



never too young:

the experiences of younger bowel cancer patients

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Executive summary

The number of people under the age of 50 who are diagnosed with bowel cancer each year in the UK is slowly rising. In 2009, the latest year for which figures are available, there were 2,132 people under the age of 50 diagnosed with bowel cancer, compared with 1,698 people in 1999. This is an increase of almost a quarter over the decade. Younger bowel cancer patients (by which we mean, people diagnosed under the age of 50) have a qualitatively different experience of diagnosis, treatment and care.

At Bowel Cancer UK, we hear from younger bowel cancer patients who express frustration at the difficulty and delays in getting a diagnosis. They often feel as if they are the only young person diagnosed with bowel cancer, and feel frustrated at not being able to find information and support specifically for younger bowel cancer patients. We want to change this.

Key findings

We conducted research into the experiences of younger bowel cancer patients. We also put a survey into the field, with 109 responses from people diagnosed under 50. The main topics that were raised in the survey were:

- Six out of ten younger patients were not aware of the symptoms of bowel cancer prior to being diagnosed, and were not aware of bowel cancer as a disease younger people could get.
- One in four people waited over six months after developing symptoms before going to see their doctor.
- Nearly one in two women and one in ten men either saw their GP more than five times before being referred to a specialist, or were diagnosed as an emergency before being referred.
- One in five women had to wait over a year before being diagnosed, compared with one in ten men.
- One in two respondents to our survey were given choices about their treatment options.
- Only one in four women and just fewer than one in two men were happy with the levels of support they received.
- More than one in two younger bowel cancer patients felt that they had no one their age with bowel cancer to talk to. Peer support from other young patients was identified as a major factor that could have improved treatment.
- Four in ten people felt that most of the information they received was targeted at older people.
- Fewer than one in three women and only half of men were offered advice on fertility prior to their treatment for bowel cancer.
- Four out of five younger patients were not offered support on all the issues that concerned them.

Our key recommendations

During one of the biggest reforms since the creation of the NHS, we want to ensure that the new institutions and structures support the needs of younger bowel cancer patients.

We have set out ten recommendations in the report that we believe will transform the experiences of younger bowel cancer patients. From these, our key recommendations are:

1. **A bowel disease decision aid tool** developed for use in primary care to enable GPs to make informed decisions about who to refer for diagnostic tests. This must be implemented in all NHS Boards as part of a strategy for better risk assessment of people under 50 with symptoms of bowel cancer. This may require additional research.
2. **Revision of clinical guidance** to ensure that people under 50 with symptoms, or at high risk of bowel cancer, get appropriate tests to rule out bowel cancer first not last. Clinical guidance bodies in all four UK nations should consult with and involve bowel cancer patients and experts when reviewing guidelines around referral for suspected cancer and diagnosis of bowel cancer.
3. **Adequate screening and surveillance** put into place by Clinical Commissioning Groups in England, Health Boards in Scotland and Wales, and the Northern Ireland Health and Social Care Board for families at high risk (e.g. due to genetic conditions, where there is a strong family history of the disease or someone has an inflammatory bowel condition). Department of Health needs to support this through public policy.
4. **Endoscopy capacity to be increased** by NHS commissioning bodies in all four UK nations to ensure that endoscopy units are able to deliver high-quality, timely services to meet current and future demand so this is not a barrier to diagnosis for younger patients.
5. **Younger bowel cancer patients to be given access to the services** that they need including fertility, sexual relationships, and support to deal with long-term psychological and physical effects of treatment. These must form part of commissioning guidance in all four nations.

Terminology

In this report, we are using the term “younger bowel cancer patients” to mean people aged under 50. People aged under 40 are not covered by clinical guidance or bowel cancer screening programmes in any of the four UK nations.

Age-specific incidence rates of bowel cancer increase sharply from around age 50.

Methodology

To research this report, we put a 45-question survey in the field (See Appendix A), with 109 responses from people who were under 50 when first diagnosed with bowel cancer.

The survey was run by Bowel Cancer UK and circulated to our network of supporters. It was also promoted via the Bowel Cancer UK website and digital media channels. Respondents were self-selecting.

In addition, we ran a three-hour focus group in December 2012 that was attended by 10 people who were under 50 when first diagnosed with bowel cancer. This allowed us to explore in more detail the views and experiences of younger bowel cancer patients. Some of the attendees from that event are featured in this report as case studies.

The writing of the report was supported by desk-based research that looked at historical trends of bowel cancer in people under 50 and other writing into the experiences of younger bowel cancer patients. We also considered the impact on younger bowel cancer patients of the Health and Social Care Act (2012) and the reorganisation of the NHS.

The report was authored entirely by Bowel Cancer UK and Bowel Cancer UK retained full editorial control.

Rachel Bown



Introduction

Why focus on younger bowel cancer patients?

Every year, over 2,100 people under the age of 50 are diagnosed with bowel cancer in the UK.¹ While this accounts for just 5% of people diagnosed with the disease in this country each year,² this group of people, and their family and friends, have an experience of diagnosis, treatment, care, and in many cases life after bowel cancer, that is qualitatively different from older people.

At Bowel Cancer UK, we hear from young people affected by bowel cancer, who tell us stories of heartbreak and of hope. These stories often contain frustration at the difficulty and delays in getting a diagnosis of bowel cancer, at feeling as if they are the only young person diagnosed with bowel cancer, and at not being able to find information and support specifically for younger bowel cancer patients. We want to change this.

This report is part of a Bowel Cancer UK campaign to improve the experience of younger bowel cancer patients. You're never too young to be diagnosed with bowel cancer, and you should never be too young to access the services, treatment, care and support you need to get through bowel cancer.

¹ Cancer Research UK, <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bowel/incidence/uk-bowel-cancer-incidence-statistics#By2>, accessed 4 March 2013

² *ibid*

Younger people and bowel cancer Symptoms, and “what’s normal for you?”

While being diagnosed with bowel cancer under the age of 50 indicates that a person may have strong risk factors (possibly genetic), these risk factors may not be obvious from family history, and the specific genetic risk factors may not be fully understood. Therefore, understanding and acting on symptoms remains essential - for most people under 50, experiencing symptoms will be the first thing that alerts them to the fact that something may be wrong.

The vast majority of respondents to our survey first went to their GP because they were experiencing symptoms, although in most cases they didn’t know what the symptoms were of.

Commonly asked questions on the Bowel Cancer UK Information Line³

- "I have had looser stools for about 6 weeks, should I see my GP?"
- "Over the past 6 months I have been feeling sick, have bloating and constipation a lot of the time. My doctor says I have Irritable Bowel Syndrome (IBS). I would appreciate your advice."
- "My stools have been looser for some time now and I often feel sick. I try to eat a healthy diet with fruit and vegetables, and don't eat much red meat. I also exercise, and don't smoke. I'm in my twenties. Could it be IBS or do I need to see a doctor?"

A lot of younger people who contact the Bowel Cancer UK information line do so because they are experiencing pain or uncomfortable symptoms, and they have very little frame of reference in which to interpret these symptoms. This can be seen from some of the questions our nurses are commonly asked (see text box). A lot of the time, people contact us with a vague sense that something is wrong, but they are not sure what it is, or what to do about it.

There is a wider need to ensure young people understand their digestive system, their body's rhythms and routines, and where to go when they feel something is wrong. This is not just a point about bowel cancer - we are often asked about a variety of bowel and digestive dysfunctions, by people who do not know where else to go. While there is a lot of information online regarding digestive problems, there is a section of people who need support to negotiate the information and advice available.

Young people at higher risk of bowel cancer

Some young people in the UK are at higher risk of bowel cancer because of a strong family history of the disease, or because of a particular genetic condition. Familial Adenomatous Polyposis (FAP) is an inherited condition that is responsible for less than one out of every 100 cases of bowel cancer. It can cause polyps to grow in the colon from a very early age, which if untreated can lead to people developing bowel cancer at an average age of 39 years. Similarly, Hereditary Non Polyposis Colorectal Cancer (HNPCC), also known as Lynch Syndrome, can cause bowel cancer to develop before a person reaches 70 years of age.

28.8% of the population aged 30-70 years old have one or two direct family relatives with bowel cancer. For people at the highest risk, the British Society of Gastroenterologists recommend⁴ regular colonoscopies from as young as 25 years old. In addition, people with an inflammatory bowel condition such as ulcerative colitis or Crohn's disease can also be at higher risk of developing bowel cancer.

People affected by these conditions should have access to regular screening through surveillance programmes. However, these high-risk groups of people are often not identified. Even if they are, they often do not have the regular screening that current British Society of Gastroenterology guidelines⁵ recommend. Patients at high risk are often under-screened because of a poor understanding of these conditions by doctors in primary and secondary care. There is a lack of information about the experiences of this group of people. Patients on a surveillance list who wait longer than six weeks for a surveillance endoscopy procedure are not included in monthly waiting times returns.

³ These questions are derived from real questions received by the Bowel Cancer UK Information Line in 2012.

⁴ Cairns et al (2010), BSG/ACPGBI Guidelines for Colorectal Cancer Screening and Surveillance in Moderate to High-Risk Groups, <http://www.mph.ed.ac.uk/endo/docs/clininfo/BSGCRcancerSurv2010.pdf>

⁵ ibid

While those patients may not have symptoms, they will be at higher risk and should not be overlooked in waiting-time metrics. In addition, information about how many people are affected by these conditions and how they are identified for surveillance screening is not collected. It is essential that younger patients at higher risk of developing bowel cancer are properly identified and included in surveillance screening programmes.

Clinical Guidelines and younger people

Younger people are often overlooked in public policy and clinical guidance on bowel cancer. National Institute for Health and Clinical Excellence (NICE) clinical guidelines (which apply in England and Wales) on referral for suspected lower gastrointestinal cancer only covers people aged over 40 with specific symptoms, or people over 60 with more general symptoms. There is no guidance for people under 40.⁶ Similarly, the clinical guideline for the diagnosis and treatment of colorectal (bowel) cancer sets out at the beginning that occurrence of colorectal (bowel) cancer is strongly related to age, with the majority of cases occurring in people aged over 65.⁷

The NICE guidance is replicated in the Northern Ireland Referral Guidance for suspected cancer. In Scotland, the situation is similar, with the Scottish Intercollegiate Guidance Network (SIGN) Clinical Guideline on the Diagnosis and Management of Colorectal Cancer recommending a “watch and wait policy” (with no suggested timeframe) for people under 40.⁹ This is despite there being more than 500 people under 40 being diagnosed with bowel cancer each year in the UK.

The impact of this is that there is inadequate guidance around the risk assessment and diagnosis of people under 50 who present with symptoms of bowel cancer. There are no guidelines to support GPs in referring people under 40, and the guidelines for people between 40 and 50 are open to interpretation. Our survey indicates that younger bowel cancer patients are vulnerable to late diagnosis of bowel cancer. This may be in part due to GPs not being able to rely on guidance to justify referrals to busy endoscopy units.

Our research suggests that younger patients have to return to the GP multiple times before getting a referral to a specialist. In addition, research suggests that many patients with a strong family history do not receive the services recommended in British Society of Gastroenterology (BSG)/Association of Coloproctologists of Great Britain and Ireland (ACPGBI) guidance.¹⁰ Investment is being put into various awareness-raising campaigns (for example, Be Clear on Cancer and Detect Cancer Early), but unless the message of ‘rule out bowel cancer first not last’ is reinforced in clinical guidelines, younger people will continue to struggle to be taken seriously.

A different experience

When diagnosed, younger bowel cancer patients often feel as if they are the only younger person diagnosed with bowel cancer. They find it difficult to access information on topics such as fertility, returning to work, or raising a young family. And when, as they hopefully will be, they are given the all-clear after treatment, they often have remaining questions about diet, exercise and lifestyle.

This report explores the experiences of younger bowel cancer patients in detail as they move through the diagnosis, treatment and care pathway. The report examines what they need from the health and social care system, often in the words of younger bowel cancer patients themselves. Finally, we look at what needs to change in the system and who needs to do what in order to ensure that younger bowel cancer patients are fully supported every step of the way.

⁶ NICE CG27: Referral Guidelines for Suspected Cancer (April 2011), <http://www.nice.org.uk/cg27>

⁷ NICE CG131: The Diagnosis and Management of Colorectal Cancer (November 2011), <http://www.nice.org.uk/nicemedia/live/13597/56998/56998.pdf>

⁸ Northern Ireland Referral Guidance for Suspected Cancer (December 2012), [http://www.cancerni.net/files/file/Northern%20Ireland%20Referral%20Guidance%20for%20Suspected%20Cancer%20_Dec12\(2\).pdf](http://www.cancerni.net/files/file/Northern%20Ireland%20Referral%20Guidance%20for%20Suspected%20Cancer%20_Dec12(2).pdf)

⁹ SIGN 126: Diagnosis and Management of Colorectal Cancer (December 2011), <http://www.sign.ac.uk/pdf/sign126.pdf>

¹⁰ K J Monahan, S K Clark and BSG Cancer Group, ‘A National Survey of Local Hereditary Colorectal Cancer Services in the UK: A Highly Variable Approach?’, 2013

What are the historical trends around younger bowel cancer patients?

Across the individual nations in the UK, the availability of records of the age profile of people diagnosed with bowel cancer varies. We have pulled together historical data from England, Northern Ireland, Scotland and Wales over the past ten years (measured back from 2009, the latest complete UK data available).

Number of cases of colorectal (bowel) cancer (C18-C21) by age in England,¹¹ Northern Ireland,¹² Scotland¹³ and Wales¹⁴: 1999 – 2009

Age Range	1999	2004	2009
Under 30	77	106	161
30-39	371	342	422
40-49	1,250	1,262	1,549
Total number of people under 50 diagnosed with bowel cancer	1,698	1,710	2,132
Total number of people diagnosed with bowel cancer	38,628	35,549	41,142

The number of people diagnosed with bowel cancer under the age of 50 in the UK has risen over the past ten years. The proportion of people diagnosed with bowel cancer who are under 50 has also risen.

We can see above that in 1999, the proportion of people diagnosed with bowel cancer in the UK who were under 50 was 4.4%. Compare this to 2009, when 5.18% of people diagnosed with bowel cancer were under 50, we see that not only is the number of people under 50 diagnosed with bowel cancer going up, but it is increasing at a faster rate than the number of people over 50 diagnosed with bowel cancer.

¹¹ Hansard source, (Citation: HC Deb, 16 October 2008, c1470W), <http://www.publications.parliament.uk/pa/cm200708/cmhansrd/cm081016/text/81016w0024.htm#0810171002110>

¹² Northern Ireland Cancer Registry, Incidence & Survival 1993-2011, <http://www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/Colorectal/>

¹³ Information Services Division Scotland (ISD Scotland), Colorectal Cancer Annual Incidence, <http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Colorectal/>

¹⁴ NHS Wales, Trends in Incidence 1985-2010, <http://www.wales.nhs.uk/sites3/page.cfm?orgid=242&pid=61810>

Who are younger bowel cancer patients?

Latest figures show that in 2009, 2,132 people under 50 were diagnosed with bowel cancer.

These numbers break down into the following age ranges:

Age Range	Males Cases	Female Cases	Male Rates	Female Rates
0 to 04	0	0	0	0
05 to 09	0	0	0	0
10 to 14	3	3	0.1	0.2
15 to 19	6	9	0.3	0.5
20 to 24	22	21	1	1
25 to 29	52	45	2.5	2.3
30 to 34	71	73	3.7	3.8
35 to 39	143	135	6.5	6
40 to 44	280	279	12	11.7
45 to 49	514	476	24	21.5

Statistics taken from Cancer Research UK website¹⁵

Of the 2,132 people under 50 diagnosed with bowel cancer, 1,091 (51%) were male and 1,041 (49%) were female. 8% were aged under 30, 20% were between 30-39 and 73% were aged 40-49.¹⁶

Information is not routinely collected on the demographic breakdown of this group of people. One of the difficulties in providing relevant information that is meaningful to younger bowel cancer patients stems from this lack of routinely collected data. It is not clear how the group of 2,100 people diagnosed each year breaks down in terms of race, religion, ethnicity, geographical location, disability or socio-economic status.

The people who responded to our survey tended to be younger than the UK average of young people with bowel cancer. Of the respondents to our survey, 20% were aged between 20-29, 32% were aged between 30-39 and 48% were aged between 40-49 when they were diagnosed. Just over two thirds of respondents were female and one third were male. We received responses from people in every government region and all four UK nations.

¹⁵ Cancer Research UK website, accessed 28 February 2013, <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bowel/incidence/uk-bowel-cancer-incidence-statistics#By2>

¹⁶ Numbers may not add up to 100% due to rounding.

What issues did our survey tell us that younger bowel cancer patients face?

Bowel Cancer UK surveyed people who had been diagnosed with bowel cancer under the age of 50. We wanted to understand more about their experiences of bowel cancer and their views on their bowel cancer pathway. We had 109 responses from people diagnosed under 50, and some common themes have emerged.

Awareness of bowel cancer as a disease younger people can get

- Prior to being diagnosed with bowel cancer, 90% of women were not aware that they could be at risk of bowel cancer, compared with 69% of men.
- 91% of people think that there is a perception that bowel cancer only affects much older people.
- 69% of men and 56% of women were not aware of the symptoms of bowel cancer prior to being diagnosed.
- People diagnosed with the earliest stage bowel cancer were more likely to have been aware of the symptoms prior to diagnosis.

There is an image of bowel cancer as a disease that only affects older people. This image is reflected in clinical guidance in the UK. Of course, the vast majority – around 95% – of people diagnosed with the disease are aged over 50. However, younger people can get bowel cancer, they do get bowel cancer, and their symptoms should not be ignored simply because it is relatively rare in younger people.

In our survey, 82% people said that prior to being diagnosed, they were not aware that they could be at risk of developing bowel cancer at their age. Women in particular were unaware that bowel cancer could affect younger people – nearly 90% of women were not aware, compared to 69% of men. More than nine out of ten respondents thought that there was a perception among the general public that bowel cancer only affects much older people.

This perception is consistent with the overall relatively low public profile of bowel cancer compared to other cancers. A study by Thames Cancer Registry of UK national newspapers found that bowel cancer received just 14% of the coverage of common cancers in 2011, despite it being the second biggest cancer killer in the UK.¹⁷

Two-thirds of people said they were not aware of the symptoms of bowel cancer prior to being diagnosed. However, looking deeper into this, 60% of respondents who were diagnosed with Stage 1 bowel cancer said that they were aware of the symptoms of bowel cancer prior to being diagnosed. This compares to 35% of people diagnosed at Stage 2 and 41% at Stage 3 and Stage 4 who were aware of the symptoms prior to diagnosis.

Raising awareness of the symptoms of bowel cancer must go hand in hand with raising awareness of the disease as something that can affect younger people. While it is true that risk increases with age, it is important that we raise awareness in younger people in a sensitive way that highlights risk without causing undue alarm.

¹⁷ J Konfortion, R Jack & E Davies, Coverage of common cancers in UK national newspapers in relation to cancer awareness campaigns (2011)

Knowing the symptoms and acting on them

- 95% of younger bowel cancer patients first went to the doctor because they had symptoms but did not know what of, or had an illness unrelated to bowel cancer.
- 30% of women and nearly 20% of men either waited over 6 months after developing symptoms to go to the doctor, or didn't go at all.
- 25% of people put off going to the doctor because they were either embarrassed to talk about their symptoms, or they avoided thinking about them.

95% of younger bowel cancer patients responding to our survey did not initially associate their symptoms with bowel cancer. Most went because they had symptoms but did not know what of, or because they had an illness unrelated to bowel cancer.

Worryingly, while nearly 40% of our respondents went to see their GP in the first six weeks of experiencing symptoms (the period of time symptoms should persist for before being urgently referred, according to NICE guidance¹⁸), 30% of women and nearly 20% of men either waited over six months before they went to see their GP, or did not go at all. This is consistent with figures from the Royal College of GPs that showed people with the most common symptoms of bowel cancer (a change in bowel habit, fatigue, rectal haemorrhage, rectal pain and weight loss) are likely to wait over two months before going to see a doctor.¹⁹

This is a significant group of people, and more needs to be done to encourage younger people to go to their GP sooner. Delays in visiting a GP can not only prolong discomfort for the individual, they may allow the disease to develop to a later stage before being detected, which can affect chances of survival.

The main reason people gave for delaying going to the GP was that they thought their symptoms would go away. However, one in four people said that they either avoided thinking about their symptoms, or they were embarrassed to talk about them. Again, this is a significant group of people, and messages about symptoms need to be framed so that they resonate with younger people and highlight the importance of acting quickly.



Amanda

¹⁸ NICE CG27: Referral Guidelines for Suspected Cancer, para 154, <http://www.nice.org.uk/cg27>

¹⁹ Professor Greg Rubin et al, RCGP National Audit of Cancer Diagnosis in Primary Care (2011), Table 7.1-9, https://www.dur.ac.uk/school.health/erdu/cancer_audit/

Delays in diagnosis

- 42% of women either saw their GP more than five times before being referred to a specialist, or were diagnosed as an emergency before being referred. This was true of only 11% of men.
- 34% of men and 20% of women were referred to a specialist on their first visit to their GP.
- Irritable Bowel Syndrome (IBS), haemorrhoids (piles) and anaemia are the most common conditions to be diagnosed with before being correctly diagnosed with bowel cancer.
- 23% of women had to wait over a year to be diagnosed, compared with just 11% of men.

We have stated above that clinical guidelines do not empower GPs to refer younger people with symptoms of bowel cancer on for diagnostic testing. The effects of this can be seen in the experiences of younger bowel cancer patients. While it is understandable that people will have differing experience of the primary care system based on their different symptoms and age profile, it is not clear what young people with symptoms of bowel cancer can expect from the system. One in three men and one in five women responding to our survey were referred to a specialist after their first visit to a GP. At the other end of the spectrum, 42% of women either saw their GP more than five times before being referred, or saw their GP but were diagnosed as an emergency before being referred, compared with only 11% of men.

These findings suggest that younger bowel cancer patients often have a different experience to older bowel cancer patients. Royal College of GP figures show that over 60% of people (of all ages) who go on to be diagnosed with bowel cancer are referred within one month of first seeing a doctor, yet 13% wait more than two months.²⁰ The findings of our survey suggest more research is needed to understand the specific experience of younger bowel cancer patients, and the different experiences of men and women.

A significant group of younger people we heard from said that they were initially investigated for another condition, before being correctly diagnosed. Six out of ten people were investigated for something other than bowel cancer, with the most common conditions being Irritable Bowel Syndrome (IBS) and haemorrhoids (piles). Women were also likely to be investigated for anaemia before being diagnosed. While anaemia is not necessarily an incorrect diagnosis, the underlying cause of it should be sought. This is an area that requires further research into the experiences of younger patients. In some cases, specialist assessment of IBS, haemorrhoids or anaemia in younger women will be due to the GP wishing to rule out cancer as a cause of the condition, which is welcome. However, many younger bowel cancer patients feel that their cancer has been overlooked initially, because of their age.

Of the people who responded to our survey, 80% of the people diagnosed with Stage 1 bowel cancer said that they were not investigated for another condition before being correctly diagnosed. Only 30% of people diagnosed at Stage 2 and Stage 3, and 23% of people diagnosed at Stage 4 were not investigated for another condition before being correctly diagnosed.

Overall, more than one in three women compared to one in five men waited more than six months from seeing their GP to being diagnosed with bowel cancer. 23% of women waited over a year before being diagnosed, compared with just 11% of men. If one factors in that 60% of the respondents also waited over six weeks before going to see their GP initially, a pattern emerges of younger people being diagnosed too slowly. This is particularly worrying as bowel cancer symptoms can be very vague or relatively silent in the early stages. Therefore, when people do have clearer symptoms, it is imperative that bowel cancer is ruled out quicker in the diagnostic process.

²⁰ibid

Stage of diagnosis

- 48% of younger patients were diagnosed with either Stage 3 or Stage 4 bowel cancer.
- 29% of men and only 17% of women were diagnosed with either Stage 1 or Stage 2 bowel cancer.
- 21% of people were not told what stage bowel cancer they had.

Early diagnosis is key to improving chances of survival from bowel cancer. While we at Bowel Cancer UK know a lot of people who have been diagnosed at Stages 3 and 4 and survived, the fact remains that getting diagnosed earlier gives you a better chance of survival.

The younger bowel cancer patients we heard from in our survey tended to have later stage disease. Half of the people who responded to our survey were diagnosed at either Stage 3 or Stage 4. Men were more likely than women to be diagnosed with Stage 1 or Stage 2 bowel cancer (29% of men compared to 17% of women). Correspondingly, 49% of men said that, when first diagnosed, the bowel cancer had not spread to their lymph nodes or another part of their body. Only 31% of women, fewer than one in three, could say the same thing.

One in five people were not told what stage their bowel cancer was at. The number of people not being told what stage disease they have is concerning. At Bowel Cancer UK, we talk to a lot of patients who want to hear about people diagnosed with the same stage disease who have come through treatment and are living beyond bowel cancer. If patients are not being routinely told what stage disease they have, this makes it more difficult for them to reach out to the wider bowel cancer community and connect to other patient success stories.

Reducing the delays in diagnosis detailed above is crucial to ensuring that more young people receive a correct diagnosis of bowel cancer as soon as possible, to improve their chances of survival.



Stuart, Sophie (4), Sam (8) & Katie

² Hospital Episode Statistics, <http://www.hesonline.nhs.uk>

Experience of treatment

- Half the people in our survey were given choices about their treatment options.
- Peer support from other young patients, information on side-effects, advice on diet and support for family were most likely to have improved treatment.

Once diagnosed, many younger bowel cancer patients have a positive experience of treatment and care. Nearly everyone in our survey said they were partially or completely happy with the treatment and care they received. Looking deeper into this, there was a mixed picture about a patient's choice over the treatment they received. 50% of people were given choices about their treatment options and 49% were not (1% did not know), and there was little difference between men and women on this.

However, many people did have suggestions as to what could have improved their treatment and care. 48% of the people we surveyed said that they would have welcomed peer support from other younger patients. This peer support was particularly important for younger people. 61% of people aged under 40 said that they wanted peer support from other young people.

Information on the side-effects of treatment (41%), advice on diet and lifestyle (39%), counselling and support for a partner or family (36%) were also areas picked out by young patients as areas for improvement. Women were also more likely to want counselling (36% of women compared to 11% of men), access to complementary therapies (31% of women compared to 18% of men), and advice on fertility (19% of women compared to 11% of men).



Katie Scarbrough and Sophie, now-a-days

Information

- Only 26% of women and 44% of men were happy with the levels of support they received.
- The hospital, charity websites and talking to others online are the most frequently used sources of information for younger patients.
- Younger patients prefer receiving information in person from the doctor and through patient information leaflets.

Younger bowel cancer patients receive information from a variety of sources and in a variety of ways. While most people (91%) receive information directly from the hospital (although one in ten people did not), 54% of people also access information from charity websites such as Bowel Cancer UK's. On top of this, 28% seek out other younger patients online, via discussion boards or social media. Women also sought information from other patients that they met (21%) and NHS or healthcare provider websites (19%), while men rarely used these sources of information (3.7% of men picked each answer respectively).

When asked about which formats they preferred to receive information, 67% of younger bowel cancer patients said "in person from my doctor", while 66% said through patient information leaflets. Information from a nurse (59%) and on charity websites (54%) were also popular sources of information.

The information and support available to younger bowel cancer patients must to be better tailored to their needs. Only 26% of women and 44% of men said they were happy with the level of support they received. This consistency of message needs to be heard and acted upon. Younger bowel cancer patients must be able to access peer support, information and share experiences in a way that works for them and ensures that they do not feel like they are facing bowel cancer alone.

Genetic testing

- 37% of younger patients have not been offered genetic testing.

Our survey indicates a mixed picture around the availability of genetic testing. 37% of people who responded said that they had not been offered any genetic testing, while 20% had only been offered it for themselves. 34% of people said that they had been offered genetic testing for themselves and their families.

Isolation, social media and being part of a community

- 58% of younger bowel cancer patients felt that they had no one their age with bowel cancer to talk to.
- 41% of people said that most of the information they received was targeted at older people.
- 39% said that they felt as if they were the only young person with bowel cancer.

As we have seen above, many younger people think of bowel cancer as a disease that affects much older people. This means that being diagnosed with bowel cancer at a relatively young age can often be an isolating experience. Contact with other younger bowel cancer patients can not only provide peer support but also give stories of hope to people who have just had a diagnosis, or who are going through treatment.

A significant number of respondents to our survey stated that:

- "I had no one my age with bowel cancer to talk to" (58% agreed);
- "Most of the information I received was targeted for older people" (41% agreed);
- "I felt like I was the only young person with bowel cancer" (39% agreed); and
- "I felt isolated" (33% agreed)

Peer support from other young patients was identified as the number one thing that could have improved the experience of treatment among the younger patients that we surveyed (see above). For patients who felt that they had access to information about their treatment, talking to people online was an important part of the process (see above). A lot of younger bowel cancer patients tell us that social media plays an important role in connecting with other patients.



Joel and family

The effects of treatment for bowel cancer

- Fear of recurrence of bowel cancer, the side-effects of treatment and whether children or other relatives may be at risk are the top concerns of younger bowel cancer patients.
- 87% of women and 75% of men have not been offered support on all issues that concern them.
- Peripheral neuropathy and bowel dysfunction are the most common long-term medical effects experienced by younger bowel cancer patients still in active treatment.

Younger bowel cancer patients are likely to have different concerns to older patients when it comes to the effects of their treatment. Younger patients are more likely to either have or be thinking about trying for children²¹; they will be at an earlier stage of their working lives and careers; they may have a different lifestyle or approach to relationships to people over 50; and they will likely have different expectations and aspirations for their future lives.

We asked younger bowel cancer patients to tell us what were the top five things that worried them about the effects of their treatment. Understandably, most people were scared of the recurrence of bowel cancer (82% of people said this). Setting that aside for the moment, the top five issues that most concerned young patients were:

- The side-effects of my treatment (68%)
- Whether my children/other relatives might be at risk of developing bowel cancer (67%)
- Body image (45%)
- Money (40%)
- Ability to work in the future (37%)

There is a wide range of issues that concern young people with bowel cancer. Worryingly, 87% of women and 75% of men have not been offered support for issues that concern them.

There is an inconsistency of experience here – some people are offered support on a wide range of topics, some are offered support on a limited range, and many people – more than one in four – have not been offered any support at all.

Many young people still in active treatment are experiencing long-term medical effects of that treatment. Peripheral neuropathy (60%) and bowel dysfunction (34%) were the most common long-term medical effects that younger patients are dealing with due to treatment for bowel cancer. In addition, 29% of women were experiencing urology problems, compared to 9% of men. As people move through and beyond treatment, the impact of these effects may change.



Alisha

²¹ The average age of women in the UK having their first child is 30. OECD Family Database report SF2.3: Mean age of mothers at first childbirth (24 February 2012), <http://www.oecd.org/social/family/SF2.3%20Mean%20age%20of%20mother%20at%20first%20childbirth%20-%20updated%20240212.pdf>, accessed 3 March 2013.

Body image, sexual relationships and fertility

- Fewer than one in three women were offered advice on fertility prior to their treatment for bowel cancer.
- Nearly half of men were offered advice on fertility.
- 27% of men experience sexual dysfunction as a long-term medical effect of treatment, compared to 8% of women.

Bowel cancer, and the treatment and care for the disease, can impact on the body image, sexual relationships and fertility of younger bowel cancer patients. Fewer than one in three women were offered advice on fertility prior to treatment for bowel cancer. For men, nearly half were offered advice on fertility. It is not clear whether people with different types of cancer are more likely to be offered advice on fertility. Further research is needed.

In our survey, 27% of men responding told us that they were experiencing some form of sexual dysfunction as a long-term medical effect of their treatment. Only 8% of women were experiencing sexual dysfunction. Nearly half of women and more than one in three men listed “body image” as a concern. Younger people are likely to be sexually active, and bowel cancer can and does have an impact on how many younger people feel about their bodies. It is vital that younger bowel cancer patients are supported to deal not only with the medical effects of their treatment, but also the impact on their body image and sexual relationships.

Bowel cancer and work

- 50% of women and 63% of men worked during their treatment for bowel cancer.
- 60% of people felt that their employer supported their return to work after treatment.

Since 2005, people with cancer have been protected by law against discrimination in the workplace on the basis of their condition. The Equality Act (2010), and previously the Disability Discrimination Act (2005), protects people with cancer from the point of diagnosis. Younger bowel cancer patients have different experiences of work during their diagnosis and treatment. Some are employed and take time off work, some are self-employed, and some people may not have been in work when they were diagnosed. However, going to work after treatment can be an important step in getting “back to normal” after bowel cancer.

Encouragingly, nearly half of the people who responded to our survey said they felt well supported by their employer during their treatment. Similarly, six out of ten people said they felt supported to return to work after treatment, whether this was through a gradual return to work, time off for follow-up appointments, or flexible working. This is welcome progress. A YouGov survey of UK line managers in 2010 found that fewer than half of them were aware that the employees who were diagnosed with cancer were protected in law²². We welcome the fact that, in many cases, the experience of young people with bowel cancer in employment is a positive one, and we encourage employers to ensure that they support colleagues with a cancer diagnosis through treatment and back to work, if possible.

²² As quoted in The People Bulletin, 24 November 2010, http://www.apbusinesscontacts.com/the_people_bulletin-pb_2/cancer.aspx

Ten recommendations for change

Through hearing from younger bowel cancer patients, we have started to build up a picture of their experiences, what gets in the way for them, and what needs to be done. We at Bowel Cancer UK want a sea-change in the experience of younger patients. The 2,100 young people diagnosed with bowel cancer every year cannot be overlooked. The government is investing £7.5 billion on improving cancer outcomes, and Bowel Cancer UK want to ensure that that money is used to improve diagnosis, treatment and care for all patients with bowel cancer. You should never be too young to access high-quality services, treatment and care for bowel cancer.

This change requires action on all sides – from individual GPs, the Department of Health, Clinical Commissioning Groups, NHS Trusts, charities such as Bowel Cancer UK, and the general public. Everyone has a part to play. We want to see:

1. **A bowel disease decision aid tool** developed for use in primary care to enable GPs to make informed decisions about who to refer for diagnostic tests. This must be implemented in all NHS Boards as part of a strategy for better risk assessment of people under 50 with symptoms of bowel cancer. This may require additional research.
2. **Revision of clinical guidance** to ensure that people under 50 with symptoms, or at high risk of bowel cancer, get appropriate tests to rule out bowel cancer first not last. Clinical guidance bodies in all four UK nations should consult with and involve bowel cancer patients and experts when reviewing guidelines around referral for suspected cancer and diagnosis of bowel cancer.
3. **Adequate screening and surveillance** put into place by Clinical Commissioning Groups in England, Health Boards in Scotland and Wales, and the Northern Ireland Health and Social Care Board for families at high risk (e.g. due to genetic conditions, where there is a strong family history of the disease or someone has an inflammatory bowel condition). Department of Health needs to support this through public policy.
4. **Genetic screening** routinely offered to all younger bowel cancer patients and their families. Many young people are concerned about whether their children or relatives are likely to develop bowel cancer. Genetic counselling and testing can alleviate this worry, and will help catch bowel cancer early where it does develop.
5. **A registry of younger bowel cancer patients** in the UK established to allow further research about the epidemiology of cancer in this group of people so we can identify and target those at risk better in the future.
6. **Endoscopy capacity to be increased by NHS** commissioning bodies in all four UK nations to ensure that endoscopy units are able to deliver high-quality, timely services to meet current and future demand so this is not a barrier to diagnosis for younger patients.
7. **Younger bowel cancer patients to be given access to the services** that they need including fertility, sexual relationships, and support to deal with long-term psychological and physical effects of treatment. These must form part of commissioning guidance in all four nations.



8. **Messages and images about bowel cancer** should accurately reflect the true demographics of the disease so that it has relevance to younger age groups, without causing mass panic. Health and Wellbeing Boards and Local Authorities in all four UK nations should review their current information and update it to take this into consideration.
9. **Training courses** run by the professional bodies such as the Royal College of GPs should adequately reflect the full demographics of the disease so that young patients are not mis-diagnosed on the basis that they are too young to have bowel cancer, but rather supported and informed throughout their bowel cancer pathway.
10. **Experiences of younger bowel cancer patients** should be considered, visible and represented in public debate by Healthwatch and consumer champion organisations for people who use health and social care services in UK nations.

We look forward to working with Government, the NHS and professional bodies to take these recommendations forward.

For further information about our 'Never Too Young' campaign, please visit www.bowelcanceruk.org.uk or contact Nick Bason, Head of Policy & Public Affairs at Bowel Cancer UK on nick.bason@bowelcanceruk.org.uk.

Appendix A- Our survey of younger bowel cancer patients

Young people's campaign – Bowel Cancer UK campaign

Thank you for agreeing to complete our survey. It should take no more than 20 minutes to complete and we appreciate your input in helping Bowel Cancer UK to understand the issues affecting young people with bowel cancer.

Your answers are completely confidential. If you have any concerns about bowel cancer, please do not hesitate to contact the Bowel Cancer UK Information and Support Service on 0800 8 40 35 40.

Eligibility

1. **Were you diagnosed with bowel cancer under the age of 50?**

- YES...Continue
- NO...Thank and close

2. **How old were you when you were first diagnosed with bowel cancer?**

-years old

About you

3. **Are you male or female? Choose one:**

- Male
- Female

4. **What age are you NOW? Choose one**

- Under 21
- 21-39
- 40-49
- 50-59
- 60 or over

5. **What area of the UK do you live in? Pick 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

Knowledge and perceptions of bowel cancer

6. **Prior to being diagnosed, were you aware that at your age you could be at risk of developing bowel cancer? Choose one:**

- Yes
- No
- Don't know

7. **Prior to being diagnosed, did you know what the symptoms of bowel cancer are? Choose one:**

- Yes
- No
- Don't know

8. **Do you feel that there is a perception among the general public that bowel cancer only affects the much older generations? Choose one:**

- Yes
- No
- Don't know

Pre-Diagnosis

9. **Prior to being diagnosed, did you have an inflammatory bowel condition, for example Crohn's disease or Ulcerative Colitis? Choose one:**

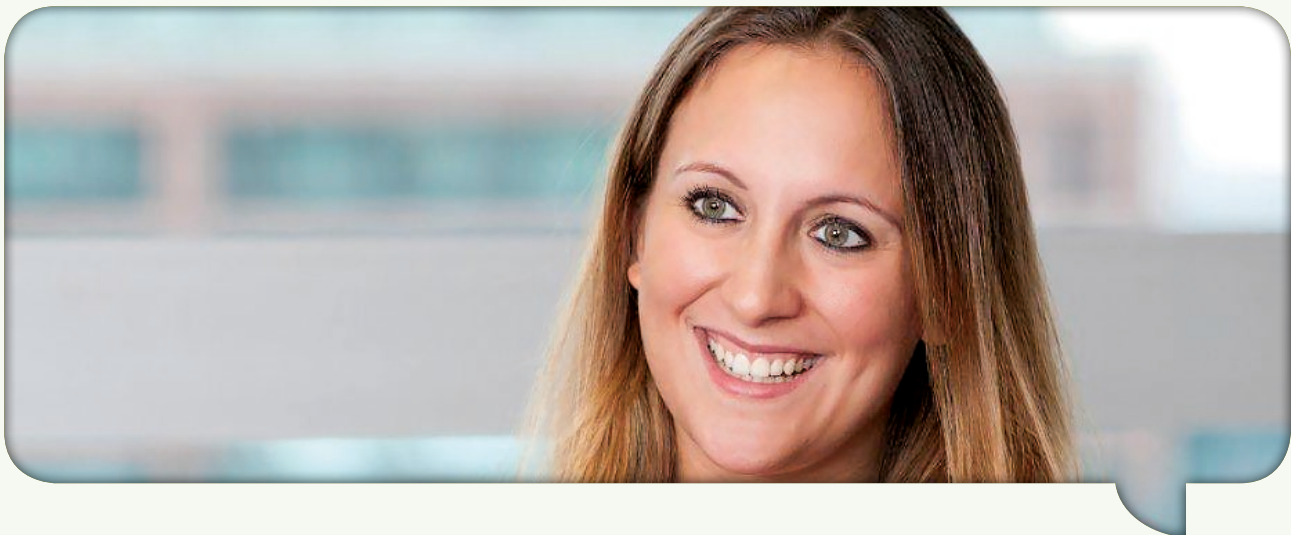
- Yes
- No

10. **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 under the age of 60.

If you are not sure, please click 'Don't Know'. Choose one:

- Yes
- No
- Don't know



11. If you answered No or Don't Know to Q5, is there any anyone else in your family who has been diagnosed with bowel cancer? Choose one:

- Yes I had a relative with bowel cancer (Please specify their relationship with you and their age (for example mother's mother or father's brother))
- I was the first person diagnosed in my family
- Don't know

12. Prior to being diagnosed, were you on a surveillance programme (for example, under the care of a hospital department and having regular colonoscopies)? Choose one:

- Yes
- No

13. 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 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
- Other (please specify)

14. 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
- Other (please specify)

15. 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? Choose one:

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

16. 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
- Other (please specify)
- Not applicable

17. How many times did you see your GP about your symptoms before being referred to a specialist? Choose one:

- 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

18. Did you ask your GP if he/she thought you could have bowel cancer based on your symptoms? Choose one:

- Yes (go to Q19)
- No (go to Q20)

19. 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/she would refer me to a specialist
- GP refused to refer me to a specialist because they were convinced it was something else
- Other (please specify)

Diagnosis

20. Before being diagnosed with bowel cancer, were you investigated for another condition? Choose one:

- Yes (go to Q21)
- No (go to Q22)
- Don't know (go to Q22)

21. 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)
- Other (please specify).....
- Don't know

22. Altogether, how long was it from the time you first reported your symptoms to your GP to being diagnosed with bowel cancer? Choose one:

- 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

23. When you were diagnosed, what stage of disease were you told you had? Choose one:

- Stage 1
- Stage 2
- Stage 3
- Stage 4
- Other (please specify)
- I wasn't told

24. 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)? Choose one:

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

Treatment

25. Were you treated by the NHS or privately? Choose one:

- By the NHS
- Privately
- A mixture of both

26. Were you happy with your treatment and care? Choose one:

- Yes
- No
- Partially

27. Did you have access to a colorectal nurse specialist? (Note: Not a stoma care nurse). Choose one:

- Yes
- No
- Don't know

28. When you were diagnosed, were you given choices about your treatment options? Choose one:

- Yes
- No
- Don't know

29. 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
- Other (please specify)

30. 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
- Other (please specify)

31. Has your doctor ever told you that cost is the reason you couldn't have a particular treatment for bowel cancer? Choose one:

- Yes
- No
- Don't know

Information and support given to you

32. Did you feel that you had enough information to make informed choices about your treatment? Choose one:

- Yes (go to Q33)
- No (go to Q34)
- Don't know (go to Q34)

33. Where did that information come from? Choose all that apply:

- 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

**34. 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
- Other (please specify)

35. 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

Post-Treatment

**36. Since your treatment, have you been offered genetic testing?
Choose one:**

- Yes, for me
- Yes, for me and my family
- No
- Not sure

37. What are the five topics that worried you most about the effects of your treatment? Choose five:

- 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

38. 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

39. Are you still in active treatment? Choose one:

- Yes (go to Q40)
- No (go to Q41)

40. 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)
- Other (please specify)

**41. Were you offered advice on fertility prior to your treatment?
Choose one:**

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

42. If you worked while being treated for bowel cancer, did you feel well supported by your employer? Choose one:

- Yes, I felt well supported
- No, I did not feel well supported
- I did not work during my treatment

43. Did your employer support your return to work after your treatment (for example a gradual return to full time working, flexibility on location, time off for follow-up appointments with healthcare professionals)?

- Yes
- No
- Not applicable

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

- [Free text]

45. We would love to hear your story. Please enter your email address if you would be happy for us to contact you.

- Insert email address

Your email address is for use by Bowel Cancer UK only and WILL NOT be shared with anyone else without your prior consent

Thank you for your time in completing this survey. Your answers are very important to us to help Bowel Cancer UK to understand the issues affecting young people with bowel cancer.

Bowel Cancer Information and Support Service
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www.bowelcanceruk.org.uk

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