

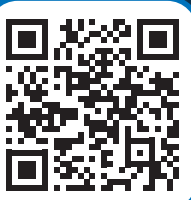


Prostate  
Cancer  
Research



prostate  
**progress**

Be part of the change



Visit [www.ProstateProgress.org](http://www.ProstateProgress.org)



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### A patient's voice

'Prostate cancer affects 1 in 4 Black men and we need to arrest this killer!'

**David**

Joining Prostate Progress is simple, safe and will help save lives. Watch our video to learn more.



### A patient's voice

'I want to see earlier diagnosis and better understanding of prostate cancer in younger men.'

**Gareth**



### A patient's voice

'By harnessing the power of our own health information... we can help bring the world a step closer to a future where this disease no longer poses a threat, where it is caught early, where it is treated effectively and humanely, and where many lives are saved.'

**Stephen**



Watch a special video message from fellow prostate cancer patient Stephen Fry



<https://youtu.be/MhCkS8smCbc>

Visit [www.ProstateProgress.org](http://www.ProstateProgress.org)



# What is Prostate Progress?



**Prostate Progress** is an exciting new initiative by Prostate Cancer Research, a UK charity, that will change the way prostate cancer is diagnosed, treated and cared for.

**Prostate Progress** brings together your health data and personal experience in one place, making it easy for your healthcare team and researchers to assess the full picture of your health, wellbeing and quality of life.

By joining **Prostate Progress**, anyone in the UK who has ever been diagnosed with prostate cancer can help improve prostate cancer care and research, using a phone, tablet or computer.

People with lived experience of prostate cancer have been involved in the creation, design and governance of **Prostate Progress** to ensure that it meets the needs of patients and others affected by prostate cancer.

## WHY AM I BEING INVITED?

You are being invited to join **Prostate Progress** because you are over the age of 18 years, you live in the UK and have been diagnosed with prostate cancer at some point in the past.

## DO I HAVE TO JOIN?

No. Joining is entirely your choice. You may want to discuss your decision with family or friends. If you join and then change your mind, you can withdraw at any time – please see the “Can I withdraw from **Prostate Progress**?” section for more information.

## WHAT IF I HAVE A PROBLEM?

You can contact us at [progress@pcr.org.uk](mailto:progress@pcr.org.uk). We will aim to respond to your email as soon as possible.







### A patient's voice

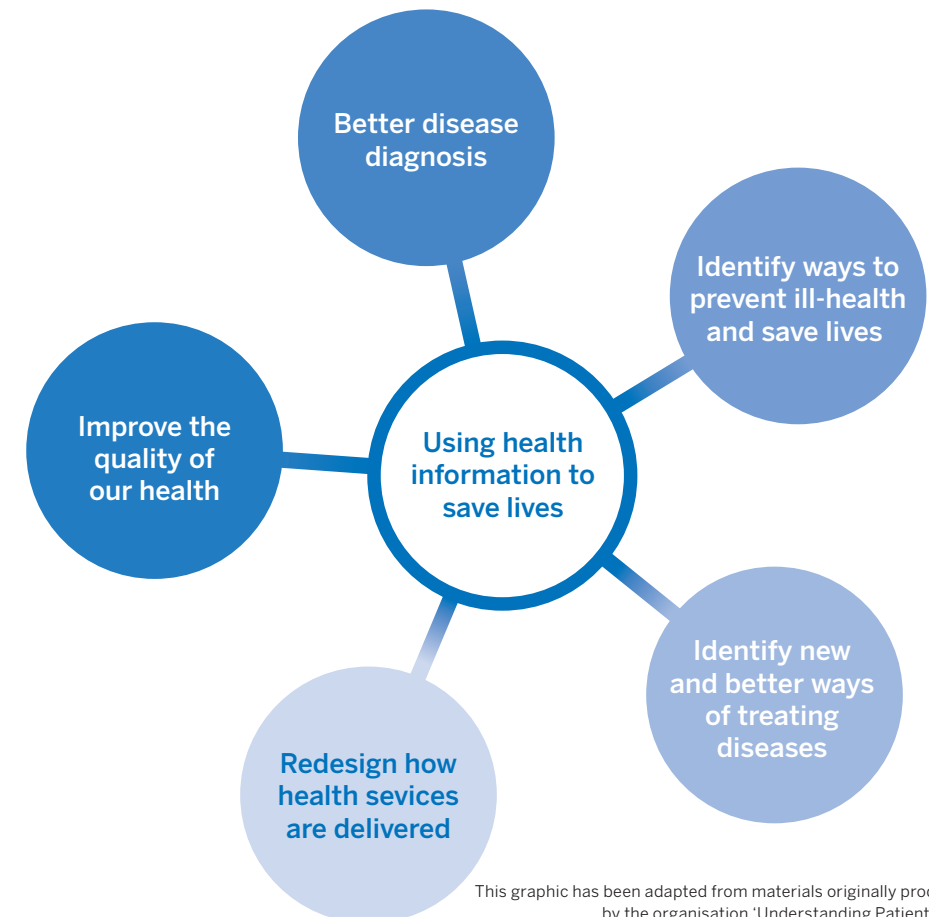
‘There are gaps in our knowledge of prostate cancer. Collecting data will provide better support to future men.’

**Aidan**



## OUR COMMITMENTS TO YOU

-  We will always be guided by what is best for patients
-  We will always include patients in our decision making bodies
-  We will only approve research that may benefit the public
-  We will never sell your information for insurance or advertising purposes
-  We will always be transparent and communicate with you about major changes
-  We will protect your privacy and information as if it were our own



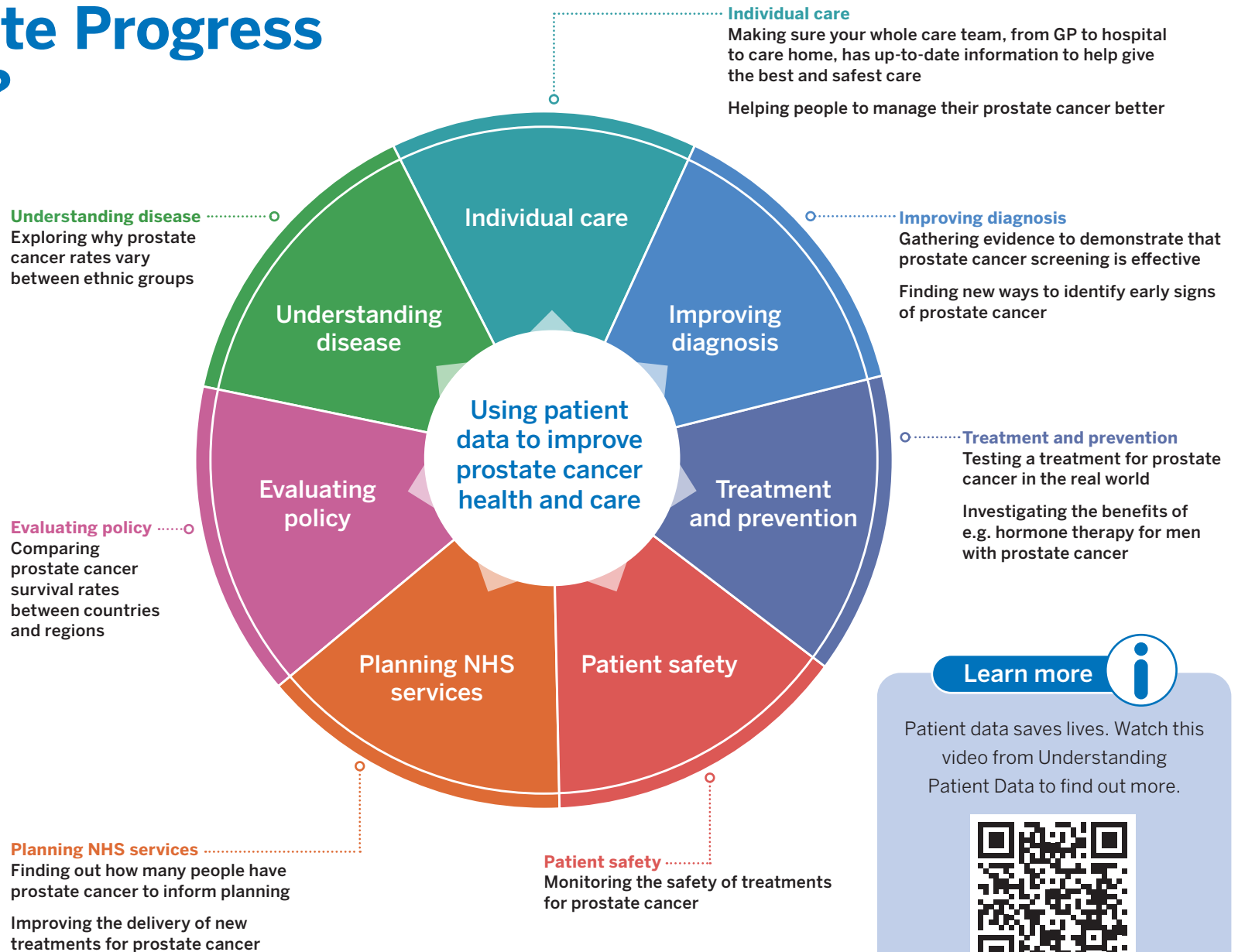
This graphic has been adapted from materials originally produced by the organisation 'Understanding Patient Data'

# Why is Prostate Progress so important?

There is huge potential to make better use of information from people's patient records. Data is vital for your individual care, but also to improve health, care and services across the UK.

The information we learn from **Prostate Progress** can be used to understand more about prostate cancer, develop new treatments and tests to better diagnose it, monitor safety, plan new NHS services and evaluate policies.

Learn more about the various ways that participating in **Prostate Progress** and sharing your patient data can be used to help improve health and care for you and for everyone else.



**Learn more**

Hear from patients about what inspired them to join Prostate Progress.



<https://youtu.be/O3qCiRAOJUK>

**Learn more**

Patient data saves lives. Watch this video from Understanding Patient Data to find out more.



<https://youtu.be/fJ2hyXCOOyQj>

This graphic and video have been adapted from materials originally produced by the organisation 'Understanding Patient Data'

# What joining involves



## WHAT WILL I BE ASKED TO DO?

If you decide to join **Prostate Progress**, we will ask you to:

### 1 READ AND SIGN A CONSENT FORM

This is a document that will ask you to provide confirmation that you agree to take part in **Prostate Progress**, and will include a request for your permission to:

Permit us to access health-related records, tissues, samples and other digital and physical health-related information about you. We will access, store and link to these to maintain an accurate picture of your prostate cancer and your health. These may be held by the NHS or other organisations (such as disease registers or GP practices) within the UK.

To link to these health-related records, tissues, samples and other digital and physical health-related information about you, we will use some of your identifiable data, like your name, date of birth or your NHS/CHI/H&C number.

We will keep collecting information about you from health-related records, tissues, samples and other digital and physical health-related information as the research programme goes on, for many years. This means if you remain in **Prostate Progress**, we will continue to collect information about you over the course of your lifetime.

### 2 FILL IN A QUESTIONNAIRE ABOUT YOURSELF

We will ask you to complete a questionnaire about yourself and your prostate cancer treatment to date: My Prostate Cancer Experience. This will include information about you, your diagnosis and your treatment.

A few questions will ask about things that some people feel are private, such as your ethnicity or your sexual orientation. We ask these questions because there is often a link between these factors and people's health, and gathering this key information helps us to better tailor research, resources, and support.

### 3 FILL IN A QUESTIONNAIRE ABOUT YOUR HEALTH A FEW TIMES A YEAR

We will ask you to fill in a questionnaire about your health: My Prostate Cancer Health. This helps us to gain a full picture of your health. By completing it a few times a year we can see how your health changes over time.

A few questions will ask about things that some people feel are private, such as your erectile function. You may also find some questions are not relevant to you. Some questions may be relevant for some people but not others. You do not have to answer any question that you don't feel comfortable with.

### WILL YOU CONTACT ME AGAIN?

If you agree to take part in **Prostate Progress**, we may contact you again in the future including to send you reminders about completing your questionnaires. You can update your preferences on what further communication you would like to receive from us at any time, either directly from the emails we send you, or through your online account. However, you will not be able to opt-out of all communication without withdrawing from the research programme (for more information on withdrawing from the programme, please see the "can I withdraw from **Prostate Progress**" sub-section).

Reasons we might want to contact you include (but are not limited) to:

- Send you news and updates
- Invite you to take part in other studies or guest questionnaires which we think you may be interested in
- Let you know about suitable research and clinical trials that you may be eligible for
- Ask you about your experiences of taking part

You do not have to say yes to taking part in any other research studies or provide any other information if you do not wish to.

Learn more



Hear from patients about why it is so important for other people to join Prostate Progress.



<https://youtu.be/Otue-JaDToE>



### WHO WILL DO THE RESEARCH AND HOW WILL IT WORK?

The research will be done by researchers from the UK and countries around the world and could be from organisations such as universities, charities or industry.

Any researcher who applies to do research will need to go through a strict application process, where their proposals will be carefully reviewed by a Data Access Committee. The Data Access Committee includes scientific experts and members of the public with lived experience of prostate cancer.

The Data Access Committee will only approve health-related research proposals that are for the public good and come from registered researchers. Any researchers who are granted access will only be able to see de-personalised data about you. This means that they will not be able to see your name, contact details or any information that will directly identify you as an individual. In addition, researchers who are granted access will also need to sign an agreement that says they will not try to re-identify any of the participants from the data they are able to see.

### WILL ANYONE KNOW WHO I AM?

No, we put in place strict safeguards to prevent anyone from being able to identify you. All your data and information is stored on secure data servers based in the UK that use industry standard encryption and controls in line with the UK laws and best practices.

### HOW LONG WILL I BE INVOLVED?

**Prostate Progress** will run for a very long time. We hope to collect as much information as we can about participants' prostate cancer as they get older, so researchers can look back to find the earliest signs of disease and produce more effective tests to detect it and treatments to cure it.

That's why, if you decide to take part, we would like to be able to keep track of your health for the rest of your life, using your health records. Researchers may continue to use your data in studies, even after you die, or if you lose mental capacity. For more information on how we look after your data, please see section 3: "How we protect your data".



### Patient testimonial

## Henry

#### What inspired you to be part of Prostate Progress?

It was the value in hearing other patient stories, for patients and for their loved ones, their friends and family. I think Prostate Progress will be really useful to patients, families, healthcare professionals generally, but particularly researchers who will have a lot of data available to them.

#### How have you been involved in the development of Prostate Progress?

I'm one of quite a few patients who are on Prostate Progress' Steering Committee. One of the reasons that I was asked to be on it is that I'm a gay man and there's a diverse group of patients involved at a governance level.

Projects like this really need to make the effort to actively address inclusion to make sure that all minority communities know that they're definitely welcome. It would be pointless to set up a register like this and end up missing vast groups of people, because you just wouldn't have accurate data either for patients and relatives looking at it or for researchers trying to make advances in prostate cancer research.

Prostate Cancer Research and its partners have really gone to great lengths to include patients. Patients have been consulted and involved in governance from the outset, and we are helping to ensure that the whole project is as inclusive and representative as possible.

#### Do you have anything you wish to say to others with prostate cancer?

Because of the risks of minority communities not feeling welcome, it's particularly important that people from the LGBTQ+ community, Black men and members of other minorities come forward, and offer their data to Prostate Progress. The more of us that take part, the more useful the whole project is for everyone.





### CAN I WITHDRAW?

You can withdraw from **Prostate Progress**, or reduce your involvement, at any time.

You don't have to give a reason, but we will ask you to choose between two options:

**1. Partial withdrawal** - this means we will not contact you again, or get any further information from your health records, but we can still analyse the data you gave before you withdrew.

**2. Full withdrawal** - this means we will not contact you again and we will destroy all the data we collected from you. Data is made available to researchers in stages. It won't be possible to remove your data from any research that was done before you withdrew, we can only do this when we create a new release of data for research. You can find out more information about how often this happens in our privacy notice:

[www.pcr.org.uk/prostate-progress](http://www.pcr.org.uk/prostate-progress)



### WITHDRAWAL OPTIONS

	Option 1 Partial withdrawal	Option 2 Full withdrawal
Can we continue to get new information from your health records and other data sources?	NO	NO
Can we continue to use the data you already gave us?	YES	NO*

\*We will destroy the data we have for you. However, it won't be possible to remove your data from any research that took place before you withdrew.

If you would like to withdraw you can do this by filling in a short form, which you can find on our website [www.pcr.org.uk/prostate-progress](http://www.pcr.org.uk/prostate-progress).

### Why is Prostate Progress so important?

“ I want to see a cure for prostate cancer in my lifetime. ”

Mike

“ I have it, and it took my father. Maybe this can help others to understand and catch it before it's too late. ”

Bernard

“ Further research into the diagnosis and treatment of prostate cancer may help me now and other men in the future. ”

Phil

“ I would wish to benefit from this initiative and to help others through my own personal experiences. ”

Olson

“ I hope it may help in the treatment and understanding of prostate cancer. ”

Nick

“ Everyone's experiences can lead to a better understanding. ”

Robert

“ I have prostate cancer and wish to help others. ”

Nicholas

“ If my results and experience can be added to an overall database where more knowledge and treatments can be developed I would be happy to help. ”

David

“ Knowledge is power. ”

Clive

“ Many men don't know they have prostate cancer. Let's work together and help more men with prostate cancer live longer. ”

Chris

“ I have had prostate cancer and want to support others who find themselves in the same position, and those trying to find a cure for this cancer. ”

Philip

Visit [www.ProstateProgress.org](http://www.ProstateProgress.org)

# Benefits and risks of taking part

## BENEFITS OF TAKING PART

- **Better understand and manage your own disease**

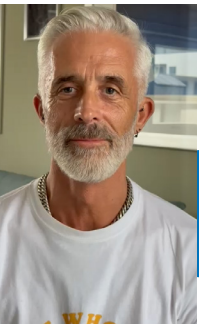
For those living with prostate cancer, joining **Prostate Progress** may help you and your doctor better understand your own prostate cancer journey and better manage your disease, including side effect and symptom management.

- **Personalised referrals**

You may also benefit from personalised clinical trial referrals and knowledge about precision medicines you may be suitable for.

- **Developing new treatments and finding better ways to predict prostate cancer in the future**

For everyone who has ever been diagnosed with prostate cancer, joining **Prostate Progress** is an act to help others. You will be giving your time and data for free to help researchers make discoveries about prostate cancer. This will benefit future generations, helping world-leading researchers find better ways to diagnose, treat – and hopefully cure – prostate cancer.



'I want to be cured without invasive surgery that is going to change my life forever.'

Tim

- **Addressing health inequalities**

By gathering information about the whole population that is affected by prostate cancer, we can detect areas and groups of people that have worse health outcomes and target resources towards those who need them most.

- **Personal feedback in the future**

In the future, we may contact you to offer you some personal feedback about your health arising from your data. You might find this helpful, but you might not.

'As a black male with prostate cancer, I know the importance of helping initiatives to improve outcomes for Afro-Caribbean men'

Alphonso



## RISKS OF TAKING PART

- **Privacy breaches**

We are taking a lot of security precautions, including being certified according to standards set by the NHS for holding sensitive health data. However, the risk can never be zero. There is a small risk that, if there was a security breach, someone could see or use the data we have about you.

- **Learning things that make you worried**

In the future, if you agree to take part in additional research studies, you might learn new information about your health that makes you feel worried. You will always have a choice in whether to take part in additional activities.

- **Future, unknown risks**

There may also be other risks that we don't know about yet, and we will get in touch if a new risk emerges.

Learn more



### Screening for bowel cancer



Learn more about how patient data has helped to save lives in the past.

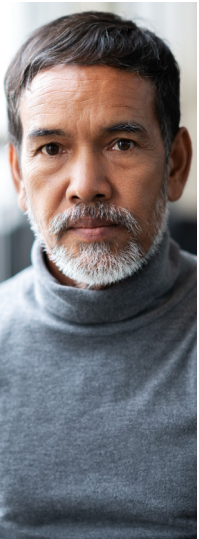
### Improving early breast cancer diagnosis for Black African women



Learn more about how patient data has helped to save lives in the past.



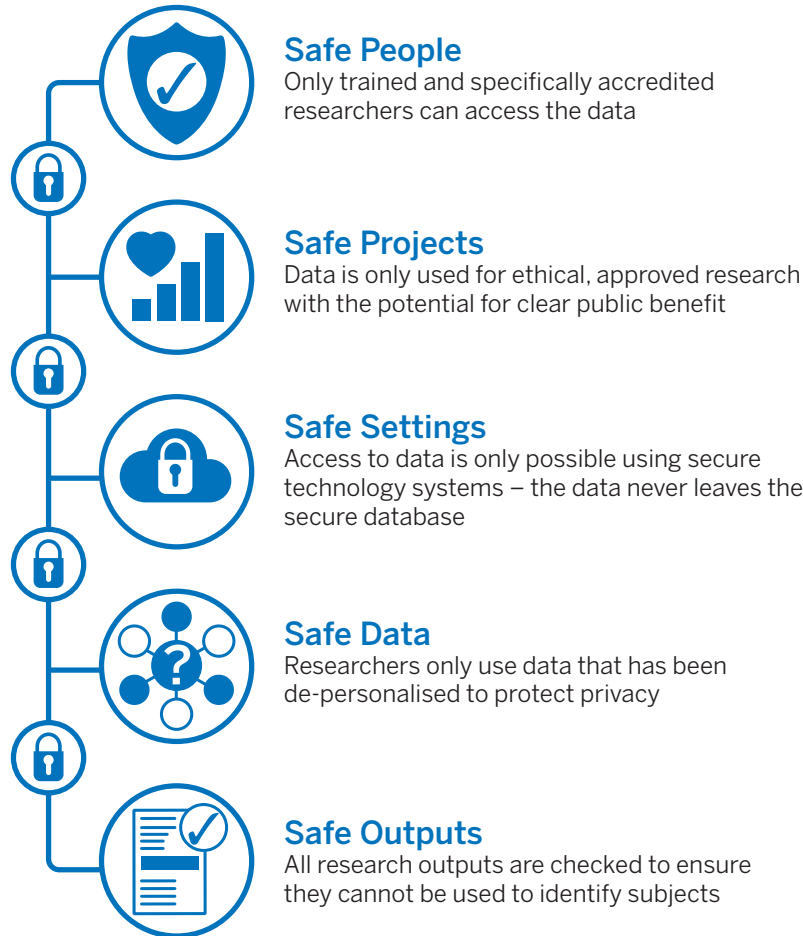
# How we protect your data



## HOW DO WE PROTECT YOUR DATA?

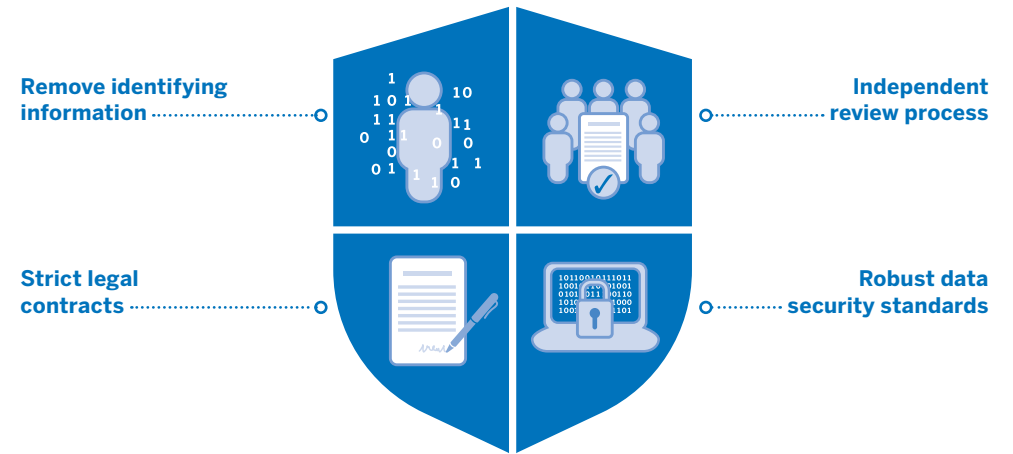
We follow the 'Five Safes' framework of data handling.

The 'Five Safes' framework is a set of principles which enable data services, like **Prostate Progress**, to provide safe research access to data. The framework has become best practice in data protection whilst fulfilling the demands of open science and transparency.



## HOW IS DATA KEPT SAFE?

There are four ways that your privacy is shielded:



## WHO IS RESPONSIBLE FOR MY DATA?

**Prostate Progress** is a project of Prostate Cancer Research. Prostate Cancer Research will be responsible for your data and will strictly govern who has access to it. In addition, any researcher who is granted access will also need to agree to protect your data (please see the "who will have access to my data" sub-section for further information). Looking after your privacy and the security of your data is very important to us. The following sections provide more detail on how your data will be managed.

People with lived experience of prostate cancer have been involved in **Prostate Progress** right from the start. We established a patient panel who were a key part of our decision making body during the design and build of the platform. Patients sit on our Data Access Committee and this committee governs which research projects have access to the database.



### A patient's voice

'My dad had prostate cancer, my brother has prostate cancer, another brother died of it and now I have it. An illness that affects so many men and their families deserves a joined up approach.'

**David**

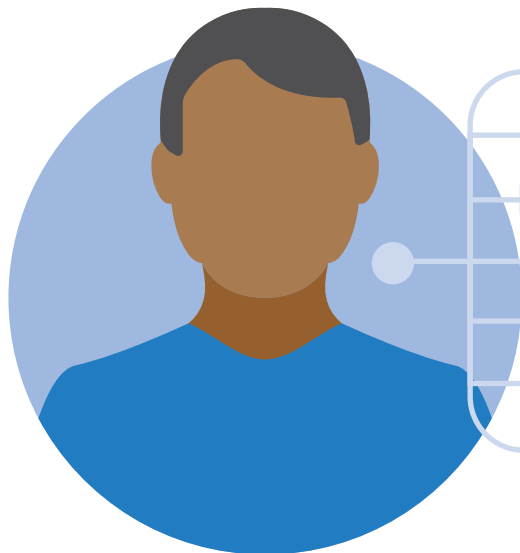
## HOW IS MY DATA STORED?

Your data will be stored and managed securely, in line with data protection laws including the UK General Data Protection Regulation (UK GDPR) and the relevant security standards. Full details of where and how we store your data is available in our Privacy Policy here:

• [www.pcr.org.uk/prostate-cancer-research-pcr-privacy-policy](http://www.pcr.org.uk/prostate-cancer-research-pcr-privacy-policy)

All the information we collect about you will be encrypted when it is in transit and at rest and stored according to strict security standards in UK-based servers. Your data will never leave these secure servers and will never be sent outside the UK for any reason.

Your health-related data that we make available to researchers will be de-personalised or de-identified. De-personalising or de-identifying health data involves removing – or disguising – your personal information so that it is difficult to single you out of the dataset. We will use a process called Pseudonymisation.

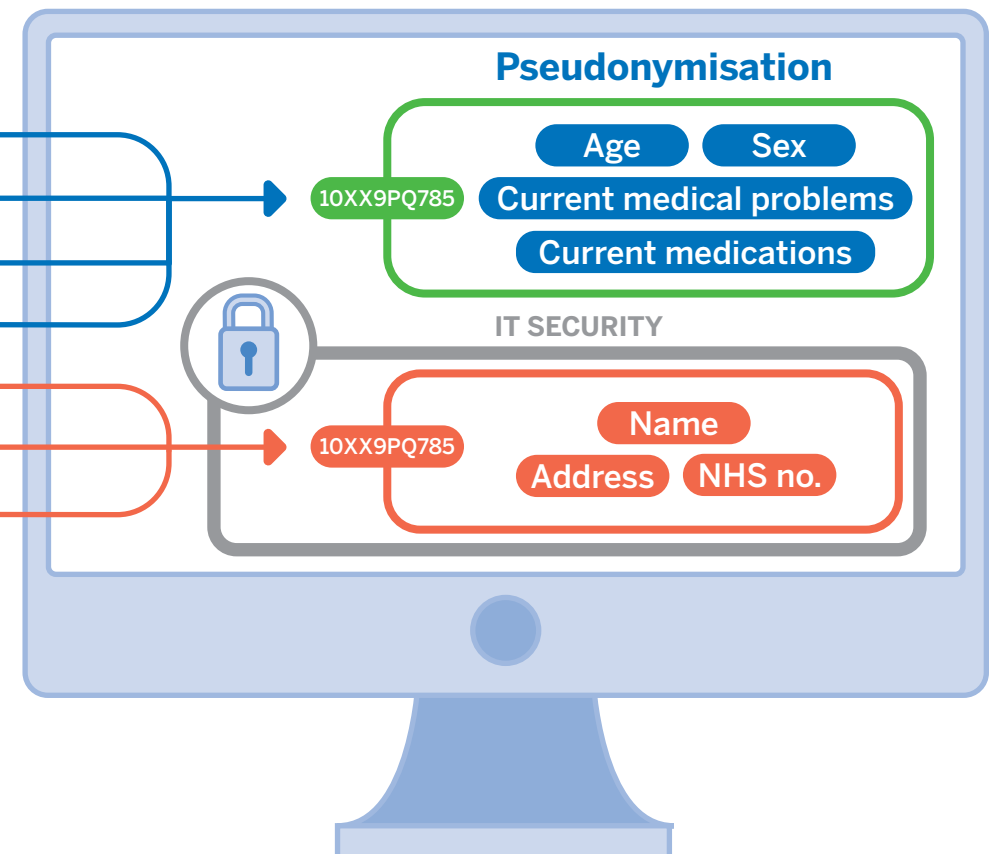


Age  
Sex  
Current medical problems  
Current medications  
Name  
Address  
NHS no.

**Pseudonymisation – how your data is de-personalised/  
de-identified and your privacy protected**

## WHAT IS PSEUDONYMISATION?

- This means that a unique marker is used in place of identifying information (name, NHS/CHI/H&C number, address, etc.). This marker is sometimes created by scrambling the identifying information, to produce a random-looking string of letters and numbers.
- This unique marker does not itself reveal an individual's identity, but distinguishes between individuals in a set of data. The original identifying information is kept separate from the dataset through technological and legal barriers and is not shared with any researchers or any organisations.





## WHO WILL HAVE ACCESS TO MY DATA?

### PROSTATE CANCER RESEARCH

If you decide to join **Prostate Progress**, we will store the personal identifiable data (such as your name and address) that you provide. A limited number of trained staff at **Prostate Progress** and in the NHS will have access to this data so we can contact you and link to health-related records and other important health-related information about you. We may wish to contact you about a suitable trial or new treatment you may be eligible for, or we might find something that would be beneficial to tell you and your healthcare team about. No external organisation would ever be able to contact or identify you without your explicit permission to do so.

Having access to your personal identifiable data also means that we can link your health-related records to the other data that we collect, for example, your questionnaire data. This helps us build a full picture of your health. Before letting researchers see this information we will remove any information that could be used to identify you. If you lose mental capacity we would like to continue processing your de-personalised data to enable research into health and disease; however, we will break the link with your identifiable data to ensure we comply with the Mental Capacity Act.

### PROCESSORS FOR NHS RECORDS

To access health-related information about you that is stored by the NHS and other UK-based health organisations, we will need to share some of your identifiable data (for example your NHS/CHI/H&C number, name or date of birth) with them. We will only share what is absolutely necessary, and strict controls will be in place to protect your personal data.

'The sharing of information and data is absolutely essential. There are so many people working behind the scenes that are trying to find better treatments, cures, and to do something that's going to make life better for all of us. It's a small step for us, once diagnosed, to help by agreeing to join Prostate Progress and sharing our experiences, our information and our data.'

Neil



## APPROVED REGISTERED RESEARCHERS

Registered researchers conducting studies that only involve data held by **Prostate Progress** will only be able to access your de-identified data for their research via a highly secure online data storage system. These secure systems only allow registered researchers to use the data within them for legitimate research purposes. It will never be possible for researchers to download your de-personalised data from a secure online data storage system.

We will never allow access to your data for anything other than for health research that is for the public good. We will never sell or provide your personal identifiable data for the purposes of advertising or, for example, to insurance companies.

Your name and identifiable information will never be used when the findings from **Prostate Progress** are published and promoted.

### Examples of where approved registered researchers may come from



**Non-profit research organisations** including universities and charities.

**Commercial organisations** for example pharmaceutical companies when they are researching and developing new drugs or treatment, and technology companies that provide software or data analysis services.



**Branches of national government** such as the Department of Health and Social Care and NHS England.

**Local authorities**



**Primary care networks** which are local networks that include GPs and community, social care and mental health services, as well as pharmacies and voluntary services.

**Integrated care systems (ICSs)** which are groups of GP surgeries, and integrated care organisations, which are groups of health and care providers in an area.





# How we are run and funded

## ABOUT OUR FUNDING

**Prostate Progress** is funded by Prostate Cancer Research, sponsorship from the Life Sciences industry, charity partners, trusts and foundations and members of the public via donations.



We will always be open about who funds **Prostate Progress** and this information can be found on our website [www.pcr.org.uk/prostate-progress](http://www.pcr.org.uk/prostate-progress).



'The more information and support that PCR receive, then the quicker they can find a solution to this life changing cancer.'

**Paul**

Funding partners will be allowed to apply to do research with the data from **Prostate Progress**. They will be charged a fee to help with **Prostate Progress**' running costs. Like all requests, these applications will go through our Data Access Committee. All research applications, whether from funders or researchers at industry companies, academic organisations, government, the NHS, or other charities, will be reviewed in the same way and held to the same standards.

All registered researchers using **Prostate Progress** will help with its running costs on a means-tested basis.

## HOW ARE WE RUN?

Prostate Cancer Research is a charity registered with the Charity Commission for England and Wales (charity number 1156027). We work with organisations such as the NHS, other charities and companies to deliver **Prostate Progress**. The governance of **Prostate Progress** is made up of medical and health experts as well as people with lived experience of prostate cancer.

## WILL YOU SELL OR PROFIT FROM MY DATA?

We will charge approved registered researchers to access the information held on **Prostate Progress**. This includes any patient information that you have supplied to us or given us access to. The reason we charge is to

help recover our costs in processing, delivering and sustaining the data in **Prostate Progress**. We will also share a portion of any revenue we receive with the NHS and other organisations who have supplied data being used.

If any surplus revenue is made that goes beyond cost recovery and revenue sharing with the NHS and other organisations, this surplus will go towards expanding **Prostate Progress** to cover all of the UK and have as many people affected by prostate cancer taking part, and to Prostate Cancer Research to support and fund our other charitable activities.

## WHAT WILL HAPPEN TO THE FINDINGS FROM RESEARCH?

We will seek to publish any discoveries made by Prostate Cancer Research from **Prostate Progress** in scientific papers. Any discoveries made by other researchers will be required to be made available online and they will be encouraged to publish in scientific papers where possible. Your identity and any personal details will be kept confidential.

You should be aware that it will take several years for discoveries to emerge from the research connected to **Prostate Progress**.

Any researchers doing research with **Prostate Progress** may profit from discoveries they make.

You can choose to receive regular updates to keep you informed about our progress and the discoveries arising from **Prostate Progress**.

## PATIENT INVOLVEMENT

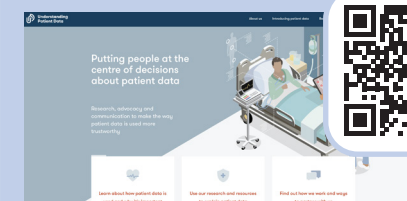
Members of the public with lived experience of the disease have been and will continue to be involved in the development of **Prostate Progress**. This includes focus groups, interviews, a patient panel, in our governance and on our Data Access Committee.

Learn more



For answers to common FAQs about patient data, how it can be used, by who and why – please visit Understanding Patient Data's website.

 **Understanding Patient Data**



# Where to get help and support?

Your most important resources are your GP and hospital team. They know your medical history and are best placed to advise you.



The infopool ([www.theinfopool.co.uk](http://www.theinfopool.co.uk)) has information on testing and diagnosis, choosing a treatment, living with side effects, palliative and end-of-life care and how to join a clinical trial. Importantly, you can access hundreds of stories from others who have been affected by prostate cancer, including their partners and carers.



## Find a prostate cancer support group

Tackle Prostate Cancer support patient groups around the UK. You can search for local or online groups on their support group page.

Helpline: 0800 035 5302

9am–9pm, 365 days a year



## Access to a nurse or support line



### Cancer Research UK

Helpline: 0808 800 4040

9am–5pm, Monday–Friday



### Macmillan Cancer Support

Helpline: 0808 808 0000

8am–8pm, Monday–Friday



### Prostate Cancer UK

Helpline: 0800 074 8383

9am–5pm, Monday–Friday (Wednesday: 10am–5pm)



## For help with Prostate Progress

**Email us:** [progress@pccr.org.uk](mailto:progress@pccr.org.uk)

**Call us:** 02037355444

**Write to us:** Prostate Cancer Research, Suite 2, 23-24 Great James Street, London, WC1N 3ES

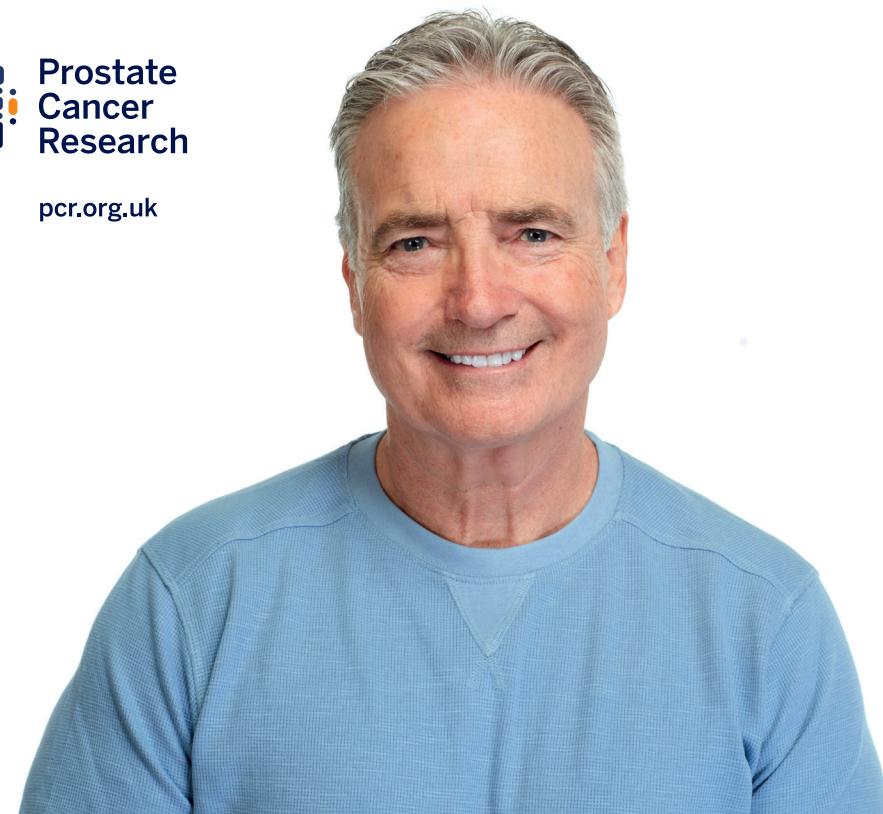
# About us

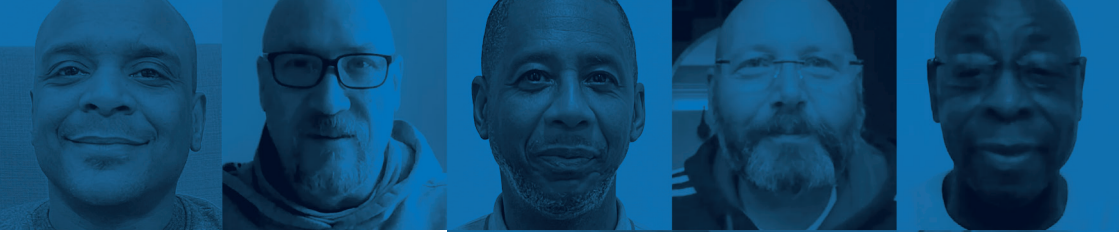
Prostate Cancer Research was originally founded in 1988 by Professor John Masters, a scientist who was passionate about finding new treatments for prostate cancer.

Since then, we have continued to strive forward to build a future where people are free from the impact of prostate cancer.

It is only through research that we can build a future in which no family will have to fear losing a loved one to prostate cancer. But here at Prostate Cancer Research we're not just working to add years to life; we're also about adding life to years. Prostate cancer and the way it is currently treated brings physical and emotional side effects for the patient, their family and community, cuts too many lives short, and steals away the time that families should be able to spend together and enjoy.

Together, and with your help, we can change this.





020 3735 5444 • [progress@pcr.org.uk](mailto:progress@pcr.org.uk)    

Prostate Cancer Research is a registered charity in England and Wales (1156027)