



Never Too Young

Tackling the challenges faced by people under 50 with bowel cancer



Bowel CancerUK
Beating bowel cancer together

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Thank you

No one understands the unique experience of diagnosis, treatment and support for bowel cancer like those directly affected, and we would like to thank the younger people whose experiences make up this report, including:

- the younger people living with bowel cancer who attended our Never Too Young workshop in 2019 which inspired this work
- the 1,295 people who completed our survey
- the patients and family members who shared their experiences and allowed us to use their pictures and tell their stories in this report

We would also like to thank the National Colorectal Cancer Nurses Network and our Medical Advisory Board for their support and insight and for helping to disseminate the survey to patients.

Executive summary

Bowel cancer is the UK's fourth most common cancer and the second biggest cancer killer. However, the disease is treatable, even curable, if diagnosed early, but too often it is diagnosed at a late stage when the chances of survival are much lower. Most people with bowel cancer are over 50, but a significant number of people are diagnosed with the disease when they are younger.

To understand more about the unique experiences of younger people with bowel cancer and how we can improve them, we started our Never Too Young campaign in 2013. Since then, we've influenced policies at a national level to enable faster diagnosis of younger patients. This report describes the results of a survey of more than 1,000 younger bowel cancer patients conducted during the winter of 2019/2020 and prepared before the outbreak of the COVID-19 pandemic. These results, captured at a time of 'business as usual' for the NHS, show that the improvements achieved to date are still not enough: younger people with bowel cancer are still facing significant barriers to early diagnosis, not being tested for genetic conditions that may inform their treatment options, and not being properly supported once medical treatment has ended.

The COVID-19 pandemic has been an unprecedented crisis, having a profound impact on NHS services across the UK and will continue to do so for the months and years to come. Sadly, those with bowel cancer have been disproportionately affected by the crisis, with countless people unable to access lifesaving treatment and surgeries during this time, as well as cancer screening and surveillance being paused. As a result, the pandemic has served to amplify existing issues experienced by younger people with bowel cancer. As the NHS starts to restore and recover services, it is essential that now, more than ever, the findings and recommendations of this report are urgently acted on to improve the diagnosis, treatment and care of younger people moving forward.

Half of younger people surveyed didn't know that they could develop the disease before their diagnosis.

As a result, they were more likely to delay getting help as they assumed their symptoms were something less serious or would go away. We want to raise awareness of the small but present risk to people under 50, not to alarm, but to ensure that younger people recognise symptoms need to be reported to their GP.

Four in ten people had to visit their GP three or more times before being referred for further tests.

GPs play the vital role of 'gate-keeper' to further investigation; they must be equipped with the knowledge and tools to refer younger people with bowel cancer symptoms at the earliest opportunity. Although there is guidance for GPs for the referral of people under 50 with symptoms of bowel cancer, this hasn't been effectively translated into practice and as a result patients are still facing damaging delays. We found that some patients were even told by their GP that they were too young to have the disease, leading to unacceptable delays to their diagnosis and treatment.

Nearly half of those diagnosed with bowel cancer after 2017 hadn't been offered testing for Lynch syndrome.

This is despite guidance to test all bowel cancer patients for this condition being introduced that year. A disproportionate number of young bowel cancer patients have Lynch syndrome, a genetic condition which increases the chance of developing bowel cancer to up to 80%. It's crucial that the guidance is followed. Without the test, patients may receive a treatment that won't work for them, will not receive regular surveillance and are unable to advise their family members to be tested.

One in five younger patients with bowel cancer told us they did not have access to a Clinical Nurse Specialist (CNS),

a key contact for patients, who manage their care and act as the first point of contact for queries and concerns. Patients with access to a CNS were more likely to feel involved in their treatment and had a better level of information and support than those who didn't. 63% of those who had access to a CNS were highly satisfied with their involvement, compared to 39% of those who didn't.

Patients experienced varying levels of support at different points in their diagnosis, treatment and care.

We found that 94% of people felt supported during their treatment, but one in four felt the support they needed wasn't there after treatment had ended. Younger bowel cancer patients often have different concerns to those diagnosed after 50. Information and support must reflect this by being appropriate to their age and life-stage.

40% of people were not satisfied with the amount of support and information about fertility and family planning they received.

Similarly, the level of mental health and wellbeing support was also seen as unsatisfactory.

These findings highlight the areas where change to policy and practice is urgently needed to improve outcomes for the 2,500 people aged under 50 diagnosed with bowel cancer every year in the UK.

We urgently recommend:

- 1** People and GPs should be aware of the symptoms of bowel cancer and that it can affect people under the age of 50
- 2** Younger people going to their GP with symptoms of bowel cancer should be referred for further tests without unnecessary delays
- 3** Younger patients with the disease should have treatment, care and support tailored to their needs
- 4** All younger bowel cancer patients should be tested for Lynch syndrome as soon as they are diagnosed
- 5** Challenges in the healthcare system amplified by COVID-19, such as endoscopy capacity, must be addressed urgently to prevent further barriers to diagnosis for younger people

Methods

The findings in this report are based on the responses of 1,073 people who had been diagnosed with bowel cancer under the age of 50 in the UK who completed an online survey, and a further 222 individuals who responded on behalf of someone who had been diagnosed with bowel cancer under the age of 50 in the UK.

We conducted this survey between Thursday 28 November 2019 and Sunday 5 January 2020. The survey was disseminated online through social media, in emails to our supporters and campaign network. The survey was also disseminated to patients through the National Colorectal Cancer Nurses Network (NCCNN) and our Medical Advisory Board (MAB).



I fully believe that cancer is not just a physical battle but more of a mental battle.

Luke, stage 4, diagnosed aged 32



1 Bowel cancer in younger people

Every year over 2,500¹ people under the age of 50 are diagnosed with bowel cancer in the UK². While this accounts for only six percent of those diagnosed with the disease, the number is increasing.³ The size of this group of patients is comparable with the number of people of all ages diagnosed with different cancer types, such as cervical cancer (3,192)⁴ and testicular cancer (2,364).⁵ Despite this, awareness that this is a disease that younger people can be diagnosed with is low amongst the general public and healthcare professionals.

As a result, people under 50 can find it harder to get a diagnosis through referral by their GP, with one in four being diagnosed as an emergency, compared to one in seven in over 50s. Delays in being referred for crucial and potentially lifesaving tests lead to younger people being diagnosed at a later stage when their chance of survival is worse. One in four bowel cancer patients under 50 are diagnosed at the latest stage in comparison to one in five in those over 50.

Our Never Too Young campaign

Our Never Too Young campaign was launched in 2013 after we increasingly heard from younger bowel cancer patients that they were being diagnosed late, having been told they were too young to have the disease. They also told us of their frustration about the lack of support they received when dealing with the effects of bowel cancer and its treatment.

Our Never Too Young campaign is leading the change for younger bowel cancer patients. We are:

- raising awareness amongst the public and clinical community
- campaigning for the identification of those at high risk of developing bowel cancer at a younger age. This includes people with Lynch syndrome, a condition which increases the risk of bowel cancer to up to 80%
- influencing policy changes to improve the early diagnosis of younger people with bowel cancer
- meeting the information and support needs of this frequently overlooked group

In 2015 we surveyed younger bowel cancer patients. The results revealed a shocking picture of delays in diagnosis and a lack of support and care for younger people with bowel cancer. Since then, we've achieved a number of successes.

1 cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer/incidence#heading-One, Accessed March 2019

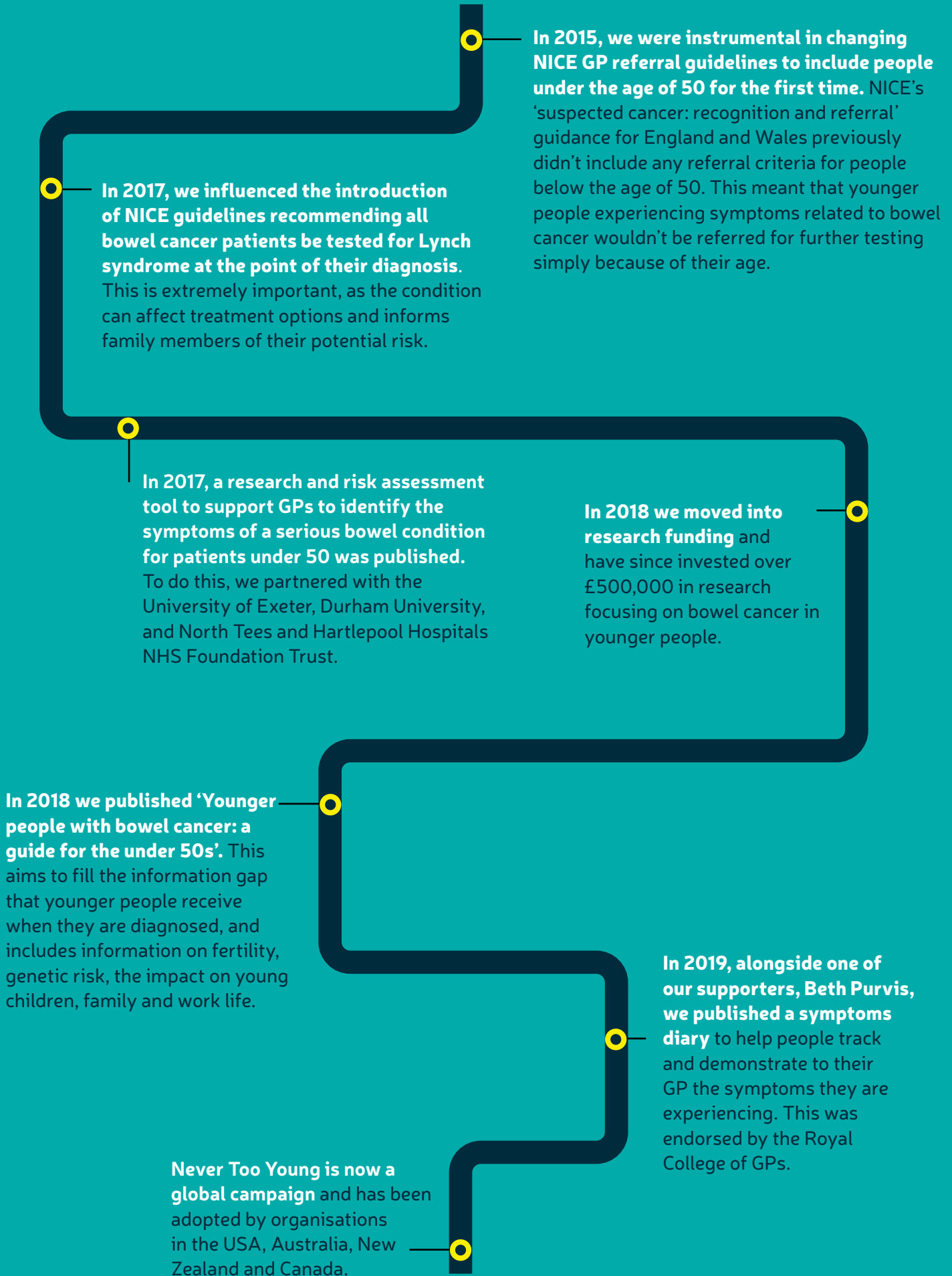
2 2,083 in England, 214 in Scotland, 109 in Wales and 78 in Northern Ireland

3 [thelancet.com/journals/langas/article/PIIS2468-1253\(19\)30147-5/fulltext](https://thelancet.com/journals/langas/article/PIIS2468-1253(19)30147-5/fulltext)

4 cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/incidence, Accessed 11 February 2020

5 cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/testicular-cancer/incidence, Accessed 11 February 2020

Never Too Young campaign successes



2 Our findings

These findings describe the results of a survey conducted before the outbreak of the COVID-19 pandemic in the UK. The results, captured at a time of 'business as usual' for the healthcare system, show that improvements achieved to date are still not enough. Sadly, people with bowel cancer have been severely affected by the COVID-19 crisis, unable to access lifesaving treatment and surgeries during this time, with cancer screening also paused. Consequently, the pandemic has served to amplify the existing issues experienced by younger people with bowel cancer.

2.1 Diagnosis

Key findings

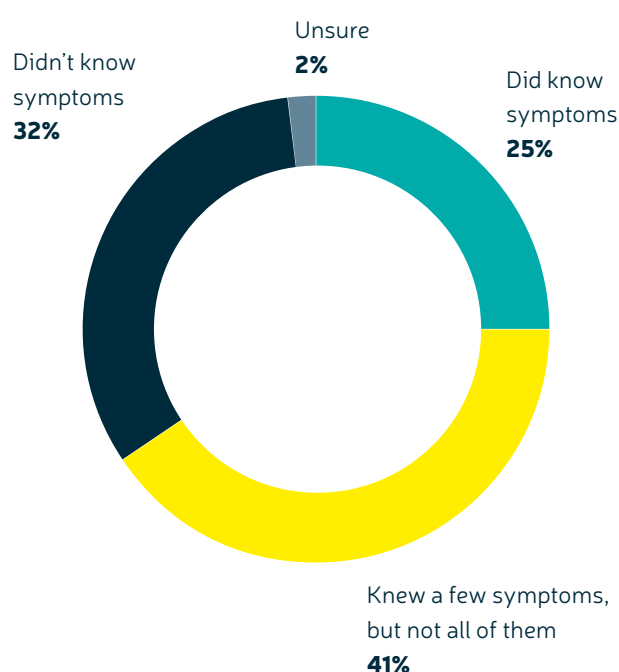
- Prior to being diagnosed half of people didn't know they could develop bowel cancer under the age of 50
- One in three delayed making an appointment with their GP for at least three months, and this was more common in people unaware of the symptoms of bowel cancer
- Four in ten saw their GP three or more times about their symptoms before being referred for tests

People's awareness and delays

Early diagnosis is the key to ensuring more people live longer with and survive bowel cancer. An estimated nine in ten people survive the disease if diagnosed at the earliest stage, compared with just one in ten of those diagnosed at the latest stage⁶. However, early diagnosis in those under 50 is hindered by the belief that younger people don't get bowel cancer. Our survey shows that half (50%) of younger people with bowel cancer didn't know that under 50s could develop the disease until they were diagnosed themselves.

Awareness of the symptoms in the under 50s is also low, with three in ten (32%) saying that before being diagnosed, they were unaware of them. Four in ten (42%) said they knew a few symptoms but not all of them [see Figure 1].

Figure 1: Awareness of bowel cancer symptoms before diagnosis



⁶ Cancer Research UK (2019), Colorectal one year survival rates (cancerresearchuk.org/sites/default/files/cancer-stats/colorectal_one_year_survival/colorectal_one_year_survival.xlsx)

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I didn't even ask if it could be bowel cancer as I never thought my symptoms could lead to that.

Rachael, stage 3, diagnosed aged 23

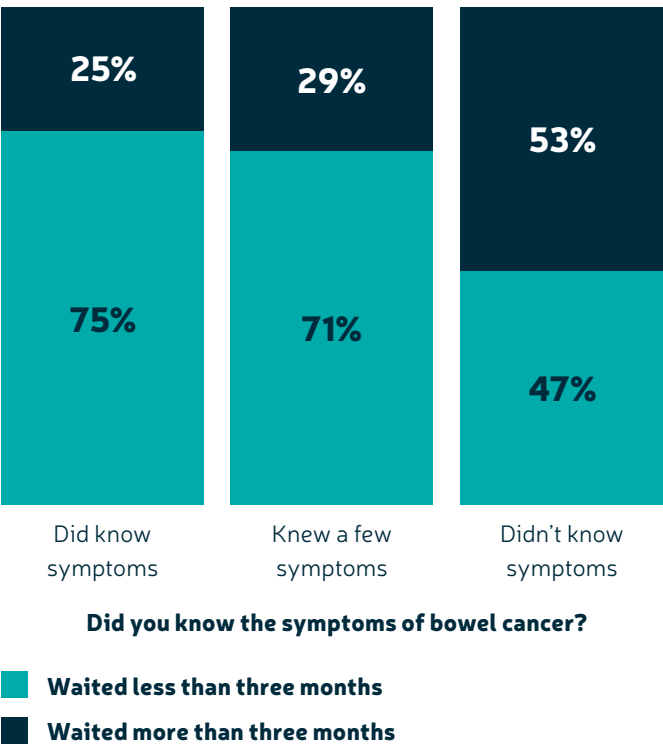
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Nearly three in four people who received a diagnosis via their GP went to their doctor with symptoms that they didn't suspect to be bowel cancer. This is despite the fact that the majority were experiencing some of the most severe symptoms: 75% had rectal bleeding and 52% a persistent change in bowel habit.

Nearly a third (30%) of people delayed making an appointment with their GP for at least three months after they developed symptoms. Our survey suggests that people's awareness of bowel cancer symptoms influenced the length of time they waited. One in four of those who already knew the symptoms waited at least three months to make an appointment to see their GP. However, this rose to just over half of those who did not know the symptoms prior to being diagnosed [see Figure 2].

Figure 2: Impact of symptom awareness on whether patients waited more than three months to book GP appointment



Three in five (60%) of those that delayed going to their GP did so because they thought their symptoms would go away. But people were less likely to delay going to their GP for this reason if they already knew the symptoms of bowel cancer: just one in six (16%) waited because they thought their symptoms would disappear.

Knowing the symptoms of bowel cancer is crucial to empowering younger people to go to their GP and obtain an early diagnosis. More must be done to improve awareness in people under the age of 50 about their risk, the signs of bowel cancer and the action they need to take.

GP awareness and delays

Low public awareness in the under 50s is not the only factor that delays diagnosis. Many people who responded to our survey went to their GP with worrying symptoms but were not referred for further tests. This was often because they were considered too young, or because their GP initially diagnosed them with other conditions more common in people of their age.

Some people asked their GP specifically whether their symptoms could be bowel cancer. Of those, four in ten were told that they were too young to have bowel cancer. Many were subsequently diagnosed with late stage bowel cancer. While it should be recognised that GPs will come across very few patients with bowel cancer aged under 50, age alone should not be a 'rule out' for the disease and appropriate NICE and Scottish referral guidelines should be followed. In Northern Ireland, guidance needs to be updated to reflect the risk of bowel cancer in younger people.

"I needed more support at diagnosis. I was constantly told I was too young to have anything major wrong with me."
Liam, stage 3, diagnosed aged 34

Around four in ten (43%) of people being referred saw their GP three or more times and one in six (16%) had to see their GP more than five times [see Figure 3]. While there is a place for monitoring strategies in people under 50 sharing vague symptoms, over half of these respondents had rectal bleeding, which should have triggered a different course of action if the NICE and Scottish referral guidelines were being followed.

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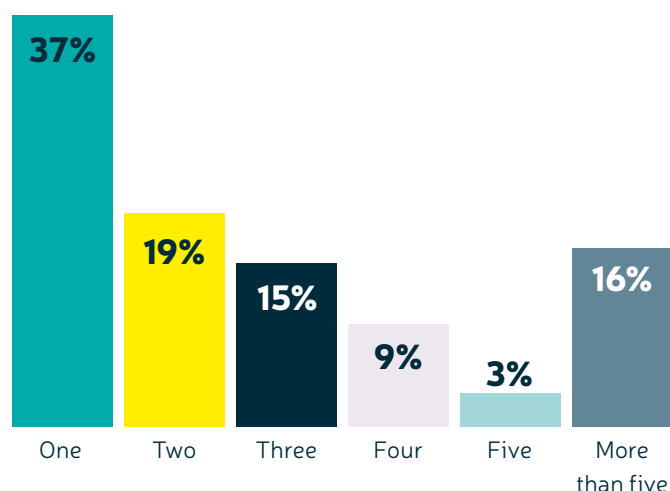
For a year before my diagnosis, I was going back and forth to my doctors with red flag symptoms. I even asked if it could be bowel cancer, but I was told I was too young. My cancer was only discovered by accident during a separate operation, and by then I was stage 4.

Sophie, stage 4, diagnosed aged 36

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Figure 3: The number of times people saw their GP about symptoms before being diagnosed with bowel cancer



People's symptoms were often initially attributed by their GP to other more common conditions. Two thirds (65%) of respondents were initially diagnosed with another condition. Of those, 41% were diagnosed with irritable bowel syndrome (IBS), 38% with haemorrhoids and 26% with anaemia.

"I went to my GP 18 times. I had acute constipation, was bleeding profusely and every time I went to my GP he said I was constipated and prescribed laxatives. I begged for a scan but was denied."

Karen, stage 4 diagnosed aged 43

For some people, GP delays resulted in them being diagnosed in A&E. One in six (16%) of the people in our survey who had visited their GP about their symptoms were subsequently diagnosed after going to A&E and almost a third (29%) of those had seen their GP more than five times. Of people who had visited their GP about their symptoms before being diagnosed in A&E, three in four (76%) received a misdiagnosis from their GP, with half of this group being told they had IBS.

Waiting long periods for a diagnosis can have an impact on the chances of survival for patients. The majority of the people in our survey who saw their GP more than five times were diagnosed at either stage 3 or 4, where the cancer has spread to nearby lymph nodes or other parts of the body.

"I went to the doctor seven times with all the main red flag symptoms of bowel cancer. Three months passed and it was affecting my job and home life. I was rushed to A&E only to be discharged with painkillers and an appointment for a colonoscopy, which led to my diagnosis."

Kelly, stage 4, diagnosed aged 28

Suspected bowel cancer referral guidance across the UK

NICE guidance in England and Wales, known as 'NG12' states that GPs should refer all patients under 50 presenting with rectal bleeding and one other symptom associated with bowel cancer (change in bowel habit, extreme tiredness, weight loss and pain or a lump in the tummy) for a colonoscopy. In Scotland guidance recommends referral for high risk symptoms at all ages, and management within primary care for those with 'transient low risk features'. Despite this guidance, people are still facing huge barriers to getting a referral. In Northern Ireland, guidance suggests that only those over 40 should be referred for further investigation even when they have the most severe symptoms. All guidance across the UK must reflect best practice and be adhered to if younger people with bowel cancer are to be diagnosed at the earliest stage.



“

I remember thinking that my GP didn't think much of my symptoms as I was young and healthy. I tried to stay as positive as I could; my wife was pregnant with our first child so I had a lot to live for. He's now two years old.

Jaimin, stage 4, diagnosed aged 30

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2.2 High risk groups

Key findings

- Only 22% of people had been asked about their family history of bowel cancer during initial contact with their GP
- Around half of people had not been offered testing for Lynch syndrome after being diagnosed with bowel cancer

Family history of bowel cancer

Some people have a higher risk of developing bowel cancer than the general population. A person's family history of bowel cancer (if any of their relatives have had the disease) should be considered when assessing their risk of developing it themselves and be a trigger for further investigation. However, we've found that GPs were missing this key piece of information when first seeing patients with bowel cancer symptoms.

Of those diagnosed after 2015, just one in five (22%) were asked whether they had a family history of bowel cancer. Even when patients presented with rectal bleeding, three quarters of people weren't asked about their family history. Best practice guidance must be developed to ensure that GPs ask patients about their family history to identify their risk, rather than assuming their risk is low because of their age.

“Knowing my family history of bowel cancer at a young age, my GP should have referred me to a specialist earlier. It should not have taken two years, repeated appointments and me asking time after time to be referred for them to finally agree to send me to a specialist.”

Rachel, stage 3, diagnosed aged 38

Lynch syndrome

Each year approximately 1,200 people in the UK are diagnosed with bowel cancer linked to Lynch syndrome,⁷ a genetic condition which can increase a person's lifetime risk of bowel cancer to up to 80%. There are an estimated 175,000 people⁸ with Lynch syndrome in the UK, but fewer than 5% of those individuals have been diagnosed.⁹ This is due to a lack of diagnostic testing being carried out across the UK which results in thousands of people at high risk of developing bowel cancer in their lifetime not being aware of it.

With such a heightened risk, many people with Lynch syndrome develop bowel cancer before they reach 50. It is essential that those with the genetic condition are identified and placed on a surveillance programme to ensure they receive regular colonoscopies.

Despite guidance introduced in 2017, only half (54%) of people in our survey diagnosed after 2017 had been offered Lynch syndrome testing. One in seven (14%) of those people offered testing were diagnosed with Lynch syndrome and almost every one of those people was subsequently offered surveillance colonoscopies. Although access to surveillance is encouraging, this can't be done without initial Lynch syndrome testing.

Lynch syndrome testing guidance across the UK

In 2017, NICE published guidance (DG27) for universal testing of Lynch syndrome for all people diagnosed with bowel cancer in England and Wales, which was also adopted by Scotland's Molecular Pathology Consortium that year. The Royal College of Pathologists also updated their UK-wide guidelines in 2017, recommending universal testing in line with NICE. However, in 2018 we found that only 22% of hospitals across the UK were testing all bowel cancer patients for Lynch syndrome at the time of diagnosis, as per the guidance. We found that the biggest barrier to hospitals implementing NICE guidance for Lynch syndrome testing was a lack of clarity over commissioning arrangements – this must be addressed to ensure that NICE guidance is implemented.

7 cancerresearchuk.org/about-cancer/causes-of-cancer/inherited-cancer-genes-and-increased-cancer-risk/inherited-genes-and-cancer-types?_ga=2.235087752.828568685.1581421505-1684366086.1549620513#inherited_genes0

8 National Institute for Health and Care Excellence (2016) Diagnostics consultation document: Molecular testing strategies for Lynch syndrome in people with colorectal cancer nice.org.uk/guidance/dg27/documents/diagnostics-consultation-document

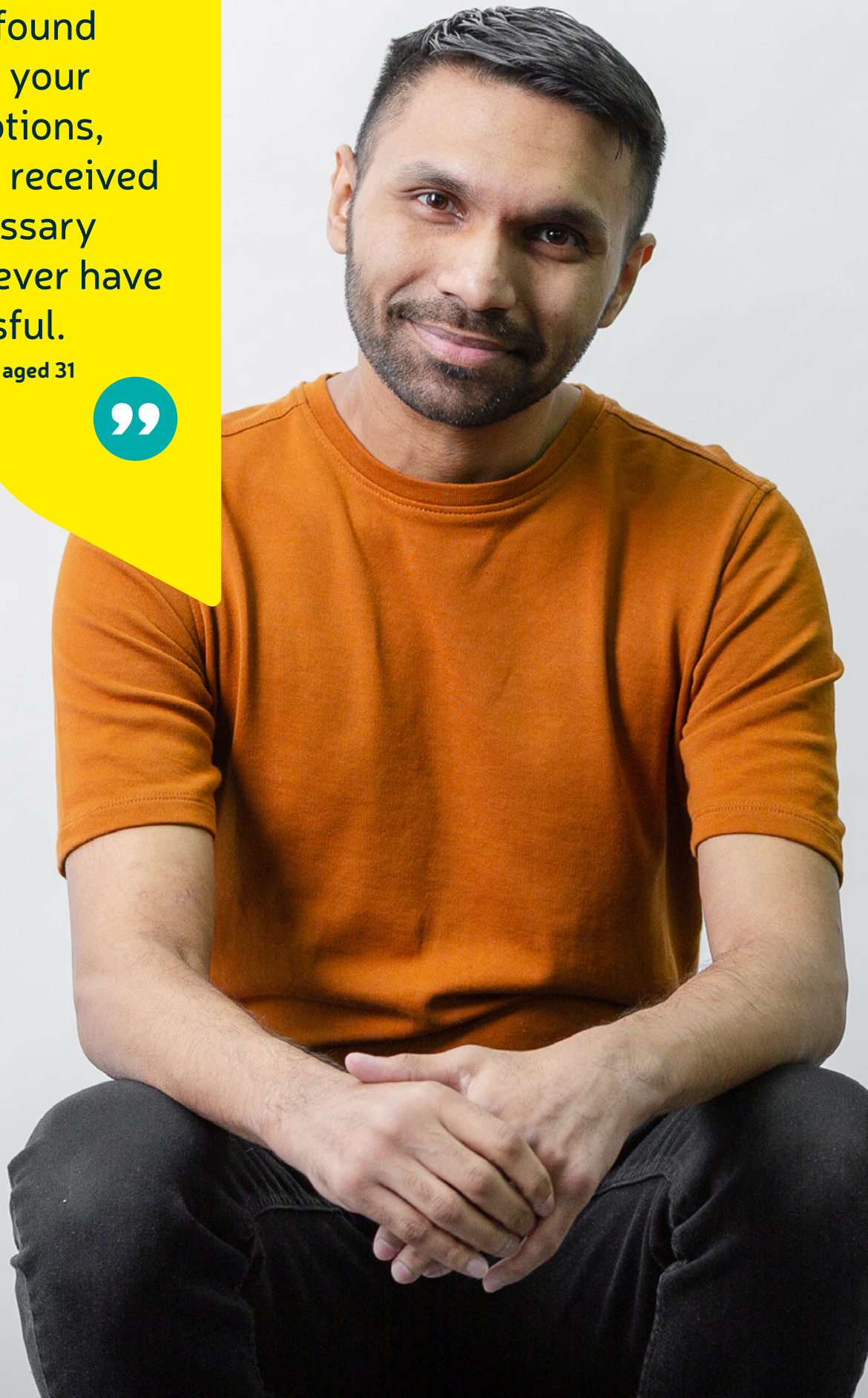
9 Snowsill T. et al (2016), Molecular testing for Lynch syndrome in people with colorectal cancer, Peninsula Technology Assessment Group (PenTAG) University of Exeter Medical School (Report for NICE) nice.org.uk/guidance/dg27/documents/diagnostics-assessment-report

“

I waited eight months to be tested for Lynch syndrome. I found out it affects your treatment options, and some I'd received were unnecessary and would never have been successful.

Mo, stage 4, diagnosed aged 31

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2.3 Treatment and support

Key findings

- One in five did not have access to a Clinical Nurse Specialist (CNS)
- One in four felt that the support they needed wasn't there after their treatment ended
- Over half didn't have enough support and information about mental health and the consequences of treatment on sex, intimacy and romantic relationships
- The impact of treatment on fertility and family planning was a key concern but 40% said they didn't receive enough information and support on this topic

Clinical Nurse Specialists

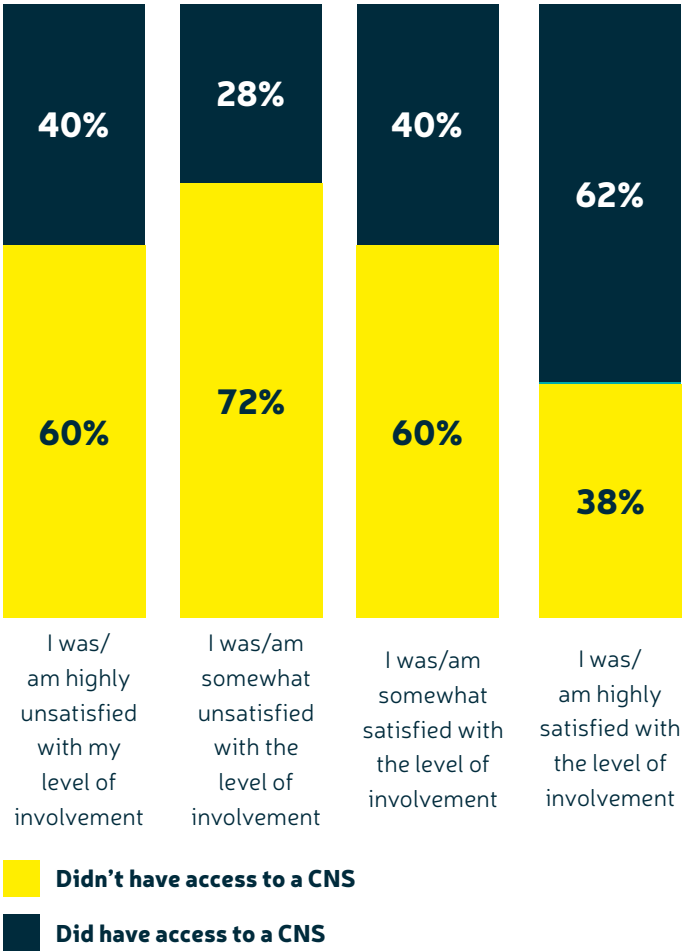
A CNS is a nurse with specialist qualifications to manage and care for patients with bowel cancer. The CNS usually acts as a patient's 'key worker'; the first point of contact for any queries or concerns. However, many younger bowel cancer patients are missing out on this vital support: over a fifth of people surveyed (22%) didn't have access to a CNS.

Our survey results show that whether or not a patient had a good or bad experience of their treatment and care was influenced by their access to a CNS. Those with a CNS were more likely to be highly satisfied with their involvement in their treatment options (63% in comparison to 39% of those who did not have access to a CNS) [see Figure 4].

“Honestly my nurse and oncologist were amazing, they made me very comfortable and aware of what to expect at every stage of my treatment. Post treatment is definitely harder than during treatment. When you're sick you can focus on getting better, but when you're better it's very hard to get back to normal life.”

James, stage 4, diagnosed aged 18

Figure 4: Access to a CNS and patient satisfaction with level of involvement in their care



It's recommended that CNSs conduct a Holistic Needs Assessment (HNA) with their patients.¹⁰ An HNA helps to find out what practical, physical, emotional or spiritual needs patients may have. However, only one in eight (12%) said they received an HNA, 68% said they didn't and 20% said they were unsure. There are clear benefits of receiving an HNA, with nearly all of those who did receive one (91%) reporting that they were given information and support based on their care needs.

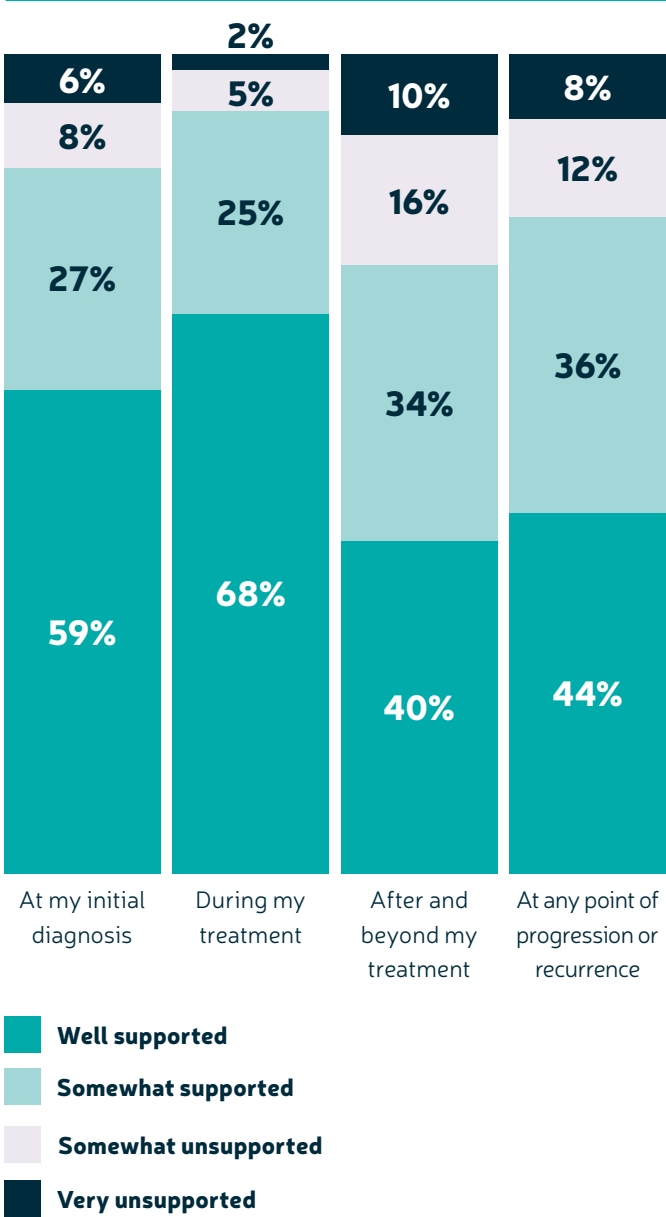
“I needed more support during treatment. I feel like I’m a patient number, rather than a person. I rarely see the same doctor or healthcare professional. They are treating me with chemotherapy but they don’t discuss what/why/how with me.”
Elizabeth, stage 3, diagnosed aged 41

Levels of support for patients vary at different points in their diagnosis, treatment and care

How supported people felt when they were given their diagnosis varied with the stage at which they were diagnosed. Seven out of ten (68%) people in our survey diagnosed at stage 1 felt well supported through their initial diagnosis, compared to only five out of ten (54%) of those diagnosed at stage 4. Overall, people felt most supported by their hospital team while they were receiving treatment, with seven out of ten (69%) feeling well supported, and a quarter (25%) feeling somewhat supported [see Figure 5]. However, the picture changes after treatment ends, with one in four (26%) reporting that they were unsupported or very unsupported by their hospital team once their treatment was over. Ongoing support needs to include the patient’s entire wellbeing, not just their physical illness. The impacts of treatment can be far reaching.

“Only the cancer was focused on. I was plunged rapidly into menopause due to radiotherapy which led to depression due to hormone changes. At one stage I felt suicidal. I understand that the main focus is on getting rid of the cancer but more information about this would have been welcome.”
Sally, stage 3, diagnosed aged 39

Figure 5: The level of support felt from patients’ hospital care team





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When going through treatment I had a real sense of ‘just having to get on with things’. However, once I finished I found it very difficult. The regular monitoring became less frequent and I felt as though I was adrift at sea.

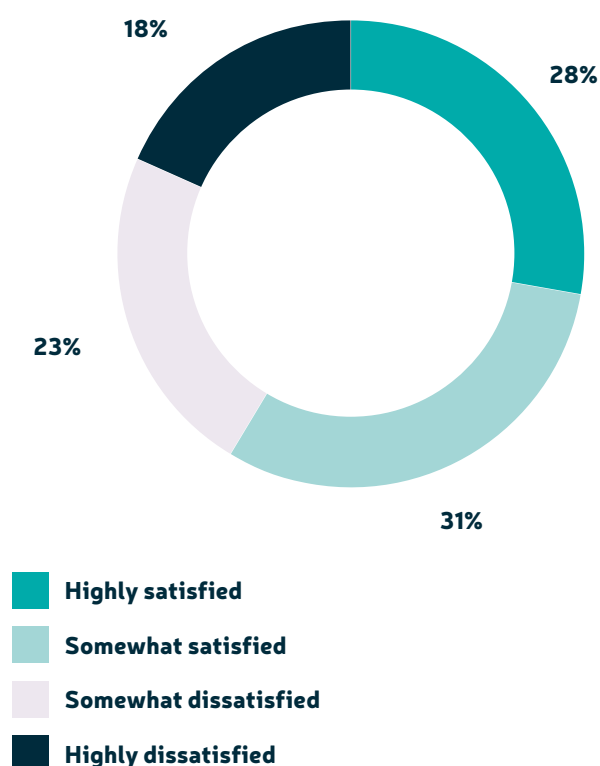
Sarah, stage 3, diagnosed aged 39

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Over half of people hadn't been made aware of all the potential side effects of their treatment. Three in ten (30%) of those who didn't have access to a CNS said that they had been made aware of all the consequences of their treatment, compared with 44% of those who did have access to a CNS had been made aware of the consequences. Fewer people were satisfied with the information they received regarding practical consequences of treatment including diet, exercise and lifestyle changes (65%) than were with information on physical side effects (78%).

Four in ten (40%) people who considered fertility and family planning important to them were dissatisfied with the amount of information and support they received on this subject [see Figure 6]. This proportion went up to five in ten (51%) for people who didn't have access to a CNS.

Figure 6: Patient satisfaction with the level of support received to manage the consequences of treatment on their fertility and family planning



“I needed more support with my loss of fertility which I still really struggle with. Even after my treatment was complete and I got better I struggled exceptionally and felt there was no aftercare for what you’ve just been through.”

Claire, stage 2, diagnosed aged 35

Just over half (54%) of people were not satisfied with the support and information they received around the impact of their treatment on sex, intimacy and romantic relationships. This increases to seven in ten (68%) of people who did not have access to a CNS. Similarly, around half of people were unsatisfied with the support and information they received relating to mental health and wellbeing. Of those who didn't have access to a CNS, 70% felt unsupported and that they didn't have enough information on this topic.

Healthcare professionals must consider the life stage of younger bowel cancer patients when deciding what information and support is appropriate.

10 breastcancernow.org/sites/default/files/pubs177_secondary_best_practice_report_2018_final.pdf

2.4 Findings from family and friends

“I just want doctors to know that you’re never too young. That’s what failed my sister. If she’d been diagnosed sooner maybe she’d have lived. We’ll never know now. The process after diagnosis was slow and nobody knew what was happening.”

Emma responding on behalf of her sister, diagnosed stage 4 at age 36

The survey was open to people who wanted to complete it on behalf of someone who was diagnosed with bowel cancer under the age of 50. This was to ensure family and friends could include the experiences of loved ones who have died.

Within this sample, the experiences tended to be starker. 45% had been diagnosed at stage 4, 27% had been diagnosed in A&E and 35% had been diagnosed through their GP and needed to visit them more than five times before being referred.

People generally felt that patients had been poorly supported throughout their journey – for example 13% did not feel their loved one had been supported by their hospital team throughout treatment (compared to 6% amongst patients). Family and friends also thought their loved ones were less satisfied with the level of information and support that they received on the consequences of their treatment.



I questioned if Caroline’s cancer was an early stage. The answer was an emphatic ‘no’. Caroline was just 41 years old when she passed away, a year after her diagnosis and a day after our daughter’s 10th birthday.

Daniel, husband of Caroline





My dad was diagnosed with advanced bowel cancer and passed away at 41. We were told that because he was diagnosed at a young age, my sister and I may also be at risk. If we spot any symptoms, we'll go straight to our GP.

Chloe, daughter of Wayne



3 What needs to happen now?

The findings presented in this report show that much more needs to be done if younger bowel cancer patients are to have the diagnosis, treatment and care that they desperately need. The COVID-19 pandemic has sadly exacerbated these existing issues and our recommendations call for significant changes across the health system. As the NHS moves to restore and recover its cancer services, these changes must be adopted to transform services that deliver improved outcomes for younger people with bowel cancer.

Recommendations

1

People and GPs should be aware of the symptoms of bowel cancer, and that it can affect people under the age of 50.

To achieve this:

- Public Health bodies in the UK must develop awareness campaigns targeted at younger people, which include bowel cancer symptoms and risk
- NICE, NHS Healthcare Improvement Scotland, and The Royal College of GPs (RCGP) should collaborate on a best practice guide for GPs on bowel cancer in the under 50s that includes:
 - a. Information on bowel cancer risk and symptoms in younger people
 - b. Recommendations to ask younger patients to monitor their symptoms and return if they persist, especially where symptoms are vague (i.e. the patient does not present with rectal bleeding) where GPs suspect a different diagnosis to bowel cancer initially
 - c. Advice on investigating the risk of bowel cancer, including asking patients about their family history of the disease

2

Younger people going to their GP with symptoms of bowel cancer should be referred for further tests without unnecessary delays.

To achieve this:

- Primary Care Networks in England must monitor and report on GP adherence to NICE NG12 clinical guidance to ensure it is being reflected in practice
- The Wales Cancer Network must work alongside the Welsh Government and other partners to ensure NICE NG12 is consistently implemented and monitored across all health boards as part of the Single Cancer Pathway performance measure
- The Scottish Primary Care Cancer Group must monitor and report on GP adherence to Scottish referral guidelines for suspected cancer to ensure it is being reflected in practice
- The Northern Ireland Cancer Network should work with Health and Social Care organisations to develop a referral pathway for people under the age of 40 presenting with symptoms of bowel cancer, including rectal bleeding and persistent change in bowel habit. This must be supported with the appropriate monitoring and reporting measures to ensure adherence
- NHS Healthcare Improvement Scotland should review and update the existing SIGN guidelines for bowel cancer to reflect current best practice
- GPs should consider the use of FIT to guide referral for younger people presenting lower risk bowel cancer symptoms in line with NICE DG30 and the NI's Rebuilding Health and Social Care Plan. As the NHS recovers from the impact of COVID-19, this approach will particularly support the risk stratification of patients waiting for colonoscopy.

- The NHS must optimise ventilation capability in endoscopy units in order to increase endoscopy capacity during COVID-19. The use of available endoscopy units within the private and independent sector should also be utilised.

Policy context:

England and Wales

It has now been five years since the National Institute for Health and Care Excellence (NICE) guidance made important progress to include the under 50s for the first time in their primary care suspected cancer recognition and referral criteria, known as 'NG12'.

Scotland

Under Scottish referral guidelines for suspected bowel cancer, patients under 40 years of age in the absence of high risk features are considered in primary care management as having 'transient low risk features'. It is advised that a watch and wait for four weeks is undertaken and patients should be referred if symptoms persist.

Northern Ireland

Under the Northern Ireland referral guidance for suspected cancer, patients are referred from primary care under 'red flag' criteria. The guidance only recommends referral for people with rectal bleeding and persistent change in bowel habit for suspected cancer if they are 40 years and over.

3

Younger patients with bowel cancer should have treatment, care and support tailored to their needs.

To achieve this:

- The NHS must ensure younger people with bowel cancer have access to a Clinical Nurse Specialist (CNS) or key worker who conducts a holistic needs assessment (HNA) to obtain their specific information and support needs
- The Cancer Patient Experience Survey (CPES) in each nation must report data such that both tumour type and age can be stratified to monitor access to a CNS
- Younger bowel cancer patients should be signposted by their CNS to trusted support and information sources that:
 - a. cover a wide range of needs including mental health and wellness, diet and lifestyle, and practical consequences of treatment in addition to information about their disease and treatment pathway
 - b. consider their patients' life stage when tailoring the information and support provided to younger people with bowel cancer, including fertility and family planning, and menopause for women
 - c. provide support not only for the patient, but for the patient's family and friends including counselling services

We provide a number of information booklets, including our 'Younger people with bowel cancer – A guide for the under 50s' booklet. We encourage all healthcare professionals who are supporting younger people with bowel cancer to use our resource, available at bowelcanceruk.org.uk.

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All younger bowel cancer patients should be tested for Lynch syndrome as soon as they are diagnosed.

To achieve this:

- NHS England must rapidly establish a national funding pathway for Lynch syndrome testing to be carried out on all bowel cancer patients, in line with NICE DG27 guidance. This pathway must be shared with Cancer Alliances and Clinical Commissioning Groups indicating clear funding arrangements.
- The All Wales Medical Genetics Service (AWMGS) must continue to ensure the All Wales Lynch Syndrome Testing Pathway, launched in 2019, is implemented across all health boards in Wales so that all bowel cancer patients are tested for Lynch syndrome in line with NICE guidance
- The Scottish Molecular Pathology Consortium (MPC) must update their guidelines to test all bowel cancer patients for Lynch syndrome at the point of their diagnosis and work with the Scottish Genetics Laboratory Management Committee and Health Boards to implement a national system for Lynch syndrome testing
- The Health and Social Care Board, Northern Ireland, must continue to ensure all bowel cancer patients are tested for Lynch syndrome at diagnosis
- The national bowel cancer screening programme in England must extend its service to those who have Lynch syndrome and other high risk groups so they also receive the same high quality service as the eligible asymptomatic population. This would be the most efficient and effective method to deliver, monitor and evaluate a national screening and surveillance service, utilising existing infrastructure
- Health Boards in Wales must implement high quality processes to ensure all patients who have Lynch syndrome, and other high risk groups, are offered appropriate surveillance in-line with national guidance
- The clinical pathways sub-group of the National Endoscopy Programme in Wales must ensure Health Boards are adequately supported to implement surveillance guidelines by monitoring, evaluating and reporting on this
- Public health bodies in Scotland and Northern Ireland must ensure that robust Lynch syndrome surveillance registries are created to ensure appropriate monitoring of bowel cancer patients with Lynch syndrome
- Current surveillance guidance has been altered as a result of the COVID-19 pandemic. As the risk of infection decreases and more COVID-19 free spaces are established, the NHS must reinstate routine surveillance in all UK nations in line with the British Society of Gastroenterology (BSG) and Association of Coloproctology of Great Britain and Ireland (ACPGBI) guidelines for the management of hereditary colorectal cancer.

Although NICE guidance for Lynch syndrome testing has been in place since 2017, our 2018 freedom of information (FOI) request found that confusion over commissioning responsibility posed the biggest barrier to implementing Lynch syndrome testing across the UK. This survey further demonstrates problems have not been fixed, with the percentage of people offered testing post 2017 only 6% higher than before 2017. Bowel Cancer UK is now working closely with NHS England to implement a national Lynch syndrome testing pathway and NHS Wales has begun routine testing of all bowel cancer patients.

Bowel Cancer UK is the UK's leading bowel cancer charity. We're determined to save lives and improve the quality of life of everyone affected by the disease.

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

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