PROSTATE CANCER OUTCOMES | REGISTRY AUSTRALIA AND NEW ZEALAND

PROSTATE CANCER ACROSS AUSTRALIA AND NEW ZEALAND

ANNUAL REPORT 2021

PCOR-ANZ 2021 summary report:
an overview of diagnoses, management decisions and patient-reported outcomes

MOVEMBER® | MONASH University

THE PCOR-ANZ ANNUAL REPORT 2021

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

Suggested citation
Papa N, O'Callaghan M, Mark S, Millar J and Breen S. Prostate cancer across Australia and New Zealand: PCOR-ANZ 2015–2019 Summary Report, October 2022.

ACKNOWLEDGEMENTS

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

The success of the registry relies on the support of the clinical community who generously contribute their time to working with PCOR-ANZ on a voluntary basis. In particular, Movember 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 initiative. The operations of PCOR-ANZ would also not be possible without our tireless team of Study Coordinators, data collectors and Program Coordinator Marie Pase.

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

Any enquiries about this report should be directed to:

PROSTATE CANCER
OUTCOMES REGISTRY OFFICE

School of Public Health and
Preventive Medicine

Monash University
553 St Kilda Rd
Melbourne VIC 3004

Phone: +61 3 9903 0673

Email: pcor@monash.edu

Website:
https://prostatecancerregistry.org/

FUNDING & ENDORSEMENTS

MOVEMBER®

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

ACT Government | ACT Health

ACT Government | Canberra Health Services

University of Tasmania

Menzies Institute for Medical Research

Cancer Institute NSW
cancer.nsw.gov.au

APCRC-Q Australian Prostate Cancer Research Centre Queensland

CHOMNZ | centre for health outcome measures new zealand

QUT ihbi Institute of Health and Biomedical Innovation

Northern Territory Government

Monash University

Government of South Australia
SA Health

SA-PCCOC
South Australian Prostate Cancer Clinical Outcomes Collaborative

PCOR-ANZ is endorsed by:

Urological Society of Australia and New Zealand

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

Société Internationale d'Urologie SIU

RCPA The Royal College of Pathologists of Australasia

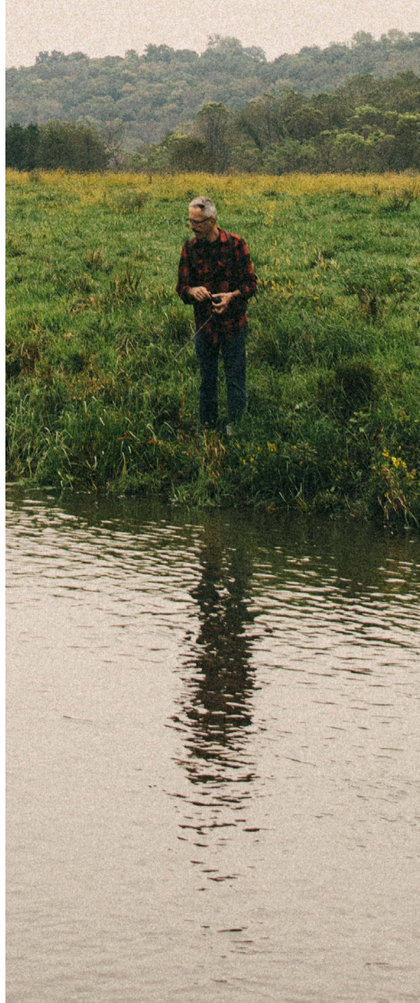
MOGA

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

WANT MORE INFORMATION?
Visit our websites

→ PCOR-ANZ

→ TRUE NORTH



FOREWORD

Despite the ongoing challenges of the COVID-19 pandemic, the Prostate Cancer Outcomes Registry – Australia and New Zealand (PCOR-ANZ) and Movember continued to work closely together over the 2020–2021 period.

Key areas of focus being to improve and transform the governance structure and to update the technology underpinning PCOR-ANZ.

As the sole funder of PCOR-ANZ, Movember has invested more than $21 million into the registry to date. Continued investment in clinical-quality registries such as PCOR-ANZ is a vital mechanism to enable improvements in diagnosis, treatment and outcomes for men diagnosed with prostate cancer.

TRANSFORMING PCOR-ANZ OVER 2021–2022

Over the 2021–2022 period, a raft of changes were implemented to transform the governance structure of PCOR-ANZ to better align their operations with the Australian Framework for Clinical Quality registries.[i,ii] Movember and PCOR-ANZ worked closely together to update policies and procedures governing all aspects of registry operations, with two key transformations being:

- **Protocol updates** for both PCOR-ANZ and PCOR jurisdictions to better reflect their primary focus of improving care and outcomes for men diagnosed with prostate cancer.
- **Change in governance structure** with four new committees established to replace the single PCOR-ANZ Steering Committee. Each new committee has its own focus, enabling them to take a more specialist governance role and include a boarder range of experts to provide strategic and day-to-day direction to the registry. These Committees include the Governance, Advisory, Data Advisory, and People with Lived Experience Committees.

PCOR-ANZ and Movember have also been collaborating on the building and testing of a new registry platform. This new technology enables electronic collection of patient-reported outcomes measures (PROMs) – initially via email, and in 2023 via SMS. The improved technology underpinning the new platform will also enable future innovations, which allow for greater clinician access to quality-of-care data. Following an intense 18 months of building and testing, the new database platform is due to go live as this report is published in October 2022.

THE IMPACT OF COVID-19

Despite the transformational successes that we were able to bring to fruition over the 2021–2022 period, the COVID-19 pandemic did continue to affect registry operations. The largest impacts were felt in Victoria where data collectors were unable to access rooms to retrospectively collect 2019 diagnoses during much of the 2020 calendar year. This will also be a problem for the next annual reporting cycle where the impacts were particularly felt by NSW in terms of extended lockdowns.

At present, states like Victoria still have a large backlog of data collection, the main impact of which is on the collection of PROMs 12 months after diagnosis. Data in this report, and future reports will clearly show this impact with a decreased rate of PROMs completion as a lack of access to diagnosis and treatment data from clinical records meant that the eligibility of men to complete the PROMs questionnaires could not be confirmed.

THE 2021–2022 ANNUAL REPORT

Given the challenges and delays of COVID-19, this latest annual report has been provided in an abbreviated format, providing an overview of current trends with respect to the diagnosis, care and outcomes of men with prostate cancer.

The clinical data included was collected from men diagnosed in the 5-year period between 2015, when PCOR-ANZ commenced operations as a bi-national registry, and 2019. It also includes PROMs data from those men, which was collected 12 months post treatment; or 12 months post diagnosis if commencing active surveillance/ watchful waiting (AS/WW).

In this brief report, we have chosen to focus on bi-national comparisons between Australia and New Zealand. We hope clinicians, researchers and consumers alike will find it a useful guide to understanding ongoing trends.

Finally, we would like to acknowledge our debt of gratitude to the 382 participating clinicians, 250 participating hospitals and all of our dedicated PCOR-ANZ staff and committee members whose continued efforts make this report possible, especially under the challenging circumstances we are currently facing. But in particular, it is the men with prostate cancer who gave their time to complete PROMs questionnaires that we wish to thank. It is only your willingness to share your data that allows us to continue to help improve outcomes and standards of care for men diagnosed with prostate cancer.

i. Australian Commission on Safety and Quality in Health Care, Framework for Australian clinical quality registries. Sydney. ACSQHC, March 2014. Available at https://www.safetyandquality.gov.au/sites/default/files/migrated/Framework-for-Australian-Clinical-Quality-Registries.pdf accessed August 2022.
ii. Australian Commission on Safety and Quality in Health Care, National Arrangements for Clinical Quality Registries. Available at https://www.safetyandquality.gov.au/our-work/health-and-human-research/national-arrangements-clinical-quality-registries accessed August 2022.

PROFESSOR SANCHIA ARANDA
Outgoing Chair of the PCOR-ANZ Steering Committee

PAUL VILLANTI
Executive Director - Programs

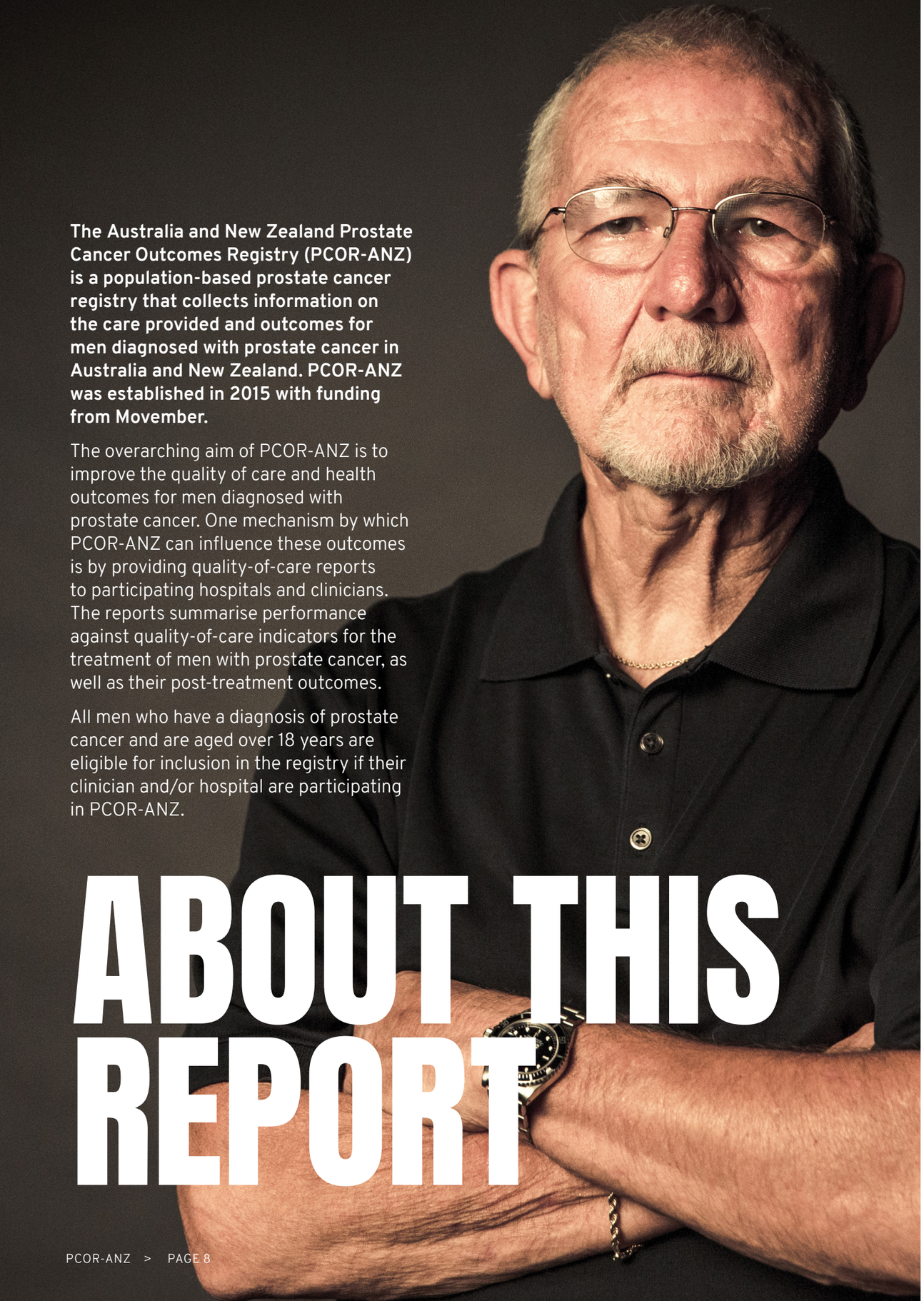
A SPECIAL ACKNOWLEDGEMENT

On behalf of Movember and all the stakeholders associated with PCOR-ANZ, I would like to acknowledge the outstanding contribution that Professor Sanchia Aranda has made as Chair of the PCOR-ANZ Steering Committee since 2018. Sanchia has overseen and guided a period of significant growth in both clinician and hospital participation in PCOR-ANZ, as well as leading important changes to the PCOR-ANZ governance structure and operating frameworks.

Over this time, we have seen significant improvements in treatment and care practices that have been realised through the use of this unique bi-national data set. Improvements that positively impact the lives of men living with prostate cancer. It has been a privilege to have had Sanchia on the team, and we wish her continuing success in the next chapter of her life.

- PAUL VILLANTI

CONTENTS



ABOUT THIS REPORT

The Australia and New Zealand Prostate Cancer Outcomes Registry (PCOR-ANZ) is a population-based prostate cancer registry that collects information on the care provided and outcomes for men diagnosed with prostate cancer in Australia and New Zealand. PCOR-ANZ was established in 2015 with funding from Movember.

The overarching aim of PCOR-ANZ is to improve the quality of care and health outcomes for men diagnosed with prostate cancer. One mechanism by which PCOR-ANZ can influence these outcomes is by providing quality-of-care reports to participating hospitals and clinicians. The reports summarise performance against quality-of-care indicators for the treatment of men with prostate cancer, as well as their post-treatment outcomes.

All men who have a diagnosis of prostate cancer and are aged over 18 years are eligible for inclusion in the registry if their clinician and/or hospital are participating in PCOR-ANZ.

HOW MANY PEOPLE CONTRIBUTE TO PCOR-ANZ?

Currently, across Australia's seven participating States/Territories and New Zealand, a total of 382 clinicians are actively contributing to PCOR-ANZ, including 341 urologists, 23 radiation oncologists and 18 medical oncologists. In addition, 250 clinical sites/hospitals are participating, of which 136 are public hospitals and 114 are private hospitals.

This annual report includes information from 56,922 men who had a diagnosis of prostate cancer between 2015–2019 (Figure 1). It also includes patient-reported outcome measures (PROMs) collected from 29,938 men 12 months after diagnosis for those men diagnosed during this period.

USE OF DATA BY PCOR-ANZ

PCOR-ANZ analyses the data collected and produces bi-annual reports summarising individual clinician and hospital performance against quality-of-care indicators for prostate cancer. The results are benchmarked against other clinicians and hospitals. These benchmarks represent the levels of care that all clinicians and hospitals should aim to meet in order to ensure the best possible outcomes for men diagnosed with prostate cancer.

These reports also identify men who may have been flagged as falling outside of expected standards of care, or who are experiencing worse than expected outcomes (e.g. men with high levels of urinary, bowel or sexual bother at 12 months). These reports also assess any changes in treatment and/or patient outcomes over time.

For the first time, in 2021 PCOR-ANZ has also circulated specific reports to radiation oncologists and radiation therapy facilities focussing on radiation oncology quality indicators.

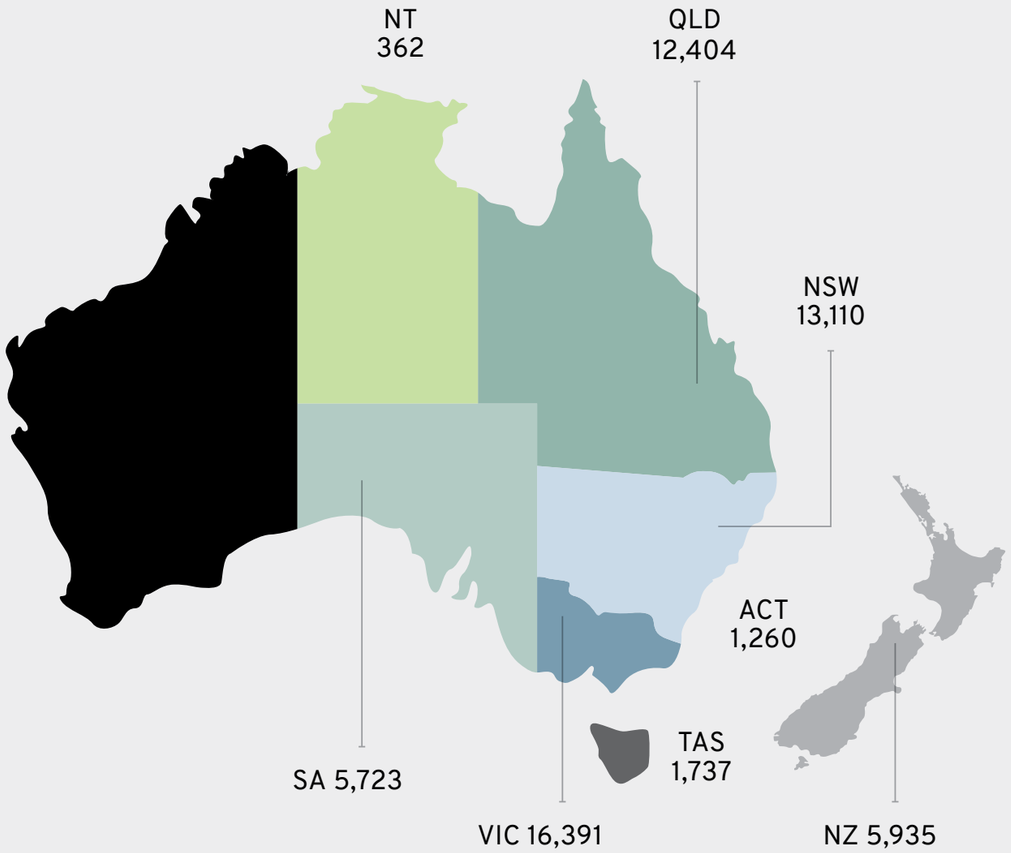
The data produced by PCOR-ANZ enable health service providers to:

- assess patterns of care and treatment outcomes;
- reduce variation in treatment and outcomes for men diagnosed with prostate cancer;
- improve compliance with best practice-based guidelines for the treatment of prostate cancer;
- monitor trends in the incidence of prostate cancer in populations and survival over time;
- determine the clinical effectiveness of treatments in a real-world setting.

THE IMPACT OF COVID-19

SARS-CoV-2 2019 (COVID-19) lockdowns in 2020 had a significant impact on PCOR-ANZ operations, particularly in Victoria. As a result, registry operations transformed to a remote-working model. It is a tribute to the PCOR-ANZ teams that, in the face of these challenges, in 2019 we enrolled the highest number of men of any year to date. Nevertheless, these challenges have impacted the ability to produce a full report for the 2020 data.

HOW MANY PEOPLE ARE INVOLVED IN PCOR-ANZ?



382
CLINICIANS CURRENTLY ENROLLED (2022)

341 urologists
23 radiation oncologists
18 medical oncologists

250
PARTICIPATING SITES (2022)

136 Public
114 Private

1,138
QUALITY OF CARE REPORTS GENERATED IN 2019

407 reports for clinicians
707 reports for hospitals

29,938
PEOPLE COMPLETED OUR QUESTIONNAIRES (2015-2019)

56,922
PEOPLE ENROLLED IN THE 2015–2019 DATASET

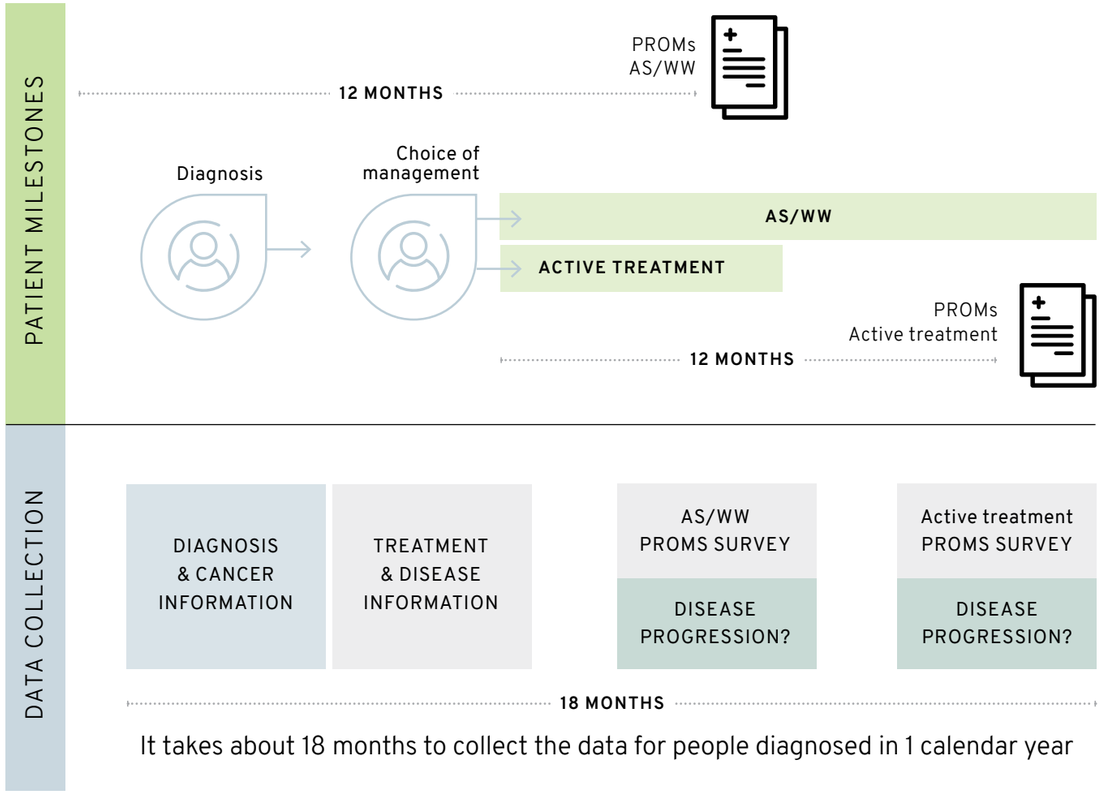
NB: in addition, 23,865 people were enrolled in pre-existing VIC and SA databases (1998-2015)

FIGURE 1: DATA COLLECTION AND PARTICIPATION IN PCOR-ANZ

WHAT INFORMATION DO WE COLLECT?

Diagnosis information	**Cancer information**	**Treatment & disease information**	**PROMs** (PATIENT-REPORTED OUTCOME MEASURES)
How prostate cancer is diagnosed e.g.: • TRUS (trans-rectal ultrasound-guided biopsy) • TURP (transurethral resection of the prostate) • Transperineal biopsy	• Cancer stage • Gleason score • Cancer risk category • Prostate-specific antigen (PSA) levels	• Treatments provided (e.g. surgery, radiotherapy, chemotherapy, androgen deprivation therapy) • Whether active surveillance or watchful waiting protocols were followed • Disease progression	Quality-of-life questionnaires are sent 12 months following diagnosis (in the case of active surveillance/ watchful waiting [AS/WW]) or 12 months after treatment starts using the expanded prostate cancer index-26 symptom questionnaire (EPIC-26)

WHEN DO WE COLLECT INFORMATION?



It takes about 18 months to collect the data for people diagnosed in 1 calendar year

OVERVIEW OF THE 2019 DATASET

ENROLMENT IN PCOR-ANZ

In 2019, PCOR-ANZ collected data on 16,191 men who were diagnosed with prostate cancer (Figure 2, appendix Table A1) with a median age of 68 years (interquartile range: 62–74). This is the highest annual number of diagnoses recorded in the registry to date and represents 66% of all men with a diagnosis of prostate cancer within Australia's seven participating States/ Territories and New Zealand (N=24,406 estimated cases).[i] Overall, enrolment continues to grow year-on-year due to the hard work of the registry managers and data collectors to recruit sites, go out in the field, and fetch, input and process data on thousands more patients every year.

Of note in 2019, there was a 50% increase in prostate cancer cases notified to PCOR-ANZ from New Zealand in comparison to 2018. This improvement in database notifications is chiefly as a result of improvements in the systematic identification of men diagnosed with prostate cancer by PCOR-ANZ with two sources of case identification, direct from biopsy and a regular data download from the NZ Cancer registry. All public hospitals in New Zealand now contribute data to PCOR-ANZ, but this report has incomplete data from some regions so is not fully representative.

While the majority of other states and territories had smaller increases, or relative stability in the number of diagnoses notified to PCOR-ANZ, Tasmania had an overall decrease of 15% when compared with 2018. This decrease in reported diagnoses occurred as a result of late notifications of men diagnosed with prostate cancer in 2019, alongside delayed recruitment of new clinicians to PCOR-ANZ, and therefore does not likely represent a true decrease in the overall number of diagnoses of prostate cancer in Tasmania for the 2019 calendar year.

QUALITY OF CARE REPORTS

PCOR-ANZ generates reports for the participating hospitals and clinicians that summarise their performance against quality-of-care indicators for the treatment of men with prostate cancer. These are generated bi-annually and include reports tailored for both urologists, and for radiation oncologists. In 2019, 431 reports were generated for participating hospitals and a further 707 for clinicians.

PATIENT-REPORTED OUTCOME MEASURES (PROMS)

Overall, 8,670 (54%) of men recruited completed the EPIC-26 quality-of-life questionnaire. The questionnaire asks about symptoms and quality of life 12 months after treatment, or 12 months after the decision to start active surveillance or watchful waiting (AS/WW). The proportion of men completing the EPIC-26 quality-of-life questionnaire has shown little change since 2016 (Figure 3; appendix Table A2).

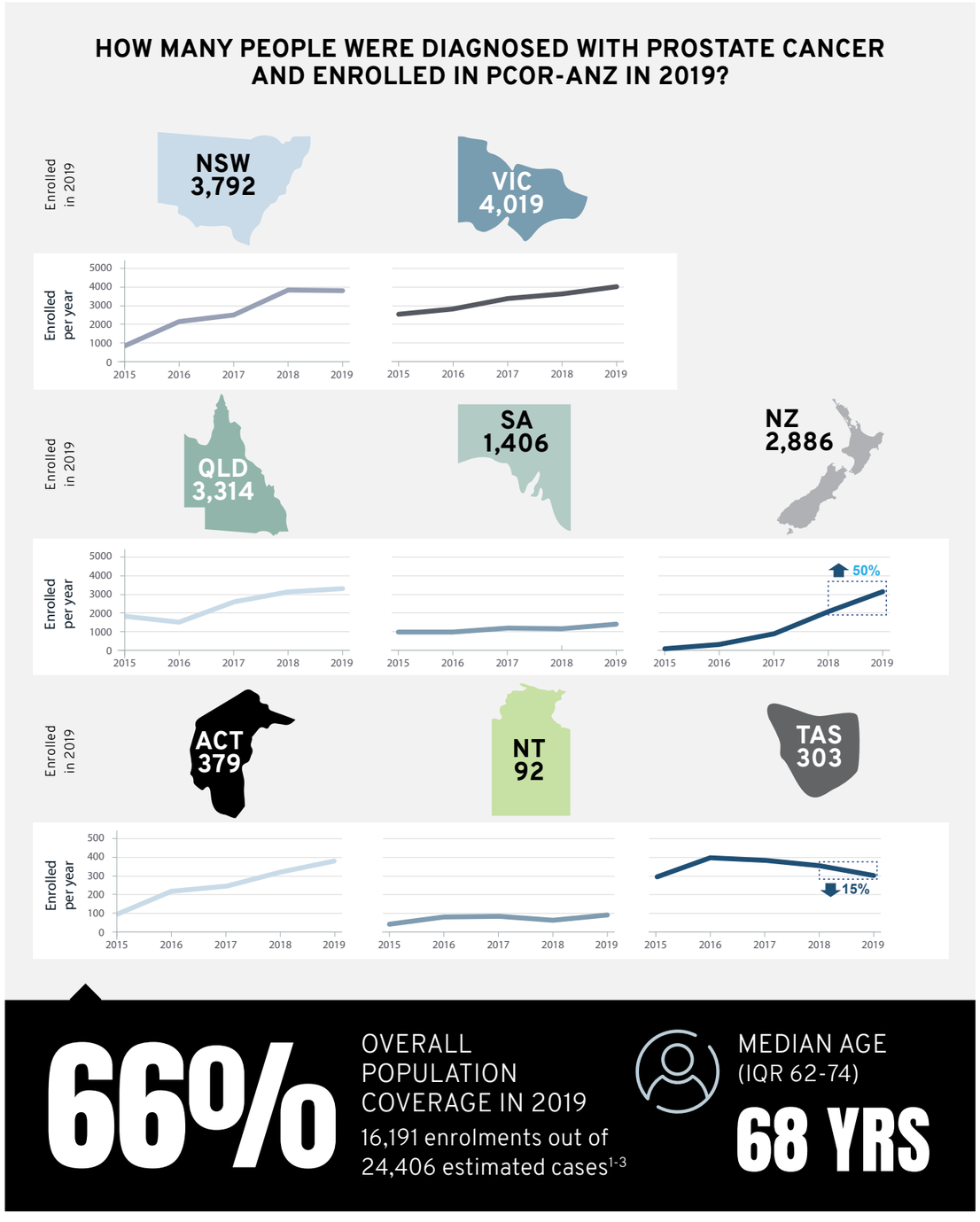


FIGURE 2: TOTAL NUMBER OF ENROLMENTS IN PCOR-ANZ IN 2019 BY JURISDICTION, AND CHANGES OVER TIME

[1]These calculations are based on the proportion of registry cases compared to the local statutory registry's estimate of what the cases will be in that year, since registries lag, sometimes by years, in the actual enumeration of cases in the jurisdiction. This means the percentages are the best estimate, and also that the proportion we report for a particular year might change as the state and territory cancer registries finalise their actual counts. This year, the AIHW updated their incidence model, changing their estimated cases, and this in turn alters our percentages. The Australian Institute of Health and Welfare (AIHW)[1] estimated 22,449 cases will be counted in Australia in 2019, from which we subtracted the current best estimate of what the Western Australia cases will be in 2019 (2,262 men)[2] and added the best current estimate of New Zealand cases for 2019 (4,219).[3]

OVERVIEW OF THE 2019 DATASET

HOW MANY MEN RETURNED THEIR PROMS QUESTIONNAIRES TO PCOR-ANZ IN 2019?

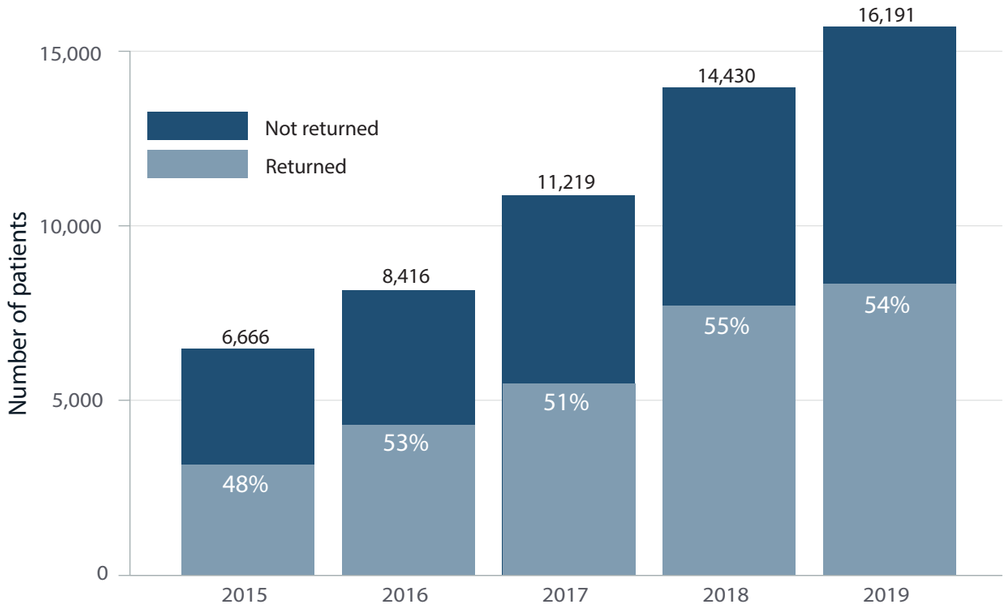


FIGURE 3: TOTAL ENROLMENT IN PCOR-ANZ AND OVERALL PROPORTION OF RETURNED EPIC-26 QUESTIONNAIRES BY YEAR

The Australian Capital Territory (ACT) and Tasmania collected the highest proportion of EPIC-26 questionnaires at 84% and 83% respectively while the lowest response rate was 37% in South Australia (Figure 4, appendix Table A2). The biggest change in the proportion of questionnaires completed from 2018 to 2019 was an increase in Tasmania as a result of increased efficiency of local data-collection methods. The proportion of questionnaires also dropped in Victoria, largely as a result of COVID-19 lockdowns during the data-collection period.

WHAT PROPORTION OF PEOPLE RETURNED THEIR PROMS QUESTIONNAIRE IN 2019 IN EACH JURISDICTION?

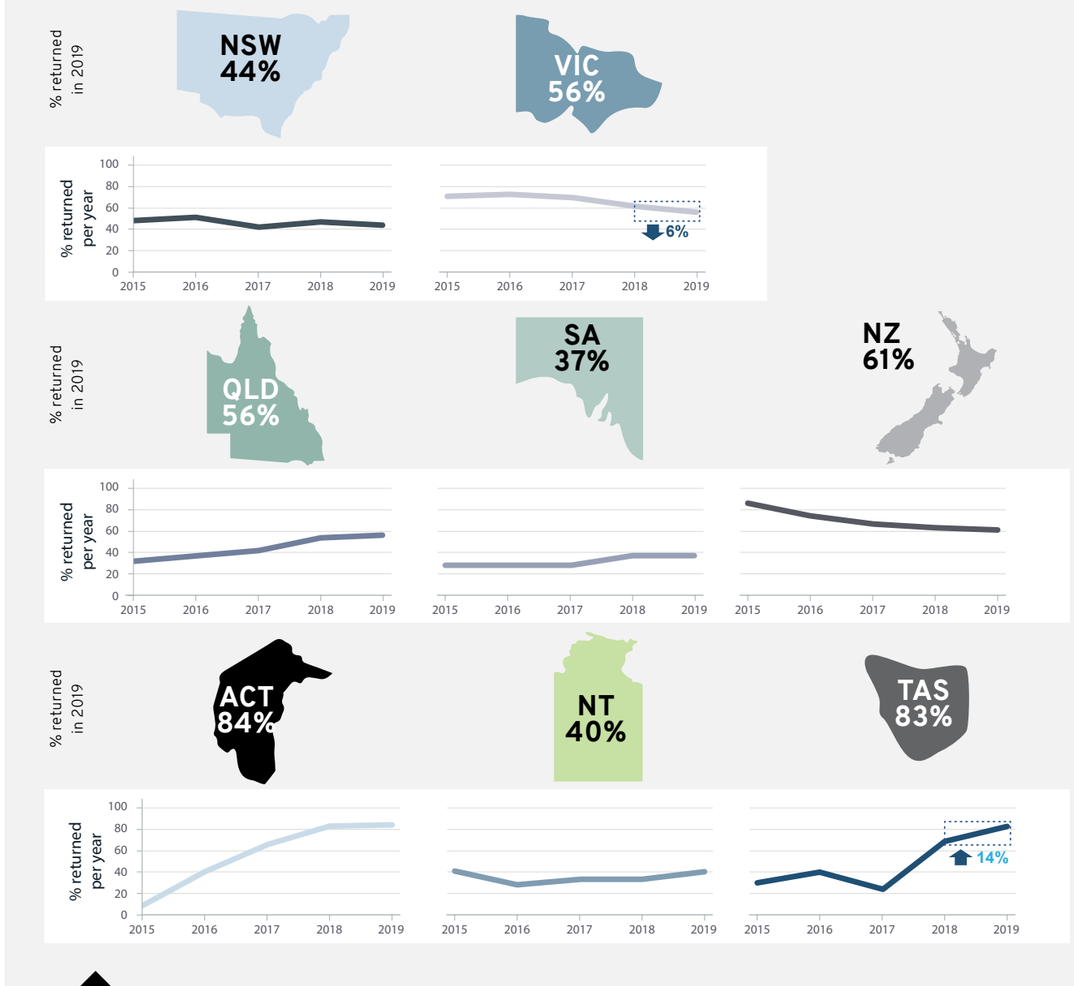


FIGURE 4: PROPORTION OF EPIC-26 QUALITY-OF-LIFE QUESTIONNAIRES COMPLETED BY JURISDICTION, AND CHANGES OVER TIME

PCOR-ANZ: DIAGNOSIS

METHOD OF PROSTATE CANCER DIAGNOSIS

There are two main methods for diagnosing prostate cancer;

1. **a transrectal ultrasound-guided (TRUS) biopsy** – where a needle is inserted through the rectum into the prostate to remove a sample of tissue.
2. **a transperineal (TPB) biopsy** – where a needle is inserted through the skin between the anus and the scrotum to remove a sample of tissue.

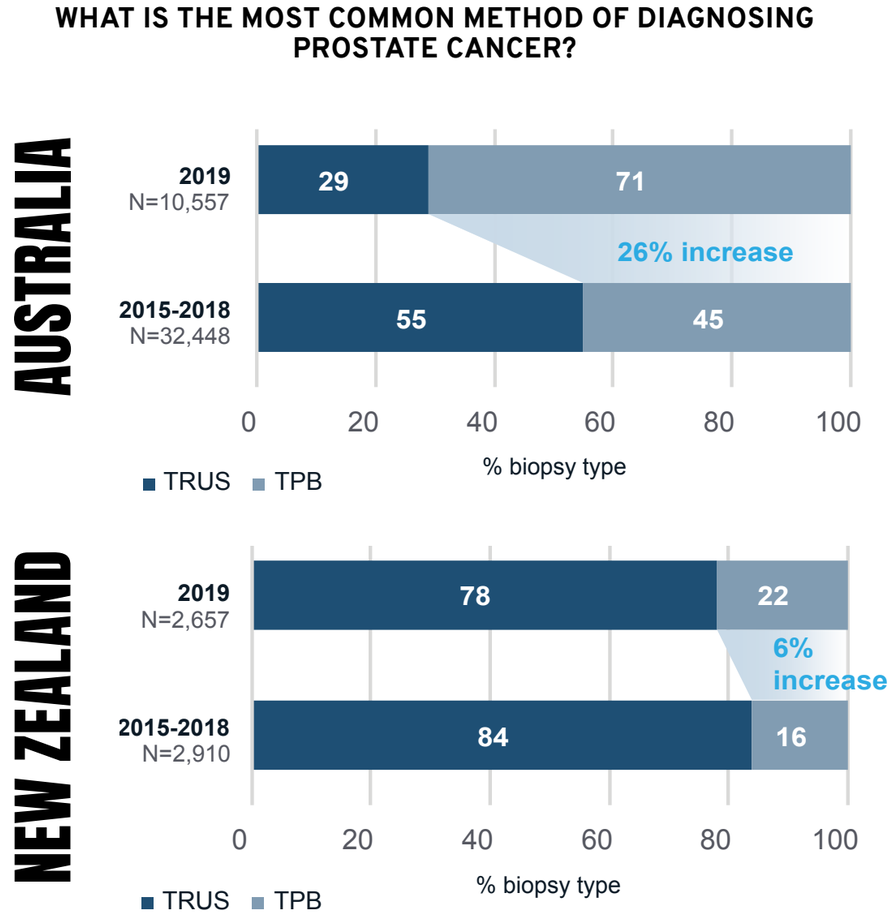
TPB, commonly performed under general anaesthetic, is a safer and more effective method of prostate biopsy than the traditional transrectal ultrasound-guided biopsy (TRUS biopsy). It almost eliminates the risk of infection that occurs in approximately 2% of men undergoing a TRUS biopsy.

TPB also facilitates access to the anterior part of the prostate (i.e. closest to the front of the body) which is far more difficult to access via TRUS. Combined with a pre-biopsy magnetic resonance imaging (MRI) scan, TPB allows precise targeting of tumours to ensure that high-risk regions of the prostate are sampled.

In 2019, compared with previous years, diagnosis via TPB increased 26% in Australia, however only a 6% increase was evident in New Zealand (Figure 6, appendix Table A3). This is because TPB requires specialised equipment, which is not available in many public hospitals in New Zealand. TRUS therefore remains the standard of care in New Zealand.

The increased use of pre-biopsy MRI will enable a considerable number of men to avoid unnecessary biopsy and its attendant risks of sepsis and discomfort if the imaging is negative. While MRI is available in main treatment centres in metropolitan New Zealand, very few urology units have the funding available to implement scanning prior to biopsy. Accessibility is an added challenge for rural men. In Australia, MRI for diagnosis has been reimbursed by Medicare since 2018, and a Medicare Benefits Scheme (MBS) item code for MRI-guided biopsy has been available from 2020.

It is also important to note that using a combination of a digital rectal exam and TRUS biopsy can be an impediment to the diagnosis of prostate cancer. The procedures can be uncomfortable and TRUS carries a risk of sepsis, but importantly, many men, including men from certain cultural backgrounds such as Māori, object to the procedure based on their social and cultural beliefs. TRUS biopsy is undertaken in outpatients as a routine in New Zealand, whereas TPB is not available in all urology units and is usually undertaken under general anaesthetic. However, TPB has a lower infection risk compared with TRUS, and can be targeted to improve diagnostic accuracy. It is therefore important for equity in New Zealand that there is increased support for broader access to TPB.



People diagnosed by other methods (such as transurethral resection of the prostate [TURP]) have been excluded from this analysis as the overall numbers are comparatively small.

TBP is becoming the preferred method of diagnosis for prostate cancer, and its use is rising in both countries

FIGURE 5: DIFFERENCES IN METHOD OF DIAGNOSIS (PERCENT OF ENROLLED POPULATION) BETWEEN AUSTRALIA AND NEW ZEALAND 2015–2019

PCOR-ANZ: DIAGNOSIS

Men diagnosed with prostate cancer are assigned a clinical risk category that is determined by tumour grade, prostate-specific antigen (PSA) level, and the extent to which the cancer has spread as measured by examination.

This method of measuring cancer risk was originally devised by Dr Anthony D'Amico, and then refined by the US National Comprehensive Cancer Network (NCCN) and so these groups are often referred to as 'NCCN risk groups'. Monitoring the risk category at the time of diagnosis is important as treatment options are based upon risk group. Risk group is also an indicator of survival.

There are five risk groups for localised prostate cancer (very-low, low, intermediate, high and very-high), and two more for when the cancer has either spread locally (e.g. to a lymph node in the pelvis) or more widely throughout the body (metastatic).

The proportions of men who fall into each of the NCCN risk groups after being notified to PCOR-ANZ have remained relatively unchanged year on year since PCOR-ANZ started collecting data (see PCOR-ANZ Annual Report 2020, Figure 5, for year-on-year data 2015–2018[4]). These proportions have again remained stable in 2019 in Australia, but some differences were noted in New Zealand when compared with 2015–2018 (Figure 6, appendix Table A4).

In New Zealand, the proportion of men diagnosed with high/very-high-risk disease and notified to PCOR-ANZ has increased from 19% across 2015–2018; to 24% in 2019.

There was also a small increase seen in the metastatic disease category (i.e., cancer which has spread to other parts of the body) from 2015–2018 to 2019 (5.9% to 7.8%). Conversely, the number of men diagnosed with low-risk disease and notified to PCOR-ANZ has decreased from 31% across 2015–2018 to 25% in 2019 in New Zealand.

These changes could potentially be due to many factors, including the changes in data collection that increased the number of men who are included in the report; and recent changes to the way prostate cancer is diagnosed that have increased accuracy (e.g. the wider use of multiparametric MRI [mpMRI]). To accurately assess the factors behind such changes, we need to continue our efforts to reach population coverage.

One notable difference between Australia and New Zealand in 2019 is a higher proportion of men diagnosed with low-risk disease and notified to PCOR-ANZ in New Zealand (25%) compared with Australia (18%). However, whether this difference represents population-wide differences between the two countries, or lower mpMRI use pre-biopsy in New Zealand, will also not be clear until we have higher levels of population coverage across both countries within PCOR-ANZ.

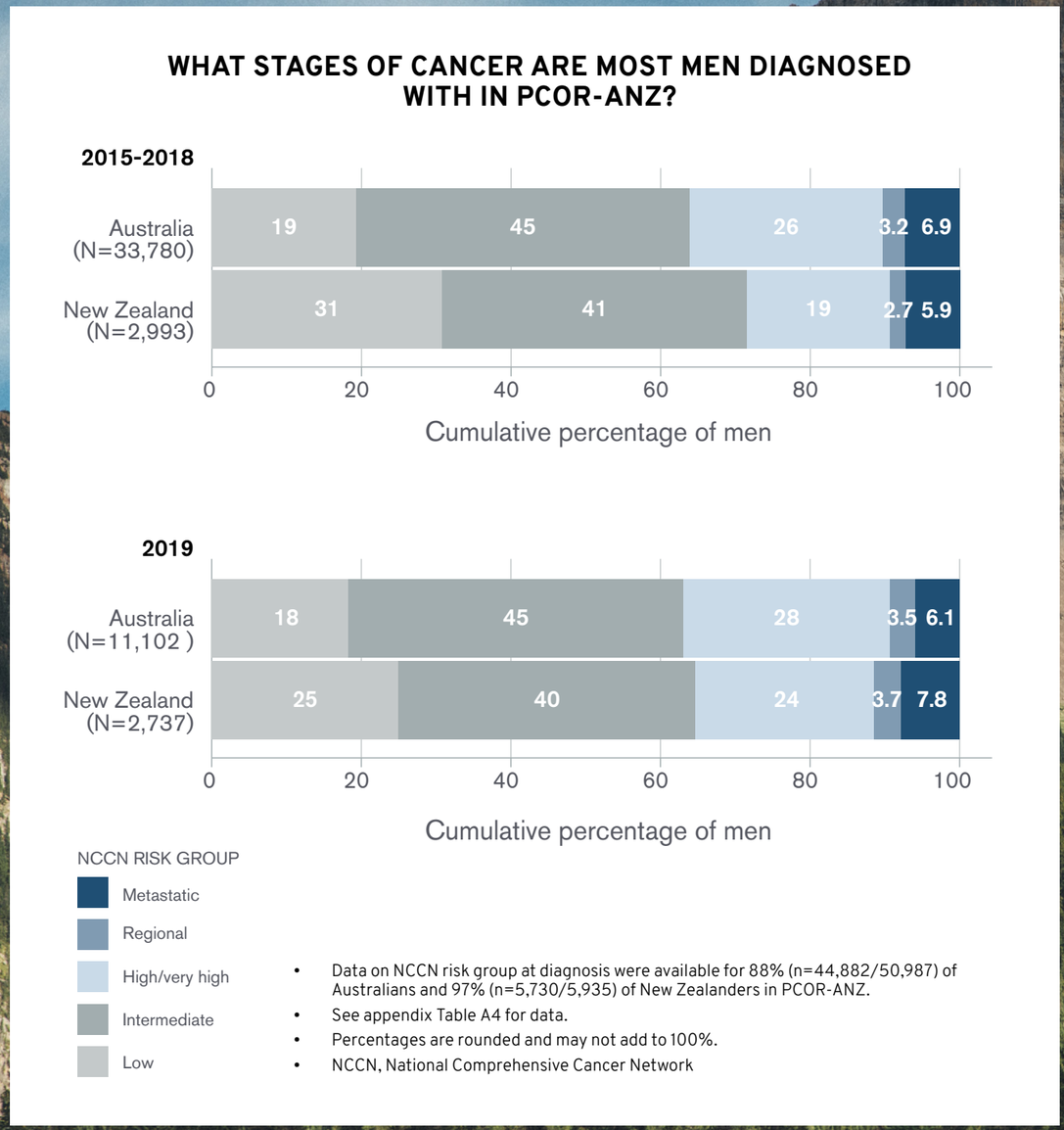


FIGURE 6: PROPORTION OF MEN PER NCCN RISK GROUP, BY COUNTRY (2015–2019)

MANAGEMENT OF PROSTATE CANCER

Typically, prostate cancer is slow growing, and this allows time to make a decision on the best possible treatment option. The best treatment for prostate cancer will depend on the risk category of the cancer, the age and general health of the patient, as well as any specific urinary problems, the attitude of the patient to the potential side-effects and convenience of the options, and the local availability of options in terms of expertise, technology, and cost.

The numerous recognised options that might be considered by a patient and his doctors are:

- **Active surveillance (AS):** monitoring of low-risk prostate cancer that isn't causing problems or symptoms, avoiding unnecessary treatment while actively monitoring for changes that would trigger immediate action.
- **Watchful waiting (WW):** another way of monitoring prostate cancer for men in whom disease progression is unlikely to cause a problem during their lifetime. Generally suggested to older men or those with other health concerns where treatments may be hard to handle.
- **Surgery:** for localised and locally advanced prostate cancer, radical prostatectomy removes the prostate, part of the urethra and the seminal vesicles.
- **Radiation therapy:** provides a controlled targeted radiation to wipe out cancer in the prostate and surrounding tissue. Temporary ADT may be given with radiation therapy to enhance the effects of radiation.
- **'Permanent' Androgen Deprivation Therapy (ADT):** also known as hormone therapy. As prostate cancer needs testosterone to survive, ADT reduces testosterone production in the body to shrink the cancer and to keep it under control generally for years, if the ADT is given by itself.
- **Chemotherapy:** the use of drugs which kill or slow the growth of cancer cells.

Low-risk prostate cancer across Australia and New Zealand has been increasingly managed by active surveillance between 2015 (69%) and 2019 (80%). This trend is in line with the major clinical guidelines which recommend surveillance for men with low-risk cancer. This is an important consideration because many cancer treatments have adverse side effects, yet some cancers will never progress far enough to trouble the patient during the rest of his life.

Men with intermediate-risk disease represent the largest group diagnosed with prostate cancer across Australia and New Zealand (Figure 7). They were most commonly treated with surgery, although radiation therapy has been rising in frequency over time.

Just under half the men diagnosed with high-risk disease were treated with surgery and this has remained fairly constant between 2015 and 2019.

A more prominent change has occurred in the treatment of men who have regional disease (i.e., men in whom the cancer has spread to a lymph node). There has been notable growth observed in the proportion of men receiving radiation therapy (35% to 59%).

While the general increase in the use of radiation therapy documented in PCOR-ANZ may be partially due to the increasing participation of radiation therapy centres in the registry, actual practice changes are also likely to be behind the observed increases.

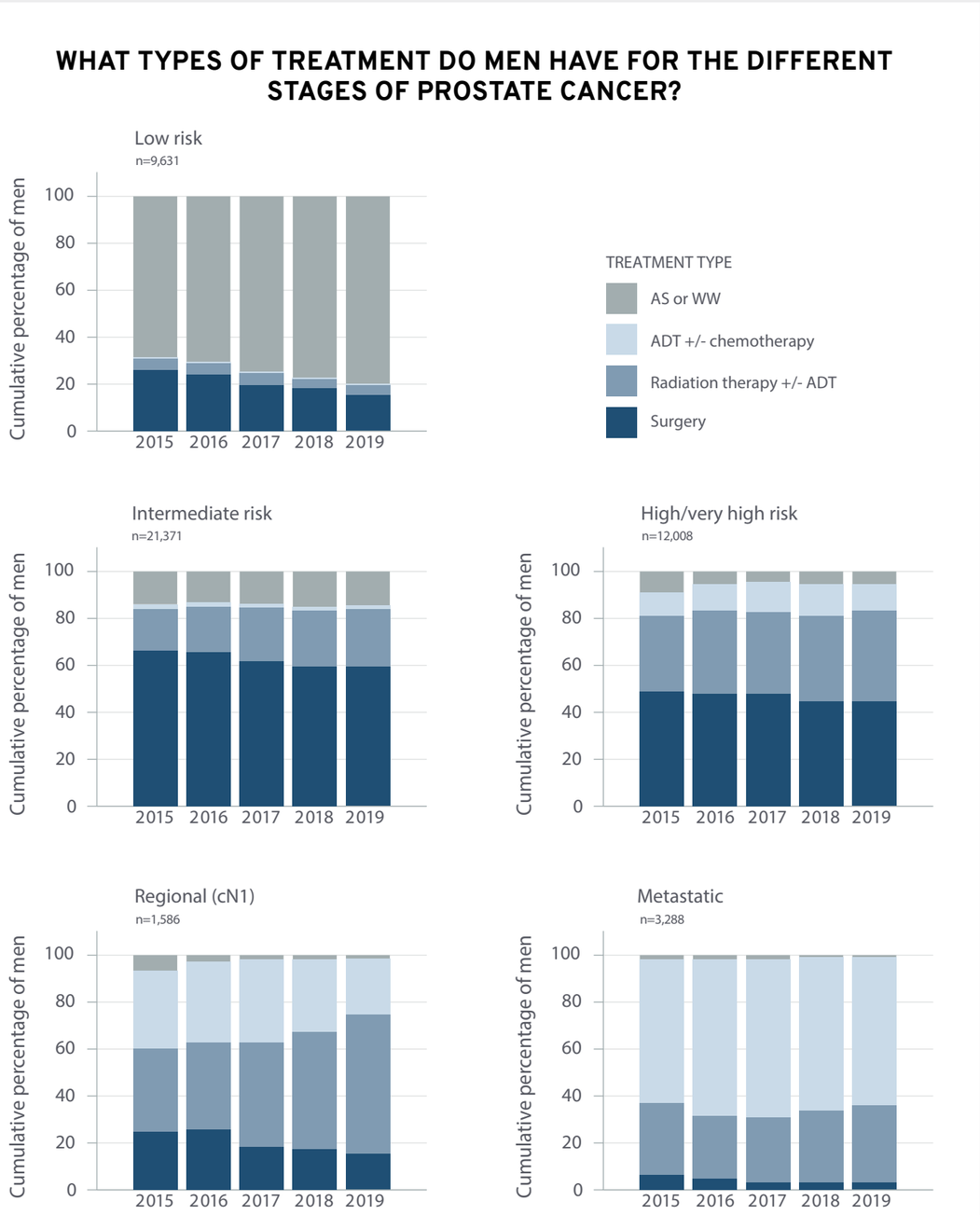


FIGURE 7: MANAGEMENT PROVIDED BY NCCN RISK GROUP AND YEAR (2015–2019)

- When multiple treatments are recorded, the most "invasive" is assigned, i.e., surgery > radiation therapy > ADT > observation.
- Data on NCCN risk group and primary treatment were available for 84% (n=47,884/56,922) 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.
- Percentages are rounded and may not add to 100%.
- ADT, androgen-deprivation therapy; AS, active surveillance; NCCN, National Comprehensive Cancer Network; WW, watchful waiting.

PATIENT-REPORTED OUTCOMES

PATIENT-REPORTED OUTCOMES FOR MEN DIAGNOSED WITH PROSTATE CANCER

Patient-reported outcomes are collected approximately 12 months after treatment, or 12 months after diagnosis for those men who are undergoing AS/WW. We use the EPIC-26 questionnaire, which collects information about symptoms specific to prostate cancer and/or its treatment.

The questionnaire measures urinary, sexual and bowel function. The questionnaire also asks men how much of a problem each of the symptoms was for them. Moderate or big problems are grouped in this report as 'bother'. No problems, very small or small problems are grouped as 'no bother'.

Prostate cancer treatment has significant effects on quality of life, and these are different between treatments.

It is therefore important to consider health-related quality of life when management decisions are being made. The PROMs seen in PCOR-ANZ suggest that:

- Urinary bother is generally more frequent in older men, while sexual bother is more frequent in younger men.
- Surgery resulted in the highest rates of reported sexual bother with AS/WW having the lowest level.
- Bowel bother was more frequent among men who were administered radiation therapy treatment, particularly in those aged under 70.

THE IMPACT OF COVID-19

As a result of COVID-19 lockdowns, data collection for 2019 diagnoses was delayed, particularly in Victoria, with data collectors unable to access rooms during the repeated and extended lockdowns. This delay in data collection resulted in a decreased proportion of men completing the EPIC-26 quality-of-life questionnaire. This is because clinical data (such as dates of diagnosis and treatment) are required to enable collection of outcomes at 12 months post treatment. The effects of COVID-19 are likely to be even more pronounced in the 2020 dataset, where additional states such as NSW were also under lockdown. The full effects of COVID-19 on the diagnosis and treatment for men with prostate cancer will become clearer as full data collection resumes and will be the focus of future reports.

- 'No problems', 'very small problems' and 'small problems' have been combined into 'No bother'; 'big problems' and 'moderate problems' have been combined into '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 Tables S3 for more information on bother, and S6 for follow-up methodology and quality-of-life completion rates.
- ADT, androgen-deprivation therapy; AS/WW, active surveillance/watchful waiting; EPIC, Expanded Prostate Cancer Index Composite; RT, Radiation Therapy.

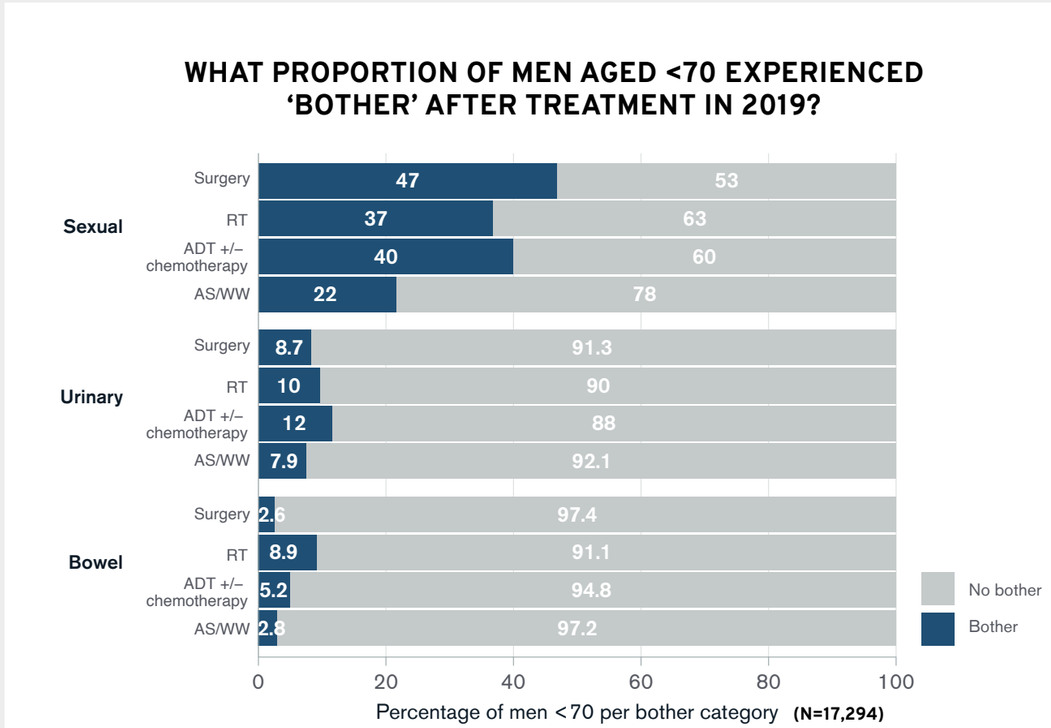


FIGURE 8: PATIENT-REPORTED BOTHER 12 MONTHS AFTER TREATMENT, BY EPIC-26 DOMAIN AND TREATMENT TYPE

FUTURE DIRECTIONS

PCOR-ANZ continues to mature and expand across Australia and New Zealand. Recent updates to the governance structure have been completed and we welcome new members to our newly formed Governance, Advisory, Data Advisory and People with Lived Experience Committees. We are also in the final stages of updating the technology underpinning the PCOR-ANZ database, with the launch of the new PCOR-ANZ Technology Solution, including an updated system for the electronic capture of patient outcomes in late 2022.

Supporting continuous quality improvement is paramount to the PCOR-ANZ, with quality indicator reports circulated to radiation oncologists for the first time in 2021. A very high level of engagement with these reports has been noted with much positive feedback.

"I have found the report extremely helpful to confirm that my practice is meeting the quality indicators and aligns with those of my colleagues in New Zealand and Australia. It also enables me to identify particular side effects my patients are experiencing that they may not readily raise with me in clinic, so I can ensure I focus on asking about these issues during follow-up appointments to ensure they are managed and optimised as best as possible."

COMMENT FROM NZ RADIATION ONCOLOGIST, JUNE 2022

We encourage clinicians and researchers to engage with PCOR-ANZ through the various governance committees and to use registry data and infrastructure for research projects, as a useful basis for intervention studies, and as a tool for implementation of science programs designed to translate knowledge into improved outcomes.

As data in the registry matures, we aim to continue monitoring emergent trends in diagnosis and treatment. Our future focus is on the identification of inequity in the diagnosis, treatment and outcomes for men diagnosed with prostate cancer. In this way, registries such as PCOR-ANZ can contribute to meaningful change in patient treatment and outcomes.

REFERENCES

01 AIHW cancer data in Australia. Web report, last updated 01 Jul 2022. Available at https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/summary Accessed August 2022.

02 New Zealand Ministry of Health/Manatu Hauora. New Cancer Registrations 2019. Available at https://www.health.govt.nz/publication/new-cancer-registrations-2019 Accessed August 2022.

03 Department of Health. (2020). Cancer incidence, mortality and survival in Western Australia, 2017. Information and Performance Governance Directorate. Department of Health, Perth. Statistical Series Number 112. Available at https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/WA-Cancer-Registry/Recent-reports/Incidence-Mortality-and-Survival-2017.pdf Accessed August 2022

04 Papa N, O'Callaghan M, Millar J. Prostate Cancer in Australian and New Zealand Men: Patterns of care within PCOR-ANZ 2015–2018. Melbourne, VIC: Monash University & Movember; March 2021.

PUBLICATIONS

PCOR-ANZ publications from 2021 and 2022 are listed below. For a historical list of publications please **click here**

2022

Shemesh B, Opie J, Tsiamis E, Ayton D, Satasivam P, Wilton P, et al. Codesigning a patient support portal with health professionals and people with prostate cancer: An action research study. Health Expect. 2022 Apr 11. doi: 10.1111/hex.13444. Online ahead of print.

Koo K, Papa N, Evans M, Jefford M, IJzerman M, White V, et al. Mapping disadvantage: identifying inequities in functional outcomes for prostate cancer survivors based on geography. BMC Cancer. 2022;22(1):283.

Papa N, Bensley JG, Hall K, Evans M, Millar JL. Quantifying the effect email reminders have on patient reported outcome measure returns in a large prostate cancer registry. J Patient Rep Outcomes 2022;6(1):19.

Rechtman M, Forbes A, Millar JL, Evans M, Dodds L, Murphy DG, et al. Comparison of urinary and sexual patient-reported outcomes between open radical prostatectomy and robot-assisted radical prostatectomy: a propensity score matched, population-based study in Victoria. BMC Urol. 2022;22(1):18.

Foley GR, Blizzard CL, Stokes B, Skala M, Redwig F, Dickinson JL, et al. Urban-rural prostate cancer disparities in a regional state of Australia. Sci Rep. 2022;12(1):3022.

Kelly BD, Perera M, Bolton DM, Papa N. Social determinants of health: does socioeconomic status affect access to staging imaging for people with prostate cancer. Prostate Cancer Prostatic Dis. 2022; Feb 15. doi: 10.1038/s41391-022-00508-7. Online ahead of print.

Sampurno F, Kowalski C, Connor SE, Nguyen AV, Acuña ÀP, Ng CF, et al. Knowledge and insights from a maturing international clinical quality registry. J Am Med Inform Assoc. 2022;29(5):964–969.

Ong WL, Thangasamy I, Murphy D, Pritchard E, Evans S, Millar J, et al. Large variation in conservative management for low-risk prostate cancer in Australia and New Zealand. BJU Int. 2022;130(S1):17–19.

Gondoputro W, Thompson J, Evans M, Bolton D, Frydenberg M, Murphy DG, et al. How Does Age Affect Urinary Continence following Robot-Assisted Radical Prostatectomy? A Prospective Multi-Institutional Study Using Independently Collected, Validated Questionnaires. J Urol. 2022;207(5):1048–1056.

2021

DI Pryor, JM Martin, JL Millar, H Day, WL Ong, M Skala, et al. Evaluation of Hypofractionated Radiation Therapy Use and Patient-Reported Outcomes in People With Nonmetastatic Prostate Cancer in Australia and New Zealand. JAMA Netw Open. 2021;4(11):e2129647.

Mark S, Clarke J, Shand B, Millar J, Papa N. Setting up the Prostate Cancer Outcomes Registry of New Zealand: reflecting and influencing clinical practice. N Z Med J. 2021;134(1546):79–88.

Bensley JG, Dhillon HM, Evans SM, Evans M, Bolton D, Davis ID, et al. Self- reported lack of energy or feeling depressed 12 months after treatment in people diagnosed with prostate cancer within a population-based registry. Psychooncology. 2021;31(3):496–503.

Liang G Qu, Jack G, Perera M, Evans M, Evans S, Bolton D, Papa N. Impact of delay from transperineal biopsy to radical prostatectomy upon objective measures of cancer control. Asian J Urol. 2021;9(2):170–176.

Wah W, Papa N, Evans M, Ahern S, Earnest A. A multi-level spatio-temporal analysis on prostate cancer outcomes. Cancer Epidemiol. 2021;72:101939.

O'Callaghan M, Papa N, Pase M, Frydenberg M, Mark S, Moretti K, et al. Patterns of care for prostate cancer treatment and improving outcomes – are national registries the answer? BJU Int. 2021;128(S1):6–8.

Azad AA, Tran B, Davis ID, Parente P, Evans M, Wong S, et al. Predictors of real-world utilisation of docetaxel combined with androgen deprivation therapy in metastatic hormone-sensitive prostate cancer. Intern Med J. 2021; Mar 12. doi: 10.1111/imj.15288. Online ahead of print.

Papa N, Perera M, Murphy DG, Lawrentschuk N, Evans M, Millar JL, et al. Patterns of primary staging for newly diagnosed prostate cancer in the era of prostate specific membrane antigen positron emission tomography: A population-based analysis. J Med Imaging Radiat Oncol. 2021;65(6):649–654.

Wah W, Ahern S, Evans S, Millar J, Evans M, Earnest A. Geospatial and temporal variation of prostate cancer incidence. Public Health. 2021;190:7–15.

INDEX OF FIGURES AND TABLES

APPENDICES

TABLE A1: ENROLMENT IN PCOR-ANZ BY YEAR OF DIAGNOSIS AND JURISDICTION

Year	ACT	NSW	NT	NZ	QLD	SA	TAS	VIC	Total
2015	95	833	41	78	1,814	977	296	2,532	6,666
2016	218	2,153	81	260	1,519	966	398	2,821	8,416
2017	246	2,486	84	811	2,611	1,212	383	3,386	11,219
2018	322	3,846	64	1,900	3,146	1,162	357	3,633	14,430
2019	**379**	**3,792**	**92**	**2,886**	**3,314**	**1,406**	**303**	**4,019**	**16,191**
Total	1,260	13,110	362	5,935	12,404	5,723	1,737	16,391	56,922

TABLE A2: PERCENTAGE COMPLETION OF EPIC-26 QUESTIONNAIRES BY YEAR OF DIAGNOSIS AND JURISDICTION

Year	ACT	NSW	NT	NZ	QLD	SA	TAS	VIC	All
2015	8.4	48	41	86	32	28	30	71	48
2016	40	51	28	74	37	28	40	73	53
2017	66	42	33	67	42	28	24	70	51
2018	83	47	33	63	54	37	69	62	55
2019	**84**	**44**	**40**	**61**	**56**	**37**	**83**	**56**	**54**

TABLE A3: PERCENTAGE DISTRIBUTION OF BIOPSY TYPE (TRUS VERSUS TPB) BY COUNTRY AND YEAR OF DIAGNOSIS

Year	Country	N	TRUS	TP
2015-18	**Australia**	32,448	55	45
	NZ	2,910	84	16
2019	**Australia**	10,557	29	71
	NZ	2,657	78	22

TABLE A4: PERCENTAGE DISTRIBUTION OF NCCN RISK CATEGORY BY COUNTRY AND YEAR OF DIAGNOSIS

Year	Country	N	Low	Inter	High or very High	Regional	Metastatic
2015-18	**Australia**	33,780	19	45	26	3	7
	NZ	2,933	31	41	19	3	6
2019	**Australia**	11,102	18	45	28	4	6
	NZ	2,737	25	40	24	4	8

TABLE A5: PERCENTAGE OF PEOPLE REPORTING MODERATE OR BIG 'BOTHER' IN THREE FUNCTIONAL DOMAINS BY AGE AND PRIMARY TREATMENT

Age	Treatment	N	Urinary	Sexual	Bowel
<70	**Surgery**	10,596	9	47	3
	Radiation therapy	2,310	10	37	9
	ADT ± Chemotherapy	500	12	40	5
	AS/WW	3,888	8	22	3
≥70	**Surgery**	3,287	11	39	4
	Radiation therapy	3,507	11	35	9
	ADT ± Chemotherapy	1,124	14	29	9
	AS/WW	2,042	9	27	5

Movember Team
PO BOX 60
East Melbourne
VICTORIA 8002
Australia

1300 GROW MO
(1300 4769 66)

www.movember.com
info@movember.com

Writing and editorial assistance for the Annual Report 2021 was provided by Lesley Cunliffe (PhD) and funded by Movember.