



Improving Bowel Cancer Outcomes:

A roadmap for change



Bowel Cancer UK

Beating bowel cancer together

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Executive Summary

Bowel cancer remains the second biggest cancer killer in the UK, despite being treatable and curable especially if diagnosed at an early stage.¹ More than 42,500 people are diagnosed with the condition and around 16,500 people lose their lives to the disease each year, accounting for 10% of all annual cancer deaths.² But this should not still be the case. More than 9 in 10 people survive their bowel cancer diagnosis for five years, if diagnosed at the earliest stage (stage 1). However, this decreases significantly to around 1 in 10 if patients are diagnosed at stage 4.

In the past 40 years, as a result of national cancer control plans with a focus on early diagnosis and advances in, and adoption of, life-saving cancer research, bowel cancer survival has more than doubled.³ Despite these significant improvements, the UK still lags behind comparable countries with similar healthcare systems, levels of wealth and comparable data.⁴ A study on cancer survival in high-income countries found that five-year survival for bowel cancer was the lowest in the UK at around 60%, which is approximately where Australia was 15 years ago.⁵ While the UK is making progress in improving survival, other countries have also been doing the same with five-year survival in Australia reaching 70.8% for the equivalent time period.⁶

The biggest reason for this is because the UK is poorer at diagnosing bowel cancers at an early, more treatable stage than the best performing countries. In 2018, only 39.6% of bowel cancers were diagnosed at stage 1 and stage 2 in England, with 25.3% of bowel cancer cases diagnosed at stage 4.⁷ Given the association between delayed diagnosis and poorer prognosis, improvements in this area are integral to increasing overall bowel cancer survival.

This was the reality of bowel cancer before COVID-19 but the pandemic has had a profound impact on healthcare services and will continue to be felt for months and perhaps years to come. Whilst the full effect of the pandemic on bowel cancer outcomes is yet to be realised, we anticipate that COVID-19 may have hampered progress further and are concerned that, without investment, bowel cancer survival may return to a level not seen since 2010.⁸

If this is to be avoided, several key challenges facing bowel cancer services will need to be urgently addressed. This report sets out the challenges and priorities for the short, medium and long-term so more people can survive their bowel cancer diagnosis in the future. We hope it will act as a call to action for policymakers in the NHS and Parliamentarians to work together with us to identify and implement the solutions that bowel cancer patients need now.

Recommendations

Bowel cancer patients and services across all four nations of the UK face many of the same issues and challenges. Some of our recommendations below focus on the NHS in England, aligned to the goals set out in the NHS Long Term Plan. However, as health is a devolved matter, we would like to see similar commitments and work undertaken in Scotland, Wales and Northern Ireland.

1. Governments across the UK must provide sufficient funding to health education bodies to grow the cancer workforce in order to meet rising demand. In England, additional funding must be provided to increase the cancer workforce by at least 45% to deliver world-class cancer services by 2029 and meet the ambitions set in the Long Term Plan.
2. NHS England should develop a detailed plan that sets out the steps that will need to be taken to meet the goal of diagnosing 75% of bowel cancers at stage 1 or 2 by 2028.
3. The Government must provide sufficient funding required to fully implement the recommendations from Sir Mike Richards' 2020 review of diagnostic services, to rebuild and expand endoscopy facilities to meet patient demand, including proposed new models.
4. Across all four nations, NHS leaders must continue to monitor the recovery of bowel cancer services, and implement interventions to limit the impact of COVID-19 where possible by encouraging people to seek help and by increasing capacity in diagnostic and treatment services to manage patient demand.
5. The Department of Health and Social Care should work to ensure that addressing the variation associated with bowel cancer care and outcomes is incorporated as part of the wider cross-Government focus on tackling health inequalities through the 'levelling up' agenda.
6. NHS England should scale-up and roll out effective innovations in a timely and appropriate manner to increase capacity and improve patient experience whilst also ensuring that the appropriate infrastructure is in place to continually monitor their effectiveness and impact on health inequalities.
7. Governments should work with NHS leaders to develop a detailed plan to fully implement the UK National Screening Committee recommendation for bowel cancer screening in a timely manner, and scope out the necessary infrastructure required to support the future of risk stratification.
8. NHS England should monitor the implementation of Lynch syndrome testing and surveillance pathways to ensure that people with the genetic risk factor receive the appropriate risk management.



Short-term priorities

To ensure that the short-term disruption caused by the pandemic does not have a lasting impact on bowel cancer outcomes and survival, immediate action is required to clear the growing backlog by expanding capacity in diagnostic and treatment services. This should also be accompanied by public awareness campaigns on the signs and symptoms of bowel cancer and clear communication that the NHS is safe and open to receive patients.

Continued restoration and recovery of bowel cancer services after COVID-19

The COVID-19 pandemic has had a significant impact on bowel cancer services, placing further pressure on a system that was already under strain. Although this is the case for a number of conditions and other cancers, there is reason to believe that bowel cancer has been disproportionately affected by the disruption, especially diagnostic services. Between April 2020 and March 2021, 2,800 (9%) fewer patients started treatment for bowel cancer compared to pre-pandemic times.⁹ This is a result of the pause of the bowel cancer screening programme, a significant drop in urgent suspected cancer referrals and the removal of endoscopy tests, unless in an emergency, at the beginning of the COVID-19 pandemic. The impact of this was seen in the 6% increase in the number of patients diagnosed in emergency settings where patients are much more likely to present with more advanced disease.¹⁰

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 to just 5% of normal activity.¹¹ 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.

2,800 (9%) fewer patients started treatment for bowel cancer compared to pre-pandemic times.⁹

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. Trusts 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.

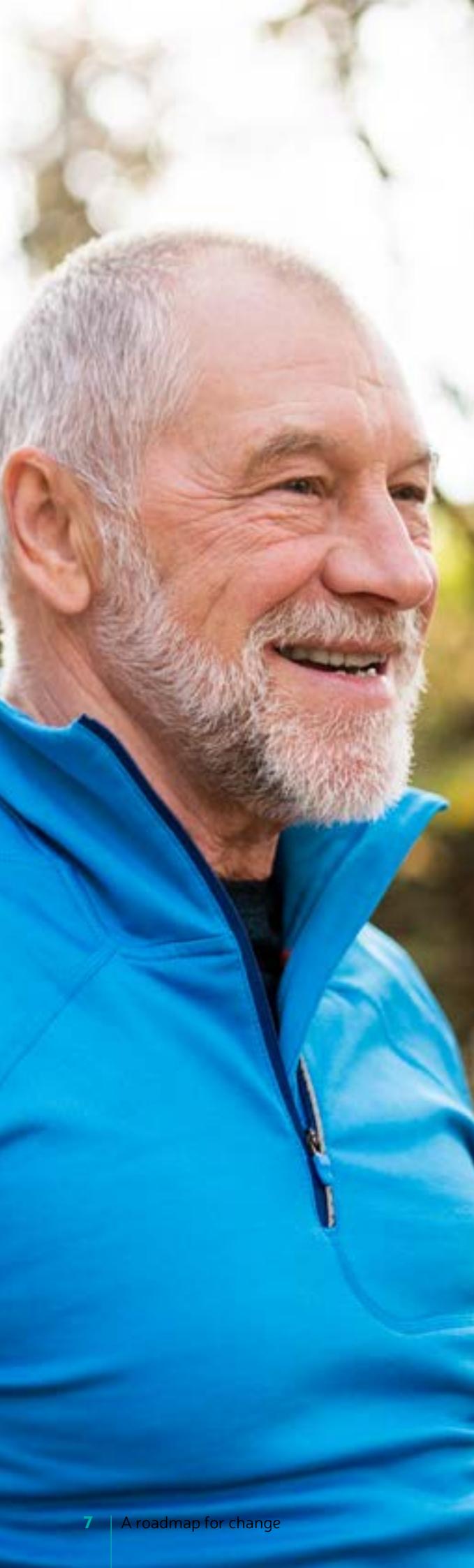
The full impact of the pandemic on bowel cancer outcomes is yet to be realised but we anticipate that, without investment, five-year bowel cancer survival rates could reduce to a level not seen since 2010.¹² There is a hidden backlog of patients who are waiting to come

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I originally contacted my GP in April 2020 during the first COVID-19 lockdown. I had blood (a very small amount) when I went to the toilet. I had a telephone consultation with the GP and was told that it was probably piles and not to worry. So I didn't! I lost both my parents in 2020, so had other things on my mind. The problem continued and got worse. I tried to get a GP appointment on numerous occasions and finally got a video appointment with 'Push Doctor' in July of this year. Luckily she took my concerns seriously and emailed my GP for a physical examination, stool sample and blood test. I was diagnosed with advanced localised rectal cancer and I'm currently waiting for chemo to start. I think she probably saved my life!

Janette

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forward which could take the overall waiting list across all therapy areas to 13 million, well beyond the current figure of 5.5 million.¹³ Any delays to diagnosis, treatment and management greatly reduce individual prognosis and create an additional burden on the health system.¹⁴

This hidden backlog undoubtedly will include many bowel cancer patients as there were 4,600 fewer bowel cancers diagnosed between April and December 2020 compared to the previous year.¹⁵ NHS staff have worked hard

4,600 fewer bowel cancers diagnosed between April and December 2020 compared to the previous year.¹⁵

to get services back up and running, whilst simultaneously managing the ongoing demands of COVID-19. However, much of this recovery is based on the ambition of returning to pre-pandemic levels of activity which will not be sufficient to address the backlog in cancer care, meet rising patient demand or transform bowel cancer outcomes.

The unique impact of the pandemic was in part recognised by the development of the Cancer Services Recovery Plan, published by NHS England in December 2020. This plan set out the importance of the resumption of bowel cancer screening, increasing endoscopy capacity through the roll out of triage tools, and expanding the endoscopy workforce by decommissioning Bowel Scope screening.¹⁶ However, the plan came to an end in April 2021 as it was only developed to cover the 2020/21 financial year.

It is crucial that there is a continued emphasis on increasing capacity in diagnostic and treatment services to help address the bowel cancer backlog and limit the long-term impact of the pandemic on bowel cancer outcomes. During future peaks of COVID-19, and periods of increased demand due to annual winter pressures, there must be limited redeployment of staff in key cancer services. This includes support staff who are integral to the running of services. The recovery of cancer services should be regularly monitored through cancer waiting times data and the number of cases diagnosed in comparison to pre-pandemic levels.

Harnessing innovation to improve bowel cancer services

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.

Many trusts have implemented more streamlined triage processes through e-referral systems, increased coordination with primary care and GPs, and merged waiting lists with other trusts to maximise capacity across regions.¹⁷ NHS England have also begun piloting 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

Many trusts have implemented more **streamlined triage processes** through e-referral systems, increased coordination with **primary care and GPs**, and **merged waiting lists with other trusts** to maximise capacity across regions.

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.¹⁸

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.

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I believe that Colon Capsule Endoscopy (CCE) can change the incidence of colorectal cancer in the United Kingdom. If CCE can be accessed equitably, conveniently, and accessibly it will be much easier for people to seek diagnostic help for new bowel symptoms. Furthermore, ubiquitous faecal immunochemical testing (FIT), coupled with CCE services that are run in local GP practices, community centres, pharmacies, or even done at home, will remove many of the barriers to diagnosing this curable condition.

Newer, smarter, colon capsules with artificial intelligence reporting capabilities are on the immediate horizon, which will make this highly patient-acceptable diagnostic test, even better. CCE will also have an environmental impact by reducing disposable waste and carbon miles travelled by patients. This is the mission and vision of NHS Scotland's ScotCap service, which is the first national health service in the world to make CCE available throughout its territory.

Professor Angus J M Watson, Consultant Colorectal Surgeon, NHS Highland

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Medium-term priorities

Simply returning to pre-pandemic outcomes for bowel cancer is not good enough and a concerted effort to transform services and survival is now needed. In order to reach the ambition set by the Government to have 75% of all cancers diagnosed at an early stage by 2028, it will be imperative to address the barriers which prevent earlier diagnosis. The initiatives in the Long-Term Plan (LTP) that related to bowel cancer, such as lowering the screening age to 50, are a good starting point, however it is highly unlikely that just implementing the initiatives in the LTP alone will deliver the stage shift required to meet the early diagnosis ambition by 2028.

There is no silver bullet to improving bowel cancer survival and outcomes, so action is needed on all fronts including increasing timely presentation to primary care, better adherence to cancer referral guidelines, and optimisation of screening and quicker translation of research into clinical practice. There will need to be significant and concerted action over the remaining seven years of the LTP, including going further than the current initiatives within the plan, to reach this ambition and match the bowel cancer outcomes of the best countries internationally.

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

Increasing diagnostic capacity to improve earlier diagnosis

The single-most important factor in improving bowel cancer outcomes relates to the stage at which patients are diagnosed. When caught at its earliest stage, 98% of bowel cancer patients will survive for one year or more, compared to 44% at the latest stage. Five-year net survival for patients diagnosed at stage 1 is over 90%, compared to just 10% at stage 4.¹⁹ These figures show when diagnosed early, bowel cancer is treatable and curable.

When caught at its earliest stage, **98% of bowel cancer patients will survive** for one year or more, compared to 44% at the latest stage.

In recent years, there has been a significant increase in demand across diagnostic services for bowel cancer tests due to a growing ageing population and the drive for earlier cancer diagnosis including the introduction and expansion of the national bowel cancer screening programme and a lower referral threshold for investigative cancer tests. Gastroenterology has developed

In 2018, a workforce census carried out by the Royal College of Pathologists indicated that only **3% of histopathology departments** have sufficient staff capacity.

and expanded at a greater rate than any other acute major medical specialty over the past 30 years.²⁰ However, even before the pandemic, chronic workforce and equipment shortages continued to limit diagnostic capacity to transform bowel cancer outcomes.

Like many other specialties, gastroenterology suffers from recruitment problems and in 2018 43% of advertised posts were unfilled.²¹ Similarly in 2018, a workforce census carried out by the Royal College of Pathologists indicated that only 3% of histopathology departments have sufficient staff capacity.²² These long-standing workforce shortages are also likely to have been exacerbated by the pandemic. For example, the pandemic has contributed to a significant loss of training opportunities for many gastroenterologists with 53% now unlikely to meet their annual progression targets.²³ Combined with the growing workforce burnout and low staff morale, the quality of patient care inevitably suffers. There is an urgent need for investment in this area, particularly in light of Health Education England's estimate that 45% aggregate workforce growth will be required to deliver world class cancer services by 2029.

These shortages also extend to the equipment and facilities for endoscopy services. The recent Getting It Right First Time (GIRFT) report for gastroenterology concluded that there is an urgent need to review and expand endoscopy capacity by revisiting working models for managing demand, establishing different emergency and elective waiting lists, and adjusting departmental resources.²⁴ A particular issue relates to the increasing number of endoscopy units that are struggling to achieve or retain Joint Advisory Group (JAG) accreditation on Gastrointestinal Endoscopy due to long waiting times. Of the 178 endoscopy units assessed, 74 units (41%) did not receive JAG accreditation which reduces their access to financial incentives under the scheme.²⁵ In other findings, around 20 trusts will require a full redevelopment of their endoscopy services, whilst it is estimated that 200 new endoscopy rooms will be needed to meet future demand.²⁶

Health Education England's estimate that **45% aggregate workforce growth will be required to deliver **world class cancer services** by 2029**

In April 2020, I'd noticed I was going to the loo more often. We'd just returned from six weeks in Australia so I assumed that my body was just adjusting, but then I discovered blood. It wasn't every time or even every day, so I wanted to be sure before I went to the doctors and with the pandemic in full swing, I wasn't even sure about going. In August, I went to my GP surgery. I answered 'no' to the questions the doctor asked but they referred me anyway. The consultant did a small examination – he wasn't worried but referred me for a fuller examination. A week later I received a letter, I had an ulcer in my colon and needed further tests which found a tumour on the left side of my colon. We learned that it was cancerous, but they caught it early so assured me that they were going to remove it. After surgery I was told I didn't require any further treatment. I wasn't expecting that as I'd never heard of anyone not having some kind of treatment. I'm thankful that my experience was so positive and have total faith that the NHS will look after me again. I want to make sure that more people have the same experience that I've had and that more cases are found early enough.

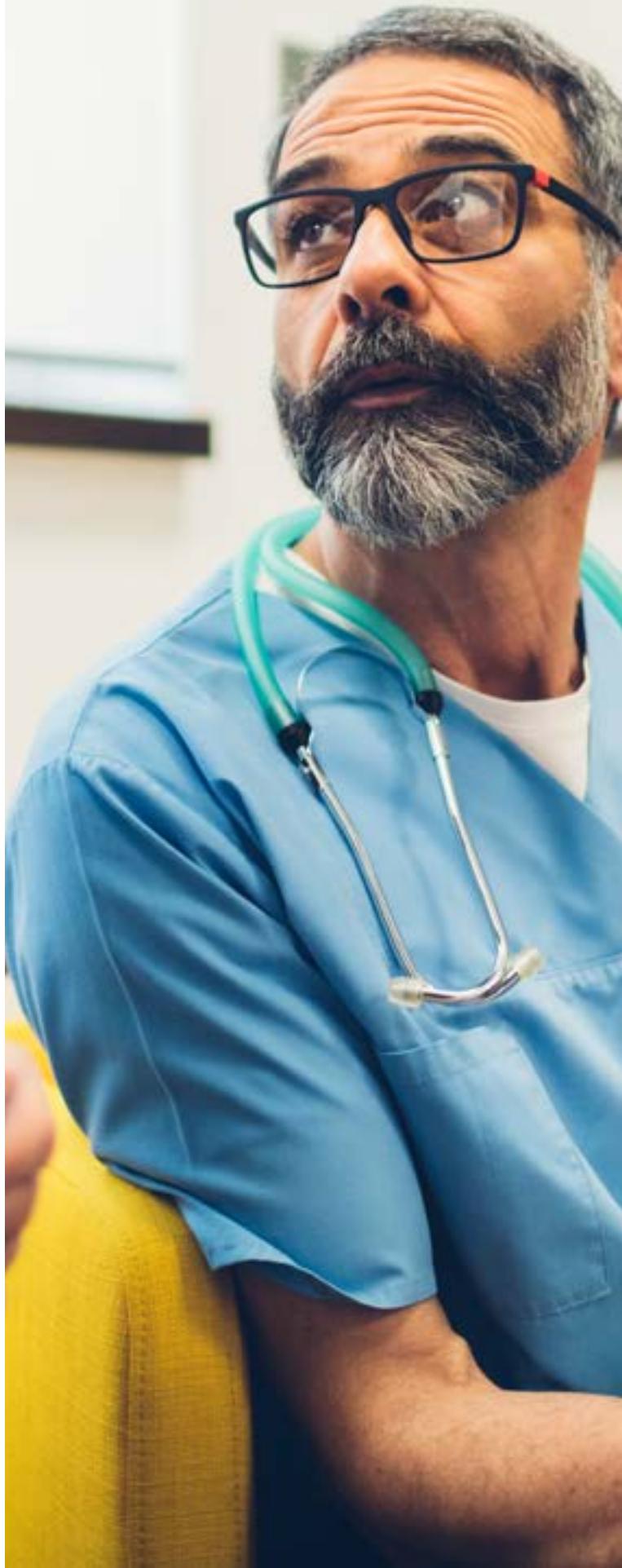
Sacha

Reducing inequalities and unwarranted regional 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.

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.²⁷

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.²⁷ 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.





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.²⁸

Uptake of screening varies significantly according to several factors including socioeconomic status, ethnicity, gender, and age. In Scotland, the offer of bowel screening is taken by just 52% of the most deprived groups in the population, compared to 73% for the least deprived.²⁹ Asian people are half as likely to take up screening compared to the rest of the population, with rates being particularly low amongst Muslims.^{30,31} 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.³²

The quality and standard of care delivered for bowel cancer patients also varies significantly across the country. For example, waiting times for gastroenterology clinics can

range from one to 27 weeks. There is also variation in terms of how capacity is used across the system. This is particularly relevant to the field of endoscopy and the number of procedures that are carried out. Generally, with more rooms, trusts can perform more gastrointestinal endoscopies. However, the number of annual endoscopies carried out by trusts with ten rooms ranges from 10,000 to 30,000 and, in a particularly stark example, one trust with five rooms is carrying out more gastrointestinal endoscopies than another trust with 12 rooms.³³ This initial variation in terms of capacity has knock-on implications for waiting times, timely diagnosis and swift access to curative treatment.

Both of these factors clearly have an impact on overall outcomes as people living in more deprived areas generally have a lower chance of surviving bowel cancer. This is particularly stark in Wales, where there is a deprivation gap in survival of almost nine percentage points, wider than across breast, lung and prostate cancers.³⁴

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 long-standing capacity issue within the screening programme will deliver lasting benefits and improvements to bowel cancer outcomes.

Asian people are half as likely to take up screening compared to the rest of the population, with rates being particularly low amongst Muslims.^{30,31}

Long-term priorities

Optimisation of the bowel cancer screening programme

The optimisation of the national bowel cancer screening programme provides one of the main opportunities to improve bowel cancer outcomes and prevent some cancers from developing. Indeed, 90% of patients diagnosed via the national screening programme are likely to be cured, compared to 70% for a GP referral and 50% for emergency settings. However, there are several issues with the screening programme which is resulting in the fact that only 10% of bowel cancer cases are detected via the screening programme, and twice as many patients are still being diagnosed in emergency settings.³⁵

The UK National Screening Committee (UKNSC) recommends that Faecal Immunochemical Testing (FIT) screening is offered every two years to men and women aged 50-74 and tested at a threshold of 20ug/g. However, none of the UK nations have been able to fully implement this recommendation due to shortages in the endoscopy and pathology workforce. Whilst the age extension from 60 to 50 has already begun, it will take until at least 2025 to be fully implemented across England because it has not been accompanied by the appropriate expansion of endoscopy and pathology capacity.

There have also been shortfalls in the sensitivity of FIT, which is recommended to be tested at a threshold of 20ug/g. Long-standing shortages in endoscopy have meant that FIT screening for bowel cancer had to be introduced in 2019 in England at 120ug/g, a less sensitive level than in Scotland at 80ug/g. However, no nation to date has made the commitment to increase the sensitivity of FIT screening.

Even if no action were taken to lower the screening age or raise the sensitivity of the test, increasing informed uptake across all demographics would improve the effectiveness of the screening programme. 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.³⁶

Looking to the future, an optimised screening programme should encompass a risk-stratified approach.³⁷ Risk stratification would allow the programme to determine an individual's likelihood of developing bowel cancer based on their age, sex, ethnicity, lifestyle behaviours and previous screening result. People deemed at higher risk can then be screened more frequently, and those at lower risk can be screened less, making better use of NHS resources and money. Further research is required to define what an optimised risk stratified approach for bowel cancer screening will look like, and the FIT values within the current bowel cancer screening should be used to help inform this research. Any future changes to the bowel cancer screening programme must be accompanied by the appropriate expansion in the relevant workforce.

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I had stomach pains off and on for about a year but I'd had a few very stressful years with my mother and daughter both being ill, then my mother's death and daughter having a breakdown so I assumed my stomach pains were down to stress. Around the start of 2021, I became very tired and was out of breath after walking a short distance so I went to my GP. They ordered blood tests which found that I had severe anaemia, so I was referred for a lot of tests and eventually had a colonoscopy where the cancer was discovered - it was stage 2 bowel cancer. I was told surgery was my only option and offered 6 months of mop up chemotherapy. My Oncologist said it was up to me whether or not to have the chemo as it may only offer a 5% increase of future recurrence but I decided to go ahead with this. I had not recognised any symptoms of this being cancer due to my stressful situation and I thought, incorrectly, that blood would have shown but none was visible. I wish the screening test age would be lowered as it may have picked up my cancer before I'd gone to my GP.

Julie

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Implementation of universal Lynch syndrome pathway

A key part of optimising the screening programme for bowel cancer hinges on the implementation of a universal Lynch syndrome pathway to ensure people at high risk of developing bowel cancer can be offered routine high-quality surveillance screening. There are 170,000 people in the UK living with Lynch syndrome, an inherited condition resulting from genetic mutations. It causes 1,200 bowel cancers each year and patients living with the syndrome can have up to an 80% higher lifetime risk of developing the disease. Existing National Institute for Health and Care Excellence (NICE) guidance recommends that anyone diagnosed with bowel cancer should be tested for the presence of Lynch syndrome along with cascade testing of their first- or second-degree family members to identify all people with the syndrome.³⁸

Whilst there is no cure, testing is crucial to ensure that people with Lynch syndrome and their families receive appropriate risk management. If all people with colorectal cancer and their family members were tested for the condition and enrolled into appropriate surveillance pathways in 2028, it could result in a 0.9%-point increase improvement in the proportion of cancers diagnosed early.³⁹ At an individual level, research has shown that regular colonoscopy can reduce the risk of dying from colorectal cancer by as much as 72%. This early diagnosis can provide the platform for a variety of other interventions such as taking aspirin, encouraging lifestyle changes, and directing patients to surveillance pathways to support early detection.

Despite this clinical significance and subsequent guidance, only around 5% of people living in the UK are made aware that they carry the gene. Testing for Lynch syndrome is afflicted by significant regional variation and different funding arrangements. In 2018, only 6% of 204 Clinical Commissioning Groups (CCGs) commissioned their local hospitals to carry out the testing in line with NICE guidance, and evidence from molecular testing laboratories indicates that fewer than 20% of people with bowel cancer are tested.⁴⁰

If all people with colorectal cancer and their family members were tested for the condition and enrolled into appropriate surveillance pathways in 2028, it could result in a **0.9%-point increase improvement** in the proportion of cancers diagnosed early.³⁹

For the implementation of a universal Lynch syndrome pathway across the UK to be successful, it must be supported by adequate capacity in endoscopy and genetic services. This implementation should reflect the recommendation in the 2019 review of Adult Screening Programmes to expand existing programmes to include targeted testing for people with genetic mutations, such as Lynch syndrome.⁴¹

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In August 2018 I started to notice blood in my poo my doctor reassured me it was highly unlikely to be bowel cancer at such a young age despite my dad dying from the disease in 2001 at 53. By October, I was experiencing abdominal pain most evenings, feeling bloating, tired, and I lost a lot of weight. I went back to my doctor who again reassured me it was unlikely cancer but referred me for my own peace of mind. I waited thirteen weeks for my colonoscopy, during this time I continued to go to the doctors as my symptoms were getting worse and I was feeling extremely worried, anxious and upset. My worst fears were confirmed when a 3.5cm tumour was identified. I'll never forget the nurse stroking my hair with tears in her eyes whilst I sobbed and spoke about my son's birthday party happening a week later. After surgery I was told I had stage 1 bowel cancer and that no further treatment was required! As there is a history of bowel cancer in my family (my mum was also diagnosed with the disease in November 2018), my colorectal nurse referred me to the genetics counselling team who were able to confirm that my tumour was caused by Lynch syndrome. Although it means I'm at a higher risk of developing certain cancers and there is a 50% chance my son will have the gene, I feel fortunate to be aware of this. It means myself and other family members can be closely monitored through regular colonoscopies. If I choose to, I can have a hysterectomy in the future to reduce my risk of developing ovarian cancer.

Helen

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Glossary of terms

Bowel cancer screening Programme

The screening programme invites those eligible to take an at-home Faecal Immunochemical Test every two years to check for potential signs of bowel cancer.

Colon Capsule Endoscopy

Variation of the endoscopy procedure that uses a camera attached to the long thin tube to look inside the colon and rectum.

Endoscopy

A procedure which involves using a long, thin, flexible tube to investigate organs inside the body and help perform certain types of surgery.

Faecal immunochemical test (FIT)

Test which looks for hidden blood contained in a stool from the lower intestines and provides one of the most reliable indicators of susceptibility to colorectal cancer.

Gastroenterology

Medical speciality focused on benign and malignant disorders in the digestive system including the liver, pancreas and gallbladder.

Histopathology

Diagnoses and study of diseases of the tissues, a key part in the diagnostic process for cancer through examining the tissue removed from suspicious growths.

Joint Advisory Group on Gastrointestinal Endoscopy

Established in 1994 in response to the expanding multidisciplinary nature of endoscopy, the JAG provides endoscopy training, accreditation of endoscopy services and screening endoscopists.

Lynch syndrome

A genetic condition that can increase the lifetime risk of bowel cancer by up to 80% and can increase the risk of some other cancers including womb and ovarian.

UK National Screening Committee

National body that advises ministers and the NHS in the four UK countries about all aspects of population screening and supports implementation of screening programmes.

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Bowel Cancer UK is the UK's leading bowel cancer charity. We're determined to save lives and improve the quality of life of everyone affected by the disease.

We support and fund targeted research, provide expert information and support to patients and their families, educate the public and professionals about bowel cancer and campaign for early diagnosis and access to best treatment and care.

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This report has been funded by Johnson and Johnson Medical Devices Companies and Olympus, who had no editorial control over its content.

Registered Charity Number 1071038 (England and Wales) and SC040914 (Scotland)