

# Prostate cancer Insights

Issue 13 | Winter/Spring 2019



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and me  
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JOHN-  
JULES**

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surveillance  
comes of age**  
How monitoring rather  
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# Editor's note

For thousands of men diagnosed with localised prostate cancer each year in the UK, choosing what to do next can be a stressful experience. While radiotherapy and surgery are the most common options, active surveillance can often be overlooked – despite recent research proving it to be as effective as the other treatments over ten years, with fewer side effects. Why is that?

After two years of consulting with hundreds of men and health professionals, we uncovered a variety of reasons – from anxiety and distrust of the process by men, to consultants simply not offering active surveillance or being inconsistent with how they do it. We explore them all in our main feature (p8) and explain our new protocols to give all men the best possible experience of active surveillance, wherever they are in the UK.

Together with our big plans for a five-year trial of a potential new screening programme (see p6), we're working hard to make sure no man is diagnosed too late to have their cancer treated successfully – and with the least impact on their day-to-day lives.

## Editorial team

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# INBOX

Tell us what you think about the magazine and our stories online at [prostatecanceruk.org/news](http://prostatecanceruk.org/news). We want to hear what you've got to say.



## Dear Insights

I closely monitor many medical advances and am surprised I haven't seen any reference to research into the patented liquid biopsy, Parsortix, and the isolation of circulating tumour cells. It can define the status of any cancerous cells and the probable organ location of the cancer with remarkable accuracy. Several hospitals now offer the test.

**Roger Smith**

Dear Mr Smith,

The advances being made in liquid biopsies, like Parsortix, are raising some really exciting possibilities for more accurately diagnosing and treating men with prostate cancer. We're currently funding a trial called CTC-STOP, which is using circulating tumour cells to better judge how well a treatment is working for man. However, there are still difficulties with these techniques, including extracting enough tumour cells from the blood. So we are investing in other types of liquid biopsies too, such as our PARADIGM trial, where researchers are looking for fragments of DNA released by the cancer cells. To find out more about our research, visit [prostatecanceruk.org/research](http://prostatecanceruk.org/research)



## Dear Insights

I had high-intensity focused ultrasound (HIFU) in London on the NHS following a referral from my local hospital. It was not automatically offered as a treatment – I had to really insist. Initially, I was offered radiotherapy or surgery but didn't like the percentage risk of side effects. For me, HIFU worked very well indeed. Four months post-surgery and I have no side effects at all, with PSA readings reduced by 95 per cent. Compared to the other treatments on offer, this is revolutionary and – in my case – wonderfully effective.

**Paul Savage**

Dear Mr Savage,

Thank you for sharing your experience of HIFU. At the moment, further tests are needed to prove that the benefits of HIFU compare to those of existing treatments for all men with prostate cancer, and we're committed to funding that research. Currently, HIFU is only available on the NHS at a very limited number of specialist centres – either as part of a clinical trial or where data is being collected to monitor outcomes. For anyone interested in this treatment, please call our Specialist Nurses on **0800 074 8383**, who can give you more details about where to access it.



## Dear Insights

My husband, John, completed his 100<sup>th</sup> parkrun on Saturday 13 October – over half of which have been done while undergoing treatment for advanced prostate cancer. He only missed two Saturdays when in hospital and his best time for the year was the day after his first chemo. We think it was steroid enhanced! His personal best is 27m 40s and his last 'run' was 1hr 24m. But time doesn't matter; it's the taking part that counts. Due to the increased pain the growing tumour gave him in his hip, he had to stop for a several weeks during the summer, but he was always determined to reach his 100<sup>th</sup> run. I'm so proud of him.

**Wendy Johnson**



### GET IN TOUCH!

You can contact us via social media or email on the addresses below, or write to us at:

**Insights magazine  
Prostate Cancer UK  
Fourth Floor,  
The Counting House  
53 Tooley Street  
London SE1 2QN**



## Dear Insights

I had robotic surgery at Manchester's Christie Hospital to remove my prostate, which thankfully went very well. Like quite a few others, I guess, I only went to my GP for the PSA test due to the publicity on prostate cancer in the media at the

beginning of 2018, and I am very thankful to Prostate Cancer UK and people like Stephen Fry and Bill Turnbull for highlighting the issue. I received a very nice reply from Bill on Twitter when I thanked him.

**Paul Corrick**



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**editor@prostatecanceruk.org**

# PROSTATE CANCER NEWS

## Robot-assisted prostate surgery available for first time in Northern Ireland

Men in Northern Ireland will no longer have to travel out of the country to have a robotic prostatectomy, after Belfast City Hospital announced its new Da Vinci machine will begin operating on up to 100 men this year.

Since early 2016, men have not been able to have any type of prostatectomy surgery in Northern Ireland. And most men opting for robot-assisted surgery had to endure travelling to Addenbrokes Hospital in Cambridge for the operation. But now, Belfast's new £1.5 million robot will give the more than 1,000 men diagnosed with prostate

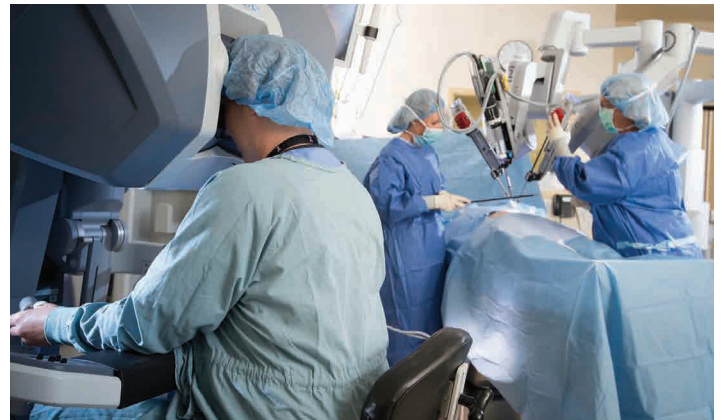
cancer each year in Northern Ireland the option of the less invasive surgery closer to home.

"It's great news that the Northern Ireland Health and Social Care Board are taking key steps to improve access to prostate cancer surgery at a safe standard," says Martin Abrams, our Change Delivery Manager. "But it's important that access to surgery forms part of a wider plan for improving all aspects of prostate cancer treatment, within an overall cancer strategy for Northern Ireland."

Thankfully, Northern Ireland's Department of

Health confirmed last autumn that it's likely to develop a cancer strategy for the country. It's currently the only Home Nation without one and is something we've long campaigned for as crucial for helping men there at risk of prostate cancer, or living with and after the disease.

"We'll be maintaining pressure around this issue until plans for a cancer strategy are confirmed," says Martin. "And we'll continue to champion the needs of men with prostate cancer throughout the process so that more lives can be saved in Northern Ireland."



## Early research shows immunotherapy's potential for one mutation of aggressive prostate cancer

A new investigation of tumour samples by the Institute of Cancer Research (ICR) suggests some men with advanced prostate cancer that carries a certain genetic fault may respond unusually well to immunotherapy. The results are a boon for these men, as their type of cancer is more likely to become treatment-resistant and kill quicker than other advanced disease.

Immunotherapy is a type of treatment that uses

the body's own immune system to help fight disease. It's already been proven to be effective in many other types of cancer, and now this ICR study adds to increasing evidence that it could also be effective for small numbers of men with advanced prostate cancer.

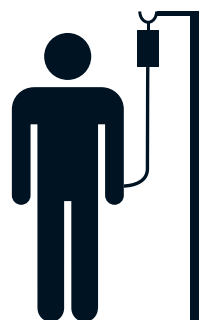
"Our study found that some men with advanced prostate cancers have genomic mutations in their tumours that make the disease unstable, aggressive and resistant

to standard therapies," says Professor Johann de Bono, who headed up the research.

The researchers examined 127 tumour biopsies and genetic data from a further 254 patients. They discovered that men with these 'mismatch' repair mutations only live about half as long as others whose advanced prostate cancer doesn't carry such mutations.

"We discovered that these tumours have key

hallmarks which make them particularly likely to respond to checkpoint inhibitor immunotherapy," says Professor de Bono. "We are now developing tests that could pick out patients with these mutations, and we're running new clinical trials to see if immunotherapy can offer new hope for these men."



# Thousands of men with advanced disease could live longer with first-line radiotherapy

Upfront radiotherapy could extend the lives of 3,000 men in England alone, say researchers, after the latest results from the long-running STAMPEDE trial were revealed. Treating the prostate straightaway with radiotherapy alongside standard hormone therapy treatment was found to increase three-year survival rates for men whose cancer had only spread to nearby nodes and bones to 83 per cent. This compared with 73 per

cent of men who didn't get radiotherapy. But for men whose cancer had spread more widely, radiotherapy showed no extra benefit.

Because more than 8,000 men are diagnosed with advanced prostate cancer in England each year, and 40 per cent of those have cancers that would benefit from upfront radiotherapy, the researchers estimate at least 3,000 men could have their lives extended by the treatment.

"These findings could and should change standard of care worldwide," said Dr Chris Parker, lead researcher of the study at The Royal Marsden. "Until now, it was thought that there was no point in treating the prostate itself if the cancer had already spread because it would be like shutting the stable door after the horse has bolted. However, this study proves the benefit of prostate radiotherapy for these men."

We're now calling for upfront radiotherapy to be extended to this group of men without delay, providing them with an additional treatment option and precious extra time with their loved ones.



## FROM THE LAB Reinventing the PSA test

**Professor of Nanotechnology at the University of Birmingham, Paula Mendes is turning her skills to prostate cancer for the first time with one of our Research Innovation Awards. She's hoping to reinvent the PSA blood test using technology developed in her lab.**

The current PSA test can be inaccurate, missing some cancers and falsely detecting others that don't need treatment. This means many men with aggressive prostate cancer don't get the treatment they need fast enough, and men with less dangerous prostate cancer undergo unnecessary treatments that leave them with life-changing side effects.

But Professor Mendes' research has identified over 50 forms of PSA, all with the same protein but with different sugars attached to it. Importantly, different types of sugars are linked to different problems with the prostate, including cancer. "The current test for prostate cancer scans the body for all types of PSAs, but we now know that only four of these forms of PSA are linked to prostate cancer," she explains.

Her plan is to take advantage of this, and create a test where the type of PSA, rather than the amount, is detected. It uses tiny, coloured nanoparticles, which contain a 'pocket' that specifically binds the PSA

sugars associated with prostate cancer, like a lock and key. The more such sugars it detects, the higher a man's chance of having aggressive prostate cancer that needs urgent treatment.

"At the end of two years, we want to demonstrate that our technology can detect high- or low-risk prostate cancer with high accuracy," says Professor Mendes. She then hopes to run a larger clinical trial and ultimately make the test part of a future screening programme for prostate cancer. Find out more about this and our other Research Innovation Award projects at [prostatecanceruk.org/research](http://prostatecanceruk.org/research)



If you'd like to comment on this or other news stories, go to [prostatecanceruk.org/news](http://prostatecanceruk.org/news) and join the conversation

# Screening in sight

**Our Director of Research, Dr Matthew Hobbs, explains why we're tantalisingly close to trialling a possible screening programme for prostate cancer and the impact it could have for thousands of men's lives each year.**

Prostate cancer often doesn't have any symptoms until it has started to grow and spread beyond the prostate to other parts of the body. Every year, over 9,000 men are diagnosed with prostate cancer too late and told that it can't be cured. A screening programme could help us to catch many of these earlier. Just imagine the impact of that!

So I'm delighted to say that, after decades of research led by us and thanks to your generous support, we're now at the point where prostate cancer screening could be within reach for the first time. That's because we're close to funding our biggest ever research project to turn it into a reality.

Over the next five years, the trial we're planning will recruit 20,000 men to see if the various advances we've made in diagnostic techniques over the past 30 years can be brought together to form a national screening programme.

But this kind of ground-breaking research doesn't come cheaply: the trial will cost almost £5 million. But that's still a bargain compared to the thousands of lives that could be saved every year. Just look at the impact screening has had on other conditions, like breast cancer. Since mammograms started in 1988, the death rate from breast cancer in the UK has almost halved.

Our version of the mammogram for prostates pulls together research into genetics and the increased risk from family history, tests for biological markers in the blood, and advanced new mpMRI scans that will give us the accuracy needed for a national screening programme.

In practice, this would mean that men would be invited for a blood test at their GP. If this was positive they would be referred to a hospital to have an mpMRI scan, before being referred to a urologist to have a biopsy if the scan couldn't rule out cancer. This requires the different specialities to work together across the whole country and has never been attempted anywhere in the world before for prostate cancer.

The chance to make history is tantalisingly close, with a trial in sight that should create the world's first national screening programme for prostate cancer – and it's all down to your continued support. Thank you all so very much. Together we can stop prostate cancer being a killer.

## How our proposed screening trial would work

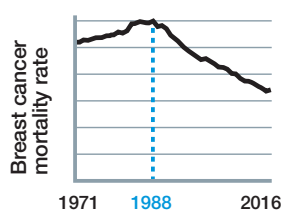
Each of the 20,000 men on the five-year trial would be given three tests that aim to identify prostate cancer:

- the standard PSA test;
- a risk-assessment tool for GPs that combines the PSA result with other information about a man to give a combined score of his prostate cancer risk;
- and an advanced 'biomarker' blood test.

## How our potential screening programme came together

### 1988

Breast cancer screening begins in the UK, saving thousands of lives.



### Early 90's

PSA first used for prostate cancer diagnosis. Although concerns are known about its accuracy, it's the best test available.



### 1995

Our first grant into genetics research helps understand each man's risk of prostate cancer. Our continued research discovers hundreds of genes involved.



### 2008

We start funding research into using mpMRI scans to reduce unnecessary biopsies, providing evidence leading to the PROMIS trial.

### 2010

One of our previous PhD students Hayley Whitaker, develops a test for a blood biomarker that could be used for prostate cancer diagnosis.



If a man gets a positive score on any of these tests then he'll be sent for an advanced type of MRI scan known as mpMRI and – if needed – a biopsy. By the end of the trial, we'll be able to see how many aggressive cancers are detected by each of the three tests and how many men they sent for further tests unnecessarily.

If the trial proves successful, this new pathway for diagnosis will be put forward to the National Screening Committee for consideration as the first ever national screening programme for prostate cancer in the UK.

Professor Hash Ahmed from Imperial College London, who helped trial and rollout mpMRI scans around the country, says: "In the UK, we are leading the world in having a national implementation of mpMRI and targeted biopsy.

"As a result of all the work the UK has done in diagnosis, we now have a once-in-a-lifetime opportunity to give men more time with their families."



**Over the next five years, the trial we're planning will recruit 20,000 men to see if the various advances we've made in diagnostic techniques over the past 30 years can be brought together to form a national screening programme.**

Dr Matthew Hobbs, Director of Research, Prostate Cancer UK

## "A screening programme could have caught my cancer in time"



**Tony was diagnosed with prostate cancer in 2017 at the age of 60. He's a keen runner and after visiting the doctor for a persistent groin pain, he was told that he had incurable prostate cancer that had spread to his bones.**

"When you hear that you have prostate cancer it's devastating. When you hear that it's incurable, it's indescribable. The thought of not seeing my five-year-old grandson grow to be a teenager was absolutely devastating – he's the apple of my eye.

"My urologist told me that I could've had the cancer for 10 years. A screening programme could have caught my cancer in time, which would have given me many more years with my family.

"Knowing my son and grandson are at greater risk because of my diagnosis is so hard to deal with. I really hope that within a few years' time, when my son is in his 40s, that we have a screening programme in place."

### 2017

PROMIS results show that mpMRI can reduce unnecessary biopsies.



### 2018

We start to establish trials to combine new tests, including mpMRI, to prove whether they are good enough to have a screening programme for prostate cancer in the NHS.

### 2019

Trial begins recruitment. GP surgeries sign up to take part and send out invitations to men eligible for the trial.



### 2021

Pilot phase of trial completes to show that recruitment is on track and the process is feasible.



### 2024

Recruitment to trial finishes and results are analysed to see the accuracy of these new tests. If the results are as hoped, we call for a screening programme for prostate cancer.

### Onwards

A biobank of samples from the trial are saved so that in future newer ways to diagnose prostate cancer can be tested against current tools.

# ACTIVE SURVEILLANCE COMES OF AGE

**Recent research has proven that active surveillance is as effective as surgery or radiotherapy for localised prostate cancer. But this way of monitoring is still overlooked by many men, and there has been no agreed standard for how it should be done using the latest diagnostic technology – until now. We find out why and how our new best practice protocols could help men and health professionals make the most of active surveillance.**

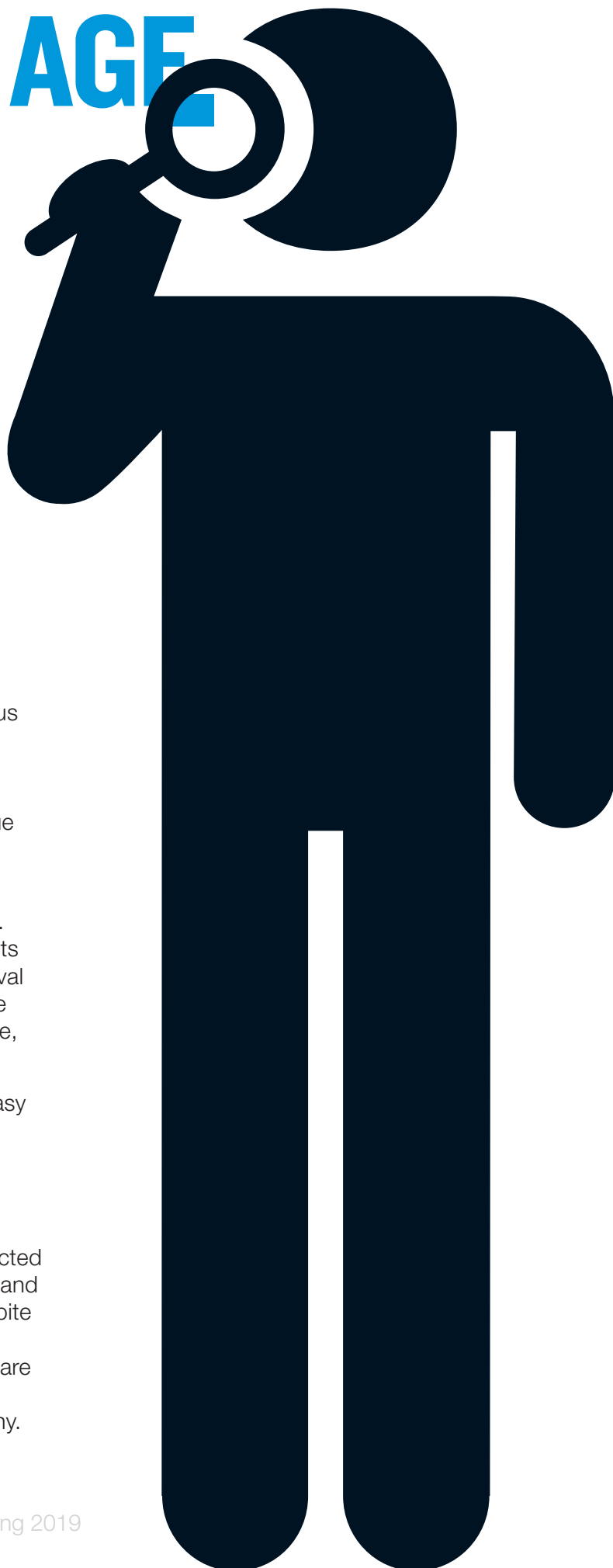
When the multimillion-pound ProtecT trial reported its findings in 2016, it was hugely reassuring for some men with localised prostate cancer (cancer that hasn't spread beyond the prostate) who were either on active surveillance or considering it.

Today, active surveillance involves monitoring the cancer with regular PSA tests and MRI scans – plus repeat biopsies if needed. The aim is to delay – or even avoid altogether – more radical treatments like surgery and radiotherapy, whose unpleasant side effects can include erectile dysfunction, fatigue and incontinence.

Some men thought this 'doing nothing' course of action was riskier or like having no treatment at all. But the ProtecT trial finally disproved these fears. Its researchers found there was no difference in survival rates after 10 years for men with localised prostate cancer, whether they initially had active surveillance, surgery or radiotherapy.

"It provides reassurance for an option that's not easy to cope with mentally," one man already on active surveillance told us. Another said it gave them the evidence they needed to opt for "what could be otherwise seen as a gamble."

They were in a focus group of men that we conducted in 2017, looking to understand their attitudes to – and experiences of – active surveillance. Because despite all the evidence in its favour, eight per cent of men diagnosed with low-risk localised prostate cancer are still being potentially 'over-treated' with surgery or radiotherapy instead – and we wanted to know why.





## Addressing men's concerns about active surveillance

So we went on to survey almost a thousand men on the subject and discovered a significant group who remained unconvinced by the ProtecT trial's findings. They were still unsure active surveillance was as effective as other treatment choices and, looking at the reasons they gave, we found three main concerns among them.

One was a general anxiety about having cancer in your body and the risk of it spreading to other parts of the body. Another was a concern about how often you'd be tested while on active surveillance, particularly with intrusive biopsies, and whether the support services to do this well might be cut in future. And the third was how accurate the detection methods used were, so they could be certain about the type and extent of their cancer.

There was also some dissatisfaction at the length of time the trial was conducted over, with many men saying (understandably) that they would expect to 'survive' longer than 10 years with localised disease anyway.

"What we learnt from these findings is how important it is for men to have their cancer accurately diagnosed and their risk of progression individually assessed if they're to feel safe on active surveillance, particularly in the first two years when anxiety is potentially higher," says Andrew Seggie, who heads up Prostate Cancer UK's work to improve how active surveillance is carried out on the NHS.

He's identified five key things that the men said would help them choose and stay on active surveillance: being given clear information about the side effects and risks of all treatment options; emotional support; clarity around the process; continuity of care; and the ability to speak to clinicians about any concerns or questions they have.



**Often – and understandably – family members would encourage men to get their cancer radically treated. Which is why they also need the right information and support if more men are going to opt for active surveillance.**

Andrew Seggie, Prostate Cancer UK

## Robin's story

**Robin Porter was diagnosed with localised prostate cancer in 2006. He has been on active surveillance ever since.**

"I think many of us, when we hear the word 'cancer', think we should be cutting it out. But I was advised that because my cancer was at a relatively early stage, it would be perfectly safe to go on to active surveillance where my cancer would be monitored. It means that if there is any indication that my cancer is getting dangerous, they will act and probably give me radiation treatment or surgery.

"I suppose the downside of being on active surveillance is that you do have the stress. And obviously, unless you're a very special type of person, when you go and have the tests you are always thinking: 'Is this the time they're going to say sorry Robin, you're going to have to have the operation?'"



**I think with all anxiety, if you're lucky enough – as I am – to have a wonderful wife to tell what's worrying you, just by talking about it and getting reassurance helps.**

"So unless you're advised to have treatment very quickly, I think you should try and step back from your prostate cancer. Speak to the people you love and take advice from people."

Watch our video of Robin and his wife talking about their experience of active surveillance at [prostatecanceruk.org/robin](http://prostatecanceruk.org/robin)



## Helping health professionals agree a standard of care

So now we knew what was stopping men from choosing active surveillance, what about the doctors and nurses? How could we help them better offer the treatment?

During our research, we found there was huge variation in how health professionals were delivering active surveillance. Some had a strict protocol; others were developing one or had none at all, working flexibly with each patient.

It doesn't help that NHS guidelines for active surveillance haven't been updated since 2014, either (though they are currently under review). It means there is no agreed process for using modern MRI scans pre-biopsy or in follow-up assessments, or how frequent those follow-ups should be. Some were waiting three months between check ups, others a whole year.

All of which left men on active surveillance feeling confused. "Many men told us they didn't know why they were seen when they were, what their PSA results meant for them and what they needed to do after a repeat test," says Andrew.

So we got an expert panel of men and clinicians together in a room in March 2018 and hammered out a consensus on the best way to deliver active surveillance using today's technology. For the first time, health professionals now have an agreed set of protocols for when a man's cancer is safe enough to be put on active surveillance, how often they should be followed up using what tests and scans (including the latest mpMRI scanning techniques), as well as what point in the cancer's progression the man should stop active surveillance and have treatment.

"This is really useful to help us make decisions and do the best for men with the diagnostic technology we have now," says Dr Sam Merriel, a GP and researcher who sat on the expert panel. The protocols also recommend every man has a personalised active surveillance plan, which Dr Merriel says will help join up the patient's care at the GP and the hospital.

"Having that plan from the man's urology team with how often follow-ups should be and when he should be retested, all clearly agreed with the patient and their treating team, is really helpful for GPs," he says.

"It's also really important men have that ongoing clear plan and a point of contact, which is often a urology nurse. It gives them confidence that there are robust guidelines around active surveillance, and they have more input into that process and what they want."



**A clear plan and a point of contact, which is often a urology nurse, give men the confidence that there are robust guidelines around active surveillance and they have more input into that process.**

Dr Samuel Merriel, GP



## Bringing it back to the individual

Allan Higgin was on active surveillance for three years before having a prostatectomy. Having a good relationship with his urologist gave him a lot of confidence in the process.

“I felt I was monitored very closely, with consultations every three months for the first year,” he says. “So if something did start to happen, it would be picked up quite quickly and action could be taken. And in the event, that’s what happened.”

He’s pleased to see much of his good experience reflected in the new protocols, but says he wasn’t offered all the information he needed at first about his cancer or made aware of all the treatment options. Also, the telephone number he was given for a nurse by his hospital wasn’t always answered.

“I hope the new protocols will help end this postcode lottery of treatment and information provision and make everything less grey and woolly,” says Allan. “Having active surveillance is a very individual decision and it’s a shame others don’t get the same reassurance I had.”

The challenge for Prostate Cancer UK now is to help educate and train as many health professionals in the new protocols as possible, while also spreading the word to men and their families about the benefits of active surveillance and the quality of care they should expect.

“With our new protocols, we’re taking the odds out of active surveillance and bringing it back to the individual,” says Andrew Seggie. “It’s not a ‘doing nothing’ approach with the odd, impersonal NHS letter sent through the post.

“Since more than half of all men diagnosed with prostate cancer each year in the UK have localised disease, there are thousands who could avoid the potential life-changing side effects of over-treating low-risk prostate cancer by choosing active surveillance in the first instance. I hope these new measures will give them the reassurance and confidence to do so.”



**I hope the new protocols will help end this postcode lottery of treatment and information provision and make everything less grey and woolly.**

Allan Higgin



## What we want our new protocols to do

**Our new protocols for active surveillance will aim to make clear to men and health professionals:**

- who is suitable for active surveillance and who isn’t
- how often men should be tested and what the tests should be
- when men should be moved off active surveillance for treatment
- what kinds of support men should get at what stage
- how there should be a personalised active surveillance plan for men and their GPs.

Our protocols haven’t yet been officially published, but when they are (and we’re close!) we will be working hard to ensure GPs, nurses and clinicians across the UK are up to speed with the new best practice. Until then, look out for the latest developments at [prostatecanceruk.org/news](https://prostatecanceruk.org/news)



# Meet Sandie, our award-winning Wrexham nurse

**Voted for by her colleagues, patients and their families, Sandie Jones scooped our inaugural People's Choice Award for her extraordinary 20-year career caring for men – from biopsy to post-treatment support. We spoke to her and one of her grateful patients, and find out why we're campaigning for more nurses like Sandie across the UK.**

Sandie Jones, a prostate cancer Clinical Nurse Specialist from Wrexham Maelor Hospital has won our inaugural People's Choice Award for her outstanding dedication to supporting men with prostate cancer over the last 20 years.

The new award – which includes a £1,500 bursary for training or service improvement in Sandie's local area – is nominated for by patients, colleagues, and family members of men living with the disease. It was announced at the British Association of Urological Nurses (BAUN) conference in November.

“When you hear that you've got cancer, your whole world is turned upside down in an instant,” says Frank Maddocks, who was cared for by Sandie and nominated her for the award. “Thankfully, Sandie guided me through every step of the way. Without her, I don't know what I would have done. She's truly professional, incredibly kind and goes above and beyond for every single one of her patients. There's no one more deserving of this award.”

When Sandie started at Wrexham Maelor Hospital, there were no nursing services for men with prostate cancer, leaving many to come to terms with their diagnosis and meander through their treatment on their own. So she immediately set up a nurse-led follow-up clinic, providing them with the support, information and the ongoing care that they desperately needed.

Sandie went on to become the point of contact for men right from diagnosis – providing patients with their biopsy results and talking them through their treatment options. She even trained to become the only nurse in Wales able to perform prostate biopsies, so patients were cared for by her throughout their entire prostate cancer journey.

“This award means so much to me,” she said. “It means that I've been doing right by the men that I'm here to support, which to me is more important than anything. I love my job and knowing that I've made a difference in some small way has made everything truly worthwhile.”

Sandie is also a founding member of a local prostate cancer support group and has raised lots of money for local prostate cancer charities, climbing Mount Kilimanjaro last year and raising over £6,000. She's now looking forward to retirement and is currently training one of her colleagues to continue the prostate cancer services that she has set up at Wrexham.



Sandie (centre) receiving her award from BAUN and Prostate Cancer UK representatives in November.

## We're campaigning for more Sandies

“Nurses like Sandie can make all the difference, ensuring men feel supported and cared for throughout their prostate cancer journey. But the prostate cancer nursing workforce in the UK is currently under-resourced and not prepared for the increasing number of men diagnosed with the disease each year.

“Significant numbers of nurses are coming up to retirement or intending to leave within the next decade, and there are no clear plans to train a new workforce. We urgently need more nurses with the specialist knowledge required to care for men with prostate cancer – and Prostate Cancer UK is campaigning to ensure this void is filled before it's too late.”

**Leceia Gordon-Mackenzie,  
Change Delivery Senior Officer**

# PROSTATE CANCER UK UPDATE

## MANarama rebrand raises £150k

The ground-breaking MANarama campaign, which saw the National League undergo a mid-season re-brand for the first time in its history last September, has raised an astonishing £150,000 for us. Vanarama's six-week fundraising drive involved the commercial vehicle-leasing company transforming its naming rights for the fifth and sixth tiers of English football until Non-League Day on 13 October. Under the slogan, 'Lease a van save a man,' they also donated £50 for every vehicle leased during that period.

A giant cheque for the equally giant amount was presented at the televised Non-League

Day match between FC Halifax and Chesterfield. Ultra-marathon hero and Prostate Cancer UK ambassador Kevin Webber (pictured below), who had just completed seven walking marathons in seven days for us, was also given a guard of honour by both sets of fans before kick-off.

"We're proud to have Prostate Cancer UK as our first ever charity partner and look forward to working with them more going forward," said National League Chief Executive Michael Tattersall, who walked alongside Kevin on the final day of his challenge.



## Partnership a good bet in Scotland

A six-month partnership with William Hill in Scotland has raised £25k and given our volunteers the chance to reach thousands of its customers with life-saving information. From April to September last year, the bookmaker's 310 Scottish stores put up awareness-raising posters and gave away more than 10,000 prostate cancer pocket guides, while more than a hundred allowed our volunteers to talk to their customers in-branch.

Store managers were so enthused by the partnership that they organised a sponsored hike, a football tournament and a Brew and Bake sale to raise money. There was even a motion in the Scottish Parliament, signed by a third of MSPs, backing the partnership and helping us build some powerful support for our work to improve diagnosis and treatment in Scotland.

We're now exploring plans to extend the partnership with William Hill so we can continue talking to their customers, many of whom are men traditionally hard to reach with messages about their health risks.



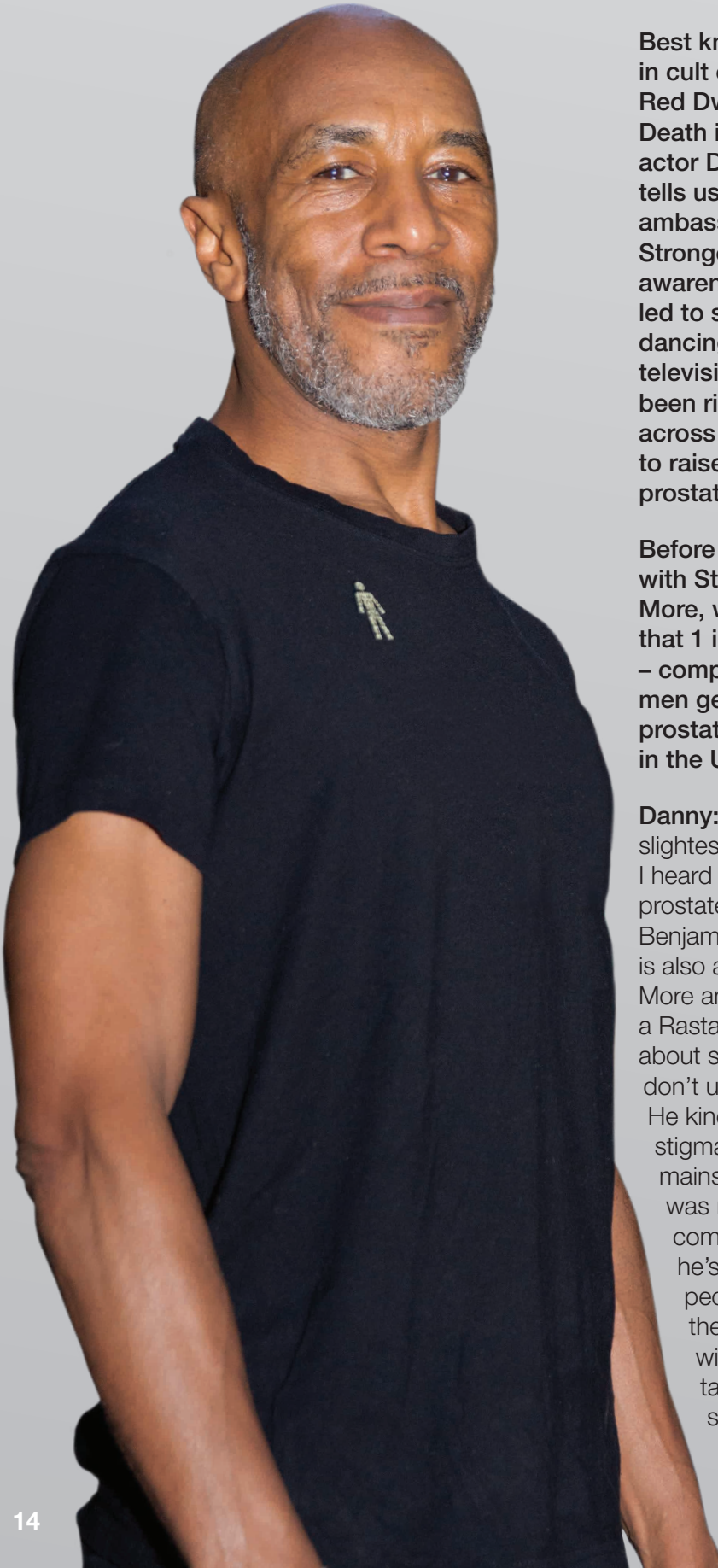
## BMA prize for our online guides

We're delighted to have won a Patient Information Award from the British Medical Association with one of our online self-management guides. 'How to manage sex and relationships' was praised for helping men make decisions when it comes to prostate cancer and its treatment's impact on their private lives, such as getting an erection. One of the judging panel said: "I think this resource is to be applauded for covering such a wide range of important topics in such

a constructive, unbiased and empathetic way."

Our five 'How to manage' guides use a variety of interesting ways – from slideshows and quizzes to trackers and animations – to help men work out what their symptoms are and where they can access the care and treatment they need. They're a great first point of call for those who may not feel comfortable about bringing up sensitive issues with their doctor or nurse. Since we launched them in 2017, our online guides have been used almost half-a-million times. Explore them for yourself at [prostatecanceruk.org/guides](http://prostatecanceruk.org/guides)

# Danny John-Jules



**Best known for his roles in cult comedy classic Red Dwarf and drama Death in Paradise, actor Danny John-Jules tells us how being an ambassador for our Stronger Knowing More awareness campaign led to stripping off and dancing on national television, and why he's been riding motorbikes across the Caribbean to raise awareness of prostate cancer.**

**Before getting involved with Stronger Knowing More, were you aware that 1 in 4 black men – compared to 1 in 8 men generally – will get prostate cancer in the UK?**

**Danny:** Not in the slightest! The first person I heard talking about prostate cancer was Benjamin Zephaniah (who is also a Stronger Knowing More ambassador). He's a Rastafarian talking about stuff that Rastas don't usually talk about. He kind of broke the stigma; he went into mainstream media and was reaching the black community. I think he's definitely helped people to realise there's a problem with black men not taking this disease seriously enough.

But it wasn't until I heard a prostate cancer survivor tell his story at the Stronger Knowing More campaign launch event that it really hit home. It was a rude awakening for all the black people in the room – both men and women. You could literally hear a pin drop.

**Why do you think black men aren't talking about it?**

**Danny:** A lot of things come into that: religion, machismo and the impression that the first thing that's going to happen is an intimate intrusion on the medical side of the things. But despite the fact it can often be successfully treated if caught early, awareness in black communities remains relatively low. The most devastating thing in a community is often the thing that nobody wants to talk about.

**Since then, you've been stripping and dancing on TV to raise awareness of the disease. How did that happen?**

**Danny:** I was approached to take part in the first series of ITV's The Real Full Monty because of the work I was doing for Prostate Cancer UK.

It was a great laugh, and the night it aired, your website crashed because people wanted more information. The show was also nominated for a TV Bafta, and it was while Wayne Sleep and I were dancing down the red carpet at the awards ceremony that I met one of the producers of Strictly Come Dancing.

### **You also rode a motorbike around the Caribbean raising awareness.**

**Danny:** I've been making motorbike shows with my good friend Steve Keys for many years and we've been all over the world – but never the Caribbean. Which is amazing, considering I filmed seven series of Death in Paradise on the island of Guadeloupe, and both my parents were from neighbouring Dominica. So after my final series, we decided to do Two Wheels One Love and ride around both countries speaking to men and raising awareness of prostate cancer.

### **Were black men over there aware of their increased risk?**

**Danny:** Generally not. But as we got chatting, some did reveal they either had prostate cancer or knew someone who'd had it. One of the French-speaking producers working on Death in Paradise revealed he'd been diagnosed. Also, when we were

researching our trip, we were introduced to the British High Commissioner of St Lucia, who told us about his father sadly dying of prostate cancer after refusing treatment. He was the local herbalist – basically an unofficial pharmacist – and thought he could cure it naturally. Of course, he couldn't. His last breath was sat on the toilet and his son had to lift him off – such a terrible story. But he was of a different old-fashioned generation, who died due to ignorance.

### **How about back in the UK. Are things beginning to change?**

**Danny:** We probably all hear the word 'cancer' every day. But it isn't until someone well-known, like Bill Turnbull, talks about it in the press that men really seem to sit up and listen. Someone who used to be on the TV every day is so familiar to us – like a family member. That's when men take a reality check and stop suffering in silence.

By continuing to raise awareness and funds, we are giving our sons and grandsons a fighting chance of a better diagnostic tool and treatments. My son is 12. Because I work with you, he already has an understanding of what prostate cancer is. I'm not preaching to him, it's just part of our normal everyday conversation.

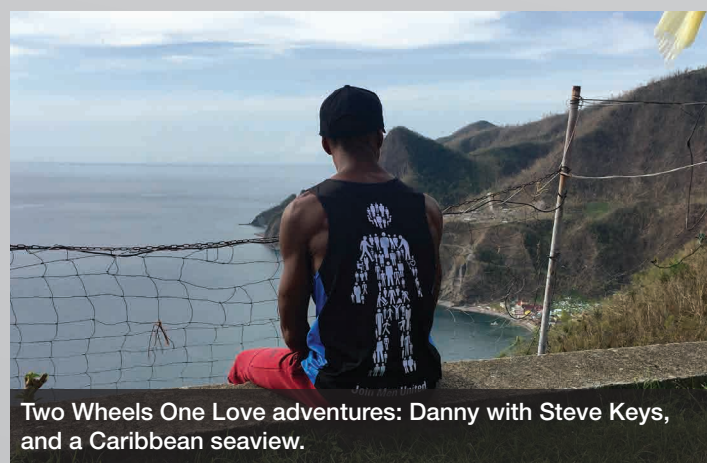
### **What would your advice be to black men over the age of 45 – particularly with a family history of prostate cancer?**

**Danny:** Some men are still unaware that you can go and get a simple PSA blood test. They will assess that and

decide whether they need further exploration. On the whole, it will start and end with the blood test unless something is seen to indicate there is a problem. It's pretty simple. So my advice would be: go and speak to your GP about whether the PSA blood test is right for you.



## **By continuing to raise awareness and funds, we are giving our sons and grandsons a fighting chance of a better diagnostic tool and treatments.**



Two Wheels One Love adventures: Danny with Steve Keys, and a Caribbean seaview.

To find out more about your risk of prostate cancer visit [prostatecanceruk.org/risk](http://prostatecanceruk.org/risk)

# THE MANUAL

Your questions answered about  
**copng with the emotional fallout from prostate cancer**



**Being diagnosed with prostate cancer can be a shock and it may take some time to adjust to the change in your life. You may feel like you need to put on a brave face, but inside feel scared, worried, stressed, helpless or even angry.**

**It's okay to show people how you're really feeling and ask for help if you need it.**

**Health psychologist Dr Emily Robson, who works in our Health Information team, answers some of your questions and concerns about coping with the emotional fallout from prostate cancer.**



**Q** I feel down most of the time, but how do I know if I'm depressed?

**A** There may be several times in your life when you experience ups and downs – this is normal and everyone feels low or anxious from time to time. But talk to your GP if you feel very low a lot of the time, if your sleep pattern or appetite changes, or if you get angry easily, as these could be signs of depression.

Anxiety and depression can be triggered by stressful or difficult situations, like being diagnosed with prostate cancer. If you're having tests or treatment, you'll probably have a lot on your mind. You may worry about how bad your cancer is or how your family will feel, or you may feel anxious about making a decision about treatment.

But there is treatment and support that could help if you think you're depressed or struggling with anxiety, so speak to your GP.

**Q** What things can I do to improve my mood?

**A** Lots of things. If you have depression, your GP may prescribe you medication or refer you for talking therapy with a counsellor or psychologist. You could also try joining a support group or online community (such as ours, see p22) where men get together to share their experiences of having prostate cancer. You can ask questions, share worries and know that someone understands what you're going through.

It may also help to set yourself some goals and things to look forward to, even if they're only small. Look after yourself and try to make time to relax. Some men find listening to music or mindfulness can help. Keeping active is also a great way to lift your mood and improve your physical fitness. If you're not used to exercising, start slow and pace yourself.



**It may help to set yourself some goals and things to look forward to, even if they're only small.**

Remember, you may not find a quick fix and it could take some time before you start feeling better. Think about how you've coped with difficult situations in the past and try to use the same techniques to deal with your feelings this time.

**Q** What if I'm not very good at talking about how I feel, especially to people I don't know?

**A** It can be difficult to open up, whether to health professionals or people that you're close to. We know that some men don't like showing their emotions in front of their family or friends. But remember that prostate cancer can impact those around you, too.



Your family and friends might be having difficult feelings as well, so talking about your own feelings could be helpful for everyone.

When talking to health professionals, try planning exactly what you'll say before your appointment. You could write down a couple of points that you really want to talk about, so you don't forget or get distracted. Try not to feel embarrassed or afraid to talk about things that are important to you. Remember that your doctor or nurse will have lots of experience talking to people with cancer about similar concerns. They're trained to listen and provide you with support.

**Q** I feel tired and I've got no motivation to do anything. What can I do?

**A** That can happen when you're feeling down. It's a good idea to try to keep some routine and structure to your day-to-day life to help manage this. It could help to write down a daily plan. Try thinking about some essential tasks you have to do each day and find time to fit them in. These might include showering and dressing, eating a well-balanced diet, doing exercise or some household chores, or spending time with your family and friends. Reward yourself with a small treat if you complete all your tasks for the day. This can help keep you feeling motivated.

**Q** I'm finding it difficult to live with the side effects of treatment. Will I ever feel normal again?

**A** It may take some time. Many men experience side effects like erectile dysfunction, incontinence, hot flushes and fatigue and these can be hard to deal with. But there is treatment and support available, so speak to your medical team if you're worried. Our online 'How to manage' guides have lots of tips on dealing with side effects and so may help you feel more in control. Visit [prostatecanceruk.org/guides](http://prostatecanceruk.org/guides).

If you feel well enough, try to carry on with things as normal. Spending time with your family and friends can make a big difference to the way you feel. It might also help to join our online community, where you can

talk to others who are going through similar things. Knowing that you're not alone in the way you feel can be reassuring.

Be patient and kind to yourself as you come to terms with changes in your life. It can be a long process and you may feel the loss of things that have changed. Writing down your thoughts each day is a good way to track how far you've come. Or you can contact our Specialist Nurses for more support (see p22 for details).



**It might also help to join our online community, where you can talk to others who are going through similar things. Knowing that you're not alone in the way you feel can be reassuring.**



**To find out more about the emotional impact of prostate cancer, visit [prostatecanceruk.org/emotions](http://prostatecanceruk.org/emotions)**

# March with us all over the UK

March for Men is back and bigger than ever in 2019



We've stepped up the number of locations for this year's March for Men, with 10 different events happening across the UK. So now there are more ways to show your support for us closer to home.

Our local marches will be taking place in London, Leeds, Nottingham, Birmingham, Bristol, Cardiff, Liverpool, Manchester, Glasgow and Belfast. Each will have a choice of a short 2.5km, medium 5km or long 10km route, so everyone can join in.

But that's not all. Our popular Football March for Men will also be returning, with a choice of four marathon-length routes, taking in the sights of football clubs across London before converging at Wembley Stadium.

And for anyone who can't make one of our organised events or just fancies taking on their own walking challenge, you can organise your own march at a time and place that suits you. Our fundraising team are here to help you get started with all the planning advice and resources you need.

For more info and to book your place on a March for Men event, call us on **020 3310 7388** or visit **[marchformen.org](http://marchformen.org)**



- Bristol**  
Saturday 1 June
- Liverpool**  
Sunday 2 June
- Belfast**  
8-9 June
- London**  
Saturday 15 June
- Glasgow**  
Sunday 16 June
- Cardiff**  
Sunday 16 June
- Birmingham**  
Saturday 22 June
- Manchester**  
Sunday 23 June
- Nottingham**  
Sunday 23 June
- Leeds**  
Saturday 29 June

# In the SPOTLIGHT

## Adam Churton from London

Twelve friends have rowed 160km from Ireland to Wales in just 20 hours to raise more than £70,000 for us, having astonishingly never picked up an oar before.

Led by Adam Churton – whose dad was diagnosed with advanced prostate cancer in 2011 – the #Row4aCure crew crossed the Irish Sea from Arklow in a traditional Celtic longboat. They rowed through the night, in hour-long shifts, to arrive at Abersoch in the early hours of the morning on 26 July.



“The whole experience was incredible, rowing with the sun setting in front of us with no land in sight,” Adam said. “We were all novice rowers, but we pulled together and no one ever complained.”

Adam hopes the money raised will help create a new prostate cancer screening programme to

save the lives of more men like his dad.

“Due to the incredible advances in research and treatments that charities like Prostate Cancer UK are helping to fund, my father is still going strong today,” he said.

Watch a video of their brilliant feat at [row4acure.co.uk](http://row4acure.co.uk)



### writing a brilliant blog about his experiences at mymanofmen.wordpress.com

“Dad loved watching Only Fools and Horses. My nickname for him was ‘Dave’, because Mum and I thought he looked like Rodney, who was called Dave by Trigger. That’s why I called dad Dave – his love for the programme and my love for him. He took his nickname well and that humour helped us through the bad days.

“It was not nice seeing dad paralysed, but what I can say is that even though dad

couldn’t walk, even being in the bed, he was still there. He was still my dad. We would still have a laugh and a joke together and he would always ask me about what was going on at school and talk about things to me.

“Although some may have questioned his quality of life, every moment spent with us made it priceless.”

William Kilgannon was 12 when his dad, Brian, died from advanced prostate cancer in 2015. Since then, he’s raised funds and awareness about how the disease affects families, including



Tell us about your Top Dad: email [editor@prostatecanceruk.org](mailto:editor@prostatecanceruk.org)

# THANK YOU

## £30,000

Luke Hemmings, a sports scientist at Preston North End FC, was so inspired by doing our Football to Amsterdam cycle ride, he rode from John O’Groats to Land’s End then ran to Dover. Incredible!

## 6 summits

Steve Graham has one peak left in his challenge to climb the highest mountain on each of the seven continents after topping Everest in June. He’s raised £3,200 for us so far.



## 250 marchers

Camille Rhodes organised her own March for Men in Peterborough in October, with everyone taking part raising more than £13k.



## £10,000

Lunch4Life’s Glitter Ball in October was joined by Wayne Sleep and Victoria Derbyshire, with a live auction helping to raise this brilliant amount.

## 1 Big Sing

The Magnificent AK47 Choir raised over £3k from a Big Sing day, a month-long walking challenge and a special performance for March for Men.



# GET INVOLVED

Five things you can do to support us

## 1 Men United Match Days Various dates

Join us at football grounds around the country to collect money from fans for the most common cancer in men. You'll meet lots of like-minded people, enjoy the match day buzz, and get a ticket to watch

the match afterwards. Find out more at [prostatecanceruk.org/matchday](http://prostatecanceruk.org/matchday)



## 2 Donate your day All year round

Got a special day coming up? Whether it's your birthday or your wedding day, you can support us while you celebrate by taking a collection or selling badges to your guests. It's a great way to mark

your occasion and we've lots of ideas, resources and support to help you do it. Find out more at [prostatecanceruk.org/dyd](http://prostatecanceruk.org/dyd)

## 3 March for Men May-June

Thanks to the thousands of you who've taken part over the last two years, our March for Men programme has raised close to £2 million – helping to bring us one step closer to stopping prostate cancer being a killer. This year, our local marches are happening in 10 UK cities, from London

and the Midlands to Cardiff and Glasgow (see p18 for full details). There's also our marathon-length Football March for Men and a whole host of other ways you can do your own march for us in 2019. Find out more and secure your place at [marchformen.org](http://marchformen.org)



## 4 Prostate Cancer UK Golf Championship Before 1 September

Could you be crowned one of our champion golfers in 2019? Host a golf day to raise funds for us and the winning player will earn a place at one of three regional finals at the world-class courses of Sandy Lodge, Haggs Castle or Lymm. Former European Open Champion

Andrew Murray will be offering a free golf clinic for every finalist on the day, too. Find out more at [prostatecanceruk.org/golf](http://prostatecanceruk.org/golf) or call **020 3310 7235**.

## 5 Darts All year round

Whether you throw at home or for your local team – or you're just an avid fan of the sport – we've got loads of fun, money-making ideas to turn your passion for darts into vital funds for our research. From an all-day darts marathon to sponsored exhibition matches, organise an event that hits the

bullseye with your friends and family using our darts fundraising pack. Order yours at [prostatecanceruk.org/darts](http://prostatecanceruk.org/darts)



# EVENTS

## CALENDAR MARCH – AUGUST 2019

### MARCH

#### 3-7 World's Biggest Pub Quiz

Put your knowledge to the test by joining PubAid's World's Biggest Pub Quiz, happening in thousands of pubs across the UK. Either get your local signed up or find a pub near you that's already taking part at [pubaid.com/quiz](http://pubaid.com/quiz)

### APRIL

#### 12 Tough Mudder

Take on the ultimate obstacle course race over 10-12 miles (or a shorter route of five miles) that will test your stamina, resilience and teamworking abilities. Events are held right across the UK until 9 September, with this first one in London's Finsbury Park.

### MAY

#### 25-26 Edinburgh Marathon Festival

Taking in the beautiful East Lothian coast over the Bank Holiday Weekend, this running extravaganza offers a range of distances, from 5km up to a full marathon. With a team relay and junior races also available, there's something for all the family!

#### 25-26 London to Brighton Challenge

Take on 100km on foot, from the capital to the coast, and enjoy wonderful countryside for much of the off-road route. Either walk, jog, or run along half, quarter and full-distance options.



### JUNE

#### 8 Jurassic Coast Challenge

Starting at Poole Harbour, choose from 25, 50 or 100km walking routes that take you past the famous landmarks of Dorset Coast – from Durdle Door to West Bay Cliffs. Beautiful.

#### 28-30 Grand Depart Classic

This is your chance to cycle the first stage of the 2019 Tour de France, a week before the pros. Taking place in Brussels, Belgium, this three-day event (with one day in the saddle) will see you cycling on roads freshly paved for the world-famous event.



### JULY

#### 14 Great Weston Ride

This is a fabulous 57-mile challenge bike ride from Bristol to Weston-super-Mare. You and your trusty two-wheeled steed will follow a spectacular route through the Mendips and across the Somerset Levels.

#### 27 Walk the Night

Take a night-time hike around London's most famous landmarks in the second year of this hugely popular new fundraiser for breast and prostate cancer. Choose from half and full-marathon distances and commit to raising £199.

### AUGUST

#### 3-4 Prudential RideLondon

Join the capital's festival of cycling and ride along closed roads throughout the city and out into Surrey. Choose either the 46 or 100-mile route and enjoy the support of thousands lining your way. Join our team – one of the biggest in the event – and we'll have your back from start to finish.

### The Kiltwalk

Join thousands of people as they don some tartan and tackle a 5, 13 or 26-mile walk around a Scottish city, raising funds that receive an incredible 40 per cent top-up from

the Sir Tom Hunter Foundation. Events are taking place in Glasgow (28 April), Aberdeen (2 June), Dundee (18 August) and Edinburgh (15 September).

Find out more at [thekiltwalk.co.uk](http://thekiltwalk.co.uk)



Check out full details and sign up to all these events, plus many more, at [prostatecanceruk.org/events](http://prostatecanceruk.org/events)



# Our services

## Specialist Nurses 0800 074 8383

(Mon to Fri 9am-6pm,  
Wed 10am-8pm)  
Our Specialist Nurses have the time to listen and answer your questions on anything to do with prostate cancer and prostate disease.

## One-to-one telephone support 0800 074 8383

Talk things over with someone who's been there. We can match you with trained volunteers who've had a similar experience.

## Online community

Join the community online and talk to others who know what you're going through. You can ask questions, post information and share your ups and downs.  
**community.**  
[prostatecanceruk.org](http://prostatecanceruk.org)

## Fatigue support 0800 074 8383

If you have prostate cancer and you're struggling with fatigue, our Fatigue support service is designed to help you manage your tiredness so you can do the things you want to do.

## Information on prostate cancer 0800 074 8383

We provide free information on prostate cancer and prostate disease. Order or download copies from the publications section of our website or call our Specialist Nurses for help choosing the publications you need.



**Superb, compassionate reassurance from people that care and have experience so can help.**

One-to-one telephone support user

## Regional services

To find out what local support and services are available in your area go to [prostatecanceruk.org/find-local-support](http://prostatecanceruk.org/find-local-support)

## Prostate cancer support groups

Meet and talk to other people affected by prostate cancer who understand what you're going through. There are more than 120 independent groups across the UK.

## Live chat

Our Specialist Nurses are available online to answer your questions and help you find the information you need.

The blue men on this map represent the locations of support groups who have asked to be listed on our website. Find a group near you at: [prostatecanceruk.org/supportgroups](http://prostatecanceruk.org/supportgroups)

Please note that some groups run meetings in more locations than the one listed.



Find out more about our services at [prostatecanceruk.org/get-support](http://prostatecanceruk.org/get-support)

# Other useful organisations

## Bladder and Bowel UK

[www.bbuk.org.uk](http://www.bbuk.org.uk)

0161 607 8219

Information and support for anyone experiencing bladder and bowel problems.

## British Association for Counselling and Psychotherapy

[www.itsgoodtotalk.org.uk](http://www.itsgoodtotalk.org.uk)

01455 883 300

Provides information about counselling and details of therapists in your area.

## Cancer Black Care

[cancerblackcare.org.uk](http://cancerblackcare.org.uk)

020 8961 4151

Provides information and support to people from black and minority ethnic communities who are affected by cancer.

## Cancer Research UK

[cancerresearchuk.org](http://cancerresearchuk.org)

0808 800 4040

Provides information about living with cancer.

## Complementary and Natural Healthcare Council

[www.cnhc.org.uk](http://www.cnhc.org.uk)

020 3668 0406

Details of complementary therapy practitioners who meet national standards of competence and practice.

## Macmillan

### Cancer Support

[www.macmillan.org.uk](http://www.macmillan.org.uk)

0808 808 0000

(Mon-Fri, 9am-8pm)

Provides practical, financial and emotional support for people with cancer, their family and friends.

## Maggie's Centres

[www.maggiescentres.org](http://www.maggiescentres.org)

0300 123 1801

Provide information and support to anyone affected by cancer. Their website holds a list of centres across the UK and has an online support group.

## NHS Choices

[www.nhs.uk](http://www.nhs.uk)

Provides information to support you in making health decisions, including an A-Z of treatments and conditions, and information on NHS health services in your local area.

## Penny Brohn UK

[www.pennybrohn.org.uk](http://www.pennybrohn.org.uk)

0303 3000 118

Offers support using complementary therapies and self-help techniques – working hand-in-hand with medical treatment.

## Relate

[www.relate.org.uk](http://www.relate.org.uk)

0300 100 1234

Relationship counselling and sex therapy for individuals and couples.

## Sexual Advice Association

[www.sda.uk.net](http://www.sda.uk.net)

Website and app with advice and information about erectile dysfunction.

## Tackle Prostate Cancer

[www.tackleprostate.org](http://www.tackleprostate.org)

0800 035 5302

Also known as the National Federation of Prostate Cancer Support Groups, it works closely with us to provide local support to patients and families.

# Remote support could revolutionise post-treatment care

Funded by the Movember Foundation, our global prostate cancer care initiative TrueNTH has spent several years developing and testing a new supported self-management programme to better help men once they've finished prostate cancer treatment. Now, after a successful trial led by the University of Southampton, we're in discussions with NHS providers to roll it out across the UK.

## What is supported self-management?

It's a 'risk-stratified' programme of remote monitoring and support for men living with or after prostate cancer, using an online portal to link men up with their care team and identify quickly who needs help and support.

## Why's it needed?

Research by TrueNTH showed that a significant proportion of men felt abandoned by the healthcare system after their initial prostate cancer treatment was completed. They felt their follow up care was poorly structured and didn't address their specific issues.

## How does the programme work?

Once a man has completed his treatment, his care team work with him to identify his individual needs. They then provide him with a support worker and invite him to attend a workshop with other men like him, which offers the tools and knowledge to better manage his needs – including a login to the online portal.

## What's so special about it?

Uniquely, the programme is all done remotely after the initial consultation and workshop. Using the online portal, men can contact their care team, access their PSA results, search for health information and complete assessments that help monitor their changing needs.

## What are the benefits?

The system helps health professionals identify which men need more help at a particular time, more quickly and easily than before, and reduces the number of outpatient appointments needed. So it's more efficient and convenient for everyone involved.

## Where is the programme currently available?

So far, it's been adopted by eight NHS Trusts in England, and discussions are ongoing with other Trusts in England, Wales and Scotland to offer it too.

## What do men say about it?

"Worth its weight in gold," says John, a patient on the programme in Dartford and Gravesham NHS Trust.

# Ready, steady, SHOP!



**PROSTATE  
CANCER UK**

Get kitted out at our online shop:  
[shop.prostatecanceruk.org](http://shop.prostatecanceruk.org)