



Never too young:

**Supporting people at higher
risk of bowel cancer**

Campaign briefing

Supporting people at higher risk of bowel cancer

Bowel cancer is the second most common cause of cancer death in the UK. Over 15,700 people die each year. In total, over 40,000¹ men and women are diagnosed with bowel cancer in the UK every year, making it the fourth most common cancer.

People in higher risk groups are likely to develop bowel cancer much younger than the general population. Clinical guidance recommends that people in high-risk groups should be in a surveillance screening programme², which is proven to save lives by preventing or detecting bowel cancer at an early stage.



Steve and his wife Gina (pictured) on their wedding day in September 2013. Steve was diagnosed at 30. There was a spread to his lung, which was treated. Steve is currently halfway through chemotherapy as the cancer in his lung had returned.

¹Cancer Research UK – Bowel cancer incidence statistics (2010) <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bowel/incidence/>

²A surveillance screening programme principally involves periodic colonoscopy, as recommended by the British Society of Gastroenterologists.

Stuart R Cairns et al, Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups (update from 2002), Gut;59, 666-690, 2010 http://www.bsg.org.uk/images/stories/docs/clinical/guidelines/endoscopy/ccs_10.pdf

High-risk groups

Genetic factors contribute to up to 30% of cases³ of bowel cancer, affecting between 8,000 - 12,000 people per year. Genetic factors mean either a strong family history of bowel cancer, or genetic conditions such as familial adenomatous polyposis (or FAP) or hereditary non polyposis colorectal cancer (HNPCC), also known as Lynch syndrome. People with long-term inflammatory bowel disease (IBD) are also at higher risk.

Family history

20-30% of all instances of bowel cancer can be attributed to family history^{4,5}. The risk of someone getting bowel cancer significantly increases if they either have one close relative with the disease who were aged under 50 at diagnosis⁶, or two close relatives who were aged 60 or over at diagnosis. It is estimated that nearly 30% of the population aged 30-70 have one or two close family relatives with bowel cancer⁷.

Genetic conditions

A lower proportion of bowel cancer cases (5%) are caused by genetic conditions such as FAP and Lynch syndrome. However, the risk of someone with either of these conditions developing bowel cancer in their lifetime is very high – nearly 100% and 80% respectively. This generally happens at a relatively young age. People with FAP develop bowel cancer at an average age of 39⁸ and those with Lynch syndrome typically diagnosed under 50 years of age.

Inflammatory bowel disease

The two major inflammatory bowel diseases, Crohn's disease and ulcerative colitis, can increase the risk of bowel cancer by almost double if they are active for a long time⁹. Current guidance¹⁰ recommends that all patients with IBD should be offered screening colonoscopy approximately 10 years after the onset of symptoms in order to assess the extent of the disease and other endoscopic risk factors, including polyps. Inflammatory bowel disease can occur at any age, but most frequently starts in people aged between 10 and 40¹¹.

³K 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

⁴NHS Choices <http://www.nhs.uk/Conditions/Cancer-of-the-colon-rectum-or-bowel/Pages/Causes.aspx>

⁵P Lichtenstein et al, Environmental and heritable factors in the causation of cancer--analyses of cohorts of twins from Sweden, Denmark, and Finland, 2000

⁶Stuart R Cairns et al, 2010

⁷RJ Mitchell et al, Prevalence of family history of colorectal cancer in the general population, Br J Surg, 92, 1161-4, 2005

⁸Kory W Jasperson, MS and Randall W Burt, MD. APC-Associated Polyposis Conditions, 1998. <http://www.ncbi.nlm.nih.gov/books/NBK1345/>

⁹Crohn's and Colitis UK Information Sheet – Bowel Cancer and IBD <http://www.nacc.org.uk/downloads/factsheets/cancerrisk.pdf>

¹⁰Stuart R Cairns et al, 2010

¹¹Crohn's and Colitis UK, Understanding Colitis and Crohn's Disease <http://www.crohnsandcolitis.org.uk/Resources/CrohnsAndColitisUK/Documents/Publications/Booklets/Understanding%20Colitis%20and%20Crohns%20Disease.pdf>

The importance of surveillance screening

Surveillance screening is an effective way of preventing bowel cancer in people at higher risk: it has achieved an 81% reduction in mortality for “moderate risk groups” and a 72% reduction in mortality in families with Lynch syndrome¹². Referral guidelines by the British Society of Gastroenterology (BSG) recommend that:

- People at the highest risk of developing bowel cancer should have multiple colonoscopies at one to five year intervals from as young as 25.
- People at high-moderate risk should be seen every five years between ages 50 and 75¹³.

However, there is currently an inconsistent approach to the management of these people. This is a result of poor clinical and public awareness, patients not being seen quickly enough, and a failure to provide adequate follow ups. An inconsistent approach to managing people at higher risk of bowel cancer will undermine efforts to save lives from this treatable disease, and can mean that lives are unnecessarily lost.

Access to surveillance programmes

A national survey of hereditary bowel cancer services in the UK¹⁴ found wide variations in the local management of bowel cancer patients with a family history of the disease. The study found that:

- Many clinicians were not aware of British Society of Gastroenterology (BSG) guidelines on the surveillance of people at higher risk.



Katie (far right) passed away when she was 32. Katie is pictured here with her husband Stuart and their two children Sophie and Sam.

¹²I Dove-Edwin, P Sasieni, H J W Thomas, Prevention of colorectal cancer by colonoscopic surveillance in individuals with a family history of colorectal cancer: 16 year, prospective, follow-up study. BMJ 2005. <http://www.bmj.com/content/331/7524/1047?goto=reply>

¹³S R Cairns et al, 2010

¹⁴K J Monahan, 2013

- More than 1 in 5 clinicians did not think there was an adequate surveillance service for higher risk patients. There is no apparent formal patient pathway in 52% of centres and only 33% of centres maintain a registry of patients.
- 64% of clinicians believed that someone else should be carrying out surveillance work.
- Tumour genotype testing for patients diagnosed with cancer under 50 years of age (recommended in BSG guidelines) was performed 'usually' or 'always' in under half of the centres surveyed (47%)¹⁵.

Waiting times for people at higher risk

Patients at higher risk of developing bowel cancer are also often made to wait unacceptable lengths of time before being seen. The Global Rating Scale census¹⁶ - an assessment of how well endoscopy units are performing against a set of criteria - found that many endoscopy units across the UK are struggling to see all their surveillance patients within their planned appointment date. In addition, patients on a surveillance waiting list waiting beyond 6 weeks are not included in monthly waiting times reports by endoscopy units¹⁷.

Annual statistics obtained show that more than a quarter of hospitals in the UK undertaking surveillance have waiting times of more than 6 weeks for a surveillance endoscopy. Worryingly, these statistics also show that 35 hospitals in the UK have a waiting list of more than 26 weeks for surveillance endoscopies¹⁸.

Despite a high number of people at an increased risk of developing bowel cancer, information about how many people are affected and how they are identified for surveillance screening is not collected. There is also a low level of general awareness about the risk factors that contribute to bowel cancer. A pan-European study found that only 54% of people knew about family history as a risk factor¹⁹. Clear information needs to be available on who may be at higher risk of bowel cancer.

¹⁵K J Monahan, 2013

¹⁶Global Rating Scale Report: England (April 2013) <http://www.thejag.org.uk/downloads%5CNational%20Policies%20and%20Reports%5CGRS%20census%20report%20England%20April%202013%20v1.0.pdf>

¹⁷'Never Too Young' report, Bowel Cancer UK http://www.bowelcanceruk.org.uk/media/192215/1311_bcuk_youngpersons_campaignreport.pdf

¹⁸Data correct as of April 2013. Provided by the Royal College of Physicians

¹⁹M R Keighley et al, Public awareness of risk factors and screening for colorectal cancer in Europe, *Eur J Cancer Prev*.;13(4),257-62, August 2004 <http://www.ncbi.nlm.nih.gov/pubmed/15554552>

Recommendations

It is important that information is made available to GPs and the public on the risk factors contributing to bowel cancer. This should be underpinned by a greater quality of data gathering on these risk factors.

Bowel Cancer UK has five recommendations to improve services for people in high-risk groups:

1. All health authorities should have a surveillance programme, with a clearly defined pathway for people at higher risk of developing bowel cancer.
2. Clear information should be made available to GPs and the public on the risk factors contributing to bowel cancer. This should be underpinned by a greater quality of data gathering on these risk factors.
3. As people with FAP or Lynch syndrome typically develop bowel cancer at a young age, anyone diagnosed with bowel cancer under the age of 50 should have a genetic test for these and other related conditions. These tests should be done in a timely manner to minimise stress for the patient, so that they and their families can be included in a surveillance programme if necessary.
4. There needs to be adequate endoscopy service capacity to ensure that people are able to have a screening colonoscopy on time. This should be driven through appropriate performance indicators, including the reporting of surveillance patients waiting longer than 6 weeks for an endoscopy.
5. Designation of a single named lead person in each hospital trust, with responsibility for the local management of hereditary colorectal cancer patients. They should be responsible for the maintenance of a registry of these patients and the establishment of links with clinical genetics centres.



Lynne and her son Matthew are pictured here. Matthew was 20 when he had treatment for bowel cancer. Shortly after Matthew's treatment, Lynne was diagnosed with bowel cancer.

Support our campaign

- Visit www.bowelcanceruk.org.uk/never-too-young for more information about the Never Too Young campaign
- Use **#never2young** to join the conversation on Twitter and Facebook
- Follow us on Twitter **@Bowel_Cancer_UK** and like our Facebook page at facebook.com/charitybcuk to stay up to date with our campaign
- If you are a young person affected by bowel cancer, share your story with us so we can build up a comprehensive picture of young people's experiences of bowel cancer across the UK. Email your story to press@bowelcanceruk.org.uk
- Add your voice by signing up to support our campaign at www.bowelcanceruk.org.uk/never-too-young
- Help us raise funds so we can increase the services and information we provide for younger bowel cancer patients at www.bowelcanceruk.org.uk/donate

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

For further information, please visit www.bowelcanceruk.org.uk/never-too-young or contact Nick Bason at nick.bason@bowelcanceruk.org.uk

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