PROSTATE CANCER IN AUSTRALIAN AND NEW ZEALAND MEN

PCOR-ANZ 2015–2017: PATTERNS OF CARE AND PATIENT-REPORTED OUTCOMES

ACKNOWLEDGEMENTS

First and foremost, the Chair, the Steering Committee and Movember acknowledge and thank the thousands of men who have contributed to this project. The strength of the registry is built upon the generosity of every man who has given his time freely to complete a patient-reported outcomes measures (PROMs) questionnaire and consented to us collecting his data. Without your support and willingness to allow us to use your information, we would not be able to achieve any of the outcomes that the Prostate Cancer Outcomes Registry – Australia and New Zealand (PCOR-ANZ) is striving towards; namely, improving all aspects of the quality of care for men diagnosed with prostate cancer, within Australia and New Zealand, and globally.

Likewise, we are grateful for the support and professionalism demonstrated by members of the clinical community who have agreed to participate in PCOR-ANZ. This is a voluntary registry and the participation of so many on the front line of prostate cancer diagnosis and treatment across Australia and New Zealand reflects a continuous dedication within this community to improving the lives of their current and future patients.

The Chair and the Steering Committee would particularly like to acknowledge the generous and ongoing support of Movember. Their vision to establish and fund this bi-national Prostate Cancer Registry is world leading, and very clearly demonstrates a dedication to improving the quality of care and the quality of life for men diagnosed

and treated for prostate cancer. Similarly, we are grateful for the important work undertaken by the ethics committees in each jurisdiction and the Aboriginal Program Development Committee, who ensure that our registry operates in an ethically responsible and culturally appropriate manner.

Movember thanks the PCOR-ANZ Steering Committee members and in particular, the leadership demonstrated by Professor Sanchia Aranda. Professor Aranda has been in the position of Chair since November 2018 and under her guidance, we have seen PCOR-ANZ continue to go from strength to strength. We also pay particular acknowledgement to Professor Sue Evans, who as the former Academic Lead of PCOR-ANZ, was critical in establishing and operating PCOR-ANZ from its inception. Her tireless dedication to its success over many years cannot be overstated. We wish Sue all the best in the next phase of her career.

Finally, we extend our appreciation to all our endorsing societies who have put their weight behind this initiative. Their public recognition of the significant impact the registry will have on clinical quality in Australia and New Zealand is commendable. These include: 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 the Société Internationale d'Urologie (SIU).

FUNDING/CITATION

MOVEMBER®

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

ACT Government | ACT Health

APCRC-Q Australian Prostate Cancer Research Centre Queensland

Government of South Australia — SA Health

Cancer Institute NSW — cancer.nsw.gov.au

CHOMNZ | centre for health outcome measures new zealand

MONASH University

NORTHERN TERRITORY GOVERNMENT

QUT ihbi Institute of Health and Biomedical Innovation

SA-PCCOC South Australian Prostate Cancer Clinical Outcomes Collaborative

UNIVERSITY of TASMANIA | MENZIES Institute for Medical Research

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

PCOR-ANZ is endorsed by:

MOGA

RCPA The Royal College of Pathologists of Australasia

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

UROLOGICAL SOCIETY OF AUSTRALIA AND NEW ZEALAND

SIU SOCIÉTÉ INTERNATIONALE D'UROLOGIE

MESSAGE FROM THE CHAIR

More Australian and New Zealand men face a prostate cancer diagnosis at some time in their lives than any other type of cancer. Recent data from the World Health Organisation showed that Australia and New Zealand have one of the highest rates of prostate cancer, globally. On the brighter side, statistics show that mortality rates are declining, and more men are surviving.

Surviving prostate cancer is important, as is promoting an acceptable quality of life and functional status for survivors. With survival rates high in Australia and New Zealand, increased emphasis is turning towards best-practice treatment and quality of life. Treatment decision making in prostate cancer is complex given the wide variation in the aggressiveness of the disease and the range of treatment options. Conventional population-based registries focus on cancer incidence, mortality and survival. But they rarely collect data on factors related to treatment decision making and quality of life such as tumour stage at diagnosis, accompanying co-morbidity, other prognostic indicators, treatment, treatment side-effects and quality of survival. Without these data, it is impossible to learn from experience when selecting the best treatment options and supporting men to make the best decisions for their situation. These data also help to build understanding of the true disease burden and aid the implementation of evidence-based support services. PCOR-ANZ aims to fill this gap.

In my first year as Chair of the PCOR-ANZ Steering Committee, it has been enormously pleasing to observe the progress being made regarding recruitment and reporting. It is encouraging to see population coverage tip over 50% bi-nationally, and this will continue to improve in the coming year as we drive towards our target of 90%. Of significance is the commencement of registry-wide quality indicator reporting which, for the first time, will enable us to evaluate bi-national variations in diagnostic practices, treatment provision and the quality of life experienced by survivors. This is a major step forward in terms of our goal of driving improvements in prostate cancer outcomes and the performance of our healthcare system. The benchmarking made possible through PCOR-ANZ is leading the way in supporting clinicians to improve cancer treatment and support.

I have also been impressed by the tireless dedication shown by all members of the PCOR-ANZ team. Our committed team of Study Coordinators oversee the many tasks involved with project implementation and data collection with enormous dedication and diligence. This ensures that PCOR-ANZ continues to meet the high standards and rigors of ethical oversight incumbent upon us. Likewise, our voluntary Steering Committee members are stewarding PCOR-ANZ with a level of professionalism and passion for quality improvement that is uniquely impressive. We also thank every clinician who participates in data provision to the registry and praise their commitment to improving prostate cancer outcomes.

The data reported here are still relatively young but as we mature year on year, I have no doubt that this dataset will become a vital pillar in the effort to ensure that all men in Australia and New Zealand benefit from world-leading prostate cancer outcomes and are physically and mentally healthy in survivorship.

I look forward to 2020 with great optimism and enthusiasm.

PROFESSOR SANCHIA ARANDA
CHAIR, PCOR-ANZ STEERING COMMITTEE

MOVEMBER REPORT

Movember is committed to seeing fewer men die from prostate cancer. We want to make sure that treatment for prostate cancer is the best it can be. We also believe that quality of life is just as important as quantity of life, so we want to see that men living with and beyond prostate cancer are both physically and mentally well. That's why we fund projects like this, which have ambitions as big as our own.

Once again, we are proud to be the principal funder of PCOR-ANZ. As our investment in this program reaches $14M, it is exciting to see many of the ambitions we have for this initiative being realised this year. We see six new research projects being initiated through our first competitive grant round. These projects will utilise this valuable dataset to answer questions targeted at improving treatment outcomes for men. We see bi-national benchmark reports being released to clinicians and hospitals participating in PCOR-ANZ. World-class reports that are designed to provide data-driven information on the management and treatment outcomes of their patients. The milestones achieved this year are exciting and ground-breaking and not to be underestimated. They set PCOR-ANZ on a path that will lead to significant improvement of outcomes for men and their families, and we are genuinely excited by that.

This year also saw us commence an infrastructure upgrade project that will sustain PCOR-ANZ for many years to come and enable us to respond more rapidly to the changing landscape of prostate cancer diagnosis and treatment. This upgrade will also enable us to explore and implement data linkage efforts to expand the dataset and gain even more valuable insight into prostate cancer treatment and outcomes.

Movember also entered an exciting new digital health collaboration with Genie Solutions, Australia's leading practice management software provider. Through PCOR-ANZ, and the integration of our True North digital health platform with Genie technology, this partnership will enable men living with prostate cancer to complete online questionnaires that will assist them to:

• Regularly track and follow-up on changes to physical and mental health over time

• Receive personalised and tailored insights on managing treatment side effects

• Understand the experiences of other men receiving similar treatment

• Share responses with treating clinicians for care, management and follow-up

We aim to partner with all major electronic medical record providers over the coming years.

With so many important milestones achieved this year, we at Movember look forward to 2020 with great anticipation. The foundations have been laid and we feel this initiative is in a strong position to make a significant impact on treatment outcomes for men with prostate cancer.

PAUL VILLANTI
EXECUTIVE DIRECTOR - PROGRAMS

GLOSSARY

ADT	Androgen-deprivation therapy.
AS	Active surveillance
EBRT	External beam radiation therapy
EPIC-26	Extended Prostate Cancer Index Composite-26 questions
GP	General practitioner
IQR	Interquartile range
ISUP	International Society of Urological Pathology
MOGA	Medical Oncology Group of Australia
MRI	Magnetic resonance imaging
NCCN	National Comprehensive Cancer Network
NSW-PCCR	New South Wales Prostate Clinical Cancer Registry
PCOR	Prostate Cancer Outcomes Registry
PCOR-ANZ	Prostate Cancer Outcomes Registry – Australia and New Zealand
PROMs	Patient-reported outcome measures
PSA	Prostate-specific antigen
QoL	Quality of life
RPCA	Royal College of Pathologists of Australia
SA-PCCOC	South Australia Prostate Cancer Clinical Outcomes Collaborative
RT	Radiotherapy
SIU	Société Internationale d'Urologie
TRUS	Trans-rectal ultrasound
TURP	Transurethral resection of the prostate
USANZ	Urological Society of Australia and New Zealand
WW	Watchful waiting

TABLE
OF CONTENTS

PRO TIP

This report is interactive and clicking on the table of contents list will take you to the relevant section of the report. Also, where you see a link in the text, clicking on it will take you to the section of the report or the external website that is mentioned in the link.

EXECUTIVE SUMMARY

As PCOR-ANZ enters its fifth year of operation as a bi-national registry, we have passed the important milestone of having the majority of men newly diagnosed with prostate cancer registered with us across the region as a whole (54% estimated population coverage). We have enrolled 244 clinical sites and 337 clinicians, and our key goal of 90% population coverage overall now feels truly within our grasp. We are extremely grateful to all those on the Steering Committee and the Data Coordinators for helping us get this far and of course to the clinicians and institutes who are so willing to collaborate with us. We look forward to being able to deliver data that is fully representative of prostate cancer practice and outcomes across Australia and New Zealand in the near future.
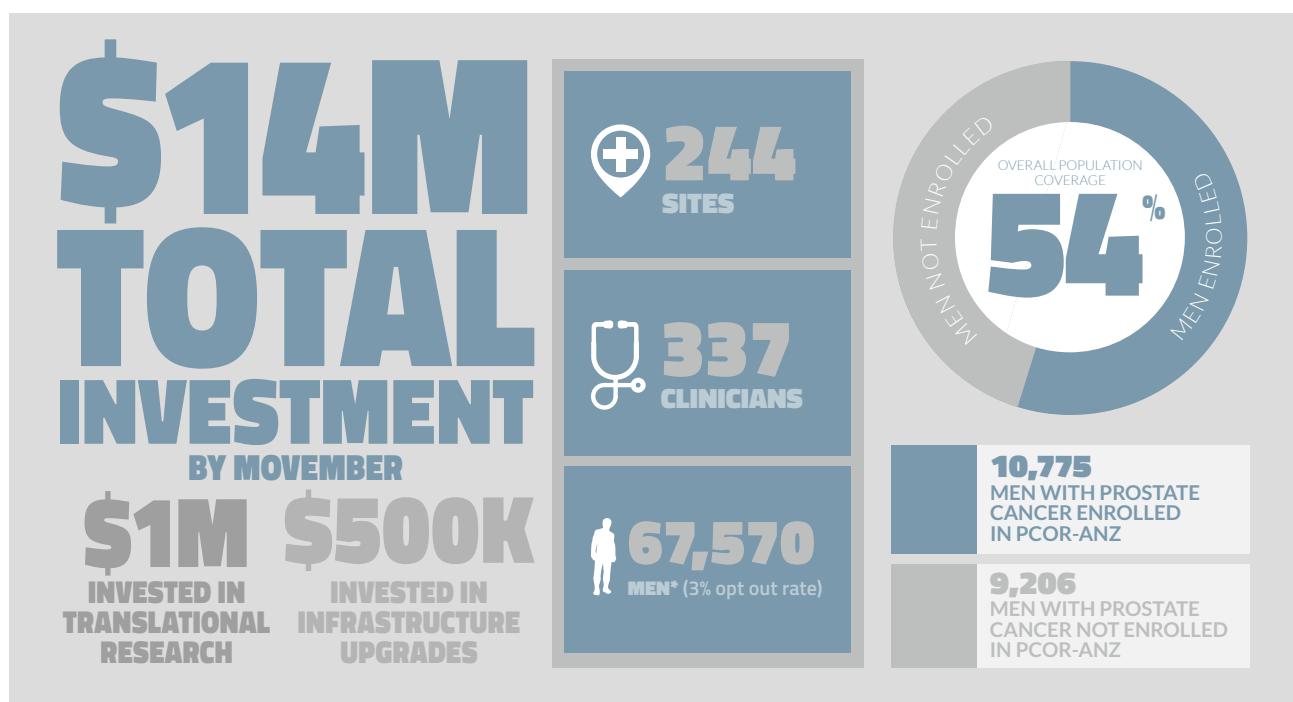
Of course, datasets this large come with their own special ongoing challenges, and our day-to-day operations have been significantly boosted by the recent infrastructure upgrade funded by Movember. To further enhance our operating capacity, Movember are seeking a new provider of registry software to help support these increasingly complex activities, while maintaining the high levels of data security we require.

One major advance for 2019, has been the roll out of our first wave of bi-national quality indicator reports to healthcare providers. The reports cover a range of surgery-focused outcomes that are benchmarked using the full Australia–New Zealand dataset, and are delivered bi-annually to participating members. To this point, 231 reports have been delivered, and this number will increase substantially in early 2020. A working group has been convened to begin identifying indicators to expand our reporting into radiation therapy outcomes, as well as doing further work on optimising the presentation of the reports. Over time, we intend to track these outcomes and analyse how well these reporting metrics are doing at driving positive clinical-practice change.

Given the incredible richness of the data that we hold, encouraging innovative research into what further insights the database can yield is one of our

INFOGRAPHIC 1: RECRUITMENT OVERVIEW

$14M TOTAL INVESTMENT BY MOVEMBER

$1M INVESTED IN TRANSLATIONAL RESEARCH

$500K INVESTED IN INFRASTRUCTURE UPGRADES

244 SITES

337 CLINICIANS

67,570 MEN* (3% opt out rate)

OVERALL POPULATION COVERAGE **54%**

MEN NOT ENROLLED

MEN ENROLLED

10,775 MEN WITH PROSTATE CANCER ENROLLED IN PCOR-ANZ

9,206 MEN WITH PROSTATE CANCER NOT ENROLLED IN PCOR-ANZ

*Men enrolled to date consists of 43,705 men enrolled in PCOR-ANZ since 2015, and 23,865 men enrolled in pre-existing VIC and SA databases since 1998.

key objectives. Several peer-reviewed publications based on PCOR-ANZ data were released last year in a variety of international journals **(see page 48)**, and we hope there will be many more to come. Six out of eight quality-improvement research grant applications were funded by Movember in 2019, and they are committed to funding future research using this valuable dataset. We also hope that this report will help inspire more external research teams to apply to interrogate our data through the data access process outlined on the website.
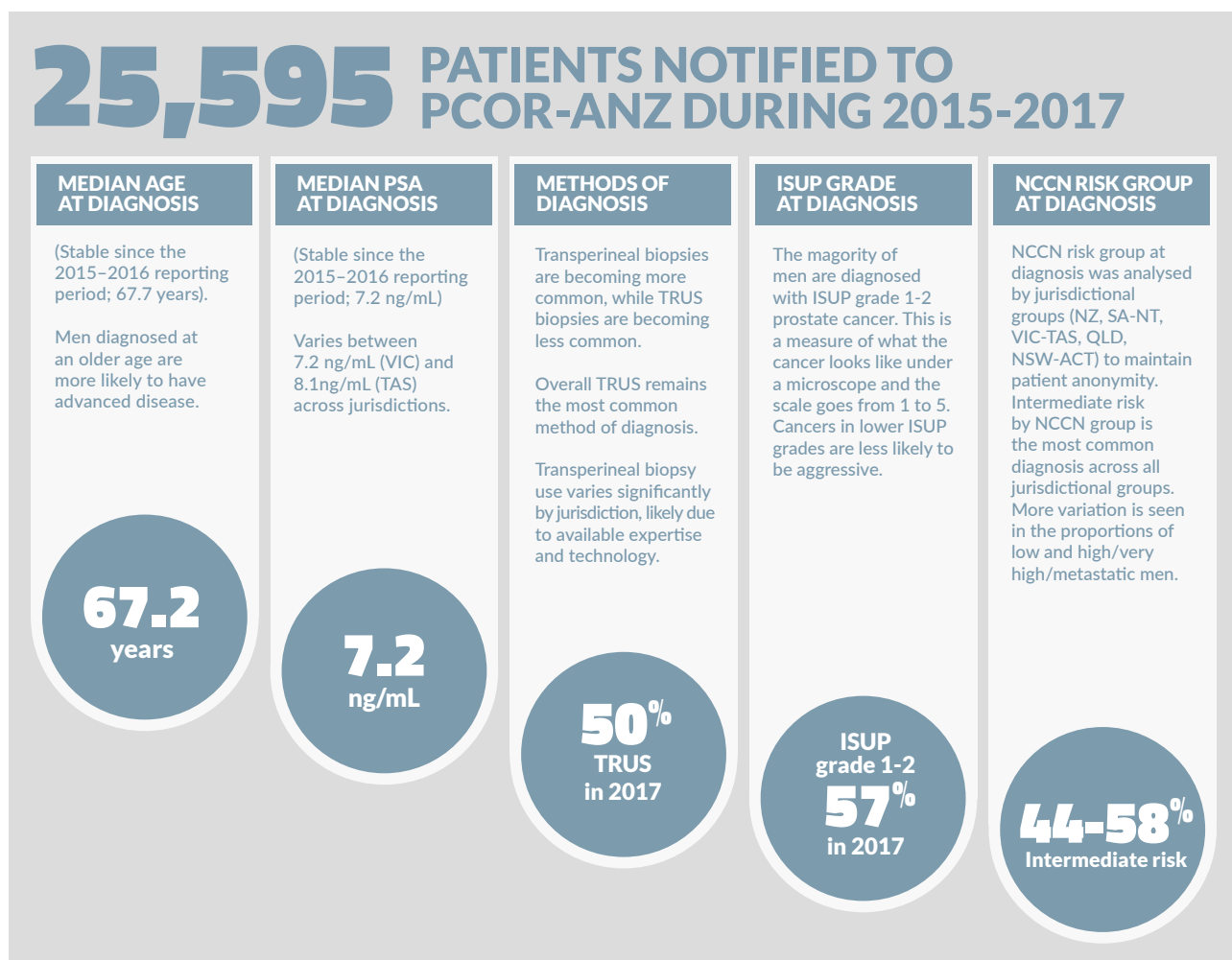
DEMOGRAPHICS AND DIAGNOSIS

Men diagnosed with prostate cancer and notified to PCOR-ANZ over 2015–2017 are most commonly in the 65–69-year age group – unchanged since reporting began in 2009 (66 years)[1] and consistent with national data.[2,3] Trans-rectal ultrasound (TRUS)-guided biopsy remains the most common method of diagnosis (50% of all diagnoses) across PCOR-ANZ. However, overall its use is distinctly decreasing in favour of transperineal biopsy, which has grown from 24% of diagnosis methods in 2015 to 38% in 2017. This is reflective of the growing preference for transperineal biopsy in the international clinical community due to a potential lower risk of infection and sepsis.[4]

Distinct jurisdictional differences in the risk group at diagnosis continue to be apparent. Low-risk disease is most commonly diagnosed in NZ (33% of diagnoses), and least commonly diagnosed in New South Wales/Australian Capital Territory (6% of diagnoses). This trend towards lower-risk diagnoses in New Zealand is similar to the 2015–2016 analysis, over which time their population coverage grew from 9% to 24%. It will be interesting to see if this remains the case as their population coverage grows further.

INFOGRAPHIC 2: DEMOGRAPHICS AND DIAGNOSIS

25,595 PATIENTS NOTIFIED TO PCOR-ANZ DURING 2015-2017

MEDIAN AGE AT DIAGNOSIS

(Stable since the 2015–2016 reporting period; 67.7 years).

Men diagnosed at an older age are more likely to have advanced disease.

67.2 years

MEDIAN PSA AT DIAGNOSIS

(Stable since the 2015–2016 reporting period; 7.2 ng/mL)

Varies between 7.2 ng/mL (VIC) and 8.1ng/mL (TAS) across jurisdictions.

7.2 ng/mL

METHODS OF DIAGNOSIS

Transperineal biopsies are becoming more common, while TRUS biopsies are becoming less common.

Overall TRUS remains the most common method of diagnosis.

Transperineal biopsy use varies significantly by jurisdiction, likely due to available expertise and technology.

50% TRUS in 2017

ISUP GRADE AT DIAGNOSIS

The magority of men are diagnosed with ISUP grade 1-2 prostate cancer. This is a measure of what the cancer looks like under a microscope and the scale goes from 1 to 5. Cancers in lower ISUP grades are less likely to be aggressive.

ISUP grade 1-2 57% in 2017

NCCN RISK GROUP AT DIAGNOSIS

NCCN risk group at diagnosis was analysed by jurisdictional groups (NZ, SA-NT, VIC-TAS, QLD, NSW-ACT) to maintain patient anonymity. Intermediate risk by NCCN group is the most common diagnosis across all jurisdictional groups. More variation is seen in the proportions of low and high/very high/metastatic men.

44-58% Intermediate risk

TREATMENT CHOICES

The uptake of active surveillance or watchful waiting in men with low-risk disease across all of 2015–2017 is 66% (n=2,703/4,087), a slight increase compared with the smaller 2015–2016 cohort (63%, n=1,708/2,717). However, 34% of men with low-risk disease are still receiving active treatment overall (surgery or radiotherapy; n=1,378/4,087); and this proportion increases to 44% in men under 60 years of age (n=516/1,166). These are both slight increases over the smaller 2015–2016 cohort of men with low-risk disease, of whom 31% of men overall (n=775/2,483) and 42% of men under 60 (n=354/840) chose active treatment.[1]
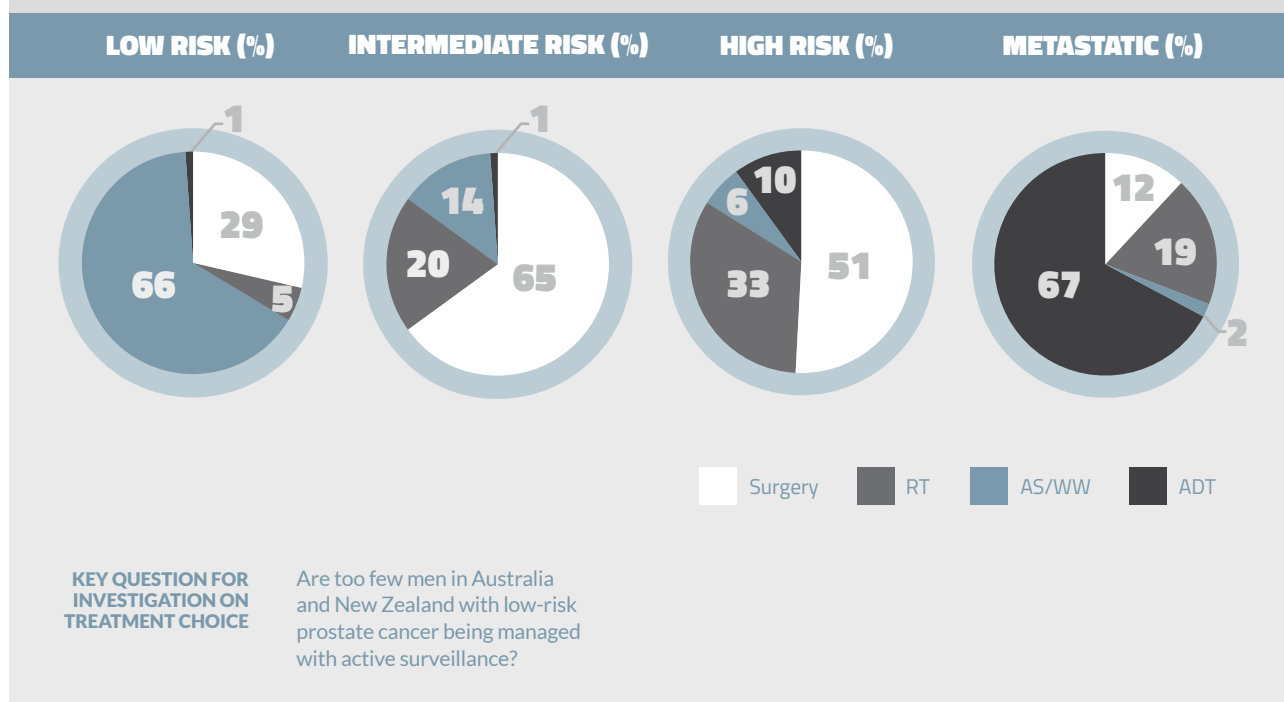
This should be food for thought for our region, since international guidelines[5,6] recommend considering and offering active surveillance. This is a concern particularly in younger men, for whom uncertainty regarding the need for immediate active treatment may be outweighed by the risks of immediate and persistent side effects given their greater life expectancy. Internationally, the proportion of men having active treatment in low-risk disease varies widely, with recent reports suggesting 42% of men in the United States,[7] yet only 4% of men across England and Wales[8] undergo active treatment in low-risk disease. Investigation into why such treatment decisions are being made across our region may, therefore, be warranted.

In high-risk prostate cancer, it is notable that 10% of men underwent androgen-deprivation therapy (ADT; with or without chemotherapy) within PCOR-ANZ. Large, well-conducted, multicentre trials have compared the outcomes for men with higher-risk prostate cancer treated with ADT alone, or ADT plus radiotherapy.[9,10] Overall survival in the men who underwent ADT plus radiotherapy was longer than if ADT was used alone; and deaths from prostate cancer were at least half as likely to occur in the ADT plus radiotherapy group. Therefore, for the 'average' high-risk case, ADT alone is not as good as the combination with radiotherapy. In a proportion of men, attempted long-term control with the addition of radiotherapy would not be indicated because of other factors, however, this may be a relevant topic for investigation.

INFOGRAPHIC 3: TREATMENT CHOICES

50% OF MEN UNDERWENT RADICAL SURGERY (11,289/22,456)

LOW RISK (%)	INTERMEDIATE RISK (%)	HIGH RISK (%)	METASTATIC (%)

Low Risk: 66, 29, 5, 1
Intermediate Risk: 65, 20, 14, 1
High Risk: 51, 33, 6, 10
Metastatic: 67, 19, 12, 2

Legend: Surgery | RT | AS/WW | ADT

KEY QUESTION FOR INVESTIGATION ON TREATMENT CHOICE
Are too few men in Australia and New Zealand with low-risk prostate cancer being managed with active surveillance?

*In this analysis, 'ADT' refers principally to men who received ADT as their primary therapy without radiotherapy or surgery; this may also include men who have received ADT with or without chemotherapy; small numbers of men who received chemotherapy alone are included in this group.
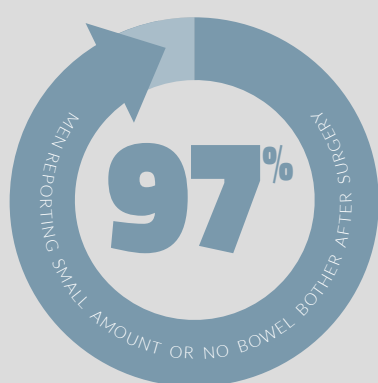
57% OF MEN RESPONDED (13,240 OF 23,304 QUESTIONNAIRES)

BOWEL BOTHER

URINARY BOTHER

SEXUAL FUNCTION

97%
MEN REPORTING SMALL AMOUNT OR NO BOWEL BOTHER AFTER SURGERY

~1 IN 10 MEN

~2 IN 5 MEN

HAVE A PROBLEM WITH SEXUAL FUNCTION AFTER SURGERY

97% of men report that bowel function is only a small amount or no bother after surgery ('no bother', 'very little bother' or 'small bother' on EPIC-26). This is similar to men who choose AS/WW. After radiotherapy or ADT 91-93% of men report small-to-no bother.

~1 in 10 men report moderate to big urinary bother across all treatment types. This is also similar to men on AS/WW.

Sexual function is most affected by prostate cancer treatment, compared with urinary and bowel function. There is not much variation in the effect of treatment on sexual function between PCOR-ANZ jurisdictions.

PATIENT-REPORTED OUTCOMES

The PROMs analysis remains a key focus for PCOR-ANZ and the proportion of men responding to the EPIC-26 questionnaire is encouragingly on the rise. In this analysis, 57% of men (N=13,240/23,304) responded to our questionnaires, compared with 50% of men in the 2015–2016 analysis.[1]

Across treatment groups, fewer than one-in-ten men report moderate or big problems with bowel function (range 3–10%) and the numbers are similar for urinary function (range 9–12%). Problems with sexual function are much more widely reported across all treatment groups, ranging from 22% for the active surveillance/watchful waiting group, to 44% for the surgery group. However, it should be noted that, in other recent analyses, poor sexual function is commonly reported at baseline in men diagnosed with prostate cancer.[11] Overall, the pattern of patient-reported outcomes seen in PCOR-ANZ was similar to that seen in a large contemporary cohort study from the United States, which used the same EPIC-26 survey instrument.[11] We hope these outcomes will provide valuable information about the risks and benefits of treatment for men across Australia and New Zealand, which will assist the decision-making process during their journey with prostate cancer.

ABOUT THIS REPORT

This report is targeted to clinicians contributing to PCOR-ANZ and their host institutions, together with men who have prostate cancer and their families, across Australia and New Zealand. The document is not designed to be a comprehensive description of prostate cancer and the treatments available in Australia, but a summary of the activities of the registry.

Data in this report describe the observed patterns of diagnosis and care of men with prostate cancer in Australia and New Zealand. General distributions and trends are presented, but in-depth analysis and specific statistical tests are outside the scope of this report. PCOR-ANZ data is available for researchers to access under strict security protocols and it is hoped that this report will stimulate data requests and research projects to examine specific questions and observations in more detail.

ETHICAL REPORTING

To protect the identities of men within the registry and the clinicians and institutes who support this work, for certain analyses, this report has combined data from smaller jurisdictions. For example, Tasmania has been combined with Victoria, and the Australian Capital Territory has been combined with New South Wales. A similar approach has been taken with rarer treatment types such as chemotherapy, which has been combined with ADT in most cases. Therefore, in this report 'ADT' refers principally to men who have received ADT without radiotherapy or surgery, but may include men treated with chemotherapy as well as ADT; a minority of men who receive chemotherapy alone are also included in this group.

The report also groups together the men who have been managed by 'active surveillance' with those who are managed by 'watchful waiting'. While these management approaches are quite different they can be difficult to differentiate at a population level. Because of the way the data is reported in the database, small numbers of men who 'refused treatment', 'couldn't make up their mind', 'had no treatment indicated because of more important health problems' or 'did not have active treatment for various other reasons' are also included in this category. However, these numbers are expected to be very low, so this category of men is considered to be representative of men who choose active surveillance/watchful waiting as a management option.
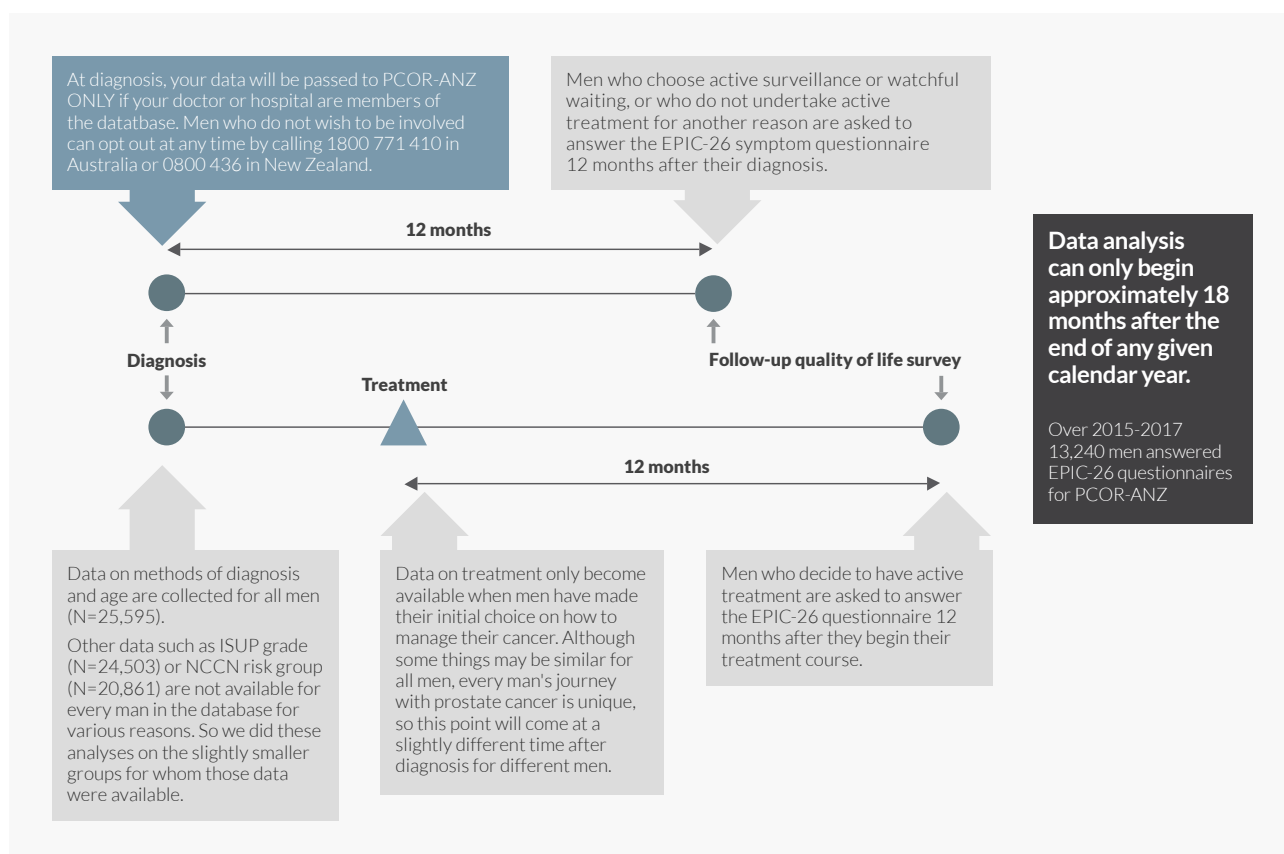
WHAT DATA ARE WE USING?

The data contained in this report were extracted from the PCOR-ANZ database on the 2nd of September 2019 and relate to men with a diagnosed date between 01/01/2015 and 31/12/2017. Treatment and PROMs data for these men were collected up to 2nd of September 2019. Data were available for the Australian Capital Territory, New South Wales, the Northern Territory, New Zealand, Queensland, South Australia, Tasmania and Victoria. Data from Western Australia were not available for inclusion in this report.

We report on data for men who have been diagnosed at least 18 months in the past, as this allows time for cancer notifications to be received by PCOR-ANZ jurisdictions, treatment to occur, and a 12-month period to elapse. Twelve months after primary treatment, PCOR-ANZ requests that men complete a symptom questionnaire known as 'EPIC-26' and this data is included in **Chapter 4**. The steps in this process mean that we cannot include men who have been diagnosed more recently in the report **(see infographic 5)**.

The 2015–2017 database includes 25,595 men but, for various reasons, not all men have data for every reported diagnostic, treatment, or PROMs category. Therefore, the total number of men in some of the report analyses is fewer than 25,595 – representing the number of men for whom that specific data was available.

INFOGRAPHIC 5: HOW DATA COLLECTION WORKS

At diagnosis, your data will be passed to PCOR-ANZ ONLY if your doctor or hospital are members of the datatbase. Men who do not wish to be involved can opt out at any time by calling 1800 771 410 in Australia or 0800 436 in New Zealand.

Men who choose active surveillance or watchful waiting, or who do not undertake active treatment for another reason are asked to answer the EPIC-26 symptom questionnaire 12 months after their diagnosis.

Data analysis can only begin approximately 18 months after the end of any given calendar year.

Over 2015-2017 13,240 men answered EPIC-26 questionnaires for PCOR-ANZ

12 months

Diagnosis

Treatment

Follow-up quality of life survey

12 months

Data on methods of diagnosis and age are collected for all men (N=25,595).

Other data such as ISUP grade (N=24,503) or NCCN risk group (N=20,861) are not available for every man in the database for various reasons. So we did these analyses on the slightly smaller groups for whom those data were available.

Data on treatment only become available when men have made their initial choice on how to manage their cancer. Although some things may be similar for all men, every man's journey with prostate cancer is unique, so this point will come at a slightly different time after diagnosis for different men.

Men who decide to have active treatment are asked to answer the EPIC-26 questionnaire 12 months after they begin their treatment course.

HOW DO I GET THE MOST OUT OF THE REPORT?

The answer to this question really depends on who you are and what information you're looking for. So, here is a summary of what you can find in each section of the report to help you navigate to the things you want to know:

STATISTICS AND TRENDS AT A GLANCE

Each chapter starts with an at-a-glance summary of the key points for that data section. This will help all readers quickly access the key themes of the report and point you to where to find the more detailed data analyses or statistics that you may be interested in.

KEY CONTENT AND GRAPHS

The main sections of the report provide an overview of the key analyses that have been completed and explain some of the clinical implications of this data. Detailed statistical analyses or in-depth data review, however, are outside the scope of this report.

NOTES FOR MEN AND THEIR FAMILIES

Each chapter has some notes sections intended entirely for men who have been diagnosed with prostate cancer, their families and friends or carers. These sections will explain some of the concepts in the data chapters in more detail and point you to useful sources of further information if you are interested in learning more about certain things that are mentioned in the report.

PRO TIP

Where you see 'N=' or 'n=' and then a number, this is just a short-hand way of letting you know how many men, or answers to questionnaires (or any other variable) were included in the analysis you're looking at. The capital 'N' represents the larger group, and the small 'n's' represent the smaller groups that make up that large group, so they add up to the total 'N'.

This helps people understand how much they can trust that data. For example, if only five men answered a questionnaire, the results that come out of it may not be reliable to many other people. But if several hundred to several thousand men answer a questionnaire, as is the case for our PROMs questionnaires, their combined answers are likely to be representative of the population as a whole.

1. THE PROSTATE CANCER OUTCOMES REGISTRY
AUSTRALIA AND NEW ZEALAND (PCOR-ANZ)

With this report, PCOR-ANZ has reached a significant milestone. For the first time, we can confirm that more men who have been diagnosed with prostate cancer across our region have joined PCOR-ANZ than those who have not. In the 2017 cohort of men from Australia and New Zealand, 54% of men with a prostate cancer diagnosis (N=10,775/19,981) have been enrolled in our database, meaning we are well on our way to achieving our goal of 90% population coverage **(see also Appendix 1)**. The database now has a working relationship with 244 institutes and 337 clinicians **(see also Appendix 2)** – an enormous effort on behalf of our specialised team of Data Coordinators. Perhaps even more importantly, this signals just how dedicated our clinical community is to improving the quality of care they are providing to men with prostate cancer across our region. There's still a way to go of course, and clinicians or institutes who want to be part of PCOR-ANZ can contact their local Data Coordinator – details can be found on the PCOR-ANZ website under 'Who's involved' **(see also Appendix 3 for a full list of Jurisdictional teams and Steering Committee members)**.

As a clinical quality registry, our function is to systematically monitor the quality of healthcare provided to men who have been diagnosed and treated with prostate cancer across Australia and New Zealand. But our overarching goal is to help the clinical community achieve the best possible health outcomes for those men. One key channel through which PCOR-ANZ is aiming to achieve this, is by the delivery of bi-national quality indicator reports to clinicians and institutes twice yearly (see Quality Indicator Reporting). As an ethically governed, securely administered bi-national database, with robust data-collection standards, we hold in one place an unprecedented wealth of data on treatment choices and patient-reported outcomes (PROMs) across the prostate cancer communities of two nations. So, another key aim of PCOR-ANZ is to inspire further research into this data.

DELVE INTO THE DATA: INSPIRATION FOR RESEARCH TEAMS

At a 'database-wide' level, the PCOR-ANZ team can monitor overarching trends in prostate cancer incidence, survival, treatment choices and PROMs – and we can review and publicly report jurisdictional variations in those general data over time, as we do in this report. But there are so many more valuable insights that can be teased out of the information in our database. So, our other key approaches to improving prostate cancer quality of care are to:

- Support ongoing research into the evidence–practice gap.

- Provide an infrastructure upon which intervention or other studies can be established.

This, we hope, is how we can inspire our scientific or clinical readers to delve more deeply into our database. Do you have a burning question about prostate cancer care on a state-wide, national or bi-national level? Can you envisage how a robust database such as ours can be used to ethically track clinical interventions in a way that simply hasn't been possible before?

We know that the PCOR-ANZ database has enormous potential to answer key questions on prostate cancer care, and in 2019, Movember administered a round of competitive grant funding to research teams who want to use this data. Of eight project applications with a focus on quality improvement, six were granted funding. However, data from PCOR-ANZ can also be accessed by any qualified research team who would like to mine this information, under the appropriate ethical guidelines. So please, read this report with an eye to envisaging what questions you would ask of our data, and how the answers could make a difference to men living with prostate cancer across Australia and New Zealand.

$14M TOTAL INVESTMENT
BY MOVEMBER

$1M
INVESTED IN TRANSLATIONAL RESEARCH

$500K
INVESTED IN INFRASTRUCTURE UPGRADES

NEW FOR 2019

COMPETITIVE GRANT FUNDING

COMPETITIVE GRANT FUNDING

Grants were awarded to six out of eight project applicants. Look out for future funding rounds on the PCOR-ANZ website.

THE FIRST BI-NATIONAL QI REPORTS HAVE BEEN DELIVERED

Reports are delivered in the strictest confidence and measure 12 key quality indicators across mainly surgical outcomes. Radiotherapy outcomes will be added soon.

231
REPORTS DELIVERED TO PARTICIPATING INSTITUTES AND CLINICIANS

HELP US
REACH POPULATION COVERAGE

Healthcare providers: Contact your PCOR jurisdictional coordinator under 'Who's involved' at the website below.

Patients: Look out for The Stamp and ask your doctors if they're involved. And if you're registered with PCOR-ANZ, don't forget to fill out your questionnaire.

Find out more at:
https://prostatecancerregistry.org

PARTNER IMPROVING MEN'S HEALTH

OVERALL POPULATION COVERAGE
54%

10,775 ENROLMENTS OUT OF **19,981** ESTIMATED CASES

NT	SA	QLD	NSW	ACT	VIC	TAS	NZ
97	87	76	43	100	82	100	24

PERCENTAGE (%) OF COVERAGE GOAL
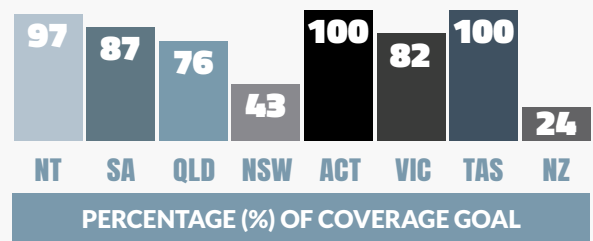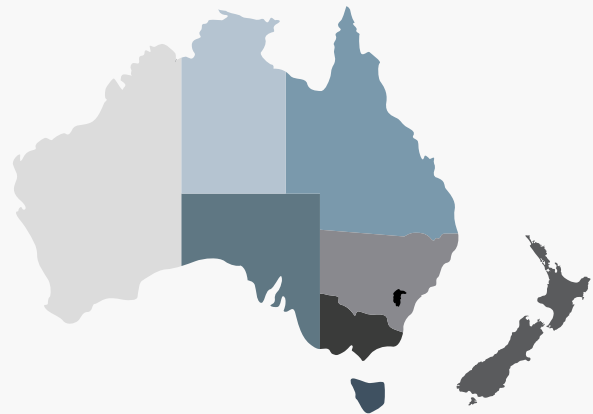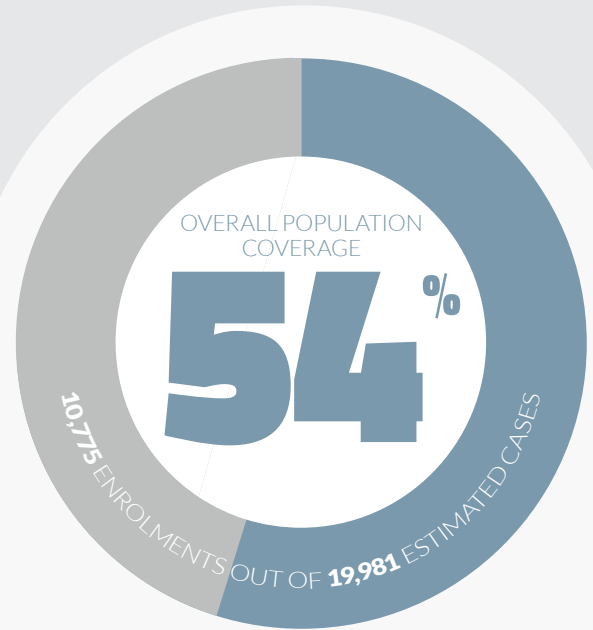
244
SITES

132 public
112 private

337
CLINICIANS

300 urologists
20 radiation oncologists
17 medical oncologists

67,570
MEN (3% opt out rate)

Men enrolled to date consists of 43,705 men enrolled in PCOR-ANZ since 2015, and 23,865 men enrolled in pre-existing VIC and SA databases since 1998.

QUALITY INDICATOR REPORTING

We are incredibly proud to have released the first quality indicator reports in prostate cancer that cover data from two nations, expanding from the single state-based reports generated in Victoria. These reports form the backbone of our efforts to work directly with clinicians and institutions to improve outcomes for men treated for prostate cancer.

A PCOR-ANZ Steering Committee working group collaborated with data scientists to publish a high-quality report that presents outcomes accurately, simply and intuitively for readers. All reports are developed and delivered within a secure environment to ensure confidentiality for the patients, institutions, and clinicians involved.

These confidential reports measure 12 quality indicators, which have been defined in the context of what excellent care looks like for men with prostate cancer in Australia and New Zealand. Each quality indicator compares the performance of the individual clinician or institution to the bi-national average, and has been carefully selected to be meaningful and actionable for healthcare providers who are contributing to PCOR-ANZ. Currently, these metrics relate largely to surgical treatment, but additional reports relating to radiation therapy are under development.

In 2019, 231 reports were distributed to contributing clinicians and institutes – and this number will grow substantially in early 2020. So far, the reports have been enthusiastically received. Before distribution, all reports undergo a rigorous data-checking process to ensure that high-quality data is delivered to clinicians for action, and we continually apply a data- and process-improvement mentality.

At a bi-national level we are doing well. The median level of performance is close to the indicator benchmarks for:

- Documenting prostate-specific antigen (PSA) levels at diagnosis and post-surgery.
- The proportion of men with low-risk prostate cancer receiving surgery.
- Positive surgical margins in pT2 patients.
- Urinary bother at 12 months post-surgery.
- Bowel bother at 12 months post-surgery.

Areas that appear to need additional efforts across the country to improve outcomes include:

- Documenting clinical T category at diagnosis.
- The rate of positive surgical margins in patients with intermediate and high-risk prostate cancer.
- Sexual bother 12 months after surgery.

PCOR-ANZ will track how the bi-national averages change across all these quality indicators, and we will highlight trends in future reports. This will help us identify areas in which this evidence-based outcomes data can be used to help inform positive changes in clinical practice on a bi-national level.

INFOGRAPHIC 7:
QUALITY INDICATOR REPORTS

CLICK ON THE 2 THUMBNAIL IMAGES TO ENLARGE

AS A MAN LIVING WITH PROSTATE CANCER, WHAT DOES PCOR-ANZ MEAN TO ME?

You, and other men like you, are the reason everyone involved in PCOR-ANZ gets up and goes to work in the morning. You may be more used to reading in the media about the passion that people have for breast cancer initiatives? Well, at PCOR-ANZ, we're equally as passionate about prostate cancer and the effects that it has on the men in our families. In fact, there are about as many Australian and New Zealand men affected by prostate cancer as there are women affected by breast cancer **(see infographic 8)**.

As we're sure you're aware, this cancer can have a huge impact on men's lives and the lives of those around them. And we believe that requires a huge effort to try and help those living with this disease have the best possible quality of care, and the best possible outcomes from that care. So as well as your own healthcare team, you can rest assured that you have a whole other team of data scientists and clinicians working on a state, national and bi-national level to make sure that the quality of care you receive is the best it can be, and continues to improve as time goes on.

Of course, for us to have any kind of impact, we rely on men allowing their data to be entered into the database and to answer the symptom questionnaires we send out. Knowledge, they say, is power. And in this case, your data contributes to an outstanding wealth of knowledge on prostate cancer that we and our associated research teams are constantly tapping into to deliver powerful, practical insights on the quality of prostate cancer care across our region. This is your data. And this report, guys, is all about you.

UNDERSTANDING THIS REPORT

Some blokes might look at a report, going on for over 60 pages, and feel they'll get around to it someday. We hope not though. For guys and their families who are thinking about treatment, this report has unique information about what *actually* happens in Australia and New Zealand. For guys after treatment, this report shows that you are not alone: there are lots of men out there living with prostate cancer, and some are just like you.

First, a word about statistics. For each man treated with prostate cancer theirs is an individual story. Some guys will see a minor impact on their life; some will have really difficult problems. To summarise this range of different possibilities, we have to use statistics. Some of these stats report the chances that men are in a certain group. For individual men, chances are they will be in the most common group, obviously; but for every man, there is a small chance they are in an uncommon group. Other figures or statistics report the 'average' and the spread of the data – this spread is often called the 'interquartile range' (IQR). In any of these measures where we can work out an average, the IQR provides the boundaries that include half the men we report on. This then provides a guide for whether there is a huge range (a wide or large IQR) for a particular outcome, or whether there is usually not much variation (a small IQR).

The other thing to be aware of when we talk about patient-reported outcomes, is the way we use 'scores'. We reduce everything to numbers. It's hard to know really what a score of, say, 85, or say, 35, means. High scores near 100 are really good, and 0 really bad. Differences of 2-3 aren't really noticeable. While it can be hard to work out exactly what it might be like to have a score of, for example, 30, this is worse than a score of 60; but better than 0. This scoring system allows everyone to make comparisons over time and between different circumstances.

So, what does it all mean? For men who are thinking about treatment, this is real-world information about the sort of treatments and outcomes they might expect, and can help them consider their options. These decisions are best made with advice and help from a specialist, local doctor, and other supporters. The quality of life scores, coming from thousands of real men across Australia and New Zealand, combine to illustrate what's likely or unlikely to occur and help men make comparisons between options.

Finally, men and their friends and family reading this report should feel reassured that the authors and contributors, from all over Australia and New Zealand, want to work to look at and discuss this data, which we are sharing here, because they are all deeply committed to always do the best they can, and always to work to improve. They go out of their way to contribute to this bi-national effort enabled by Movember, so that guys with prostate cancer can have the best possible results.

JEREMY MILLAR

PROSTATE CANCER IS THE MOST COMMON CANCER AMONG MEN IN BOTH AUSTRALIA AND NEW ZEALAND[12,13]

(excluding non-melanoma skin cancer)

IN BOTH AUSTRALIA AND NEW ZEALAND, ONLY LUNG CANCER CAUSES MORE DEATHS AMONG MEN[12,14,15]

WE ARE GETTING BETTER AT DIAGNOSING AND TREATING PROSTATE CANCER OVER TIME AND THE OUTCOMES ARE IMPROVING[12]

AN ESTIMATED

19,508

AUSTRALIAN MEN WERE DIAGNOSED WITH PROSTATE CANCER IN 2019.

Making it only slightly less common than breast cancer in Australian women (estimated 19,535 cases in 2019).

IN NEW ZEALAND

3,842

MEN WERE DIAGNOSED WITH PROSTATE CANCER IN 2017.

This is more common than breast cancer diagnosis in New Zealand women (3,286 cases in 2017)

33%
IMPROVEMENT

PROSTATE CANCER MORTALITY
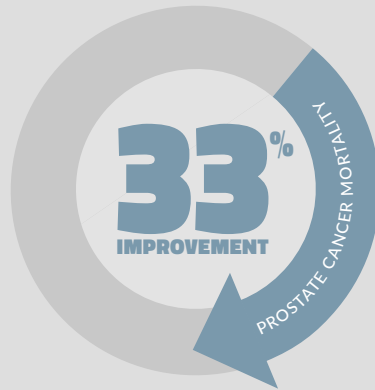
BETWEEN 1982 AND 2019 PROSTATE CANCER MORTALITY HAS IMPROVED BY 33%

IN AUSTRALIA, THE RATE OF PROSTATE CANCER DIAGNOSIS IS GOING DOWN OVER TIME.

The incidence rate has dropped by ~8% since 2014.

2019 — 130 CASES PER 100,000 MEN

2014 — 141 CASES PER 100,000 MEN

OVER 9 IN 10 MEN

DIAGNOSED WITH PROSTATE CANCER CAN EXPECT TO LIVE LONGER THAN 5 YEARS

(95.2% 5-Year relative survival rate, 2011-2015)

THE RISK OF A MAN BEING DIAGNOSED WITH PROSTATE CANCER BY HIS

85TH BIRTHDAY

IS NOW...

1 IN 6

Please note, these numbers are reported by the Australian Institute of Health and Welfare (AIHW) and the New Zealand Ministry of Health (NZMOH). It can take several years for these organisations to collect final data and report accurate numbers, so these are both estimates and the latest reported figures available.

2. DIAGNOSING PROSTATE CANCER

STATISTICS AND TRENDS AT A GLANCE: DIAGNOSIS

AVERAGE AGE AT DIAGNOSIS (MEAN): 67.7 years

62% of men diagnosed with prostate cancer across the region are under 70 years of age.

The most common age group for diagnosis is 65–69 years – this has remained the same since 2016.[1,16]

MOST COMMON METHOD OF DIAGNOSIS: TRUS, 50% of all men in 2017

TRUS is becoming less common over time as transperineal biopsy becomes more popular due to having a potentially lower infection risk.[4]

There were marked differences across jurisdictions, with transperineal biopsies used to diagnose approximately half of all men in Tasmania and Victoria, but used to diagnose only a minority of men in other jurisdictions.

Diagnosis by transurethral resection of the prostate (TURP) becomes more common as men age **(see Supplementary Figure S3)**.

MEDIAN PSA LEVEL AT DIAGNOSIS: 7.2 ng/mL

The median PSA at diagnosis has not significantly altered over time,[1,16] but there is some variation across jurisdictions with the highest level in Tasmania (median 8.1 ng/mL) and the lowest in New South Wales and New Zealand (both, median 7 ng/mL).
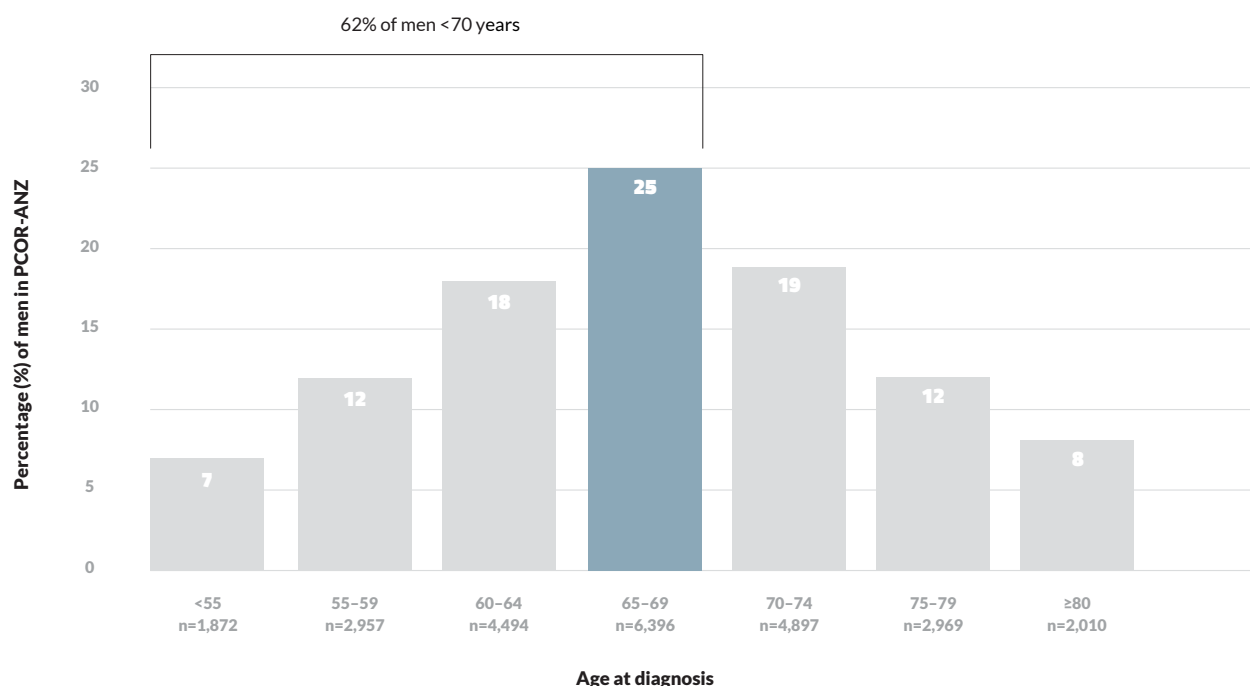
MOST COMMON ISUP GRADE AT DIAGNOSIS: ISUP grade 2, 30% of all men (excluding missing data)

The overall proportions of ISUP grade at diagnosis have remained remarkably stable over time.

MOST COMMON NCCN RISK GROUP AT DIAGNOSIS: Intermediate, 44–58% of all men across different jurisdictional groups, excluding those for whom NCCN cannot be determined

As men age, the proportions of men in the high and metastatic NCCN risk groups increases. Of men who are diagnosed at 80 years or older, 48% are in the high risk, and 23% are in the metastatic risk groups.

62% of men <70 years

Percentage (%) of men in PCOR-ANZ

| <55 n=1,872 | 55–59 n=2,957 | 60–64 n=4,494 | 65–69 n=6,396 | 70–74 n=4,897 | 75–79 n=2,969 | ≥80 n=2,010 |

Age at diagnosis

- Data on age at diagnosis were available for 100% of men in this analysis (N=25,595).
- Percentages are rounded and may not add to 100%.

Prostate cancer is usually diagnosed in older men, and the data collected by PCOR-ANZ from 2015–2017 reflects this well.

The most common age group for diagnosis was 65–69 years, which has remained consistent over the life of the registry (see PCOR-ANZ reports dated 2018 and 2016;[1,16] and **see Supplementary Figure S2 for age at diagnosis by jurisdiction**).

On a broader timescale, the age at diagnosis with prostate cancer has fallen from an average age of ~70–72 in the late 1990s to the current levels of ~68 years in 2009 and thereafter remained stable.[17] A number of factors contribute to this change in the age of diagnosis, particularly whether or not PSA case-finding is common, and the age range that this test is recommend for – if it is offered at all. Overall life expectancy for men also plays a role because prostate cancer becomes more common as men age,[2] and there has been an increase in the number of men living beyond 70 over the last 30 years in both Australia and New Zealand.[18,19] Life expectancy determines how PSA testing is carried out in community practices and testing, in turn, influences diagnosis.

NOTES

PSA TESTING – PSA testing was introduced in Australia in 1987 and New Zealand in 1991.[12,20,21] How the test is used can change who is diagnosed and the age of diagnosis. Exactly how to use PSA testing is still being debated and not all health authorities agree on the details. PSA screening – systematic testing of all men at risk in the population – is contested. Deciding to have a PSA test can be difficult and there are a lot of things that men should consider before they go ahead.

If you have no other symptoms and are considering having a PSA test, it's best to first talk to your GP about the pros and cons specific to you, your age, your family history and any other health concerns you may have.

READ MORE ABOUT PSA TESTING IN AUSTRALIA AND NEW ZEALAND.
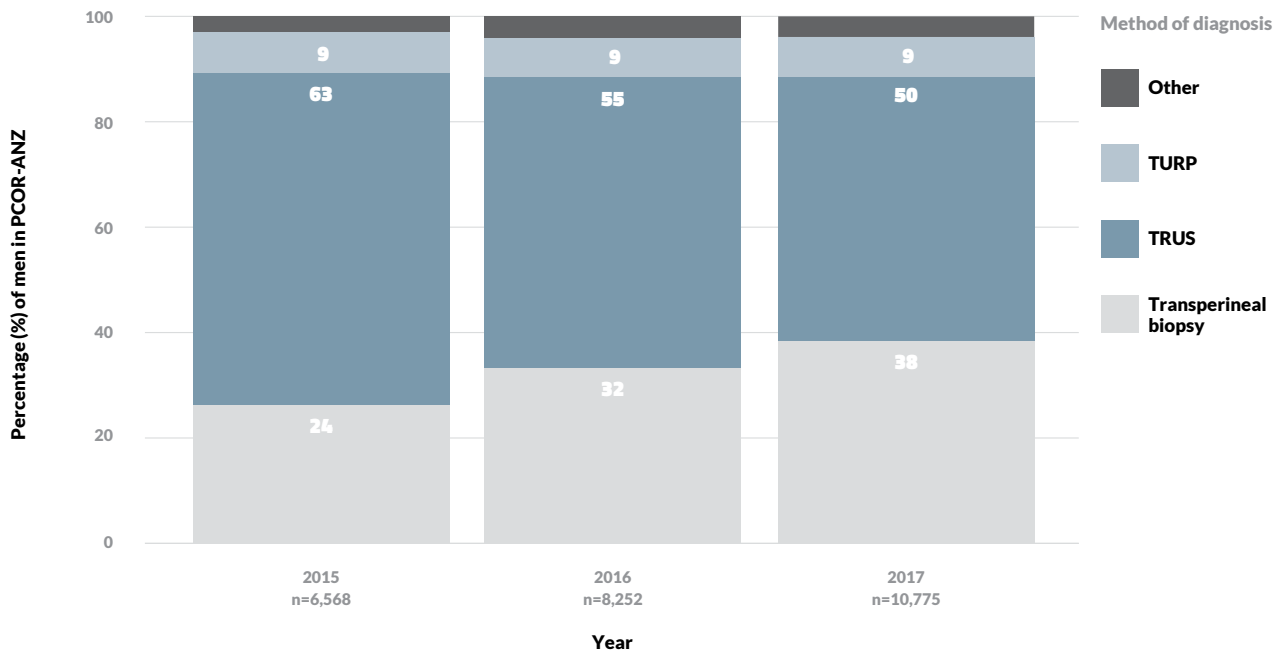
- Data on method of diagnosis were available for 100% of men in this analysis (N=25,595).
- Percentages are rounded and may not add to 100%.

TRUS biopsy has been used to diagnose prostate cancer for many years, although its use appears to be diminishing (63% in 2015, 50% in 2017). At the same time, transperineal biopsy use is increasing (24% in 2015, 38% in 2017).

Sepsis and infection are key complications of TRUS biopsy, which are likely to have contributed to this change in practice over time. There is some evidence that transperineal biopsy may have a reduced rate of sepsis and infection, although the accuracy at detecting significant prostate cancers appears similar.[4,22] Transperineal biopsies can also be targeted after an MRI scan, potentially diagnosing more clinically relevant prostate cancers, plus fewer cases of low-grade disease.[4]

Recently, it has been suggested that TRUS should be phased out and replaced by transperineal biopsy for these reasons. Transperineal biopsies, however, require a general anaesthetic and specialist equipment, making it more costly to scale up.[4]

The frequency of TURP diagnoses remains stable in the PCOR-ANZ data set between 2015 and 2017, at 9%. A small number of men are diagnosed with prostate cancer in other ways such as a biopsy of a metastatic site or at the time of radical cystectomy for bladder cancer and the frequency of such events also appears to be unchanged.

NOTES

Prostate cancer can be diagnosed in many different ways, but needle biopsy of the prostate is the most common. There are two common approaches for this:

TRUS – (trans-rectal ultrasound)-guided biopsy – a needle is inserted into the prostate through the rectum, guided by ultrasound. The tissue is then sent for analysis by a pathologist.

TRANSPERINEAL BIOPSY – the biopsy needle is inserted through the perineum (the area between the anus and the scrotum) and the tissue is sent for analysis by a pathologist.

There can also be another way to diagnose prostate cancer – using TURP.

TURP – (trans-urethral resection of the prostate) can also be a source of diagnoses. TURP is a surgical procedure undertaken in men with lower urinary tract symptoms. This procedure involves removing a small amount of prostatic tissue to help men who have difficulty urinating because of prostate enlargement, rather than as part of a diagnostic test. This enlargement occurs with aging and is usually not a cancer. The tissue removed is often sent for pathology and this can lead to an incidental diagnosis of prostate cancer in some of the men. Some patients diagnosed in this way will go on to have a confirmatory biopsy by either TRUS or transperineal approaches, depending on their circumstances.

READ MORE ABOUT DIAGNOSIS
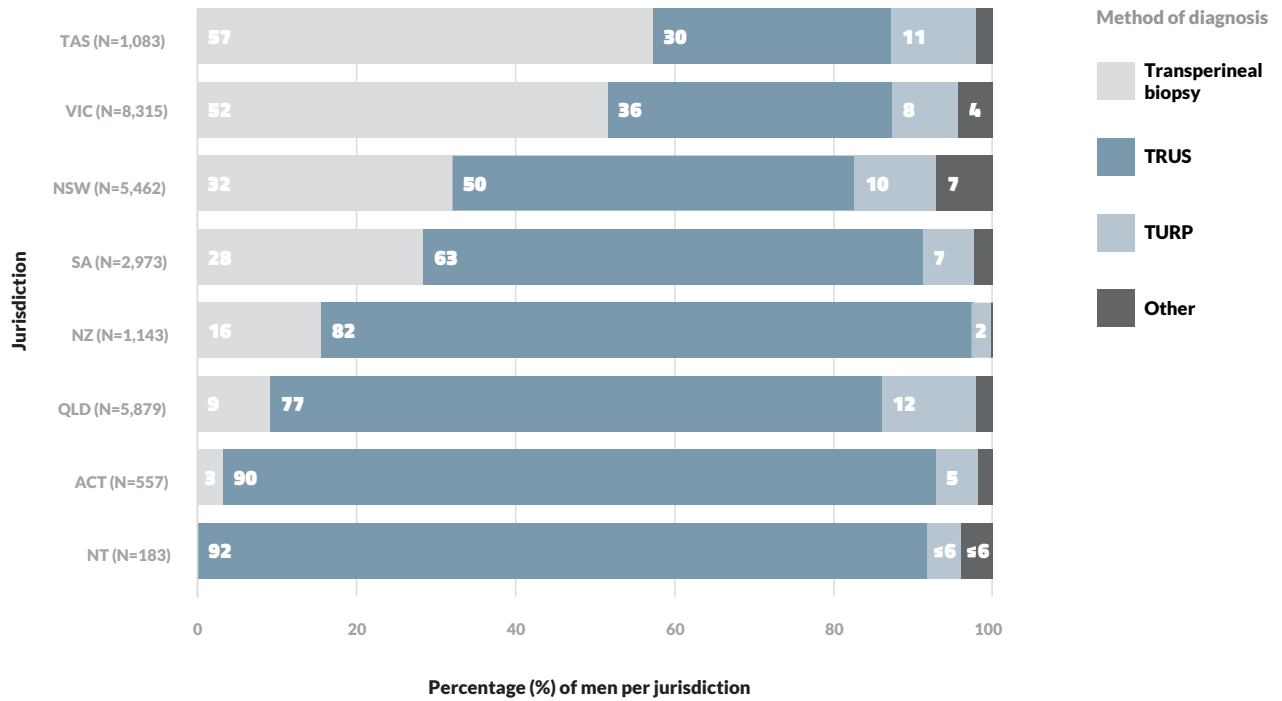
Percentage (%) of men per jurisdiction

- Data on method of diagnosis were available for 100% of men in this analysis (N=25,595).
- Jurisdictions have been ordered by decreasing use of transperineal biopsy to aid between-group comparisons.
- Percentages are rounded and may not add to 100%.

Each jurisdiction contributing to PCOR-ANZ reports a different distribution in the use of diagnostic techniques for prostate cancer. Tasmania and Victoria report the highest proportion of diagnoses made by transperineal biopsy, while the Australian Capital Territory and the Northern Territory have the lowest proportions. There may be many reasons for these differences, particularly access to medical facilities and expertise. The Northern Territory remains the highest user of TRUS biopsy (proportionally) which is likely to be driven by access to the medical facilities and expertise required for transperineal biopsy.

Diagnosis by TURP and other techniques are performed in all jurisdictions with some variation. The lowest proportion of diagnoses by TURP are reported in New Zealand. This pattern may be explained by country-specific guidelines which determine that only patients meeting specific age and PSA criteria have tissue sent for pathology.[23] **(See Supplementary Figure S3 for method of diagnosis by age at diagnosis.)**

FIGURE 4: **PSA LEVEL (ng/mL) AT DIAGNOSIS BY JURISDICTION (2015–2017)**
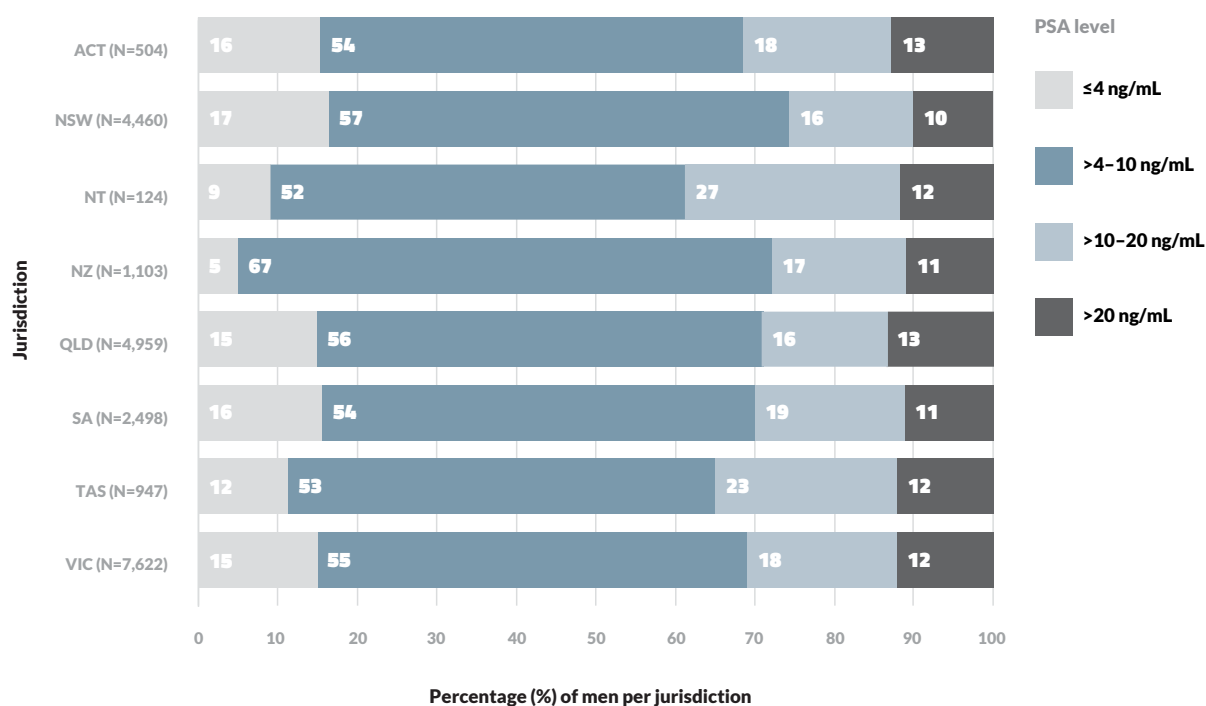
- Data on PSA level at diagnosis was available for 87% (N=22,217/25,595) men in PCOR-ANZ.
- Jurisdictions have been ordered alphabetically.
- Percentages are rounded and may not add to 100%.

Across the jurisdictions of PCOR-ANZ, New South Wales had the lowest proportion of men diagnosed with PSA levels greater than 20 ng/mL (10%), while Queensland and the Australian Capital Territory had the highest proportion (13%). Elevated PSA levels at the time of diagnosis may be due to jurisdictional differences in PSA testing patterns in primary practice, differences in referral pathways for clinical investigation or differences in the population age structure. The overall distribution of PSA levels at diagnosis has remained relatively stable since PCOR-ANZ reporting began in 2016.[1,16]

NOTES

PSA – (prostate-specific antigen) is measured in blood samples. A 'normal' PSA level depends on your age, but as a rule of thumb, if total PSA levels are greater than 3.0 ng/mL prostate cancer is more likely, and further tests will probably be needed.

Keep in mind, elevated PSA levels may also be due to prostate infection or increased prostate size (which grows with age). It doesn't always mean prostate cancer. It's important for a doctor to confirm the elevated PSA level's cause and next steps.

If prostate cancer is confirmed, the PSA level at diagnosis can help predict the cancer's risk of growing and spreading. High levels of PSA caused by prostate cancer typically indicate high-risk disease.[6]

READ MORE ABOUT PSA TESTS

FIGURE 5:   PROPORTIONS OF ISUP GRADES AT DIAGNOSIS, BY YEAR (2015–2017)
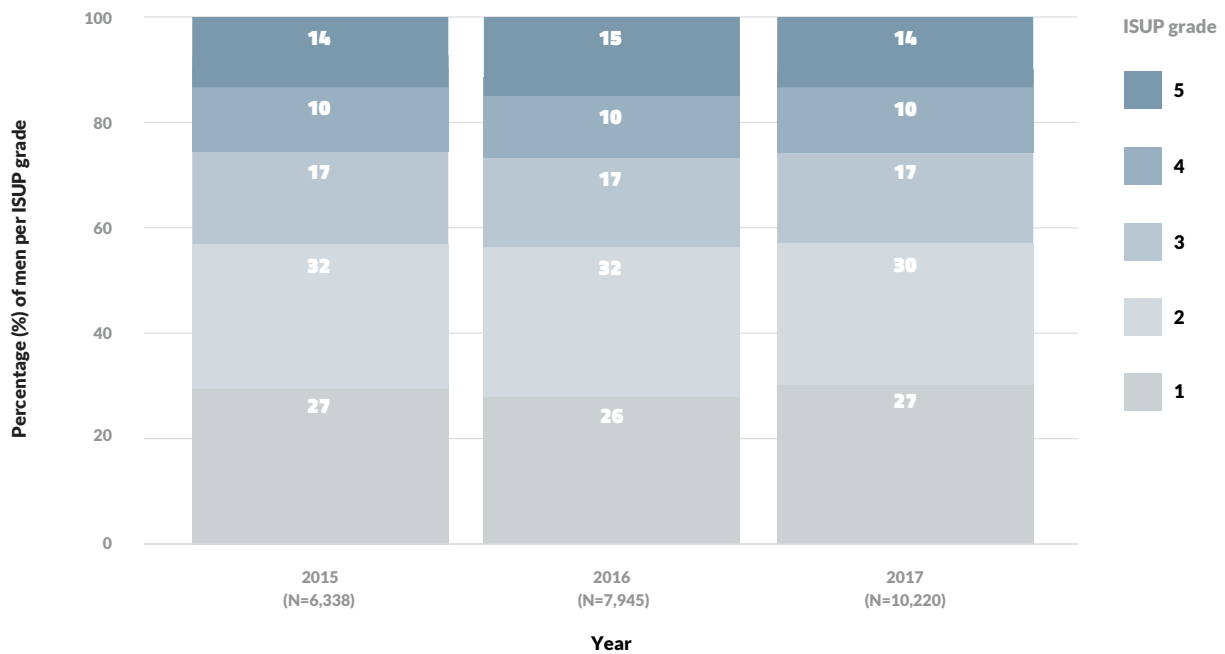
- Data on ISUP grade at diagnosis were available for 96% (N=24,503/25,595) of men in PCOR-ANZ.
- Percentages are rounded and may not add to 100%.

ISUP (International Society of Urological Pathologists) grades provide a measure of the aggressiveness of prostate cancer and are closely aligned to the Gleason Score grading system that was used previously.[24] In PCOR-ANZ data from 2015–2017, there have been no notable changes in the ISUP grade that men are assigned at the time of diagnosis. ISUP grade at diagnosis is one of the most important determinants of survival,[25] making this trend an important one to monitor for changes in the registry.

PRO TIP

An important component of staging prostate cancer is the grade of the cancer. The grade describes what the cancer cells look like under a microscope. This appearance is strongly associated with how the tumour is likely to behave ('how aggressive it is'). Tissue is examined after a biopsy has been performed, or with tissue scraped in men who have a TURP.

The Gleason system scores prostate samples on a scale of 1 to 5. Scores close to 1 are considered 'low-grade' (similar to normal cells) while those close to 5 are considered 'high-grade'. A biopsy sample will be given two Gleason grade numbers, one for the most common cell type, and one for the second most common cell type (e.g. 3 + 4).

In 2015, the ISUP released a new prostate cancer grading system – the ISUP grade.[24] This system also grades the prostate cancer on a scale from one to five – similarly, cancers with lower ISUP grades tend to be less aggressive, while cancers with higher scores tend to be more aggressive. This table compares the 2005 modified Gleason grading system with the 2015 ISUP grades.

2005 MODIFIED GLEASON GRADING SYSTEM	2015 ISUP GRADING SYSTEM
3+3, 3+2, 2+3, 2+2	1
3+4	2
4+3	3
4+4, 3+5, 5+3	4
4+5, 5+4, 5+5	5
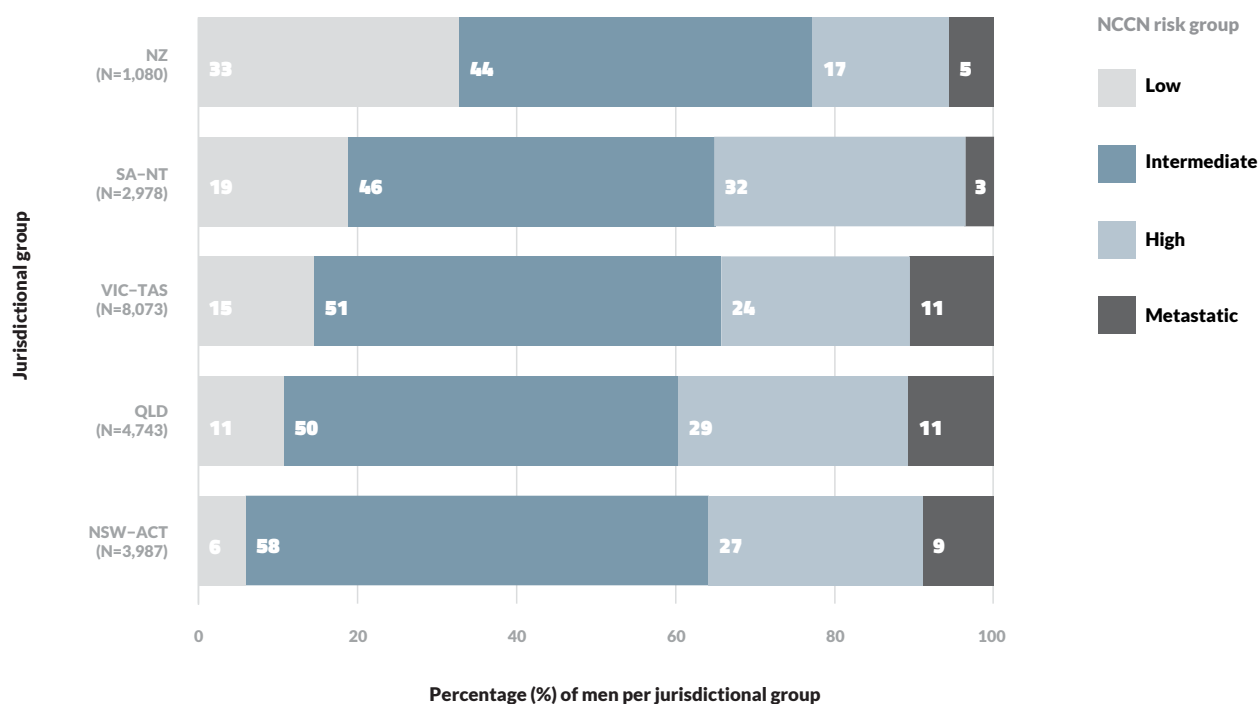
- Data on NCCN risk group at diagnosis were available for 81% (N=20,861/25,595) of men in PCOR-ANZ.
- To avoid reporting small patient numbers, and maintain patient and provider anonymity, the jurisdictional groups SA-NT, VIC-TAS, and NSW-ACT are used in this analysis.
- For simplicity, 'low' and 'very low' risk groups have been combined into one 'low' group; and 'high' and very high' risk groups have been combined in to one 'high' group.
- For details of missing data in the calculation of NCCN risk groups, see Supplementary Table S2.
- Percentages are rounded and may not add to 100%.

Prostate cancer risk level at the time of diagnosis varies between jurisdictions. Prostate cancer is most commonly low risk at the time of diagnosis in New Zealand, while South Australia and Northern Territory have the highest proportion of men diagnosed with high-to-very-high-risk disease. In all jurisdictions, intermediate-risk disease was the most common. Metastatic disease at the time of diagnosis was most commonly seen in Queensland and Victoria-Tasmania. These differences in risk at diagnosis may be attributed to differences in PSA testing practices (PSA screening and/or testing men who have no other symptoms leads to more diagnoses of low-risk disease). **(See also Supplementary Figure S4 for NCCN risk group at diagnosis across all jurisdictions.)**

NOTES

PROSTATE CANCER RISK AND NCCN RISK GROUP
– Prostate cancer risk levels are determined by a number of factors. PCOR-ANZ uses the internationally recognised National Comprehensive Cancer Network (NCCN) method of measuring risk.[26] A combination of PSA blood test results, clinical staging information and the Gleason grade or ISUP grade from a prostate biopsy are used to assign a risk level (although ISUP grade is now recommended by the NCCN,

some institutes still use the Gleason system, see Pro Tip). When deciding on treatment, risk level is considered, but other factors such as personal preference, a man's general health, age and life expectancy are also key.

The NCCN have written a comprehensive guideline for patients[27] that covers all aspects of prostate cancer including more information on risk level, which you can READ HERE

Percentage (%) of men per NCCN risk group
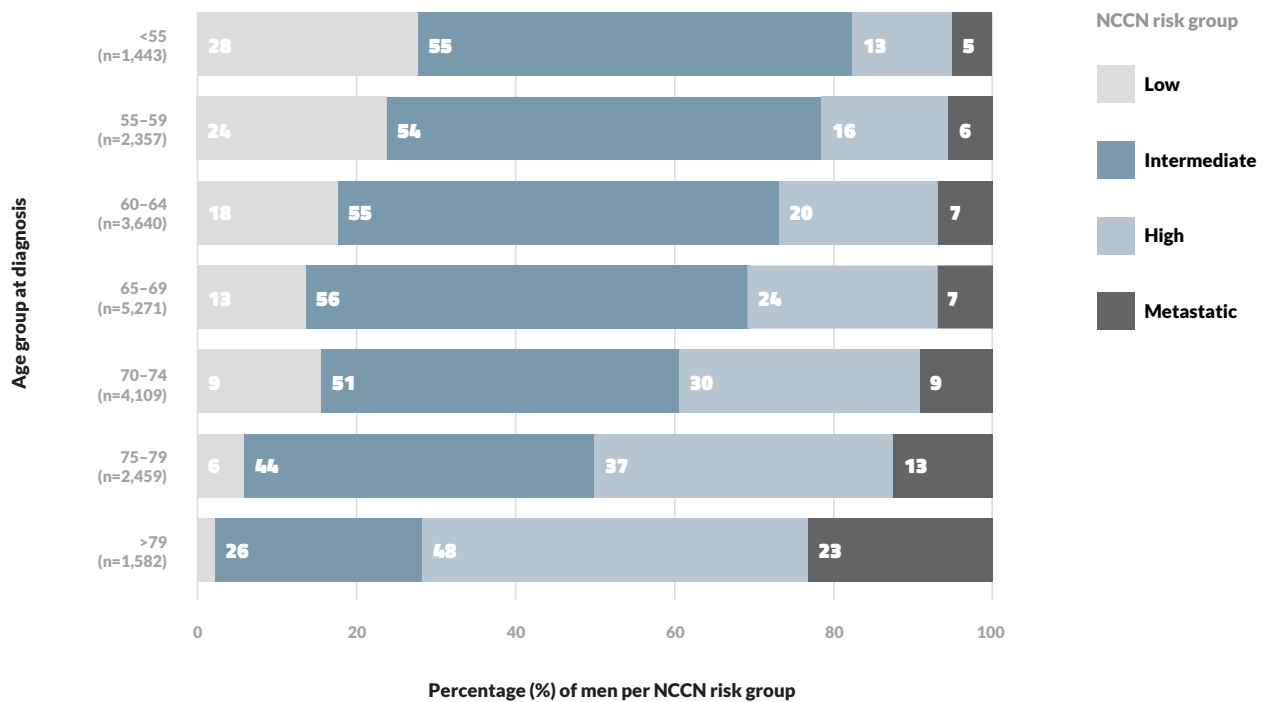
- Data on NCCN risk group at diagnosis were available for 81% (N=20,861/25,595) of men in PCOR-ANZ.
- For simplicity, 'low' and 'very low' risk groups have been combined into one 'low' group; and 'high' and very high' risk groups have been combined into one 'high' group.
- Percentages are rounded and may not add to 100%.

Age at the time of diagnosis was strongly correlated with the risk. Younger men are more likely to be diagnosed with low-risk disease, and less likely to be diagnosed with high-risk disease. The opposite is true of older men. Those aged 80 years or older at the time of diagnosis with prostate cancer are most likely to have high-risk or metastatic disease, and least likely to have low-risk disease. This same group of men are most likely to be diagnosed with prostate cancer incidentally via TURP or other methods **(Figure S3)**.

This pattern has frequently been observed, and has important implications.[28]High-risk disease is more likely to be fatal, and is therefore more important to treat than low-risk disease. Yet older men are typically less suited to surgical treatment, and may also be affected by multiple co-morbidities. This pattern highlights the need for effective treatments of high-risk disease in patients who are likely to be frail and elderly, a group sometimes neglected in a clinical-trial setting.

" I make it loud and clear to all my male friends around the same age that I get my prostate checked all the time, and do they get theirs checked, and generally the answer was no, and I said well get off your arse and get it done. Because prevention is better than medication, and if you can get early stage diagnosis, you may not require as much medication, or any. "

– Ross, 69 years, metropolitan[29]

" I think, for the ordinary bloke in the street—with people having arguments about population-level screening as opposed to individual patient management, as it were, and the interpretation of results, it's very difficult for the average person to make much sense of it, so that makes the individual relationship with the GP and the specialist so important, because you just have to trust them to interpret the information and say what's best for you. "

– Ben, metropolitan, 61 years, prostate cancer[30]

3. TREATING PROSTATE CANCER

STATISTICS AND TRENDS AT A GLANCE: TREATMENT

LOW RISK:

66% of men with low-risk disease had either active surveillance or watchful waiting. 34% of men across Australia and New Zealand chose active treatment (surgery or radiotherapy; n=1,378/4,087) and may have been over treated. In men under 60 years of age, 44% (n=516/1,166) underwent immediate surgery or radiotherapy. This is a slight increase over the 2015–2016 analysis (42%, n=354/840).[1]

INTERMEDIATE RISK:

65% of men with intermediate-risk disease had surgery, 20% had radiotherapy and 14% started active surveillance or watchful waiting.

HIGH RISK:

84% of men received treatment with curative intent (51% of men received surgery, 33% received radiotherapy); 16% opted for non-curative treatment (6% received watchful waiting or active surveillance and 10% received ADT*).

METASTATIC DISEASE:

12% of men underwent surgery and 19% had radiotherapy, with only 2% of men opting for active surveillance or watchful waiting.

ADT* was the most common choice at 67%.

*'ADT' was administered without radiotherapy or surgery, but may include men treated with chemotherapy as well as ADT. Small numbers of men who had chemotherapy alone with no recorded ADT are in this group.

PRO TIP

- In all calculations in this chapter, missing data has been excluded
- Data in this summary are across all jurisdictions
- The US NCCN risk grouping system is used by PCOR-ANZ,[24] however, to simplify this analysis:
  - 'low' and 'very-low' NCCN risk groups are combined into one 'low-risk' group
  - 'high' and 'very high' are combined into one 'high-risk' group
  - 'regional' and 'metastatic' groups have also been combined and termed 'metastatic'. This includes men with metastases to local pelvic lymph nodes ('N1' in the tumour-node-metastasis or 'TNM' system), as well as men with more distant metastatic disease ('M1').

READ MORE ABOUT THE TMN SYSTEM HERE AND VIEW THE NCCN'S PATIENT GUIDELINES HERE

ABOUT THIS ANALYSIS

This report simplifies the many combinations of treatment into four large categories in order to make the data more easily understood. Because of this, it necessarily obscures some of the details and subtleties available in our underlying data.

TREATMENT CATEGORIES

We categorise men by the first main treatment for their prostate cancer after diagnosis. This approach separates men with prostate cancer into groups with commonalities of procedure and side-effects within these groupings. The groupings are by the 'dominant' main treatment. Within these groups, disease control, side-effects, cost, and procedures are expected to be similar between men.

THE EFFECT OF SUBSEQUENT TREATMENTS

Grouping men by their first major treatment 'hides' subsequent treatments that may occur, such as radiotherapy for a proportion of men after surgery, or ADT after radiotherapy or, less commonly, surgery. This means that the cancer control and side-effects that men might experience after all their treatment is combined, is 'attributed' to one of the four main treatments. However, the actual outcome might be more validly attributed to treatments other than the first (or first 'dominant') one. Nevertheless, for men faced with a treatment choice, they must start with one of these four major categories as their main treatment, and whichever treatment they have, they might have to have further treatment. So, from the point of view of men looking at initial treatment, the broad outcomes depending on that first treatment are important, and are what we examine in this report.

TABLE 1: TREATMENT GROUPINGS USED IN THE PCOR-ANZ ANALYSIS

ANDROGEN-DEPRIVATION THERAPY (ADT)	Includes ADT as long-term treatment without any intended radical surgery or radiation therapy. Also includes some men who might have other anti-testosterone treatment or chemotherapy; and some men who received chemotherapy alone.
ACTIVE SURVEILLANCE/ WATCHFUL WAITING	Includes all men who do not have any active treatment or ADT: • 'active surveillance' • 'watchful waiting' • 'refused treatment' • 'couldn't make up their mind' • 'no treatment indicated because of more important other problems' It covers many reasons, but the fundamental characteristic is that these men are not having surgery, radiotherapy, ADT, or any other anti-prostate-cancer drug treatment.
RADIOTHERAPY	Men treated with radiotherapy without surgery first, includes: • Men treated with ADT prior to the radiotherapy, given as 'neoadjuvant' ADT, and also during the radiotherapy (concurrent ADT). This is a strategy indicated in most men with intermediate-risk and high-risk prostate cancer. • Radiotherapy includes men having brachytherapy either alone or in combination with external beam radiotherapy (EBRT).
SURGERY	Men treated with radical prostatectomy as the first treatment: • Includes men treated with surgery and then – because of concerns about the findings at surgery – treated with radiotherapy soon after. • Also includes the small group of men who might get ADT prior to the surgery.

FIGURE 8: NUMBER OF MEN IN EACH NCCN RISK GROUP AT THE POINT OF TREATMENT, BY JURISDICTIONAL GROUP (2015–2017)

Number of men
percentage (%) per group shown in bar
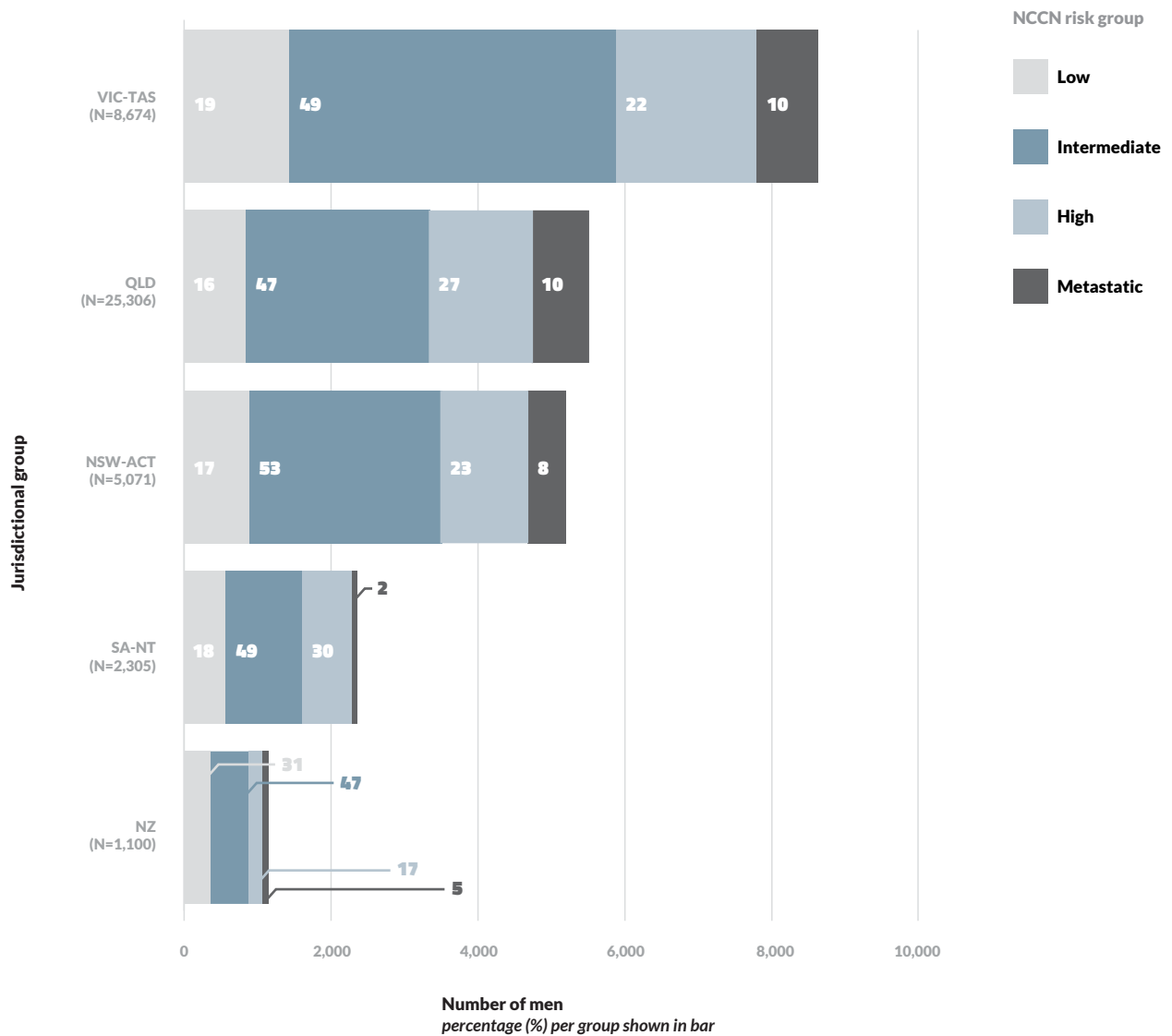
- Data on NCCN risk group at the point of primary treatment was available for 88% (N=22,456/25,595) of men in PCOR-ANZ.
- To avoid reporting small patient numbers, and maintain patient and provider anonymity, the jurisdictional groups SA-NT, VIC-TAS, and NSW-ACT are used in this analysis.
- Percentages are rounded and may not add to 100%.

NOTES

RISK CATEGORISATION – 'Risk categorisation' describes the way in which men with prostate cancer can be assigned or 'categorised' into well-defined risk groups. The men in one risk group will have prostate cancer with a predicted similar prognosis, and responsiveness to treatment. This helps guide advice and treatment. The US NCCN risk grouping system is used by PCOR-ANZ – read the Pro Tip on page 27 for more information.

PROSTATE CANCER TREATMENT – The treatment offered to a man with prostate cancer depends on many factors. The 'risk categorisation' is the strongest factor. But life-expectancy (determined by a man's age and by the presence of other medical problems) is also important.

The local availability of potential treatments will also influence treatment. Cost can sometimes be an issue – not just the cost of treatment, but also the time and money required to travel to the treatment centre, including accommodation costs if the treatment requires prolonged stays a long way from home. Treatment for men with prostate cancer can also change over time and often different treatments are combined.

READ MORE ABOUT PROSTATE CANCER AND DIFFERENT TREATMENTS IN GENERAL

HERE'S SOME MORE INFORMATION SPECIFIC TO WHETHER PROSTATE CANCER IS LOCALISED OR ADVANCED.

Percentage (%) of men per treatment group and jurisdicational group
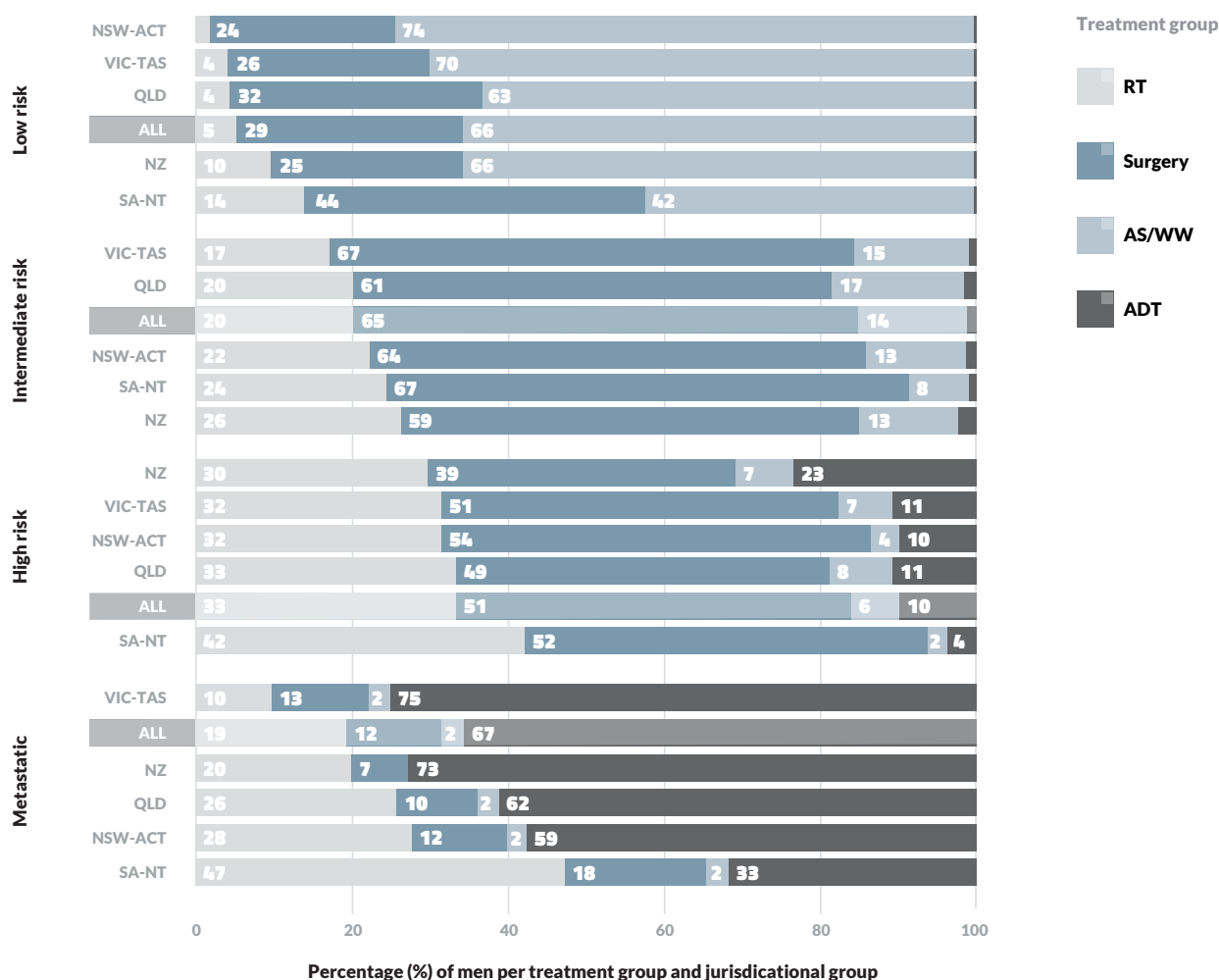
- Data on primary treatment and NCCN risk group was available for 88% (N=22,456/25,595) of men in PCOR-ANZ.
- To avoid reporting small patient numbers, and maintain patient and provider anonymity, the jurisdictional groups SA-NT, VIC-TAS, and NSW-ACT are used in this analysis.
- Jurisdictions are ordered by increasing proportion in that risk group treated with radiotherapy.
- 'ADT' was administered without radiotherapy or surgery, but may include men treated with chemotherapy as well as ADT. Small numbers of men who had chemotherapy alone with no recorded ADT are in this group.
- Metastatic disease may include patients with pelvic lymph node involvement.
- The treatment type distribution across all ANZ jurisdictions combined, and thus an average, is labelled 'ALL'.
- See Supplementary Table S3 for a summary of management provided to men by NCCN risk group including 'missing' and 'other' figures.
- Percentages are rounded and may not add to 100%.

PATTERNS OF PROSTATE CANCER TREATMENT ACROSS PCOR-ANZ

The patterns of treatment for men with prostate cancer in Australia and New Zealand **(Figure 9)** illustrate the dependency on risk grouping. Men diagnosed with metastatic disease are, in two thirds of cases, treated with ADT. In the case of men with low-risk disease, almost no men are. Active surveillance or watchful waiting is commonly used in men with low-risk disease, consistent with the view that many men with low-risk disease might not need immediate active treatment.[5,6] Active surveillance/watchful waiting becomes increasingly less common as a treatment

option as risk increases and is quite uncommon in men with metastatic disease at first diagnosis.

Across all jurisdictions, the bi-national average use of active surveillance/watchful waiting in men with low-risk disease is 66%. There is some variation from this average, with the rate in South Australia/ Northern Territory being 42%.[7] Australian and International guidelines recommend the use of active surveillance for all men with low-risk prostate cancer.[5,6] So, it is notable that 34% of men with low-risk disease receive active treatment (surgery or radiotherapy; n=1,378/4,087). This proportion increases in men under 60 years of age, of whom 44% (n=516/1,166) underwent

immediate surgery or radiotherapy in this 2015–2017 analysis. These are both slight increases over the smaller 2015–2016 cohort of men with low-risk disease, of whom 31% of men overall (n=775/2,483) and 42% of men under 60 (n=354/840) chose active treatment.[1] In our earlier report,[1] a higher proportion of the total men came from Victoria and South Australia, and so the slight increase in the total proportion of low-risk men having active treatment might reflect the addition of men from locations where active treatment for low-risk men is more prevalent than in Victoria and South Australia.

By way of comparison, data from the United States in 2015 shows an average active surveillance/watchful waiting rate of 42% in men with low-risk disease.[7] However, according to the UK's 2019 National Prostate Cancer Audit, only 4% of UK men with low-risk disease undergo radical treatment.[8] So, although a greater proportion of men in Australia and New Zealand are being managed with active surveillance than is the case in the US, other countries use active surveillance in low-risk disease more frequently. This, therefore, may be an area that requires further investigation within our region.

Surgery is the primary treatment method in 29% of all men in Australia and New Zealand first diagnosed with low-risk disease, and increases in frequency with intermediate-risk disease, to become the primary treatment in 65% of men. Surgery is employed less commonly in high-risk disease (51% of men), and in men with metastatic disease (12%). This proportion might seem high for men with 'metastatic disease', but it includes men with involved regional lymph nodes but not more-distant spread.

In high-risk prostate cancer, it is notable that 10% of men underwent ADT (with or without chemotherapy). Large, well-conducted, multicentre trials have compared the outcomes for men with higher-risk prostate cancer treated with ADT alone, or ADT plus radiotherapy.[9,10] Overall survival was significantly improved in men who underwent ADT plus radiotherapy versus those who had ADT

monotherapy; and deaths from prostate cancer were at least half as likely to occur in the ADT plus radiotherapy group. This indicates that in the high-risk group, ADT plus radiotherapy ought to be the preference. However, in a proportion of men, attempted cure with the addition of radiotherapy would not be indicated because of other factors. Nevertheless, this may be a relevant topic for further investigation.

TREATMENT DIFFERENCES BETWEEN JURISDICTIONAL GROUPS

Across Australia and New Zealand there is variation within risk groupings. For example, active surveillance/watchful waiting is more commonly employed in men with low-risk disease in New South Wales/Australian Capital Territory, and in Victoria/Tasmania; and less commonly in Queensland and South Australia/Northern Territory. Overall, 5% of men with low-risk disease are managed primarily with radiotherapy, but this varies markedly across jurisdictions, from a level of 2% in New South Wales/Australian Capital Territory, to 14% in South Australia/Northern Territory.

Treatment for men with intermediate-risk disease is more consistent across Australia and New Zealand. Surgery is used as primary treatment in 65% of men, and ranges across jurisdictions from 59% in New Zealand to 67% in South Australia/Northern Territory, and in Victoria/Tasmania. Radiation therapy is used in 20% of men with intermediate-risk disease overall, with a range from 17% in Victoria/Tasmania, to 26% in New Zealand.

In men with high-risk disease, New Zealand and South Australia/Northern Territory stand out as different from other locations. In the case of New Zealand, surgery is less frequently used in this disease category, and the difference is made up by a higher proportion of men treated with ADT. In the case of South Australia/Northern Territory, the difference is in the higher use of radiotherapy – 42% of these men are treated with radiotherapy, whereas in every other jurisdiction, this proportion is between 30 and 33%.

" Rather than put me through the side effects of having the prostate removed at my age, they thought they'd just watch it and see how it goes. **"**

– 57 years, Victoria[31]

" So there are those risks in it [the treatment]. With anything, I think you've just got to face up to it. **"**

– Malcolm, regional, 77 years, prostate cancer[30]

4. PATIENT-REPORTED OUTCOMES

STATISTICS AND TRENDS AT A GLANCE: PROMs

URINARY BOTHER:

Around 1 in 10 men (range 9–12%) report 'moderate' or 'big' problems with urinary function 12 months after treatment regardless of treatment type chosen. This includes men who choose active surveillance or watchful waiting (10%).

BOWEL BOTHER:

Only 1 in 30 men report that bowel bother is a moderate or big problem 12 months after surgery, similar to men who choose active surveillance or watchful waiting.

The rate is higher for men choosing ADT (7%) or radiotherapy (9%).

SEXUAL BOTHER:

Around 1 in 4 men have a moderate or big problem after ADT*. This is similar to men who choose AS/WW (22%).

Men are more likely to have a moderate or big problem after surgery (~2 in 5 men, 44%) and radiotherapy (1 in 3 men, 33%).

URINARY FUNCTION:

Men report similar scores for urinary function and irritation/obstruction across radiotherapy, ADT and active surveillance/watchful waiting.

After surgery, men report lower function scores (worse performance) for incontinence compared to other treatment modalities, but higher function scores (better performance) for irritation/obstruction.

BOWEL FUNCTION:

Men report similar scores for urinary function and irritation/obstruction across radiotherapy, ADT and active surveillance/watchful waiting.

SEXUAL FUNCTION:

Sexual function is rated low by men far more than either urinary or bowel function, even for men on active surveillance/watchful waiting.

Men on ADT* reported the lowest sexual function score.

There is not much variation in the effect of treatment on sexual function between PCOR-ANZ jurisdictions.

*'ADT' was administered without radiotherapy or surgery, but may include men treated with chemotherapy as well as ADT. Small numbers of men who had chemotherapy alone with no recorded ADT are in this group.

Comparing the follow-up patient-reported bother and function between treatment types is difficult, since the state of function and bother before the treatment is, on average, the most important determinant of bother and function after the treatment. For example, men with a problem with bowel function because of another longstanding condition might have the same problem with bowel function after surgery; but it likely has nothing to do with the surgery. In general, men treated with ADT or radiotherapy are older, and are more likely to have other medical and physical problems than men treated with surgery. This inevitably affects their postoperative bother and function and cannot be easily taken into account if trying to make comparisons.

BOTHER BY TREATMENT CATEGORY ACROSS PCOR-ANZ

Less than 10% of all men on active treatment reported moderate or big bowel bother overall **(Figure 10)**. Men treated with ADT (7%) or radiotherapy (9%) reported the highest frequency of bowel bother 12 months after primary treatment.

Moderate or big urinary bother was reported at similar frequencies in all four treatment groups, ranging from 9% of men treated with surgery, to 12% of men treated with active surveillance/watchful waiting **(Figure 10)**.

Moderate or big sexual bother was reported in 37% of all men followed up at twelve months after treatment. Sexual bother was most commonly reported in men who had surgery. Almost half (44%) of the men who had surgery reported moderate or big sexual bother, compared with 34% of men who had radiotherapy, 27% who had ADT and 22% who opted for active surveillance/watchful waiting.

Across all treatment categories, this data on self-reported bother is consistent with that seen in the 2018 report.[1]

BOTHER ANALYSED BY JURISDICTIONAL GROUPS

BOTHER AFTER SURGERY

For men who had surgery as their primary treatment, moderate or big bowel bother ranged in frequency from 1% of men in New Zealand to 4% of men in South Australia/Northern Territory. **(Figure 11)**. New Zealand men are least likely to report urinary bother after surgery (5%), whereas men from New South Wales/Australian Capital Territory are most likely to do so (10%). There was

little regional variation in sexual bother 12 months after surgery with moderate or big sexual bother consistently reported across all jurisdictions (range, 42–46%).

BOTHER AFTER RADIOTHERAPY

Bowel bother was most commonly reported in men who had radiotherapy. The highest frequencies of bowel bother after radiotherapy were reported by men from New Zealand (13%) and the lowest frequencies by men from New South Wales/Australian Capital Territory and South Australia/Northern Territory (both 8%; **Figure 11**).

The frequency of moderate-to-big urinary bother ranged between jurisdictions, with the highest frequency of urinary bother reported by men from Queensland and lowest frequency of bother by men from New South Wales/Australian Capital Territory. Thirty-four percent of men treated with radiotherapy reported moderate-to-big sexual bother. The lowest frequency of bother was reported by men from Victoria/Tasmania and the highest frequency by men from Queensland and South Australia/Northern Territory (41%).

BOTHER AFTER AS/WW

Bowel bother after AS/WW is reported on average by 7% of men in PCOR-ANZ, ranging from 6% in Queensland to 9% in South Australia/Northern Territory. More variation in bother scores between jurisdictions is seen for urinary bother (11% in Victoria/Tasmania to 17% in South Australia/Northern Territory). Sexual bother shows variation between jurisdictions from 21% in Victoria/Tasmania to 39% in Queensland and South Australia/Northern Territory. These differences are intriguing as AS/WW does not initially include a medical intervention. Differences may represent variation in patient symptoms when first diagnosed.

BOTHER AFTER ADT

Bother scores across the bowel and urinary domains showed some variation following ADT treatment. Queensland had the lowest average bowel bother (2%) with South Australia/Northern Territory being the highest (7%). South Australia/Northern Territory also had the highest urinary bother at 22% on average with Victoria/Tasmania being the lowest (9%).

After ADT, the highest proportion of men were concerned about sexual bother (22%), although this showed less jurisdictional variation (19–28%).

FIGURE 10: PATIENT-REPORTED BOTHER 12 MONTHS AFTER TREATMENT, ACROSS ALL JURISDICTIONS, BY TREATMENT TYPE (2015–2017)
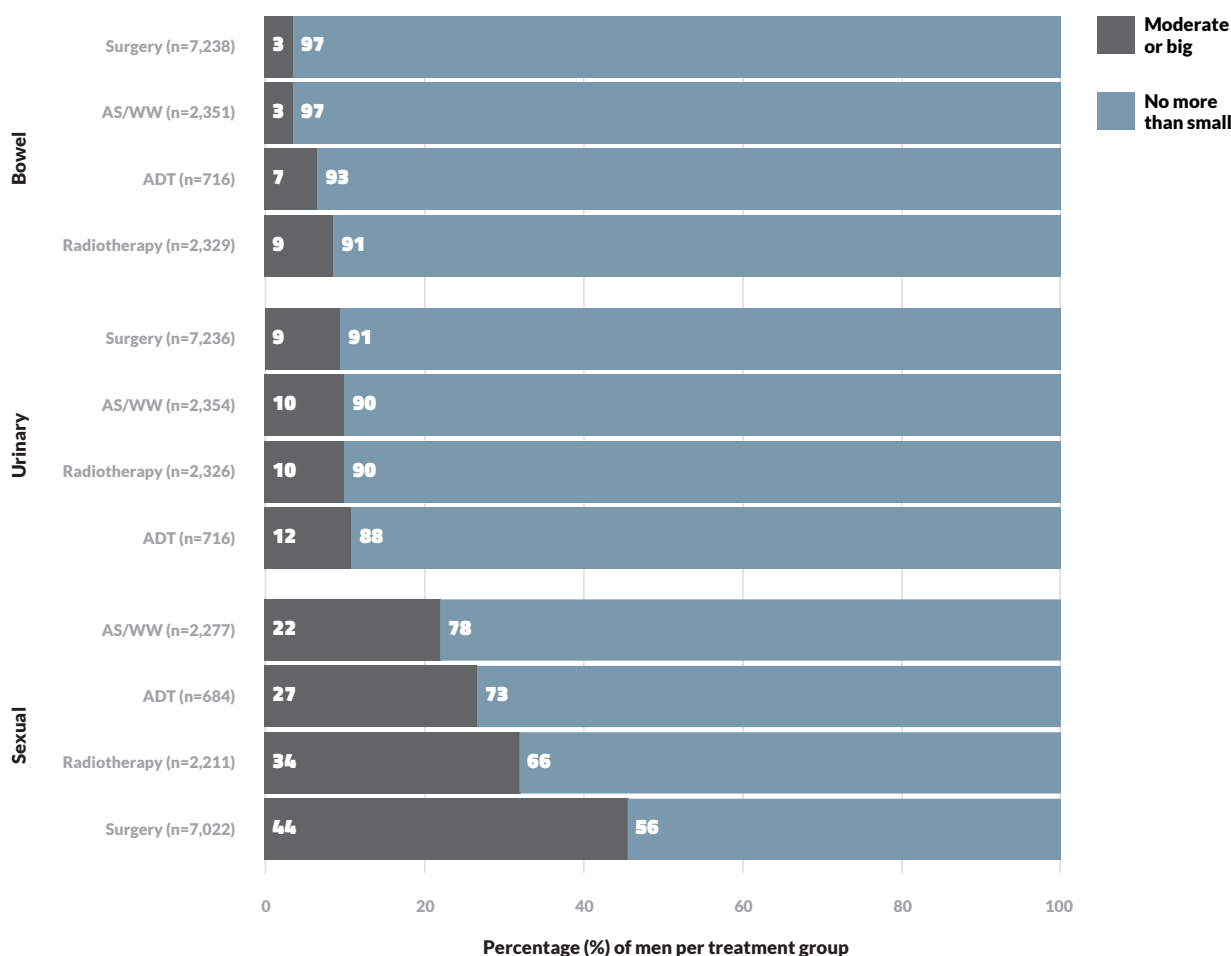
- The 'EPIC-26' instrument was used.
- 'No bother', 'very small bother' and 'small bother' have been combined into one category; 'big bother' and 'moderate bother' have been combined into another.
- For ease of comparison, for each side-effect category treatment groups are arranged in increasing proportion of subsequent reported bother.
- 'ADT' was administered without radiotherapy or surgery, but may include chemotherapy; this group also includes a minority of men receiving chemotherapy alone.
- See Supplementary Table S4 for follow-up methodology and quality of life completion rates.
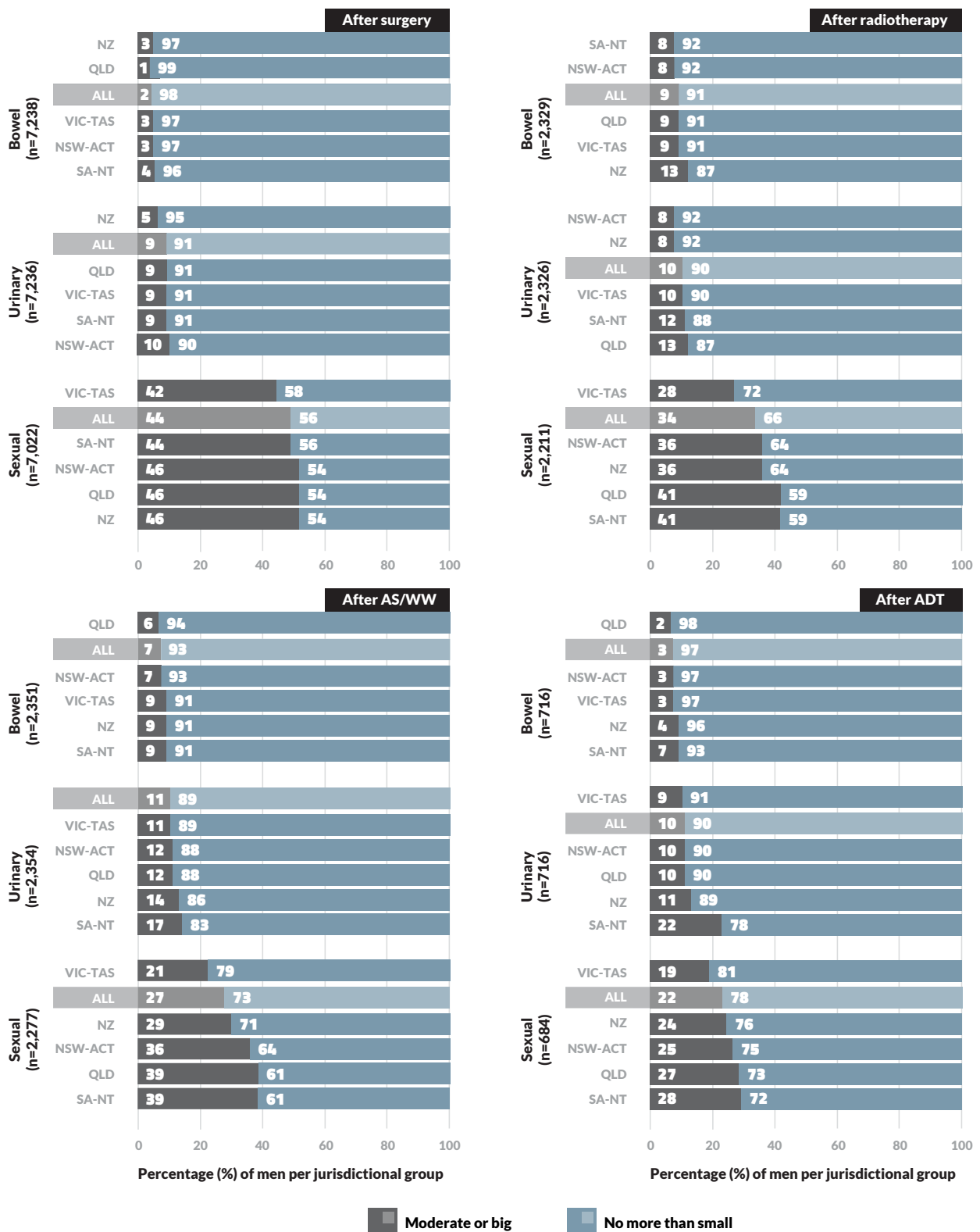- Percentages are rounded and may not add to 100%.

NOTES

WHAT'S THE DIFFERENCE BETWEEN 'BOTHER' AND 'FUNCTION'?

Men in PCOR-ANZ are asked to report bother and function scores by answering the EPIC-26 questionnaire 12 months after treatment. We analyse three specific domains of urinary, bowel and sexual bother and function. Men are asked to rate how much of a problem they are having with each of these areas in the four weeks prior to the survey.

For 'bother' scores, the EPIC-26 questionnaire asks men to rate their side effects as giving them 'no problem' 'very small' 'small' 'moderate' or 'big' problems. In this way, the question measures how much any symptoms a man might be experiencing are interfering with his life.

The function part of the EPIC-26 questionnaire asks more specific questions about particular symptoms, such as 'leaking urine', 'increased frequency of bowel movements', 'ability to have an erection' and so on. These 'function' scores do not necessarily correlate with the 'bother' scores. For example, one man may be experiencing leaking urine more than once a week (function), but he has learned how to manage it and does not find it a particular problem in his life, so he marks it as a 'very small problem' (bother). Another man may find this same level of urine leaking to be more concerning for him and he may mark it as a moderate or big problem.

FIGURE 11: **PATIENT-REPORTED BOTHER 12 MONTHS AFTER PRIMARY TREATMENT BY JURISDICTIONAL GROUP (2015-2017)**

After surgery

Bowel (n=7,238)
Group	Moderate or big	No more than small
NZ	3	97
QLD	1	99
ALL	2	98
VIC-TAS	3	97
NSW-ACT	3	97
SA-NT	4	96

Urinary (n=7,236)
Group	Moderate or big	No more than small
NZ	5	95
ALL	9	91
QLD	9	91
VIC-TAS	9	91
SA-NT	9	91
NSW-ACT	10	90

Sexual (n=7,022)
Group	Moderate or big	No more than small
VIC-TAS	42	58
ALL	44	56
SA-NT	44	56
NSW-ACT	46	54
QLD	46	54
NZ	46	54

After radiotherapy

Bowel (n=2,329)
Group	Moderate or big	No more than small
SA-NT	8	92
NSW-ACT	8	92
ALL	9	91
QLD	9	91
VIC-TAS	9	91
NZ	13	87

Urinary (n=2,326)
Group	Moderate or big	No more than small
NSW-ACT	8	92
NZ	8	92
ALL	10	90
VIC-TAS	10	90
SA-NT	12	88
QLD	13	87

Sexual (n=2,211)
Group	Moderate or big	No more than small
VIC-TAS	28	72
ALL	34	66
NSW-ACT	36	64
NZ	36	64
QLD	41	59
SA-NT	41	59

After AS/WW

Bowel (n=2,351)
Group	Moderate or big	No more than small
QLD	6	94
ALL	7	93
NSW-ACT	7	93
VIC-TAS	9	91
NZ	9	91
SA-NT	9	91

Urinary (n=2,354)
Group	Moderate or big	No more than small
ALL	11	89
VIC-TAS	11	89
NSW-ACT	12	88
QLD	12	88
NZ	14	86
SA-NT	17	83

Sexual (n=2,277)
Group	Moderate or big	No more than small
VIC-TAS	21	79
ALL	27	73
NZ	29	71
NSW-ACT	36	64
QLD	39	61
SA-NT	39	61

After ADT

Bowel (n=716)
Group	Moderate or big	No more than small
QLD	2	98
ALL	3	97
NSW-ACT	3	97
VIC-TAS	3	97
NZ	4	96
SA-NT	7	93

Urinary (n=716)
Group	Moderate or big	No more than small
VIC-TAS	9	91
ALL	10	90
NSW-ACT	10	90
QLD	10	90
NZ	11	89
SA-NT	22	78

Sexual (n=684)
Group	Moderate or big	No more than small
VIC-TAS	19	81
ALL	22	78
NZ	24	76
NSW-ACT	25	75
QLD	27	73
SA-NT	28	72

Percentage (%) of men per jurisdictional group

Legend: ■ Moderate or big   ■ No more than small

- To avoid reporting small patient numbers, and maintain patient and provider anonymity, the jurisdictional groups SA-NT, VIC-TAS, and NSW-ACT are used in this analysis.
- The 'EPIC-26' instrument was used.
- 'No bother', 'very small bother' and 'small bother' have been combined into one category; 'big bother' and 'moderate bother' have been combined into another.
- For ease of comparison, for each side-effect category treatment groups are arranged in increasing proportion of subsequent reported bother.
- 'ADT' was administered without radiotherapy or surgery, but may include chemotherapy; this group also includes a minority of men receiving chemotherapy alone.
- See Supplementary Table S5 for number of responses to the EPIC-26 questionnaire by jurisdictional group and primary treatment.
- Percentages are rounded and may not add to 100%.
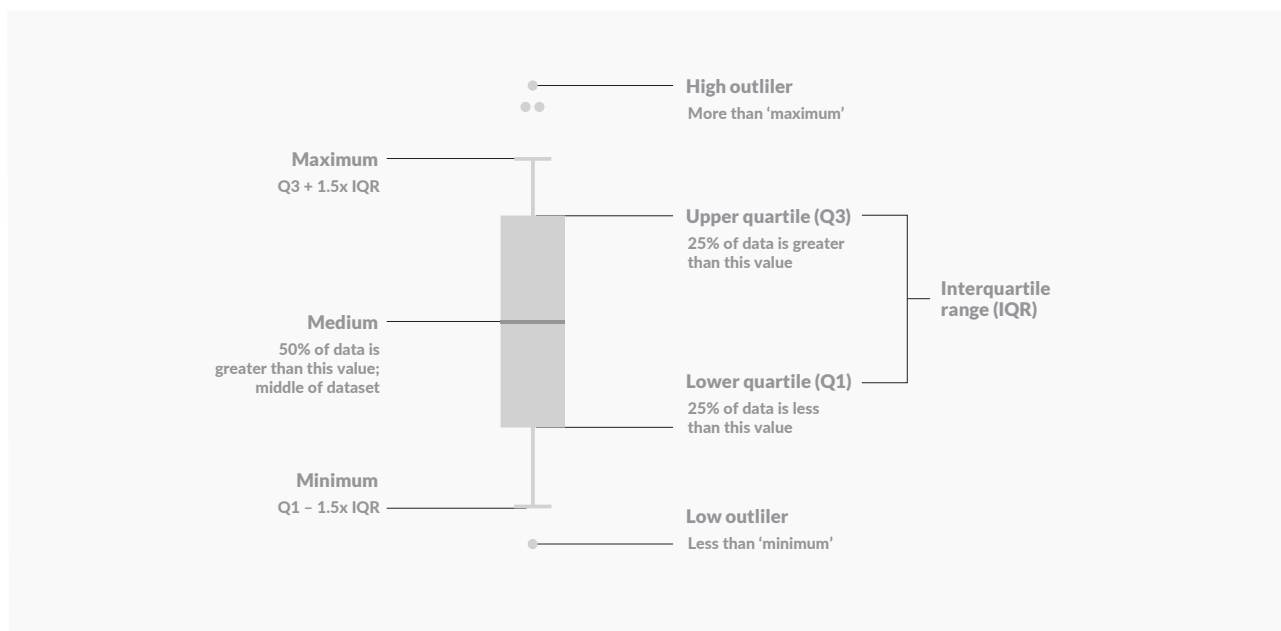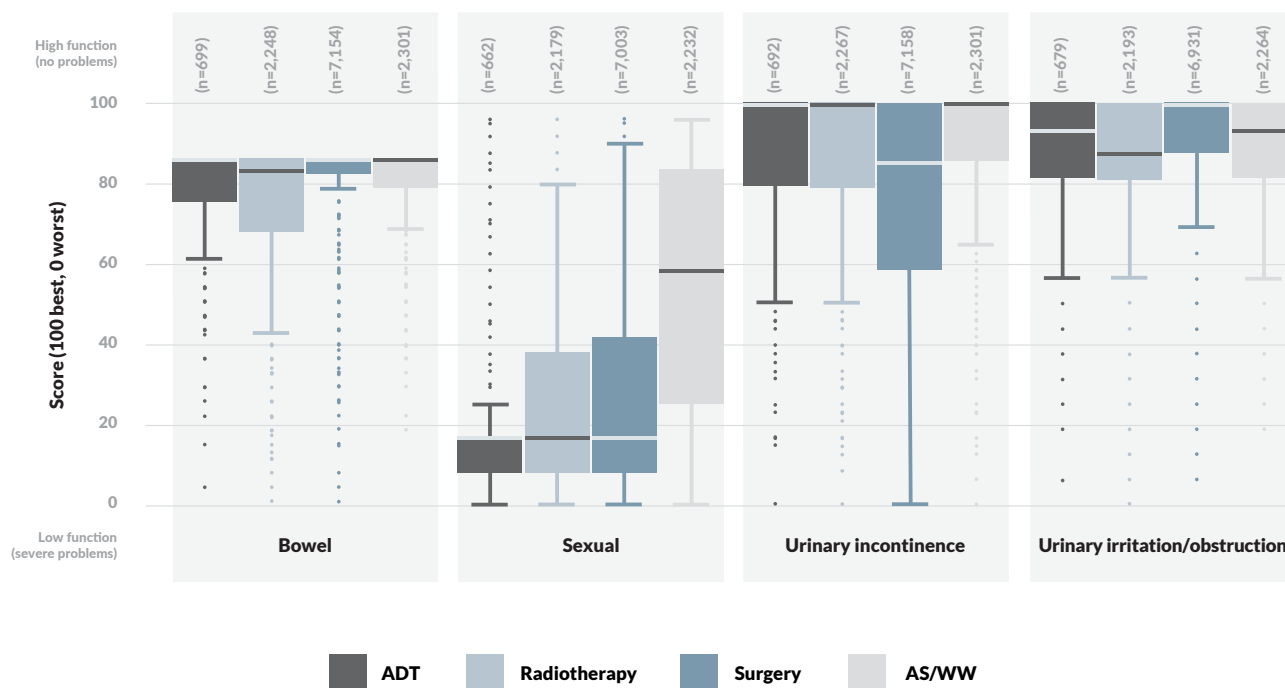
FIGURE 12: HOW TO INTERPRET A BOX PLOT

High outliler
More than 'maximum'

Maximum
Q3 + 1.5x IQR

Upper quartile (Q3)
25% of data is greater
than this value

Interquartile
range (IQR)

Medium
50% of data is
greater than this value;
middle of dataset

Lower quartile (Q1)
25% of data is less
than this value

Minimum
Q1 – 1.5x IQR

Low outliler
Less than 'minimum'

FIGURE 13: PATIENT-REPORTED FUNCTION
12 MONTHS AFTER PRIMARY TREATMENT ACROSS ALL JURISDICTIONS (2015–2017)

High function (no problems)

Score (100 best, 0 worst)

Low function (severe problems)

| Bowel | Sexual | Urinary incontinence | Urinary irritation/obstruction |

Legend: ADT, Radiotherapy, Surgery, AS/WW

- The 'EPIC-26' instrument was used.
- In each of the 'domains' of bowel function, sexual function, urinary irritation and urinary incontinence, scores range from 0 (worst) to 100 (best). Response options for each EPIC item form a Likert scale, and multi-item scale scores are transformed linearly to a 0-100 scale, with higher scores representing better health-related quality of life
- No adjustment can be made for pre-diagnosis function, so comparisons between treatments may be affected by differences in groups prior to treatment.
- 'ADT' was administered without radiotherapy or surgery, but may include chemotherapy; this group also includes a minority of men receiving chemotherapy alone.
- For information on number of responses per domain and treatment groups, see Supplementary Table S5.

Figure 13 provides an overall summary of bowel, sexual and urinary function 12 months after surgery, radiotherapy, ADT and following initiation of active surveillance/watchful waiting. Sexual function is the most significant area where men report functional impact.

SEXUAL FUNCTION

It is clear that sexual function is often impacted after treatment and that this occurs across surgery, radiotherapy and ADT. Even men who have no active treatment report sexual function scores that are not perfect. This likely reflects age-related changes in sexual function and varies considerably in this sample of men. Overall, ADT appears to affect men most significantly. Although ADT is reportedly used most often in men over 80 years old **(see Figures 5 and 6)**, without an age-matched baseline, it's difficult to know if this is a treatment- or age-related effect. The differences at 12 months are unlikely to be clinically notable between the ADT group, compared with either surgery or radiotherapy, though they are clinically different compared with those men managed by active surveillance/watchful waiting group. On average, there is no clinically important difference in sexual function at 12 months when men who had surgery are compared with men who had radiotherapy. But bear in mind, generally when men are studied before any treatment, men who go on to have surgery have better sexual function, compared with men who go on to have radiotherapy or no treatment. These men, having other treatments, turn out to have poorer sexual function to begin with.[11] This is because men selected for surgery are younger and have a good general level of health to enable a major procedure. Patients unfit for surgery are more likely to be referred for radiotherapy or have no treatment. In addition, many men treated with radiotherapy in Australia and New Zealand also receive temporary ADT with the radiotherapy, and will be on this—or have recently ceased it—when the questionnaire is done. A proportion of these men treated with radiotherapy and ADT will see a reduction in sexual bother and improvement in function with longer follow up.[32]

URINARY FUNCTION

For urinary irritation/obstruction at 12 months, there would appear to be a clinically important difference, on average, between the men treated with surgery and the men treated with radiotherapy – with more irritation reported by the radiotherapy group. Those treated with ADT or AS/WW showed reduced function compared with surgery, but not to the extent of radiotherapy. In the case of incontinence, men treated with surgery report more incontinence and this is a clinically important difference compared with all three other treatment groups.

BOWEL FUNCTION

Historically, bowel function has been expected to be compromised by prostate cancer treatment, particularly by radiotherapy. In this data set, there is no clinically important difference on average between the groups at 12 months, though those treated with radiotherapy show greater variation than other treatment groups. This observation is similar to recent studies following patients using the same survey for a period of five years.[11]

PRO TIP

The EPIC-26 questionnaire asks a range of questions about symptoms which are specific to prostate cancer treatment. Each response is given a score, and then scores are aggregated into separate domain summary scores for: urinary incontinence, urinary irritation/obstruction, bowel and sexual function.

For each domain, a score of 100 represents best possible health and a score of 0 represents worst possible health. These scores are reported for each of the main treatment groups of prostate cancer. On the range from 0–100, small differences in scores are not noticeable to men: scores of 0 and 1 are practically the same; as would be scores of 49 and 50, or 99 and 100. Research suggests that the minimum 'clinically important' differences (i.e. the smallest differences that patients will notice) are scores of:[33]

- 10 to 12 for sexual function
- 6 to 9 for urinary incontinence
- 5 to 7 for urinary irritation
- 4 to 6 for bowel function

PCOR-ANZ FUNCTION SCORES IN CONTEXT

All domains showed considerable variation in the degree of function reported by individual participants (with the exception of bowel function after surgery). To date, PCOR-ANZ does not collect baseline function measures, which have been reported to be key determinants of post-treatment performance. This data is not currently feasible to collect at a population level across all PCOR-ANZ jurisdictions. The ProtecT trial reports baseline PROMs taken for men aged 50–69 years with localised prostate cancer prior to randomised allocation to active surveillance (n=545), surgery (n=553) or radiotherapy (n=545).[34] In this cohort of men, the baseline scores were good for the bowel, urinary incontinence and urinary irritation domains, but poor for the sexual domain. While this trial is restricted to men with localised disease, has not reported all domain scores, and does not include hormonal treatment, it does give some indication as to how men may have functioned across PCOR-ANZ prior to treatment. The study data is taken from a group of men in the UK, so there may be some variation with the population of Australia and New Zealand.[34]

Another recently published clinical trial in men with localised prostate cancer[11] used the EPIC-26 questionnaire to evaluate men's symptoms at baseline through to five years after treatment. This cohort of men were from the United States and aged 59–70. Those with favourable-risk disease received treatment with active surveillance (n=363), nerve-sparing prostatectomy (n=675), EBRT (n=261), or low-dose-rate brachytherapy (n=87); men with unfavourable-risk disease had treatment with prostatectomy (n=402) or EBRT with ADT (n=217). A similar range of baseline scores were seen in this trial, with low scores only being reported in the sexual domain before treatment began.

Encouragingly, over five years, most of the side effects that men reported as problems eventually went back to normal, with only two particular exceptions. Men who had a prostatectomy reported clinically important worse incontinence after five years compared with all other options. And men who had a prostatectomy for unfavourable-risk disease reported worse sexual function at five years compared with men who underwent EBRT with ADT.[11]

NOTES

### WHAT QUESTIONS ARE ASKED IN EPIC-26?[35,36]

SEXUAL FUNCTION – men are asked to self-report problems associated with having an erection, reaching orgasm, and the quality and frequency of erections.

URINARY FUNCTION – this domain is divided into two components, urinary irritation/obstruction and urinary incontinence.

- Urinary irritation/obstruction is assessed through questions relating to pain or burning on urination, bleeding on urination, weakness of the urine stream and the need to urinate frequently during the day.

- Urinary incontinence focuses on the extent to which men self-report having leakage of urine, control of urine, the number of pads required per day and dripping.

BOWEL FUNCTION – men are asked to report urgency to have a bowel movement, increased frequency of bowel movements, losing control of stools, bloody stools, and abdominal, rectal or pelvic pain.

FIGURE 14: PATIENT-REPORTED FUNCTION, 12 MONTHS AFTER PRIMARY TREATMENT ACROSS ALL JURISDICTIONS (2015–2017)
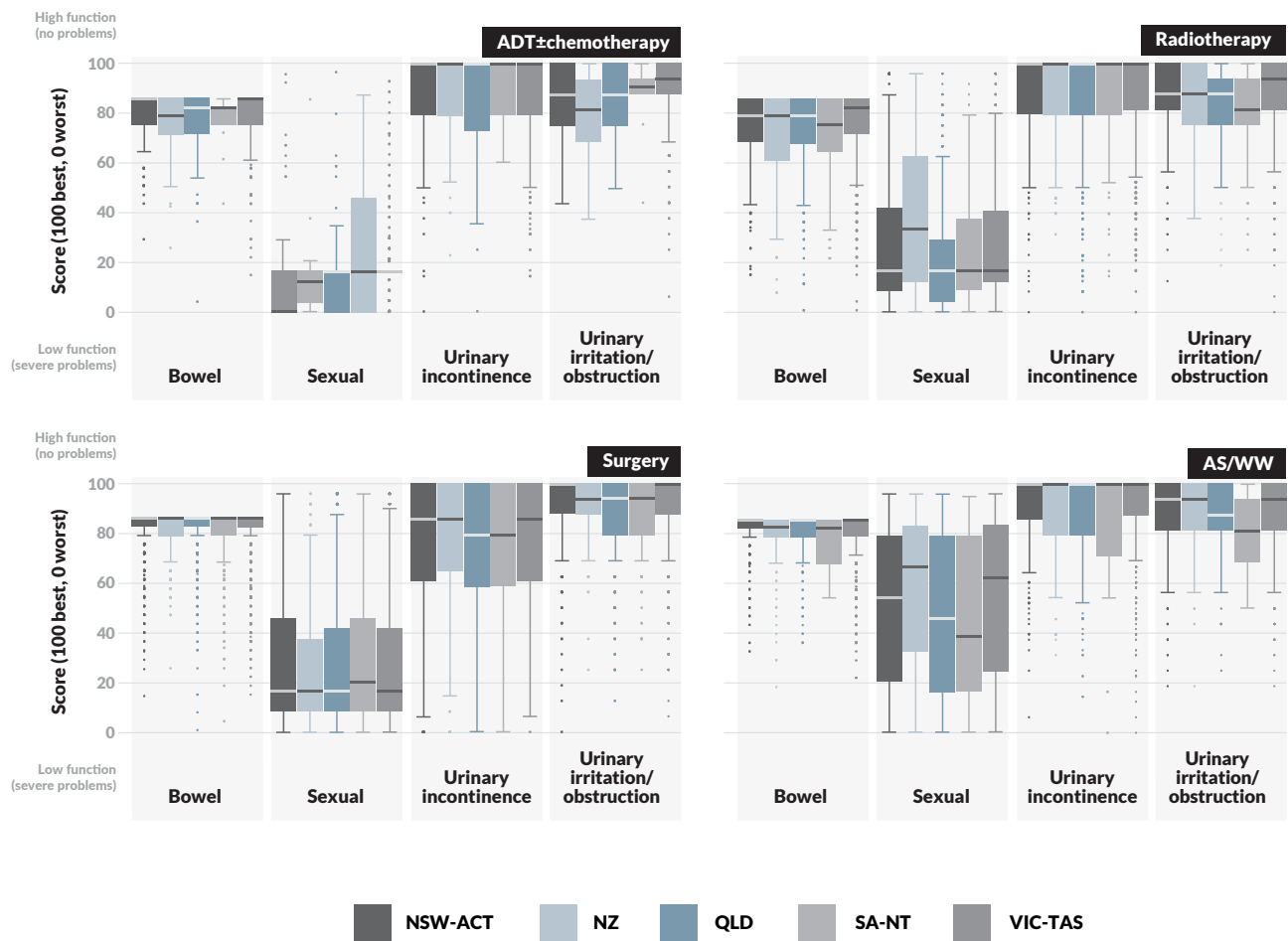
- To avoid reporting small patient numbers, and maintain patient and provider anonymity, the jurisdictional groups SA-NT, VIC-TAS, and NSW-ACT are used in this analysis.
- The 'EPIC-26' instrument was used.
- In each of the 'domains' of bowel function, sexual function, urinary irritation and urinary incontinence, scores range from 0 (worst) to 100 (best).
- No adjustment can be made for pre-diagnosis function, so comparisons between treatments may be affected by differences in groups prior to treatment.
- 'ADT' was administered without radiotherapy or surgery, but may include chemotherapy; this group also includes a minority of men receiving chemotherapy alone.
- For information on number of responses per domain and treatment groups, see Supplementary Table S5.

TONY WALKER – WHY ARE PROMs IMPORTANT?

I know when I was diagnosed with prostate cancer that the questions came thick and fast. How do I know what the best treatment is for me? What will life be like after my treatment? What types of side-effects can I expect and how common are they? What impact will my diagnosis and treatment have on my mental health and relationships?

As a health professional I was fortunate enough to be able to speak to the right people and get good advice to help me make the right decisions, but I know this is not the experience of all men and their families following a diagnosis.

This is where Patient Report Outcome Measures, or PROMs, come in. PROMs are questionnaires that ask for information about health outcomes from a patient's perspective. In the case of men diagnosed with prostate cancer this includes level of pain, urinary, bowel and sexual problems, the most common side effects of treatment and their mental health and quality of life over time.

PROMs help healthcare providers, and the healthcare system as a whole, learn about health outcomes that matter to us as patients. At the end of the day, good healthcare outcomes are not just about treatments we receive being clinically successful, but importantly include having our symptoms managed, being able to do the things we like to do, and minimising the impact of our health conditions and treatments on our everyday lives.

I'd definitely encourage all men diagnosed with prostate cancer to complete a PROM questionnaire if asked by their healthcare provider. By completing a PROM, you can help improve communication between you and your healthcare provider. This can let them know more about your condition and how treatment is affecting you, which can help you and your healthcare provider decide whether changes to your treatment may be required. They can also help you and your healthcare provider track your progress over time and compare your outcomes with those of other similar patients. Importantly, it can also help you make informed decisions about your treatment.

ASSOCIATE PROFESSOR TONY WALKER ASM
(CONSUMER REPRESENTATIVE)

> **It's essential to [talk] and not really great drama [because] when we look at the ladies in our life they've had to endure much worse.**
>
> – Simon, 61 years, regional.
> (speaking about how Australian men
> tend to brush health concerns aside)[29]

> **So there are those risks in it [the treatment]. With anything, I think you've just got to face up to it.**
>
> – Domenico, 81 years, metropolitan, prostate cancer.
> (speaking about reduced sexual function)[30]

5. FUTURE DIRECTIONS

Movember is committed to the long-term support of PCOR-ANZ in order to maximise the value that the registry delivers to men in Australia and New Zealand. A number of initiatives are underway to help realise this value.

INITIATIVES

QUALITY INDICATOR REPORTS:

Reporting quality indicators for surgery will continue in each jurisdiction.
This process is set to become a routine activity moving forwards.

Expansion of quality indicator reporting to radiation therapy. A working group has been convened to select the indicators for reporting and optimise the presentation of these reports.

We can now begin tracking the impact that quality indicator reporting has across Australia and New Zealand and identifying how each metric can drive positive changes. This work will initially follow international leaders in this space particularly from the Michigan Urological Surgery Improvement Collaborative (MUSIC).[37]

REGISTRY COVERAGE:

A key objective will be to increase the number of men recruited to the registry. Many jurisdictions have achieved population coverage (over 90% recruitment of new cases) and we are working towards all jurisdictions meeting this goal.

Expanding the jurisdictions of the Registry to recruit men in Western Australia has progressed well in the past 12 months and a collaboration is expected to be in place shortly.

RESEARCH:

In addition to benchmarking the standard of care in Australia and New Zealand, PCOR-ANZ provides a data repository for research efforts, particularly around delivery of quality care. In 2019, six new projects projects were funded by Movember and are set to deliver increased value for the registry in the future (see **'Table 2'** on next page).

REGISTRY OPERATIONS:

Movember is currently seeking a new provider of registry software to support the increasingly complex activities of PCOR-ANZ. The new platform is expected to be selected and implemented in 2020. This presents an excellent opportunity for PCOR-ANZ to build on past successes and remain at the cutting edge of technology moving forwards. The new platform will maintain the current high levels of security and help achieve data-collection efficiencies.

TABLE 2: RESEARCH PROJECTS FUNDED BY MOVEMBER IN 2019

PROJECT	RESEARCH TEAM
Less is More – Evaluating and Enhancing the Adoption of Short-course Radiotherapy in Australia (EASY-AUS).	David Pryor, Farhan Syed, Liesel FitzGerald, Jarad Martin, Jeremy Millar, Wee Loon Ong, Marketa Skala, Heather Day, Sandra Turner, Amy Hayden, Raymond Chan.
Clinician-level quality of care reports - dealing with the complex issue of outliers.	Sue Evans, Peter Heathcote, Mark Frydenberg, Stephen Mark, Jane Fisher, Maggie Kirkman, David Currow.
Identifying clinician-related barriers to active surveillance for low-risk prostate cancer in Australia and New Zealand.	Nathan Lawrentschuk, Isaac Thangasamy, Wee Loon Ong, Declan Murphy, Elizabeth Pritchard, Susan Evans, Jeremy Millar, Venu Chalasani, Prem Rashid, Matthew Winter, Ian Vela, David Pryor, Stephen Mark.
Evaluating the benefits, harms and cost-effectiveness of variation in compliance with best practice guidelines for the treatment of localised prostate cancer.	David Smith, Manish Patel, Shomik Sengupta, Ian Vela, Andrew Kneebone, Henry Woo, Sue Evans, Michael O'Callaghan, Dominic Cancian, Karen Canfell, Karen Chiam, Michael Caruana.
Predicting Urinary Incontinence and Erectile Dysfunction after Prostate Cancer Surgery.	Kim Moretti, Michael O'Callaghan, Andrew Vincent, Kerri Beckmann, David Smith, Stephen Mark, Mark Frydenberg, Sue Evans, Jude Clarke, Scott Walsh, Tina Kopsaftis, Melanie Evans, David Merry.
Real time App for PCOR-ANZ results: Proof of concept and value to Urologists.	Stephen Mark, Steve Brough, Mark Frydenberg, Kevin Bax, Jude Clarke, Frank Frizelle, Mark Weston, Sue Evans, Andrew Runting, Michael Nugara

REFERENCE MATTER

PCOR-ANZ PUBLICATIONS 2018–2019

A full list of publications and abstracts can be found on the PCOR-ANZ website (https://prostatecancerregistry.org/). Peer-reviewed publications for the period 2018–2019 follow.

Earnest, A., Evans, S. M., Sampurno, F., & Millar, J. Forecasting annual incidence and mortality rate for prostate cancer in Australia until 2022 using autoregressive integrated moving average (ARIMA) models. BMJ Open 2019 9:e031331.

Hoque, D.M.E., Earnest, A., Ruseckaite, R., Lorgelly, P., Sampurno F., Evans, M., Evans, S.M. A randomised controlled trial comparing completeness of responses of three methods of collecting patient-reported outcome measures in men diagnosed with prostate cancer. Qual Life Res. 2019 28(2): 687-694.

Kannan A, Kirkman M, Ruseckaite R, Evans SM. Prostate cancer awareness, case-finding, and early diagnosis: Interviews with undiagnosed men in Australia. PLoS One. 2019 Mar7; 14(3):e0211539. DOI: 10.1371/journal.pone.0211539.

Kerri Beckmann, Michael O'Callaghan, Andrew Vincent, Penelope Cohen, Martin Borg, David Roder, Sue Evans, Jeremy Millar, Kim Moretti. Extent and predictors of grade upgrading and downgrading in an Australian cohort according to the new prostate cancer grade groupings: Asian Journal of Urology, March 2019.

Michelle Forgione, Sally Sara, Andrew D. Vincent, Martin Borg, Kim Moretti, Michael E. O'Callaghan. Satisfaction with care in men with prostate cancer: European Journal of Cancer Care. Eur J Cancer Care. 2019;28:e13028.

Ong W.L., Evans S.M., Evans M., Tacey M., Dodds L., Kearns P., Milne R.L., Fouroudi F., Millar J. Trends in Conservative Management for Low-risk Prostate Cancer in a Population-based Cohort of Australian Men Diagnosed Between 2009 and 2016. European Urology Oncology. 2019. Article in Press. May. https://doi.org/10.1016/j.euo.2019.04.006

REFERENCE LIST

1. Evans S.M., Tikellis G., Brooks A, Currow D., Davis I.D., Delprado W., Frizelle F, Frydenberg M., Heathcote P., James E., Marks S., McNeil J.J., Miller C, Millar J.L., Moretti K., Pryor D., Roder D., Skala M., Smith D., Villanti P., Walker A., White C. 2018. Prostate Cancer Outcomes Registry-Australia and New Zealand Report 2018. Reporting on data 2015–2016. Melbourne, VIC: Monash University & Movember; Feb 2019.

2. Cancer Australia. Prostate cancer in Australia statistics [Internet]. Strawberry Hills, NSW: Australian Government, 2019 August 26 [cited 2010 Jan 31]. Available from https://prostate-cancer.canceraustralia.gov.au/statistics

3. Ministry of Health New Zealand. Prostate Cancer Awareness and Quality Improvement Programme: Improving outcomes for men with prostate cancer [Internet]. Wellington, NZ: NZMOH; 2013 May [cited 2020 Feb 14]. Available from https://www.health.govt.nz/system/files/documents/publications/prostate-cancer-awareness-and-quality-improvement-programme-v2.pdf

4. Grummet J, Gorin MA, Popert R, O'Brien T, Lamb AD, Hadaschik B et al. "TREXIT 2020": why the time to abandon transrectal prostate biopsy starts now. Prostate Cancer Prostatic Dis [Internet]. 2020 Jan 13 [cited 2020 Feb 3]. doi: 10.1038/s41391-020-0204-8. [Epub ahead of print]

5. Briganti A, Fossati N, Catto JWF, et al. Active surveillance for low risk prostate cancer: The European Association of Urology Position in 2018. Eur Urol. 2018 Sep;74(3):357–368.

6. Prostate Cancer Foundation of Australia and Cancer Council Australia, PSA Testing Guidelines Expert Advisory Panel. Clinical practice guidelines. PSA testing and early management of test-detected prostate cancer [Internet]. Sydney, NSW: PCFA-CCA 2016 Jan 20 [cited 2020 Feb 3]. Available from wiki.cancer.org.au/psaguidelines

7. Mahal BA, Butler S, Franco I, Spratt DE, Rebbeck TR, D'Amico AV et al. Use of Active Surveillance or Watchful Waiting for Low-Risk Prostate Cancer and Management Trends Across Risk Groups in the United States, 2010–2015. JAMA. 2019 Feb 19;321(7):704–706.

8. National Prostate Cancer Audit. Annual Report 2019. Results of the NPCA Prospective Audit in England and Wales for men diagnosed from 1 April 2017 – March 2018 [Iinternet]. NPCA; 2020 Jan 9. Report No.: 6. Available at https://www.npca.org.uk/reports/

9. Fosså SD, Wiklund F, Klepp O, Angelsen A, Solberg A, Damber J-E, et al. Ten- and 15-yr Prostate Cancer-specific Mortality in Patients with Nonmetastatic Locally Advanced or Aggressive Intermediate Prostate Cancer, Randomized to Lifelong Endocrine Treatment Alone or Combined with Radiotherapy: Final Results of The Scandinavian Prostate Cancer Group-7. Eur Urol. 2016 Oct;70(4):684–691.

10. Mason MD, Parulekar WR, Sydes MR, Brundage M, Kirkbride P, Gospodarowicz M, et al. Final Report of the Intergroup Randomized Study of Combined Androgen-Deprivation Therapy Plus Radiotherapy Versus Androgen-Deprivation Therapy Alone in Locally Advanced Prostate Cancer. J Clin Oncol. 2015 Jul 1;33(19):2143–50.

11. Hoffman KE, Penson DF, Zhiguo Z, Huang L-C, Conwill R, Laviana AA, et al. Patient-Reported Outcomes Through 5 Years for Active Surveillance, Surgery, Brachytherapy, or External Beam Radiation With or Without Androgen Deprivation Therapy for Localized Prostate Cancer. JAMA. 2020 Jan 14;323(2):149–163.

12. Australian Institute of Health and Welfare 2019. Cancer in Australia 2019. Cancer series no.119. Cat. no. CAN 123. Canberra: AIHW.

13. Ministry of Health New Zealand. New cancer registrations 2017 [Internet]. Auckland, NZ: MOHNZ; 2020 [updated 2020 Jan 19; cited 2020 Jan 31]. Available from https://www.health.govt.nz/publication/new-cancer-registrations-2017

14. Ministry of Health New Zealand. Mortality 2017 data tables [Internet]. Auckland, NZ: MOHNZ; 2020 [updated 2019 Dec 18; cited 2020 Jan 31]. Available from https://www.health.govt.nz/publication/mortality-2017-data-tables

15. Ministry of Health New Zealand. Cancer Patient Survival: 1994 to 2011 [Internet]. Auckland, NZ: MOHNZ; 2015 Apr 14 [updated 2015 Aug 19; cited 2020 Jan 31]. Available from https://www.health.govt.nz/system/files/documents/publications/cancerpatient-survival-1994-2011-apr15-v2.pdf.

16. Prostate Cancer Outcomes Australia. Annual Report 2016 [Internet]. Melbourne, VIC: Monash University & Movember; 2016 [cited Jan 31, 2020]. Available from https://prostatecancerregistry.org/publications/newsletters-annual-reports

17. Ferlay J, Colombet M and Bray F. Cancer Incidence in Five Continents, CI5plus: IARC CancerBase No. 9 [Internet]. Lyon, France: International Agency for Research on Cancer; 2018. Available from: http://ci5.iarc.fr

18. Australian Institute of Health and Welfare. Older Australia at a glance [Internet]. Canberra, ACT; AIHW 2020 [2018 Sept 10; cited 2020 Feb 3]. Available at https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/demographics-of-older-australians/australia-s-changing-age-and-gender-profile

19. Ministry of Social Development, Super Seniors. Our aging population [Internet]. Wellington, NZ: MSD 2020 [cited 2020 Feb 3]. Available at http://www.superseniors.msd.govt.nz/about-superseniors/media/key-statistics.html

20. Best Practice Advisory Centre New Zealand. PSA screening in asymptomatic men [Internet]. Dunedin, NZ: BPAC-NZ; July 2010 [cited 2020 Feb 3]. Available from https://bpac.org.nz/BT/2010/July/docs/best_test_jul2010_psa_screening_pages14-18.pdf

21. Prostate Cancer Foundation of Australia. Do you need the test? [Internet]. St Leonards, NSW; PCFA 2020 [cited 2020 Feb 3]. Available at http://psatesting.org.au/info/

22. Garcia C, Winter M, Bergersen P, Woo H, Chalasani V. Does transperineal prostate biopsy reduce complications compared with transrectal biopsy? A systematic review and meta-analysis of randomised controlled trials. J Urol 2016 May 7;195(4, Suppl 1):e328.

23. Ministry of Health New Zealand. Prostate cancer management and referral guidance [Internet]. Wellington, NZ: NZMOH; 2015 Sept [cited 2020 Feb 3]. Available at https://www.health.govt.nz/system/files/documents/publications/prostate-cancer-management-referral-guidance_sept15-c.pdf

24. Epstein JI, Zelefsky MJ, Sjoberg DD, Nelson JB, Egevad L, Magi-Galluzzi C, et al. A Contemporary Prostate Cancer Grading System: A Validated Alternative to the Gleason Score. Eur Urol. 2016;69(3):428–435.

25. Erickson E, Sandeman K, Lahdensuo K, Nordling S, Kallajoki M, Seikkula H, et al. New prostate cancer grade grouping system predicts survival after radical prostatectomy. Human Pathol 2018 Jan 26;75:159–166.

26. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology: Prostate Cancer Version 4.2019 [Internet]. Plymouth Meeting PA, USA: NCCN 2019 Aug 15 [cited 2020 Feb 3]. Available from https://www.nccn.org/professionals/physician_gls/pdf/prostate.pdf

27. National Comprehensive Cancer Network Guidelines for Patients: Prostate cancer [Internet]. Plymouth Meeting PA, USA: NCCN 2019 [cited 2020 Feb 3]. Available from https://www.nccn.org/patients/guidelines/content/PDF/prostate-patient.pdf

28. Huynh-Le MP, Myklebust TÅ, Feng CH, Karunamuni R, Johannesen TB, Dale AM, et al. Age dependence of modern clinical risk groups for localized prostate cancer – A population-based study. Cancer. 2020 Jan 3. doi: 10.1002/cncr.32702. [Epub ahead of print]

29. Kannan A, Kirkman M, Ruseckaite R, Evans S. Prostate cancer awareness, case-finding, and early diagnosis: Interviews with undiagnosed men in Australia. PLoSOne. 2019 Mar 7;14(3):e0211539.

30. Kirkman M, Young K, Evans S, Millar J, Fisher J, Mazza D, et al. Men's perceptions of prostate cancer diagnosis and care: insights from qualitative interviews in Victoria, Australia. BMC Cancer. 2017 Oct 27;17:704.

31. Hall S. Understanding the barriers and facilitators of adherence to active surveillance: a qualitative study of men with low risk prostate cancer [Thesis]. Melbourne: Monash University; 2018. 94 p.

32. Kikkawa K, Iba A, Khjimoto Y, Noda Y, Sonomura Y, Hara I. Impact of age on quality of life in patients with localized prostate cancer treated with high-dose rate brachytherapy combined with external beam radiotherapy. Int J Urol. 2018 Apr;25(4):366–71.

33. Skolarus TA, Dunn RL, Sanda MG, Chang P, Greenfield TK, Litwin MS, et al. Minimally Important Difference for the Expanded Prostate Cancer Index Composite Short Form. J Urol. 2015 Jan 1;85(1):101–6.

34. Lane A, Metcalfe C, Young GJ, Peters TJ, Blazeby J, Avery KN, et al. Patient-reported outcomes in the ProtecT randomized trial of clinically localized prostate cancer treatments: study design, and baseline urinary, bowel and sexual function and quality of life. BJU Int. 2016 Dec;118(6):869–879.

35. Martin NE, Massey L, Stowell C, Bangma C, Briganti A, Bill-Axelson A et al. Defining a Standard Set of Patient-centered Outcomes for Men with Localized Prostate Cancer. Eur Urol. 2015 Mar;67(3):460–467.

36. Morgans A, van Bommel A, Stowell C, Abrahm JL, Basch E, Bekelman JE, et al. Development of a standardized set of patient-centered outcomes for advanced prostate cancer: An international effort for a unified approach. Eur Urol. 2015 Nov;68(5):891–898.

37. Michigan Urological Surgery Improvement Collaborative (MUSIC). [Website] Ann Arbour, MI, USA: MUSIC 2020 [cited 2020 Feb 14]. Available at https://musicurology.com/

INDEX OF FIGURES AND TABLES

APPENDICES

APPENDIX 1

FIGURE A1a: **POPULATION COVERAGE BY JURISDICTION – TOTAL INCIDENCE OF PROSTATE CANCER ANALYSED BY NOTIFICATION TO PCOR-ANZ (2015–2017)**

Percentage (%) of men per treatment group
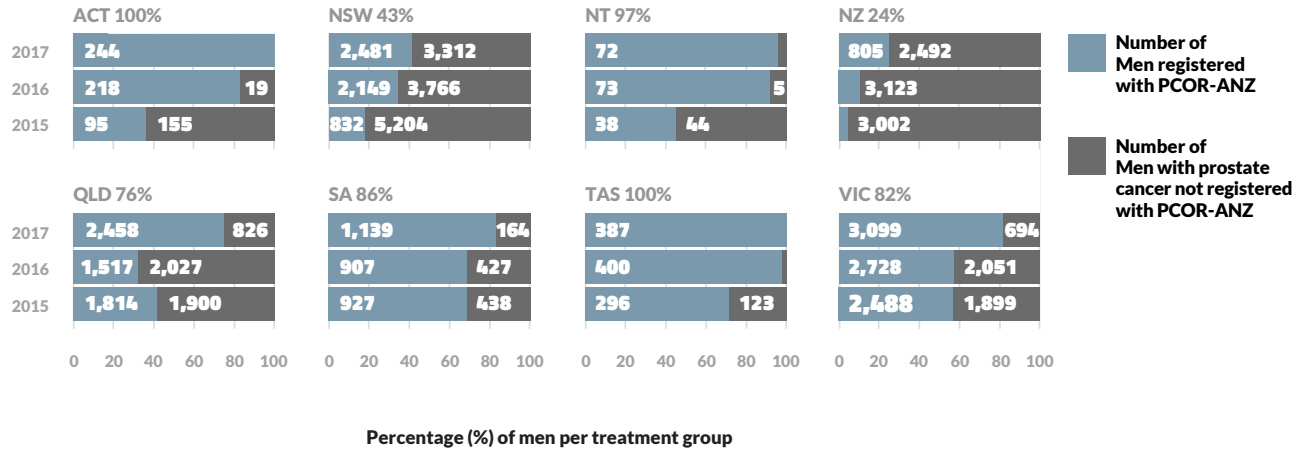
- See Supplementary Table S1 and Figure S1 for further details on population coverage.

FIGURE A1b: **TOTAL PROSTATE CANCER NOTIFICATIONS TO PCOR-ANZ (2015-2017)**
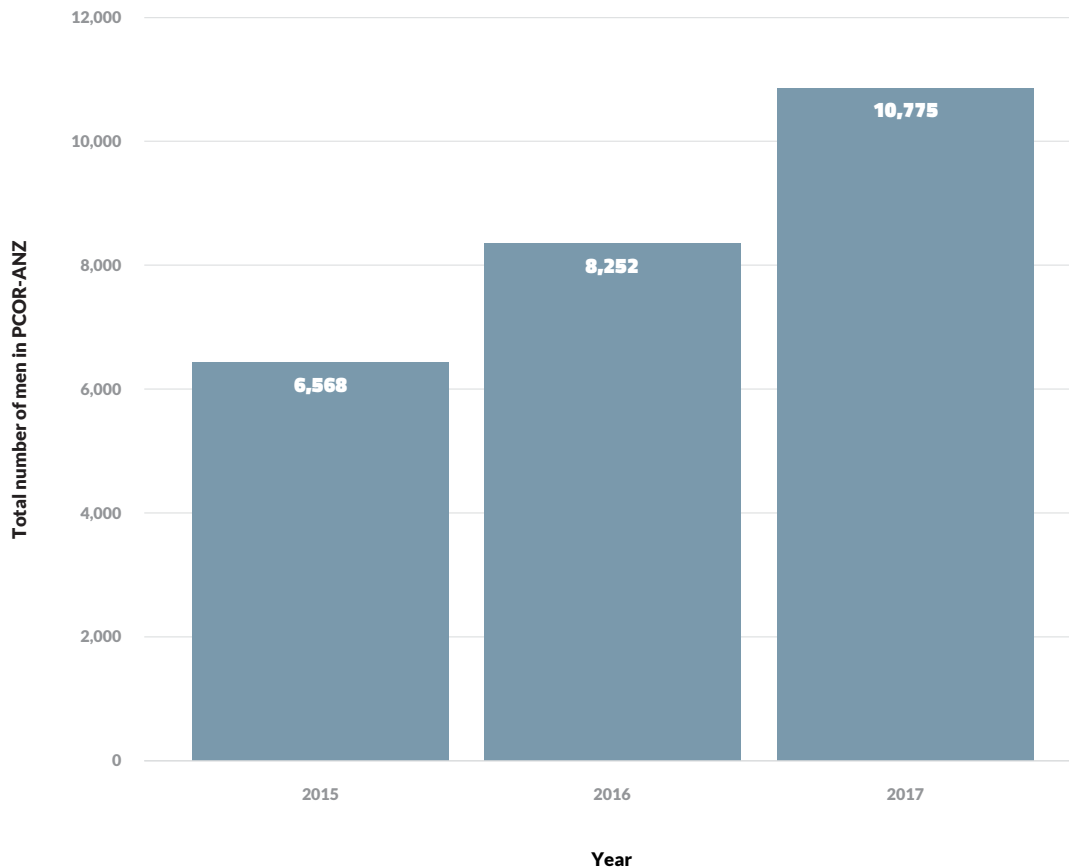
- Please note: in some jurisdictions, cases will be added to the registry after the year of diagnosis. This means the numbers reported here may be slightly higher than those included in previous reports.

**TABLE A2: TOTAL NUMBER OF PARTICIPATING SITES WITHIN EACH JURISDICTION
BY NUMBER OF PUBLIC AND PRIVATE SITES**

Jurisdiction	Total no. recruiting sites	PUBLIC sites recruited	PUBLIC % of total	PRIVATE sites recruited	PRIVATE % of total
ACT	7	2	29%	5	71%
NSW	42	35	83%	7	17%
NT	3	2	67%	1	33%
NZ	30	18	60%	12	40%
QLD	49	12	24%	37	76%
SA	18	8	44%	10	56%
TAS	8	2	25%	6	75%
VIC	87	53	61%	34	39%
WA	0	0	0%	0	0%
Total	244	132	54%	112	46%

APPENDIX 3

INFOGRAPHIC: HOW PCOR-ANZ WORKS

PCOR-ANZ

Hosted at
Monash University
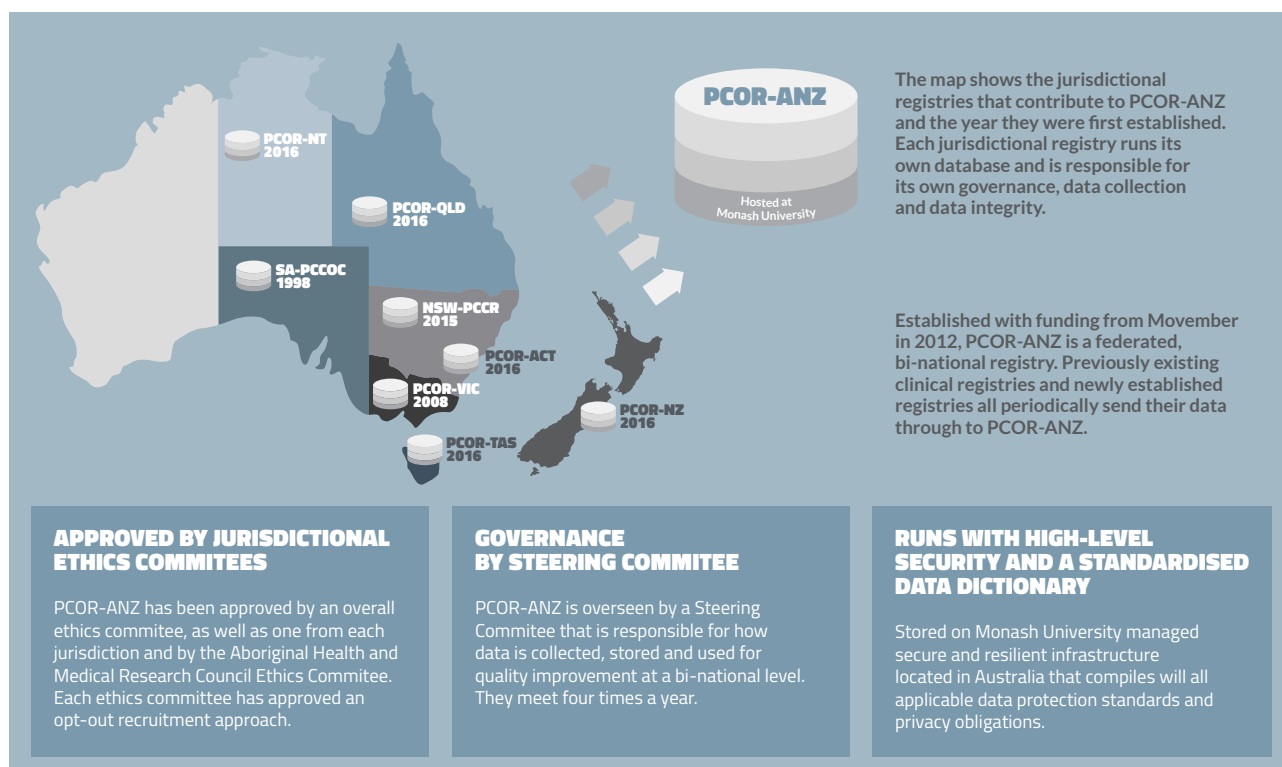
The map shows the jurisdictional registries that contribute to PCOR-ANZ and the year they were first established. Each jurisdictional registry runs its own database and is responsible for its own governance, data collection and data integrity.

Established with funding from Movember in 2012, PCOR-ANZ is a federated, bi-national registry. Previously existing clinical registries and newly established registries all periodically send their data through to PCOR-ANZ.

PCOR-NT 2016
PCOR-QLD 2016
SA-PCCOC 1998
NSW-PCCR 2015
PCOR-ACT 2016
PCOR-VIC 2008
PCOR-NZ 2016
PCOR-TAS 2016

APPROVED BY JURISDICTIONAL ETHICS COMMITEES

PCOR-ANZ has been approved by an overall ethics commitee, as well as one from each jurisdiction and by the Aboriginal Health and Medical Research Council Ethics Commitee. Each ethics committee has approved an opt-out recruitment approach.

GOVERNANCE BY STEERING COMMITEE

PCOR-ANZ is overseen by a Steering Commitee that is responsible for how data is collected, stored and used for quality improvement at a bi-national level. They meet four times a year.

RUNS WITH HIGH-LEVEL SECURITY AND A STANDARDISED DATA DICTIONARY

Stored on Monash University managed secure and resilient infrastructure located in Australia that compiles will all applicable data protection standards and privacy obligations.

DATA SECURITY AND DATA QUALITY

Data security: Data are collected in each jurisdiction from medical records, pathology records and directly from men with prostate cancer. Each jurisdiction periodically transmits data to the central PCOR-ANZ registry, hosted by Monash University. The registry maintains resilient infrastructure that is certified compliant with International Standards Organization (ISO) 27001 Information Systems Security Standards.

Data definitions: It is imperative that data fields are well defined, so that data are collected accurately across all jurisdictions. To ensure this occurs, PCOR-ANZ has a 'data dictionary' which describes and clearly defines each data element, including when it is to be collected; and how it is to be recorded.

PCOR-ANZ is contributing to a large global movement towards standardising data collections and global benchmarking of quality of care. PCOR-ANZ researchers have worked alongside the ICHOM to develop standardised datasets for localised[1] and advanced[2] prostate cancer disease. If you would like further detail, the ICHOM website is http://www.ichom.org

TABLE A3: JURISDICTIONAL TEAMS AND STEERING COMMITTEE MEMBERS

Note: The following lists of Steering Committee members and Jurisdictional team members are accurate as of the 30th November 2019.

PCOR–ANZ GOVERNANCE AND PROJECT LEADERSHIP MEMBERS

PCOR-ANZ STEERING COMMITTEE	
Sanchia Aranda	Chair
Andrew Brooks	NSW Representative
David Currow	Quality of Care Expert
Ian Davis	Medical Oncology Representative
Warick Delprado	Pathology Representative
Frank Frizelle	NZ Representative
Mark Frydenberg	Urologist Representative
Peter Heathcote	USANZ Representative
Ellie James	Movember Representative
Michael Jones	Acting TAS Representative
Saad Maqsood	NT Representative
Stephen Mark	USANZ Representative
John McNeil	Custodian Representative
Jeremy Millar	VIC Representative
Kim Moretti	SA Representative
David Pryor	QLD Representative
David Smith	Epidemiologist
Farhan Syed	ACT Representative
Jeff Thavaseelan	WA Representative
Paul Villanti	Movember Representative
Tony Walker	Consumer Representative
Craig White	Medical Administrator

PCOR-ANZ DATA COORDINATION CENTRE (MONASH UNIVERSITY)	
Sue Evans	Former Academic Lead
Jeremy Millar	Acting Academic Lead
Marie Pase	PCOR-ANZ Coordinator
Maggie Johnson	PCOR-ANZ Project Officer

JURISDICTIONAL REGISTRY TEAMS AND STEERING COMMITTEE MEMBERS

PCOR-ACT			
Mirka Smith	PCOR-ACT Coordinator		
Paul Dugdale	Principal Investigator		
Farhan Syed	Clinical Lead		
DATA COLLECTION TEAM MEMBERS			
Elizabeth Denham			
STEERING COMMITTEE MEMBERS			
Elizabeth Chalker	Paul Dugdale	Alan Philp	Mirka Smith
Farhan Syed			

JURISDICTIONAL REGISTRY TEAMS AND STEERING COMMITTEE MEMBERS

PCOR-NSW

Serina Teuss		PCCR-NSW Coordinator	
David Currow		Principal Investigator	
Andrew Brooks		Clinical Lead	
DATA COLLECTION TEAM MEMBERS			
Amanda McParlane	Colin Moloney	Will Ooi	Rebecca Sebastian
Julie Sherring	Karen Silva	Nicole Ward	
STEERING COMMITTEE MEMBERS			
Andrew Brooks (Chair)	Andrej Bece	Claire Cooke-Yarborough	David Currow
Warick Delprado	Brett Dillon	Howard Gurney	Elizabeth Hovey
Andrew Kneebone	Mark Louie-Johnsun	David Malouf	Tony Maxwell
Manish Patel	Grant Sara	David Smith	Ben Smith
Phillip Stricker	Henry Woo		

PCOR-NT

Juvy McPhee		PCOR-NT Coordinator	
Saad Maqsood		Clinical Lead	
DATA COLLECTION TEAM MEMBERS			
Juvy McPhee			
STEERING COMMITTEE MEMBERS			
	Sarah Dugdale	Henry Duncan	Michelle Ganzer
Kar Giam	Ruby Hilario	Narayan Karanth	Don Lockley
Saad Maqsood	Juvy McPhee		

PCOR-NZ

Judith Clarke		PCOR-NZ Coordinator	
Stephen Mark		Clinical Lead	
DATA COLLECTION TEAM MEMBERS			
Catherine Beaton	Natasha Burgess	Christina Campbell	Judith Clarke
Trudu Dugmore	Barbara Gordon	Kim Inskeep	Vivienne McLennan
Liz Mitchell	Angela Read	Rosie Ross	Kathryn Trotter
STEERING COMMITTEE MEMBERS			
Frank Frizelle (Chair)	Jeremy Millar	Simon Van-Rij	Kevin Bax
Douglas Iupati	Gilbert Taurua	Brian Wilson	Ann Richardson
Judith Clarke			

PCOR-QLD

Heather Day		PCOR-QLD Coordinator	
Colleen Nelson		Principal Investigator	
David Pryor		Clinical Lead	
DATA COLLECTION TEAM MEMBERS			
Mandy Chandler	Yu-Qian Chau		
STEERING COMMITTEE MEMBERS			
David Pryor (Chair)	Stefan Antoniou	Geoff Coughlin	Tony Gianduzzo
Jacob Gleeson	Kiran Hazratwala	Peter Heathcote	Colleen Nelson
Jamie Reynolds	David Sillar	Aneta Suder	HS Teng
Chris Tracey	Roger Watson	Patsy Yates	

JURISDICTIONAL REGISTRY TEAMS AND STEERING COMMITTEE MEMBERS

PCOR-SA	
Tina Kopsaftis	SA-PCCOC Clinical Data Coordinator
Michael O'Callaghan	Senior Researcher and Educator
Kim Moretti	Clinical Lead
Robyn McGeachie	Data Manager
Scott Walsh	Data Manager

DATA COLLECTION TEAM MEMBERS			
Jessie Bennett	Helen Claridge	Elspeth Raymond	Jessica Reid

STEERING COMMITTEE MEMBERS			
Kim Moretti (Chair)	Martin Borg	Braden Higgs	Kym Horsell
Ganessan Kichenadasse	Tina Kopsaftis	David Merry	Michael O'Callaghan
Sophie Otto	Ken Pittman	Scott Walsh	

PCOR-TAS	
Jasmine Prichard	PCOR-TAS Coordinator
Brian Stokes	Manager, Tasmanian Cancer Registry
Marketa Skala	Clinical Lead

DATA COLLECTION TEAM MEMBERS			
Emmerson Easley	Jasmine Prichard	Joy Sutton	

STEERING COMMITTEE MEMBERS			
Marketa Skala (Chair)	Anthony Eaton	Liesel Fitzgerald	Robert Jensen
Michael Jones (Acting Chair, Clinical Lead 2019)	Louise Nott	Brian Stokes	

PCOR-VIC	
Melanie Evans	PCOR-VIC Coordinator
Ellie Tsiamis	Research Officer
Prof. Jeremy Millar	Clinical Lead

DATA COLLECTION TEAM MEMBERS			
Caitlin Bush	Whitey Comte	Sharon Daly	Erica Flint
Katrina Hall	Dawn Hevey	Robyn Howden	Kate Hunter
Esther Johns	Maggie Johnson	Justin Lang	Patrick McCoy
Joanie McPhee	Yehudi Saling	Lisa Selbie	Kathryn Sheridan
Abdullah Sheriffdeen	Christine Sherwell		

STEERING COMMITTEE MEMBERS			
Jeremy Millar (Chair)	Damien Bolton	Anthony Costello	Ian Davis
Lachlan Dodds	Melanie Evans	Sue Evans	Helen Farrugia
Mark Frydenberg	Paul Kearns	John McNeil	Declan Murphy
Colin O'Brien	Max Shub	Kathryn Whitfield	

SUPPLEMENTARY DATA

TABLE S1: ESTIMATED POPULATION COVERAGE OF PCOR-ANZ BY JURISDICTION (2015–2017)

YEAR MEN DIAGNOSED WITH PROSTATE CANCER	ACT	NSW	NT	NZ	QLD	SA	TAS	VIC	WA	TOTAL ACROSS ALL JURISDICTIONS
PCOR-ANZ 2015	95	832	38	78	1,814	927	296	2,488	-	6,568
Population diagnosed with prostate cancer 2015	250	6,036	82	3,080	3,714	1,365	419	4,387	1,889	21,222
% population coverage	**38%**	**14%**	**46%**	**3%**	**49%**	**68%**	**71%**	**57%**		**31%**
PCOR-ANZ 2016	218	2,149	73	260	1,517	907	400	2,728	-	8,252
Population diagnosed with prostate cancer 2016	237	5,915	78	3,383	3,544	1,334	403	4,779	1,803	21,476
% population coverage	**92%**	**36%**	**94%**	**8%**	**43%**	**68%**	**99%**	**57%**		**38%**
PCOR-ANZ 2017	244	2,481	72	805	2,548	1,139	387	3,099	-	10,775
Population diagnosed with prostate cancer 2017	244	5,793	74	3,297	3,374	1,303	387	3,793	1,716	19,981
% population coverage	**100%**	**43%**	**97%**	**24%**	**76%**	**87%**	**100%**	**82%**		**54%**

- Please note that AIHW prostate cancer projections (used in conjunction with actual numbers [national] when available to derive the denominator data) are updated annually and may be different that those cited in previous annual reports.

FIGURE S1: SUMMARY OF DATA SOURCES USED TO CALCULATE POPULATION COVERAGE

	ACT	NSW	NT	NZ	QLD	SA	TAS	VIC
2015								
2016								
2017								

Interpolation between last actual numbers and AIHW projections

Modelled from New Zealand data up to 2016

Actual counts taken from Victoria Cancer Statistics (June 2018)

FIGURE S2: AGE AT DIAGNOSIS BY JURISDICTION (2015–2017)

Age group
- <55
- 55–59
- 60–64
- 65–69
- 70–74
- 75–79
- >79
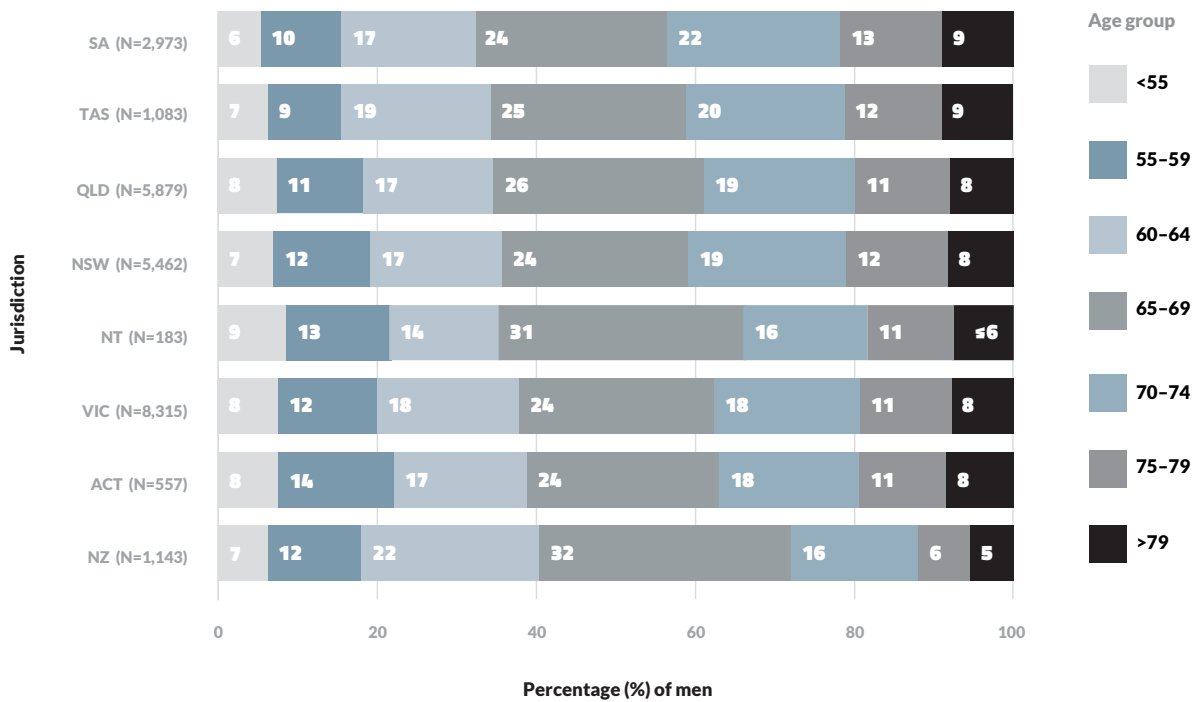
- Data on age were available for 100% of men in this analysis (N=25,595).
- Jurisdictions are ordered by increasing proportions of men <65 years.
- Percentages are rounded and may not add to 100%.

Across all PCOR-ANZ jurisdictions, the most common age for diagnosis of prostate cancer is 60–70 years. South Australia reports the highest proportion of men diagnosed at over 70 years of age, while this group is least common in New Zealand. These differences in age may be attributable to differences in the age structure of each jurisdiction, i.e. South Australia has an older population overall.

FIGURE S3: METHOD OF DIAGNOSIS BY AGE AT DIAGNOSIS ACROSS ALL JURISDICTIONS (2015–2017)
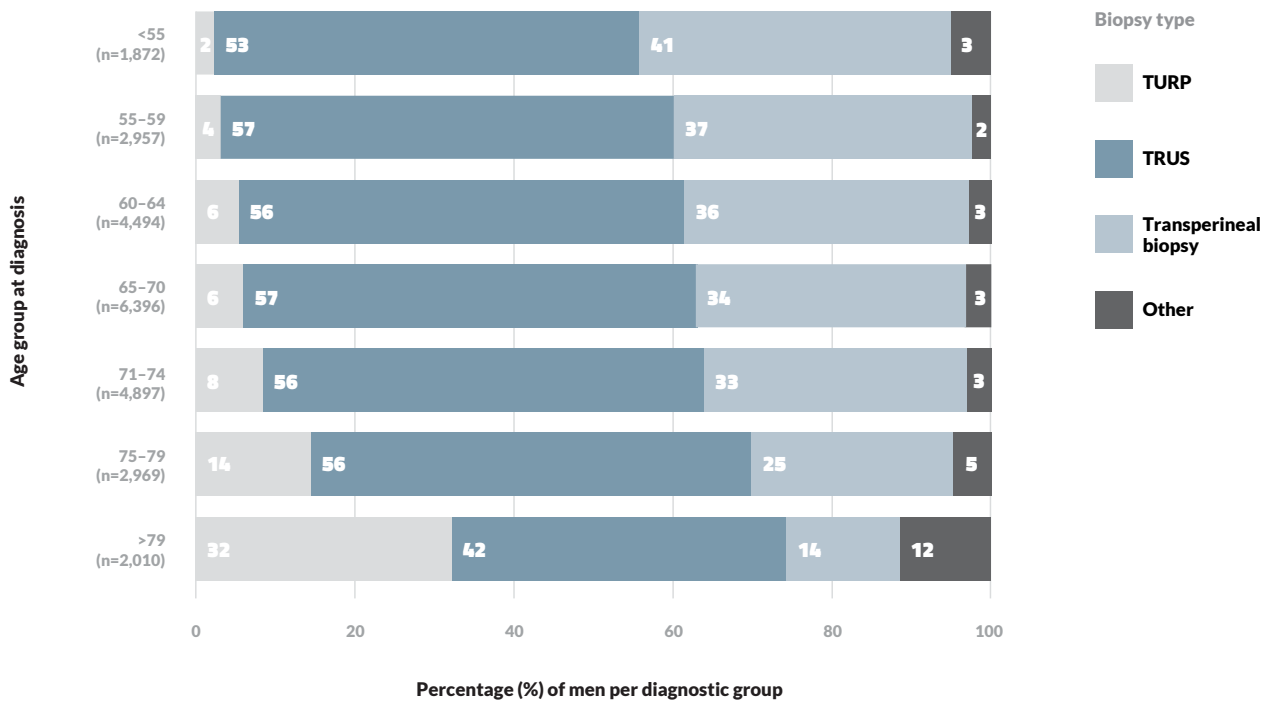

Percentage (%) of men per diagnostic group

• Data on age were available for 100% of men in this analysis (N=25,595).
• Percentages are rounded and may not add to 100%.

PCOR-ANZ shows a clear difference in the method of diagnosis in the context of the age at which a patient is diagnosed with prostate cancer. Men in the oldest age group (>80 years) are most commonly diagnosed by TURP or 'other' methods. This indicates that the over-80's are most likely to have a diagnosis of prostate cancer made incidentally, while they are being treated or investigated for other reasons e.g. treatment of lower urinary tract symptoms.

The youngest group of men (54 years or less at the time of diagnosis) were most commonly diagnosed by transperineal biopsy. This method of diagnosis requires a general anaesthetic, with younger patients being most likely to be suitable for this procedure. TRUS biospy was the most common method of diagnosis across all age groups with the exception of men aged over 80 years.

FIGURE S4: **PROPORTION OF MEN PER NCCN RISK GROUP AT DIAGNOSIS ACROSS JURISDICTIONS (2015–2017)**
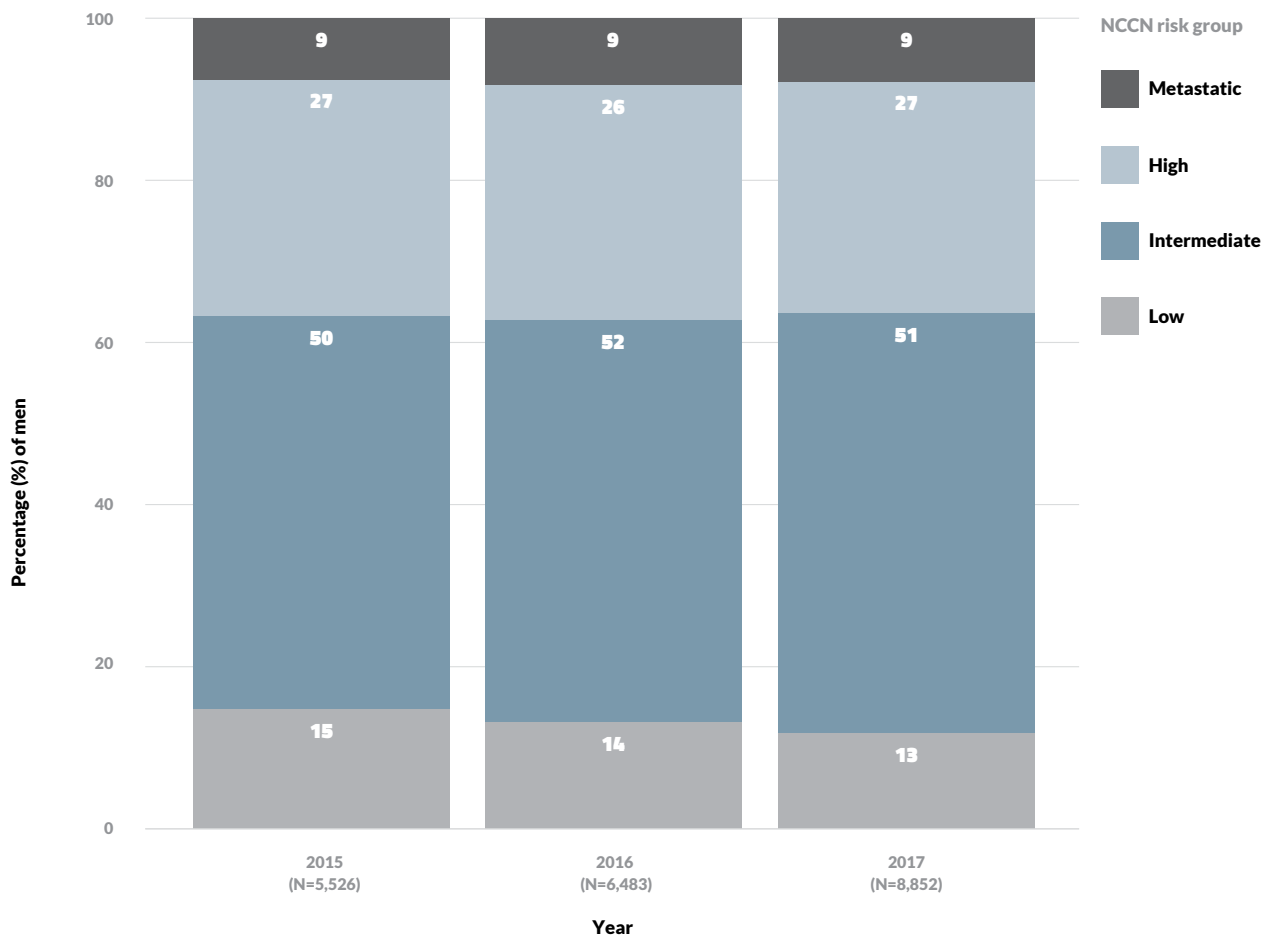
- NCCN risk group data was available for 81.5% of men in this analysis (N=20,861/25,595)
- For simplicity, 'low' and 'very low' risk groups have been combined into one 'low' group; and 'high' and very high' risk groups have been combined in to one 'high' group.
- Percentages are rounded and may not add to 100%.

Prostate cancer risk levels are determined by a number of factors including ISUP grade at diagnosis, PSA levels and clinical stage (including metastases). PCOR-ANZ uses the National Comprehensive Cancer Network (NCCN) risk stratification to group men with similar risk levels at the time of diagnosis.

During the period 2015–2017, the proportion of men diagnosed in each group has remained stable. Risk groupings assigned to patients are important for determining which treatments are most suitable for them, making this trend an important one for the registry to monitor over time.

SUMMARY OF THE COMPLETENESS OF DATA FIELDS REQUIRED TO CALCULATE THE NCCN RISK GROUPS

COMPLETENESS OF DATA FOR CALCULATING NCCN RISK GROUP AT DIAGNOSIS	TOTAL ACROSS ALL JURISDICTIONS N (%)
Clinical T category	17834/25595 (70%)
Gleason sum	24699/25595 (96%)
PSA level	21958/22357 (98%)

The assignment of NCCN risk groups requires recorded data about clinical T stage, Gleason score and PSA levels at the time of diagnosis. The later of these two variables are typically well reported, while clinical T stage is more often missing in clinical records (30%). PCOR-ANZ quality indicator reports include levels of documentation of each of these variables which is anticipated to improve over time. This will allow much more accurate NCCN classification.

TABLE S3: **SUMMARY OF MANAGEMENT PROVIDED TO MEN BY NCCN RISK GROUP IN AUSTRALIA AND NEW ZEALAND ACROSS JURISDICTIONS (2015–2017)**

PRIMARY TREATMENT	LOW RISK	INTERMEDIATE RISK	HIGH RISK	VERY HIGH RISK	METASTATIC	TOTAL
Surgery	1166 (27%)	7179 (61%)	2653 (47%)	62 (25%)	229 (11%)	11289 (47%)
Radiotherapy	212 (5%)	2255 (19%)	1681 (30%)	111 (45%)	365 (18%)	4624 (19%)
Chemotherapy	0 (0%)	6 (0%)	36 (1%)	6 (2%)	419 (21%)	467 (2%)
ADT	6 (0%)	129 (1%)	464 (8%)	39 (16%)	842 (42%)	1480 (6%)
Active surveillance/ Watchful waiting	2703 (62%)	1548 (13%)	306 (5%)	9 (4%)	30 (1%)	4596 (19%)
Other treatments	37 (1%)	170 (1%)	68 (1%)	0 (0%)	19 (1%)	294 (1%)
Missing	203 (5%)	526 (4%)	438 (8%)	18 (7%)	120 (6%)	1305 (5%)
TOTAL	**4327 (100%)**	**11813 (100%)**	**5646 (100%)**	**245 (100%)**	**2024 (100%)**	**24055 (100%)**

In the period 2015–2017, surgery remains the most common treatment type for prostate cancer, contributing to 49% of treatments. Radiotherapy was the next most common treatment accounting for 18% of treatments overall. Of men diagnosed with very high-risk disease, radiotherapy is the most common treatment (46%). Chemotherapy and ADT as monotherapies remain uncommon across Australia and New Zealand as the first treatment men receive, though many will progress to receive these therapies later in the course of their disease. Watchful waiting/active surveillance is used as the first management strategy in 15% of cases, primarily in men with low-risk disease. Primary treatment data is missing for 8% of men in PCOR-ANZ.

**TABLE S4: FOLLOW-UP METHODOLOGY AND QUALITY OF LIFE
SURVEY COMPLETION RATE BY JURISDICTION (2015–2017)**

12 MONTH PROMS (2015-2017)	ACT	NSW	NT	NZ	QLD	SA	TAS	VIC	TOTAL
APPROACH USED TO COLLECT SURVEY DATA FROM MEN	Phone, Email, Letter	Phone, Email, Letter	Letter	Email, Letter	Letter	Letter	Phone, Email, Letter	Phone, Email, Letter	—
EPIC-26 RESPONSE RATE N (%)	256/533 (48%)	2,428/5,062 (48%)	61/179 (34%)	792/1,023 (77%)	2,317/5,154 (45%)	789/2,525 (31%)	399/992 (40%)	6,198/7,836 (79%)	13,240/23,304 (57%)

PCOR-ANZ collects patient reported outcome measures (PROMS) at 12 months after the first treatment received by men. The survey instrument used to record this is the EPIC-26, which is designed to assess prostate cancer specific symptoms. Each jurisdiction collects this data in a slightly different way, with phone call, email and letter collection of data permitted within the protocol. Each jurisdiction also has a different response rate to PROMs data requests ranging from 79% in Victoria to 31% in South Australia.

TABLE S5: NUMBER OF RESPONSES TO THE EPIC-26 QUESTIONNAIRE FOR PATIENT-REPORTED FUNCTION, BY JURISDICATIONAL GROUP AND PRIMARY TREATMENT

	ADT*		RADIOTHERAPY		SURGERY		AS/WW	
	Jurisdictional group	No. responses	Jurisdictional group	No. responses	Jurisdictional group	No. responses	Jurisdictional group	No. responses
BOWEL	NSW-ACT	121	NSW-ACT	462	NSW-ACT	1,370	NSW-ACT	439
	NZ	46	NZ	160	NZ	345	NZ	196
	QLD	105	QLD	482	QLD	1,268	QLD	282
	SA-NT	13	SA-NT	132	SA-NT	611	SA-NT	25
	VIC-TAS	414	VIC-TAS	1,012	VIC-TAS	3,560	VIC-TAS	1,359
	TOTAL	**699**	**TOTAL**	**2,248**	**TOTAL**	**7,154**	**TOTAL**	**2,301**
SEXUAL	NSW-ACT	112	NSW-ACT	478	NSW-ACT	1,378	NSW-ACT	441
	NZ	48	NZ	161	NZ	342	NZ	201
	QLD	103	QLD	470	QLD	1,256	QLD	271
	SA-NT	9	SA-NT	102	SA-NT	503	SA-NT	24
	VIC-TAS	390	VIC-TAS	968	VIC-TAS	3,524	VIC-TAS	1,295
	TOTAL	**662**	**TOTAL**	**2,179**	**TOTAL**	**7,003**	**TOTAL**	**2,232**
URINARY INCONTINENCE	NSW-ACT	119	NSW-ACT	476	NSW-ACT	1,393	NSW-ACT	444
	NZ	49	NZ	162	NZ	345	NZ	197
	QLD	104	QLD	492	QLD	1,280	QLD	279
	SA-NT	11	SA-NT	123	SA-NT	589	SA-NT	23
	VIC-TAS	409	VIC-TAS	1014	VIC-TAS	3,551	VIC-TAS	1,358
	TOTAL	**692**	**TOTAL**	**2,267**	**TOTAL**	**7,158**	**TOTAL**	**2,301**
URINARY IRRITATION/OBSTRUCTION	NSW-ACT	111	NSW-ACT	415	NSW-ACT	1,202	NSW-ACT	422
	NZ	47	NZ	157	NZ	338	NZ	190
	QLD	99	QLD	476	QLD	1,248	QLD	275
	SA-NT	10	SA-NT	125	SA-NT	600	SA-NT	23
	VIC-TAS	412	VIC-TAS	1,020	VIC-TAS	3,543	VIC-TAS	1,354
	TOTAL	**679**	**TOTAL**	**2,193**	**TOTAL**	**6,931**	**TOTAL**	**2,264**

*'ADT' was administered without radiotherapy or surgery, but may include chemotherapy; this group also includes a minority of men receiving chemotherapy monotherapy.