

Written evidence submitted by Bowel Cancer UK (ECS0033)

About Bowel Cancer UK

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.

1. Almost 43,000 people are diagnosed with bowel cancer each year, making it the fourth most common cancer in the UKⁱ. Sadly, around 16,500 people lose their life each year to this disease, making it the second biggest cancer killer. **This shouldn't be the case as bowel cancer is treatable and curable, especially if diagnosed at an early stage.**
2. More than 9 in 10 people survive their bowel cancer diagnosis for five years, if diagnosed at the earliest stage (stage I). However, this significantly decreases to around 1 in 10 if diagnosed at stage IVⁱⁱ.

Expanding the capacity and skills of the cancer workforce by 2021

3. As part of the Phase 1 Cancer Workforce Plan, Health Education England was already planning to invest in an additional 746 Consultants working in cancer by 2021, as well as identifying system wide actions such as improved retention to secure a further 535 FTE Consultants. These plans included 316 more gastroenterologists and 94 FTE additional histopathologists which are vital in the diagnosis of bowel cancer.
4. To support the growth of capacity and skills needed Health Education England worked with the Joint Advisory Committee on Gastrointestinal Endoscopy to develop a Clinical Endoscopy Training Programme to support workforce capacity and capability in response to increasing demand for endoscopy services. GI endoscopic procedures, traditionally carried out by doctors, are being performed increasingly by nurses and other non-medical registered practitioners – known as clinical endoscopists. The Cancer Workforce Plan was to invest in 200 additional clinical endoscopists, in addition to the 200 already committedⁱⁱⁱ.
5. The Cancer Workforce Plan progress report stated that as of April 2019, 218 trainees had completed or are in training with the ambition to commence training up to a total of 400 by end 2021^{iv}. Overall findings from the initial evaluation found the clinical endoscopists trainees were helping to meet endoscopy services demands at their NHS trust and were freeing up medical staff.
6. It is unclear whether the initial targets have been achieved for all medical specialities identified within the Cancer Workforce Plan, especially due to the COVID-19 pandemic. Many diagnostic and cancer staff were redeployed during the first wave and non-essential endoscopic activity was redeployed therefore we urge Health Education England to provide a final report of the progress made against this commitment, and provide clear recommendations on the next steps for these initiatives.

Ensuring most patients receive a definitive diagnosis or ruling out of cancer within 28 days of urgent referral for bowel cancer

7. The Faster Diagnosis Standard (FDS) was a new performance standard due to be introduced from April 2020 to ensure patients who are referred for suspected cancer have a timely diagnosis. Following an initial recommendation in the 2015 Independent Cancer Taskforce report and reaffirmed in the NHS Long Term Plan, the standard would ensure patients will be diagnosed or have cancer ruled out within 28 days of being referred urgently by their GP for suspected cancer.
8. However, due to the breakout of the COVID-19 pandemic in March 2020 the work to routinely collect and publish the waiting times for the FDS was put on pause. This decision was understandable given the immense pressure NHS services were under and the fact that there was a significant drop in suspected urgent cancer referrals, a de-facto pause in the national bowel cancer screening programme and the removal of endoscopy tests unless in an emergency. As a result, the vague commitment date of from 2020 was not met due to circumstances out with their control, but if the pandemic had not occurred then they would have likely met the commitment date.
9. As part of NHS England's 2021/22 Priorities and Operational Planning Guidance, systems were expected to meet the new Faster Diagnosis Standard from Q3 introduced initially at a level of 75% for all cancers. To support the delivery of this, the FDS data began to be published from April 2021. By November 2021, this target was nearly met (71%) for all urgent referrals for patients with suspected cancer. **This was certainly not the case for people urgently referred for suspected bowel cancer, as 50% of patients were waiting longer than 28 days after being urgently referred for suspected bowel cancer^v.** While most of these people won't be diagnosed with cancer, it's important that patients can be seen as quickly as possible because the anxiety of waiting is immeasurable. For patients referred for further tests following an abnormal result of their initial bowel screening FIT test, 48% were waiting longer than 28 days to confirm or rule out bowel cancer^{vi}.
10. The COVID-19 pandemic has caused significant disruption for bowel cancer services resulting in poor performance against all cancer waiting times targets. **Yet, meeting bowel cancer waiting times, especially FDS, is crucial to ensure patients receive the best possible care and the best chance of receiving curative treatment.** We welcome the introduction of the Faster Diagnosis Standard as it helps provide greater understanding of the pressures diagnostic services are under, and if the target ambition is met it should help provide a better patient experience but more consideration is required about the resources needed.
11. Before implementation of this commitment, there wasn't adequate consideration on the current capacity within certain diagnostic services and the need investment in more staff in order to meet the ambition of 75% for some referral pathways. This is the case for the suspected lower gastrointestinal pathway which has been evident for a significant period of time since in November 2021, only 82% of potential bowel cancer patients were seen by a specialist within two weeks of urgent referral, against a target of 93.5%^{vii}.
12. As one of NHS England's key cancer waiting times target – which aims to see at least 85% of patients begin their first cancer treatment within 62 days of an urgent GP referral for suspected cancer – has never been met for bowel cancer since it was introduced^{viii}. Whereas, performance against the 31 day target for definitive treatment for cancer following decision is usually met and has only been missed by small margins throughout the COVID-19 pandemic. **The data remains clear, timely access to endoscopy services is a major barrier to bowel cancer patients starting treatment.**

13. We welcome the ambition set of 75% all people on urgent referral for suspected cancer to be a definitive diagnosis or rule out of cancer within 28 days, but greater attention must be paid to individual referral pathways to ensure equity of access can be achieved across different cancer sites, and across the country in the future. If the current target of 75% was to be met for patients with suspected bowel cancer, it will require significant investment in the workforce, kit and infrastructure to increase needed capacity within endoscopy and pathology services. **The demand on the lower gastrointestinal pathway is only going to increase as the Bowel Cancer Screening Programme extends the eligibility to all people over 50 over the next three years.**
14. Moving forward, it is vital that the Government and NHS England use the high quality robust Cancer Waiting Times data set to understand the demand on different diagnostic services to inform comprehensive workforce planning which must be matched with the needed investment to help reduce geographical variation across the country and meet their ambition to improve cancer outcomes by diagnosing the majority of cancers at an early stage by 2028. However, as it takes a minimum of three to five years to train newly qualified staff to become specialists in crucial cancer professions, efforts must be made to increase capacity within services by implementing the recommendations of the 2020 review of diagnostic services and harnessing innovation by upscaling new technologies such as Colon Capsule Endoscopy.

Meeting the Government ambition to diagnose 75% of cancers at an early stage by 2028

15. In recent decades, as a result of national cancer control plans with a focus on early diagnosis and advances, and adoption, in life-saving bowel cancer research, bowel cancer survival has more than doubled in the last 40 years^{ix}. Despite these significant improvements, the UK still lags behind comparable countries internationally with similar healthcare systems, levels of wealth and comparable data^x.
16. **England is also poorer at diagnosing cancers at an early, more treatable stage than the best performing countries^{xi}**, as only 39.6% of bowel cancers cases were diagnosed at stage I and II in England in 2018. Later stage diagnosis contributes to worse bowel cancer survival with 25.3% bowel cancer cases diagnosed at stage IV in England in 2018^{xii}. The reasons for this are multifactorial but one of the biggest barriers is the lack of capacity in endoscopy services.
17. The ambition set by the Government as part of the NHS England Long-Term Plan (LTP) is extremely welcome since survival is strongly related to stage at diagnosis. However, even before the pandemic, **we were not on the right trajectory as progress towards the Government's commitment to increase the proportion of cancers diagnosed early (stage I and II) to 75% by 2028, was slow and had been stubbornly stable for a number of years.**
18. As bowel cancer is the fourth most common cancer, and second biggest cancer killer, it will be imperative to drastically increase earlier diagnosis of bowel cancer for the Government to meet the ambition of the LTP so it must be a major pillar within the Government's efforts to improve early diagnosis of cancer.
19. The challenge ahead is immense, made more difficult by the profound impact COVID-19 has had on healthcare services, resulting in a substantial cancer backlog delaying diagnosis and treatment for bowel cancer patients. However, 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^{xiii}. As the NHS works to recover from this crisis, it must also take the opportunity to transform into a more resilient system which delivers world-class outcomes for its patients – and Government must support it to do so.

20. With a growing and ageing population, demand continues to outstrip capacity in diagnostic and cancer treatment services. Simply returning to pre-pandemic levels of activity will not be enough to meet rising patient demand, nor move the needle on improving bowel cancer survival. **One of the most significant barriers to improving bowel cancer survival in England, is the lack of capacity in endoscopy and pathology services due to workforce shortages and a lack of key diagnostic equipment and facilities which is a result of years of inadequate long-term workforce planning and underfunding.**
21. When setting this ambition as part of the NHS LTP, it is not clear whether the Government fully understood the challenge ahead as they haven't provided sufficient funding and resources, to date, in order to address the barriers which are preventing timely and earlier diagnosis. There is no silver bullet to meet this ambition but it will require substantial investment to implement a range of interventions.
22. While, the initiatives in the LTP related to bowel cancer, such as lowering the screening age to 50, are a good starting point to help increase the proportion of bowel cancers diagnosed at an early stage. 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 will need to be significant and concerted action over the remaining 6 years of the Long-Term Plan, including going further than the initiatives, to reach this ambition and match bowel cancer outcomes of the best countries internationally.**
23. **Staff shortages are already limiting the ability to implement initiatives in the Long Term Plan, and optimise evidence-based interventions.** For example, the NHS Long Term Plan commits to lowering the screening age from 60 to 50 which has begun, but it will take until at least 2025 to be fully implemented. This will result in more people needing follow up tests which will require more endoscopy staff to deliver this commitment. Yet, due to shortages in the endoscopy and pathology workforce, FIT screening for bowel cancer had to be introduced in England at 150ug/g, a less sensitive level than in Scotland at 80ug/g. This means that bowel cancers and potentially pre-cancerous growths are going undetected in England each year. **It is extremely frustrating that staff shortages continues to dictate our ability to have a world-class, world-leading bowel cancer screening programme, as it is of the best ways to detect bowel cancer at the earliest stage, and in some cases prevent bowel cancer from developing in the first place.**
24. To rise to the challenge and meet this commitment, there must be urgent investment in the workforce, kit and infrastructure to support diagnostic and cancer services to expand capacity and improve earlier diagnosis. We'd also encourage the Government to work more closely with key stakeholders especially royal colleges and medical research charities to understand opportunities to increase capacity to improve patient experience and outcomes.

*For further information, please contact Corrie Drumm, Policy and Campaigns Manager
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- ⁱ Cancer Research UK <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer> September 2021
- ⁱⁱ Office for National Statistics, [Cancer survival by stage at diagnosis for England](#), 2019
- ⁱⁱⁱ Health Education England Cancer Workforce Plan Phase 1
<https://www.hee.nhs.uk/sites/default/files/documents/Cancer%20Workforce%20Plan%20phase%201%20-%20Delivering%20the%20cancer%20strategy%20to%202021.pdf>
- ^{iv} Health Education England Cancer Workforce Plan progress report
<https://www.hee.nhs.uk/sites/default/files/documents/Cancer%20Workforce%20Plan%20phase%201%20progress%20update%20FINAL.pdf>
- ^v NHS England Provider-based Cancer Waiting Times for November 2021-22 (Provisional)
<https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/monthly-prov-cwt/2021-22-monthly-provider-cancer-waiting-times-statistics/provider-based-cancer-waiting-times-for-november-2021-22-provisional/>
- ^{vi} NHS England Provider-based Cancer Waiting Times for November 2021-22 (Provisional)
<https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/monthly-prov-cwt/2021-22-monthly-provider-cancer-waiting-times-statistics/provider-based-cancer-waiting-times-for-november-2021-22-provisional/>
- ^{vii} NHS England Provider-based Cancer Waiting Times for November 2021-22 (Provisional)
<https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/monthly-prov-cwt/2021-22-monthly-provider-cancer-waiting-times-statistics/provider-based-cancer-waiting-times-for-november-2021-22-provisional/>
- ^{viii} NHS England Cancer Waiting Times for Q3 <https://www.england.nhs.uk/statistics/2012/02/24/waiting-times-cancer-q3/> September 2021
- ^{ix} Cancer Research UK <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer/survival> September 2021
- ^x International Cancer Benchmarking Partnership 5-year net survival changes (1995-1999 to 2010-2014), Cancer Research UK https://www.cancerresearchuk.org/sites/default/files/cancer-stats/icbp_5_year_survival_countries/icbp_5_year_survival_countries.pdf
- ^{xi} IBCP SURVMARK-2 stage distribution for colon cancer 2010-2014
https://gco.iarc.fr/survival/survmark/visualizations/viz8/?groupby=%22country%22&cancer=%22Colon+cancer%22&country=%22Australia%22&gender=%220%22&age_group=%2215-99%22&show_ci=%22%22
- ^{xii} Public Health England National Disease Registration Service: Staging data in England
https://www.cancerdata.nhs.uk/stage_at_diagnosis
- ^{xiii} State of Health and Care: the NHS Long Term Plan after COVID-19, Institute for Public Policy Research
<https://www.ippr.org/files/2021-03/state-of-health-and-care-mar21.pdf> March 2021