Better bowel cancer care in Scotland

October 2013
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Foreword

The incidence of bowel cancer in Scotland is high and outcomes are poor compared with other countries in the UK and around the world.

For a number of years, Beating Bowel Cancer has received reports from patients in Scotland who have had difficulty accessing the best services for them – whether it be the drug that their clinician wishes to prescribe or receiving the support of a bowel cancer clinical nurse specialist.

We are keen to ensure that all bowel cancer patients receive high quality services, improving their outcomes and experience along the way. This report makes an assessment of recent progress, setting out whether cancer plans and strategies in Scotland have had the desired impact. It also makes recommendations on how things could be improved.

We are calling for better publication of data on bowel cancer in Scotland, a speedy review of access to newly licensed treatments and the introduction of measures to improve bowel cancer screening. Beating Bowel Cancer is committed to working with the local NHS, parliamentarians and the Scottish Government to identify the best way to implement these changes.

By working together, we will be able to improve the lives of the 4,000 patients that are diagnosed with bowel cancer every year in Scotland.

Mark Flannagan
Chief Executive, Beating Bowel Cancer
Executive summary and recommendations

Bowel cancer places a significant burden on the health service in Scotland. It affects 4,000 patients each year but people are still being diagnosed too late and long-term survival is poor\(^1\). Furthermore, Beating Bowel Cancer hears from patients who are not receiving the support or services that we would like to see delivered.

Our research has identified that implementation of policies to date has not been good, nor are there appropriate monitoring systems in place to record and publish data on the performance of the local NHS in delivering against these policies. Beating Bowel Cancer is concerned that, without prompt action, patients will continue to receive substandard services.

It is only by working together that we will be able to improve outcomes for patients across Scotland. This report undertakes an assessment of existing policies on cancer in Scotland and makes recommendations for how services and outcomes can be improved.

Our recommendations are:

**Incidence, mortality and survival**

Recommendation 1: The Scottish Government should review the data that are currently available on bowel cancer and put systems in place to ensure they are published in a timely manner.

**Reducing risk and early diagnosis**

Recommendation 2: The Scottish Government should continue to take action on the well-known bowel cancer determinants – obesity, diet and nutrition. Population-wide public health interventions should be developed and rolled out across Scotland.

Recommendation 3: The Scottish Government should consider monitoring data on referrals from primary care for bowel cancer diagnosis, routes to diagnosis and stage at diagnosis to monitor progress and identify areas where service improvements are needed.

Recommendation 4: Healthcare Improvement Scotland should increase its target and aim for bowel cancer screening participation of at least 75% in order to identify more patients at a stage where their cancer can be treated. Particular efforts need to be made to ensure that rates of involvement in screening improve among men and in areas of higher social deprivation.

Recommendation 5: The Scottish Government should support the roll out of a flexible-sigmoidoscopy screening programme in Scotland without delay, including setting firm timelines for its introduction.

Recommendation 6: NHS Scotland should take steps to improve referral to secondary care for bowel cancer patients, particularly among those patients who are diagnosed through the Scottish Bowel Cancer Screening Programme, to support the achievement of waiting times targets for all patients.
Improving the quality of bowel cancer care

Recommendation 7: Data on performance against bowel cancer quality performance indicators should be published and broken down to a local level to allow comparison across NHS Health Boards.

Recommendation 8: Supportive care measures should be put in place to ensure that patients are given the information and support they need to make informed decisions about their care.

Recommendation 9: The Bowel Cancer National Audit should be rolled out across Scotland and incentives should be put in place to encourage NHS health boards to supply information.

Ensuring better treatment

Recommendation 10: Following the publication of the Scottish Medicines Consortium review and the Individual Patient Treatment Requests review, the Scottish Government must implement measures without delay that ensure bowel cancer patients in Scotland have full and equal access to drug treatments they require.

Recommendation 11: Bowel cancer patients should be offered the option of laparoscopic surgery and in order to support this, data should be collected and published on the number of bowel cancer patients undergoing laparoscopic surgery across all NHS health boards.

Recommendation 12: The Scottish Government should introduce a new system to ensure that all patients in Scotland get access to radiotherapy, where appropriate. This should take into account the specific challenges of delivering radiotherapy for people in rural areas.

Enhancing patient experience

Recommendation 13: A comprehensive cancer patient experience survey should be rolled out in Scotland to allow an assessment of the full extent of the quality of treatment and care for cancer patients.

Recommendation 14: A review of the performance of regional cancer network bowel cancer activities should be undertaken to identify innovative aspects in care and treatment that have been introduced at a regional level and this information should be shared across all networks in Scotland.

Recommendation 15: Training for healthcare professionals should be put in place to improve the support provided to patients with bowel cancer on how to manage their condition. This could be managed by NHS Education for Scotland.

Recommendation 16: Every bowel cancer patient should have access to a clinical nurse specialist. Data on the caseload of clinical nurse specialists for cancer should be collected and published to enable benchmarking of access for patients with bowel cancer across NHS health boards.
Introduction

Bowel cancer is a major public health concern in Scotland. It is the third most commonly diagnosed cancer in both men and women with almost 4,000 new cases diagnosed each year. 95% of cases occur in people over 50². Future projections of the prevalence of bowel cancer in Scotland suggest that there will be a 20% increase between 2013 and 2017³.

Over a quarter of the people diagnosed with bowel cancer in Scotland will die from the disease each year⁴, yet bowel cancer can be beaten if diagnosed early. Over 90% of patients diagnosed with early stage bowel cancer will survive five years from diagnosis compared to less than 7% of patients diagnosed with late stage disease⁵.

Scotland fares poorly in relation to five year survival compared with the rest of the world. For the period 2003-2007, five year survival in Scotland was 54.9%⁶. This compares with 62% in Norway, 62.6% in Sweden and 65.9% in Australia⁷.

A number of Scottish Government initiatives have been launched in recent years, including Better Cancer Care: An Action Plan published in 2008 and the Detect cancer early campaign launched in 2011. However, a lot remains to be done. The Scottish Government is yet to take decisive action to improve access to bowel cancer treatments; bowel cancer screening participation is less than 55%⁸, patient choice is not yet at the heart of rhetoric around bowel cancer services and the provision of data to monitor bowel cancer services is poor.

Beating Bowel Cancer is firmly committed to improving bowel cancer outcomes for all people in Scotland. We will contribute to on-going reviews of access to treatment issues in Scotland through the Health and Sport Committee’s review of access to newly licensed medicines and the Scottish Government’s review of medicines assessment processes that is currently being led by Professor Routledge.

This report presents an analysis of bowel cancer in Scotland – it sets out data on the impact of bowel cancer in Scotland, assesses measures by the Scottish Government to tackle the disease and makes recommendations of where improvements could be made.
Incidence, mortality and survival rates for bowel cancer in Scotland

Incidence

Scotland has the highest bowel cancer incidence rate in the UK\(^9\). Figure 1 shows the incidence rate for bowel cancer in Scotland from 2005 to 2010. Incidence of bowel cancer reached a peak in 2009 of 55.2 per 100,000 people, falling to 54.5 per 100,000 in 2010.

Figure 1: Incidence rates for bowel cancer in Scotland, 2005-2010\(^{10}\)

Incidence rates in Scotland are considerably higher for men at 66.6 per 100,000 compared to women at 42.3 per 100,000. Overall, however, incidence rates have been stabilising for men and falling for women in recent years\(^{11}\). There also appears to be higher incidence for both men and women from socially deprived backgrounds\(^{12}\), thus highlighting inequalities in bowel cancer incidence.

Figure 2 illustrates the incidence rates for bowel cancer across NHS boards in Scotland. It depicts wide ranging regional variation, with NHS Western Isles reporting the highest incidence rate at 76 per 100,000, nearly double the level of NHS Orkney which reported the lowest at 38.1 per 100,000\(^{13}\).
Mortality

Figure 3 illustrates mortality rates for bowel cancer in Scotland from 2005 to 2010. As the graph shows, mortality rates have been falling since 2005 with the relative number of deaths attributed to bowel cancer decreasing from 21.9 per 100,000 in 2005 to 19.1 per 100,000 in 2010\(^\text{15}\).

Figure 3: Mortality rates for bowel cancer in Scotland, 2005-2010\(^\text{16}\)

Notes: directly age-standardised using the European standard population.

Figure 4 illustrates mortality rates for bowel cancer across NHS boards in Scotland. As with the incidence rate, there is regional variation across NHS boards. NHS Shetland reports the highest mortality rate at 21.4 per 100,000 people, while the mortality rate in NHS Western Isles is 15.5 per 100,000\(^\text{17}\).
Survival

Survival is a key indicator of the overall effectiveness of health services in the management of patients with cancer. For bowel cancer, the most commonly used indicators to effectively measure survival rates are one and five year survival rates. Figure 5 shows one and five year relative survival rates for bowel cancer in Scotland. There was a significant improvement between 1983 to 1987 and 1998 to 2002, although progress appears to have stalled by the latest period for which figures are available (2003-2007).
Figure 6 shows that one year survival is broadly similar between men and women\textsuperscript{21}. It also shows that the five year survival rate for women is slightly higher than that for men, although the gap between the sexes has narrowed in recent years.

**Figure 6: One and five year relative survival for men and women over time\textsuperscript{22}**

Making data available is key to ensuring an up-to-date understanding of the incidence of bowel cancer. Some data that are used in this section are a number of years old so it is important that the Scottish Government works with Information Service Division Scotland to ensure that data are made available in a timely manner.

**Recommendation 1:** The Scottish Government should review the data that are currently available on bowel cancer and put systems in place to ensure they are published in a timely manner.
Reducing risk and improving early diagnosis

Reducing Risk

Bowel cancer is a major public health issue in terms of both primary and secondary prevention. Lifestyle factors can affect an individual’s risk of getting bowel cancer. Although the risk of bowel cancer can never be eliminated, by living healthier lifestyles the risk can be significantly reduced. Promoting healthier lifestyles is therefore a key part of beating bowel cancer. To reduce the risk of bowel cancer, individuals should eat a healthier diet with less alcohol and red meat and take regular exercise. These actions have been shown to reduce bowel cancer risk by almost 50%.

Scotland has one of the highest levels of obesity in the developed world with over a million adults and over 150,000 children who are obese and this is predicted to worsen with adult obesity levels reaching over 40% by 2030. In addition, Scotland has the highest level of alcohol consumption in the UK.

Lowering people’s risk of cancer is very important if we are to reduce the number of people who develop bowel cancer. The Scottish Government and NHS Health Scotland have introduced a number of measures to tackle these issues, including Preventing Overweight and Obesity in Scotland: a Route Map towards Healthy Weight and Changing Scotland’s Relationship with Alcohol: A Framework for Action.

Beating Bowel Cancer is committed to promoting healthy lifestyles and reducing people’s risk of developing bowel cancer. By raising awareness of bowel cancer and the need to lead a healthy lifestyle to reduce the risk of developing the disease, we hope to reduce the number of people who develop bowel cancer. It is vital that the Scottish Government supports this activity and targets its initiatives at those who are most at risk.

Recommendation 2: The Scottish Government should continue to take action on the well-known bowel cancer determinants – obesity, diet and nutrition. Population-wide public health interventions should be developed and rolled out across Scotland.

Ensuring early diagnosis

When bowel cancer is diagnosed early, patient outcomes improve significantly. Improving the percentage of early stage diagnoses will help to reduce premature deaths from bowel cancer. One of the key challenges in bowel cancer is therefore ensuring earlier diagnosis. There are three elements to this:

- Raising awareness of signs and symptoms so that patients present earlier
- Ensuring primary care medical staff take the concerns of patients presenting with symptoms seriously and refer them for testing where appropriate
- Improving screening and diagnostics to ensure that bowel cancer is swiftly and accurately identified when present

Research in the British Journal of Cancer found that 6% of people died within 30 days of being diagnosed with bowel cancer in Scotland between 2003 and 2007, yet bowel cancer is beatable if
it is diagnosed at an early stage. More than 93% of patients diagnosed with early stage bowel cancer will survive five years from diagnosis compared to just 6.6% of patients diagnosed with late stage disease.\(^{28}\)

**Raising awareness of signs and symptoms and improving referral**

Raising awareness of the signs and symptoms of bowel cancer is vital to ensuring earlier diagnosis. People who are aware of what to look for are more likely to visit their GP for referral, before their cancer has reached an advanced stage.

It is encouraging that the Scottish Government invested £30 million in a new early diagnosis campaign in 2011. The national Detect cancer early campaign was launched to improve early diagnosis for the three most common cancers in Scotland – breast, bowel and lung cancer.\(^{29}\)

The aim of the programme is to save more than 300 lives a year by increasing the number of people diagnosed in the earliest stages of the disease.\(^{30}\) The campaign seeks to:

- raise public awareness of the signs and symptoms of cancer and the need to participate in screening programmes
- improve GP referral processes
- augment diagnostic and screening capacity
- increase early referral\(^{31}\)

Beating Bowel Cancer welcomes these measures and would urge the Scottish Government to undertake the proposed assessment of the effect of advances in diagnostics and social marketing policies and further horizon scanning in order to deliver five year survival improvements.\(^{32}\)

There is also a role for pharmacies in advising patients about the signs and symptoms of bowel cancer. Beating Bowel Cancer has worked with the Royal Pharmaceutical Society in Scotland to provide written information about bowel cancer and bowel cancer screening that they can share with members of the public.\(^{33}\)

Currently collection and publication of data in Scotland on routes to diagnosis, stage at diagnosis and consequent survival is poor. This means that there is a lack of data on the proportion of bowel cancer patients who are diagnosed as an emergency. This is critically important as evidence shows those who present as emergencies are likely to have more developed cancer and poorer outcomes.\(^{34}\)

The data that should be made available include:

- the proportion of referrals from primary care that result in a diagnosis of bowel cancer
- routes to diagnosis data to highlight the proportion of bowel cancer patients diagnosed via screening, urgent referral and emergency admission
- stage at diagnosis
Publication and analysis of these data would allow the NHS and the Scottish Government to monitor progress with the Detect cancer early campaign and to identify areas where improvements to services are needed.

**Recommendation 3:** The Scottish Government should consider monitoring data on referrals from primary care for bowel cancer diagnosis, routes to diagnosis and stage at diagnosis to monitor progress and identify areas where service improvements are needed.

**Bowel cancer screening**

The Scottish Bowel Cancer Screening Programme is available in all NHS boards. All men and women aged between 50–74 years are invited to participate and to be screened every two years and a new Government announcement has now extended the programme to cover people over 74 years. Beating Bowel Cancer welcomes this new development. In addition, Beating Bowel Cancer is pleased that screening is available for patients in Scotland from the age of 50 as evidence suggests that the number of patients developing bowel cancer at an earlier age than 50 is increasing.

A review of the programme from November 2009 to October 2011 reported that overall uptake was 54.5%, a rise of 0.8% compared with the two year period November 2008 to October 2010. Uptake for females was 57.9% and uptake for males was 51.0%. This means uptake is still below the minimum threshold of 60% set by Health Improvement Scotland with rates even lower in areas of higher deprivation. For example, men in the most deprived quintile have a participation rate of less than 40%. Participation is significantly lower than in other screening programmes such as for breast and cervical cancer where participation is at 75% and 73% respectively.

While there has been progress in moving towards this target of 60% uptake, much more needs to be done to improve uptake, particularly amongst men and socially deprived groups.

Figure seven depicts the marked regional variation in participation in the screening programme in NHS boards across Scotland, with NHS Lanarkshire reporting the lowest uptake for both men and women at 44.2% and 50.9% respectively.
Overall 2.5% of people who complete the screening test receive a positive result, the highest positive screening test result rates for both men and women were in NHS Lanarkshire and NHS Greater Glasgow respectively.

A combined approach should be taken to encourage participation in the bowel cancer screening programme, the Detect cancer early initiative should support this. Beating Bowel Cancer urges Healthcare Improvement Scotland to raise its expectations of participation to encourage NHS boards to take a more proactive approach to improving participation, and meet the 75% standard of the best-performing screening programme in Scotland.

**Recommendation 4:** Healthcare Improvement Scotland should increase its target and aim for bowel cancer screening participation of at least 75% in order to identify more patients at a stage where their cancer can be treated. Particular efforts need to be made to ensure that rates of involvement in screening improve among men and in areas of higher social deprivation.

In 2010, research found that flexible-sigmoidoscopy screening, a one-off test, which detects bowel polyps and cancers early before any symptoms develop, could reduce deaths from the disease by 43%, and the incidence of bowel cancer by one third, when carried out once in those aged between 55–64 years.

In November 2012, the Scottish Government stated that it had “been working closely with experts to consider the benefits of flexible sigmoidoscopy technology within an already screened population”. It announced that £2 million has been set aside to undertake a feasibility pilot.

Given the significant impact it can have, it is disappointing that the Scottish Government has yet to make a firm commitment to roll-out this screening across Scotland. The Scottish Government should
take immediate action on this issue to ensure that patients can benefit from this effective screening as soon as possible.

**Recommendation 5:** The Scottish Government should support the roll out of a flexible-sigmoidoscopy screening programme in Scotland without delay, including setting firm timelines for its introduction.

**Waiting times**

Scotland’s *Better Cancer Care* action plan[^49] established targets for waiting times in Scotland, these included:

- Extending the 62-day urgent ‘referral to treatment’ target to include patients that had had a positive cancer screening test and to all patients referred urgently with a suspicion of cancer
- Introducing a new 31-day target for all patients diagnosed with cancer from decision to treat to treatment, whatever their route of referral
- Ensuring that a minimum threshold of 95% of all eligible patients waited no longer than the above targets[^50]

The most recent data on waiting times from July to September 2012 illustrate that, across Scotland, of those patients who were suspected of having cancer, 94.0% started treatment within 62 days of urgent referral and 97.6% of patients started treatment within 31 days of decision to treat, regardless of the route of referral[^51].

However, the picture for patients with bowel cancer is more mixed. According to the latest statistical information on cancer waiting times the number of patients seen within 62 days of being urgently referred from the bowel cancer screening programme was 84.0%, significantly less than the 95% target, although more positive progress was reported against the 31-day standard, where 100% of people who participated in the breast screening programme were referred for treatment within the target time[^52].

**Recommendation 6:** NHS Scotland should take steps to improve referral to secondary care for bowel cancer patients, particularly among those patients who are diagnosed through the Scottish Bowel Cancer Screening Programme, to support the achievement of waiting times targets for all patients.
Improving the quality of bowel cancer care

Improving the quality of bowel cancer care will help to ensure that not only do patients have a better experience but also that better outcomes are achieved. This was at the heart of Better cancer care and in 2010 the NHS Scotland Healthcare Quality Strategy was published, setting out three quality ambitions for the NHS in Scotland. These included:

- Mutually beneficial partnerships between patients, their families and those delivering healthcare services to ensure needs are met and values are respected and support shared decision-making
- Patients do not suffer from avoidable harm or injury from the healthcare they receive and are always treated in an appropriate, clean and safe environment
- The most appropriate treatments, interventions, support and services will be provided to patients at the right time, with no regional inequalities

Beating Bowel Cancer is keen to ensure that these ambitions lead to better care for patients with bowel cancer.

Quality in bowel cancer care

To support delivery of both Better cancer care and the healthcare quality strategy, a National Cancer Quality Steering Group was established. The primary function for this group was to develop quality performance indicators (QPIs) and oversee the implementation of the governance framework for these indicators. To date, Healthcare Improvement Scotland has published QPIs for breast, renal, prostate and hepatopancreatobilary cancers.

NHS Scotland consulted on draft QPIs for bowel cancer during summer 2012. The consultation focused on twelve suggested indicators that spanned diagnosis, radiotherapy, surgery, chemotherapy and stoma care. The draft QPIs also included details of how the indicators would be measured and set out targets that NHS bodies should aim to meet.

Beating Bowel Cancer welcomes the development of these indicators and would urge adoption without delay. Measurement against these indicator targets will be key to ensuring that performance is improved at a local level. These data should be published and broken down by local authority level to allow benchmarking of NHS health board performance.

Recommendation 7: Data on performance against bowel cancer quality performance indicators should be published and broken down to a local level to allow comparison across NHS Health Boards.

However, there are areas of the bowel cancer pathway that do not appear to feature in the QPIs, for example, no mention is made of end of life care. The consultation document states that multi-disciplinary team management of patients with liver only metastases and KRAS genetic biomarker testing for all patients with liver only metastases are areas that will be considered in future. Yet, no mention has been made of when these areas might be considered and what information sources might be used to inform future decisions about their inclusion. The QPIs must be reviewed on a regular basis to ensure that they remain relevant and to identify any gaps.
Beating Bowel Cancer also believes that supportive care should be implemented alongside QPIs so that patients receive the support they need to manage their condition. It is encouraging that the Living with Cancer Group has developed an action plan to address these issues. Joint working between healthcare, social care and voluntary sector providers will be key to ensuring patients with bowel cancer receive the information and support they need.

In addition, there are several decision points throughout the bowel cancer pathway such as the choice between open and laparoscopic surgery, between different types of chemotherapy or where to go for treatment. Bowel cancer patients must be supported to make informed choices about their care and treatment at all stages.

**Recommendation 8: Supportive care measures should be put in place to ensure that patients are given the information and support they need to make informed decisions about their care.**

**The role of data and clinical audit**

National clinical audits, such as the National Bowel Cancer Audit in England, are known to drive up quality in cancer services. To date, only the South East Scotland Cancer Network has participated in the audit and Beating Bowel Cancer would urge other cancer networks to contribute data to the audit. It is encouraging that steps have been taken by NHS Scotland to review the resources available to undertake audits of NHS care, this should enable NHS health boards to participate in the audit and increase the information available on bowel cancer services in order to improve patient care.

Beating Bowel Cancer welcomes the current focus on developing a sustainable data repository for cancer audit data. We support measures that will improve the timeliness and availability of data on bowel cancer. Our Bowel Cancer Map was launched in 2011 and we want to build on this so that patients, carers and NHS organisations can access data on bowel cancer and use it to inform their decisions.

**Recommendation 9: The Bowel Cancer National Audit should be rolled out across Scotland and incentives should be put in place to encourage NHS health boards to supply information.**
Ensuring better treatment

Improving access to, and uptake of, bowel cancer treatments is a priority for Beating Bowel Cancer. Patients with bowel cancer may be offered a variety of treatment options as part of their care plan, including surgery, chemotherapy, radiotherapy and drug treatment\(^64\). Although the clinical evidence for the use of these treatments is clear, not all patients are able to access the treatments that their clinicians wish to prescribe.

Drug treatments

New treatments have transformed the survival prospects of bowel cancer patients. However, while the quality of care and outcomes for bowel cancer patients have improved, Beating Bowel Cancer is concerned that the UK, including Scotland, still lags behind Europe in terms of survival and access to medicines\(^65\).

Beating Bowel Cancer regularly hears from patients in Scotland who have not been able to access the drugs that their clinicians wish to prescribe. These patients’ experiences are backed up by research from the Rarer Cancers Foundation which found that there has been limited progress in Scotland to reduce regional inequalities in access to cancer drugs\(^66\).

The Scottish Government has published some national guidelines on the issue of access to newly licensed drugs. These have included CEL 17: Introduction and Availability of Newly Licensed Medicines in the NHS in Scotland, published in 2010, which set out that NHS boards should align local policies and ensure consistency of approach on access to medicines\(^67\). CMO 1: Guidance to further strengthen the safe and effective use of new medicines across the NHS in Scotland was published in February 2012. This guidance provided greater clarity on making Scottish Medicines Consortium (SMC)-approved medicines available and measures to assist NHS boards in making local decisions on access to treatments\(^68\). Of particular interest to Beating Bowel Cancer, this guidance set out the need for peer support in the consideration of individual patient funding treatment requests and the need for NHS boards to publish examples of good practice\(^69\).

However, national guidelines to support fair individual patient treatment requests (IPTR) have not had the desired impact on access for patients in Scotland. Our experience suggests that national guidance on local decision-making processes is not sufficient and that there are still unacceptable regional inequalities in access to treatment in Scotland\(^70\). Although we recognise that the Cancer Drugs Fund model in England is not perfect, it has benefited 23,000 cancer patients to date\(^71\).

Research from the Rarer Cancers Foundation has shown that there are now 23 treatments that are not routinely available in Scotland which may be available in England through the Cancer Drugs Fund. As a result, people in Scotland are now more than three times less likely to gain access to a cancer drug, which is not routinely funded, than people in England\(^72\).

Beating Bowel Cancer has welcomed the ongoing inquiry from the Health and Sport Committee in the Scottish Parliament into access to newly licensed medicines and awaits its recommendations with interest.
A significant step forward came in November 2012 when Health Secretary, Alex Neil MSP, announced that there will be a review of “every aspect of the introduction of new medicines from national advice to local decision-making to establish whether any further improvements can be made”. There are two main strands to the review:

- Professor Philip Routledge will review current new medicines assessment processes of the SMC against those of similar organisations elsewhere, to see if there are any areas of good practice that Scotland could learn from.
- Chief Pharmaceutical Officer, Professor Bill Scott, in cooperation with Professor Charles Swainson, will assess how the SMC’s decisions are implemented by NHS boards to ensure there is a consistent and effective approach to prescribing policies across the country, including IPTRs to establish whether any further improvements can be made.

This review presents potential for the situation in Scotland to be improved. It is untenable that patients with bowel cancer in Scotland are not benefiting from the drugs that their clinicians wish to prescribe, simply due to the Scottish Government’s current policies. With the both reviews expected to report back to the Health Secretary shortly, we would encourage the Scottish Government to implement any proposed recommendations to improve the current system without delay.

Furthermore, the Scottish Government recently announced the establishment of a £21 million Rare Conditions Medicines Fund to cover the cost of medicines for rare diseases that have not been accepted for use by the SMC. The new fund will be available from March 2013 until the introduction of value-based pricing expected in January 2014. While Beating Bowel Cancer welcomes the development of the new fund, we hope that bowel cancer patients will be able to benefit from this opportunity to access innovative treatments.

**Recommendation 10: Following the publication of the Scottish Medicines Consortium review and the Individual Patient Treatment Requests review, the Scottish Government must implement measures without delay that ensure bowel cancer patients in Scotland have full and equal access to drug treatments they require.**

**Surgery**

Surgery forms a significant proportion of treatment for patients with bowel cancer. In Scotland, more than 75% of those diagnosed with bowel cancer between 2001 and 2005 had an operation as part of their treatment. There have been significant advances in surgical techniques in recent years, which means that patients may have the opportunity to have less invasive types of surgery such as laparoscopic surgery.

Beating Bowel Cancer believes that all patients should have an option in the type of surgery they are offered, including laparoscopic surgery, while also ensuring that patients can access the most up to date surgical techniques delivered by appropriately trained surgeons. As a result of Better cancer care, NHS Education for Scotland (NES) has undertaken a review of laparoscopic colorectal surgery and a clinical skills board has been established in Dundee for all laparoscopic surgical techniques, including colorectal surgery. A training course has also been developed.
Beating Bowel Cancer welcomes the focus on training and development of skills in laparoscopic surgery, which are key to ensuring that this surgery is only performed by those who are qualified to do so. It is currently difficult to ascertain the extent to which patients in Scotland are able to access this type of surgery and Beating Bowel Cancer would urge the Scottish Government to improve the collection and publication of data on laparoscopic surgery. Making these data available at a local level should drive greater access as it would highlight areas where eligible patients are not receiving this surgery.

**Recommendation 11:** Bowel cancer patients should be offered the option of laparoscopic surgery and in order to support this, data should be collected and published on the number of bowel cancer patients undergoing laparoscopic surgery across all NHS health boards.

**Radiotherapy**

The Scottish Government has been looking ahead to radiotherapy capacity since the publication of its report, *Radiotherapy activity planning for Scotland*, in 2005. In that time, there have been additional developments in radiotherapy such as Intensity Modulated Radiotherapy (IMRT) and Image Guided Radiotherapy (IGRT), which will require additional NHS resources.

The delivery of radiotherapy in Scotland takes place in five different centres across the country. Not all centres offer the same type of radiotherapy as different centres have expertise in different radiotherapy techniques. The progress report on *Better Cancer Care* set out that the Scottish Radiotherapy Advisory Group would focus on future demand and capacity planning and undertake a national procurement exercise for the replacement of radiotherapy equipment.

Any challenges in terms of resourcing particularly expensive radiotherapy equipment should not have a negative impact on patient access to these treatments. Beating Bowel Cancer is keen to ensure that all eligible patients get access to appropriate radiotherapy for their condition, whether it be to shrink a tumour prior to surgery, to destroy cancer cells, or to relieve symptoms.

**Recommendation 12:** The Scottish Government should introduce a new system to ensure that all patients in Scotland get access to radiotherapy, where appropriate. This should take into account the specific challenges of delivering radiotherapy for people in rural areas.
Enhancing patient experience

Enhancing bowel cancer patients’ experiences of care is a top priority for Beating Bowel Cancer. Through our work with patients, along with existing data on patient experience, we know that the support and advice that patients are given can have a major impact on their wellbeing. We have identified the following issues that really matter to patients:

- How long they waited before seeing their GP
- How many visits they made to their GP before referral
- Whether they are offered a choice of treatment
- If they are given information about the choices available to them
- If they are supported to manage symptoms and side-effects
- Integration between hospital and community care

It is important that mechanisms are put in place to capture patients’ views on their experience of care.

Better Together patient experience programme

*Better Together* is a national patient experience programme designed to support NHS boards, frontline staff and patients in driving forward service improvement. Designed to complement many of the actions in *Better cancer care*, the programme publishes an annual survey on inpatient experience. It surveys patients in six specific areas:

- Admission to hospital
- The hospital and ward
- Care and treatment
- Hospital staff
- Arrangements for leaving hospital
- Care and support services after leaving hospital

The survey results provide important feedback on the quality of care patients receive, therefore enabling future improvements to be made. The 2012 *Scottish Inpatient Patient Experience Survey* reported that overall 85% of patients said they felt involved in their care and treatment and reported the care received as excellent or good. However, the survey does not explicitly take into account experiences of bowel cancer patients.

We believe the specific experiences of bowel cancer patients need to be captured to identify areas for service improvement. The *National Cancer Patient Experience Survey* provides a comprehensive picture of the experience of cancer patients in England and the data can be broken down by cancer type and to hospital level. This provides an invaluable resource which can be used to monitor services, to highlight areas where improvements need to be made and to support patients in making informed decisions about where they access care. We would urge the Scottish Government to roll out a similar survey in Scotland to gather data specific to cancer patients’ experience of care.
**Recommendation 13:** A comprehensive cancer patient experience survey should be rolled out in Scotland to allow an assessment of the full extent of the quality of treatment and care for cancer patients.

**Cancer networks**

NHS boards collaborate in planning cancer services through three regional cancer networks: North of Scotland Cancer Network (NoSCAN), South East Scotland Cancer Network (SCAN) and West of Scotland Cancer Network (WoSCAN). Both SCAN and WoSCAN undertake activities dedicated to improving bowel cancer patient outcomes.

**WoSCAN**

The Colorectal Cancer Managed Clinical Network (MCN) was established in 2000 to deliver the best available treatment and care to every patient with colorectal cancer in the West of Scotland. The MCN brings together healthcare professionals from all the various specialities treating bowel cancer, either in a single hospital or across a number of hospital sites, into recognised multi-disciplinary teams (MDTs)79. A clinical audit in 2010 assessed the MDTs and found that the West of Scotland continues to provide a high quality service, with most units meeting the key national standards on leak rates, mortality and the quality of rectal cancer surgery80. One of the key objectives for 2013 is to address both regional and local MDT gaps in bowel cancer in the West of Scotland through a regional audit81.

**SCAN**

SCAN has tumour-specific groups covering nine types of cancer, including bowel cancer. The aims of the SCAN Colorectal Group are to promote the highest standards of cancer care across the region, and ensure equity of access to cancer services across the region, with care delivered locally where feasible and cancer services that fully meet the needs of patients.

Activities such as these should be supported and expanded where they have demonstrated an improvement in care for bowel cancer patients. Good practice needs to be identified and rolled out across Scotland as quickly as possible and networks can have a crucial role in achieving this.

**Recommendation 14:** A review of the performance of regional cancer networks’ bowel cancer activities should be undertaken to identify innovative aspects in care and treatment that have introduced at a regional level and this information should be shared across all networks in Scotland.

**NHS Education for Scotland (NES)**

Healthcare professionals need specific skills and expertise to be able to support patients to play an active role in decisions about their care and to manage their own condition as independently as possible. The NES board is responsible for leading NHS Scotland workforce development, education and training in Scotland. As part of its activities, NES runs **Supporting Self Management**, a learning resource to help healthcare professionals develop the knowledge and understanding to support patients to manage their care. This self management resource has been designed primarily for nurses and allied health professionals to engage with patients and empower them to be involved in
their care. This is an important resource for building relationships with patients and enabling them to take control of managing their disease effectively.

Beating Bowel Cancer believes that further work needs to be undertaken to promote and empower patients to understand and manage their condition. This will contribute to improving bowel cancer patient experience.

**Recommendation 15:** Training for healthcare professionals should be put in place to improve the support provided to patients with bowel cancer on how to manage their condition. This could be managed by NHS Education for Scotland.

**Bowel cancer clinical nurse specialists (CNSs)**

The role of bowel cancer CNSs has demonstrated to improve the experience and outcomes of patients. Better cancer care outlined that CNSs “are often the one constant factor in the patient’s journey and are fundamental to supporting people throughout.” Beating Bowel Cancer believes that it is imperative for all bowel cancer patients should have access to a CNS.

Despite the national recognition for bowel cancer CNSs in Scotland, it is difficult to assess the extent of access to these nurses due to a lack of data. Better reporting would enable charities such as Beating Bowel Cancer to monitor the case load of CNSs and encourage benchmarking between services and NHS boards. This would help to improve service provision and ultimately outcomes for patients.

**Recommendation 16:** Every bowel cancer patient should have access to a clinical nurse specialist. Data on the caseload of clinical nurse specialists for cancer should be collected and published to enable benchmarking of access for patients with bowel cancer across NHS health boards.
References

1 ISD Scotland, Cancer in Scotland (2011), October 2012
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