PROSTATE CANCER OUTCOMES | REGISTRY AUSTRALIA AND NEW ZEALAND

Prostate Cancer in Australian and New Zealand Men

PCOR-ANZ 2015–2018:
Patterns of care, patient-reported outcomes and selected treatment analyses

ANNUAL REPORT 2020

MOVEMBER® | MONASH University

Acknowledgements

Firstly, to all the men who consent to participating in the Prostate Cancer Outcomes Registry – Australia and New Zealand (PCOR-ANZ), the Chair, the Steering Committee and Movember extend our heartfelt thanks. Your data is helping us better understand and tackle the challenges that you, and others in your position are facing. This is the first step on the road to upholding best practice care, and working towards improvements where we can, for men with prostate cancer across our region.

Equally, the success of the registry relies on the support of the clinical community who so generously contribute their time to working with PCOR-ANZ on a voluntary basis. We are extremely grateful for your efforts and acknowledge that it is your belief in the potential of this project to improve the lives of your patients that is carrying us forward.

To our tireless team of Study Coordinators, data collectors and Program Coordinator Marie Pase, who manage the challenges of data collection, and database upgrades with aplomb, we would also like to extend our sincere thanks. You are the people that keep this project running so successfully and our appreciation for your data wrangling skills cannot be overstated.

In particular, Movember would like to thank the members of the PCOR-ANZ Steering Committee, Chaired by Professor Sanchia Aranda, who dedicate endless hours to the guidance of this project. You are the driving force behind the registry and help us shape our vision of what PCOR-ANZ can achieve now and into the future, for which we are extremely grateful.

Finally, we extend our appreciation to all our endorsing societies who continue to support 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

ACT Government | Canberra Health Services

Northern Territory Government

Monash University

CHOMNZ | centre for health outcome measures new zealand

Government of South Australia | SA Health

Cancer Institute NSW | cancer.nsw.gov.au

University of Tasmania

Menzies Institute for Medical Research

QUT ihbi Institute of Health and Biomedical Innovation

APCRC-Q Australian Prostate Cancer Research Centre Queensland

SA-PCCOC South Australian Prostate Cancer Clinical Outcomes Collaborative

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

PCOR-ANZ is endorsed by:

MOGA

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

Société Internationale d'Urologie SIU

Urological Society of Australia and New Zealand

RCPA The Royal College of Pathologists of Australasia

Suggested citation:

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Message from the Chair

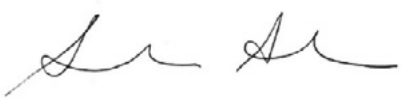
After a year that saw our healthcare system rocked by the COVID-19 global pandemic, we are reminded of the importance of The Prostate Cancer Outcomes Registry – Australia and New Zealand (PCOR-ANZ). We know that the impact of the coronavirus pandemic (causing COVID-19 disease) has been significant on patients and clinicians alike. Emerging data from Cancer Australia[i] suggests that diagnostic and treatment services for prostate cancer were reduced during the initial wave of the pandemic (March – June 2020) and the effect of later lockdowns on healthcare services, such as that in Victoria (July – October 2021), remains to be seen.

In time, PCOR-ANZ will be able to bring a quantifiable, data-driven perspective to the question of whether this had any impact on overall diagnostic and treatment trends, patient-reported outcomes and, importantly, overall survival. Providing insight into trends, patterns of care and emerging treatments in prostate cancer across Australia and New Zealand is a key objective of the registry. Reflecting on another year of data in this hugely valuable dataset, it is encouraging to see the continuous and steady growth in size of PCOR-ANZ.

This report covers clinical data collected in the four-year period between 2015, when PCOR-ANZ began operating as a bi-national registry, and 2018. It also includes important follow-up data from quality-of-life questionnaires answered by men 12 months post treatment. We are heartened by the steady expansion in the proportion of new cases captured in the registry, notably a 26% increase in patient enrolment between 2017 and 2018. The registry now represents an estimated 72% of the population of men diagnosed with prostate cancer in Australia and New Zealand annually. High population coverage means our data are representative of practice across Australia and New Zealand, allowing analysis that is directly relevant to the jurisdictions we cover, while at the same time minimising the potential for bias.

We are proud to be collaborating with 354 clinicians and 244 hospitals and clinics across Australia and New Zealand. PCOR-ANZ now includes data from 315 urologists, 22 radiation oncologists and 17 medical oncologists. Recruitment and data-collection are primary activities for registry personnel, and we extend our sincere thanks to our team of data collectors and study co-ordinators for the enormous amount of work they do to make this possible. Likewise, we are sincerely grateful to all the clinicians and healthcare personnel who continue to see the value in a population-wide clinical quality registry.

We also extend our gratitude to Movember, who generously support PCOR-ANZ operations and continuously seek to invest in innovative initiatives and programs to drive PCOR-ANZ forward. With their support, we are on track to become one of the world's most comprehensive prostate cancer registries, placing Australia and New Zealand at the forefront of prostate cancer clinical quality. The year ahead will involve enormous technological transformation for PCOR-ANZ and with that comes great opportunity. Our valued community of healthcare providers, researchers and men with prostate cancer should feel confident that we are striving to maximise outcomes from the important data you trust to us. The future of PCOR-ANZ and its contribution to improving the quality of care provided to all men diagnosed and treated for prostate cancer in Australian and New Zealand looks very exciting indeed.



PROFESSOR SANCHIA ARANDA
CHAIR, PCOR-ANZ STEERING COMMITTEE

i. Review of the impact of COVID-19 on medical services and procedures in Australia utilising MBS data: Lung and prostate cancers [Internet]. Surry Hills, NSW: Cancer Australia; 2020 November. 44p. Available from https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/review-impact-covid-19-medical-services-and-procedures-australia-utilising-mbs-data

Movember Report

Movember is encouraged by the significant progress that PCOR-ANZ has made in a year of exceptional challenges.

Working towards a world where fewer men die from prostate cancer and those living with the disease live happier, healthier and longer lives, PCOR-ANZ celebrated several successes.

As the principal funder of PCOR-ANZ, Movember's investment in the registry reached AUD $17M.

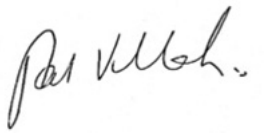
We achieved record levels of population coverage across Australia and New Zealand. Having reached this milestone, we can shift our focus to accelerating the use of the data to improve the lives of men. We will continue to work closely with the clinical community to do this, supporting new and innovative approaches to improving the quality of treatment and care.

We launched a data linkage pilot project, which will see PCOR-ANZ enriched with government datasets, and we continued the roll-out of bi-annual clinical quality indicator reports. Fundamental to the objectives of PCOR-ANZ, these reports provide our participating urologists and hospitals with regular, evidence-based performance benchmarking against a set of indicators that matter to both healthcare providers and patients alike.

We also took a significant step forward in our initiative to upgrade the technology behind PCOR-ANZ, entering into a landmark partnership with Montreal-based Electronic Data Capture (EDC) and registry software company Dacima Software Inc. (Dacima). Over the coming year, Dacima will lead the design and development of the new PCOR-ANZ database, drawing on their experience in designing registry databases for different acute and chronic diseases, vaccine monitoring, surveillance of infectious diseases, medical procedures and medical devices. Once delivered, the upgraded system will support future growth opportunities of PCOR-ANZ for many years to come.

Finally, we welcomed Dr. Nathan Papa to the leadership team in the position of Academic Lead of PCOR-ANZ. Nathan brings clinical expertise and a wealth of enthusiasm to grow this valuable dataset, increase clinical uptake and advance clinical care outcomes for men.

As we close out 2020, we are thankful for the dedicated team of steering committee members, study coordinators and data collectors who have stewarded the program through a difficult year with care and dedication to the mission. We are especially grateful to Professor Sanchia Aranda for her commitment and dedicated leadership as Chair of the Steering Committee. Defined by innovation and transformation, we look forward to the coming year with enthusiasm as we continue to grow PCOR-ANZ into one of the most comprehensive and detailed prostate cancer surveillance systems in the world.



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	Radiation Therapy
SIU	Société Internationale d'Urologie
TRUS	Transrectal ultrasound
TURP	Transurethral resection of the prostate
USANZ	Urological Society of Australia and New Zealand
WW	Watchful waiting

Contents

Executive summary

PCOR-ANZ now has four full years of data to analyse since it became a bi-national registry (2015–2018), allowing a more robust look at practice trends. This year, new analyses focused on trends in biopsy approach, radiation therapy modality and interventional management across different segments of the database. The data that has previously been covered on diagnosis, treatment and patient-reported outcome measures (PROMs) is summarised in Chapter 1, with the remainder of the report being dedicated to the new analyses.

Patient-reported outcomes

Understanding the quality of life reported by men with prostate cancer remains a unique strength of PCOR-ANZ. The 2015–2018 dataset includes over 20,000 responses to the short-form Extended Prostate Cancer Index Composite–26 question (EPIC-26) questionnaire, which is delivered 12 months after primary treatment (Supplementary Table 6). These data demonstrated differences in the 'level of bother' experienced across different treatments and questionnaire domains.

PROMs are measured one year after treatment, or one year after diagnosis for men under observation through active surveillance (AS) or watchful waiting (WW). At this one-year mark, men having surgical treatment were most likely to report being bothered by their sexual function (45% moderate-to-big bother, compared with 22% after AS or WW). However, these men were least likely to be bothered by their bowel function (3% moderate-to-big bother, compared with 9% for men who had radiation therapy; see Figure 11).

Our quality-of-life surveys also allow calculation of the median score in different side-effect domains for different treatment groups. The median scores for bowel function and urinary irritation are worse after treatment with radiation or androgen-deprivation therapy (ADT) with or without chemotherapy (95.8 for both domains) compared with surgery or AS or WW (100 for both domains; Supplementary Table 4). By contrast, the median urinary continence score was worse in men after surgery (85.5) compared with other management decisions (100 for all other treatment groups). Men who had AS or WW report the best scores in each side-effect domain compared with all other treatment groups. This effect is most marked in the average score for sexual function.

In 2020, we released the third round of quality indicator reports. These reports provide a benchmark for quality-of-life measures at 12 months post-treatment or -diagnosis, by clinician and institution. The reports compare the individual benchmarks with the bi-national standard. Work is underway to assess the impact of these reports and more deeply understand how they can improve the quality of life of men within PCOR-ANZ over time.

Notable trends in prostate cancer management across PCOR-ANZ

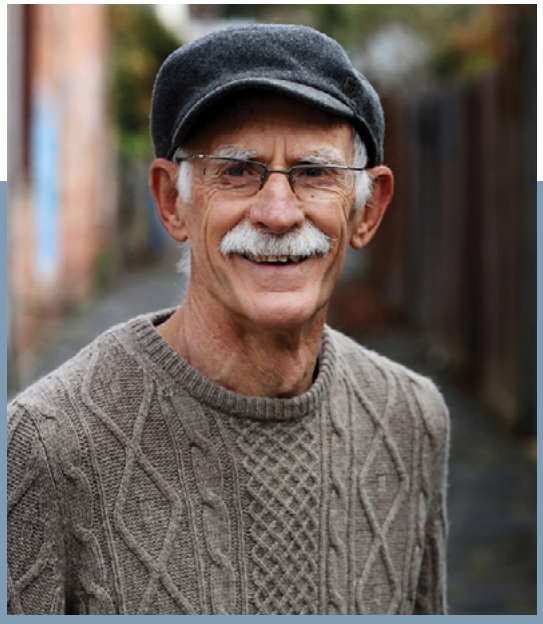
Changes in biopsy method

In keeping with trends noted in previous PCOR-ANZ reports,[1,2] the 2018 data demonstrate for the first time that transperineal biopsy is now performed more frequently (46% of diagnoses [n=6,029/13,079]) than transrectal ultrasound (TRUS)-guided biopsy (43% of diagnoses [n=5,643/13,079]) across the

men in PCOR-ANZ (Figure 8). Australian rates of transperineal biopsy are among the highest in the world, and funding changes for Medicare Benefits Schedule codes in 2020 will encourage the uptake of transperineal approaches in Australia. Transperineal biopsy has advantages over TRUS-guided biopsy with respect to lower rates of post-procedure sepsis and being able to sample the anterior prostate more readily.[3] However, the need for theatre time, new skills, special equipment, and usually a general anaesthetic, has restrained universal adoption.

Management choices based on risk category

In line with international guidelines,[4,5] the use of AS or WW as a treatment strategy for men with low-risk cancer continues to increase. Seventy-one percent of men from PCOR-ANZ who had low-risk cancer opted for AS or WW in 2018 (vs 54% in 2015) with a concomitant fall in surgery (24% versus 39%; Figure 9). South Australia–Northern Territory is the region with the lowest use of AS or WW in the low-risk category. In 2018, 29% of men in this category within PCOR-ANZ opted for radical treatment, which may be contrasted with the lowest reported rate of 5% for the UK and Wales (men diagnosed 2018–2019).[6] For men in the high/very-high-risk category, those in NZ were least likely to have a prostatectomy, and most likely to be managed with ADT (with/without chemotherapy; Figure 10). Consistent with our prior data, overall ~10% of men with high/very-high-risk cancer were managed with ADT (with or without chemotherapy; Figure 9).



Management choices based on residence or institution

We further explored notable trends across the PCOR-ANZ database by analysing the management data by residential area (urban versus rural) and socio-economic status; using deidentified postal area data.

Across PCOR-ANZ, transperineal biopsies are proportionally more common than TRUS for men living in metro areas compared with outer regional/remote areas (62% vs 37% in 2018; Figure 15). Similar findings apply in the areas with highest quintile of socioeconomic status (Figure 14). However, all subgroups are increasingly opting for transperineal biopsy.

Similarly, robotic prostatectomy was proportionally more common in metro and more socially advantaged areas compared to rural and more socially disadvantaged areas (Figures 19 and 20).

Short-course radiation therapy

Following the publication of major randomised controlled trials,[7,8] rapid adoption of short-course (moderately hypofractionated) radiation therapy was noted across PCOR-ANZ (Figures 21 and 22).

In the first half of 2016, almost no patients were treated with this approach, rising steadily to 42% in the first half of 2019. This was most pronounced for men with intermediate-risk prostate cancer, 61% in the first half of 2019.

Executive summary

Quality indicator reporting

We are proud to continue releasing quality indicator reports that cover data from two nations, expanding from the registry's beginning as a state-based report 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-value, quality indicator report that presents outcomes accurately, simply and intuitively for authorised readers. All the quality indicator 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 identified through a clinician-led process that defined best-practice care 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 2020, 583 reports were distributed to contributing clinicians and institutes. 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 quality-improvement mentality, following a Plan, Do, Study, Act (PDSA) model for improvement.

PCOR-ANZ will track how the bi-national averages change across all these quality indicators, and we will highlight trends in future annual reports. We continue to refine the indicators we have to make them the most relevant and useful to clinicians and institutions. Work is underway to develop a separate set of indicators for radiation oncology providers. Additionally, a pilot program trialling a mobile application to provide urologists close to real-time feedback on quality outcomes is set for completion in late 2021. These initiatives will help deepen our engagement with clinicians and 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.

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HOW TO INTERPRET THE DASHBOARD

This report includes data on men diagnosed at Institute ID: **1234** during the diagnosing period of **01 Jan 2015 - 31 Dec 2017**. This report was produced on **13 Jun 2019**.

PROSTATE CANCER OUTCOMES | REGISTRY AUSTRALIA AND NEW ZEALAND

Institute: 1234
Diagnosis Period: 01 Jan 2015 - 31 Dec 2017
Report Date: 13 Jun 2019

DASHBOARD

Refer to 'HOW TO INTERPRET PERFORMANCE SUMMARY CHART' below.

QUALITY INDICATOR	Page No	Range (%)	PERFORMANCE SUMMARY CHART COMPARISON TO INSTITUTE AVERAGE*
DIAGNOSIS			
1. PSA level is documented at diagnosis	11	0-100	
2. Clinical T category is documented in the medical record	12	0-100	

Range (%) refers to the minimum and maximum values on the performance summary chart.

For example, in the 'Clinical T category is documented in the medical record' quality indicator, performance ranges from 0 to 100% for the last two reporting periods.

HOW TO INTERPRET PERFORMANCE SUMMARY CHART

The black dot shows your results for men diagnosed between 01 Jul 2016 and 30 Jun 2019

The white diamond shows your results at the time of the last report

The triangle shows the median of all PCOR-ANZ Institutes for men diagnosed between 01 Jul 2016 and 30 Jun 2019

The vertical blue line shows the aspirational target for this indicator. The aspirational target is set using the *Achievable Benchmark of Care Approach*[1,2], which estimates the benchmark based on the top performing Institutes that account for 10% of patients in the registry.

The lightly shaded area shows the range of achievement for the middle 50% (25-75%) of contributors to this report

[1]Kiefe CI, Allison JJ, Williams OD, Person SD, Weaver MT, Weissman NW. Improving quality improvement using achievable benchmarks for physician feedback: a randomized controlled trial. JAMA. 2001 Jun 13;285(22):2871-9.

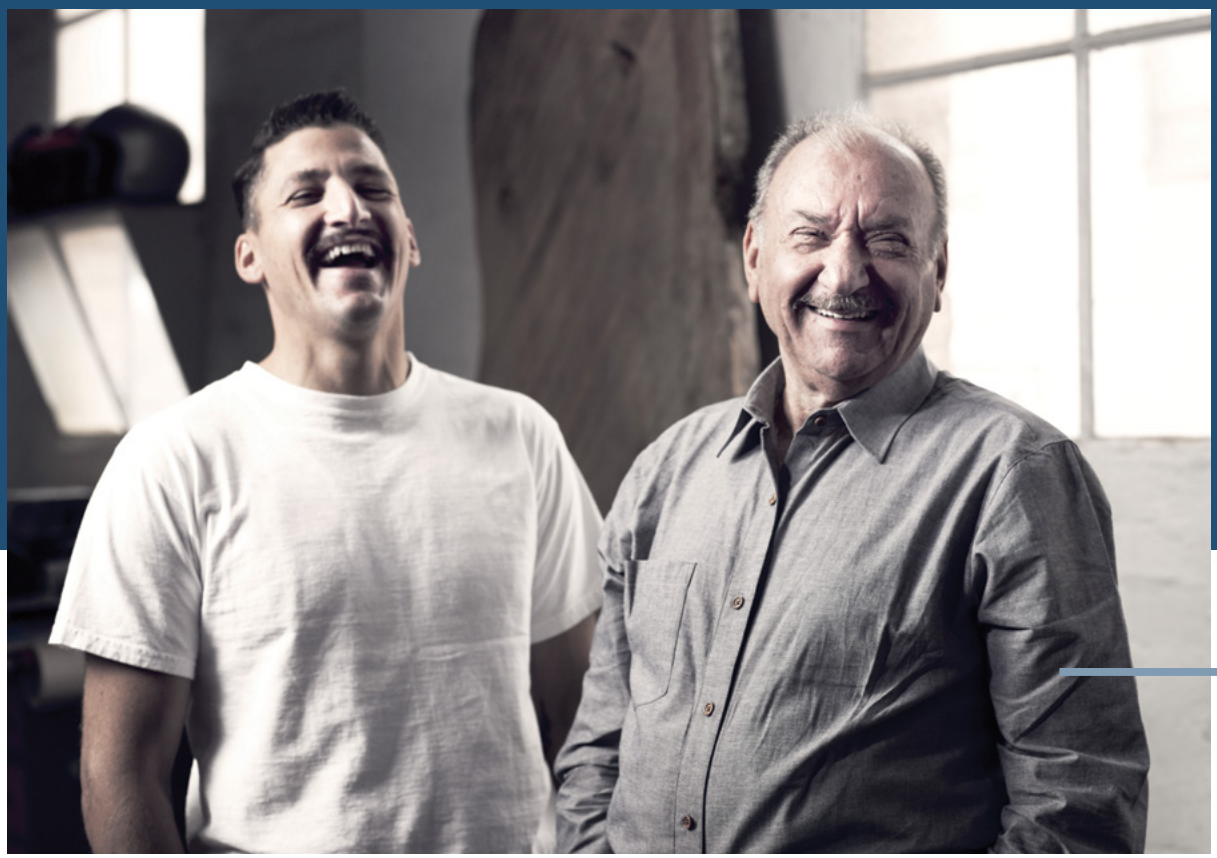
[2]Paddock SM. Statistical benchmarks for health care provider performance assessment: a comparison of standard approaches to a hierarchical Bayesian histogram-based method. HEALTH SERVICES RESEARCH. 2014 Jun; 49(3):1056-73.

Institute: 1
Diagnosis Period: 01 Jul 2015 - 30 Jun 2018
Report Date: 30 Oct 2019

DASHBOARD

QUALITY INDICATOR	Page No	Range (%)	PERFORMANCE SUMMARY CHART COMPARISON TO INSTITUTE AVERAGE*
DIAGNOSIS			
1. PSA level is documented at diagnosis	13	0-100	
2. Clinical T category is documented in the medical record	14	0-100	
TREATMENT			
3. PSA level documented post radical prostatectomy	15	0-100	
4. High/very high risk or metastatic disease with no treatment	16	NA	NOT BENCHMARKED
5a. Low-risk disease in men who have a radical prostatectomy	17	0-100	
5b. Active treatment in men with low-risk disease	18	0-100	
CLINICAL OUTCOMES			
6. Mortality	19	NA	NOT BENCHMARKED
7. Positive surgical margins post radical prostatectomy (intermediate risk)	20	0-100	
8. Positive surgical margins post radical prostatectomy (high risk)	21	0-100	
9. Positive surgical margins post radical prostatectomy (pT2)	22	0-100	
PATIENT-REPORTED OUTCOMES			
10. Urinary bother at 12-month follow-up post prostatectomy	23-26	0-100	
11. Bowel bother at 12-month follow up post radiation therapy†	27-28	0-100	
12. Sexual bother at 12-month follow up post prostatectomy	29-30	0-100	

* See page 1 for a description on how to interpret the Performance Summary chart.
† Absence of a black dot or a grey dot indicates that none of your patients met the eligibility criteria for this indicator.



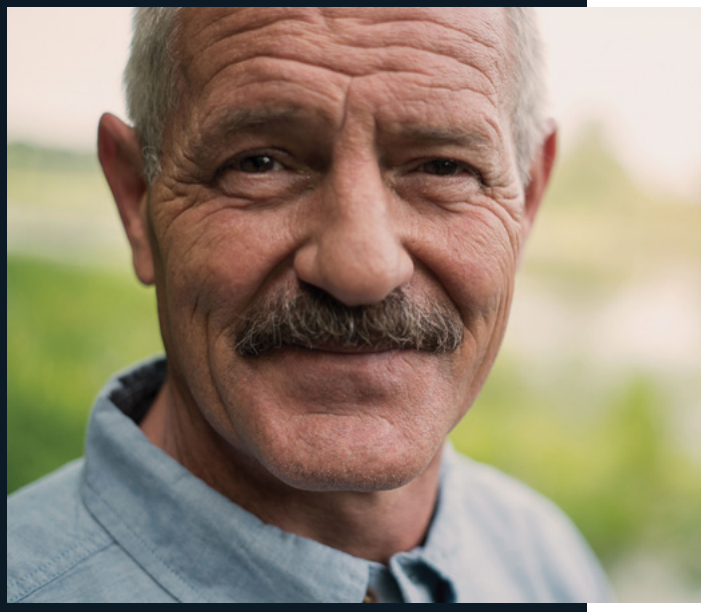
Looking to the future

The year 2021 opens a new phase for the registry. Movember's recent partnership with Dacima Software, a global company specialising in electronic data capture, paves the way to modernise the database infrastructure and streamline data collection. A new initiative to link PCOR-ANZ with government administrative data sets will see the registry expand. The integration of an electronic PROMs capture system containing automated-reminder functionality will provide a multimodal way for men to record their treatment outcomes through the submission of their EPIC-26 questionnaire, and is expected to improve response rates. Once these initiatives are fully integrated, PCOR-ANZ data capture will become more efficient, and the use of the expanded dataset more flexible. This enables us to provide more value for all stakeholders; clinicians, researchers and patients alike.

We also look forward to tracking other trends across the database such as utilisation of magnetic resonance imaging (MRI) and prostate-specific membrane antigen–positron emission tomography (PSMA-PET); or uptake of adjuvant versus salvage radiation therapy for example. As use of the quality indicator reports expands, we also intend to track how the bi-national averages change across the range of quality indicators, which could potentially be used to inform changes to clinical practice.

About this report

This report is targeted to clinicians contributing to PCOR-ANZ and their host institutions, and others interested in improving the quality of prostate cancer treatment. The document is not designed to be a comprehensive description of prostate cancer and the treatments available in Australia and New Zealand, but rather a summary of the activities of the registry and the data contained within it.



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

Ethical reporting

To protect the identities of men within the registry and the clinicians and institutes who support this work, certain analyses use 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 less-common treatment types such as chemotherapy, which has been combined with ADT. Therefore, in this report 'ADT' refers principally to men who have received ADT without radiation therapy 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 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 or watchful waiting as a management option.

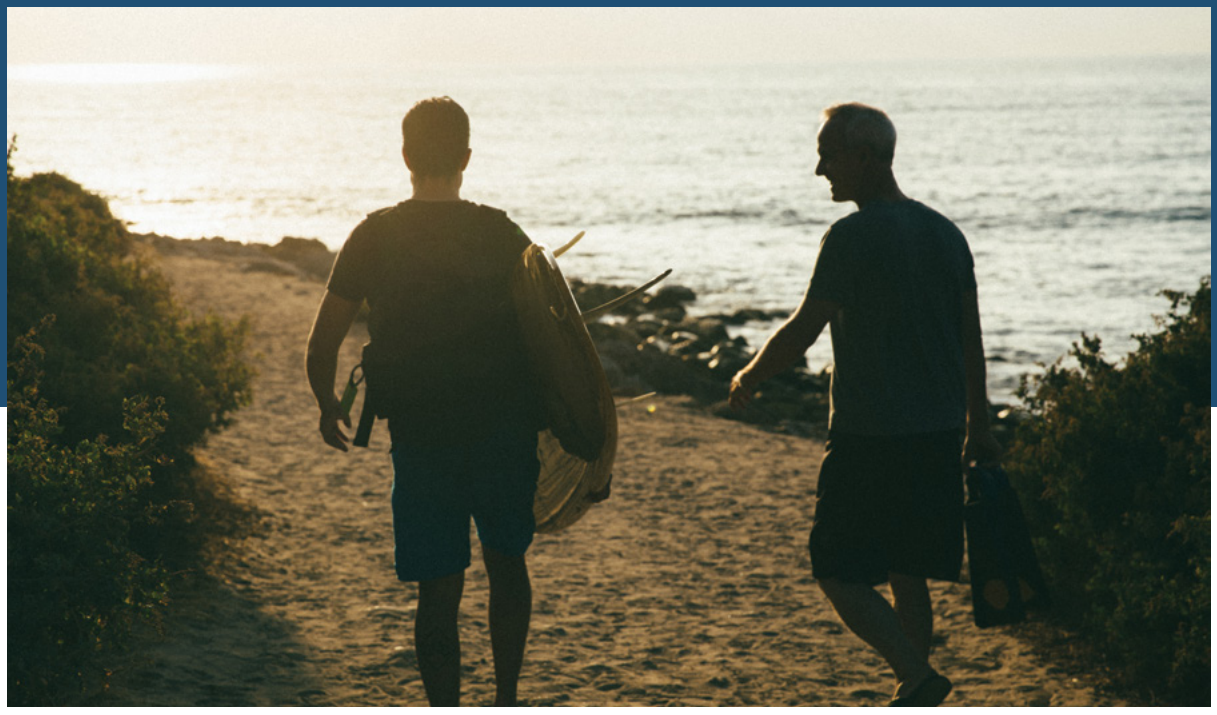
What data are we using?

The data contained in this report were extracted from the PCOR-ANZ database on the 3rd September 2020 and primarily relate to men diagnosed between 1st January 2015 and 31st December 2018. Treatment and PROMs data for these men were collected up to 3rd September 2020. 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 primarily report on data for men who have been diagnosed at least 18 months prior to inclusion, 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 1.

The steps in this process mean that we cannot include men who have been diagnosed more recently in the report (see infographic). The 2015–2018 database includes 39,953 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 39,953 – representing the number of men for whom that specific data was available.

These annual reports use data from the commencement of the bi-national PCOR-ANZ project in 2015. However, Victoria and South Australia have state prostate cancer registries that pre-date 2015. Additionally, in limited specific analyses, men with available treatment data but incomplete follow-up have been included in the certain analytic sets. Therefore, there is a larger set of men in some constituent PCOR-ANZ-related registries than can be analysed in other publications where the sample size of available men can vary.



About this report

Data on method of diagnosis and age are collected for all men (N=39,953). Other data such as Grade Group or NCCN risk group are not available for every man in the database. These analyses are performed on the slightly smaller groups of men for whom those data were available.

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 begins approximately 18 months after the end of any given calendar year. Over 2015–2018, 20,913 men answered EPIC-26 questionnaires for PCOR-ANZ.

Data on treatment only become available once the initial treatment decision has been made, which will be at a slightly different point in time for different men.

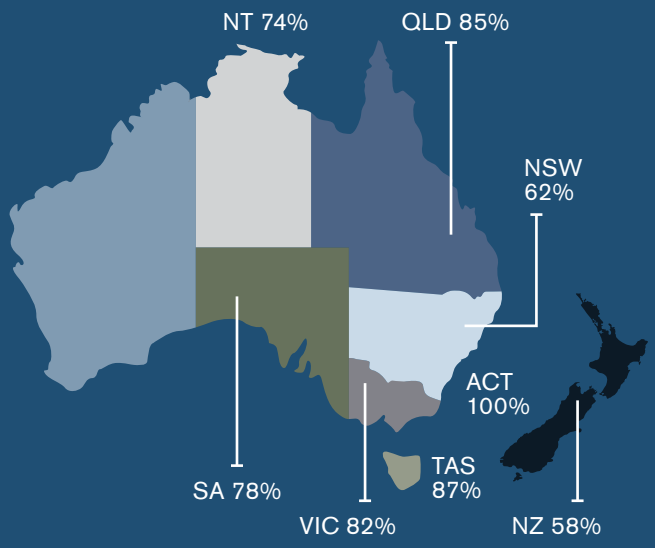
Men undergoing active treatment are sent the EPIC-26 questionnaire 12 months after treatment commences, or 12 months after the latest round of active treatment in a given year.

$17M

total investment by Movember

$1M
invested in translational research

$1.85M
invested in infrastructure upgrades



72% **OVERALL POPULATION COVERAGE IN 2018**
13,938 enrolments out of 19,282 estimated cases

244
SITES

133 public
111 private

354
CLINICIANS

315 urologists
22 radiation oncologists
17 medical oncologists

39,953
MEN ENROLLED 2015–2018

NB: in addition, 23,865 men were enrolled in pre-existing VIC and SA databases (1998–2015).

583
QI REPORTS DELIVERED TO PARTICIPATING CLINICIANS

Reports are delivered in the strictest confidence and measure 12 key quality indicators across mainly surgical outcomes.

New to 2020

Infrastructure update

In partnership with Dacima Software, database infrastructure will be updated and data-capture processes streamlined.

Electronic PROMs capture

Multimodal data capture with automated reminders will make answering questionnaires more convenient for men.

Data linkage pilot

A pilot program linking PCOR-ANZ with government administrative data sets is underway.

Interested in contributing?

Healthcare providers: Contact your PCOR jurisdictional coordinator under 'Who's involved'.
Planning research? Find out more about how to access data under 'Governance'.

https://prostatecancerregistry.org

Chapter 1

PCOR-ANZ population overview and patient-reported outcomes

Thanks to the dedication of our data collectors and co-ordinators, and the valued contribution of participating clinicians and hospitals, PCOR-ANZ continues to grow year on year. Between 2017 and 2018, the number of men with prostate cancer recruited to the registry increased by 26%, bringing the estimated population coverage to 72%.

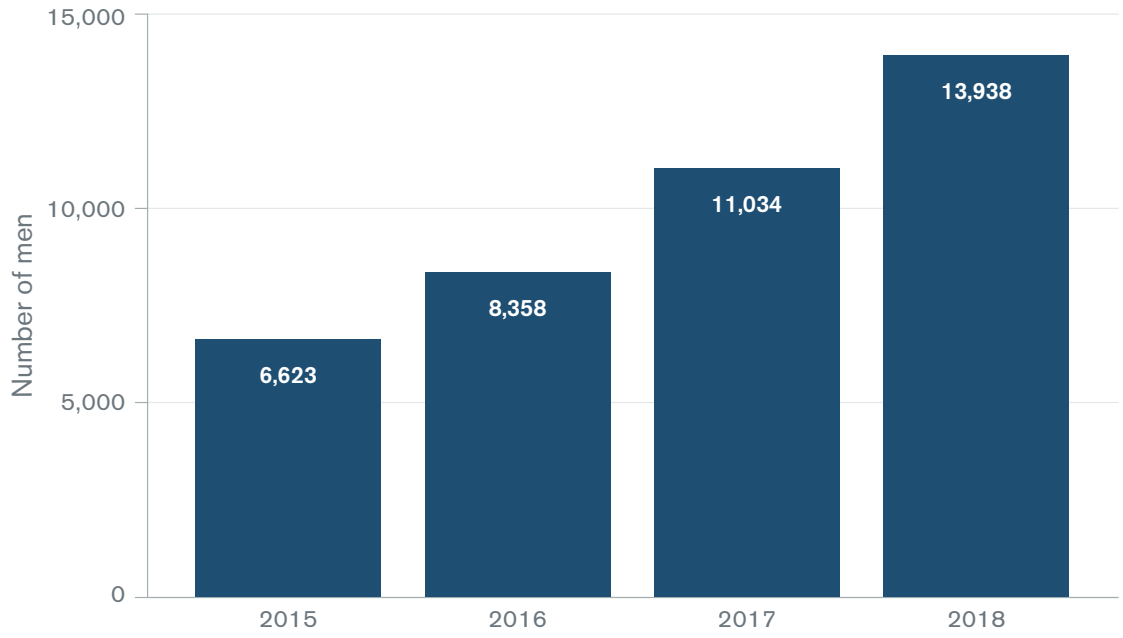
Patient status at diagnosis

The median age at diagnosis overall was 68.0 years for 2015–2018, with slight age increases year-on-year, from 67.6 years in 2015 to 68.3 years in 2018 (Figure 2).

There have been minimal changes over time in grade group at diagnosis (the most common is grade group 2; 31%; Figure 3). Similarly, prostate-specific antigen (PSA) at diagnosis has remained stable over time (median 7.3 ng/mL; interquartile range [IQR] 5.1–11.4; Figure 4).

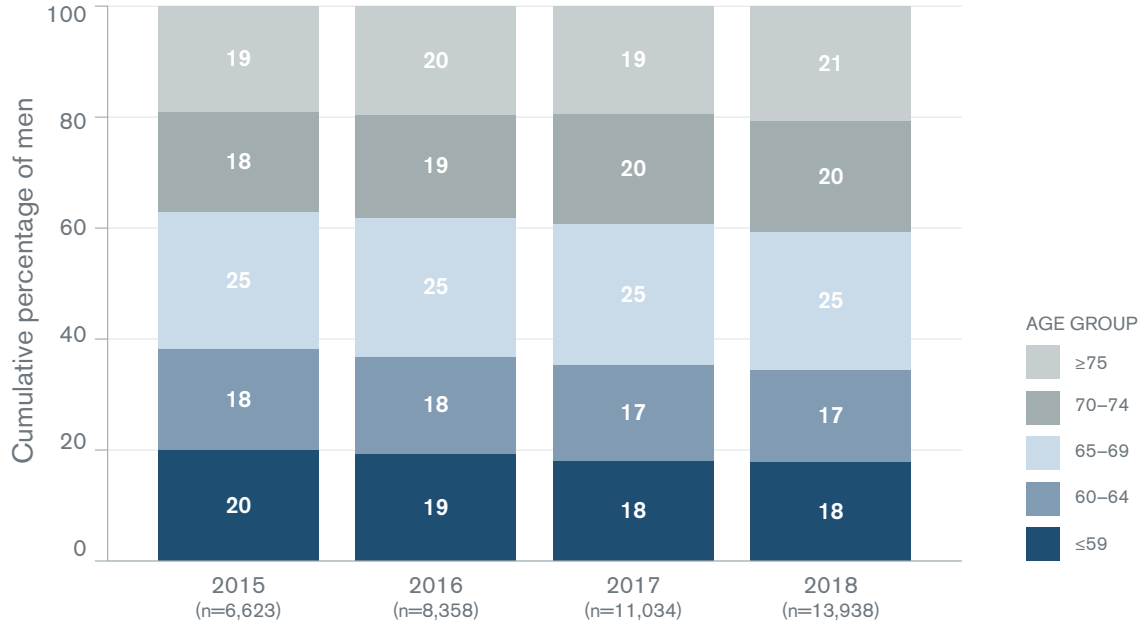
The most frequent National Comprehensive Cancer Network (NCCN) risk group at diagnosis is intermediate (45% of men), with 9.6% of men being diagnosed with non-localised disease (Table S1, Figure 5). Intermediate risk remains the most common risk group at diagnosis for all age groups (Figure 6); except for men who are diagnosed aged 75 and over, for whom high/very-high-risk disease is more common (43% of men >75 years). Similarly, intermediate-risk disease is most common across all jurisdictions at diagnosis (Figure 7), although there is some variation between New Zealand and Australia in the low-risk subgroup proportions (31% of men are diagnosed with low-risk disease in New Zealand versus 18–22% of men across Australian jurisdictions).

FIGURE 1: Number of men diagnosed per year in PCOR–ANZ



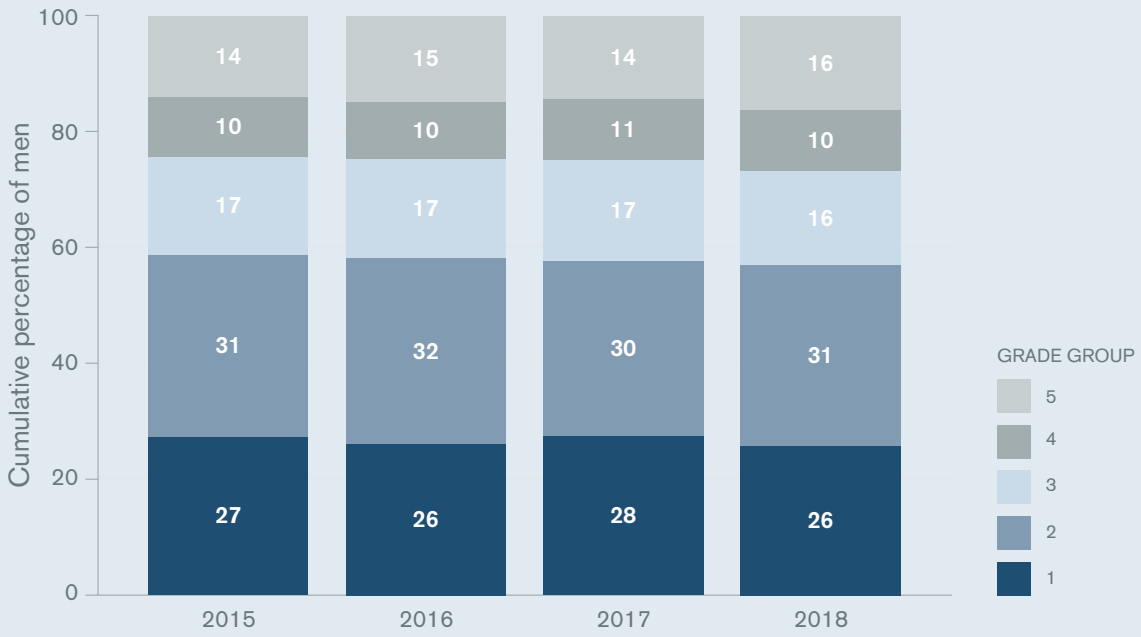
- Data on diagnosis were available for 100% of men in each year of this analysis (N=39,953).
- See Supplementary Table S1 for more information on the characteristics of men diagnosed over time.

FIGURE 2: Age group at diagnosis by year, shown as percentage of total men in each year



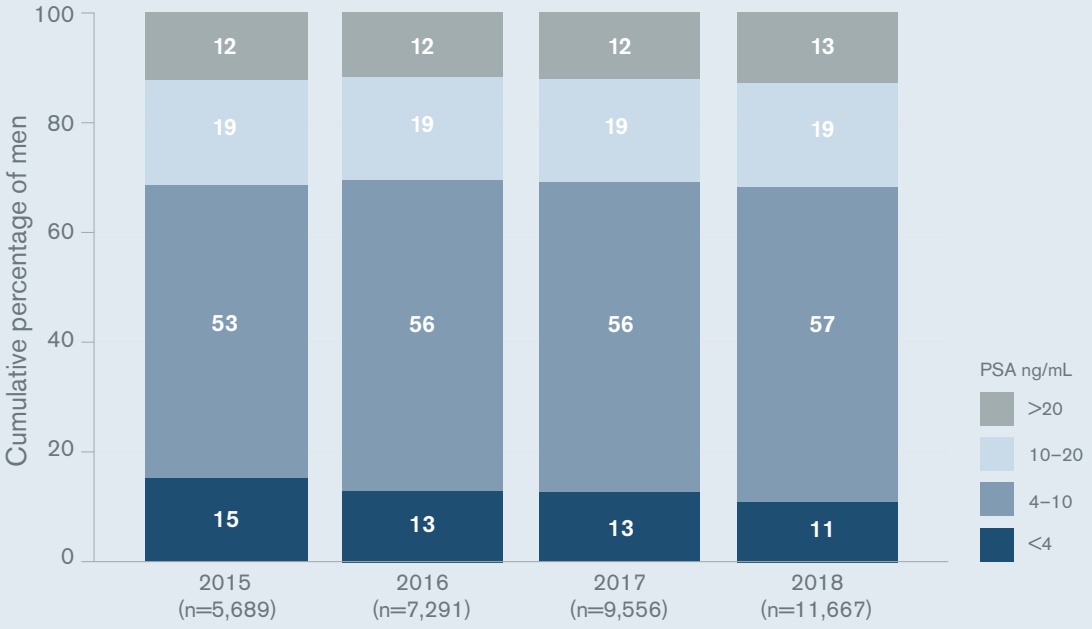
- Data on age at diagnosis were available for 100% of men in each year of this analysis (N=39,953).
- See Supplementary Table S1 for more information on the characteristics of men diagnosed over time.
- Percentages are rounded and may not add to 100%.

FIGURE 3: Proportion of Grade Group by year, shown as percentage of total men in each year



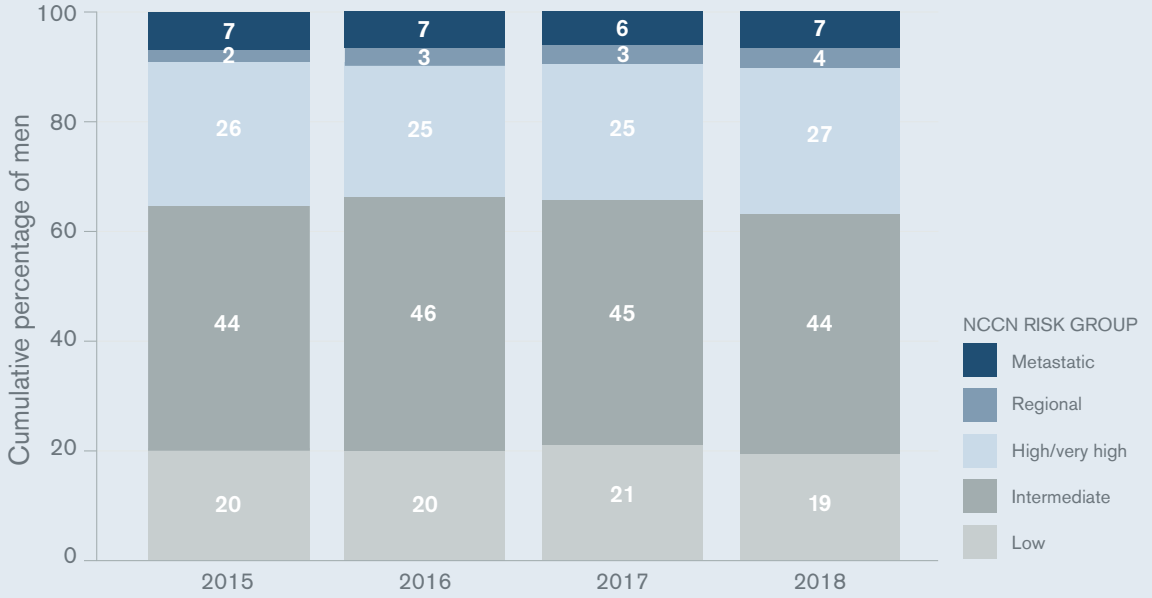
- Data on pathological grade at diagnosis were available for 96% of men in each year of this analysis (n=38,535/39,953).
- See Supplementary Table S1 for more information on the characteristics of men diagnosed over time.
- Percentages are rounded and may not add to 100%.

FIGURE 4: PSA level (ng/mL) category per year of diagnosis, shown as a percentage of total men in each year



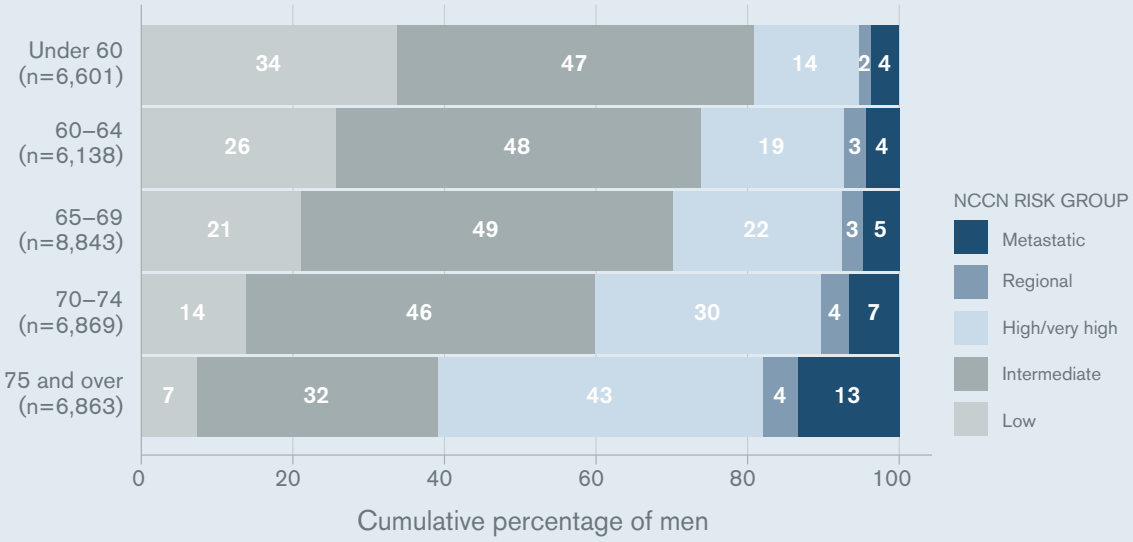
- Data on PSA level at diagnosis were available for 86% (n=34,203/39,953) of men in PCOR-ANZ.
- See Supplementary Table S1 for more information on the characteristics of men diagnosed over time.
- Percentages are rounded and may not add to 100%.
- PSA, prostate-specific antigen.

FIGURE 5: Proportion of men by NCCN risk group by year, shown as a percentage of total men in each year



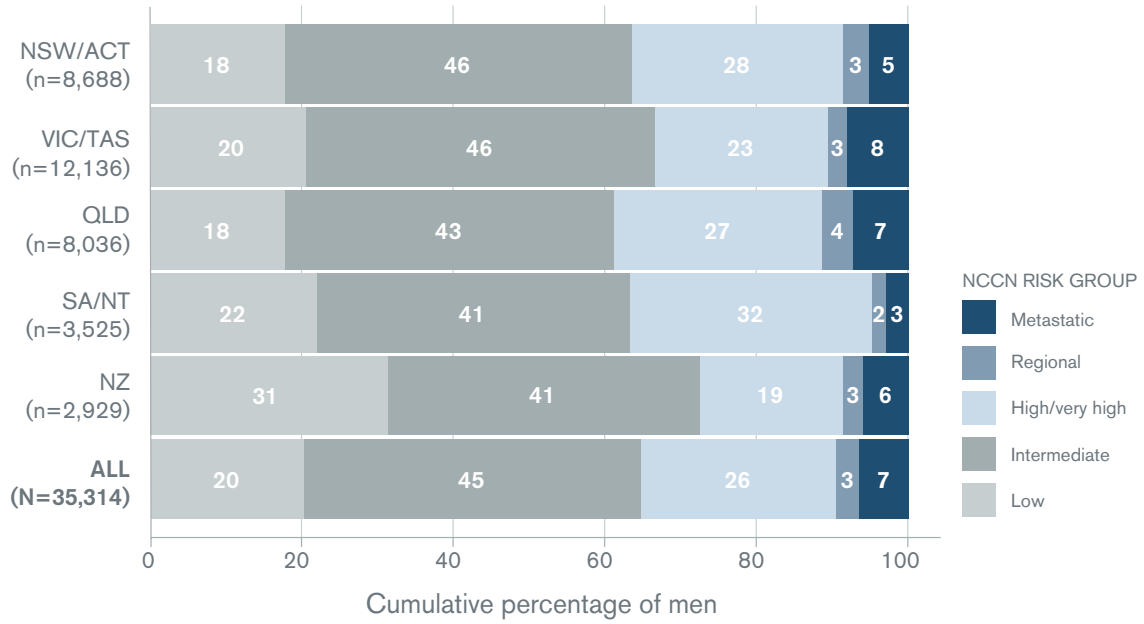
- Data on NCCN risk group at diagnosis were available for 88% (n=35,314/39,953) of men in PCOR-ANZ.
- See Supplementary Table S1 for more information on the characteristics of men diagnosed over time.
- Percentages are rounded and may not add to 100%.
- NCCN, National Comprehensive Cancer Network.

FIGURE 6: Proportion of men by NCCN risk group by age group, shown as a percentage of total men



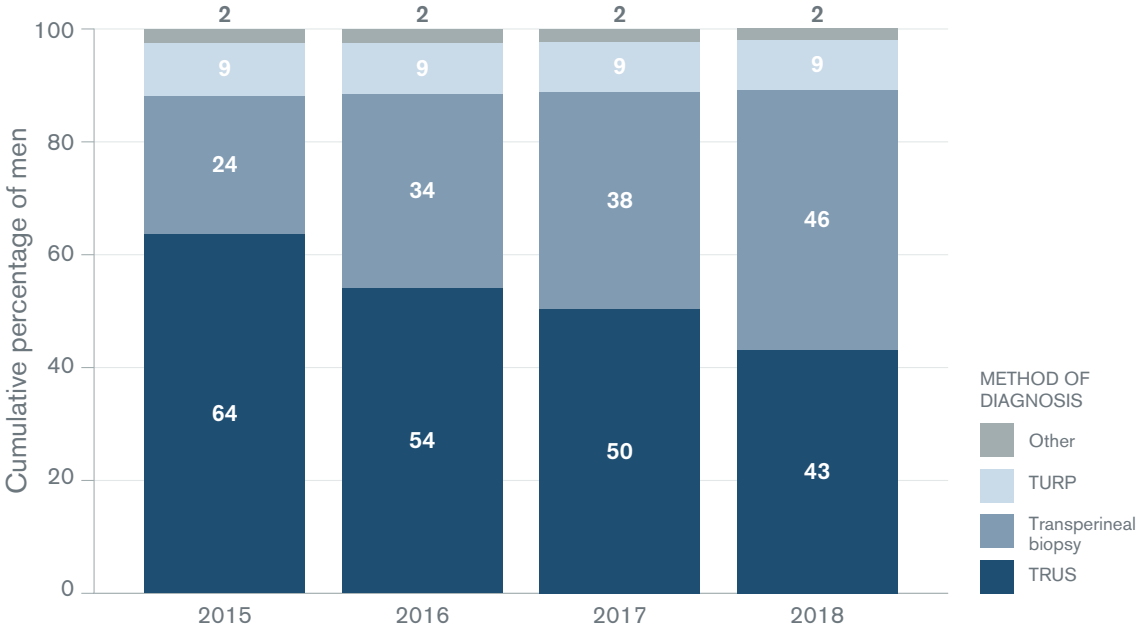
- Data on NCCN risk group at diagnosis were available for 88% (n=35,314/39,953) of men in PCOR-ANZ.
- See Supplementary Table S1 for more information on the characteristics of men diagnosed over time.
- Percentages are rounded and may not add to 100%.
- NCCN, National Comprehensive Cancer Network.

FIGURE 7: Proportion of men per NCCN risk group by jurisdiction, shown as a percentage of total men



- Data on NCCN risk group at diagnosis were available for 88% (n=35,314/39,953) of men in PCOR-ANZ.
- See Supplementary Table S2 for more information on NCCN risk groups.
- Percentages are rounded and may not add to 100%.
- NCCN, National Comprehensive Cancer Network.

FIGURE 8: Summary of method of diagnosis by year, shown as a percentage of total men in each year (2015–2018)



- Data on method of diagnosis were available for 97% of men in this analysis (n=38,761/39,953).
- Percentages are rounded and may not add to 100%.
- See Supplementary Table S1 for more information on diagnosis method.
- TRUS, transrectal-ultrasound-guided biopsy; TURP, transurethral resection of the prostate.

Method of diagnosis and primary treatment

In 2018, for the first time, transperineal biopsy was performed more frequently than TRUS biopsy. Incidental transurethral-resection of the prostate (TURP) diagnoses remain stable at 9% (Figure 8).

Observation methods such as AS or WW continue to increase as a management choice for low-risk disease, from 54% in 2015 to 71% in 2018 (Figure 9). Concomitantly, there was a decline in surgery for this risk group, from 39% to 24%.

Regional disease (defined as cN1) has increasingly frequently been treated with radiation therapy over the period.

There was some notable inter-jurisdiction variation in primary treatment (Figure 10). Compared with other jurisdictions, South Australia Northern Territory report lower use of AS or WW in men with low-risk disease, and systemic therapy is more common in New Zealand for men with high/very-high-risk localised cancer. There is an apparent difference in the percentage of patients in South Australia Northern Territory who receive radiation therapy for regional disease compared with other jurisdictions. However, given the total sample size for the analysis in this jurisdiction is n=38, it is difficult to tell if this reflects a true difference. In intermediate-risk disease, the most common subgroup, there was less variation in treatment patterns.

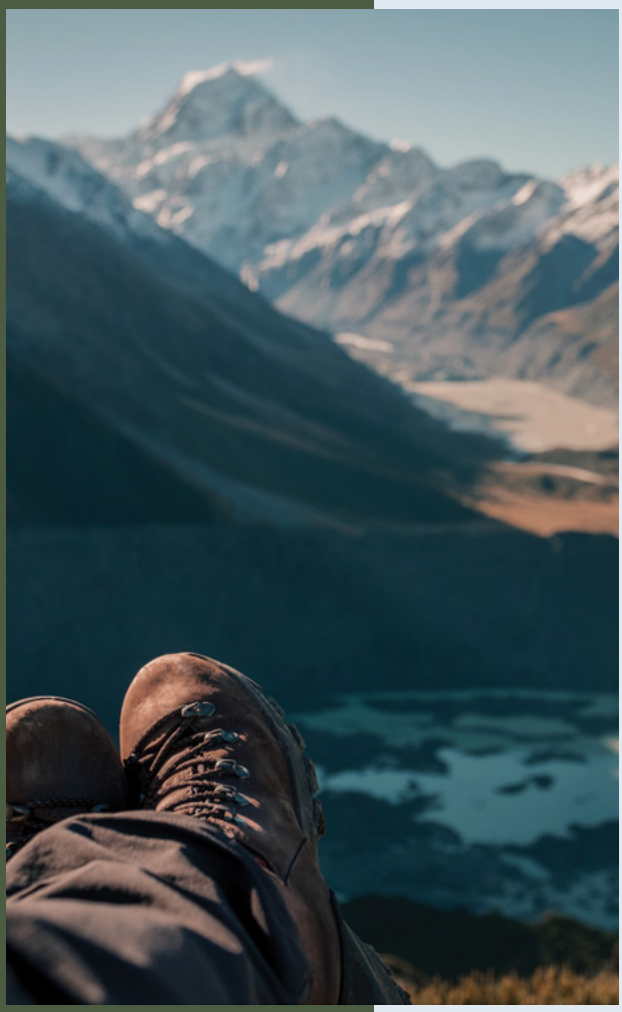
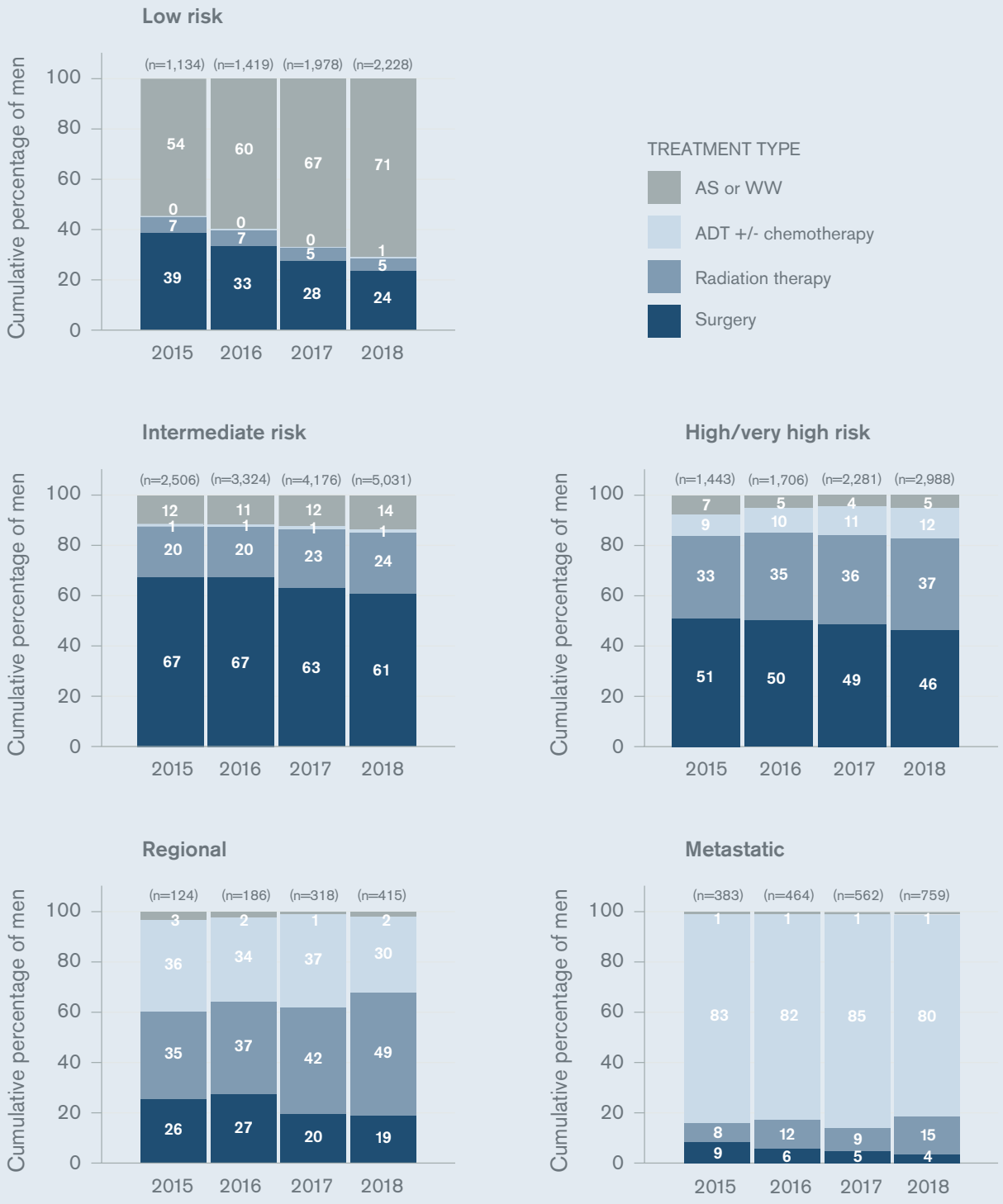
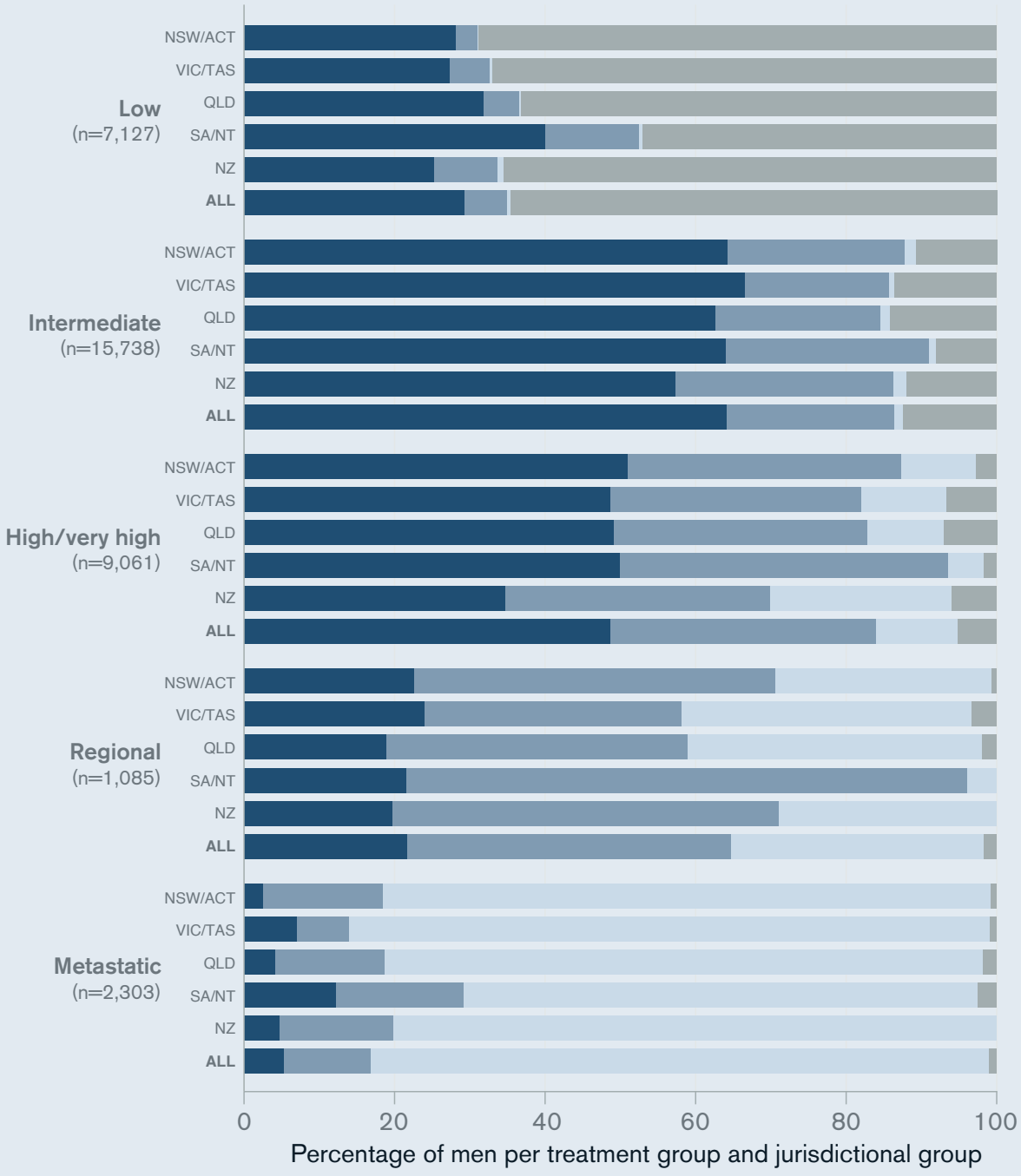


FIGURE 9: Management provided to men by NCCN risk group



- Data on NCCN risk group and primary treatment were available for 84% (n=33,425/39,953) of men in PCOR-ANZ.
- 'ADT' was administered without radiation therapy or surgery, but may include chemotherapy; this group also includes a minority of men receiving chemotherapy alone.
- See Supplementary Table S2 for more information on management and NCCN risk groups.
- Percentages are rounded and may not add to 100%.
- ADT, androgen-deprivation therapy; AS, active surveillance; NCCN, National Comprehensive Cancer Network; WW, watchful waiting.

FIGURE 10: Primary treatment across NCCN risk groups and by jurisdictional group (2015–2018)

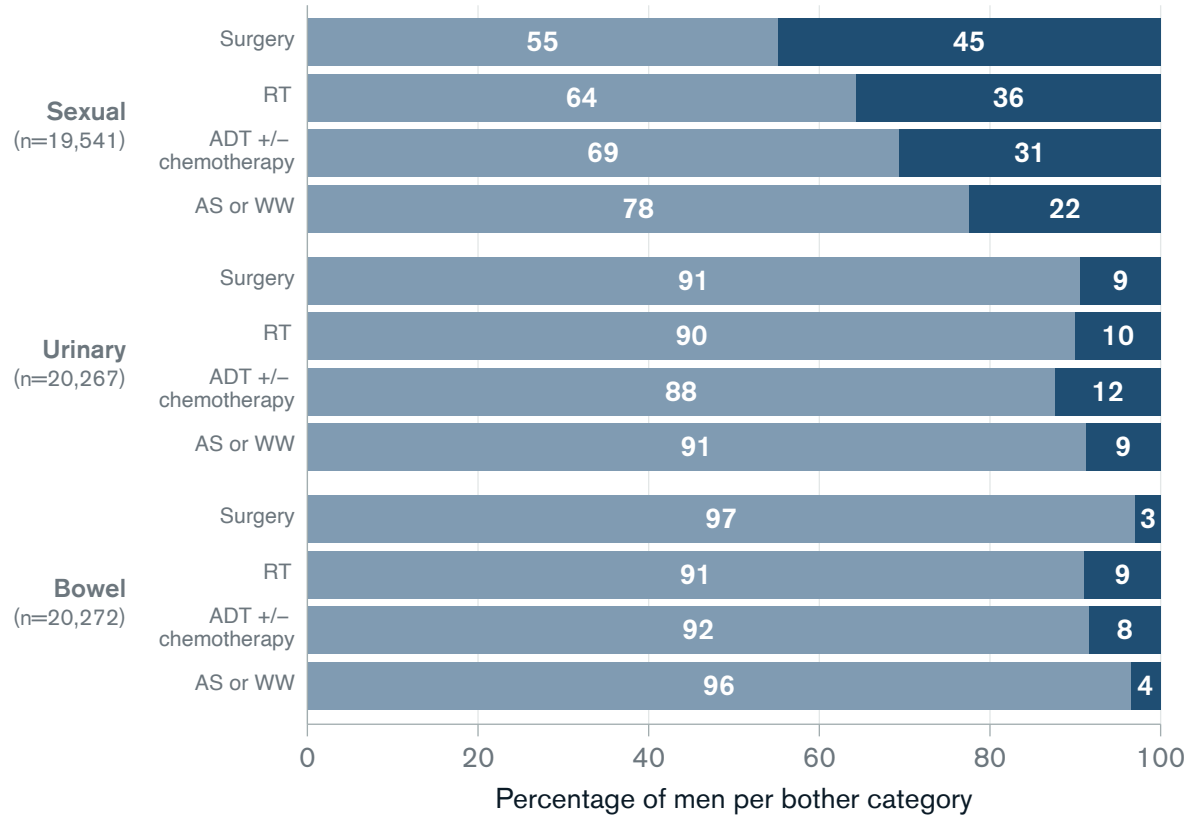


TREATMENT TYPE

- AS or WW
- ADT +/– chemotherapy
- RT
- Surgery

- Data on primary treatment and NCCN risk group was available for 88% (n=35,314/39,953) 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.
- 'ADT' was administered without Radiation therapy 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.
- The treatment type distribution across all ANZ jurisdictions combined, and thus an average, is labelled 'ALL'.
- See Supplementary Table S2 for a summary of management provided to men by NCCN risk group including 'missing' data.
- ADT, androgen-deprivation therapy; AS, active surveillance; NCCN, National Comprehensive Cancer Network; RT, Radiation therapy; WW, watchful waiting.

FIGURE 11: Patient-reported bother 12 months after treatment, across PCOR-ANZ, by EPIC-26 domain and treatment type (2015–2018)



- 'No bother', 'very small bother' and 'small bother' have been combined into one category; 'big bother' and 'moderate bother' have been combined into another.
- 'ADT' was administered without radiation therapy or surgery, but may include chemotherapy; this group also includes a minority of men receiving chemotherapy alone.
- See Supplementary Tables S3 for more information on bother, and S6 for follow-up methodology and quality-of-life completion rates.
- Percentages are rounded and may not add to 100%.
- ADT, androgen-deprivation therapy; AS, active surveillance; EPIC, Expanded Prostate Cancer Index Composite; RT, radiation therapy; WW, watchful waiting.

EPIC-26 scoring

The EPIC-26 questionnaire asks 26 questions about symptoms which are specific to prostate cancer treatment.[9]

Each response is given a score, and then specific groups of scores are aggregated into separate domain function summary scores for each of urinary incontinence, urinary irritation/obstruction, bowel and sexual function. For each functional domain, a score of 100 represents best possible function and a score of 0 represents worst possible function. These scores are reported for each of the main treatment modality 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:

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

Separately men are asked different EPIC questions such as, "How big a problem has your sexual function/urinary function/bowel habits been over the last 4 weeks?". This allows measurement of how big a "bother" men are having with their function. For example, it may be there is little change in (say) sexual function but some men might be very bothered by even a small change.

Trends in PROMs

Approximately 12 months after treatment or diagnosis for AS or WW, men registered with PCOR-ANZ are sent the short-form EPIC-26 questionnaire (see Supplementary Table S6 for format and completion rates).

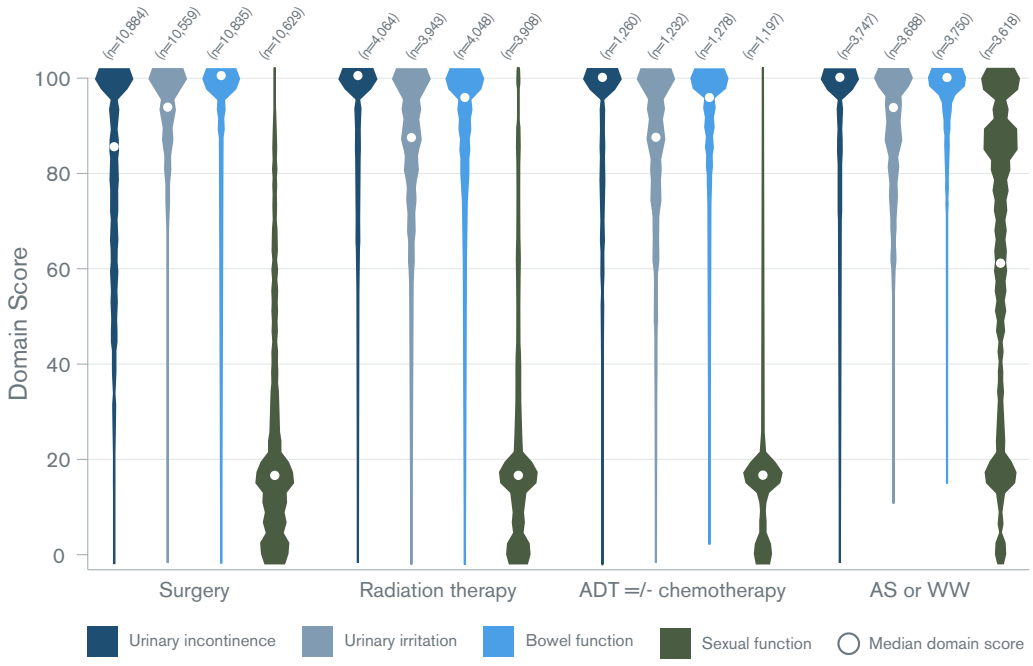
Sexual function was the domain where most patients self-reported moderate or big bother, particularly post-surgery (45%; Figure 11). There were no major differences between treatments for urinary bother. Major bowel bother was the least-reported problem. It was proportionally more common for radiation therapy and systemic therapy than surgery, but both were under 10%.

Violin plots (Figure 12) display the distribution, or spread, of domain scores and are useful for displaying multimodal outcomes. The area and width of the violin is relative to the number of patients with the related score shown on the vertical axis. In other words, the coloured area is widest where there are the most men with the corresponding score, and narrowest or disappears where there are the fewest or none.

For urinary incontinence, there were proportionally more surgical patients with domain scores below 60, as evidenced by the thicker violin at lower scores, than the other modalities; 25% for surgery versus 9% for radiation therapy, 11% for ADT and 6% for AS or WW.

For urinary irritation, the analogous percentages were 2% for surgery versus 7% for RT, 6% for ADT and 5% for AS or WW; and for the bowel-function domain, it was 2% for surgery versus 9% for RT, 7% for ADT and 3% for AS or WW. The sexual-function domain scores were markedly different between men treated with interventions or systemic therapies and those who were undergoing AS or WW. Whereas peaks were observed at low scores, 0 and 20, for men treated; for those managed by AS or WW, the modal scores were at the higher end, 80 and 100.

FIGURE 12: Distribution of responses to the function domains of the EPIC-26 proms questionnaire (combined data 2015 2018)



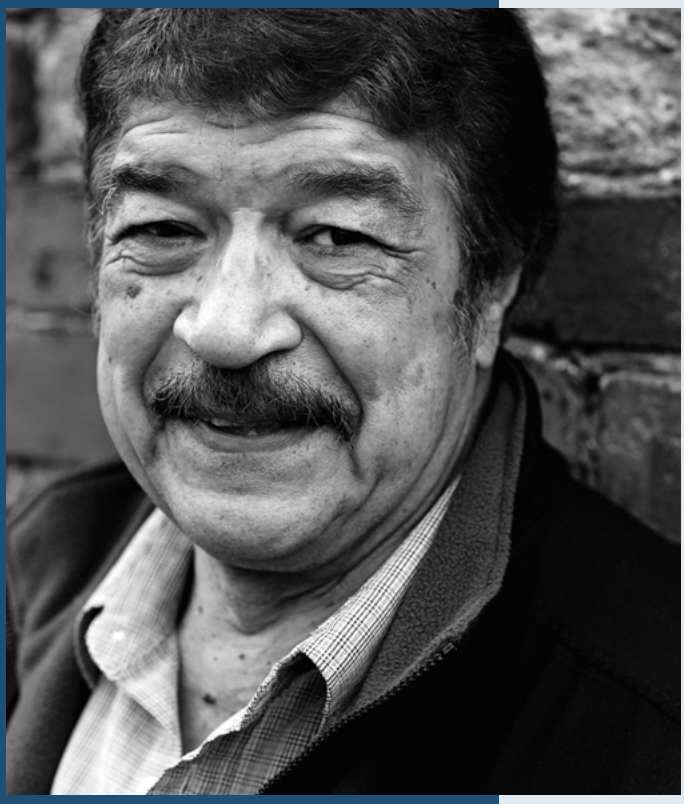
- 57% of men who were sent the EPIC-26 questionnaire responded (n=20,913/36,466).
- In each of the 'domains' of bowel function, sexual function, urinary irritation and urinary incontinence, scores range from 0 (worst) to 100 (best).
- No adjustment can be made for pre-diagnosis function, so comparisons between treatments may be affected by differences in groups prior to treatment.
- 'ADT' was administered without radiation therapy or surgery, but may include chemotherapy; this group also includes a minority of men receiving chemotherapy alone.
- ADT, androgen-deprivation therapy; AS, active surveillance; EPIC, Expanded Prostate Cancer Index Composite; PROMs, patient-reported outcome measures; WW, watchful waiting.

Chapter 2

Trends in prostate biopsy

There is strong advocacy amongst clinicians to move away from TRUS biopsy to transperineal biopsy.[10] Transperineal biopsy is associated with significantly reduced infectious complication rates compared to TRUS biopsy,[3] though with potentially higher readmission rates for urinary retention.[11]

We present results examining the magnitude of this trend towards transperineal biopsy and its differential uptake amongst jurisdictions, socioeconomic status (SES) quintiles and areas of residence.



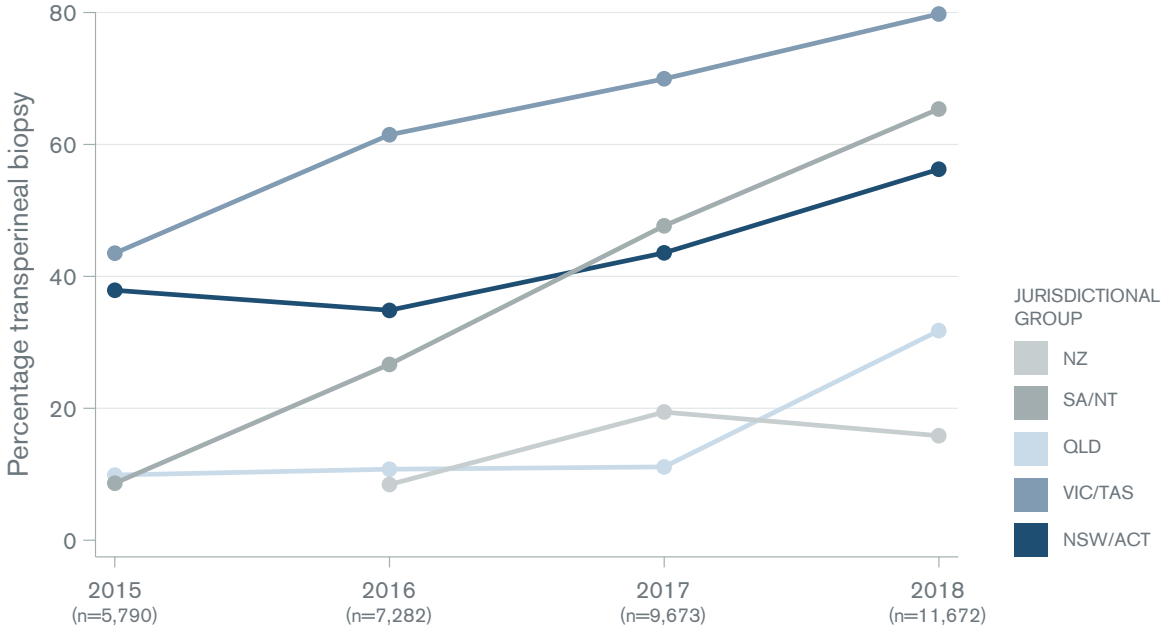
For this analysis, the proportion of diagnoses made by transperineal biopsy versus TRUS biopsy was examined.

Postal area code was used with correspondences from the Australian Bureau of Statistics to classify patients according to residence: major metropolitan, inner regional and outer regional/remote, and by SES quintile using the Index of Relative Socioeconomic Advantage and Disadvantage metric.[12] Diagnosing institutions were classified as metropolitan or regional and public or private by the individual jurisdictional registries.

Most jurisdictions recorded rises in transperineal biopsy (Figure 13), but large variations exist; in 2018 Victoria–Tasmania had the highest recorded proportion (80%) with New Zealand having the lowest (16%).

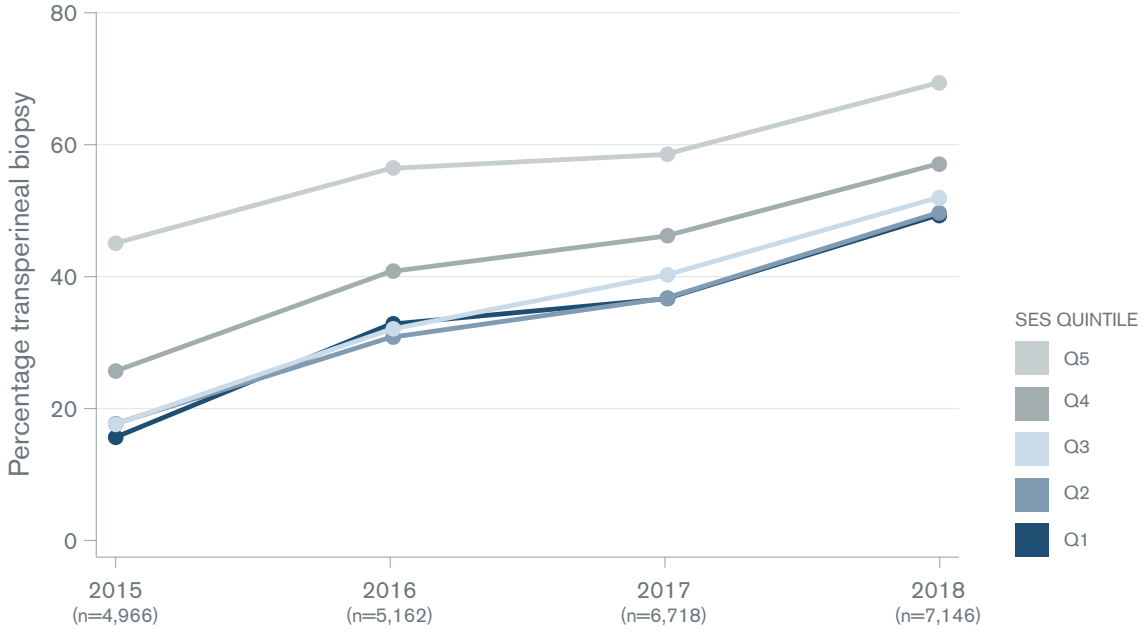
Across all SES quintiles, transperineal biopsy increased (Figure 14). The absolute percentage gap between the most advantaged (Q5) to the most disadvantaged (Q1) persisted through the years, falling only slightly from 29% in 2015 to 20% in 2018.

FIGURE 13: Proportion of diagnoses by transperineal biopsy (versus TRUS biopsy), by jurisdiction



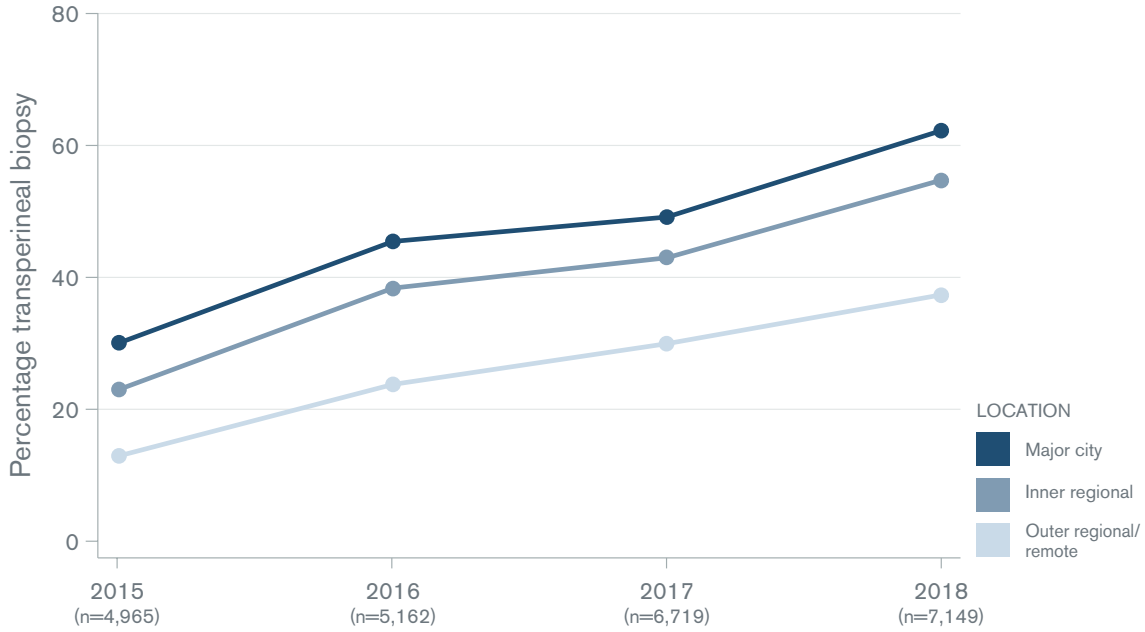
- Data on transperineal vs TRUS diagnosis method and jurisdiction were available for (n=34,417) of men.
- See Supplementary Table S5 for more information on diagnosis method.
- TRUS, transrectal-ultrasound-guided biopsy.

FIGURE 14: Proportion of diagnoses by transperineal biopsy (versus TRUS biopsy) per SES quintile



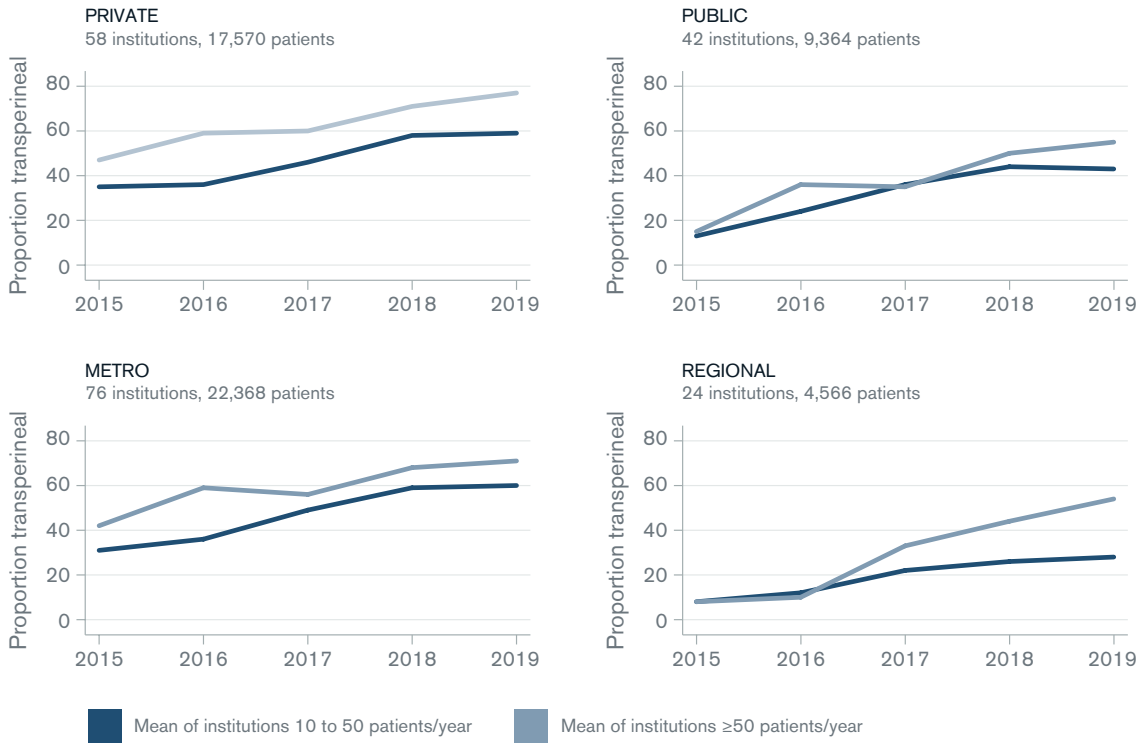
- Socioeconomic status (SES) was divided into quintiles with Q1 being the most disadvantaged and Q5 being the most advantaged.
- Data on transperineal vs TRUS diagnosis method and SES quintile were available for 68% (n=23,992/34,417) men. Data were not available for NSW or NZ.
- See Supplementary Table S5 for more information on diagnosis method.
- Postal code was used with correspondence from the Australian Bureau of Statistics to classify patients according to residence: major metropolitan, inner regional and outer regional/remote, and by quintile of socioeconomic status using the Index of Relative Socioeconomic Advantage and Disadvantage metric.
- SES, socioeconomic status; TRUS, transrectal-ultrasound-guided biopsy.

FIGURE 15: Proportion of diagnoses by transperineal biopsy (versus TRUS biopsy) by residence



- Data on transperineal vs TRUS diagnosis method and residence were available for 70% (n=23,995/34,417) of men in this analysis. Data were not available for NSW or NZ.
- See Supplementary Table S5 for more information on diagnosis method.
- Postal code was used with correspondence from the Australian Bureau of Statistics to classify patients according to residence: major metropolitan, inner regional and outer regional/remote.
- TRUS, transrectal-ultrasound-guided biopsy.

FIGURE 16: Proportion of diagnoses by transperineal biopsy (versus TRUS biopsy) per institution type



- Data on diagnosis and institution were available for 78% of men in this analysis (n=26,934/34,417).
- See Supplementary Table S1 for more information on the characteristics of men diagnosed over time.
- TRUS, transrectal-ultrasound-guided biopsy.

Similarly, use of transperineal biopsy rose for patients residing in both metropolitan and regional areas, but the percentage gap between metro and outer regional/remote patients increased from 17% in 2015 to 25% in 2018 (Figure 15).

At the institutional level, transperineal biopsy was more common in private than public hospitals and metropolitan than regional hospitals (Figure 16). Within each of these categories, high-volume institutions (≥50 patients/year), on average, performed proportionally more transperineal biopsies.

Chapter 3

Trends in interventional management

Recent data from Victoria showed divergence in the type of interventional treatment men were receiving according to whether they were diagnosed in the private or public health system.[13] We explored this finding using bi-national data, grouped by NCCN risk category and examined the relative components of open and robotic surgery. Further, we looked at the time trends of robotic versus open surgery by SES quintile and area of residence.

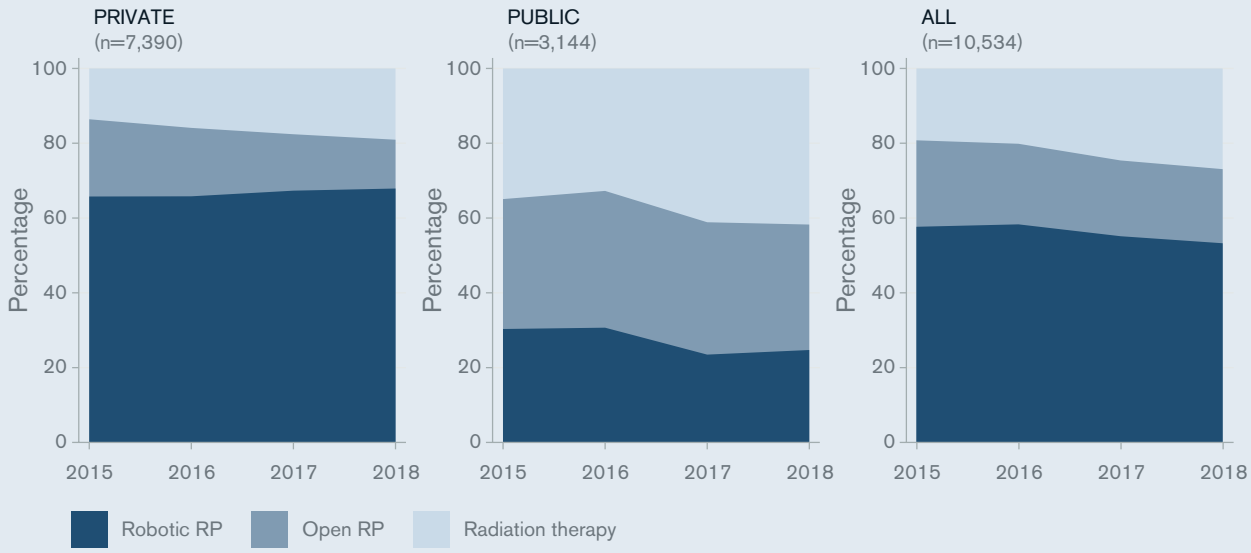
Patients receiving interventional treatment (surgery or radiation therapy) were analysed by the type of diagnosing institution, public or private, and by NCCN risk group (intermediate or high/very high).

In 2018, for intermediate-risk patients diagnosed in private institutions, surgery was the most common interventional treatment (81%) with the majority being robotic (68% versus 13% open). For public patients, surgery was still the most common intervention (though proportionally lower, 58%) but open surgery was the more frequent approach (34% versus 25%). See Figure 17 for trends and Supplementary Table S5 for patient numbers.

For high/very-high-risk patients in 2018, surgery was more frequent in private patients (63%) whereas the inverse was true for public patients (63% had radiation therapy; see Figure 18 for trends).

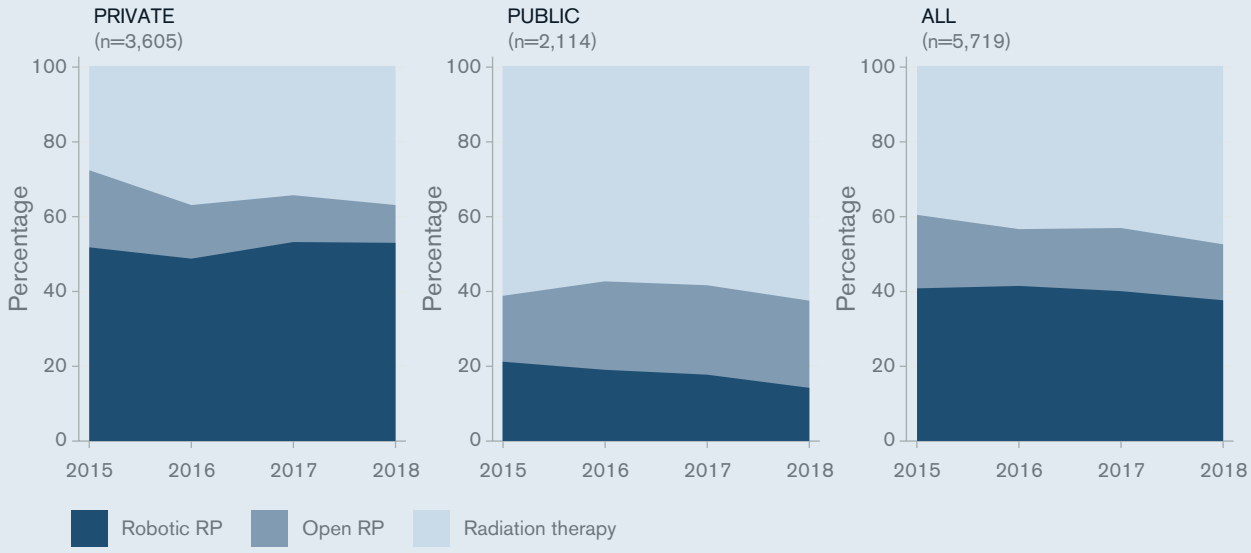
Small proportional increases over time were noted in the use of radiation therapy, though this is likely owing to more radiation oncology institutions and clinicians joining the registry (Figures 17 and 18).

FIGURE 17: Types of interventional treatment chosen by men diagnosed with intermediate-risk prostate cancer over time



- Diagnosing institutions were classified as public or private by the individual jurisdictional registries.
- There were (n=10,534/11,785) men with intermediate-risk disease and recorded interventional treatment in this analysis.
- RP, radical prostatectomy.

FIGURE 18: Types of interventional treatment chosen by men diagnosed with high-risk prostate cancer over time



- Diagnosing institutions were classified as public or private by the individual jurisdictional registries.
- There were (n=5,719/6,572) men with high/very-high-risk disease and recorded interventional treatment in this analysis.
- RP, radical prostatectomy.

The proportion of robotic and open prostatectomies was analysed according to patient residence and SES quintile in the same way as in Chapter 2.

Very minimal increases were noted in the proportion of surgeries performed robotically over time (72% to 73%) with the absolute percentage gap between Q5 (most advantaged) and Q1 (most disadvantaged) narrowing slightly (16% to 12%; Figure 19). The gap was maintained between metropolitan patients and outer regional/remote patients (15–16%; Figure 20).

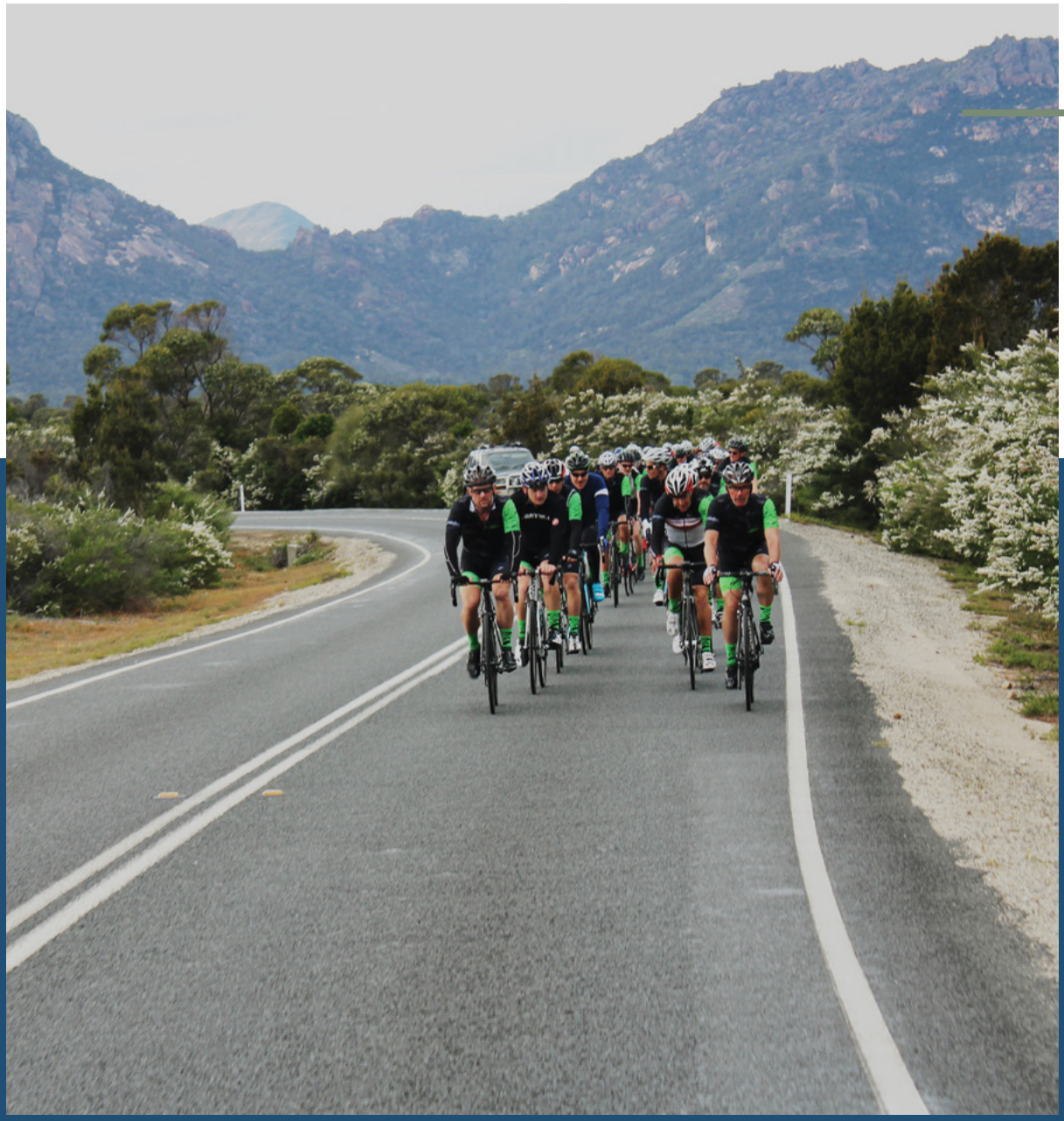
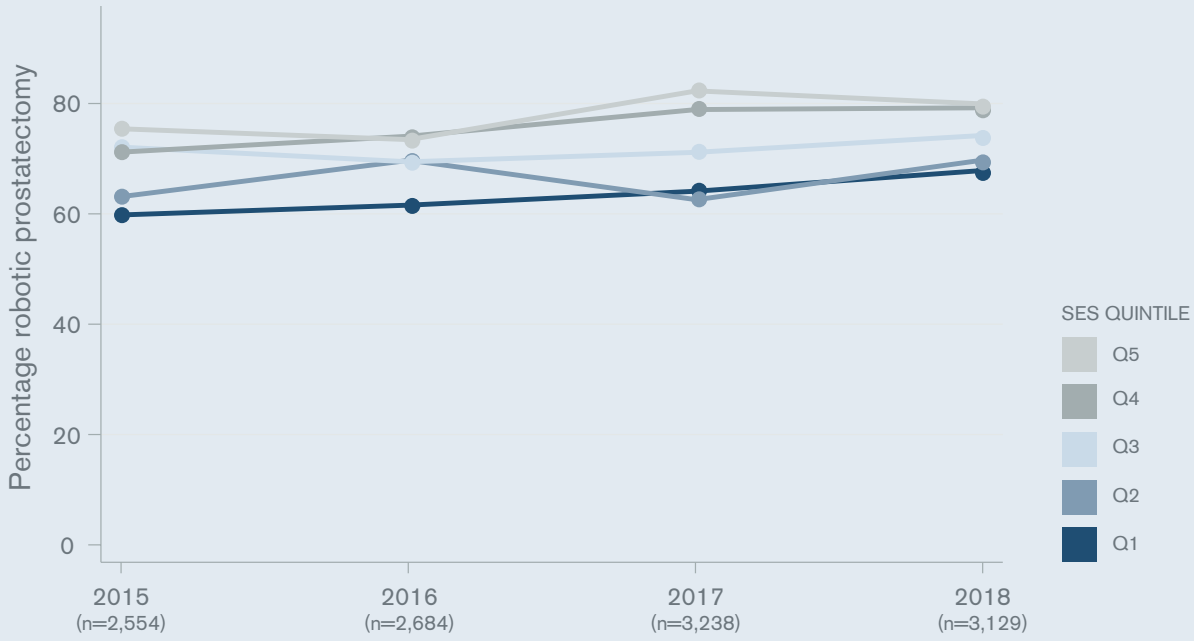
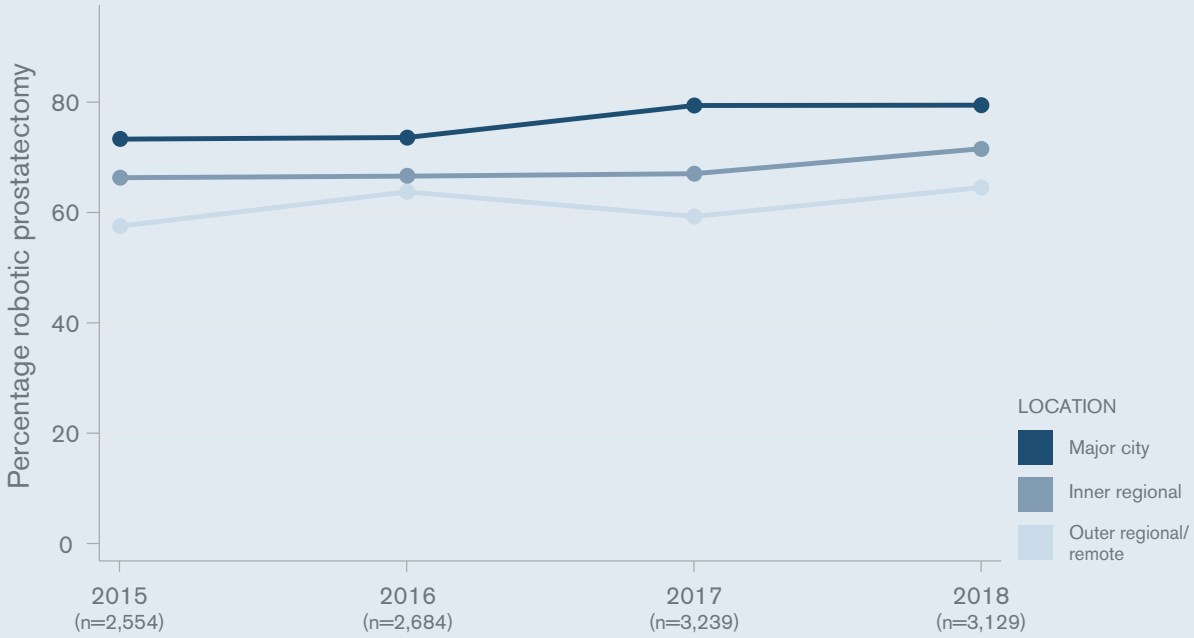


FIGURE 19: Percentage robotic versus open prostatectomy by SES quintile



- Data on robotic vs open prostatectomy were available for 72% (n=11,605/15,944) of men in this analysis. Data were not available for NSW or NZ.
- Socioeconomic status (SES) was divided into quintiles with Q1 being the most disadvantaged and Q5 being the most advantaged.
- Postal code was used with correspondence from the Australian Bureau of Statistics to classify patients according by quintile of socioeconomic status using the Index of Relative Socioeconomic Advantage and Disadvantage metric.
- For more information on prostatectomy and SES please see Supplementary Table S5.

FIGURE 20: Percentage robotic versus open prostatectomy by residence



- Data on robotic vs open prostatectomy and residence were available for 72% (n=11,606/15,944) of men in this analysis. Data were not available for NSW or NZ.
- Postal code was used with correspondence from the Australian Bureau of Statistics to classify patients according to residence: major metropolitan, inner regional and outer regional/remote.
- For more information on prostatectomy and residence please see Supplementary Table S5.

Chapter 4

Trends in short-course radiation therapy

Major randomised controlled trials demonstrating non-inferiority of moderately hypofractionated (short course) radiation therapy versus conventional fractionation were released in 2016.[7,8] We observed the uptake of short-course radiation therapy in different jurisdictions and among different risk groups since this time.

Short-course primary radiation therapy was defined as a dose in the range of 54 to 66 gray (Gy) with dose per fraction of 2.8 to 3.3 Gy.

Long course was defined as a dose greater than 68 Gy with dose per fraction of 1.7 to 2.3 Gy. Any patient receiving brachytherapy was excluded.

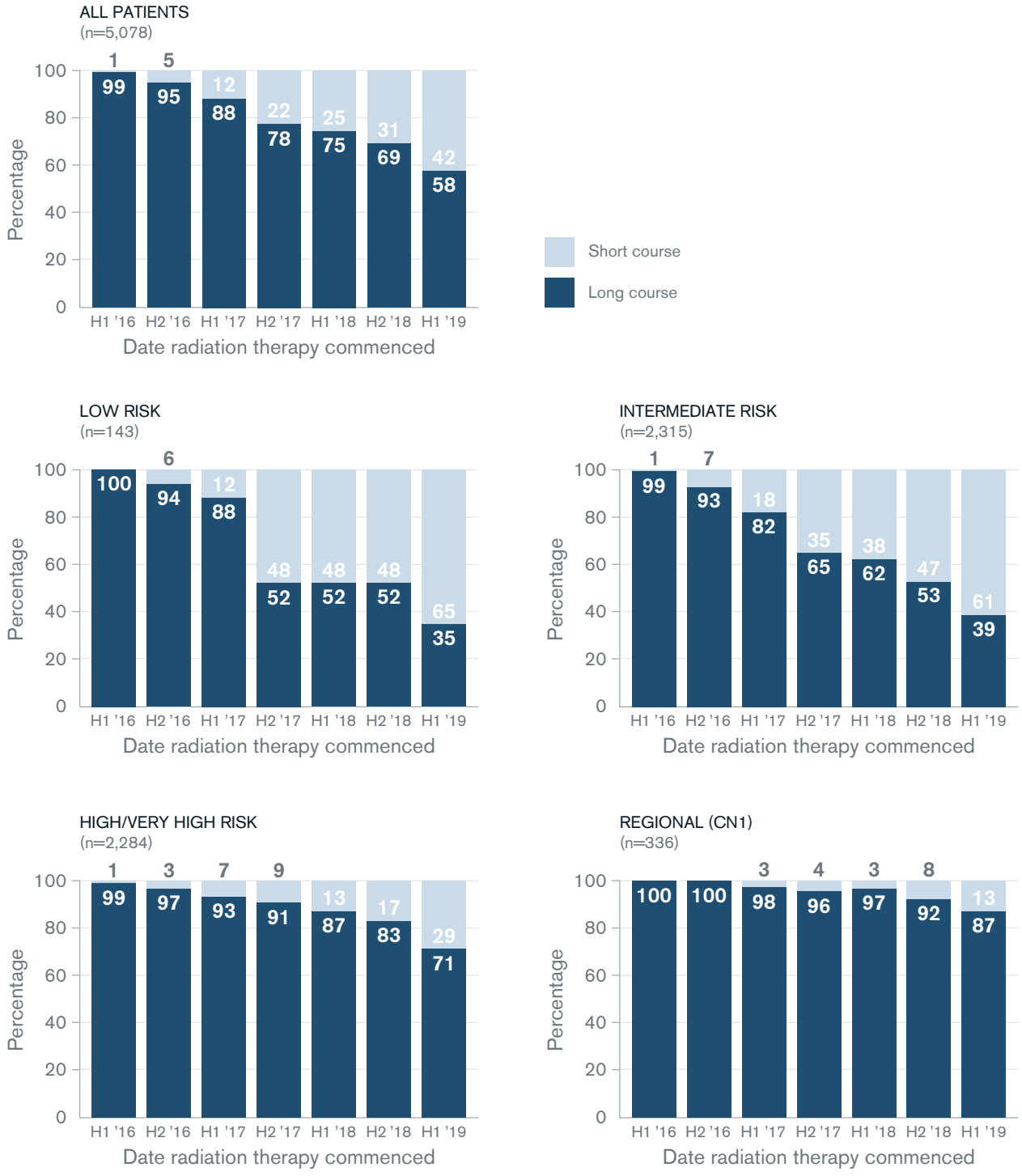
Following the release of the trial data,[7,8] the proportional uptake of the short-course regime was swiftly noted in the registry (Figures 21 and 22).

From almost no patients in the first half of 2016 (H1 '16), 42% of patients treated with primary radiation therapy received short-course versus long-course radiation therapy in the first half of 2019 (H1 '19).

This shift to hypofractionated radiation therapy was most pronounced for the intermediate NCCN risk group, the subgroup with the most positive data for this approach.

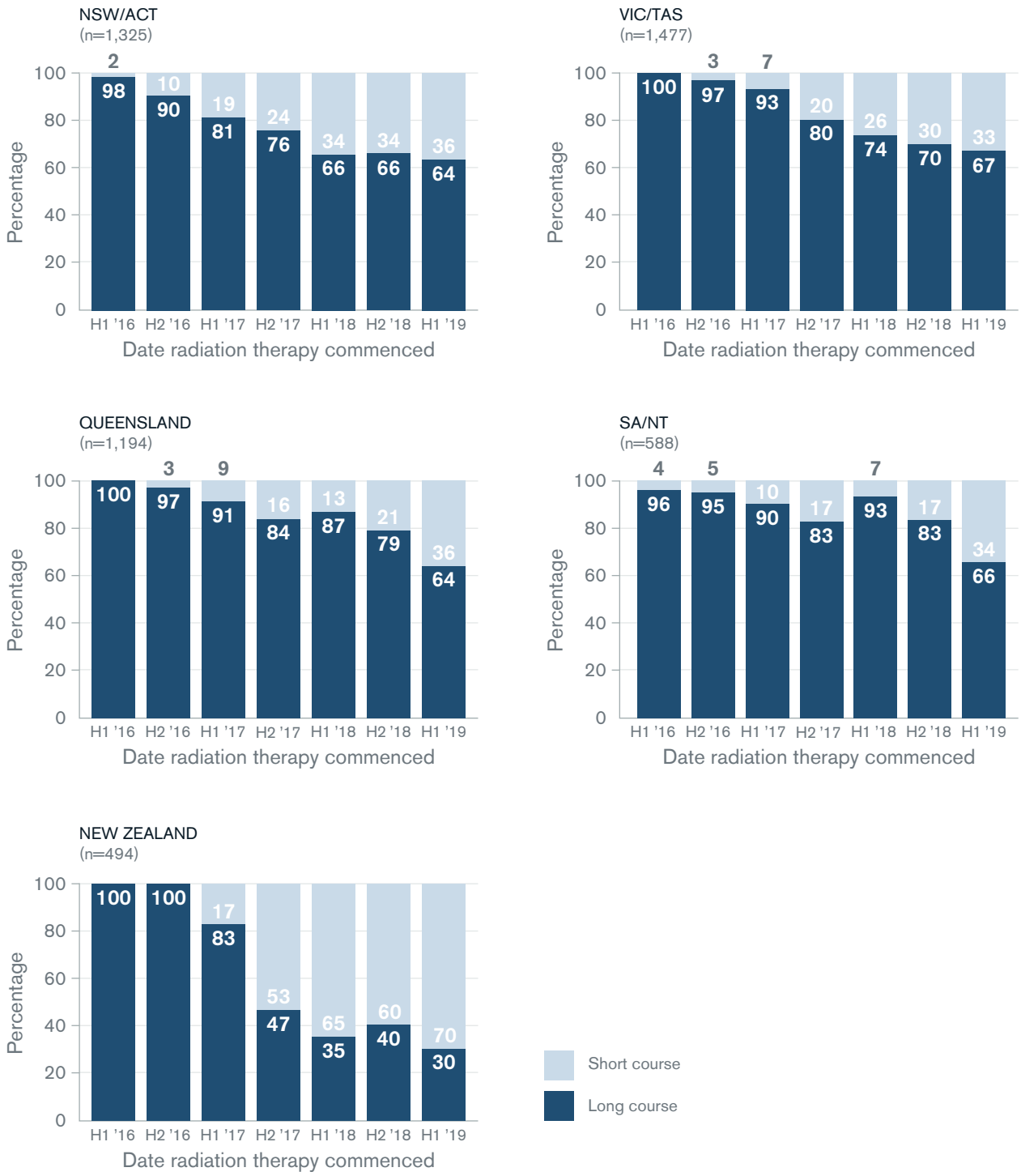
Moderate variation in speed of uptake was noted between jurisdictions with a particularly swift adoption noted in New Zealand.

FIGURE 21: Proportional use of short- vs long-course radiation therapy by NCCN risk at diagnosis



- Percentages are rounded and may not add to 100%.
- H1/H2 refers to the first or the second half of the year.
- NCCN, National Comprehensive Cancer Network.

FIGURE 22: Proportional use of short- vs long-course radiation therapy by jurisdiction



- Percentages are rounded and may not add to 100%.
- H1/H2 refers to the first or the second half of the year.

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Appendices

TABLE A1: Total number of participating clinicians within each jurisdiction, including specialty

JURISDICTION	TOTAL CLINICIANS	MEDICAL ONCOLOGIST	MEDICAL ONCOLOGIST %	RADIATION ONCOLOGIST	RADIATION ONCOLOGIST %	UROLOGIST	UROLOGIST %
ACT	11	2	18%	1	9%	8	73%
NSW	97	9	9%	4	4%	84	87%
NT	4	1	25%	1	33%	2	67%
NZ	63	1	2%	10	16%	52	83%
QLD	61	3	5%	4	7%	54	89%
SA	22	0	0%	0	0%	22	100%
TAS	9	0	0%	1	11%	8	89%
VIC	88	2	2%	1	1%	85	97%
WA	-	-	-	-	-	-	-
Total	**354**	**18**	**5%**	**22**	**6%**	**315**	**89%**

TABLE A2: Total number of participating sites within each jurisdiction by institution type

JURISDICTION	TOTAL SITES	PUBLIC	PUBLIC %	PRIVATE	PRIVATE %
ACT	8	2	25%	6	75%
NSW	42	36	86%	6	14%
NT	3	2	67%	1	33%
NZ	31	19	61%	12	39%
QLD	49	12	24%	37	76%
SA	18	8	44%	10	56%
TAS	8	2	25%	6	75%
VIC	85	52	61%	33	39%
WA	0	0	0%	0	0%
Total	**244**	**133**	**55%**	**111**	**45%**

Supplementary tables

TABLE S1: Number of men in reporting categories across PCOR-ANZ (2015–2018)

		YEAR				
		2015	2016	2017	2018	All
AGE	≤59	1,322	1,620	1,992	2,485	7,419
	60-64	1,204	1,466	1,913	2,328	6,911
	65-69	1,645	2,083	2,792	3,459	9,979
	70-74	1,194	1,559	2,207	2,785	7,745
	≥75	1,258	1,630	2,130	2,881	7,899
GRADE GROUP	1	1,769	2,115	2,931	3,442	10,257
	2	2,016	2,606	3,221	4,177	12,020
	3	1,100	1,380	1,839	2,169	6,488
	4	658	811	1,119	1,402	3,990
	5	901	1,191	1,521	2,167	5,780
	Missing	179	255	403	581	1,418
PSA AT DIAGNOSIS (ng/mL)	<4	866	955	1,223	1,277	4,321
	4–10	3,040	4,111	5,380	6,686	19,217
	10–20	1,084	1,375	1,803	2,219	6,481
	>20	699	850	1,150	1,485	4,184
	Missing	934	1,067	1,478	2,271	5,750
NCCN RISK CATEGORY	Low	1,203	1,492	2,070	2,362	7,127
	Intermediate	2,608	3,454	4,373	5,303	15,738
	High/V High	1,547	1,832	2,439	3,243	9,061
	Regional	130	198	326	431	1,085
	Metastatic	406	493	597	807	2,303
	Missing	729	889	1,229	1,792	4,639
DIAGNOSIS METHOD	TRUS	4,185	4,461	5,486	5,643	19,775
	TP	1,605	2,821	4,187	6,029	14,642
	TURP	621	757	969	1,150	3,497
	Other	155	193	242	257	847
	Missing	57	126	150	859	1,192

PSA, prostate-specific antigen; TP, transperineal biopsy; TRUS, transrectal ultrasound-guided biopsy; TURP, transurethral resection of the prostate.

TABLE S2: Summary of management provided to men by jurisdiction (2015–2018)

NCCN	TREATMENT				
	RADICAL PROSTATECTOMY	RADIATION THERAPY	ADT+/- CHEMOTHERAPY	OBSERVATION	MISSING
LOW					Total missing=368
NSW/ACT	399	42	≤10	975	
VIC/TAS	669	128	≤10	1,634	
QLD	444	65	≤10	880	
SA/NT	238	74	≤10	279	
NZ	231	77	≤10	598	
INTERMEDIATE					Total missing=701
NSW/ACT	2,413	887	54	403	
VIC/TAS	3,654	1,051	43	743	
QLD	2,116	740	44	477	
SA/NT	790	332	12	99	
NZ	676	341	21	141	
HIGH/VERY HIGH					Total missing=643
NSW/ACT	1,114	793	219	59	
VIC/TAS	1,306	890	305	178	
QLD	1,054	722	217	151	
SA/NT	434	378	41	15	
NZ	188	191	131	32	
REGIONAL					Total missing=42
NSW/ACT	67	142	85	≤10	
VIC/TAS	74	105	119	≤10	
QLD	59	125	122	≤10	
SA/NT	11	38	≤10	≤10	
NZ	15	39	22	≤10	
METASTATIC					Total missing=135
NSW/ACT	11	68	344	≤10	
VIC/TAS	68	65	814	≤10	
QLD	24	84	457	≤10	
SA/NT	≤10	≤10	28	≤10	
NZ	≤10	26	137	≤10	

Missing NCCN risk group = 4,639

TABLE S3: Number of men who reported bother by treatment type across PCOR-ANZ (2015–2018)

	TREATMENT				
	RADICAL PROSTATECTOMY	RADIATION THERAPY	ADT+/- CHEMOTHERAPY	OBSERVATION	OTHER/ MISSING
SEXUAL BOTHER					
NONE/SMALL	5,886	2,547	853	2,853	360
MODERATE/BIG	4,787	1,413	377	825	163
MISSING	6,798	4,053	2,082	4,301	2,655
URINARY BOTHER					
NONE/SMALL	9,929	3,757	1,145	3,488	521
MODERATE/BIG	1,034	417	162	335	53
MISSING	6,508	3,839	2,005	4,156	2,604
BOWEL BOTHER					
NONE/SMALL	10,626	3,815	1,197	3,689	558
MODERATE/BIG	327	374	110	134	24
MISSING	6,518	3,824	2,005	4,156	2,596

TABLE S4: Patient-reported function 12 months after primary treatment, across PCOR-ANZ (2015–2018)

PRIMARY TREATMENT	RESPONDERS	10TH PERCENTILE	25TH PERCENTILE	MEDIAN	75TH PERCENTILE	90TH PERCENTILE
DOMAIN - URINARY INCONTINENCE						
SURGERY	10,844	39.75	58.50	85.50	100.00	100.00
RADIATION THERAPY	4,064	60.50	79.25	100.00	100.00	100.00
ADT +/- CHEMOTHERAPY	1,260	54.25	76.00	100.00	100.00	100.00
OBSERVATION	3,747	66.75	85.50	100.00	100.00	100.00
DOMAIN - URINARY IRRITATIVE/OBSTRUCTIVE						
SURGERY	10,559	81.25	87.50	93.75	100.00	100.00
RADIATION THERAPY	3,943	62.50	81.25	87.50	100.00	100.00
ADT +/- CHEMOTHERAPY	1,232	62.50	81.25	87.50	100.00	100.00
OBSERVATION	3,688	68.75	81.25	93.75	100.00	100.00
DOMAIN - BOWEL						
SURGERY	10,835	83.33	95.83	100.00	100.00	100.00
RADIATION THERAPY	4,048	62.50	83.33	95.83	100.00	100.00
ADT +/- CHEMOTHERAPY	1,278	66.67	87.50	95.83	100.00	100.00
OBSERVATION	3,750	79.17	91.67	100.00	100.00	100.00
DOMAIN - SEXUAL						
SURGERY	10,629	0.00	8.33	16.67	44.50	73.67
RADIATION THERAPY	3,908	0.00	8.33	16.67	40.33	73.67
ADT +/- CHEMOTHERAPY	1,197	0.00	4.17	16.67	16.67	30.50
OBSERVATION	3,618	12.50	26.33	61.17	87.50	100.00

TABLE S5: Biopsy and prostatectomy method across PCOR-ANZ by SES quintile and residence (2015–2018)

			YEAR			
SES QUINTILE			**2015**	**2016**	**2017**	**2018**
Q1	BIOPSY METHOD	TRUS	749	611	782	594
		Transperineal	139	298	452	580
	PROSTATECTOMY METHOD	Open	155	162	175	146
		Robotic	231	260	313	309
Q2	BIOPSY METHOD	TRUS	660	551	693	551
		Transperineal	142	245	402	546
	PROSTATECTOMY METHOD	Open	137	118	193	138
		Robotic	235	272	323	319
Q3	BIOPSY METHOD	TRUS	743	625	787	689
		Transperineal	159	294	529	748
	PROSTATECTOMY METHOD	Open	138	156	174	156
		Robotic	357	355	430	450
Q4	BIOPSY METHOD	TRUS	813	657	780	697
		Transperineal	281	452	668	930
	PROSTATECTOMY METHOD	Open	168	160	155	151
		Robotic	416	458	581	577
Q5	BIOPSY METHOD	TRUS	703	623	674	553
		Transperineal	577	806	951	1,258
	PROSTATECTOMY METHOD	Open	176	197	158	177
		Robotic	541	546	736	706
RESIDENCE			**2015**	**2016**	**2017**	**2018**
MAJOR CITY	BIOPSY METHOD	TRUS	2,271	1,777	2,094	1,689
		Transperineal	973	1,474	2,014	2,765
	PROSTATECTOMY METHOD	Open	456	450	425	412
		Robotic	1,242	1,244	1,620	1,576
INNER REGIONAL	BIOPSY METHOD	TRUS	789	711	918	775
		Transperineal	235	441	689	932
	PROSTATECTOMY METHOD	Open	180	204	247	209
		Robotic	352	404	499	522
OUTER REGIONAL/ REMOTE	BIOPSY METHOD	TRUS	607	579	704	620
		Transperineal	90	180	300	368
	PROSTATECTOMY METHOD	Open	138	139	183	146
		Robotic	186	243	265	264

Biopsy method: missing SES quintile = 136, missing residence = 133.
Prostatectomy method: missing SES quintile = 52, missing residence = 51.

PCOR-ANZ, Prostate Cancer Outcomes Registry - Australia and New Zealand; SES, socioeconomic status; TRUS, transrectal-ultrasound-guided biopsy

TABLE S6: Follow-up methodology and quality-of-life survey completion rate by jurisdiction (2015–2018)

12-MONTH PROMS	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/N (%)	520/ 833 (62)	4,264/ 8,809 (48)	98/ 249 (39)	1,913/ 2,806 (68)	3,904/ 7,889 (49)	1,229/ 3,483 (35)	575/ 1,312 (44)	8,410/ 11,085 (76)	20,913/ 36,466 (57)

EPIC, expanded prostate cancer index composite; PROMs, patient-reported outcome measures.

TABLE S7: Estimated population coverage of PCOR-ANZ by jurisdiction (2015–2018)

YEAR MEN DIAGNOSED WITH PROSTATE CANCER	ACT	NSW	NT	NZ	QLD	SA	TAS	VIC	WA	TOTAL ACROSS ALL JURISDICTIONS
PCOR-ANZ 2015	95	833	41	78	1,814	956	296	2,510		6,623
Population diagnosed with prostate cancer 2015	250	6,036	82	3,080	3,714	1,365	419	4,387	(1,889)	19,333
% population coverage	**38**	**14**	**50**	**3**	**49**	**70**	**71**	**57**		**34**
PCOR-ANZ 2016	218	2,153	79	260	1,520	946	399	2,783		8,358
Population diagnosed with prostate cancer 2016	237	5,915	79	3,383	3,544	1,334	403	4,779	(1,803)	19,674
% population coverage	**92**	**36**	**100**	**8**	**43**	**71**	**99**	**58**		**42**
PCOR-ANZ 2017	246	2,487	81	811	2,598	1,185	386	3,240		11,034
Population diagnosed with prostate cancer 2017	246	5,793	81	3,297	3,374	1,303	387	3,793	(1,716)	18,274
% population coverage	**100**	**43**	**100**	**25**	**77**	**91**	**100**	**85**		**60**
PCOR-ANZ 2018	321	3,847	58	1,899	3,062	1,081	359	3,311		13,938
Population diagnosed with prostate cancer 2018	321	6,163	78	3,297	3,589	1,387	412	4,035	(1,826)	19,282
% population coverage	**100**	**62**	**74**	**58**	**85**	**78**	**87**	**82**		**72**

Please note that the 'Population diagnosed with prostate cancer' numbers are estimates based on historical Australian Institute of Health and Welfare (AIHW) and New Zealand Ministry of Health data and may not be precise. Changes in reporting and practice patterns (e.g. PSA testing) can impact the accuracy of these estimates.

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