Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Gwasanaethau endosgopi

This response was submitted to the Health and Social Care Committee consultation on Endoscopy Services

EN 07

Ymateb gan: | Response from: Bowel Cancer UK

Endoscopy services: follow up inquiry

Bowel Cancer UK

Overview

We welcomed the Endoscopy Action Plan when published in 2019 and believe significant progress has been made in a number of areas. There are parts of the bowel cancer pathway that still require improvements, but we recognise the efforts of the National Endoscopy Programme Board (NEP) to work within the backdrop of COVID-19.

The speed and accuracy of diagnosing bowel cancer is of critical importance to patient outcomes. Bowel cancer is the second biggest cancer killer in Wales. However, it shouldn't be because it is treatable and curable especially if diagnosed early.[1] Nearly everyone survives bowel cancer if diagnosed at the earliest stage. However, this drops significantly as the disease develops.

Latest figures from StatsWales show bowel cancer patients continue to face delays getting diagnosed following an urgent suspicion of cancer referral. These diagnostic delays mean many patients fail to start vital treatment within the 62-day target (from referral with suspicion of cancer to the commencement of treatment).

The extent of the delays to accessing diagnostic tests, such as colonoscopy, varies across the nation with figures for September 2022 showing slightly higher than one third of lower gastrointestinal (GI) patients, including bowel cancer, were seen within this time. Only 35.1% of patients began treatment within 62 days in September's data[2]. This is a significant way short of where performance against the target (75%) should lie.

These waiting times figures show there is still a long way to go to deliver sustainable and robust endoscopy services across Wales.

COVID impact and increasing demand

The COVID pandemic led to a reduction in bowel cancer services in the NHS in Wales with a significant drop in referrals and investigations, as well as a considerable pause to the bowel screening programme.

Whilst these were understandable decisions taken to reduce transmission and prioritise patients requiring emergency treatment, as well as to ease the demand for Personal Protective Equipment (PPE), the disruption saw endoscopy procedures reduced substantially and this in turn has impacted upon delivery of all the objectives set out in the original Endoscopy Action Plan.

Endoscopy clinics were felt to provide a particular risk due to the increased chance of airborne transmission and many gastroenterologists were redeployed to support general medicine due to their dual accreditation as general physicians.

Lower GI referral data (available since December 2021) shows the total numbers being referred into the cancer diagnostic pathway and helps to show changes in demand.[3]

The data suggests that referrals for suspicion of lower GI cancers has increased in recent months (May 2022 to September 2022) with approximately 3,200 referrals each month. This is an almost 25% increase on the number of referrals seen during the previous five months. However, the data shows little change in the number of people being diagnosed with lower GI cancers each month.[2]

Bowel Screening Programme

Bowel Screening Wales faced a backlog of approximately 19 weeks following a pause of the screening programme in 2020. Since the resumption of the bowel cancer screening programme there has been a fantastic effort by staff to tackle the backlog. The 19-week backlog was recovered by September 2021.

This recovery was driven by a large increase in invitations to the programme and these successful efforts allowed Bowel Screening Wales to progress with planned optimisation of the programme. At the end of October 2021, the age criteria for eligibility were widened by including 58 and 59 year olds and more recently, in October 2022, the age criteria were widened further to include 55 to 57 year olds[4]. Previously invitations would be sent out to those aged 60-74 only.

Plans are in place to increase access further, dropping the age of eligibility to 50 years of age, while also increasing the sensitivity of the FIT test by dropping the positivity threshold to 80µg Hb/g faeces from the current level of 150µg/g. This programme of optimisation is scheduled to make its final changes in October 2024.

These changes would bring the bowel screening programme in Wales in line with the eligibility and sensitivity criteria seen in Scotland. England has plans for age reduction and while the FIT threshold is currently lower than seen in Wales (120 µg/g), there are no plans to bring this down to 80 µg/g at the current time. Northern Ireland published a cancer strategy in March 2022 which commits to reducing both age of eligibility and FIT thresholds to those sought by Bowel Screening Wales. There are no published optimisation plans for bowel screening in Northern Ireland at the current time.

The UK National Screening Committee (UKNSC) recommends further reductions in the sensitivity of the FIT test with a reduction to 20µg/g.[5] No nation of the UK has set out plans to reach this recommended level to date.

With the successful completion of optimisation of bowel screening in Wales in 2024, there is an opportunity for Wales to move to a UK-leading position by further optimising FIT thresholds to the 20 µg/g level advised by the UKNSC as being the most cost-effective FIT threshold.

At this level of sensitivity, the bowel screening programme would be more likely to identify patients at higher risk of developing bowel cancer in future and remove polyps to reduce this risk. This would alleviate financial pressure on the NHS however it would place further demand on screening colonoscopy lists, so investment in workforce would be essential.

The Welsh Government should support Bowel Screening Wales to explore the possibility of moving to this lower threshold when the current programme of optimisation ends. This would require a clear understanding of current and future demand based on demographic changes and the workforce required to meet future demand.

The bowel screening programme in Wales should also take steps in the coming years to prepare for a risk-stratified or personalised approach to bowel screening. Research is set to commence that will explore the impact of a number of demographic indicators (eg sex, ethnicity, deprivation, etc) on personal risk and how this may lead to a more flexible model of screening.

We welcome recent agreements to introduce GP endorsement letters, these have been shown to be effective at increasing uptake of bowel screening.

JAG accreditation

The Endoscopy Action Plan set out a recommendation that Health Boards would continue to work towards Joint Advisory Group on Gastrointestinal Endoscopy (JAG) accreditation.

JAG accreditation is a key component in delivering robust and sustainable screening colonoscopies and combined with lower FIT thresholds, can lead to a higher likelihood of detection of patients with bowel cancer and of those at higher risk of developing bowel cancer in future.

While work continues on this issue there have been delays and this objective is not likely to be met by the end of the original timeline. COVID has had a large impact on this workstream, but the NEP continues to seek ways to support Health Boards with the JAG accreditation process.

A number of sites across Wales have been identified as having the greatest likelihood of achieving accreditation in the next year, and they will be given focused support to achieve this goal.

qFIT – the symptomatic pathway

A key recommendation within the Endoscopy Action Plan was to set out a standardised referral pathway to endoscopy. The NEP published an agreed pathway in 2021.[6] qFIT can be used by primary or secondary care staff to help guide the management of patients with bowel cancer symptoms onto the correct referral pathway so they can be seen urgently.

While most Health Boards have adopted the new pathway in primary care, there is one Health Board yet to complete this process. We are aware that a rollout of the referral pathway by GP clusters in this area should be completed in the next few months. This is an important step in improving the bowel cancer diagnostic pathway.

qFIT is a test similar to the FIT used in bowel screening but with a lower sensitivity threshold (i.e. 10 µg/g). It is for people presenting with symptoms of bowel cancer and can be used, by GPs for example, to aid their decision to refer. This has the potential to reduce unnecessary colonoscopies and alleviate demand on colonoscopy services.

While the evidence is still being gathered across the UK, early indications are that the inclusion of qFIT in referral guidance could see a reduction in the number of people referred to secondary care services (-15.1%).[7]

Following the publication of a consensus on the use of qFIT, by the British Society of Gastroenterology and the Association of Coloproctology of Great Britain and Ireland in June 2022[8], there is now work underway to update NICE guidance. Embedding this consensus in formal NICE guidelines will solidify the role of qFIT in the referral pathway.

Innovation – Colon Capsule Endoscopy (CCE)

The pandemic has induced a culture of innovation and uptake that could bring significant benefits for bowel cancer patients in years to come. Faced with the widespread disruption of routine services, the NHS had to innovate either through the accelerated adoption of new technologies or changing clinical practice in terms of how patients are diagnosed, managed, and treated.

CCE has the potential to be particularly transformative through improving the diagnostic experience for patients and reducing the demand on traditional endoscopy services. The cameras are swallowed and then take pictures of the bowel as they pass through the colon. They can be used at home enabling patients to go about their normal day as well as reducing the demand on colonoscopy services so that those requiring urgent further tests can be prioritised.

A recent study has also shown the potential for Artificial Intelligence to support clinical decision-making and ensure that patients with advanced bowel cancer receive the right treatment.[9]

Training for the use of CCE has taken place across all Health Boards in Wales and a pilot has recently begun in four Health Boards. Bowel Cancer UK has been involved in the rollout of CCE in Scotland[10] and England, and we are prepared to support efforts in Wales too.

Building on innovations adopted throughout the pandemic will rely on ensuring that the infrastructure is in place to continually monitor their performance. If deemed effective, solutions should be scaled-up in a timely and appropriate manner to help increase capacity and improve patient experience of diagnostic and treatment services.

This monitoring should extend to assessing the impact of these innovations on reducing health inequalities. For example, the increased use of virtual clinics is widely viewed as one of the pandemic-induced innovations that should be embedded in the coming years. However, it will also be important to consider the impact of the reduction in face-to-face appointments for patients who rely on this service and aren't able to access the appropriate digital tools.

Lynch syndrome – testing and surveillance

In 2019, Wales became the first UK nation to commit to testing all newly diagnosed bowel cancer patients for Lynch syndrome. This condition can be passed from generation to generation and increase lifetime risk of bowel cancer by up to 80%.

The NEP has discussed conducting a Lynch audit to understand whether testing is being conducted as promised. Unfortunately, due to increasing pressures resulting from the pandemic, this audit has not taken place. We would like to see an audit of Lynch testing and surveillance to determine the current state of play, and to better understand what barriers may exist.

England, from April 2023, will incorporate Lynch surveillance within their bowel screening programme. This means that a more formalised programme of follow up with those at higher risk of developing bowel cancer will take place, with participants being screened every two years.

An additional benefit is that with screening colonoscopists being JAG accredited in English screening hubs, the quality of investigation will be higher for this at-risk group.

We believe Lynch syndrome surveillance in Wales should also be brought into the bowel screening programme, as JAG accreditation progresses, to improve surveillance among people with Lynch syndrome.

Workforce and equipment

The two biggest overarching barriers that have continually undermined attempts to improve bowel cancer outcomes, and that must be urgently addressed, are the chronic workforce and equipment shortages across bowel cancer diagnostics, and unwarranted regional variation and health inequalities.

Replacing old equipment and investing in additional kit, combined with further resources to deliver increased training places for endoscopists would create an environment where pressures on equipment and staff capacity are reduced. This would lead to improved outcomes for patients as they access speedier and more accurate diagnosis.

We recognise and welcome recent increases to workforce across the diagnostic pathway, in particular a recruitment drive in endoscopy, in Wales but the historic data in relation to cancer waiting times reinforce the need for greater action to address workforce capacity issues.

A comprehensive workforce strategy that aims to meet the demands of the future and not only those of today is needed urgently to ensure continued progress in endoscopy services and to underpin the aims of the anticipated Cancer Services Action Plan.

Long-standing issues with diagnostic workforce capacity have been exacerbated by the impact of the COVID pandemic. A workforce strategy that aims to prepare the NHS for the future must also aim to build in the additional capacity that is required to absorb shocks to the service, thus ensuring continuation of services as far as possible.

Reduced pressure on workforce and equipment capacity will also lead to the time and space for local services to innovate and transform, keeping to the forefront of technological advances to the benefit of their patients.

Reducing inequalities and variation

Bowel cancer services are subject to significant variation across the whole patient pathway from awareness of the signs and symptoms of bowel cancer, access to screening, and quality of care. This variation affects people from different population demographics and socioeconomic groups leading to inconsistent outcomes across the country and feeding into many existing narratives around healthcare inequalities. For example, people from deprived populations are almost half as likely to recognise a change in bowel habit as a potential symptom of bowel cancer.

Uptake of screening varies significantly according to several factors including socioeconomic status, ethnicity, gender, and age. Asian people are half as likely to take up screening compared to the rest of the population, with rates being particularly low amongst Muslims.[11] Uptake of screening is also lower amongst men, at 55% compared to 60% for women, whilst a large prospective study found that women with disabilities are

25% less likely to participate in bowel screening.[12] Bowel Screening Wales commissioned Learning Disability Wales to review accessibility within the bowel screening programme for people with learning disabilities and have accepted their recommendations. We welcome this move by Bowel Screening Wales as it is a clear indication of the focus on widening accessibility of the screening programme.

Patient information

Clear and accessible information for people concerned about bowel cancer symptoms or going through the bowel cancer diagnostic pathway is crucial.

Bowel Cancer UK provides a number of resources for patients and clinicians. The following are examples of the information available to people with concerns about bowel cancer or who are going through the diagnostic pathway:

https://www.bowelcanceruk.org.uk/about-bowel-cancer/our-publications/

https://www.bowelcanceruk.org.uk/about-bowel-cancer/symptoms/

https://www.bowelcanceruk.org.uk/about-bowel-cancer/diagnosis/

https://www.bowelcanceruk.org.uk/about-bowel-cancer/screening/

https://www.bowelcanceruk.org.uk/news-and-blogs/coronavirus-faqs/

Patient awareness of potential signs and symptoms of bowel cancer and timely presentation is a key driver of variation in outcomes. A recent survey, conducted by YouGov on behalf of Bowel Cancer UK, indicated that 45% of people in the UK are not aware of a single symptom of bowel cancer.[13]

Levels of awareness have a strong association with socioeconomic status as people from more deprived populations are less likely to recognise signs and symptoms of cancer than those in the least deprived.

Patient information aimed at increasing informed uptake across all demographics would improve the effectiveness of the screening programme, for example. To increase informed uptake, interventions must be targeted at groups where uptake is particularly

low such as ethnic minorities, people from low socioeconomic groups and disabled people whilst there is also a need to address the perceived stigma around bowel health.

Wider issues affecting uptake include concerns around the cleanliness of the test, misconceptions that the test is not applicable if people don't have any apparent symptoms, and fear and denial around the outcome. Measures that have been shown to be effective at increasing uptake are often based in primary care through the provision of a GP endorsement letter combined with face-to-face health promotion.

In the symptomatic pathway, work should be undertaken to ensure patients are clearly informed about the reason(s) for their referral and what to expect in the diagnostic pathway, including estimated timelines that reflect the Optimum Pathway.

Conclusion

The work of the NEP, Bowel Screening Wales and staff throughout the NHS, from GPs to SSPs, endoscopists to gastroenterologists, we have seen big strides within the bowel cancer diagnostic pathway.

There are still major concerns regarding the length of time people are waiting for their diagnosis of bowel cancer and this must be addressed through investment in recruitment, training, workforce planning and equipment.

Wales has set in place many foundations on which a sustainable endoscopy service can be built but it will require further focus and support from the Welsh Government to achieve such an outcome.

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