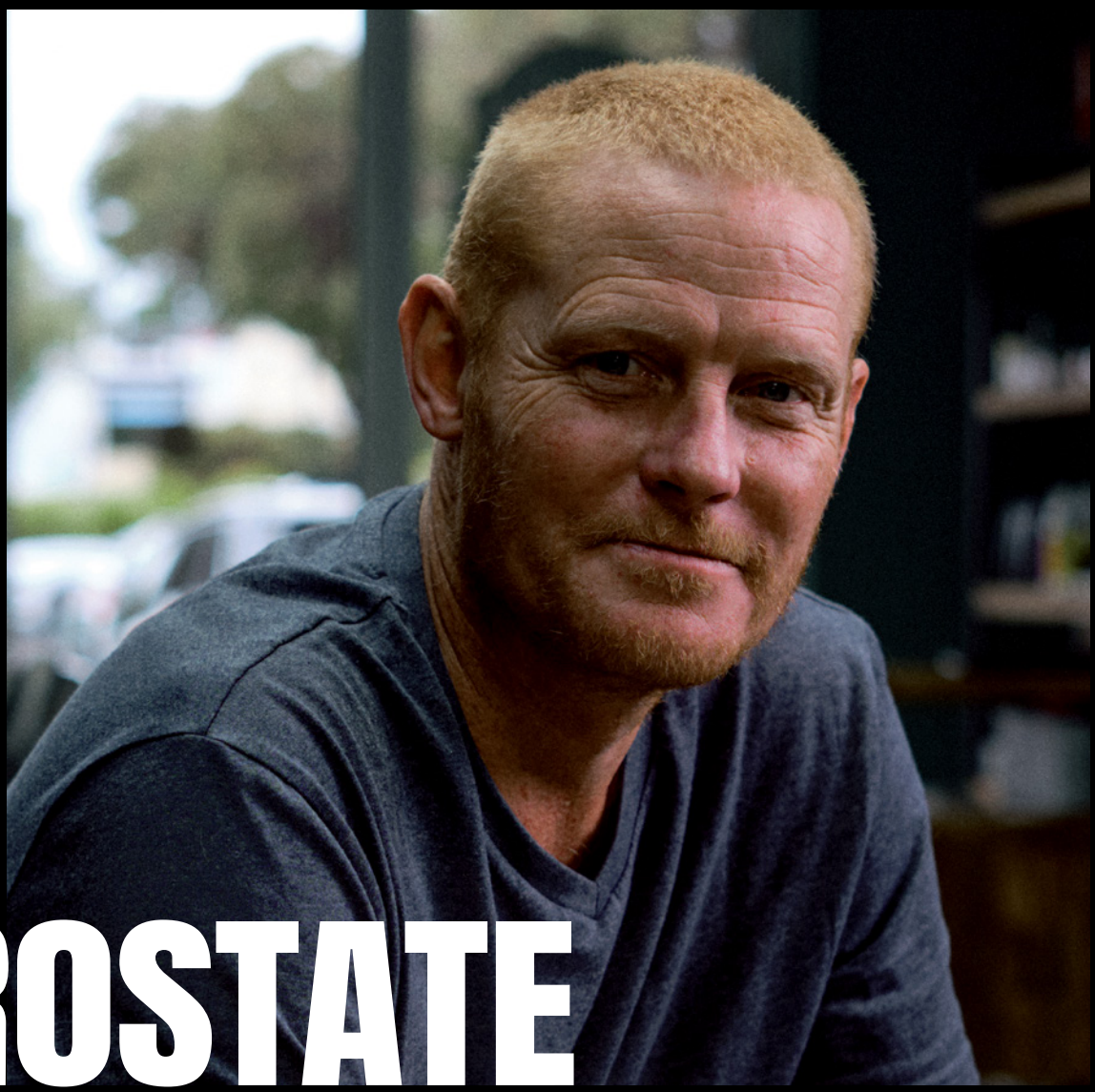
IPCOR
IRISH PROSTATE CANCER
OUTCOMES RESEARCH



PROSTATE CANCER IN IRELAND

WHAT WE KNOW FROM 600 MEN INVESTIGATED FOR PROSTATE CANCER IN IRELAND

Prepared using data from the IPCOR Registry 2025–2026

MOVEMBER®

UCD DUBLIN

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PRINCIPAL INVESTIGATOR NOTE

This is the first annual report from the Movember-funded Irish Prostate Cancer Outcomes Research (IPCOR) research programme, developed here in University College Dublin (UCD), Ireland, building on the strong foundations established through earlier phases of IPCOR. We believe that IPCOR currently represents the very best in clinical quality research at an international level, and has evolved into an efficient and impactful research programme. At its core is support for the delivery of high-quality clinical care while optimising outcomes for patients driven by the collection of clinical data and patient-reported outcome measures (PROMs).



IPCOR is now recruiting across three clinical organisations: the Mater hospital campus, St Vincent's hospital campus and the Galway hospital campus. These three sites were selected because they are the busiest prostate cancer diagnostic and treatment centres in Ireland, representing both the public and private sectors. The academic and hospital management at these sites are strongly supportive of the IPCOR research programme, and have been involved at the highest level. IPCOR as a large-scale academic research programme supports cancer research and people being treated in these hospitals, but is also a key component in their accreditation process as comprehensive cancer centres.

IPCOR has pioneered a number of research areas in Ireland, becoming the largest cancer-specific registry in the country. Utilising a fully digital solution and patient-facing consent process, men complete the consent process using tablet computers, and their data are stored instantly in our cloud server. IPCOR collects over 600 clinical data points on every participant, building a detailed longitudinal record of their cancer journey. These data are instantly available to researchers, and a live dashboard showing key clinical and outcome indicators is readily available. This is not the case for any other disease process in Ireland. Data are also delivered back to nursing and medical staff both in their survivorship clinics and in routine IPCOR data sessions, where gaps in clinical care and areas for improvement are identified. This has a direct impact on the quality of clinical care provided.

The clinical data collected in the first year come from four hospitals across two campuses (Mater and St Vincent's) and have provided an excellent picture of the current diagnostic pathways, using prostate specific antigen (PSA) level, physical exam, magnetic resonance imaging (MRI) of the prostate, and targeted transperineal prostate biopsy across all sites. Long diagnostic waiting times are highlighted and these need to be addressed to bring us in line with international standards.

Staging imaging is provided increasingly by prostate-specific membrane antigen positron emission tomography-computed tomography (PSMA PET-CT) imaging and is guided by national guidelines in keeping with best international practice. IPCOR and the collection of PROM data have created an awareness of the significant impact of treatment on individuals, and huge improvements in nurse-led survivorship have been realised in the last few years across our clinical sites. PROM data collected in IPCOR are now being provided to both participants and their treating nurses to improve clinical interactions, and make encounters more meaningful and comprehensive.

IPCOR has developed a clinical research programme from the ground up, building the foundations and providing the data for high-quality clinical and translational research. An ambitious research programme is driven by the UCD research team led by Professor William Watson, Dr Noa Gordon and Mr Rowan Kearns, our prostate cancer outcomes research fellow. A scientific publication plan is in place and many researchers, including summer students, public health medicine students and collaborators, have utilised the IPCOR registry for ongoing research that is presented at national and international meetings. Many urology trainees and other clinicians are also utilising the IPCOR registry to answer important clinical research questions. In translational research, a programme to obtain fresh prostate tissue from surgical prostatectomy specimens for primary culture and other research is now in place, allowing a wide variety of scientific research projects to develop. A bio-repository has been set up, which collects urine and blood specimens through the clinical research centres at hospital sites, and these specimens are stored in UCD for future research projects. All of these materials are linked to the participants' longitudinal clinical and PROM data, making this a very valuable asset suitable for international collaboration.

IPCOR is here to drive change and make an impact. It does this by collecting high-quality data upon which robust decisions by healthcare providers can be made. We present the collected data to hospital management every 6 months and together we highlight areas that need more attention and focus. Annual reports are produced at each site and participating clinicians also receive personalised reports containing data from their patients, highlighting differences and variations in results. The collected data are also being used to identify men who may be suitable for clinical trials and to assist with trial recruitment at a time when hospitals are seeking accreditation as cancer centres.

Patients have been at the heart of IPCOR since its inception, and this evolved into our Lived Experience Advisory Panel (LEAP), a group of ten men treated for prostate cancer who advise and guide our activities and research programme. We are indebted to them for their advice and engagement. Indeed, the inclusion of PROMs in the current IPCOR programme (such as the Shared Decision Making Questionnaire and the Financial Toxicity Questionnaire) were direct recommendations by the LEAP group, and for the first time in Ireland are allowing us to recognise important issues in these areas.

I want to thank the nurses and clinicians at each site for their support of the IPCOR programme. Of course I would also like to thank all of our participants who have given so much of themselves at a stressful time in their lives to improve the lives of those who follow behind. Finally, I would like to thank the wonderful IPCOR research team, who bring so much youth, vitality, energy and motivation to our efforts. I do hope that their time with IPCOR will allow their future careers to grow and succeed.

MR DAVID GALVIN
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MOVEMBER NOTE

When a man is told he might have prostate cancer, what happens next should not depend on where he lives or how his care is funded. When he is treated, success should be judged not only by whether the cancer is controlled but by how well he is living afterwards. IPCOR makes both of these visible in Ireland, and this first report shows it is already doing so.

What sets IPCOR apart is how its data are joined together. Men are enrolled at biopsy, before they know their result, and followed from GP referral through diagnosis, treatment and survivorship. For each man, his clinical record, his own account of his quality of life and his biological samples are linked across public and private hospitals and radiotherapy services. Men who turn out not to have cancer stay in the registry as a comparison group. The result is Ireland's largest cancer-specific registry and a research-ready national asset.

The early findings show why this matters. In the public system, men waited a median of 181 days from rapid access clinic referral to biopsy, compared with 57 days privately. Once imaging was available, clinical review was prompt in both; most of the gap comes from access to MRI and biopsy capacity, which points to where added capacity would most shorten the wait. There are encouraging signals of clinical quality too: 79% of men with low-risk disease are managed with active surveillance, and agreement between biopsy and surgical grading has risen to 69%, up from 57% in the first IPCOR cohort.

The men's own reports complete the picture. Six months after surgery, the share of men leaking urine daily had risen from 13% to 47%, the share reporting poor-to-no erectile function from 34% to 88%, and the share reporting depression as a moderate or big problem from 5% to 24%. Only 14 of 110 men reported using any aid for sexual function, and more than one in four reported some financial strain. These are early results, and IPCOR will follow how they change over time.

They are also the outcomes men tell us matter most, and ones routine health data never capture. The financial and shared decision-making measures were added at the request of the Lived Experience Advisory Panel, ensuring the registry measures what matters to men, not only what is easy to count.

What is really exciting to see in its first year is that this evidence is already in use. The data goes back to the clinicians and nurses who care for these men, so they can see their own results and act on them. It is informing evaluation of national guidelines through an HRB-funded collaboration with the NCCP, and is being piloted in survivorship clinics led by advanced nurse practitioners.

Movember's investment has been catalytic: to help rebuild the infrastructure, prove the model and show its value. As the registry grows by around 1,000 men a year, its value to the health system, researchers and partners will only increase. IPCOR is a national infrastructure for better prostate cancer care, and a foundation worth building on.

Our thanks to Mr David Galvin and the IPCOR team, the site investigators and staff, LEAP, the Movember community in Ireland whose fundraising makes this work possible, and above all the 603 men who chose to take part.



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ABOUT THIS REPORT

This report covers the period from March 2025 to June 2026 and provides an overview of the Irish Prostate Cancer Outcomes Research (IPCOR) registry methodology and infrastructure, alongside clinical insights, learnings, and impacts during its first 15 months of recruitment.

During this period, recruitment sites (four hospitals across two campuses) were initiated sequentially starting from the end of March 2025, based on local site activation requirements and processes. IPCOR commenced recruitment at its fifth hospital (at a third campus) in July 2026, bringing the project to full operational capacity across all five public and private hospital sites where high-risk patients are referred for prostate biopsies, and are explicitly consented. In addition to recruitment (Mater Misericordiae University Hospital, Mater Private Network, St Vincent's University Hospital, St Vincent's Private Hospital and University Hospital Galway), radiation oncology data are collected from a sixth data collection-only treatment site, St Luke's Radiation Oncology Network.

The IPCOR registry recruitment and data collection are ongoing, with participant numbers and available data continuing to grow daily. The figures presented in this report reflect the initial cohort enrolled and diagnosed between March 2025 to June 2026, many of whom are still progressing through diagnostic and treatment pathways.

In the reporting period, 752 participants were successfully contacted and approached for explicit consent across four hospitals, of which 603 agreed to be included in the registry. The registry is expected to expand by about 1,000 participants each year. These figures show the future value of the IPCOR registry in highlighting diagnosis, care and outcomes for people with prostate cancer.

15
MONTHS OF ENROLMENT

6
PARTICIPATING SITES

752
SUCCESSFUL CONTACTS

603
MEN INCLUDED IN THE REGISTRY

EXECUTIVE SUMMARY AND KEY FINDINGS

>80%
OF MEN APPROACHED CONSENTED TO PARTICIPATE

>600
VARIABLES COLLECTED FOR EACH PATIENT

>300
SAMPLES BIOBANKED

>80%
BASELINE PROMs COMPLETION

During its first reporting period, March 2025 to June 2026, the current Movember-funded Irish Prostate Cancer Outcomes Research (IPCOR) programme established a prospective, longitudinal prostate cancer registry across major diagnostic and treatment centres in Ireland. Of 752 men approached, **603 consented to participate,** of whom **416 have been diagnosed with prostate cancer** by the reporting cut-off and **312 have received treatment.**

IPCOR combines **detailed longitudinal clinical information** with **patient-reported outcome measures (PROMs)** and **biological samples,** creating an infrastructure designed not only to describe prostate cancer care, but to identify variation, support clinical quality improvement and enable clinical and translational research. Although these findings represent an early and still-maturing cohort, several important signals are already emerging.



Access to diagnosis differs substantially between public and private care. One of the clearest findings is the difference in time from referral to prostate biopsy. The median time from Rapid Access Prostate Clinic (RAPC) referral to biopsy was **181 days in the public system compared with 57 days in private institutes.** These findings highlight diagnostic waiting times and important differences in access to timely prostate cancer assessment.

Prostate cancer diagnosis is increasingly based on contemporary diagnostic pathways, but variation remains. The registry provides a detailed picture of current diagnostic practice, including prostate-specific antigen (PSA) assessment, magnetic resonance imaging (MRI) and targeted transperineal biopsy. It also identifies variation between sites and sectors, including continued use of transrectal ultrasound-guided (TRUS) biopsy in a small proportion of cases within the public system. There is an increased uptake of prostate-specific membrane antigen positron emission tomography-computed tomography (PSMA PET-CT), reflecting a shift towards contemporary imaging practice and alignment with national guidance.

Patient-reported outcomes reveal the substantial impact of prostate cancer treatment. The greatest pre- to post-treatment changes were observed among men undergoing surgery. Daily urinary pad use increased from **3% before treatment to 47% post-treatment,** while the proportion reporting poor-to-no erectile function increased from **34% to 88%**. The proportion reporting sexual function as a moderate-to-big problem increased from **22% to 50%.** These findings highlight the importance of considering outcomes reported directly by participants alongside conventional clinical measures.

The impact of prostate cancer extends beyond physical function. IPCOR has expanded its PROMs programme to examine aspects of the cancer experience identified as important by participants, including financial toxicity, shared decision-making and supportive care needs. Early findings show that 28% of respondents experienced at least mild financial toxicity, participants under active surveillance expressed the lowest rates of satisfaction with the shared decision-making process, while unmet supportive care needs were particularly evident in the sexuality and psychological domains, especially in participants undergoing surgery. These data provide an opportunity to identify where additional information, counselling, rehabilitation and supportive services may be needed.

IPCOR is designed to turn data into clinical improvement. Clinical and patient-reported data are fed back to participating teams through live dashboards, regular data sessions, site reports and individual clinician reports. This enables variation and gaps in care to be identified and provides an evidence base for quality-improvement initiatives. IPCOR is simultaneously supporting research, policy and guideline evaluation, clinical trial recruitment, and the development of a linked biobank for translational research.

These first findings demonstrate the value of combining detailed clinical data with the patient voice. As recruitment continues and 12-month and longer-term follow-up data mature, IPCOR will increasingly be able to examine variation in care and outcomes over time, benchmark clinical practice and identify opportunities to improve prostate cancer care in Ireland.

ABBREVIATIONS AND GLOSSARY

ADT
Androgen deprivation therapy (hormonal therapy). A treatment that blocks the body's natural hormones that help cancer grow.

AICRI
All Ireland Cancer Research Institute.

ANP
Advanced nurse practitioner. A nurse who has completed advanced education and training, and is allowed to practice at a higher level of autonomy and responsibility.

AS
Active surveillance. When a person does not receive active treatment. Instead, their health is monitored regularly.

Biopsy
The removal of a small sample of tissue from the body, for examination under a microscope, which helps to diagnose disease.

Bone scan
A nuclear medicine imaging test that uses a tiny, safe amount of a radioactive substance to find abnormal metabolic activity or damage in the bones.

Brachytherapy
A type of radiation therapy that involves implanting radioactive material, which is sealed in needles or seeds, into or near cancerous cells.

CAPRA score
Cancer of the Prostate Risk Assessment score. A CAPRA score (from 0–10) predicts an individual's likelihood of metastasis (i.e. the cancer spreading) and the chances of dying from cancer or from any cause. A score of 0–2 indicates low-risk (CAPRA LR), a score of 3–5 indicates intermediate-risk (CAPRA IR), and a score of 6–10 indicates high-risk (CAPRA HR).

CT
Computed tomography. This type of scan uses X-rays to make detailed, cross-sectional images of the body.

De-identified data
Data that has had all personally identifiable information removed.

DOAC
Data Oversights & Access Committee.

EBRT
External beam radiation therapy. This therapy uses a machine outside the body to aim high-energy X-ray or particle beams directly at a tumour to destroy cancer cells.

Eircode
The national postcode system of the Republic of Ireland. An Eircode is entirely unique to each individual address.

EORTC-QLQ-C30
European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire. This 30-item questionnaire is designed to measure the health-related quality of life of people with cancer.

EORTC-QLQ-PR25
European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire for Prostate Cancer. This 25-item, prostate-specific quality of life questionnaire is designed to be used alongside the core EORTC QLQ-C30 instrument.

EPIC-26
Expanded Prostate Cancer Index Composite (short form with 26 items). This comprehensive instrument is designed to evaluate patient function and bother after prostate cancer treatment, including issues relating to incontinence, bowel problems, impotence and levels of vitality.

FACIT-COST
Functional Assessment of Chronic Illness-Comprehensive Score for Financial Toxicity. This 12-question survey is designed to assess financial distress experienced by people with chronic illnesses, especially those undergoing cancer treatment.

GDPR
General Data Protection Regulation. A privacy and security law passed by the European Union.

Gleason score
The Gleason grading system is used to indicate how aggressive the prostate cancer is by assigning a grade or score. The higher the score, the more likely the cancer is to grow and spread quickly.

GP
General Practitioner.

HRB
Health Research Board. Ireland's primary health and social care research funding agency.

IPCOR
Irish Prostate Cancer Outcomes Research

ISUP grade
International Society of Urological Pathology grade. A revised grading system for prostate cancer based on the Gleason score.

IT
Information technology.

Median
The middle value in a series of values that are arranged from smallest to largest.

Metastatic
Metastatic cancer is cancer that has spread from another part of the body, also known as secondary cancer.

MRI
Magnetic resonance imaging. An MRI scan generates detailed images of soft tissues in the body using radio waves and strong magnets.

NCCP
National Cancer Control Programme.

NCRI
National Cancer Registry Ireland.

OECI
Organisation of European Cancer Institutes.

PET-CT
Positron Emission Tomography-Computed Tomography. This scan combines two types of medical imaging: positron emission tomography (PET) and computed tomography (CT). It provides detailed information about both the structure and function of body tissues and organs, which is helpful in diagnosing and managing various diseases, particularly cancer.

PI-RADS
Prostate Imaging Reporting and Data System. A standardised scoring system for prostate MRI that assesses the likelihood that an identified lesion represents clinically significant prostate cancer. Scores range from PI-RADS 1 (very low likelihood) to PI-RADS 5 (very high likelihood).

PROM
Patient-reported outcome measure. This term covers all types of questionnaires that are completed directly by patients to assess their health, symptoms, functioning and quality of life from their own perspective, without interpretation by a clinician.

PSA
Prostate-specific antigen. A protein produced by prostate cells. It may indicate prostate cancer and can be used to monitor its recurrence after treatment.

PSAD
Prostate-specific antigen density. A clinical calculation used to evaluate prostate cancer risk by comparing a patient's total blood PSA level to the physical volume (size) of their prostate gland. It determines how much PSA is being produced per cubic centimetre (cc or mL) of prostate tissue.

PSMA PET-CT
Prostate-specific membrane antigen positron emission tomography-computed tomography. This specialised type of medical imaging uses a radioactive tracer to detect prostate cancer cells throughout the body.

RAPC
Rapid Access Prostate Clinic. This type of clinic provides a fast, efficient service for men who need further tests to determine whether they have prostate cancer. These clinics are funded by the NCCP in the eight designated cancer centres in Ireland.

RP
Radical Prostatectomy. Surgery that removes the whole prostate and seminal vesicles.

RT
Radiotherapy. The use of high-energy radiation to destroy cancer cells or control their growth.

SCNS-SF34
Supportive Care Needs Survey Short Form-34. This is a validated 34-item patient tool that evaluates the perceived unmet needs of adults with cancer over the previous month.

SDM-Q-9
9-item Shared Decision Making Questionnaire. This tool measures the subjective experience of shared decision-making during a medical consultation.

SLRON
St Luke's Radiation Oncology Network.

STRATCANS
STRATified CANcer Surveillance. An evidence-based clinical monitoring programme designed for men with early-stage, localised prostate cancer who are undergoing active surveillance.

TP biopsy
Transperineal biopsy. A prostate biopsy performed by passing biopsy needles through the skin of the perineum to obtain tissue samples from the prostate.

TRUS biopsy
Transrectal ultrasound-guided biopsy. A prostate biopsy in which tissue samples are taken through the rectum, using transrectal ultrasound to guide the biopsy needle.

TURP
Transurethral resection of the prostate. A surgical procedure in which prostate tissue is removed through the urethra.

UCD
University College Dublin

SECTION 1

BACKGROUND



1.1 SETTING THE SCENE

The healthcare system of the Republic of Ireland is complex and largely divided between public and private institutes. These two systems frequently intermingle with patients moving between them, funded privately or through public treatment purchase programmes. In addition, cancer care, rehabilitation medicine, obstetrics and gynaecology, and other specialties also sit in stand-alone centres operating in silos.

Despite having advanced communication systems, with many of the world's largest information technology (IT) companies headquartered across Ireland, there has been very little investment in the healthcare infrastructure over time. Information gathering is poor, and outside of a limited national cancer registry, no national clinical dataset is collected on specific cancers. Clinical data are not routinely pooled or compared across healthcare sites, leading to gaps in the understanding of variation in treatment or outcomes. Like many countries, healthcare resources in the Republic of Ireland are limited, and budgetary decisions require a strong evidence base that can be used to examine outcomes, support decisions and appropriately support patients.

In proposing the Irish Prostate Cancer Outcomes Research (IPCOR) registry project, an essential need to collect high-quality, longitudinal and multi-institute clinical data to inform clinicians, policymakers and health care economists was recognised. A relevant use case is assessment of the diagnostic pathway for prostate cancer, explicitly described in national guidelines by the National Cancer Control Programme (NCCP). Introducing several new steps, including magnetic resonance imaging (MRI) scans, transperineal prostate (TP) biopsies and prostate-specific membrane antigen positron emission tomography-computed tomography (PSMA PET-CT) scans, adoption of these guidelines, resource planning and the clinical impact of these changes would be impossible without a clinical registry linked with patient-reported outcomes.

1.2 IMPORTANCE OF IPCOR

Based in University College Dublin (UCD), IPCOR is a large-scale research project supporting expansion of cancer research infrastructure and contributing to important initiatives such as the All Ireland Cancer Research Institute (AICRI) and the Organisation of European Cancer Institutes (OECI) cancer centre accreditation of participating hospital sites. Within hospital sites, the IPCOR project and its staff advocate for patient voices, the importance of high-quality data, and the Movember mission for men's health improvement. Our efforts are enabling local quality improvement projects by engaging other research teams, radiology, advanced nurse practitioners, medical teams and cancer data audit personnel.

The first wave of IPCOR (2016–2020) came to its natural end with the COVID-19 pandemic. This allowed the IPCOR team to take stock of the project thus far and reflect on its challenges and limitations. Specifically, a plan was put in place to address a number of objectives that had not been realised. These were:

1. Receiving and analysing clinical data in real time.
2. Reporting back data in real time, including to doctors and nurses.
3. Obtaining baseline patient-reported outcome measures (PROMs).
4. Digitisation of the registry and electronic PROMs collection.
5. Explicit opt-in patient consent for contact and follow-up.

Under the Irish legislation that underpins the National Cancer Registry Ireland (NCRI), cancer data to support research can be collected across the country. It was this legislation that allowed the IPCOR project to collect data without patient consent in the previous wave of IPCOR. However, this posed a huge limitation on the project because, without explicit consent, IPCOR was unable to contact participants, request donation of biological materials, consider their involvement in additional research or engage participants for feedback as their participation was passive rather than active and intentional.

Under the European Union General Data Protection Regulation (applicable since 2018) and following on from previous experience, it was important that the IPCOR investigators become the data controllers through University College Dublin (UCD). Movember presented a solution to many of these challenges by providing access to a cloud-based database (Dacima by EvidentIQ). This allows clinical data to be recorded and reported almost instantaneously, including live clinical dashboards, displaying up-to-date data for all participants and their complete diagnostic and treatment pathway. This technology has made the single greatest contribution to achieving our goals.

In addition to clinical data, the Dacima database also supports the digital and routine collection of PROMs. Reflecting on our PROMs research, and working closely with our Lived Experience Advisory Panel (LEAP), we further enhanced the collection of validated PROMs with additional research-driven questionnaires to expand our knowledge on the financial impact of a cancer diagnosis and shared treatment decision-making. We resourced the collection of radiotherapy data which were largely impossible in the previous wave of IPCOR because the radiotherapy service is delivered in a separate clinic system called the St Luke's Radiation Oncology Network (SLRON) and has its own IT infrastructure that is not shared with general hospitals. Access to each hospital system required separate ethical and legal arrangements, which have now been put into place alongside other recruitment sites.

Explicit consent is an active, time-consuming process, often done face to face, requiring trained personnel at each participating site. Although this is an expensive process requiring compromise in full prostate cancer coverage, it brings enormous benefits such as giving the project a face in the form of a professional representing the project who can provide support and encouragement to participants.



IPCOR integrates longitudinal clinical data, patient-reported outcomes and biological samples into a centralised digital registry, creating a comprehensive infrastructure that captures the full biological and clinical spectrum of prostate cancer.

This research-ready resource enables quality analysis and provides robust datasets and samples to support advancements in clinical care and translational research.

1.3 OVERVIEW OF IPCOR

IPCOR infrastructure consists of three major components: the longitudinal clinical datasets, patient surveys, and a biobank inclusive of blood, urine and prostate cancer tissue samples (**Figure 1, Table 1**). The three components are all linked together at an individual level. Together, these capture sociodemographic data, clinical details, long-term outcomes, patient experiences and disease biology, and form a comprehensive infrastructure.

The IPCOR longitudinal clinical datasets comprise over 600 clinical variables and the PROMs dataset includes over 200 variables collected at multiple timepoints. The complete Registry Data Dictionary is published on the IPCOR website (https://www.ipcor.ie/data-access-policy/ipcor-2-data-dictionary/).

Figure 1: Overview of IPCOR

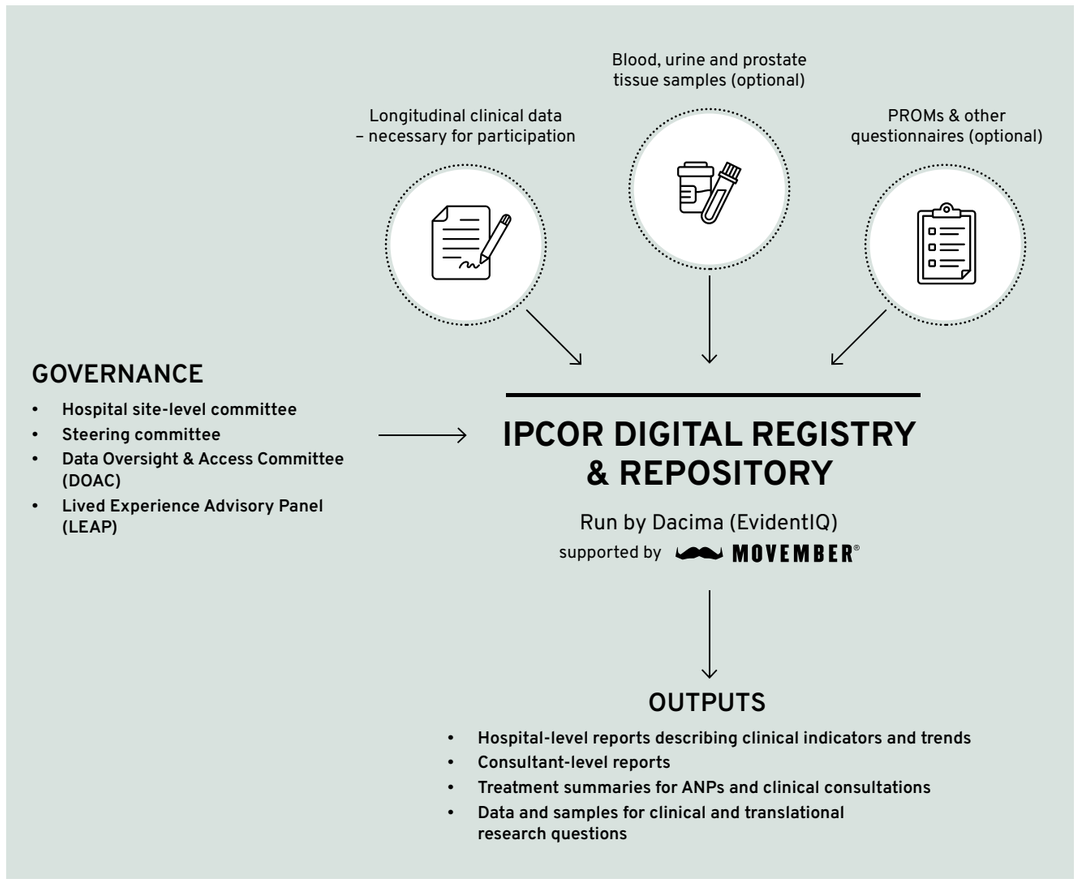


Table 1: IPCOR Infrastructure Descriptions

IPCOR Infrastructure
The longitudinal clinical datasets
a. Minimum clinical dataset (demographics, biopsy details, diagnosis)
b. Treatment dataset (surgery, active surveillance [AS], radiotherapy [RT], chemotherapy, androgen-deprivation therapy [ADT], ablation and any other treatments)
c. Follow-up dataset (vital status, recurrence)
The PROMs dataset
a. Baseline (pre-treatment)
b. 6 months post diagnosis (3 to 6 months post-treatment)
c. 12 months after treatment
d. Annually (on the treatment anniversary every 12 months)
The Biobank
a. Urine samples
b. Blood samples
c. Tissue samples

The overarching purpose of the IPCOR registry is the production of regular reports assessing clinical quality and patient experience, enabling advancements in clinical and translational research. IPCOR also collects consent from participants for future contact, contacting general practitioner (GP) offices, and utilisation of data for research and development of medical tests and devices by healthcare companies (**Table 2**).

Table 2: Rates of Specific Opt-in Consents in the IPCOR Registry

Consent to	Number of participants, n (%)*
Data collection	603 (100%)
PROMs	500 (83%)
Providing biological samples	516 (86%)
Using data for prostate cancer research	599 (99%)
Share data with healthcare companies to develop tests and devices	594 (99%)
Future contact	482 (80%)
GP contact	598 (99%)

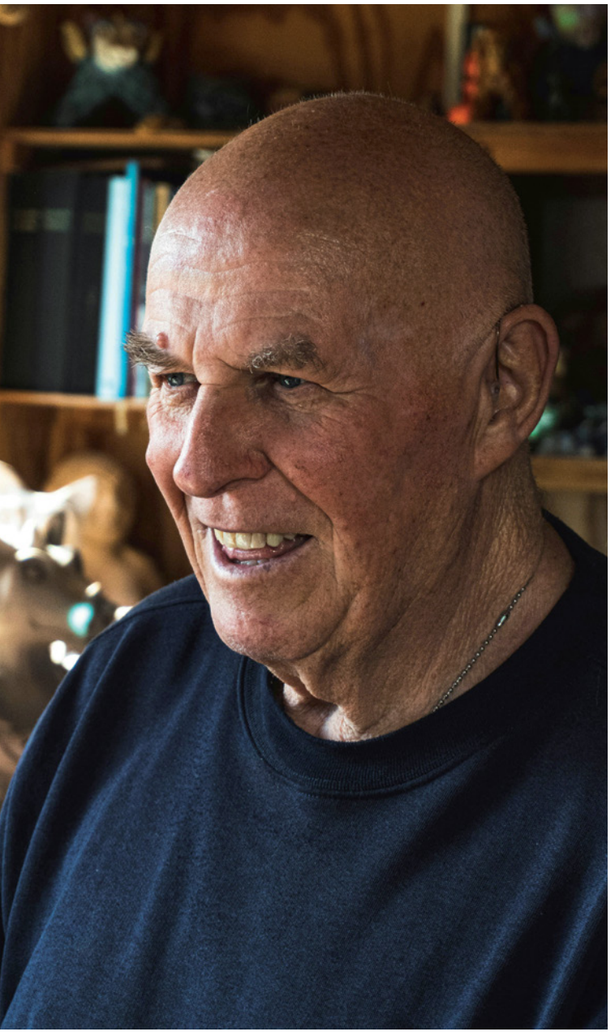
*Percentage based on the total number of IPCOR participants (n=603).

1.4 IPCOR METHODOLOGY

Site Establishment

IPCOR is a centralised resource, enabling multi-institutional comparisons where data insights from several major Rapid Access Prostate Clinics (RAPCs) can be compared.

IPCOR extends the national cancer registry dataset for prostate cancer and fills a major gap in prostate cancer outcomes analysis across Irish hospitals. For the purpose of this report, data have been aggregated and divided into public and private where relevant.



Site Selection

In the first phase of IPCOR, 16 public and private hospitals across Ireland were identified that provided a novel dataset including 95% of national prostate cancer cases. However, the decision to provide an explicit opt-in consent process for an extended dataset required the consistent physical presence of IPCOR research personnel on site. Following a thorough evaluation of each site and ensuring a mix of public and private hospitals, both rural and urban populations, and representation of the breadth of the Irish population, the three busiest campuses (including two campuses with both public and private hospitals) with the highest diagnostic and treatment activity levels of prostate cancer were selected: the University Hospital Galway, the Mater Misericordiae University Hospital and Mater Private Hospital, and the St Vincent's University and Private Hospitals.

Conveniently, two of these three campuses are affiliated with UCD for academic research. In addition, the absence of radiotherapy data in the previous wave of IPCOR was overcome by also placing resources within the St Luke's Radiation Oncology Network (SLRON) for data collection. By concentrating our resources in these three major hospital systems, we aim to capture about two-thirds of the prostate cancer burden in Ireland. **Data from four hospitals across two campuses are included in this report.**

In the Republic of Ireland, there are accelerated pathways for the diagnosis of prostate cancer. Men aged 50–70 years (or from age 40 years if they have a first-degree relative with prostate cancer), with elevated consecutive prostate-specific antigen (PSA) results are referred by their GPs to a RAPC available at over eight major public hospitals. Three of these are covered by IPCOR. The IPCOR consent process (detailed ahead) begins tracking participants from the date they were referred to the RAPC by their GP up to diagnosis, then treatment, and beyond in cases of recurrence.

Site Staff

The physical presence of IPCOR research personnel on site brings invaluable human interaction, providing a visible professional face for the registry, and people who can provide support and encouragement to participants through the project.

At each site, our qualified and experienced research staff engage with potential participants to introduce IPCOR, its purpose and how it works, and explain participants' legal rights under European General Data Protection Regulation (GDPR). Our staff collect blood samples, process and freeze serum and plasma, and also the first morning urine sample submitted by a subset of participants. In the course of the project we have recognised the positive influence of human interaction on participants. Receiving updates on the project and use of their data greatly motivates people to participate more enthusiastically. This process also improves access to research for marginalised groups such as those who experience difficulty reading.

Research staff at sites are integrated within clinical teams, attend multidisciplinary tumour boards, and coordinate with several departments involved in the diagnostic and treatment process. An extensive legal agreement between UCD and participating hospital sites covers data collection and provides the IPCOR team with honorary hospital staff status to allow them to approach potential participants.

Figure 2: Site Staff



LIADAN O'HARE
Research Nurse



EIMEAR DONOHOE
Research Nurse



MARIA VAN KAMPEN
Research Assistant



SHRAAVANI ANSURKAR
Research Assistant



VINIT KALE
Research Assistant



ABDI ADAM
Research Assistant

Recruitment and Consent

Following several rounds of discussion with relevant stakeholders including data protection and GDPR professionals, the ideal opportunity for recruitment was determined to be the day of biopsy. This allowed time for participants to understand the project and interact with the staff for documentation and sample collection. This timepoint ensures that baseline survey data can be collected before any decision about treatment has been made.

The registry also includes registrants who went on to have a negative biopsy result because written informed consent was obtained before the biopsy result was known. This is a deliberate design feature and strength of IPCOR. These participants were referred with the same clinical suspicion as those eventually diagnosed with prostate cancer, and retaining biopsy-negative individuals in the registry provides a comparative cohort for baseline characteristics and diagnostic parameters. IPCOR successfully contacted 92% of eligible patients; 8% remained unreachable by phone despite repeated attempts.

Due to variations in hospital site processes, a remote consent pathway for people who miss the informed consent/enrolment window was introduced in September 2025. These individuals receive information and guidance over several telephone conversations and are sent a secure digital link or paper consent form to sign from home.

Comparing the prostate cancer cohort in the IPCOR registry against all people with a new prostate cancer diagnosis across participating sites shows that the IPCOR registry captures an average of 75%–90% of incident prostate cancer cases at participating hospitals.

Longitudinal Clinical Data Collection

Data are entered into the IPCOR registry longitudinally and extracted from patient charts at multiple timepoints: **biopsy appointment** (biopsy details and demographics), **2–3 weeks after biopsy** (confirmation of prostate cancer diagnosis from histology), **3 months after a positive diagnosis** (treatment and referral check), 6 months after diagnosis (vital status for those who consented to receive post-treatment questionnaires) **and 12 months after the start of treatment** (treatment updates, re-biopsies, and post-treatment PSA and scans for recurrence) **with annual follow-up visits thereafter** (recurrence, death and secondary treatments, particularly in those consented for annual questionnaires).

Automated lists within the registry environment track these milestones, and patients appear and filter out according to set timelines and clinical criteria. Sociodemographic variables are recorded at recruitment and updated at subsequent survey timepoints. Vital status and death notification are rechecked before dispatch of patient questionnaires. If information about the cause of death was unavailable in patient records, this was requested from the participant's GP.

People undergoing radiation therapy referred to SLRON are followed through the ARIA system or Mosaiq based on the referring institute and whether treatment took place within the public or private system.

Data collection status through June 2026 is shown in **Figure 4,** opposite. Out of 603 enrolled IPCOR participants, 416 had confirmation of a prostate cancer diagnosis entered and 312 had treatment reports entered in the registry.

Figure 3: Consent Process

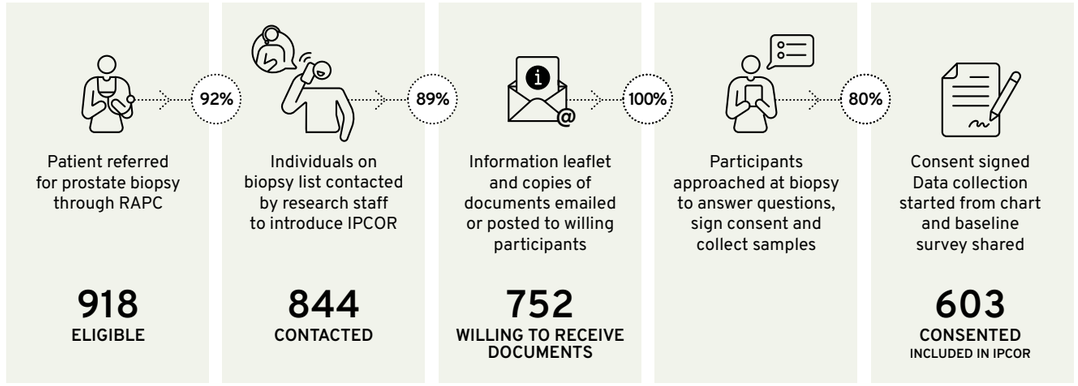
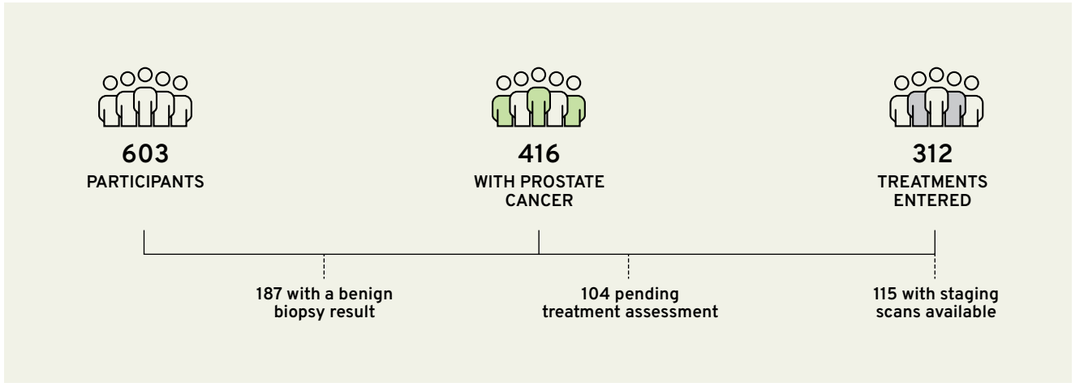


Figure 4: Data Collection Status

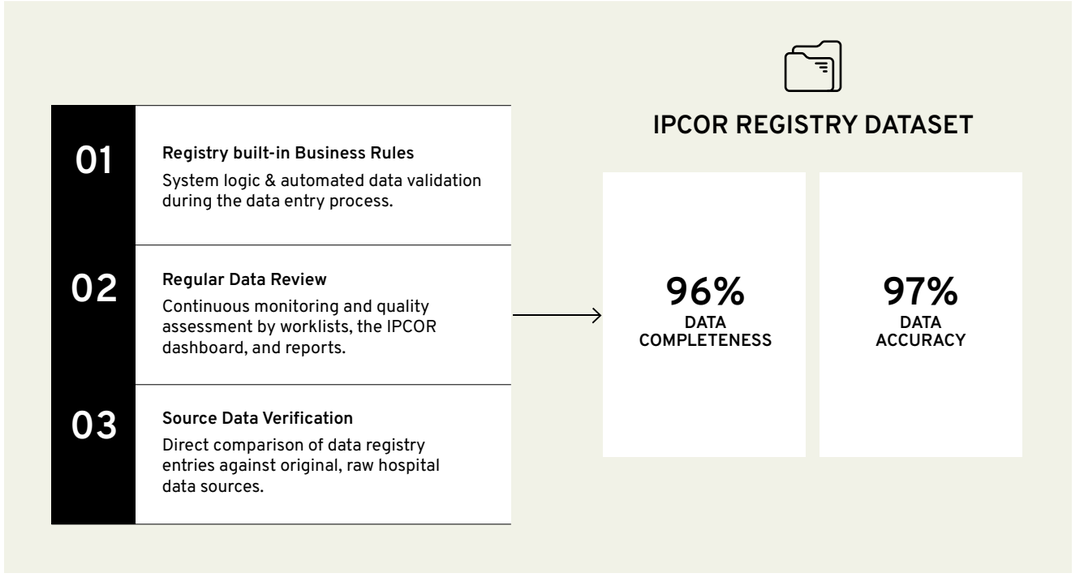


Data Quality Assessment

The IPCOR data team and external Data Oversight & Access Committee (DOAC) experts evaluate registry data based on the five main dimensions of quality defined by the Health Information and Quality Authority (HIQA) Data Quality Framework for Health. They are Relevance, Accuracy & Reliability, Timeliness & Punctuality, Coherence & Comparability, and Accessibility & Clarity.

To assess these quality aspects, we employed a three-level data quality control process (**Figure 5**). Data quality assessments are conducted site-wide, reducing in frequency to bi-annual checks once the staff are trained and meeting the expected value of 95% data accuracy. Queries on missing data and clarification of ambiguous information, such as pathological confirmation of disease, are forwarded through site investigators to relevant departments.

Figure 5: Data Quality Standards

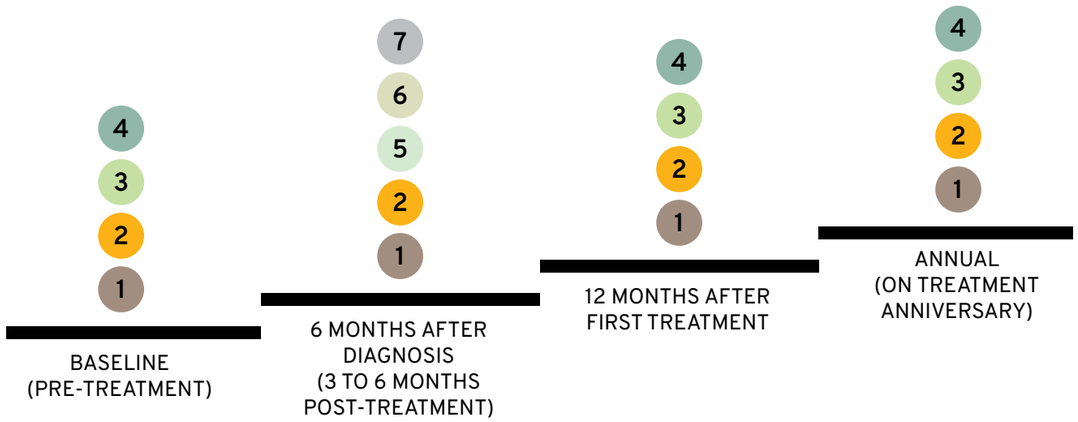


PROMs Data Collection

Within IPCOR, the frequency and timepoint of PROMs collection was implemented in line with recommendations of the International Consortium of Health Outcome Measurements (ICHOM)[1] (**Figure 6**). Additional tools such as financial toxicity, shared decision making and supportive care needs were added on the advice of our patient panel, LEAP.

PROMs surveys are self-reported by IPCOR participants and are completed online or on paper (sent via post) according to the preference recorded at consent. Of the 603 participants, 500 (83%) were willing to receive these PROMs questionnaires; completion rates at baseline and at 6 months after diagnosis are shown in **Table 3**, opposite.

Figure 6: Overall Descriptions of PROMs and Surveys



1 DEMOGRAPHICS

- Ethnicity
- Living situation/ dependents
- Education
- Occupation/income
- Insurance status
- Comorbidities

2 EPIC-26

- Urinary domain
- Bowel domain
- Sexual domain
- Libido & sexual aids

3 EORTC-QLQ-C30

- Daily activity level
- Symptoms in past week
- Overall physical health
- Overall mental health

4 EORTC-QLQ-PR25

- Urinary symptoms
- Bowel symptoms
- Systemic symptoms
- Sexual symptoms/ activity

5 SCNS-SF34

- Physical needs in past month
- Emotional needs in past month
- Informational needs in past month
- Supports available in past month

6 FACIT-COST

- Savings/expenditure
- Financial worry/stress
- Effect on employment
- Burden on family

7 SDM-Q-9

- Informed decision-making
- Satisfaction with physician input
- Agreed with treatment decision
- Felt involved in decision

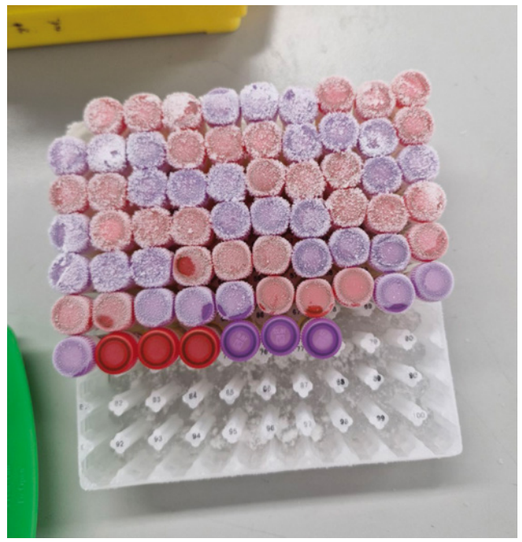
Table 3: PROMs Completion Rate

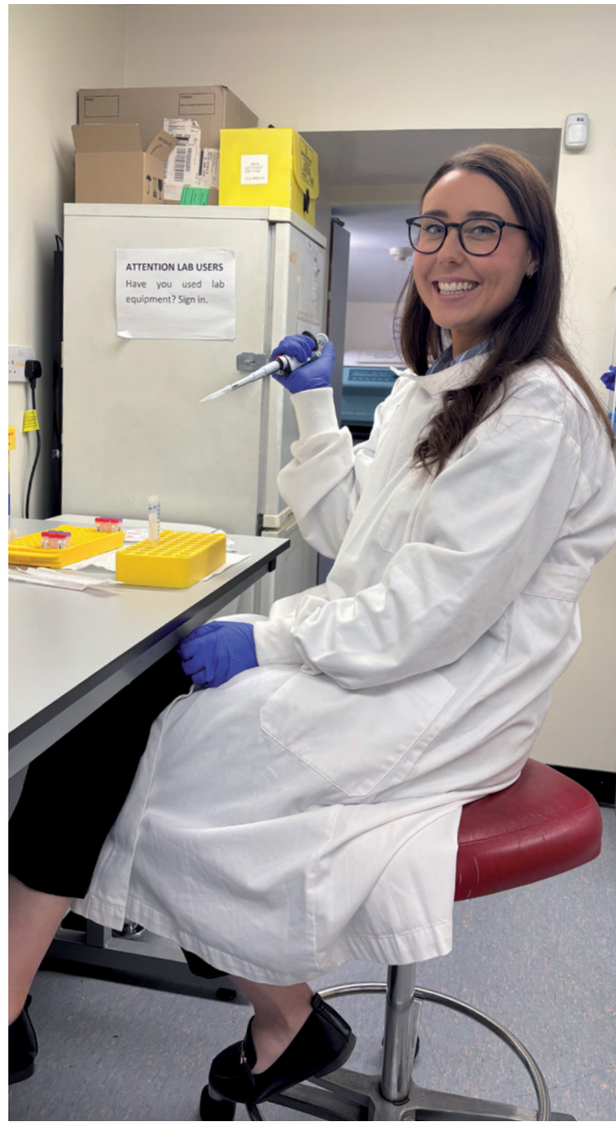
	Eligible cohort (n)	PROMs completed (n)	Completion rate
Pre-treatment	500	401	80.2%
6 months post diagnosis (3 to 6 months after treatment)	161	113	70.2%

Biobank

The IPCOR biobank stores biological samples in line with high standards set by the UCD Conway Institute Biobank. Each sample is linked to the corresponding registrant's clinical data, providing a research-ready resource to support biomarker discovery and translational research.

Effective biological sample collection and storage is critical in biomedical research, impacting the quality and reliability of results. By adhering to best practices and understanding the specific needs of different biological materials, researchers can ensure the integrity of their samples. See **Appendix 1** for details on the IPCOR Biobank Sample Storage and Transportation Standards.





The types of samples collected and numbers biobanked for IPCOR are shown in **Table 4**.

- Blood (serum and plasma): drawn by a research nurse at the biopsy appointment. This is the biobank's principal resource for biomarker and translational studies.
- Urine: collected by participants upon first morning void on biopsy day.
- Prostate tissue: consent is recorded at recruitment, but tissue is taken only for ethics-approved tumour marker studies.

Table 4: Samples Collected

Type of sample	Number of samples collected
Urine	129
Blood	191
Paired blood and urine	91
Consent for tissue	516



Biobank Quality Assurance

Biological assurance for patient samples involves a comprehensive approach to ensure the integrity and reliability of samples used in research. This includes:

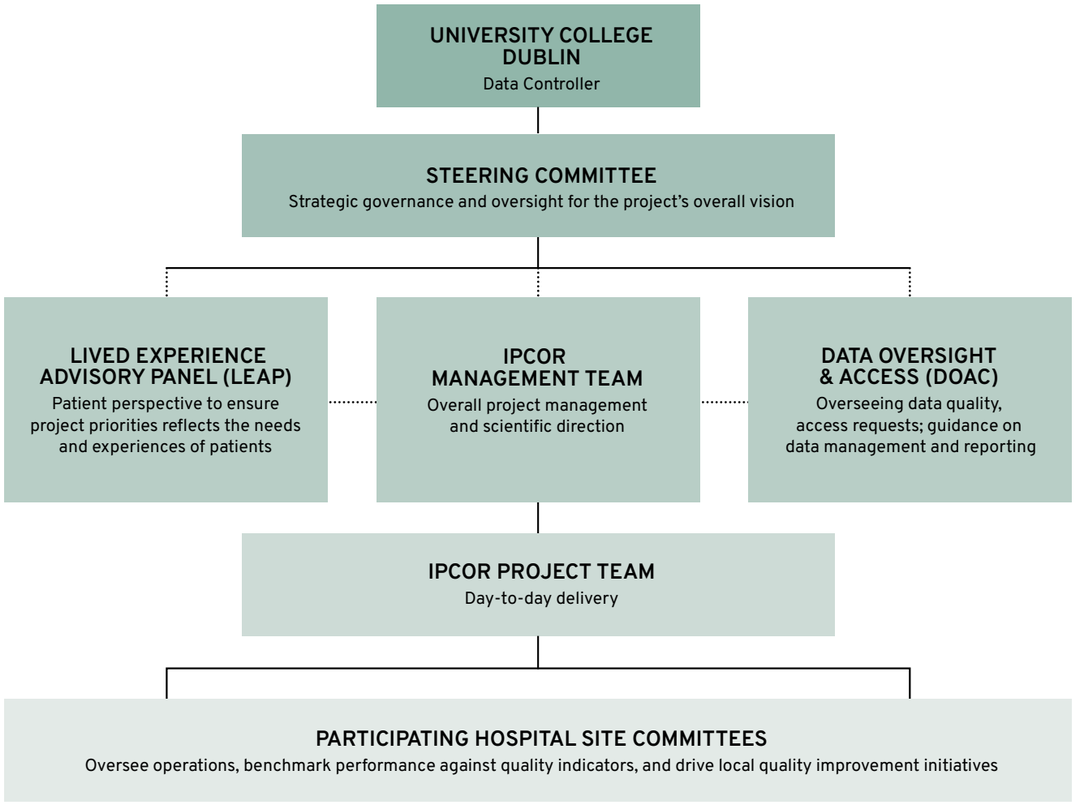
- Proper collection and processing of biological samples.
- Transport of patient samples according to sample transportation guidelines.
- Monitored storage of biological samples to allow their long-term use in future research.
- Accurate data management.

Governance

To ensure all purposes of IPCOR are fulfilled, the internal and external governance bodies meet regularly and review all activities and future plans for the project. The organisational structure and functions of participating committees are shown in **Figure 7**. The membership and specific responsibilities of these committees are further outlined in **Appendix 2**.

In addition to the below, UCD legal and data protection experts provide detailed oversight of the registry to ensure compliance with organisational and national regulatory policies.

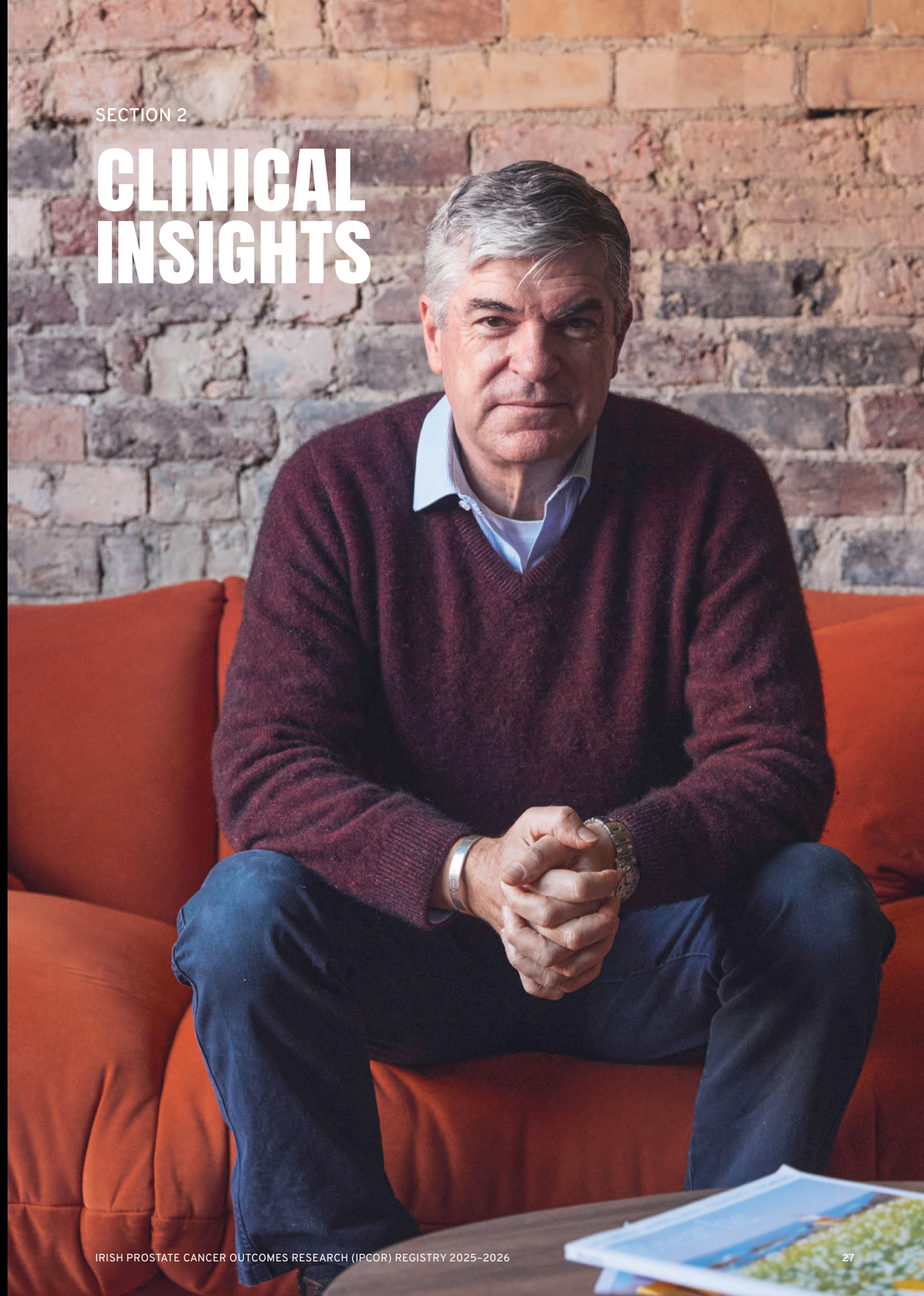
Figure 7: IPCOR Governance



*Dashed lines show advisory relationships, without line authority.

SECTION 2

CLINICAL INSIGHTS



"The creation of LEAP — the Lived Experience Advisory Panel — in 2020 as a key component of the IPCOR research project was very significant. LEAP members are all men who have had a prostate cancer diagnosis, and we are very keen to share our experiences and to work with the research team to make sure that the work of IPCOR is always relevant to patient experiences and needs. There are currently ten men on the LEAP team. We meet regularly to discuss whatever is happening in IPCOR — sharing the patient perspective, making suggestions and recommendations on everything that is happening, highlighting key issues and unmet needs of people living with prostate cancer and their loved ones, reviewing draft forms and publications, sharing information amongst individual communities, and spreading the word about what IPCOR is doing. As Chair of LEAP, I attend the weekly IPCOR team meetings, making sure that the LEAP voice is always heard. LEAP is an established part of IPCOR, central to everything that IPCOR is doing, and working with IPCOR all the way — a wonderful example of meaningful, genuine patient engagement in research."

MR MARTIN SWEENEY
Chair of LEAP
Co-Investigator HRB Secondary Data Analysis Project



The IPCOR registry tells us a great deal about prostate cancer care in Ireland. These data support clinicians and hospital management to monitor clinical quality, identify trends, and benchmark the quality of care.



Analysis of the IPCOR dataset enables understanding of the prostate cancer pathway in Ireland from GP referral and diagnostic investigation, through primary treatment, to patient-reported functional and cancer outcomes.

The indicators fall into four groups: health system performance; sociodemographic profile; treatment; and long-term follow-up (**Table 5**). These were selected because they can be measured consistently across sites and are actionable locally. In addition, waiting time and diagnostic measures inform service planning within the RAPC, while treatment and surgical pathology indicators allow urology and radiation oncology teams to track clinical quality against national guidelines.

As IPCOR collects registrants' clinical information and PROM data, the indicators in this section can be read alongside the patient experience data in Section 3. This allows linking, which provides additional detail from the patient experience perspective and about how effectively patients are supported during their treatment journey.

Table 5: Indicators

Health system	• Waiting time from GP referral to RAPC appointment • Times to MRI, biopsy and treatment start • Biopsy type and outcome (prostate cancer diagnosis) • Prostate cancer burden • Radiation oncologist consultation for treatment decision
Sociodemographic profile	• Distance from treatment centre • Ethnicity, household income, employment status, education level • Smoking status, family history of prostate cancer
Treatment	• Primary treatments assigned by risk groups • Surgery: type, surgical pathology outcomes, nerve sparing status • Radiation: type, combination therapy, institute, complications • AS: time to second biopsy, monitoring type
Long-term follow-up	• Biochemical recurrence* • Secondary treatments assigned • Vital status (annually post-treatment)

*Two consecutive PSA rises of ≥0.2 ng/mL after radical prostatectomy and Phoenix criteria (PSA level 2 ng/mL above the nadir) after local curative therapy such as radiotherapy.

One in four participants in IPCOR has a family history of prostate cancer. Having a first-degree relative with prostate cancer doubles a person's risk of getting the disease.[2]

2.1 DEMOGRAPHIC CHARACTERISTICS

Demographic characteristics of IPCOR participants are shown in **Table 6**.

Ethnicity, family history and smoking status were collected for all 603 recruited participants, of whom nearly 85% were ethnically Irish. Additional socio-demographic information, including education, occupation and income, is collected as part of PROMs and these details are only available for 398 participants (66%) who completed the demographic section of questionnaires.

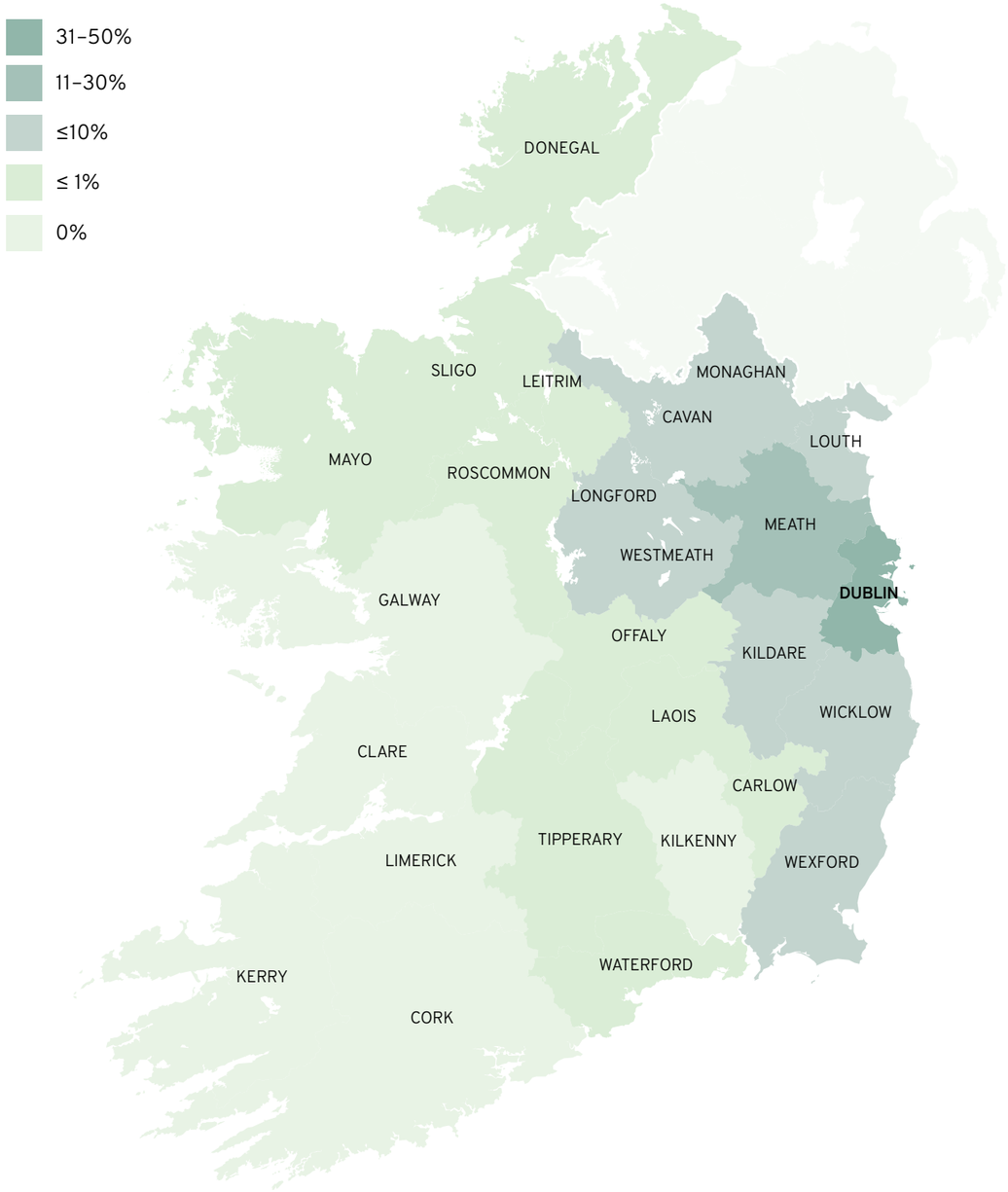
Addresses are used to determine the geographic distribution of participants being treated at each site. The majority of the country's specialised cancer centres (and therefore the IPCOR participating sites) are located in Dublin, meaning that many participants travelled from other counties and provinces. This distribution is shown in the map below (**Figure 8**, page 30). Registrants are drawn overwhelmingly from Dublin and its neighbouring counties, with Dublin (42.1%) and Meath (22.7%) together contributing almost two-thirds of the cohort.



Table 6: Demographic Characteristics of IPCOR Participants

Characteristics	Participants, n (%)
Age group (n=603)	
<50 years	25 (4.1%)
50–54 years	44 (7.3%)
55–59 years	109 (18.1%)
60–64 years	127 (21.1%)
65–69 years	127 (21.1%)
70–74 years	97 (16.1%)
75–79 years	49 (8.1%)
≥80 years	25 (4.1%)
Ethnicity (n=603)	
Irish	512 (84.9%)
Any other White background	32 (5.3%)
African	15 (2.5%)
Other	12 (2.0%)
Not available	32 (5.3%)
Smoking status (n=603)	
Never smoked	283 (46.9%)
Ex-smoker	173 (28.7%)
Current smoker	91 (15.1%)
Not available	56 (9.3%)
Family history (n=603)	
Yes	143 (23.7%)
No/unknown	460 (76.3%)
Education (n=398)	
Tertiary level	213 (53.5%)
Secondary school	160 (40.2%)
Primary school	15 (3.8%)
No formal education	5 (1.3%)
Not available	5 (1.3%)
Occupation (n=398)	
Retired	170 (42.7%)
Employed full-time	118 (29.6%)
Self-employed	70 (17.6%)
Employed part-time	14 (3.5%)
Other	11 (2.8%)
Unemployed	11 (2.8%)
Not available	4 (1.0%)
Income (n=398)	
>€55,000	171 (43.0%)
€35,000–55,000	72 (18.1%)
€15,000–35,000	66 (16.6%)
<€15,000	37 (9.3%)
Not available	52 (13.0%)

Figure 8: Map Showing Where IPCOR Registrants Come From



The proportion of participants who travelled a distance of >10 km for diagnosis and treatment was 65% in public hospitals versus 34% at private hospitals

Although most specialist cancer centres are located in Dublin, the majority of IPCOR registrants (57.9%) reside outside Dublin county. The public and private systems show differences in catchment: with 65.2% of public hospital registrants residing outside Dublin compared with 41% of private hospital registrants.

Distance travelled follows the same pattern. Among the 527 registrants with a recorded Eircode, two-thirds (65.6%) of those attending private hospitals lived within 10 km of their centre, compared with just over a third (34.9%) of those attending public hospitals. Conversely, of the 131 registrants travelling >50 km, 85% attended public hospitals and 15% attended private hospitals.

This type of analysis is valuable to understand which participants travel the furthest for diagnosis and treatment, impacting travel costs, appointment attendance and access to supportive services. The NCCP funds the Travel2Care scheme, administered by the Irish Cancer Society, which provides financial support towards travel costs for eligible patients travelling beyond a specified distance to a designated national cancer centre or satellite centre.

Table 7: Distance to Treatment Centre

	Public Hospitals, n (%)	Private Hospitals, n (%)
County of residence (n=603)		
Within Dublin county (n=254)	146 (34.8%)	108 (59.0%)
Outside Dublin (n=349)	274 (65.2%)	75 (41.0%)
Total	**420 (100%)**	**183 (100%)**
Approximate distance (n=527)*		
<10 km (n=231)	130 (34.9%)	101 (65.6%)
10–50 km (n=165)	131 (35.1%)	34 (22.1%)
>50 km (n=131)	112 (30.0%)	19 (12.3%)
Total	**373 (100%)**	**154 (100%)**

*Participants with available Eircode.

2.2 PATIENT PATHWAY

IPCOR participants wait an average of 153 days for a prostate cancer diagnosis, primarily due to delays in MRI and biopsy capacity; this exceeds national and international recommended diagnostic timelines.[3]

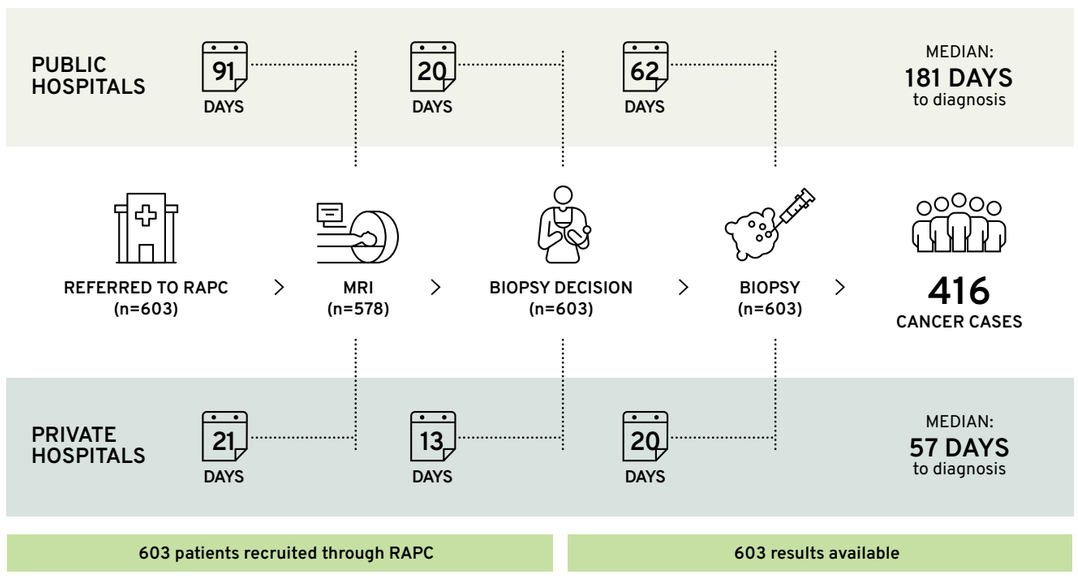
The RAPCs were established by the NCCP to shorten the interval between GP referral and prostate cancer diagnosis. IPCOR captures each date along that pathway: GP referral; MRI; biopsy decision; and biopsy. This allows RAPC performance to be measured against their stated purpose and alongside internal hospital indicators. The median intervals shown in **Figure 9** are derived from these dates for all 603 registrants across participating sites, divided between the public and private systems. RAPC referral indicators and specific internal hospital performance indicators can be assessed via the dates of referrals and reports captured by IPCOR.

Overall the median interval from referral to a RAPC to biopsy was 153 days. However, this interval was much longer for registrants managed in public hospitals (181 days) compared with those managed in private hospitals (57 days); a difference of approximately 4 months. The number of days shown includes weekends and public holidays.

The difference between the public and private pathways is largely due to the two steps that depend on access to a service (rather than on clinical decision-making). The wait from RAPC referral to MRI was 91 days in public hospitals compared with 21 days privately, and the corresponding wait from biopsy decision to biopsy was 62 versus 20 days. In contrast, the interval from MRI to biopsy decision was short in both pathways (20 and 13 days, respectively), indicating that clinical review is prompt once imaging is available (**Table S1** in **Appendix 3**). Access to diagnostic imaging and to biopsy capacity therefore accounts for most of the additional time taken in the public pathway.

Waiting times between milestones depend on a variety of factors and do not reflect quality of care or patient-related reasons for delays in appointment scheduling. On average, the histopathology report with final results to confirm diagnosis is available about 2–3 weeks (10–15 working days) after the biopsy procedure.

Figure 9: Patient Referral Timeline



2.3 BIOPSY & DIAGNOSIS

Use of the Prostate Imaging Reporting and Data System (PI-RADS) V.2 scoring system and PSA density (PSAD) are powerful tools to risk-stratify patients, and these help to reduce the number of unnecessary biopsies and avoid over-treatment. PSAD is auto-calculated in the IPCOR registry when updated PSA and prostate volume from MRI are captured.

Transperineal biopsy (TP) was the diagnosis method used in 90.4% of IPCOR registrants. National guidelines recommend either a transrectal or TP route for targeted biopsy, recommending TP for men at high risk of post-transrectal sepsis.[4] In IPCOR, all registrants managed at private hospitals were diagnosed using TP, while 86.7% of those managed in public hospitals were diagnosed using TP; transrectal ultrasound-guided biopsy (TRUS) was used in a further 13.3% of participants (**Table S2** in **Appendix 3**).

The national clinical guideline[4] recommends multiparametric MRI before prostate biopsy (Recommendation 3.1.1) and use of the PI-RADS scoring system to interpret it (3.2.1). Biopsy is recommended for PI-RADS 4 and 5 lesions (3.2.2) and should be considered at PI-RADS 3 (3.2.3).

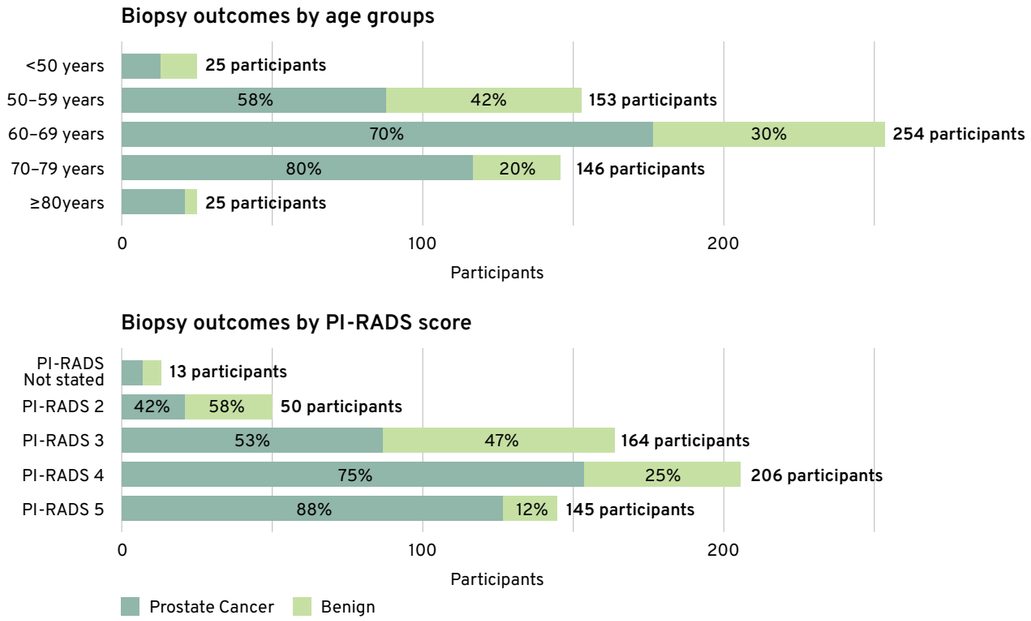
Where MRI is negative (PI-RADS 1 or 2) the guideline sets out two paths: omitting biopsy should be considered through shared decision-making (3.4.1), or systematic biopsy is recommended where clinical suspicion of cancer remains high (3.4.2). Because IPCOR records the pre-biopsy MRI result and PI-RADS score alongside the histology outcome for registrants, it can describe how this pathway operates in practice. Figure 10 shows biopsy outcomes stratified by age group and MRI PI-RADS score (see also **Table S3** in **Appendix 3**). Additional stratification by PSAD is provided in **Figure S1** and **Table S4** in **Appendix 3**.

A pre-biopsy MRI result was recorded for 578/603 registrants (95.9%), of whom 565 (93.7% of the cohort) had a PI-RADS score documented. Biopsy positivity rose consistently with PI-RADS score, from 42.0% at PI-RADS 2 to 87.6% at PI-RADS 5.

Most biopsies followed a PI-RADS 4 or 5 scan, and 80.1% of these were positive, supporting the strength of Recommendation 3.2.2 in practice. Fifty registrants (8.7%) proceeded to biopsy after an MRI reported as PI-RADS 2, of whom 21 (42.0%) were diagnosed with prostate cancer. These biopsies fall within Recommendation 3.4.2, which recommends systematic biopsy where clinical suspicion remains high despite a negative MRI.

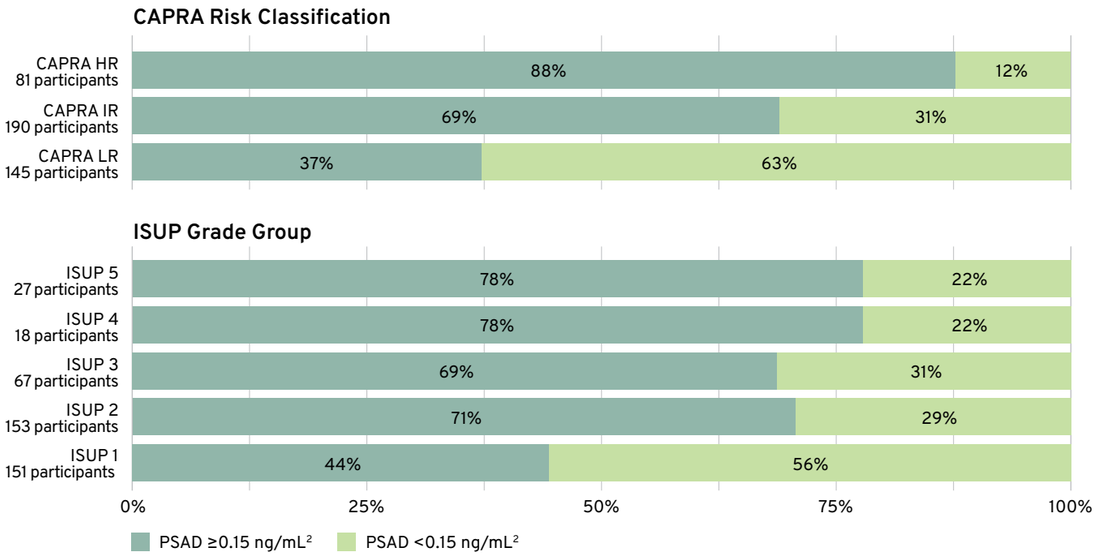
Biopsy positivity also increased with age, from 52.0% in registrants aged <50 years to 84.0% in those aged ≥80 years, consistent with the established relationship between age and prostate cancer incidence.

Figure 10: Biopsy Outcome by Age Group (n=603) and MRI Result (n=578)



* PI-RADS 1 not reported because the total number of participants in this category was <5.

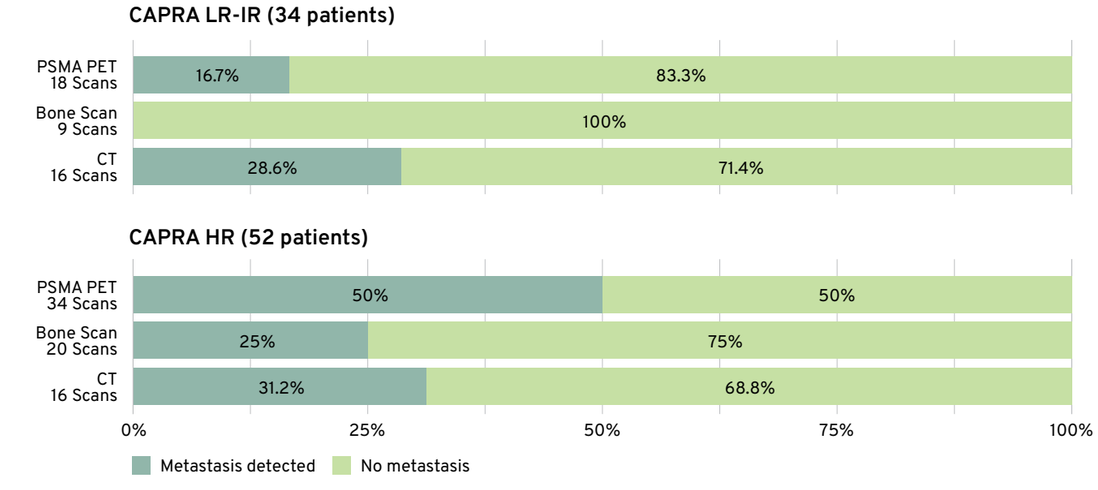
Figure 11: Prostate Cancer by PSAD and Risk Groups (CAPRA, ISUP)



The International Society of Urological Pathology (ISUP) grade and Cancer of the Prostate Risk Assessment (CAPRA) score are commonly utilised risk stratification systems in Ireland. To better contextualise staging scans, treatment decisions and overall distribution of people with prostate cancer, these systems (along with PSAD) have been used to stratify IPCOR participants (**Figure 11;** see also **Table S5** in **Appendix 3**).

To date, 113 scans have been ordered for staging 86 participants in line with national guidelines,[4] and 32 of these presented with metastatic-positive findings on their staging imaging. The cohort referred for additional staging have been stratified into CAPRA risk groups (**Figure 12**; see also **Table S6** in **Appendix 3**). Of these scans, 62% (70/113) were performed on high-risk (HR) individuals and 27/70 (39%) identified metastatic disease. In the low (LR) and intermediate (IR) risk groups, only 7/43 scans (16%) showed metastasis positive.

Figure 12: Staging Imaging Findings by CAPRA Risk Group



CAPRA (Cancer of the Prostate Risk Assessment) score is a 0-to-10 point scale that predicts an individual's risk of cancer recurrence, metastasis, and mortality following treatment. The score is calculated using points assigned to: age at diagnosis, PSA at diagnosis, Gleason score of the biopsy, clinical stage and percent of biopsy cores involved with cancer.A CAPRA score of 0 to 2 indicates low-risk (CAPRA LR). A CAPRA score of 3 to 5 indicates intermediate-risk (CAPRA IR). A CAPRA score of 6 to 10 indicates high-risk (CAPRA HR)

2.4 TREATMENT

Of the IPCOR participants diagnosed with low-risk CAPRA score prostate cancer, 79% are initially managed with AS. This compares favourably with international standards,[5,6] with further room for improvement.

Table 8: Primary Treatment Assigned for People with Prostate Cancer

	Number of participants, n (%)
Surgery	93 (29.8%)
Radiation therapy	72 (23.1%)
Active surveillance	123 (39.4%)
Androgen deprivation therapy only	15 (4.8%)
Watchful waiting	9 (2.9%)
Total participants started treatment	**312 (100%)**

Among 416 people diagnosed with prostate cancer by the reporting cut-off, 312 have started treatment or selected a treatment plan (**Table 8**). The remaining individuals are in ongoing consultation, undergoing further staging scans or awaiting a treatment start date. **Figure 13** shows the distribution of treatment plans stratified by CAPRA risk group. In men with a low-risk CAPRA score (0–2), 79% were initially managed with AS. Of the 32 participants presenting with metastatic disease on staging imaging, 24 (75.0%) were managed with androgen deprivation therapy (ADT), 7 (21.9%) underwent surgery, and one was placed on watchful waiting (**Table S7** in **Appendix 3**).

The NCCP clinical guidelines recommend that patients should be seen by both a urologist and a radiation oncologist.[4] While documentation of patient referral is incomplete, the registry has successfully tracked 127 referrals to radiation oncology specialists, 72 (57%) of whom received radiation therapy as the primary treatment while the remaining referrals selected other care plans, primarily surgical intervention. Secondary treatments will be captured and added in successive reports after documentation of biochemical recurrence.

Of the 93 registrants scheduled for surgery, 75 (80.6%) have had the procedure and have a final surgical pathology report. Surgical notes and surgical pathology reports were accessed after operative procedures to document intra-operative and tumour-related variables. Clavien grade 3 and above complications are also documented from operative notes.

Figure 13: Treatment Assigned based on CAPRA Risk Group

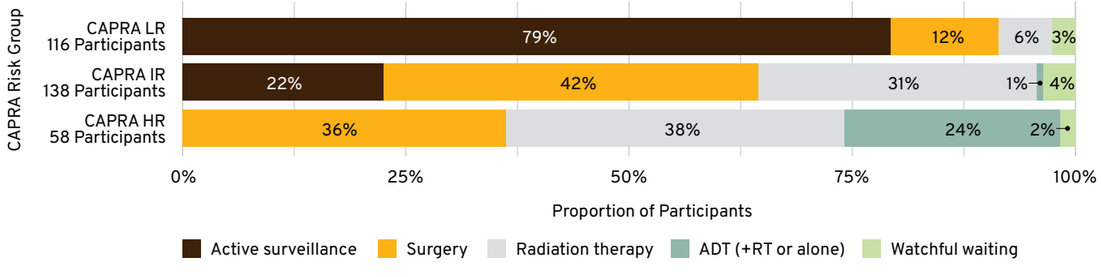


Table 9: Surgical Outcomes

	Positive Margins	Negative Margins	Total
Total, n (%)	**21 (28.0%)**	**54 (72.0%)**	**75 (100%)**
Pathological stage, n (%)			
pT2	9 (18.0%)	41 (82.0%)	50 (100%)
pT3	12 (48.0%)	13 (52.0%)	25 (100%)
Nerve-sparing status, n (%)			
Nerve-sparing	12 (34.3%)	23 (65.7%)	35 (100%)
Non nerve-sparing	7 (21.9%)	25 (78.1%)	32 (100%)
Unknown	2 (25.0%)	6 (75.0%)	8 (100%)
Margin focality, n (%)*			
Focal (single lesion)	10 (47.6%)		
Multifocal (multiple lesions)	10 (47.6%)		
Unknown	1 (4.8%)		
Margin Extent n (%)*			
≤1 mm	7 (33.3%)		
>1 mm	13 (61.9%)		
Unknown	1 (4.8%)		

*Among positive margins.



Positive margins were identified in 21/75 reports (28.0%), with higher margins in locally advanced T3 disease, as expected (**Table 9**).

The decision to undergo nerve-sparing robotic prostatectomy in men with T2 disease is a complex discussion between the individual and the surgeon, where the person is aware of the extensive and sometimes challenging effort made to preserve the erectile nerves during surgery, and in our experience this accounts for many of the focal (<1mm) margins, many of which either have low-grade disease present at the margin and are considered clinically insignificant.

The recognised challenge of "Gleason grade restaging" or "Gleason regrading" may cause discrepancy between the initial biopsy grade assigned at diagnosis and the definitive pathological grade obtained after radical prostatectomy (RP). This can lead to "upgrading" (grade increase) or "downgrading" (grade decrease). A key factor contributing to these discrepancies is tumour heterogeneity. A high clinical concordance of Gleason scores in IPCOR reflect the high accuracy of diagnostic biopsies conducted at participating hospital sites. This high concordance rate reflects the quality of radiology and pathology departments.

Concordance between biopsy and post-prostatectomy Gleason grade was high (69.3%), with 18.7% of patients upgraded and 12.0% downgraded (**Figure 14**). This compares favourably with the first IPCOR cohort, where concordance was 57.0%, broadly consistent with an international median of 52.9%.[7] The higher concordance in the current IPCOR cohort may reflect improvements in diagnostic pathways, including increased use of pre-biopsy MRI and targeted biopsy.

Figure 14: Concordance Between Gleason Scores at Biopsy and Post-Prostatectomy

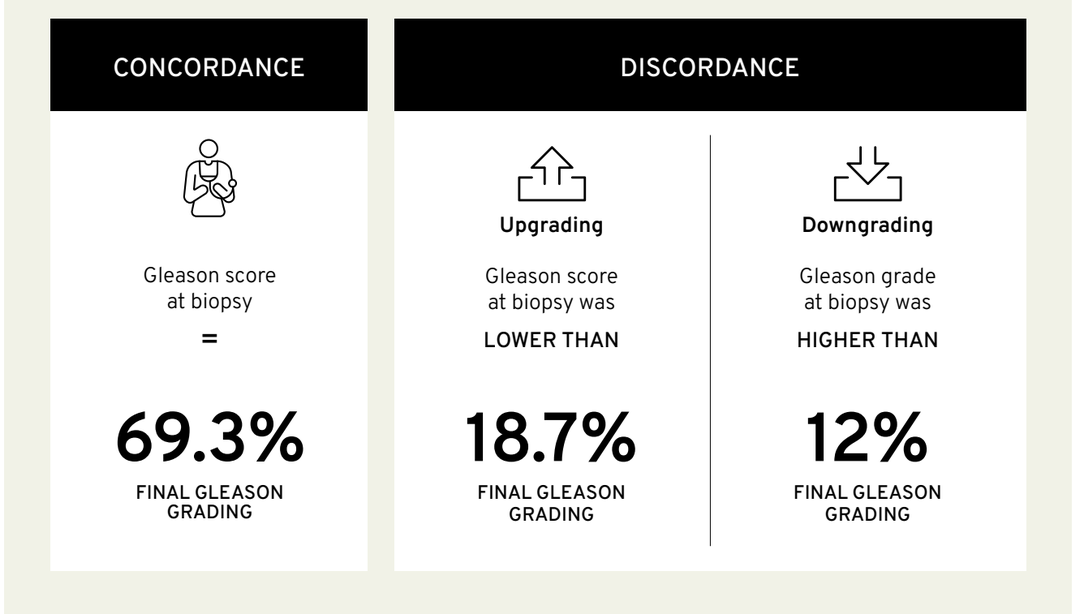


Table 10: Radiotherapy

	RT only (n=38)	RT + ADT (n=34)	Total (n=72)
Type of RT			
EBRT	16	25	41
Brachytherapy	13	1	14
Pending reports	9	8	17

Standard radiotherapy protocols involve delivering 60 Gy via 20 daily fractions across a 4-week period. Participants in the low-risk category typically underwent radiotherapy alone, whereas those in the intermediate-to-high risk groups were prescribed ADT in conjunction with radiotherapy to enhance clinical efficacy.

Among the 72 participants who started RT, 38 (52.8%) were managed with radiotherapy only, while 34 (47.2%) were treated with a combination of radiotherapy and ADT; 41 participants (56.9%) underwent external beam radiation therapy (EBRT) and 14 (19.4%) received brachytherapy (**Table 10**).

Among participants undergoing repeat biopsy during AS, 43.5% were upgraded from Gleason 3+3 to 3+4, highlighting the importance of risk-adapted surveillance in identifying disease reclassification.

Of 123 patients managed with AS, 23 (18.7%) had undergone a repeat biopsy, at a median of 210 days after diagnosis (**Table 11**). Of these, 10 (43.5%) were upgraded from Gleason 3+3 to 3+4. The 2025 NCCP Active Surveillance guideline[8] recommends a risk-adapted approach based on the modified STRATCANS strategy, tailoring the intensity of PSA monitoring, MRI, clinical review and re-biopsy according to individual risk of progression. These findings highlight the role of ongoing surveillance in identifying disease reclassification while supporting a more individualised approach to follow-up.

Table 11: Active Surveillance Re-Biopsies

	Participants undergoing active surveillance
Patients with re-biopsy, n (%)	23/123 (18.7%)
Median time to re-biopsy	210 days
Gleason score at re-biopsy (Gleason 3+3 at diagnosis), n (%)	
Gleason 3+3	13/23 (56.5%)
Gleason 3+4	10/23 (43.5%)

Post-treatment PSA values are entered at all follow-up timepoints. Biochemical recurrence after radical prostatectomy is calculated as two consecutive PSA rises of ≥0.2 ng/mL. The Phoenix criteria defines biochemical failure after local curative therapy such as focal ablation and radiation therapy as a rise in PSA level to 2.0 ng/mL above the lowest PSA achieved (nadir). During the current reporting window, participants had not yet reached the designated post-treatment follow-up milestones. Therefore, follow-up insights will be detailed in future annual reports.

SECTION 3

PATIENT-REPORTED INSIGHTS



Over recent decades, improvements in cancer treatments have significantly increased survival after a prostate cancer diagnosis. However, living longer does not necessarily equate to living well, and there are several reports of long-lasting physical, sexual, psychological, social and emotional repercussions of prostate cancer treatments on men and their partners.

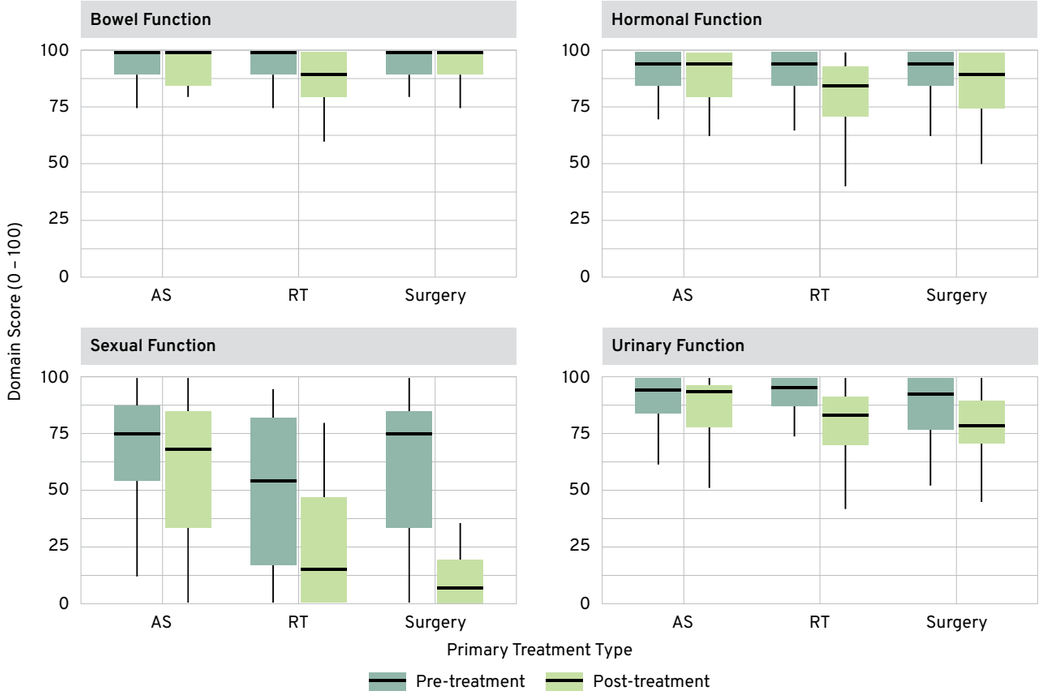
The extent to which prostate cancer survivors experience physical and psychological impairments varies according to several factors. These include, but are not limited to, stage of disease at diagnosis, primary treatment, and pre-existing comorbidities. Collecting PROMs data is a valuable method of measuring these impairments. PROMs survey forms empower individuals to report their experience and, when fed back to clinicians, to help enhance the clinical consultation and examination.

3.1 EPIC-26 PRE- AND POST-TREATMENT

Significant changes in sexual function domain scores from baseline to post-treatment were observed in participants who had undergone surgery. Post-surgical participants completed questionnaires between 3 to 6 months after surgery.

The number of responses with valid EPIC-26 domain scores is shown in **Table S8** in **Appendix 3**. **Figure 15** shows EPIC-26 major domain scores at baseline and 6 months after starting treatment in 206 participants who had AS, RT or surgery and completed PROMs. Overall EPIC-26 domain scores were relatively stable among participants managed with AS, while greater changes were observed after active treatment. The most pronounced change was in sexual function after surgery, with additional decline in urinary function. Changes in bowel and hormonal function were comparatively modest across treatment groups.

Figure 15: EPIC-26 Major Domain Scores Pre- and Post-Treatment



Boxes show the 25th to 75th percentiles (the Interquartile range); internal line indicates the median values. Whiskers represent 1.5 times of the Interquartile range. Individual outliers were removed.
*See Supplementary Table S8 for the number of valid responses per domain and treatment included in the values shown in the above figure.

About the measure: The EPIC-26 includes 26 items across five domains (urinary incontinence, urinary irritative/obstructive, bowel, sexual, and hormonal). Responses are provided on a Likert scale and multi-item scale scores are transformed linearly to a 0–100 scale, with higher scores indicating better health-related quality of life. Scores cannot be calculated if more than 20% of the items within a domain summary are missing.

Figure 16: EPIC-26 Leakage of Urine Data Pre- and Post-Treatment

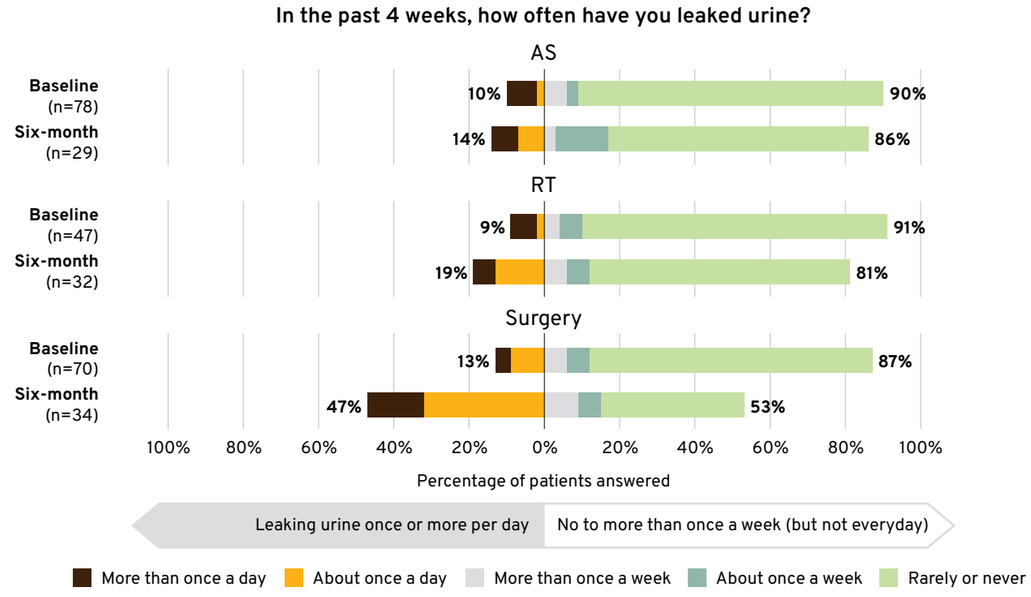
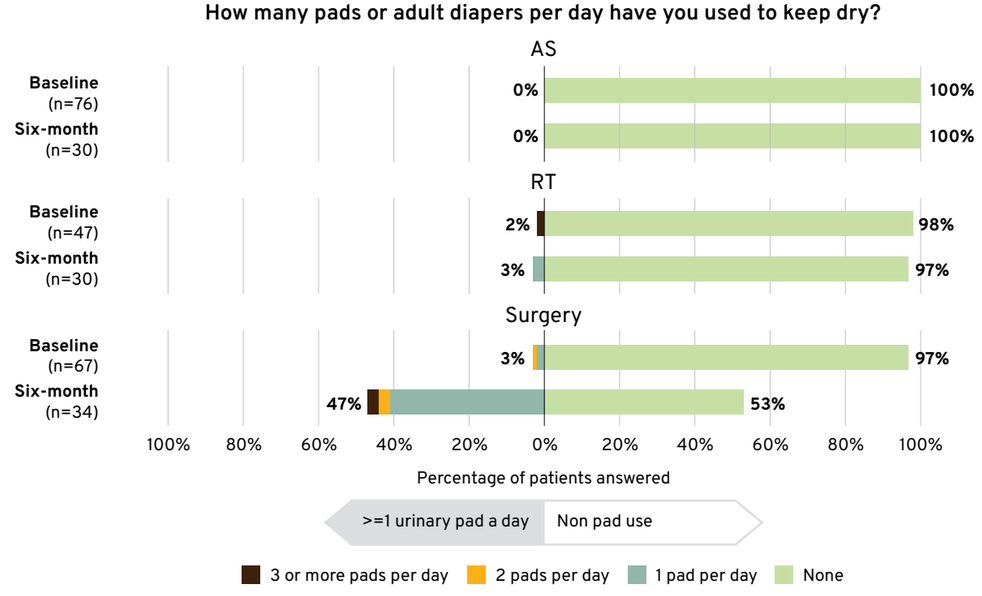


Figure 17: EPIC-26 Pads and Diaper Use Data Pre- and Post-Treatment



The domain-level pattern is clearest in the individual continence questions (**Figure 16, Figure 17; Table S9** in **Appendix 3**). Deterioration in urinary continence was common among participants undergoing surgery. At follow-up (6 months after starting treatment), almost half of participants who had surgery reported daily urinary leakage and pad use; 47% leaked urine at least once per day (versus 13% at baseline) and 47% used one or more pad per day (versus 3% at baseline). In comparison, urinary outcomes were less affected in participants receiving RT or managed with AS.

Figure 18: EPIC-26 Ability To Have an Erection Pre- and Post-Treatment

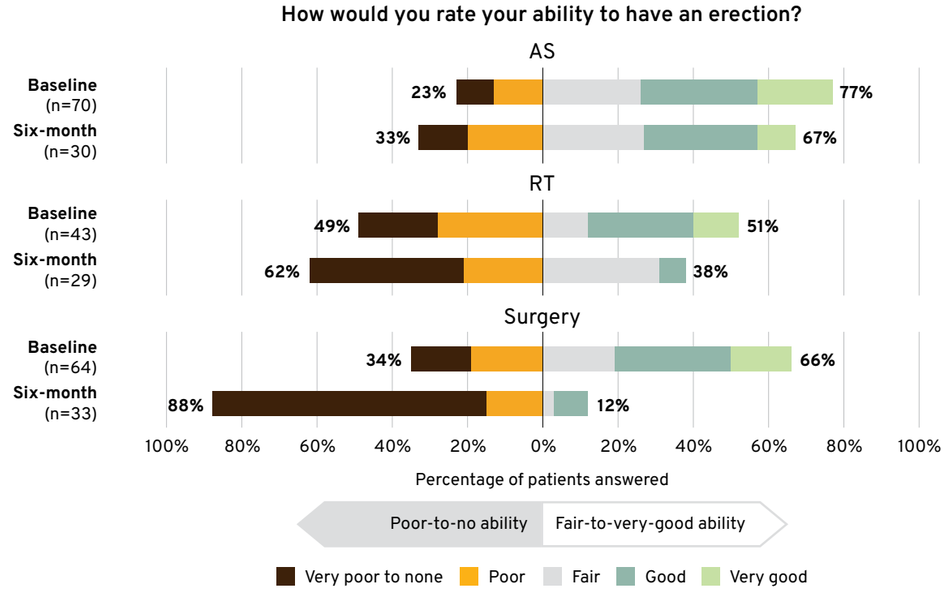
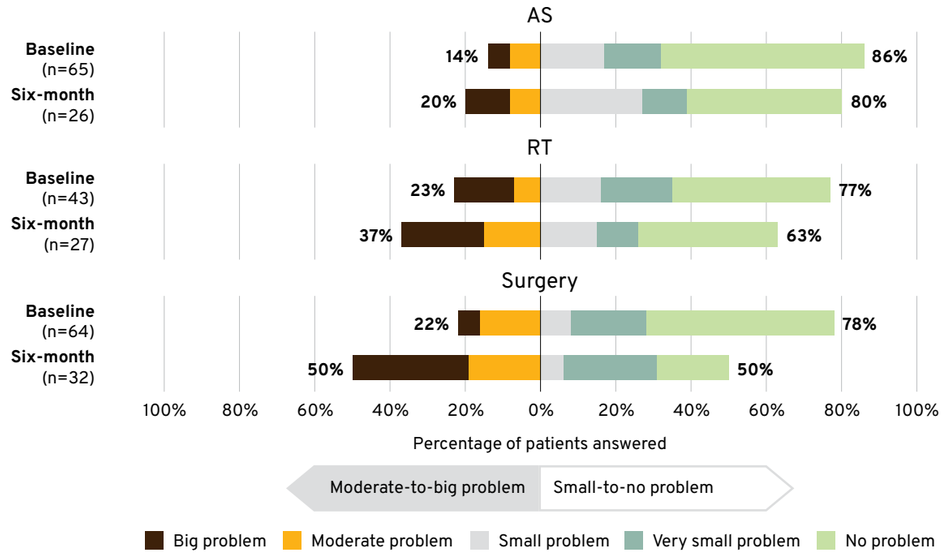
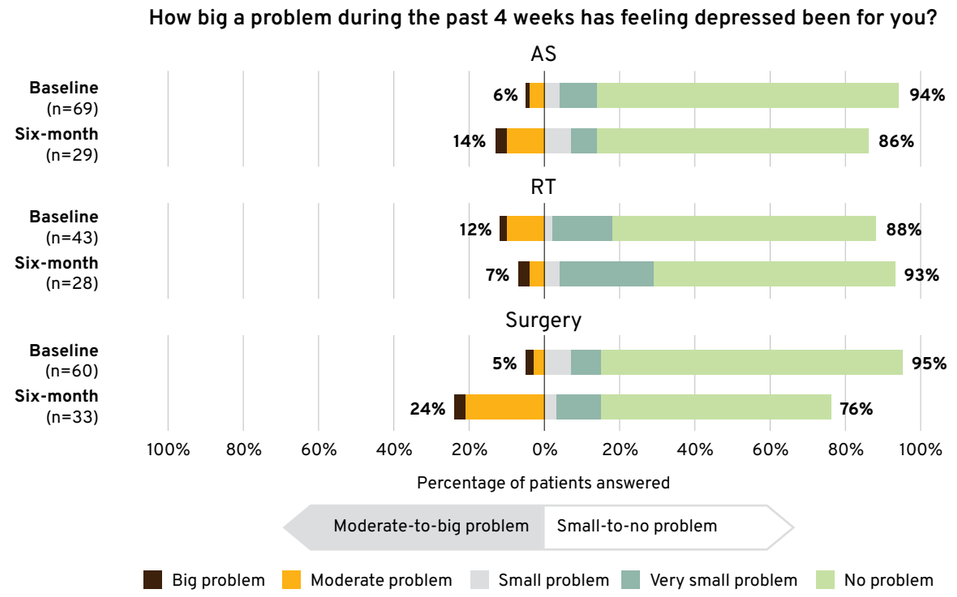


Figure 19: EPIC-26 Overall Sexual Function Pre- and Post-Treatment



Of all the EPIC-26 domains, sexual function showed the most marked deterioration after treatment, particularly following surgery (**Figure 18, Figure 19; Table S9** in **Appendix 3**). For participants who had surgery, the proportion with poor/very poor erectile ability increased from 34% at baseline to 88%, while those reporting sexual function as a moderate/big problem increased from 22% to 50%. Despite this burden, only 14 of the 110 participants who completed post-treatment PROMs reported using medical devices to support sexual activity or erections, including ten who had undergone surgery. Further research on correlation with socioeconomic barriers is planned.

Figure 20: EPIC-26 Feelings of Depression Pre- and Post-treatment



An increase in reported problems with depression was also evident after surgery. For those with available data, 24% of participants reported depression as a moderate or big problem at follow-up compared with 5% at baseline (**Figure 20; Table S9** in **Appendix 3**). This finding suggests that the early consequences of treatment may extend beyond physical and sexual function.



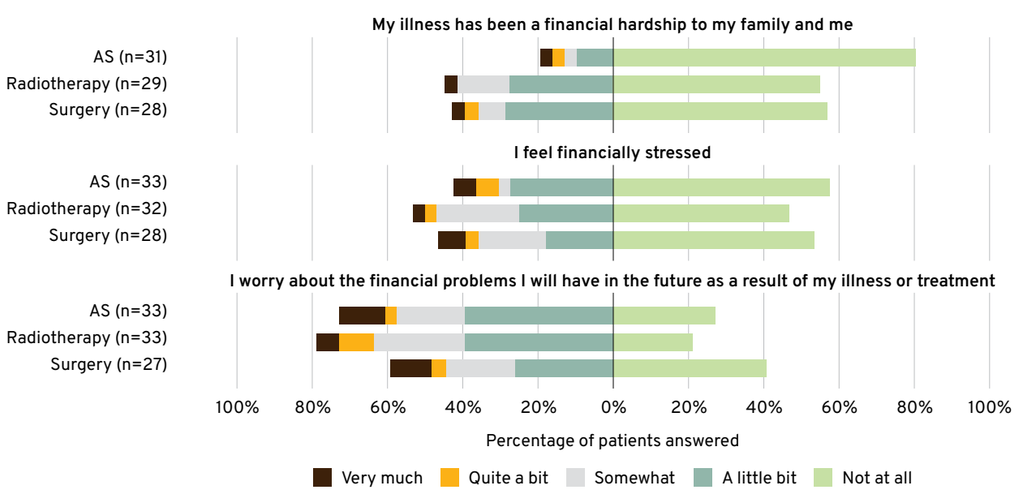
3.2 FINANCIAL TOXICITY

Participants who received active treatment expressed higher rates of financial hardship. Approximately one-quarter of participants reported moderate-to-high levels of stress, and overall results suggest that concerns about future financial difficulties are experienced by the majority of participants to varying degrees.

In the context of IPCOR, financial toxicity is the strain and emotional stress caused by the direct and indirect costs associated with a prostate cancer diagnosis and treatment. Of the 113 participants who completed the FACIT-COST questionnaire post-treatment, 104 (92%) provided sufficient responses for a valid FACIT-COST score. Overall, 71.8% of participants reported no financial toxicity and 28.2% reported at least mild financial toxicity.

Although most participants reported little financial burden and distress, several aspects of financial wellbeing were affected (**Figure 21**). Confidence in having sufficient financial resources to cover treatment costs was low for many participants, and concerns about future financial problems were common. Financial stress was reported by a substantial minority, while relatively few participants considered their illness to be a major financial hardship for themselves or their families (**Table S10** in **Appendix 3**). Stratified analyses suggested that financial toxicity was more common among participants with lower household income, lower educational attainment, and those who were unemployed, retired or who had dependent children, indicating that baseline socioeconomic circumstances may influence the financial impact of prostate cancer.

Figure 21: Financial Hardship in People with Prostate Cancer by Treatment



About the measure: The FACIT-COST is a validated 11-item patient-reported outcome measure used to assess financial toxicity experienced by people with cancer. Items are scored on a 5-point Likert Scale from 0–4 and the overall score ranges from 0–44 (lower scores indicate greater financial toxicity).

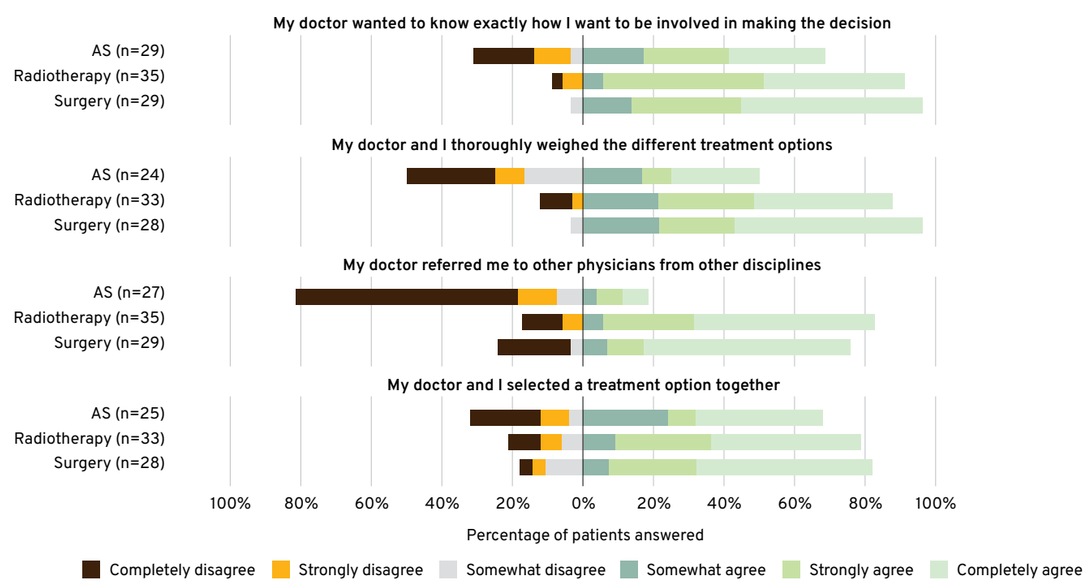
3.3 SHARED DECISION MAKING

Lower agreement was observed for questions regarding referrals to other specialists and the extent to which clinicians explored participant's preferred level of involvement in decision-making. Participants under AS expressed the lowest rates of satisfaction with the shared decision-making process.

Shared decision-making is a collaborative process through which patients and healthcare professionals work together to make healthcare decisions based on the best available clinical evidence while incorporating patient preferences, values, and individual circumstances. Contemporary prostate cancer discourse places increasing emphasis on patient involvement throughout the treatment decision-making process. A total of 110 participants completed the SDM-Q-9 questionnaire, of whom 97 (88%) provided sufficient responses for calculation of a valid score.

Responses to individual questions indicated generally positive experiences of discussing treatment options and jointly selecting a treatment with clinicians (**Figure 22**). Lower levels of agreement were observed for questions relating to referral to other specialists and whether clinicians explored each participant's preferred level of involvement in decision-making. Participants managed with AS reported the lowest overall levels of satisfaction with the shared decision-making process (**Table S11** in **Appendix 3**), suggesting a potential area for further investigation and improvement in how surveillance decisions are discussed and supported.

Figure 22: Shared Decision Making by Treatment



About the measure: The SDM-Q-9 is a validated nine-item patient-reported measure assessing different stages of the shared decision-making process. Each item is rated on a 6-point Likert scale, from 0 (completely disagree) to 5 (completely agree). Item scores are summed and transformed to a 0–100 scale, with higher scores indicating greater perceived involvement in decision-making.

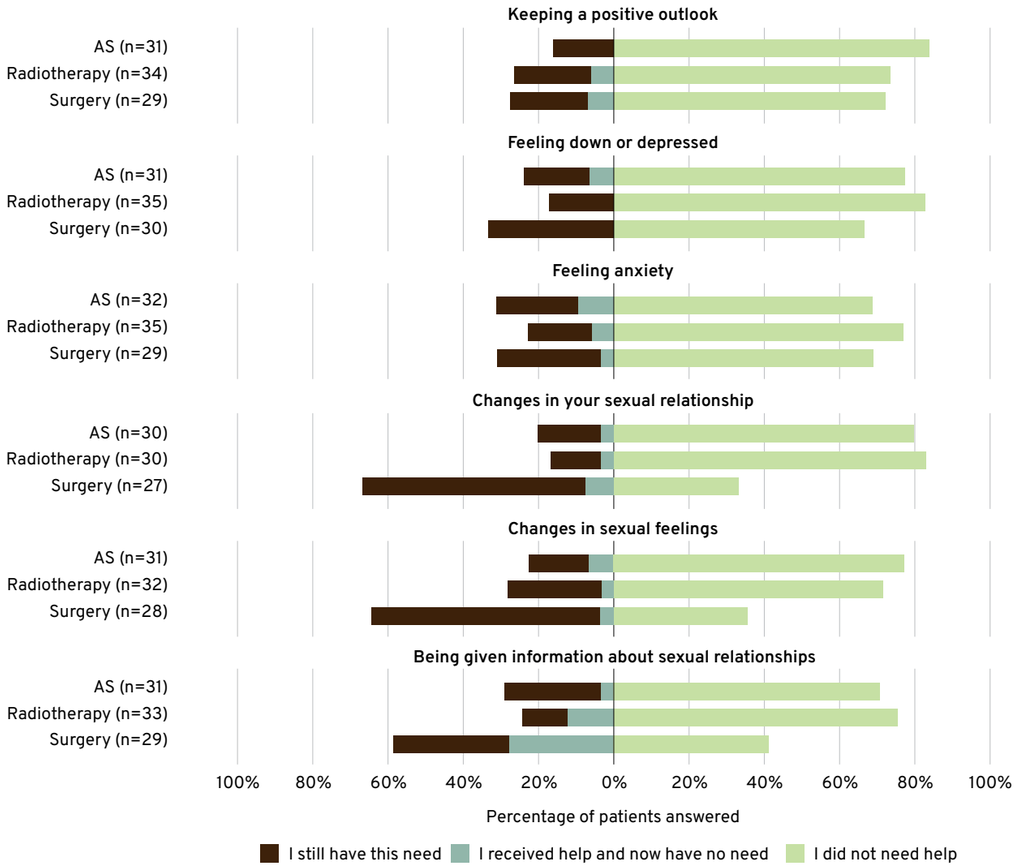
3.4 UNMET SUPPORTIVE CARE NEEDS

Sexuality-related supportive care needs showed the greatest variation across treatment groups. Findings suggest that men undergoing surgery, in particular, may benefit from additional support and referral to address ongoing sexual concerns.

Supportive care needs refer to the physical, psychological, sexual, informational and practical support that people may require during/after cancer diagnosis and treatment to manage the impact of cancer on their health, wellbeing and daily life. A total of 109 participants completed this questionnaire.

Across all domains, most responses indicated that participants felt no supportive care was needed. However, the proportion of responses indicating either a previously addressed need or a current unmet need varied by domain. Supportive care needs were most frequently reported in the Psychological and Sexuality domains (**Figure 23**). Participants treated with surgery reported the highest proportion of current unmet sexual supportive care needs, while those receiving ADT also reported a high prevalence of both current and previously addressed sexual support needs (**Table S12** in **Appendix 3**).

Figure 23: Psychological and Sexuality Supportive Care Needs by Treatment



About the measure: The Supportive Care Needs Survey – Short Form 34 (SCNS-SF34) is a validated 34-item patient tool that evaluates the perceived unmet needs of adults with cancer over the previous month. The questionnaire covers supportive care needs across five domains: Physical and Daily Living, Psychological, Sexuality, Patient Care and Support, and Health Systems and Information. For each item, responses were grouped into three categories: I did not need help, I received help and now have no need, and I still have this need. This distinguishes participants with no identified need from those whose needs have been addressed and those with a current unmet supportive care need. Scores are standardised on a 0–100 range, with higher scores reflecting greater unmet needs.

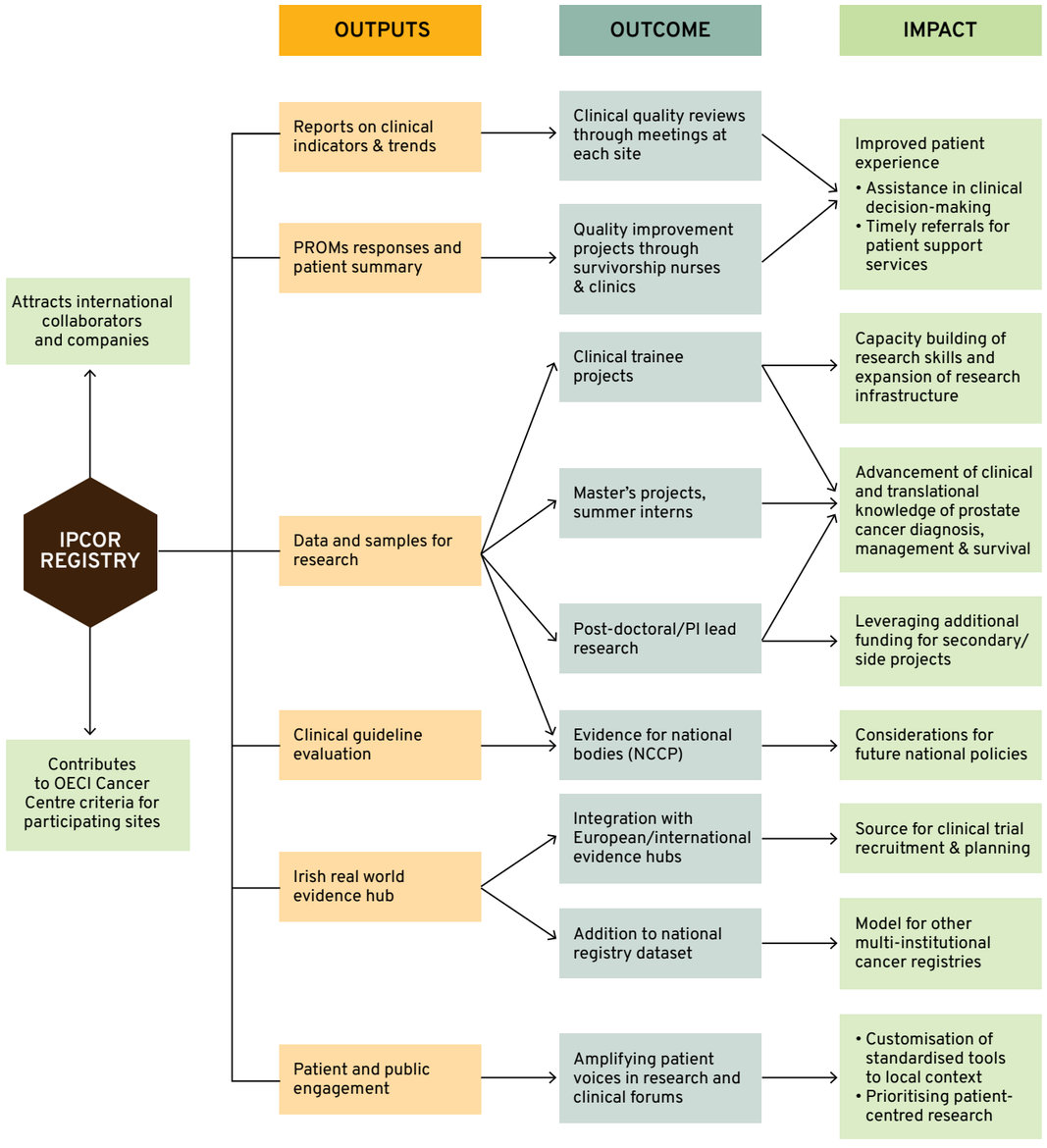
SECTION 4

IMPACT

DIRECT AND INDIRECT IMPACTS OF IPCOR

There are numerous outputs generated from the IPCOR registry on a regular basis. These outputs have both short- and long-term impact on a hospital site, and at the patient and health system level. **Figure 24** shows the outputs, outcomes and eventual impact of the IPCOR project.

Figure 24: IPCOR Impact



4.1 CLINICAL QUALITY REPORT & IMPROVEMENT

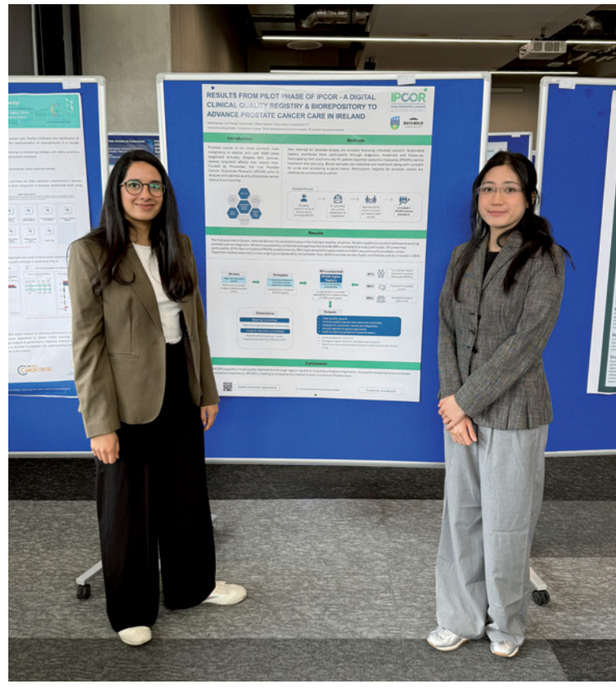
IPCOR regularly generates outputs from the registry for internal monitoring, clinical quality evaluation purposes, scientific publications, and dissemination of pertinent information to relevant bodies such as the NCCP. Regular reporting activities include:

1. Routine registry reports describing the number of participants enrolled, consented, withdrawn, completed etc. for process evaluation.
2. Hospital site-level clinical quality reports with aggregated data shared with participating hospitals and clinicians analysing quality indicators. These can be generated on demand but are otherwise shared bi-annually.

As a first collaborative effort for a quality improvement initiative at the first two participating IPCOR sites, we are providing copies of PROMs responses to willing participants who undergo prostatectomy. This initiative aims to enhance the interaction between the Advanced Nurse Practitioners (ANPs) in survivorship clinics who attend to patients post-operatively. A copy of each participant's PROMs responses and a succinct treatment summary will also be forwarded to the ANP that each individual will be seeing. The impact of this will be tracked and reported for future quality improvement projects.

4.2 RESEARCH PROJECTS/ COLLABORATIONS

IPCOR continues to support collaborative research by providing high-quality registry data, biospecimens and clinical expertise for research projects led by investigators within our team, and for collaborative projects with external partners. IPCOR supports a growing portfolio of internally led research projects addressing clinically relevant questions to improve prostate cancer care and patient outcomes. Many of these research priorities are identified in partnership with LEAP, ensuring that the research programme addresses the issues of greatest importance to people living with and beyond prostate cancer. These research activities strengthen national and international collaborations, facilitate generation of evidence to inform clinical practice and policy, and contribute to scientific dissemination through conference presentations, peer-reviewed publications and knowledge exchange activities. IPCOR also supports research capacity building through teaching and supervision of UCD Masters of Public Health (MPH) students and Summer Student Research Awards (SSRA), providing opportunities for students to contribute to clinically-relevant prostate cancer research.



4.2.1 ONGOING MAJOR EXTERNAL COLLABORATIONS

1. Project title: STANDARDISATION OF IRISH PROSTATE CANCER DATA USING OMOP CDM FOR ML-BASED PI-RADS 3 BIOPSY DECISION SUPPORT.

   Collaboration with: The All Island eHealth Hub for Cancer and The University of Limerick — Jeremiah Akintomide (PhD candidate), Katie Crowley (Principal Investigator), Mohsin Memon (Research Assistant).

   About the project: This collaborative project aims to improve biopsy decision-making for men with PI-RADS 3 lesions by developing a machine learning-based risk-stratification tool. IPCOR is contributing de-identified registry data to the OMOP Common Data Model for standardisation, creating a research-ready dataset for model development and validation. The project will strengthen the use of standardised registry data to support future data-driven clinical decision-making.

2. Project title: DEVELOPMENT OF A COMPREHENSIVE PRECISION MEDICINE FRAMEWORK FOR THE TREATMENT OF PROSTATE CANCER.

   Collaboration with: UCD, School of Biology and Environmental Science — Antoinette Perry (Principal Investigator), Maria Prencipe (Co-investigator), Kate Duffy (PhD candidate).

   About the project: This collaborative project aims to develop a precision medicine framework to support more personalised treatment strategies for prostate cancer. IPCOR is contributing patient-derived clinical data and biological samples to support the development of three-dimensional tumour models and the identification of biomarkers associated with disease progression and treatment response. The project will advance translational research and contribute to improving personalised prostate cancer care.





4.2.2 ONGOING INTERNAL RESEARCH PROJECTS

1. Project title: FINANCIAL TOXICITY IN MEN UNDERGOING TREATMENT FOR PROSTATE CANCER: ASSESSING THE ECONOMIC BURDEN OF PROSTATE CANCER IN IRELAND.

   Researchers: Megan Daly (MPH student), Carla Perrotta (Project Supervisor), Noa Gordon.

   About the project: This study examines the financial impact of prostate cancer diagnosis and treatment on men in Ireland using the FACIT-COST questionnaire. As the first national evaluation of financial toxicity in this population, the project aims to quantify financial hardship and identify factors associated with increased economic burden to inform supportive care services and policy. Early findings indicate that many participants experience mild to moderate financial toxicity.

   Status: Data analysis is continuing because data are being accumulated through ongoing data collection.

   Research outputs: Early findings have been accepted for a poster presentation at the European Public Health Conference in Bilbao, November 2026.

2. Project title: BASELINE PATIENT-REPORTED OUTCOMES FROM THE SECOND IRISH PROSTATE CANCER OUTCOMES RESEARCH (IPCOR) COHORT: BENCHMARKING QUALITY OF LIFE AT DIAGNOSIS.

   Researchers: Sean Fennessy (MPH student), Patricia Fitzpatrick (Project Supervisor), Noa Gordon.

   About the project: This study examines baseline PROMs collected at the time of diagnostic biopsy to establish a benchmark for quality of life before treatment. The project investigates how sociodemographic and clinical factors influence urinary, bowel, sexual and general health outcomes at diagnosis. Findings identified significant associations between age and selected socioeconomic factors with quality-of-life outcomes.

   Status: Completed.

   Research outputs: Early findings have been accepted for poster presentations at the Irish Society of Urology conference in September 2026, and the European Public Health Conference in Bilbao, November 2026. A manuscript is under preparation for submission to a peer-reviewed medical journal.

3. Project title: SHARED DECISION-MAKING IN PROSTATE CANCER CARE: A MIXED-METHODS EVALUATION USING IPCOR DATA.

   Researchers: Mouli Trivedi (MD SSRA student), Noa Gordon

   About the project: This project evaluates shared decision-making (SDM) among men with prostate cancer using patient-reported SDM-Q-9 data collected through IPCOR. It combines a structured review of the international literature with exploratory analyses of registry data to examine how SDM is delivered in routine practice and its relationship with treatment pathways and patient experience.

   Status: Data analysis is continuing because data are being accumulated through ongoing data collection.

4.2.2 ONGOING INTERNAL RESEARCH PROJECTS (cont'd)

4.	Project title:	EXPLORING SUPPORTIVE CARE NEEDS AMONG MEN LIVING WITH AND BEYOND PROSTATE CANCER: A QUALITATIVE STUDY TO INFORM SUPPORTIVE CARE AND SURVIVORSHIP PROGRAMMES IN IRELAND.
	Researchers:	Noa Gordon, Martin Sweeney
	About the project:	This qualitative study explored the supportive care and survivorship needs of men living with and beyond prostate cancer through patient focus groups conducted across Ireland. The findings provide patient-informed recommendations to improve survivorship services, including psychological support, sexual health services, care coordination, and access to reliable information and peer support.
	Status:	The study has been completed, and the findings inform ongoing collaboration between IPCOR and the National Cancer Control Programme (NCCP) to support the development of patient-centred survivorship services.
	Research outputs:	Findings were presented at the European Association of Urology (EAU) Annual Congress (London) in March 2026. A manuscript is under preparation for submission to a peer-reviewed medical journal.

5.	Project title:	PARTNER EXPERIENCES, INTIMACY AND SUPPORT NEEDS FOLLOWING A PROSTATE CANCER DIAGNOSIS IN IRELAND.
	Researchers:	Rowan Kearns
	About the project:	This mixed-methods study will explore the sexual concerns, intimacy-related challenges and supportive care needs of partners of men treated for prostate cancer in Ireland. Using partner-reported survey data from the Sexual Concerns In Partners of Patients with Prostate cancer – Female (SCIPPP-F) survey, the project aims to generate evidence to inform couple-centred survivorship care and support services.

6.	Project title:	GUIDELINE CONCORDANCE WITH NCCP PROSTATE CANCER DIAGNOSIS AND STAGING RECOMMENDATIONS: RISK-CONCORDANT IMAGING AND PSMA-PET USE IN THE IPCOR1–IPCOR2 REGISTRY.
	Researchers:	Rowan Kearns
	About the project:	This study evaluates the implementation of the NCCP prostate cancer diagnosis and staging guidelines (2015 and 2022) using data from the first wave of IPCOR (2016–2020) and the current IPCOR registry. The project examines adherence to MRI-first diagnostic pathways, risk-concordant staging imaging, and the use of PSMA-PET in men with high-risk prostate cancer to identify opportunities to improve guideline implementation and service planning.

4.3 IPCOR, POLICY & GUIDELINES

IPCOR continues to work closely with the NCCP to generate evidence that informs national prostate cancer policy, clinical guidelines and service planning. Through the Health Research Board (HRB)-funded secondary data analysis programme, IPCOR and the NCCP are collaborating on analyses of both the first wave of IPCOR (2016–2020) and the current IPCOR registry (March 2025 to June 2026). Research using previous IPCOR data is examining the implementation of national guidelines, planning and provision of pre-biopsy MRI, and unmet supportive care needs. Complementary analyses of IPCOR data are evaluating implementation of the NCCP Active Surveillance guideline, shared decision-making, and the appropriate use of diagnostic imaging, including high-cost modalities such as PSMA-PET. These collaborations provide timely evidence to support guideline implementation, and the planning and delivery of high-quality, evidence-based prostate cancer services in Ireland.

IPCOR also maintains a longstanding partnership with Movember, the principal funder of the programme. Beyond financial support, Movember is an active research and quality improvement partner, contributing to the development of patient-centred research priorities, international collaborations, and initiatives to improve the quality of prostate cancer care in Ireland. This partnership ensures that IPCOR remains aligned with international best practice while generating evidence to improve outcomes for men living with prostate cancer in Ireland.

The Principal Investigator of IPCOR is actively involved in several forums, societies and organisations that engage with policymakers who impact men's health. In the past year, this has included joining Movember Ireland in a session in the Oireachtas, meetings with the NCCP, Irish Society of Urology and Irish Cancer Society.

4.4 PUBLIC ENGAGEMENT & AWARENESS

Public engagement and raising awareness of prostate cancer has been a key component of IPCOR. Along with general information regarding screening, diagnosis, treatment and survivorship, we hope these efforts will promote public participation and progress dissemination efforts to wider audiences throughout the island of Ireland.

- Awareness activities: Focused in the month of November to encourage conversations around men's health.
- International Men's Day events featuring professionals speaking with the audience on men's health.
- Campus walks and UCD Conway Mo Bakesale to raise funds for Movember.
- Feature videos and posts in UCD events/forums and social media platforms.
- Informative stalls with interactive activities at participating hospital sites.



- In collaboration with Patient Voice in Cancer Research (PVCR), IPCOR participates in several activities aimed at informing the public on ways to engage with research as well as presenting to researchers on how best to engage with patient partners to co-develop their projects.
- Sharing knowledge and experience gained through LEAP and other initiatives provides IPCOR investigators valuable insight on long-term patient group involvement and the impact of including patient voices in large scale project planning and long-term outputs.



IPCOR WEBSITE AND DIGITAL DISSEMINATION

Our website, www.ipcor.ie, is a tool for dissemination of all sorts of IPCOR-related information aimed at participants, researchers, clinicians and the general public. Along with information about data access information for collaboration and research initiation, we have tried to utilise this platform to keep participants updated on high-level insights from the registry. An essential aspect of this platform is signposting to relevant/verified services and information sources related to prostate cancer, including Irish Cancer Society, Prostate Cancer Ireland and ARC cancer support centres.

Updates on the project including research publications and annual reports (including historic documents from the initial phases of IPCOR) are all archived and available through the IPCOR website. The website also includes a Contact Us page for questions and requests.

Website: www.ipcor.ie

Email: ipcorsupport@ucd.ie

Contact number/helpline: +353-1-6200600

Linkedin: https://www.linkedin.com/company/irish-prostate-cancer-outcomes-research/



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