Welcome from Patrick Figgis, Chairman of Bowel Cancer UK

I’m delighted to welcome you to the latest edition of Spotlight. Throughout the magazine, you can read about how we’re supporting and funding targeted research, providing expert information and support to patients and their families, educating the public and professionals about the disease and campaigning for early diagnosis and access to best treatment and care. There are also stories from supporters like Stacey, who has been raising awareness of bowel cancer since her dad died and Cristina who was diagnosed with stage 3 bowel cancer and has found running a great source of motivation.

We also feature lots of varied ways you can support us, from fundraising at work, to taking part in one of our events or setting up a Star of Hope Fund in memory of a loved one.

Our vision is a future where nobody dies of bowel cancer, but we can’t achieve this alone. We need people like you to join us and take action. Your support truly makes a difference and we are hugely grateful.

Thank you.
New podcast episodes

Building on the success of our first podcast series, hosted by BBC’s George Alagiah, we’ve launched our second series.

We published three new episodes where George interviewed supporters and leading experts on bowel cancer, as well as discussing his own treatment and stage 4 diagnosis.

In the first episode of series two, George interviews Barbara Hibbert who has stage 4 bowel cancer, and surgeon Nicola Fearnhead from Addenbrooks Hospital in Cambridge, about the different types of surgery available for patients.

The second episode features George speaking with Greig Trout who was diagnosed with stage 2 bowel cancer, and Claire Foster, Professor of Psychosocial Oncology from the University of Southampton, about how to look after your emotional health whilst living with and beyond bowel cancer.

Lastly in the third episode, George chats to Steve Clark who has stage 4 bowel cancer, and oncologist Professor Mark Saunders from The Christie NHS Hospital in Manchester, about how chemotherapy can help treat the disease.

In Spring 2020, the third series will be released. Listen now at bowelcanceruk.org.uk/podcast
Improving bowel cancer screening
The faecal immunochemical test (FIT) looks for blood in poo, which could be a sign of bowel cancer or pre-cancerous growths (polyps). But FIT isn’t always able to detect or rule out bowel cancer effectively. In his project, Professor Robert Steele will link results from FIT to other patient information (like age and gender) to work out if some patients might benefit from completing a more sensitive screening test. This could lead to earlier diagnosis for some and less unnecessary investigations for others.

New research
In October we announced funding for four new research grants worth £440,000, which brings our total investment in research to just over £1.3 million.
The following is a short overview of the funded research projects:
Reducing undetected bowel cancers
Colonoscopy is the main test used to diagnose bowel cancer. However, no test is 100% reliable and sometimes a cancer (or pre-cancerous growth) is not found during a colonoscopy. Professor Eva Morris is investigating why this happens by examining colonoscopy data from hospitals in England. This knowledge can be used to improve colonoscopy services and reduce the number of undetected cancers.

Improving rectal cancer treatment
Dr Alex Greenhough will be investigating why chemoradiotherapy works well for some patients with rectal cancer and not for others. He and his team will study samples from patients and measure the amount of one specific protein. They believe this protein may affect how well the treatment works. This work will drive further research that could help improve treatment decisions. This will mean only those patients most likely to benefit from chemotherapy and radiotherapy before surgery will be offered it.

Understanding how bowel cancer grows in younger people
It’s thought that bowel cancers in younger people may grow more quickly than in people aged over 50. Professor Mohammad Ilyas and his team will be using artificial intelligence to examine cancer cells and the community of healthy cells around them in the bowel. They’ll compare samples from younger and older patients to get information about how cancer grows and develops in younger patients, to help predict how well patients respond to different treatments. This helps clinicians tailor treatment decisions.

More information
Find out more at bowelcanceruk.org.uk/research
Be inspired by Stacey

When Stacey Hartley’s dad died from advanced bowel cancer in 2017, she started a campaign in her local area to raise awareness of the symptoms of the disease.
“My dad Tommy was just 63 years old when he was diagnosed with stage 4 bowel cancer in September 2016.

He’d been having symptoms for months without saying anything, until my mum noticed blood in the toilet and made him go to his GP. He’d lost a lot of weight, but we had put it down to him being on a diet, which he had been on for a while.

My dad was so strong through seven months of chemotherapy and it was working, as two scans showed the tumours had shrunk. Although it was palliative treatment, this was the best news we could ask for. However, my dad fell ill with sepsis at the end of April 2017 and was in and out of hospital for a week. He passed away on 5 May, the day before his 64th birthday.

This came just three months before my brother’s wedding, and five months before my own.

Since losing my dad I’ve raised nearly £500 for Bowel Cancer UK in his memory. I took part in the #thisisbowelcancer campaign during Bowel Cancer Awareness Month and raised more money by selling cake pops at my workplace.

I also started an initiative in Liverpool called #TheTommyMovement to increase awareness of the disease and the signs and symptoms. I asked bars, restaurants and shops to display Bowel Cancer UK symptoms posters in their restrooms, both public and staff facilities. I currently have around 12 companies involved including my local McDonalds, The Gym Group, The Everyman Theatre and Bierkeller.

It’s so important to recognise the signs and symptoms of bowel cancer. If you spot any visit your GP. Don’t be embarrassed and don’t ignore them, it could save your life.”

Get involved

Feeling inspired by Stacey’s campaign?
Order your free symptoms posters and display them in your local community, visit bowelcanceruk.org.uk/ourpublications
Support for you

From diagnosis and treatment to living with and beyond bowel cancer, we provide expert information and support for everyone affected by the disease.

Meet Together
In December we held our first Meet Together event in London, which was a social gathering for anyone affected by bowel cancer looking to get support from others.

We know that it can be useful to share your experience of bowel cancer with those who have been through something similar. Because of this, we’re planning more Meet Together events throughout England, Scotland and Northern Ireland this year, to enable patients, family members and carers to meet and connect.

Keep an eye on our website for updates on future events.

Shrewsbury and Telford Hospital Trust partnership
We’ve been working in partnership with the Shrewsbury and Telford Hospital NHS Trust on a pilot project to make sure patients at the hospital can access our services at diagnosis and during treatment.

As part of this project, patients in Shropshire were given leaflets and information that directs them to a unique website page that highlights the information we offer that they may find useful. This project is due to run until April 2020, and if successful, we hope to roll out this way of working across the UK.

Patient Day 2020
Following on from the success of our two ‘Living well with bowel cancer’ events held last year in Manchester and Edinburgh, we’ll be hosting other events in London and Scotland this spring.

We’ll publish more information on our website and social media channels closer to the time, so watch this space.
Growing our network of surgical fellows
In September we awarded funding for two new surgical fellows, funded jointly with the Royal College of Surgeons of England. Mr Joshua Burke will be investigating a new way to prevent a serious complication that can occur following bowel cancer surgery, called anastomotic leak. Miss Rachael Clifford will look at ways to improve how well radiotherapy works for patients with rectal cancer.

Take part in research
If you were diagnosed with bowel cancer under 40, you might be able to take part in a research study looking for genetic causes of bowel cancer in younger people. The SCOTTY Study is looking for patients (who do not have Lynch syndrome) and their unaffected parents to give a blood sample.

Get in touch with the study organisers to find out more. Email scottystudy@ed.ac.uk

Our research blog
Visit our research blog for the latest bowel cancer research updates. We’ve highlighted some of our recent blogs below:

• Read about how artificial intelligence is helping researchers study digital images of bowel cancer samples. As research develops, this means patients could be better matched to the best treatment for them.

• Patient representative Pete Wheatstone tells us about exciting research he’s involved with. This focuses on getting cutting edge new laboratory techniques out of the lab and into the clinic.

Read more at bowelcanceruk.org.uk/research
Making bowel cancer screening FIT for purpose

Bowel cancer screening can save lives. Screening aims to detect bowel cancer at an early stage, when treatment has the best chance of working. The test can also prevent bowel cancer through finding and removing polyps (pre-cancerous growths) which might develop into cancer.
Each of the screening programmes in the UK use home tests, which look for hidden blood in poo. If you are registered with a GP and within the eligible screening age range, a test will be automatically posted to you, so you can complete it in the privacy of your own home.

The screening programmes in England, Scotland and Wales now use a test called FIT, the faecal immunochemical test. It’s easier to use and more accurate than the previous test. We’ve been campaigning for FIT to be used for many years and we’re working hard to ensure Northern Ireland soon follows suit.

But the choice of screening test is only one part of the picture. To be most effective at detecting bowel cancer early, we need to screen people from the age of 50 and for the test to be used in a way that detects the most cancers. FIT is a quantitative test, meaning the sensitivity to blood can be adjusted. However across the UK the test is being used at a less sensitive level than research recommends, meaning some cancers may be missed. And currently only Scotland tests everyone from the age of 50, with testing starting at 60 in England, Wales and Northern Ireland.

In order for these vital improvements to bowel cancer screening programmes to be achieved, the NHS needs sufficient staff to deal with the increase in demand this will bring. At the moment hospitals across the UK simply do not have enough staff in services that diagnose bowel cancer, in particular endoscopy and pathology units, to meet this need.

We’re campaigning for governments to end this capacity crisis. Each part of the UK must develop and implement a fully funded long term plan to increase capacity in NHS endoscopy and pathology services, so that they can cope with the growing demand an optimised bowel cancer screening programme would bring.

Learn more

Find out more about our capacity crisis campaign at bowelcanceruk.org.uk/capacitycrisis
Living well after treatment

Our booklet ‘Living well – after bowel cancer treatment’ covers topics such as feelings after treatment, how to have a healthy diet and keep active, possible worries around follow up appointments, dealing with side effects and going back to work.

Your feelings after treatment
After treatment you may experience a whole range of unexpected emotions. Not everyone reacts in the same way and there’s no right or wrong way to feel. Telling your friends and family how you feel or speaking to your healthcare team might help.

Diet and physical activity
After your cancer treatment you may find you can’t eat the same foods as before. For example, you may need to follow a low-fibre diet. You can include fruit and vegetables in your diet by removing the skin, pith and seeds before eating.

Regular physical activity can help you keep fit and improve your mood and wellbeing. Walking is a good way of keeping active while you’re recovering from treatment.

Dealing with side effects
After treatment you might experience side effects, such as trouble sleeping, fatigue and bowel problems. Some people find things like changing their work-life balance, focusing on the positive things in their lives, improving diet and keeping physically active are helpful. Speak to your healthcare team who can help you find the best ways to manage your side effects.

When my friends asked me how I was, I always said, ‘I’m fine’, then wondered why I didn’t get the support I wanted. Now, I try to be honest and get far better results.

Mike

More information
Order or download a copy of this booklet at bowelcanceruk.org.uk/ourpublications
Be inspired by Cristina

Cristina was diagnosed with stage 3 bowel cancer in 2018. “The phrase I was always hearing since my diagnosis was ‘it’s a journey and a process’. It’s a fair description - an operation and 12 rounds of chemotherapy is certainly a process and the journey is what you make of it.”

“From the outset, I felt a need to keep my body moving. Chemo lays you low, but I found that exercising when I could had a positive effect on everything, from my mood to my general health, and it seemed to reduce the side effects of the chemo.

I’ve been a runner for many years and that was my motivation. I’m not fast and never have been, but I’m determined and that’s the key. I had already signed up for a running event before I was diagnosed and decided to set myself a goal of completing a 10k run seven weeks after my last chemo - and I did it! It wasn’t easy. It was emotional and it seemed very strange running it for personal reasons.

My journey has only just begun. I will keep running and keep encouraging anyone diagnosed with bowel cancer to ‘get moving’. Gentle exercise like walking is just as effective as pounding the pavements. It’s not how you exercise, it’s the fact that you do exercise that will have a positive impact.”

Fundraise for us

Inspired by Cristina’s story? Visit bowelcanceruk.org.uk/challenge2020 to find out about our new virtual running event
Our work across the UK

In addition to our head office in London, we have offices in Edinburgh and Cardiff and two homebased staff in Northern Ireland. We’re doing amazing things to save lives and improve the quality of life of everyone affected by bowel cancer right across the UK.

We held our largest ever study day in Northern Ireland in November. The free event was an essential update for healthcare professionals on the changes to the bowel screening programme, the importance of genetic counselling, top tips for practitioners on how to look after themselves in challenging situations and talks from surgeons, nurses and patients.

We hosted a ‘Living well with bowel cancer’ event in Edinburgh, a free get together for people to share experiences with others affected by bowel cancer, as well as hear presentations and an opportunity to try yoga and learn about mindfulness.

We’re a key partner of the Moondance Bowel Cancer Project, which aims to transform five year bowel cancer survival rates in Wales within a decade. Thanks to funding from the Moondance Foundation, this exciting programme of work challenges all aspects of the patient pathway; from improving awareness of symptoms and increasing screening uptake, to driving down diagnostic waiting times and transforming surgery.

We’re working with Northern Ireland’s Department of Health and a number of other partners on developing their first cancer strategy in ten years.

We’re proud of our ongoing collaboration with the Wales Cancer Network and have provided funding to support Wales’ first
bowel cancer clinical lead. Professor Jared Torkington, Consultant Colorectal Surgeon at Cardiff and Vale Health Board, has been appointed to this post and will lead improvements in bowel cancer across the whole of Wales.

Claire Donaghy, our Head of Scotland and Northern Ireland, has been appointed to the role of Chair of the Scottish Cancer Coalition. The coalition is a group of 30 cancer charities who work together to address key challenges facing cancer patients in Scotland. It lobbies and engages with the Scottish Government and other external bodies such as the Scottish Medicines Consortium.

We’re delighted the Welsh Government is putting emphasis on the newly developed endoscopy programme. During 2018 we were instrumental in bringing about a National Assembly Committee Inquiry into endoscopy services in Wales. That inquiry report in April last year recommended that the Endoscopy Programme Board should develop an action plan by the end of 2019. That plan was published in the autumn and promises to deliver much needed improvements in endoscopy services in Wales.
Support us at work

Does your work have a charity partnership programme? If so, why not nominate us?
Your work could play a pivotal role in making our vision of a future where nobody dies of bowel cancer a reality by raising awareness and vital funds.

A partnership is good for business
Partner with us and strengthen your brand profile. By generating positive PR around our partnership, we can help you stand out. We can also help you reach new audiences by connecting you with our supporters.

Increase staff engagement
Our partnership can help motivate staff and encourage team building throughout your organisation.

Demonstrate that you are a responsible business
We can support you to achieve your corporate social responsibility goals and work with you to improve the health and wellbeing of your staff and customers.

“Whilst our main purpose is to raise funds and awareness, there are also many benefits. We find that our fundraising events are great for team building.”
Edwards & Co, pictured above

Learn more
Find out more about how we could work together at bowelcanceruk.org.uk/support-us
Marina Edwards shares how she’s remembering her husband Daniel and helping others affected by bowel cancer through his Star of Hope Fund.

“Daniel was diagnosed with bowel cancer in April 2018 when he was only 38 years old and died after a short battle in June 2018. After he died, I decided that I wanted to raise awareness and funds and discovered the charity’s Star of Hope Funds.

It’s been pretty tough for our family since Daniel died but having his Fund is a way of holding him close to us. It’s a permanent place online where we can remember the wonderful and amazing man he was. I’m able to share my story, photos and memories of him, and I know that my daughter and I will visit and use his Fund for the rest of our lives.

As well as collecting donations for Bowel Cancer UK, we’ve held a memorial Ball and a friend has done two skydives. All the money we’ve raised is recorded on his Fund and if it helps save just one person’s life that would make me, my family, and most importantly Daniel, very proud.

I would highly recommend anyone who’s lost a loved one to bowel cancer to set up a Star of Hope Fund.”

Read more about Star of Hope Funds at bowelcanceruk.org.uk/starofhopefunds

Marina, Daniel and their daughter
Walk Together
Last September, hundreds of supporters joined us to Walk Together raising over £150,000. A massive thank you to all those who took part in London, Edinburgh, Belfast and Cardiff, as well as those who organised their own walk in their own local area. Your support has been incredible.

Christine walked to support her friend Lee who has stage 4 bowel cancer. She said: “What a brilliant day and what a fabulous group of people turning up to all walk together, it was a quite an emotional day.”

Come along this September. With your support, we can continue to help those going through treatment, to remember loved ones and help stop people dying of bowel cancer. Visit bowelcanceruk.org.uk/walktogether
Challenge 2020

What’s your New Year’s resolution? If you’re looking to take up running for the first time or aiming for a new PB and you share our determination to save more lives and improve the quality of life of everyone affected by bowel cancer, then we’ve got a challenge for you.

Choose to take on our 16km, 42km or 268km challenge wherever you like, whenever you like and at your own pace. Run, jog or walk the distance in a day, a week, a month or before 30 April.

“Rather than breaking down, I decided to try and make a change and take on a big challenge.” Stacey walked 42km last September after her grandad, dad and uncle were diagnosed with bowel cancer.

Join our team at bowelcanceruk.org.uk/challenge2020

Brew Together this April

Join us this April and hold a Brew Together event to support Bowel Cancer Awareness Month. Put the kettle on, come together with friends and family and host your fundraiser at home, work or out in your local community. Sign up to receive a free fundraising kit and dedicated support from our fundraising team.

Find out more at bowelcanceruk.org.uk/brewtogether
Events diary

Find out more about any of these events or other ways you can get involved at bowelcanceruk.org.uk

January
Challenge 2020
(January - April)

March
All Sustainable Bring and Buy year - recycle, upcycle, resell and swap secondhand items
1 The Vitality Big Half, London
8 Inverness Half Marathon
28 Spar Omagh Half Marathon, County Tyrone
29 London Landmarks Half Marathon

April
All Brew Together month
5 Kilomathon Edinburgh
26 Virgin Money London Marathon
26 Glasgow Kiltwalk

May
2-3 Walk, jog or run the Isle of Wight Challenge
3 Belfast City Marathon
16-17 Jurassic Coast Challenge
23-24 London 2 Brighton Challenge
23/24 Edinburgh Marathon Festival
25 Vitality London, 10,000
30-31 The Jungle NI Rampage, obstacle adventure race

June
All Step up for 30 month
TBC Walled City Marathon, Derry/Londonderry
13-14 Lake District Challenge
14 Swansea Half Marathon
20 Ben Nevis Trek, Scotland
27-28 Cotswold Way Challenge

July
18 Sunrise Trek, South Wales