National Bowel Cancer Audit

Patient Report 2016

1. Introduction

Colorectal cancer, commonly known as bowel cancer, is a major cause of illness, disability and death in the UK. The National Bowel Cancer Audit (NBOCA) was established to describe and compare the diagnosis, care and outcomes of patients diagnosed with bowel cancer in England and Wales.

The audit's overall aim is to measure the quality of care and survival of patients with bowel cancer in England and Wales.

The 2016 Annual Report includes data on over 30,000 patients diagnosed with bowel cancer between 1 April 2014 and 31 March 2015.

This patient report includes a guide to audit terms and summarises the main findings of the 2016 Audit Report. The full report, which contains more information regarding methods of data collection and analysis, as well as individual trust results, can be accessed at: www.digital.nhs.uk/bowel.

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2. Guide to Audit Terms

Abdomino-perineal excision of the rectum (APER) – An operation to remove the entire rectum and anal canal.

Anterior resection – An operation to remove part, or all, of the rectum.

Association of Coloproctology of Great Britain and Ireland (ACPGBI) – An association of colorectal surgeons and others involved in the care of patients with colon and rectal cancer and other colorectal diseases.

Adjusted – A way of reporting results that takes into account differences between the patients that each trust or region is treating. This allows comparisons to be made more fairly.

Adjuvant treatment – Treatment (commonly radiotherapy and/or chemotherapy) given following surgery.

Bowel cancer screening – The NHS bowel cancer screening programme offers the "FOB test" every two years to all men and women in England aged 60 to 74. It checks for the presence of blood in a stool sample, which could be an early sign of bowel cancer.

Bowel scope screening involves using a thin, flexible tube with a camera on the end to look inside the lower part of the bowel and the back passage (rectum). This is called a flexible sigmoidoscopy. The test looks for, and removes, any non-cancerous growths (polyps) that could develop into cancer over time. This is a one-off test offered to some people at age 55 in England. The screening is being rolled out in England and should be available to everyone by 2020.

Those who have the camera test at age 55 should continue to have the two yearly FOB test from age 60 to 74 even if the camera test result is normal. The aim of screening is to diagnose cancer at an earlier stage when the chances of cure are higher.

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).

Clinical Effectiveness Unit (CEU) – An academic group formed of individuals from the Royal College of Surgeons of England and the London School of Hygiene and Tropical Medicine. It conducts several national clinical audits, including the National Bowel Cancer Audit.

Colostomy – A stoma (surgical opening) formed by bringing the large bowel (colon) out onto the surface of the skin.

Curative intent – This is where the aim of the treatment is to cure the patient of the disease.

Enhanced recovery programme – A programme designed to help people recover more quickly after having major surgery.

Funnel plot – A type of graph used to display variation. Each dot represents a region of the country or a hospital trust. The further to the right the dot appears, the more patients they have seen over the given time period. The higher the dot appears the more frequently the outcome has occurred. The dotted black lines are statistically calculated limits which help us to assess the variation in outcomes. Dots that fall outside the outermost black lines are potential outliers (i.e. not performing as we might expect); only 1 in 500 dots would be expected to fall outside the outer limits by chance alone.

Grade – The description of a tumour based on how abnormal the tumour cells and the tumour tissue look under a microscope. It is an indicator of how quickly a tumour is likely to grow and spread.

Hartmann's procedure – An operation to remove an area of the bowel on the left hand side of the abdomen and top end of the rectum. It also involves the formation of a Colostomy.

NHS Digital (formally The Health and Social Care Information Centre (HSCIC) – The trusted source of data and information relating to health and social care. The Clinical Audit and Registries Management Service (CARMS) manages the running of the audit and the data collection.

Hospital Episode Statistics (HES) – A database which contains information on all inpatients treated within NHS trusts in England. This includes details of admissions, diagnoses, treatment and discharge.

Ileostomy – A stoma (surgical opening) constructed by bringing the end or loop of small intestine (the ileum) out onto the surface of the skin.

Laparoscopic – Also called minimally invasive surgery or keyhole surgery, it is a type of surgical procedure performed through small cuts in the skin instead of the larger cuts used in open 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.

Lymph nodes – Lymph nodes are 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.

Multi-disciplinary team (MDT) – A group of people with different special healthcare skills who work together to discuss the diagnosis and treatment plan for patients throughout their care.

Metastases – Cancer that has spread from where it started in the body. These can also be called secondary cancers.

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Neo-adjuvant treatment – Treatment (commonly radiotherapy and/ or chemotherapy) given before surgery. This is usually given to reduce the size, grade or stage of the cancer so that the surgery has better results for the patient.

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

Palliative care – The care given to patients whose disease cannot be cured. It aims to improve quality of life rather than extending life.

Per cent (%) – Per 100. For example, "40% of patients" means 40 out of 100 patients.

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

Recurrent disease – When cancer returns. Cancer that returns in the same area of the body is known as a local recurrence, and in a different part of the body is called a distant recurrence or metastases.

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.

Strategic clinical networks – Collection of hospital trusts in England, grouped by geographic region.

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. Colostomy and Ileostomy are types of stoma.

Trust – An organisation within the English NHS, made up of one or more hospitals, and generally serving one geographical area.

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3. Care pathways

Referral Source

Patients can present with symptoms related to bowel cancer to their GP or accident and emergency departments. Some patients will have no symptoms at all and are diagnosed with bowel cancer via screening services. A full description of screening services is provided in Section 2 – Guide to Audit Terms.

- 55 out of every 100 patients (55 per cent) were diagnosed with bowel cancer following a referral from their GP.
- Nearly 10 per cent of patients were diagnosed through the NHS bowel cancer screening programme.
- Patients diagnosed through the NHS bowel cancer screening programme were more likely to have an early cancer and be treated with a plan to cure them than patients diagnosed through other means.
- 19 per cent of patients were diagnosed with bowel cancer from an emergency admission (usually via accident and emergency).
- Patients diagnosed following an emergency admission were more likely to have a large cancer that has grown into nearby tissues and more likely to have cancer that had spread to other parts of the body.
- As shown in Figure 3.1, there was much variation in the proportion of patients diagnosed from each referral source across England and Wales. Differences in patient characteristics, such as age, in each region may contribute to this variation.

Care Pathways

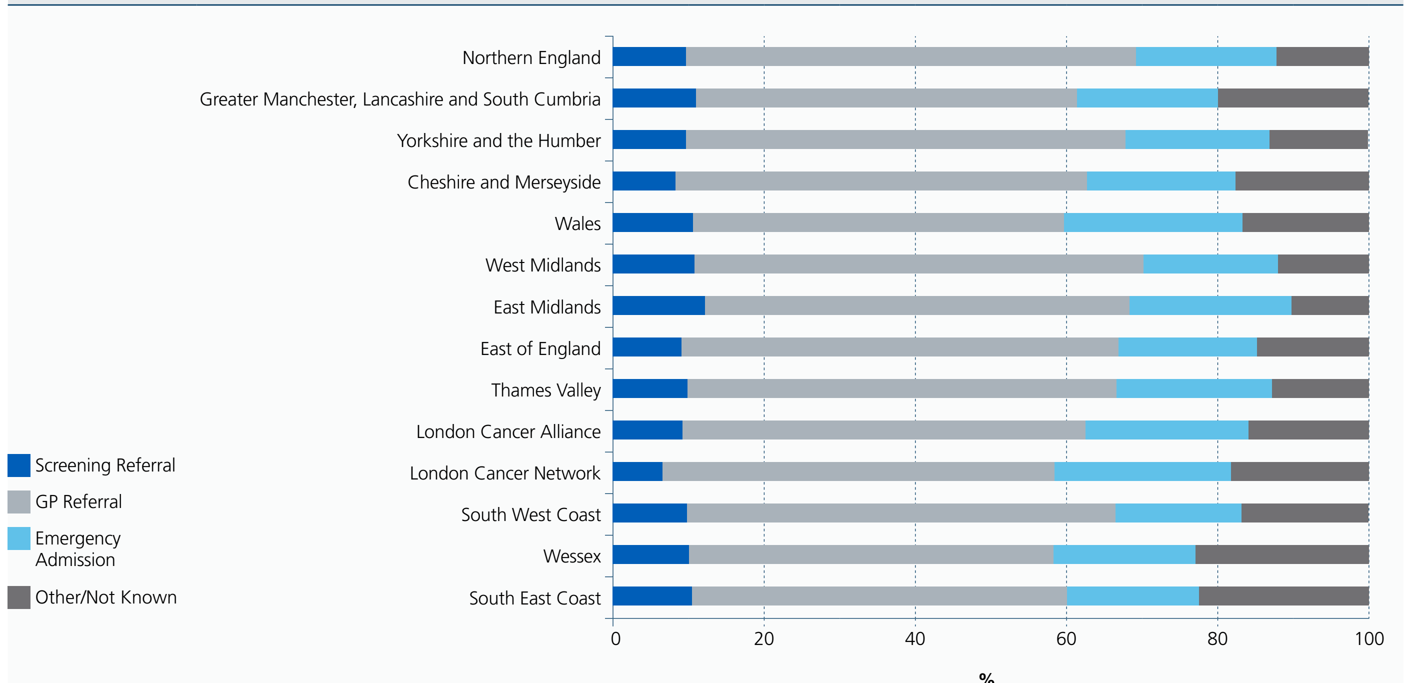
Three out of every four patients diagnosed with bowel cancer are treated with a plan to cure the disease.

A major resection is the surgical removal of part of the bowel to remove the cancer. It is usually the treatment type most likely to cure the cancer. 63 per cent of patients with bowel cancer undergo a major resection. 37 per cent of patients do not have a major resection.

The reason for a patient not undergoing a major resection can be due to:

- **Too much cancer –** advanced disease which may have spread beyond the bowel and cannot be removed (12 per cent).
- **Too frail –** the patient may be too frail to have a major operation due to other medical conditions (4 per cent).
- **Too little cancer –** it may be possible to remove small and early cancers from the bowel surface without removing a whole section of the bowel (4 per cent).
- **Other –** 16 per cent of patients either do not fit into one of these groups or data sent to the audit is not complete enough to tell us which of the above groups the patient falls in to.

Figure 3.1
Referral source of the 30,122 patients diagnosed with bowel cancer between 1 April 2014 and 31 March 2015 by network/Wales



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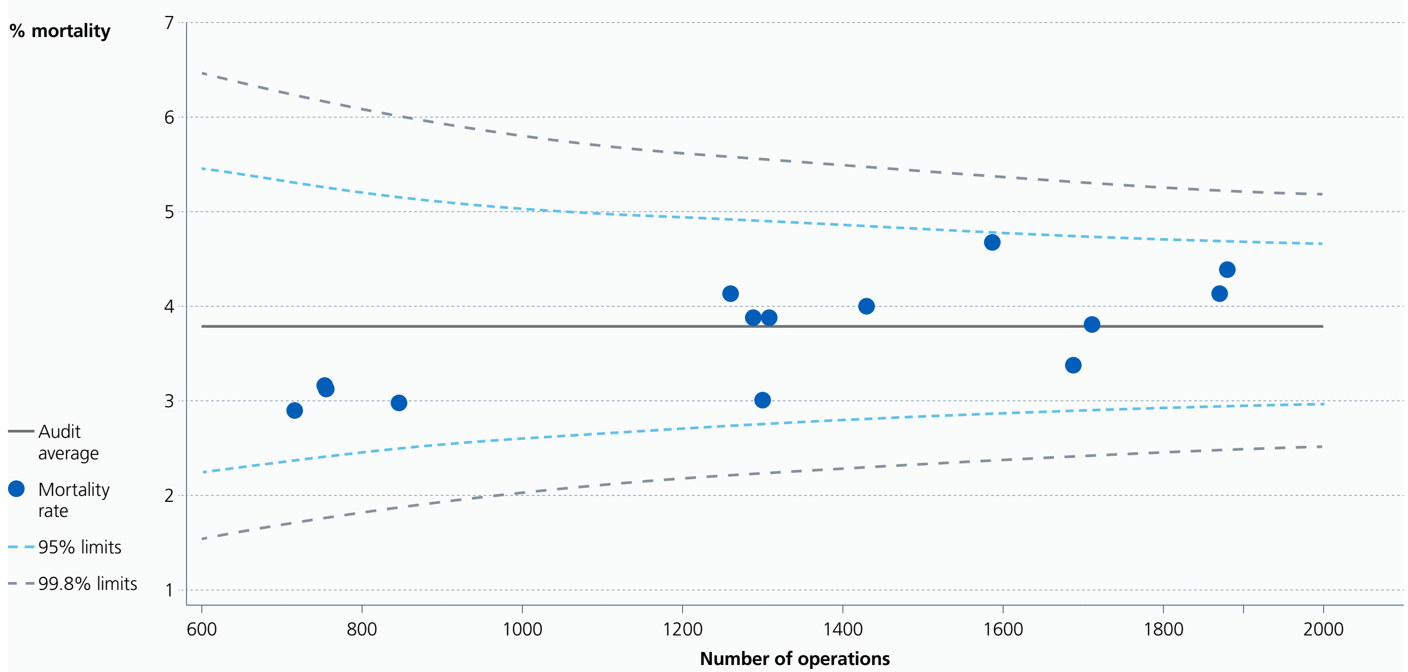
4. Surgical care

90-day survival

The surgical removal of bowel cancer (major resection) can have excellent outcomes for patients, but like all major surgery, can lead to serious complications, and can occasionally risk life.

- The proportion of patients surviving at least 90-days following major resection has steadily increased over five years from 94.6 per cent in 2011 to 96.2 per cent in 2015.
- There were no regions in England and Wales with higher death rates in the 90-day period following major resection than would be expected by chance alone. This is shown in a funnel plot in Figure 4.1. See Section 2 – Guide to Audit Terms for information on how to understand funnel plots.

Figure 4.1
Death rates in the 90-days after surgery by English strategic clinical network/Wales for patients diagnosed between 1 April 2014 and 31 March 2015



Some patients with bowel cancer may develop a blockage of the bowel. If this occurs it may be necessary for patients to undergo an emergency operation to remove the cancer. This type of operation carries with it more risks than planned surgery.

- 'Urgent' or 'emergency' major resection had a risk of death of 12.3 per cent at 90-days (compared to 2.1 per cent in patients with planned surgery).

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Length of stay

The length of time a patient needs to stay in hospital after major resection will depend on their health before the operation, the type of operation performed, problems that occur during their hospital stay and social care they receive after surgery. A prolonged length of hospital stay following major resection may not only have a negative impact on the patient but is expensive for the hospital.

Leaving hospital too early however, may lead to unplanned readmissions to hospital. The number of patients who have unplanned readmissions is a way of measuring the quality of hospital care for bowel cancer patients.

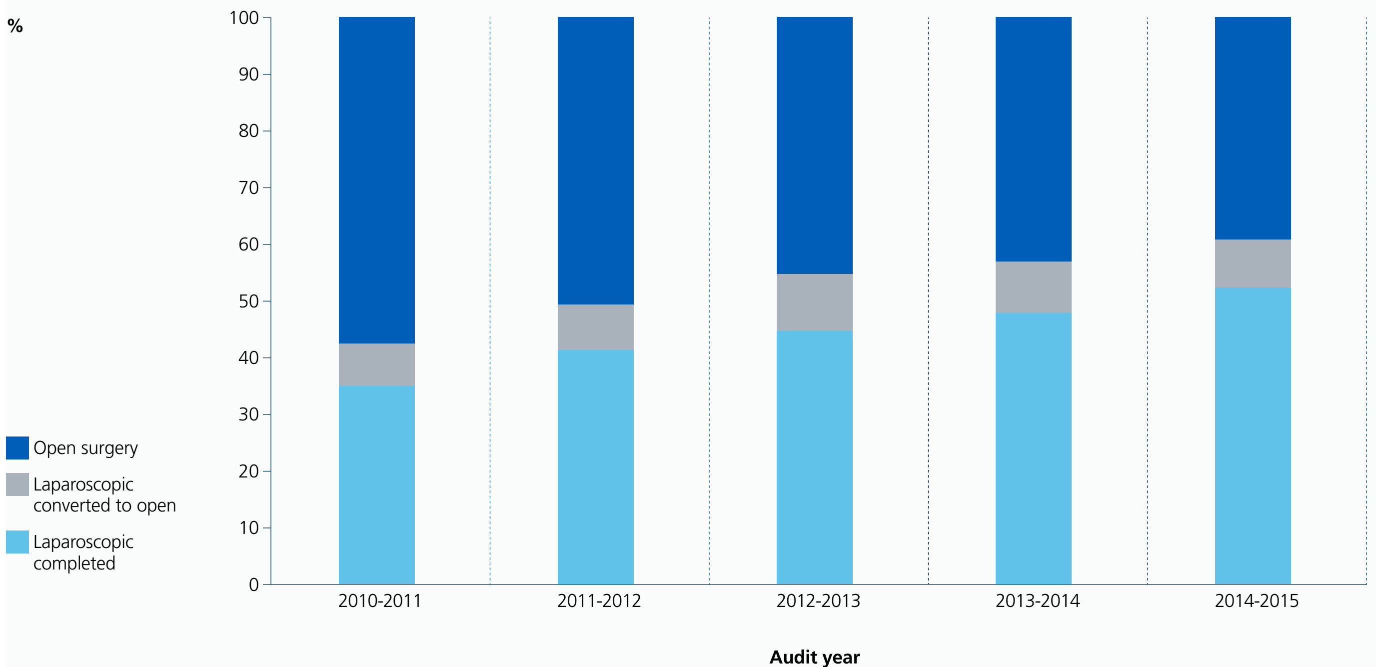
- Just over two thirds of bowel cancer patients were still in hospital five days after their major resection.
- There were large differences in length of stay depending on where in England or Wales patients had their surgery. The percentage of patients in hospital more than five days after major resection ranged from 59 per cent to 81 per cent.
- Overall, one in ten patients had an unplanned readmission within 30-days following their major resection. This has been the same for the last five years.

Surgical access

Whether a patient should have laparoscopic (keyhole) surgery depends on many factors, including where the cancer is in their body, how big it is, and if they have had prior surgery on their abdomen. Some operations may be started laparoscopically and then changed to open during the operation.

- The proportion of major resections performed laparoscopically has continued to increase year on year and now more than half of major resections are completed laparoscopically. Surgical access by audit year is shown in Figure 4.2.
- There has been no increase in the rate of conversion from laparoscopic to open surgery.

Figure 4.2
Surgical access by audit year



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5. Survival

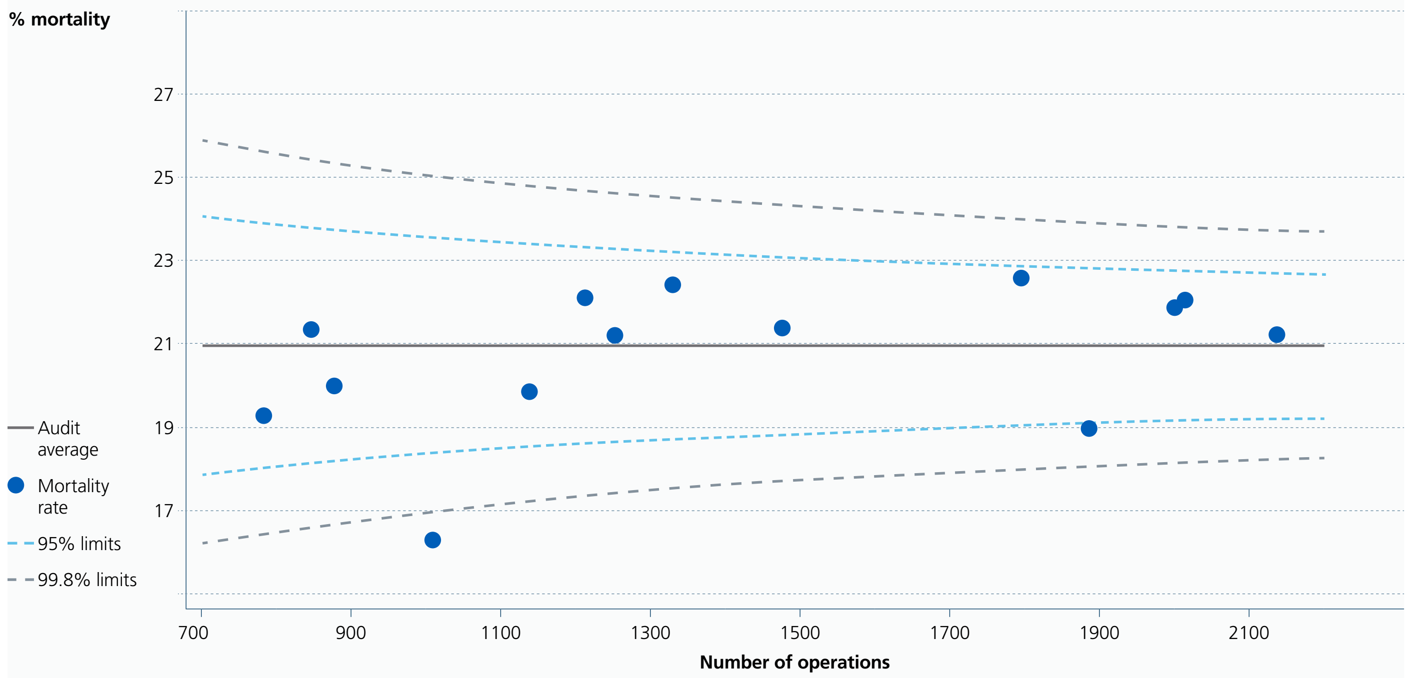
Two-year survival

For the vast majority of bowel cancer patients, survival and cure remain the primary concern after diagnosis. We use death within 90-days of surgery to look at death related to major resection. Longer-term mortality will also capture death from the cancer itself as well as from other causes. A patient who has had treatment for bowel cancer will visit hospital for check-ups usually for five years. The majority of cancer patients who develop cancer recurrence will do so within the first two years of follow-up. It is for this reason that the audit measures two-year survival.

- Overall two-year survival rates for all patients diagnosed with bowel cancer have remained stable at 66 per cent since 2010.
- Two-year survival was dependent on the treatment the patient has had:
  - o Major resection – 82 per cent
  - o Local excision – 92 per cent
  - o No tumour excision – 31 per cent
- There was wide variation in two-year patient survival depending on where the patient was diagnosed. This could be because of differences in the patient and their cancer (such as their age, other medical conditions and how far their cancer has spread) in different regions.
- In patients undergoing major resection there were no regions with higher death rates two-years after surgery than would be expected. This is shown in Figure 5.1.

Figure 5.1
Adjusted two-year surgical outcomes for patients undergoing a major surgical resection between 1 April 2012 and 31 March 2013, by English strategic clinical network/Wales, including trusts/MDTs with more than ten operations

Adjusted two-year mortality rate by network/nation



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6. Rectal cancer

Patient management

Patients with rectal cancer often have different treatment than patients with cancer of the colon. Radiotherapy, alone or in combination with chemotherapy, is often used before surgery.

- 54 per cent of rectal cancer patients had a major resection to remove the rectal cancer.
- Of the 3,608 patients who had a major resection to remove the rectum over the last year, 37 per cent received radiotherapy before surgery.
- The proportion of patients receiving radiotherapy before surgery varied from 29 per cent to 66 per cent depending on the region where they had treatment.

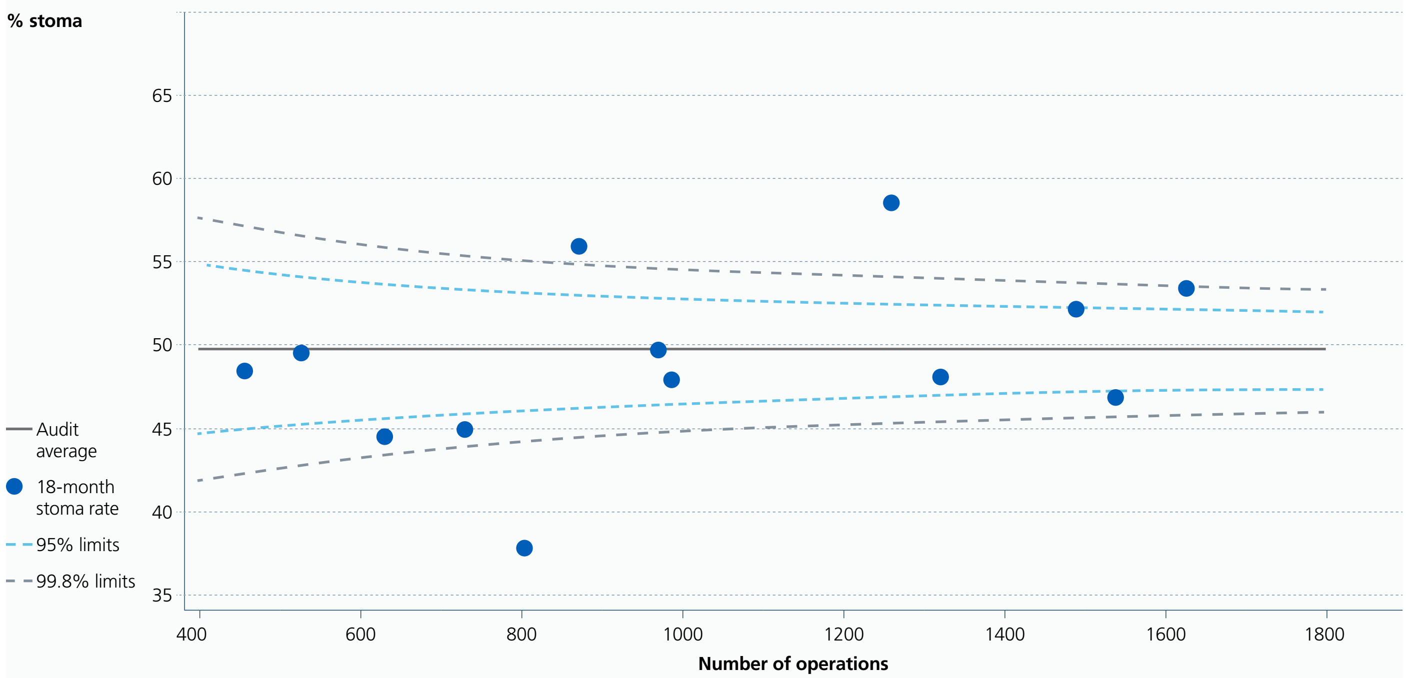
Stoma

An important issue for patients having part of their rectum surgically removed is the need for an intestinal stoma, a surgical opening in the abdomen through which the bowel is brought out onto the surface of the skin. Some rectal cancer operations mean the patient will need a stoma for the rest of their life, known as a permanent stoma. In other operations, patients are given a stoma to make their operation safer. These patients may have their stoma removed at a later date, known as a temporary stoma.

- 83 per cent of patients having part of their rectum surgically removed had a stoma formed during that operation.
- 32 per cent of rectal cancer patients had an operation which required a permanent stoma.
- 65 per cent of patients who had a temporary stoma had undergone a stoma removal within 18 months of their operation. Patients may not have their stoma removed for many reasons including, personal choice, other medical conditions meaning that a further operation may be dangerous, or not being offered a removal by their doctor.
- There was much difference between regions in rates of stoma removal. This is shown in Figure 6.1.

Figure 6.1
Adjusted 18-month stoma rate by English strategic clinical network for rectal cancer patients undergoing a major resection between 1 April 2011 and 31 March 2014

Adjusted 18-month stoma rate by network



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7. Recommendations for patients

- An awareness of the symptoms of bowel cancer is important and individuals should visit their GP if they have any concerns regarding this. Information about symptoms can be found at: www.nhs.uk/Conditions/Cancer-of-the-colon-rectum-or-bowel/Pages/Symptoms.aspx
- All men and women aged 60 to 74 should take part in the NHS bowel cancer screening programme every two years. Those over 74 who wish may request to be screened. More information can be found at: www.cancerscreening.nhs.uk/bowel/index.html or provided from GPs.
- There are many sources of further information and support available regarding bowel cancer for both patients and carers. These are accessible via GP services and online from bowel cancer charities.

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0300 303 5678
enquiries@nhsdigital.nhs.uk

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