

NEWSLETTER



Prostate
Cancer
Research
pcr.org.uk

Transforming research. Transforming lives.



Innovating hormone therapy to work for longer

Read more about the research Dr Luke Gaughan is leading, page 8 [➤](#)

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Welcome



There is so much to update everyone on this month, as many of the initiatives we have been working on for a while came to fruition.

We try to combat some of the biggest challenges in prostate cancer and this month we are launching many exciting new projects to tackle racial inequality. Black men are twice as likely to be diagnosed with prostate cancer than white men and so we are delighted that we have commissioned new research that will be trying to understand exactly what is happening, both medically and socially, and helping to provide solutions to the much higher mortality rate. We believe this work will help level the playing field for a community that particularly needs answers, and also bring insights with the potential to help all men.

We also brought together many of the wonderful scientists we support alongside patients. Not only does this help scientists to understand the patient perspective and make sure their research is as relevant to their real-life concerns as it can be, but it also helps patients get a good understanding of the science that is underway and helps our scientists to make new collaborations with each other.

The PCR translational team that we established last year have had their first major success too. We have known for some time that early-stage companies trying to turn good research into actual treatments and diagnostics really struggle. So we are absolutely delighted to have received a pledge from the UK government to match everything we raise for prostate cancer companies that fits with their healthy ageing initiative for up to £18m for the next three years. This will help us get the most promising new treatments to patients more quickly.

Just one final note. It's incredibly important that people affected by prostate cancer get the right information, so please, once you've finished with this newsletter, consider passing it on to someone else.

Oliver Kemp
CEO


Prostate cancer accounts for 26% of male cancer diagnoses and is now **the most commonly diagnosed cancer in the UK.**

While prostate cancer is treatable when localised within the prostate, it becomes life-limiting and potentially terminal when cancerous cells spread around the body. We are committed to funding innovative research that fills gaps in current understanding. It is only through research that we can make progress.

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

 [@prostatecancerresearch](https://www.instagram.com/prostatecancerresearch)

 [@PCR_News](https://twitter.com/PCR_News)

 [/prostatecancerresearchnews](https://www.facebook.com/prostatecancerresearchnews)

 [/prostate-cancer-research](https://www.linkedin.com/company/prostate-cancer-research)

< Featured on cover: Dr Luke Gaughan's research focuses on facilitating hormone therapy to work for longer and harder. Read more on page 8.

Mike's story

I believe that research is vital

My own journey with prostate cancer started back in April 2014 when, at the end of a routine GP appointment, my doctor recommended a prostate examination, to which I readily agreed. Like most men who undergo the procedure I had no concerns regarding the outcome, but when my doctor advised me that my prostate was enlarged I did feel somewhat uneasy.

When the resultant blood test showed an above-average PSA reading, I was referred to my local hospital for a biopsy and it was during this procedure that I was convinced that I had cancer. Although the doctor carrying out the biopsy was talking to me throughout the procedure, she did make one 'matter-of-fact' statement that I instinctively knew was not normal. On that basis when I subsequently attended hospital for the biopsy results, the prostate cancer diagnosis came as no shock to me.

At the time I was given the options of either surgery or radiotherapy and, after due consideration, chose the former. Even though I was 67 at the time, I was in good health overall and my specialist had no doubts about my suitability for surgery. Despite the number of patients my specialist must have had referred to him over the years, he exhibited a wealth of both empathy and reassurance, and I left the clinic feeling remarkably upbeat.

However, as my only grandchild had been born in April, I made a decision to defer my operation slightly until after her christening, then underwent a radical prostatectomy in early August. Thanks to the skill of my specialist, coupled with the less invasive nature of the operation performed by way of robotics,

I was out of hospital in a little over 48 hours.

Following the surgery I naturally had a period when I felt extremely tired, but this was coupled with a feeling of being quite 'down'. Fortunately, the literature provided to me at the time of my diagnosis helped me fully understand the effects of the operation. At the same time, I did experience some frustration at my inability to fully control my bladder but, as the weeks passed, there were massive improvements on all fronts, which culminated in my return to work in January 2015. This was a major factor in 'getting back

to normality'. I have to say that my treatment had no adverse effect on my effectiveness at work (although my ex-boss might beg to differ) and I eventually retired in late 2019.

I am pleased to say that my PSA level is within the acceptable range and I take great comfort from the regular monitoring with which I am provided.

My overriding feelings having experienced prostate cancer are twofold. Firstly, I have heard many people say that it's only when you're confronted by your own mortality that you fully appreciate how good life is, and I've never lost sight of this belief. While there can be no words to fully describe my gratitude to them, the National Health Service can only provide reactive treatment. As one in eight men will experience prostate cancer in their lifetime, I believe that research is vital to not only find ways to achieve earlier diagnosis but also to offer more effective treatments, ahead of a possible cure.



Living with hormone therapy

Managing hot flushes and sweats



Maintaining a healthy lifestyle can reduce the hot flushes and sweats



A number of medicine options are available to help with the side effects of hormone treatment



For more information about prostate cancer, please request a free copy of our patient booklet pccr.org.uk

What is hormone therapy?

Hormones are chemicals that are used to send messages to different parts of the body. Testosterone is a hormone, made in the testicles, which can drive the growth and spread of prostate cancer. Hormone therapies work in different ways to prevent testosterone from stimulating prostate cells, from blocking the testosterone itself to stopping it from being produced. You may receive hormone therapy on its own or in combination with other treatments, such as radiotherapy. It is one of the main treatments for prostate cancer, but it does come with a range of side effects. Which of these side effects you experience will depend on the type of hormone therapy that you have and the treatment length.

Hot flushes

Hot flushes (sometimes called hot flashes) and sweats are caused by the changing levels of hormones in the body. They are a very common side effect of hormone therapy for prostate cancer.

You are less likely to have hot flushes if you are taking anti-androgen drugs such as bicalutamide. Hot flushes are more likely if you are taking LHRH agonists such as zoladex. They can range from mild, where your face feels warm, all the way to severe, where you experience heat and sweats that affect your whole body. You may also experience heart palpitations (feeling your heart beating faster) and feelings of irritability. Hot flushes tend to last for around four-to-five minutes but may last for up to a few hours.

Some people find that their hot flushes begin to improve as their treatment progresses, becoming shorter and happening less often. However, others have hot flushes throughout their hormone therapy.

There are ways to manage hot flushes and treatment options are available. You will be able to speak to your doctor to decide which approach or treatment is the most suitable for you.

Lifestyle changes

Hot flushes can be triggered by certain food and drink – including spicy foods, tea, coffee and alcohol – so you may want to avoid or limit these.

It's also important to ensure that you are drinking enough water (the current recommendation is six-to-eight glasses per day). You may also find having cold drinks can help you to cope with hot flushes.

You should maintain a healthy weight or take steps to lose weight if you need to. Keeping active and eating a healthy, balanced diet will help with this.

If you currently smoke, you should try to stop as this can also reduce hot flushes.

Keep your room cool. For example, you can open windows or use a fan. It may also help if you wear layers of thin clothing or use layers of bedding so that you can remove them if you get too hot. If you are able to, choose natural fabrics such as cotton or silk for clothing and bedding.





Some people find it helpful to keep a record of when they have hot flushes. You can track what you have been doing when the hot flushes happen so that you can learn what triggers them. This enables you to avoid these triggers in the future.

Medicines

There are medications available on prescription to manage hot flushes. You will be able to speak to your doctor about the different options available. 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.

Medroxyprogesterone is usually the first choice of treatment but if this medication doesn't work for you, you may be offered a drug called Cyproterone. Certain antidepressant drugs have been shown to help with hot flushes – for example, venlafaxine and paroxetine – but make sure you speak with your doctor about any other side effects these drugs may have. In rare cases, your doctor may prescribe other medicines such as Gabapentin or a type of medicine called a progestogen.

Complementary therapies

There is some indication that there are complementary therapies that may help with hot flushes and sweats. There have been very few studies looking at this link, so more research is needed to fully understand their role in managing these side effects. Speak to your GP before trying complementary therapies as some of them may impact on your cancer treatment. They may also be available on the NHS, in which case your doctor may be able to help you to access them.

Acupuncture is one type of complementary therapy used to help hot flushes. It involves inserting thin needles into specific places on someone's body. Some people find that it makes hot flushes more manageable.

There is also some evidence that cognitive behavioural therapy (CBT), a type of talking therapy that focuses on changing negative thought patterns, could be used to manage hot flushes.

Emotional wellbeing

It can be difficult to talk about how you feel, but it may help you. You can talk to people who 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 or nurse may be able to refer you to a counsellor who can help you deal with the emotional impact of side effects from your cancer treatment.

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



Update on our Registry Pledge campaign

In December 2021 we launched a pledge campaign to support our plans for a prostate cancer registry. To everyone who has signed a pledge in support of this we want to say a big **THANK YOU**. You helped us sail past our initial 1,000 target and we are now closing in on 2,000 pledges. This has made a huge difference and we hope to have some more exciting updates for you on this in our winter newsletter.

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

You can still pledge your support!

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



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

Stephen Fry
PCR supporter, writer,
actor and presenter

New grant funding

New research to tackle prostate cancer inequalities

This month, we are announcing our first group of projects specifically created to bring more equality to cancer research, care and treatment. To the best of our knowledge, we are the first UK charity to tackle this unmet need so directly.

We exist to create a world in which cancer treatments are better, kinder and more effective, where every person has the power to know which treatment is right for them and get that treatment, and where a cancer diagnosis is no longer something to be feared.

This cannot be achieved without more research. Research that reveals the still unknown details of the intricate biology underlying cancer, creates new therapies and understands the many ways in which a cancer diagnosis can change a life and how to make that journey as easy as possible. At PCR, we are now directing five times as much research as we were four years ago.

Our ongoing work has the potential to benefit any person affected by prostate cancer, anywhere in the world. **But Black men face an even more challenging situation:** more likely to get prostate cancer, more likely to have cancer at a younger age, less likely to receive the same quality of care, and more likely to die. **It's clear that prostate cancer is different in Black men, and we are missing so many answers as to why that is.**

It's a question of doing the right thing, because breakthroughs and new technologies should be for everyone. Having realised how unfairly disadvantaged this community was by prostate cancer, we could not stand by and do nothing about it. **It's also a question of knowledge.** We need as much knowledge as possible to tackle prostate cancer effectively for everyone. When so much research has, up to now, been based on just a section of the population – white people of European descent – we must have been missing insights.

We are launching some tremendously exciting projects that should yield incredibly important results. These include a PCR test, which could detect prostate cancer more accurately in the blood than a PSA test by being able to detect



EPIGENETIC MARKERS FOR PROSTATE CANCER

Prof Dmitry Pshezhetskiy
and Mr Mathias Winkler
UNIVERSITY OF EAST ANGLIA



TACKLING BARRIERS TO EARLY DIAGNOSIS

Dr Floor Christie-de Jong
UNIVERSITY OF SUNDERLAND



INVESTIGATING THE LINK BETWEEN WHERE WE LIVE AND PROSTATE CANCER

Dr Hari Iyer and Professor
Timothy Rebbeck
DANA-FARBER CANCER
INSTITUTE, HARVARD



IDENTIFYING BLACK MEN AT INCREASED RISK OF DEVELOPING PROSTATE CANCER

Dr Greg Brooke and
Dr Antonio Marco
UNIVERSITY OF ESSEX



MAPPING DIFFERENCES IN TREATMENT PATTERNS

Professor Robert Horne and
Dr Jonathan Shamash
UNIVERSITY COLLEGE LONDON

imprints, like fingerprints, that prostate cancer cells leave on blood cells. This project, based in Norwich, may uncover if the cutting-edge field of epigenetics, the study of how our environment changes the way our genes work, is one of the reasons Black men are more likely to get cancer. It should also bring this test, which should be cheap, quick and more realistically practical than other promising technologies like MRI, to the next stage of its development.

This project is exciting as we know we can't rely on existing technologies to improve early detection to the levels seen in other cancers where more refined technology already exists. But having the technology isn't enough. We need to understand all the reasons that men are diagnosed late. **For example, men may feel embarrassed, and our work with athlete Linford Christie OBE last year revealed that less than a quarter of Black men were aware that prostate cancer is twice as high in Black than white men.** A project in Sunderland will work with community members in Scotland and the north east to delve into the reasons that Black men don't seek help early, and develop, test and refine tactics that might help, including training peer educators. This project is very much rooted in the community, and control of it sits with men with prostate cancer – not with academics. The tactics developed to encourage men to seek help early can be applied to other groups, in other locations.

We also, for the first time, have a research project based in the USA. In Harvard, a team is looking at how where we live affects our ability to access healthcare. They will examine whether factors ranging from the amount of street light at night, distance from hospitals and the number of healthcare staff available across a region affect access to prostate cancer diagnosis, treatment and how much treatment will benefit you. Evidence from this project will be useful to influence policy on both sides of the Atlantic.

We're also continuing to focus on hormone therapy, adding two new projects to complement our ongoing work in Newcastle and Aberdeen (which are not specific to any ethnicity, and are showing promising results). **The male hormones that cause cancer are known to be more active in Black men, and some evidence suggests that they are less likely to opt for and stick with**

hormone therapy. Hormone therapy is a key treatment type for many people and the more we know about it, the better. First, a group in Essex are investigating a protein that exists in 90% of the general population but only half of the Black population. They believe that when this protein is missing, hormone signalling increases and so does the risk of prostate cancer. This work could provide more insights into the androgen receptor (AR), one of the most important proteins in prostate cancer, and identify men who are at greater or lesser risk from prostate cancer and may need more or less testing and treatment. To complement this work, a team in London will dig through NHS records in England to see if there are any patterns showing if men from different ethnicities are more or less likely to choose and keep to different treatments. They will also speak to patients directly to uncover what stops men from continuing with their treatment and how they could be better supported.

We are funding and launching these projects because they will benefit the community that most needs our help, but there isn't a single one of them that doesn't have **the potential to give evidence and insights that will also benefit every individual and family affected by prostate cancer.**



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





Science news

LOOKING TO LIQUORICE FOR FUTURE RESEARCH

Recent headlines have claimed that 'liquorice may play a role in treating and preventing cancer'. These headlines were based on research from scientists at the University of Illinois Chicago in the USA.

The scientists are investigating whether substances from the liquorice plant can prevent or stop prostate cancer from growing and have found that these substances show anti-cancer effects. Dr Gnanasekar Munirathinam, who is leading the research, said 'More research is needed into exactly how these could best be used to develop therapies, but this appears to be a promising area of cancer research.'

So, should we all stock up on liquorice? Not yet. Eating too much black liquorice can interact with certain medications, as well as potentially leading to serious health conditions such as raised blood pressure and an irregular heart rhythm. Everyone should avoid eating large amounts of liquorice in a short space of time, but particularly those aged over 40 with a history of heart disease or high blood pressure.

'Very few clinical trials in humans have been conducted,' Dr Munirathinam cautioned. 'We hope our research on prostate cancer cells advances the science to the point where therapies can be translated to help prevent or even cure prostate and other types of cancer.'

A NEW HORMONE THERAPY FOR ADVANCED PROSTATE CANCER

Combining darolutamide, a new type of hormone therapy, with chemotherapy and current standard hormone therapy enables men with advanced prostate cancer to live longer. This is according to results from an international, phase 3 clinical trial called ARASENS.

A total of 1,306 patients with advanced prostate cancer took part in the trial, with half of them receiving darolutamide, chemotherapy and hormone therapy and the other half receiving chemotherapy and hormone therapy. Those patients who received darolutamide took longer to develop hormone therapy resistance and had a 32.5% lower risk of dying than those who did not receive darolutamide. Taking darolutamide in combination with chemotherapy and hormone therapy did not lead to an increase in side effects.

Dr Matthew R. Smith, who led the study, said 'Despite progress in recent years, survival is short for patients with metastatic prostate cancer. Results from ARASENS are an important step forward, and triplet therapy with darolutamide should become a new standard of care for the treatment of patients with metastatic hormone-sensitive prostate cancer.'

PROTEIN LINKED TO PROSTATE CANCER SPREAD

Many cancers grow very slowly and remain confined to the prostate for decades, causing little if any effect on the individual. However, some prostate cancers grow rapidly, are aggressive and lead to advanced disease. At the moment, we don't fully understand why prostate cancer spreads in some men but not in others.

Researchers at MedUni in Vienna have identified how changes to a protein called KMT2C could drive this growth and spread.

KMT2C regulates the processes within our cells. Certain changes or mutations can mean it no longer acts as a regulator, so there is an increase in a gene that causes cells to grow and multiply, driving the spread of cancer.

A blood test can be used to identify whether KMT2C has mutated, which could enable doctors to identify those people whose cancer is likely to spread. There are also drugs targeting the gene that KMT2C regulates currently in clinical trials. They could therefore be re-purposed to treat advanced prostate cancer in the future.

EXERCISE TO REDUCE ANXIETY

Taking part in a supervised exercise programme could help to reduce anxiety and fear of cancer progression in men on active surveillance.

This is according to research from the University of Alberta in Canada. As part of a clinical trial exploring exercise and prostate cancer, men undergoing active surveillance took part in a 12-week, supervised, high-intensity impact training (HIIT) programme. These men were then compared to a group who did not take part in the exercise programme. The main study results, which were published in 2021, showed that those men who took part in the exercise programme had improved cardiovascular fitness and reduced PSA levels.

Researchers then analysed the mental health outcomes following the exercise programme. They found that patients reported a small but significant reduction in anxiety related to their prostate cancer and a reduction in fear of their cancer progressing. The exercise programme was also linked to reduced fatigue, reduced stress and better self-esteem.

Active surveillance is often the best option for those with low-risk prostate cancer. Studies have shown that many patients on active surveillance

opt to undergo treatment within a few years, sometimes despite showing no signs of cancer progression. The researchers are calling for more and larger studies to explore these findings further and confirm their results.

SCREENING FOR PROSTATE CANCER

Combining results from the PSA test with another blood test could be used to predict a person's risk of developing prostate cancer.

Researchers from London universities have developed a way to estimate prostate cancer risk by combining the results from PSA and hK2, another prostate cancer marker, with a person's age. They found that using both PSA and hK2 together is a far more accurate predictor for the disease than either test alone. The screen still identified the same proportion of cancers but reduced false positives by three quarters compared to standard PSA testing.

Professor Sir Nicholas Wald, who led the study, said 'The next step is to test the feasibility of this approach in practice with a pilot project inviting healthy men for screening. If the project is successful, we believe this approach ought to be considered as part of a national screening programme for all men.'

1/8

Around one in eight men will get prostate cancer at some point in their life

Yes, I'd like to support prostate cancer research

Title and name

Address

Postcode

Gift Aid Declaration

You can boost your gift by 25p for every £1 donated

☐ 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.

Signature _____ Date _____

☐ I am not eligible for Gift Aid.

I wish to make a donation to PCR:

☐ £20 ☐ £40 ☐ £50 ☐ Other £ _____

Cheques payable to Prostate Cancer Research

I wish to donate by credit/debit card:

Mastercard / Visa / Visa Debit / CAF card
(please delete as appropriate or specify other)

Cardholder's name _____

Card number _____

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Staying in touch with PCR

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Researcher Q&A

Ryan Nelson

PHD STUDENT

NEWCASTLE UNIVERSITY CENTRE FOR CANCER

Could you tell us about your journey into cancer research?

I started working as a research technician directly after completing my bachelor's degree. This gave me a chance to experience cancer research hands-on, gaining a strong set of laboratory skills that I knew I would need if I was to pursue a career in academia. I spent a total of four years as a technician, both in the UK and abroad, before coming back to Newcastle to work in the lab of Dr Luke Gaughan as a PhD student on a Prostate Cancer Research-funded project.

Your project is looking at the androgen receptor. Could you explain what this is?

The androgen receptor is distributed around the cells of our body. As you may expect, the cells of the prostate have more androgen receptors than other tissues. Essentially, the androgen receptor is a docking station for androgen hormones such as testosterone. When testosterone binds to the androgen receptor, they form a complex that binds to the DNA within our cells activating certain genes. Some of these genes, for example, can make cells grow or produce proteins such as prostate specific antigen.

Could you give us a brief overview of your PCR project and the team you are working with?

Truncated forms of the androgen receptor, termed 'androgen receptor variants', can give rise to treatment resistance in men with advanced prostate cancer. Our project aims to understand the process by which androgen receptor variants are generated and how we can stop this process.

Ultimately, we aim to develop drugs to inactivate the proteins that are essential for the generation of

androgen receptor variants to provide more effective therapies in advanced prostate cancer.

On this project, I currently work alongside Dr Luke Gaughan (group leader). Within the wider lab we have a range of other PhD students, post-doctoral researchers and clinicians with various expertise in scientific research.

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

We hope our work will prolong and improve the effectiveness of current therapies for men with advanced prostate cancer. We know androgen receptor variants are detectable in 70% of locally advanced anti-androgen-treated patient samples, which increases to approximately 95% in metastatic disease – suggesting that these androgen receptor variants are key drivers to disease progression. There are currently no drugs blocking the generation of androgen receptor variants, and therefore work from this project could lay the foundations for novel treatment options.

What does your typical day look like?

My days can be quite varied depending on which experiments I am running. Often, no two days are the same. Typically, I aim to spend the morning in the lab setting up experiments such as drug combination studies, followed by an afternoon of data analysis and discussing results with colleagues to plan future work.

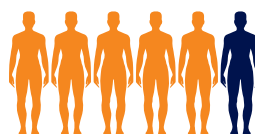
What's your favourite thing about working in cancer research?

I really enjoy the variety of people I get to work alongside and learn from. As well as other biologists, we collaborate with chemists, clinicians and bioinformaticians.

HORMONE THERAPY STOPPING RESISTANCE IN ITS TRACKS



- 1 Hormone therapy is one of the main forms of prostate cancer treatment



- 2 Hormone therapy will stop working for nearly all patients



- 3 Hormone therapy stops the androgen receptor (AR) from telling cancer cells to grow



- 4 The outside of the AR acts as a switch. When the switch is on, the AR tells cancer to grow



- 5 The switch is turned on by male hormones and turned off by hormone therapy



- 6 This project will explore how AR variants (ARVs) are made and how to stop this process



- 7 ARVs don't have a switch so they are always on. Hormone therapy doesn't work on ARVs



- 8 Preventing ARV production could keep hormone therapy working for longer

Partnership with UKRI's Healthy Ageing Challenge

Announcing a groundbreaking £36M research fund

We are delighted to announce that we have partnered with the government body UK Research and Innovation (UKRI) on their Healthy Ageing Challenge. We are honoured to be their first ever charity partner.

UKRI's Healthy Ageing Challenge Investment partnership programme combines government funding and private investment in research and business, supporting innovators to produce products and services that promote healthy ageing, which can be adopted at scale.

Our partnership will combine government grant funding and investment by PCR to fund better ways to diagnose and treat prostate cancer. The total funding available under the programme includes £18 million of grant funding and £18 million of equity investment.

We're joining other investment partners Northstar Ventures, Nesta and 24Haymarket.

We aim to offer several million over the next few years in equity funding, aligned with funding by UKRI, for early stage companies that are working on treatments, diagnostics and services that tackle prostate cancer. Our initial investment is £300K, and long-term this investment partnership will accelerate our journey towards a future in which men diagnosed with prostate cancer live longer and with a better quality of life.

“Diagnosed late, prostate cancer can be fatal and for those diagnosed early, the treatments as well as the condition itself, can have long-term repercussions for health and wellbeing. Strategic investment in support of innovations that meet the needs and preferences of patients is the key to bringing about positive change for all those diagnosed with prostate cancer. We are absolutely delighted to be the first charity to partner with Innovate UK in this way.”

Oliver Kemp
CEO of PCR



**Prostate
Cancer
Research**

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IN PARTNERSHIP WITH



**UK Research
and Innovation**

Meet the scientists

Bringing scientists and patients together

20

Current research projects being funded by PCR

In January 2020, we hosted our first ever **Meet the Scientists** event in London, bringing together families affected by prostate cancer, researchers and PCR staff. Over two years, multiple lockdowns and some brilliant new researchers later, we brought the unique event to Manchester – this time even bigger and better.

If research is going to make a real difference for people affected by prostate cancer, we need to work with patients at every stage of the research process. Scientists may be the experts in the lab, but those with prostate cancer are the experts on their own lived experiences of cancer and its treatments. If we're to solve the problem of prostate cancer as quickly and effectively as we can, we need to bring all of these experts together. **As one participant noted during the event 'The future is in this room.'**

PCR staff and patient representatives were assigned tables, with scientists visiting a different table every 20 minutes. We wanted to encourage meaningful, two-way conversations with each guest being able to learn from one another. Guests felt it was 'very good and conducive to easy conversations with the scientists' and 'a lot more comfortable, engaging and relevant than presentations'.

The room was buzzing with conversation all day, with guests reluctant to end their discussions when their 20 minutes was up.

Patients and scientists shared their thoughts and ideas on their personal experiences, the needs of people living with cancer and the latest prostate cancer research. It was wonderful to be able to come together with those working with us to build a world in which people are free from the impact of prostate cancer – whether that be as someone impacted by prostate cancer themselves, or as a scientist undertaking research. It's important to us to empower those people impacted by prostate cancer who are less confident in understanding and discussing science. Feeling more confident in this area enables patients to have more meaningful discussions with healthcare professionals and feel more ownership of their own care. Following Meet the Scientists, 96% of non-scientists at the event said that they felt more confident about being able to understand science and research.

For our scientists, meeting those impacted by their research enabled them to gain further insights into what prostate cancer patients really need, learn more about the current issues they face and receive feedback on their ideas. All the scientists fed back that it was beneficial to meet people affected by prostate cancer, with one scientist noting that their conversations at the event 'will help our modelling of disease' and 'provided some excellent feedback'.

It also serves as a reminder of the bigger picture of their research – building a better future for those with prostate cancer – which may sometimes be lost in their day-to-day work in the lab. 'It was a moving experience presenting our research to patients – I was really encouraged and touched by their enthusiasm and encouragement,' explained researcher Dr Anna Wilkins.





4.8

Patients scored the event 4.8 out of 5

4.75

Scientists scored the event 4.75 out of 5

96%

96% of non-scientists felt more confident about being able to understand science and research after the event



All scientists found it beneficial meeting patients and people affected by prostate cancer



All patient representatives felt more informed about prostate cancer as a result of the event

There was also the opportunity for scientists to connect with each other during the event.

Collaboration is a key part of scientific research and with our researchers spread out across the UK, we make efforts to bring them together to build relationships and share ideas. As a result of the networking sessions during the event, more than half of the scientists said that it was very likely that they would collaborate with another scientist at the event in the future. This gives us a better chance of making breakthroughs even more quickly.

The event was a huge success, with the biggest challenge being trying to ensure the researchers moved round to the correct tables at the end of each session.

Patient representatives (including those impacted directly and indirectly) and staff gave the event a score of 4.8 out of 5, and scientists scored it 4.75. PCR Patient Representative Dafydd Charles said: 'The event was exceptional, and I am looking forward to briefing my support group on some of the brilliant work that the researchers are undertaking for all prostate cancer patients.'

We would like to thank all our guests, whose attendance made the day so special and without whom the event would not have been possible. A huge thank you also to the staff at the Science and Industry Museum in Manchester, where the event was held. They ensured the event ran smoothly and were always on hand to help throughout the day.

The wellbeing of our guests was of the utmost importance to us, and we put in place precautions to ensure Covid safety during the event. The venue itself was well ventilated and we asked our guests to take a lateral flow test before travelling. If their test was positive, or if they felt unwell, they were asked not to attend. Temperature checks with no-contact thermometers were also carried out as people arrived.



Empowering people affected by prostate cancer



A prostate cancer diagnosis is a life-changing and bewildering experience.

As Tony, who was diagnosed with prostate cancer in 2017, said: 'Navigating your way through treatment options is horrendous, particularly the options that they never tell you about!'

These are just some of the problems that patients and their loved ones may face when they are diagnosed with prostate cancer:

- Making a choice between equally effective treatments
- Uncertainty about the impact and side effects
- Being unaware of all the options available
- Feeling pressured, i.e., by a surgeon pushing surgery
- Regretting their choice afterwards
- Not feeling confident enough to decide with their healthcare team

Our research has shown us that these problems are widespread. They are even worse in less well-educated and non-white communities.

We know that close to half of the population of the UK have low health literacy.

Low health literacy is linked with:

- Increased visits to A&E
- Increased hospital stays
- Higher mortality rates

Launching The Infopool

This is why in January 2023 we are launching The Infopool. This is a new website to help people affected by prostate cancer make better informed decisions and learn ways to manage the impacts of their treatment.

How will it do this?

The Infopool will provide access to clear, easy-to-understand information about treatment options.

It will be driven by real-world information, experiences and stories from hundreds of people just like you. It will contain practical strategies, tips and advice from people who have been through this before.

The Infopool will be designed especially for people with low health literacy. We are also committed to ensuring that The Infopool includes experiences from a diverse and inclusive community.

What do we hope to achieve?

We hope that users of The Infopool will be able to make better informed decisions on treatment options and better manage their side effects.

How can you help?

If you feel like you or your partner faced any similar problems, we really, really want to hear from you. Every person's knowledge is unique. **By sharing your experience on The Infopool – good, bad and everything in between – you can help others in the future.**



Health literacy refers to the skills (language, literacy and numeracy), knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care information and services effectively.



This project is made possible in part through a grant from the National Lottery Community Fund.

Sign up to share your experience

Join us at pccr.org.uk/the-infopool

Myk's story

I'm lucky enough to take on this challenge



Watch Myk's story

My name is Myk Nutt and I was diagnosed with prostate cancer in August 2021 at the age of 60. Having been offered a few different treatment options I decided on a prostatectomy, which is the removal of the prostate and any cancer there within.

The operation took place in October 2021 and was very successful. This was a four-hour operation and took a few months to fully recover from. After the wonderful treatment I had received at Southmead Hospital in Bristol, I decided I wanted to start supporting the wonderful work that Prostate Cancer Research (PCR) does in the fight against this terrible disease.

I'd joined the PCR Facebook group and saw there was a walking challenge in February 2022, which would involve walking 56 miles in 28 days. This was something I wanted to fully support, fitness allowing. I hadn't been able to do too much walking while recovering from the operation, and committing to, on average, two miles every day seemed like quite a challenge.

When the challenge began, I was still in a fair amount of abdominal pain, which was enough of a challenge, but add to that the incontinence that also comes with having your prostate removed, and the word 'challenge' became all too real. Even with all that, I knew I was very lucky to still be around to even consider the challenge. So, with that in mind, there was no way I couldn't at least attempt it.

The best part of the challenge for me was getting to know,

and chat with, the incredible people who donated their time and money to this great cause. And also getting fantastic praise and encouragement from all those who run #TeamPCR. It was that sort of thing that kept me going, especially on days when the weather wasn't great and I wasn't feeling up to it.

I managed to raise £600 from generous donations from family and friends. My nephew Kirk Jones even filmed a short promo video for me to put on my Facebook donations page to help encourage people to donate. I would definitely join in with other fundraising challenges for #TeamPCR when health and time allow. I would also encourage everyone to get involved, whether you've

had prostate cancer or not, because one in eight men in the UK will get this disease, and that could be you, or your grandfather, father, husband, brother or even your son.

If you want to support PCR but don't think you could complete one of the challenges, let me reassure you, it's not whether you complete or finish it. It's not even about being able to raise huge sums of money, although that can help! It's about showing your support to help fight this disease in whatever way you can. Thank you for taking the time to read this, and I hope it's encouraged you to get involved.

Myk Nutt





Prostate
Cancer
Research

pcr.org.uk

Transforming research.
Transforming lives.



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



Downloadable guide
to writing your will
available online

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

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