

Patient Report 2021

The National Bowel Cancer Audit (NBOCA) aims to improve patient care. The audit compares differences in bowel cancer treatments and patient outcomes across England and Wales, and makes suggestions to improve future care for bowel cancer patients. This report was produced in collaboration with the NBOCA Patient and Carer Panel, who represent and support the rights and interests of patients.

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This report mostly includes findings for patients newly diagnosed with bowel cancer between 01 April 2019 and 31 March 2020. It aims to explain key findings from the NBOCA report for the general public, including an introduction to bowel cancer and its treatment, and explanations of key terms (page 5).

WHAT IS BOWEL CANCER?

Bowel cancer is the 4th most common cancer in the United Kingdom, with over 41,000 people diagnosed every year.

Of all the cancers, bowel cancer is the second biggest killer.

7 out of 10 people with bowel cancer have cancer of the colon, 3 out of 10 have cancer of the rectum (see diagram).

At the time of a bowel cancer diagnosis, 1 out of 5 people will have cancer that has already spread to other parts of their body.

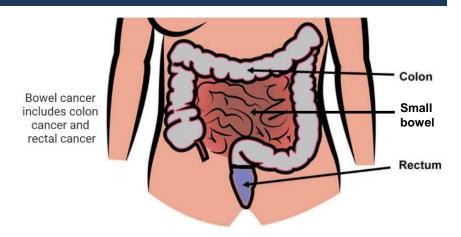
WHAT IS SCREENING?

Screening looks for early signs that cancer may be present. The aim is to find the cancer as early as possible.

In England and Wales, screening is usually offered to people aged 60-74 years every 2 years, although there are plans to start screening at 50.

Screening is done from home and involves providing a small poo sample. A new screening method called FIT testing (faecal immunochemical testing) was introduced in 2019.

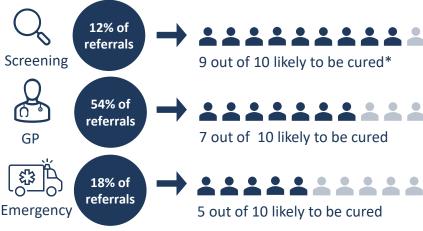
People diagnosed via screening are more likely to have their cancer found at an <u>early stage</u> and be cured.



Non-cancerous growths (polyps) can form in the lining of the bowel. Over time, some of these polyps may develop into cancers. Once a cancer has formed, it can spread through the bowel wall and into surrounding blood vessels and lymph glands. The cancer can then sometimes spread to other parts of the body.

HOW ARE PEOPLE DIAGNOSED WITH BOWEL CANCER?

32,641 patients were diagnosed with bowel cancer in England and Wales between 01 April 2019 and 31 March 2020. The diagrams below show how people were diagnosed and how likely they were to be cured depending on the means by which the diagnosis of bowel cancer was found.



16% of referrals were via 'Other' methods (for example, referral from a hospital doctor), or the referral method was "Unknown".

* Unfortunately, only 6 out of 10 people invited to bowel cancer screening in England and Wales took up the offer!

HOW IS BOWEL CANCER TREATED?

Colon cancer

Colon cancer treatment is more straightforward than rectal cancer treatment. People often undergo surgery only. The part of the colon containing the tumour is removed along with the associated blood supply and lymph nodes. Those people with colon cancer that is at high risk of coming back in the future ("recurrence") may be given chemotherapy after surgery. However, there is variation in how many people get this chemotherapy varying from 55% to 67% between different regions, and with even more variation between hospitals.

Rectal cancer

The treatment of rectal cancer is complex. People may receive various combinations of surgery, radiotherapy, and **chemotherapy**. The diagrams below show how many people get each type of treatment.

Overall, one third of people with rectal cancer will also have radiotherapy before their surgery. However, this varies between regions from 14% to 62%. People with rectal cancer that is at high risk of coming back in the future ("recurrence") may be given chemotherapy after surgery in addition to the treatments before surgery.

"Local excision"



Early rectal tumours can be removed using cameras and instruments put directly inside the bowel. There is no need to remove parts of the bowel, only the tumour.

Surgery



This can involve one of two main operations:

- "Anterior resection"
- "Abdominoperineal resection (APER)"

These involve removing the section of bowel that contains the tumour.

Other procedures



A "stent" may be put inside the bowel or "stoma" formed in order to avoid blockages within the bowel. These are generally used for tumours which are incurable. The tumour is not usually removed.

Other treatments



Some people may just have chemotherapy and/or radiotherapy which may or may not be curative.

SURGERY FOR BOWEL CANCER

Length of Stay - Prolonged stays in hospital after surgery can put people at increased risk of problems such as infections.



6 days

9 days

emergency planned surgery surgery

Reoperation - Serious complications after surgery can mean that people need to have a second operation.



operation after their original surgery. This also varies between hospitals.

Keyhole Surgery - This can help with a faster recovery after surgery.



6 out of 10 people have keyhole ("laparoscopic") surgery, with wide variation between hospitals

Readmissions - People may need to come back into hospital after their surgery. This may be due to complications such as problems with their wounds.



1 out of 10 people are re-admitted within one month of their operation. This rate varies between hospitals.

1 out of 10 people have to go back for another



also help with a faster recovery after surgery. 565 robotic surgeries were recorded this audit



report, compared to 450 last audit report. There is wide variation between hospitals in the number of robotic surgeries performed over the last 5 years.

90-day Survival - NBOCA reports the number of people who are alive at 90 days after their surgery. Some people may require an emergency operation for bowel cancer which has more risks than planned surgery.



of people are alive 90 days after planned surgery

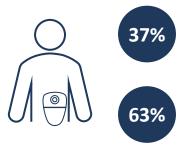


of people are alive 90 days after emergency surgery

90-day survival after planned surgery has improved from 96.5% in the 2017 annual report, to 97.4% this audit report. Similarly, 90-day survival after emergency surgery has improved from 87.1% to 91.3%.

HOW MANY PEOPLE END UP WITH A STOMA?

Stoma formation: People that have surgery for bowel cancer may require a "stoma". The numbers below refer to people having surgery for rectal cancer. Patients with colon cancer can also have a stoma. However, this is less common and NBOCA does not currently report on this.



Overall, 3 out of 10 people have a surgical procedure which leaves them with a permanent stoma. This is either an "Abdominoperineal resection" or a "Hartmann's procedure". This rate varies between hospitals from 7% to 85%.

Most other people will have an "anterior resection". This means that the two ends of bowel left after the tumour is removed are joined back together. 6 out of 10 people who have an anterior resection will have a temporary stoma made. This is called a "loop ileostomy". The "loop ileostomy" diverts poo into a bag before the join to allow it to heal. This also means that if the join were to leak the consequences should be less serious. The stoma can be "reversed" (it is not permanent) once the join has healed.

3 out of 10 people who are given a "loop ileostomy" during their "anterior resection" will not have had it reversed 18 months after their surgery. There is large variation between hospitals in the number of these stomas reversed.

HOW MANY PEOPLE SURVIVE TO 2 YEARS WITH BOWEL CANCER?

For most people, survival and cure remain the primary concern after diagnosis.

People may not have surgery for these reasons:

'Too little' cancer - early cancers are sometimes removed without major surgery

'Too much' cancer - their disease has spread too far to be cured. They will need palliative care.

'Too frail' - the person is not fit enough to have surgery due to other medical problems If a bowel cancer returns after treatment, this is most likely to occur within the first 2 years. This is why NBOCA measures 2-year survival rate. There is variation between hospitals in 2-year survival. For the first time this audit period, this variation has markedly reduced.

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8 out of 10 people survive beyond 2 years if they have had their cancer removed by surgery. 3 out of 10 people survive beyond 2 years if they have not had their cancer removed.

7 out of 10 people survive beyond 2 years overall. This survival rate has not improved over time.

GENETIC TESTING FOR LYNCH SYNDROME



Lynch syndrome is an inherited genetic defect. People with Lynch syndrome have an risk of bowel cancer. Although bowel cancer is the most common cancer associated with Lynch syndrome (accounts for 3% of bowel cancer cases in the UK), people with Lynch syndrome are also at increased risk of other cancers.

<u>Current national guidelines</u> recommend that **all people** who are diagnosed with bowel cancer undergo genetic testing for Lynch syndrome. Once identified, people undergo closer monitoring for bowel cancer according to <u>British Society of Gastroenterology guidelines</u>, and other members of the family may need to be tested. In addition, bowel cancer treatment may change in terms of the operation chosen to remove the cancer and the type of chemotherapy that is used.

The NBOCA is collecting information about MMR testing in hospitals across England and Wales. However, only 16% of patients had a result recorded this audit period. A <u>previous survey in 2019</u> carried out by NBOCA found that 58% of hospitals in England and Wales reported that they offered MMR testing for all patients. This proportion is likely to have increased since then. NBOCA will be performing an up-to-date survey in 2022 to re-evaluate this.

RECOVERY OF BOWEL CANCER SERVICES FROM THE COVID-19 PANDEMIC



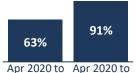
NBOCA has undertaken additional work looking at the impact of the COVID-19 pandemic on bowel cancer services in England and Wales.

Early in the COVID-19 pandemic, there was a large impact on the diagnosis and treatment of bowel cancer patients. However, bowel cancer services have largely recovered since then.

Bowel cancer diagnoses

Early pandemic - April 2020 to June 2020

63% of the expected number of bowel cancer diagnoses were seen in England between April 2020 to June 2020, compared to 2019



Mar 2021

Pandemic – April 2020 to March 2021 91% of the expected number of

91% of the expected number of bowel cancer diagnoses were seen in England between **April 2020 to March 2021**, compared to 2019

The impact on new bowel cancer diagnoses, and the extent to which the number of diagnoses have recovered, has varied by region. The regions hit hardest by COVID-19 infections tended to have more "missed " diagnoses.

Jun 2020

By March 2021, patients just below and patients just above screening age had the most "missed" diagnoses. The bowel screening programme seems to have helped with recovery of the number of diagnoses in patients of screening age. There was also a larger deficit in patients from more deprived areas.

Bowel cancer treatment

Early pandemic - April 2020 to June 2020



of the expected number of bowel cancer operations took place in England between **April 2020 to June 2020**, compared to 2019



of the expected number of bowel cancer operations took place in Wales between **April 2020 to June 2020**, compared to 2019





of the expected number of bowel cancer operations took place in England between **April 2020 to December 2020**, compared to 2019



of the expected number of bowel cancer operations took place in Wales between **April 2020 to December 2020**, compared to 2019



of the expected number starting adjuvant chemotherapy for colon cancer in England between **April 2020 to June 2020**, compared to 2019



of the expected number starting curative radiotherapy for rectal cancer in England between **April 2020 to June 2020**, compared to 2019



of the expected number starting adjuvant chemotherapy for colon cancer in England between **April 2020 to February 2021**, compared to 2019



of the expected number starting curative radiotherapy for rectal cancer in England between **April 2020 to March 2021**, compared to 2019



By March 2021, patients starting curative radiotherapy in England had the least "missed" treatments.

It is not clear whether the numbers of patients starting adjuvant chemotherapy had fully recovered by February 2021.

For further information on the impact of the Covid-19 pandemic on cancer patients in general, the <u>Cancer Data dashboard</u> provides statistics for England in an interactive resource.



RECOMMENDATIONS FOR THOSE WITH BOWEL CANCER AND THE WIDER PUBLIC

The full NBOCA report detailing care by hospital and region is available at www.nboca.org.uk/reports/



If your bowel cancer is found early, it is more likely to be cured. Be aware of the signs and symptoms of bowel cancer and visit your GP promptly if you have concerns. You can find information about signs/symptoms of bowel cancer here:

https://www.nhs.uk/conditions/bowel-cancer/symptoms/



You are more likely to have your bowel cancer cured if it is found via screening. More information can be found for England at www.nhs.uk/conditions/bowel-cancer-screening/ and Wales at http://www.bowelscreening.wales.nhs.uk/ or provided by your GP.



Prior to COVID-19 outcomes for bowel cancer were improving. You can view trust/hospital/MDT results as well as which facilities are available at each site at https://www.nboca.org.uk/trust-results/



If you or a family member have been diagnosed with bowel cancer and have not been offered genetic testing for Lynch syndrome, you should mention this to the doctor in charge of your care.



Each year NBOCA publishes additional short reports and scientific papers. These can be accessed at https://www.nboca.org.uk/reports/ and https://www.nboca.org.uk/reports/phasea poor reviewed publications/. This year we

https://www.nboca.org.uk/reports/nboca-peer-reviewed-publications/. This year, we have also published two papers on the impact of COVID-19 on bowel cancer services. This included the results of a <u>survey</u> and work looking at <u>surgery performed</u> during the first wave of the pandemic.



NBOCA launched a new Quality Improvement initiative in October 2021. The initiative is targeted at two key aspects of bowel cancer care:

- 1. Improving Patient Experience
- 2. Improving Cancer Outcomes

The Quality Improvement Plan can be found on the NBOCA website at: https://www.nboca.org.uk/reports/quality-improvement-plan/.

ADDITIONAL READING



Bowel Cancer UK

https://www.bowelcanceruk.org.uk/

Cancer Research UK

https://www.cancerresearchuk.org/about-cancer/bowel-cancer

NHS Choices

https://www.nhs.uk/conditions/bowel-cancer/

Macmillan

https://www.macmillan.org.uk/information-and-support/bowel-cancer

EXPLANATION OF TERMS USED IN THE PATIENT REPORT

Abdominoperineal excision of the rectum (APER) - an operation to remove the entire rectum and anal canal. This leaves a permanent stoma.

Anterior resection - an operation to remove part, or all, of the rectum.

Chemotherapy - drug therapy used to treat cancer. It may be used alone, or in combination with other types of treatment (for example surgery or radiotherapy).

FIT testing - this involves providing a small poo sample which is tested for blood. Abnormal levels of blood detected will require further investigation with a telescope examination of the bowel.

Hartmann's procedure – an operation to remove part of the bowel where the remaining end of bowel is brought out as a stoma called a 'colostomy'. This is usually permanent but sometimes may be reversed.

Laparoscopic - a type of surgical procedure performed through small cuts in the skin instead of the larger cuts used in open surgery. Also called keyhole surgery.

Local excision - a procedure done with instruments inserted through the anus (often during a colonoscopy), without cutting into the skin of the abdomen to remove just a small piece of the lining of the colon or rectum wall.

Loop ileostomy - type of stoma involving small bowel, often used for people who have an anterior resection and is not necessarily permanent.

Lymph nodes - small bean shaped organs, also referred to as lymph 'glands', which form part of the immune system. They are distributed throughout the body and can be one of the first places to which cancers spread.

Lynch syndrome - is an inherited genetic defect which increases your risk of bowel cancer. People with Lynch syndrome are also at increased risk of other cancers.

Open surgery - an operation carried out by cutting an opening in the abdomen.

Radiotherapy - the treatment of disease, especially cancer, using X-rays or similar forms of radiation.

Robotic surgery - this is a relatively new advancement in surgery and allows surgeons to control surgical instruments whilst sitting at a special console away from the patient during the operation.

Screening - the aim of screening is to try to detect cancers earlier. People aged 60-74 are invited to take part in bowel cancer screening every 2 years. They do this by providing a small poo sample. Recently it has been agreed that the screening age will be lowered to 50 years.

Stage - staging is a way of describing the size of a cancer and how far it has grown. Staging is important because it helps decide which treatments are required. Further information on staging can be found on this Bowel Cancer UK page.

Stent - a flexible, hollow tube designed to keep a section of the bowel open when it has become blocked.

Stoma - a surgical opening in the abdomen through which the bowel is brought out onto the surface of the skin, in order to collect poo into a bag. Colostomy and ileostomy are types of stoma.

90-day survival - NBOCA reports the number of people who are alive at 90 days after their surgery. This is because the majority of deaths occurring within 90 days of surgery have been shown to be the result of complications from the surgery.

FURTHER INFORMATION



www.nboca.org.uk



We would like to thank the NBOCA Patient and Carer Panel which consists of patient and carer representatives, as well as bowel cancer charity representatives, for their invaluable contribution to the formation of this report. Details of the NBOCA Patient and Carer Panel can be found here: https://www.nboca.org.uk/about/our-team/