Written evidence submitted by Bowel Cancer UK (CSV0050)

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.

Key recommendations

The Government must use the 2021 Comprehensive Spending Review to:

- continue to invest in the cancer workforce by proving Health Education England with multi-year funding to reach the 2017 Cancer Workforce Plan target for 45% growth in the cancer workforce by 2029, and meet future patient demand
- expand diagnostic capacity in endoscopy and pathology services, and fully implement the recommendations of the 2020 Richards review of diagnostic services including providing the NHS with the capital investment to expand endoscopy capacity by the 200 extra endoscopy suites needed to meet patients demand
- provide sufficient funding for the workforce and kit required to fully implement the UK National Screening Committee's Bowel Cancer Screening Programme recommendation, and support the timely implementation of the recommendations set out in the 2019 Richards review of screening

Why do bowel cancer outcomes in England – in particular survival – still lag behind comparable countries internationally?

1. Over 42,000 people are diagnosed with bowel cancer each year, making it the fourth most common cancer in the UK[i]. 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 IV[ii].

3. 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[iii]. Despite these significant improvements, the UK still lags behind comparable countries internationally with similar healthcare systems, levels of wealth and comparable data[iv].

4. The most recent International Cancer Benchmarking (ICBP) study on Cancer Survival in High-Income Countries Phase 2 (SURVMARK-2) found that five-year survival for bowel cancer in England (2010-2014) was 58.9%, which is approximately where Australia was 15 years ago (59.6%, 1995-1999)[v]. While, England is making progress in improving bowel cancer survival, international countries have also been doing the same with five-year survival in Australia reaching 70.8% in the most recent data (2010-2014)[vi].

5. **England is also poorer at diagnosing cancers at an early, more treatable stage than the best performing countries**[vii], 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[viii]. The reasons for this are multifactorial but addressing them are integral to increase early diagnosis, reduce late stage diagnosis and improve overall bowel cancer survival.

Improving bowel cancer outcomes and survival by increasing capacity

6. In the case of bowel cancer, early diagnosis saves lives so 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.

7. **Gastroenterology has developed and expanded at a greater rate than any other acute major medical specialty over the past 30 years**[ix]. This is due in part to increased demand for both diagnostic and therapeutic endoscopy because of a growing ageing population, 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.

8. In 2019, the Joint Advisory Group on Gastrointestinal (GI) Endoscopy census found there has been a 12%-15% increase in activity across all GI procedures with largest increase in bowel cancer screening[x]. **Fewer services were able to meet waiting targets compared with 2017, with endoscopists, nursing and physical capacity cited as the main reasons**.

9. Endoscopy services, in particular those for colonoscopy, were already under considerable strain before the pandemic. This largely related to constraints on the workforce and Health Education England (HEE) previously estimated the NHS will require a growth of 45% in its cancer workforce to deliver world-class cancer services by 2029. In 2020, Cancer Research UK estimated that to achieve this level of growth across key cancer professions would require an addition investment of between £142 million and £360 million for staff training and education[xi]. We welcomed the £46 million investment in the diagnostic and cancer workforce made in the 2020 Spending Review but this investment must be maintained. **The Government must use the 2021 Comprehensive Spending Review to provide multi-year funding to train more cancer staff to meet current and future demand.**

10. The 2020 review of diagnostic services led by Professor Sir Mike Richards called for a substantial and urgent expansion of diagnostic capacity with proposed new service delivery models that could transform diagnostic services in England[xii]. The report estimated that **around 20 NHS trusts will require a complete rebuild of their endoscopy facilities and other need improvements**[xiii]. It also estimated that **200 new endoscopy rooms are required to meet patient need**, which must also be a priority for investment in diagnostic services.

11. We are eagerly awaiting the publication of the Getting It Right First Time (GIRFT) report on Gastroenterology services in England, to give a true reflection of the growing demand on endoscopy, the impact COVID-19 had on the growing backlog and provide clear recommendations to optimise current capacity. **The GIRFT report contains vital analysis of the current state of endoscopy services and must inform the 2021 Comprehensive Spending Review**, and the recommendation must be implemented as a matter of urgency.

How will COVID-19 affect efforts to catch up to the best cancer outcomes internationally?

12. The COVID-19 pandemic has had a profound impact on healthcare services and will continue to have an impact for months and perhaps years to come. The full impact 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**[xiv].

13. In April 2020 – March 2021, **3,200 fewer patients started treatment in England for bowel cancer compared to pre-pandemic times**[xv]. This is a result of the pause of the bowel cancer screening programme, a significant drop in urgent suspected cancer referrals and removal of endoscopy tests, unless in an emergency, at the beginning of the COVID-19 pandemic. While these decision were made for patient safety this has created a growing cancer backlog.

14. While the NHS staff have worked incredibly hard to restore cancer diagnostic and treatment services, a substantial backlog of patient demand has built up as a result of continued disruption to NHS services throughout the peaks of the COVID-19 pandemic. Simply returning to pre-pandemic levels of activity will not be enough to not meet rising patient demand nor help move the needle on diagnosing more bowel cancers at an early stage.

15. The pressure NHS staff has experienced since the beginning of the pandemic is immense and the toll this has taken on the ability to retain and retrain staff is still to be realised. However, there is emerging evidence that suggests it will have likely have damaging effect on retention with now **one in four NHS staff say they are more likely to leave their jobs than before the pandemic**[xvi]**.** Given the existing staff shortages across the cancer workforce, even a fraction of these staff leaving would exacerbate capacity challenges in diagnostic services, and further limit our ability to transform bowel cancer services and outcomes.

16. Yet, there have been some positive advances as a result of the COVID-19 pandemic. Faced with changes to routine care, the NHS had to innovate either through the accelerated adoption of new technologies such as Colon Capsule Endoscopy; or changing in clinical practice by delivering chemotherapy more in the community or at home or allowing advanced bowel cancer patient's treatment breaks, without fear of losing their funding.

17. Innovation adopted throughout the pandemic will require further and ongoing evaluation to understand their effectiveness and impact. However, if it is deemed effective, it must be scaled up and implemented nationally in a timely and appropriate manner to help increase capacity and improve patient experience of diagnostic and treatment services. As some of the innovations adopted throughout the pandemic may not be appropriate for every patient, further evaluation must understand if they may negatively impact patient outcomes or widen health inequalities further, and appropriate action must be taken.

18. To transform bowel cancer services and improve outcomes it is imperative that the NHS harnesses this environment for innovation moving forward, and is continued to be empowered to implement and deliver effective interventions, at pace and scale.

Will implementing the Long Term Plan for cancer improve cancer outcomes to the level of the best countries internationally?

19. 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, 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.

20. 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. 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.

21. There is no silver bullet to improving bowel cancer survival and outcomes, so action is needed all fronts. **There will need to be significant and concerted action over the remaining 7 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**.

22. The bowel cancer screening programme 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. Yet, currently only 1 in 10 bowel cancers are diagnosed via the screening programme. **To increase the proportion of bowel cancers diagnosed at the earliest stage, it is imperative to optimise the bowel cancer screening programme through age extension, increasing sensitivity and improving informed uptake across all demographics.**

23. The UK National Screening Committee (UKNSC) recommends that 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 recommendations **due to shortages in the endoscopy and pathology workforce, and 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-cancers growths are going undetected in England each year.

24. While age extension, an initiative in the LTP, to lower screening from 60 to 50 has now begun, it will take until at least 2025 to be fully implemented across England because of ongoing staff shortages in endoscopy and pathology services. However, **the commitment to increase the sensitivity of FIT screening or increase informed uptake across all demographics were not included as part of the LTP**. This is extremely disappointing as they could make a significant impact in improving early diagnosis of bowel cancer, and prevent more cases from developing.

25. The 2019 Independent Review of Screening in England, conducted by Professor Sir Mike Richards, set out recommendations to transform cancer screening programme including simplifying governance, improving robust data collection and moving towards risk-stratified screening[xvii]. **The NHS must provide a detailed plan, with timelines, on how these recommendations will be implemented, and the Government must provide sufficient funding required to support their implementation.**

26. Most people are diagnosed once they've visited their GP with potential cancer symptoms so supporting timely presentation by the public will be crucial to delivering stage shift. Whilst there has been efforts to improve public recognition and timely response to the signs and symptoms of bowel cancer in recent years, through the Be Clear on Cancer campaigns and

more recently through Help Us Help You. More effort is required as there is still an alarmingly low awareness of bowel cancer symptoms, as more than four in 10 adults in the UK are unaware of a single symptom of bowel cancer[xviii]. Further data is needed to inform the development of future interventions so they can be targeted and effective to the demographic groups and communities most in need.

27. Cancer Waiting Time targets were routinely missed pre-COVID-19 as a result of systemic and long-standing gaps in capacity within diagnostic services. The 62-day target for patients with bowel cancer to begin treatment following an urgent GP cancer referral has not been met since at least December 2011[xix], if ever. **It is clear that demand on endoscopy services continues to outstrip capacity, and delays to diagnosis have an impact on bowel cancer outcomes. T**he Government must train more staff in diagnostic services to help bring waiting time targets under control, and provide the NHS with sufficient funding required to increase capacity.

28. Updates in 2015, to the NICE NG12 referral guidelines for suspected cancer resulted in a lower threshold of referral for further testing for suspected cancer, with the aim to detect more cancers at an early stage. However, better compliance and improved use of the NG12 cancer referral guidelines by GPs is needed to help optimise appropriate recognition and timely referral of potential bowel cancer patients. This also applies to wider guidance, such as DG27 for testing for Lynch syndrome in people diagnosed with bowel cancer and DG30 for use of qFIT as a triage tool, and must be supported by the wider environment by removing barriers to implementation.

29. Around 20% of all bowel cancers cases are diagnosed after emergency presentation when the disease has very likely progressed to late stage and therefore has much poorer outcomes. The optimisation of the bowel cancer screening programme is the best way to reduce the proportion of bowel cancers diagnosed after emergency presentation. However, it will take years to implement the UKNSC recommendation, substantial effort must be made to improve earlier diagnosis through shifting stage IV bowel cancer cases to stage III, as five-year survival at stage III is around 65% but this drops to around 10% if diagnosed at stage IV. By implementing new innovate models for diagnostic pathways, such as rapid diagnostic centres, for people with vague but concerning symptoms, it will hopefully allow people to be seen by a specialist or offered endoscopy tests before they end up in A&E with a bowel obstruction, as well as improve patient experience from referral to diagnosis.

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