A Burning Issue: Oesophageal and stomach cancer in Wales

Tenovus Cancer Care
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Foreword

Improving outcomes for everyone affected by cancer is our priority at Tenovus Cancer Care. Cancers of the oesophagus and stomach (oesophago-gastric) have some of the poorest outcomes in Wales. So much so, they are considered two of the six “less survivable” cancers.

Despite making up just 4.5% of all cancers, they are responsible for 7.7% of all cancer deaths. We are on a mission to close this deadly gap and provide a better chance of survival for everyone affected.

Although we have seen improvements in incidence rates and survival over time, people diagnosed with oesophago-gastric cancers still have a shockingly low life expectancy.

Unfamiliarity with symptoms and delays in diagnosis make these cancers more deadly than others, and these factors can often be linked to deprivation. By the time people are diagnosed, it is frequently in emergency settings when the cancer is at a later stage, with fewer treatment options.

This report highlights the inequalities, identifies issues along the pathway, and makes tangible recommendations to consider.

Early detection is the key to better outcomes. Improving symptom awareness, increasing access to diagnostic procedures, embracing new technologies, and monitoring patients most at risk will enable earlier diagnosis and thereby increase survival.

The report presents several opportunities to improve outcomes which, if implemented, could result in hundreds of people living longer.

Judi Rhys MBE
Chief Executive, Tenovus Cancer Care

Unfortunately for oesophageal and stomach cancer, patient outcomes remain poor. To secure the improvements we have witnessed across other cancers, it is vital we take bold steps to examine our practice and prepare to transform our ways of working.

Pilot projects across Wales are introducing new diagnostic tools – such as trans-nasal endoscopy and swallowable sponge tests. These new interventions are proven to work and need to now be adopted, and rolled out nationally.

Complexities concerning the location of these cancers within the body impact on the treatment options available to patients. Clinicians in Wales are responding through the development and trailing of new treatment regimens, such as the SCOPE studies running out of Velindre Cancer Centre. These studies have helped develop new advanced changes in oesophageal radiotherapy techniques and have significantly improved patient care.

National audits provide the insight we need to better understand a person’s cancer journey and identify areas for improvement. In the case of oesophago-gastric cancers our findings tell us the pathway is currently too long. Targeted improvements in primary and secondary care would contribute to fewer people presenting as an emergency.

Progress has been slow in reconfiguring diagnostic and treatment services when it is determines that these can only be provided on a tertiary basis. Some of these issues have not been resolved despite numerous service reviews over the past 20 years leaving services more fragile and less resilient that they should be.

Within this report Tenovus Cancer Care has done a welcome job drawing together various strands of work to comprehensively lay out the challenges and workable recommendations to assist policy makers and decision makers, helping them to better understand the landscape occupied by people affected by oesophageal and stomach cancer with a view to improving their chances of survival. We now have a collective responsibility to follow with action.

Professor Tom Crosby,
National Cancer Clinical Director, Wales Cancer Network

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Introduction

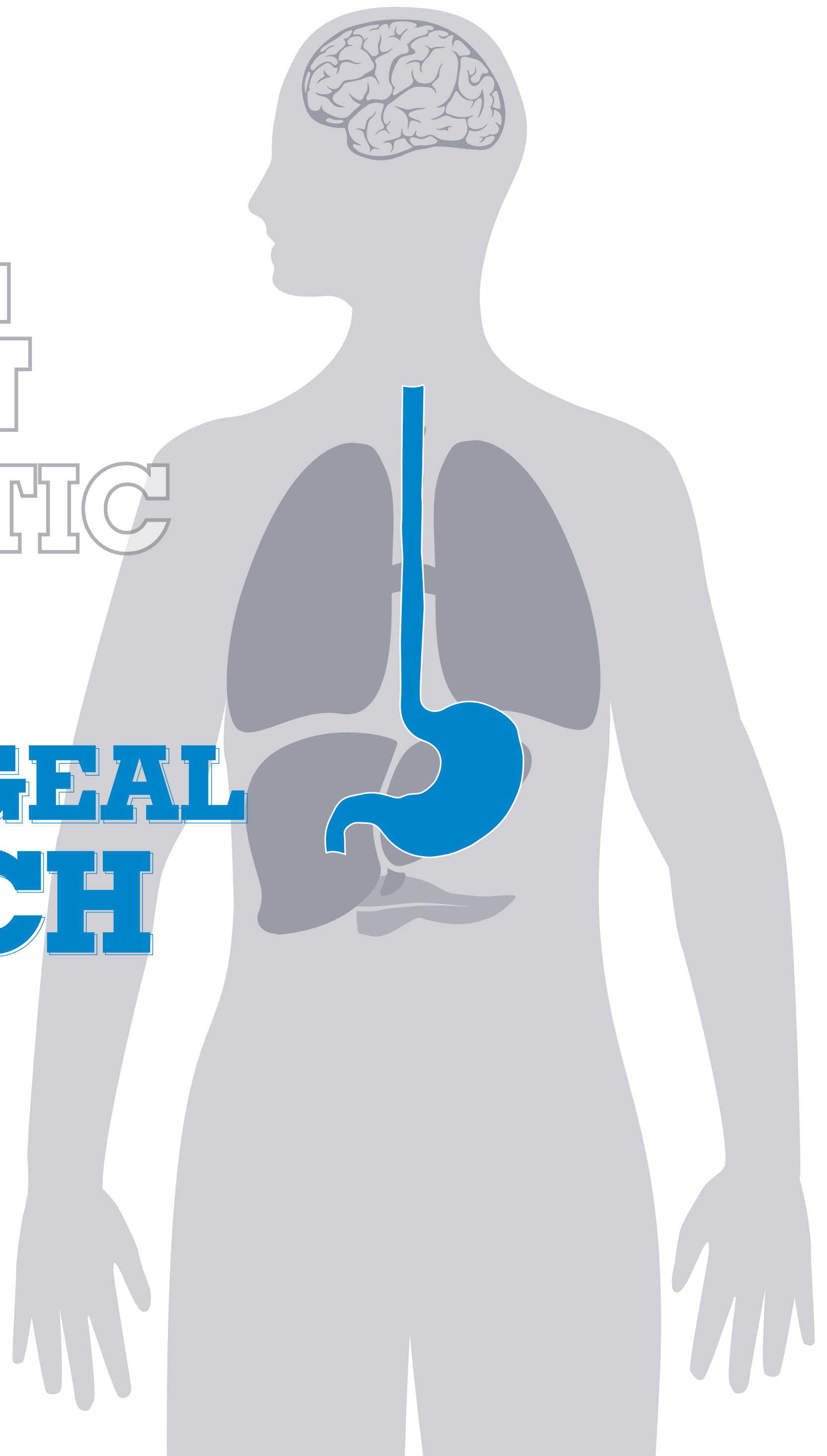
Cancer survival rates have improved significantly over the last 40 years and today approximately half of those diagnosed with cancer will live for 10 years or more after diagnosis.

There are however, six cancers which remain a challenge when it comes to survival. These are lung, pancreatic, liver, brain, oesophageal and stomach, which together are referred to as 'Less Survivable Cancers'. These cancers account for a quarter of cancer cases in Wales but are responsible for half of all cancer related deaths.

Four of these six Less Survivable Cancers are of the Upper-Gastrointestinal tract, and two of these, oesophageal and stomach cancer, have historically had very little public attention, but can have devastating consequences for individuals and their families

In attempt to raise the profile around the challenges facing people diagnosed with these two Less Survivable Cancers Tenovus Cancer has pulled together a combination of publicly available data, freedom of information requests, and the findings of a round table event, to produce this report which identifies three clear recommendations to help deliver improved outcomes.

BRAIN
LUNG
PANCREATIC
LIVER
OESOPHAGEAL
STOMACH



State of the nation

Incidence and mortality

Oesophageal and stomach cancer occur when abnormal cells grow in an uncontrolled manner in either of these organs.

In 2020, 445 people were diagnosed with oesophageal cancer and 348 people were diagnosed with stomach cancer in Wales (WCISU, 2023). Men are more than twice as likely to be diagnosed with oesophageal or stomach cancer compared to women. Despite incidence rates and survival for these cancers marginally improving over time, oesophageal and stomach cancers were still responsible for 680 deaths in 2021.

This means that whilst oesophageal and stomach cancers accounts for just 4.5% of cancer incidence in Wales in 2020, they accounted for 7.7% of cancer deaths.

Survival and staging

Like most cancers, survival is largely dependent on the stage of diagnosis, meaning early detection and diagnosis is key. However, there is currently no UK wide screening test available to detect early stage oesophageal and stomach cancer and the majority of cases are diagnosed in the late stages of the disease. 42% of oesophageal cancers and 43% stomach cancers are diagnosed at stage 4. Compare this to a more survivable cancer, such as breast, where only 5% are diagnosed at stage 4 (WCISU 2023).

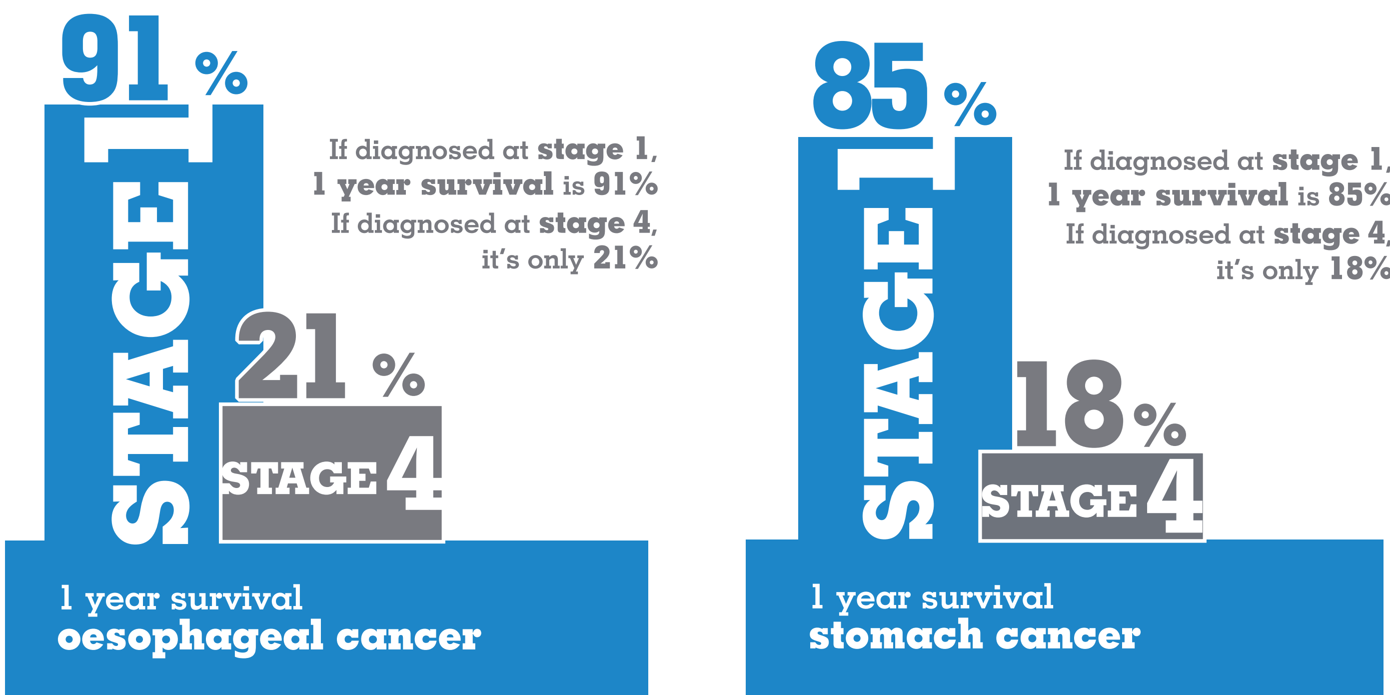
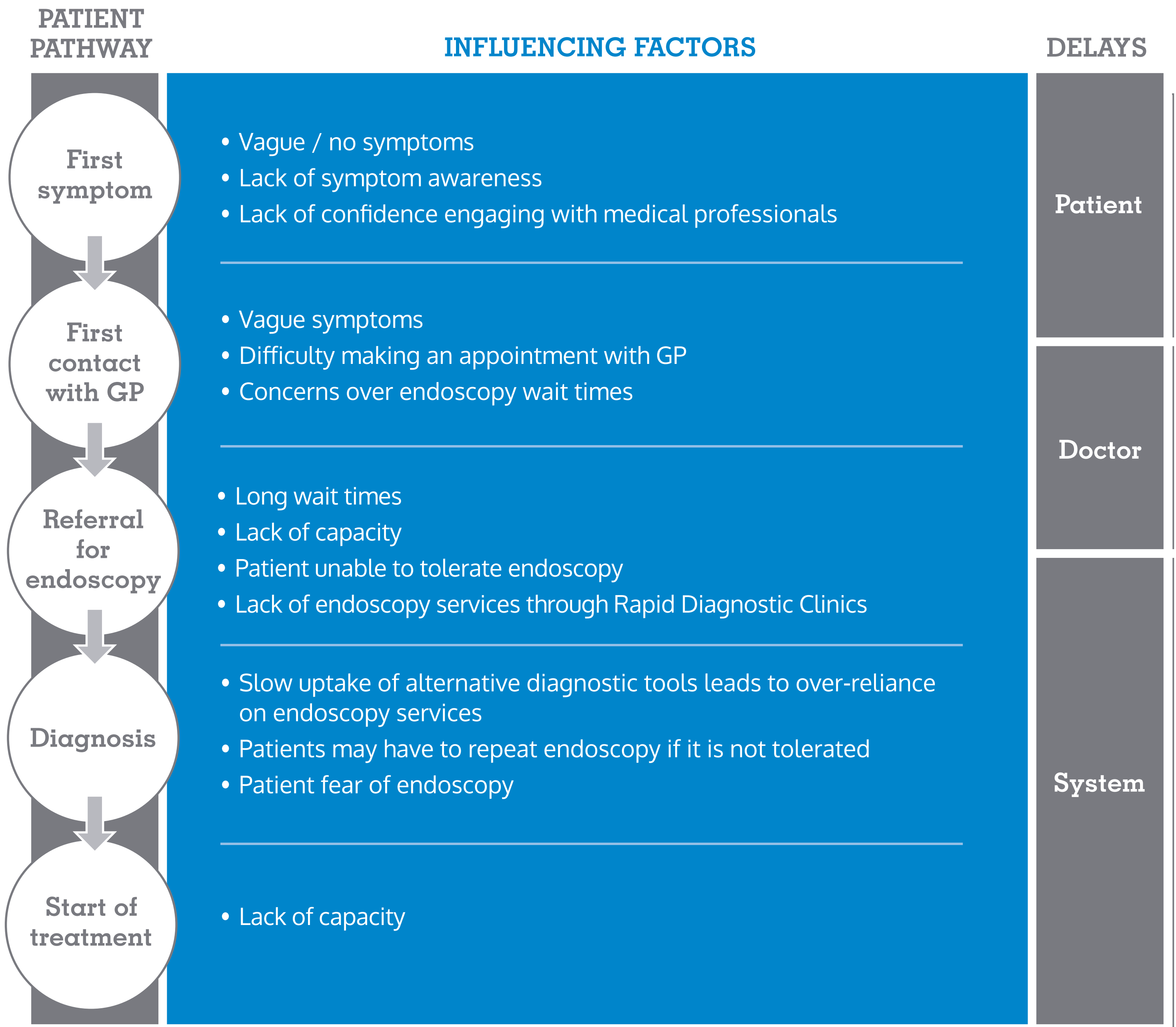


Figure 1. Stage of diagnosis severely impacts survival rates of both oesophageal and stomach cancer.

While lifestyle choices play a role in the incidence of both oesophageal and stomach cancer, it is clear that the biggest opportunity to improve outcomes in Wales lie in the area of earlier diagnosis. By identifying the causes of delays in the diagnostic phase of the cancer pathway, we can develop an action plan to significantly reduce the burden of late diagnosis.

Areas of delay



Symptom awareness

The first step in diagnosis is for individuals themselves to recognise and act on symptoms.

As both oesophageal and stomach cancer often have vague, or no symptoms, increasing symptom awareness can be challenging. A UK wide survey performed by the Less Survivable Cancer Taskforce in November 2022 discovered that symptom awareness for oesophageal and stomach cancers is low (Less Survivable Cancer Taskforce, 2023). Only 1% and 4% of people surveyed recognised the symptoms of oesophageal and stomach cancer, respectively.

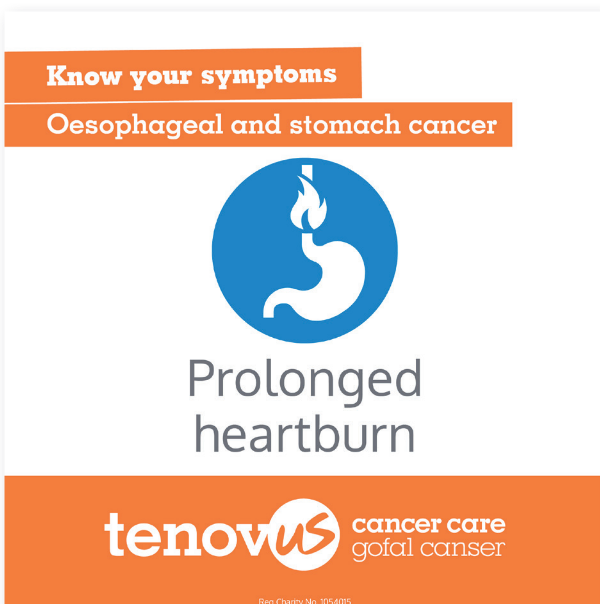


Figure 2. Sharing graphics such as these can help raise symptom awareness with the public.

> When consultants diagnosed me with oesophageal cancer I couldn't believe it.
>
> For about a year I'd been having symptoms - difficulty swallowing, heartburn and fatigue.
>
> However, I wasn't too worried, and even when I finally went to my GP, I didn't think for one minute the symptoms were cancer. I was convinced I had an ulcer.
>
> I'd delayed going to my GP until swallowing anything had become unbearable. I couldn't swallow anything, not even water, without severe pain.

Christine was diagnosed with late-stage oesophageal cancer in 2018, and whilst treatment has worked well for her, and earlier diagnosis could have made treatment easier and less invasive.

Patient delay

"Patient delay" refers to the time taken between a person recognising a red flag symptom and contacting their GP. There are several reasons why people may delay seeing their GP;

- Fear of a cancer diagnosis
- Lack of understanding regarding the significance of their symptom
- Confusing symptoms with other health issues which are already diagnosed
- Concern over adding additional pressure on the NHS
- Difficulty getting an appointment
- Difficulty taking time off work
- Managing caring responsibilities

Despite the wide variety of reasons why people may delay seeing their GP, many are linked to deprivation.

A study conducted in Aneurin Bevan and Cardiff and Vale University Health Boards found that the median time interval between a person first experiencing symptoms and then presenting those symptoms to their primary care physician was 12 weeks (Blake et al. 2017b). This represented the majority (76%) of the total delay experienced by people from the start of their symptoms until their first definitive treatment.

This study also found that the median patient delay for oesophageal and stomach cancer patients was 5 weeks longer for those living in the most deprived quintile (13 weeks) than those living in the least deprived quintile (8 weeks).

As symptoms of heartburn and indigestion can mask those of oesophageal and stomach cancer, pharmacies play a role in raising awareness amongst those who regularly buy relief medication for these conditions. Pharmacists are often well known within the community and can engage with a wide range of people. A targeted symptom awareness campaign in England in 2015 resulted in a 20% increase in oesophageal cancer diagnosis the following month (Allum 2020).

RECOMMENDATION

We recommend a Wales wide symptom awareness campaign with particular focus on those living in areas of high deprivation with emphasis on the role played by pharmacists who are well placed to begin dialog with local customers who regularly buy over the counter medication to treat heartburn and indigestion, gently encouraging them to begin a discussion with their GP.

Emergency presentation

Emergency presentation is correlated with poorer outcomes for people affected by cancer, as it normally indicates that the cancer has more than likely progressed.

In Wales, an average of 19% of people with oesophageal or stomach cancers are diagnosed in an emergency setting. Often, this could be due to a lack of symptom awareness, slow referrals, or missed opportunities for onward referrals by GPs. However, these cancers are often symptomless until the later stages, so emergency presentations will be inevitable in some cases.

As can be seen from the graph below, rates of emergency presentation of oesophageal and stomach cancers vary dramatically between Welsh health boards. Understanding this variation could provide answers about how health boards could make improvements, by sharing best practice and learning from each other.

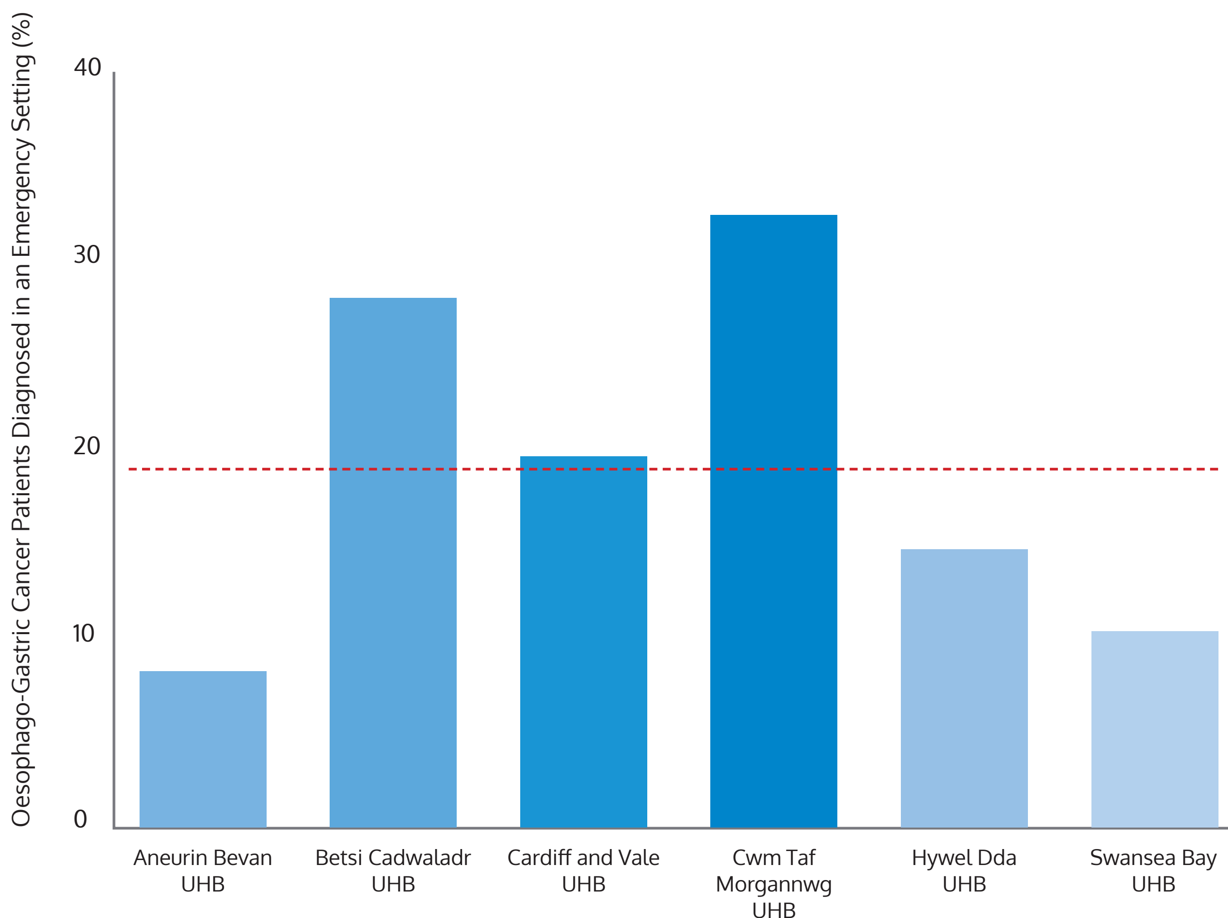


Figure 3. Differences exist between different Welsh health boards on the proportion of people diagnosed with oesophageal or stomach cancer in an emergency setting in 2022. The red dashed line represents the national Welsh average. Data extracted from Park et al, (2023).

Doctor delay

Once people have recognised their own symptoms and taken steps to see their GP, it has been found that 48% of people with symptoms reported visiting their GP twice or more before being referred to secondary care (Wales Cancer Patient Experience Survey, 2021). This number indicates that either people are struggling to communicate the extent of their symptoms, or that GPs sometimes fail to recognise their potential severity. These discrepancies in care can be seen in the time it takes for a referral to secondary care to be made, which can range from 1 day to 18months (Blake et al. 2017).

Referral for a diagnostic procedure such as endoscopy may be influenced by knowledge of the current pressures on endoscopy services within Wales.

Endoscopy waiting times

Even before the Covid pandemic, endoscopy services in Wales were under significant pressure due to high demand. During the pandemic endoscopy provision was dramatically impacted when services were further reduced. Recovery of the backlog continues to be hampered by lack of capacity within the system due to many issues, including challenges around the workforce, lack of appropriate clinical spaces and funding.

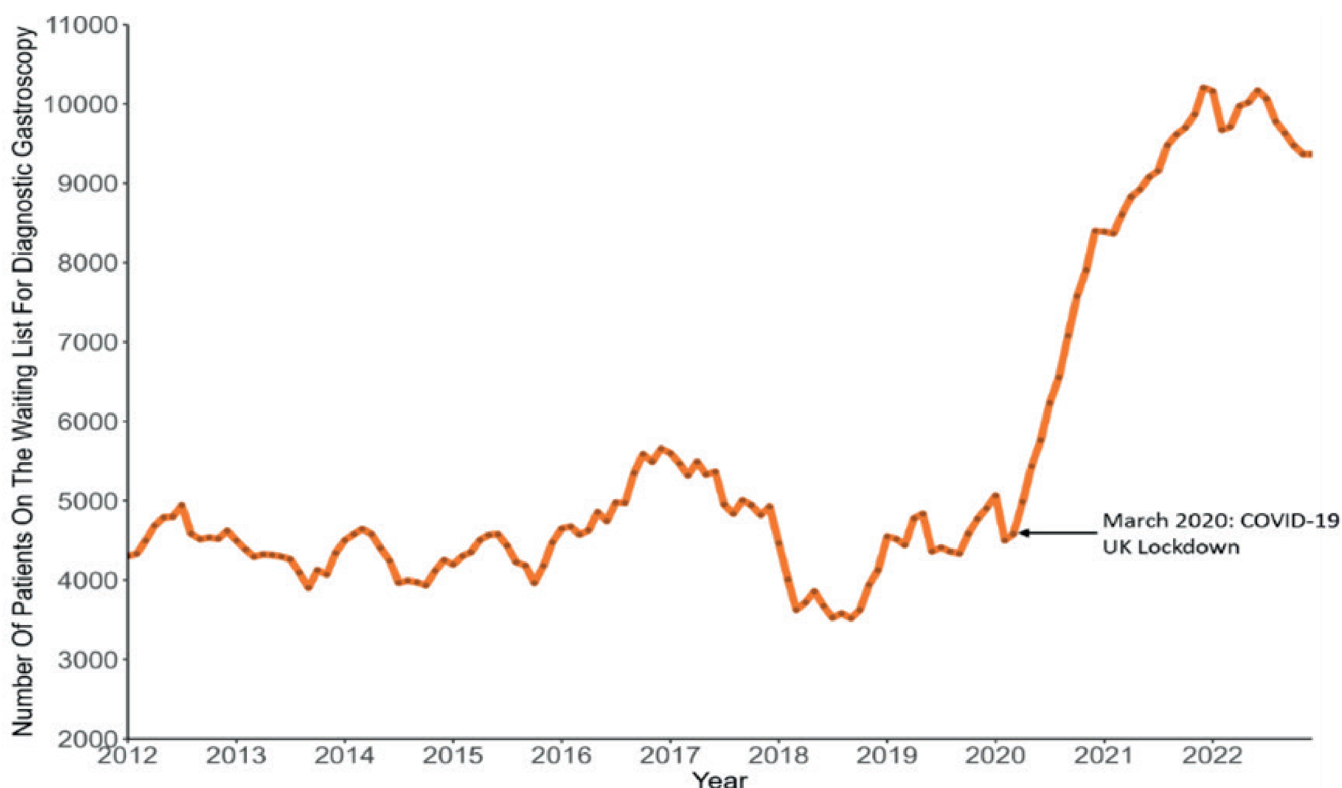


Figure 4. The number of people on the waiting list for a diagnostic gastroscopy in Wales 2012-2022. Stats Wales

To reduce endoscopy waiting times to ensure a more effective referral pathway for all those experiencing symptoms of oesophageal or stomach cancer, capacity to perform endoscopy must be increased. However, embracing newer or more efficient diagnostic techniques such as the swallowable sponge test and transnasal endoscopy (TNE) could reduce demand for these services thereby reducing waiting times and improving early diagnosis rates.

Swallowable Sponge Test

The swallowable sponge test is a medical device which can be used to detect Barrett's oesophagus and early-stage oesophageal cancer. The test involves a small sponge that has been compacted into a biodegradable capsule attached to a string which can be swallowed. The capsule dissolves and the sponge is retrieved using the string which collects cells from the lining of the oesophagus as it is being removed. These cells can then be analysed for specific biomarkers to ascertain whether a person has abnormalities which would indicate either Barrett's oesophagus or oesophageal cancer.

The swallowable sponge test does not require any sedation or local anaesthetic and takes less than 30 minutes. It does not require specialised equipment nor extensive training and could be easily used in a primary care setting. The test has been demonstrated to be well tolerated by people and is also a cost-effective method to detect Barrett's oesophagus and oesophageal cancer.

Transnasal Endoscopy (TNE)

TNE is an alternative approach to gastroscopy, which is the usual endoscopic test used to investigate gastro-oesophageal symptoms in people. It uses the nasal route to insert an ultra-thin endoscope as opposed to the trans oral route used in gastroscopy.

Because TNE uses the nasal route, it does not aggravate the gag reflux, so is better tolerated by patients and therefore does not require sedation. Often when gastroscopy is not well tolerated, sedation is required, which needs the presence of an anaesthetist.

Failure to tolerate gastroscopy is the most common reason for repeated appointments which cause increased service demand and delayed diagnosis.

By improving patient tolerance, TNE has a higher patient safety profile, reduces required staff numbers and has a shorter recovery time.

RECOMMENDATION

We recommend that the NHS in Wales, through the NHS Executive and the new Diagnostics Board continue to review and plan for an expansion of endoscopy services within Wales with a focus on the adoption of new and emerging innovative technologies such as the swallowable sponge test and TNE.

"The introduction of new diagnostic techniques such as TNE and the swallowable sponge test has the potential to positively impact the pressures currently being faced by our endoscopy services across Wales. These less invasive diagnostics are beneficial for our patients, can offer efficiency savings in our endoscopy departments and crucially can contribute to earlier diagnosis of upper gastrointestinal cancers. At Moondance Cancer Initiative, we have been working with four health boards in Wales to accelerate the introduction of both TNE and the swallowable sponge test but we would like to see this progressed nationally at pace. "

Professor Jared Torkington
Clinical Director, Moondance Cancer Initiative

Barrett's surveillance

Barrett's oesophagus is a condition which causes cells to grow abnormally within the oesophagus. Although not life-threatening, Barrett's oesophagus is the only known precursor to oesophageal cancer, and it is estimated 3% of people with Barrett's will go on to develop cancer.

Because Barrett's oesophagus can develop into oesophageal cancer, it is recommended that people are monitored regularly using endoscopy, the frequency of which is determined by the length of the abnormal segment of oesophagus (Fitzgerald et al. 2014; NICE, 2023). Typically, this results in people with Barrett's oesophagus having a surveillance endoscopy every 2-5 years.

The importance of this surveillance must not be underestimated, as there is a 30% reduction in mortality for people with Barrett's oesophagus who received endoscopic surveillance compared to those who did not (NICE 2023).

Using freedom of information requests, we explored how many people with oesophageal cancer were already being actively monitored for Barrett's oesophagus. We found that for one Welsh health board as many as 32% of oesophageal cancer patients were having regular endoscopy in 2019. This represents a population who rightfully should have been diagnosed at the very earliest stages of the disease and yet in the same year only 17% of people with oesophageal cancer within that Health Board were diagnosed at stage 1 and 2.

A registry to record people with Barrett's oesophagus would aid the development of a national approach to ensure that people with Barrett's are monitored at appropriate intervals. This would result in a significant increase in the proportion of oesophageal cancers which are diagnosed at stages 1 and 2 in Wales.

"A Barrett's registry would be incredibly helpful in better understanding the differences in accessing care, as well as variations in Barrett's surveillance and dysplasia detection rates between different geographical locations. It would allow us to better standardise care across the nation, promoting timely high-quality endoscopy (or swallowable sponge testing), hopefully resulting in earlier diagnosis of neoplasia and better outcomes."

Dr Hasan Haboubi
Consultant Gastroenterologist, Cardiff & Vale University Health Board

RECOMMENDATION

We recommend through the new NHS Executive and National Diagnostics Board, NHS Wales creates a new national registry for people with Barrett's oesophagus as part of the implementation of the National Diagnostic Transformation Strategy

Next Steps and recommendations

Early diagnosis of oesophageal and stomach cancer must be made a national cancer priority in Wales. To achieve a step change in cancer outcomes for those who are diagnosed with these cancers, we have outlined three clear and simple areas of focus. These are:

1. Increase awareness of the vague and non-specific symptoms of oesophageal and stomach cancer

Public awareness of oesophageal and stomach cancer symptoms is low, especially for the vague and non-specific symptoms, such as heartburn. Public awareness campaigns can be utilised at both a national level and within local communities to increase health education and symptom awareness of oesophageal and stomach cancer. Pharmacy interventions can also be employed to specifically target people with persistent heartburn symptoms at point display/purchase of heartburn medication. These interventions will raise awareness of vague symptoms and promote help-seeking behaviour to ensure people consult their GP as soon as potential cancer symptoms occur.

2. Increase and expand the capacity of endoscopy services in Wales with a focus on embedding new and innovative technologies

Endoscopy services have been under increasing pressure since the COVID-19 pandemic. To expand endoscopy capacity, priority should also be placed on ensuring a sustainable workforce including increase in training and recruitment. In addition, innovative technologies such as TNE and swallowable sponge tests will drive the transformational change needed to ensure people can undergo diagnostic testing and surveillance promptly. These new interventions should be rolled out across Wales at pace. Increasing and expanding the capacity of endoscopy services is crucial to ensure Barrett's oesophagus and people are diagnosed with oesophageal or stomach cancer promptly.

3. Create a national registry for people with Barrett's oesophagus in Wales

To understand the impact of Barrett's oesophagus, improved data collection is needed for Barrett's oesophagus in Wales. The creation of a national registry for Barrett's oesophagus will standardise the collection of data relating to Barrett's oesophagus between local health boards. Improved data collection is required to evaluate the impact of Barrett's oesophagus on oesophageal cancer in Wales. In the absence of a national screening programme for oesophageal cancer, Barrett's oesophagus represents a unique opportunity to identify people most at risk of oesophageal cancer and diagnose them at the earliest possible opportunity where treatment options are the most optimal.

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