PROSTATE CANCER OUTCOMES | REGISTRY AUSTRALIA AND NEW ZEALAND

# PATIENT EXPERIENCES WITH PROSTATE CANCER

## PCOR-ANZ SUMMARY REPORT 2024

An overview of the health outcomes that matter to men

MOVEMBER® | MONASH University

# INTRODUCTION

**Words by John A. Dobson**

When men share their experiences of prostate cancer they help each other. It means we're not alone in our prostate cancer journey.

I was diagnosed with prostate cancer in 2009 at the age of 62. It came as a complete shock. I'd always been healthy, with no symptoms and no family history of cancer. A routine blood test early in the year showed my PSA had risen slightly, and just weeks later, I was sitting in a urologist's office facing an unpleasant digital rectal exam and booking a transrectal biopsy.

A biopsy confirmed the diagnosis, seven of twelve samples were positive. My heart sank and I felt quite numb. I remember thinking, "How long have I got left?" My doctor said he believed he could cure me, but the lack of clear guidance was unsettling. I was handed a booklet and told to go away and decide which treatment I wanted. The uncertainty made me feel like I was playing Russian Roulette with my treatment choice.

I joined a local prostate cancer support group in Hobart, where I found warmth, honesty, and understanding from men who had been through it too. Talking openly with others made all the difference during this difficult stage. Around the same time, I took part in a University of Tasmania psychology program for men diagnosed with prostate cancer, that helped me face the emotional side of cancer and the aftereffects of treatment.

After months of research and procrastination, a report from Johns Hopkins University (USA) finally "flicked the switch" as it outlined in layman's terms when action should be taken to treat the cancer based on a man's biopsy results. I chose a radical prostatectomy, the so-called gold standard of the time, because I felt it gave me the best chance of long-term survival.

I was terrified about the thought of the operation, but it went smoothly, and I was discharged after only a couple of days in hospital. Recovery wasn't easy and I was off work for about 4 weeks. The early stage of recovery was really challenging, involving catheter use, urinary retention, two unplanned return visits to hospital and a memorable moment learning self-catheterisation. After that, I suffered a small amount of incontinence for some months. I also experienced erectile dysfunction for about 4-5 years following my surgery.

Now, more than 16 years later, I'm still cancer-free, with undetectable PSA levels. I stay active, going to the gym twice a week, and do a range of exercises. Looking back, I sometimes wonder if I really needed the operation, but I know I was lucky and I consider myself blessed in any event.

The Prostate Cancer Outcomes Registry of Australia and New Zealand (PCOR-ANZ) plays a vital role in supporting men with prostate cancer by capturing detailed information about their treatment journeys. By understanding how men live after treatment, clinicians and researchers gain valuable insights into what truly matters to patients, enabling more tailored and compassionate care.

The voice of men is essential for improving clinical practice. It highlights which treatments deliver the best outcomes from the patient's perspective and identifies areas where additional support may be needed. Most importantly, it helps men to make informed decisions based on what the likely outcomes of their treatments may be and enhances their ability to live well beyond diagnosis.

# ABOUT THIS PATIENT EXPERIENCES SUMMARY

The Prostate Cancer Outcomes Registry – Australia and New Zealand (PCOR-ANZ) collects information on prostate cancer care, and the outcomes reported by men following treatment or observation for their cancer. The information collected highlights how men feel 12 months after treatment or observation, and their experiences with urinary function, bowel function and sexual wellbeing. By understanding these firsthand experiences, healthcare professionals can better tailor care, and work towards improving the support and information provided to others facing prostate cancer.

This Patient Experiences Summary is relevant for men with prostate cancer of any stage. It may also be helpful for families, caregivers and the general public. This summary uses the term 'men' when talking about people included in the PCOR-ANZ. It's important to recognise that the PCOR-ANZ includes everyone with a prostate, including members of the LGBTIQA+ community who may use different pronouns, and be affected by prostate cancer, such as transgender women, male-assigned non-binary people, and intersex people.

The information in this Patient Experiences Summary was collected from men who were diagnosed with prostate cancer between 2020-2022 and participated in the PCOR-ANZ. For more details about the data included, please refer to the PCOR-ANZ 2024 Annual Report, which can be found here.

## WHAT IS THE AUSTRALIA AND NEW ZEALAND PROSTATE CANCER OUTCOMES REGISTRY (PCOR-ANZ)?

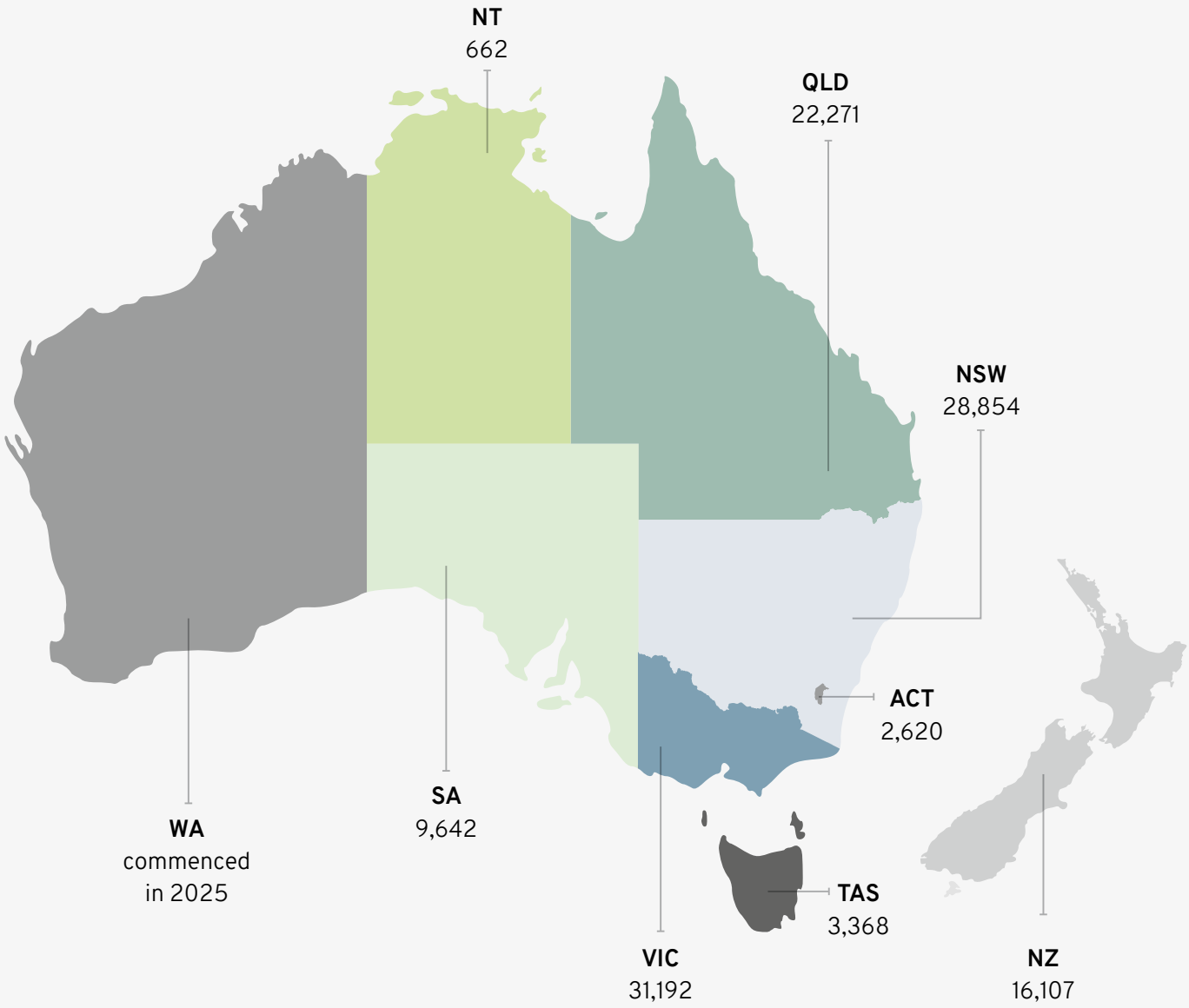
The PCOR-ANZ is a registry operating in New Zealand and all Australian states and territories, which is funded by Movember. Registries in general, are systems that use a database to track patient care and outcomes to help improve treatment and services.

The PCOR-ANZ is designed to collect two kinds of information for men with prostate cancer across Australia and New Zealand:

- **Clinical information** provided by doctors and treatment centres when patients are diagnosed with, and treated for, prostate cancer.
- **Patient experiences** that are collected directly from the men with prostate cancer themselves using 'PROMs' or patient-reported outcome measures.

## HOW MANY PEOPLE ARE INVOLVED IN PCOR-ANZ?

Men included in the registry and diagnosed between 1st January 2015, and 31st December 2022




**411**

**DOCTORS (2024)**

**258**

**HOSPITALS AND CLINICS (2024)**

**55,815**

**MEN WHO HAVE COMPLETED A PROM (2015-2022)**

**114,716**

**MEN INCLUDED IN THE REGISTRY (2015-2022)**

## WHAT ARE PATIENT-REPORTED OUTCOME MEASURES (PROMS)?

PROMs, in general, are questionnaires that collect direct feedback from patients on specific aspects of their wellbeing or health status that are relevant to a particular condition. PROMs questionnaires are tested in clinical studies and validated as being able to provide a good representation of peoples' experiences with a particular disease or treatment.

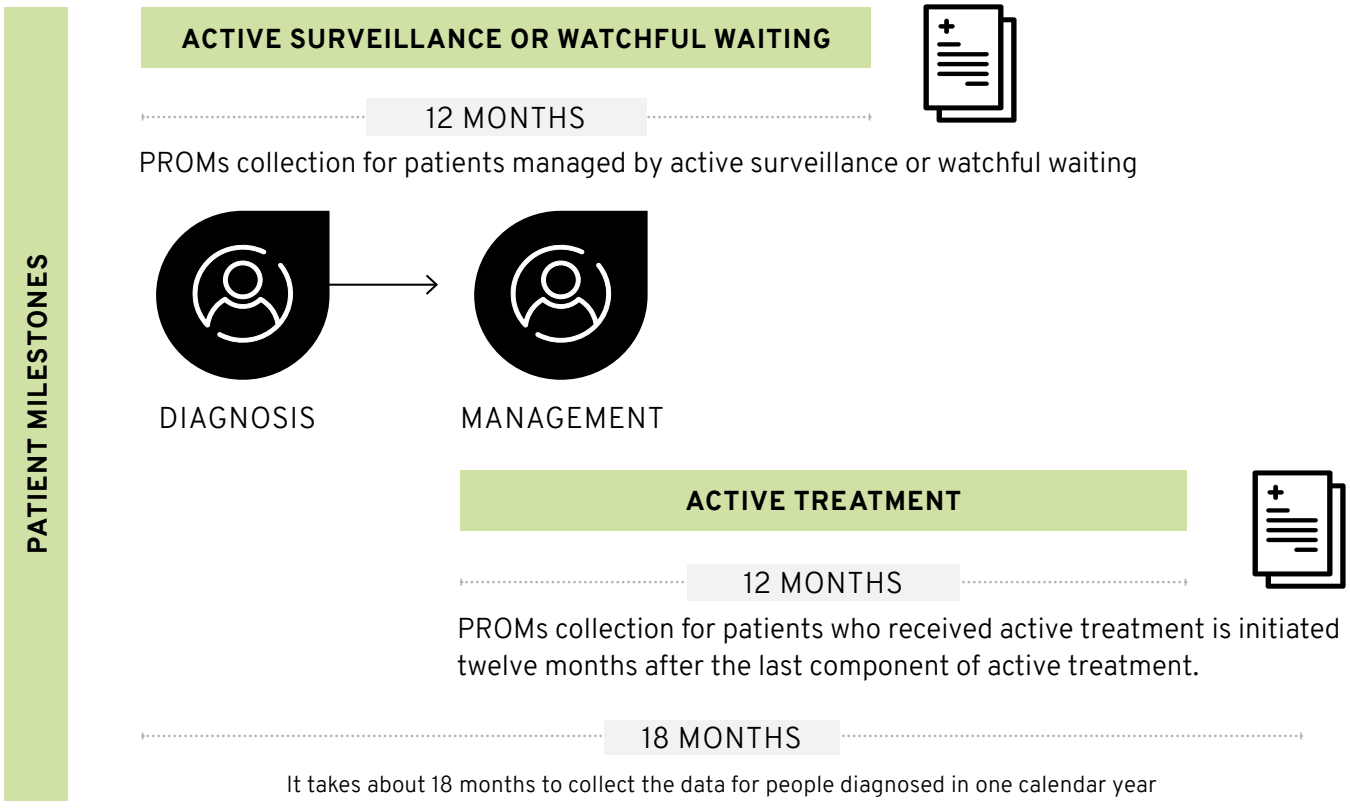
The PCOR-ANZ PROMs questionnaire is based on several key questionnaires that are used globally with men who have prostate cancer. It asks several questions about functional areas that may be affected by prostate cancer or its treatment, such as sexual wellbeing, and urinary and bowel functioning. These PROMs are a valuable source of information to help identify where care for men with prostate cancer can be improved. There is more information about the questions that are asked in the PCOR-ANZ questionnaire on page 21. This Patient Experiences Summary, focuses on the outcomes that matter most to men with prostate cancer, rather than reporting on every measure collected by PCOR-ANZ.

## WHEN DOES PCOR-ANZ COLLECT INFORMATION?

Clinical information is collected from doctors and treatment centres at the time of diagnosis; and twelve months after treatment or observation for prostate cancer.

Patient experiences/PROMs are collected from men who are registered with PCOR-ANZ in a questionnaire that is sent twelve months after diagnosis (for men managed with active surveillance or watchful waiting); or twelve months after treatment begins (for those receiving active treatment).

## WHEN DO WE COLLECT INFORMATION?



# HOW IS PROSTATE CANCER MANAGED?

Prostate cancer management depends on several factors, including a man's age, overall health, the risk level of the cancer, and personal preferences. Because every person is different, treatment plans can vary. This summary focuses on the most common and widely used treatment options.

## ACTIVE SURVEILLANCE

Monitoring for prostate cancer that has little risk of progressing, to avoid or delay unnecessary treatments and their potential side effects. Regular check-ups, including blood tests, scans or biopsies (tissue samples), are performed to decide if or when treatment should start.

## WATCHFUL WAITING

Monitoring for prostate cancer that is designed to help manage symptoms if they occur. It involves fewer tests than active surveillance and is suitable for people who have other health conditions or are elderly. Treatment is only given if symptoms need managing.

## SURGERY

Surgery to remove the prostate gland is called 'radical prostatectomy'. It can be performed as open surgery, or via a keyhole incision (laparoscopic surgery), or by using a surgical robot. Surgery is usually an option when the cancer has not spread widely – known as 'localised' or 'locally advanced' prostate cancer.

## RADIATION THERAPY

Radiation therapy is used to kill prostate cancer cells with high-energy rays or particles. It is most often provided as 'external beam radiation therapy' in which x-rays are aimed at the cancer from outside the body. Or as 'brachytherapy' in which radioactive sources are inserted directly into the prostate.

## RADIATION THERAPY & ADT (HORMONE THERAPY)

In some people, hormone therapy or 'ADT' (short for androgen-deprivation therapy) is given alongside radiation therapy and it can help increase the effectiveness of the radiation therapy. ADT may be given for varying time periods when in combination with radiation therapy, depending on the cancer and the doctor's advice.

## ADT (HORMONE THERAPY) WITH OR WITHOUT CHEMOTHERAPY

ADT alone, or provided with chemotherapy, is usually given as an option for people with more advanced prostate cancer, particularly when it has spread beyond the prostate. These people tend to have complex treatment plans.

Prostate cancer cannot be eradicated by this treatment plan, but it can help slow its growth and relieve some of the more advanced symptoms of the cancer. It may also help people live longer.

**All of these prostate cancer management plans have their own range of side effects. The PROMs questionnaires help reveal, in general, what people in each different group have experienced. You should talk to your doctor if you would like to understand any of these management plans in more detail.**

# FINDING RELEVANT INFORMATION

This Patient Experiences Summary is organised according to prostate cancer risk groups at diagnosis. Each section covers the typical treatments men in each risk group receive in Australia and New Zealand; as well as the outcomes shared by men in that group.

Doctors usually discuss the prostate cancer risk group, Gleason Score, or Grade Group with their patients. Knowing this information can help identify which group of men in the summary had prostate cancer that is at a similar stage. This summary is based on the average responses across large numbers of men. Each individual with prostate cancer will have their own unique experience, so this information should only be used as a general guide.

If any questions arise about the information included in this summary, consider speaking with a doctor.

## WHY ARE RISK GROUPS IMPORTANT?

When a prostate cancer biopsy is examined, the cancer is put into a risk group based on the different characteristics of the cancer cells that are found. The 'risk group' gives an indication of how likely the cancer is to spread outside the prostate; or indicates if it has already spread. Risk groups are used, along with other information such as age and general health, to help decide on the most appropriate management plan for the cancer. These risk groups help organise the PROMs responses into categories of people who have had similar types of prostate cancer management. This provides an overall picture to help understand and improve these experiences.

For more information about prostate cancer risk groups and diagnosis – check out the Resources and Support section on page 19.

## PCOR-ANZ: A SNAPSHOT OF MEN, 2020-2022

More information on these data can be found here.

### LOCALISED DISEASE Cancer that is confined to the prostate

**Low risk**

**17%**

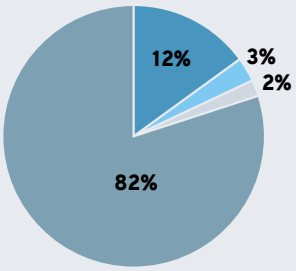
More information on page 10

Cancer that is slow growing and least likely to spread.

Gleason Score of 6 or a Grade Group 1 and a PSA less than 10ng/mL.

Men with **low-risk** disease were most commonly managed by:

- ACTIVE SURVEILLANCE (82%)
- SURGERY (12%)
- RADIATION THERAPY (3%)
- WATCHFUL WAITING (2%)




**Intermediate risk**

**45%**

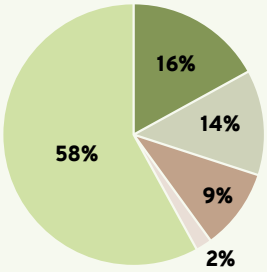
More information on page 12

Cancer that has a moderate likelihood of growing and/or spreading.

Gleason Score of 7 or a Grade Group of 2 or 3.

Men with **intermediate-risk** disease were most commonly managed by:

- SURGERY (58%)
- RADIATION THERAPY (16%)
- ACTIVE SURVEILLANCE (14%)
- RADIATION THERAPY PLUS ADT (9%)
- WATCHFUL WAITING (2%)




**High risk**

**27%**

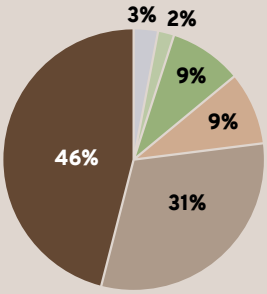
More information on page 14

Cancer that has a high likelihood of growing and/or spreading.

Gleason Score between 8–10 or a Grade Group over 3 or a PSA greater than 20ng/mL.

Men with **high-risk** disease were most commonly managed by:

- SURGERY (46%)
- RADIATION THERAPY PLUS ADT (31%)
- RADIATION THERAPY (9%)
- ADT WITH/WITHOUT CHEMOTHERAPY (9%)
- WATCHFUL WAITING (3%)
- ACTIVE SURVEILLANCE (2%)




### ADVANCED DISEASE Cancer that has spread beyond the prostate

**Regional**

**4%**

Cancer that has spread to nearby areas such lymph nodes or tissue close to the prostate.

**Metastatic**

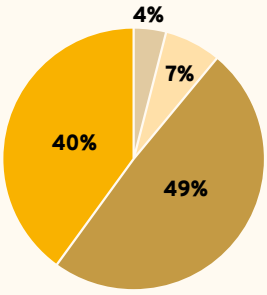
**8%**

More information on page 16

Cancer that spread to distant parts of the body such as other lymph nodes, bones or organs.

Men with **advanced** prostate cancer were most comonly managed by:

- ADT WITH/WITHOUT CHEMOTHERAPY (49%)
- RADIATION THERAPY PLUS ADT (40%)
- SURGERY (7%)
- RADIATION THERAPY (4%)

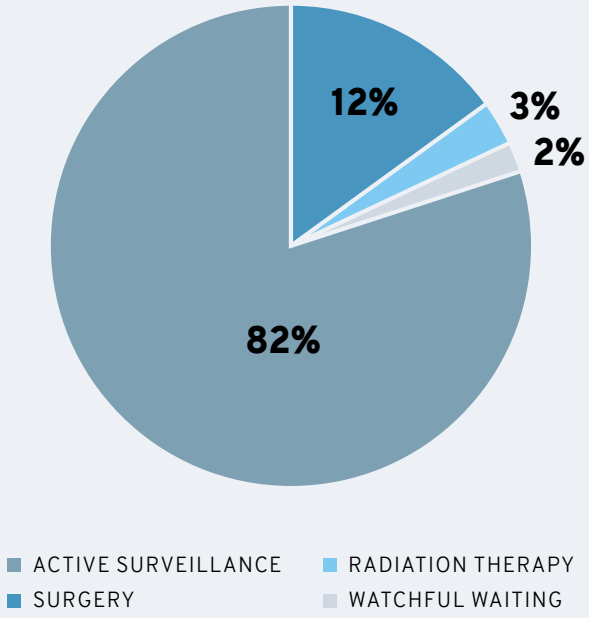


# LOW-RISK PROSTATE CANCER

Men diagnosed with low-risk prostate cancer are least likely to experience their cancer growing or spreading.

Low-risk prostate cancer is typically managed with active surveillance, but active treatment options are sometimes used. The PROMs presented below are from men who had the most common management options seen in PCOR-ANZ.

**17%** **Men with low-risk disease were most commonly managed by:**




**LOW RISK** Gleason score of 6 or a Grade Group 1 and a PSA less than 10ng/mL

| What do men with low-risk prostate cancer experience after active surveillance? | |
|---|---|
| Needed more than one urinary pad per day | **3%** |
| Experienced more than one urinary leak per day | **7%** |
| Have interest in sex | **46%** |
| Sexual function is a problem | **23%** |
| Can have a fair-very good erection | **66%** |
| Used sexual aids (devices or medications) | **26%** |
| Lack of energy is a problem | **10%** |

| What do men with low-risk cancer experience after surgery? | |
|---|---|
| Needed more than one urinary pad per day | **27%** |
| Experienced more than one urinary leak per day | **17%** |
| Have interest in sex | **44%** |
| Sexual function is a problem | **47%** |
| Can have a fair-very good erection | **33%** |
| Used sexual aids (devices or medications) | **62%** |
| Lack of energy is a problem | **13%** |

| What do men with low-risk cancer experience after radiation therapy? | |
|---|---|
| Needed more than one urinary pad per day | **5%** |
| Experienced more than one urinary leak per day | **7%** |
| Have interest in sex | **33%** |
| Sexual function is a problem | **37%** |
| Can have a fair-very good erection | **41%** |
| Used sexual aids (devices or medications) | **36%** |
| Lack of energy is a problem | **21%** |
| Bowel habits are a problem | **7%** |

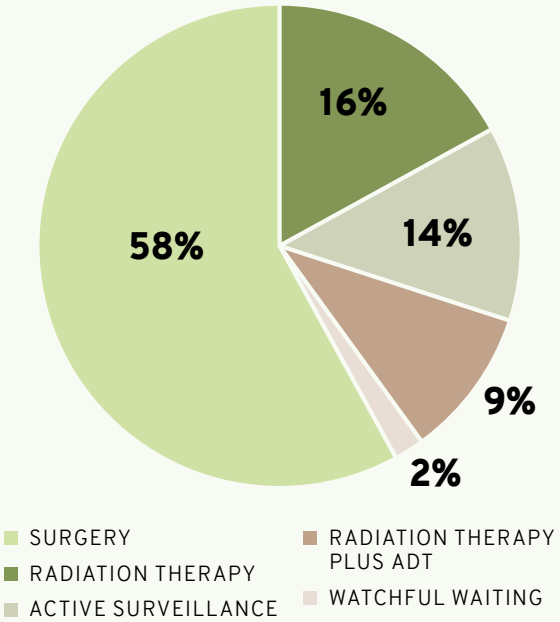
More information on low-risk prostate cancer can be found here

# INTERMEDIATE-RISK PROSTATE CANCER

Men diagnosed with intermediate-risk prostate cancer have a moderate chance that the cancer could grow or spread over time.

The most common types of management for intermediate-risk prostate cancer are surgery and radiation therapy. Radiation therapy may be used alone or in combination with hormone therapy (ADT). The PROMs from men in these different treatment groups are shown below.

**45%** **Men with intermediate-risk disease were most commonly managed by:**

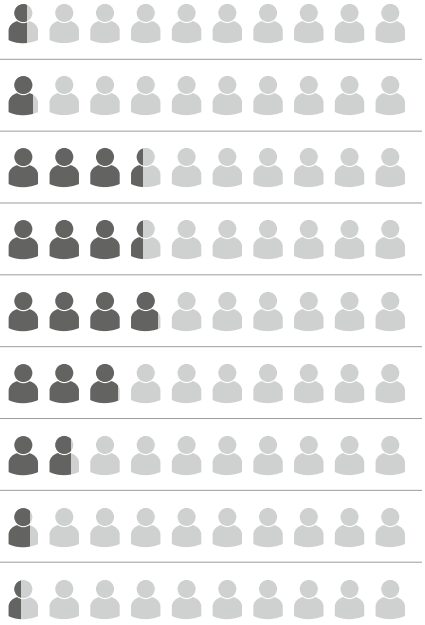



**INTERMEDIATE RISK** Gleason score of 7 or a Grade Group 2 or 3

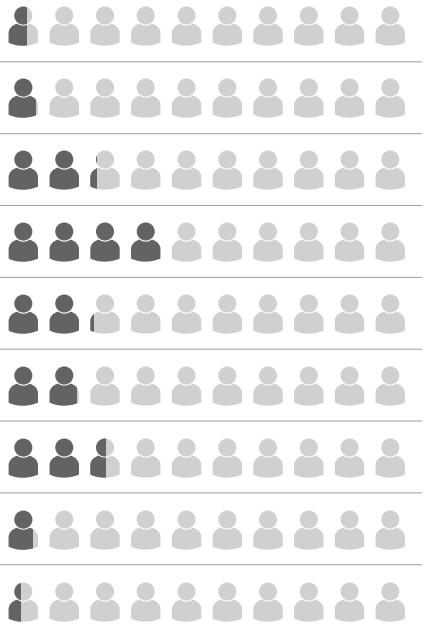
| What do men with intermediate-risk prostate cancer experience after surgery? | |
|---|---|
| Needed more than one urinary pad per day | **29%** |
| Experienced more than one urinary leak per day | **19%** |
| Have interest in sex | **40%** |
| Sexual function is a problem | **46%** |
| Can have a fair-very good erection | **25%** |
| Used sexual aids (devices or medications) | **64%** |
| Lack of energy is a problem | **11%** |

| Do older men who receive surgery answer these questions differently? | |
|---|---|
| Men who were 75 years and over reported more side effects relating to urinary incontinence. | |
| Needed more than one urinary pad per day | **39%** |
| Experienced more than one urinary leak per day | **26%** |

| What do men with intermediate-risk prostate cancer experience after radiation therapy? | |
|---|---|
| Needed more than one urinary pad per day | 6% |
| Experienced more than one urinary leak per day | 8% |
| Have interest in sex | 34% |
| Sexual function is a problem | 34% |
| Can have a fair-very good erection | 39% |
| Used sexual aids (devices or medications) | 29% |
| Lack of energy is a problem | 17% |
| Bowel habits are a problem | 7% |
| Losing bowel control is a problem | 4% |



| What do men with intermediate-risk prostate cancer experience after radiation therapy combined with ADT? | |
|---|---|
| Needed more than one urinary pad per day | 6% |
| Experienced more than one urinary leak per day | 9% |
| Have interest in sex | 22% |
| Sexual function is a problem | 40% |
| Can have a fair-very good erection | 21% |
| Used sexual aids (devices or medications) | 19% |
| Lack of energy is a problem | 25% |
| Bowel habits are a problem | 8% |
| Losing bowel control is a problem | 4% |



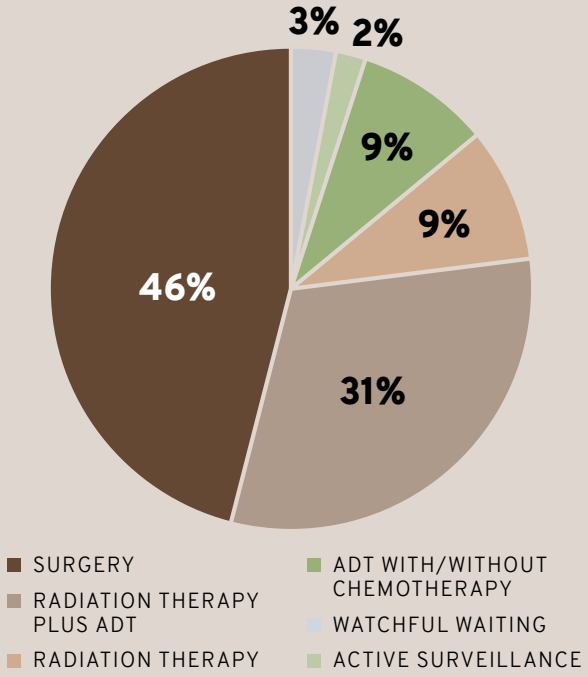
More information on intermediate-risk prostate cancer can be found here

# HIGH-RISK PROSTATE CANCER

Men who are diagnosed with high-risk prostate cancer have a high likelihood that the disease will grow or spread outside of the prostate.

These men are most commonly managed with surgery or radiation therapy. For high-risk cancer, radiation therapy is most often used in combination with hormone therapy (ADT). The PROMs from men in these most common treatment groups are shown below.

**27%** **Men with high-risk disease were most commonly managed by:**




**HIGH RISK** Gleason score of 8-10 or a Grade Group over 3, or a PSA over 20ng/mL

| What do men with high-risk prostate cancer experience after surgery? | |
|---|---|
| Needed more than one urinary pad per day | **37%** |
| Experienced more than one urinary leak per day | **26%** |
| Have interest in sex | **33%** |
| Sexual function is a problem | **46%** |
| Can have a fair-very good erection | **13%** |
| Used sexual aids (devices or medications) | **52%** |
| Lack of energy is a problem | **14%** |

**Do men who receive surgery answer these questions differently in different age groups?**

More younger men reported bother with sexual wellbeing side effects:

| | | |
|---|---|---|
| Men 60 years and under | Sexual function is a problem | **54%** |
| Men 75 years and over | Sexual function is a problem | **33%** |

| What do men with high-risk prostate cancer experience after radiation therapy? | |
|---|---|
| Needed more than one urinary pad per day | **9%** |
| Experienced more than one urinary leak per day | **12%** |
| Have interest in sex | **20%** |
| Sexual function is a problem | **38%** |
| Can have a fair-very good erection | **20%** |
| Used sexual aids (devices or medications) | **14%** |
| Lack of energy is a problem | **26%** |
| Bowel habits are a problem | **10%** |
| Losing bowel control is a problem | **6%** |

| What do men with high-risk prostate cancer experience after radiation therapy combined with ADT? | |
|---|---|
| Needed more than one urinary pad per day | **11%** |
| Experienced more than one urinary leak per day | **12%** |
| Have interest in sex | **9%** |
| Sexual function is a problem | **38%** |
| Can have a fair-very good erection | **7%** |
| Used sexual aids (devices or medications) | **12%** |
| Lack of energy is a problem | **34%** |
| Bowel habits are a problem | **10%** |
| Losing bowel control is a problem | **6%** |

More information on high-risk prostate cancer can be found here

# ADVANCED PROSTATE CANCER

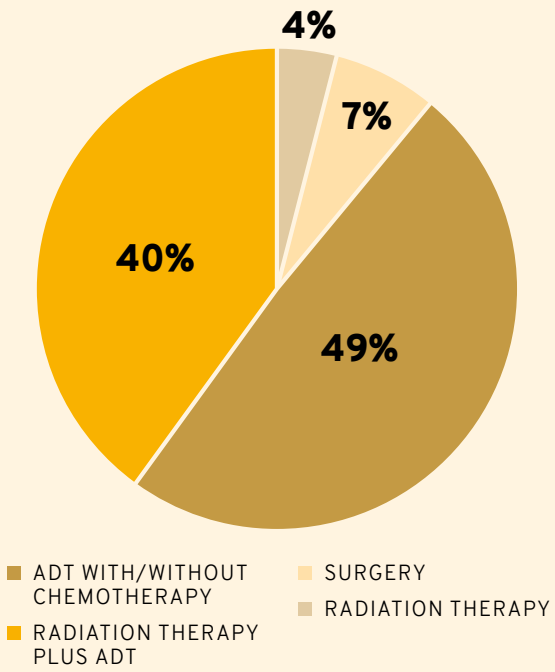
## REGIONAL AND METASTATIC DISEASE

Men who are diagnosed with Advanced Disease have cancer that has spread beyond the prostate.

In **Regional Disease** the cancer has spread to nearby areas such lymph nodes or tissue close to the prostate. In **Metastatic Disease** the cancer has spread to distant parts of the body such as other lymph nodes, bones or organs.

Men diagnosed with advanced prostate cancer often have complex treatment plans including surgery, radiation therapy, hormone therapy (ADT), and chemotherapy. The PROMs presented below come from men who have been on the most common management plans.

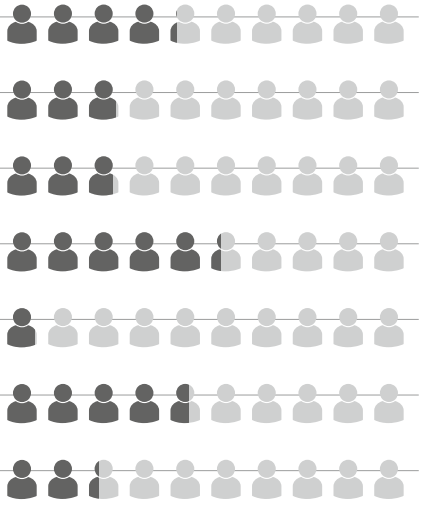
**12%** **Men with advanced-risk disease were most commonly managed by:**




**ADVANCED DISEASE** Cancer that has spread outside of the prostate

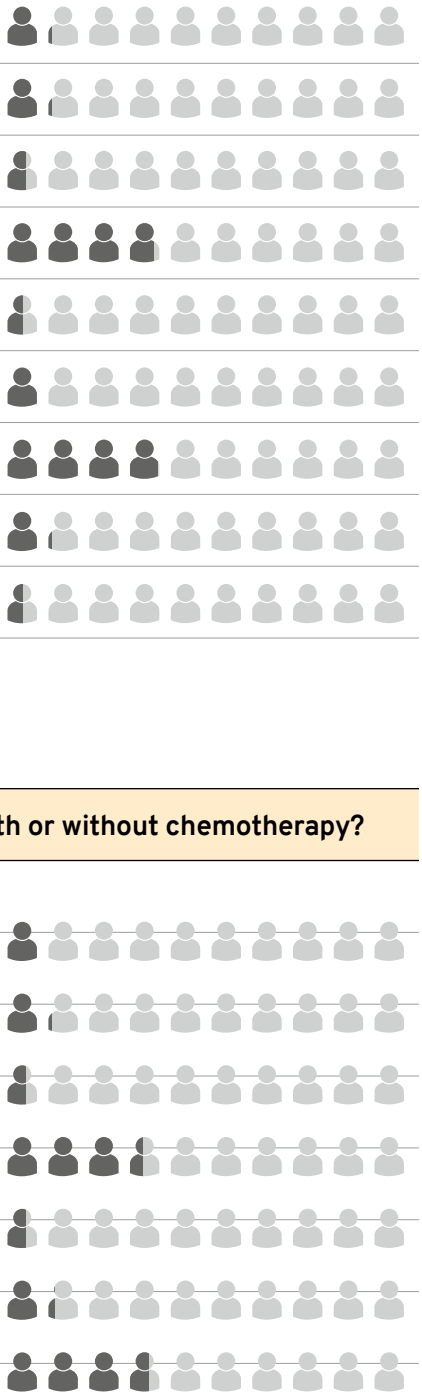
**What do men with advanced prostate cancer experience after surgery?**

| | |
|---|---|
| Needed more than one urinary pad per day | **42%** |
| Experienced more than one urinary leak per day | **29%** |
| Have interest in sex | **28%** |
| Sexual function is a problem | **53%** |
| Can have a fair-very good erection | **9%** |
| Used sexual aids (devices or medications) | **46%** |
| Lack of energy is a problem | **23%** |



| What do men with advanced prostate cancer experience after radiation therapy combined with ADT? | |
|---|---|
| Needed more than one urinary pad per day | **11%** |
| Experienced more than one urinary leak per day | **11%** |
| Have interest in sex | **6%** |
| Sexual function is a problem | **38%** |
| Can have a fair-very good erection | **5%** |
| Used sexual aids (devices or medications) | **10%** |
| Lack of energy is a problem | **39%** |
| Bowel habits are a problem | **11%** |
| Losing bowel control is a problem | **5%** |

| What do men with advanced prostate cancer experience after ADT with or without chemotherapy? | |
|---|---|
| Needed more than one urinary pad per day | **10%** |
| Experienced more than one urinary leak per day | **11%** |
| Have interest in sex | **6%** |
| Sexual function is a problem | **34%** |
| Can have a fair-very good erection | **6%** |
| Used sexual aids (devices or medications) | **12%** |
| Lack of energy is a problem | **36%** |



**Note:**
For regional disease – of the 157 patients receiving ADT with or without Chemotherapy, 40 were receiving ADT with Chemotherapy, 116 were receiving ADT only, and 1 was receiving Chemotherapy only.

For metastatic disease – of the 799 patients receiving ADT with or without Chemotherapy, 384 were receiving ADT with Chemotherapy, 412 were receiving ADT alone, and 3 patients were receiving Chemotherapy alone

More information on advanced-risk prostate cancer can be found here

# RESOURCES AND SUPPORT

## RESOURCES

**Life After Prostate Cancer Treatment**
Movember, True North
View resources

**Sex and Intimacy After Prostate Cancer**
Movember, True North
Read article

**Prostate Cancer Foundation Australia**
has developed a suite of evidence-based resources to assist people impacted by prostate cancer
View resources

**Prostate Cancer: A Guide for Newly Diagnosed Men**
Prostate Cancer Foundation of Australia
Read booklet

**Understanding Advanced Prostate Cancer**
Prostate Cancer Foundation of Australia
Read booklet

**Prostate Cancer Foundation of New Zealand**
View resources

**Men's Physical, Sexual and Mental Health Information**
Healthy Male
Visit website

## SUPPORT CONTACTS

**PCFA Telenurse**
Phone: 1800 22 00 99
Email: telenurse@pcfa.org.au

**Cancer Council**
Phone: 13 11 20
Web: cancer.org.au/support-and-services/cancer-support-nurse

**McGrath Nurse**
Web: mcgrathfoundation.com.au/contact/
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# PATIENT-REPORTED OUTCOME MEASURES (PROMS) USED IN THE PCOR-ANZ

The PROMs collected by PCOR-ANZ include questionnaires used all over the worls with men with prostate cancer. The main questionnaire is called the EPIC-26, which stands for Expanded Prostate Cancer Index Composite – 26 items.

The table below describes how the answers to these questions have been translated into the outcomes contained in this report.

| OUTCOME | HOW IT WAS CATEGORISED? |
|---|---|
| **The EPIC-26 Questionnaire [1,2]** | |
| **Lack of energy is a problem** | Reported as a 'moderate to big problem' |
| **Needed more than one urinary pad per day** | Reported as the number of pads or adult diapers required in the last four weeks<br>(Scale of 0 to 3 or more) |
| **Experienced more than one urinary leak per day** | Reported as the number of leaks experienced over the last four weeks on a scale of 1-5 with a value of one being more than once per day.<br>(Other options were: 2: about once a day; 3: more than once a week; 4: about once a week; 5: rarely or never.) |
| **Bowel habits are a problem** | 'Overall, how big a problem have your bowel habits been for you during the last 4 weeks?' reported as a 'moderate-to-big problem' |
| **Losing bowel control is a problem** | 'Losing control of your stools' reported as a 'moderate-to-big problem' |
| **Sexual function is a problem** | 'Sexual function or lack of sexual function' reported as a 'moderate-to-big problem' |
| **Can have a fair–very good erection** | 'Ability to have an erection' reported as fair/good/very good |
| **Two further questions on sexual wellbeing [3]** | |
| **Have interest in sex**<br>From the EORTC QLQ-PR25 Questionnaire | 'Ability to have an erection' reported as fair/good/very good |
| **Used of sexual aids (devices or medications)**<br>From the Utilisation of Sexual Medications/Devices Questionnaire | 'Have you used any medications or devices to aid or improve erections?' answered as 'yes' or 'no'. |


1. EPIC-26. The Expanded Prostate Cancer Index Composite. Short Form. Available at: https://medschool.umich.edu/departments/urology/research/quality-life-tools/epic accessed September 2025
2. Szymanski KM, Wei JT, Dunn RL, et al. Development and Validation of an Abbreviated Version of the Expanded Prostate Cancer Index Composite Instrument for Measuring Health-related Quality of Life Among Prostate Cancer Survivors. Urology 2010;76:1245–50. https://doi.org/10.1016/j.
3. Martin NE, Massey L, Stowell C, et al. Defining a standard set of patient-centered outcomes for men with localized prostate cancer. Eur Urol. 2015;67(3):460-467. doi:10.1016/j.eururo.2014.08.075

# ACKNOWLEDGEMENTS

This summary is the result of generous contributions, thoughtful collaboration, and deep engagement from individuals and groups across Australia and New Zealand.

We extend our heartfelt thanks to the men with lived experience who are included through the Prostate Cancer Outcomes Registry – Australia and New Zealand (PCOR-ANZ). Your participation is central to improving care and outcomes for others affected by prostate cancer.

We are especially grateful to the Consumer Reference Group, formed specifically to guide the development of this report. The group included nine individuals with lived experience from Victoria, New South Wales, South Australia, and New Zealand. Their insights, reflections, and feedback were instrumental in shaping the tone, structure, and relevance of this resource. To support meaningful input, a draft version of the report was circulated in advance, followed by a dedicated consultation workshop and further contributions via email. This process enabled thoughtful review and focused discussion on clarity, accessibility, visual presentation, and personal resonance. Their recommendations directly informed the final language and design, ensuring the resource reflects what matters most to those living with prostate cancer.

We also warmly thank the clinicians, researchers, and registry teams across Australia and New Zealand for their ongoing commitment to improving patient outcomes through their contributions to the registry.

Finally, we gratefully acknowledge Movember as collaborators and funders, who have invested over $28.5 million into the PCOR-ANZ to improve the care and outcomes of men living with prostate cancer.

This work would not be possible without the time, effort, and generosity of so many, and we are truly thankful.

This report was produced on behalf of the Australia and New Zealand Prostate Cancer Outcomes Registry (PCOR-ANZ).

**Suggested citation**
Bensley J, Breen S, King M, Krishnaprasad K, Mark S, Millar J, O'Callaghan M, Odutola M, Patel M, Roydhouse J, Steeper M, Teuss S, Tod E, Toh EA, Zeps N. Patient Experiences with Prostate Cancer: PCOR-ANZ Summary Report 2024, October 2025.

Any enquiries about this report should be directed to:

AUSTRALIA AND NEW ZEALAND PROSTATE CANCER OUTCOMES REGISTRY

MOVEMBER
Level 4, 21-31 Goodwood Street
Richmond VIC 3121

**Phone:** +61 1300 476 966
**Email:** clinical.quality@movember.com
**Website:** prostatecancerregistry.org

# FUNDING & ENDORSEMENTS

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PCOR-ANZ is principally funded by Movember, primarily in partnership with:

ACT Government | ACT Health

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Menzies Institute for Medical Research

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APCRC-Q Australian Prostate Cancer Research Centre Queensland

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Northern Territory Government

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Government of South Australia
SA Health

SA-PCCOC
South Australian Prostate Cancer Clinical Outcomes Collaborative

PCOR-ANZ is endorsed by:

Urological Society of Australia and New Zealand

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**Movember Team**
PO BOX 60
East Melbourne
VICTORIA 8002
Australia

**1300 GROW MO**
(1300 4769 66)

**www.movember.com**
info@movember.com

Editorial assistance for the PCOR-ANZ Summary Report 2024 was provided by Lesley Cunliffe (PhD) and funded by Movember.

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