

# Tenovus Cancer Care

## Upper Gastrointestinal Cancers Roundtable and Recommendations



MSD has provided funding for a roundtable and to enable the subsequent report generation.

MSD has had no editorial control or input into the agenda of the roundtable or contents of the report.

Cancers of the oesophagus and stomach have some of the poorest cancer patient outcomes in Wales, so much so that they are considered two of the six “less survivable” cancers.

By the time people present and are diagnosed with these cancers, disease is often advanced and a significant proportion of patient present to acute services when the cancer is at a later stage, spreading throughout the body, leading to poor outcomes.

Tenovus Cancer Care believes this is unacceptable and that greater concerted and coordinated action is required to improve outcomes. We organised a digital roundtable event on the 26<sup>th</sup> April 2023, bringing clinicians; the Third Sector; the pharmaceutical industry and other cancer stakeholders together in an online space to discuss the challenges we face in Wales and the solutions we need to prioritise and action.

**The recommendations from the roundtable can be grouped into the following five categories:**

### 1. Awareness and Education

The Welsh Government, NHS Wales and / or the Third Sector to develop and deliver a public awareness campaign to encourage members of the public to act early on prolonged symptoms of stomach and oesophageal cancer and to raise awareness of risk factors and risk reduction.

The Third Sector and partners to improve and increase public education and awareness. To develop, pilot and roll-out a point-of display/point of sale symptom awareness campaign where common symptom relief medications are sold, such as community pharmacies.

NHS Wales to produce streamlined, user-friendly information concerning stomach and oesophageal cancer that tackles common myths concerning diagnosis and treatment. For example, information about how Trans-Nasal Endoscopy (TNE) is much more tolerable needs to be produced and distributed to encourage others to come forward, and information for patients on long-term medications for indigestion.

### 2. NHS Organisation

The new NHS Wales Executive prioritises the reduction of variation between health boards, with particular attention given to improving cancer patient outcomes. This would include identifying better and consistent methods of sharing best practice across all areas.

### 3. Diagnostics

The Wales Cancer Network (WCN) and partners to explore and consider championing innovative approaches to screen for and identify stomach and oesophageal cancers at an early stage.

The Welsh Government and NHS Wales to support the roll-out of TNE across Wales.

Health and Care Research Wales, NHS Wales, and partners to consider how to introduce and widen access to swallowable sponge diagnostic tests through clinical trials (BEST 4) and/or pilot schemes in Wales. This should be targeted at ‘at risk’ group such as patients on long term PPI (proton pump inhibitors) or patients on Barrett’s screening waiting lists.

The Wales Cancer Network and Upper GI Cancer Site Group to review, pilot and optimise the Upper GI cancer pathway to test innovations such as i) surveillance of people with familial history of Upper GI cancers; ii) a common GI referral pathway for primary care to refer patients into; and iii) the potential role that could be played by community pharmacies in picking up red flag symptoms and direct referral into secondary care.

#### 4. Support During Treatment

NHS Wales and the Wales Cancer Network to widen access to prehabilitation for patients with a stomach or oesophageal cancer diagnosis ahead of their treatment, including non-surgical and palliative treatments. Nutritional assessment and support is critical to toleration of treatments.

The Wales Cancer Network to ensure that all stomach and oesophageal cancer patients receive their holistic needs assessment, and their wishes are captured in a care plan.

#### 5. New Treatments & Clinical Trials

The Wales Cancer Network and partners to review and resolve issues around access and adoption of new treatments across the cancer pathway, with a particular emphasis on Upper GI cancer treatments.

Health and Care Research Wales and the Wales Cancer Research Centre to review and recommend the steps required to improve the quantity and equity of access to Upper GI cancer clinical trials across Wales.

## Introduction

There are some cancers which have seen remarkable progress in survivability but others that are just as deadly as they were 40 years ago. Together, six of these less survivable cancers - lung, pancreatic, liver, brain, oesophageal and stomach, are responsible for a half of all deaths from common cancers and make up a quarter of cancer cases.

Four of the less survivable cancers - pancreatic, liver, oesophageal and stomach are Upper Gastrointestinal (Upper GI) cancers. Whilst pancreatic cancer and liver cancer are well served by charities in Wales such as Pancreatic Cancer UK, the British Liver Trust and related charities – other cancer types, such as lung cancer, stomach cancer and oesophageal cancer are less well served and patient groups for these cancer types are underrepresented.

Tenovus Cancer Care has prioritised its policy and advocacy activity around these three cancers and the changes needed to improve comparably poor cancer patient outcomes.

## The Picture in Wales

Unfortunately, in the case of Upper GI cancers they can present with quite vague symptoms, leading to late presentation and poor outcomes in long-term survivability. In Wales in 2021, 77% of patients presented with stage three or four cancers which are often incurable.

England has a 2% to 4% better survival rate for Upper GI cancers than Wales and Wales is performing worse than England in one- and five-year survival rates for both stomach and oesophageal cancers.

However, the situation is not all doom and gloom, with the potential for better intervention, earlier diagnosis, and more rapid treatment to improve cancer outcomes in Wales. There is also much variation between Welsh health boards, and this may hold the key to improving outcomes.

## The Upper GI Roundtable and Discussion

Tenovus Cancer Care, with the support of MSD, convened a roundtable on the 26th April 2023. The event brought together clinicians with Upper GI cancer expertise in Wales, the Third Sector, the pharmaceutical industry, and other cancer stakeholders together for a virtual event.

Attendees heard from the Chair, Tenovus Cancer Care's Chief Executive, Judi Rhys MBE; the Wales Cancer Network's Upper GI Cancer Site Group (CSG) lead, Dr Carys Morgan and the Wales Cancer Network's leadership fellow, Dr Laura Munglani. Their presentations provided layers of context for the discussion that followed.

The discussion was facilitated by the Chair who welcomed contributions from all attendees. This report provides a summary and overview of the discussion, and recommendations to improve stomach and oesophageal cancer outcomes in Wales.

The discussion managed to cover the following five categories, under which the roundtable recommendations can be found:

1. [Awareness and Education](#)
2. [NHS Organisation](#)
3. [Diagnostics](#)
4. [Support During Treatment](#)
5. [New Treatments and Clinical Trials](#)

## Awareness and Education

There seemed to be a consensus from those present that there needed to be a greater understanding and awareness of symptoms among both patients and GPs. Unfortunately, the proportion of patients presenting with early-stage disease remains very low. Dr Carys Morgan, Upper GI cancer site group lead at the Wales Cancer Network, highlighted that while there have been a number of campaigns in recent years to raise the profile for symptoms of oesophageal cancer or reflux oesophagitis, there has not been much work on this in Wales.

With regards to patient education, panellists raised concerns that 35% of patients present with acute symptoms such as an upper GI bleed or acute abdominal pain. The panellists believed that through improved patient education and ability to act on concerns symptoms could be picked up at an earlier stage.

Dr Dai Samuel stated that there remained a significant stigma and fear concerning cancer, particularly Upper GI cancers. He argued that this is why many patients do not present because they fear that a cancer diagnosis will always be a death sentence. He encouraged starting education around cancer in schools and colleges and getting children to tell their parents and grandparents about the symptoms and encouraging open discussion about cancer. He noted that the Moondance Cancer Initiative (MCI) had done a similar project with bowel cancer awareness in schools.

Dr Jeff Turner emphasised the importance of additional patient information on upper GI endoscopies. He noted that the test is widely regarded as unpleasant, and many patients would benefit from learning what is involved in the test as well as teaching them more about TNE which is a better tolerated test and less unpleasant for patients. He stated that this would have the potential to reduce the risk of patients hearing about an uncomfortable procedure and being discouraged from presenting with symptoms.

There was also a discussion concerning the resources available for patients. Concerns were raised that patients could be overwhelmed by the leaflets and information presented to them when going through the diagnostic and treatment pathways. It was suggested that information could be streamlined to ensure that all patients are receiving similar information at appropriate times through their pathway.

Furthermore, attention was paid to a scheme in Powys "Livelife Cancer Awareness", funded by the Lingen Davies Cancer Fund, where community champions, well known within local communities, come forward and raise awareness of symptoms and encourage others to present to primary care. It was suggested that such a scheme would encourage the understanding that early presentation is key to better outcomes. It was noted that such a scheme may be useful in rural communities and may be critical to increasing trust and action in more disadvantaged areas.

## Recommendations

The Welsh Government, NHS Wales and/ or the Third Sector to develop and deliver a public awareness campaign to encourage members of the public to act early on prolonged symptoms of stomach and oesophageal cancer and to raise awareness of risk factors and risk reduction.

The Third Sector and partners to improve and increase public education and awareness. To develop, pilot and roll-out a point-of display/point of sale symptom awareness campaign where common symptom relief medications are sold, such as community pharmacies.

NHS Wales to produce streamlined, user-friendly information concerning stomach and oesophageal cancer that tackles common myths concerning diagnosis and treatment. For example, information about how TNE is much more tolerable needs to be produced and distributed to encourage others to come forward, and information for patients on long-term medications for indigestion.

## NHS Organisation

There were numerous concerns raised during the meeting relating to variations between Welsh health boards.

"...there is unacceptable variation from services that are just miles apart."

Contributor, Wales Cancer Network

It was suggested that reducing discrepancies between health boards may hold the key to improving outcomes.

One example of such a discrepancy was the subject of an audit undertaken by Dr Laura Munglani, Welsh Clinical Leadership Training Fellow and Haematology Registrar with the WCN. She has examined the timeframe of the patient pathways between an initial visit to the GP and their subsequent A&E admission and cancer diagnosis and has made several evidence-based improvement ideas. It was noted that sharing improvement ideas and best practice between health boards could be vital to improving the situation across Wales.

## Recommendations

The new NHS Wales Executive prioritises the reduction of variation between health boards, with particular attention given to improving cancer patient outcomes. This would include identifying better and consistent methods of sharing best practice across all areas.

## Diagnostics

Panellists highlighted that there is a lack of clear screening tests for oesophageal or gastric cancers apart from Barrett's screening for those patients with suspected Barrett's oesophagus. There was a potential role for surveillance of people with a familial history of Upper GI cancers or higher risk groups. It was suggested that there should be an exploration of innovative ways in which high-risk groups could be screened, or by using research to identify how best to pick up these cancers at an early stage.

Participants acknowledged issues with access to diagnostics, something that had been made worse still by the pandemic. It was suggested that TNE could be one option to decrease diagnostic waiting times, as could the use of cytosponge to test for pre-cancerous changes to the oesophagus. It was noted that it would be important to explore its use through clinical trials (by participating in the BEST 4 trial) and /or a pilot scheme in high-risk groups as in other UK nations.

It was suggested that the introduction of a common GI referral pathway, where urgent suspected cancer referrals could be automatically re-routed, would avoid situations where patients referred to the wrong speciality are then returned to the GP.

It was argued that community pharmacies could play an important role in picking up red-flag symptoms and direct referral to secondary care to shorten the pathway for patients with suspected symptoms for various cancers. Dr Rachael Barlow stated that pharmacists had been carrying out a health MOT as part of their "Prehab to Rehab" programme with Cardiff and Vale UHB. She noted this included a template that sits within the primary care record which is completed by a pharmacist or a prehabilitation assistant practitioner.

## Recommendations

The Wales Cancer Network and Partners to explore and consider championing innovative approaches to screen for and identify stomach and oesophageal cancers at an early stage.

The Welsh Government and NHS Wales to support the roll-out of TNE across Wales.

Health and Care Research Wales, NHS Wales, and partners to consider how to introduce and widen access to swallowable sponge diagnostic tests through clinical trials (BEST 4) and/or pilot schemes in Wales. This should be targeted at 'at risk' group such as patients on long term PPI (proton pump inhibitors) or patients on Barrett's screening waiting lists.

The Wales Cancer Network and Upper GI Cancer Site Group to review, pilot and optimise the Upper GI cancer pathway to test innovations such as i) surveillance of people with familial history of Upper GI cancers; ii) a common GI referral pathway for primary care to refer patients into; and iii) the potential role that could be played by community pharmacies in picking up red flag symptoms and direct referral into secondary care.

## Support During Treatment

While it was acknowledged that treatments for cancer are complicated, they are improving. The centralised surgical centre in South Wales was noted as having improved pathological outcomes as well as 30-day mortality. Surgical trial participation and research opportunities have been improved at this early stage.

Emphasis was placed throughout the discussion on the need to support those going through treatment. It was noted that early access to prehabilitation was crucial for patients going through very intense curative treatments or even palliative treatments and viewed as being part of the optimal treatment pathway. Patients require early access to nutritional assessment and support to remain well enough for complex and intensive treatments.

There was also a discussion about how improved treatment times could lead to reduction in stress and anxiety for patients. Work done by Annie Hughes, a senior cancer pathway project manager at Aneurin Bevan Health Board showed that where the wait between endoscopic diagnosis and CT scan is

shortened from two weeks to 24 hours, the result has been far less anxiety for patients and shorter time to treatment.

Additionally, participants raised the importance of patient fitness while undergoing treatment. While emphasis is often placed on the fitness of patients undergoing multimodal therapy, it is also important to ensure fitness levels throughout the pathway to increase the proportion of patients being able to manage intensive treatments. One plan was highlighted, input as close to endoscopic diagnosis as possible, with all patients offered a structured exercise programme, dietetic intervention, anxiety, and fatigue management as well as access to pharmacists, cardiologists and specialist diabetes nurses in order to optimise comorbidities.

There was also some suggestion that beyond medical support, attention should be paid to the level of welfare support given to patients. Referred to as What Matters conversations, holistic needs assessments consider welfare benefits and daily living advice. It was noted that through engagement with the third sector there had been improvement to the Cancer Journey pilot in Powys.

## Recommendations

NHS Wales and the Wales Cancer Network to widen access to prehabilitation for patients with a stomach or oesophageal cancer diagnosis ahead of their treatment, including non-surgical and palliative treatments Nutritional assessment and support is critical to toleration of treatments.

The Wales Cancer Network to ensure that all stomach and oesophageal cancer patients receive their holistic needs assessment, and their wishes are captured in a care plan.

## New Treatments and Clinical Trials

There were some concerns raised over the treatment pathways for cancer in general but particularly Upper GI cancers. There are issues around time to starting neo-adjuvant chemotherapy that needs to be resolved as increasingly with new treatments there is no standardised approach for managing the neo-adjuvant treatment pathway. This is important to the introduction of new drugs where biomarker results will be required for decision making.

It was noted that despite new drugs coming to the market and new immunotherapies being approved in different settings, many clinicians are struggling to deliver them throughout the pathway due to capacity in the workforce and physical space to deliver treatments. Although contributors noted that they had pushed Welsh Government on this matter, there were still funding concerns which may impact whole pathway approaches.

There were also concerns raised over the lack of clinical trials taking place in Wales. It was noted that the resource available in Wales for trials was unsuitable and that trials themselves had become increasingly demanding in terms of the time required to facilitate them. It was suggested that trials could be run centrally for the whole of Wales reducing the burden and time associated with opening a new study.

Additionally, it was suggested that for more 'niche' studies, health boards or cancer centres would need to work together to facilitate trials. Bronglais was heralded as an example of where consultants and research nurses had been funded to give them protected time for clinical trials. This had resulted in over 700 patients being entered into clinical trials compared to just five, 18 months before. It was also noted that the creation of networks between three health boards has resulted in the sharing of information, challenges, and best practice.



## Recommendations

The Wales Cancer Network and partners to review and resolve issues around access and adoption of new treatments across the cancer pathway, with a particular emphasis on Upper GI cancer treatments.

Health and Care Research Wales and the Wales Cancer Research Centre to review and recommend the steps required to improve the quantity and equity of access to Upper GI cancer clinical trials across Wales.

## Conclusion

Tenovus Cancer Care wishes to thank everyone for attending the roundtable event and contributing their insight and expertise to the wide-ranging discussion.

The findings and recommendations from the from the roundtable will be used to inform Tenovus Cancer Care's Upper GI cancer policy and communications activity. This will be progressed in partnership with the Upper GI CSG, the WCN, and other organisations looking to improve stomach and oesophageal cancer outcomes and deliver improvements to cancer services in Wales.