



#Never2Young

Leading change
for younger bowel
cancer patients

bowel
canceruk

save
lives

Thank you

We would like to say thank you to some people without whom we could not have completed this report.

The 401 people diagnosed with bowel cancer under the age of 50 who completed our survey.

Professor Willie Hamilton, Professor of Primary Care Diagnostics, University of Exeter

Rachel Haynes, Everywhere Brand

Michael Machesney, Pathway Director for Colorectal Cancer, London Cancer, UCL Partners

Professor Greg Rubin, Professor of General Practice and Primary Care, Durham University

Special thanks to all the people who sent us selfies for this campaign.

Bowel Cancer UK supports research and campaigns to stop bowel cancer. We are determined to save lives and improve the quality of life for all those affected by bowel cancer.

Our aspiration is to transform survival rates from 1 in 2 people surviving for 5 years to 3 in 4 people surviving bowel cancer by 2025.



www.bowelcanceruk.org.uk

Bowel Cancer UK is a registered charity in England and Wales with charity number 1071038 and company number 3409832. Registered as a charity in Scotland charity number SC040914.

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Please note: Throughout this report, where we refer to “younger bowel cancer patients”, we mean people who were diagnosed with bowel cancer under the age of 50.

A note from our Chief Executive



Deborah

Every day I speak to younger people with bowel cancer and their families. Through social media and our extensive network of volunteers and supporters, I come across people who are newly diagnosed or who are going through gruelling treatment regularly. I also speak to too many families and friends of people we have lost far too young because they were simply diagnosed too late to be successfully treated. The fear, pain, elation and sometimes despair bowel cancer causes is a roller coaster no one wants to be on. We are determined to bring it to a halt.

Only around 5% of all diagnoses of bowel cancer are in the under 50s, but this is increasing rapidly, up by nearly 25% since 2004. While we understand that bowel cancer can be difficult to identify in younger patients, we need to find a solution if lives are to be saved.

This report comes two years after the launch of our campaign. It tells a story of people who do not think bowel cancer is relevant to them and who do not recognise the symptoms as something to worry about. The report highlights delays in getting diagnosed and shocking variations in treatment, care and support for younger people. There is still much to do.

Yet through this campaign we are making progress. I am proud of the changes we are making to clinical practice and guidelines, to improving the identification of people with genetic conditions and the research we have commissioned to speed up the diagnosis of younger patients. I am also proud that we are changing the debate – from being told that this was a marginal issue, it is finally being taken seriously and not just in the UK. Our campaign is now also being run in the US and Australia. Finally the voices of younger bowel cancer patients are being heard.

Our ground-breaking Never Too Young campaign will continue until we have dramatically improved the diagnosis, treatment and care for younger patients and stopped people dying so needlessly. We will also continue to share the stories of those most closely affected to highlight the human impact of this cruel disease. We are not prepared for them to be ignored and overlooked again.

Whether you are a clinician, a scientist, a policy maker, a patient or one of our supporters - please join with us so we can STOP bowel cancer in younger patients.

Deborah Alsina

Deborah Alsina

Chief Executive, Bowel Cancer UK

Executive summary

There are around 2,100 people under the age of 50 diagnosed with bowel cancer every year in the UK. While this is only 5% of everyone diagnosed with bowel cancer in the UK each year, the numbers of people diagnosed under 50 are increasing - up by nearly 25% since 2004 - and the impact is often disproportionately worse.

Nationally, 3 out of 5 people diagnosed under the age of 50 will be diagnosed with Stage 3 or 4 bowel cancer. Only 1 in 5 are diagnosed at the earliest stage of the disease, when survival rates are much higher. This means that many younger people have a lower chance of survival than they should.

This is happening for several reasons. Many younger people are not aware that they may be at risk of bowel cancer. Even where they are aware of what the symptoms of the disease are, they do not recognise them as serious when they experience symptoms. This can lead to delays in going to see the GP. For younger people with conditions that put them at higher risk of developing bowel cancer, genetic testing and surveillance screening for younger people are patchy.

Once at the GP, there are variations in how younger people are treated. Some GPs are very good at investigating the possibility of bowel cancer early, while others are not. Many younger people express their frustration to us about their experiences with their GP. Once diagnosed, we hear stories about the lack of information, isolation and inadequate support that younger people experience.

Our Never Too Young campaign, launched in 2013, aimed to change the debate and to highlight the experiences of younger people, to share their stories to improve their diagnosis, treatment and care so that more lives are saved and to ensure that younger people receive the support and care they need.

Two years on from the launch, we have conducted a survey of over 400 people diagnosed under the age of 50, to understand more about their experiences and opinions and check on progress. We believe this is the largest attitude and opinion survey of this group of patients ever undertaken.

The results of our survey paint a picture of a group of people who, before diagnosis, were not aware that they could be at risk of bowel cancer, who either did not know the symptoms of the disease, or did not recognise the significance of symptoms; and who delayed going to their GP, at high cost to their health. Once they were in the health system, many found it hard to get referred for diagnostic testing, and once diagnosed, struggled to get support on dealing with treatment, side-effects and other issues that affected them. **We found:**

- 4 out of 5 people were not aware that they could be at risk of bowel cancer at their age.
- 3 out of 5 people were not aware of the symptoms prior to diagnosis.
- 1 in 4 people waited over 3 months after getting symptoms before going to the GP.
- 1 in 5 people had to see their GP 5 times or more before being referred to a specialist.

- 1 in 5 people took over a year to be diagnosed after first seeing their GP.
- 1 in 4 people felt ignored by their GP.
- 70% of men and 46% of women who asked the GP if it could be bowel cancer felt that the GP dismissed it because they were too young.
- 1 in 2 people were not being offered genetic testing for them or their family.
- 1 in 2 people did not get enough information on what to expect from treatment and side effects.
- 1 in 2 people who wanted advice on fertility prior to treatment did not get it.
- 9 out of 10 people were not offered support on all issues that concerned them.
- 1 in 2 people said that they had no one their age they could talk to.

These findings highlight variations in the health system. We welcome the fact that 3 out of 4 people felt that their GP took them seriously, yet for the one that was not taken seriously, the consequences can be significant. We need to change this so that every younger person with bowel cancer symptoms has a swift and conclusive diagnosis.

Since we launched our campaign in 2013, we have made much progress. This includes:

- Younger people being included for the first time in clinical guidelines for referral for suspected cancer.
- Securing funding for a research project that will ultimately help GPs identify which younger people to refer through for diagnostic testing.
- Producing an information booklet for younger people on the issues they told us they wanted to know about.
- A mandate from Royal College of Pathologists on testing for Lynch syndrome in people diagnosed with bowel cancer under the age of 50 and putting Lynch syndrome testing on the agenda, in some areas, for the first time.

- Forming a global coalition around the Never Too Young campaign to lead change across the globe.
- Raising the profile of and interest in the issues affecting younger patients.

However, more needs to be done. People are still experiencing delays in diagnosis, they are not getting the support they need, and they are feeling isolated. In chapter five of this report we have set out what we believe needs to be done by Government, the NHS, health bodies and commissioners across the UK.

You can help us in the following ways:

- Help us to fund research into bowel cancer in younger people at www.bowelcanceruk.org.uk/donate
- Raise awareness of our campaign among your friends, family and colleagues and encourage them to act on any concerns and show their support for the Never Too Young campaign.
- Sign up to be a campaign supporter at www.bowelcanceruk.org.uk

Bowel cancer in younger people and our campaign

There are around 2,100 people under the age of 50 diagnosed with bowel cancer every year in the UK, including 38 people aged 19 or under¹. While this is only 5% of everyone diagnosed with bowel cancer in the UK, this young cohort is not a small cancer group. The numbers are comparable to the number of people of all ages diagnosed with cervical cancer (3,064) or testicular cancer (2,207) each year². In addition, the number of people diagnosed with bowel cancer under 50 is going up, having increased by nearly 25% since 2004³. There is evidence that incidence among younger people is also rising in other countries, such as the United States of America (USA)^{4,5}.

Age range	Male cases	Female cases
0 to 09	0	1
10 to 19	17	20
20 to 29	75	83
30 to 39	215	188
40 to 49	775	725
TOTAL	1,082	1,017

Average number of new cases per year: 2009-2011 (Cancer Research UK figures, accessed 30 April 2015)

60% of younger bowel cancer patients are diagnosed with either Stage 3 or Stage 4 bowel cancer, a higher proportion than people of any other age apart from those over the age of 90⁶. Only 18% of younger patients are diagnosed with Stage 1 bowel cancer, when the chance of survival is highest⁷.

Age range	Male deaths	Female deaths
0 to 09	0	0
10 to 19	1	0
20 to 29	13	17
30 to 39	56	48
40 to 49	219	188
TOTAL	289	253

Average number of deaths per year: 2010-2012 (Cancer Research UK figures, accessed 30 April 2015)

Younger people are likely to have better overall health than older people and less likely to have co-morbidities. More than 95% of people diagnosed under 50 at Stages 1, 2 and 3 survive for more than a year after diagnosis. However, this falls to just 64% of people under 50 diagnosed with Stage 4 bowel cancer surviving for more than a year⁸. These survival rates are higher than for any other age group, but there is no reason why this many younger patients should be dying.

3 out of 5

people diagnosed under 50 have stage 3 or 4 bowel cancer.



People at higher risk

When looking at people diagnosed with bowel cancer under the age of 50, it is important to recognise that some people are likely to be at higher risk of developing bowel cancer compared with the general population. We will not go into detail here on each specific risk strand, but the salient groups of people at higher risk of bowel cancer in this age range are:

- 01 |** People with a genetic condition such as Lynch syndrome or Familial adenomatous polyposis (FAP). Lynch syndrome is the direct cause of around 1,000 cases of bowel cancer each year. People with Lynch syndrome develop bowel cancer at a median 42-48 years of age. People with FAP develop bowel cancer at a median 39 years of age.
- 02 |** People with a strong family history of bowel cancer.
- 03 |** People with a long-standing inflammatory bowel disease, usually one that has lasted for more than ten years.

It is vital that people in these high-risk groups have access to regular relevant surveillance screening, to ensure early detection of possible bowel cancer before symptoms manifest themselves.

Our Never Too Young campaign

// I would be dead if I had not challenged the system.

Survey respondent //

We launched our Never Too Young campaign in 2013. When speaking to our supporters and patients in person and on social media, we heard from a lot of younger patients about the frustration they were feeling about their experiences of diagnosis, their treatment, and the lack of support many received in dealing with the effects of bowel cancer and its treatment.

At the time, these experiences were not being discussed in national policy circles. National screening programmes and clinical guidance did not cover younger people. The Scotland Bowel Cancer Screening Programme began at age 50, with screening in England, Wales and Northern Ireland beginning at age 60.

Two years ago, Bowel Cancer UK published the results of a survey specifically of people diagnosed with bowel cancer under the age of 50⁹. Our results revealed a picture of delays in diagnosis, isolation and a lack of peer support and gaps in support and care services on issues affecting younger people. Our Never Too Young report made recommendations for change, endorsed by patients and clinical experts, which would improve the experiences of younger people affected by bowel cancer.

Two years on, we wanted to know what had changed. In February 2015 we again asked people diagnosed under the age of 50 about their experiences. More than 400 people responded. We believe this is the largest survey ever undertaken of the experiences and opinions of people diagnosed with bowel cancer under the age of 50.

This is the story of what it is like to be diagnosed with bowel cancer under the age of 50. We present the findings of our research and look at what problems we still need to solve. Our campaign has made progress on many of the issues we highlighted but there is still a long way to go.

Survey results

In February 2015 we issued a survey asking people diagnosed with bowel cancer under 50 in the UK about their experiences and opinions (see Appendix A). We received responses from over 400 people.



Gender of respondents



Age range	Survey respondents	UK, yearly % of people diagnosed under the age of 50
Under 19	2%	2%
20-29	10%	8%
30-39	35%	19%
40-49	52%	71%

Each column may not add up to 100% due to rounding

As the above table shows, our survey respondents tended to be slightly younger than people diagnosed with bowel cancer under the age of 50 nationally in the UK.

Stage of diagnosis	Survey respondents	England staging data for people under 50, 2012
1	9%	14%
2	19%	19%
3	34%	31%
4	17%	23%
Unknown	20% (These are people who stated that they were not told their stage of diagnosis)	14%

Each column may not add up to 100% due to rounding

While there are some variations, our survey respondents were broadly representative in their spread of staging data compared with national figures.

Awareness of bowel cancer

" I never suspected I could have bowel cancer.

Survey respondent "

Awareness of bowel cancer is shockingly low in this age group. 90% of people thought that there was a perception among the general public that bowel cancer only affects the much older generations.

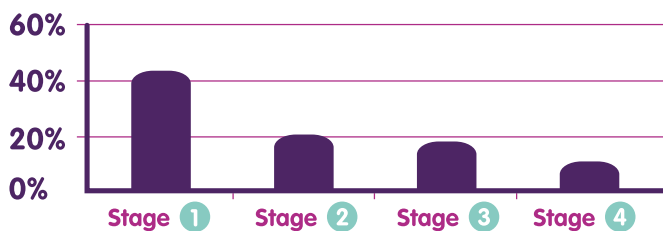
4 out of 5 people were not aware that they could be at risk of bowel cancer at their age.



people were not aware that they could be at risk of bowel cancer at their age.

4 Survey results

Awareness of the risk of bowel cancer prior to diagnosis, by stage of diagnosis



Only 20% of respondents knew that they could be at risk of developing bowel cancer at their age. Awareness was highest among men, with 24% of men aware that they could be at risk of bowel cancer compared with only 18% of women. Awareness has increased since 2013, but is still far too low.

We saw a difference in reported awareness when we looked at people diagnosed at different stages of the disease. People diagnosed with later stage disease reported lower awareness that they could be at risk of bowel cancer prior to diagnosis. What we see here is that low awareness of the disease is associated with late-stage diagnosis

Making change: Influencing clinical guidance

In 2013, clinical guidelines on referring people with suspected cancer (i.e. people with symptoms) only addressed symptoms in people aged over 40. There were no guidelines for GPs on how to deal with people under 40 with symptoms of bowel cancer. Since then, guidelines in England and Scotland have changed.

In 2014, the Scottish Referral Guidelines for Suspected Cancer was reviewed. In the new guidance, the watch-and-wait time for people with low-risk-but-not-no-risk symptoms has been reduced from 6 weeks to 4 weeks. The age restrictions on patients displaying high risk symptoms have now been removed completely so that any person displaying these symptoms should be referred no matter their age.

In England, the National Institute for Health and Care Excellence have reviewed their Referral for Suspected Cancer guidelines for the first time since 2005. The revised guideline included guidance for GPs on how to deal with people under the age of 40 who present with symptoms of bowel cancer.

Knowing the symptoms and acting on them

43% of people said they were aware of the symptoms of bowel cancer prior to being diagnosed.

However, only 35% of men reported knowing the symptoms compared with 46% of women. This is concerning, especially as men were more likely to be aware that they could be at risk of bowel cancer. There was little difference in levels of symptom awareness between people diagnosed with different stages of bowel cancer.

When looking at what prompted people to first go to the GP, 77% said that they were experiencing symptoms but did not suspect bowel cancer. This is interesting as nearly half said that they were aware of the symptoms before being diagnosed. Only 16% said that they either suspected or knew they had symptoms of bowel cancer.

These results show us that most younger people do not think that they can get bowel cancer. Either they don't know the symptoms, or they do know the symptoms but don't know that the symptoms are relevant to them. Where that occurs, they are diagnosed with later stage disease.

3 out of 5 people were not aware of the symptoms prior to diagnosis.

" I knew my symptoms were not good and it could have been anything from piles to bowel cancer, but only because I googled it. I didn't know anything before that.

Survey respondent

Patient delays

There remains a persistent problem with people delaying going to the GP after developing symptoms.

56% of respondents to our survey went within 6 weeks of developing symptoms compared with 39% in 2013. However, 28% of people waited over 3 months before seeing their GP, including 7% who waited over a year. While there has been some improvement in the proportion of people going to their GP quickly, there is still a core of people who do not act on their symptoms for months.

1 in 4



people waited over 3 months after getting symptoms before going to the GP.



I had symptoms for 6 months before I visited my GP. They told me there was nothing to worry about.

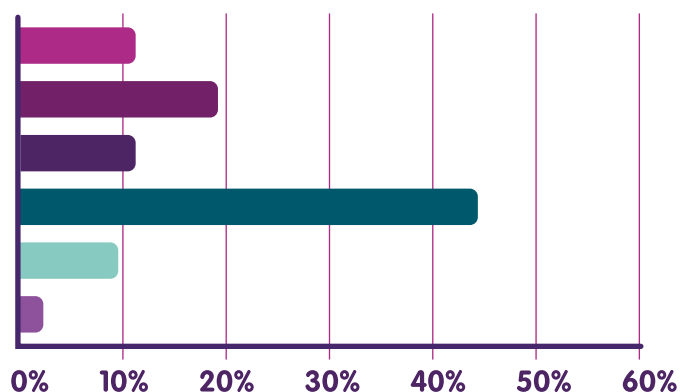
Survey respondent



The main reasons people gave for putting off going to the GP were that they thought their symptoms would go away or that they were not worried about their symptoms. Further research is needed to ask a similar question to people diagnosed with bowel cancer at an older age, to investigate any differences in patient delays.

Research in America has shown that, regardless of whether they were picked up via surveillance screening, symptomatic presentation or another route, 86% of people diagnosed with bowel cancer under the age of 50 will be experiencing symptoms at the point of diagnosis¹⁰. While many of these people should be picked up via surveillance screening for high-risk groups, symptoms awareness remains vital.

Why did you delay going to the GP?



- I was embarrassed to talk about my symptoms
- I knew I had some symptoms but I was not worried about them
- I didn't have time to go to the GP
- I thought my symptoms would go away
- I avoided thinking about my symptoms
- I was worried it might be cancer

Making change: A global partnership

Since launch, our Never Too Young campaign has gone global.

In 2013, Bowel Cancer UK and Colon Cancer Alliance (CCA) in the USA became the founding members of the Never Too Young global alliance. CCA have coordinated a similar Never Too Young campaign with over 30 American colon cancer charities. The alliance has been joined by Bowel Cancer Australia, who are doing similar work under the Never Too Young banner in Australia.

Bowel Cancer UK is proud to have led the way globally on bowel cancer in younger people.



GP delays

" I feel badly let down by the speed with which the process has taken place.

Survey respondent

Our survey highlighted delays experienced once people go to see their GP. 20% of respondents saw their GP 5 or more times before being referred to a specialist. 41% saw the GP no more than twice before being referred to a specialist. This compares poorly to the average for all bowel cancer patients, where 69% see their GP no more than twice before being referred¹¹.

10% of respondents to our survey saw their GP but were diagnosed as an emergency before being referred to a specialist. This group is of concern, although the figure is lower than in older patients, where around 25% of people see their GP but are diagnosed as an emergency before being referred.

1 in 5 people saw their GP 5 times or more before being referred to a specialist.



There was a strong gender split on how many times respondents waited before being referred to a specialist. 54% of men were sent to a specialist after only 1 or 2 GP visits compared with only 35% of women. Only 15% of men went to the GP 5 or more times, or were diagnosed as an emergency before the GP could refer, compared with 37% of women.

56% of people diagnosed at Stage 1 were referred to a specialist after only 1 or 2 visits to the GP, compared with only 33% of Stage 4.

We still see people waiting too long between reporting symptoms to their GP and being diagnosed with bowel cancer. For 33% of people it took more than 6 months to be diagnosed after first seeing their GP. For 13% of people it took 6-12 months for a diagnosis and 20% of people took more than a year. These figures are similar to our findings in 2013, and extremely concerning. We must find a way to speed up this diagnosis pathway.

23% of people said that they felt ignored by their GP. Only 34% said that they were happy with the level of support they received.

Making change: The BODYSHOP study

It can be difficult for GPs to identify which younger people to refer through for diagnostic testing. Symptoms can be vague and the risk of bowel cancer in younger people is relatively low.

With funding from the Department of Health, a team from Exeter and Durham Universities, with input from Queen Mary's in London and Bowel Cancer UK's Deborah Alsina, have started a study, called BODYSHOP, aiming to address this problem.

They have obtained 1,000 copies of the GP records of young patients with bowel cancer along with 10,000 patients with inflammatory bowel disease, and over 30,000 patients with neither disease. They are identifying the symptoms reported by all three groups of patients so they can be compared.

Ultimately, this research should be able to produce guidance for GPs on which younger patients should be referred for a colonoscopy.

1 in 5 people took over a year to be diagnosed after first seeing their GP.





The importance of acting quickly

Once at the GP, 20% of respondents asked their GP if they thought it could be bowel cancer.

Of those who did ask, 54% of respondents said their GP dismissed the idea because they thought they were too young, a similar proportion to our results in 2013. Men and women were equally likely to ask, but 70% of men reported that the GP dismissed it because they were too young compared with 46% of women. There is still significant progress to be made here to address these gender variations and perception that GPs are dismissing the possibility of bowel cancer in young people who go on to be diagnosed with the disease.

Of the respondents who asked the GP if they thought it could be bowel cancer, only 11% of people diagnosed at Stage 1 reported that the GP dismissed it because they thought the person was too young. This compares to 65% of people at Stage 3 and Stage 4. These results suggest an association between a GP acting quickly and earlier diagnosis for younger people.

// My first sentence to the GP was that I was concerned about having symptoms of bowel cancer. They told me I was too young.
Survey respondent //

 **70%** who asked the GP if it could be bowel cancer felt that the GP dismissed it because they were too young.
 **46%**

Genetic testing

// I have Lynch syndrome. No one seems to know how to monitor me.
Survey respondent //

29% of respondents have been offered genetic testing for themselves at some point (up from 20% in 2013), and 24% have been offered genetic testing for them and their family (down from 34% in 2013). This means that just under half of people

diagnosed with bowel cancer under the age of 50 have not been offered genetic testing. Women were more likely to be offered genetic testing for themselves (30% of women and 26% of men) and for them and their family (26% of women and 21% of men).

These are concerning results. Since July 2014, Royal College of Pathologists guidelines mandate that everyone diagnosed under 50 should be tested for Lynch syndrome at diagnosis. While many of the respondents to our survey will have been diagnosed before this guideline came into force, it still appears that younger people are not getting access to the testing they need at the right time. A diagnosis of Lynch syndrome can affect treatment decisions so it is vital that this test is carried out at diagnosis. Our research shows that half of health authorities in England and Scotland, and more than half in Wales, do not routinely offer testing for Lynch syndrome in younger bowel cancer patients¹². Ultimately, all people diagnosed under 50 and their families should be offered genetic testing.

Making change: Genetic testing for people with Lynch syndrome

People with Lynch syndrome have a higher risk of developing bowel cancer early, yet fewer than 5% of people with Lynch have been identified in the UK.

We called for better testing for Lynch syndrome in our Never Too Young report, and in July 2014 the Royal College of Pathologists mandated testing for Lynch syndrome for people diagnosed with bowel cancer under the age of 50, at the point of diagnosis.

In early 2015 Bowel Cancer UK investigated the impact of this mandate, using Freedom of Information requests to health bodies across the UK. Our work showed that progress is being made on Lynch syndrome testing, and prompted several health trusts to implement testing at diagnosis.

However, there is still variation in this approach, and we continue to work to address this.

Experience of treatment

Overall, only 68% of respondents were happy with their treatment and care.

74% of respondents did have access to a Colorectal Nurse Specialist during their treatment. This is lower than the average for people of all ages with bowel cancer. In the Cancer Patient Experience Survey 2014, 91% of people with bowel cancer were given the name of a Colorectal Nurse Specialist (CNS), although only 77% of people with bowel cancer found it easy to contact their CNS¹³.

It is simply unacceptable that only 68% of people are happy with the treatment and care that they receive. Either the specialist service is failing to provide good service to a small-but-significant minority, or the service is being delivered in such a way that falls below patient expectations. We must see improvements here.

3 out of 10



people were not happy with their treatment and care.

//

After my surgery I was left on my own. Nobody at the hospital could decide what to do with me – I ended up in A&E.

Survey respondent

//

Information

//

It was after all my treatment that I struggled the most.

Survey respondent

//

The top five things that respondents felt could have improved their treatment were:

1. More information on what to expect and/or dealing with side effects (49%)
2. Advice on diet and lifestyle (41%)
3. Peer support from other young patients (41%)
4. Support for my partner/family (41%)
5. Counselling (40%)

However, only 11% said that they had been offered information and support to deal with all the issues that concerned them.

Of particular concern here is that half of respondents said that they did not have enough information on what to expect or how to deal with the side-effects of treatment. A higher proportion of younger patients feel that they do not have enough information about the side-effects of treatment compared with the average for all bowel cancer patients. The Cancer Patient Experience Survey 2014 showed that 83% of bowel cancer patients of all ages had received written information about side effects, and 57% had been told about side effects that could affect them in the future¹⁴. The gap in information for younger patients is a significant issue that the specialist service must address. Treatment for bowel cancer can be tough, and the side-effects can be difficult and, in some cases, long-lasting. Younger people must be given the information they need to support them through this experience.

9 out of 10



people were not offered support on all the issues that concerned them.

18% of people did not feel as if they had enough information to make informed choices about their treatment. This is concerning, as the NHS Constitution sets out that patients have a right to be involved in discussions and decisions about their health and care, and to be given information to be able to do this¹⁵. It also sets out the principle that the NHS aspires to put the patient at the heart of everything it does, including involving patients in decisions about their treatment and care¹⁶.

Making change: Support for younger people

Our Never Too Young campaign revealed a stark lack of support for younger people to help them deal with the issues that are relevant to them.

Following this, Bowel Cancer UK secured funding to develop a comprehensive information booklet specifically aimed at younger people.

Launched in May 2015, this resource is accredited by the Information Standard and endorsed by clinical experts and patients. It is available for free from www.bowelcanceruk.org.uk



The effects of treatment for bowel cancer

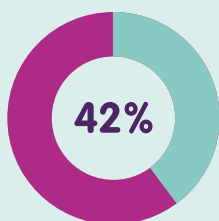
Many people, not just younger people, experience long-term medical effects of treatment. However, survival rates for younger people tend to be longer, and an important part of survivorship is minimising long-term impact of the disease and treatment.

The most common long-term effects of treatment reported by our survey respondents were peripheral neuropathy (47% reported experiencing this), bowel dysfunction (42%) and psycho social effects (37%).

“ This survey is the first time I have been asked about the side effects that I am living with. ”

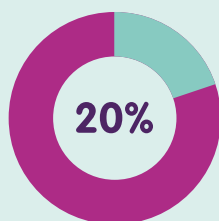
Survey respondent

Are you experiencing any long-term medical effects of treatment?



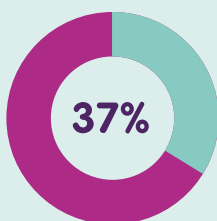
Bowel dysfunction

e.g. incontinence

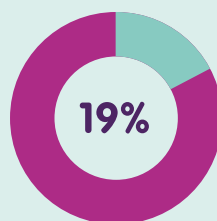


Sexual dysfunction

e.g. for erectile dysfunction or dyspareunia

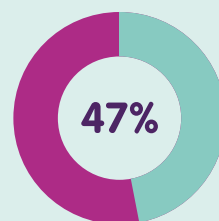


Psycho social effects



Urology problems

e.g. incontinence or stoma formation



Peripheral neuropathy

e.g. painful fingers and toes

Sexual relationships and fertility

" No one could tell me how the chemo would affect my ability to have another child. I still don't know, a year down the line.

Survey respondent

The impact of treatment on sexual relationships and fertility are issues that are often raised by younger people. 57% of people aged under 19 and 41% of people aged 20-29 were concerned about the effects of treatment on their sexual relationships. In addition, 62% of people aged 20-29 and 42% of people aged 30-49 were concerned about the effect of treatment on their body image.

Respondents under the age of 29 were more likely to cite fertility as an issue of concern, with those under 19 citing it as the biggest thing that worried them. Of those people who said fertility was a relevant issue for them, only half had been offered advice on fertility prior to treatment. Men were more likely to be offered advice on fertility (56% of men for whom fertility was an issue compared with 46% of women for whom fertility was an issue).



1 in 2 people who wanted advice on fertility prior to treatment did not get it.

Isolation, social media and being part of a community

" I was the youngest person that I ever saw at the clinic.

Survey respondent

Our survey reconfirmed that gaps in support persist for people diagnosed with bowel cancer under 50. 1 in 3 people said that most of the information they received was targeted at older people, they felt isolated, and they felt like they were the only younger person with bowel cancer. More than half said that they had no one their age with bowel cancer to talk to.

Younger people with bowel cancer often turn to social media to seek out other people with similar experiences. One way of doing this is via the #never2young hashtag on Twitter, which has proved extremely effective in creating an online support network for people with bowel cancer under the age of 50.

Making change: #never2young

Younger bowel cancer patients tell us that they often feel like the only younger person with the disease.

In 2013, we spoke to a lot of younger people on Twitter, and saw the way that they connected with each other. We launched the #never2young hashtag, to encourage younger bowel cancer patients to speak to each other online and provide peer support.

Since then, our campaign pages have been seen over 185,000 times, and our campaign films have been viewed more than 150,000 times. The #never2young hashtag has been used worldwide by younger bowel cancer patients.



1 in 2 people said that they had no one their age with bowel cancer to talk to.

What needs to happen next?

This report shows that many younger bowel cancer patients are struggling to get the diagnosis, treatment and support that they need from the health service. There are areas of good practice, but too often the experience of younger people with bowel cancer is poor. The human cost of this is too great to allow it to continue.

Since we published our original report in 2013, we have made significant progress on many issues affecting younger people. In some areas change can be slow, as evidence needs to be developed, interrogated, and translated into clinical practice. However, despite what we have already achieved, there is more to be done. Bowel Cancer UK is calling on the Government, the NHS, commissioners and health bodies across the UK to implement the recommendations below to ensure younger bowel cancer patients have access to the services and support they need.

Faster progress on genetic testing, support and surveillance screening for those at higher risk

- 01 | Health bodies across the UK** to implement the Royal College of Pathologists guideline on reflex testing for Lynch syndrome for people diagnosed with bowel cancer under the age of 50.
- 02 | The NHS** to improve surveillance screening services for groups at higher risk. This must include a nationwide high quality screening system which could be run by the NHS bowel cancer screening programmes in each UK nation. This will require additional capacity within our endoscopy services.

- 03 | The Government** to commit to better surveillance screening and genetics services. We have called for this to be included in the new Cancer Strategy for England, due to be produced by the Cancer Strategy Task Force and ratified by the UK Government in Summer 2015. This commitment must be backed up by action by central and local health bodies. We are also pressing for similar changes in Wales, Scotland and Northern Ireland.

Improved clinical guidance and practice on bowel cancer in younger people

- 04 | Clinical guidance bodies** to ensure guidelines for younger people are reflected in practice. We welcome the inclusion of people under the age of 50 in Scottish Medicines Consortium (SMC) and NICE guidance, and will be monitoring how this influences the experiences of people when they visit their GP with possible symptoms of bowel cancer.
- 05 | The UK research community** to work with us to improve understanding of the development and genetic profile of bowel cancer tumors in younger people. This will ensure we diagnose people quickly and deliver the best possible treatment for them.
- 06 | The NHS and commissioners** to support ongoing education and training programmes to ensure that all relevant healthcare professionals, including GPs, are aware that younger people can develop bowel cancer and rule it out much more quickly within the diagnostic pathway.

- 07 | Commissioners** to invest in diagnostic testing to make sure that, once referred, people get the right test at the right time. Waiting times for endoscopy services vary across the country, and demand for these services is predicted to rise. Currently the system is failing many younger patients and those at higher risk for the disease.

Improved information for younger people on bowel symptoms

- 08 | Public health bodies** to communicate bowel cancer symptoms and risk to younger people. The risk of bowel cancer is low in many people under the age of 50, but it can and does happen. We want to see this risk highlighted, not to alarm people, but to make sure that younger people recognise symptoms as serious if they do experience them.

Better information and support for younger bowel cancer patients from healthcare practitioners

- 09 | Healthcare professionals** to direct younger patients to trusted information sources. Support for younger bowel cancer patients must also be made available, with patients signposted to relevant sources of information. Bowel Cancer UK's booklet on support for younger people, published in May 2015, provides a range of information, advice and suggestions of where to find further support. We encourage all health professionals who are supporting younger people with bowel cancer to use our resource, available at www.bowelcanceruk.org.uk.

What Bowel Cancer UK is doing

- 01 | Making policy change through campaigning.** We will continue our policy and campaigning work for younger bowel cancer patients, pushing for change and monitoring uptake of new practice. Where we see, for example, health bodies not implementing the Royal College of Pathologists mandate on reflex Lynch syndrome testing, a lack of investment in endoscopy services, or patchy surveillance screening for people at higher risk of the disease, we will work with patients, supporters, parliamentarians, policy makers and leading clinicians to change this.
- 02 | Investing in research on bowel cancer in younger people.** Our research programme will include a strand of work dedicated to understanding more about how bowel tumors develop in younger people. This will build on our involvement in research projects with Exeter and Durham Universities, Genomics England and the Association of Coloproctology of Great Britain and Ireland, and will look specifically at how to improve diagnosis and treatment of bowel cancer in younger patients.
- 03 | Collaborating with global partners on bowel cancer in younger people.** We are working at a global level to coordinate messages about bowel cancer in younger people. Ourselves, Colon Cancer Alliance in the United States of America and Bowel Cancer Australia are working together to share knowledge, combine our resources and connect people on social media to make sure that we can lead the way and make change for younger bowel cancer patients together. We are also working with a range of international organisations to identify key gaps in research and are planning to work together to address these issues. We hope that by working with our international partners we can make progress more quickly on behalf of younger bowel cancer patients.

What you can do to help us

Bowel Cancer UK could not make a difference without your support. Here's what you can do to support our #never2young campaign:

- 01 | Help us fund research into bowel cancer in younger people.** We know there are gaps in our knowledge about how bowel cancer in younger people develops. For example, we need to know more about how we can better identify people most at risk with a strong family history but without a known genetic condition, or whether screening would be beneficial for certain people at a younger age. Funds you donate or raise can help us commission research to answer key questions such as this. Donate to support our campaign at www.bowelcanceruk.org.uk/donate
- 02 | Raise awareness of our campaign.** Since our campaign began, we have enlisted celebrity supporters who have helped us reach over 17 million people. Our films have been seen 150,000 times, and we have reached millions of people through the media. You can help us continue to do this by sharing this report, our infographics and our films with your friends and contacts including through social media. This really does make a difference as the more people are aware that younger people can develop bowel cancer, the greater the chance that they might act quickly if they have any concerns and the more likely positive policy changes can be made.
- 03 | Sign up to be a campaign supporter.** Our network of campaign supporters helps us to highlight issues by writing to their MP or local Parliamentarian, writing to local papers or to local commissioners who choose which health services to invest in. By helping us in your area, you can increase the number of people we reach with our campaign. Sign up at www.bowelcanceruk.org.uk

We must redouble our efforts to make the change needed to stop bowel cancer in people under the age of 50. People are still experiencing delays in diagnosis, they are not getting the information and support they need, and they are still feeling isolated or not fully involved in the decisions and issues that affect them.

Our #never2young campaign for younger bowel cancer patients will continue, informed by the results of this survey. You can stay up to date with our work in this area at www.bowelcanceruk.org.uk.

For more information on this research or Bowel Cancer UK's work on bowel cancer in people under the age of 50, please contact Nick Bason, Head of Policy & Communications, at nick.bason@bowelcanceruk.org.uk.

Appendices

Appendix A - Methodology

This report was produced using the following methodology:

- Desk research was carried out between January and March 2015.
- A survey of 40 questions (See Appendix B) was run online using the Survey Monkey service between 12 January 2015 and 11 March 2015. This survey was promoted via social media channels, online patient forums, health professional networks and on the Bowel Cancer UK website. We received 401 responses from people who were diagnosed with bowel cancer under the age of 50 (an additional 18 respondents indicated that they had not been diagnosed under 50, and ended their response at Question 1). Respondents were self-selecting.
- Comments on a draft of this document were sought from members of the Bowel Cancer UK Medical Advisory Board (see www.bowelcanceruk.org.uk for a list of members).

Appendix B – Our survey of younger bowel cancer patients, 2015

01 | Were you diagnosed with bowel cancer under the age of 50 in the UK?

- Yes
- No – Thanks and close

02 | Are you male or female?

- Male
- Female

03 | How old were you when you were first diagnosed with bowel cancer?

- Under 19
- 20-29
- 30-39
- 40-49

04 | What age are you now?

- Under 19
- 20-29
- 30-39
- 40-49
- 50-59
- 60 or over

05 | What area of the UK do you live in? Pick the one that most closely applies.

- East Midlands
- East of England
- London
- North East England
- Northern Ireland
- North West England
- Scotland
- South Central England
- South East England
- South West England
- Wales
- West Midlands
- Yorkshire & the Humber

06 | Prior to being diagnosed, were you aware that at your age you could be at risk of developing bowel cancer?

- Yes
- No
- Don't know

07 | Prior to being diagnosed, did you know what the symptoms of bowel cancer are?

- Yes
- No
- Don't know

08 | Do you feel that there is a perception among the general public that bowel cancer only affects the much older generations?

- Yes
- No
- Don't know

09 | Prior to being diagnosed, did you have a strong family history of bowel cancer? This would mean that: (a) one of your close relatives (father, mother, brother, sister, child) had been diagnosed under the age of 50, or (b) two of your close relatives had been diagnosed over the age of 60, or (c) two close relatives to each other (e.g. mother and maternal grandmother) had been diagnosed over the age of 60. If you are not sure, please click 'Don't know'.

- Yes
- No
- Don't know

10 | Is there anyone else in your family who has been diagnosed with bowel cancer?

- I was the first person diagnosed in my family
- I don't know
- Yes I had a relative with bowel cancer

11 | Prior to being diagnosed, were you on a surveillance programme (for example, under the care of a hospital department and having regular colonoscopies)?

- Yes
- No

12 | What prompted you to first approach your doctor or GP? Choose all that apply:

- I went to my doctor because of the symptoms I was experiencing but I didn't suspect that I had bowel cancer
- I went to my doctor because I was concerned that I had symptoms of bowel cancer
- I knew that I had symptoms of bowel cancer
- I was contacted as part of a follow-up through a bowel cancer surveillance programme
- I went to my doctor for an illness unrelated to bowel cancer

13 | When you first went to your doctor about your symptoms, which of the following symptoms of bowel cancer did you have? Choose all that apply:

- Bleeding from your bottom and/or blood in your poo
- A change in bowel habit lasting for 3 weeks or more (e.g. more frequent)
- Unexplained weight loss
- Extreme tiredness for no obvious reason
- A pain or lump in your tummy

14 | After first developing the worrying symptoms (you now know to be bowel cancer), how long did you wait until you went to see your GP?

- Up to 6 weeks
- Over 6 weeks
- Over 3 months
- Over 6 months
- Over a year
- I didn't see my GP

15 | If you delayed going to your GP, what was the reason? Choose all that apply:

- I was embarrassed to talk about my symptoms
- I knew I had some symptoms but I wasn't worried about them
- I didn't have time to go to the GP
- I thought my symptoms would go away
- I avoided thinking about my symptoms
- I was worried it might be cancer
- Not applicable

16 | How many times did you see your GP about your symptoms before being referred to a specialist?

- 1
- 2
- 3
- 4
- 5
- More than 5
- I did not see my GP, I was diagnosed as an emergency
- I did see my GP but was diagnosed as an emergency

17 | Did you ask your GP if he/she thought you could have bowel cancer based on your symptoms?

- Yes
- No

18 | How did your GP react when you asked about whether you could potentially have bowel cancer? Choose all that apply:

- GP dismissed it because they thought I was too young
- GP said the chance of bowel cancer at my age was very small, but it was possible
- GP said he would refer me to a specialist
- GP refused to refer me to a specialist because they were convinced it was something else

19 | Before being diagnosed with bowel cancer, were you investigated for another condition?

- Yes
- No
- Don't know

20 | What other condition(s) was/were diagnosed before you were correctly diagnosed with bowel cancer (excluding pre-existing conditions)? Choose all that apply:

- Irritable bowel syndrome (IBS)
- Heartburn
- Indigestion
- An inflammatory bowel condition, for example Crohn's disease
- Diarrhoea
- Constipation
- Haemorrhoids (Piles)
- Anaemia
- Anal fissures (anal tears)
- Don't know

21 | Altogether, how long was it from the time you first reported your symptoms to your GP to being diagnosed with bowel cancer?

- Up to 2 weeks
- Up to a month after first symptoms
- Up to 3 months after first symptoms
- Up to 6 months after first symptoms
- Up to 12 months after first symptoms
- More than 12 months after first symptoms

22 | When you were diagnosed, what stage of disease were you told you had?

- Stage 1
- Stage 2
- Stage 3
- Stage 4
- I wasn't told

23 | When your bowel cancer was first diagnosed, had it spread to the lymph nodes, or another part of your body (e.g. your liver or your lungs)?

- Yes, to my lymph nodes
- No
- Don't know
- Yes, to another part of my body

24 | Since your diagnosis, have you been offered genetic testing?*

- Yes, for me
- Yes, for me and my family
- No
- Don't know

25 | Were you happy with your treatment and care?

- Yes
- No
- Partially

26 | Did you have access to a colorectal nurse specialist? (Note: Not a stoma care nurse).

- Yes
- No
- Don't know

27 | When you were diagnosed, were you given choices about your treatment options?

- Yes
- No
- Don't know

28 | How did you feel about your level of involvement in choosing the treatment you were given? Choose all that apply:

- I felt I had a real say in the treatment I was given
- I felt my doctor was best placed to make the decision for me
- I felt I wasn't given any choice in my treatment
- I felt I was given the wrong treatment for me
- I felt I didn't have the right information to make an informed choice about treatment
- I felt I wasn't given enough information about my treatment

29 | What could have improved your treatment? Choose all that apply:

- More information about my treatment options
- Access to a colorectal nurse specialist
- Access to a stoma care nurse
- More information on what to expect and/or dealing with side effects
- Peer support from other young patients
- Better understanding of my treatment and needs by my employer
- Counselling
- Better communication from my medical team
- Advice on diet and lifestyle
- Support for my children
- Support for my partner/family
- Advice on fertility
- Being offered complementary therapies

30 | Has your doctor ever told you that cost is the reason you could not have a particular treatment for bowel cancer?

- Yes
- No
- Don't know

31 | Did you feel that you had enough information to make informed choices about your treatment?

- Yes
- No
- Don't know

32 | Where did that information come from?

- The hospital
- Your GP
- Charity websites (for example Bowel Cancer UK, Macmillan or Cancer Research UK)
- NHS or other healthcare provider websites
- Talking to other people online, either through discussion boards, Facebook or Twitter
- Family and friends
- Other patients that you met

33 | In what formats do you prefer to receive/look at information? Choose all that apply:

- Information on charity websites
- Email
- Patient information leaflets
- Letter
- In person from my doctor
- In person from my nurse

34 | As someone who was diagnosed with bowel cancer at an early age, how did you feel about the level of support you received? Choose all that apply:

- Most of the information I received was targeted for older people
- I felt ignored by my GP
- I felt ignored by my consultant
- I felt like I was the only young person with bowel cancer
- I had no one my age with bowel cancer to talk to
- I felt isolated
- I was happy with the level of support I received
- None of the above

35 | What are the five topics that worried you most about the effects of your treatment? Choose no more than five answers:

- Diet
- Exercise and lifestyle
- Fertility
- Sex and relationships
- Body image
- Money
- Ability to work in the future
- Side effects of my treatment
- Whether my children/other relatives might be at risk of developing bowel cancer
- Fear of recurrence of bowel cancer

36 | Have you been offered information and support to deal with these issues?

- Yes on some issues that concern me
- Yes on all issues that concern me
- No

37 | Were you offered advice on fertility prior to your treatment?

- Yes
- No
- This wasn't an issue for me

38 | Are you experiencing any long-term medical effects of treatment? Choose all that apply:

- Bowel dysfunction (for example incontinence)
- Sexual dysfunction (for example erectile dysfunction or dyspareunia)
- Psycho social effects
- Urology problems (for example incontinence or stoma formation)
- Peripheral neuropathy (for example painful fingers)

39 | Is there anything else you would like to tell us about your experiences of bowel cancer treatment and care?

- Free text

40 | Thank you for your time in completing this survey. Please enter your email address if you would be happy for us to contact you.

- Free text

**In our 2013 survey, this question read: "Since your treatment, have you been offered genetic testing?"*

Appendix C - References

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¹⁶ *ibid*



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Bowel Cancer UK Head Office

Willcox House, 140-148 Borough High Street,
London SE1 1LB

Bowel Cancer UK in Scotland

20 Queen Street, Edinburgh EH2 1JX

Registered Charity Number (England & Wales) 1071038 | Scottish Charity Number SCO40914 |
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