

# Screening for bowel cancer

More than 16,000 people die from bowel cancer each year in the UK. It is the second most common cause of death from cancer.<sup>1</sup> The aim of the NHS Bowel Cancer Screening Programme is to reduce the number of deaths by diagnosing patients at an earlier and more treatable stage. Bowel Cancer UK's Director of Press, Public Relations, and Public Affairs, Ian Beaumont, talks to Dawn Powell about bowel cancer and the screening programme.

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## Who is most at risk of developing bowel cancer?

More than 80% of those diagnosed with bowel cancer are over the age of 60, but an increasing number of cases are diagnosed in people under the age of 45 as well.

## What are the typical symptoms of this disease?

Symptoms include: a change in bowel pattern that lasts for more than 4 weeks; bleeding from the bottom or blood in stools; unexplained tiredness and pain; or a lump in the abdomen. The symptoms of bowel cancer are similar to other less serious conditions, such as piles, so some cases will be diagnosed late because people are not initially tested for bowel cancer, or are embarrassed to talk about their symptoms. However, we advise anyone with concerns to seek advice as soon as possible: nine out of 10 cases will probably not be bowel cancer—the sooner the investigation is done, the sooner most people can be reassured that everything is okay.

## How can general practitioners and other health-care professionals in primary care ensure that patients are diagnosed at an early stage?

Bowel Cancer UK is very keen for general practitioners to be more aware of bowel cancer. If more patients can be diagnosed at an early-stage than are now, the numbers of deaths would decrease significantly. At the moment, in the UK, 15% fewer people are diagnosed early compared with rest of western Europe.<sup>2</sup>

## The NHS Bowel Cancer Screening Programme was launched in England in 2006, in Scotland last year, and will be rolled out in Wales this year. What does it involve?

A test kit called a faecal occult blood test is sent to all people aged 60–69 in England and to all those aged 50–74 in Scotland and (from the end of 2008) Wales. People are invited to provide stool samples, which are sent to a laboratory and analysed. 98% of these samples will be given

the all clear, but 2% will show an abnormal response that might or might not be bowel cancer. In these cases, people will be invited to have a colonoscopy at their local screening centre to identify if they have the disease.

## How will this help patients with bowel cancer?

Screening for bowel cancer will ultimately reduce the number of deaths, through helping to identify and treat cancer at an earlier stage in people who have no symptoms. Bowel cancer is the most easily treated cancer when caught early, so by catching cases through screening before they progress, we can potentially save—even by conservative estimates—1,000 to 1,500 lives a year.

## The screening programme in England was launched later than planned. What was the reason for this and have the problems now been resolved?

In December 2005, we [ie, Bowel Cancer UK] were told that the screening programme might be cancelled. We wrote to the health secretary and campaigned for the programme to go ahead as planned. At the moment, we are happy with the way that things have progressed. The enthusiasm for the programme shown by the screening centres [which treat people who are identified as being potentially at risk through the programme], screening hubs [which are responsible for coordinating the dispatch and processing of the test kits], and by the Government has been encouraging. Gordon Brown's announcement at last year's Labour Party Conference that the programme will be extended beyond 2009 and include 70–75 year olds from 2010 was an important step forward.

## Bowel Cancer UK's report on the screening programme, published last year, found that the majority of patients invited to participate in screening do not return a test.<sup>3</sup> Why do think people are not responding and how can more people be encouraged to send their kits back?

Everybody involved in the screening programme needs to do all they can to promote it and encourage as many eligible people as possible to take part. It is still very much a new programme and one that people are getting used to. But, we hope that as more and more people around the country are screened and report back favourably about the experience, uptake will increase and more people will be diagnosed earlier.

**Participation was particularly low among hard-to-reach groups, such as south Asian communities. How can the NHS encourage these groups to take part?**

Bowel Cancer UK is committed to encouraging hard-to-reach groups, including ethnic minorities to take part in the screening programme. We will shortly be undertaking a pilot project among ethnic-minority groups in the Midlands, which, if successful, we hope to roll-out further across the country—ideally, in partnership with the NHS.

**How is bowel cancer currently treated?**

Fluorouracil was the only drug available for nearly 50 years. Then suddenly, about 10 years ago, a revolution in bowel-cancer therapy started. Two new chemotherapy drugs—irinotecan and oxaliplatin—that help to extend life were launched, and then we had oral chemotherapy. More recently, the biological agents bevacizumab and cetuximab, which are designed to work with chemotherapy, became available. These therapies have made a massive difference to patients' quality of life and life expectancy, including patients in the more advanced stages of the disease. The potential for these treatments is still growing because clinicians are getting more adept at using them in different combinations and doses.

**Bowel Cancer UK has campaigned fiercely against the decision by NICE not to recommend bevacizumab and cetuximab<sup>4</sup> as treatments for bowel cancer. Why do you feel so strongly about this decision?**

We did not campaign fiercely against NICE—we campaigned and are still campaigning fiercely for patients to get access to treatments that can help them. NICE has a job to do and we respect it as an organisation, but its decisions, particularly when they are negative, can be used as an excuse by primary-care trusts to not give certain treatments to patients. We should remember that these recommendations are only guidelines; they are not legally binding. When they work, bevacizumab and cetuximab can be absolutely amazing in the way that they target tumours. Patients who have late-stage disease suffer most in the current system, and they are the ones that could benefit the most from these treatments. In certain cases, although still

very much the exception, using these drugs could mean that the patient moves towards being free of disease.

**After an appeal against the decision failed, your charity publicly criticised NICE's appeal process. What were your main objections?**

The main problem with the process—unbelievably really—is that it does not allow new evidence. NICE based its decision on data that were out of date when the guidance was originally published and archaic by the time of the appeal. In a criminal appeal, the appellant (whoever that may be) is allowed to submit new evidence. That is the whole point of having an appeal.

**The Health Select Committee issued a report on NICE<sup>5</sup> at the beginning of this year, in which it recommended that NICE should have access to the same material as the licensing bodies and to registered clinical trials. If NICE had this access when it was reviewing bevacizumab and cetuximab, do you think it would have made a different decision?**

I think if NICE did have that information, its decision would have been different. As I said when I gave evidence to the Health Select Committee last year: the decisions NICE makes about treatments are almost always based upon data that are out of date and on outcomes (primary endpoints) that are different to those for clinical trials. If its decisions were based more on the results of clinical trials and on their primary endpoints (eg, progression-free survival; quality of life) rather than QALYs [Quality-adjusted Life Years], then NICE would—or should—approve more drugs.

**NICE is in the process of reviewing cetuximab<sup>6</sup> as a first-line treatment for metastatic bowel cancer to coincide with ongoing trials investigating this indication. What do you think the outcome will be?**

Cetuximab, like the other biological agent bevacizumab, has proved to be very effective for many patients, despite the negative NICE guidelines. In an abstract study published by the Mount Vernon Cancer Centre, for example, the average life expectancy of patients who received the drug was 14 months versus 4 months for those denied access to it. NICE's estimated life expectancy of the benefit of cetuximab was only 5 months. There is considerable evidence for the drug's efficacy at first line, and Bowel Cancer UK has contributed to the NICE appraisal of its use in that setting. I would hope that the drug is approved by NICE, but it perhaps does not pay to be overly optimistic.

**In the meantime, what action are you taking to help patients to gain access to these drugs?**

We will fight for every patient whose clinicians believe will benefit from the drugs. Although it is a very convoluted way of getting these drugs to the patients, we are forcing primary-care trusts—one after the other—to look at the medical story rather than the financial story. It is definitely giving them cause for thought.

**Primary-care trusts will only pay for these treatments if there are exceptional circumstances. How are these defined?**

The amount of exceptional circumstances you find when you look at a patient's pathway in detail is amazing and the definition of what is exceptional is expanding all the time. Since the NICE decision in January 2007, we have developed a range of methods to show that a patient has exceptional circumstances. All patients are important, but we have to follow the procedures that the primary-care trusts put down. The clinical assessment is the basis for the appeal and a patient's situation or the experience they have to date, such as being misdiagnosed for a long time, is used to build the case for treatment.

**NICE is due to publish guidance on erythropoietin and darbepoetin for cancer-induced anaemia.<sup>7</sup> What are these treatments and are they beneficial for patients?**

Erythropoietins offer a much less debilitating alternative to blood transfusions in tackling anaemia. Clinicians are now able to relieve cancer-related pain to a great extent, so a patient being in pain is unacceptable. Excessive tiredness, which is a side-effect of cancer, is also not acceptable. Patients should not be tied to their bed because of tiredness.

**NICE has taken a long time over this particular review (it announced it needed further evidence before it make a decision at the end of last year). How do you feel about this?**

We are not happy with the continuing delay in getting access to drugs that will make a significant difference to patients. But if NICE is taking new evidence into account and this leads to a better outcome for patients, then obviously that will be welcomed.

**Bowel Cancer UK celebrates its 21st anniversary this year. What have been your main achievements over the past 21 years and what do you hope to achieve in the next 21?**

We believe we have achieved a great deal in our first 21 years. We have helped to put bowel cancer on the map and to reduce the stigma and embarrassment surrounding it. There is still much more to be done, however. Early-stage bowel cancer is highly treatable, but too many people are still not diagnosed until they have late-stage cancer, often because they are too embarrassed to act on their symptoms.

Our Advisory Service was the first of its kind dedicated to bowel cancer and it remains the most significant contribution we have made to raising awareness of the symptoms of this disease and answering people's questions and concerns. Over the next 21 years, we will build on what we have already achieved. We want to ensure that the screening programme is fully rolled out and bedded in. We want it to become part of the fabric of our society, so that people's default position is to act on their concerns. Then I am sure that we will have the same positive outcomes as the breast-cancer lobby. The number of deaths from breast cancer is falling dramatically because the disease is now identified much earlier.<sup>8</sup>

**References**

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