# NEWSLETTER











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Putting people at the centre of research

# Welcome

Over the last few years, we have looked to broaden our academic research portfolio, funding the very best and most innovative research being delivered by world-leading institutions across the UK. In 2018, we began this work in earnest and, as a result, we have now cemented our position as a vital funder of leading research into prostate cancer. We are now funding 15 of the highest-quality research projects and contributing to approximately 14% of all non-profit prostate cancer research in the UK: a major jump from 3% in 2017.

Although COVID-19 slowed down some of our research owing to lab closures in 2020/21, we will more than double our research spend in 2021/22. At the same time, we've rapidly expanded the breadth and depth of our patient involvement and information work that both enables us to focus on the things that matter and helps us engage the hardest-to-reach parts of our community.

We started off this journey by wanting a more balanced academic research portfolio that would have an impact on men's lives. Since then, we have changed our approach significantly. We've put much more focus on targeting key needs where we can have impact for patients within the prostate cancer ecosystem. This started with the Ecosystem report in 2019, which led to us funding some significantly underfunded areas where there are significant patient needs – such as bone metastases projects.

In recent months we were delighted to have committed to a programme of research looking at the needs of the Black community. As you may be aware, you are twice as likely to get prostate cancer if you're Black and you are significantly more likely to die from it. We have already received several fascinating proposals that aim to meet some of these needs and we look forward to assessing them over the next few months.

Of course, our other 15 research projects continue to progress and many of the seven projects we funded back in 2019 are approaching the halfway stage. It's fascinating to see these projects starting to produce results and I look forward to sharing more of their successes in forthcoming newsletters.

As always, look after yourselves and I hope to see more of you in person in 2022.

**Oliver Kemp CEO** 

Charlotte Bevan's (left) research focuses on the link between

Featured on cover: Dr Claire Fletcher (right) and Professor

to our supporter community to work in the best way we can to help create a better future for all those affected by prostate cancer. As part of this, we invited you to complete a feedback form on our last newsletter and how well it's working.

We are keen to listen



enjoy reading the newsletter

This is what you said:



found the newsletter was easy to understand



felt more connected to the PCR community as a result of reading the newsletter



felt more connected to our research as a result of reading the newsletter



The most popular articles included information on prostate cancer diagnosis and treatment, research updates. prostate cancer in the news and personal patient stories

Connect with us to stay up-to-date with our latest news and tell us your stories:



@prostatecancerresearch



@PCR\_News



f /prostatecancerresearchnews



in /prostate-cancer-research

obesity and prostate cancer. Read more on page 3.

#### **Robin's story**

# I am fortunate that my prostate cancer is low-grade and non-aggressive

I was diagnosed with prostate cancer in June 2015. I had been experiencing some urinary problems and initially, like other men my age, had put this down to getting a bit older although I thought that it could be an enlarged prostate. I also have type-2 diabetes, which makes me more susceptible to infections, so I also thought that I might have an infection.

I thought I'd better get it checked out and went to see my GP. My GP referred me for further investigations, and I found myself on a two-week pathway for investigations into prostate cancer. After a short while, a biopsy, and a scan, I found myself listening as my consultant and a specialist nurse gave me the news that I have prostate cancer. I was not particularly expecting this as I thought it was just likely to be an enlarged prostate.

I am fortunate that it is currently low-grade and non-aggressive and I am currently on active monitoring, with regular blood tests and check-ups with the specialist hospital team who are fantastic.

While I knew a little bit about prostate cancer, one of the things that really helped me was the Prostate Cancer Research booklet 'Treating Prostate Cancer'. It is clearly laid out and written in easy-to-understand terms, and I know I can refer to it should I need to check anything if my situation changes.

I think it is really important that the patient voice and patient experience are at the centre of patient care and that this is central in the development of new services and treatments. I now have the opportunity to promote this in several ways.

One is in my role as a patient, carer and publicinvolvement participant for a university where I speak to healthcare students from a range of professions as part of their education and learning. I have also taken part in reviewing research proposals through Prostate Cancer Research to provide the patient perspective and I have found this really interesting. I have enjoyed being able to ensure that the patient voice is represented in all aspects of research and treatment options.

I am passionate about supporting research into prostate cancer that aims to lead to new and improved treatments and better outcomes, both now and for other men in the future, and in time finding a cure for prostate cancer.

**Robin Giles** 





common questions can be found on our website pcr.org.uk/



Join the Patient Voice group and help us to know what matters to you pcr.org.uk

#### Researcher Q&A

# **Dr Valeriia Haberland**



**Dr Valeriia Haberland**Senior Research Associate in Bioinformatics
UNIVERSITY OF EAST ANGLIA

# How did you get into cancer research?

I come from a computational background (PhD in Computer Science, King's College London), but I was always inclined to apply my skills to the biomedical field because of the positive impact you could make in people's lives. Cancer is a complex and multidimensional disease with different risk factors, evolution and treatments. That's why I'm here, very hopeful my current project will have an impact in prostate cancer.

# What's your favourite thing about working in cancer research?

When the results start coming together and you see a whole new picture emerging, with the details sharpening with every new piece of information, like when you are painting. It's exciting.

# Your project is using machine learning. Could you explain what this is?

Machine learning is part of artificial intelligence (AI), which encompasses many computational techniques and algorithms that enable automated learning. It reveals additional information from lots of data that would not be possible to find manually.

# Could you give us a brief overview of your PCR project?

Prostate cancer is one of the most common types of cancer among men. It is highly diverse, ranging from cancers that progress slowly and are unlikely to cause any symptoms to aggressive deadly cancers. Unlike breast cancer there isn't an established framework to divide prostate cancer into subtypes. Such a framework would allow the right treatment to be chosen at an early stage and avoid overtreating patients with non-aggressive prostate cancer.

Our project aims to determine subtypes of prostate cancers using machine learning and many measurements in cancer cells.

The project was conceptualised by Prof Daniel Brewer (UEA), Dr Dan Woodcock (University of Oxford) and Prof David Wedge (University of Manchester). We hope our project will improve subtype identification and possibly uncover new subtypes, which will be translated into clinical practice and improve patient care.

# What will this project mean for those living with prostate cancer?

For the patient, we hope to facilitate better treatment and diagnosis, improving quality of life and recovery rates. Overtreatment may reduce quality of life unnecessarily for less aggressive subtypes of prostate cancer, while lack of timely and appropriate treatment for aggressive ones may lead to shorter survival and higher probability of metastasis. There are also different subtypes of aggressive prostate cancer, some of which, for example, might not be sensitive to hormone therapy and so require a different treatment. We try to untangle these issues by not only looking for specific biomarkers, but also by looking at a bigger picture that will help us to assess the risks for patients more accurately and encourage the development of subtype-targeted drugs.

# What do you think is the most exciting recent development in cancer research?

The most exciting development has been achieved in treatment – in particular, immunotherapy, where the immune system is trained to attack tumour cells. However, not all patients respond to immunotherapy, and we believe identifying prostate cancer subtypes would give us an opportunity to predict the success of this therapy for individual patients.

## AI COMPUTING SOLUTIONS FOR PROSTATE CANCER



 Prostate cancer is the name for all cancers that start in the prostate but every cancer is different







2 This variation can make it difficult to know how to treat an individual's cancer



3 Some cancers are pussycats – they grow slowly and remain in the prostate for decades



4 Others are tigers – they are aggressive, grow rapidly and lead to advanced disease



5 This project will use AI tools to analyse a huge amount of data





6 The researchers will develop a new way to classify prostate cancer and separate the tigers from the pussycats





7 This could be used to decide which treatments would be best for each patient



8 Classification has already revolutionised the treatment of breast cancer

# Research update





You can read more about our research grants on our website pcr.org.uk/ our-research



Current research projects being funded by PCR In the last few months, the research team have been busy travelling across the UK to meet some of our scientists face-to-face for the first time since January 2020. We worked with the scientists and their labs to keep everyone safe and ensure that every visit complied with COVID-19 regulations.

Meeting the faces behind the research and exploring their labs is particularly important after the pandemic, which has put the research community under some strain. Building strong relationships with PCR-funded researchers is key in enabling us to support them to deliver their incredible work, especially in challenging times such as last year's lockdowns, which restricted access to labs. Professor lain J. McEwan, Dr Jorge de la Rosa, Professor Bart Cornelissen and Professor Gert Attard all welcomed us to their respective labs to meet their fantastic teams, update us on the progress of their projects and outline the next steps.

We were also able to explore **Dr Harveer Dev**'s lab for the first time. Harveer's project was delayed due to COVID-19 restrictions, but it was great to see that his team have hit the ground running, investigating why damaging the DNA inside cancer cells only works as a treatment for some prostate cancer patients. In addition to investigating new therapies such as PARP inhibitors, Harveer also showed us an irradiator, which can mimic the effects of radiotherapy on cells. This is important as, while PARP inhibitors may become available for many more men in the future, radiotherapy is standard treatment for many men with prostate cancer right now, and, while new treatments are needed, we should also look at improving the treatments we currently have.

As well as catching up with old friends, we were able to meet some of our new scientists who were funded through our 2020 grant call.

Dr Claire Fletcher and Professor Charlotte
Bevan invited the team to their lab at Imperial
College London. We learned all about their project
investigating the relationship between obesity and
prostate cancer, which began in June, and which
we highlighted in our autumn research update. One
of the interesting aspects of this visit was to follow
the journey the researchers take when they get a
call from Charing Cross Hospital to let them know
that a patient has asked for a part of their tumour,
removed routinely during their treatment, to be
donated to the research project, and to watch as
what could be considered clinical waste becomes
an invaluable source of information that will benefit
many more patients.

We also travelled further afield to meet with **Dr Kirsteen Campbell** at the Beatson Institute in Glasgow, named after oncology pioneer Colonel Sir George Beatson, whose sword still hangs on the wall of the boardroom where we sat with Kirsteen and her colleagues to discuss her work. This team have seen that a protein called MCL-1, which they have experience of in breast cancer, appears to be important in advanced prostate cancer. They are working to unravel its exact function and consider if it could lead to new treatments for advanced disease. It was brilliant to see how the researchers at the institute collaborate and work together, combining their individual strengths to bring their projects to life.







PCR scientists and staff during site visits

#### Side effects from treatment

# Managing urinary incontinence



Around one in eight men will get prostate cancer



Prostate cancer accounts for 26% of male cancer diagnosis in the UK Urinary incontinence or leaking urine is a common side effect of prostate cancer treatment. Some treatments for prostate cancer, such as prostatectomy and radiotherapy, can cause damage to the nerves and muscles needed for peeing. Your individual risk of developing urinary incontinence will depend on your treatment and whether you have had problems with leaking urine before.

Urinary incontinence can range from mild, where you leak small amounts of urine when you cough or sneeze, to severe, where you leak more frequently. Incontinence following surgery is usually temporary but it can take up to six months to improve. There are also many treatment options available, and you can speak to your doctor to decide which treatment is most suitable for you.

#### **Pelvic floor exercises**

The muscles you need for peeing are called pelvic floor muscles and exercising these muscles helps with urinary incontinence. The NHS recommends that you sit comfortably and squeeze these muscles 10 to 15 times. If you are unsure of where to find these muscles, you will be able to feel them if you imagine that you are trying to stop the flow of urine when you pee. Be aware that stopping the flow of urine midstream can harm your bladder, so do these exercises at another time.

#### **Absorbent pads**

Absorbent pants and absorbent pads that can be worn inside underwear are available. There are different types and sizes available depending on the amount of absorbency that you need and your own personal preferences. They are designed to be as discreet as possible and can make it easier to manage leaks. It is important to change pads regularly and clean the skin around the area to prevent soreness. Depending on where you live, you may be able to get free products on the NHS, but they are available in most supermarkets and pharmacies. Products can also be ordered online and most retailers will offer discreet packaging and delivery.

Penile sheaths are an alternative to absorbent pads. These fit over the penis like a condom and a tube attaches the sheath to a drainage bag that collects any leaking urine.

#### Access to public toilets

It can be reassuring to know that you can access public toilets easily when out. The charity Bladder and Bowel UK offer free Just Can't Wait cards, which you can show in shops, restaurants and other establishments to access a toilet quickly and without further explanation. The card cannot guarantee access to a toilet, but it is accepted and recognised by most establishments.

Order your free Just Can't Wait card here: bbuk.org.uk/just-cant-wait-card-request Most people find that leaking urine after surgery is temporary and that they can manage their urinary incontinence with pelvic floor exercises, strengthening exercises such as Pilates, absorbent products and lifestyle changes.

## Lifestyle changes

Smoking causes coughing, which puts pressure on the pelvic floor muscles, so stopping smoking may help. You should also avoid drinking caffeine and alcohol as they irritate the bladder.

Maintaining a healthy weight is important as excess weight can add additional strain. Lifting heavy objects and high-impact exercise such as running can add pressure to pelvic floor muscles but strengthening exercises such as Pilates can help to strengthen these muscles and relieve symptoms.

Ensure you are drinking enough water (the current recommendation is six-to-eight glasses per day). Reducing the amount of water that you drink can cause dehydration as well as reducing bladder capacity, which can make incontinence worse.

Constipation can put pressure on the pelvic floor muscles, so it's important to eat a fibre-rich diet and drink plenty of fluids. If you do become constipated, seek treatment as soon as possible.

#### Sling surgery

If lifestyle changes and pelvic floor exercises don't help and you are still leaking urine, your doctor may recommend sling surgery. This involves an operation to insert a sling to support the urethra (the tube that runs through the penis and enables urine to pass out from the body) and prevent leaks. Sling surgery may not be suitable if you experience heavy leaking or if you have had radiotherapy.

Following surgery, you may experience stinging when peeing and some people have difficulty in emptying their bladder completely when they pee.





#### **Artificial sphincter**

Another option is an artificial urinary sphincter, which is inserted via an operation. Following the surgery, you may notice blood in your urine and a slight burning sensation when you pee.

The artificial sphincter is made up of three parts:

- A cuff that surrounds the urethra. When filled with fluid, the cuff tightens around the urethra, preventing urine from leaking.
- A small pump placed in the scrotum, which connects to the cuff. This pump is used to control the fluid in the cuff, depending on whether you want to stop the flow of urine.
- A balloon or fluid-filled reservoir placed in the tummy. Fluid is passed between the reservoir and the cuff to control urine flow.

Unfortunately, for some people the artificial sphincter will stop working so they will need to have another operation.

#### **Medicines**

If lifestyle changes and pelvic floor exercises don't help and you are unable to have surgery, your doctor may prescribe medicines. There are a variety of medicines that can relieve urinary incontinence. You and your GP will decide which medicine is best for you, based on your personal experience and any other health conditions you may have.

## **Emotional wellbeing**

It can be difficult to talk about urinary problems but expressing how you feel may help. You can talk to people that you know and trust, such as friends and family. Some people find it easier to talk to someone they don't know, and your doctor may be able to refer you to a counsellor.

Some men find support groups extremely valuable. They provide a safe space to ask questions, share experiences and listen to others in a similar situation. This can help you understand your own emotions and realise that you are not alone.



patient booklet

# Science news

# GUT BACTERIA FUEL RESISTANCE TO HORMONE THERAPY

Our gut microbiome includes the bacteria, fungi and other tiny organisms that live in our digestive system. There is an increasing focus on how it impacts on health and wellbeing, and it has been linked to many diseases, including cancer.

Researchers at the Institute for Cancer Research in London have found some gut bacteria may help prostate cancers grow and resist hormone therapy. The researchers compared the gut microbiomes of men with hormone-resistant prostate cancer with those whose cancer was still responding to hormone therapy. They identified specific bacteria associated with treatment resistance. Certain bacteria also seem to be linked with better patient outcomes.

'The next step will be to further explore how we apply these signatures in patients, with the aim of devising tests to pick out men who would benefit from faecal transplants, antibiotic therapy and other strategies to manipulate the microbiome,' explained Professor Johann de Bono, one of the researchers. 'In the long-term, our aim would be to produce a "yoghurt" enriched with favourable bacteria to prevent resistance to treatment.'

# CAN EXERCISE SLOW PROSTATE CANCER GROWTH?

Researchers in Australia have found evidence that exercise could play a vital role alongside treatment in slowing cancer growth.

When we exercise, our muscles release proteins called myokines and the researchers believe myokines can suppress tumour growth. Prostate cancer patients with obesity receiving hormone therapy took part in a 12-week exercise programme. Blood samples were collected from patients before and after the programme.

Following the programme, myokine levels had increased in the blood. The blood samples were then applied to prostate cancer cells in the lab. Cells that received the post-exercise sample grew more slowly.

The study involved 10 patients and these are very early results. However, they do contribute to a wider body of research indicating the importance of exercise.

# URINE TEST TO MEASURE PROSTATE CANCER RISK

Prostate cancer tumours can be very different from each other. It can be difficult to know the best way to treat an individual's cancer as we don't always know which will become aggressive.

Researchers at the University of East Anglia have fine-tuned their prostate cancer urine test, called PUR. It can now identify those men at 'intermediate risk' who need immediate treatment and those who can instead undergo active surveillance, avoiding unnecessary side effects.

'Previously we have shown that PUR can identify men with high-risk cancer, which requires immediate treatment, and also low-risk cancer that has a very low rate of progression and does not generally need treatment,' explained lead researcher Dr Jeremy Clark. 'But there is a third category of men with "intermediate risk", which falls in between these extremes. Around half of men diagnosed with prostate cancer fall into this group and the treatment pathways for them have been less clear, until now.'

PUR is still being evaluated in a larger study, but researchers hope it could be used in the future to inform decisions about treatment.

# PROTEINS PREDICT OUTCOMES FOR AFRICAN-AMERICAN MEN

High levels of two proteins in the blood can identify African-American patients who are likely to develop lethal prostate cancer. This is according to research presented at the 2021 American Association for Cancer Research Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved.

Researchers found high levels of these proteins, called PTN and TNFRSF9, could predict whether a person was likely to die from their prostate cancer with 78.2% accuracy in African-American men. They could not be used to predict outcomes for European-Americans.

This research could be used to develop a way to identify African-American men with high-risk prostate cancer and determine treatment. One in four Black men will be diagnosed with prostate cancer, compared to one in eight white men and one in 13 men of other ethnicities.

These are very early results presented at a conference, so further research is needed to confirm the findings.



Prostate cancer deaths in 2018: 358,989 globally 13,145 in UK

Deaths estimated in 2035: 630,715 globally (75% increase) 20,922 in the UK

(59% increase)

# Patient webinar series

In December 2021 and January 2022, PCR, in collaboration with Tackle Prostate Cancer, have organised a number of free Zoom webinars on the themes of 'Looking and Feeling Great' and 'Supporting Others', as part of our 'Living Well with Prostate Cancer' webinar series, which has been running since August 2021.

In December 2021, these sessions will include the following:

- 10th December, 2–4pm 'Skin Fitness' workshop Run by Look Good Feel Better
- 14th December, 10am–12pm

   Body Confidence' workshop
   Run by Look Good Feel Better

   To sign up for these sessions, go to pcr.org.uk/living-well/December

In January 2022, we have the final session of this series. Brought to you in association with leading charity Maggie's, we are delivering a webinar designed specifically for wives, husbands and partners, but patients are also welcome to attend.

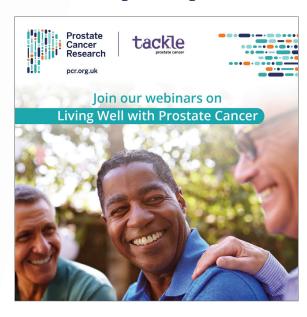
10th January, 11am–12:30pm

 Helping Wives, Husbands and Partners
 Understand and Cope'

 To sign up for it, go to

 pcr.org.uk/living-well/January

Don't worry if you can't make any of these (or wish to watch some of our previous webinars in the series): you can watch them all on demand at **pcr.org.uk/living-well-library** 



and book for our

webinars at pcr.org.uk/

living-well

# Yes, I'd like to support prostate cancer research

Title and name	I wish to make a donation to PCR:
Address	☐ £20 ☐ £40 ☐ £50 ☐ Other £ Cheques payable to Prostate Cancer Research
Postcode	I wish to donate by credit/debit card:
Gift Aid Declaration You can boost your gift by 25p for every £1 donated	Mastercard / Visa / Visa Debit / CAF card (please delete as appropriate or specify other)
☐ I am a UK taxpayer. I understand that if I pay less income tax and/or capital gains tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I want to Gift Aid my donation today, and any donations I make in the future or have made in the past 4 years.	Cardholder's name
Signature Date	Expiry date Security code (last three digits on back of card)
☐ I am not eligible for Gift Aid.	We will take payment online through our website
Staying in touch with PCR	
We keep our supporters updated about our research and send our newsletter and appeals by post.  For us to contact you digitally or by phone/SMS, please opt in below:	
	SMS Opt-out of all further PCR communications

### Research insight

# Journey of a new treatment from lab to clinic

Many promising research discoveries never become new therapies, with good potential treatments falling by the wayside owing to a lack of funding and support. We are committed to working, both independently and with others, to stop promising treatments slipping through the net before they can get to patients.

The journey from lab to clinic is a long and rigorous process, involving several steps, and our position is that patients should be involved at every stage.

# Drug discovery and development

The first step is identifying potential medicines. This stage can be long and complex, and often involves a number of different scientific fields, including biology, chemistry, pharmacology and even physics and computer science. This stage involves research into the biological mechanisms that underpin prostate cancer to identify which features of the cancer should be attacked by new treatments. Once a target is identified, researchers can begin to develop drugs that will act on it. This process often happens over multiple cycles, with the candidate drug being tested for its biological effects, then refined chemically to improve it, then tested again. High throughput screening is a technique often used at the start of this stage to test huge numbers of potential drugs. at once and identify candidates that seem promising.

#### **Pre-clinical research**

Before any new prostate cancer treatment is tested in men, it is tested in the laboratory to determine a safe starting dose for in-human studies. Researchers also assess the potential toxicity to ensure it won't harm patients. In pre-clinical trials, researchers conduct tests using computer models, cells and animals. These different tests are referred to as in silico, in vitro and in vivo. Animal testing is only undertaken if other results suggest that the candidate may be suitable for testing in humans, and great care is taken to minimise experiments carried out on animals and to safeguard their welfare.

#### **Clinical trials**

Clinical trials are medical research studies that involve patients, healthy participants or both. They involve rigorous testing to answer the following questions:

- · Is the treatment safe?
- Does the treatment work and, if so, how well?
- · What is the best dose to give?
- · Are there any side effects?
- · Does it impact on quality of life?

#### Phase I

Although the treatment has been tested in lab and animal studies, the safety and side effects in people can't be known for sure until the drug is very carefully tested in humans.

A small number of people, who may be healthy volunteers, are given the medicine. The researchers start with small doses in a small number of volunteers, and only increase the dose for subsequent groups if there are no severe side effects. The researchers use these results to calculate a dose that is both safe and effective for further clinical trials.

#### Phase II

In Phase II trials, patients are given the dose of drug that was refined in the phase I study. Researchers continue to monitor safety, side effects and dosing, but also put more focus on investigating how well the new treatment works. They can involve more than 100 participants.

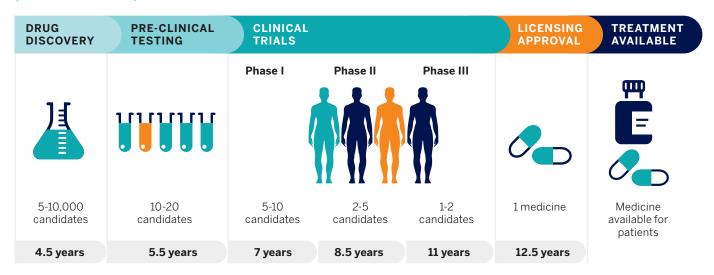
#### Phase III

Drugs that are successful in Phase II trials may then be tested in Phase III, to see if they work in a larger number of people. Phase III trials compare the new treatment to the current standard treatment for prostate cancer, so every patient will receive cancer therapy, even if they are in the 'placebo' group. Researchers also continue to investigate the safety and side effects. These trials are large, often recruiting thousands of people.





TIMELINE AND DEVELOPMENT STAGES FOR A PHARMACEUTICAL PRODUCT (INDUSTRY AVERAGE)



#### Licensing

Before a drug can be prescribed in the UK, it needs to be granted a licence. In the UK, drugs are licenced by the Medicines and Healthcare Products Regulatory Agency (MHRA) and the European Medicines Agency (EMA). They receive information gathered throughout the drug-development journey to make decisions based on safety and weigh up the benefits and side effects of the treatment. Licences include information on who can be prescribed the treatment and its recommended dosage.

# Getting treatment on the NHS

Drugs must be reviewed and recommended by National Institute of Health and Care Excellence (NICE) before they can be made available on the NHS in England, Wales and Northern Ireland. The Wales Medicines Strategy Group (AWMSG) may also recommend drugs in Wales. In Scotland, drugs are reviewed by the Scottish Medicines Consortium (SMC). These bodies evaluate the cost-effectiveness of the new treatment, reviewing the potential costs against the impact. These bodies are placing increasing importance on patient experience and real-world evidence when making decisions on recommending treatments.

# Phase IV / Post-marketing surveillance

A new drug continues to be monitored long after it has been licenced and is being used in the general population. Researchers continue to investigate the safety, efficacy and side effects of the treatment over longer periods of time, collecting data on long-term risks and benefits.

#### **Raising awareness**

# Men's Health Awareness Month 2021



Men burying their head in the sand is contributing to health anxiety, our research shows.

Nearly half of all men (49%) don't know where their prostate is, and women are more likely than men to know the symptoms that could indicate a prostate issue, according to our research.

In partnership with a cancer-care provider, GenesisCare, we polled over 2,000 people from the UK to investigate awareness of prostate cancer and the barriers people face in seeking medical advice. We are sharing the findings as part of our campaign for Men's Health Awareness Month, which has so far been featured in the *Independent*, the *Mirror*, the *Sun* and Gentside.

Our results highlighted the importance of a support network, as just over a third of men admitted that it was their partner who persuaded them to see a doctor. Almost four in 10 men (39%) who have received a prostate cancer diagnosis said it took seeing someone they knew being diagnosed to motivate them to see a doctor themselves.

David Matheson, PCR Patient Representative and prostate cancer survivor, explains: 'I was diagnosed in September 2012 after I'd been to see my GP. I'd had symptoms for quite a long time, which of course – being a man – I roundly ignored until I was pressed and prevailed upon by Catherine, my wife, to go to the doctor.'

Half of men admit they tend to 'bury their head in the sand' when it comes to health-related matters (49%). So much so, that while 86% are aware that an early cancer diagnosis can be lifesaving, 36% admit that they have delayed seeking health advice, which has contributed to health anxiety.

Our campaign is supported by TV presenter and prostate cancer survivor Dominic Littlewood, who said: 'This research has shown us that men's reluctance to see a doctor isn't just a stereotype. I hope reading this will encourage men to take control of their health and if they have any concerns, see a GP.'

Men lack confidence when it comes to interacting with medical professionals too. More than one in four men (28%) admit that they are not comfortable asking medical professionals

questions and a worrying 43% stated that they were uncomfortable asking questions about the treatment options available. The main reasons that men don't ask questions are finding it intimidating (38%) and worrying that they won't be able to explain what they mean (27%).

Asking questions to medical professionals or discussing symptoms doesn't always come easily, but our research shows that men who did ask questions were more than twice as likely to feel that the treatment they received was right for them.

As our Head of Research and Communications, Dr Naomi Elster, explains: 'Cancers are not all treated the same and it's important that your treatment is the best one for you. Now that we can see how much happier people are with their treatment if they're comfortable asking questions, we really hope more do. While medical professionals are experts in their field, you are the expert when it comes to you, and open communication will help you to work together to find the best approach for you as an individual.'

As part of the campaign, we released a short video to raise awareness of the issues uncovered in the survey. Naomi, David and Dominic took part in interviews, highlighting the key issues faced by men with prostate cancer.

Together with GenesisCare, we aimed to empower men at every stage of their journey: how to spot potential signs, when to speak to medical professionals and how to discuss and access the best treatments available.



admit they tend to 'bury their head in the sand' when it comes to healthrelated matters



aware that an early diagnosis can be life-saving



delayed seeking health advice



admit they are not comfortable asking medical professionals questions



stated that they were uncomfortable asking questions about treatment options



IN PARTNERSHIP WITH





Transform the world's understanding of living with prostate cancer

# Putting people at the centre of research

PCR intend to set up the first-of-its-kind prostate cancer registry in the UK. This registry would revolutionise prostate cancer diagnosis, treatment and care by putting real people at the centre of it all. But joining would not only benefit others. You would also be able to access more relevant information about your treatment and care, be kept informed about the most relevant clinical trials you are eligible for, and provide critical evidence to speed up and shape vital research. We are in the planning stage for this registry, but we need your support to make it a reality!



'I am delighted to pledge my support for this new prostate cancer registry'

Stephen Fry PCR supporter, writer, actor and presenter

# Pledge your support!

Online: Go to pcr.org.uk/pledge and fill out the online pledge card.

By post: Fill out the pledge card that came with this newsletter and send it back to us in the pre-paid envelope.

### Why do we want to do this?

There are still so many unknowns that people affected by prostate cancer continue to face. To help scientists find the answers Prostate Cancer Research want to set up this registry.

#### What is a prostate cancer registry?

A registry is a database of information on individuals' medical histories and changes to their experience over time. This will help us learn much more about how a disease affects people's lives.

#### What would it mean to join a registry?

Anyone affected by prostate cancer will be able to join. There will be many ways to engage with the registry, from completing occasional surveys about your experience, to sharing your medical information in a safe, secure, anonymised way.

#### Is my data safe and secure?

Your privacy is our most important concern. The registry will use the highest levels of encryption and security throughout the collection, storage and use of your personal and medical information.

#### How would you use my data?

Your personal information would never be shared with anyone. All data that researchers have access to is anonymised and nothing identifiable is ever released. You can leave the registry at any time and have all your data removed.

## Why do we need you to pledge?

Your pledge will help us to demonstrate to others that the registry can work and make the case to secure the funding needed to make this a reality.

To find out more please visit pcr.org.uk/pledge



years supporting prostate cancer research. Help us to do more with a prostate cancer registry.

## Francis' story

# A great night, a great cause

Research and development, often abbreviated as 'R&D', is the life blood of any organisation wishing to thrive and prosper. Nowhere is this more relevant than in the field of health and wellbeing where research is of fundamental importance to enabling advances in medical diagnostics, and the development of new treatments and drugs. Massive improvements in public health and life expectancy are sure to follow. But without vital research such achievements will be impossible.

Prostate cancer – particularly the need for greater research into improved treatments and ultimately a cure – is a particularly poignant subject for me, having lost my older brother to this awful disease in April 2011.

At the beginning of the year, with the 10th anniversary of Joe's death fast approaching, I felt I should do something special to mark the occasion. Joe loved live music, particularly country and folk, and having duly listened to the grapevine I finally settled on the ideal band: The Whiskey Priests. This is a group of very talented musicians based in Staffordshire, playing the fiddle, banjo/guitar, accordion, double bass and drums. Alas, the dreaded COVID conspired to put a spanner in the works, which meant an April date had to be ruled out. However, with the eventual lifting of restrictions a new date, Saturday, 21st August, was finally agreed.

The night itself was a brilliant success and well worth waiting for. Although restrictions had been lifted on indoor events, the attendance was restricted to 66% of normal capacity, with everybody seated at tables, served by charming waiting staff equipped with a contactless payment terminal. As might be expected, taking payment was entirely pain-free. Additionally, on every table there was a card giving a brief background on the work of Prostate Cancer Research, including a QR code to facilitate ad-hoc donations to a dedicated JustGiving page.

With the Village Hall suitably festooned with balloons and other decorations kindly provided by Prostate Cancer Research, a party atmosphere was quickly entered into. Before long the dance floor was filled with revellers keen to show their prowess doing the jive, enjoying rock and roll, or singing along to rousing renditions of 'Brown Eyed Girl', 'Wild Rover', 'Rhinestone Cowboy', etc. It's hardly surprising that people wanted to let their hair down, given that this was the first live indoor event of any kind to be held in the area for over 18 months. And all in aid of such a great cause.

The evening raised a total of £3,700 for Prostate Cancer Research, made possible with the help of great teamwork by family, friends and the lovely PCR staff in London.

And yes, there will be an encore. Because of the numerous requests for more of the same, The Whiskey Priests have been booked for a return performance in the new year, on Saturday, 29th January 2022. Another full house is surely guaranteed.

#### Francis O'Malley





If you would like to fundraise for us, drop us a line on 0203 735 5448 or email us at events@pcr.org.uk



Transforming research. Transforming lives.



We offer a free will-writing service with Guardian Angel (RRP £90)





# Leave a gift for the future

Together, we will develop and deliver breakthrough treatments

Families affected by prostate cancer need breakthrough treatments. Research is the only way we can turn this hope into reality. It's thanks to our supporters who leave us a gift in their will that we are able to progress towards our vision of a world where people are free from the impact of prostate cancer.

If you would like to leave us a gift in your will, please get in touch with our legacy team.

**Prostate Cancer Research** Suite 2, 23-24 Great James Street London WC1N 3ES 0203 735 5444 info@pcr.org.uk

pcr.org.uk/legacy-donation