NEWSLETTER



Transforming research. Transforming lives.

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Advancing research despite the pandemic

WINTER 2020

A round-up of prostate cancer research news

Managing erectile dysfunction Analysing funding across the UK

Introducing the Versiti Project

Meet a team member

Thanks to our **fundraisers**

Welcome (

Welcome to the winter 2020 edition of our newsletter. On behalf of the scientists and trustees of the organisation, I would like to offer my sincere thanks and appreciation for your support during an incredibly tough period for both individuals and organisations right across the country.

COVID-19 has made everything harder for everyone and we are certainly no exception. We've been affected by the general downturn in the economy and have also been constrained by what we can do about it, as successful events like the London Marathon have been cancelled for our supporters. Thankfully the team took a step back in late March 2020 to think about how we could firstly survive this, but also how we could be more focused and effective on the other side of the pandemic.

We knew that our name and our brand no longer reflected who we were, so we asked people to help us show the world who we have become. We are no longer a centre focused on a single location. We fund the best science, wherever it is in the UK – from Aberdeen to London. Thanks to some pro bono help, we created a brand that combined the scientific rigor and patient focus of the organisation and added a new emphasis on innovation. We have updated our visual identity to reflect this and have now become Prostate Cancer Research. You will see this change reflected in the design of this newsletter and also on our website.

We continued to engage with patients through webinars with our scientists and we expanded our patient panels to gain your opinions on the best research to fund. As a result, we were shortlisted for an impact award by the Charity Times for our patient-engagement work. I'd like to thank all of you who have responded to surveys or been part of Zoom calls and online communities. You have helped to shape the direction of the organisation to ensure that we remain focused on what will make a difference to patients.

Finally, we opened a grant round during the first UK lockdown because we knew that no one else was doing so for prostate cancer at this time and that therefore the new ideas being developed by scientists wouldn't see the light of day if we didn't act. Our process is now nearing the end and we have a shortlist of a range of approaches from innovative individuals at crucial stages of their careers. We hope that our support means that there won't be a huge lack of new prostate cancer research starting for the next few years. By the time our next newsletter comes out, we will be able to tell you how many of these projects we have been able to fund.

We understand that many of you have been affected by COVID-19 socially, physically and financially, but if you are in a position to support these projects then we would be very grateful for your help.

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:











Featured on cover: Dr Harveer Dev has just started his research project, which is based on the gene-editing tool that was awarded the 2020 Nobel Prize for Chemistry.

Peter Smith's story

I always read the interesting personal stories in the PCR newsletter with a mixture of emotions. These stories are written by men who are often having a tough time because they have advanced prostate cancer – they suffer side effects of treatment and they may worry about premature death. They are brave to tell their stories so frankly.

I no longer have prostate cancer. My PSA has been undetectable since my prostate was surgically removed in 2008, and my consultant surgeon believes I shall never have prostate cancer again.

Prostate cancer starts in the gland and is initially confined to it. During

this period, radical surgery is an option and can lead to a possible cure. An old friend of mine, who will be 88 in December 2020, was always worried about getting prostate cancer. We used to talk about it and I learned more about the disease. He did get it, over 20 years ago; his prostate was removed and his cancer has never recurred.

I realised that the key had to be detecting cancer early, so when I was 60 – although feeling very fit and well – I started having an annual PSA test. The reading was slightly higher than it should have been. Two years later, I had it tested again and it was still rather too high. I spoke to my doctor again and decided to consult a urologist. There were many tests: blood tests, a biopsy, two scans, a test to see if I had other urinary problems, and then: 'Well, you have

early stage prostate cancer.' I was very concerned but quite calm. I felt that there was time to take further advice, do some more study and then to make a balanced decision.

During this time, I was given a copy of an American book: Dr. Patrick Walsh's *Guide to Surviving Prostate Cancer.** It is a long, comprehensive book and I read it carefully. I finally decided that the best option was to have my prostate removed and in February 2008 the operation was done, robotically and skilfully in London. It's a serious operation. It has side effects and there is a recovery time, but it worked totally.

I never worry about prostate cancer now: my concerns are for those who are less fortunate – those who need better control of advanced cancer, those who want a longer life with their loved ones. For this reason, I am a supporter of Prostate Cancer Research: to help those for whom prostate cancer is still a continuing fear.



Science news

CRISPR-CAS9 RESEARCHERS WIN NOBEL PRIZE

The 2020 Nobel Prize for Chemistry has been awarded to Emmanuelle Charpentier and Jennifer A. Doudna for the discovery and development of the gene-editing tool CRISPR-Cas9. CRISPR-Cas9 has already revolutionised cancer research and is being used by scientists to decode the genetics of cancer. The tool has two parts: a small RNA sequence and Cas9. The RNA sequence guides the Cas9 to a specific part of the genome and Cas9 then acts as 'molecular scissors' and cuts the DNA so that this part of the sequence can be changed. By using CRISPR-Cas9 to edit certain genes, researchers can observe the effect this has on the development or progression of cancer. This enables them to identify the mutations important in driving cancer, which can then be translated into new treatments. PCRfunded scientists Dr Jorge de la Rosa and Dr Harveer Dev are both using CRISPR-Cas9 to investigate the genetics that underpin prostate cancer and treatment response.



Dr Jorge de la Rosa

Investigating why the tumoursuppressor gene PTEN is altered and how these key faulty genes play a role in tumour growth and spread



Dr Harveer Dev

Understanding why certain tumours are vulnerable to DNA-Damaging Agents (DDAs), such as radiotherapy and PARP inhibitors, to identify who will benefit from these treatments



Featured on cover

TIMING OF RADIOTHERAPY

Following prostatectomy, some men will be offered radiotherapy to ensure that all the cancer cells have been eliminated and reduce the risk of cancer returning. This is known as adjuvant radiotherapy. Others may opt to receive salvage radiotherapy if their cancer returns. Researchers at University College London conducted a review based on three clinical trials comparing the outcomes of men who had undergone adjuvant radiotherapy with men who had undergone salvage radiotherapy. They found men who received adjuvant radiotherapy following surgery did not have better outcomes after five years than those who received early salvage radiotherapy. In fact, event-free survival was 89% for adjuvant radiotherapy and 88% for early salvage radiotherapy. Dr Claire Vale, who led the review, explained: 'Our findings suggest that following surgery, patients whose cancer is confined to the prostate, or has spread only to nearby tissues or organs, can safely be spared routine post-operative radiotherapy and its associated side effects. Radiotherapy need only be given to men if they show early signs that the cancer may be returning.'

GENES DRIVING THE SPREAD OF PROSTATE CANCER

A recent study, published in *Nature Cancer*, identified 16 genes that work together to drive the spread of prostate cancer. Researchers from Rutgers University in New Jersey analysed prostate cancer cells taken from both mice and humans. They found certain gene patterns were associated with prostate cancer spreading to other parts of the body, including the bones. Screening for these genes in people diagnosed with prostate cancer could identify those who are most at risk of developing advanced disease and help inform treatment options. Dr Antonina Mitrofanova, one of the researchers, explained: 'Our results show that molecular profiling at the time of diagnosis can help inform more personalised therapy leading to better outcomes for those with this advanced form of disease.' The researchers also believe the genes could be used to identify which patients are more likely to respond to hormone therapies.



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



Large waistlines or excess belly fat may be linked to a higher risk of poor outcomes from prostate cancer. A study from the University of Oxford monitored the health of 218,225 men, who were initially cancer-free, over a 10-year period. Although the researchers found no clear link between prostate cancer outcomes and total body fat or BMI, they did find a link with the amount of body fat around the waist or the belly. Those in the top 25% for waist circumference had much poorer outcomes than those in the bottom 25%. More research is needed to confirm the findings of this study and the researchers hope to conduct further research into the link between body fat and aggressive forms of prostate cancer.

IPATASERTIB FOR AGGRESSIVE PROSTATE CANCER

The experimental cancer drug lpatasertib has been undergoing a major phase-III clinical trial. Recent results suggest that when used alongside the standard hormone treatment abiraterone, Ipatasertib could treat an aggressive group of prostate cancers. The trial has tested whether the drug can be used to treat people with advanced prostate cancer in which the PTEN gene has been lost. In individuals with PTEN loss cancer cell growth is increased, and these tumours can be difficult to treat. A protein called Akt is involved in the increased cancer cell division. Ipatasertib works by binding Akt, and this can stop cancer cells dividing. The trial found that combining lpatasertib with abiraterone successfully reduced disease progression. These early results are encouraging, and the overall survival benefit will be determined as the trial continues.

Stop press

PCR COLLABORATES WITH CELLCENTRIC

Prostate Cancer Research and CellCentric are delighted to announce a new collaborative partnership focused on creating a new patientfocused information and engagement programme for people affected by prostate cancer.

CellCentric is working with PCR to better understand the prostate cancer patient journey and support the development of our new patient programme, which will engage people with the latest research and clinical developments within universities and industry.

Through this new programme, we aim to ensure that our patient community is informed, connected and empowered. This new digital platform will enable people to easily and freely access clear and concise information on the latest developments in prostate cancer research. It will also enable patients to engage with this research by providing insights from their own lived experiences. In doing so, we aim to ensure that the drugs of the future are developed with the patient's quality-of-life impact as a top priority.

To find out more about this new partnership, please visit pcr.org.uk/pcr-collaborates-with-cellcentric/. If you are interested in taking part in this new patient-engagement project, either through completing an online survey or taking part in an online patient panel, please register your interest by completing the form on pcr.org.uk/cellcentric/



IN PARTNERSHIP WITH

CellCentric

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Prostate cancer treatments

Managing erectile dysfunction

Some treatments for prostate cancer, such as prostatectomy and radiotherapy, can cause damage to the nerves and blood vessels needed for an erection. Other treatments, such as hormone therapy, reduce the amount of testosterone in the body, which can reduce your sex drive and also lead to problems getting and maintaining an erection.

Erectile dysfunction can range from mild, where an erection may be possible but either the penis is not firm enough for sex or cannot be maintained, to severe, where an erection is not possible, either spontaneously or during sexual stimulation. It is possible for erectile function to improve following surgery but this can take between three months and three years. There are also many treatment options available. You will be able to speak to your doctor to decide which treatment is the most suitable for you.

Seek medical advice as soon as possible if you have an erection that lasts for more than two hours. This can be a rare side effect of tablets, injections, pellets and creams.

Tablets

Drugs known as phosphodiesterase type 5 inhibitors or PDE5 inhibitors are one of the main treatments for erectile dysfunction following prostatectomy. Sildenafil citrate (Viagra) is an example of a PDE5 inhibitor as well as tadalafil (Cialis), vardenafil (Levitra) and avanafil (Spedra). PDE5 inhibitors increase the blood flow to the penis and some sexual stimulation is still needed for the erection. As a result, they may not work for those who are undergoing hormone therapy and have a decreased sex drive. Tadalafil can then work for up to 36 hours, but sildenafil, vardenafil and avanafil work for four to six hours. This means that during this time, you should be able to get an erection following sexual stimulation.

Always tell your doctor about any other medication that you are taking, as PDE5 inhibitors must not be taken with nitrates. Nitrates are used to treat heart problems and are also found in some recreational drugs.

Injections

Penile injections are another option for treating erectile dysfunction if tablets do not work for you. The drugs used in the injections include alprostadil (Caverject or Viradil Duo) and aviptadil with phentolamine mesilate (Invicorp). They work by opening the blood vessels and increasing blood flow to the penis, directly causing an erection within 10 minutes of the injection. A doctor or nurse will teach you how to administer the injections. There may be some pain when the drug is injected but this is usually mild.

Pellets

Pellets are another way that the drug alprostadil can be prescribed and taken. The pellets are known as Muse and they are small and can be inserted into the tip of the penis using an applicator. Again, this should cause an erection within 10 minutes. Pellets can sometimes cause pain or a burning sensation in the penis.

Creams

Alprostadil creams (also known as Vitaros) are available on prescription. Similar to the pellets, the cream can be inserted into the tip of the penis with an applicator. It can take up to 30 minutes for the cream to have an effect. Cream can also cause pain or a burning sensation in the penis.



Around one in

will get prostate cancer at some

point in their life

eight men



More answers to common questions can be found on our website pcr.org.uk



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

Vacuum pump

If medication does not work or is not suitable, a vacuum pump can be used. A plastic cylinder is placed over the penis and when the vacuum is applied, blood is sucked into the penis to give an erection. Once the penis is erect, a soft plastic ring called a constriction ring can be placed over the base of the penis to trap the blood and maintain the erection. The constriction ring should not be left on for longer than 30 minutes.

Implant

There is also the option of penile prosthesis, but this is usually only considered if other measures don't work. It involves placing an implant in the penis during an operation. The most commonly used form of this treatment is inflatable implants. Two inflatable cylinders are implanted in the penis and connected to a pump placed in the scrotum. When you want an erection, you can squeeze the pump so that fluid is pumped into cylinders that expand to produce an erection. Semi-rigid rods are another form of implant. They are placed in the penis and can be bent or straightened so that the penis can be positioned up for an erection and down for when you don't want an erection.

Lifestyle

Keeping active and maintaining a healthy weight can help to increase your sex drive and ability to get an erection. Smoking is known to be a factor in erectile dysfunction, so stopping smoking may also help.



Emotional wellbeing

It can be difficult to talk about difficulties with getting an erection, but expressing how you feel may help you. 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 or nurse may be able to refer you to a counsellor who can help you deal with the emotional impact of erectile dysfunction.

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.

I'd like to support research into prostate cancer

Title and name	I wish to make a donation to PCR to the value of: □ £20 □ £40 □ £50 □ Other £
Address	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 I am a UK taxpayer. I understand that if I pay less income tax and/or capital at tax than the amount of Gift Aid claimed on all my donations in that tax year it is responsibility to pay any difference. I want to Gift Aid my donation today, and and donations I make in the future or have made in the past 4 years. Signature	Card number
☐ I am not eligible for Gift Aid.	We will take payment online through our website
Staying in touch with PCR We would like to keep you updated about our research. We will send you our bi-annual newsletter and appeals by post, but for us to contact you by phone, email or message, you will need to opt-in directly. Please tick your preferences below: Email	

Transforming research

Analysing funding across the UK





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)



Between 2016/17 and 2017/18 there was a 13.5% decrease in money spent on prostate cancer in the UK, versus a 3.6% decrease of overall specific cancer site funding



Prostate cancer receives only 8% of the funding spent on specific cancer sites* Cancer is one of the most important challenges of our time. With a range of charities working to meet the needs of patients, we wanted to ensure that we had an in-depth and up-to-date understanding of the entire prostate cancer ecosystem including the science and the funding landscape. This was so that we could guarantee we were spending our supporters' money where it was most needed and most likely to make a difference.

In November 2020, we published our review of the strengths and weaknesses in current prostate cancer research, which is available in full at **pcr.org.uk/ecosystem**. Using this report in conjunction with our understanding of what matters most to patients, we are in an even stronger position to spend money where it has the most impact – including filling some of the gaps left by the current system, so that we can accelerate innovation.



Our key findings included the range of challenges faced by younger scientists (which mean that we are losing talented researchers from the field of prostate cancer research), specific gaps in our knowledge of the science of prostate cancer (which are delaying better treatments for patients), the extent to which funding and clinical trials are concentrated in the 'Golden Triangle' of London-Oxford-Cambridge, and the difficulty scientists face in getting funding for high-risk, high-reward ideas. The findings of this report were directly taken into account when we chose the projects we would like to fund next. We have selected innovative projects addressing key knowledge gaps, including some by scientists who, without extra support, may change career. We are already working on ways to improve our impact even further, such as creating specific funding and non-financial support to scientists at certain career stages, ensuring that we distribute grants in a fair and equitable way so that we fund the best research – wherever it takes place. We are also continuing to monitor progress against critical knowledge gaps that stand in the way of better care for patients.

You will have noticed that, in this issue, we have changed how we look and describe ourselves to better reflect who we are. Part of this change means that we now summarise what we do as 'Transforming research. Transforming lives.' 'Transforming research' so that it works better – including by understanding and filling the gaps left by the current system – is intrinsically linked to our ability to transform lives.

^{*}The Global Cancer Observatory, International Agency for Research on Cancer, WHO (2018). United Kingdom fact sheet. gco.iarc.fr/today/fact-sheets-populations

Our latest commissioned patient study

Introducing the Versiti Project



Join the patient voice group and help us to know what matters to you pcr.org.uk In 2020, Prostate Cancer Research (PCR) commissioned social-research agency Versiti to conduct a patient study to help us understand the experiences of people living with prostate cancer – both in normal circumstances and in the context of COVID-19. This research aims to ensure that PCR develops a patient and information programme that meets the needs of people with prostate cancer and is aligned with our focus on research that matters to patients.

Insights were generated through an online research community of 37 men living with prostate cancer. Over 14 days in August 2020, participants engaged in individual and group discussions, projective techniques, drawing tasks, surveys and other research activities to help us understand and appreciate their cancer journey. The research also involved the cancer patients interviewing their loved ones or carers to find out about how their prostate cancer had impacted on their family and friends.

The findings from the study are incredibly insightful and provide us with a good understanding of the lived experiences of the prostate cancer patient journey. Key findings focused on the provision of information, feelings of empowerment and the connection with other patients.

The findings from this research are being used to support the creation of our new patient information and education programme, the details of which we are looking forward to sharing with you in our next newsletter.



Cancer patients expect information to be communicated in clear and simple terms that are sensitive and compassionate, while also being direct and descriptive.

Many of the men felt like they were on their own when it came to navigating the healthcare system, with reports that they have had to fight for treatment routes, but were ill-equipped in knowing what questions to ask.

Patients need to be empowered to have effective conversations. Many feel ill-equipped to have a two-way discussion with their consultant and question the options presented to them.

The lack of clear, accessible information has led many patients to attempt to restore a sense of control in an uncertain and disempowering situation by mastering their understanding of their own disease.

Contributing to the community can give meaning and connection. Many of the men have been profoundly touched by the connections they have made along the way with other cancer patients.

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Meet a team member: Uloaku lkegwu

Meet Uloo

Widely known as Uloo in her sphere of contacts and at PCR, this unassuming chartered accountant joined us in April 2017.

Since I joined, I have witnessed tremendous growth in the charity – especially in the past two years. PCR has seen growth in staff numbers, fundraising activities, research and financial turnover.

As the Head of Finance, I oversee the financial activities in PCR and ensure that there is adequate collaboration with other departments. The finance team is a crucial department in our charity. Just like in every other organisation, we work with the departmental heads to set the annual budget and medium-term financial plan. My responsibility is to ensure that financial policies and procedures are adhered to and that our immediate and long-term financial objectives are achieved.

I have found it essential to be involved in the Finance, Audit and Risk Committee, where decisions are made regarding management of the key areas of finance, budgetary issues and risks to the charity.

As a finance person, being involved in the 2020 'Meet the Scientists' event has been one of the highlights of my time at PCR. The event gave me the opportunity to chat with patients as well as scientists who work behind the scenes to make sure new treatments are found for prostate cancer. It was good to know the challenges faced by patients and scientists and what positive difference the involvement of PCR is making.

The team is the financial heartbeat of the charity, so we work collaboratively with other teams to ensure that our incomes grow, our expenses are kept low and our funds

Our collaboration goes beyond working with colleagues. We also work with external auditors to validate our entire year's financial transactions and ensure that our financial statements meet the required standards before being published.

are well invested.

Compliance to statutes and regulatory standards are very pertinent to us at PRC. The team develops internal controls to ensure that financial and regulatory standards are maintained. Financial monitoring and reporting are embedded in our day-to-

as the London Marathon.
It brought home the
enormous work and
passion my colleagues
put in to achieve great
success. Also seeing Mo
Farah in real life at the
2019 London Marathon
was a bonus for me.

Working for PCR has also given me

the opportunity to be part of

big fundraising events such

The most rewarding thing for me working for PCR is knowing that I am making positive impact in the lives of families that have been affected by prostate cancer.







By 2023 we will scale up the amount of our research grants to £5M and projects to at least 23 per year



Thank you to our fundraisers



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

This year has been tough on fundraising and we are so grateful to everyone who has supported us in any form in 2020. Without you, we wouldn't be able to fund the much-needed research that our world-class scientists are conducting, so thank you all from the bottom of our hearts.

Our Virtual London Marathon team

We would like to thank our amazing Virtual London Marathon team, who on 4th October 2020 braved terrible weather to tackle a marathon in their local areas to raise money for Prostate Cancer Research, Despite the disappointment of the cancelled London Marathon for amateur runners, the team were determined to complete the 26-mile distance and stepped up to complete the virtual race with relentless enthusiasm and energy! They really showed what the London community and an absolute refusal to give up. We are really grateful for everyone's continued support and are so proud of you all. Display those earned them!

From Oxted to Penzance

We would also like to a give a massive shout-out to David Rundle, Jonathan Lee and Mark O'Connor for their momentous cycle from Oxted to Penzance in aid of PCR. Inspired by David's father Mark (who took on his own cycling challenge for us during the first lockdown), the boys covered 350 miles in total over three days and raised £6,854 – an absolutely incredible achievement! Thank you all for being absolute legends.



A previous London Marathon team member, Dougie Critchley, decided to take part in the Amsterdam Marathon when lockdown first hit London earlier in 2020. Unfortunately, the race had to be cancelled owing to the ongoing pandemic, but Dougie decided he would just run his own marathon in London instead. Dougie has raised over £3,700 for PCR through this personal challenge and we are so thankful for his support and the generosity of his friends and family.

Another thank you we would like to make for a London Marathon run is to Richie Thomas, who completed his 36th marathon on 4th October in aid of PCR and Street Child and raised over £5,000 in the process! If you want to learn more about Richie's incredible effort, you can read a recent interview with him on our website.



Introducing Maestro Madness

Taking on a much-loved but underappreciated classic, the Austen Maestro, this group of friends are ready to embark on a trip like no other to raise funds for and awareness of prostate cancer research. Listen to their story – why they're fundraising for us and all about the classic car from Chris and Rob – on the first episode of our new podcast, Prostate Pod available at pcr.org.uk/news-centre/



Richie Thomas Λ

Jack's unique cards

Our incredible supporters have also been getting creative over the past few months to support our research. Jack Finnis, a 16-year-old artist. designed greeting cards and sold them on his website with all profits going to PCR. He raised a brilliant £356.95, and doesn't plan to stop there! He has designed Christmas cards to sell to further support our research, alongside other local charities. His designs are absolutely beautiful and completely capture the spirit of Christmas. Thank you, Jack, for your creativity and for choosing to support us! If you're looking for some extra special cards this Christmas, Jack's designs are available to buy from his website at jackfinnis.com



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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