

HCP Newsletter

Spring 2025

infopool
So what's new?

 **infopool**
the prostate
resource
theinfopool.co.uk



 **Prostate
Cancer
Research**
pccr.org.uk

Suite 2, 23-24 Great James Street,
London WC1N 3ES

Registered charity no. 1156027



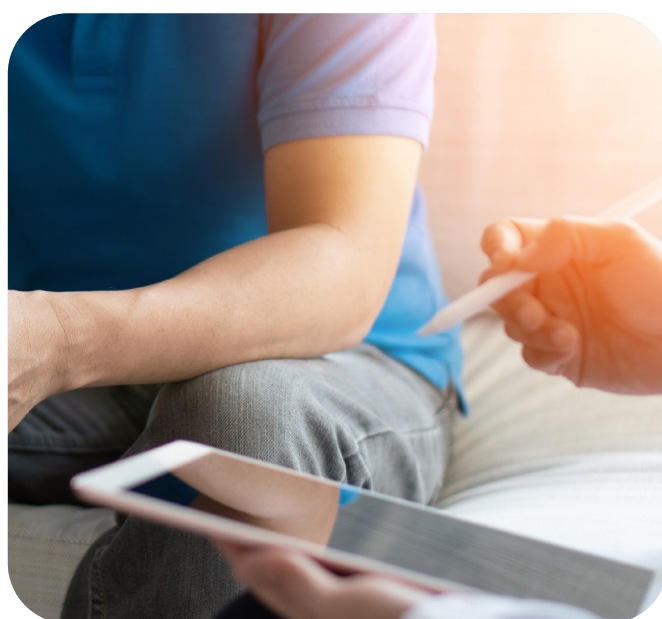
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Prostate Cancer Healthcare Professionals Newsletter:
Prostate Cancer Patient Resources and infopool update.

Edition: First Edition, Spring 2025

Author: Susannah Ramsay,
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Welcome to the first PCR infopool newsletter for healthcare professionals

Thank you for your continued support. This newsletter will keep you updated on the latest developments in **the infopool**, including **new sections**, **its impact since launching in April 2023**, and **free signposting materials** to help direct patients to trusted information.

In addition to updates on the infopool, this edition also highlights other key **Prostate Cancer Research initiatives**, including:

- **Prostate Progress** – the first-of-its-kind prostate cancer registry.
- **Real Talk** – a campaign focused on raising awareness of prostate cancer in the Black community.
- **Our landmark Socio-Economic Report on Screening** – providing crucial evidence to support earlier prostate cancer screening.

We hope you find these resources valuable, and we appreciate your ongoing support in improving prostate cancer care and education.



Who are Prostate Cancer Research and what are our goals?

Our goal is clear: we are advancing groundbreaking research and treatments to create a future where prostate cancer no longer threatens lives. Our focus is on delivering innovative solutions and improving quality of life for patients, families, and communities affected by prostate cancer.

How You Can Support Our Work

- 1 Signpost patients and their families to the infopool** as a trusted source of information.
- 2 Order free infopool materials** – including flyers, posters, and business cards – to help raise awareness in your clinical practice.
- 3 Share information about the infopool with fellow healthcare professionals** and voluntary organisations in your network.
- 4 Cascade details to relevant teams within your Trust**, including urology, oncology, and radiotherapy departments.
- 5 Add the infopool to your NHS Trust's website** to ensure more patients can access accurate, up-to-date information.
- 6 Refer patients to take part in Prostate Progress**, our first-of-its-kind patient data platform, to help shape the future of prostate cancer research and care.

Background

The infopool was launched in April 2023 as a **groundbreaking, culturally representative, and fully accessible** online prostate cancer resource. Developed in collaboration with **patients and healthcare professionals**, it is designed to support men and their partners—particularly those from **underserved and high-risk communities**—in navigating the complex information surrounding prostate cancer.

Unlike many other resources, the infopool uses a multimedia approach—including videos, animations, infographics, and cartoon strips—to make information more engaging and easier to understand. From choosing a treatment to managing side effects and finding a clinical trial, it empowers patients to take control of their prostate cancer journey.

- **PIF TICK Accreditation** – Awarded by the **Patient Information Forum**, recognising the infopool as a **high-quality, trustworthy** source of information.
- **Endorsed by the British Association of Urological Nurses (BAUN)** – The largest urological nursing association in the UK.
- **Shaw Trust Accessibility Accreditation** – Ensuring the site meets high standards for **digital accessibility**, at WCAG 2.2AA standard.

We are thrilled to share some exciting news!

We've received three-year continuation funding of **£496,344** from The National Lottery Community Fund to take the infopool to the next phase!

This support will help us expand the infopool—the go-to resource for reliable, accessible information on testing, diagnosis, treatment, side effects, and clinical trials.

Launched in 2023, it is now a trusted source of prostate cancer information right across the UK.

A huge thanks to National Lottery players for all their support!



Key features of the infopool

- Designed for underserved and high-risk communities, including men with low health literacy and individuals from Black British, Black African, and Black Caribbean (BBAC) communities.
- Features over 1,000 real-life stories (in both video and written format) from patients, partners, and carers.
- Comprehensive, accessible information on:
 - Testing and diagnosis
 - Treatments and side effects
 - Shared decision-making
 - Managing healthcare conversations
 - Palliative and end-of-life care
 - Clinical trials and more
- Aligns with national and international guidelines, guided by a multidisciplinary Clinical Advisory Board of urologists, oncologists, clinical nurse specialists, health inequality experts, and histopathologists.



New interactive information toolkits for patients and a couple of new sections

In late 2024 we launched four new, interactive information toolkits on the infopool, designed to empower and support patients on their prostate cancer journey.

Mastering conversations

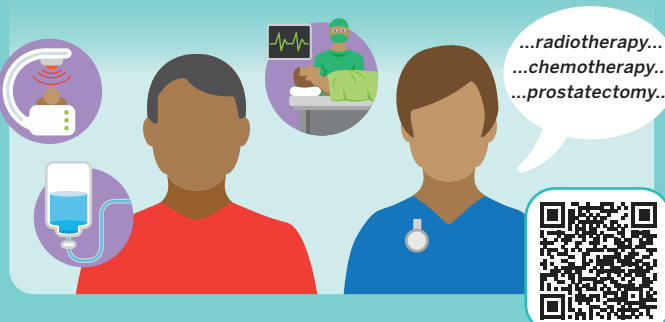
Communicating with healthcare teams can be challenging, with many patients struggling to have effective conversations. They often leave appointments feeling frustrated—this is especially true for people with lower health literacy and those from Black and other ethnic minority communities.

This toolkit helps patients get the most out of their healthcare interactions. It describes who they will meet along their treatment pathway and gives tips for managing difficult conversations and voicing concerns.



Shared decision making

Shared decision making (SDM) is a collaborative process where patients are supported by their healthcare team to make informed decisions about their own treatment and care. It's a key component of the NHS's long-term plan for personalised care, but many patients aren't familiar with the concept, and it doesn't always occur. This toolkit explains SDM, its benefits and how patients can take an active role in their own treatment decisions.



These toolkits have been made possible by the provision of educational grants from Astellas Pharma Ltd., Novartis and Parexel.

The toolkits are inspired by feedback from people with prostate cancer and their families. They use engaging formats such as animations, infographics, cartoon strips and patient videos.

How to access and make use of side effects support



Patients tell us that they struggle to find the right support to manage their side effects. This series of toolkits includes information on common side effects and how to find support.

Each major side effect has its own dedicated page, including:

- **Peeing problems (urinary incontinence)**
- **Sexual problems**
- **Hot sweats and fatigue with hormone therapy**
- **Late effects of radiotherapy treatment**
- **Emotional and psychological issues**



Learning about clinical trials



Clinical trials can be a valuable treatment option for some people. However, many are unaware that a trial may be an option for them. Concerningly, Black men and other ethnic minorities are generally underrepresented in clinical trials.

This toolkit busts common myths, answers the most common questions around clinical trials and shares stories from people who have taken part in a trial. It also highlights the importance of diversity in trials and signposts patients to our clinical trial finder.



What you can do?



Book a 10-15 minute demo via Microsoft Teams with me for a quick tour round the new sections of the infopool and sections that you may not have noticed, so that you can decide the best way to signpost your patients to the information that is most suitable to their needs.



Scan the QR code or click here to book your tour of the infopool



The infopool: Growing Reach and Impact

Since launching, **over 200,000 people** have accessed information through the infopool. The most visited pages include:

- Patient Stories
- Living with Side Effects
- Testing & Diagnosis Tool

The **infopool is now signposted by over 184 NHS hospitals** across the **entire prostate cancer pathway**. Healthcare colleagues are actively using the **free materials** in **patient information packs** and displaying **posters and leaflets** in clinics, helping to improve patient support and education.

Thank You for Your Support

We are grateful to everyone who participated in our **2024 survey**. Your feedback has helped us understand the impact of the infopool, and we are excited to share some of the key **results, testimonials, and insights** from both colleagues and patients.

We hope this feedback is valuable for your own clinical practice and helps demonstrate the real-world difference the infopool is making. Thank you for your continued support in helping us reach more men with trusted, accessible information.



The diagrams, cartoons and short videos explain the treatments clearly, in a language that most of my patients understand...



9 IN 10

HCPs surveyed refer between 1-10 patients to the infopool each week

PCR Healthcare Professionals Survey, 2024.

64 IN 100

HCPs surveyed use the infopool each week

98 IN 100

HCPs surveyed would recommend the infopool to a colleague (98%)

94 IN 100

patient users expressed high or extremely high satisfaction (94%)

93 IN 100

users would recommend the infopool to others (93%)

It saves the average healthcare professional approximately

3.5 HOURS

per month on average vs looking for alternative information

184



NHS hospitals have adopted the infopool into their clinical pathways and are signposting to the infopool Patient Testimonials

160



hospitals have ordered our Treating Prostate Cancer Q&A Booklet, an offline accompaniment to the infopool



I think the infopool is a fantastic new resource and I really encourage people to signpost their patients towards it. It spans the whole of the patient journey, it is not just for newly diagnosed patients.



Scan the QR code or click here to take part in a short survey



What you can do?



Please do feedback to me on how you are using the infopool and how this is impacting on your own clinical practice. (sramsay@pcr.org.uk).

What is new and how to order

To help you direct patients to **trusted, accessible prostate cancer information**, we offer a range of **free materials** designed for clinics, patient packs, and hospital settings.

Patient-facing materials

A5 Patient Flyers (1-page, double-sided)

- Features a QR code linking to the infopool.
- Summarises key resources, including clinical trials, treatment options, diagnosis information, and patient stories.
- Designed for inserting into patient packs or handing out in clinics.

Business-Size Cards

- Compact QR code cards designed for easy distribution in clinics and patient packs.

A3 & A4 infopool Poster

- Available in multiple versions with different demographic images to reflect the diversity of your patients.
- 3 versions available.

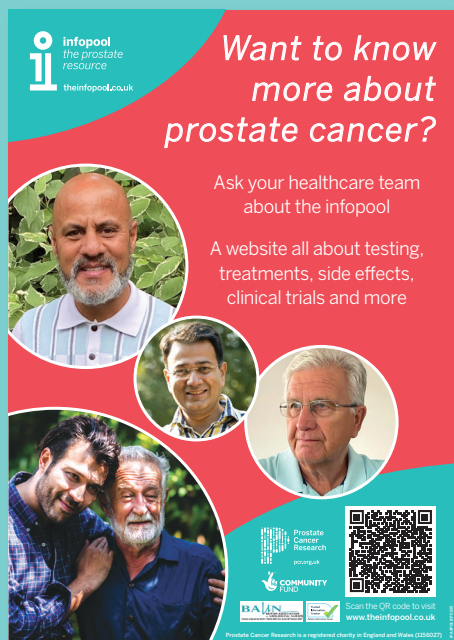
If you'd like to **order materials** or discuss how we can better support your clinic, please get in touch.



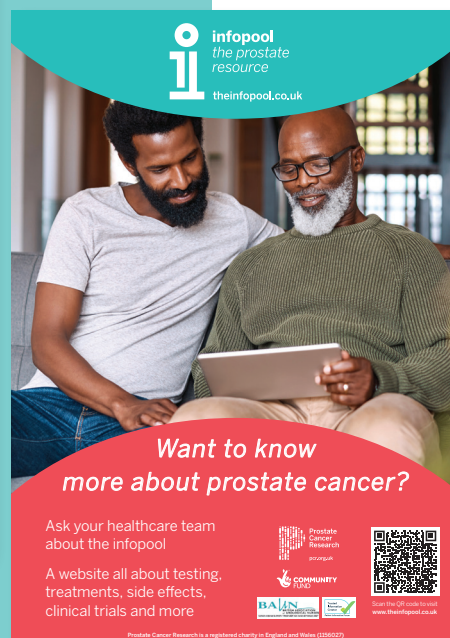
A5 Patient Flyers



Business-Size Cards



A3 & A4 infopool Poster – version 1



A3 & A4 infopool Poster – version 2



A3 & A4 infopool Poster – version 3

“It's the best thing out there because it's got more things related to Black men across different aspects of Prostate Cancer, than any other tool.”

Specialised QR Code Flyers & Posters



We have developed **quick-link flyers and posters** (A5 and A4 sizes) in collaboration with **HCPs** to help **signpost specific sections of the infopool**, making it easier for patients to find relevant information:

1 Learn More About Prostate Cancer

QR Code links to:

- What is prostate cancer?
- How is prostate cancer diagnosed?
- What is a prostate biopsy?
- Exploring treatment options.

2 Managing Side Effects

QR Code links to:

- Dealing with peeing problems.
- Getting support for sexual health issues.
- Managing hot sweats and fatigue.
- Late effects of radiotherapy treatment.
- Living with side effects stories.
- Emotional and psychological support.



I've got a lot of encouragement from the infopool. There are people there who have a very positive outlook on things.



3 Shared Decision-Making

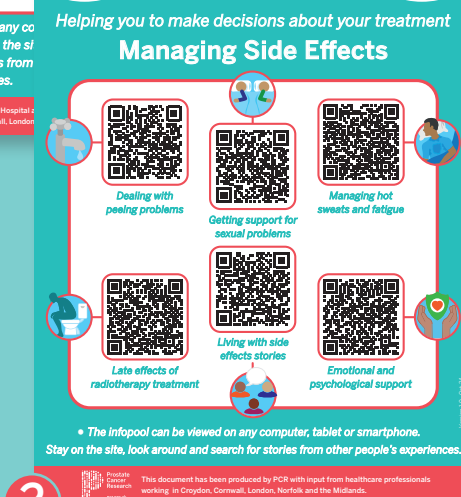
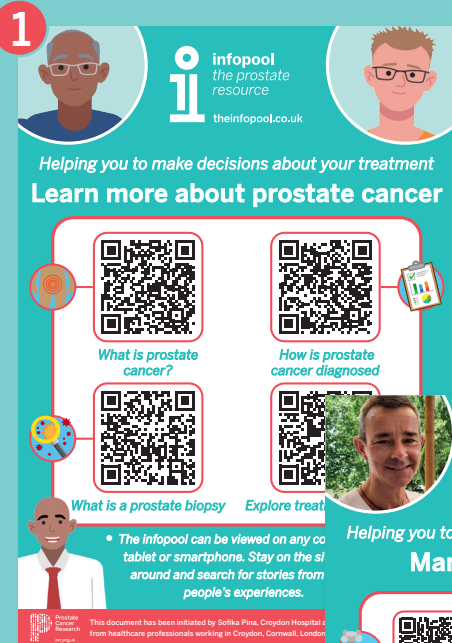
QR Code links to:

- What is shared decision-making?
- Understanding treatment choices.
- How to have a productive conversation with your HCP.

4 Clinical Trials

QR Code links to:

- Learning about clinical trials.
- Clinical trial finder.
- Clinical trials: The facts and what to ask.
- Patient stories from clinical trials.
- Understanding Prostate Progress and how to participate.



4

More quick-link QR code crib sheets will be available soon!

Newly Updated: 'Treating Prostate Cancer' Booklet



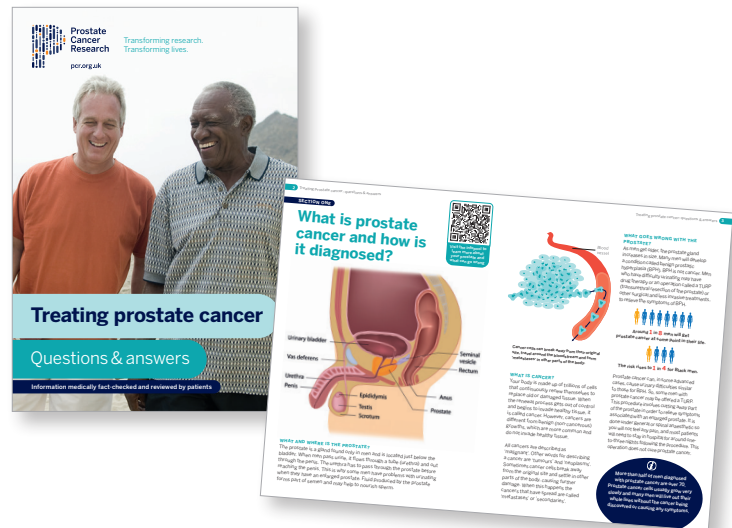
- Q&A Booklet (A5 size, 90 copies per box)
- Designed to provide **clear, accessible** information on **prostate cancer** and **treatment options** in a **question-and-answer** format.
- Multiple QR codes link to relevant pages and video explainers on the infopool
- Includes a **tear-out page** with suggested **questions** for patients to ask their HCPs.
- The booklet was updated in January 2025 and now includes:
 - An updated section on clinical trials
 - Help to make good decisions about care and treatment including information on shared decision making.
 - Information on Prostate Progress our first-of-its-kind data platform.
 - A new section that provides support to access and make use of side effects support. This includes information on peeing problems, sexual issues, late effects of radiotherapy and hot sweats and fatigue.

infopool Introductory Welcome Pack



Ordering a free infopool introductory welcome pack provides you with essential materials to help signpost patients to trusted information. Each pack includes:

- 500 A5 flyers
- 250 business-size cards
- 6 posters (3x A3 and 3x A4)
- 25 of each QR code quick-link A5 flyers
- 25 A5 Prostate Progress flyers
- 1 box of A5 'Q&A: Treating Prostate Cancer' booklets (90 copies)



Prostate Progress Materials Available to Order



(For more details on Prostate Progress please refer to Section 6.)

We now offer **free Prostate Progress signposting materials**, which can be ordered through the materials portal or as part of the **welcome pack**. Available materials include:

- **A5 Flyers**
 - **Version 1:** Featuring **Stephen Fry**, encouraging patients to sign up and share their information.
 - **Version 2:** **NHS/PCR** advert promoting patient participation in data sharing.
- **A5 'Be a Part of the Change' Booklets**
 - Explains **what Prostate Progress is**, how patients can join, the **benefits and risks**, **data protection measures**, how it is run and funded, and where to get support.

How to Reorder Materials



Many of you now have direct access to our Materials Ordering Portal. If you have received your login details, please follow the instructions below.

New Users

If you have not yet been set up with an account, please email sramsay@pcr.org.uk, and I will arrange this for you. Once your account is created, you will be able to order any of our free materials directly at your convenience.

Ordering Process

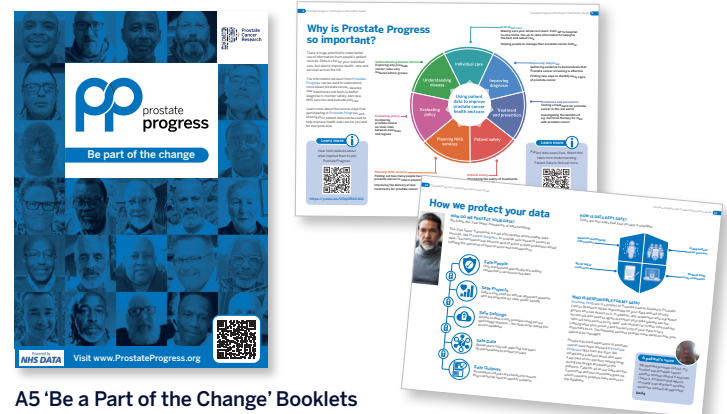
- Orders are processed within **3-5 working days**.
- You will receive an **order confirmation and reference number** once your request has been submitted.
- Please ensure you provide your **full work address, department, building, floor**, and the **name and position** of the recipient to avoid delivery issues.

Materials Ordering Portal

- Portal Link (see QR code to the right):
<https://www.theinfopool.co.uk/HCPs-reorder>
- **Username:** Your email address (in lowercase)
- **Temporary Password:** pcr001
- **Recommended Device:** Use a laptop or desktop rather than a mobile device for the best experience.



A5 Flyers



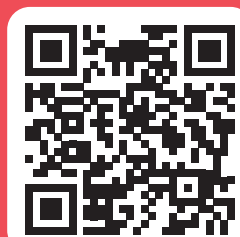
A5 'Be a Part of the Change' Booklets

Additional Support

- A step-by-step video guide is available – <https://youtu.be/5C1z-LLgDEM>



- If you misplace the ordering portal link, you can also find it on the infopool website—scroll to the bottom of the homepage and look for the blue footer band, then click on “Information for HCPs.”
- Any feedback for improvements welcome!
- Please do let me know if there are any additional signposting materials that we can produce and provide that would help you signpost to either the infopool or Prostate Progress.



Scan the QR code to visit our Materials Ordering Portal



HCP webinars

Throughout the year, we host a series of live educational webinars designed specifically for healthcare professionals. These sessions provide expert insights on key topics in prostate cancer care and are recorded for on-demand access.

- Access past webinars anytime: <https://www.theinfopool.co.uk/HCPs>
- Upcoming Webinars: We hold 3-4 webinars per year—check our HCP page for the latest updates.



Past HCP webinars – available on demand



1 'Advanced Prostate Cancer: Maintaining Quality of Life When Considering Treatment Options'

- Life on Hormone Treatment – Phil Goodall
- Overview of Treatments – Louisa Fleure, Consultant Nurse, Guys and St Thomas' Hospitals NHS Trust
- Maximising QoL, treatment adherence and managing side effects – Debbie Victor, Uro-Oncology CNS (oncology), Royal Cornwall Hospitals NHS Trust
- PARP and genetics – Louisa Fleure, Consultant Nurse, Guys and St Thomas' Hospitals NHS Trust

“Many thanks for organising such an informative and interesting webinar.”

2 'Radiotherapy and Management of Late Effects'

- Late Effects of Radiotherapy: A patient's perspective – Tony Ash
- Radiotherapy Late Effects: What HCPs can do to help support patients experiencing the consequences of Radiotherapy treatment and its impact on quality of life – Monica Thornton, Lead Radiotherapy Late Effects Macmillan Radiographer, University Hospitals of Derby and Burton
- Late Effects of Radiotherapy: A new support information resource – Dr Sara Nelson, Head of Health Information, PCR

“The webinar was great especially the infopool information. The business cards and the booklets sound fab; we can add these to our information packs.”



Upcoming Webinar May 2025

- Topic: “Robotic-Assisted Radical Prostatectomy – Importance of Patient Feedback to Improve Surgical Outcomes”
- This session will explore how incorporating patient perspectives can help refine surgical approaches and post-operative care.



Sign up to our mailing list to be notified of the next webinar date



3 'The Role of the Research Nurse in Clinical Trials and How Clinical Nurse Specialists can be More Involved'

- Why patients want to know about clinical trials – Steve
- The role of the research nurse in clinical trials – Kelly Leonard, Senior Research Nurse & Team Leader, Cambridge Urology Translational Research & Clinical Trials Office, Cambridge University NHS Trust
- How HCPs can support the future of research and care – David James, Director of Patient Projects and Influencing, PCR

4 'Overcoming Challenges of Informed Decision Making in the Treatment of Prostate Cancer'

- A patient's perspective – Clem
- Informed decision making in metastatic prostate cancer – Debbie Victor, Uro-oncology CNS Oncology, Royal Cornwall Hospitals Trust
- Importance of informed decision making at diagnosis of prostate cancer with favourable prognosis – Vineetha Thankappan Nair, Macmillan Lead CNS, Prostate Cancer Specialist Nurse, Cambridge University Hospital

Prostate Progress (our patient data platform)



Be part of the change

In July 2024, Prostate Cancer Research (PCR) and NHS England (NHSE) announced the launch of Prostate Progress, a pioneering patient data platform designed to transform prostate cancer testing, treatment and care. This platform will provide secure access to healthcare data for research, support innovative solutions, and improve treatment outcomes.

Prostate Progress has been selected as the first-ever Network Driver Project by NHS England's Data for R&D programme. We are working closely with NHS England's Research Secure Data Environment (SDE) Network, which includes 11 subnational SDEs to ensure secure access to healthcare data for approved research led by academics, industry, and NHS researchers. In its first phase Prostate Progress is collaborating with three SNSDEs covering a third of the UK population. In subsequent phases we intend to roll this out to other SNSDEs and then the devolved nations.

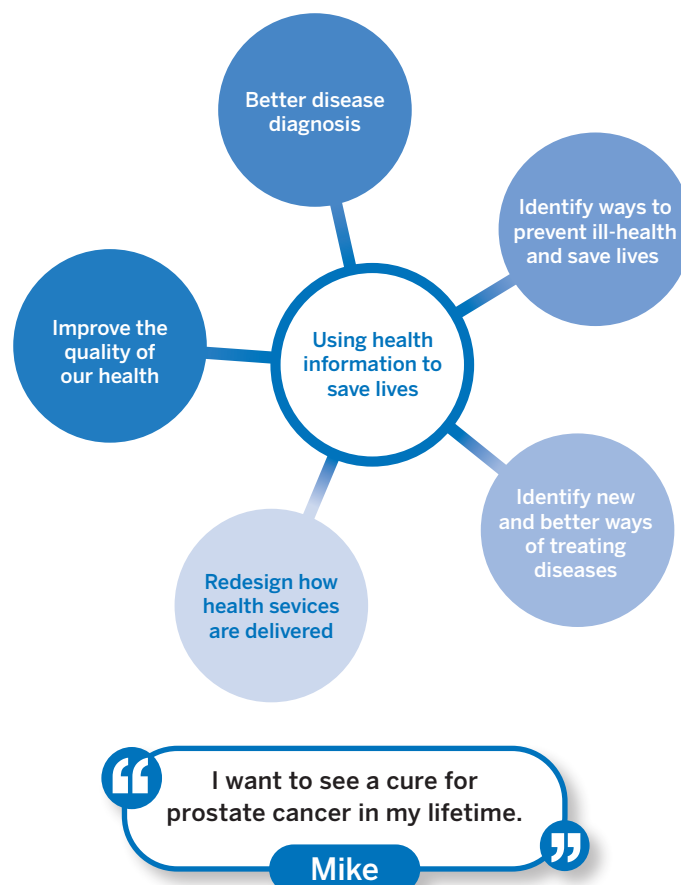
Prostate Progress has received UK-wide Research Ethics Committee approval.



Over **4,000** patients from across the UK have already joined Prostate Progress. Our target is **10,000** patients signed up by 2025.

How do patients get involved

- Anyone in the UK who has been diagnosed with prostate cancer can participate from the comfort of their home via phone, computer, or tablet.
- Patients sign up at www.ProstateProgress.org
- Participation means registering an account, providing informed consent, and completing baseline health questionnaires with periodic follow-up surveys.



How can you help support Prostate Progress

- **Order Free Signposting Materials** – Order **flyers, posters and participant information sheets** to support patients in finding trusted information.
- **Raise Awareness in Clinics** – Display **NHS-branded posters and leaflets** in waiting areas and include materials in **patient information packs**.
- **Share with Colleagues & Networks** – Inform **other healthcare professionals, voluntary organisations, and support groups** about Prostate Progress.
- **Promote on Your Website & Social Media** – Help more patients and professionals discover Prostate Progress by sharing **links and resources online**.
- **Cascade Information to Key Teams** – Ensure **urology teams, oncology departments, and primary care networks** are aware of this valuable resource.



Scan the QR code to visit
www.ProstateProgress.org

Real Talk Saves Lives campaign



See the full campaign
pccr.org.uk/realtalk



We were proud to launch our **dynamic Real Talk campaign** in **September 2024**, addressing the stark racial disparities Black men face with prostate cancer. Led by **Premier League** footballer **Clinton Morrison**, actor **Colin McFarlane**, and comedian **Aurie Styla**, the campaign raised awareness within Black communities and reinforced our mission to eradicate inequality in prostate cancer outcomes.

Real Talk is a collaboration between **Prostate Cancer Research (PCR)** and **Ipsen Ltd.**, with campaign amplification partially funded by Ipsen Ltd.

The Stark Reality

- **1 in 4 Black men** will be diagnosed with prostate cancer—compared to **1 in 8 White men** and **1 in 13 men of other ethnicities**.
- Black men are **twice as likely** to die from the disease as White men.
- Despite this, **polling by PCR** of 2,000 Black adults in the UK found that **less than a third** were aware of their **higher risk**.

Multi-platform campaign via a website, social postings and films, created to reach Black people wherever they may be looking



The Real Talk project is a collaboration between Prostate Cancer Research (PCR) and pharmaceutical company Ipsen Ltd. The amplification of the campaign has been partially funded by Ipsen Ltd.



The Campaign

To confront this lack of awareness head-on, **Real Talk** used **culturally relevant storytelling** to spark **honest conversations** about prostate cancer:

- **Comedy Film:** Set in a barbershop, the short film encouraged Black men to have a **“Real Talk”** about prostate cancer symptoms and diagnosis.
- **Survivor & HCP Video:** A powerful interview with **Black prostate cancer survivors and healthcare professionals**, sharing their experiences and reinforcing the importance of **early detection and open conversations**.
- **National Media Coverage:** The campaign was featured in major outlets, including **Sky Sports and The Independent**, increasing visibility and driving engagement.

How You Can Help

As **healthcare professionals**, you play a vital role in **continuing this conversation**:

- **Share the campaign** with colleagues and patients to help raise awareness.
- **Encourage Black men in your care** to discuss their risk with others and seek **early detection** options.
- **Support ongoing efforts** to address disparities in diagnosis and treatment.

Together, we can **close the gap** in prostate cancer outcomes and ensure **Black men get the information and care they need**.

Socio-economic Impact of Prostate Cancer Screening & our Proactive for Your Prostate Campaign

Please do download a copy of our landmark report about the socio-economic impact of prostate cancer screening.



Scan the QR code to download the report

Our **Socio-economic Impact of Prostate Cancer Screening report** provided the first comprehensive cost-benefit analysis of introducing a **screening programme** in the UK. The findings highlighted that early detection would not only **save thousands of lives** but also **reduce NHS costs, lessen productivity losses, and ease the economic burden on families**. The report demonstrates that screening for **high-risk groups**—Black men and those with a family history—would be both **clinically effective** and **deliver a positive socio-economic benefit for the country**.

Through our **Proactive for Your Prostate** campaign, we are calling for **urgent action** by the UK National Screening Committee and the governments of the UK to implement targeted screening for high-risk groups, and to **accelerate investments in innovative diagnostics and AI** to ensure we can reach a time when **early detection can be available for all men**. With growing political and clinical backing, we are keeping up the pressure to ensure prostate cancer screening becomes a reality.



Supporters of the campaign include Karen (pictured above with her deceased husband Mark) and Brian (right), whose lives have been impacted by prostate cancer



138,642 of you signed the petition submitted to 10 Downing Street on 27 August



More than 100 MPs have offered their support in a variety of ways



Over 6,000 people have written to their MP sharing their stories

Thank You & Stay Connected



That's it for this Spring edition—thank you for your attention. We hope this update has been helpful and would love to hear your feedback.

We welcome your insights on:

- How you are signposting patients to the infopool
- How you are sharing this resource with colleagues
- The most useful sections for you and your patients
- Any additional materials or support you'd find valuable
- Ways we can work together to further raise awareness of the infopool and our other resources

Please feel free to reach out to me via email (sramsay@pcr.org.uk) with any feedback or suggestions. We truly appreciate your support in ensuring patients have access to **trusted, accessible prostate cancer information**.

On behalf of Prostate Cancer Research

Susannah Ramsay

Susannah Ramsay
Senior Programme Manager



Scan the QR code or click here to take part in a short survey

