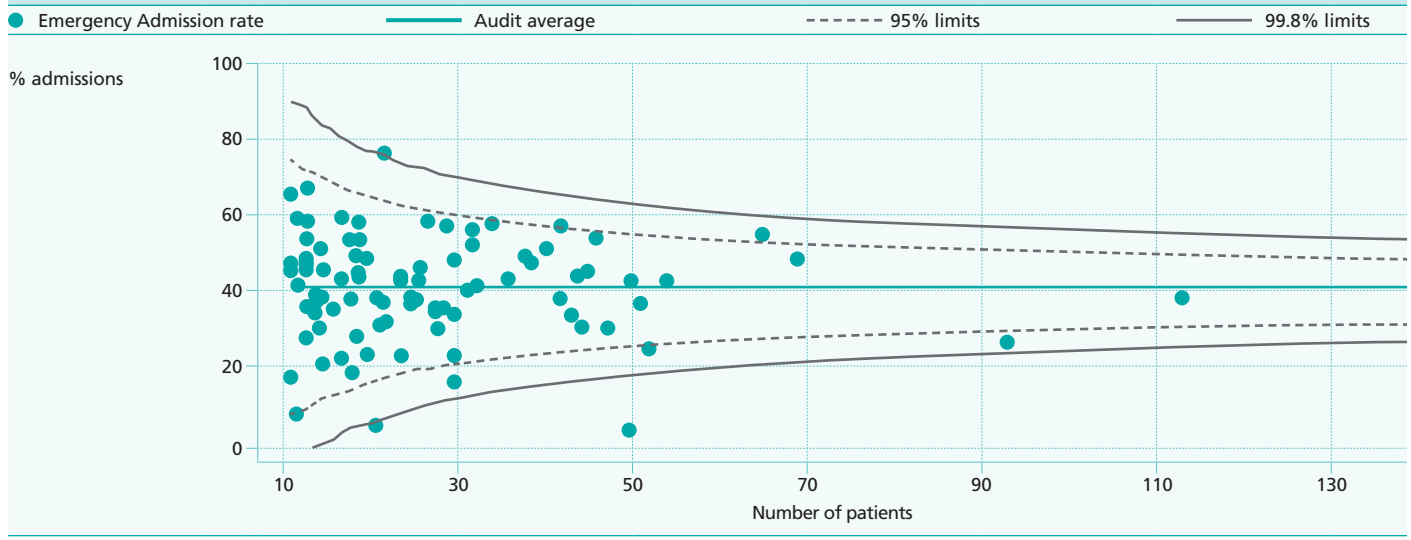


Figure 8.3
Adjusted admission rates by trust for *emergency admissions* of patients on a best supportive care pathway



Adjusting the data for admissions in the last 30 days and 60 days before death, respectively, produces the following results:

- 195 (6.75%) of 2,887 patients on a best supportive care pathway have an emergency admission in the last 30 days before death
- 436 (15.1%) of 2,887 patients on a best supportive care pathway have an emergency admission in the last 60 days before death.

There is little comparative information from observational studies on emergency admissions for O-G cancer patients in the last month of their life. However, compared to data from Canada, it seems that the 30-day readmission rates observed in England are low [Barbera et al 2010].

8.3. Discussion

Patients diagnosed with oesophago-gastric cancer on the best supportive palliative care pathway have the worst prognosis and limited life expectancy compared to other O-G cancer patients. Avoidable service utilisation near end-of-life, either planned or as emergency hospital admissions, may interfere with the aims of palliative treatment as proposed in the Department of Health's End-of-Life Care Strategy.

A substantial proportion of these palliative care patients have at least one emergency admission to hospital in the last months of their life. There is substantial variation between NHS trust rates of emergency admission but the current Audit database does not have sufficient power to detect differences due to systematic factors; the observed level of variation was consistent with the expected influence of random fluctuations. This issue will be examined further in later reports as more data become available.

9. Conclusions and recommendations

This is the first report of the second phase of the National Oeosophago-Gastric Cancer Audit in England and Wales. It provides an assessment of organisational policies and procedures for O-G cancer patients and detailed analysis of current practice and clinical outcomes of care.

The audit continues to be the largest audit on oesophago-gastric cancer in the world. The implementation of the audit and collection of data has only been feasible because of the substantial support of staff in NHS trusts and Cancer Networks, the professional bodies (RCR, AUGIS, BSG) and patient groups, and the funding provided by the Healthcare Quality Improvement Partnership.

The results of the organisational audit suggest that progress has been made over the last few years in meeting the recommended structure of NHS services for oesophago-gastric cancer [DH 2001]. All but two specialist centres have the minimum of three consultant surgeons recommended for providing curative surgical services, and the majority of Cancer Networks and NHS trusts have access to key therapies. Most categories of patients are also now routinely discussed at MDT meetings. However, there is inconsistency in procedures for the inclusion of patients on a palliative care pathway and private patients. Moreover, the attendance of members of the palliative care team at MDT meetings could be improved.

With regard to the treatment of patients with high grade dysplasia, the majority of NHS organisations provide access to oesophageal resections, either at the trust/board level or in another hospital. Other therapeutic procedures for patients with oesophageal HGD were less widely available. Further attention should focus on systematic referral of HGD patients to the MDT and procedures to ensure diagnosis of high grade dysplasia is made by two pathologists with gastro-intestinal interest.

The further analysis of the data collected during the First National Oesophago-Gastric Cancer Audit demonstrates that, overall, clinicians are providing good quality care for patients in line with recommended standards. In particular, the estimated survival times for patients who receive curative treatment are higher than quoted in other studies. Around three-quarters of these patients survived at least 1 year from diagnosis. At 3 years nearly 50% of patients with stomach tumours were still alive, while around 45% of patients with an oesophageal tumour were alive.

The Audit has highlighted a number of areas where Cancer Networks and NHS trusts should investigate their results further. These include:

- **Referral patterns**
  The pathway to diagnosis has important implications for early diagnosis and treatment plan and should be investigated further at local level. The analysis demonstrates substantial variations between Cancer Networks in the proportion diagnosed after emergency admission. A careful assessment of the underlying reasons for this variation may help to devise strategies to improve early diagnosis.

- **Palliative chemotherapy**
  We estimate that the overall completion rate of patients undergoing palliative chemotherapy is 53%. Completion rates were lower among older patients, more frail patients and patients from more deprived population groups. The results raise questions about patient selection criteria and the benefit of palliative chemotherapy over best supportive care in patient groups less likely to complete therapy. The Audit also found substantial variation in completion rates between NHS trusts and greater effort should be made by individual NHS trusts to ensure that complete data is submitted to the Audit on this treatment modality and its outcome.

- **Admissions of patients on a best supportive care pathway**
  Half of all patients on a best supportive care pathway had at least one hospital admission between diagnosis and death, and 40% of patients had at least one emergency admission. There is substantial variation between NHS trusts in the rates of emergency admission, but the rate of emergency admissions in the last 30 and 60 days of life is low.

Recommendations

1. All patients diagnosed with oesophageal high grade dysplasia and oesophago-gastric cancer should be discussed within specialist MDT meetings. This should include patients on a palliative care pathway.
2. 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.
3. The diagnosis of oesophageal high grade dysplasia should be based on two independent assessments by pathologists with gastrointestinal interest.
4. Cancer Networks should have access to endoscopic therapies including endoscopic mucosal resection, stent insertion and ablation therapies, such as radiofrequency ablation or argon beam coagulation.
5. Standardized tools should be used more frequently in the nutritional assessment of oesophago-gastric cancer patients.
6. For patients referred for treatment, networks should know the proportion referred following an emergency hospital admission and, working with NHS commissioners and providers, develop strategies for reducing emergency admissions within the network.
7. Clinicians should carefully assess eligibility of patients for palliative chemotherapy, especially in those of older age and low performance status. This assessment should balance clinical considerations with patient choice.
8. In line with the Department of Health's End of Life Care Strategy, networks, trusts and commissioners should know the rate of emergency (re-)admissions of palliative care patients and develop strategies to offer improved support to patients and reduce emergency re-admissions.

Appendix 1: Organisation of the Audit

The project is assisted by a Clinical Reference Group (CRG), the membership of which is drawn from all of the clinical groups involved in the management of oesophago-gastric cancer and overseen by a Project Board, which has senior representatives from the four participating organisations and the funding body.

Members of Clinical Reference Group		
Mike Hallisey	Consultant Surgeon Birmingham	Association of Cancer Surgeons
Paul Barham	Consultant Surgeon Bristol	Association of Upper Gastrointestinal Surgeons of Great Britain & Ireland
Martin Richardson	Consultant Surgeon	Cancer Networks
Helen Laing	Clinical Audit Commissioning Manager	Healthcare Quality Improvement Partnership (HQIP)
Jan van der Meulen (chair)	Professor of Clinical Epidemiology	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
Vicki Owen-Holt	Specialist Nurse	Royal College of Nursing
Nic Mapstone	Consultant Pathologist	Royal College of Pathologists
Hans-Ulrich Laasch	Consultant Radiologist	Royal College of Radiologists
Sam Ahmedzai	Professor of Supportive Care Medicine	Palliative Care Representative
Tom Crosby	Consultant Clinical Oncologist	Cancer Services Co-ordinating Group, Wales
Nick Carroll	Consultant Radiologist and Endoscopist	UK EUS Users Group
Fiona Macharg	Specialist Dietitian	British Dietetic Association Oncology Group
Greg Rubin	Professor General Practice and Primary Care	Primary Care Representative

Members of Project Board	
Dr David Sanders	British Society of Gastroenterologist
Professor Mike Griffin	Association of Upper Gastrointestinal Surgeons of Great Britain & Ireland
Julie Henderson	Health and Social Care Information Centre
Helen Laing	Healthcare Quality Improvement Partnership (HQIP)
Professor Jan van der Meulen (chair)	London School of Hygiene and Tropical Medicine
Dr Diana Tait	Royal College of Radiologists

Appendix 2: Summary of data used from the First National Oesophago-Gastric Cancer Audit

Overall case-ascertainment

The Audit used Hospital Episode Statistics (HES) to estimate how many of the patients diagnosed between 1 October 2007 and 30 June 2009 were submitted by English NHS trusts. The estimate was based on the activity data from HES that was linked to the audit dataset.

In total, English NHS trusts submitted information to the Audit on 19,320 patients. However, information about the tumour characteristics and treatments received was not entered for 1,764 patients and 1,121 patients were diagnosed outside the audit period. A further 171 were removed because they were either duplicates, or were not within the scope of the Audit. Consequently, the Audit received clinical information on 16,264 patients, which gives a case-ascertainment of 71%. This is an increase of 10% from the 61% case-ascertainment in the Second Annual Report.

Data on Welsh patients was submitted for patients diagnosed with an O-G tumour between 1 January 2008 and 30 June 2009. There were 1,037 patients in the data supplied by CANISC. 22 of these patients were found to have a tumour outside the scope of the audit and were excluded from subsequent analysis. The details of 1,015 Welsh patients were included in the Audit.

Case-ascertainment by English Cancer Networks

The majority of the 30 English Cancer Networks achieved a high level of case-ascertainment. Over the full 18-month period, 18 networks achieved over 70% case-ascertainment. Only two networks failed to achieve 50%.

Completeness of submitted data

In terms of the O-G cancer treatments performed in England and Wales, the Audit received information on 3,803 curative surgical procedures and 3,630 courses of curative oncological therapy, 4,328 courses of palliative oncological therapy, and 3,249 endoscopic/radiological palliative therapies.

The completeness of data submitted by English NHS trusts could not be judged for oncological or endoscopic/radiological palliative therapies due to the lack of a reliable denominator. For surgical resections, a comparison could be made using HES. We identified 4,290 surgical resections in the HES dataset. Comparing this with the 3,515 surgical resections performed in English trusts gives an estimated case-ascertainment rate of 82 per cent.

Data completeness of treatment intent and treatment modality was consistently high, with valid values for 94% and 93% of patients overall, respectively. The pretreatment M-stage data item had the lowest level of completeness amongst these four items, although five regions had values for at least 90% of patients. Pretreatment M-stage is an important determinant of whether treatment intent will be curative or palliative, and should be available after a patient has a CT-scan.

Twelve regions uploaded treatment information for at least 90% of patients who were planned to receive curative treatments and only one region had entered treatment information for less than half of its patients. No region had low levels of completeness on all the selected data items.

The level of data completeness across NHS trusts was more variable (appendix 4). Some NHS trusts provided a large number of records and complete records. Others were providing fewer details. In particular, six cancer centres submitted treatment data on less than 50% of patients.

Many NHS trusts have achieved a high level of case-ascertainment in this Audit. We commend their staff for the effort and diligence made during the 21 month Audit duration. For others, participation was limited, either because few patients were registered or because clinical information was incomplete.

A number of cancer centres failed to participate fully. It is unclear whether this was because the data were not available or was a failure to input the data. Given their central role in the organisation of care, cancer centres should be taking the lead in the implementation of procedures for monitoring of treatment selection and outcomes of care within the Cancer Networks, including participation in the national Audit.

Appendix 3: Participation of NHS organisations in the Organisational Audit

All English Cancer Networks and the two Welsh Cancer Networks returned the Network level organisational audit.

The English and Welsh NHS organisations that returned the Trust-level organisational audit were (note: not all NHS organisations were included in the analysis because of missing or duplicate responses):

Network Code	Cancer Network	Trust Name
N01	Lancashire and South Cumbria	Blackpool Teaching Hospitals NHS Foundation Trust
		East Lancashire Hospitals NHS Trust
		Lancashire Teaching Hospitals NHS Foundation Trust
		University Hospitals of Morecambe Bay NHS Foundation Trust
N02	Greater Manchester and Cheshire	Bolton NHS Foundation Trust
		Central Manchester University Hospitals NHS Foundation Trust
		East Cheshire NHS Trust
		Mid Cheshire Hospitals NHS Foundation Trust
		Pennine Acute Hospitals NHS Trust
		Salford Royal NHS Foundation Trust
		Tameside Hospital NHS Foundation Trust
		The Christie NHS Foundation Trust
		Trafford Healthcare NHS Trust
		University Hospital of South Manchester NHS Foundation Trust
		Wrightington, Wigan and Leigh NHS Foundation Trust
N03	Merseyside and Cheshire	Aintree University Hospital NHS Foundation Trust
		Clatterbridge Centre for Oncology NHS Foundation Trust
		Countess Of Chester Hospital NHS Foundation Trust
		Liverpool Heart and Chest Hospital NHS Foundation Trust
		Royal Liverpool and Broadgreen University Hospitals NHS Trust
		Southport and Ormskirk Hospital NHS Trust
		St Helens and Knowsley Hospitals NHS Trust
		Wirral University Teaching Hospital NHS Foundation Trust
N06	Yorkshire	Airedale NHS Foundation Trust
		Bradford Teaching Hospitals NHS Foundation Trust
		Calderdale and Huddersfield NHS Foundation Trust
		Harrogate and District NHS Foundation Trust
		Leeds Teaching Hospitals NHS Trust
		Mid Yorkshire Hospitals NHS Trust
		York Teaching Hospital NHS Foundation Trust
N07	Humber and Yorkshire Coast	Hull and East Yorkshire Hospitals NHS Trust
		Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
		Scarborough and North East Yorkshire Healthcare NHS Trust
N08	North Trent	Barnsley Hospital NHS Foundation Trust
		Chesterfield Royal Hospital NHS Foundation Trust
		Doncaster and Bassetlaw Hospitals NHS Foundation Trust
		Sheffield Teaching Hospitals NHS Foundation Trust
		The Rotherham NHS Foundation Trust
N11	Pan Birmingham	Heart of England NHS Foundation Trust
		Sandwell and West Birmingham Hospitals NHS Trust
		University Hospital Birmingham NHS Foundation Trust
		Walsall Healthcare NHS Trust
N12	Arden	George Eliot Hospital NHS Trust
		South Warwickshire NHS Foundation Trust
		University Hospitals Coventry And Warwickshire NHS Trust
N20	Mount Vernon	East and North Hertfordshire NHS Trust
		Luton and Dunstable Hospital NHS Foundation Trust
		West Hertfordshire Hospitals NHS Trust

Network Code	Cancer Network	Trust Name
N21	North West London	Chelsea and Westminster Hospital NHS Foundation Trust
		Ealing Hospital NHS Trust
		Imperial College Healthcare NHS Trust
		North West London Hospitals NHS Trust
		The Hillingdon Hospitals NHS Foundation Trust
		West Middlesex University Hospital NHS Trust
N22	North London	Barnet and Chase Farm Hospitals NHS Trust
		North Middlesex University Hospital NHS Trust
		Royal Free Hampstead NHS Trust
		The Princess Alexandra Hospital NHS Trust
		The Whittington Hospital NHS Trust
		University College London Hospitals NHS Foundation Trust
N23	North East London	Barking, Havering And Redbridge Hospitals NHS Trust
		Barts and The London NHS Trust
		Homerton University Hospital NHS Foundation Trust
		Newham University Hospital NHS Trust
		Whipps Cross University Hospital NHS Trust
N24	South East London	Guy's and St Thomas' NHS Foundation Trust
		King's College Hospital NHS Foundation Trust
		South London Healthcare NHS Trust
		The Lewisham Hospital NHS Trust
N25	South West London	Croydon Health Services NHS Trust
		St George's Healthcare NHS Trust
		The Royal Marsden NHS Foundation Trust
N26	Peninsula	Northern Devon Healthcare NHS Trust
		Plymouth Hospitals NHS Trust
		Royal Cornwall Hospitals NHS Trust
		Royal Devon and Exeter NHS Foundation Trust
		South Devon Healthcare NHS Foundation Trust
N27	Dorset	Dorset County Hospital NHS Foundation Trust
		Poole Hospital NHS Foundation Trust
		Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
N28	Avon, Somerset and Wiltshire	Royal United Hospital Bath NHS Trust
		Taunton and Somerset NHS Foundation Trust
		University Hospitals Bristol NHS Foundation Trust
		Yeovil District Hospital NHS Foundation Trust
N29	3 Counties	Gloucestershire Hospitals NHS Foundation Trust
		Worcestershire Acute Hospitals NHS Trust
		Wye Valley NHS Trust
N30	Thames Valley	Buckinghamshire Healthcare NHS Trust
		Great Western Hospitals NHS Foundation Trust
		Heatherwood and Wexham Park Hospitals NHS Foundation Trust
		Milton Keynes Hospital NHS Foundation Trust
		Oxford University Hospitals NHS Trust
		Royal Berkshire NHS Foundation Trust
N31	Central South Coast	Hampshire Hospitals NHS Foundation Trust
		Isle of Wight NHS Trust
		Portsmouth Hospitals NHS Trust
		Salisbury NHS Foundation Trust
		University Hospital Southampton NHS Foundation Trust
		Western Sussex Hospitals NHS Trust
N32	Surrey, West Sussex and Hampshire	Ashford and St Peter's Hospitals NHS Trust
		Royal Surrey County Hospital NHS Foundation Trust
N33	Sussex	Brighton and Sussex University Hospitals NHS Trust
		East Sussex Healthcare NHS Trust

Network Code	Cancer Network	Trust Name
N34	Kent and Medway	Dartford and Gravesham NHS Trust
		Maidstone and Tunbridge Wells NHS Trust
		Medway NHS Foundation Trust
N35	Greater Midlands	The Dudley Group NHS Foundation Trust
		The Royal Wolverhampton Hospitals NHS Trust
		The Shrewsbury and Telford Hospital NHS Trust
N36	North of England	County Durham and Darlington NHS Foundation Trust
		North Cumbria Acute Hospitals NHS Trust
		North Tees and Hartlepool NHS Trust
		Northumbria Healthcare NHS Foundation Trust
		South Tees Hospitals NHS Foundation Trust
		The Newcastle upon Tyne Hospitals NHS Foundation Trust
N37	Anglia	Bedford Hospital NHS Trust
		Cambridge University Hospitals NHS Foundation Trust
		Hinchingbrooke Health Care NHS Trust
		Ipswich Hospital NHS Trust
		James Paget University Hospitals NHS Foundation Trust
		Norfolk and Norwich University Hospitals NHS Foundation Trust
		Peterborough and Stamford Hospitals NHS Foundation Trust
		The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust
		West Suffolk NHS Foundation Trust
N38	Essex	Basildon and Thurrock University Hospitals NHS Foundation Trust
		Colchester Hospital University NHS Foundation Trust
		Mid Essex Hospital Services NHS Trust
		Southend University Hospital NHS Foundation Trust
N39	East Midlands	Burton Hospitals NHS Trust
		Derby Hospitals NHS Foundation Trust
		Kettering General Hospital NHS Trust
		Northampton General Hospital NHS Trust
		Nottingham University Hospitals NHS Trust
		Sherwood Forest Hospitals NHS Foundation Trust
		United Lincolnshire Hospitals NHS Trust
		University Hospitals of Leicester NHS Trust
W	Wales	Abertawe Bro Morgannwg University Health Board
		Betsi Cadwaladr University Health Board
		Hywel Dda Health Board
		Velindre NHS Trust

Appendix 4: Referral patterns between Cancer Networks

Network code	Network name	No. of patients	No. of GP referrals	Adjusted rate of GP referral	No. of Emergency Admissions	Adjusted rate of Emergency Admissions	No. of urgent GP referrals	Adjusted rate of urgent GP referrals
N01	Lancashire and South Cumbria	458	331	68%	43	11%	240	72%
N02	Greater Manchester and Cheshire	1,044	646	63%	197	18%	434	67%
N03	Merseyside and Cheshire	681	362	55%	140	18%	290	80%
N06	Yorkshire	424	318	75%	74	18%	184	58%
N07	Humber and Yorkshire Coast	169	101	57%	15	12%	79	77%
N08	North Trent	706	441	65%	92	12%	312	71%
N11	Pan Birmingham	360	262	73%	33	9%	173	66%
N12	Arden	237	147	61%	54	23%	118	82%
N13	Mid Trent	724	509	70%	136	19%	381	74%
N14	Derby/Burton	286	200	69%	61	22%	132	66%
N15	Leics, Northants and Rutland	577	351	62%	186	30%	214	61%
N20	Mount Vernon	232	138	60%	52	21%	85	63%
N21	West London	289	157	54%	59	21%	108	70%
N22	North London	88	43	49%	13	15%	30	68%
N23	North East London	476	230	52%	110	19%	187	81%
N24	South East London	265	154	59%	54	19%	125	82%
N25	South West London	227	147	65%	51	23%	94	65%
N26	Peninsula	636	430	67%	78	13%	295	67%
N27	Dorset	267	186	68%	45	17%	71	38%
N28	Avon, Somerset and Wiltshire	448	325	69%	48	12%	229	70%
N29	3 Counties	534	368	67%	109	22%	251	68%
N30	Thames Valley	487	382	76%	56	13%	255	68%
N31	Central South Coast	684	453	65%	97	15%	398	88%
N32	Surrey, West Sussex and Hampshire	211	153	68%	18	10%	77	51%
N33	Sussex	310	229	70%	23	9%	130	56%
N34	Kent and Medway	430	261	58%	66	19%	214	82%
N35	Greater West Midlands	505	396	77%	48	10%	259	66%
N36	North of England	1,252	867	73%	225	16%	603	70%
N37	Anglia	896	638	71%	88	9%	387	61%
N38	Essex	199	126	64%	40	18%	83	66%
	England	**14,102**	**9351**		**2311**		**6438**	

Appendix 5: Completeness of outcome assessment for palliative chemotherapy treatment of NHS organisations

Treatment outcome missing in more than 70% of cases

The purpose of the table below is to highlight incompleteness in ascertaining treatment outcome in patients undergoing palliative chemotherapy.

Outcome assessment may not always be feasible due to patient's health status or local organisation of care delivery. The proportion of patients with missing outcomes should be assessed locally to consider how data collection can be improved.

Due to selection bias when the proportion of patients with *missing* treatment outcome is high, the proportion of patients *completing* treatment should not be considered as a marker of clinical quality or appropriateness of care.

Where the number of patients is smaller than five, this is indicated by the notation '<5' instead of reporting actual numbers.

Trust name	Patients	Patients with missing treatment outcome	
	N	N	%
University Hospitals of Morecambe Bay NHS Trust	30	30	100
Lancashire Teaching Hospitals NHS Foundation Trust	17	15	88
East Lancashire Hospitals NHS Trust	8	8	100
The Christie Hospital NHS Foundation Trust	<5	<5	100
East Cheshire NHS Trust	<5	<5	100
Salford Royal Hospitals NHS Trust	<5	<5	100
Bolton Hospitals NHS Trust	<5	<5	100
Wrightington, Wigan and Leigh NHS Trust	<5	<5	100
Stockport NHS Foundation Trust	35	33	94
Wirral University Teaching Hospital NHS Foundation Trust	18	13	72
Scarborough and North East Yorkshire Healthcare NHS Trust	<5	<5	100
University Hospital Birmingham NHS Foundation Trust	62	59	95
Sandwell and West Birmingham Hospitals NHS Trust	<5	<5	100
George Eliot Hospital NHS Trust	<5	<5	100
Yeovil District Hospital NHS Foundation Trust	<5	<5	100
Taunton and Somerset NHS Trust	19	14	74
Royal United Hospital Bath NHS Trust	<5	<5	100
North Bristol NHS Trust	12	9	75
Great Western Hospitals NHS Foundation Trust	<5	<5	100
Frimley Park Hospital NHS Foundation Trust	<5	<5	75
Western Sussex Hospitals NHS Trust	8	8	100
Brighton and Sussex University Hospitals NHS Trust	6	6	100
East Kent Hospitals NHS Trust	<5	<5	100
University Hospital of North Staffordshire NHS Trust	20	18	90
The Shrewsbury and Telford Hospital NHS Trust	15	12	80
The Queen Elizabeth Hospital King's Lynn NHS Trust	<5	<5	100
Basildon and Thurrock University Hospitals NHS Foundation Trust	8	6	75
England total	**291**	**263**	**90%**

Appendix 6: Completion rates of patients with palliative chemotherapy treatment between NHS Organisations

The purpose of the table below is to highlight the variability of patients completing palliative chemotherapy treatment.

Completion of palliative chemotherapy may not always be feasible due to patient's disease progression, patient choice or other social factors affecting adherence to and completion of treatment.

The proportion of patients completing treatment should be assessed locally to guide patient selection for treatment and potentially, improve completion rates.

Due to selection bias when the proportion of patients with *missing* treatment outcome is high, the proportion of patients *completing* treatment should not be considered as a marker of clinical quality or appropriateness of care. However, where rates of patients with missing treatment outcome are low, local assessment may help to ascertain underlying factors of low completion.

Where the number of patients is smaller than five, this is indicated by the notation '<5' instead of reporting actual numbers. For trusts with less than ten patients with known outcome, results are starred.

Trust name	Patients	Patients with missing treatment outcome	Patients with known outcome	Patients that completed treatment
	N	%	N	%
Blackpool, Fylde and Wyre Hospitals NHS Trust	26	39	16	63
University Hospital of South Manchester NHS Foundation Trust	15	7	14	43
Tameside and Glossop Acute Services NHS Trust	8	13	*	*
Central Manchester and Manchester Children's University Hospitals NHS Trust	14	57	*	*
Pennine Acute Hospitals NHS Trust	32	50	16	69
St Helens and Knowsley Hospitals NHS Trust	8	38	*	*
The Cardiothoracic Centre Liverpool NHS Trust	<5	67	*	*
Aintree University Hospitals NHS Foundation Trust	21	48	11	73
Clatterbridge Centre for Oncology NHS Foundation Trust	6	50	*	*
Countess of Chester Hospital NHS Foundation Trust	10	40	*	*
Royal Liverpool and Broadgreen University Hospitals NHS Trust	14	29	10	60
Southport and Ormskirk Hospital NHS Trust	8	63	*	*
Warrington and Halton Hospitals NHS Foundation Trust	16	56	*	*
Bradford Teaching Hospitals NHS Foundation Trust	21	5	20	60
York Hospitals NHS Foundation Trust	35	43	20	40
Harrogate and District NHS Foundation Trust	10	0	10	50
Airedale NHS Trust	8	38	*	*
Leeds Teaching Hospitals NHS Trust	81	4	78	55
Calderdale and Huddersfield NHS Foundation Trust	<5	0	*	*
Mid Yorkshire Hospitals NHS Trust	<5	0	*	*
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	23	0	23	74
Hull and East Yorkshire Hospitals NHS Trust	12	0	12	58
Barnsley District General Hospital NHS Foundation Trust	<5	33	*	*
The Rotherham NHS Foundation Trust	<5	0	*	*
Chesterfield Royal Hospital NHS Foundation Trust	<5	33	*	*
Sheffield Teaching Hospitals NHS Foundation Trust	37	5	35	37
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	9	0	*	*
Heart Of England NHS Foundation Trust	41	17	34	65
University Hospitals Coventry and Warwickshire NHS Trust	20	40	12	58
Nottingham University Hospitals NHS Trust	51	0	51	35
Sherwood Forest Hospitals NHS Foundation Trust	14	0	14	21
United Lincolnshire Hospitals NHS Trust	45	2	44	66
Burton Hospitals NHS Trust	13	0	13	69
Derby Hospitals NHS Foundation Trust	22	0	22	68
Kettering General Hospital NHS Trust	16	0	16	100
Northampton General Hospital NHS Trust	13	15	11	45
University Hospitals of Leicester NHS Trust	45	0	45	56
Luton and Dunstable Hospital NHS Foundation Trust	5	20	*	*
East and North Hertfordshire NHS Trust	30	0	30	37
Ealing Hospital NHS Trust	<5	0	*	*
West Middlesex University Hospital NHS Trust	14	7	13	46
Chelsea and Westminster Hospital NHS Foundation Trust	9	11	*	*

Trust name	Patients	Patients with missing treatment outcome	Patients with known outcome	Patients that completed treatment
	N	%	N	%
North West London Hospitals NHS Trust	<5	50	*	*
Imperial College Healthcare NHS Trust	12	17	10	50
Royal Free Hampstead NHS Trust	11	36	*	*
The Whittington Hospital NHS Trust	<5	0	*	*
Barking, Havering and Redbridge Hospitals NHS Trust	24	21	19	5
Whipps Cross University Hospital NHS Trust	9	33	*	*
Newham University Hospital NHS Trust	6	50	*	*
Barts and The London NHS Trust	22	32	15	40
Homerton University Hospital NHS Foundation Trust	6	17	*	*
Queen Elizabeth Hospital NHS Trust	<5	0	*	*
Kingston Hospital NHS Trust	12	33	*	*
Mayday Healthcare NHS Trust	13	8	12	50
St George's Healthcare NHS Trust	15	20	12	75
The Royal Marsden NHS Foundation Trust	35	9	32	53
Epsom and St Helier University Hospitals NHS Trust	12	8	11	73
South Devon Healthcare NHS Foundation Trust	18	33	12	25
Northern Devon Healthcare NHS Trust	6	0	*	*
Royal Cornwall Hospitals NHS Trust	16	6	15	80
Royal Devon and Exeter NHS Foundation Trust	27	11	24	46
Plymouth Hospitals NHS Trust	15	13	13	62
Dorset County Hospitals NHS Foundation Trust	8	0	*	*
Poole Hospital NHS Foundation Trust	24	0	24	38
Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	15	27	11	45
Weston Area Health NHS Trust	8	25	*	*
University Hospitals Bristol NHS Foundation Trust	9	56	*	*
Hereford Hospitals NHS Trust	11	0	11	91
Gloucestershire Hospitals NHS Foundation Trust	41	2	40	60
Worcestershire Acute Hospitals NHS Trust	46	11	41	61
Heatherwood and Wexham Park Hospitals NHS Foundation Trust	12	0	12	58
Royal Berkshire NHS Foundation Trust	12	8	11	36
Oxford Radcliffe Hospitals NHS Trust	14	36	*	*
Buckinghamshire Hospitals NHS Trust	6	0	*	*
Southampton University Hospitals NHS Trust	31	16	26	62
Portsmouth Hospitals NHS Trust	38	5	36	64
Winchester and Eastleigh Healthcare NHS Trust	7	29	*	*
Basingstoke and North Hampshire Hospitals NHS Foundation Trust	6	17	*	*
Salisbury NHS Foundation Trust	22	23	17	41
Western Sussex Hospitals NHS Trust	17	0	17	47
Isle of Wight Healthcare NHS Trust	17	6	16	56
Royal Surrey County Hospital NHS Trust	21	48	11	64
Ashford and St Peter's Hospitals NHS Trust	<5	67	*	*
Surrey and Sussex Healthcare NHS Trust	<5	50	*	*
East Sussex Hospitals NHS Trust	27	26	20	50
Dartford and Gravesham NHS Trust	13	0	13	77
Maidstone and Tunbridge Wells NHS Trust	73	14	63	60
Mid Staffordshire General Hospitals NHS Trust	16	56	*	*
The Royal Wolverhampton Hospitals NHS Trust	26	0	26	50
The Dudley Group of Hospitals NHS Trust	9	56	*	*
South Tyneside NHS Foundation Trust	10	0	10	40
City Hospitals Sunderland NHS Foundation Trust	6	0	*	*
North Cumbria Acute Hospitals NHS Trust	27	30	19	58
Gateshead Health NHS Foundation Trust	11	55	*	*
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	61	10	55	38
Northumbria Healthcare NHS Foundation Trust	21	24	16	56
South Tees Hospitals NHS Trust	31	0	31	45
North Tees and Hartlepool NHS Foundation Trust	30	20	24	63
County Durham and Darlington NHS Foundation Trust	37	11	33	42

Trust name	Patients	Patients with missing treatment outcome	Patients with known outcome	Patients that completed treatment
	N	%	N	%
Bedford Hospital NHS Trust	17	6	16	75
Peterborough and Stanford Hospitals NHS Foundation Trust	19	5	18	89
James Paget Healthcare NHS Foundation Trust	26	0	26	31
West Suffolk Hospitals NHS Trust	8	13	*	*
Cambridge University Hospitals NHS Foundation Trust	49	4	47	81
Norfolk and Norwich University Hospital NHS Trust	29	0	29	24
Hinchingbrooke Health Care NHS Trust	10	0	10	70
Southend Hospital NHS Trust	19	32	13	23
Essex Rivers Healthcare NHS Trust	37	16	31	10
Ipswich Hospital NHS Trust	< 5	0	*	*
England total	**2,022**	15	**1,713**	**53**

England total (full analysis of patients with known outcome, includes patients from trusts with low outcome ascertainment, Appendix 5)	Patients	Patients that did not complete treatment		Patients that completed treatment	
	1741	824	47%	917	53%

Appendix 7: Revised dataset

National Oesophago-Gastric Cancer Audit
New Patient Registration sheet –
Patients with Oesophageal High Grade Glandular Dysplasia

Patient Details

Surname: _____ Forename: _____

NHS number: _____ Postcode: _____

Sex: Male ☐ Female ☐ Not specified ☐ Date of birth: _____

Initial Referral to Local Oesophago-gastric Team and Diagnostic Process

Source of referral

From surveillance service: ☐ Symptomatic referral ☐ Not known ☐

Date of endoscopic biopsy in which HGD was first diagnosed: _____

Hospital where the endoscopic biopsy was taken: _____

Was a second biopsy performed? Yes ☐ No ☐

Did the second biopsy show HGD? Yes ☐ No ☐

Endoscopic Report

HGD appearance

Flat mucosa ☐ Nodular lesion ☐ Depressed lesion ☐ Not known ☐

Barrett's Segment

Present ☐ Absent ☐ Not known ☐

Length of Barrett's Segment, if present

Length of ***Circumferential*** Columnar Lining (nearest 0.5 cm): C ____.___cm

Maximum length including tongues/islands of Columnar Lining (nearest 0.5 cm): M ____.___cm

HGD Lesion (based on pathology report)

Unifocal ☐ Multi-focal ☐ Not known ☐

Was diagnosis confirmed by second pathologist? Yes ☐ No ☐ Not known ☐

Planned Treatment

Hospital at which treatment plan made _____

Date treatment plan agreed _____

Was the treatment plan agreed at an MDT meeting? Yes ☐ No ☐

Will the patient be referred to a specialist hospital for treatment? Yes ☐ No ☐ Not applicable ☐

Planned treatment modality

Surveillance	☐	Radiofrequency ablation	☐
Oesophagectomy	☐	Argon plasma coagulation	☐
Photo dynamic therapy	☐	Multipolar electrocautery	☐
Endoscopic Mucosal Resection (EMR)	☐	Laser therapy	☐
Endoscopic Submucosal Dissection (ESD)	☐	Cryotherapy	☐

Use of Endoscopic Mucosal Resection (EMR) / Endoscopic Submucosal Dissection (ESD)

EMR/ESD was not performed:	☐	Performed for diagnostic purpose:	☐
Performed for therapeutic purpose:	☐	Performed for both diagnostic and therapeutic purpose:	☐

Date of EMR/ESD: _____

Results of EMR/ESD:

Complete excision:	☐	Incomplete, follow up Oesophagectomy	☐
Incomplete, follow up surveillance	☐	Incomplete, follow up EMR/ESD	☐

Post-treatment Histology (pathology results based on EMR/ESD)

No high grade dysplasia or carcinoma	☐
High grade dysplasia confirmed	☐
Intramucosal carcinoma identified	☐
Submucosal carcinoma or worse	☐

National Oesophago-Gastric Cancer Audit

New Patient Registration datasheet (Oesophageal Gastric Cancer Patients)

Patient Details

Surname: _____ Forename: _____

NHS number: _____ Postcode: _____

Sex: Male ☐ Female ☐ Not specified ☐ Date of birth: _____

Initial Referral and Diagnosis Data

Source of referral: Direct from GP ☐ Barrett's Surveillance ☐ Emergency admission ☐

Open access endoscopy ☐ From other consultant ☐ Not known ☐

Priority of referral: (GP referral only) Urgent ☐ 2-week wait ☐ Routine referral ☐

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 1/3 ☐ Middle 1/3 ☐ Lower 1/3 ☐ ***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

Invasive 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)

None ☐

CT scan ☐ PET / PET – CT scan ☐

Endoscopic ultrasound (EUS) ☐ EUS Fine needle aspiration ☐

Staging laparoscopy ☐ Other investigation ☐

Pre – Treatment Stage

Which TNM version do you use: TNM v6 ☐ TNM v7 ☐

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

ECOG (WHO) Performance Status

- 0 Carries out all normal activity without restriction ☐
- 1 Restricted but walks/does light work ☐
- 2 Walks, full self care but no work. Up and about >50% of the time ☐
- 3 Limited self care, confined to bed or chair for >50% waking hours ☐
- 4 Fully disabled, confined to bed/chair ☐

Comorbidities (please tick all that apply)

None ☐

Cardiovascular disease	☐	Liver failure or cirrhosis	☐	Diabetes	☐
Chronic renal impairment	☐	Barrett's oesophagus	☐	Mental illness	☐
Cerebro/periph vascular	☐	Chronic respiratory disease (including COPD/asthma)			☐
Other significant condition	☐				

Treatment Plan

Date final care plan agreed**:** _____

Treatment intent:

- Curative: ☐
- Non-curative (palliative) ☐ (ie. surgery, chemotherapy, radiotherapy, endoscopy)
- No active treatment (supportive care) ☐ (ie. non -specific symptomatic treatments)

Details of planned treatment

Curative modality		Palliative modality	
Surgery only	☐	Palliative surgery	☐
Chemotherapy and surgery (any combination)	☐	Palliative oncology (unspecified)	☐
Chemo-radiotherapy and surgery (any combination)	☐	Endoscopic palliation therapy	☐
(Definitive) Radiotherapy only	☐	No active treatment (supportive care)	☐
Definitive chemo - radiotherapy	☐		
Endoscopic mucosal resection	☐		

Treatment part of a clinical trial:

Patient eligible, consented and entered trial ☐ Patient eligible, declined trial ☐

Reasons for palliative treatment (please tick all that apply)

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

National Oesophago-Gastric Cancer Audit
Postoperative Datasheet (Oesophageal Gastric Cancer and HGD Patients)

Patient details (for patient identification only)

Surname _____ Forename _____

NHS number _____ Date of birth _____

Admission and Surgical Details (Main procedure only)

Hospital name: _____

Date of admission: _____ Date of operation: _____

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

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

Height (in cm) _____ (to calculate body mass index)

Weight (in kg) _____ (to calculate body mass index)

Smoking: current smoker ☐ ex-smoker ☐ non-smoker (history unknown) ☐

never smoked ☐ Not known ☐

Procedure

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 thoracic phase of the operation

Open operation ☐ Laparoscopic converted to open ☐ Laparoscopic completed ☐

Oesophageal

- Oesophagectomy:
  - Left thoraco-abdominal approach ☐
  - 2 – Phase (Ivor-Lewis) ☐
  - 3 – Phase (McKeown) ☐
  - Transhiatal ☐
- Thoracotomy (Open & Shut) ☐

Gastric

- Gastrectomy:
  - Total ☐ Extended total ☐
  - Proximal ☐ Distal ☐
  - Completion ☐ Merendino ☐
  - Wedge/localised gastric resection ☐
  - Bypass procedure / Jejunostomy only ☐
- Laparotomy (Open and Shut) ☐

Nodal Dissection

Oesophagectomy: None ☐ 1 – field ☐ 2 – field ☐ 3 – field ☐

Gastrectomy: D0 (peri-gut resection) ☐ D1 ☐ D2 ☐ D3 ☐

Postoperative complications and course (please tick all that apply)

None	☐	Respiratory:	
Anastomotic leak	☐	Pneumonia	☐
Chyle leak	☐	ARDS	☐
Haemorrhage	☐	Pulmonary embolism	☐
Cardiac complication	☐	Pleural effusion	☐
Acute renal failure	☐	Wound infection	☐
Other	☐		

Unplanned return to theatre? Y ☐ N ☐ Death in hospital? Y ☐ N ☐

Date of discharge or death: _____

Postoperative pathology and staging

Length of tumour _____

Site:

Oesophagus: Upper $^1/_3$ ☐ Middle $^1/_3$ ☐ Lower $^1/_3$ ☐

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:

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

Proximal resection margin involved? Yes ☐ No ☐

Distal resection margin involved? Yes ☐ No ☐

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

Number of lymph nodes examined: _____

Number of lymph nodes positive: _____

Postoperative stage

Which TNM version do you use: TNM v6 ☐ TNM v7 ☐

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

Patient had neoadjuvant therapy prior to surgery: Yes ☐ No ☐

National Oesophago-Gastric Cancer Audit

Chemotherapy/Radiotherapy Datasheet (Oesophageal Gastric Cancer Patients)

Please fill in this datasheet for every course of oncological treatment received by a patient with oesophago-gastric cancer. Most patients will only require one datasheet to be completed. For patients who have both neoadjuvant and adjuvant therapy, complete two separate datasheets.

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 ☐

Details of therapy

Chemotherapy details (if applicable)

Date first cycle started: _____

Outcome of treatment:

Treatment completed as prescribed ☐

Reason if incomplete

Patient died ☐

Progressive disease during treatment ☐

Acute chemotherapy toxicity ☐

Technical or organisational problems ☐

Patient choice (interrupted or stopped treatment) ☐

Not known ☐

Radiotherapy details (if applicable)

Date first fraction started: _____

Outcome of treatment:

Treatment completed as prescribed ☐

Reason if incomplete

Patient died ☐

Progressive disease during treatment ☐

Acute radiotherapy toxicity ☐

Technical or organisational problems ☐

Patient choice (interrupted or stopped treatment) ☐

Not known ☐

Post oncology fitness (for neoadjuvant therapy only)

Patient proceeded to planned curative surgery: Yes ☐ No ☐ Not applicable ☐

National Oesophago-Gastric Cancer Audit
Endoscopic / Radiological Palliative Therapy Datasheet
(Oesophageal Gastric Cancer Patients)

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: _____

Date of endoscopic / radiological procedure: _____

Dysphagia Rating Scale

0 ☐ No dysphagia

1 ☐ Able to eat solids

2 ☐ Able to eat semi-solids only

3 ☐ Able to consume liquids only

4 ☐ Complete dysphagia

9 ☐ Not known

Procedure details

Type of procedure (tick all that apply)

Insertion of stent ☐ Laser therapy ☐ Argon plasma 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 ☐

Details of stent procedure, if inserted

Type of stent:

Plastic: expandable ☐ Metal: covered ☐ Metal: Anti-reflux ☐ Not known ☐

Biodegradable ☐ Metal: uncovered ☐ Other ☐

Method of stent placement:

Fluoroscopic control ☐ Endoscopic control ☐ Fluoroscopic & Endoscopic ☐ Not known ☐

Did the stent deploy successfully? Yes ☐ No ☐ Not known ☐

Immediate complications following stent insertion (tick all that apply)

No complication ☐ Postoperative stricture ☐ Perforation ☐

Haemorrhage ☐ Other complications ☐

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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.

CASU
The Clinical Audit Support Unit of the Health and Social Care Information Centre (HSCIC) 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.

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
(Computer Tomography) 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.

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.

Gastrectomy
A surgical procedure to remove either a section (a partial gastrectomy) or all (a total gastrectomy) of the stomach. In a total gastrectomy, the oesophagus is connected to the small intestine.

The Health and Social Care Information Centre
The Health and Social Care Information Centre is a special health authority that provides facts and figures to help the NHS and social services run effectively. The Clinical Audit Support Unit (CASU) is one of its key components.

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.

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.

Minimally invasive surgery
A procedure performed through the skin or anatomical opening using a laparoscopic instrument rather than through an opening. Full minimally invasive oesophagectomies involve thoracoscopy for the chest-phase of the operation and laparoscopy for the abdominal phase. Oesophagectomies using minimally invasive techniques for only the abdominal or chest phase are commonly referred to as hybrid operations.

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.

NCEPOD
National Confidential Enquiry into Patient Outcome and Death. NCEPOD is an independent, government-funded body whose remit is to examine medical and surgical care, often by undertaking confidential surveys and research.

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.

Oesophagectomy
The surgical removal of all or part of the oesophagus. The procedure can be performed by opening the thorax (a trans-thoracic oesophagectomy) or through openings in the neck and abdomen (a trans-hiatal oesophagectomy).

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.

PET
An 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.

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

Urgent (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.

The Royal College of Surgeons of England is dedicated to enabling surgeons achieve and maintain the highest standards of surgical practice and patient care. To achieve this, the College is committed to making information on surgical care accessible to the public, patients, health professionals, regulators and policy makers.

Registered charity number: 212808

Want to know more about the National Oesophago-Gastric Cancer Audit?

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