right test, right time

Diagnosing bowel cancer early
About bowel cancer

Bowel cancer is the fourth most common cancer in the UK and the second biggest cancer killer. There are currently more than 235,000 people in the UK living with or after bowel cancer and over 40,000 people are diagnosed each year. Bowel cancer incidence is strongly related to age. Approximately 95 per cent of cases are diagnosed in people over the age of 50. However there is a growing proportion of younger people being diagnosed with the disease.

Most bowel cancers develop from polyps which are usually non-cancerous and, once detected, can be removed easily if caught early enough. Nearly all bowel cancers develop in the large bowel — two-thirds of these are in the colon and one-third in the rectum. Symptoms of bowel cancer include: blood in your poo, a change in bowel habit, unexplained weight loss, extreme tiredness for no obvious reason or a pain or lump in the stomach.

Bowel cancer can be treated using a combination of surgery, chemotherapy, radiotherapy and, in some cases, biological therapy. If diagnosed at the earliest stage, bowel cancer can be treated successfully, with nine out of ten people surviving for more than five years. However, only one in ten people are diagnosed at this stage.
Methodology

In September 2013 we ran a survey asking people about their experience of having an endoscopic procedure, such as a colonoscopy or a flexible sigmoidoscopy (flexisig).

Our survey ran for six weeks and a total of 708 people responded. We asked a number of questions to help us to create a detailed picture of endoscopy services from the perspective of patients, ranging from how they were first directed to endoscopy services, to what prompted them to see their GP, and their information needs. The survey was self-selecting and was emailed to our known patient contacts, volunteers and supporter base, as well as promoted on social media. Local Healthwatch organisations and Clinical Nurse Specialists also helped to disseminate our survey.

We conducted desk research and analysed publicly available statistics from all four nations, and consulted with clinical experts on our Medical Advisory Board. Requests for additional information, such as the number of “did not attends” and cancellations; number of incomplete procedures; and waiting times for surveillance and symptomatic patients were also made from health and social care trusts (HSCTs) in Northern Ireland and health boards in Scotland. We received a response from all health boards in Scotland and four out of five HSCTs in Northern Ireland, although not all organisations collected the information requested.

About Bowel Cancer UK

Bowel Cancer UK is determined to save lives and improve the quality of life for all those affected by bowel cancer. Since 1987 we have been raising awareness of bowel cancer, campaigning for best treatment and care and providing practical information and support.

At Bowel Cancer UK we believe that patients should be at the heart of everything we do. Listening to patients is integral to helping us identify the needs of those affected by bowel cancer and gaps that exist in service provision, so we can successfully campaign for changes that benefit patients.

We would like to thank everyone who contributed and shared their story with us. Without them, this report would not have been possible.
increase by 350,000. How this demand will be met sets serious challenges for endoscopy units across the UK, particularly as units are currently not performing enough procedures per head of population. There needs to be greater investment in endoscopy services to ensure future demand is adequately met; relying only on productivity and efficiency improvements alone is not sufficient.

Variation in waiting times

People across the UK are waiting significant lengths of time between being referred and having their test. Waiting times in Wales are particularly poor with 15 per cent of patients waiting between eight and 14 weeks and 26 per cent waiting over 14 weeks for a colonoscopy. In Northern Ireland no trust has met the target of no patient waiting more than nine weeks. In Scotland performance has dropped, with 6.8 per cent waiting longer than the recommended six week waiting time target, compared to less than two per cent in the previous month. Figures for England are more encouraging – less than two per cent are waiting more than the recommended waiting time. It is crucial that individuals are seen within the recommended waiting times to ensure they receive a timely diagnosis and access to treatment. Health authorities must do better to ensure all patients are seen on time.

The drive to see screening and symptomatic patients within the recommended waiting time target has meant that surveillance patients are often made to wait unacceptable lengths of time before being seen. This has resulted in a backlog of patients waiting for a routine endoscopy procedure, with many patients waiting months and in some cases years after their planned appointment dates. 60 per cent of units in Wales were judged inadequate for surveillance waiting times, no units in Scotland, and only 29 per cent of units in Northern Ireland received level A for timeliness. In England 20 per cent of units need to make improvements. It is essential that those at higher risk of developing bowel cancer are identified, and targeting for surveillance screening and waiting time figures are centrally monitored and recorded.

The right test

People who experience symptoms should be referred for the most reliable and accurate diagnostic test available. A colonoscopy and flexisig are the key diagnostic tests for bowel cancer. However, barium enema is still used by some clinicians to detect polyps and tumours. Barium enema is an inferior diagnostic test, with a much higher rate of missed cancer. Our survey found that one in three individuals who had a barium enema had to return for another test. Barium enema must be ruled out as a diagnostic test for bowel cancer altogether. CT colonography should be the test of choice if an individual is unable to tolerate a colonoscopy or flexisig.

Changing demand

Much of the current demand for endoscopy services is created through individuals visiting their GP as a result of experiencing symptoms – 60 per cent of our survey respondents were referred for an endoscopy by their GP. A third of these individuals had to see their GP more than three times before referral. As symptoms can often be vague, GPs need to be supported to refer the right people quickly. However national referral guidelines for suspected bowel cancer are restricted to those with “alarm” symptoms. Only half of people diagnosed with bowel cancer present with the “high-risk” symptoms that would qualify for an urgent referral. That is why we are calling for the guidelines to be liberalised so GPs can use their clinical judgement and refer patients even when their symptoms do not directly point to bowel cancer. We recognise that liberalising the guidelines would contribute to increasing demand but it is necessary to ensure individuals are referred into the system quickly.

Units need to ensure that the sources of demand are managed so all patients are seen on time and procedures are carried out to a high standard. This is even more crucial as demand is set to increase dramatically over the next few years. Between now and 2016/17 the number of lowerGI endoscopy procedures is expected to
This report highlights serious problems with endoscopy services. People are being let down by the service, with referral criteria, waiting times and quality of services being the key issues. That is why we are calling for a series of recommendations to be implemented to improve endoscopy services. We have outlined our key recommendations below. We hope that the UK governments will act on these recommendations and implement them as a matter of urgency.

**Improving quality**

The Joint Advisory Group’s (JAG) accreditation scheme for endoscopy units has been instrumental in setting out clearly what constitutes best practice and good quality care. However not all units are engaged in the JAG accreditation process. This must change. We expect all units to be fully accredited by JAG. With the added pressures that the increase in demand is likely to present, ensuring endoscopy units continue to be of the highest quality is paramount to prevent people from dying prematurely.

**Empowering patients**

Our research shows that not all patients are provided with the information they need to help them understand why they are having an endoscopy, what it involves and the importance of having the procedure. We also found that 80 per cent of our respondents were not asked about their experience of having the test. We believe it is the responsibility of all endoscopy units to capture patient experience, and ensure all patients have a positive experience of their care, and to provide them with accurate, clear and comprehensive information on their care.

**Key recommendations**

This report highlights serious problems with endoscopy services. People are being let down by the service, with referral criteria, waiting times and quality of services being the key issues. That is why we are calling for a series of recommendations to be implemented to improve endoscopy services. We have outlined our key recommendations below. We hope that the UK governments will act on these recommendations and implement them as a matter of urgency.

- **The urgent referral pathway for suspected bowel cancer should be liberalised so that GPs can refer a patient at lower levels of risk than currently apply with the NICE CG27 referral criteria. This would mean that patients with persistent ‘low risk’ symptoms or non-specific symptoms would be assessed more.**

- **Greater investment in endoscopy services to ensure future demand for services is adequately met and that we are not left with situation where patients are kept waiting for a crucial diagnostic test.**

- **JAG accreditation must be made mandatory for all units across the UK, including private providers offering NHS services, with a new standard of “outstanding” and a patient assessor present on all JAG visits. It is imperative that units receive the support, investment and resources to bring all units up to JAG standards.**
Endoscopy: preventative, diagnostic, therapeutic

People who experience symptoms where bowel cancer is suspected should be referred for the most reliable and accurate diagnostic test available. A colonoscopy and flexisig are the two main endoscopic procedures used for diagnosing bowel cancer.

A UK-wide audit² found that 65 per cent of colonoscopy procedures were performed for diagnostic purposes, 10 per cent were performed as part of the Bowel Cancer Screening Programme (BCSP) and 18 per cent were for surveillance. A diagnosis of cancer was made in 4.1 per cent of procedures; polyps in 28 per cent and 42 per cent were clear.

These endoscopic tests can detect cancerous and pre-cancerous polyps, which can be removed during the procedure, therefore it is a preventative procedure, as well as a diagnostic one. Approximately 90 per cent of bowel cancers start with polyps, some of which can take up to 10 years to develop into cancer, so it is vital that these are detected early and removed.

Early detection of polyps and tumours is essential to saving lives from bowel cancer. Individuals diagnosed at the earliest stage of the disease are more responsive to treatment and have more chance of surviving than those diagnosed later. Nine out of ten people diagnosed at the earliest stage of the disease will survive for more than five years³. That is why more people need to be referred for a colonoscopy or flexisig more quickly - whether as symptomatic patients or as referrals through the BCSP.

Of our survey respondents, 68 per cent of people were referred for a colonoscopy procedure, 23 per cent for a flexisig and five per cent of people were referred for a barium enema test.
Ensuring individuals have the right test for them is essential if we are to increase the number of people diagnosed at the early stages of the disease. This is particularly the case for individuals referred through their GP, as symptomatic presentation can imply later stage disease. However, the test that individuals are referred for varies around the UK. Some clinicians consider flexisig or barium enema to be sufficient whereas others would refer individuals for a colonoscopy. Greater clarity and guidance is needed on what symptoms should trigger which test. This will help clinicians refer patients for the right test and to help patients understand why they are being referred for a particular test. Patients should be referred for the right test first time to reduce the chances of having to have a repeat procedure, which can be stressful for the individual and costly to the health authority.

### Tests for bowel cancer

**Colonoscopy** – A colonoscopy is the gold standard test for diagnosing bowel cancer. It inspects the entire large bowel and is over 90 per cent sensitive in detecting large adenomas and cancers. A colonoscopy is the most effective way to diagnose bowel cancer and can take up to an hour to complete.

**Flexible sigmoidoscopy** – A flexisig only inspects the lower part of the colon i.e. the sigmoid colon and rectum. This part of the bowel is the most common area for polyps and other abnormalities to develop. A flexisig is a relatively quick investigation, taking around 15-20 minutes to complete.

**Computed Tomography (CT)**

**Colonography** – CT scanners and computer technology are used to build up a three-dimensional picture of the bowel, to enable tumours and polyps to be detected. This is a less invasive test. Research has also shown it to be more effective than barium enema.

**Barium enema** – This is a simpler test. Barium sulphate and air is passed through the bowel for an X-ray to be taken. It is the least effective of all the diagnostic tests for bowel cancer.
Recommendations

Barium enema should be ruled out as a diagnostic test for bowel cancer. CT colonography should be a viable option for those who are unable to have a full colonoscopy. This means that greater investment is needed to ensure radiologists are trained and experienced to carry this procedure out to a high standard across the UK.

Further research needs to be carried out on what symptoms should trigger which test. This would ensure there is greater clarity and guidance to help clinicians refer patients for the right test and help patients understand why they are being referred for a particular test.

There is good evidence to suggest that barium enema is an inferior diagnostic test, with a high rate of missed cancer. Our survey showed that one in three people who had a barium enema had to return for another test, compared to one in ten and one in five individuals who initially had a colonoscopy or flexisig respectively. Repeat procedures can lead to delays in the patient pathway and access to life-saving treatment.

Although barium enema can be useful for diagnosing certain bowel conditions, it should not be used as a diagnostic test for bowel cancer. However, some trusts in England carry out as many as 8.5 barium enema procedures per 1,000 whereas others carry out as few as 0.02 per 1,000.

There are also some units which have stopped carrying out barium enemas altogether, such as NHS Dumfries and Galloway in Scotland, which stopped carrying out the procedure in 2012. This is an unacceptable level of variation. It should not be the case that some people are referred for a diagnostic test that units elsewhere would regard as inadequate for patients.

The NICE Clinical Guideline is clear: a colonoscopy or flexisig should be offered before a barium enema. It also states that CT colonography should be considered as the alternative to colonoscopy and flexisig before barium enema, where radiology teams have the experience to competently carry out this procedure.

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**Sharon Woods**

“My experience of the colonoscopy was a good one. I was very embarrassed and nervous at first but all those involved calmed my nerves. The team explained what everything was, what was going to happen and any discomfort I might feel. It’s a painless procedure, which takes minutes and can help with diagnosis. In my eyes it is worth the couple of hours you are in hospital. If I hadn’t had the screening, would I be here now?”

Barium highlighting the bowel
The demand for endoscopy services stems from a number of sources. Individuals may be referred for a colonoscopy or flexisig for one of the following reasons:

- they have seen their GP because they are experiencing symptoms which require investigation
- they have participated in one of the national Bowel Cancer Screening Programmes and have received a positive screening test result
- they may require routine testing because they are in a surveillance screening programme for people at higher risk of developing bowel cancer
- they have attended A&E with symptoms which require investigation

Units need to ensure that all patients are seen on time and procedures are carried out to the highest standard. However managing these sources of demand can place strain on the service and can present units with challenges. For example, trusts and health boards have to ensure that their units have the workforce and the equipment ready to see all patients who require an endoscopic procedure. Knowing where demand stems from can help with being able to manage the demand.

This management is crucial as the demand for endoscopy services is set to increase dramatically over the coming years. A 10-15 per cent year on year increase over the next five years has been predicted. This will equate to approximately a 75 per cent increase in the total number of endoscopies carried out. By 2016/17 the total number of lower gastrointestinal (GI) endoscopies could increase by as much as 350,000, from 1,116,000 in 2013/14 to 1,482,000 in 2016/17.
In 2011/12, there were c.504,000 colonoscopies and c.323,000 flexisigs undertaken in England. By 2016/17 c.739,000 colonoscopies and c.743,000 flexisigs would need to be undertaken to meet the expected demand. To achieve this there would need to be 110 extra endoscopy clinical sessions per year for an average-sized trust, and around 220 extra sessions for a large trust. In order to facilitate these procedures it is estimated that the number of endoscopy rooms in England will need to increase from 620 currently to 670 in 2015 if all rooms were used to their maximum capacity.

This increase in demand is due to a number of factors including: an increase in the number of symptomatic and screening patients due to an ageing population; the roll-out of the Bowel Scope Screening Programme in England, which is expected to increase the number of flexisig procedures by 325,000 procedures a year by 2016/17; a continual increase in symptom awareness; the age extension to the existing screening programmes; the shift from barium enema to colonoscopy; and the move from faecal occult blood test (FOBT) to faecal immunochemical testing (FIT).

Sources of demand

Reasons for referral to endoscopy services

- **60%** GP
- **12%** Emergency admission
- **6%** BCSP
- **12%** Bowel condition
- **8%** Family history
- **2%** Genetic condition
GP referrals

Most of the demand for endoscopy is created through people visiting their GP as a result of experiencing symptoms. Of our survey respondents, 60 per cent were referred for a diagnostic endoscopy test by their GP. Worryingly, 72 per cent of those who were experiencing symptoms did not know what could be wrong and only 21 per cent knew that they were experiencing symptoms of bowel cancer. As more people become aware of the symptoms of bowel cancer and with an aging population, the number of people seeing their GP is likely to increase, creating more demand for endoscopy services.

Reducing the number of pre-referral GP appointments that a person has to attend is essential to improving the timeliness of a person’s diagnosis. We know that the symptoms of bowel cancer that people present their GP with can be vague but serious, which makes the decision of when to refer for diagnostic testing a difficult one. In our survey one in three individuals referred to endoscopy services through their GP were found to have a tumour and one in five individuals had polyps removed. Of those who saw their GP more than three times, nearly half had a tumour detected. It is therefore vital that GPs are supported to identify the right people for referral quickly and accurately.

However one in five respondents saw their GP more than three times before being referred for an endoscopy. This is in line with findings from a report on the promptness of cancer diagnosis in primary care, which found that 21 per cent of bowel cancer patients saw their GP three times or more.

Number of GP visits before referral

- 53% Once
- 26% 2-3 times
- 21% > 3 times

Reasons for seeing a GP

- 72% Did not know what might be wrong
- 21% Symptoms of bowel cancer
- 7% Illness unrelated to bowel cancer
Kathleen Neilly

“I had a colonoscopy less than two years after seeing my GP when I first started to experience symptoms. I was passing blood in my poo, experienced a change in bowel habit and I was extremely tired for no reason but my GP kept telling me that because I had two kids it was likely to be piles. I saw my GP more than three times before I was referred. Even then I had to wait four months before I actually saw a consultant.”

Making the referral guidelines work for patients

National guidelines are in place to assist GPs to make this decision. Patients who GPs decide do meet the criteria for suspected bowel cancer are referred through the two-week wait (TWW) pathway. In England, Wales and Northern Ireland it is the NICE Referral Guideline for Suspected Cancer that applies and in Scotland, the Scottish Intercollegiate Guidance Network (SIGN) Clinical Guideline on the Diagnosis and Management of Colorectal Cancer outlines the suspected cancer pathway.

However, guidelines on referral for suspected cancer are restricted to those with ‘alarm’ symptoms, such as rectal bleeding in people over 60, and many people diagnosed with bowel cancer do not meet the strict criteria for urgent referrals. In fact only half of people diagnosed with bowel cancer present with the ‘high-risk’ symptom pattern that would qualify for an urgent referral. The remaining 50 per cent have no obvious symptom pattern9 and therefore do not meet the criteria for an urgent referral. These patients take longer to be diagnosed and have a worse prognosis10.

It was hoped that the TWW route would identify up to 90 per cent of all bowel cancer patients11, although 60-70 per cent would be a more achievable target. However, only 27 per cent receive their diagnosis from being referred through this route12. The remaining symptomatic patients receive their diagnosis through the following routes:

- 26% are diagnosed in emergency care
- 20% are diagnosed as a routine GP referral
- 26% are diagnosed as an inpatient elective
- 9% are diagnosed as other outpatient
- 1% are diagnosed upon death
- 9% unknown

One criticism of the referral guideline is that the criteria is based on findings from people who have been referred and so does not take into account the primary care population, where the guidelines are mainly applied13. Symptoms such as anaemia are often missed in primary care, as NICE guidance only recommends the urgent referral of those with pronounced iron deficiency14. One study found that a third of patients with bowel cancer had anaemia, which was not severe enough to meet current NICE guidance15.

Patients who have symptoms of bowel cancer would benefit from better access to diagnostic testing through primary care even if it is another bowel condition and not cancer that is found. We know that 88 per cent of patients would opt for tests if their symptoms indicate just a one per cent risk of cancer16 yet current guidance recommends a minimum risk of five per cent before tests for cancer are undertaken. Patients want their symptoms to be tested sooner than suggested by current guidelines.

The guidelines need to change to support GPs to make referrals for patients who do not follow the ‘high-risk’ symptom pattern. We recognise that this would contribute to the rising demand for endoscopy services. However a liberalisation of the guideline would reduce the number of times a patient sees their GP for the same symptoms, enable GPs to refer more patients for a diagnostic test and improve the timeliness of a person’s diagnosis.
Bowel Cancer Screening Programme

The Bowel Cancer Screening Programme (BCSP) also generates referrals for endoscopic procedures. It was first introduced in England in 2006 and was subsequently rolled out to the rest of the UK. Approximately six per cent of our survey respondents were referred through this programme. This figure reflects broadly the findings from the National Colonoscopy Audit, in which nine per cent of colonoscopies were performed under the BCSP. Flexisig is now being introduced by the NHS in England as an additional screening test, known as “Bowel Scope Screening” (BSS). By 2016 everyone aged 55 will be invited to have this “one-off” procedure. Individuals can decide to accept the invitation up until the age of 60 when they will then be transferred to the BCSP.

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Surveillance for ‘high-risk’ patients

Demand for endoscopy services is also generated by people who require surveillance screening because of their likelihood in presenting risk factors for bowel cancer. These risk factors include genetic conditions such as Lynch syndrome, a strong family history of bowel cancer or a bowel condition such as inflammatory bowel disease (IBD)\(^17\). One in five individuals who responded to our survey were referred for an endoscopy for one of these reasons.

Referral guidelines\(^18\) by the British Society of Gastroenterology recommend that those at the highest risk should have multiple colonoscopies at one to five year intervals from as young as 25, and individuals at high-moderate risk should be seen every five years between ages 50 and 75.

Surveillance screening has been shown to be effective. It can achieve an 81 per cent reduction in mortality for ‘moderate risk’ groups, and a 72 per cent reduction in mortality in families with Lynch syndrome. Surveillance programmes that detect bowel cancer early are also cost-effective, as surveillance screening is cheaper than treating someone for bowel cancer.

However recommendations that people with Lynch syndrome should be screened every two years are not always followed. There is a highly variable approach to the management of these patients between health bodies, as well as variability in the quality of surveillance of these patients, for example, in the use of chromoendoscopy for the surveillance of patients with IBD. This is of serious concern given that lives can be saved if those at high risk of developing bowel cancer are identified and screened effectively.

There are other high-risk patient groups such as those who have had previously been diagnosed with bowel cancer and those who have previously had polyps detected. Maintenance and timeliness of colonoscopic surveillance for these patients requires vigilance and regular audit to ensure the quality of this surveillance.

“Before finding the tumour my consultant asked me why I was wasting his time. 30 seconds later he found a 10mm tumour. I have Lynch syndrome. My tumour was discovered age 35. My twin and my father were diagnosed at the same time.”

Survey respondent

Emergency admissions

Individuals who are referred for a colonoscopy or flexisig through emergency admission are an unplanned source of demand for endoscopy services. This unplanned demand places strain on the service. Patients referred through this route have poorer outcomes. A patients’ chance of
surviving one year after their diagnosis is halved if diagnosed through an emergency admission. This is because those diagnosed in emergency care are likely to present with late stage disease. Just over one in ten of our respondents were referred after being admitted to hospital. While it is likely, given the nature of the disease, that some patients will be diagnosed in emergency care, we should aim to minimise the number of people diagnosed through this route. If we are to improve bowel cancer outcomes and save more lives, more needs to be done to encourage individuals to see their GP when experiencing symptoms or to take part in the BCSP.

Barriers to meeting demand

Meeting the projected demand is essential if more people are to be diagnosed at an earlier stage of the disease. However units face the following barriers to meeting this demand:

Crude colonoscopy rates per 100,000 in 2010/11 - international comparisons

Rates of colonoscopy

Many units are struggling to meet the demand for endoscopy services because they are not carrying out enough colonoscopies per head of population compared to other countries. In Poland 1,208 colonoscopies are carried out per 100,000 people. To achieve the same rate of colonoscopy, England would have to carry out an extra 205,038 procedures. This equates to an increase of 48 percent.

Rates also vary between the devolved nations and within each nation. Figures from the National Colonoscopy Audit show that the variation between the devolved nations during the audit period ranged from 23.3 in Wales to 46.8 procedures per 100,000 of population in Scotland. Scotland and Northern Ireland have higher rates of colonoscopy per population than England and the number of colonoscopies carried out per head of population in Wales is woefully short of the UK average of 32.2.
It is unclear why this level of variation exists between nations. It may in part be due to differences in cancer incidence level or the age of population – an older population means a higher incidence of bowel cancer – but this by no means fully explains the stark variation demonstrated. However, what is clear is that this level of variation cannot continue. Patients are losing out in some areas and, as demand increases, this will only get worse unless it is addressed.

**Productivity**

Lack of capacity and inefficient use of existing resources are key constraints to meeting the demand for endoscopy services. A report by the NHS Improvement team on endoscopy services found that capacity could be increased through better management and more efficient use of available resources. In particular, data collection, effective planning, regular reviews and improving patient experience all contributed to a better run service. Resources aimed at helping endoscopy units use their existing resources efficiently have already been developed. In association with the Joint Advisory Group for Gastrointestinal Endoscopy, NHS Improving Quality has developed a suite of tools called “Productive Endoscopy” to engineer improvements in productivity.

**Investment**

Despite the rise in demand for endoscopy and the projections for further increases in demand, little investment has been made in the infrastructure of endoscopy units both at a national and local level. An investigation by GP Magazine found that 85 per cent of trusts in England had no plans to make additional investment in endoscopy service in 2012/2013. Yet greater up-front investment in endoscopy units would provide long-term cost savings for the NHS, as it is less costly to treat bowel cancer in the earlier stage of the disease than later. Relying on local trusts and boards to make better use of existing capacity is insufficient.
Turning up for appointments

Patients who fail to attend an appointment without prior notice or who cancel appointments at the last minute can take up extra time and resources and contribute to delays in the system as well as impact on waiting times. These are referred to as “did not attend (DNA)” and “could not attend (CNA).” The reason why a patient does not attend a clinic appointment is varied. However, understanding why people do not attend appointments is important to ensuring a unit does not have gaps in their schedule.

Units can minimise DNA rates through introducing measures such as direct booking, which allows patients to choose the date and time most convenient for them. Carrying out pre-assessments before their appointment also ensures compliance. A unit in Northern Ireland reported that pre-assessments have helped significantly with decreasing the number of DNAs and last minute cancellations. Comprehensive and clear information on what the procedure involves, why it is being carried out and what patients can expect can reduce the anxiety that may put patients off from attending, as well as help them to understand the importance of attending on the day.

Recommendations

- Every health board and trust has a named individual with responsibility for the management of hereditary colorectal cancer, ensuring accurate risk assessment and appropriate screening, maintaining a patient registry, and developing links with regional clinical genetics centres. Regular audit of those who require surveillance due to IBD or a previous diagnosis of bowel cancer is also needed to ensure the quality of this type of surveillance.

- The urgent development of a quality standard for colonoscopic surveillance. A quality standard which outlines what constitutes best practice in relation to the appropriateness of colonoscopic surveillance, frequency, risk groups and method for high-risk individuals would contribute to improving the effectiveness, quality and patient experience of the procedure, as well as ensuring variation in clinical practice is minimised.

- The urgent referral pathway for suspected bowel cancer should be liberalised so that GPs can refer a patient at lower levels of risk than currently apply with the NICE CG27 referral criteria. This would mean that patients with persistent ‘low risk’ symptoms or non-specific symptoms could be assessed more quickly.

- All health boards and trusts should proactively and regularly monitor the demand for their endoscopy services to ensure effective capacity planning. Units need to ensure there is sufficient room and staff availability, that equipment such as endoscopes are available when needed, that the right staff are on site and ready to start on time, and that patients are fully informed and prepared. Difficulties in these areas will impact on the ability of units to effectively manage their demand.

- All units should adopt the “Productive Endoscopy” tools produced by JAG and NHS Improving Quality. These tools are aimed at helping endoscopy units use their existing capacity efficiently.
Waiting for a diagnostic test is a stressful and uncertain time for anyone. Diagnostic waiting times are an important element of the overall cancer care pathway. How soon an individual is seen determines how soon a diagnosis can be made or given the “all clear”, and how soon treatment can begin. Waiting times are also an important indicator of how well endoscopy units are meeting demand for the service, so it is important that these are monitored, measured and responded to.

Waiting time targets across the UK

Diagnostic waiting time targets were introduced to ensure patients were waiting the shortest length of time possible from referral to treatment. Waiting times were introduced in England and Northern Ireland in 2008 and in Scotland in 2007 as part of the 18-week referral to treatment standard. In England and Scotland the recommended waiting time is six weeks. However Scottish health boards work towards achieving a local target of four weeks. The recommended waiting time in Northern Ireland is nine weeks. There is no recommended waiting time target for diagnostic tests in Wales. Instead units have an operational standard of seeing patients within eight weeks.

Are health bodies meeting the waiting time target?

Although waiting time targets have contributed immensely to bringing down the length of time a patient is waiting for a diagnostic test, there are still significant and unacceptable levels of variations between nations and within each nation.
England

England has seen a marked improvement in the last decade with waiting times for diagnostic testing falling quite dramatically since the six-week target was introduced. The NHS Operating Framework states that less than one per cent of patients referred for a diagnostic endoscopy should be waiting beyond the waiting time target. Trusts which do not meet this standard receive a financial penalty as set out in the NHS Standard Contract.

At the end of February 2014, 571 people, which equates to approximately 2 per cent of the total waiting list, in England were waiting more than six weeks for a colonoscopy and 236 people, 1.5 per cent of the total waiting list, were waiting for a flexisig. However there is stark variation in waiting times between providers in England, ranging from 186 out of 477 people waiting for more than six weeks in Plymouth NHS Trust to 35 out of the 526 people waiting for a colonoscopy at the North West Hospital Trust.
Scotland

Scotland has seen a marked improvement in the length of time people wait for a colonoscopy. At the start of 2013, 19 per cent of those waiting for a colonoscopy had been waiting over six weeks. The latest figures from December 2013 show that this had dropped to 6.8 per cent. This is an increase from the previous quarter in which only two percent were waiting more than six weeks. The decrease in performance has been due to demand and capacity issues experienced by NHS Fife and NHS Forth Valley, in which 139 out of 415 people and 175 out of 383 people were waiting more than six weeks for a colonoscopy, respectively.

Wales

Waiting times in Wales are a particular problem. Health boards in Wales perform poorly in comparison to the rest of the UK, with 15 per cent of patients waiting between eight and 14 weeks for a colonoscopy and 26 per cent waiting over 14 weeks. In some health boards the percentage of patients waiting over 14 weeks is as much as 40 per cent. The figures for patients waiting for a flexisig are no better. There are a total of 2,538 patients waiting for a flexisig and 22 per cent of these are waiting over 14 weeks and 13 per cent waiting between eight and 14 weeks.
Northern Ireland

The ministerial target for diagnostic reporting times in Northern Ireland states that from April 2013 no patient should wait longer than nine weeks for a diagnostic test. At the end of December 2013 only the Northern Trust met this target for patients waiting for a flexisig. There were a total of 2,304 patients waiting for a colonoscopy and 1,279 waiting for a flexisig. Of these, 11 per cent of those waiting for a colonoscopy and nine per cent of those waiting for a flexisig were waiting longer than the nine week waiting time target.

Waiting times for patients at higher risk

The drive to see screening and symptomatic patients within the recommended waiting time target has meant that surveillance patients at higher risk of developing bowel cancer, e.g. those with a genetic condition such as Lynch syndrome, are often made to wait unacceptable lengths of time before being seen. Individuals on a surveillance list waiting beyond six weeks are not included in the monthly waiting times returns but we know from freedom of information requests that there is a backlog of patients waiting for a routine endoscopy procedure, with many patients waiting months and in some cases years after their planned appointment dates. In Northern Ireland waiting times at the Western Trust for surveillance patients were between four to nine months beyond their due date. The longest wait for surveillance patients at NHS Fife in Scotland is currently three years beyond their target date.

The Global Rating Scale (GRS) census, which measures how well endoscopy units are performing, showed that from April 2013, many units assessed for their ability to see surveillance patients within their planned appointment date were not meeting the standard required.

Units are rated on a scale of A to D, with A being ‘excellent’ and D meaning ‘inadequate’. Wales and Scotland are performing particularly badly, with 60 per cent of units in Wales and 41 per cent in Scotland achieving level D. No units in Scotland received level A. This is both disappointing and worrying. Only 29 per cent of units in Northern Ireland are achieving scores of A, with the majority of units requiring improvement. Figures for England are better, with 82 per cent of units achieving level A. However there are still 20 per cent of units that need to make improvements.

| NHS Fife – Number of patients waiting beyond their appointment date in December 2013 |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
|                                 | Over 3 years    | 2.5-3 years     | 2-2.5 years     | 18 months -2 years | 1 year - 18 months | 6 months – 1 year | Less than 6 months |
| Victoria Hospital               | 3               | 29              | 21              | 37              | 48              | 115             | 234             |
| Queen Margaret’s Hospital       | 11              | 10              | 18              | 17              | 47              | 118             | 144             |
| Total                           | 14              | 39              | 39              | 54              | 95              | 233             | 378             |
Solving the problem of waiting times

The inability to see surveillance patients within their planned appointment date can have unnecessary tragic consequences for patients, their families and friends. Many of these patients are at higher risk of developing bowel cancer due to being predisposed to the disease - either through having a strong family history of bowel cancer, through having a genetic condition such as familial adenomatous polyposis (FAP) or having a bowel condition such as Crohn’s disease or colitis.

According to our survey, polyps were detected in more than a third of patients referred for one of these reasons and nearly one in ten had a tumour detected. Timely and high quality colonoscopic surveillance is vital to those who are at most risk of developing bowel cancer and this must be urgently addressed by all nations.

It cannot be acceptable that so many people are waiting for so long to be diagnosed with a life-threatening disease. Endoscopy is a critical part of the referral to treatment cancer pathway. Figures for England and Scotland are encouraging, however, health bodies in Wales and Northern Ireland need to address this issue as a matter of urgency or the situation is likely to get worse. As demand for the service is rapidly increasing, sustainable change and urgent improvement to waiting times are needed. The devolved governments must work with health bodies to bring down waiting times and to ensure waiting times are met consistently across all nations. It cannot be right that the length of time a person waits for a diagnostic test varies depending on where they live in the UK. Waiting time targets should be consistent across all devolved nations.

Recommendations

- Patients waiting beyond six weeks for surveillance procedures should be included in the monthly diagnostic returns to allow for greater transparency and push forward improvements in waiting times.
- All UK governments need to make greater investment in endoscopy services to ensure demand for services is adequately met, so that patients are not kept waiting for a crucial diagnostic test.
An endoscopy is a complex diagnostic procedure that can detect bowel cancer early and remove potentially cancerous polyps at the same time. However, higher detection rates for bowel cancer are reliant upon the colonoscopy being of the highest quality, rather than simply undertaking colonoscopies more frequently.

A poor quality endoscopy can result in an incomplete procedure leading to missed cancers and serious complications, putting patients at risk. With the added pressures that the expected increase in the demand for colonoscopic procedures will bring, ensuring services continue to be of the highest quality is paramount to prevent people from dying prematurely.

Incomplete procedures and missed cancers

Completion rates are a key quality indicator for ensuring that an endoscopy is carried out to the highest standards. Incomplete tests can result in repeat procedures, which are not only inconvenient and distressing for the patient, but are also costly and contribute to demand on the service.

The national colonoscopy audit identified the following factors as contributing most to incomplete procedure:

- pain or uncontrolled looping of the colonoscope (49 per cent)
- narrowing of the colon (25.9 per cent)
- poor bowel preparation (22 per cent)

Ensuring procedures are carried out to the highest standard by a trained, experienced and highly skilled endoscopist is crucial to navigating the scope around the colon to ensure adenomas and tumours are detected.
Improving quality

British Society of Gastroenterology (BSG) guidelines state that a colonoscopist must complete at least 90 per cent of the procedures carried out. A BSG colonoscopy audit found that the UK average was 92.3 per cent, with all nations reaching this target except Wales, which achieved a completion rate of 89.8 per cent. However completion rates alone do not present the whole picture.

We need a better measure of what constitutes quality. Recent research found that combining completion rates with patient comfort and sedation is a better measure with which to distinguish performance of colonoscopy and is associated with higher polyp detection rates.

Some people are diagnosed with cancer despite having a recent colonoscopy – known as post colonoscopy colorectal cancer (PCCRC). This is due to cancers being missed or cancer developing from missed or incompletely removed polyps. Miss rates for small adenomas range from 25-50 per cent, 6-12 per cent for large adenomas and around four per cent of cancers are missed at colonoscopy. However rates of PCCRC are not systematically collected and reported on at a local and national level. We need to be able to clearly understand the root cause of why the cancer or polyp/s was not detected or removed during the procedure. Understanding this would improve cancer detection and therefore increase survival rates.

Certifying colonoscopists

JAG assesses whether trainee colonoscopists are competent enough to carry out endoscopy procedures independently. The certification process assesses trainees against several criteria including achieving a >90 per cent completion rate and a >10 per cent polyp detection and removal rate. The purpose of the certification process is to ensure all new colonoscopists have achieved a minimum standard before they can carry out procedures without supervision. However it is not currently compulsory for all trainees to be certified. A system needs to be put in place where all surgical colonoscopists are assessed against this competency framework and performance data is made available for all patients to consider.

JAG accreditation

Quality assurance measures are integral to standardising service provision and ensuring that patients receive the same level of high quality care regardless of where they live in the UK. The JAG scheme has been instrumental in setting out clearly what constitutes best practice and good quality care. The JAG accreditation system measures and assesses units against the GRS. The GRS is made up of the four following domains, which each have a number of standards relating to them:

1. Clinical Quality and Safety
2. Quality of Patient Experience
3. Workforce
4. Training

For units to become JAG accredited they need to score an A for timeliness and a B in all other domains.

JAG also ensures that the care and services provided by units is patient centred. However no patient representatives are included on JAG visits to ensure that services are meeting the needs of patients. We believe that if JAG is to make an accurate assessment on whether a unit is patient-centred then patients themselves need to be a part of this process.
JAG in the nations

England

JAG accreditation in England is only mandatory for endoscopy units wishing to be screening centres. Although the vast majority of NHS providers are engaged with the JAG accreditation process, only 48 per cent of NHS providers have fully met JAG criteria and a further 26 per cent have been assessed but require improvement. In comparison, only 15 per cent of private providers are JAG accredited. 74 per cent of private providers have not been assessed compared with only seven per cent of NHS acute hospitals.

In England, commissioners are increasingly deciding to buy services from private providers who can offer additional capacity and help manage patient overflow. However, as many of these are not accredited, their quality cannot be assured. Private providers must be held to the same standards that apply to NHS providers. It is unacceptable that so many private providers are not engaged with the accreditation process. Every unit, regardless of whether they are NHS providers or private, must meet JAG standards. Patients should not be referred to a unit which is not JAG accredited to have a test that carries risk.

Northern Ireland

JAG accreditation was introduced in Northern Ireland in 2008 and only screening centres have to be accredited. Currently there is one screening centre per trust. This means that only five units out of 17 are engaged with JAG. However only one unit is fully accredited. The remaining four require improvement.

Scotland and Wales

In Scotland and Wales, units are not required to be JAG accredited. To date, only two out of the 20 units in Wales are accredited. In Scotland, Health Improvement Scotland has been assessing all units against the GRS to determine how prepared units are for accreditation. At the time of writing, none of the 46 units in Scotland had met the required standard.

Number of units with JAG accreditation status in the UK

<table>
<thead>
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<th>Number of units with JAG accreditation status in the UK</th>
<th>England</th>
<th>Scotland</th>
<th>Northern Ireland</th>
<th>Wales</th>
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<td>Independent sector</td>
<td>Community unit</td>
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<td>164</td>
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</table>
JAG accreditation must be made mandatory for all units across the UK, including private providers offering NHS services, with a new standard of “outstanding” and a patient assessor present on all JAG visits. Health authorities in the UK must work with units to ensure they receive the support, investment and resources to bring all units up to JAG standards.

A national reporting system should be developed for annual post colonoscopy colorectal cancer rates for each trust or health board in the UK. Units should also be required to identify all PCCRC cases and undertake a root cause analysis on why any cancers and polyps were not detected or removed. Learning from the analysis should be implemented immediately.

The certification process is made compulsory for all newly qualified endoscopists and a national database on individual colonoscopists’ performance data should be made publicly available.
Good quality information is one of the main ingredients for a good patient experience. We hear from people all the time who say that either they wish they had been given better information about what was happening to them, or highlight how important the right information was to making their journey through the health service as easy as possible.

Good, accurate and accessible information can reduce anxiety, ensure a patient feels empowered by their care and is an integral component of achieving good patient experience. It can also bring benefits to the service as information can increase adherence, reduce cancellation rates and ensure bowel preparation is carried out thoroughly beforehand to avoid repeat procedures.
Information

Nearly half of individuals who completed our survey carried out their own online research before they had the test with nearly one in ten admitting that although they did not have all the information they needed, they did not seek out anymore. The reasons for not seeking out more information ranged from being too “scared,” to being too “nervous” or “embarrassed”. There were those who were not given enough information and were unable to carry out their own research due to being in hospital or being admitted for an emergency procedure. Other patients thought that everything would be explained to them on the day of the procedure or did not know that the procedure could detect bowel cancer.

Before an endoscopy

Prior to having an endoscopy, patients should be fully informed of the reason for having the test, what procedure they are going to have, what it will involve and any potential risks of the procedure. They should also be told precisely what will happen after the test.

Many of our survey respondents reported being given the information they needed on why they were having that particular endoscopy and the reasons why they were having that specific test. However for a small number of our respondents, information on what the test would look for, why their particular symptoms meant they had to have the test or the difference between the tests was lacking.

“I was attending a consultation and they decided there and then to do the sigmoidoscopy, they only said they were going to look - not what for or too much detail of what it involved.”

survey respondent

There were also issues relating to people not fully understanding what the procedure would involve physically, what the side-effects and risks of the procedure would be, and in some cases that a diagnosis of cancer was even possible.

“I didn’t understand that there was a high probability that I might come face to face literally with my own mortality when the camera came across a nasty looking tumour.”

survey respondent
Encouragingly, over 90 per cent of individuals said they were given clear instructions on bowel preparation and that they fully understood that information. However nearly one in ten said that either they did not receive clear instructions or that they did not fully understand the instructions given. In particular they did not understand what bowel preparation would involve physically, how long it would take or why they had to prepare their bowel.

Why is bowel preparation important?

Bowel preparation involves taking laxative medicines in the days leading up to an appointment to ensure the bowel is well cleaned, so the endoscopists can clearly see the bowel wall. Inadequate bowel preparation can reduce polyp detection and increase incomplete procedure rates. One study, which analysed over 12,000 colonoscopies, found that of the 198 adenomas identified, half of these were found during a repeat colonoscopy that took place after inadequate bowel preparation, and of these adenomas, 27 per cent were advanced. This is why JAG standards dictate that units should be achieving at least 90 per cent adequate or excellent bowel preparation.

Adherence to the bowel preparation process requires patients receiving good quality information on the preparation process and the importance of preparing the bowel for an endoscopy procedure.

After the endoscopy

One in five respondents to our survey did not fully understand or were given no information on what would happen after the endoscopy. Many of these did not understand what the long-term side-effects might be, whether anything had been found, the results of the endoscopy or that their bowel habit might be affected after the test. Importantly, some individuals were informed that they have cancer but were not given information on what is likely to happen next. If a patient is given a diagnosis of cancer they must be informed of every next possible step at that point and must be given details of their next point of contact, with support made readily available.

When asked what they would have liked to know before or after having the test:

- One in four would have liked more information on the potential side-effects of having an endoscopy
- One in five would have liked more information on what an endoscopy would involve and what to expect
- One in ten would have liked more information on why they were having the test
Empowering patients

“Most of the information provided was in leaflet form, it would have been good to have a nurse to talk to after the procedure to explain what happens next.”

survey respondent

Patient experience

Capturing patient experience and learning from it is vital if services are to make improvements where it matters most to patients. JAG standards require units to give patients the ‘ability to provide feedback to the service’. Disappointingly, our research found that despite this, nearly 80 per cent said they were not asked about their experiences of having the test.

Many respondents cited the level of pain and discomfort felt as the reason why they did not have a good experience of having an endoscopic test. In some cases, patients were refused a sedative despite asking for one, were unable to be sedated, were not offered pain relief or the pain relief did not have an effect. It is not acceptable that people are in pain when having the test. Patients should be informed of the advantages and disadvantages of sedation and allowed to make the choice of whether to be sedated or not.

Percentage of patients who were asked about their experience of having the test

The BSG guideline for safety and sedation during an endoscopic procedure suggests that sedation, alongside adequate pain relief and sympathetic patient management can improve both patient tolerance and acceptance and increase the technical success of the procedure.

“I asked if I needed to take any preparation and was told no. I asked if I would be sedated and was told this was not necessary. The test was the most painful experience ever (it transpired I had developed proctitis) and, on reading my notes afterwards, it stated I had refused to take prep or sedation...untrue.”

survey respondent

“I was misled about the experience and what to fully expect. A backlog of cases meant the sedation I had meant to receive was not administered appropriately in the rush to fit every one in within the designated timeslot. I experienced excruciating pain throughout the procedure and was not able to understand why this was acceptable to the staff on duty.”

survey respondent
We urge both providers and commissioners of endoscopy services to listen to patients and make good quality and relevant information in accessible formats available to people both before and after a test.

We believe that all units should seek to collect patient feedback on a regular basis and that all patients should be asked about their experience of undergoing the procedure. This feedback should be acted upon and used to change service delivery.

"Within minutes of the test I was ushered into a side room and informed I had cancer. A consultant promptly drew on a sheet of A4 paper where the tumour was and how much of my bowel would be removed. He appeared to think I was expecting this information. I was then left to find my way out of the department and go home. I was in a state of shock."

survey respondent

"Although the test itself was no problem I was told that it would not be possible to know if cancer was present until biopsy was completed. However, I could tell from the nurse’s manner that it was cancerous and this was confirmed by phone call made in error from my GP’s surgery later that afternoon. This was not a good experience."

survey respondent
Whilst overall there has been remarkable progress in the delivery of our endoscopy services, this report highlights serious problems. In some areas, people are being let down by the service with referral criteria, waiting times and quality of procedures being the key issues identified, it is imperative that these issues are resolved. Greater up-front investment is required to deal with the expected increase in demand, whilst also ensuring that the right patients are being referred, that patients are seen on time and that procedures are carried out to a high standard.

That is why, to bring about the improvements to endoscopy services that are needed, we are calling for the following recommendations to be implemented. We hope that all UK governments will act on these recommendations and implement them as a matter of urgency.

**Recommendations**

01 **The right test**

- Further research needs to be carried out on what symptoms should trigger which test. This would ensure there is greater clarity and guidance to help clinicians refer patients for the right test and help patients understand why they are being referred for a particular test.
- Barium enema should be ruled out as a diagnostic test for bowel cancer. CT colonography should be a viable option for those who are unable to have a full colonoscopy. This means that greater investment is needed to ensure radiologists are trained and experienced to carry this procedure out to a high standard across the UK.

02 **Changing demand**

- Every health body should have a named individual with responsibility for the management of hereditary colorectal cancer, ensuring accurate risk assessment and appropriate screening, maintaining a patient registry, and developing links with regional clinical genetics centres. Regular audit of those who require surveillance due to IBD or a previous diagnosis of bowel cancer is also needed to ensure the quality of this type of surveillance.
- The urgent development of a quality standard for colonoscopic surveillance. A quality standard which outlines what constitutes best practice in relation to the appropriateness of colonoscopic surveillance, frequency, risk groups and method for high-risk individuals would contribute to improving the effectiveness, quality and patient experience of the procedure, as well as ensuring variation in clinical practice is minimised.
All endoscopy units should proactively and regularly monitor their demand to ensure effective capacity planning. Units need to ensure there is sufficient room and staff availability, that equipment such as endoscopes are available when needed, that the right staff are on site and ready to start on time and that patients are fully informed and prepared. Difficulties in these areas will impact on the ability of units to effectively manage their demand.

Patients waiting beyond six weeks for surveillance procedures should be included in the monthly diagnostic returns to allow for greater transparency and push forward improvements in waiting times.

JAG accreditation must be made mandatory for all units across the UK, including private providers, with a new standard of “outstanding” and a patient assessor present on all JAG visits. Health authorities in the UK must work with units to ensure they receive the support, investment and resources to bring all units up to JAG standards. A national reporting system should be developed for annual post colonoscopy colorectal cancer rates for each trust or health board in the UK. Units should also be required to identify all PCCRC cases and undertake a root cause analysis on why any cancers and polyps were not detected or removed. Learning from the analysis should be implemented immediately.

The certification process is made compulsory for all newly qualified endoscopists and a national database on individual colonoscopists’ performance data should be made publicly available.

We urge both providers and commissioners of endoscopy services to listen to patients and make good quality and relevant information in accessible formats available to people both before and after a test.

We believe that all units should seek to collect patient feedback on a regular basis and that all patients should be asked about their experience of undergoing the procedure. This feedback should be acted upon and the results placed in the public domain.
References

3. Colorectal cancer survival by staging data briefing, National Cancer Intelligence Network (2009)
6. Letter from Professor Mike Richards, Re. Be Clear on Cancer Campaign, 8 December 2011
7. Third annual report, Improving outcomes, a strategy for cancer, Department of Health (2013)
10. ibid
12. Routes to diagnosis, National Cancer Intelligence Network (2009)
15. ibid
17. Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups (update from 2002), British Society of Gastroenterology (2010)
18. ibid
20. A national survey of hereditary colorectal cancer services in the UK, Monahan and Clark, Frontline Gastroenterology (2013)
21. Routes to diagnosis, National Cancer Intelligence Network (2010)
22. Improving outcomes: a strategy for cancer – first annual report, Department of Health (2011)
30. Freedom of information request, Western Trust (2013)
31. BSG Quality and Safety Indicators for endoscopy, British Society of Gastroenterology (2007)
32. A composite measure of colonic intubation (CIRC) is better able to distinguish performance of colonoscopy and is associated with higher polyp detection rates, Endoscopy, Valori, R et al (2014)
33. Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups, British Society of Gastroenterology (2009)
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