

## **Bowel Cancer UK response to NHS 10 Year Plan**

### **Introduction**

Bowel Cancer UK welcomes the opportunity to provide feedback on the development of the NHS 10 Year Plan and in particular, the cancer section. It is crucial that the priorities of bowel cancer patients are addressed in both the five-year funding settlement and the longer-term 10 Year Plan in order to improve the diagnosis, treatment, care, and support of patients.

In order to provide a robust, evidence-based submission, Bowel Cancer UK has consulted with our Medical Advisory Board, Scientific Advisory Board, the Colorectal Cancer Clinical Expert Group (CEG) and clinical advisors. In addition we have received feedback on the personal experiences of the bowel cancer pathway from nearly a thousand patients who responded to our patient and public survey.

This plan will be directing the future care of millions of patients over the next 10 years. Bowel Cancer UK is therefore highly concerned that the timeframe provided for this process is not conducive to producing a plan that is properly informed by the priorities and experiences of patients, public and the wider medical community. To help mitigate any issue resulting from an expedited consultation period, we strongly advise that regular review periods are built into the life cycle of the plan. These review periods must incorporate proper medical, patient and public consultation opportunities so that it is adaptable and responsive to changes in patient needs, technology and innovations, and the wider political context.

### **Bowel cancer now and in the future**

Bowel cancer is the fourth most common cancer in England and the second biggest cancer killer, with approximately 13,000 people dying from bowel cancer each year. However, this shouldn't be the case as the disease is treatable and even curable, especially if diagnosed early, with an estimated 9 in 10 people surviving bowel cancer if diagnosed at the earliest stage.

Initiatives to prevent bowel cancer, diagnose it earlier, as well as the introduction of more effective and personalised treatment methods has resulted in an increase in 5 year survival rates and a reduction in bowel cancer incidence. In fact, incidence is predicted to fall by 11% between 2014 and 2035, from 83 cases of bowel cancer per 100,000 people to 74 cases per 100,000 people. It has been estimated in 2035, 53,646 cases of bowel cancer will be diagnosed in the UK. However, as survival improves more people will be living longer with the disease. So it will be imperative that the plan fully addresses the needs of those living with the consequences of treatment and cancer, as well as how the NHS and wider public bodies can continue to ensure survival rates increase and that patients have access to the latest and most effective treatment options.

## Consultation questions

### **What are your top three priorities for improving cancer outcomes and care over the next five and ten years?**

#### **1. Optimal Bowel Cancer Screening Programme**

In the next 5 years an optimal bowel cancer screening programme must be implemented, as recommended by the UK National Screening Committee (UKNSC) and committed to by Government. This includes introducing the simpler, more accurate faecal immunochemical test (FIT) from the age of 50 - 74 every two years, with the ambition to increase the sensitivity of the test over time to 20 ug/g (from a starting level of 120 ug/g). A sensitivity threshold at this level has the potential to detect twice as many cancers and four times as many pre-cancerous adenomas.

However the biggest constraints to implementing an optimal bowel cancer screening programme are a lack of endoscopy and pathology capacity. The introduction of an optimal FIT will have substantial impact on both services that should not be underestimated. NHS England in collaboration with partners such as Public Health England, professional bodies and patient groups must develop a sensible but ambitious timeframe for implementation of this programme that also addresses how current and future services will cope with introducing FIT under the parameters specified.

Beyond this, NHS England must support early stage research on the development of risk algorithms to enable us to personalise and better target population screening, as well as enable better targeting of resources. Over 10 years the NHS must consider the use of AI and genomics to further enhance the screening programme, including how it may be used to improve diagnostic procedures. To enable this to occur, the NHS must look at how technology can be translated rapidly into clinical practice.

In addition, NHS England must also improve screening and surveillance for high risk groups, such as those with conditions like Lynch syndrome. A national screening and surveillance service should be developed through the Bowel Cancer Screening Programme, utilising existing infrastructure including the call and recall function.

#### **2. Expanding workforce capacity**

The development and publication of the new NHS 10 Year Plan is a pertinent opportunity to finally address the growing capacity crisis within diagnostic services for bowel cancer. Timely access to diagnostic tests for bowel cancer is key to either preventing bowel cancer or to giving people an opportunity of an earlier diagnosis when it is more treatable and even curable. But demand for endoscopy tests is rising at a rapid rate – at the very least nearly a million more procedures are needed year on year<sup>1</sup>. This is putting endoscopy and pathology services under unprecedented pressure because there simply aren't enough staff to deal with this demand.

While the current Government initiative to train 400 clinical endoscopists to undertake additional 450,000 endoscopies a year by 2021 is welcome, it is not enough to plug the growing gap. It is also incredibly optimistic and infeasible for 400 clinical endoscopists to undertake an additional 450,000 endoscopies. This would require each to carry out approximately 1,100+ procedures per year. Furthermore, as of May 2018, just 130 have been recruited to the training programme. With NHS hospitals struggling to cope, hospitals are being set-up to fail against waiting time targets. Currently there are thousands of patients that are waiting beyond the target set for potentially lifesaving tests, with around half of NHS hospitals in England now breaching waiting time targets for diagnostic tests every month.

The current workforce shortage represents the single biggest barrier to delivering world-class cancer care for bowel cancer patients. The Government's recent commitment to provide an optimal bowel cancer screening programme, based on the UKNSC's recommendations, relies heavily on staff being able to carry out more tests. Success of this programme's roll-out is dependent on both colonoscopy and pathology services. It is therefore imperative that the five year settlement funding and the NHS 10 Year Plan address and make specific reference to how colonoscopy and pathology capacity can be increased to support the implementation of this optimal bowel cancer screening programme in a sustainable manner.

The NHS 10 Year Plan must therefore include a fully funded action plan to tackle issues around workforce, with clear and comprehensive recommendations that address both current workforce shortages and allow for future growth.

### **3. Personalised medicine and access to innovative treatments**

In order to improve outcomes for bowel cancer it is vital that patients and clinicians have access to the latest and most effective treatment options. A personalised treatment approach provides a significant opportunity to improve outcomes for patients with advanced bowel cancer. By understanding the genetic make-up of a patient's tumour at an early stage, healthcare professionals can better target treatments that are more likely to work, as opposed to using generic treatments that may or may not work. This is particularly important given that recent research has shown bowel cancer not to be one disease but four distinct types of cancer<sup>ii</sup>. These four types of bowel cancer have been found to each have its own genetic profile and prognosis. This ground-breaking discovery could help pave the way for the development of more personalised therapies and improve and extend the range of treatment options available. In doing so, we can maximise outcomes for patients and also ensure they do not unnecessarily have to undergo the often gruelling side-effects of treatment.

However, current treatment options are limited and many treatments which are considered to be 'standard care' in other health economies are not available here, despite clear evidence of survival benefit. For example, many new and innovative treatments such as personalised immunotherapy drugs are not being approved for use on the NHS because of cost. This has financial implications for patients and their families, with many resorting to fundraising or borrowing in order to fund treatments privately. This issue has been exacerbated by the introduction of the Budget Impact Test.

Access to personalised medicines will also require patients to be tested for genetic biomarkers such as mismatch repair (MMR) deficiency. However, current commissioning arrangements are hindering access to molecular tests. In the next 5 years, with the move towards genomic based medicines and the increasing use of molecular tests, the NHS must ensure that all bowel cancer patients are tested for a range of genetic biomarkers, such as RAS, MMR and BRAF at diagnosis, so that they are given the most appropriate treatment based on their immuno-histochemical profiles.

It is therefore crucial that the new National Directory for genetic tests, as part of the National Genomic Service, is transparent in commissioning responsibility for testing and clear guidance is written for clinicians ordering these tests. The NHS must also support research and development into new, personalised, and whole pathway approaches to treatment. To achieve this, patients must have access to clinical trials.

Furthermore once NICE has approved cancers drugs for routine use in the NHS the Cancer Drugs Fund (CDF) and NHS England must not add any further restrictions to its use that do not appear in NICE guidance, for example treatment breaks.

## **2. What more can be done to ensure that:**

### **a. More cancers are prevented?**

### **b. More cancers are diagnosed early and quickly?**

In addition to an optimal bowel cancer screening programme, it is essential that other measures are taken to improve prevention and early diagnosis.

#### **Awareness of risk factors and positive lifestyle changes**

NHS England should work with Public Health England to support people in making and maintaining positive lifestyle changes, including diet and exercise, as well as educating the public on bowel cancer risk factors.

#### **Awareness of bowel cancer symptoms**

Improved awareness of bowel cancer symptoms in the population is necessary to achieve earlier diagnosis, especially where symptoms are vague and often confused with other more common and less serious illnesses and conditions. Our surveys of advanced bowel cancer patients<sup>iii</sup> and younger people with bowel cancer<sup>iv</sup> found 30% and 43% of respondents were unaware of the symptoms of bowel cancer, respectively. NHS England should work with Public Health England to educate the public and primary care on the range of bowel cancer symptoms and the importance of reporting symptoms as soon as symptoms present, as well as to help general practitioners to better identify and refer patients onwards for diagnostic tests.

#### **New models of care to speed-up diagnosis and achieve a stage shift**

The NHS must take significant proactive steps to ensure people are diagnosed at earlier stages of the disease when it is more treatable and the chance of survival is high. Data shows

that the best way to achieve this is through the bowel cancer screening programme, with just 8% of screen detected cancers diagnosed at stage 4, compared to 22% for those diagnosed via GP referral and 40% for people diagnosed in an emergency setting<sup>v</sup>. It is crucial that efforts to reduce the FIT screening age to 50 and increasing the sensitivity level to 20 ug/g are implemented as a priority in the NHS 10 Year Plan. As part of Bowel Cancer UK's patient survey to inform this consultation response, we found that 60% of patients were diagnosed after seeing their GP, but alarmingly nearly 20% of respondents waited more than twelve months to be diagnosed after their initial appointment. This indicates that beyond improvements to the bowel cancer screening programme, it is also necessary to see improvements to the diagnostic pathway as a whole to achieve a substantial stage shift in diagnosis. Currently only 9% of cancers are diagnosed via screening and approximately 24% are diagnosed via emergency admission. As the biggest survival benefits to be gained are through screening initiatives to reduce emergency admission rates must be addressed in the plan. Programmes such as the [Accelerate, Coordinate, Evaluate \(ACE\)](#) programme, the use of FIT in symptomatic patients and multi diagnostic centres should be closely monitored and new care models to achieve a stage shift must be developed.

### **Optimal screening and risk stratification**

As screening with FIT provides a quantitative result, NHS England should consider varying the threshold for defining a positive result dependent upon the individual's characteristics (such as age, gender and ethnicity)<sup>vi</sup>. Research presented to the UK NSC found that risk based stratification, with risk scoring systems, increases the accuracy of FIT-based CRC screening and could be used in preselection for colonoscopy in CRC screening programmes<sup>vii</sup>.

### **Lynch syndrome screening and surveillance**

Current British Society of Gastroenterology (BSG) guidelines<sup>viii</sup> recommend that those with the condition should receive regular colonoscopy every 18 months to 2 years. Regular colonoscopy can reduce the risk of dying from bowel cancer by 72% by detecting it early when it is more treatable. Unfortunately, there is currently an inconsistent approach in the management of Lynch syndrome across the country. This is as a result of poor clinical awareness of the condition and/ or BSG screening and surveillance guidelines, or with service organisation.

A new national approach to screening and surveillance is needed to reduce this variation. Bowel Cancer UK brought together 10 experts in the field of bowel cancer and genetics to develop a clinical consensus<sup>ix</sup> on reducing this variation. The group agreed the most efficient and effective method to deliver a national screening and surveillance service is through the Bowel Cancer Screening Programme (BCSP), utilising the existing infrastructure for providing screening to the asymptomatic population. The BCSP is delivered to a very high standard, has in place robust quality assurance mechanisms for colonoscopy and a good call and recall system.

A linked national database of people identified as Lynch syndrome gene carriers should be developed to support the Bowel Cancer Screening Programme to facilitate the call and recall of these patients. Both clinicians and patients have come forward in favour of the development of a national registry, including the Mallorca Group<sup>x</sup>. Furthermore, Bowel Cancer UK's patient experience survey found that 87% of its respondents with Lynch syndrome would consent to being part of a registry.

### **Standardising quality of endoscopy services**

Future workforce planning must address issues in variation in quality of endoscopy units by ensuring all services conducting these tests, are accredited to a high standard. Many units do not meet the quality standards set out by the Joint Advisory Group for Gastrointestinal Endoscopy (JAG). As units increasingly are both outsourcing and insourcing their backlog of endoscopy waiting lists to external private providers, this also raises significant concerns regarding variations in quality standards. This means that some patients are being referred to units whose quality cannot be assured. With the added pressures that the expected increase in demand for diagnostic testing will bring, ensuring services continue to be of the highest quality is vital to stop people dying from bowel cancer.

### **FIT in symptomatic patients**

As well as using FIT as part of the screening programme, FIT should be considered as a triage test for symptomatic patients to help detect bowel cancer at an earlier stage. To achieve this, [NICE guidance DG30](#) on the use of FIT for patients who have unexplained, low risk symptoms (and do not meet 2WW criteria) must be rolled-out to help GPs better identify and refer the right patients quickly for investigation.

However, NHS England should also monitor the potential benefit of using FIT to triage symptomatic patients that do meet the 2WW referral pathway. One pilot study in Leicester and Nottingham has shown positive interim findings, where after 6 months of triaging patients using FIT; approximately 60% of the people tested have not required further urgent investigation<sup>xi</sup>.

FIT in symptomatic therefore has the potential to improve early diagnosis, particularly for patients outside of the national screening programme age, whilst also reducing pressure on endoscopy and radiology services. Evidence for the use of FIT in symptomatic patients must continue to be developed with NHS England using results to guide wider rollout of this programme.

### **What more can be done to ensure that:**

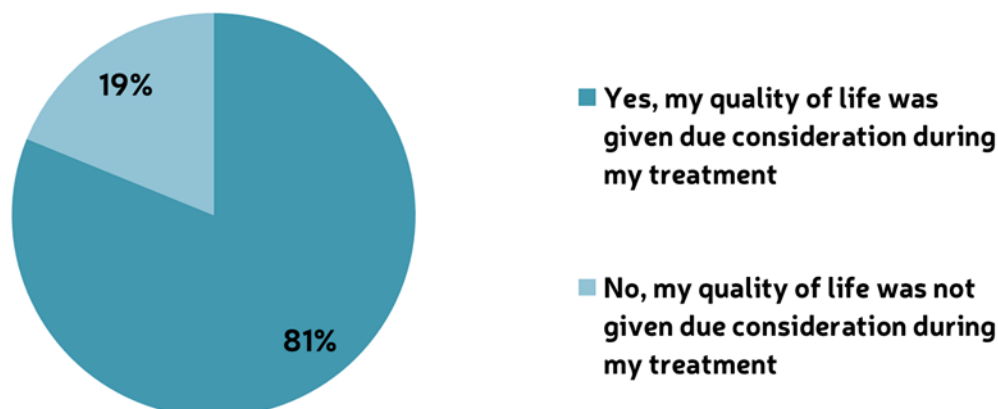
**c. People can maintain a good quality of life during and after treatment?**

**d. People with cancer have a good experience of care?**

Bowel Cancer UK conducted a patient survey during August 2018 to ensure patients' priorities are reflected in the NHS 10 Year Plan. A total of 856 patients responded, with questions

focused around quality of life during and after treatment and how it can be improved, as well as what can be done to ensure more people with cancer have a good experience of care.

When asked directly about **quality of life (Figure 1)**, most **patients (81%)** felt **healthcare professionals considered their quality of life while they were undergoing treatment**.



**Figure 1:** The extent to which quality of life was given due consideration during treatment

The main reasons for this were:

- Patients felt they received support and care from healthcare professionals throughout the whole treatment pathway (e.g. mental health support, stoma management).
- Patients had access to information and detailed discussions with relevant healthcare professionals about treatment options, side effects and quality of life.
- Healthcare professionals discussed quality of life while considering treatment options and respected patient's wishes and needs.

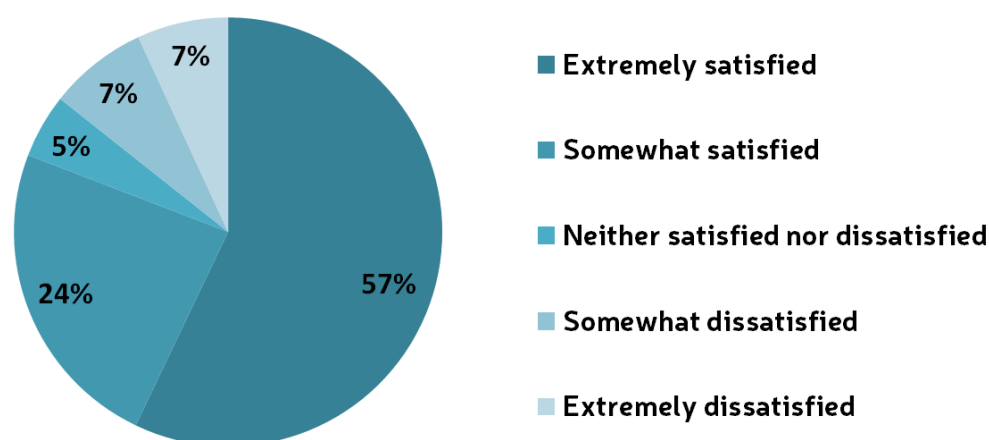
Similarly, the main reasons patients felt their quality of life was not given due consideration came down to:

- **Poor communication** from NHS healthcare professionals, particularly around the side effects of treatment, treatment options and lifestyle advice, which caused patients to feel as though they had to navigate the system themselves.
- **Side effects and lifestyle** were not given as much consideration as treatment.

**NHS England needs to ensure healthcare professionals are directly considering quality of life issues when discussing treatment options with patients.**

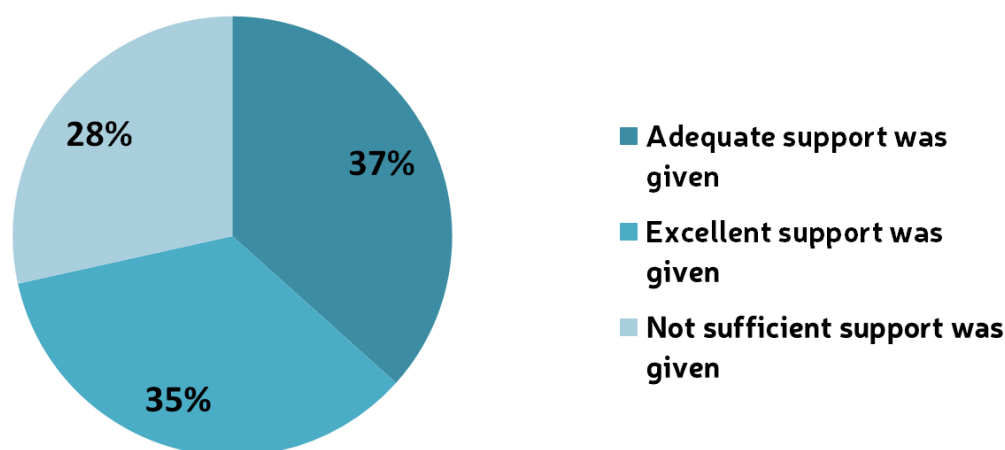
**Thorough and honest conversations about treatments, side effects, outcomes and life post-treatment need to be had with patients to ensure they feel supported and respected.**

Most bowel cancer patients were satisfied with the treatment and care they received. Over half (57%) of patients were extremely satisfied and nearly a quarter (24%) were somewhat satisfied (Figure 2). 1 in 7 patients (14%) were not satisfied with the treatment and care they received (Figure 2).



**Figure 2:** Overall patient satisfaction with the treatment and care received

However, **support received after treatment significantly drops, with nearly a third reporting support provided at this point was not sufficient (Figure 3).** Many responded stating the care provided while undergoing treatment was excellent but received near to no support with life following treatment. In fact, many stated they didn't receive an aftercare plan to help them deal with life after treatment.



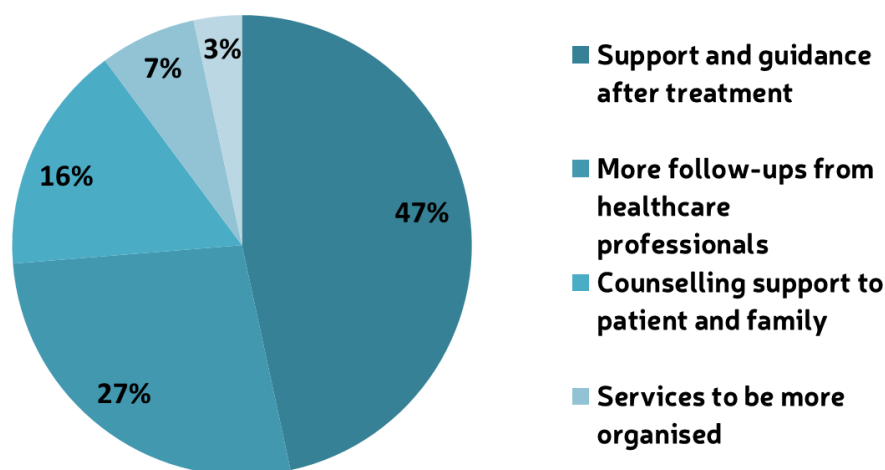
**Figure 3:** The health and social care support patients felt they received after treatment, such as an aftercare follow up plan (e.g. access to a clinical nurse specialist)

**Nearly half of patients expressed that having more support and guidance after treatment (47%) would improve their experience of care (Figure 4).** Many felt that support was only provided if they asked for it, with many saying they felt abandoned. Furthermore, access to more detailed information around diet, lifestyle and dealing with the side-effects of treatment is needed. In addition to guidance support, some felt they would have benefitted from access to support at home (3%).

Nearly a third of patients (27%) stated that having more regular follow-up checks from healthcare professionals would improve their experience of care (Figure 4). Some patients felt that there was no 'go-to' person for life after treatment regarding dealing with side effects, stoma management, and issues with wounds and infections. A number of responses stated they did not have access to a clinical nurse specialist (CNS) to help them with life after treatment and felt they had to navigate care alone.

While many struggled to obtain the care and support they needed, 7% of patients felt that the care service they did receive was unorganised and poor (Figure 4), with some stating this came down to NHS staff being too busy to provide good quality care.

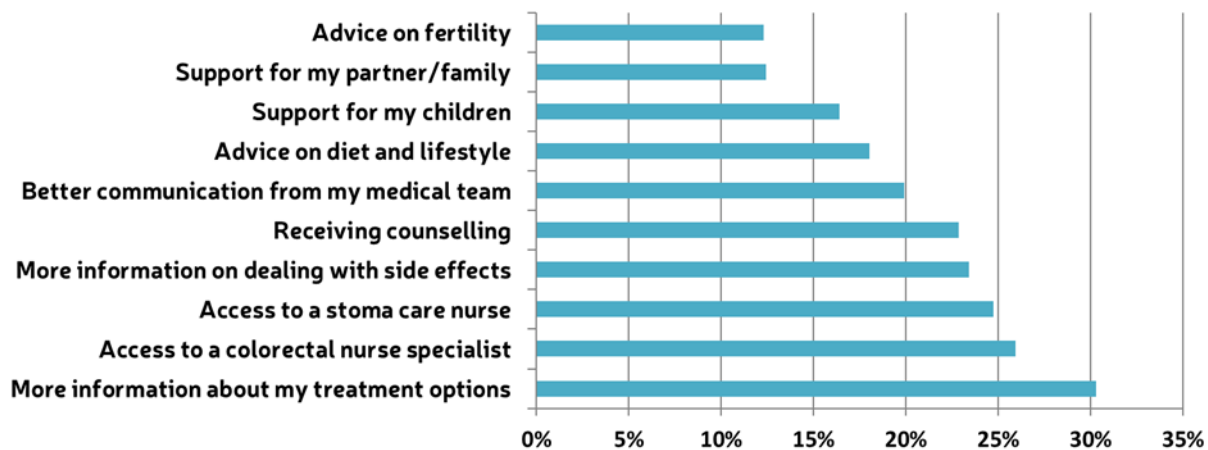
Access to counselling and emotional support was also another major factor contributing to patients' experience of care, with 16% of patients stating this would have helped them and their families to cope with effects of treatment and the stress of reoccurrence.



**Figure 4:** Ways to improve the health and social care support patients felt they received after treatment

The NHS 10 Year Plan needs to address deficiencies in the current support and care provided to patients after treatment. Improvements need to include:

- Aftercare plans put in place to help patients deal with the short-term and long-term side effects of treatment;
- Follow-up appointments with a nurse specialist;
- Provision of counselling services and signposting to emotional support groups for both patients and their families.



**Figure 5:** What patients felt could have been done generally to improve treatment experience

Patients reported on what could have been done generally to improve their treatment experience (Figure 5). **NHS England must ensure future care and treatment of bowel cancer patients includes:**

- **More support and information about treatment options,**
- **Access to a colorectal nurse specialist and stoma care nurse,**
- **More information on how to deal with side effects of treatment,**
- **Opportunities for counselling.**

Many felt that more support, particularly for loved ones, would also contribute to the improved quality of life as well as advice of fertility and diet and lifestyle.

**The following key themes emerged as priorities from the medical advisory survey to improve quality of life and treatment and care for bowel cancer patients:**

- **Need for better symptom management support and support for consequences of treatment including stoma care;**
- **Quality of life to be discussed at multidisciplinary team meetings (MDTs);**
- **Use Holistic Needs Assessments (HNAs) to identify patients who need extra emotional and information support and/or are less confident in self-managing treatment related consequences;**
- **Provision of specialist nursing;**
- **Ensuring the most appropriate chemotherapy treatment is given based on a patient's immuno-histochemical profile;**
- **Supporting patient's to have treatment breaks: lifting NHSE restrictions added to bowel cancer drugs including 6 week policy imposed on cetuximab and panitumumab;**
- **Provision of counselling service;**
- **Use of Patient Reported Experience Measures (PREMS) to continually improve care and support provided;**
- **Better provision of information and signposting to local services.**

### **3. How can we recruit, train and retain the workforce to deliver the changes we need and the priorities you have shared?**

NHS England must develop a fully-funded endoscopy action plan to tackle staff shortages in diagnostic services for bowel cancer. This should include how additional staff can be trained, recruited and retained to carry out these procedures, as well as the necessary support staff, such as endoscopy nurses. NHS England must also invest in pathology capacity to ensure bowel cancer cases, as well as advanced adenoma cases are diagnosed quickly and efficiently.

Increased job attractiveness is crucial to retaining the current and future cancer workforce. NHS England must ensure the workforce plan considers opportunities for career progression, including appropriate time and money ring-fenced for continued professional development of staff as well as attracting trainee nurses in the early stages of their career such as through nursing bursaries. Future job plans and descriptions must also embed learning and development opportunities to support career progression of staff and job attractiveness.

In addition, NHS England should increase the number of support worker roles and other administrative positions in order to support overstretched nursing staff so that this does not impede on their clinical and patient-facing time.

### **4. How can we address variation and inequality to ensure everyone has access to the best diagnostic services, treatment and care?**

#### **Making bowel cancer drugs available on the NHS**

NHS England must ensure new and innovative treatments are made accessible to bowel cancer patients.

Advances in the identification of genetic biomarkers are paving the way for the development of more effective targeted medicines but drug appraisal systems are outdated and need to be reformed to keep pace with emerging scientific discoveries. Many new treatments, such as personalised immunotherapy drugs, are currently not being approved for use on the NHS because of cost. For example, to date only two biomarker drugs, cetuximab and panitumumab, are available on the NHS for advanced bowel cancer for individuals with the RAS wild type gene. This has financial implications for patients and their families, with many resorting to fundraising or borrowing in order to fund treatments privately. This issue has been exacerbated by the introduction of the Budget Impact Test. The Government, NHS, and NICE must work closely with the pharmacological sector to ensure treatments can be made available on the NHS quickly and at a price the NHS can afford.

In order to ensure that all people with advanced bowel cancer can benefit from the development of personalised medicines, NHS England must ensure everyone is tested for these biomarkers. Wide variation exists in access to biomarker testing. Our advanced bowel cancer survey<sup>xii</sup> found that 56% of respondents were not offered the biomarker test necessary to determine if an available targeted therapy was an option. Our research also shows that,

despite guidance that recommends bowel cancer patients are tested for mutations in the MMR genes, many hospitals do not carry this testing out. Of these very few, 10%, carry this test out before treatment options are decided. This means some patients are being placed on chemotherapy options that are simply unlikely to be effective for them. As more genetic markers are identified, NHS England must test bowel cancer patients for a range of predictive genetic markers to ensure patients receive the right treatment.

### **Removal of NHS England treatment restrictions**

Once NICE has approved cancers drugs for routine use in the NHS, the Cancer Drugs Fund (CDF) and NHS England must not add any further restrictions to its use that do not appear in NICE guidance. These restrictions create variation in access and restrict patients from accessing vital life-prolonging and potentially life-saving drugs.

Both cetuximab and panitumumab were approved for use on the NHS by NICE in July 2017 (TA439) as a first line treatment for in patients who have RAS wildtype advanced bowel cancer. However, both drugs still currently appear on the current CDF list, and an additional six week treatment break restriction is in place. This treatment break is not reflected in the NICE guidance TA439 and is not applied in Wales and Scotland. It is unclear what the rationale, reasoning and evidence base is for this decision, creating uncertainty and confusion amongst both the medical and patient community as to why the restriction exists and contracting fundamental tenets of the NHS constitution. Treatment breaks are crucial to improving a patient's quality of life, which is extremely important when the median survival for advanced bowel cancer patients is 24-30 months. Unfortunately, this restriction has led to a situation where some patients are forced to remain on treatment since they are fearful that any break will result in treatment being withdrawn.

NHS England must urgently address treatment restrictions in the 10 Year Plan so that patients' access to vital drugs is not impeded by arbitrary restrictions.

### **Testing for Lynch syndrome**

Lynch syndrome is an inherited condition which causes around 1,200 cases of colorectal cancer annually in the UK, as well as over 1,000 cancers in others sites. Lynch syndrome is currently an under-recognised, under-diagnosed and under-managed condition. Fewer than 5% of gene carriers have been identified, including both people identified with Lynch syndrome following a bowel cancer diagnosis as well as family members.

[NICE DG27](#) recommends that everyone newly diagnosed with bowel cancer is tested for molecular features of Lynch syndrome. However, Bowel Cancer UK's recent Freedom of Information request found that only 6% of CCGs currently commission this testing and only 17% of hospitals are testing<sup>xiii</sup>. Alarming, 91% of the hospitals not testing for Lynch syndrome cited funding as the main barrier. Central to this issue is a lack of clarity amongst CCGs on commissioning responsibility, with many CCGs believing it is the responsibility of either NHS England or Public Health England. NHS England responded to an FOI request from

Bowel Cancer UK clarifying that, “testing should be commissioned through local budgets by CCGs given that cancer testing is based on local tariff arrangements”. It is therefore critical that NHS England establishes national protocols and funding to ensure testing can be carried out on all bowel cancer patients, and that commissioning responsibility is made clearer in the meantime.

### **Advanced multi-disciplinary teams for advanced bowel cancer**

Advanced bowel cancer patients must be discussed at regional advanced Multi-Disciplinary Team (MDT) meetings to ensure specialists such as liver and lung surgeons are consulted prior to treatment decisions. This is crucial as not involving specialists in the treatment decision of patients with advanced bowel cancer denies many patients the chance of potentially curative surgery.

[NICE CG131](#) guidance states advanced bowel cancer patients with liver metastases should be referred to tertiary advanced MDTs to assess resection. Bowel Cancer UK’s advanced bowel cancer survey<sup>xiv</sup> found a clear correlation between the involvement of specialists and the decision to resect; in cases where cancer had spread to the liver, 21% of patients did not have a liver specialist involved in their treatment decision and 37% did not have liver surgery. Furthermore, in cases where cancer had spread to the lungs, 26% of patients did not have a lung specialist involved in their treatment decision, and 55% did not have lung surgery.

This is supported by wider research<sup>xv</sup>, which found that 50% of patients seen by a liver MDT had liver surgery, compared to 41% not seen by liver specialists. It also found patients seen by liver MDTs survived on average for over 30 months, compared to 25 months for patients not seen by a liver MDT.

Bowel Cancer UK recommends the following specialist mix for advanced bowel cancer patients:

- Bowel, liver, and lung surgeons to decide and carry out the best course of surgery wherever the tumour is located;
- Oncologists with expertise in chemotherapy and radiotherapy to plan and deliver treatments;
- Radiologists capable of providing accurate imaging for tumour staging, as well as carrying out ablative and embolic therapies to treat tumours;
- Clinical nurse specialists to communicate outcomes and options from advanced bowel MDT meetings to patients, and provide high-quality information, support, and care throughout their treatment.

### **Supporting people living with advanced bowel cancer**

Patients under-going treatment for advanced bowel cancer experience a range of side-effects which significantly impact their quality of life – both physical and emotional. Unfortunately, patients often don’t get access to the treatment and support needed to alleviate these side-effects, with many occurring late and long after finishing treatment.

Possible late and long-term effects of treatment include tiredness, hernia, nerve damage, changes in bowel function, sexual function and bladder function. The side-effects caused by intense and prolonged treatment means advanced bowel cancer patients often require separate and additional treatment to address these problems.

Our survey<sup>xvi</sup> of advanced bowel cancer patients showed that the most commonly experienced side-effects experienced by our respondents were:

- Extreme nerve damage (peripheral neuropathy) – 47%
- Emotional side effects – 46%
- ‘Chemo brain’ or chemotherapy-related cognitive impairment (changes in memory, concentration and thinking processes) – 44%

More emphasis should be placed not only on the management of long-term and late effects but also their prevention. For example, research indicates that patients undergoing probiotic therapy alongside radiotherapy experience significantly reduced incidences of radiation induced side effects such as acute diarrhoea<sup>xvii</sup>. There are also surgical methods that can reduce the severity and number of post-treatment side effects, particularly for patients who present with rectal cancer<sup>xviii</sup>. However, further research is needed to better understand which treatments have what consequences and to identify and develop effective interventions to minimise them. Unfortunately, the impact of the treatment related consequence has been greatly underestimated for far too long. This is a poorly understood area by healthcare professionals. For patients, this has resulted in a lack of care and support to manage long-term and late effects and a failure to be referred for specialist care. Better and more streamlined pathways need to be in place to ensure rapid access to specialist services.

### **Earlier diagnosis and better outcomes for young people with bowel cancer**

Every year over 2,500 people are diagnosed with bowel cancer under the age of 50 in the UK. While this is only around 6% of all those diagnosed, this number is increasing. Since 2004, there has been a 48% increase in people diagnosed with bowel cancer under the age of 50. A survey of younger patients<sup>xix</sup> conducted by Bowel Cancer UK found that those under the age of 50 have a worse experience of being diagnosed, treated and cared for the condition than older people. They take longer to be diagnosed, and in some cases having to see their GP more than 5 times before being referred for crucial tests. We also found that 3 out of 5 young people were not aware of the symptoms of bowel cancer and that they could be at risk and 28% took 3 months to see GP. Many said they put off going to their GP because they thought their symptoms would go away. Consequently younger bowel cancer patients also tend to have poorer outcomes – 60% are diagnosed at the later stages of the disease and 34% are diagnosed in emergency care when the chance of survival is lower.

Younger patients also told us they struggled to find appropriate and targeted information about their condition. Only 11% said told us they had been offered information and support right for them.

The NHS Cancer Plan must address this variation in the diagnosis and outcomes between younger and older bowel cancer patients. Interventions that are looking at improving the

diagnostic pathway must also consider the extent to which they speed up the diagnosis of those under 50s. Bowel Cancer UK in partnership with the University of Durham and Hartlepool and North Tees NHS Foundation Trust, published research on a risk assessment tool to help GPs better identify the symptoms of a serious bowel condition in younger patients. NHS England should consider how this research can be implemented into practice in order to help speed up the diagnosis of younger bowel cancer patients.

### **Improving data quality and infrastructure**

High quality patient data and underlying data infrastructure is fundamental to identifying where variations in care exist and ensuring equal access to diagnostic services, treatment and care. However, there are currently numerous initiatives and groups generating data on variation and pathways for bowel cancer. This includes the National Bowel Cancer Audit, the Cancer Outcomes and Services Dataset (COSD), Clinical Services Quality Measures, Clinical Headline Indicators, the Cancer Dashboard, quality performance indicators, Get it right first time, ACE, surgeon level reporting, cancer vanguards and alliances and various separate teams in NHS England, NHS Digital, NHS Improvement, HQIP and Public Health England. Each of these access different datasets and use varying methods so it is difficult to determine which dataset is most accurate.

In order to improve quality of data collection and to agree ways to make data available for research, a working group must be convened bringing together relevant stakeholders including NHS Digital, NHS Improvement, PHE, NHR-UK, NCRAS, academics and patient representatives, to harmonise the various datasets.

### **Key outcome indicators for bowel cancer**

The NHS 10 Year Plan should include a number of evidence-based key indicators to improve bowel cancer outcomes over the next 5 and 10 years, where targets could be set at Cancer Alliance level and services should be delivered to achieve or exceed these targets. The indicators should drive the system to make sensible choices about how to allocate resource (such as more rapid adoption of FIT). Potential indicators could include:

- Overall survival more than 5 years
- Proportion of CRC diagnosed by screening
- Proportion of CRC presenting as emergencies
- Rates/cases of post-colonoscopy colorectal cancer (PCCRC)
- OR cases of PCCRC-3year
- Reduction in age standardised incidence of CRC
- Reduction in 90-day mortality after major surgery
- Reduction in 90-day mortality following elective or scheduled surgery

## Summary of key recommendations

### Optimal bowel cancer screening programme

- Implementation of an optimal Bowel Cancer Screening Programme (BCSP), as recommended by the UK NSC. This includes screening from age of 50, with FIT rolled out fully to the eligible population and a reduction in the sensitivity threshold to reach 20ug/g. In order to achieve this, a sensible but ambitious timeframe for implementation of this programme needs to be developed.
- Within 5 years we would also like to see early stage research on the development of risk algorithms to enable more personalised and better targeted screening, as well as better targeted resources.
- NHS England must also improve screening and surveillance for high risk groups, such as those with conditions like Lynch syndrome.

### Expanding workforce capacity

- The NHS 10 Year Plan and the five year settlement funding must address and make specific reference to how endoscopy and pathology capacity can be increased to support the implementation of the optimal bowel cancer screening programme in a sustainable manner.
- Future workforce planning must address issues in variation amongst endoscopy services by ensuring all staff conducting diagnostic tests, such as endoscopies, are accredited to a high standard such as the quality standards set out by the Joint Advisory Group for Gastrointestinal Endoscopy (JAG).

### Personalised medicine and access to innovative treatments

- The NHS must ensure that all patients are tested for a range of genetic biomarkers, such as RAS, MMR and BRAF at diagnosis, so that they are given the most appropriate treatment according to the immuno-histochemical profiles of their cancers.
- Support research and development into new, personalised, and whole pathway approaches to treatment. To achieve this, patients must have access to clinical trials.
- The new National Directory for genetic tests, as part of the National Genomic Service, is transparent in commissioning responsibility for testing and clear guidance is written for clinicians ordering these tests.
- The NHS must also support research and development into new, personalised, and whole pathway approaches to treatment. To achieve this, patients must have access to clinical trials.
- Once NICE has approved cancers drugs for routine use in the NHS, the Cancer Drugs Fund (CDF) and NHS England must not add any further restrictions to its use that do not appear in NICE guidance.
- The Government, NHS, NICE and SMC must work closely with the pharmacological sector to ensure treatments can be made available on the NHS quickly and at a price the NHS can afford.

- There must be reform to the methodology of appraisal processes for treatments to ensure more effective and innovative treatments can be made available to patients.

### **Prevention and early diagnosis**

- NHS England must work with Public Health England to support people in making and maintaining positive lifestyle changes as well as educating the public on bowel cancer risk factors.
- New early diagnosis models of care must be assessed and embedded into the NHS to achieve a stage shift.
- NHS England must work with Public Health England to improve awareness of bowel cancer symptoms in the population, especially where symptoms are vague and often confused with other illnesses and conditions.
- NHS England should consider risk-based stratification of FIT dependent upon the individual's characteristics (such as age, gender and ethnicity).
- The BCSP should facilitate the colonoscopic screening and surveillance of people with Lynch syndrome.
- A linked national database of people identified as Lynch syndrome gene carriers should be developed to support the BCSP to facilitate the call and recall of these patients.
- Additional investment must be made available to increase the capacity of endoscopy centres and cellular and molecular pathology laboratories, as well as genetic services.
- A dedicated clinical champion for hereditary colorectal cancer must be established in each colorectal multidisciplinary team to oversee service coordination and to ensure patient pathways are instituted.
- Future workforce planning must address issues in variation amongst diagnostic services by ensuring all staff conducting these tests, such as endoscopies, are accredited to a high standard.
- Evidence for the use of FIT in symptomatic patients must continue to be developed with NHS England using results to guide wider rollout of this programme.

### **Reducing variation and inequality**

- The Government, NHS, and NICE must work closely with the pharmacological sector to ensure treatments can be made available on the NHS quickly and at a price the NHS can afford.
- Once NICE has approved cancers drugs for routine use in the NHS, the Cancer Drugs Fund (CDF) and NHS England must not add any further restrictions to its use that do not appear in NICE guidance.
- All people with advanced bowel cancer should be tested for biomarkers in order to benefit from the development of personalised medicines.
- Advanced bowel cancer patients must be discussed at regional Advanced Multi-Disciplinary Team meetings to ensure specialists such as liver and lung surgeons are consulted prior to treatment decisions.

- Better and more streamlined pathways need to be in place to ensure rapid access to specialist services for advanced bowel cancer patients to ensure proper prevention and management of treatment side effects.

## Data

- PHE must convene a working group bringing together relevant stakeholders including NHS Digital, NHS Improvement, NHR-UK, NCRAS, academics and patient representatives, to harmonise the various datasets.
- It is recommended that over the next 5 and 10 years, a number of evidence-based key indicators are established to improve bowel cancer outcomes. These targets could be set at Cancer Alliance level and services should be delivered to achieve or exceed these targets. Targets should include: Proportion of CRC diagnosed by screening, proportion of CRC presenting as emergencies, absolute PCCRC-3year rates, OR cases of PCCRC-3year, reduction in age standardised incidence of CRC, reduction in 1 and 5 year CRC mortality, reduction in 90-day mortality, and other surgical outcomes.

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<sup>i</sup> Cancer Research UK (2015). Scoping the future: An evaluation of endoscopy capacity across the NHS in England

[https://www.cancerresearchuk.org/sites/default/files/scoping\\_the\\_future\\_-\\_final.pdf](https://www.cancerresearchuk.org/sites/default/files/scoping_the_future_-_final.pdf)

<sup>ii</sup> The Consensus Molecular Subtypes of Colorectal Cancer, Guinney, J., Dienstmann, R., Wang, X., et al, Nature Medicine, 21(11), 1350–1356, 2015

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<sup>iv</sup> <https://bowelcancerorguk.s3.amazonaws.com/Test%20images/NeverTooYoungreport2015.pdf>

<sup>v</sup> Routes to diagnosis of cancer by stage, (2012–2013), NCRAS [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis](http://www.ncin.org.uk/publications/routes_to_diagnosis)

<sup>vi</sup> [https://www.sheffield.ac.uk/scharr/sections/heds/discussion-papers/18\\_04-1.782806](https://www.sheffield.ac.uk/scharr/sections/heds/discussion-papers/18_04-1.782806)

<sup>vii</sup> [https://www.sheffield.ac.uk/scharr/sections/heds/discussion-papers/18\\_04-1.782806](https://www.sheffield.ac.uk/scharr/sections/heds/discussion-papers/18_04-1.782806)

<sup>viii</sup> Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups British Society of Gastroenterology (update from 2002) [http:// www.bsg.org.uk/images/stories/docs/clinical/guidelines/endoscopy/ccs\\_10.pdf](http://www.bsg.org.uk/images/stories/docs/clinical/guidelines/endoscopy/ccs_10.pdf)

<sup>ix</sup>

[https://bowelcancerorguk.s3.amazonaws.com/General%20pdfs/Clinical%20consensus\\_Lynch%20syndrome\\_2017\\_FINAL.pdf](https://bowelcancerorguk.s3.amazonaws.com/General%20pdfs/Clinical%20consensus_Lynch%20syndrome_2017_FINAL.pdf)

<sup>x</sup> Revised guidelines for the clinical management for Lynch syndrome (HNPCC) : recommendations by a group of European experts' The Mallorca Group, GUT 2013 62 (812–823) <https://www.ncbi.nlm.nih.gov/pubmed/23408351>

<sup>xi</sup> <https://www.bowelcanceruk.org.uk/news-and-blogs/campaigns-and-policy-blog/the-potential-of-fit-in-patients-presenting-with-bowel-cancer-symptoms/>

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<sup>xiii</sup> <https://bowelcancerorguk.s3.amazonaws.com/Campaigns/LYNCH%20SYNDROME%20REPORT%20FINAL.pdf>

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<sup>xv</sup> *ibid*

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<sup>xvii</sup> Probiotics for prevention of radiation-induced diarrhoea: A meta-analysis of randomized controlled trials, Liu, M, et al, PLoS ONE, 12(6), 2017.

<sup>xviii</sup> The APPEAR procedure for sphincter preservation Bowel & Cancer Research <http://www.bowelcancerresearch.org/bowel-cancer-research/theappear-procedure-for-sphincter-preservation/>

<sup>xix</sup> <https://bowelcancerorguk.s3.amazonaws.com/Test%20images/NeverTooYoungreport2015.pdf>