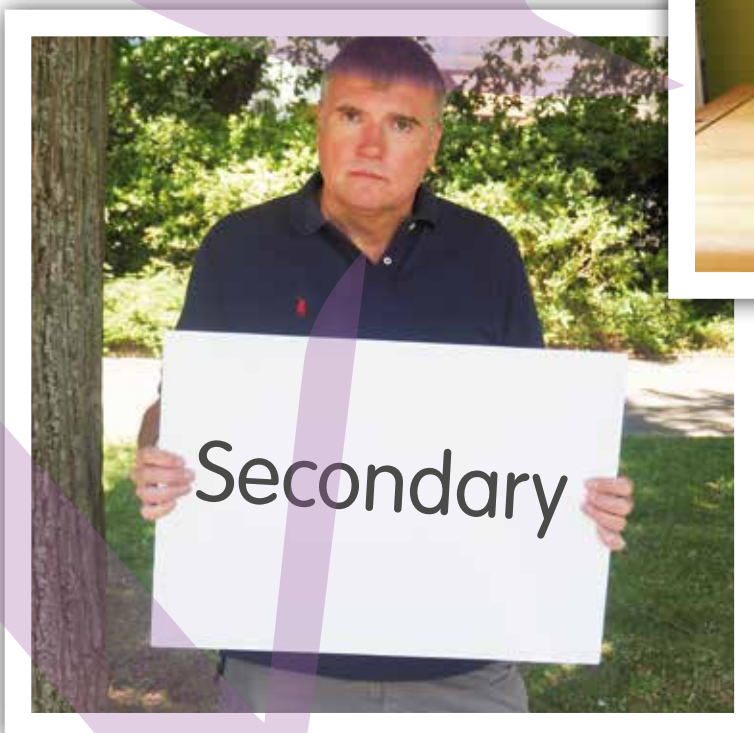


# Get Personal: Unlocking treatment options for advanced bowel cancer



# Thank you

This report draws on the findings from our survey, which was completed by a total of 111 patients diagnosed with advanced bowel cancer in the UK. Their insights were invaluable to this report, allowing us to understand the experiences of those with advanced bowel cancer and the challenges faced by them every day. Thank you to all those who responded to our survey and shared their experiences with us.

We would also like to thank our Medical Advisors who contributed to ensuring this report is clinically accurate:

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- **Prof. Robert Steele, Professor of Surgery**
- **Dr Tim Iveson, Consultant in Medical Oncology**

## About Bowel Cancer UK

We are the UK's leading bowel cancer research charity. We are determined to save lives and improve the quality of life for all those affected by bowel cancer. We support and enable research, educate patients, the public and professionals about bowel cancer, and campaign for early diagnosis and best treatment and care for all those affected.

## About bowel cancer

Bowel cancer is the fourth most common cancer in the UK and the second biggest cancer killer, affecting both men and women. Every 15 minutes in the UK someone is diagnosed with the disease. That is over 41,000 people every year. Bowel cancer is treatable and curable, especially if diagnosed early. Nearly everyone diagnosed at the earliest stage will survive bowel cancer. However, this drops significantly as the disease develops and spreads.

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If you only have time to take a quick look, we would recommend that you read the executive summary (p.4) and recommendations (p.28).

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# Executive summary

**Every year, around 10,000 people in the UK are diagnosed with advanced bowel cancer and many more go on to progress to stage 4 after being diagnosed at an earlier stage. This is when the cancer has spread from the bowel to other parts of the body – usually the liver or lungs.**

The chance of survival for these individuals is desperately low, particularly when compared with those diagnosed at an earlier stage who have a better chance of living their full life. More than nine out of ten people diagnosed with stage 1 bowel cancer survive five years or more after diagnosis, compared to just less than one in ten for people diagnosed with advanced bowel cancer.

Patients and family members who we have spoken to as part of this report have consistently told us they have had difficulty being diagnosed, do not get access to effective treatment options, including specialists, and support is not tailored to their individual needs.

To change this, we need a more ambitious programme to enable those diagnosed to live a longer and better quality of life. This report explores how the proportion of people diagnosed with advanced bowel cancer can be reduced, the importance of personalisation across the pathway and what support is necessary to enable patients and their family members to navigate a complicated treatment and care pathway.

## Reducing the proportion of people diagnosed late

Healthcare systems in the UK 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. Latest data shows that the best way to achieve this stage shift is through the UK bowel cancer screening programmes. Just 8% of screen detected cancers are diagnosed at the latest stage of the disease. This increases to 22% for those diagnosed via GP referral and jumps to 40% for people diagnosed in an emergency setting. However, low uptake rates and the accuracy of the screening test impact its effectiveness to achieve the stage shift needed. A new screening test – the faecal immunochemical test (FIT) – which is more accurate and easier to complete could help to improve this if it is implemented optimally.

## Unlocking treatment and care options

Access to the full range of treatment options, including surgery, chemotherapy, radiotherapy and targeted therapies, is essential to prolonging and enhancing quality of life for people with advanced bowel cancer. But if outcomes for people with advanced bowel cancer are to improve, a one-size fits all approach to managing, treating and caring for people with the disease will not work. Treatment needs to be personalised and tailored to each individual, from what drug they receive to what surgery or care and support they are given. Advances in the identification of genetic biomarkers is 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.

Evidence shows that patients who are seen by a specialist are more likely to undergo surgery to remove the metastasised tumour. These patients are also more likely to have higher survival rates. Despite this there is wide variation in the involvement of specialists in treatment decisions. Our survey found a clear correlation between the involvement of specialists and the decision to resect. The future of cancer treatments also lies in combining different treatment modalities, such as using surgery with radiotherapy in the treatment of lung metastases. These are the developments in treatment that could help to transform outcomes for advanced bowel cancer.

## Supporting people living with and beyond advanced bowel cancer

Support offered must go beyond treatment of the physical tumour but extend to dealing with the consequences of treatment. This includes physical side-effects of treatment, as well as wider implications of a cancer diagnosis, such as the psychological, emotional, social and financial impact on patients, their families and carers. Our survey found that 89% continue to experience side-effects after their treatment had been completed and many reported their lives had worsened as a result. Simple interventions are available to help patients manage the consequences of treatment but others are more difficult to treat and require specialist care. Unfortunately patients often do not get access to the treatment and support needed to alleviate these symptoms.

## The Get Personal Campaign

Through the Get Personal campaign we are determined to make real change happen for people diagnosed with advanced bowel cancer. We believe this is possible if the recommendations outlined in this report are implemented as a matter of urgency.

### Top recommendations:

- 1 **New models of care and interventions that can achieve a stage shift** must be developed and implemented.
- 2 All bowel cancer Multi-Disciplinary Teams (MDTs) must have access to and **include established regional advanced bowel cancer MDTs in treatment decisions**, including lung, liver, and pelvic specialists.
- 3 Clear, accessible **information and support in navigating the whole care pathway** must be provided to patients.

# Understanding advanced bowel cancer

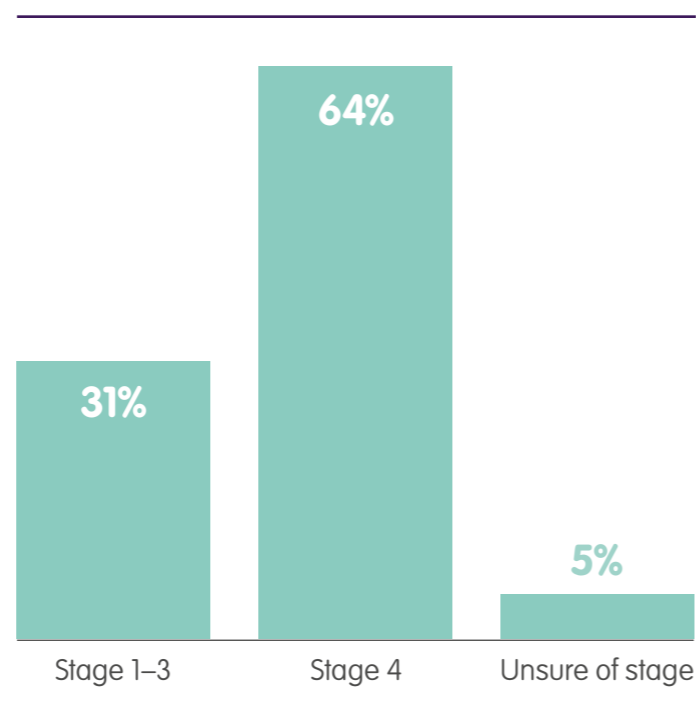
**Advanced bowel cancer is when the cancer spreads from the bowel to other parts of the body, most commonly the liver or lungs. It is also known as stage 4, secondary or metastatic bowel cancer. Of the 41,265 diagnosed with bowel cancer in the UK each year, approximately 23-26%<sup>1</sup> are diagnosed when the cancer has spread – the equivalent of around 9,490 – 10,700 people. However, even more go on to develop advanced bowel cancer after having been diagnosed at an earlier stage.**

Unfortunately, the exact number of people who progress to an advanced stage is unknown. This is because reliable data on this group of patients is not collected consistently locally or nationally. However, our survey found that while 64% of respondents were initially diagnosed at an advanced stage, 31% reported being diagnosed at an earlier stage before progressing to advanced bowel cancer. It is important that this significant gap in knowledge is rectified to enable appropriate planning for services that meet the needs of patients.

## Advanced bowel cancer is also known as:

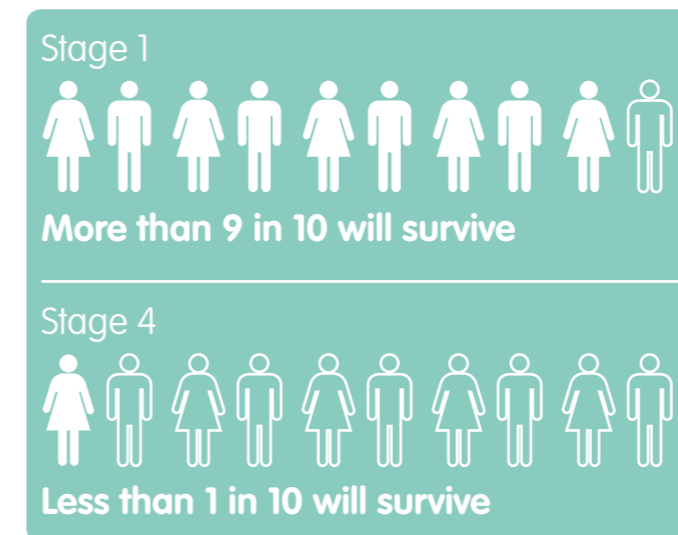
- Stage 4
- Secondary or
- Metastatic bowel cancer

Survey respondents stage at first diagnosis



## Stage and survival

The stage of a cancer is important because it affects survival rates. This is because when cancer spreads it is often more difficult to treat and so therapies are less likely to be effective at later stages of the disease. While every person will be affected differently, people with advanced bowel cancer typically have poorer outcomes compared to those diagnosed at an earlier stage. Overall, less than one in ten people with advanced bowel cancer survive for five years or more, compared to more than nine out of ten people diagnosed at the earliest stage of the disease<sup>2</sup>. We also know that those who die soon after diagnosis, i.e. within a year of being diagnosed, are more likely to be at an advanced stage where curative treatment options are not amenable<sup>3</sup>. Therefore, of the 16,000 people who die every year from bowel cancer – making it the second biggest cancer killer – many of these can be attributed to advanced bowel cancer.



## Why are people diagnosed late?

The reasons why people are diagnosed with advanced bowel cancer are multiple and complex. This can be due to the cancer type and the development and natural progression of the cancer. But it can also be, in part, due to delays in establishing a diagnosis. This includes delays in seeing a doctor, due to lack of awareness of symptoms and their potential seriousness, delays in being referred for diagnostic tests, or delays due to misdiagnosis.

In our survey, 30% of respondents reported being unaware of the symptoms of bowel cancer, nearly 20% waited more than three months to over a year to see a GP and 21% saw their GP five or more times before being diagnosed. But regardless of the reason, for these patients, being told they have advanced bowel cancer is a devastating and distressing time for them and their family and can have tragic consequences.

## The Get Personal campaign

Through the Get Personal campaign we are determined to improve survival rates and quality of life for everyone diagnosed with advanced bowel cancer. This report will address key issues affecting people with the disease across the care pathway – from diagnosis, to treatment, and support – and make a range of recommendations for policy changes that we believe will:

- **Reduce the proportion diagnosed with advanced bowel cancer** – through improved screening and access to diagnostics.
- **Unlock treatment options for advanced bowel cancer** – through improved access to the full range of treatment, including molecular testing and access to specialists.
- **Support people to live with and beyond bowel cancer** – through improved physical, emotional, and financial support, and palliative care.

The significant difference in survival rates between people who are diagnosed at an early stage compared with those who are diagnosed at an advanced stage makes it vital that we act now to improve this situation. We look forward to working with the Government, the NHS and professional bodies to take our recommendations forward.

## John Anton, 57, Hove



"I suffered with Irritable Bowel Syndrome and ulcerative colitis (UC) for about 15-20 years, so I had to have regular colonoscopy every couple of years but my symptoms eventually got worse and I was referred for an emergency colonoscopy. When I woke up from sedation I was faced with a very worried Consultant. He told me I had a large tumour in my bowel but would need further tests for staging. I was advised to have my bowel removed due to my UC history and after tests I was diagnosed as stage 3. It spread to a number of lymph nodes.

I was feeling pretty positive after my first operation. Everything was pointing in the right direction but then I had a scan and it all changed. The doctors found the cancer had spread to my liver. I was at an advanced stage. It felt like I was back to square one, as it meant more chemotherapy and more surgery.

Over the course of three years I've had to have major surgery on two separate occasions – once to remove my bowel and again to remove a large tumour from my liver and complex radiotherapy to treat a second spread back in my liver. The worse part of going through treatment was not knowing what the next steps were going to be. I had so many questions – when is my next scan; when is the follow up appointment for that scan; what happens after that; when will the MDT meeting take place; when will I hear their decision when and where is surgery going to happen; after surgery when will I get the biopsy results; what treatment will follow from that and when will I be passed from surgeon to oncologist.

This creates a lot of anxiety, which I still experience. In many ways, I know I will always be a cancer patient but I can't express how lucky and grateful I am to the NHS for the excellent treatment and care they gave me, and my family for their love and support.

I remember a time when I used to think about how me and my family could no longer go on holiday. I thought I wouldn't be able to go to the beach due to my stoma; I wouldn't be able to get life insurance; and I wouldn't be able to do a lot of the things my family and I used to do. Well, we've gone on lots of holidays since then. I realised life is too short.

Still being here has meant that I've been able to spend more time with my family and be there for those family celebrations, like our 30th wedding anniversary and my son's 30th birthday. My wife and I even renewed our vows with the family and Elvis at the Graceland Chapel in Las Vegas."

# 2 Reducing the proportion of people diagnosed late

**We know that survival of bowel cancer is closely linked to stage of diagnosis, so in order to improve survival rates we need to reduce the proportion of people diagnosed at an advanced stage by increasing opportunities to detect bowel cancer earlier.**

While there are factors beyond our control, such as natural disease progression and the genetic make-up of the cancer, other aspects that we know can also affect the stage of disease are within our control. These include increasing awareness of symptoms, minimising delays in the pathway and improving routes to diagnosis. Healthcare systems in the UK must take significant proactive steps to ensure people are diagnosed at earlier stages of the disease when it is more treatable and the chances of survival are high.

## Routes to an early diagnosis

While the reasons why people are diagnosed late are complex, we do know that the route to diagnosis can also affect the stage of cancer.

Although the majority of people are diagnosed via GP referral, latest data shows that the best way to achieve a stage shift is through screening. Those who are diagnosed through this route are less likely to be diagnosed with advanced bowel cancer than those diagnosed via GP referral or emergency presentation. In fact, data in England shows that just 8% of screen detected cancers are diagnosed at the latest stage of the disease. This increases to 22% for those diagnosed via GP referral and jumps to 40% for people diagnosed in an emergency setting<sup>4</sup>.

### The most common routes to diagnosis include:

**Screening:** a way of testing healthy people to see if they show any early signs of cancer. Individuals aged 60 (50 in Scotland) -74 are sent a home testing kit, which looks for hidden blood in poo.

#### GP referral:

- **Routine:** patients who have bowel symptoms but are not suspected as having bowel cancer or do not display symptoms that meet the criteria for an urgent suspected cancer referral;

- **Two week wait (urgent suspected cancer):** patients, who have symptoms that are suspected as being cancer, are placed on a two week waiting list to see a specialist by their GP. This is only the case in England.

**Emergency presentation:** patients who are either diagnosed at Accident and Emergency; receive an emergency GP referral to see a specialist; or receive an emergency consultant outpatient referral.

Consequently, as the stage of cancer affects survival rates, those diagnosed through screening have better survival rates compared to those diagnosed through other routes, such as emergency presentation. One-year survival figures show that 97% of people diagnosed through screening will survive. This drops to around 80% for those diagnosed via their GP and to just 49% for emergency presentation<sup>5</sup>. The following graph of survival rates by routes to diagnosis demonstrates that the biggest gain to be made, if survival rates are to be transformed, is through lowering the proportion of people who present as an emergency.

Yet despite these figures, only 10% of all diagnoses (24% in those of screening age) are detected via screening, compared with 24% through emergency presentation and 55% via GP referral<sup>6</sup>.

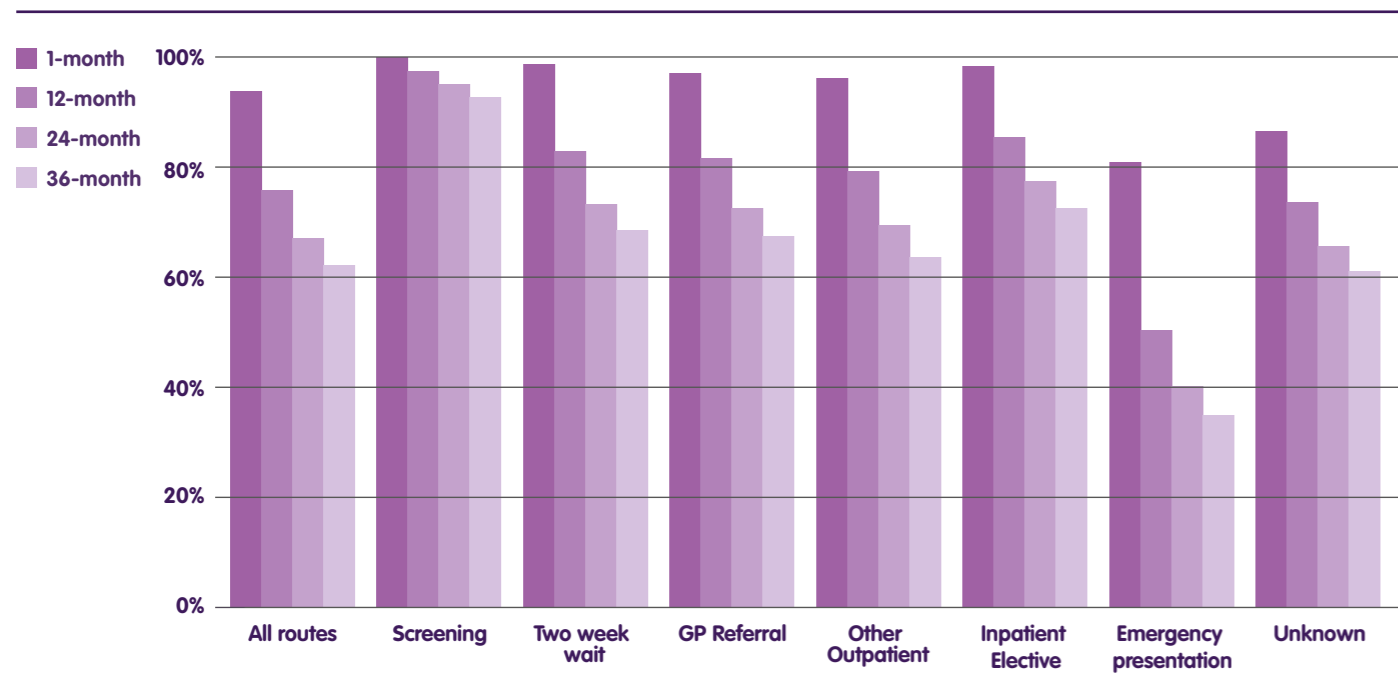
Route to diagnosis by stage of bowel cancer

	GP +2 Week Wait Referral	Emergency Presentation	Screening
Stage 1	18%	6%	37%
Stage 2	28%	26%	26%
Stage 3	32%	28%	29%
Stage 4	22%	40%	8%

It is evident that to achieve a stage shift new strategies and interventions need to be adopted. The UK bowel cancer screening programmes are such an intervention but similarly, increasing public awareness of the disease and improvements to the diagnostic pathway as a whole is also necessary. These include:

- Improving screening methods;
- Developing and implementing new care models;
- Identification and monitoring of high-risk groups.

Survival by route to diagnosis



## Reducing late diagnosis through screening

The evidence in favour of screening is overwhelming. However the screening programmes are currently limited in its ability to spearhead the significant stage shift required to reduce the proportion of people being diagnosed with advanced bowel cancer. The challenges that impact its effectiveness are primarily:

- **Uptake:** Currently just over half of people who receive the test complete it. Participation in screening across the UK varies considerably. In some areas only a third of the eligible population take part<sup>7</sup>;
- **Accuracy:** The current test only looks for the presence of blood in stools and can be affected by diet and medication. This means that it can miss up to 50% of cancers<sup>8</sup>.

Screening uptake rates by nation

57%  
Scotland

59%  
Northern Ireland

54%  
Wales

56%  
England



## FIT for purpose

FIT is proven to increase uptake, particularly in populations where uptake is typically low e.g. those from deprived communities, or from certain ethnic backgrounds. This is because it is easier to complete. It is also more accurate than the current test; detecting twice as many cancers and four times as many adenomas<sup>9</sup>. One of the reasons why FIT can be more accurate is that it is a quantitative test. This means the test can be adjusted to make it very sensitive to hidden traces of blood, so it could pick up more cancers. This could greatly reduce the proportion of people diagnosed late and improve the chance of survival for patients.

However, if we are to detect more cancers earlier, then it is crucial that FIT is brought in at a level to detect as many cancers and pre-cancerous cells as possible. Currently we know it is not possible to set FIT at the highest sensitivity level right away because it would mean more people are referred for colonoscopy. As it stands, the UK's endoscopy services do not have the capacity to meet current demands, let alone future demands. In England, at least one million more procedures are needed a year by 2020<sup>10</sup>. Urgent steps need to be taken to address the significant demand and capacity gap. Without this, the potential of FIT will not be fully realised.

FIT detects more cancers than the current screening test

2x cancers

4x adenomas

In order to improve the bowel cancer screening programmes, it is vital that changes are made. This has already begun with the introduction of a new screening test – FIT – into screening programmes in England, Scotland and Wales. At the time of writing this report Northern Ireland has yet to commit to the introduction of FIT.

# 3 Unlocking treatment options for advanced bowel cancer

## Reducing late stage diagnosis in symptomatic patients

Alongside having an effective screening programme and increasing endoscopy capacity, other means of improvement are necessary to achieve a stage shift.

Evidence shows that those who are diagnosed outside of the screening programme, following a symptomatic presentation, typically have poorer outcomes and are more likely to be diagnosed with advanced bowel cancer. Part of the reason for this is it can be difficult to know when to refer people because symptoms can be vague and are often attributed to other bowel conditions. For example, rectal bleeding can be misdiagnosed as piles but it is an early sign of bowel cancer. Referral guidelines are in place to help GPs to identify symptoms and refer patients onwards for further diagnostic testing. The problem is that many of the symptoms outlined in guidance are red flag symptoms that often mean late stage disease (i.e. stages 3 and 4). But research shows that there is a small window of opportunity to detect bowel cancer early in patients who present with symptoms<sup>11</sup>.

**“I mentioned the rectal bleeding on several occasions to my GP but was advised it was probably internal piles.”**

Within the context of NHS budgets being increasingly tightened and hospitals facing rising deficit levels, innovation in the diagnostic pathway and development of new models of care could be the key to maximising this window of opportunity.

**FIT in primary care:** Increasingly FIT is being used in primary care to rule out bowel cancer in patients who present with unexplained bowel symptoms. This means they are at low risk of bowel cancer and so do not qualify for an urgent referral. Using FIT in this way could help GPs to better identify and refer the right patients for further testing quickly and detect bowel cancer at an earlier stage<sup>12</sup>.

**Multidisciplinary diagnostic centres:** These diagnostic centres are a type of “one-stop shop” for people who present with vague symptoms. This is being piloted as part of the implementation of the Cancer Strategy in England as a way to streamline the pathway and provide rapid access to specialist assessment and diagnostic testing<sup>13</sup>.

However, it is yet to be determined whether these new models of care will lead to a stage shift, or simply speed up the pathway.

## Reducing late diagnosis in high risk groups

A third way of reducing the proportion of people diagnosed late, is through identifying and managing those who are at high risk of developing bowel cancer. These are people who are at high risk of the disease through having a genetic pre-disposition, such as Lynch syndrome or a strong family history of bowel cancer.

For example, Lynch syndrome is estimated to affect 175,000 people in the UK but currently only 5% have been identified<sup>14</sup>. This is because systematic testing of individuals is not taking place despite clinical guidance recommending that bowel cancer patients are tested for this condition. Identification of these individuals, who have up to an 80% chance of developing bowel cancer, is vital to ensure they can take steps to reduce their risk. We know that regular colonoscopy in this population can reduce the chance of dying from bowel cancer by 72% through detecting it at earlier stages<sup>15</sup>.

### Recommendations

- All hospitals must collect **meaningful and accurate data on all patients who progress to advanced bowel cancer**, in order to enable appropriate planning for services.
- Health bodies must **commit to a clear and timetabled programme to increase the sensitivity of FIT** in line with colonoscopy capacity.
- An **action plan to increase endoscopy capacity** must be developed in each nation to ensure rising demand for these tests can be met. This must include a **national training programme** to address severe staff shortages.
- New models of care and interventions **that can achieve a stage shift** must be developed and implemented.
- People who are at **higher risk of bowel cancer**, through genetic conditions such as Lynch syndrome or a strong family history of the disease, must be identified and be offered appropriate surveillance to ensure bowel cancer can be detected at earlier stages.

**Access to the full range of treatment options, including surgery, chemotherapy, radiotherapy and precision medicines, is essential to prolonging and enhancing quality of life for people with advanced bowel cancer. These treatments can relieve symptoms, keep the cancer under control, improve quality of life and help individuals live longer. In some cases, it can even cure the cancer. That is why it is crucial for patients to be informed of, and have access to, the full range of effective treatment options that are right for them.**

Although there are a range of treatment options available to advanced bowel cancer patients, there is currently no clinical agreement on the correct sequence of treatment, including whether the primary or secondary tumour should be removed first. Determining the correct sequence of treatment that would lead to the best outcome in this population remains a challenge and is one that needs resolving as a matter of urgency, if survival rates are to improve.

Current treatment options approved for use on the NHS for advanced bowel cancer are limited in their impact. Despite advances in the development of medicines, compared to many other diseases e.g. HIV, diabetes and chronic myeloid leukaemia, there have not been major, highly effective treatment breakthroughs to cure patients with advanced bowel cancer. This is further compounded by the limited access patients have to the most effective, pioneering and innovative treatments in development. Many patients are also unable to access treatment that could prolong their life and give them the best possible outcome. The resulting impact on patients both psychologically and in terms of survival is detrimental.

Patients should not just have access to treatment and care but access to treatment that is right for them. If outcomes for people with advanced bowel cancer are to improve, a ‘one-size fits all’ approach to managing, treating and caring for people with the disease will not work. Treatment needs to be personalised and tailored to each individual; from surgery, through to ongoing treatment, care and support.

Current routine treatment options available through the NHS include:

- **Surgery** – to remove the cancer tumours.
- **Chemotherapy** – to destroy the cancer cells and shrink the size of the tumour.
- **Radiotherapy** – to destroy the cancer cells and shrink the size of the tumour through the use of high energy x-rays.
- **Biological therapies (targeted medicines)** – to control, shrink and change the way cancer cells grow.

## Personalised treatment

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. 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.

**"I had to actively chase up some diagnostic tests, which took a long time and delayed my treatment. I was also not offered a discussion on any of the targeted treatments."**

### Bio-markers

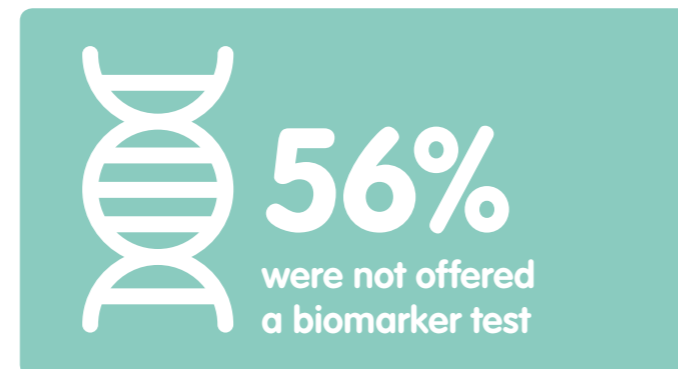
Breakthroughs in research have led to the identification of genetic biomarkers. These are individual genetic characteristics of a tumour, which can signify whether a treatment will be more effective in patients with that specific gene<sup>16</sup>. This heralds the beginning of truly personalised medicines for cancer patients.

However, to date only two biomarker drugs are available on the NHS for advanced bowel cancer. These are cetuximab and panitumumab. Both therapies are targeted at individuals with the RAS gene. If the patient has a normal RAS gene, or 'wild type,' these treatments are more likely to be effective. However, if the patient has a 'mutated' RAS gene the treatment is unlikely to work. Approximately 50% of people with advanced bowel cancer will have a normal RAS gene. Other targeted therapies are available to patients who have not responded to other treatments. They include Lonsurf and Aflibercept. Although these provide some benefit to patients, it is unclear which patients will benefit from them most, as no biomarker exists for these treatments.

Other mutations can also affect treatment options. For example, those who have a mutation in their mismatch repair (MMR) genes, which usually work to prevent cancer, do not respond well to certain types of chemotherapy. The BRAF gene has also been shown to have predictive value for the treatment of bowel cancer – a mutation in this gene could reduce the effectiveness of treatments and lead to a poorer prognosis<sup>17</sup>.

To ensure that all people with advanced bowel cancer can benefit from the development of personalised medicines, it is important that everyone is tested for these biomarkers. But while there is little national data regarding biomarker testing, our survey found that 56% of respondents reported that they were not offered the biomarker test necessary to determine if one of the available targeted therapies was an option. Our research<sup>18</sup> 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, advanced bowel cancer patients would significantly benefit from being tested for a range of predictive genetic markers to ensure patients receive the right treatment.



**"I think every cancer is unique, every patient is unique. The cancer type, the stage, the grade, the person's genes or biology, general health, environment, attitude, will be different for each person. As such this can build a bigger picture for what is the best route.**

**The personalised medicines, treatment advancements and immunotherapies allow for the patient**

**and their cancer to be treated on a case by case basis, which allows for the best chance for living life with dignity, and hope for living cancer free.**

**This takes away the feeling of being treated as a number or statistic to being treated as a person. These new methods are also showing signs of benefit, without the horrible side-effects such as the ones from chemotherapy."**

**Momenul Haque, advanced bowel cancer patient**



## Left vs right

In addition to genetic biomarkers, research is emerging that the location of a tumour could also predict the effectiveness of treatment. Recent research found that patients who have a right-sided tumour respond less well to existing treatments and have poorer outcomes, compared to those who have a tumour on the left-side of the colon. For example, those with left-sided tumours had longer median overall survival (33.3 months) compared to those with right-sided tumours (19.4 months). The same study also found a similar effect among patients receiving cetuximab – those with left-sided tumours survived for 36 months, while those with right-sided tumours survived 16.7 months<sup>19</sup>.

## Four types of cancer

The development of personalised treatment is even more important, given that recent research has shown bowel cancer not to be one disease but four distinct types of cancer<sup>20</sup>.

These four types of bowel cancer have been found to each have its own genetic profile and prognosis. For example, CMS4 is thought to be more aggressive, associated with advanced bowel cancer and poorer survival rates.

This ground-breaking discovery could help pave the way for the development of more personalised therapies for the different types of bowel cancer, and could therefore improve and extend the range of treatment options available.

If we are to achieve major improvements in survival for people with advanced bowel cancer, further research is needed to identify additional genetic markers that affect the effectiveness of treatment and to develop medicines that are targeted at the individual genetic make-up of a tumour.

### The four types of bowel cancer

- **Consensus molecular subtype (CMS) 1** – 14% of cases
- **CMS2** – 37% of cases
- **CMS3** – 13% of cases
- **CMS4** – 23% of cases

The remaining 13% of cases did not meet the profile of any of these four categories.

## Access to treatment

As well as coming to terms with a life changing diagnosis of advanced bowel cancer, patients also have to contend with additional challenges gaining access to effective treatment options. Many patients are unable to access a treatment that could prolong their life and give them the best possible outcome. This is because although treatment is available for free on the NHS, access to it is dependent on whether the treatment is approved for use.

The National Institute for Health and Care Excellence (NICE) in England and the Scottish Medicines Consortium (SMC) in Scotland approve drugs for use on the NHS based on how well the treatment works in relation to how much it costs, i.e. whether it is value for money and has a set cost threshold above which the NHS cannot afford to pay. Rising drug prices, an NHS with a finite budget and an outdated methodology for appraising drugs has meant that the current system for funding cancer medicines is unsustainable and has led to treatments not being approved for use<sup>21</sup>. Pharmaceutical companies must take this into consideration and ensure their treatments are priced responsibly.

This has financial implications for patients and their families, with many resorting to fundraising or borrowing money in order to fund treatments privately. For patients and their families, this inequity of access causes unnecessary stress, worry and anxiety when they are already struggling to come to terms with being diagnosed with advanced bowel cancer. The ultimate consequence of this is that lives are being lost to a disease that is treatable and even curable if there is access to the most effective treatment options.

These issues are likely to become more pronounced in England and Wales with the introduction of the Budget Impact Test. Under this policy any new treatment approved for use on the NHS by NICE, which is likely to cost more than £20million per year in the first three years, could be subject to indefinite delays and restricted access. This is while the NHS negotiates with the manufacturer regarding price. The proposals are likely to have a greater impact on treatments for more common conditions, like bowel cancer. This is because the more people that meet the criteria for a treatment, the easier it could be to breach the cost threshold. It could also result in pharmaceutical companies refusing to trial or provide lifesaving drugs in the UK if the cap is likely to be breached<sup>22</sup>.

It would appear there are no easy or quick solutions to improving the availability and pricing of treatments. Attempts have been made, such as the introduction of the England Cancer Drugs Fund (CDF) in 2010, which aimed to provide additional funding for cancer drugs that had not been approved by NICE. The CDF substantially increased access to biological therapies for bowel cancer, with more than 10,000 bowel cancer patients accessing treatment via this route. However, the overall cost of the programme spiralled well beyond its original budget. It was eventually reformed into a managed access scheme that sees drugs only entering the fund for a limited time until additional evidence can be gathered to support its use on the NHS.

“I asked about Lonsurf and my oncologist did not realise it was available. She then would not apply for funding that could have helped with the cost. It felt like a constant battle with my oncologist, and now I’m on a treatment that didn’t work a year ago and gives me awful side effects.”

The CDF was, in part, created in recognition that current NICE methodology is not suitable to appraise cancer drugs. This is because it does not take into account the wider societal benefits that cancer drugs have and the cost threshold has not changed since the inception of NICE, despite the increasing cost of developing cancer drugs. To ensure optimal and equitable access to the most effective treatment options for patients, there needs to be a fundamental reform to NICE methodology. Furthermore, the Government, NHS, NICE and the SMC must work closely with the pharmaceutical sector to ensure treatments can be made available on the NHS quickly and at a price the NHS can afford. They must also ensure appraisal processes are keeping pace with emerging scientific advances in treatment, such as immunotherapies, that could save more lives and improve quality of life.

### Biosimilars

The development of biosimilars is another emerging field and is increasingly being introduced into the market. These are drugs that are almost identical to an existing product produced by another pharmaceutical company and have the same safety and effectiveness as the original. While there is not yet a biosimilar for a bowel cancer drug, the development of these drugs could have implications for wider access to medicines. This includes creating increased choice for patients and clinicians, if costed appropriately, but equally it may also hinder the development of new, innovative and more effective treatments as pharmaceutical companies focus on producing biosimilars.

### Surgical decision-making

Personalised treatment also involves patients receiving the right surgical advice, delivered by clinical specialists at the right time. Typically, before patients receive treatment, they should be reviewed by teams of healthcare professionals, all with specific specialities relevant to the patients' cancer. These MDTs are recognised as the best means of developing and undertaking effective treatment decisions for patients with advanced bowel cancer. However, for MDTs to be truly effective, it is essential that the right specialists are involved in discussions and decisions regarding treatment options for patients.

**"I would have liked to have experienced real teamwork from both the medical, surgical and nursing teams. As a doctor and wife of a surgeon I know there is only so much each knows. Professionally we've seen the benefit of working with a team and of the patient experiencing joined up thinking. I don't think I got this."**

### Barbara Moss, 62, Worcester



"Like most people, I didn't expect to get bowel cancer. One day I was enjoying a 25-year teaching career, the next, I was in hospital with an advanced bowel cancer diagnosis and told I had five months left to live. This was six years after my first visit to the GP about my symptoms. It was utterly devastating! My husband was so shocked that he had to be supported. He sobbed in my arms.

I chose to research any and all available treatments, and found a drug called Avastin. My oncologist told me it was available in Europe and America, but not on the NHS.

Working with Bowel Cancer UK, I applied to authorities to fund the treatment, but was refused, despite an appeal and a solicitor's letter. This was frustrating, because I had precious little time for men in suits to decide whether or not to let me have a drug that could save my life. Cancer doesn't wait for bureaucracy, so we decided to pay for it ourselves.

The drug worked dramatically and after four months my tumour had shrunk enough for it to be removed in one operation. But the cancer came back, and so, with no hair, weakened by chemotherapy and my operation, I had to fight again, for further treatments. I felt that a dozen men in suits were playing God with my life! And they weren't listening to me! I was being ignored. I had to raise more funds for another round of treatment as my appeal for funding was again declined

Now, with thousands of pounds spent, I am in remission and have been for seven years.

In those years I have seen my sons graduate, get married, my mum turn 90, and have been able to take holidays with my loving husband.

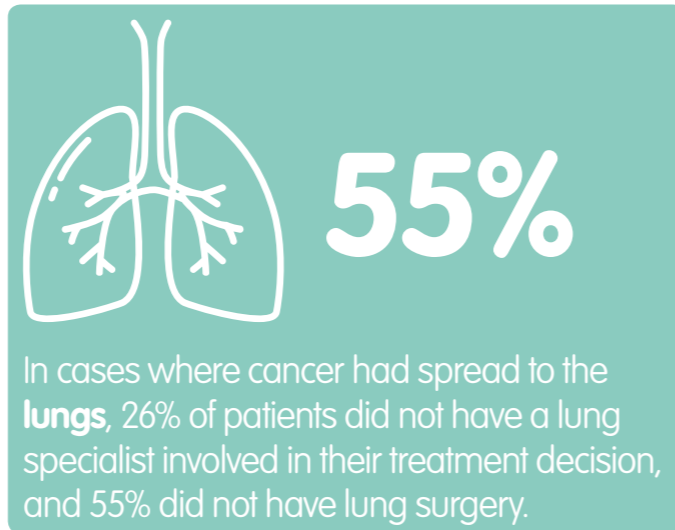
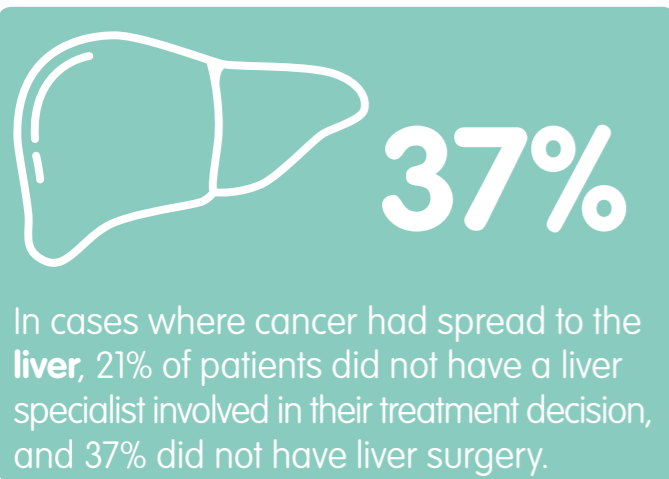
This experience has totally changed my outlook on life. As a result I've become an active patient advocate because it cannot be right that other people may not have the chances I had. I'm determined to help make sure other people survive like I have."

## Involvement of specialists

Surgery to remove cancer that has spread from the bowel to other parts of the body is a key element in the treatment pathway for patients with advanced bowel cancer. Patients normally undergo chemotherapy and/or biological treatment to shrink the tumour in order to improve the chance of removing it successfully. The decision on whether a tumour that has spread is resectable is one that can have significant implications for the prognosis of advanced bowel cancer. Those whose tumours are not deemed resectable are normally placed on a palliative care pathway rather than treated further with curative intent.

## Managing liver metastases

One area of surgical intervention is liver surgery. Approximately 20% of patients with advanced bowel cancer have liver metastases. These patients benefit significantly from surgical interventions. In fact, those treated with chemotherapy alone survive for around 6 to 22 months, compared to 44–74% of people surviving five years following liver resection<sup>23</sup>. Clinical guidance also recommends referring patients with liver metastases to specialist hepatobiliary (HPB) MDTs. Despite this there is wide variation in the involvement of specialists in treatment decisions. Our survey found a clear correlation between the involvement of specialists and the decision to resect:



This is supported by wider research, 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<sup>24</sup>. In addition, patients treated at a hospital with an HPB MDT were associated with improved survival rates. Further research has also highlighted the devastating impact that treatment decisions can have on patient outcomes. This study found that of 53 patients with liver metastases who had not been reviewed by a specialist surgeon and were being treated with palliative chemotherapy, 63% could have had their liver resected. The study concluded that the management of patients with liver metastases without the involvement of a specialist liver MDT can lead to patients being denied potentially curative treatment<sup>25</sup>.

**“The first MDT I saw said my liver metastases were inoperable after 18 cycles of chemotherapy. I had to seek a second opinion from an MDT that was very far from my home. This MDT said I was operable.”**

## The future of surgery

Increasingly, new and innovative surgical treatments for bowel cancer patients that are more effective and personalised are being developed. Most recently, we have seen great advances in combining different treatment modalities, such as drugs and surgery, to help shrink tumours to a size that makes surgery more likely to be effective at curing patients. Other forms of surgery, which have been pushing boundaries, include hyperthermic intraperitoneal chemotherapy (HIPEC), where extensive surgery is combined with hot flushing the abdomen with chemotherapy to treat peritoneal metastases.

## Access to clinical trials

Essential to facilitate new and better treatments, is the need to increase patient access to clinical trials. Currently, patients are able to join clinical trials through recommendations by doctors, and patient organisations, or by registering their interest independently. This requires patients and doctors to be aware of, or know where exactly to look for trials that relate to the patient’s specific condition. This can lead to inequality of access to relevant clinical trials. Our survey found that 80% of patients with advanced disease did not participate in a clinical trial.

It is essential that easier, faster, and smarter ways of recruiting patients for clinical trials are developed. Key to this is improving the quantity and quality of information made available to patients, and patient organisations on participation in clinical trials<sup>26</sup>.

## Personalised care

Personalisation should also extend to the care, support and information that patients and their family members receive. This is because not only is every cancer unique but every cancer patient is unique and has different information, psycho-social, and support needs. Some patients require more information and some have greater emotional support needs than others. However, many patients experience a one-size fits all approach to support and their individual needs are not taken into consideration. Adopting a personalised approach to delivering care to patients enables them to:

- 1 Gain greater information and understanding of their condition and treatment, which allows them to make better treatment decisions and better manage the side-effects of treatment
- 2 Access tailored support services, which can:
  - Increase their confidence and skill in managing the side-effects of treatment
  - Support them in dealing with broader social, psychological, and emotional side-effects of treatment
- 3 Receive consistent levels of care right for them
- 4 Play an active role in designing care services for themselves and other patients<sup>27</sup>

## Navigating the treatment and care pathway

The treatment pathway for advanced bowel cancer is incredibly complex, involving multiple healthcare professionals, a range of treatment options, a number of steps and numerous decisions to make. For patients and family members this can be overwhelming and it can be difficult to know which healthcare professional to turn to for information and support, what comes next in the treatment pathway and what decisions to make. To address this, patients should be provided with a clear and accessible checklist of who is involved in their care and what steps are involved in this process – from diagnosis right through to living with and beyond the disease. This would enable patients to better understand and engage with their treatment and care.

### Recommendations

- Patients should have **timely access to the full range of effective treatment options**, to enhance and prolong their quality of life. These options include:
  - Radiotherapy
  - Interventional radiology (such as ablation and loco-regional treatments)
  - Targeted medicines
  - All potential surgical options
- All bowel cancer MDTs must have access to, and **include, established regional advanced bowel cancer MDTs in treatment decisions**, including lung; liver; and pelvic specialists.
- There must be **further research and development into new, personalised, and whole pathway approaches to treatment** – such as identifying genetic biomarkers. To achieve this, **patients must have access to clinical trials**.
- All patients must be **tested for a range of genetic biomarkers**, such as RAS, MMR and BRAF at diagnosis to ensure they receive the right treatment.
- 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.
- 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**. They must also ensure appraisal processes are keeping pace with emerging scientific advances in treatment and that pharmaceutical companies are pricing drugs responsibly.
- Clear, accessible **information and support in navigating the whole care pathway** must be provided to patients.
- Further research is needed to establish an **optimal treatment pathway** that will lead to the best outcomes for advanced bowel cancer patients.

## Stacey Heale, 37, Southampton



“My partner, Greg, was diagnosed with advanced bowel cancer at 40 years old. Four years before his diagnosis, Greg was constantly suffering with severe symptoms, which made life difficult. But because his symptoms were always put down to other less serious conditions, we just accepted and hoped Greg would get better. However, he got progressively worse.

One night just before he was diagnosed he was in so much pain that I took him to A&E only to be sent home. I had to call for an ambulance when I got home because Greg was still in so much pain. When the paramedic arrived and examined him, he immediately drove us to the hospital and demanded that Greg have a CT scan. It was at this point that he was eventually diagnosed with bowel cancer.

Despite the consultant’s assurance that the tumour hadn’t spread, a week later we were told that his cancer had gone into his lungs and that he was inoperable. I went into complete shock, while Greg stayed calm. We had conversations about how we’d tell our kids of his condition, and cancelled all of our plans including our daughter’s first birthday party.

After Greg was diagnosed, I started researching treatment options myself as information wasn’t readily available on the NHS. I found it difficult to know who to turn to, where to go. I had to do it all myself. The system is complex and it isn’t easy finding your way around and at the same time come to terms with the fact that someone you love has advanced bowel cancer.

There’s only so much the NHS can do for people with advanced bowel cancer. It’s not a personal approach, it’s a ‘one size fits all’, set up mainly for older people. We went to a chemotherapy workshop and we were the youngest couple by decades, the nurses were chatting about extending life so they can continue to play with their grandkids – our kids are toddlers. This has to change, otherwise people like us and our family will continue go without the support needed to get through advanced bowel cancer.”

# 4 Supporting people to live with and beyond advanced bowel cancer

**Developments in the treatment and care of advanced bowel cancer means more and more people are living with and beyond the disease than before. However it also means that more people are living with the consequences of treatment and a diagnosis of advanced bowel cancer. These consequences often lead to a reduced quality of life for the individual affected and their family members.**

To improve the quality of life for those living with advanced bowel cancer, support offered must go beyond treatment of the physical tumour but extend to dealing with the consequences of treatment. This includes physical side-effects of treatment, as well as wider implications of a cancer diagnosis, such as the psychological, emotional, social and financial impact on patients and, if they have them, their families and carers.

**“I feel that the lifesaving treatment was exceptional but the emotional side of things is not treated with the same importance. Also once treatment has finished it can be very isolating and difficult to adjust back to normal life.”**

## Consequences of treatment

Patients undergoing treatment for advanced bowel cancer experience a range of side effects which significantly impact on their quality of life. Additionally, even when patients have completed their treatment and have no evidence of cancer, they often continue to experience both physical and psychological side effects. These consequences of treatment and cancer can carry on for more than six months (long-term effects) or begin months or years after they have finished treatment (late effects)<sup>28</sup>. The personal and often distressing nature of these ongoing side effects can be traumatic for patients, and their families.

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 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%

89% continued to experience ongoing side-effects even when they had completed their treatment and 32% of respondents reported stopping treatment due to the side-effects. Many respondents also reported that their lives had worsened as a result.

**“There needs be more support and after care. I was left very vulnerable and in a lot of pain, mentally and physically with no advice or anybody I could turn to. I felt so alone after treatment finished.”**

While there are some side-effects where simple interventions could provide patients with much needed relief, there are others that are more difficult to treat and require specialist care. Unfortunately patients and their families often do not get access to the treatment and support to alleviate these symptoms. Furthermore emphasis should be placed not only on the management of long-term and late effects but also their prevention. For example, acute radiation-induced diarrhoea is a common side-effect of colorectal cancer treatment that impinges on a patient’s recovery and quality of life. Research indicates that patients undergoing probiotic therapy alongside radiation therapy experience significantly reduced incidences of radiation induced side effects<sup>29</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>30</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 consequences of treatment and cancer has been greatly underestimated for far too long. This has led to this area being poorly understood by healthcare professionals and a lack of awareness of how to deal with the consequences of treatment. 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.

## Emotional and psychological support

The emotional and psychological impact of an advanced bowel cancer diagnosis on both patients and family members cannot be underestimated. Patients have reported that their diagnosis and the impact of treatment, as well as the difficulty in accessing treatment, has led to them becoming depressed and feeling isolated. In our survey 20% reported that they were not given enough emotional support during their treatment. This figure increased to just over a third when asked if their family members /carers received enough emotional support. Additionally, respondents who reported not having access to a clinical nurse specialist were significantly more likely to feel they were not given enough emotional support (50%) or that their family/caregivers were not given enough emotional support (70%) than those that did. The emotional and financial impact of advanced bowel cancer on families, as well as the potential impact of losing a family member is significant.

**“I feel like I was left to my own devices when I talk to other people about how great their support was. I had no follow up care plans or support to deal with trauma emotionally or physically and was not offered any different treatments to help my pain.”**

## Employment and financial support

In addition to the consequences of treatment and the emotional impact of advanced bowel cancer, reduced income is another burden that patients and their families have to contend with. Often patients and/or their family members have to either take time off work, reduce their hours of employment or leave employment all together, resulting in a loss of income. Research has shown that on average people diagnosed with cancer are likely to be just over £500 worse off every month due to a loss of income and increasing expenditure<sup>31</sup>. Our survey found that 75% of respondents felt that employment and/or finances were negatively impacted.

In particular, younger people were more likely to report financial hardship than older people – 88% of those under 50 reported being worse off, compared to 59% of those over 50. The younger age group was significantly more likely to have to take time off work (68%), have their income negatively affected (53%) and to have to draw on their savings (57%) than the older age group (37%, 31%, and 22% respectively).

## Palliative and end-of-life support

For those who are nearing the end of their life it is important that they are supported to make decisions that allow them and their family or carers to be prepared.

**“I would prefer honesty from the medical staff about my likely chances of survival.”**

The care provided should be well coordinated and planned so that their needs and views are taken into account. It is vital that healthcare professionals have adequate training and that the health system has capacity to provide the support and care patients need at the end of their lives.

Worryingly, our survey found that only 7% of respondents discussed an end of life care plan with a healthcare professional. This lack of both planning and patient-involvement can result in inadequate decisions being made about a patient’s care once the cancer has been found to be incurable. It can also have severe emotional and mental health consequences for those at the end of their lives, and their families supporting them.

## Conclusion

**This report shows that with timely access to effective treatment and high quality care that is personalised to each individual patient, people with advanced bowel cancer can see their survival chances and their quality of life dramatically improve. But for too many patients, opportunities to detect bowel cancer at earlier stages are missed or are not available, access to treatment is dependent on whether they have been approved for use rather than what their clinicians believe would benefit them most and individual care and support needs are not met.**

**If outcomes for people with advanced bowel cancer are to improve, a one-size fits all approach to managing, treating and caring for people with the disease will not work. Treatment needs to be personalised and tailored to each individual from what drug they receive to what surgery or care and support they are given. To make this achievable the recommendations outlined in the report must be fully implemented.**

**Advanced bowel cancer is personal. Treatment and care should be too.**

### Recommendations

- **Healthcare professionals should be educated on the physical and psychological effects of treatment** patients may experience, and equipped to provide this information in an appropriate manner to patients. There should be clear pathways and sign-posting to services where they can receive support.
- **Patients should be assessed systematically for treatment toxicities** using sensitive Patient Related Outcome Measures at every follow up visit to the cancer unit.
- **Patients and their families must have easy access to high quality information** including information on:
  - Psychological and emotional support available to them;
  - Symptom management; who and how to ask to be referred in worsening situations;
  - Welfare benefits and other financial support options available to them.
- **Every patient and family must be involved when planning end-of-life care** and their views and needs taken into consideration.

# Recommendations

**We are calling on Government, NHS and health bodies across the UK to implement the following recommendations to transform survival rates and quality of life for people with advanced bowel cancer:**

## Reducing the proportion of people diagnosed late

- All hospitals must **collect meaningful and accurate data on all patients who progress to advanced bowel cancer**, in order to enable appropriate planning for services.
- Health bodies must **commit to a clear and timetabled programme to increase the sensitivity of FIT** in line with colonoscopy capacity.
- An **action plan to increase endoscopy capacity** must be developed in each nation to ensure rising demand for these tests can be met. This must include a **national training programme** to address severe staff shortages.
- **New models of care and interventions that can achieve a stage shift** must be developed and implemented.
- People who are at **higher risk of bowel cancer**, through genetic conditions such as Lynch syndrome or a strong family history of the disease, must be identified and be offered appropriate surveillance to ensure bowel cancer can be detected at earlier stages.

## Unlocking treatment options for advanced bowel cancer

- Patients should have **timely access to the full range of effective treatment options**, to enhance and prolong their quality of life. These options include:
  - Radiotherapy
  - Interventional radiology (such as ablation and loco-regional treatments)
  - Targeted medicines
  - All potential surgical options
- All bowel cancer MDTs must have access to, and **include, established regional advanced bowel cancer MDTs in treatment decisions**, including lung, liver, and pelvic specialists.
- There must be **further research and development into new, personalised, and whole pathway approaches to treatment** – such as identifying genetic biomarkers. To achieve this, **patients must have access to clinical trials**.
- All patients must be **tested for a range of genetic biomarkers**, such as RAS, MMR and BRAF at diagnosis to ensure they receive the right treatment.

- 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.
- 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**. They must also ensure appraisal processes are keeping pace with emerging scientific advances in treatment and that pharmaceutical companies are pricing drugs responsibly.
- Clear, accessible **information and support in navigating the whole care pathway** must be provided to patients.
- Further research is needed to **establish an optimal treatment pathway** that will lead to the best outcomes for advanced bowel cancer patients.

## Supporting people to live with and beyond advanced bowel cancer

- **Healthcare professionals should be educated on the physical and psychological effects of treatment** patients may experience, and equipped to provide this information in an appropriate manner to patients. There should be clear pathways and sign-posting to services where they can receive support.
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- **Every patient and family must be involved when planning end-of-life care** and their views and needs taken into consideration.

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Bowel Cancer UK is the UK's leading bowel cancer research charity.

We are determined to save lives and improve the quality of life for all those affected by bowel cancer.

We support and enable research, educate patients, public and professionals about bowel cancer and campaign for early diagnosis and best treatment and care for all those affected.

**Find out more at [bowelcanceruk.org.uk](https://www.bowelcanceruk.org.uk)**



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