Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy'n aros am ddiagnosis neu driniaeth

This response was submitted to the Health and Social Care Committee consultation on the impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

WT 30

Ymateb gan: | Response from: Bowel Cancer UK

Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

Bowel Cancer UK

Background

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. Nearly everyone survives bowel cancer if diagnosed at the earliest stage.[1] However this drops significantly as the disease develops. We recognise COVID has put the NHS under tremendous strain but we are also aware that many of today's problems existed before the pandemic.

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).

Monthly cancer waiting time figures for Wales cover the period up to and including October 2021. Wales moved to a Single Cancer Pathway (SCP) approach in 2020 and a 75% standard was introduced at the end of that year. The SCP is a Welsh Government target for diagnosing cancer and starting treatment more quickly. It also indicates where information and support should be provided across the pathway.

The extent of the delays to accessing diagnostic tests, such as colonoscopy, varies across the nation with figures for October 2021 showing less than half of lower GI (including bowel cancer) patients were seen within this time. Only 43.6% of patients began treatment within 62 days in October's data.[2] This is a significant way short of where performance against the target should lie and is one of the lowest figures since the target was set in December 2020.

COVID impact

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. As a result of these changes to practice the number of patients on endoscopy waiting lists increased by 9,100 (73%) to 21,500 by May 2021.[3]

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.

Despite efforts to restore cancer diagnostic and treatment services, a substantial backlog of patient demand has built up following continued disruption to NHS services throughout the pandemic. Health Boards have faced several ongoing challenges which have continued to limit capacity due to changes in PPE, enhanced room cleaning, meeting social distancing requirements and the need for good ventilation systems.

The full impact of the pandemic on bowel cancer outcomes is yet to be realised but we anticipate that, without investment, five-year bowel cancer survival rates could reduce to a level not seen since 2010. There is a hidden backlog of patients who are waiting to come forward which could increase pressure on bowel cancer diagnostic services.

Signs of recovery

Cancer waiting times data suggests that referrals for suspicion of lower GI cancers has increased in recent months (July 2021 to October 2021) to pre-pandemic levels of approximately 2,500 referrals each month. However, the data shows little change in the number of people being diagnosed with lower GI cancers each month.

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, to six weeks.

This recovery was driven by a large increase in invitations to the programme and the successful efforts has allowed Bowel Screening Wales to progress with planned optimisation of the programme. At the end of October 2021, the age criteria for eligibility was widened by including 58 and 59 year olds, where previously invitations would be

sent out to those aged 60-74 only.[4]

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.

These changes would bring the bowel screening programme in Wales in line with the eligibility and sensitivity criteria seen in Scotland. The UKNSC recommends further reductions in the sensitivity of the FIT test with a reduction to 20µg/g. No nation of the UK has set out plans to reach this recommended level to date.

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 indicated that 42% of UK adults are not aware of a single symptom of bowel cancer, with 30% of adults suggesting that they would wait until their symptoms worsened before speaking to a doctor.

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.

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 clinical nurse specialists, endoscopists and pathologists 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 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. 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.

Innovation

More positively, 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.

Colon Capsule Endoscopy which 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.[5]

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.

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.[6] 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.[7]

Conclusion

While COVID undoubtedly had an impact on urgent referrals and bowel screening, the available data shows pressure on diagnostic capacity was already causing delays for patients. COVID can be said to have made a bad situation worse.

In order to prevent more bowel cancers from developing and, ultimately, reduce bowel cancer incidence in the UK there must be a serious effort to optimise the bowel cancer screening programme so that the UK can have a world-class and world-leading programme. Addressing the longstanding capacity issue within the screening programme will deliver lasting benefits and improvements to bowel cancer outcomes.

If the waiting times target in Wales is to be met for bowel cancer, we need to remove the bottleneck that exists within the diagnostic pathway. Investing in staff and kit will take the pressure off hard-working NHS staff, improve services for those diagnosed with bowel cancer and ultimately save lives.

References

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3https://www.cancerresearchuk.org/sites/default/files/covid_and_cancer_key_stats_august_2021.pdf

4 https://phw.nhs.wales/news/bowel-screening-wales-invites-people-aged-58-and-59-for-screening-for-the-first-time/

5 https://clincancerres.aacrjournals.org/content/27/12/3422

6https://www.macmillan.org.uk/documents/getinvolved/campaigns/appg/britainagainstcancer2009/cancerinequalitiesreport.pdf

7 https://bmccancer.biomedcentral.com/articles/10.1186/s12885-018-4786-7