

Bowel Cancer UK's submission to the Department of Health and Social Care's Call for Evidence to inform the new national Cancer Plan for England

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

Our response to the Call for Evidence has been informed by our patient community, leading clinical experts and the wider evidence base.

Prevention and awareness

Which cancer risk factors should the government and the NHS focus on to improve prevention? (Select the 3 most important risk factors)

- Alcohol
- Obesity
- Other Diet (eating processed meat and consuming too little fibre)

Bowel cancer is the fourth most common cancer in England, with nearly 36,500 new cases each year but the second biggest cancer killer, with over 13,600 annuallyⁱ. 54% of bowel cancer cases are preventable and action must be taken to address the most significant risk factors to drive a reduction in the incidence of bowel cancer.

Diet is key to tackling the preventative causes of bowel cancer as it is a major factor influencing risk. The two highest risk factors both sit under this category. According to Cancer Research UK, 28% of bowel cancer cases are caused by eating too little fibre and 13% are caused by eating too much processed meatⁱⁱ. It is important to increase understanding of these risk factors and for them to not be absorbed into broader obesity risk activity.

 Introduce and invest evidence based, population interventions to create healthier food environments either in the Cancer Plan or elsewhere by broader activity taken in the 10 Year Health Plan and/or Obesity Strategy

The next most significant risk factor for bowel cancer is the 11% caused by being overweight or obeseⁱⁱⁱ. Given obesity increases the risk of many types of cancer, as well as other non-cancer health conditions, it is vital action is taken to tackle this. Other relevant risk factors for bowel cancer are the 7% caused by smoking; the 6% caused by alcohol; and the 5% caused by too little physical activity^{iv}.



2. Introduce measures to address the risk factors of being overweight or obese, smoking and alcohol either in the Cancer Plan or elsewhere by broader activity taken in the 10 Year Health Plan and/or Obesity Strategy.

While the question focuses on specific risk factors, the Bowel Cancer Screening Programme (BCSP) and cascade testing for Lynch syndrome both play a role in the secondary prevention of bowel cancer. With a key theme of the 10 Year Health Plan on shifting from sickness to prevention, interventions that support this focus should be acknowledged and addressed in the Cancer Plan.

- 3. It is essential that further investment is given to the BCSP to enable a reduction in the sensitivity threshold and tackle the workforce capacity issues that are currently an issue. Additionally, cascade testing should be offered to family members of those with Lynch syndrome. More information on this is provided in the early diagnosis section.
- 4. Take additional action to promote the use of low-dose aspirin as a chemopreventative agent for bowel cancer with individuals with Lynch syndrome.

Early diagnosis

What actions should the government and the NHS take to help diagnose cancer at an earlier stage? (Select the 3 actions that would have the most impact)

- Support timely and effective referrals from primary care (for example, GPs)
- Make improvements to existing cancer screening programmes, including increasing uptake
- Increase diagnostic test access and capacity

Early diagnosis of bowel cancer is critical to improving outcomes. Nine in ten (91%) will survive for five years or more if diagnosed at stage 1, compared to one in ten (11%) diagnosed at stage 4^v . Yet only 40% of patients are diagnosed at stages 1 or 2, falling far short of the 75% ambition^{vi}.

The Cancer Plan should include the following measures:

1. Faecal Immunochemical Test (FIT) screening to be offered every two years to everyone aged 50-74, at an increased sensitivity threshold. There should be a full expansion of the threshold of 80ug/g across England, followed by a further increase of the sensitivity threshold in future years, potentially to 20ug/g. A clear timetable of roll out must be included in the Cancer Plan. Screening is one of the best ways to detect the disease at an early stage and in some cases prevent it from developing, yet only around 1 in 10 bowel cancer cases are detected via screening. Steps to increase



informed uptake to at least 75% across all demographics must be taken to improve the effectiveness of the programme.

- 2. Address diagnostic capacity and workforce shortages by: building 200 endoscopy rooms across England; increasing the size of the endoscopy and pathology workforces; commissioning work to understand how the current diagnostic workforce and pathways can be utilised more efficiently whilst additional capacity is being trained up; investing in services such as the Digital Diagnostic Capability; investing in a 'Fit for the Future' fund to double the number of CT and MRI scanners, alongside funding new equipment to modernise diagnostic tools; and undertaking granular modelling of the cancer workforce. Alongside this activity, there should be forward look on the potential of new research, such as the AI-driven blood test, miONCO-Dx that, that may significantly shape the diagnostic process and how patients are triaged.
- 3. Maintain recent progress in testing newly diagnosed bowel cancer patients for Lynch syndrome when testing is transferred from NHSE to Integrated Care Boards (ICBs) in April 2025.
- 4. Ensure cascade testing is offered to family members of those with Lynch syndrome. Regular surveillance colonoscopy for those with Lynch syndrome can reduce the risk of dying from bowel cancer by as much as 72%^{vii}. Activity in this area would support the shift of moving from sickness to prevention.
- 5. In partnership with Bowel Cancer UK, conduct a root cause analysis to understand why around a fifth of bowel cancer patients are diagnosed as an emergency presentation-where outcomes are poor- and targeted interventions developed to mitigate this.
- 6. Explore how pharmacies and NHS111 can offer symptomatic FIT to those who present with potential symptoms of bowel cancer, in-line with the theme of the health service moving more care from hospitals to communities. Appropriate training, support and safety-netting must be carefully considered.
- 7. GPs should be provided with patients FIT screening results to reduce barriers to timely responses and to support appropriate referrals or safety netting.

Treatment

What actions should the government and the NHS take to improve access to cancer services and the quality of cancer treatment that patients receive? (Select the 3 actions that would have the most impact)

Increase treatment capacity (including workforce)



- Review and update treatment and management guidelines to improve pathways (processes of care) and efficiency
- Improve the flow and use of data to identify and address inconsistencies in care

Insufficient treatment capacity is a significant concern and, as well as delaying diagnosis, impacts on time to start treatment. Analysis by Cancer Research UK and NHS England found that 15% of patients waiting over 104 days to start cancer treatment in 2022/23 had bowel cancer^{viii}.

Addressing workforce shortages is key to improving treatment times by supporting the increase of treatment capacity. We believe the Plan, or workforce modelling taking place alongside it, should:

- Develop granular workforce modelling of the cancer pathway. Neither the NHS Long
 Term Plan nor the NHS Long Term Workforce Plan covered the demand and supply of
 individual medical specialties. Without this, specialist workforce planning at a national
 level cannot take place. In 2023, the Royal College of Radiologists found a 15% shortfall in
 Clinical Oncologists, this is estimated to rise to 25% by 2027ix.
- 2. Prioritise specialities with the greatest shortfall within future recruitment and allocation of medical training places. It is concerning that demand for clinical oncology places has been low with NHS England only filling 51% of training places in 2023*. Clinicians have told us of their concerns around capacity, training, and retention within the bowel cancer workforce. Capacity is being stretched across the pathway to address key backlogs in the system, this is taking its toll on staff as they become over worked and under trained, with little free time for personal development.
- 3. Consider the impact the Cancer Plan will have on the demand for treatment modalities and workforce across different cancer sites so the Government and NHS can guarantee the right investment in medical specialities. This must be matched by investment in kit and infrastructure to provide bowel cancer patients swift access to curative treatment. To ensure all patients receive the most appropriate treatment, it is vital that not only do treatment pathways reflect the latest evidence, but that these pathways are appropriately adhered to.

The stated theme in the 10 Year Health Plan Call for Evidence to shift from analogue to digital in the health service should be consistent with the need to maximise the flow and use of data to identify and address inconsistencies in care.

The NHS Federated Data Platform (FDP) is a welcome innovation to connect databases, assist decision-making, reduce costs, and enhance patient care. By increasing opportunities to track patients from referral to treatment and holding their data in one place, it is enabling clinical



professionals to access patient records regardless of where the patient was seen and facilitate faster and more informed decisions around diagnosis and treatment.

4. Investment into the FDP must continue, and be upscaled across the country, to better prioritise waiting lists, make more informed choices and improve capacity for NHS staff. As this develops, the Government must ensure transparent engagement with the public around public data use and sharing.

Living with and beyond cancer

What can the government and the NHS do to improve the support that people diagnosed with cancer, treated for cancer, and living with and beyond cancer receive? (Select the 3 actions that would have the most impact)

- Provide more comprehensive, integrated and personalised support after an individual receives a cancer diagnosis and (if applicable) after treatment
- Improve the emotional, mental health and practical support for patients, as well as their partners, family members, children and carers
- Increase the number and availability of cancer co-ordinators, clinical nurse specialists and other staff who support patients

Almost 260,000 people in England are living with, and beyond, bowel cancer and the support people require doesn't stop when treatment does^{xi}.

The Cancer Plan should:

1. Address the specific issue of delays in reversing patient's ileostomies. The target to reverse patient's ileostomies is not being met by providers, with 38% of patients waiting 18 months or longer. This both impacts on quality of life as well as potentially causing additional complications.

The support people receive during their treatment is key to their experience of care and the Cancer Plan must ensure measures are in place to address this, including:

- 2. Ensuring access to a Clinical Nurse Specialist (CNS) or other support worker. Barriers to training and recruitment has meant that the role of CNS' has become increasingly over-stretched, potentially limiting their ability to consistently address patient concerns. Also, not all bowel cancer patients benefit from access to a CNS with 8% of patients with colorectal cancer replying 'No' when asked in the 2023 Cancer Patient Experience Survey "Did you have a main contact person within the team looking after you, such as a CNS, who would support you through your treatment"xii.
- 3. Empowering patients with enough knowledge and information about their cancer. Only 56% of patient respondents to a survey we conducted felt that they received



enough information from the NHS to understand their illness and treatment^{xiii}. Finding innovative ways for patients to access health and wellbeing information is necessary to free up NHS resources.

4. Adopting measures that enable patients to have more autonomy over their care. Online resources, such as the NHS App, should be able to show test results including FIT outcomes, as well as providing online access to hospital and GP information. 56% of respondents to a survey Bowel Cancer UK conducted said that they had used digital services during their care, however, when asked if they would like to use more digital services this figure increased to 86%xiv. With increasing levels of support for digital first care, there is huge opportunity to tap into areas of innovation.

The support people receive after their treatment also matters and post-treatment rehabilitation must also feature in the Cancer Plan, including:

5. Support after treatment to ensure patients can confidently continue with their life after their cancer treatment. Numerous responses to a survey we conducted mentioned a lack of support or advice on what drugs to take, dietary changes needed, or how to access emotional or mental health support.

There has been work and initiatives already in this area and they should continue to be delivered, including:

- 6. Implementing the recommendations from the NHS Psychosocial Task and Finish group and rolling out the NHS Comprehensive Model for Personalised Care, so that all bowel cancer patients get the physical and mental care and support they need.
- 7. Continuing of the National Cancer Patient Experience Survey and the Cancer Quality of Life Survey so that key data is routinely collected and reported on.

Research and Innovation

How can the government and the NHS maximise the impact of data, research and innovation regarding cancer and cancer services? (Select the 3 actions that would have the most impact)

- Improve the data available to conduct research
- Increase research into early diagnosis
- Speed up the adoption of innovative diagnostics and treatments into the NHS

Where data is collected, too often it's not comprehensive, available in a timely manner nor swiftly published. The following actions should be included:



- Data collection needs to be comprehensive, standardised, analysed and published promptly to help enable cancer service design and delivery across the NHS and inform research. As part of efforts to ensure improved data access, the recently announced National Health Data Research Service should be designed collaboratively with cancer stakeholders, and improvements should not be held back during the transition.
- 2. The new Health Data Research Service should have improvements in cancer treatments as a key strand of its activity. This exciting development could have a major impact on cancer research, and it is vital this opportunity is maximised.
- 3. Improving data collection on inequalities to improve cancer survival and outcomes and reduce more cases The lack of metrics around inequalities hampers research and should be addressed. Roadblocks around data collection, linkage, access, and analysis make it difficult to build understanding at a national level.

Research to improve early diagnosis should include:

- 4. Being prepared to adapt to the results of research currently underway into developing risk algorithms that would allow additional stratification of the bowel screening programme. Although this research is not due to report until 2029, this is within the timeline of the Cancer Plan.
- 5. Investment in genomic digital infrastructure. Developments in next-generation sequencing and other technologies have increased the volume of genomic data on bowel cancer. Applying artificial intelligence to this data could transform genomic capabilities within bowel cancer pathways, enabling more personalised, precise, and preventative bowel cancer management and care. Progress is limited due to challenges in infrastructure- secure digital infrastructure must be developed to enable appropriate use and sharing of bowel cancer data at scale, including combining and developing digital infrastructure based on existing genomic resources such as the Lynch syndrome registry and the UK Biobank.

To support the adoption of innovative diagnostics and treatments into the NHS, the following steps should be taken:

- 6. Routine use of genomic medicine within bowel cancer pathways to deliver personalised, precise, and preventative care that improves patient outcomes.
- 7. Investment in localised Community Diagnostic Centres (CDCs) must continue to be prioritised to start embedding genomic practices within the NHS without creating additional demands within acute facilities In the next 1-3 years, NHSE were looking to explore the role of CDCs in collecting samples to test for <u>inherited genomic diseases</u> amongst family members.



- 8. Investment in computed tomography colonography (CTC), which will become essential in supporting increased demand for colonoscopy services as bowel cancer screening and surveillance programmes expand. Colonoscopy is the most appropriate first-line test, but CTC could be an alternative assessment for those with lower FIT score, comorbidities, or those who had incomplete or failed colonoscopies. Unlike endoscopy procedures, CTC services offer the opportunity to increase diagnostic capacity through the forum of CDCs.
- 9. Equitable investment must also be given to the provision of endoscopy suites to expand diagnostic capacity and reduce waiting times as CDCs are limited in their capacity to offer tests for bowel cancer. Endoscopy procedures can only take place in large CDCs, attached to acute facilities, restricting the ability to diagnose bowel cancer outside of hospitals.

Inequalities

In which of these areas could the government have the most impact in reducing inequalities in incidence (cases of cancer diagnosed in a specific population) and outcomes of cancer across England? (Select the 3 actions that would have the most impact)

- Raising awareness of the signs and symptoms of cancer, reducing barriers and supporting timely response to symptoms
- Reducing inequalities in cancer screening uptake
- Improving earlier diagnosis of cancers across all groups

The Cancer Plan should address inequalities in screening uptake by:

1. Undertaking targeted interventions to improving uptake of screening amongst those groups and communities with the lowest participation. This would significantly improve rates of early diagnosis. Uptake of screening varies across difference demographics, including deprivation. People from the most deprived communities are less likely to take part in screening and as a result diagnoses via the screening programme are 36% lower within the most deprived areas and the mortality rate is 25% higher*v. Uptake varies across the country with the lowest uptake of 59% in North-West London compared to 75% in Gloucestershire. Studies have shown that black people are more likely to receive a diagnosis outside of national screening programmes than white people*vi.

With evidence suggesting that people from more deprived groups, ethnic minorities, older adults and people with learning disabilities are more likely than comparable groups to be diagnosed at a later stage, or as an emergency presentation, when outcomes are significantly



worse, more must be done to increase awareness of the benefits of screening, building on the first national bowel screening awareness campaign run by NHS England in 2023.

- 2. Research should be undertaken to explore why participation in the screening programme by 50-59 year olds has been lower than those aged 60-74. Addressing this gap is important part of the change required to help increase early diagnosis, and prevention, of bowel cancer.
- 3. Looking into how diagnostic services can better interact with each other to improve efficiency and reduce the workload of NHS staff.
- 4. The NHS England Core20PLUS5 initiative should be used to support health systems in understanding why certain groups are not participating in screening, or why they are experiencing barriers.

Diagnosing bowel cancer at an earlier stage is critical for outcomes. The ambitions around earlier diagnosis are not being delivered in relation to bowel cancer and this must be a priority area for the Cancer Plan.

- 5. There must be a commitment to investing in public awareness campaigns on signs and symptoms of bowel cancer to deliver stage shift. Campaigns can be designed and delivered to target groups where there is inequity in outcomes, awareness of symptoms and attendance at screening. Currently 45% of adults in the UK are unaware of a single symptom of bowel cancer*vii. If this is not addressed, it will impact on the potential to tackle early diagnosis.
- 6. While Bowel Cancer UK's ongoing '<u>Tell Your GP Instead'</u> campaign is working to improve public recognition and timely response to symptoms, a national campaign with significantly more resource is needed if there is to be notable change in the stage of diagnosis. Campaigns must also be paired with resources and clinical decision support tools for primary care health professionals to increase their awareness and recognition of symptoms and risk factors.
- 7. Public facing measures should be matched with additional resources and clinical decision support tools to increase awareness of symptoms and conditions in primary care.

Priorities for the national cancer plan

What are the most important priorities that the national cancer plan should address? (Select the 3 most important priorities)

• Earlier diagnosis of cancer



- Improving the access to and quality of cancer treatment, including meeting the cancer waiting time standards
- Reducing inequalities in cancer incidence, diagnosis and treatment

The categories listed all have a role to play in improving the outcomes and experiences of patients with bowel cancer. It is key that in a ten-year strategy they are all included.

It is essential that the new Cancer Plan addresses the interventions proposed under the response to the early diagnosis question. The stage of diagnosis for bowel cancer must be brought down. People are dying unnecessarily of bowel cancer because of this late diagnosis, with Cancer Research UK estimating that a further 6,900 bowel cancer deaths could be avoided within five years of diagnosis if cases were diagnosed one stage earlier.

Addressing the performance of cancer waiting times in relation to bowel cancer is also essential. Bowel cancer is nowhere near meeting the Faster Diagnosis Standard (FDS), the 75% early diagnosis ambition, nor the 62-day Cancer Waiting Time Standard. Only 46% of bowel cancer patients start treatment within 62 days after an urgent referral, well below the 85% target. In 2024, on average only 57% of bowel cancer patients referred from national screening met the FDS, lagging far behind other prevalent cancers with national screening programmes. For patients urgently referred for suspected cancer following a GP appointment, only 63% of bowel cancer patients receive a diagnosis or rule out of cancer within 28 days.

A broad point that will impact on the success of the new Cancer Plan is whether there are the appropriate and sufficiently resourced structures and mechanisms in place to deliver the policies included within it. When the changes to the structure of the NHS were made after 2010, so much of the knowledge and experience in cancer was lost with the removal of the Cancer Policy Team, National Cancer Action Team and Cancer Networks. There then followed several years with very minimal capacity. With the expected significant structural reorganisation over the coming years, it is paramount that the mechanisms that are essential to the effective delivery of the Cancer Plan are maintained. A well-resourced central team must remain in place as should Cancer Alliances. The role of Cancer Alliances to help drive improvements in cancer services and monitor progress and developments is essential, and having guaranteed funding is a critical component in ensuring Cancer Alliances can effectively plan and deliver activity.

The Cancer Plan must also ensure that the issues and experiences facing people with the 'common cancers'- bowel, breast, prostate and lung- are considered along with the rare and less common cancers. There is huge opportunity here in relation to bowel cancer as we know what would have an impact and there are clear, identifiable measures that offer a path forward. If the ambition to reduce cancer deaths is to be achieved in relation to bowel cancer, resources and focus to deliver the recommendations set out in this response is required. The



chance to save lives must be taken and the success of the Cancer Plan will be whether it is able to deliver this.



ⁱCancer Research UK, https://www.cancerresearchuk.org/health-professional/cancerstatistics/statistics-by-cancer-type/bowel-cancer, Accessed April 2025

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- ^v Cancer Research UK, bowel cancer incidence by sex and country
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- vi National Bowel Cancer Audit State of the Nation Report https://www.nboca.org.uk/wp-content/uploads/2025/01/NBOCA-SotN-Patient-Report-2024_v1.0_09.01.25.pdf Published January 2025
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