

# Spotlight on bowel cancer in Wales

Early diagnosis saves lives



## Thank you

We would like to say thank you to a number of people without whom we would not have been able to complete this report: Siobhan McClelland who helped us write the report and the team at Positif, members of the Bowel Cancer UK Medical Advisory Board and patients and carers who have been affected by bowel cancer. We would also like to acknowledge the ease of access to available cancer data in Wales which would not be possible without the work of colleagues at the Wales Cancer Intelligence and Surveillance Unit.

#### **Bowel cancer in Wales**

Bowel cancer is the fourth most common cancer in Wales. Every year more than 2,200 people are diagnosed with bowel cancer and over 900 people die from the disease, making it the second biggest cancer killer. However it shouldn't be, because bowel cancer is treatable and curable if diagnosed early. Nearly everyone diagnosed at the earliest stage will survive bowel cancer but this drops significantly as the disease develops. Early diagnosis really does save lives.

#### **About Bowel Cancer UK**

We are the UK's leading bowel cancer research charity. We are determined to save lives and improve the quality of life for all those affected by bowel cancer. We support and enable research, educate patients, the public and professionals about bowel cancer and campaign for early diagnosis and access to the best treatment and care across the UK.

Find out more at bowelcanceruk.org.uk

## What are we doing in Wales?

Bowel Cancer UK has been carrying out work and providing support in Wales for many years. We are supported by clinicians and researchers across the country who are part of our Medical Advisory Board. We campaign, train healthcare professionals and encourage people to take part in the screening programme. We have great supporters in Wales who fundraise to support improvements in bowel cancer care. In 2017, we appointed our first staff member to drive forward a focused programme of work which will respond to the challenges and opportunities that exist to improve outcomes for bowel cancer patients in Wales.

#### The symptoms of bowel cancer can include:



Bleeding from your bottom and/or blood in your poo



A change in bowel habit lasting three weeks or more



Extreme tiredness for no obvious reason



A pain or lump in your tummy



Unexplained weight loss

Most people with these symptoms don't have bowel cancer. Other health problems can cause similar symptoms. But if you have one or more of these, or if things just don't feel right, visit your GP

## A note from our Chief Executive

Bowel cancer is the fourth most common cancer in Wales and second biggest cancer killer. However, it shouldn't be. The disease is preventable, treatable and even curable. Yet every day, I hear directly from patients who have experienced symptoms but struggle to be referred for diagnostic tests, or get access to these tests as quickly as possible.



I also hear from the clinical community who are having difficulty coping with the increasing demand placed on services. This has to change. The introduction of a bowel cancer screening programme in recent years in Wales has made it possible to both prevent bowel cancer from occurring and also detect it early when it is most treatable and the chance of survival is high. But there is still a long way to go.

Our vision is that by 2050, no-one should die from bowel cancer and to ensure that happens, shining a spotlight on earlier diagnosis is critical.

We are increasing our capacity in Wales to help improve the prompt identification and diagnosis of bowel cancer. We know that there are significant challenges to achieving this, including less than optimal screening uptake and a national crisis in endoscopy capacity. Only by examining these areas can we begin to deliver the best possible outcomes for patients in Wales.

This is our first Wales report and focuses on the particular challenges and opportunities around early detection. I want to pay tribute to the patients who have helped inform this report, many of whom are facing ongoing treatment for their cancer. Their desire to see improvement in cancer care is what drives my team at Bowel Cancer UK.

We are pleased that the Welsh Government, the Wales Cancer Network and the wider NHS have recognised the challenge around earlier diagnosis and through the Cancer Implementation Group, have a stream of work around this aspect of cancer care.

Our role is to support and challenge this agenda; to ensure that improved patient outcomes and experiences are informing and driving clinical improvements and that pace is relentless when it comes to saving lives from bowel cancer.

We invite you to share our vision so that collectively, we take the decisive and swift action needed to ensure that by 2050, no-one dies from bowel cancer.

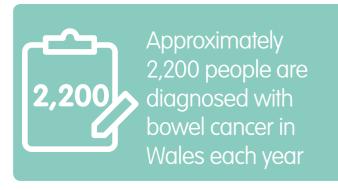
Deborah Alsına

Deborah Alsina MBE Chief Executive, Bowel Cancer UK

## Bowel cancer in Wales

#### **Incidence**

Bowel cancer is the fourth most common cancer in Wales. Approximately 2,200 people are diagnosed with bowel cancer in Wales each year. Based on this figure, by the end of this current Assembly term in 2021, approximately 9,000 more people in Wales will have been diagnosed.



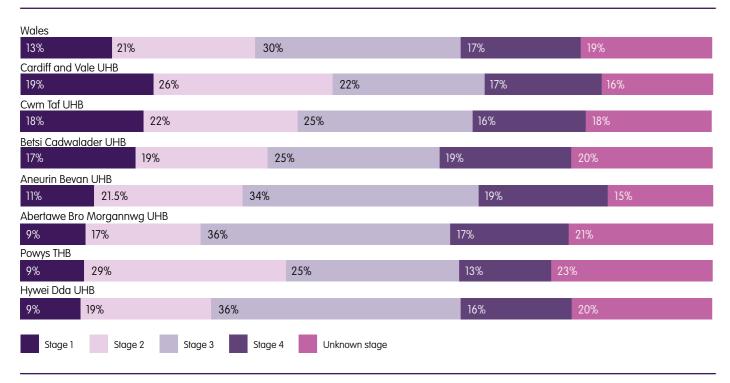
#### **Stage of diagnosis**

Early diagnosis of bowel cancer is crucial because the chance of surviving the disease is closely linked to the stage of cancer. Nearly everyone diagnosed at the earliest stage of the disease (stage 1) will survive. However, survival rates drop significantly for those who are diagnosed at the later stages (stages 3 or 4).

In Wales nearly half those diagnosed with bowel cancer are diagnosed at a late stage. If survival rates for bowel cancer are to improve, then proactive steps must be taken to reduce the proportion of those diagnosed at the later stages of the disease, and opportunities to detect bowel cancer early must be increased.

It is also of concern that for 19% of the population, the stage of bowel cancer at diagnosis is unknown. This information and data is crucial for being able to plan, deliver and improve services. For example, knowing what proportion of people are diagnosed at each stage means we can identify where improvements could be made, to better detect people with the disease and act on this information. There are a number of reasons why the proportion of unknown

Proportion (%) of bowel cancer cases with each stage at diagnosis, by health board of residence (2015)



Credit: Wales Cancer Surveillance and Intelligence Unit

stage is so high, but how data is collected and reported at health board level is a factor. Therefore, to be able to plan and deliver better treatment and care, it is vital that health boards improve the collection, reporting and accuracy of staging data. It is also important that there is continual improvement to the cancer registration system to enable ease of recording data.

### Reasons for unknown stage

- Lack of clinical data to determine stage
- Patient is too ill to be staged
- Transfer of data from different health localities e.g. patients who are diagnosed in England but treated in Wales
- Difficulties with cancer registration process

#### **Mortality**

Approximately 900 people in Wales will die from bowel cancer each year, making it the second biggest cancer killer in the country. This means by the end of 2021 over 3,600 people will die from the disease.

#### **Survival**

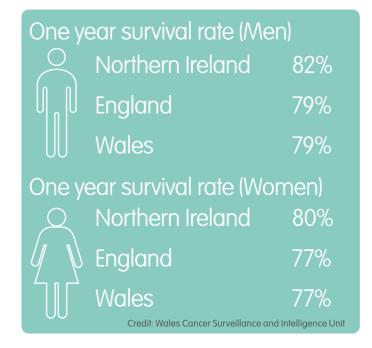
Overall in Wales, 78% of people with bowel cancer survive for one year and 58% survive for five years or more. Yet bowel cancer is treatable and curable, especially if diagnosed early. If survival rates are to be improved, new ways to ensure bowel cancer can be identified at an early stage must be developed and implemented.

Unfortunately, survival rates by health board do not currently exist, but we do know that there are differences in survival rates for bowel cancer across the UK.

International evidence, from the International Cancer Benchmarking Partnership (ICBP) and Eurocare, paints a bleak picture of survival from bowel cancer in Wales in comparison with other developed countries<sup>1</sup>.

Wales ranked 25 out of 29 European countries in five year survival rates for bowel cancer, ranking below countries such as Slovenia, Portugal and Estonia. The ICBP found the UK, in particular Wales, to be at the bottom of one year and five year survival rates in bowel cancer when compared with 13 jurisdictions with similar health care systems.

This is likely to be attributed to systemic problems in NHS Wales, including lifestyle choices, strength of 'gate keeping' systems (GPs and primary care) and late diagnosis.



## Cancer services in Wales

#### **Cancer Delivery Plan**

The key policy direction for cancer in Wales is set out in the Welsh Government's refreshed Cancer Delivery Plan<sup>2</sup>.

Whilst the Cancer Delivery Plan does not explicitly mention bowel cancer, it broadly highlights areas of service improvement and re-design that are needed to deliver lasting improvements in cancer care, patient survival and outcomes.

"We must lead a relentless drive towards earlier diagnosis. This must be one of the primary goals for NHS Wales in the coming years" Cancer Delivery Plan

The Cancer Annual Statement of progress acknowledges the new National Institute for Health and Care Excellence (NICE) guidelines for the recognition and referral of suspected cancer in primary care (2017), which encourages more referrals in the hope that more cancers will be identified at an early stage. At the same time, it recognises that implementation of the guideline will be an "enormous" challenge in Wales and access to diagnostics will need to be improved. However there are major challenges in addressing shortages in imaging equipment, pathology, radiology, oncology and in redesigning diagnostic pathways.

Whilst the broad ambition of the delivery plan is welcomed, the pace of delivery has been slow. If services and outcomes are to be transformed, delivery of the plan must be accelerated, and clear performance measures need to be established to assess impact and implementation.



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### **Endoscopy Task and Finish Group**

In 2013, the Welsh Government established a Task and Finish Group to explore concerns regarding endoscopy services across Wales. A year later, the group reported and made a number of recommendations that would address the significant challenges around capacity. Amongst these recommendations was the requirement for additional funding, a national strategy for endoscopy services, a systematic drive for improvements in quality and an overall structured approach to the management of capacity and demand.

To date, many of these recommendations are outstanding, and without leadership and ambition, the transformational change needed to improve early diagnosis of bowel cancer will not be realised. A clear, comprehensive and updated action plan is required to ensure improvements in endoscopy services in Wales, including waiting times, quality, efficiency and staffing.

#### **Cancer waiting times**

Patients in Wales follow one of two routes to treatment depending on how their cancer is found – each of these routes has a separate waiting time. The urgent suspected cancer route has a target that 95% of all confirmed cases should start treatment within 62 days. For those on the non urgent pathway, once cancer is confirmed treatment should start within 31 days. This has led to concerns that there may be delays before diagnosis for those on the non urgent pathway.

The current system is complex and very confusing for patients who will have been waiting for a diagnosis and then have a further wait to start treatment. These long waits between referral, diagnosis and treatment lead to increased levels of anxiety and uncertainty for patients. This is particularly true for patients with bowel cancer, who may not present with typical symptoms and will be recorded as having started their treatment within 31 days of diagnosis. In some cases, these patients will have been potentially waiting months before this to access the diagnostic tests needed to get their cancer diagnosis in the first place.

Since January 2018, Health Boards in Wales have been measuring performance against a new "single cancer pathway". This new system aims to start counting all patient waits from the point of a suspicion of cancer, regardless of if they have been referred urgently or non-urgently, to the start of treatment. The previous waiting time targets will continue to be published in parallel until such a point that Welsh Government and the NHS have fully evaluated the single cancer pathway approach and are satisfied that patients will not be disadvantaged by the new system.

We hope the new system will be easier to administer and easier for the patient to understand, so they have confidence their cancer is being treated promptly. However it will require strong clinical leadership to drive this forward, as well as robust analysis and evaluation to ensure it leads to better outcomes and experience for patients. In doing so, it will be important that patients and patient representatives are involved in this process from the outset.

#### **Audit and data**

Each year the Association of Coloproctology of Great Britain and Ireland (ACPGBI) carry out a comprehensive audit of services across England and Wales. The audit aims to improve patient care by looking at what services and care is provided to patients and what is not. The audit specifically looks at whether treatment is successful, which hospitals are performing well and comparing services across hospitals. Knowing this means evidence-based suggestions for improvement can be made. However, good quality data is key to improving services and understanding bowel cancer outcomes. Unfortunately, an inquiry carried out by the ACPGBI<sup>3</sup> into the audit processes and organisation of bowel cancer services in Wales found significant issues with the accuracy and consistency of data collection in the country. This inquiry was the result of data from Wales showing poorer outcomes two years after diagnosis and after surgery.

The inquiry concluded that the difference in two year follow up was due to poor data collection rather than service delivery. The inquiry recommended that the Cancer Network Information System Cymru (CaNISC) be overhauled in order to be fit for purpose.

## Early diagnosis

There are many reasons why almost half of bowel cancer patients are diagnosed late in Wales. This includes factors beyond our control, such as natural disease progression and the genetic make-up of cancer, but there are other aspects that we know can also affect the stage of disease that are within our control. These include increasing awareness of symptoms, minimising delays in the pathway, developing new models of care and improving routes to diagnosis.

#### **Routes to diagnosis**

The most common routes to diagnosis are:

- screening
- GP referral
- emergency presentation

Although the majority of people are diagnosed via GP referral, data from England shows the best way to achieve a stage shift is through screening. The significantly higher proportion of people diagnosed late suggests that urgent steps need to be taken to better identify cancers at earlier stages.

## Patrick Wymer from Cardiff was diagnosed through an emergency presentation



"I had lost some weight and my bowel movements had become more frequent and loose, then I went to the GP as I was starting to experience persistent stomach pains.

I had private medical cover through work and was referred privately for a colonoscopy when I was taken ill with severe stomach pains. In the meantime, I visited A&E and was sent home after examination but told to wait for the colonoscopy.

A week later, I was back in A&E with even worse pain and sent home again with pain killers. I made a third visit to A&E the week after, again with severe pain and vomiting. This time I was admitted and after an operation, I woke up to the news that I had stage 4 bowel cancer, which had spread to my liver and my lungs.

I don't feel my situation was taken sufficiently seriously when I went to A&E. I was refused a scan on the first two occasions and sent home in significant distress when it was pretty clear something was very wrong."

#### **Screening**

Bowel Screening Wales (BSW) invites eligible men and women aged between 60 and 74 to take part in bowel screening every two years. BSW was launched in October 2008 and aims to reduce the number of people dying from bowel cancer in Wales by 15% by 2020 in the group of people invited for screening. To achieve this, the bowel screening programme must identify cancer early when treatment is more successful and also prevent cancer through the identification and removal of polyps that may otherwise go on to become malignant.

Unfortunately, staging data for those diagnosed through screening is currently not available in Wales. However data from the English programme is overwhelmingly in favour of screening as a method to improve early diagnosis of bowel cancer. Just over 37% of cancers diagnosed through screening are detected at the earliest stage, compared to just 6% of those diagnosed as an emergency. Furthermore, cancers detected through the screening programme are more likely to be treated with curative intent. Welsh data shows that 88% of screen detected cancers were treated curatively, compared to 52% and 69% of patients diagnosed via emergency presentation and GP referral respectively.

Despite the proven benefits of participating in the BSW programme, a significant number of people are missing out on the opportunity to detect cancer early by not completing the test.

In 2016, only 54% of those invited for screening took the test<sup>4</sup>. Whilst this is a small improvement on the previous year, it is still under what is a fairly unambitious target of 60%. This also compares unfavourably to 72% take up for breast cancer screening and 77% for cervical cancer screening.



#### **Introducing FIT**

From 2019, Wales will start to replace the current screening test with a simpler and more accurate one called the faecal immunochemical test (FIT), which is also proven to increase uptake of screening. Evidence from pilot studies demonstrated a twofold increase in cancer detection and a fourfold increase in adenoma detection. It also demonstrated an increase in uptake of around 10%, including people who have previously not taken the test and harder to reach groups.

FIT works in a similar way to the current screening test by detecting hidden traces of blood in stools. While the current test only detects the presence of blood, FIT detects how much actual blood is present because it is a quantitative test. As a result, the test can be adjusted to make it very sensitive for detecting hidden traces of blood and able to pick up more cancers, but if set at a less sensitive level, it will spot fewer cancers. A high sensitivity level of haemoglobin per gram of faeces, combined with increased uptake, will result in more referrals to colonoscopy services. In Scotland the level of sensitivity has been set at 80µg Hb/g faeces and England are yet to confirm their threshold, but a sensitivity level of 120µg Hb/g faeces has been proposed. In Wales diagnostic services are struggling to cope with current demand. This means that FIT cannot be brought in at a high level of sensitivity until these issues in colonoscopy are resolved. It has therefore been set at a level of 150µg Hb/g faeces. Whilst it is widely recognised a timetabled plan is needed to increase the sensitivity level, it means that until this happens, some cancers will be missed.

#### **GP** referral

Whilst screening is the most effective way of detecting bowel cancer early, referral by GP is still the route by which most people are diagnosed. Referral through primary care is a particularly important route to diagnosis for those who experience symptoms that could be bowel cancer and those below the age covered by the screening programme.

People who experience symptoms should be referred for the most reliable and accurate diagnostic test available. Colonoscopy and flexible sigmoidoscopy are the key diagnostic tests for bowel cancer. These tests can detect cancer at the earliest stage of the disease.

While effective public health awareness programmes can alert people to the symptoms of bowel cancer and encourage them to seek advice from their GP, it is also important GPs are able to recognise these symptoms and refer appropriately and promptly. However because the symptoms of bowel cancer can often be hard to diagnose accurately and also be symptoms of other less serious and more common bowel conditions, it can be difficult for GPs to know who to refer and when. This issue can often result in delays to patients being able to access diagnostic services and in some cases, patients having to see their GP more than five times before referral.

Guidelines from NICE are in place to assist GPs to make these decisions. The NICE guidelines for suspected cancer, which were updated in July 2017, recommend that FIT is adopted in primary care to guide referral for suspected bowel cancer in people without rectal bleeding who have unexplained symptoms, but do not meet the criteria for a suspected cancer pathway referral. Using FIT in this way could help GPs to better identify and refer the right patients quickly and detect bowel cancer early. We expect to see this adopted in Wales, alongside England and Scotland where it has already been piloted and used in some areas.

The Annual Cancer report recognises that a poor interface between primary and secondary care is a major cause of delays for cancer patients. In response to this, the Welsh Government has included recognition and early referral of cancer as part of the Wales GP contract for 2017/18. This requires primary care teams to review their current approach to identify and diagnose cancer to develop strategies to improve recognition and early diagnosis<sup>5</sup>.

These interventions will support earlier diagnosis of people with cancer who present in primary care and may also potentially lead to a reduction in demand for colonoscopy services.

#### **Increasing demand for diagnostics**

Demand for endoscopy services is set to increase dramatically over the next five years. This is due to a number of factors including an ageing population, increasing symptom awareness and the introduction of FIT.

However, there is a serious lack of capacity within endoscopy units in Wales to meet even current demand and without additional investment and a new approach to service delivery, there is little chance of ensuring future demand is met.

There is an urgent need to undertake a comprehensive analysis to establish how much needs will increase and the level of capacity required to meet that future demand

### **Waiting times**

Increasing demand and a lack of capacity is resulting in health boards across Wales breaching waiting time standards for access to diagnostic tests. The current recommended waiting time in Wales is eight weeks.

Figures from September 2017<sup>6</sup> showed that approximately 33% – equivalent to nearly 2,000 people – were waiting more than eight weeks for either a colonoscopy or flexible sigmoidoscopy. Of these, 1,169 people had to wait over 14 weeks.

These waiting time figures present a worrying picture for patients and is evidence that demand for diagnostic tests is outstripping capacity. If hospitals are expected to meet waiting time targets, then they must be given the resources and capacity to enable them to meet these standards. A lack of funding, limited resources and a shortage of staff to carry out the number of procedures needed are contributing to this. There is an urgent need to make addressing this crisis in endoscopy a national priority.

In 2015 Welsh Government committed additional funding to improve waiting times for diagnostic tests, including those waiting for endoscopy procedures following a positive screening result. The Health Minister at this time stated: "The health boards have given assurance that they will deliver a maximum waiting time for diagnostic tests of eight weeks by the end of March 2015." Additional funding was also provided in 2016 and 2017.

Despite extra funding, these figures demonstrate that challenges remain, suggesting that achieving access to timely and good quality endoscopy services needs a whole systems approach and a radical re-design of the current system.

Carl Difford from Newport was on a waiting list for his colonoscopy when he was diagnosed through A&E



"I had many symptoms and was back and forth to my GP. These included weight loss, tiredness and blood in my stools, which were explained by recently having taken up running, working too hard and haemorrhoids.

My GP was understanding, but I had many repeat visits and my blood and physical examination was normal. Although bowel cancer did cross my mind, my GP thought it unlikely due to age, the negative blood test result and lack of swelling or pain.

I was referred to a consultant after visiting my GP a number of times. I waited six months to see the consultant and was then put on a waiting list for a colonoscopy.

Before this appointment took place, I was admitted to hospital as an emergency where, following further tests and an emergency colonoscopy, I was diagnosed with stage 3 bowel cancer which had spread to the lymph nodes."

#### **JAG Accreditation**

The Joint Advisory Group's (JAG) accreditation scheme for endoscopy has been instrumental in setting out clearly what constitutes best practice and good quality. Endoscopic procedures are invasive which, if not carried out to the highest standard, can cause harm to the patient. It is of the utmost importance therefore that all endoscopy services in Wales are accredited to ensure continuous improvement and increase patient confidence in the diagnostic service they are receiving. Other benefits of JAG accreditation include enhanced retention and satisfaction of the workforce and the ability to drive best practice by drawing comparisons with other endoscopy units.

It is of significant concern that not all endoscopy units in Wales are JAG accredited. With the added pressures that a continued increase in demand is likely to present, ensuring endoscopy units in Wales are of the highest quality is paramount to ensuring people receive the best possible outcomes.

## Younger people

The challenges around early diagnosis is particularly acute for those diagnosed at a younger age. Through research carried out as part of our Never Too Young campaign, we have shown that those diagnosed under the age of 50 have a qualitatively different experience of being diagnosed. We have heard from patients that have been told they are "too young to get bowel cancer" and as a result are either misdiagnosed or referred too late. However, every year in the UK over 2,500 under 50s are diagnosed with bowel cancer, with 120 of these in Wales<sup>7</sup>. This figure has been rapidly rising. Since 2004, there has been a 48% increase in those diagnosed under the age of 50.

Latest figures show that around 3 in 5 people under the age of 50 were diagnosed at stage 3 or 4. Only one in five is diagnosed at the earliest stage. This means that many younger people have a lower chance of survival than they should.

This happens for a number of reasons, notably a lack of awareness and recognition of symptoms in younger people, and variation in how they are treated when they do go to the GP.

Younger people are particularly likely to be affected by delays in diagnosis. Our research shows that younger patients report having to see their GP on multiple occasions, sometimes more than five times, before being referred for crucial diagnostic tests. We therefore welcome the inclusion of people under 50 in the NICE guidance on recognition and referral.



Every year in the UK over 2,500 under 50s are diagnosed with bowel cancer, with 120 of these in Wales<sup>7</sup>

## Caroline Richards from Bridgend was 34 when she was diagnosed with bowel cancer



"I have had what I would describe as "problem bowels" for many years. It was never anything major and I never felt the need to mention it to a doctor, until the symptoms became very pronounced.

I went to the doctor and my experience was fantastic. She spent an incredibly long time examining me and ordered bloods to be taken and told me I would need to be referred to a consultant in the hospital.

A colonoscopy was ordered. I was very ill and basically bedbound and I was unable to keep any food or water down. I was then hospitalised and given anti-sickness drugs and a drip. Their intention was to operate to remove the huge mass, part of my colon that was affected and to create a stoma. My operation went ahead almost two months from my first visit to the doctor. I was eventually diagnosed with stage 4 bowel cancer and it was explained to me that my chemotherapy was palliative.

I do believe there is a lack of support for younger people with bowel cancer. There are no real support groups that I know of for people my age. Twitter has been amazing though and I have made many friends on there via Bowel Cancer UK's social media channel."

#### Lynch syndrome

If we are serious about increasing the proportion of people diagnosed at early stages of bowel cancer, then it is necessary to ensure that those at high risk of bowel cancer are identified and managed appropriately.

People diagnosed with bowel cancer should be tested for genetic abnormalities, such as Lynch syndrome, a genetic condition that increases the lifetime risk of developing bowel cancer to up to 80%. Yet 95% of the 175,000 people estimated to have Lynch syndrome in the UK don't know they have it because of a lack of systematic testing. NICE guidelines recommend all newly diagnosed bowel cancer patients are tested for molecular features of Lynch syndrome.

Identifying those with Lynch syndrome is only the first step in reducing the risk of developing cancer. People with Lynch syndrome should also be placed in a surveillance programme to receive regular colonoscopy screening every 18 months to two years. This can help to reduce the chance of dying from bowel cancer by as much as 72% through detecting it early<sup>7</sup>. Unfortunately, we've found that people with this syndrome often have to wait unacceptable amounts of time for their routine appointments. As there is no known cure, it is crucial people with Lynch syndrome receive coordinated, timely and high quality care to reduce their lifetime risk of bowel cancer.

The newly established Wales Colorectal Cancer Site Group has confirmed that Wales will be implementing new NICE recommendations and is putting in place plans for implementation. This is a very positive step for people with Lynch syndrome and their families in Wales. Additional investment to increase the capacity of pathology laboratories, genetic services and endoscopy centres is necessary however to enable units to implement this recommendation and deliver the high quality surveillance screening service that is essential to saving lives.

95% of the 175,000 people estimated to have Lynch syndrome in the UK don't know they have it

## Recommendations – what happens next

#### Many strategies and action plans to improve cancer outcomes have been written in Wales. What we need now is action.

We are calling on the Welsh Government and NHS Wales to work together to set a timescale and create targets for improvement. We expect Welsh Government to facilitate clear clinical leadership and provide clarity about who is responsible for delivering the improvements needed to improve outcomes for patients with bowel cancer.

### The Welsh Government and NHS Wales should:

- create a national endoscopy action plan that projects current and future demand for services and addresses how services can best meet increasing demand
- develop a comprehensive assessment of the impact on colonoscopy services from the introduction of FIT and a timetabled programme for increasing the sensitivity of this test
- form new models of care to help increase the numbers of people being diagnosed with bowel cancer at an earlier stage
- implement a national endoscopy training programme to ensure Wales has enough highly trained staff to safely provide a high quality endoscopy service
- improve clinical guidance on identifying bowel cancer in younger patients
- accelerate adoption of NICE guidance, recommending everyone diagnosed with bowel cancer is tested for Lynch syndrome
- produce a high quality surveillance programme to reduce the vast variation in access, quality and timeliness of regular colonoscopy for people with Lynch syndrome
- collect meaningful and accurate data about patients with bowel cancer and ensure it is fit for auditing purposes

#### **Bowel Cancer UK will:**

- bring the voice of the patient to our policy development and implementation
- carry on investing in research to support Wales in becoming a centre of excellence for bowel cancer research
- continue to challenge and collaborate with Welsh Government and NHS Wales to improve bowel cancer services in Wales
- provide support for people affected by bowel cancer and ensure they are able to achieve the best possible outcomes

## You too can improve outcomes for those affected by bowel cancer by:

- completing the screening test when you receive it in the post
- be aware of the symptoms of bowel cancer and seek advice from your GP if you have any concerns
- sign up to be a campaign supporter
- raise funds for our vital work

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