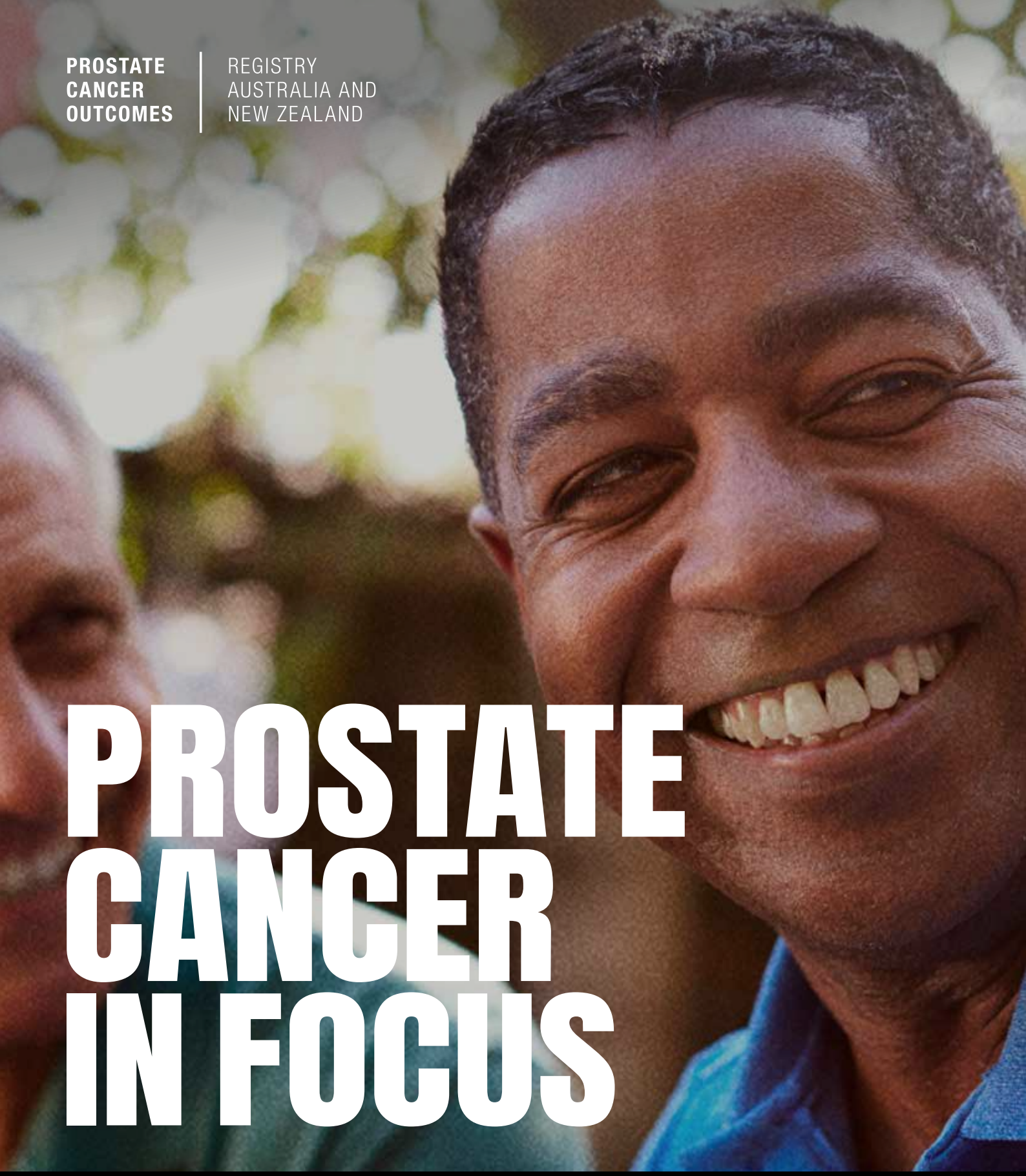

PROSTATE CANCER OUTCOMES | REGISTRY AUSTRALIA AND NEW ZEALAND

PROSTATE CANCER IN FOCUS

An overview of data from the Prostate Cancer across Australia and New Zealand, Annual Report 2023.

The experiences of 92,000 people across Australia and New Zealand.

MOVEMBER® | MONASH University

PROSTATE CANCER IN FOCUS | 2015-2021

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

Suggested citation
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ACKNOWLEDGEMENTS

We extend our thanks to all the people who have participated in the PCOR-ANZ registry and contributed to this report. Your data is helping us better understand and tackle the challenges that you, and others in your position, are facing. This is the first step on the road to upholding best-practice care, and working towards improvements where we can, for people with prostate cancer.

The success of the registry relies on the support of the clinical community who generously contribute their time to working with PCOR-ANZ on a voluntary basis. In particular, Movember vwould like to thank the members of the PCOR-ANZ Governance Committee, chaired by Professor Frank Frizelle, the Data Advisory Committee chaired by Professor Sue Evans and the Advisory Committee chaired by Associate Professor David Smith, who have dedicated endless hours to the guidance of this initiative. The operations of PCOR-ANZ would also not be possible without our tireless team of Jurisdiction Coordinators, data collectors and program coordination by the Data Coordination Centre at Monash University.

Finally, we extend our appreciation to all our endorsing societies who continue to support this initiative including the Urological Society of Australia and New Zealand (USANZ), the Medical Oncology Group of Australia (MOGA), the Royal Australian and New Zealand College of Radiologists (RANZCR), the Royal College of Pathologists of Australia (RCPA) and Société Internationale d'Urologie (SIU).

Any enquiries about this report should be directed to:

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Website: prostatecancerregistry.org

FUNDING & ENDORSEMENTS

MOVEMBER®

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

ACT Government | ACT Health

ACT Government | Canberra Health Services

University of Tasmania | Menzies Institute for Medical Research

Cancer Institute NSW
cancer.nsw.gov.au

APCRC-Q Australian Prostate Cancer Research Centre Queensland

CHOMNZ | centre for health outcome measures new zealand

QUT ihbi Institute of Health and Biomedical Innovation

Northern Territory Government

Monash University

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

The Royal Australian and New Zealand College of Radiologists
The Faculty of Radiation Oncology

Société Internationale d'Urologie SIU

RCPA
The Royal College of Pathologists of Australasia

MOGA

Please refer to each jurisdiction's website for a full list of contributing organisations.

WANT MORE INFORMATION?

Visit our websites

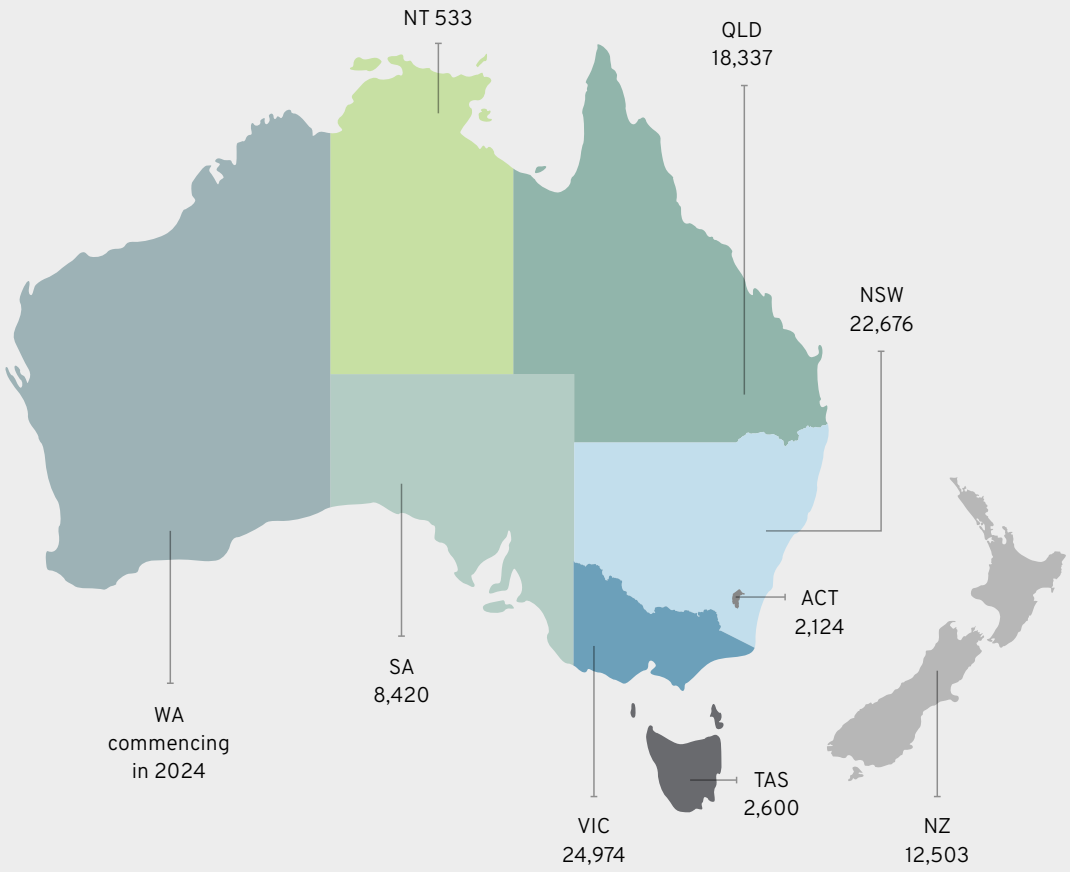
→ **PCOR-ANZ**

→ **TRUE NORTH**

ABOUT THIS REPORT

This report describes the experiences of people registered in the Australian and New Zealand Prostate Cancer Outcomes Registry (PCOR-ANZ) between 2015 and 2021. It is a summary of data that was presented in the **Prostate Cancer Across Australia and New Zealand Annual Report 2023: PCOR-ANZ 2015–2021, Patterns of care and patient-reported outcomes.**[1] Our goal is to provide an overview of the types of management for prostate cancer and identify which options are used for different people. Additionally, we have analysed the Patient-Reported Outcome Measures (PROMs) questionnaire results to provide insights into how individuals with prostate cancer feel after undergoing different management plans.

The PCOR-ANZ includes data from 92,167 people who were diagnosed with prostate cancer between 2015 and 2021. That covers about 59% of all the people in Australia and 78% of all the people in New Zealand who were diagnosed between those dates. The information PCOR-ANZ collects is used to improve care for people diagnosed with prostate cancer.



396
DOCTORS

268
HOSPITALS AND MEDICAL CLINICS

92,167
PEOPLE INCLUDED IN THE REGISTRY

46,418
PEOPLE WHO HAVE COMPLETED OUTCOME QUESTIONAIRES

1. Ong WL, Krishnaprasad K, Bensley J, Steeper M, Beckmann K, Breen S, King M, Mark S, O'Callaghan M, Patel M, Tod E, Millar J. Prostate Cancer Across Australia and New Zealand PCOR-ANZ 2015-2021 Annual Report 2023, March 2024.

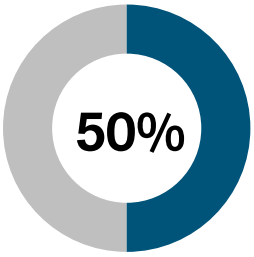
HOW AND WHEN DO WE COLLECT INFORMATION?

PCOR-ANZ collects information from participating doctors, hospitals and medical clinics across the region. This includes information on prostate cancer diagnosis, how the cancer is managed, and what treatments have been provided.

The registry also collects Patient-Reported Outcome Measures (PROMs). These are questionnaires designed to understand how prostate cancer and its management affect patients' daily lives and overall health. PCOR-ANZ collects these questionnaires 12 months after diagnosis; or 12 months after starting treatment if they are receiving surgery or radiation therapy. Understanding these impacts on health helps us better support people who have been diagnosed with prostate cancer.

Click here to see doctors, hospitals and medical clinics who are participating in PCOR-ANZ.

PROMS QUESTIONNAIRES COMPLETED (2015-2021)



46,418 questionnaires from
92,167 registered people

HOW ARE PEOPLE USUALLY DIAGNOSED WITH PROSTATE CANCER?

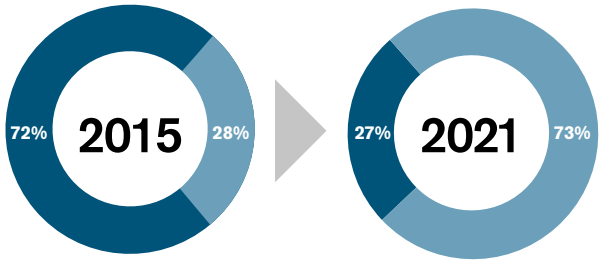
Prostate cancer is usually diagnosed by a medical pathologist examining prostate tissue samples. The process of taking these tissue samples is known as a 'biopsy', and there are two main prostate biopsy methods in general use:

- **Transperineal biopsy** (often referred to as TP biopsy) in which the biopsy needle passes through the transperineal skin (the skin between the testicles/scrotum and the rectum/anus to take the samples).
- **Transrectal ultrasound-guided biopsy** (often referred to as TRUS biopsy) in which the biopsy needle passes through the rectal wall to take samples.

Transperineal biopsy is now the recommended prostate biopsy approach as it is associated with a lower risk of complications compared with transrectal biopsy. It can also give better access to all areas of the prostate.

However, transperineal biopsy is often performed under general anaesthetic and uses specialised equipment, which is not always available or suitable for everyone.

TRANSPERINEAL BIOPSY HAS BECOME THE PREFERRED BIOPSY METHOD OVER TIME



Transrectal ultrasound-guided biopsy

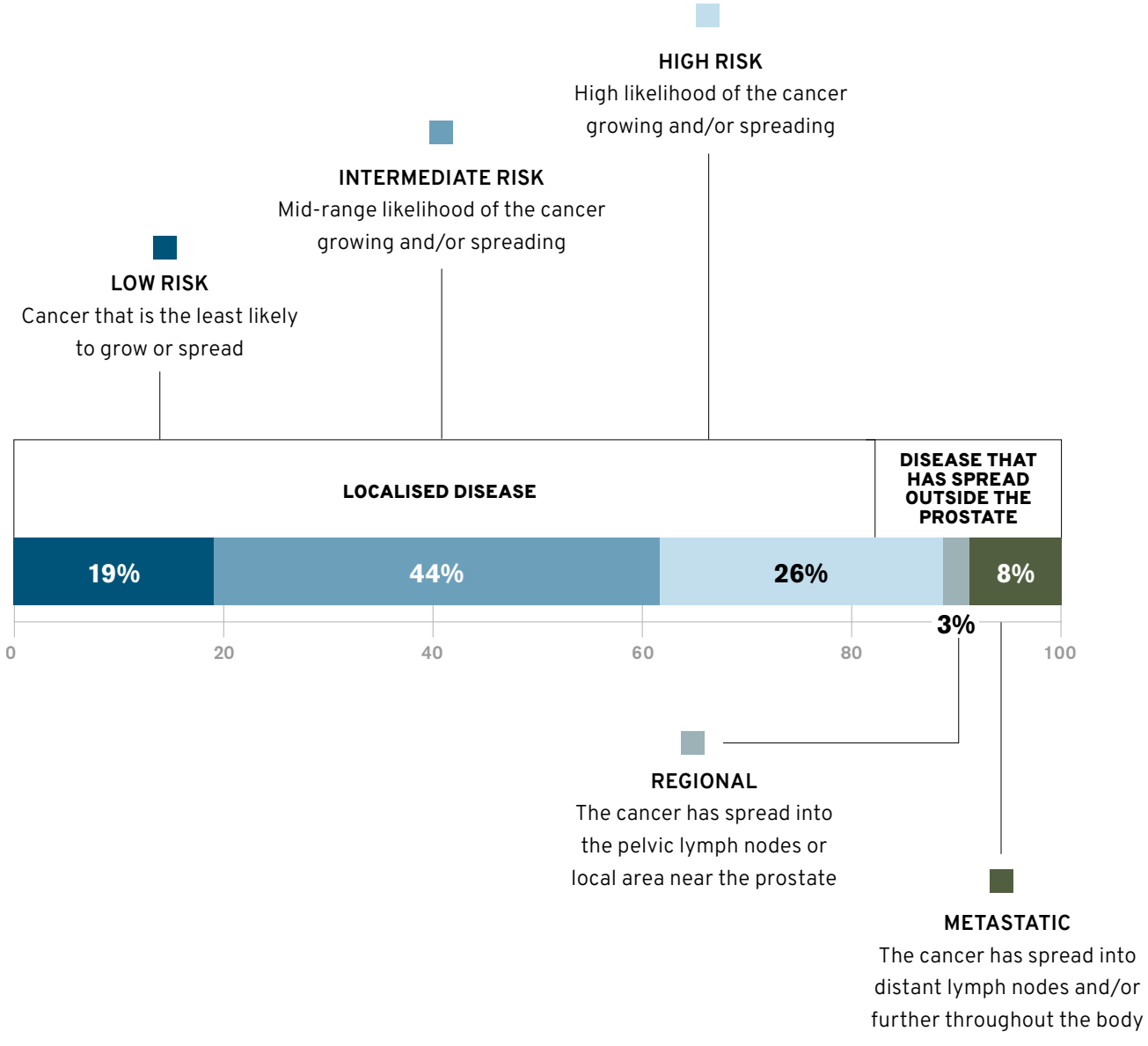
Transperineal biopsy

2015 included 5,828 people in total
2021 included 13,555 people in total

PROSTATE CANCER RISK GROUPS

WHAT PROSTATE CANCER RISK GROUPS DO PEOPLE FALL INTO AT DIAGNOSIS?

When the biopsy is examined, prostate cancers are put into different risk groups 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 tells us 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.



Between 2015-2021, PCOR-ANZ included 80,904 people with risk group information. The remaining people could not be assigned to a risk group.

HOW IS PROSTATE CANCER MANAGED?

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 your cancer and your 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 us understand, 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.

ACTIVE SURVEILLANCE & WATCHFUL WAITING

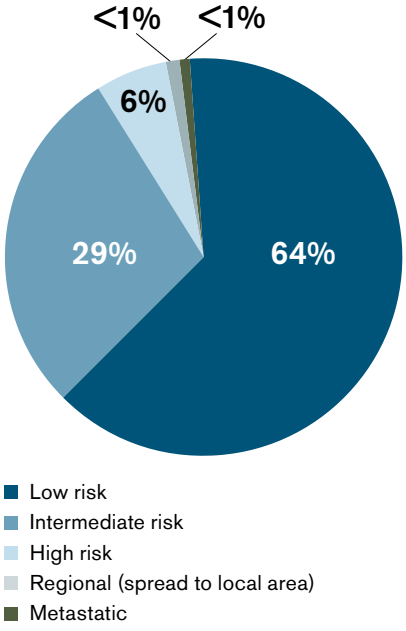
Active Surveillance (AS) - Monitoring for prostate cancer that has little risk of progressing, to avoid or delay unnecessary treatments and their potential side effects.

Watchful Waiting (WW) - Monitoring for prostate cancer that is designed to help manage symptoms when they occur.

HOW MANY PEOPLE IN PCOR-ANZ HAD AS OR WW?

17,953

PROSTATE CANCER RISK GROUPS OF PEOPLE RECEIVING AS OR WW.



WHO IS MANAGED WITH ACTIVE SURVEILIENNCE

AS is most frequently used in the management of low-risk cancer. The use of AS has increased over time.

LOW-RISK DISEASE

2015 (1,202 people)

2021 (2,070 people)

PROMS RESULTS FOR PEOPLE WITH LOCALISED PROSTATE CANCER

(LOW, INTERMEDIATE OR HIGH RISK)

Over 8,500 people answered these questions a year after their diagnosis.

HOW DO PEOPLE ON AS OR WW FEEL IN GENERAL?

Feeling depressed	7%
Lack of energy	12%
Bowel habits are a problem	3%
Losing bowel control is a problem	1%
Urinary function is a problem	8%
Needed more than 1 urinary pad per day	4%
Experienced more than 1 urinary leak per day	7%

HOW DO PEOPLE ON AS OR WW FEEL ABOUT THEIR SEXUAL WELLBEING?

Sexual function is a problem	24%
Can have a fair-very good erection	61%
Erections are firm enough for intercourse	47%
Ability to function sexually is fair-very good	60%
Have interest in sex	45%
Used sexual aids (devices or medications)	24%

ACTIVE SURVEILLANCE & WATCHFUL WAITING

Younger people with low-risk prostate cancer, were more likely to receive AS compared with older people.

UNDER 60'S

73%
ACTIVE SURVEILLANCE

1%
WATCHFUL WAITING

OVER 75'S

69%
ACTIVE SURVEILLANCE

22%
WATCHFUL WAITING

Between 2015-2021, there were
• 4,476 people under 60 years and 1,082 people over 75 years with low-risk disease in PCOR-ANZ.

PROMS RESULTS FOR PEOPLE WITH REGIONAL OR METASTATIC PROSTATE CANCER

Regional and metastatic prostate cancers are not often managed with AS or WW, so fewer than 40 people answered these questions a year after diagnosis.

HOW DO PEOPLE ON AS OR WW FEEL IN GENERAL?

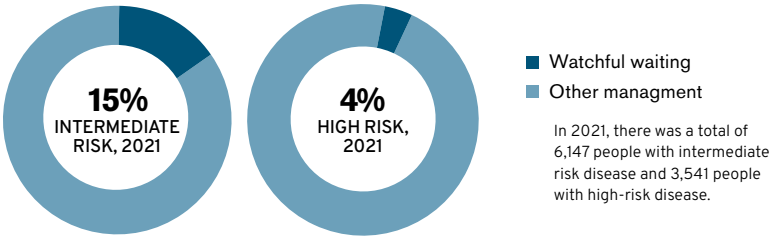
Feeling depressed	5%
Lack of energy	16%
Bowel habits are a problem	0%
Losing bowel control is a problem	0%
Urinary function is a problem	16%
Needed more than 1 urinary pad per day	8%
Experienced more than 1 urinary leak per day	5%

HOW DO PEOPLE ON AS OR WW FEEL ABOUT THEIR SEXUAL WELLBEING?

Sexual function is a problem	9%
Can have a fair-very good erection	44%
Erections are firm enough for intercourse	21%
Ability to function sexually is fair-very good	45%
Have interest in sex	31%
Used sexual aids (devices or medications)	0%

Who is managed with Watchful waiting?

Watchful waiting is a less-common management strategy that is mainly used for people with intermediate-or high-risk prostate cancer.



In 2021, there was a total of 6,147 people with intermediate risk disease and 3,541 people with high-risk disease.

SURGERY

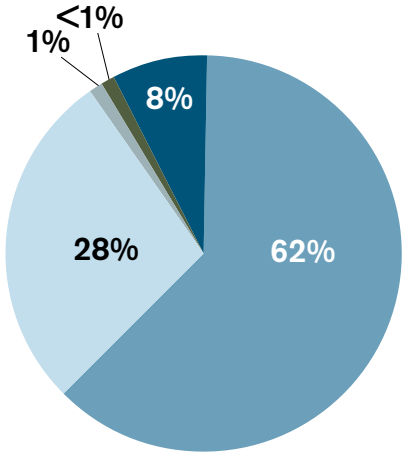
Surgery to remove the prostate gland is called 'radical prostatectomy'.
It can be performed as open surgery, or via a keyhole incision (laparoscopic surgery), or by using a surgical robot.

Surgery is usually an option when the cancer has not spread widely – known as 'localised' or 'locally advanced' prostate cancer.

HOW MANY PEOPLE IN PCOR-ANZ HAD SURGERY?

33,155

PROSTATE CANCER RISK GROUPS OF PEOPLE RECEIVING SURGERY



WHO IS MANAGED WITH SURGERY?

Surgery is the most common option for people with intermediate- or high-risk disease.

INTERMEDIATE-RISK CANCER, 2021
3 IN 5 PEOPLE

59%

HIGH RISK CANCER, 2021
ABOUT 1 IN 2 PEOPLE

46%

THESE NUMBERS HAVE REMAINED REASONABLY STABLE OVER TIME.

In 2021, there were
• 6,147 people with intermediate-risk and 3,541 people with high-risk disease in PCOR-ANZ.

PROMS RESULTS FOR PEOPLE WITH LOCALISED PROSTATE CANCER

(LOW, INTERMEDIATE OR HIGH RISK)

Over 19,000 people answered these questions a year after they had surgery.

HOW DO PEOPLE WHO HAD SURGERY FEEL IN GENERAL?

Feeling depressed	10%
Lack of energy	13%
Bowel habits are a problem	3%
Losing bowel control is a problem	1%
Urinary function is a problem	9%
Needed more than 1 urinary pad per day	31%
Experienced more than 1 urinary leak per day	20%

HOW DO PEOPLE WHO HAD SURGERY FEEL ABOUT THEIR SEXUAL WELLBEING?

Sexual function is a problem	45%
Can have a fair-very good erection	22%
Erections are firm enough for intercourse	13%
Ability to function sexually is fair-very good	24%
Have interest in sex	40%
Used sexual aids (devices or medications)	60%

SURGERY

Younger people were more likely to receive surgery compared with older people.

UNDER 60'S

79%
HIGH RISK

82%
INTERMEDIATE RISK

OVER 75'S

14%
HIGH RISK

19%
INTERMEDIATE RISK

In PCOR-ANZ between 2015-2021, there were:
• 1,930 people under 60 years and 6,385 people over 75 years with high-risk disease.
• 6,565 people under 60 years and 4,887 people over 75 years with intermediate-risk disease.

PROMS RESULTS FOR PEOPLE WITH REGIONAL OR METASTATIC PROSTATE CANCER

Surgery for regional and metastatic prostate cancers is not common. Fewer than 430 people answered these questions a year after their surgery.

HOW DO PEOPLE WHO HAD SURGERY FEEL IN GENERAL?

Feeling depressed	14%	
Lack of energy	21%	
Bowel habits are a problem	7%	
Losing bowel control is a problem	3%	
Urinary function is a problem	12%	
Needed more than 1 urinary pad per day	40%	
Experienced more than 1 urinary leak per day	25%	

HOW DO PEOPLE WHO HAD SURGERY FEEL ABOUT THEIR SEXUAL WELLBEING?

Sexual function is a problem	50%	
Can have a fair-very good erection	8%	
Erections are firm enough for intercourse	4%	
Ability to function sexually is fair-very good	9%	
Have interest in sex	25%	
Used sexual aids (devices or medications)	44%	

Why does the number of people who have surgery reduce with age?

These percentages have remained stable over time and align with international treatment guidelines for prostate cancer. These guidelines recommend considering age and life expectancy when deciding on surgery as an option, and the risk of some side effects increases with age.

RADIATION THERAPY

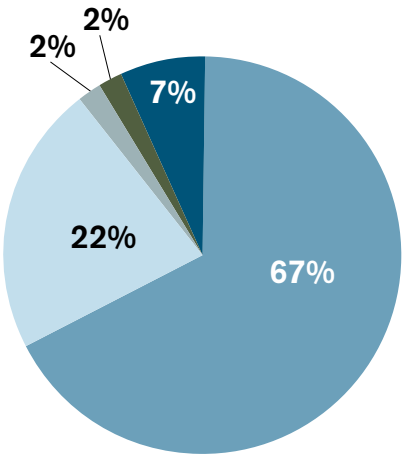
Radiation therapy is used to kill prostate cancer cells with high-energy rays or particles. It is most often provided as 'external beam radiation therapy' in which x-rays are aimed at the cancer from outside the body or as 'brachytherapy' in which radioactive sources are inserted directly into the prostate.

Please note: sometimes radiation therapy can be used with other treatments, commonly ADT, please see the next section for information on people who had radiation therapy plus ADT.

HOW MANY PEOPLE IN PCOR-ANZ HAD RADIATION THERAPY ALONE?

7,174

PROSTATE CANCER RISK GROUPS OF PEOPLE RADIATION THERAPY ALONE



WHO IS MANAGED WITH RADIATION THERAPY ALONE?

Radiation therapy alone is used most often in intermediate- and high-risk disease.

INTERMEDIATE-RISK CANCER, 2021

16%

HIGH-RISK CANCER, 2021

12%

THERE HAVE BEEN SMALL INCREASES SINCE 2015.

(From 11% in intermediate-risk and 7% in high-risk disease.)

In PCOR-ANZ in 2021, there were:
- 6,147 people with intermediate-risk and 3,541 people with high-risk disease.
- 2,493 people with intermediate-risk and 1,470 people with high-risk disease.

PROMS RESULTS FOR PEOPLE WITH LOCALISED PROSTATE CANCER

(LOW, INTERMEDIATE OR HIGH RISK)

Over 3,500 people answered these questions a year after they had radiation therapy.

HOW DO PEOPLE WHO HAD RADIATION THERAPY ALONE FEEL IN GENERAL?

Feeling depressed	8%
Lack of energy	18%
Bowel habits are a problem	7%
Losing bowel control is a problem	4%
Urinary function is a problem	9%
Needed more than 1 urinary pad per day	5%
Experienced more than 1 urinary leak per day	9%

HOW DO PEOPLE WHO HAD SURGERY FEEL ABOUT THEIR SEXUAL WELLBEING?

Sexual function is a problem	34%
Can have a fair-very good erection	36%
Erections are firm enough for intercourse	24%
Ability to function sexually is fair-very good	36%
Have interest in sex	33%
Used sexual aids (devices or medications)	27%

RADIATION THERAPY

Younger people were less likely to receive radiation therapy alone compared with older people.

UNDER 60'S

4%
HIGH RISK

7%
INTERMEDIATE RISK

OVER 75'S

12%
HIGH RISK

25%
INTERMEDIATE RISK

In PCOR-ANZ between 2015-2021, there were:
• 1,930 people under 60 years and 6,385 people over 75 years with high-risk disease.
• 6,565 people under 60 years and 4,887 people over 75 years with intermediate-risk disease.

PROMS RESULTS FOR PEOPLE WITH REGIONAL OR METASTATIC PROSTATE CANCER

As regional and metastatic prostate cancers are more commonly managed with one of the other treatment plans, only around 100 people answered these questions a year after they had radiation therapy.

HOW DO PEOPLE WHO HAD RADIATION THERAPY ALONE FEEL IN GENERAL?

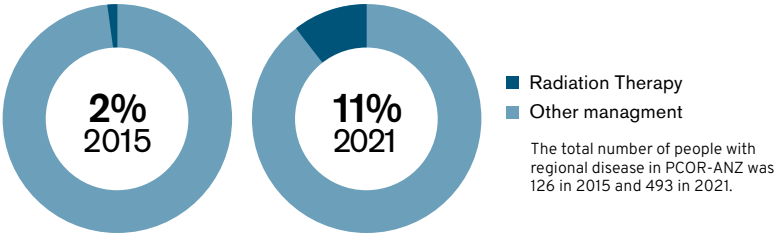
Feeling depressed	11%
Lack of energy	30%
Bowel habits are a problem	12%
Losing bowel control is a problem	7%
Urinary function is a problem	16%
Needed more than 1 urinary pad per day	11%
Experienced more than 1 urinary leak per day	13%

HOW DO PEOPLE WHO HAD RADIATION THERAPY ALONE FEEL ABOUT THEIR SEXUAL WELLBEING?

Sexual function is a problem	39%
Can have a fair-very good erection	19%
Erections are firm enough for intercourse	10%
Ability to function sexually is fair-very good	17%
Have interest in sex	16%
Used sexual aids (devices or medications)	22%

Things are changing a little in regional disease

The number of people with regional disease receiving radiation therapy alone has increased over time.



The total number of people with regional disease in PCOR-ANZ was 126 in 2015 and 493 in 2021.

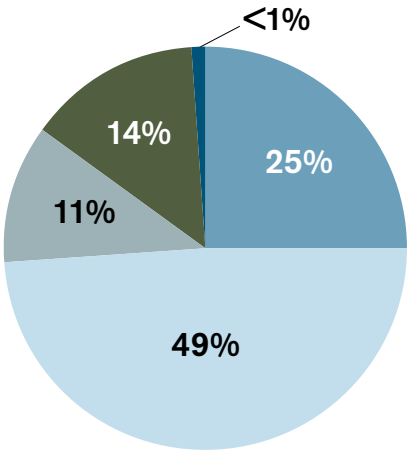
RADIATION THERAPY + ADT (HORMONE THERAPY)

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

HOW MANY PEOPLE IN PCOR-ANZ HAD RADIATION THERAPY PLUS ADT?

11,456

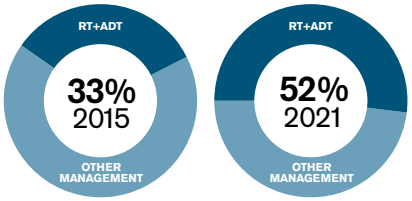
PROSTATE CANCER RISK GROUPS OF PEOPLE RECEIVING RADIATION THERAPY PLUS ADT.



WHO IS MANAGED WITH RADIATION THERAPY PLUS ADT?

This treatment plan is used most often in regional disease, and the numbers have increased over time.

REGIONAL DISEASE



METASTATIC DISEASE, 2021 – ABOUT 1 IN 3 PEOPLE

31%

THIS NUMBER HAS REMAINED STABLE OVER TIME.

In PCOR-ANZ, there were:
- 493 people with regional disease in 2021 and 126 people with regional disease in 2015.
- 1,011 people with metastatic disease in 2021.

PROMS RESULTS FOR PEOPLE WITH LOCALISED PROSTATE CANCER

(LOW, INTERMEDIATE OR HIGH RISK)

Over 4,700 people answered these questions a year after they had radiation therapy. Many may have been using ADT at the time of answering the survey.

HOW DO PEOPLE WHO HAD RADIATION THERAPY + ADT FEEL IN GENERAL?

Feeling depressed	12%
Lack of energy	31%
Bowel habits are a problem	9%
Losing bowel control is a problem	5%
Urinary function is a problem	12%
Needed more than 1 urinary pad per day	8%
Experienced more than 1 urinary leak per day	11%

HOW DO PEOPLE WHO HAD RADIATION THERAPY + ADT FEEL ABOUT THEIR SEXUAL WELLBEING?

Sexual function is a problem	37%
Can have a fair-very good erection	12%
Erections are firm enough for intercourse	7%
Ability to function sexually is fair-very good	11%
Have interest in sex	14%
Used sexual aids (devices or medications)	14%

RADIATION THERAPY + ADT (HORMONE THERAPY)

Younger people were less likely to receive radiation therapy plus ADT compared with older people.

UNDER 60'S

13%
HIGH RISK

3%
INTERMEDIATE RISK

OVER 75'S

38%
HIGH RISK

18%
INTERMEDIATE RISK

In PCOR-ANZ between 2015-2021, there were:
- 1,930 people under 60 years and 6,385 people over 75 years with high-risk disease.
- 6,565 people under 60 years and 4,887 people over 75 years with intermediate-risk disease.

PROMS RESULTS FOR PEOPLE WITH REGIONAL OR METASTATIC PROSTATE CANCER

Over 1,300 people answered these questions a year after they had radiation therapy. Many may have been using ADT at the time of answering the survey.

HOW DO PEOPLE WHO HAD RADIATION THERAPY + ADT FEEL IN GENERAL?

Feeling depressed	17%
Lack of energy	45%
Bowel habits are a problem	12%
Losing bowel control is a problem	6%
Urinary function is a problem	13%
Needed more than 1 urinary pad per day	10%
Experienced more than 1 urinary leak per day	12%

HOW DO PEOPLE WHO HAD RADIATION THERAPY + ADT FEEL ABOUT THEIR SEXUAL WELLBEING?

Sexual function is a problem	35%
Can have a fair-very good erection	6%
Erections are firm enough for intercourse	3%
Ability to function sexually is fair-very good	5%
Have interest in sex	7%
Used sexual aids (devices or medications)	11%

What about other risk categories?

Radiation therapy and ADT is most commonly used for intermediate- and high-risk groups, but is used less often in other risk groups. Across all age groups the proportion was 3-8% for regional disease and at or below 3% for metastatic disease. Very few people with low-risk cancer have this management option (less than 1% across all age groups).

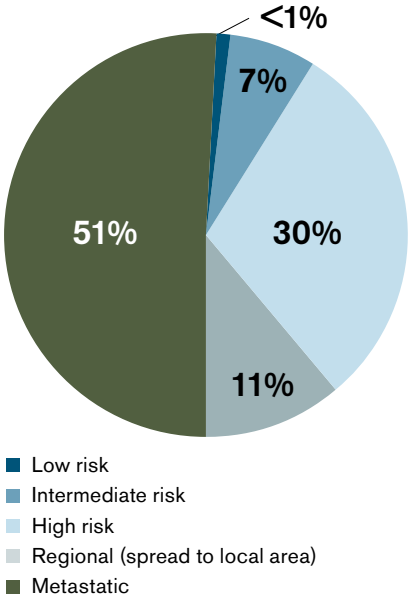
ADT (HORMONE THERAPY) WITH OR WITHOUT CHEMOTHERAPY

ADT, with or without chemotherapy, is usually provided as an option for people with more advanced prostate cancer, particularly when it has spread beyond the prostate or become metastatic. 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.

HOW MANY PEOPLE IN PCOR-ANZ HAD ADT WITH OR WITHOUT CHEMOTHERAPY?

7,017

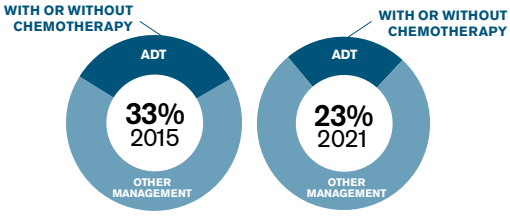
PROSTATE CANCER RISK GROUPS OF PEOPLE RECEIVING ADT WITH OR WITHOUT CHEMOTHERAPY.



WHO IS MANAGED WITH RADIATION THERAPY PLUS ADT?

This treatment plan is used most often in regional or metastatic disease.

REGIONAL DISEASE



THIS NUMBER HAS DECREASED OVER TIME.

METASTATIC DISEASE, 2021 – 2 IN 3 PEOPLE

63%

THIS NUMBER HAS REMAINED STABLE.

In PCOR-ANZ, there were:
- 493 people with regional disease in 2021 and 126 people with regional disease in 2015.
- 1,011 people with metastatic disease in 2021.

PROMS RESULTS FOR PEOPLE WITH LOCALISED PROSTATE CANCER

(LOW, INTERMEDIATE OR HIGH RISK)

Over 1,000 people answered these questions a year after diagnosis. Many may have been using ADT at the time of the survey.

HOW DO PEOPLE WHO HAD ADT WITH OR WITHOUT CHEMOTHERAPY FEEL IN GENERAL?

Feeling depressed	12%
Lack of energy	33%
Bowel habits are a problem	10%
Losing bowel control is a problem	5%
Urinary function is a problem	16%
Needed more than 1 urinary pad per day	14%
Experienced more than 1 urinary leak per day	14%

HOW DO PEOPLE WHO HAD ADT WITH OR WITHOUT CHEMOTHERAPY FEEL ABOUT THEIR SEXUAL WELLBEING?

Sexual function is a problem	30%
Can have a fair-very good erection	9%
Erections are firm enough for intercourse	4%
Ability to function sexually is fair-very good	7%
Have interest in sex	8%
Used sexual aids (devices or medications)	12%

ADT (HORMONE THERAPY) WITH OR WITHOUT CHEMOTHERAPY

Younger people were less likely to receive ADT with or without chemotherapy compared with older people.

UNDER 60'S

3%
HIGH RISK

18%
REGIONAL DISEASE

OVER 75'S

23%
HIGH RISK

43%
REGIONAL DISEASE

In PCOR-ANZ between 2015-2021, there were:
• 1,930 people under 60 years and 6,385 people over 75 years with high-risk disease.
• 279 people under 60 years and 819 people over 75 years with regional disease.

PROMS RESULTS FOR PEOPLE WITH REGIONAL OR METASTATIC PROSTATE CANCER

Over 1,600 people answered these questions a year after diagnosis. Many may have been using ADT at the time of the survey.

HOW DO PEOPLE WHO HAD ADT WITH OR WITHOUT CHEMOTHERAPY FEEL IN GENERAL?

Feeling depressed	**14%**
Lack of energy	**36%**
Bowel habits are a problem	**7%**
Losing bowel control is a problem	**3%**
Urinary function is a problem	**13%**
Needed more than 1 urinary pad per day	**11%**
Experienced more than 1 urinary leak per day	**11%**

HOW DO PEOPLE WHO HAD ADT WITH OR WITHOUT CHEMOTHERAPY FEEL ABOUT THEIR SEXUAL WELLBEING?

Sexual function is a problem	**34%**
Can have a fair-very good erection	**6%**
Erections are firm enough for intercourse	**4%**
Ability to function sexually is fair-very good	**6%**
Have interest in sex	**6%**
Used sexual aids (devices or medications)	**11%**

What about other risk categories?

Across all age groups, ADT with or without chemotherapy was used to manage 60-70% of people with metastatic disease. Its use is much less common in people with intermediate-risk (less than 4%) and low-risk (less than 1%) disease.

NOTES ON PROMS QUESTIONAIRE

The PROMs questionnaire used by PCOR-ANZ is based on two key questionnaires that are used all over the world with prostate cancer patients. The main questionnaire is called the EPIC-26, which stands for Expanded Prostate Cancer Index Composite. The list below describes how we have translated the answers to these questions into the outcomes you have read about in this report.

- **Feeling depressed** = reported on EPIC-26 as a 'moderate to big problem'
- **Lack of energy** = reported on EPIC-26 as a 'moderate to big problem'
- **Needed more than 1 urinary pad per day =** reported on EPIC-26 as the number of pads or adult diapers required in the last 4 weeks (scale of 0 to 3 or more)
- **Experienced more than 1 urinary leak per day =** reported on EPIC-26 as the number of leaks experienced over the last 4 weeks on a scale of 1-5 with a value of 1 being more than once a day.

  (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** = 'bowel habits' reported as a 'moderate to big problem' on EPIC-26
- **Losing bowel control is a problem** = 'losing control of your stool' reported on EPIC- 26 as a 'moderate to big problem'
- **Urinary function is a problem** = 'urinary function' reported on EPIC-26 as a 'moderate to big problem'
- **Sexual function is a problem** = 'sexual function or lack of sexual function' reported on EPIC-26 as a 'moderate to big problem'
- **Can have a fair-very good erection** = 'ability to have an erection' reported on EPIC- 26 as fair/good/very good
- **Erections are firm enough for intercourse** = reported as a 4 on a scale of 1 (none at all) to 4 (firm enough for intercourse) on EPIC-26
- **Ability to function sexually is fair-very good** = 'ability to function sexually' is reported as fair/good/very good on EPIC-26 (on a scale of very poor, poor, fair, good, very good)

Overall, a moderate-big problem is represented by a score of 3-4 on a scale of 0 to 4; and fair-very good is represented by a score of 3-5 on a scale of 1 to 5.

The two further questions on sexual wellbeing were phrased as follows:

- **Have interest in sex** = 'During the last 4 weeks, to what extent were you interested in sex?' was reported as 'quite a bit', 'very much' (on a scale of 'not at all, a little, quite a bit, very much')
- **Used sexual aids** = 'Have you used any medications or devices to aid or improve erections?' answered as yes or no.

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