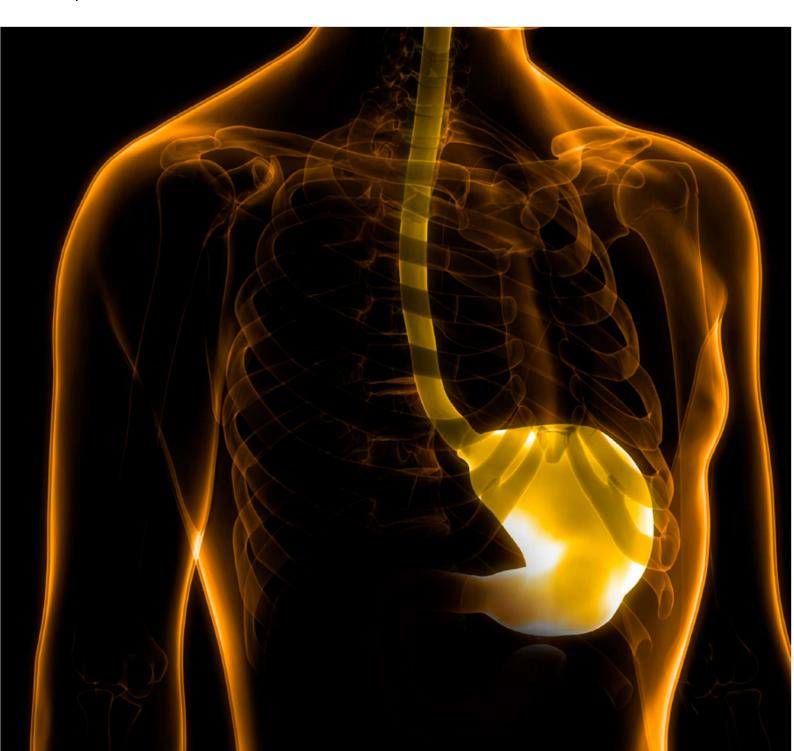




A national review of care received by people with oesophageal or stomach cancer in England and Wales

Report for patients and public to accompany the NOGCA State of the Nation Report September 2025







This report was prepared by the NOGCA Project Team, in collaboration with the NOGCA Patient & Public Involvement (PPI) Forum.

NOGCA Patient & Public Involvement (PPI) Forum members:
Matt Carter, Oxfordshire Oesophageal and Stomach Organisation
Jill Clark, Action Against Heartburn
Jennie King, Guts UK
Fiona Labrooy, Heartburn Cancer UK
Mimi McCord, Heartburn Cancer UK
Caryl Travess, patient representative

In partnership with:



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. Registered Charity no: 212808.



The National Cancer Audit Collaborating Centre (NATCAN) is commissioned by the <u>Healthcare Quality Improvement</u> <u>Partnership (HQIP)</u> and funded by NHS England and the Welsh Government as part of the <u>National Clinical Audit and Patient Outcomes Programme</u> (NCAPOP). NATCAN delivers national audits in bowel, breast (primary and metastatic), kidney, lung, non-Hodgkin lymphoma, oesophago-gastric, ovarian, pancreatic and prostate cancers.



The Association of Upper Gastrointestinal Surgery of Great Britain and Ireland is the speciality society that represents upper gastrointestinal surgeons. It is one of the key partners leading the Audit. Registered Charity no: 1093090



British Society of Gastroenterology is the speciality society of gastroenterologists. It is one of the key partners leading the Audit. Registered Charity no: 1149074



Royal College of Radiologists is the professional body for clinical radiologists and clinical oncologists. It is one of the key partners leading the Audit. Registered Charity no: 211540



This work uses data that has been provided by patients and collected by the NHS as part of their care and support. For patients diagnosed in England, the data is collated, maintained and quality assured by the National Disease Registration Service (NDRS), which is part of NHS England. Access to the data was facilitated by the NHS England Data Access Request Service.



NHS Wales is implementing a new cancer informatics system. As a result, the quality and completeness of data from Wales is likely to have been impacted due to implementation of this new system across multiple NHS organisations (Health Boards), which has resulted in data being supplied by both old and new systems. Additionally, and reflecting the uncertainty of data quality, the data submitted to the audit may not have undergone routine clinical validation prior to submission to the Wales Cancer Network (WCN), Public Health Wales.









Contents

1	1. Intro	ductionduction	. 1
2. Oesophago-gastric (OG) cancer			. 1
	2.1	Who gets OG cancer?	. 2
	2.2	What increases the risk of getting OG cancer?	. 2
	2.3	When are people diagnosed with OG cancer?	. 3
	2.4	How is OG cancer diagnosed?	. 4
	2.5	Why does early diagnosis matter?	. 4
	2.6	What happens after diagnosis?	. 4
	2.7	What treatments are available for OG cancer?	. 5
	2.8	How long do people have to wait for treatment?	. 6
	2.9	What are the outcomes of OG cancer treatments?	. 7
	2.10	High Grade Dysplasia	. 9
3	3. Look	ing Ahead	. 9
_	1 Whe	re can I find more information?	10

1. Introduction

The National Oesophago-Gastric Cancer Audit (NOGCA) is a national review that looks at how well people with oesophageal (gullet or food pipe) or gastric (stomach) cancer are cared for across England and Wales. It helps the NHS understand what is working well and where things could be improved, so that everyone affected by these cancers can receive the best possible care.

In this patient report, cancer of the upper digestive system (including oesophagus - also known as gullet or food pipe - or stomach) will be referred to as "OG" cancer.

In the past, hospitals had to submit detailed information to NOGCA by filling in special forms. This could take up valuable time for doctors and nurses. Now, the audit uses information that the NHS already collects. This means we are capturing data on more people with OG cancer and it also frees up doctors and nurses to spend more time focusing on patient care.

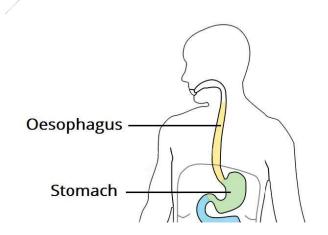
The <u>NOGCA State of the Nation Report</u> looks at care for people diagnosed with OG cancer between January 2022 and December 2023. It includes information about diagnosis, treatment types, and outcomes such as survival after surgery. By sharing these findings, our review aims to help improve services and support better outcomes for all patients.

Alongside the main report, we've created this summary especially for patients, carers and the public. Whether you are going through cancer yourself, supporting someone who is, or simply want to understand more, our aim is to provide information that is clear and helpful.

2. Oesophago-gastric (OG) cancer

Oesophago-gastric (OG) cancer is a term used to describe cancers that start in either the oesophagus (also known as the gullet or food pipe) or the stomach.

The oesophagus is the tube that carries food and drink from your mouth to your stomach. The stomach is where food is broken down to help your body absorb nutrients. Cancers can develop anywhere in the oesophagus or the stomach.



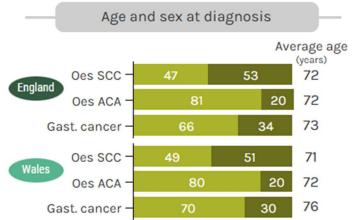
There are different types of OG cancer depending on where the cancer is and the type of cells involved. Treatment often depends on the cancer's location, how far it has spread, and your overall health. Treatments include surgery, chemotherapy, radiotherapy, immunotherapy, or a combination of these.

Early diagnosis and timely treatment can improve outcomes, so it's important to speak to your doctor if you experience symptoms such as persistent heartburn, reflux or indigestion, difficulty swallowing or unexplained weight loss.

2.1 Who gets OG cancer?

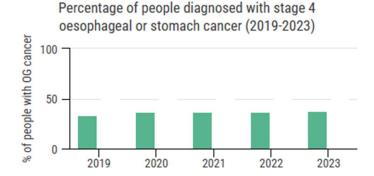
Between January 2022 and December 2023, 20,582 people in England and Wales were diagnosed with oesophageal or stomach cancer.

Most people (70%) had oesophageal cancer, while the other 30% had stomach cancer. OG cancer is more common in men—about 7 out of 10 of those diagnosed were male. The most common cancer type, oesophageal adenocarcinoma (Oes ACA), mostly affects men. However, another type, oesophageal squamous cell carcinoma (Oes SCC), affects men and women more equally.



OG cancer tends to be diagnosed later in life, with most people being diagnosed in their late 60s to early 70s. Around one in four people diagnosed were aged 80 or over.

In England, nearly 4 out of 10 people with OG cancer were diagnosed with stage 4 cancer, the most advanced stage. This means that the cancer has already spread (metastasised) to other parts of the body, which makes it harder to treat. This figure highlights the importance of spotting symptoms early.



2.2 What increases the risk of getting OG cancer?

There are a number of risk factors that make some people more likely to develop oesophageal or stomach cancer. Some of these can be changed (called *modifiable* risk factors), while others, like age or family history, cannot.

Risk factors for oesophageal cancer:

- Age: older people are more likely to develop cancer.
- Obesity: carrying excess weight, especially around the waist, increases pressure on the stomach, which can cause acid to flow back up into the oesophagus.
- Smoking and excessive alcohol use: both increase the risk of damage to the lining of the oesophagus.
- Reflux (or heartburn): this is when stomach acid leaks into the oesophagus. Ongoing reflux can damage the cells lining the oesophagus over time.
- Barrett's oesophagus: this is a condition where long-term reflux causes changes in the cells lining
 the oesophagus. In some people, these changes can develop into very abnormal cells (called highgrade dysplasia) that can turn into cancer if not treated.

• Family history: we do not yet fully understand whether oesophageal cancer can be inherited, and research is ongoing in this area. However, if a close family member, such as a parent or sibling, is diagnosed with oesophageal cancer at a young age (for example, in their 40s), then there may be an increased risk.

Risk factors for stomach (gastric) cancer:

- Age: older people are more likely to develop cancer.
- Family history: in some cases, stomach cancer can run in families. This may be due to inherited genes that increase the risk of developing the disease. If you have close relatives who have had stomach cancer, it's a good idea to speak to your doctor about your family history.
- Infection with Helicobacter pylori (H. pylori): these bacteria can irritate the stomach lining and increase cancer risk. However, these infections are now less common than they used to be.
- Smoking

Understanding these risk factors is important because some risks can be reduced. For example, stopping smoking, maintaining a healthy weight, treating reflux, and cutting back on alcohol can all help lower the risk of OG cancer.

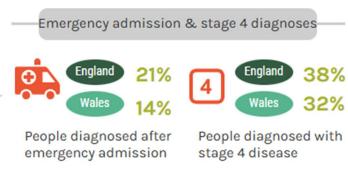
2.3 When are people diagnosed with OG cancer?

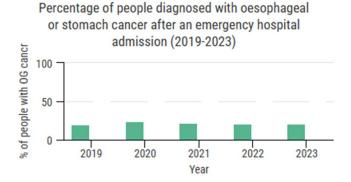
OG cancer can be difficult to diagnose early, and sometimes people don't realise something is wrong until they are struggling with symptoms.

Most people are diagnosed after seeing their GP, but some are only diagnosed after going to A&E. Between 2022 and 2023, about 1 in 5 people in England (21%) and nearly the same in Wales (18%) were diagnosed with OG cancer following an emergency admission—for example, when they came to hospital with serious symptoms like bleeding, vomiting, or severe difficulty swallowing.

Our review found that older people and those living in more deprived areas were more likely to be diagnosed following an emergency admission.

Unfortunately, these patterns have not improved in the last five years, showing the continued need for earlier recognition and diagnosis.

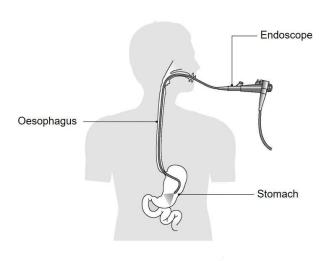




2.4 How is OG cancer diagnosed?

The main test used to diagnose OG cancer is a procedure called a **gastroscopy** (sometimes called an endoscopy). This is usually arranged after a person has been referred urgently by their GP if cancer is suspected.

During a gastroscopy, a thin flexible tube with a tiny camera on the end is passed through the mouth and down into the oesophagus and stomach. The camera allows the doctor to look closely at the lining of the oesophagus and stomach. If anything looks unusual, the doctor can take small samples of tissue (called biopsies) to be examined under a microscope.



2.5 Why does early diagnosis matter?

People who are diagnosed during an emergency admission are more likely to have advanced cancer, which means it may have spread and be harder to treat. That's why it's so important to speak to your GP if you experience any unusual symptoms like:

- Persistent indigestion, reflux or heartburn
- Difficulty swallowing
- Unexpected weight loss
- Vomiting or feeling full quickly after eating

Catching OG cancer early can make a big difference in the treatment options available and the chance of a better outcome.

2.6 What happens after diagnosis?

Once someone has been diagnosed with OG cancer, further tests are often needed. These help doctors understand how advanced the cancer is, whether it has spread, and what the best treatment options are.

These tests are known as staging investigations, and they are important for planning the right treatment. They may include:

- CT scan a detailed X-ray that looks at the chest, tummy, and pelvis
- PET scan shows how active the cancer is and whether it has spread to other parts of the body
- Endoscopic ultrasound a more detailed scan of the oesophagus and nearby areas using a special camera
- **Staging laparoscopy** a type of keyhole surgery that helps doctors look inside the abdomen to check if the cancer has spread
- Heart and lung function tests to make sure you're well enough for treatment such as surgery
- Fitness assessments to see how your body might cope with different treatments

What is the role of the Clinical Nurse Specialist (CNS)?

Everyone diagnosed with OG cancer should be given the name and contact details of a Clinical Nurse Specialist (CNS) who has expertise in OG cancer. The CNS is a key part of the cancer care team. They:

- Help you understand your diagnosis and test results
- Support you emotionally and practically
- Act as a point of contact throughout your treatment
- Help coordinate appointments and answer questions

In England, among patients with complete information in the records, 93% were seen by a CNS around the time they were diagnosed. But this support was less often available for people who came into hospital as an emergency or who died shortly after being diagnosed.

Access to Clinical Nurse Specialist



Where the data were available, 93% of people in England saw a Clinical Nurse Specialist (CNS)





People diagnosed by emergency hospital admission, and people who died within 90 days after diagnosis, were less likely to see a CNS

When looking at all people diagnosed with OG cancer, only 63% had a CNS contact documented. This doesn't necessarily mean that the others weren't supported by a CNS—it may be that the information wasn't properly recorded. But it does highlight an important issue: if data about patient care is missing, it becomes harder to know where services are working well, and where improvements are needed.

At present, data on CNS access is not available for people treated in Wales.

2.7 What treatments are available for OG cancer?

Treatment for OG cancer depends on the type of cancer, how far it has spread, and a person's overall health and fitness. Your doctor and CNS will discuss the most suitable options with you and involve you in decisions about your care.

Curative treatment

If the cancer is found early and has not spread to other parts of the body, and if the person is fit enough, then curative treatment may be possible. This means the goal is to get rid of the cancer completely.

There are several curative treatment options, depending on the cancer's type and stage:

- **Endoscopic therapy** for very early cancers, it may be possible to remove the cancer using a thin tube (endoscope) inserted into the oesophagus or stomach.
- **Surgery** major surgery may be needed to remove part or all of the affected oesophagus or stomach. This can sometimes be done using keyhole techniques.
- Systemic anti-cancer therapy this is treatment with medicines, such as chemotherapy or immunotherapy, that travel through the bloodstream to reach cancer cells in the body. These medicines can help shrink the tumour and destroy cancer cells. Immunotherapy is not suitable for everyone, and its use depends on the results of special tests on the cancer.

- **Chemoradiotherapy** this is a combination of chemotherapy and radiotherapy and is sometimes used for certain types of oesophageal cancer.
- Some people may need a combination of treatments such as chemotherapy followed by surgery.

Palliative and supportive treatment

Not everyone can have curative treatment. For some people, the cancer has already spread (metastasised) by the time it is diagnosed, or their health may mean they are not strong enough to go through intensive treatment.

In these cases, care focuses on helping the person feel as well as possible. This is called palliative care, and it may include:

- Palliative chemotherapy/immunotherapy/radiotherapy to slow down the growth of the cancer and manage symptoms.
- Best Supportive Care to help with pain relief, eating and nutrition, and emotional wellbeing.

These decisions are made carefully by a team of specialist doctors, in partnership with the patient and their family. The goal is to offer the best quality of life, respecting the person's wishes and values.

Whatever the stage of cancer, support is always available. The cancer care team, including doctors and CNSs, will help a person to understand their treatment options and guide them through the journey.

2.8 How long do people have to wait for treatment?

Waiting for cancer treatment to begin can be a very anxious time. This section explains how long people diagnosed with OG cancer typically wait for their treatment to start once cancer has been detected.

For most people, OG cancer is first found during a gastroscopy (also called an endoscopy).

To measure how long people wait for treatment, we look at the number of

Time from endoscopy to start of treatment

Curative — Non-curative — Wales

Non-curative — Wales

Average time (days)

days from this first gastroscopy to the start of treatments, including endoscopic therapy, surgery, chemotherapy, and radiotherapy (curative or palliative).

Best supportive care, like symptom management without cancer-targeted treatment, is not included in these waiting time figures.

In England, between January 2021 and December 2023, people with OG cancer waited an average of 63 days (about 9 weeks) from their first gastroscopy to starting treatment. In general, people having curative treatment wait longer than those receiving palliative treatment, because curative treatment often involves more detailed planning and extra tests.

Lots of work still needs to be done, both nationally and locally within the NHS, to reduce the time it takes for people with OG cancer to begin treatment. Faster treatment can improve outcomes and reduce the stress and uncertainty for patients and their families.

2.9 What are the outcomes of OG cancer treatments?

Curative Surgery

For some people with OG cancer, surgery offers the best chance of a cure. This section looks at how people recovered and survived after major surgery to remove all or part of the oesophagus or stomach.

To provide the most reliable picture, we looked at surgeries carried out over a three-year period (January 2021 to December 2023).

How many people had surgery?

During this time:

In England, 5,202 people with OG cancer had major surgery at a specialist OG surgical centre, including both oesophagectomies (removal of the oesophagus) and gastrectomies (removal of the stomach).

In Wales, 251 patients underwent major surgery.

How well did people do after surgery?

Overall, survival after surgery was high:

- Most people (over 95%) survived at least 90 days after their surgery.
- One year after surgery, over 84% of patients were still alive.

These figures show that surgery is generally effective and safe.

Recovery after surgery

The typical length of time people spent in hospital after surgery was between:

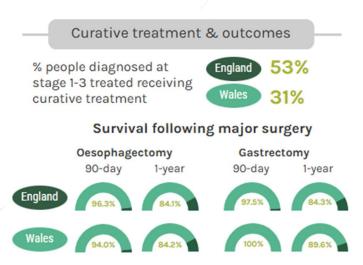
- 8 to 16 days for oesophagectomy in England
- 7 to 13 days for gastrectomy in England

This has not changed much from previous years, suggesting stable recovery times across hospitals.

Quality of surgery

One important measure of how well the surgery is performed is whether enough lymph nodes are removed and checked for signs of cancer. This helps doctors understand how far the cancer has spread and plan further treatment.

- In Wales, a high percentage (over 78%) of people had at least 15 lymph nodes removed, which meets the national standard.
- In England, data on lymph nodes were available from all surgical centres, but many reports were incomplete or missing.



Why is some information missing?

A big challenge is the way pathology (laboratory) data are recorded and submitted. Many hospitals still send this information in ways that are difficult for national systems to process. This means key details — like how much cancer was removed or how many lymph nodes were checked — don't always reach the national database, however it is available to your local doctors and nurses.

Improving the way this data is recorded and submitted is essential. It will help ensure that surgical performance can be monitored properly across all hospitals, and support efforts to improve care for future patients.

Outcomes of palliative chemotherapy

For people with advanced OG cancer, palliative chemotherapy may be offered to help control symptoms, slow the growth of the cancer, and improve quality of life.

Between January 2022 and December 2023, 55% of people in England received palliative chemotherapy for OG cancer. Of those who started treatment, many were able to complete at least four cycles, which is often considered a full course. However, completion rates varied across hospitals, suggesting that access to treatment, the types of drugs used, and how patients were selected for treatment may differ from place to place.

Why monitoring outcomes matters

Two important measures are used to understand the safety and appropriateness of palliative chemotherapy:

- 30-day mortality: whether someone dies within 30 days of starting treatment
- 90-day mortality: whether someone dies within 90 days of starting treatment

These figures help doctors and hospitals reflect on whether people are being offered the right treatment at the right time. While palliative

Non-curative treatment & outcomes

% of people diagnosed at stage 4 treated with chemotherapy and/or radiotherapy

England 56%

Wales 37%

4.3% of people died within 30 days of starting chemotherapy in England

16.7% of people died within 90 days of starting chemotherapy in England

chemotherapy can help with symptoms and sometimes extend life, it can have serious side effects. When someone is nearing the end of their life, the risks and benefits need to be carefully considered. These are often difficult decisions, made together by the patient and their doctor, based on their overall health and wishes.

For some people, focusing on best supportive care — which aims to relieve symptoms and support comfort without using cancer drugs — may be more appropriate and more in line with their goals and quality of life.

Data from Wales

In Wales, a number of people with OG cancer were recorded as receiving palliative chemotherapy. However, due to changes in the cancer data systems introduced in 2022, some information was missing. This means we were not able to reliably report on the number of treatment cycles completed or short-term outcomes for patients in Wales during this review period.

2.10 High Grade Dysplasia

High grade dysplasia (HGD) means there are abnormal cells in the lining of the oesophagus that could potentially turn into cancer if not treated. It is not cancer, but it is a serious condition that doctors monitor closely or treat early to prevent cancer from developing.

HGD may not cause any symptoms but can be associated with persistent reflux or heartburn.

Treatment options may include:

- **Endoscopic therapy** such as radiofrequency ablation (using heat to destroy abnormal cells) or endoscopic resection (removing the abnormal area during endoscopy).
- **Surgery** major surgery may be needed to remove part of the oesophagus. This can sometimes be done using keyhole techniques.
- **Surveillance** having regular check-up endoscopies to closely monitor the oesophagus for any further changes or signs of early cancer.

At present, hospitals are not required to report every case of HGD, however we were able to review 455 cases in England from 2022-2023, which provides some insights into current management patterns. We found that most people are treated with endoscopic therapy and only a small number required surgery.

3. Looking Ahead

NHS cancer services continue to provide valuable support for people with OG cancer, but further progress is needed, especially in reducing the number of people diagnosed at a late stage and addressing delays along the care pathway.

New technologies are emerging that offer hope for earlier diagnosis. Innovations like the capsule sponge and breath tests are being explored as simple ways to help detect cancer, or conditions that may lead to cancer, at an earlier stage. These developments could play an important role in helping more people access curative treatment.

NOGCA continues to work with the NHS to highlight where improvements are needed and support local teams to drive change. By making better use of data, investing in new diagnostic tools, and improving coordination between services, we hope to ensure more people are diagnosed earlier and receive timely, high-quality care.

4. Where can I find more information?

National Oesophago-Gastric Cancer Audit (NOGCA) webpages: natcan.org.uk/audits/oesophago-gastric

Cancer Research UK - about HGD https://about-cancer.cancerresearchuk.org/about-

cancer/oesophageal-cancer/stages-types-and-grades/stage-0

Cancer Research UK – about OG cancer www.cancerresearchuk.org/about-cancer/oesophageal-cancer

www.cancerresearchuk.org/about-cancer/stomach-cancer

NHS Health A to Z www.nhs.uk/conditions/oesophageal-cancer

www.nhs.uk/conditions/stomach-cancer

Macmillan Cancer Support – information

and support

www.macmillan.org.uk/information-andsupport/oesophageal-gullet-cancer

www.macmillan.org.uk/information-and-support/stomach-

cancer

The Oesophageal Patients Association -

OG cancer support

opa.org.uk

Heartburn Cancer UK – raising

awareness and promoting early diagnosis

of oesophageal cancer

www.heartburncanceruk.org

Action Against Heartburn – promoting

earlier diagnosis of oesophageal cancer

www,actionagainstheartburn.org.uk

Oxfordshire Oesophageal and Stomach

Organisation - support for patients &

carers

ooso.org.uk

Maggie's - cancer support and

information

www.maggies.org

Guts UK – charity for the digestive

system

gutscharity.org.uk

OG cancer statistics for Scotland and Northern Ireland:

- **Public Health Scotland**
- **Northern Ireland Cancer Registry**