PROSTATE CANCER OUTCOMES | REGISTRY AUSTRALIA AND NEW ZEALAND

PROSTATE CANCER ACROSS AUSTRALIA AND NEW ZEALAND

ANNUAL REPORT 2023

PCOR-ANZ 2015–2021
Patterns of care and patient-reported outcomes.

MOVEMBER® | MONASH University

THE PCOR-ANZ ANNUAL REPORT 2023

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

ACKNOWLEDGEMENTS

We extend our thanks to all the people who have participated in the PCOR-ANZ registry. 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 Governance Committee, chaired by Professor Frank Frizelle, the Data Advisory Committee chaired by Professor Sue Evans and the Advisory Committee chaired by Associate Professor David Smith, who have dedicated endless hours to the guidance of this initiative. The operations of PCOR-ANZ would also not be possible without our tireless team of Jurisdiction Coordinators, data collectors and program coordination by the Data Coordination Centre at Monash University.

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

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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?

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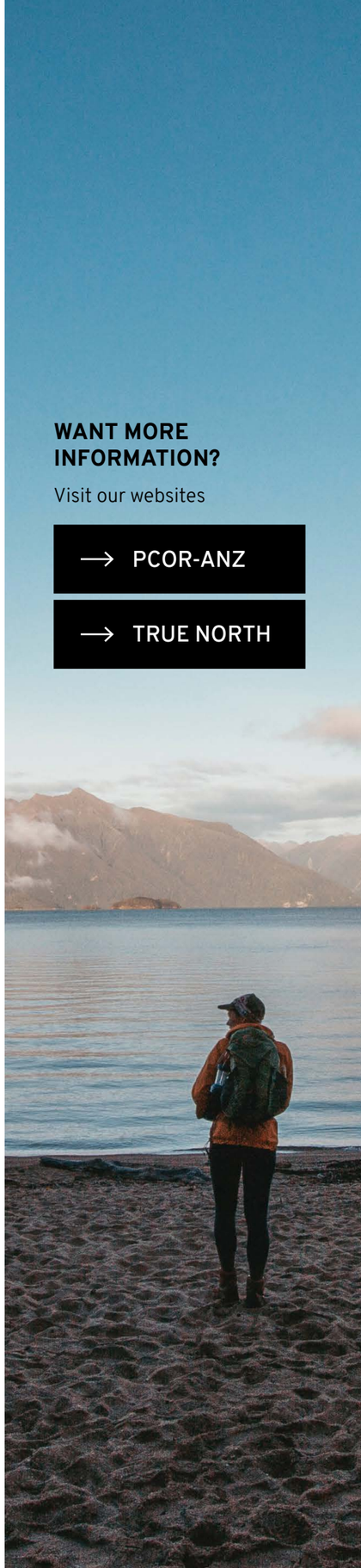
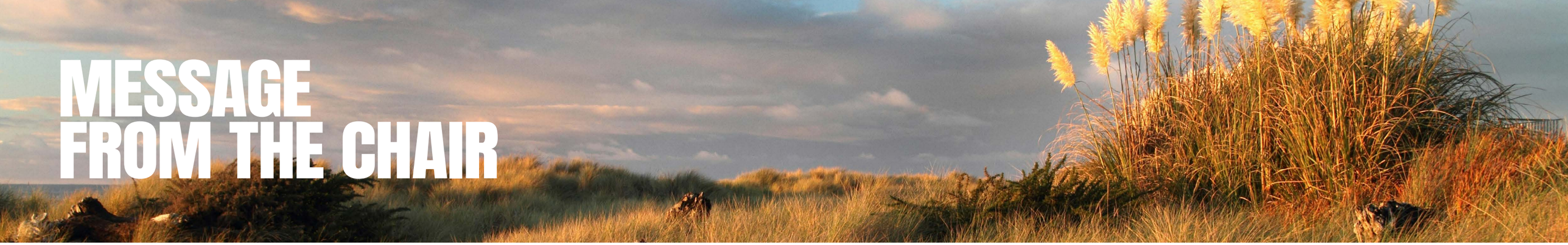




MESSAGE FROM THE CHAIR

The purpose of PCOR-ANZ is to improve outcomes for people with prostate cancer. After nine years, it has developed a large dataset. PCOR-ANZ has matured in operations and IT capacity, and has established a solid civil-society–academic-clinical partnership to underpin new initiatives across Australia and New Zealand that will be significant on a global scale.

I came to the PCOR-ANZ family as a prostate cancer 'outsider' but with an independent international perspective on efforts to improve results for patients. I can say the bi-national population coverage of PCOR-ANZ, the focus on measurable outcomes that matter to patients, and the productive interactions engendered between clinicians in the clinics and operating theatres are well focused to deliver the desired improved outcomes for all.

The last two years have been a time of rethinking, resetting, and reconfiguring; and learning from experience. We have progressed a transformation in our IT infrastructure to move data to a new platform that will provide a responsive state-of-the-art and scalable database, on which we can more easily build and develop new efforts. The administrative structure of the complex federated registry needed to be modified and bolstered. There is still work in progress; but these efforts are putting us in a great position to move forward.

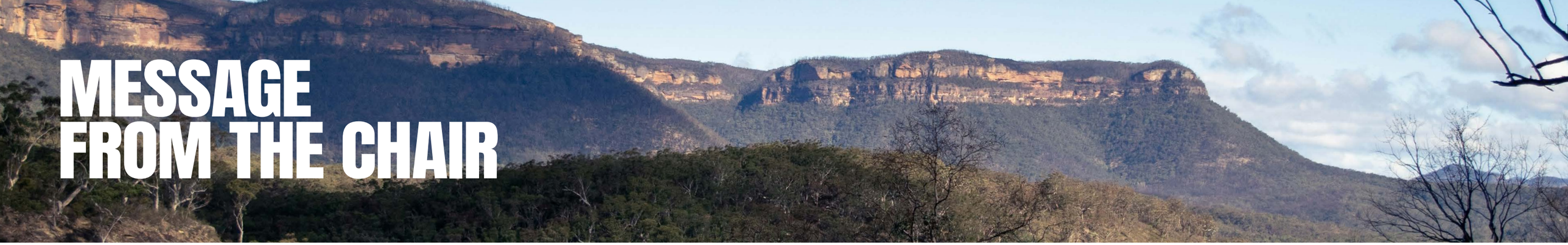
We have started to do some impressive things with the important goal of improving patient outcomes in mind. In the larger sense, we have filled the 'black hole' of information between the statutory statistics on prostate cancer incidence, and the statutory statistics on mortality. This is the only way in which we can ever understand and address the variation that we see between what happens when prostate cancer begins, and what happens when it ends.

- We have registered more than 90,000 individuals on a population-representative level across every state in Australia (except Western Australia, where we have contracts in place to launch this year) and New Zealand.
- We process and provide 'Quality Indicator' reports for clinicians and health services across Australia and New Zealand twice a year; allowing them to assess their outcomes compared with that of de-identified peers, on a risk-adjusted basis. We have developed specific radiation oncology reports and have started to provide these to radiation therapy services for their particular treatments.
- We have used the patient-reported outcome measures (PROMs) completed by our registrants to provide feedback to clinicians about their own patients who were struggling with side effects; which becomes apparent in the PROMs scores. We have piloted different ways to use the large amount of PROMs feedback provided by individuals to help people who might be struggling, testing mechanisms that could be scaled across the population. These include the TrueNth Coordinating Nurse randomised trial,[1] and the BroSupPORT[2] web-based help portal.
- Our registry has enabled work to allow understanding and reduction of inequity in prostate cancer care and outcomes. In Aotearoa New Zealand we have appointed a full-time Urology Research Registrar, Dr Eng Toh to analyse the PCOR-ANZ data set with a primary focus on ethnicity inequity.
- We have published a steady stream of important information about outcomes for patients with prostate cancer, how they have evolved and changed over time, how the patterns of diagnosis and management have changed over time, and how aspects of this are improving – you can find a list of this impressive range of publications at the end of the report. All these types of reports and information would be impossible without PCOR-ANZ. Examples are the improvements in surgical results,[3] the adoption of new biopsy and new surgical approaches,[4] the evidence-based increasing use of 'active surveillance' in people who do not need immediate treatment,[5] the widespread adoption of shorter more convenient courses of radiation therapy,[6] and insights into important variations in patterns of care, across borders, for different groups of patients, and in different health care settings.[7-9]
- We routinely hear at the individual clinician or clinic level how the comparative data we provide prompts reflection, action, and change as health services and health service providers see where they might improve or modify their approaches.
- We serve as an exemplar of a large international multi-jurisdictional clinical quality registry conforming with the standards set out by the Australian Commission on Safety and Quality in Health Care for quality clinical registries. And PCOR-ANZ has underpinned recent Australian Government funding initiatives partnering with Movember to replicate in other cancers the concepts and approaches we have pioneered in our registry.

I am very proud of the work done by the team across both countries. This report is a snapshot of where we are. We plan to do so much more, such as:

- Expand collection of baseline PROMs.
- Build capacity for longer-term follow up to allow us to garner more insights over longer timeframes of people registered in PCOR-ANZ.
- Extend our use of the PROMs we capture to assist individual patients who have problems, in a manner that works at a broad scale across the health systems in Australia and New Zealand.
- Encourage use of data by a wider range of researchers, patients, health-policy and health-funding agencies.
- Encourage partnerships with governments, research agencies, and international and civil societies to leverage the treasure trove of PCOR-ANZ data.
- Re-imagine and strengthen links between PCOR-ANZ and the clinicians and institutions that are the loci for change in many aspects of prostate cancer care, to enable them to have a clearer and more timely view of the outcomes the individuals they look after are experiencing.

Analysis of Australian Institute of Health and Welfare (AIHW) data by the Prostate Cancer Foundation of Australia (PCFA) reveals the health system expenditure on the management of people with prostate cancer is $1.36 billion in the financial year ending 2020.[10] This means the total expenditure on PCOR-ANZ—an impressive and important commitment from Movember on behalf of its supporters—makes up less than 0.1% of the health system expenditure on prostate cancer in Australia and New Zealand. It is an ambitious task and an enormous amount of work for PCOR-ANZ staff to move the prostate cancer world in Australia into a better place. Perhaps PCOR-ANZ is the solid ground on which to stand, and our organisation is the lever that Archimedes had in mind, when he was thinking ahead to say, *"Give me a place to stand and with a lever I will move the whole world."?*



MESSAGE FROM THE CHAIR

I am grateful to all who are on the PCOR-ANZ Governance, Advisory, Data Advisory, and People with Lived Experience (PLEx) committees as well as each jurisdiction coordinator for helping us get this far. Importantly, I am also grateful to all the clinicians and institutions who willingly collaborate on this bi-national effort, as without their support this work would not be possible. We aim to serve people with prostate cancer, and their involvement at all levels is essential: from those who contributed data to PCOR-ANZ to those involved in the governance of the organisation. Their assistance keeps the organisation in touch with its goals; and it is this coordinated effort that allows us to drive improvement in prostate cancer care in Australia and New Zealand.

PROFESSOR FRANK A. FRIZELLE ONZM
MBChB, MMedSc, FRACS, FACS, FASCRS, FNZMA, FASA(hon), FRCSI(hon) FRCSEd(hon)
Professor of Surgery University of Otago; Christchurch, New Zealand

MESSAGE FROM MOVEMBER

At the time of writing this message, the Australia and New Zealand Prostate Cancer Outcomes Registry (PCOR-ANZ) is entering its tenth year of operations. During this time, we have witnessed many important improvements in the provision of health care, including a decrease in the proportion of men with low-risk disease who are treated with radical prostatectomy. Sustained investments in clinical quality registries such as PCOR-ANZ are a vital mechanism to improve the care and outcomes of people living with prostate cancer. In recognition of this, Movember has invested more than $24 million into PCOR-ANZ, including funding of the flagship DACIMA registry database and the Movember electronic platform to collect patient-reported outcome measures (PROMs).

In recognition of the importance of measuring outcomes that matter most to patients, Movember has developed the electronic PROMs platform which is employed by PCOR-ANZ. This platform plays a vital role in a new $22.5 million collaboration between Movember and Cancer Australia to measure PROMs, as well as patient-reported experiences, across ten cancer conditions. This flagship collaboration will also support projects to increase the future sustainability of registries such as PCOR-ANZ, including ongoing investments in innovative technologies to support current and future registry operations, and drive real-world impact.

Equity, diversity and inclusion

Tackling disparities and inequalities in clinical care and outcomes is a key focus for Movember and we are committed to increased inclusivity for patients from culturally and linguistically diverse backgrounds. Over the next two years we will support the translation of electronic PROMs, and registry information into a range of languages other than English. This follows on from the successful development and implementation of registry materials aimed at increasing registry participation in people of Māori heritage. In 2024 we also anticipate a companion report to this PCOR-ANZ Annual Report. This report will identify inequities in the diagnosis, management and outcomes for people with prostate cancer, and outline priority areas for future action, to ensure health care is equitable for all patients across Australia and New Zealand.

Reporting and benchmarking

Registries such as PCOR-ANZ improve outcomes for people living with prostate cancer via driving changes in clinical practice. One way of achieving this is via benchmarking against quality indicators of clinical care. Movember is committed to accelerating real-world utilisation of clinical registry data to decrease current evidence–practice gaps and improve the outcomes of people living with prostate cancer. Over the next two years Movember will be supporting the implementation of new software to update the current benchmark reporting and better support quality improvement initiatives. This will also include the ability for participating clinicians to generate reports on-demand to facilitate timely access to data about local management and outcomes for patients.

Increasing registry sustainability

One of the most significant costs for clinical quality registries, which needs to be prioritised to achieve long-term sustainability, is the need for manual data entry. As part of our collaboration with Cancer Australia we will be piloting different innovative methods of data automation. Decreased costs associated with data entry also mean that registries such as PCOR-ANZ can increase activities around use of the data to support quality improvement initiatives. Movember will also continue to strongly advocate for government to provide ongoing and future support for clinical quality registries such as PCOR-ANZ. In addition, advocacy work with the broader community will be a focus over the next five years to highlight the important role of registries, how they can enable better health care, improve outcomes and support patient decision making and empowerment.

Recognising that more can be achieved in health through collaborative efforts, Movember welcomes current and future opportunities to work alongside government and our clinical partners. We aspire to a future where enhanced men's health creates a better world for all.

Movember also extends our gratitude to everyone who has contributed to PCOR-ANZ across Australia and New Zealand over the past 10 years. The wealth of data that we have worked together to collect, and which encompasses diagnosis, treatment and outcomes, will serve as a valuable resource for researchers and clinicians to enhance clinical care, and improve patient outcomes for many years to come.

PAUL VILLANTI
Executive Director - Programs

CONTENTS

ABBREVIATIONS

ACT
Australian Capital Territory

ADT
Androgen-deprivation therapy

AIHW
Australian Institute of Health and Welfare

AS
Active surveillance

ATSI
Aboriginal and Torres Straits Islander

CALD
Culturally and linguistically diverse

EPIC-26
Extended Prostate Cancer Index Composite-26 questions

MMM
Modified Monash Model

mpMRI
Multiparametric Magnetic Resonance Imaging

NCCN
National Comprehensive Cancer Network

NSW
New South Wales

NT
Northern Territory

NZ
New Zealand

PCFA
Prostate Cancer Foundation of Australia

PCOR-ANZ
Australia and New Zealand Prostate Cancer Outcomes Registry

PLEx
People with Lived Experience

PROMs
Patient-reported outcome measures

PSA
Prostate-specific antigen

QLD
Queensland

RT
Radiation therapy

SA
South Australia

SES
Socio-Economic Status

TAS
Tasmania

TP
Transperineal biopsy

TR
Transrectal biopsy / transrectal ultrasound guided biopsy

VIC
Victoria

WW
Watchful waiting

EXECUTIVE SUMMARY

The Australian and New Zealand Prostate Cancer Outcomes Registry reports here on 92,167 people with newly diagnosed prostate cancer from across Australian and New Zealand up until December 2021 (**Figure 1**). In 2021, we engaged with 268 clinical sites and 396 clinicians; which has enabled us to achieve an estimated 59% population coverage in Australia and 78% population coverage in New Zealand in 2021 (62% estimated bi-national population coverage;* see also **Table S1**). Looking forward, we anticipate a further increase in population coverage in Australia with the establishment of the PCOR in Western Australia (PCOR-WA) in 2024. In New Zealand, 100% of public hospital patients are registered.

A key advance for 2023 has been the progressive staged migration of the PCOR-ANZ database to a new platform, DACIMA. In 2024, we anticipate the migration of the remaining jurisdictions, South Australia and Victoria, to be completed. We have also reformed the national governance structures to take into account the growing size and complexity of the federated group of registries. The bi-national registry has entered its ninth year and has achieved sufficient levels of data maturity to support a range of research projects and publications. Over 30 peer-reviewed publications based on PCOR-ANZ data were published in the 2022–2023 calendar years.

*The estimated population coverage of PCOR-ANZ is based on current estimated prostate cancer incidence figures from the AIHW[23] and the New Zealand Ministry of Health.[24] Due to recent changes in AIHW calculation methods, the coverage data included for Australia in this report should not be compared to previous population coverage calculations for PCOR-ANZ. These are rough estimates only and are not suitable for decision making. See **Table S1** for more information.

EXECUTIVE SUMMARY

KEY FINDINGS

Population characteristics and diagnosis

For this report, we included people registered in PCOR-ANZ, who were diagnosed up to December 2021. Over the reporting period (2015–2021), we observed an increase in the proportion of prostate cancer diagnoses in older age groups (**Figure 2**). There has also been an increase in the diagnosis of prostate cancer in those who reside in rural and remote areas in Australia (**Figure 3**), and this likely reflects the increasing population coverage of PCOR-ANZ, with expanded participation of rural and remote institutions. Currently, information and analyses on both socioeconomic status and metropolitan versus rural living is available only for Australian residents.

- In Australia, the proportion of people diagnosed with prostate cancer across socioeconomic groups has remained stable over time (**Figure 4**).
- The relative proportions of people diagnosed per National Comprehensive Cancer Network (NCCN) risk group have changed over time. Notably, there has been a decrease in the proportion of people with low-risk prostate cancer (from 21% [1,237/5,964] in 2015 to 17% in 2021 [2,441/14,581]) and concomitant small increases in other NCCN risk groups (**Figure 6**).
- There has been a marked shift in the method of prostate biopsy in Australia and New Zealand, with the vast majority of prostate biopsies performed being transperineal in 2021 (73% [9,867/13,555]), compared with the majority being transrectal in 2015 (72% [4,203/5,828]; **Figure 8**). This likely represents one of the highest national proportions of transperineal biopsy done internationally,[11,12] although there are still large variations across the Australian and New Zealand jurisdictions. We have discussed these variations and trends in more detail in a paper published in 2023.[4]

Management

There have been changes in the patterns of management of prostate cancer across NCCN risk groups, mostly aligning with international guidelines and recommendations.[13-15]

- Across PCOR-ANZ, the proportion of men with low-risk prostate cancer who were managed with active surveillance increased from 66% (789/1,202) in 2015 to 80% (1,646/2,070) in 2021 (**Figure 12**).
- While both surgery and radiation therapy are standard treatment options for intermediate-risk and high-risk prostate cancer, with equivalent cancer control, they are associated with distinct treatment-related side effects.[16] There are large variations in the proportions of people who had surgery versus radiation therapy for intermediate- and high-risk prostate cancer across jurisdictions (**Figure 14**).
- Management of prostate cancer with regional disease (i.e. prostate cancer that has spread to regional lymph nodes) is changing in a setting of increasing availability of new technology, new investigations, and new systemic treatments.[17,18] There is an increase in the proportion of people who had radiation therapy with androgen deprivation therapy (ADT) for regional disease, increasing from 33% in 2015 (41/126) to 52% in 2021 (255/493; **Figure 12**). This pattern of practice will continue to evolve, with accumulating evidence on the role of either surgery or radiation therapy in the coming years.

Patient-reported outcome measures (PROMs)

PROMs continue to be a key area of focus for PCOR-ANZ and the data collected informs the risks and benefits of treatment for people with prostate cancer.

- PROMs completion across 2015–2021 was around 50% (46,418/92,167; **Table S2**), however, there has been considerable variation observed between jurisdictions and over time (see infographic, Chapter 4). Some jurisdictions have seen a substantial increase over time (TAS, ACT and NT) while others have seen a decrease (NSW and NZ). PROMs are being captured differently in each jurisdiction, either through letters, emails, or phone calls.
- Among people who completed their PROMs questionnaires, sexual function appears to be most adversely affected (**Figure 16, Figure 17**), with 38% (16,204/42,641) reporting moderate-to-big bother relating to sexual function overall. Comparatively lower overall proportions of people reported moderate-to-big bother relating to urinary function (10%, 4,408/44,261) and bowel function 5% (2,123/44,296). See **Table S12** for more information.
- When looking at the responses to key EPIC-26 questions in people from different treatment groups, 31% (6,603/21,303) of people receiving surgery reported use of at least one urinary pad per day compared to 7% (761/10,378) of people who had radiation therapy and 5% (458/9,949) of people on observation (**Table S12**). In comparison, people receiving radiation therapy reported the highest proportions of bother with losing bowel control (5% [6,109/10,000] compared with ~1% to <4% across other treatments or observation).

ABOUT THIS REPORT

WHAT DATA IS INCLUDED IN THE REGISTRY?

Jurisdictional PCOR collect a minimum clinical dataset relating to the diagnosis, treatment of prostate cancer as well as patient-reported outcomes.

DIAGNOSIS

- Transrectal ultrasound guided biopsy
- Transperineal biopsy
- Transurethral resection of the prostate

CANCER INFORMATION

- Cancer stage
- Gleason score
- Cancer risk category
- Prostate-specific antigen (PSA) levels

TREATMENT

- Treatments provided (e.g. surgery, radiotherapy, chemotherapy, androgen deprivation therapy)
- Whether active surveillance or watchful waiting protocols were followed
- Disease progression

PATIENT-REPORTED OUTCOME MEASURES (PROMs)

Functional outcomes using the symptom questionnaire (EPIC-26) and questions on libido and use of sexual aids:

- Twelve months following diagnosis for active surveillance or watchful waiting; or
- Twelve months after start of active treatment

WHEN DO WE COLLECT INFORMATION?

PATIENT MILESTONES

ACTIVE SURVEILLANCE OR WATCHFUL WAITING

12 MONTHS

PROMs collection for patients managed by active surveillance or watchful waiting

DIAGNOSIS → MANAGEMENT

ACTIVE TREATMENT

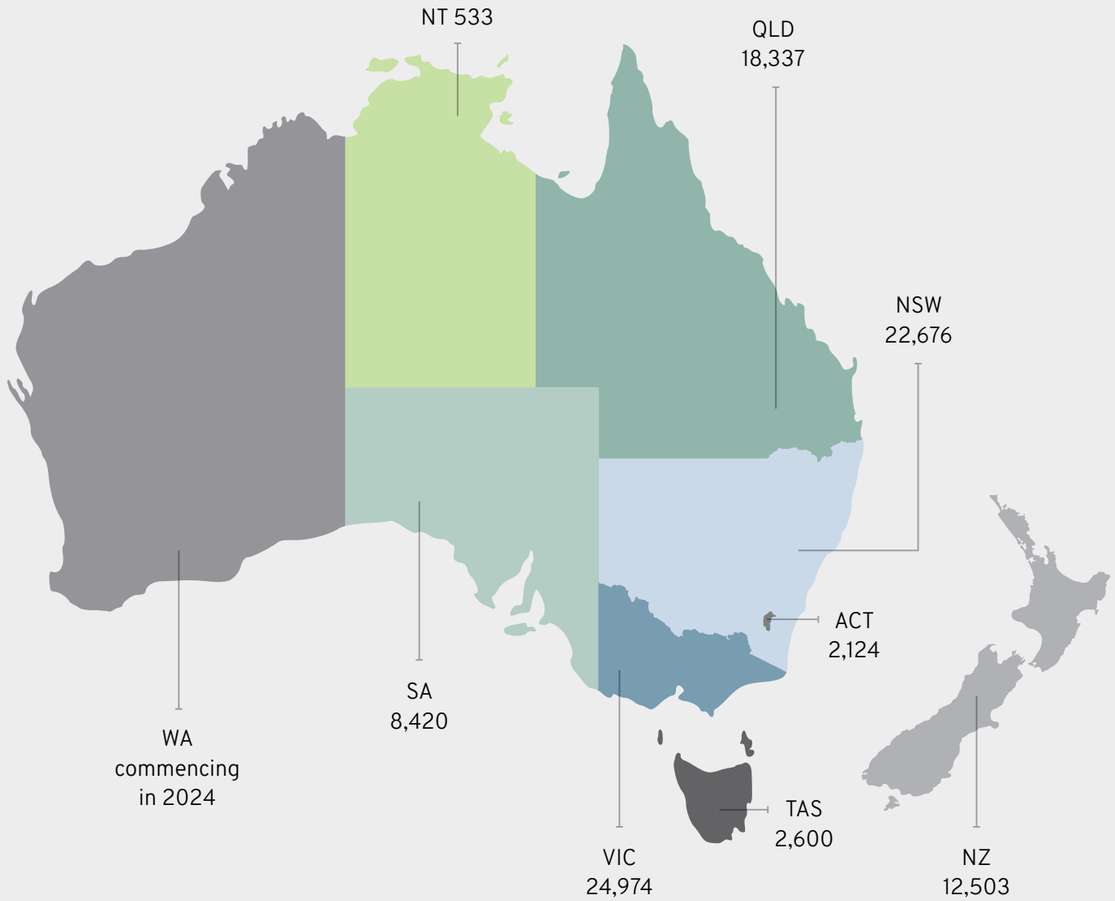
12 MONTHS

PROMs collection for patients who received active treatment is initiated twelve months after the last component of active treatment.

18 MONTHS

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

HOW MANY PEOPLE ARE INVOLVED IN PCOR-ANZ?



396
CLINICIANS CURRENTLY ENROLLED (2023)

268
PARTICIPATING SITES (2023)

1,314
QUALITY OF CARE REPORTS GENERATED IN 2023

46,418
PEOPLE COMPLETED OUR QUESTIONNAIRES (2015-2021)

92,167
PEOPLE REGISTERED IN THE 2015–2021 DATASET

METHODS

PCOR-ANZ DATASET

The Australian and New Zealand Prostate Cancer Outcomes Registry (PCOR-ANZ) is a population-based clinical quality registry. Detailed recruitment and data collection methodology for PCOR-ANZ has been previously reported.[19] In brief, patient contact occurs following notification of prostate cancer to PCOR-ANZ, and patient registration is based on an opt-out model. Currently, PCOR-ANZ includes all Australian jurisdictions (except Western Australia) and New Zealand. For this report, we included people registered in PCOR-ANZ, who were diagnosed with prostate cancer between 1 January 2015 to 31 December 2021. Diagnosis, treatment and patient-reported outcome measures (PROMs) data were collected up to 26 September 2023. Our annual reports thus lag behind on-going recruitment and accruals, but this allows the fullest description of the registrants falling within the described recruitment timeframe.

PROSTATE CANCER DIAGNOSIS AND MANAGEMENT

Each prostate cancer diagnosis was categorised based on the National Comprehensive Cancer Network (NCCN) risk classification[15] into the larger categories of low, intermediate, high-risk, regional disease (i.e. spread of cancer to lymph nodes), and metastatic disease, taking into account TNM-stage, Gleason score of the prostate biopsy, and serum PSA level at the time of diagnosis. We did not subdivide these, to differentiate low-risk versus very-low risk, favourable-intermediate-risk versus unfavourable-intermediate-risk, and high-risk versus very-high-risk (**Table A1**), because data such as prostate volume and percent biopsy core involvement cannot be fully, reliably and accurately captured across this population.

The methods of prostate cancer diagnosis analysis includes only people diagnosed via a transrectal or transperineal biopsy (the most common approaches for prostate cancer diagnosis). For the management of prostate cancer, analysis only includes those that could be categorised into NCCN risk groups and received treatment in the following categories: surgery, radiation therapy (with or without androgen deprivation therapy, ADT), primary ADT (with or without chemotherapy) and observation. People in the observation category have not received treatment within 12-months of prostate cancer diagnosis. Those with 'low risk' disease who were on observation were further stratified into those on active surveillance (AS) and those on watchful waiting (WW). The analysis excludes those who were not assigned to one of the above treatment or management modalities and individuals whose treatment could not be ascertained (i.e. missing or unknown). These exclusion criteria made up 2.9-6.7% of any specific risk category.

PATIENT-REPORTED OUTCOME MEASURES (PROMS)

In PCOR-ANZ, PROMs are captured using the Expanded Prostate Cancer Index Composite (EPIC-26)[20] questionnaire at 12 months after treatment (or 12 months after diagnosis in those on observation). There are also additional questions specific to the use of medications or devices to aid or improve erection that are collected from patients (i.e. these questions are not part of the EPIC-26 domains). PROMs were collected via phone, email, or letters; the range of methods used varies by jurisdiction (**Table S2**). PROMs completion is defined as completion of at least one PROMs question. To report a standardised measurement by jurisdiction and country, we have calculated PROMs completion as the proportion of completed PROMs returned of

total PCOR-ANZ registrants. Depending on locally applied jurisdictional eligibility criteria and deaths, this means a small number of those included in the calculation were not eligible for PROMs. This report includes PROMs questions relating to the extent of moderate-to-big bother in sexual, urinary, and bowel function, urinary leakage and use of urinary pads, bowel control, and the use of medications or devices to aid erections. Data reported on use of devices or medications to improve erections has been collected from the libido questions;[21] patients who answered yes to using any device or medication to improve erectile function, or answered yes to using any specific device/medication were marked as using devices/medications to improve erectile function. Urinary continence, urinary obstruction, sexual, bowel, and hormonal summary scores were calculated using the EPIC-26 scoring instructions. Higher EPIC-26 scores signify better function in each domain.

DATA ANALYSIS OVERVIEW

The diagnosis, management and PROMs data was reported by year of diagnosis, and stratified by jurisdictions, remoteness of residency, and socioeconomic status (SES). While some jurisdictions were combined in previous annual reports (e.g. Victoria and Tasmania), there is now a sufficiently large number of individuals registered in PCOR-ANZ in each jurisdiction, such that data for each jurisdiction is reported separately in this report. For this annual report, the measure of **remoteness** was derived from Australian residential postcodes based on the Modified Monash Model (MMM; accessed 3/1/2024).[22] MMM better reflects access to healthcare, and is frequently used by the government for healthcare policy and funding purposes. MMM measures remoteness and population size on a scale of seven categories (MM1 to MM7): metropolitan areas (MM1), regional centres (MM2), large rural towns (MM3), medium rural towns (MM4), small rural towns (MM5), remote communities (MM6) and very remote communities (MM7).

Estimated population coverage of the PCOR-ANZ dataset is based on the estimated prostate cancer incidence from the Australian Institute of Health and Welfare (AIHW) – Cancer data in Australia – updated (31st August 2023)[23] and the New Zealand Ministry of Health (updated 14 December 2023).[24] The prostate cancer incidence estimation method used by AIHW was changed in 2022 to better predict and reflect the aging nature of Australia's population, and this method will be the only one available from 2022 onwards. As a result, the data included for Australia in this report should not be compared to previous versions of the PCOR-ANZ annual report. For the years of 2020 and 2021, a breakdown by individual Australian state/jurisdiction is not available. The estimated coverage rate for Australia in 2020 and 2021 includes all of Australia (including Western Australia, where PCOR does not operate yet). New Zealand's data for 2020 and 2021 is unaffected. These are only rough estimates and are not suitable for decision making. For some smaller jurisdictions (ACT and NT), the apparent coverage rate will be >100% and reflects people seeking care in jurisdictions other than where they ordinarily reside.

SES was also derived from residential postcodes using the Australian Bureau of Statistics (ABS) Socio-Economic Indexes for Area (SEIFA) Index of Relative Socio-economic Advantage and Disadvantage (IRSAD).[25] This was subdivided into quintiles based on the Australian data, with quintile 1 (SES1) being the most socio-economically disadvantaged and quintile 5 (SES5) being the most socio-economically advantaged. Stratification by remoteness and SES were performed only in people who reside in Australia alone (i.e., excluding people diagnosed in New Zealand), given that these classifications are derived based on Australian data. Data on remoteness and SES for people diagnosed in New Zealand is not freely available for this report. Data on PROMs was stratified by the treatment modalities and age.

Eligibility to be registered in the PCOR-ANZ database is determined by several factors.[19] Patients must be 18 years of age or older at diagnosis and be resident in Australia or New Zealand. PCOR-ANZ operates on an opt-out model, however, there are two waivers of consent: if the patient is already deceased when PCOR-ANZ receives the notification, or if the patient had a transurethral resection of the prostate (TURP) procedure and is unaware that they have prostate cancer. With a waiver of consent, PCOR-ANZ does not require consent to undertake data collection. All other patients must have provided consent or not objected to being included in the database. Patients can completely withdraw from the registry at any time, or opt for data collection only (in which case the patient isn't contacted for PROMs completion). Eligibility for PROMs completion consists of having consented, the ability to understand English, being able (or having assistance available) to complete the survey instrument, being sufficiently well to answer the questions, and being at 12 months following their primary treatment date.

We created violin plots to illustrate the spread of quality-of-life domain function scores in each of the main categories of treatment received: radical prostatectomy, radiation therapy with no associated androgen deprivation, radiation therapy with androgen deprivation, and no immediate radical treatment. Violin plots illustrate the EPIC-26 functional domain scores on a scale from 0-100 (worst to best), and indicate by the width of the plot the number of people with the score. We cannot adjust for baseline score and we recognise the recorded score is likely affected not only by the treatment received, but by the way in which individuals in each treatment group probably had different scores at baseline prior to diagnosis which would also affect the score after treatment.

Note

- The **Data Quality** section provides an overview of the completeness of data for each variable included in this annual report.
- Data in this report describes the overall patterns and trends in diagnosis, management and PROMs. In-depth analysis and specific statistical tests are beyond the scope of this report. It is hoped that this report will stimulate research ideas to examine specific questions and observations in more detail. PCOR-ANZ data is available for interested researchers with research ideas to access under strict data-security protocols.

CHAPTER 1

POPULATION CHARACTERISTICS

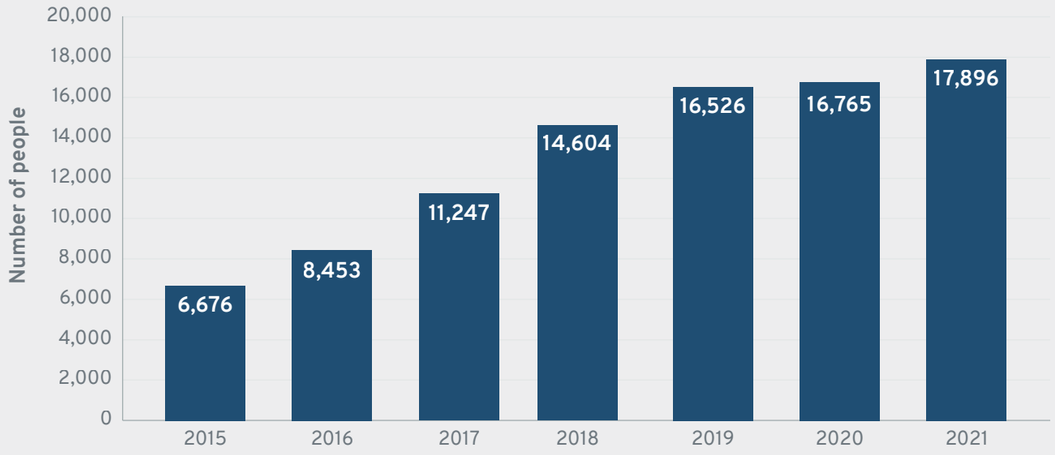
CHARACTERISTICS OF PEOPLE DIAGNOSED WITH PROSTATE CANCER

Since inception in 2015 through to the end of 2021, 92,167 individuals with newly diagnosed prostate cancer from across Australia and New Zealand have been included in the PCOR-ANZ registry, with the numbers recruited increasing across each calendar year (**Figure 1**). The number of people registered in PCOR-ANZ has almost tripled over the seven-year period since PCOR-ANZ has been operating, indicating greater coverage of prostate cancer cases from Australia and New Zealand within PCOR-ANZ over time. The relative plateau in the number of individuals diagnosed in more recent years is likely reflective of limited expansion of the coverage of PCOR-ANZ over the COVID-19 period, rather than a plateau in new prostate cancer cases in Australia and New Zealand.

The median age at prostate cancer diagnosis for the 2021 cohort was 68.7 years (**Table S3**); similar to that of the overall 2015-2021 cohort (68.3 years). Across 2015-2021, the age at diagnosis of people included in PCOR-ANZ has shifted towards older age groups, with those diagnosed at <60 years of age decreasing from 20% in 2015 (1,334/6,676) to 17% in 2021 (3,030/17,896), and those aged ≥75 years increasing from 19% in 2015 (1,265/6,676) to 23% in 2021 (4,166/17,896) (**Figure 2**).

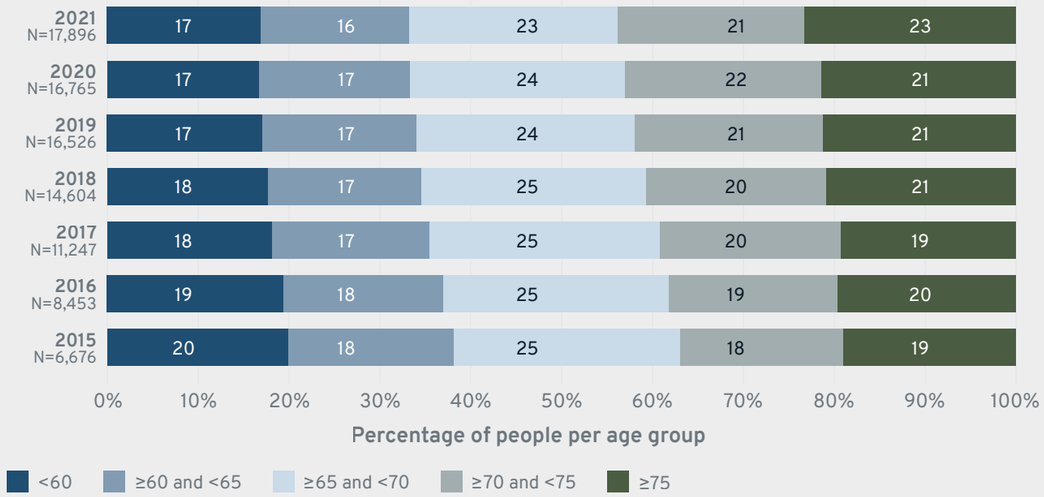
Based on the MMM remoteness classification, the majority of Australians in PCOR-ANZ (62% in 2021 [9,008/14,470]) reside in metropolitan regions (MM1), with good access to health services (**Figure 3**). There was a slight increase in the proportion of people from rural and remote areas over time, which is likely due to increasing coverage of participating institutions since the inception of PCOR-ANZ, leading to better representation of people outside metropolitan areas and larger regional centres. Approximately 30% of Australians registered in PCOR-ANZ are classified as being in the most socio-economically advantaged group (SES 5), and this has been relatively stable over time (**Figure 4**). The higher proportion of prostate cancer diagnosis in Australians in the highest socioeconomic quintile is likely driven by greater uptake of PSA testing in this group.[26] Data on remoteness and SES for people diagnosed in New Zealand is not available for this analysis.

FIGURE 1: NUMBER OF PEOPLE DIAGNOSED WITH PROSTATE CANCER AND REGISTERED IN PCOR-ANZ PER YEAR



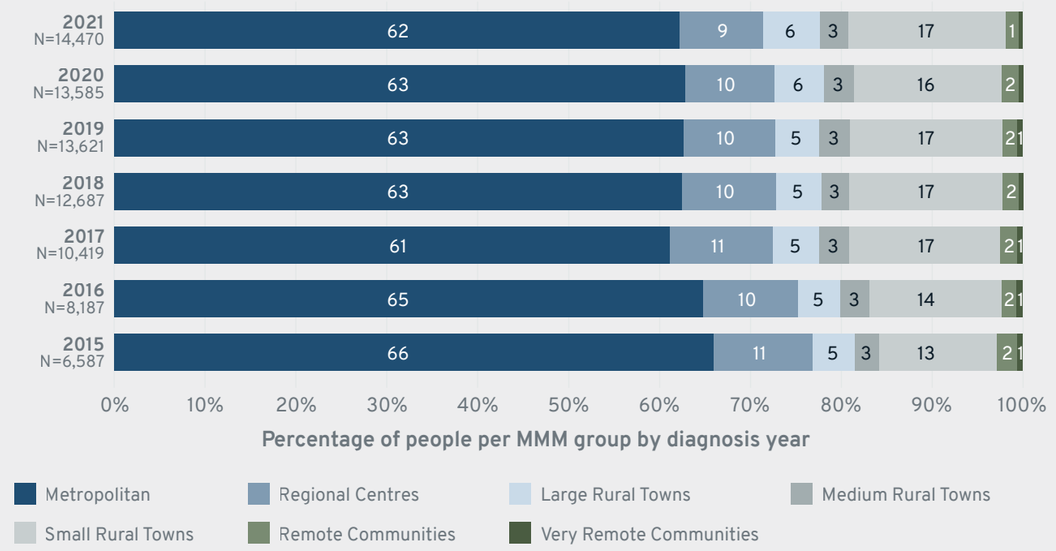
- Diagnosis date data was available for 100% (92,167/92,167) of people in the database.

FIGURE 2: AGE GROUP AT DIAGNOSIS PER YEAR AS A PERCENTAGE OF TOTAL PEOPLE REGISTERED IN EACH YEAR



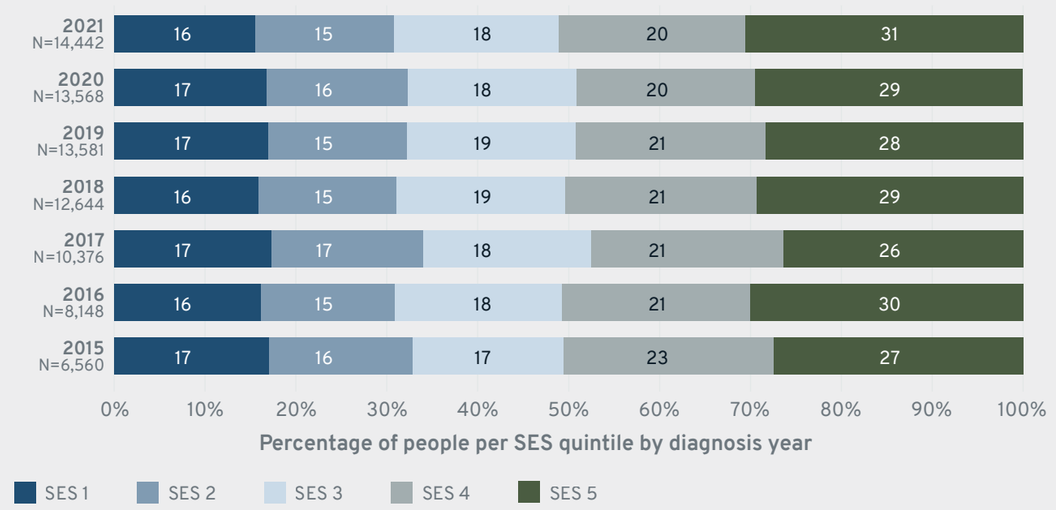
- Proportions per age group at diagnosis are calculated as a percentage of total PCOR-ANZ registrants with available age group data (from all jurisdictions combined) in each diagnosis year.
- Data on age group was available for 100% (92,167/92,167) of people in the database.
- See **Table S3** for information on mean and median age at diagnosis.
- Percentages are rounded and may not add to 100%.

FIGURE 3: MODIFIED MONASH MODEL (MMM) DISTRIBUTION FOR AUSTRALIAN RESIDENTS REGISTERED IN PCOR-ANZ, BY DIAGNOSIS YEAR



- Proportions per MMM group are calculated as a percentage of total PCOR-ANZ registrants with available MMM group data (from all Australian jurisdictions combined) in each diagnosis year.
- Data on MMM group was available for 99.9% (79,556/79,664) of Australians in the database.
- See **Table S3** for more information on the distribution of people per MMM category.
- Percentages are rounded and may not add to 100%; values <1.0% are not annotated.

FIGURE 4: SOCIOECONOMIC STATUS (SES) QUINTILE DISTRIBUTION FOR AUSTRALIAN RESIDENTS REGISTERED IN PCOR-ANZ, BY DIAGNOSIS YEAR



- Proportions per SES group are calculated as a percentage of total PCOR-ANZ registrants with available SES group data (from all Australian jurisdictions combined) in each diagnosis year.
- Data on SES group was available for 99.9% (79,319/79,664) of Australians in the database.
- See **Table S4** for more information on the distribution of people per SES category.
- Percentages are rounded and may not add to 100%.

CHAPTER 2

DIAGNOSIS OF PROSTATE CANCER

NCCN RISK CLASSIFICATION

For the 80,904 people where NCCN risk classification was available, approximately 1-in-5 had low-risk prostate cancer (19%, 15,536/80,904), approaching 1-in-2 had intermediate-risk prostate cancer (44%; 35,806/80,904), 1-in-4 had high-risk prostate cancer (26%, 21,073/80,904), and 1-in-10 had regional or metastatic disease (11%; 8,489/80,904) (**Figure 5**; refer to **Table A1** for NCCN risk group criteria). The data shows important variations in the NCCN risk categories over time. There has been a decrease in the proportion of people with low-risk prostate cancer, from 21% (1,237/5,964) in 2015 to 17% (2,441/14,518) in 2021. This decrease is made up of small increases in other NCCN risk groups (**Figure 6**).

There are variations between jurisdictions in the distribution of NCCN risk groups at diagnosis. Within the PCOR-ANZ dataset, the diagnosis of low-risk prostate cancer is more common in New Zealand than in Australia (**Figure 5**). Within Australia, there are also large variations in the diagnosis of low-risk prostate cancer, ranging from 12% (50/433) in Northern Territory, to 24% (588/2,417) in Tasmania. At the other end of the spectrum, there is also large variation in the diagnosis of metastatic prostate cancer, ranging from 2% (135/5,651) to 5% (994/19,278) in South Australia and New South Wales respectively; to 12% in Northern Territory (50/433). The reasons for these variations are complex, although the most popular method of diagnosis in any given jurisdiction is likely to play a large role. For example, in New Zealand, the lack of mpMRI access prebiopsy in most centres leads to more non-targeted transrectal biopsies, which is responsible for the higher percentage of individuals diagnosed with low-risk disease in this jurisdiction. However, there are substantial differences between the New Zealand and Australian health systems; and substantial differences in the predominant methods of diagnosis and population characteristics between countries, as well as between Australian jurisdictions. Further studies will be required to clarify the key driving factors for these variations in NCCN risk group at diagnosis between PCOR-ANZ jurisdictions.

In Australia, there were socioeconomic differences in the diagnosis of low- or intermediate-risk prostate cancer (**Figure 7**), which ranges from 58% (6,443/11,131) in the most disadvantaged quintile (SES 1) to 66% (13,355/20,145) in the most advantaged quintile (SES 5). There is a correspondingly higher proportion of people from lower socioeconomic groups who were diagnosed with high-risk prostate cancer – 30% (3,346/11,131) in the most disadvantaged quintile (SES 1) and 24% (4,892/20,145) in the most advantaged quintile (SES 5).

METHODS OF PROSTATE BIOPSY

The approach for prostate biopsy has evolved over the past decade. Transperineal biopsy (often referred to as TP biopsy or TPB; whereby the biopsy needle passes through the transperineal skin rather than through the rectal wall) is now the preferred prostate biopsy approach, recommended by international guidelines.[11,13,14] Transperineal biopsy is associated with lower risk of infection and urosepsis compared with transrectal biopsy. Transperineal biopsy also allows access to the anterior part of the prostate, which can be more difficult to access via a transrectal approach (often referred to as TRUS biopsy). However, transperineal biopsy is more resource intensive, and is commonly performed under general anaesthetic, with specialised equipment, which is not universally available.[27]

There were 76,733 people documented to have had biopsy confirmation of prostate cancer via transrectal or transperineal approaches in PCOR-ANZ. Overall, there was an increase in the adoption of transperineal biopsy over time from 28% (1,625/5,828) in 2015 to 73% (9,867/13,555) in 2021 (**Figure 8**). However, there were variations in the rate of adoption of transperineal biopsy across jurisdictions. In 2021, >95% of prostate biopsies in Victoria (96%, 3,535/3,685) and South Australia (97%, 283/292) were transperineal biopsies, and >80% of prostate biopsies in New South Wales (86%, 2,766/3,211), Queensland (83%, 1,945/2,337), and Tasmania (81%, 364/452) were transperineal biopsies (**Figure 9**). The use of transperineal biopsy remains low in certain jurisdictions in 2021, such as Northern Territory (13%, 10/75), ACT (18%, 78/434), and New Zealand (29%, 886/3,069). In Australia, while people who live in remote areas were less likely to have transperineal biopsy compared with those who live in metropolitan areas (MM1), there was a consistent increase in transperineal biopsy over time for people who live across all seven MMM groups (across 2015–2021; **Figure 10**). Similarly, there was an increase in transperineal biopsy across all Australian SES quintiles (**Figure 11**), and in 2021, the proportion of registrants who had a transperineal biopsy ranged from 82% of people in SES 1 (1,243/1,521) to 89% of people in SES 5 (2,893/3,241).

A recent publication based on PCOR-ANZ data has explored what is driving the variations in rates of transperineal and transrectal biopsies.[4] For example, changes to Medicare rebates in 2020 for prostate biopsies now means that biopsy via the transperineal route offers over double the rebate of a transrectal biopsy in Australia. However, resource availability (e.g. mpMRI), clinician familiarity, institution policies, and training are likely reasons for some jurisdictions not adopting transperineal biopsies.

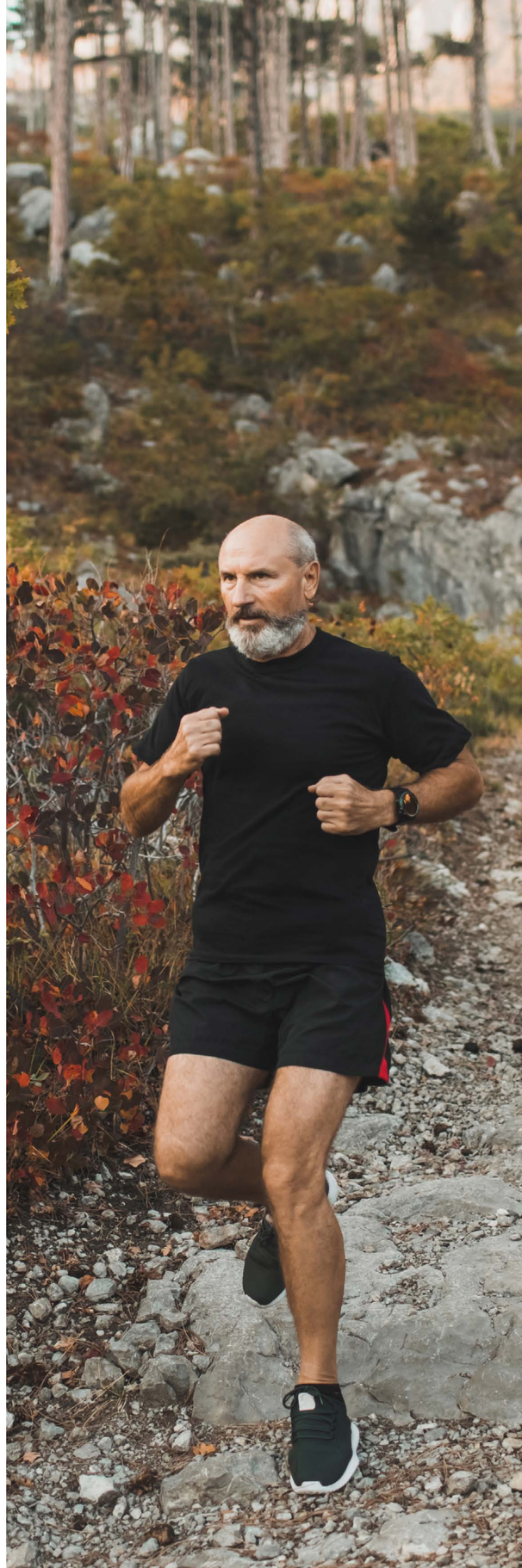
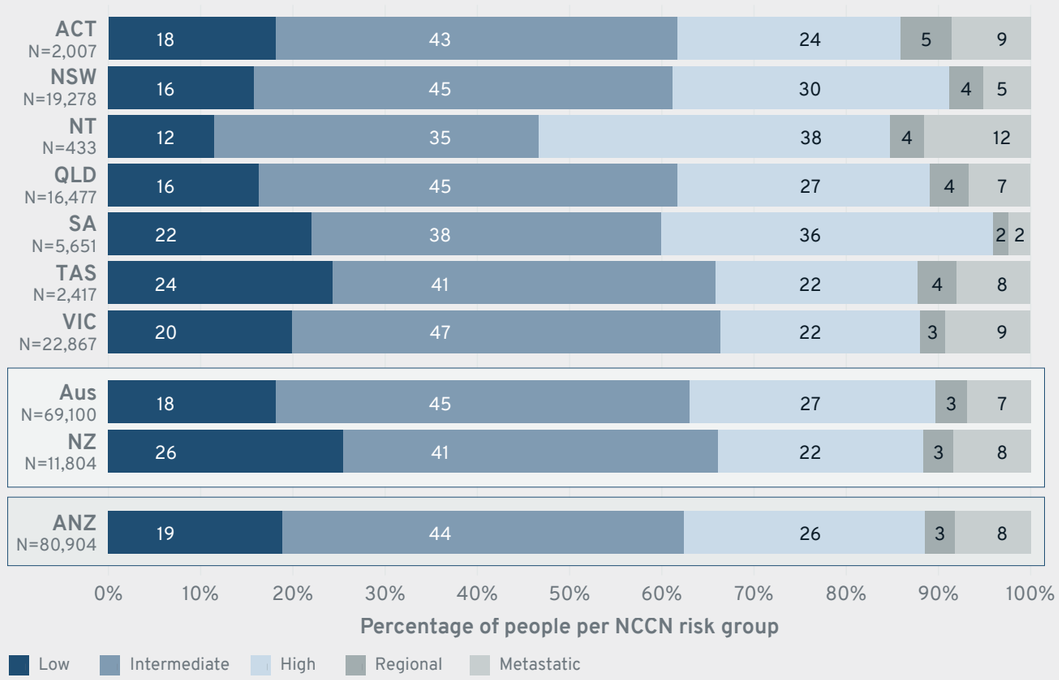
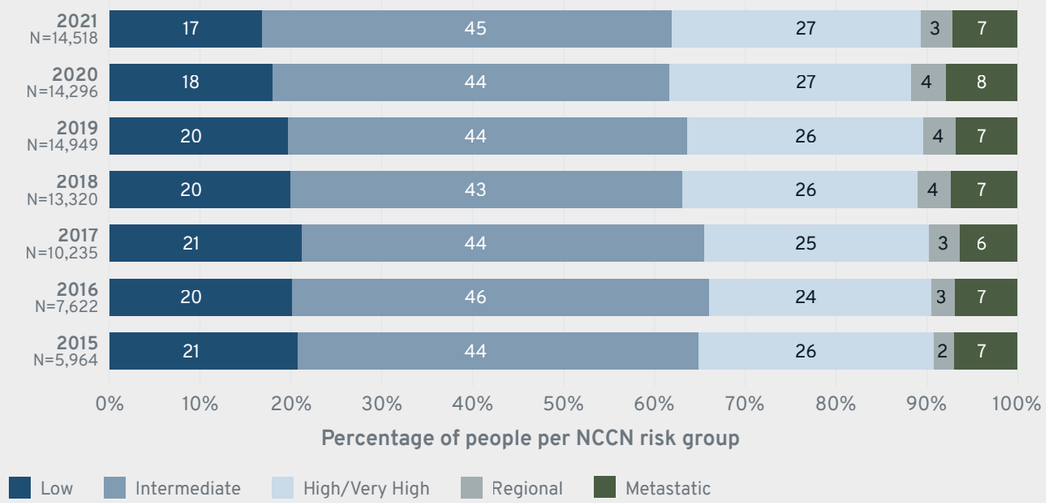


FIGURE 5: PROPORTION OF PEOPLE PER NCCN RISK GROUP AT DIAGNOSIS, BY JURISDICTION OR COUNTRY (2015–2021)



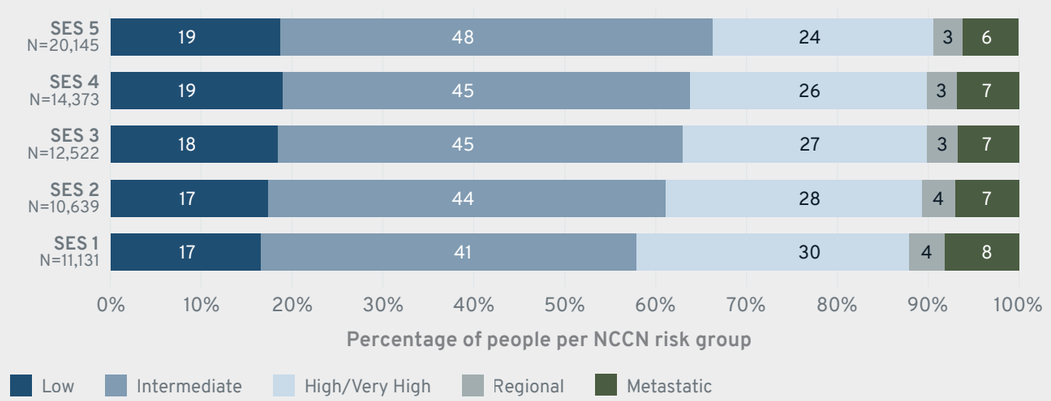
- Proportions per NCCN risk group are calculated as a percentage of total PCOR-ANZ registrants with available NCCN risk group data in each jurisdiction (from all diagnosis years combined).
- Information on NCCN risk group designation was available for 87.8% (80,904/92,167) people in the database.
- Percentages are rounded and may not add to 100%.

FIGURE 6: PROPORTION OF PEOPLE PER NCCN RISK GROUP AT DIAGNOSIS, BY YEAR



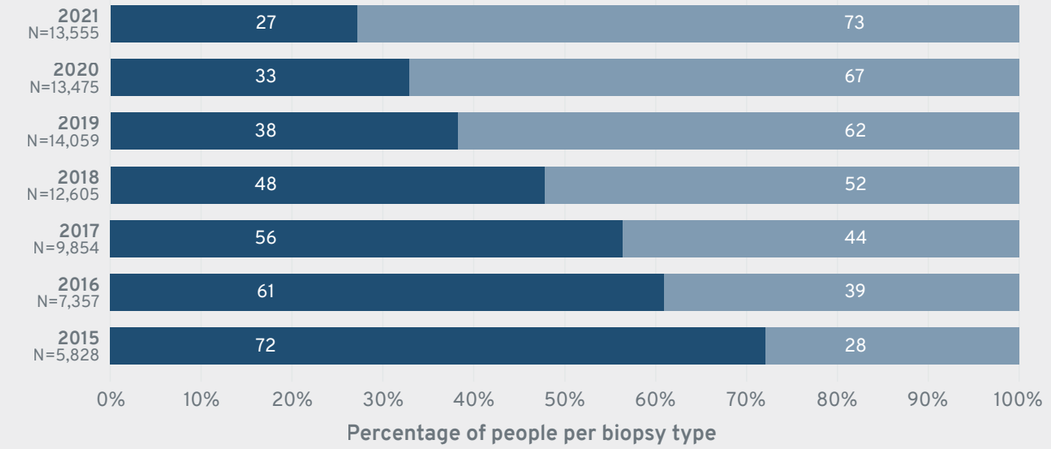
- Proportions per NCCN risk group are calculated as a percentage of total PCOR-ANZ registrants with available NCCN risk group data (from all jurisdictions combined) in each year.
- Information on NCCN risk group designation was available for 87.8% (80,904/92,167) people in the database.
- Percentages are rounded and may not add to 100%.

FIGURE 7: PROPORTION OF PEOPLE PER NCCN RISK GROUP AT DIAGNOSIS, BY SES GROUP



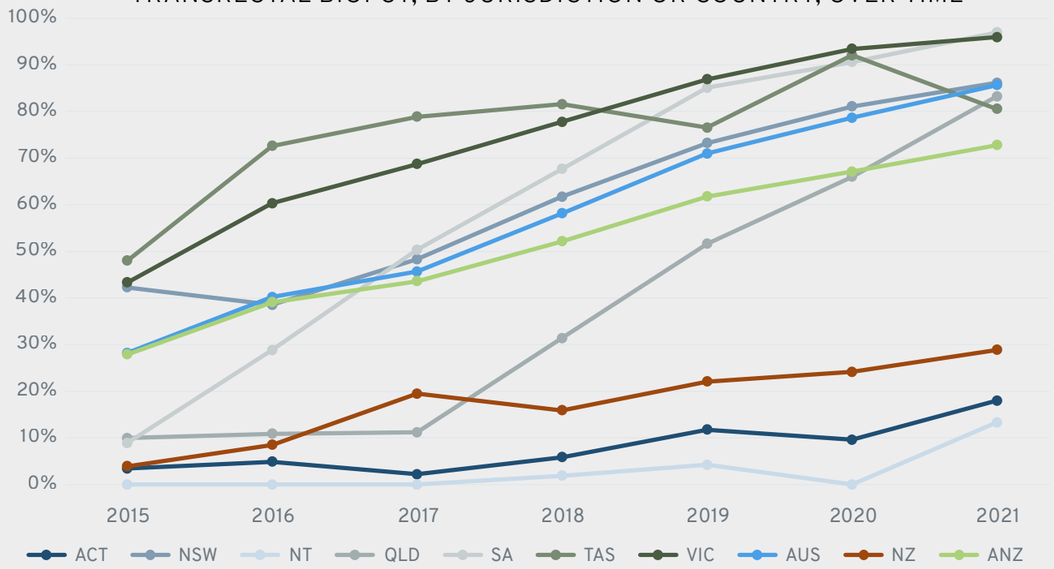
- Proportions per NCCN risk group are calculated as a percentage of total Australian PCOR-ANZ registrants with available SES data and NCCN risk group data (from all Australian jurisdictions combined) in each year.
- Information on SES group was available for 99.6% (79,319/79,664) of Australians registered in the database, of whom NCCN risk group designation was available for 86.8% (68,810/79,319).
- Percentages are rounded and may not add to 100%.

FIGURE 8: PROPORTION OF PEOPLE DIAGNOSED BY TRANSRECTAL VERSUS TRANSPERINEAL BIOPSY, BY YEAR



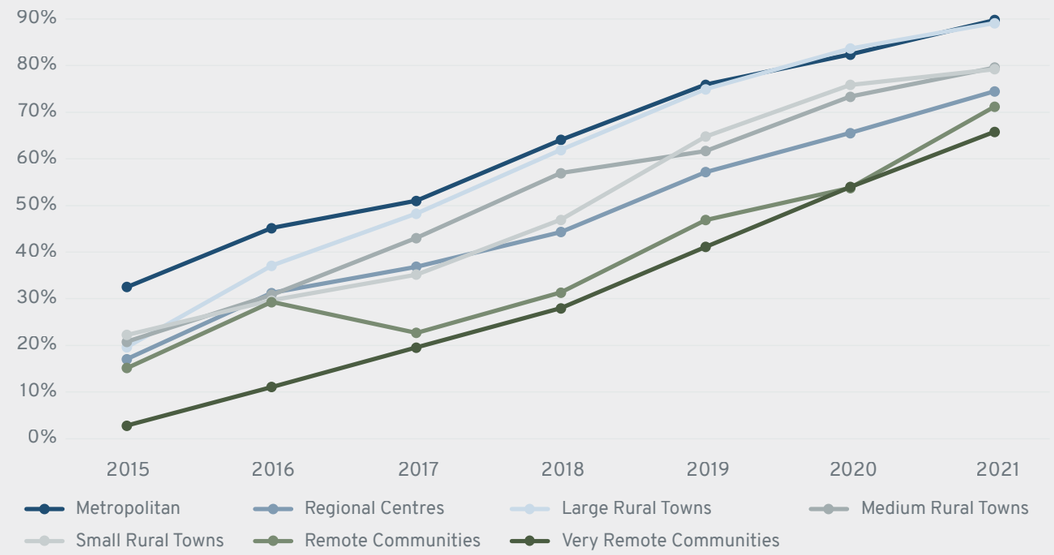
- Proportions per transrectal versus transperineal biopsy are calculated as a percentage of total PCOR-ANZ registrants who were diagnosed by either transrectal or transperineal biopsy (from all jurisdictions combined) in each year. People diagnosed by other methods were not included in this analysis.
- Information on method of diagnosis was available for 97.6% (89,957/92,167) people in the database; of whom 76,733 were diagnosed by either transperineal or transrectal biopsy (83.3% of all registrants).
- Percentages are rounded and may not add to 100%.

FIGURE 9: PROPORTION OF PEOPLE DIAGNOSED BY TRANSPERINEAL VERSUS TRANSRECTAL BIOPSY, BY JURISDICTION OR COUNTRY, OVER TIME



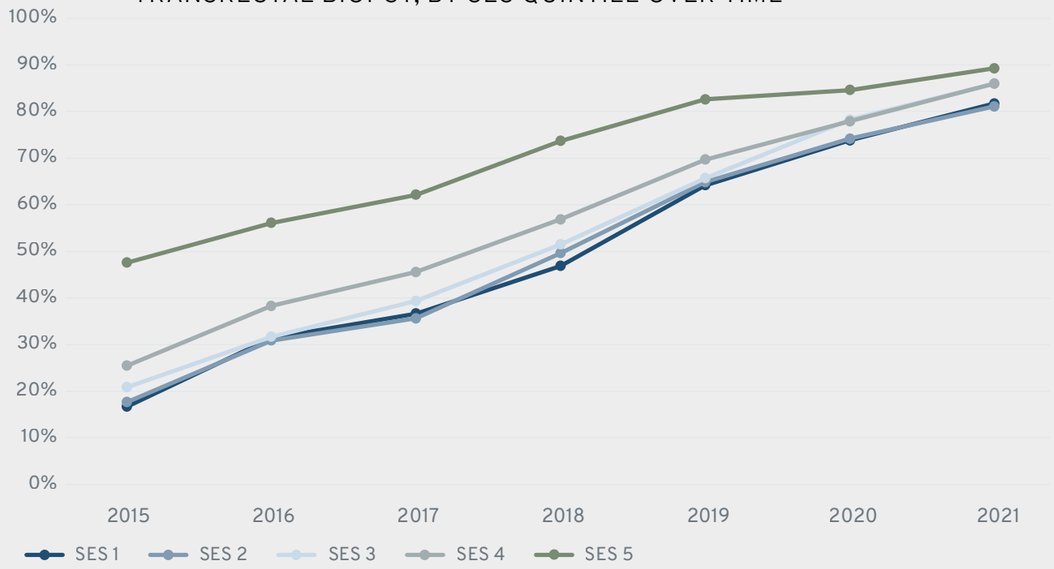
- Percentage of transperineal biopsy per year was calculated as a percentage of PCOR-ANZ registrants in each jurisdiction who were diagnosed by either transrectal or transperineal biopsy. People diagnosed by other methods were not included in this analysis.
- Information on method of diagnosis was available for 97.6% (89,957/92,167) people in the database; of whom 76,733 were diagnosed by either transperineal or transrectal biopsy (83.3% of all registrants).
- Percentages are rounded and may not add to 100%.
- See **Table S6** for more information on diagnosis method per jurisdiction or country.

FIGURE 10: PROPORTION OF PEOPLE DIAGNOSED BY TRANSPERINEAL VERSUS TRANSRECTAL BIOPSY, BY MMM GROUP OVER TIME



- Percentage of transperineal biopsy per year was calculated as a percentage of PCOR-ANZ registrants resident in Australia, in each MMM group who were diagnosed by either transrectal or transperineal biopsy. People diagnosed by other methods were not included in this analysis.
- Transperineal or transrectal biopsy was the reported method of diagnosis for 76,733 people in the database; of whom 65,143 (84.9%) also had MMM group data available (resided in Australia).
- See **Table S7** for more information on diagnosis method per MMM group.

FIGURE 11: PROPORTION OF PEOPLE DIAGNOSED BY TRANSPERINEAL VERSUS TRANSRECTAL BIOPSY, BY SES QUINTILE OVER TIME



- Percentage of transperineal biopsy per year was calculated as a percentage of PCOR-ANZ registrants resident in Australia, in each SES group who were diagnosed by either transrectal or transperineal biopsy. People diagnosed by other methods were not included in this analysis.
- Transperineal or transrectal biopsy was the reported method of diagnosis for 76,733 people in the database; of whom 64,948 (84.6%) also had SES quintile data available (resided in Australia).
- See **Table S8** for more information on diagnosis method per SES quintile.

CHAPTER 3

MANAGEMENT OF PROSTATE CANCER

Following prostate cancer diagnosis, not all people need immediate active treatment.[13-15] In those who require active treatment, the treatment options will also depend on the risk group, age, general health and life expectancy, specific urinary symptoms, the attitude of the patient towards the potential side effects and convenience of the treatment, and the local availability of options in terms of expertise, technology, and cost. There were 84,417 people with data available on the management of their prostate cancer (91.6% of registrants). Of those who received radiation therapy (including brachytherapy), 59% (13,947/23,483) were treated at public institutions and 41% (9,536/23,483) at private institutions. Of individuals who had surgery for prostate cancer, 28% (10,279/36,993) were treated at public institutions and 72% (26,714/36,993) at private institutions.

LOW RISK

In people with low-risk prostate cancer, the current guideline-recommended management is *active surveillance* (AS), which involves monitoring of prostate cancer with PSA testing, digital rectal examination, repeat biopsies, and repeat MRI, with the intention of delaying active treatment (and the associated side effects) until clinically indicated.[13-15] Another approach is *watchful waiting* (WW), especially in older individuals or those with other health concerns such that their prostate cancer is unlikely to cause them problems during their lifetime.

Data from PCOR-ANZ showed an increase in the proportion of people with low-risk prostate cancer managed with AS, increasing from 66% (789/1,202) in 2015 to 80% (1,646/2,070) in 2021 (**Figure 12**). Older people were less likely to be put on AS compared with younger people – 69% (747/1,082) in those aged ≥75 years, compared with 73% (3,281/4,476) in those aged <60 years (**Figure 13**). But 22% (233/1,082) of people aged ≥75 years were put onto WW compared with 0.6% (27/4,476) of people aged <60 years. There were jurisdictional differences in the adoption of AS for low-risk prostate cancer, ranging from 65% (222/343) in ACT to 93% (41/44) in Northern Territory (**Figure 14**). However, the proportions of people per management group are similar across the five Australian SES quintiles in the low-risk population, with the large majority opting for AS (75-77%), and most of the remainder having surgery (16-19%; **Figure 15**).

INTERMEDIATE TO HIGH RISK

Active treatment options for people with intermediate- to high-risk prostate cancer include surgery or radiation therapy (with or without ADT); and there has been relatively little change in the proportions of people observed to have each treatment option for either intermediate- or high-risk disease over time (**Figure 12**). For those with intermediate-risk prostate cancer, approximately 3-in-5 had surgery (61%, 20,676/34,098), and 1-in-5 had radiation therapy (23%, 7,692/34,098). For those with high-risk prostate cancer, around 1-in-2 had surgery (47%, 9,173/19,662), and around 1-in-3 had radiation therapy (37%, 7,257/19,662).

There are large variations across age groups in the proportions of people with both intermediate- and high-risk prostate cancer who had surgery (**Figure 13**). In both NCCN risk groups, around 4-in-5 people who were under 60 years of age had surgery (79% [1,518/1,930] high risk; 82% [5,377/6,565] intermediate risk). But the proportion of people having surgery declined through the age groups to 19% (931/4,887) in intermediate-risk and 14% (900/6,385) in high-risk people aged over 75 years. This is in line with international guidelines, which recommend taking life expectancy into account when offering surgical options.[13,15]

There are also large variations in people with intermediate-risk prostate cancer who had surgery between jurisdictions, ranging from 33% (46/139, NT) to 70% (574/823, ACT; **Figure 14**). Similarly, in people with high-risk prostate cancer, the proportion who had surgery ranged from 27% (40/149, NT) to 56% (263/466, ACT; **Figure 14**).

REGIONAL OR METASTATIC DISEASE

In people who had regional disease (i.e., those who had cancer spread to pelvic lymph nodes, but not beyond), there was an increasing proportion who had a combination of radiation therapy with ADT, from 33% (41/126) in 2015 to 52% (255/493) in 2021. There was a corresponding decrease in the proportion who had surgery, from 25% (32/126) in 2015 to 14% (67/493) in 2021; and an increase in the proportion who had radiation therapy alone (2% in 2015 [3/126] to 11% in 2021 [52/493]; **Figure 12**).

For those with metastatic disease, the proportions of individuals per treatment group have remained relatively stable over time, with a large majority having primary ADT with or without chemotherapy (>60%; **Figure 12**). Although there has been a drop in the proportion of people having surgery (8% in 2015 [31/400] to 2% in 2021 [19/1,011]. This is reflected in a relatively small increase in the proportion of people having radiotherapy (with or without ADT) for metastatic disease (**Figure 12**).

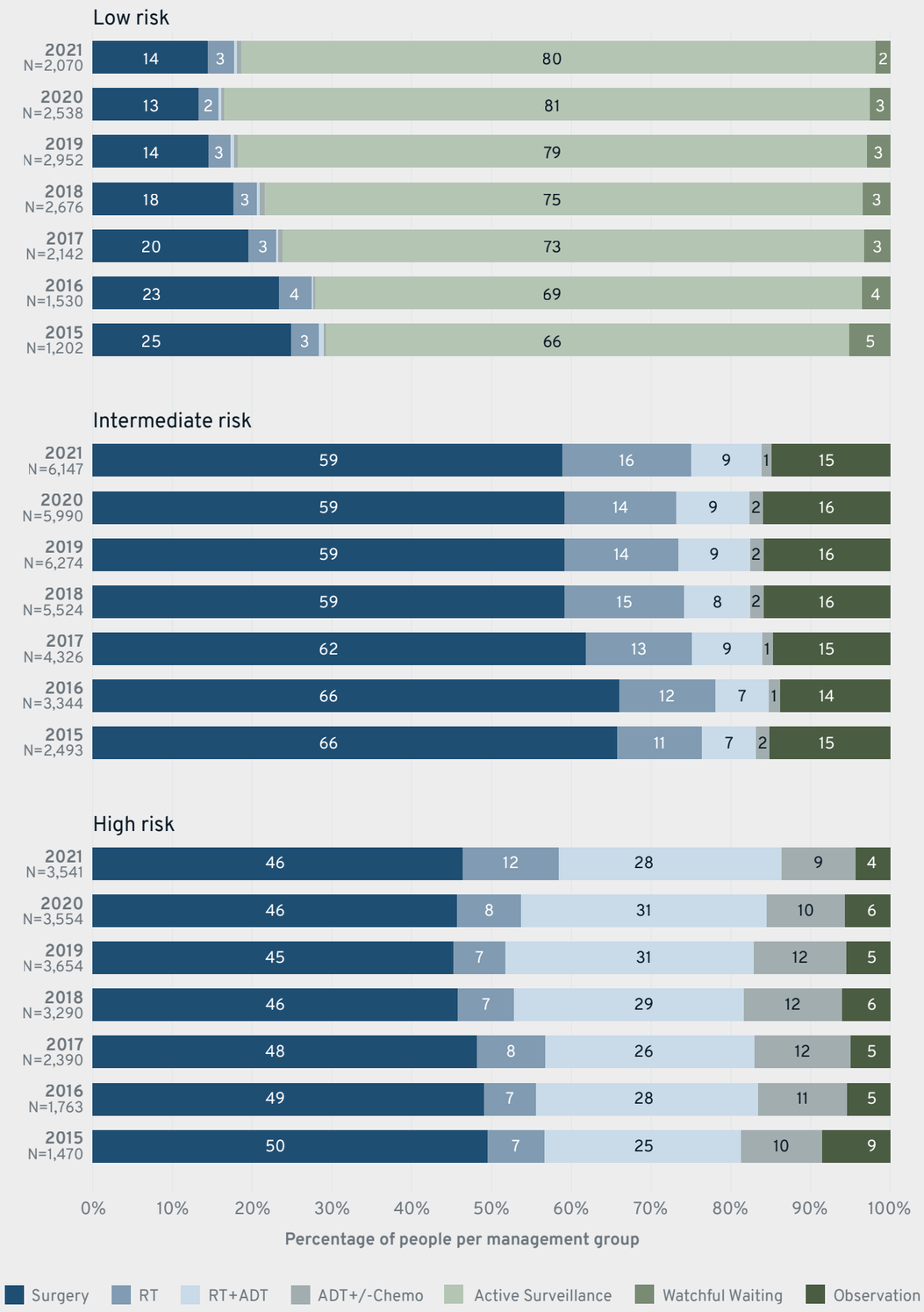
However, examining these same trends in socioeconomic and jurisdictional groups again reveals there are some differences across PCOR-ANZ. Broadly speaking, in both risk groups, people from higher socioeconomic groups were more likely to have surgery (**Figure 15**). Although in people who had metastatic disease, this is a small proportion of the whole (6% [77/1,209] in SES 5 versus 3% in SES 1 [29/874]) compared with regional disease (27% in SES 5 [168/633] versus 15% [65/422] in SES 1). And across jurisdictions, NSW had a comparatively high proportion of people having radiotherapy alone for intermediate-risk disease at 15% (103/685), compared with ≤6% among other jurisdictions. Similarly, in the metastatic group, NSW and SA both reported 8% of people being treated with radiation therapy alone compared with ≤6% among other jurisdictions (NSW 79/960; SA 10/119; **Figure 14**).

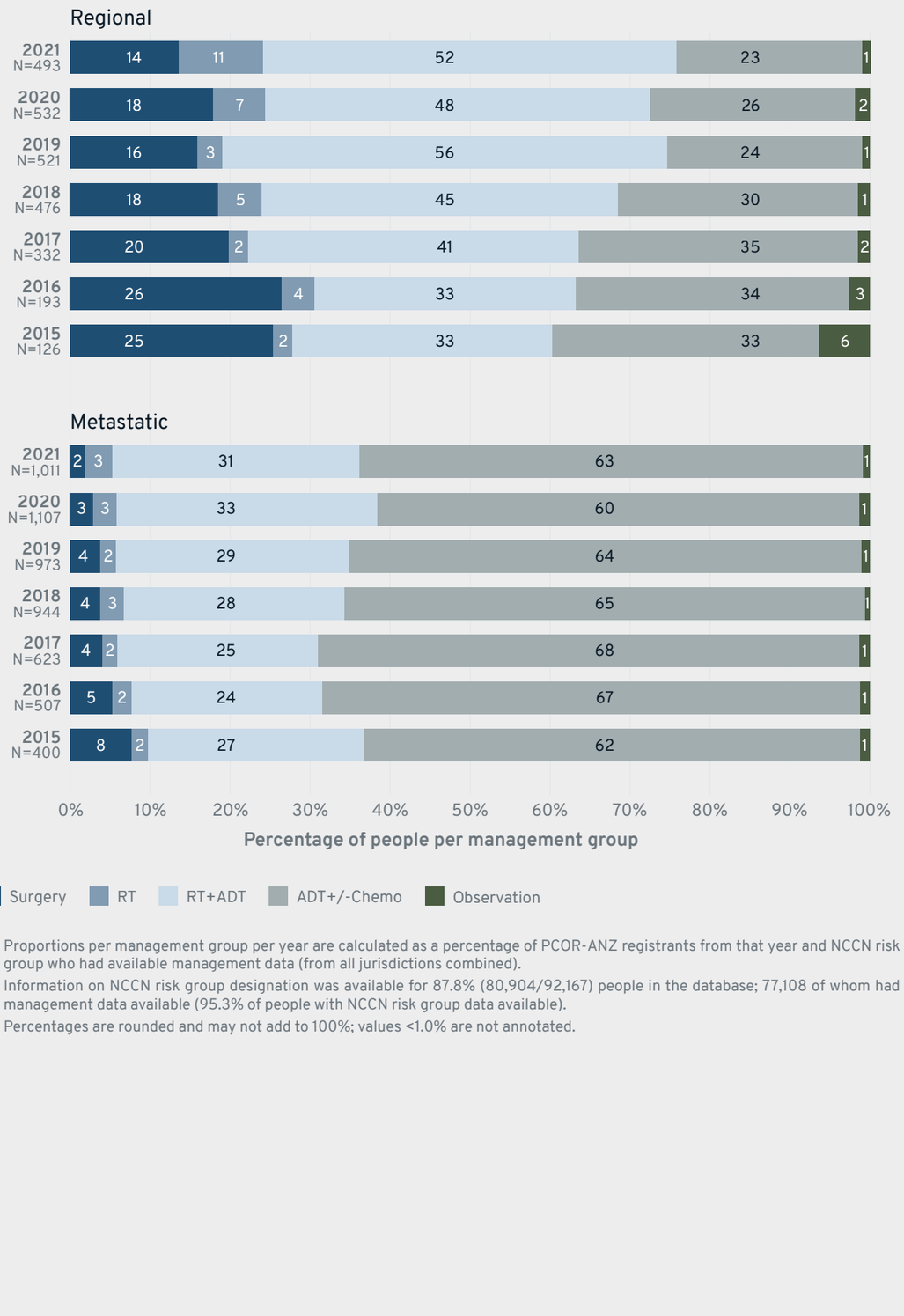
OTHER TRENDS

Overall, data in PCOR-ANZ showed an evolving pattern in the management of prostate cancer over time, which is largely in line with international guideline recommendations.[13-15] For low-risk prostate cancer, there is an increasing proportion of people who were put on observation, whether via AS or WW. We anticipate that the proportion of people with low-risk prostate cancer who are managed initially with AS is likely higher in reality than is reflected in these reported figures, as some people who are initially managed with AS subsequently cross over to have active treatment within the first 12 months of diagnosis. The reporting timelines of the database mean those registrants would be categorised into the active treatment groups (e.g. surgery or radiation therapy) in this current report.

While both surgery and radiation therapy are essentially equivalent in terms of cancer control,[28] there are large variations in the use of surgery compared with radiation therapy, when stratified by jurisdictions and socioeconomic status (**Figures 14 and 15** respectively). This may reflect people's preferences considering the potential side effects of different treatments, as well as ease of access to treatment. While, in the low-risk NCCN group, proportions of people who had surgery was relatively similar across SES quintiles (16–19% across quintiles), in other NCCN risk groups those from higher SES quintiles were consistently more likely to have surgery. This may reflect ease of access to radical prostatectomies in the private setting. Also, among people who had radiation therapy for high-risk prostate cancer, there was a higher proportion of people in NSW and SA, who did not have this in combination with ADT (**Figure 14**). This may reflect either patient preference, or the pattern of practice of the clinicians in those jurisdictions. Future work may be required to better understand these variations in practice.

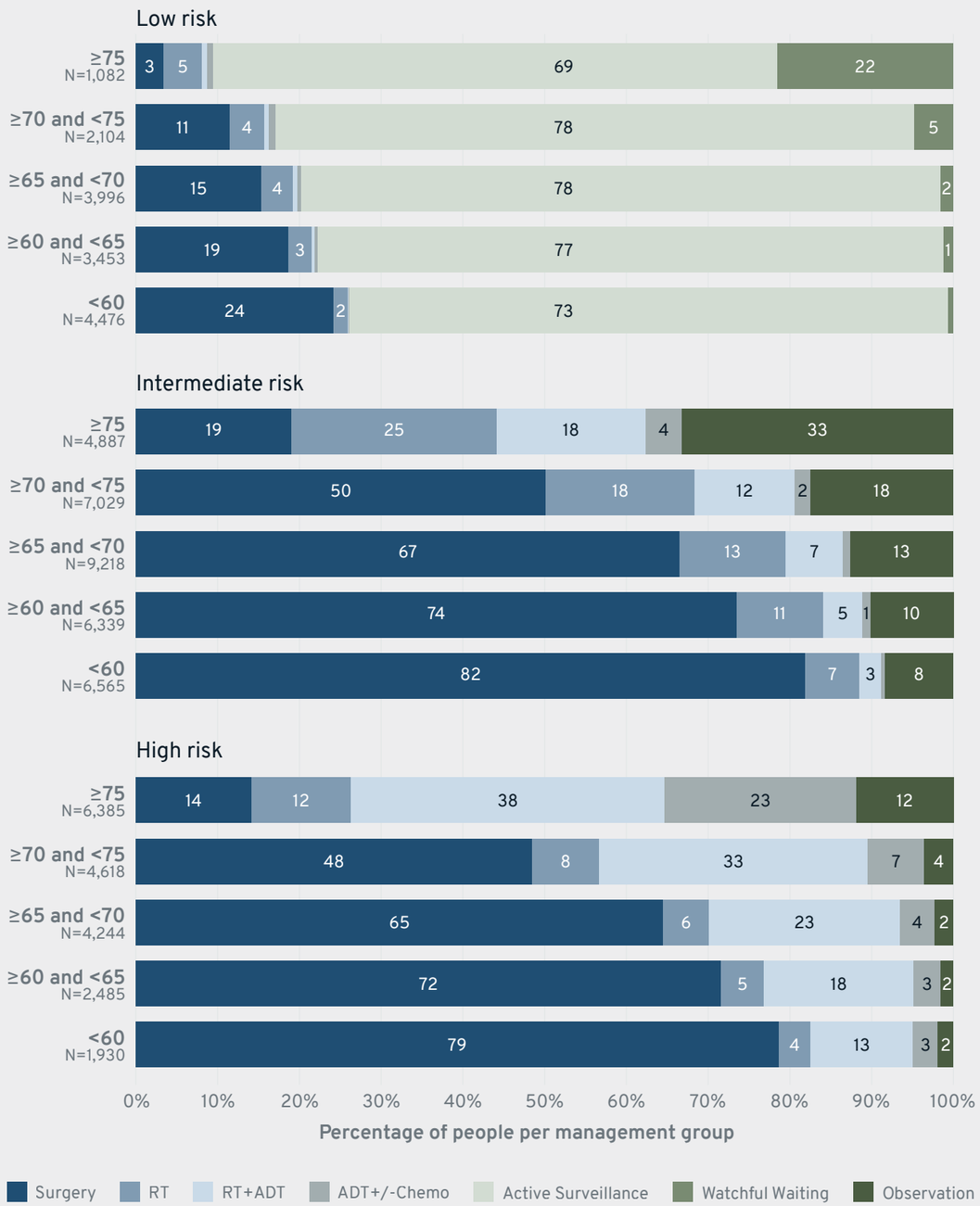
FIGURE 12: INITIAL MANAGEMENT PROVIDED BY NCCN RISK GROUP AND YEAR

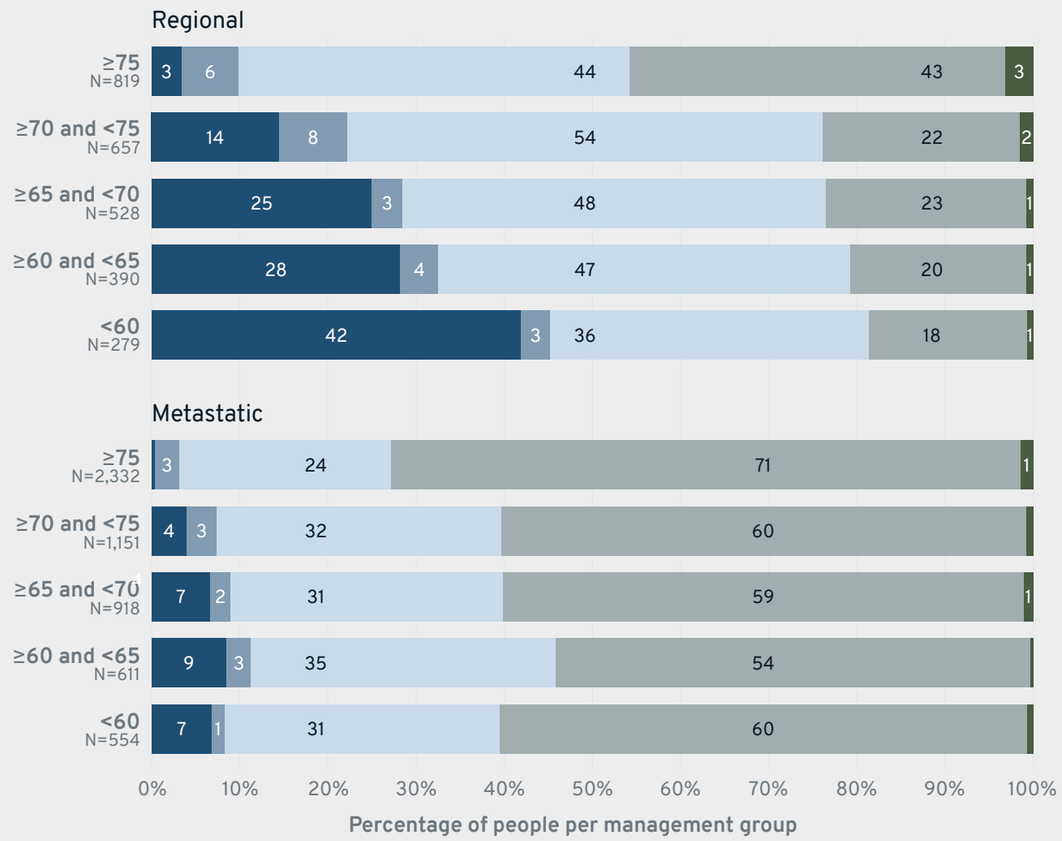




- Proportions per management group per year are calculated as a percentage of PCOR-ANZ registrants from that year and NCCN risk group who had available management data (from all jurisdictions combined).
- Information on NCCN risk group designation was available for 87.8% (80,904/92,167) people in the database; 77,108 of whom had management data available (95.3% of people with NCCN risk group data available).
- Percentages are rounded and may not add to 100%; values <1.0% are not annotated.

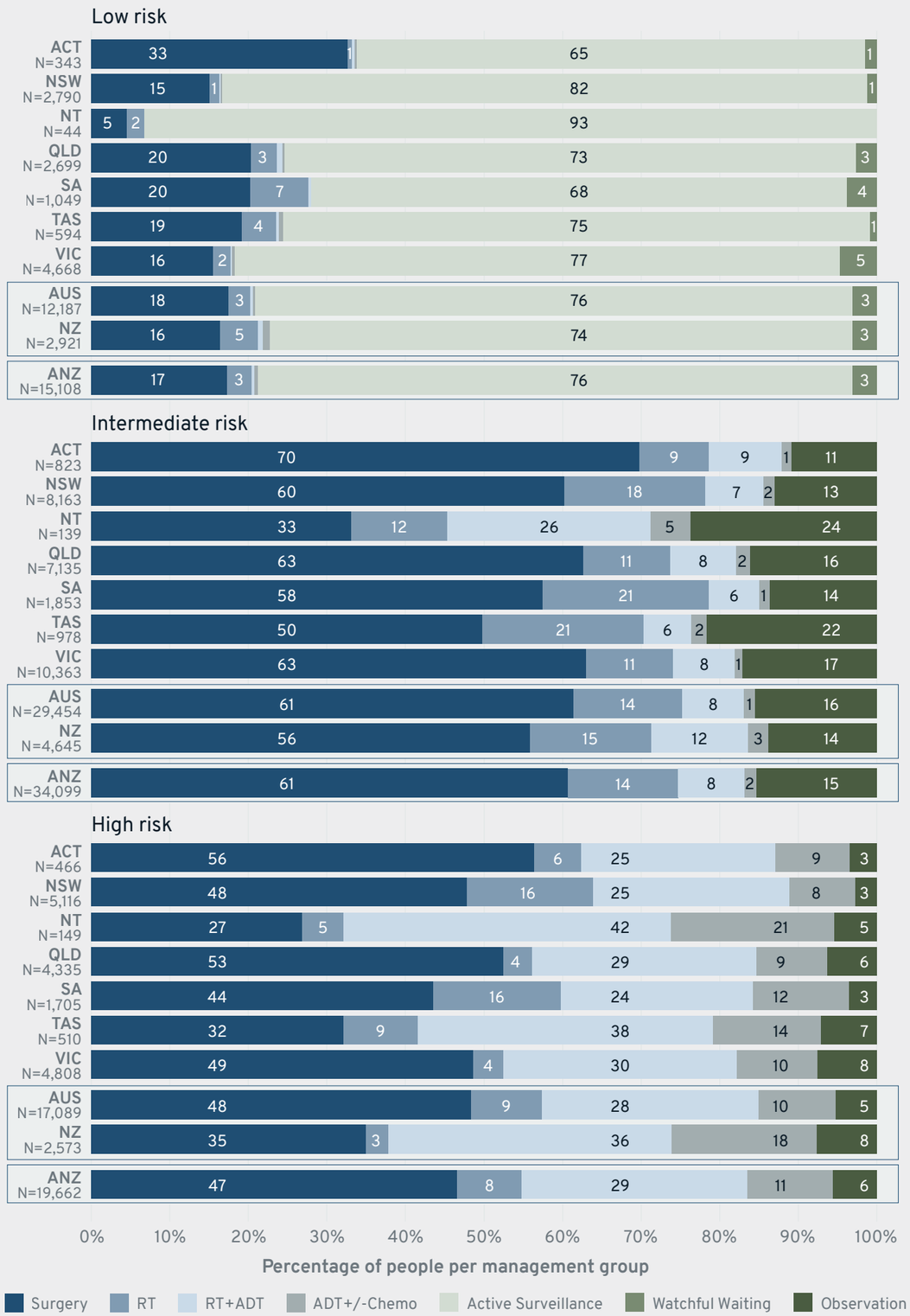
FIGURE 13: INITIAL MANAGEMENT PROVIDED BY NCCN RISK GROUP AND BY AGE GROUP (2015–2021)

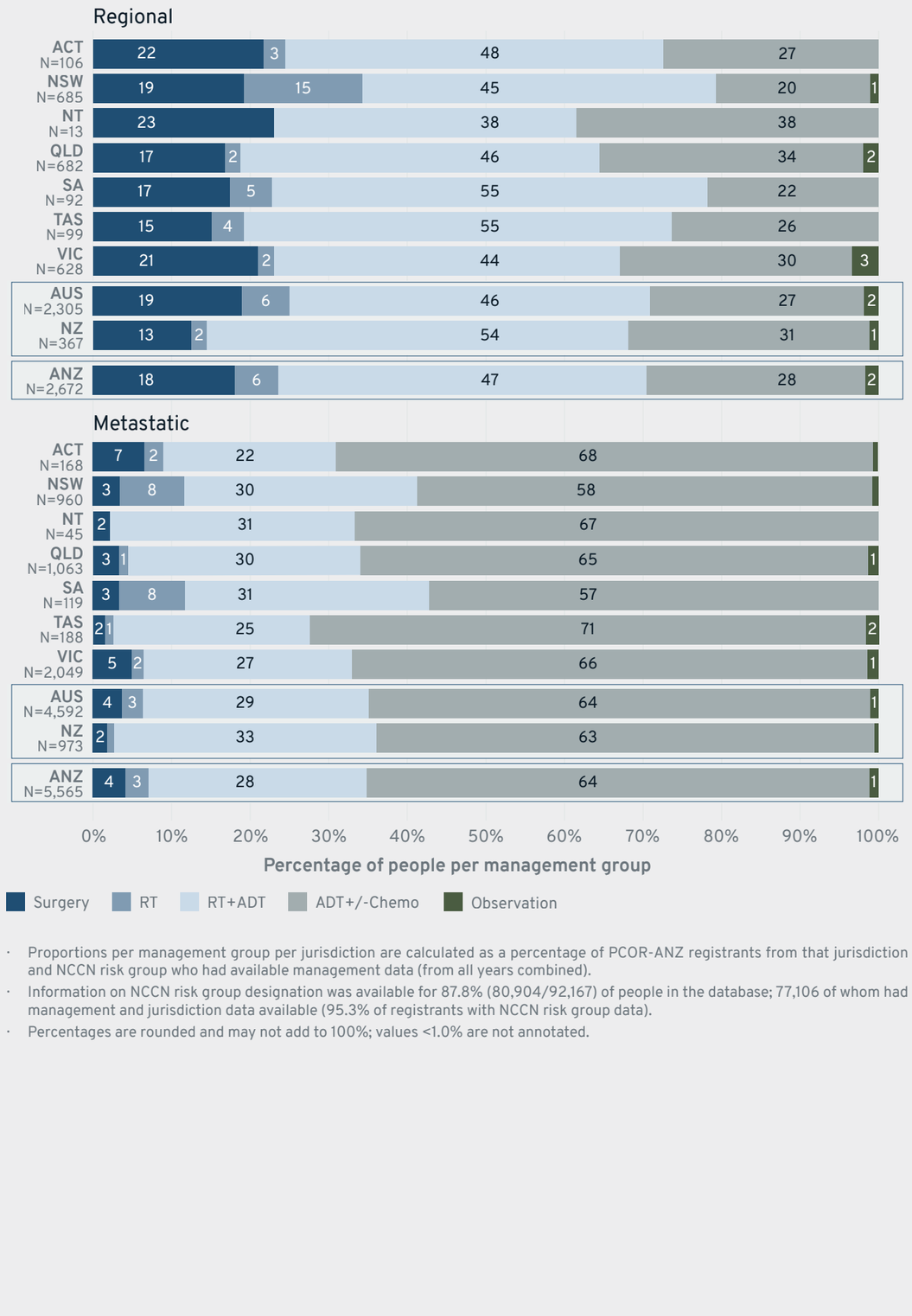




- Proportions per management group per age group are calculated as a percentage of PCOR-ANZ registrants from that age group and NCCN risk group who had available management data (from all jurisdictions combined).
- Information on NCCN risk group designation was available for 87.8% (80,904/92,167) people in the database; 77,110 of whom had age group at diagnosis and management data available (95.3% of people with NCCN risk group data available).
- Percentages are rounded and may not add to 100%; values <1.0% are not annotated.

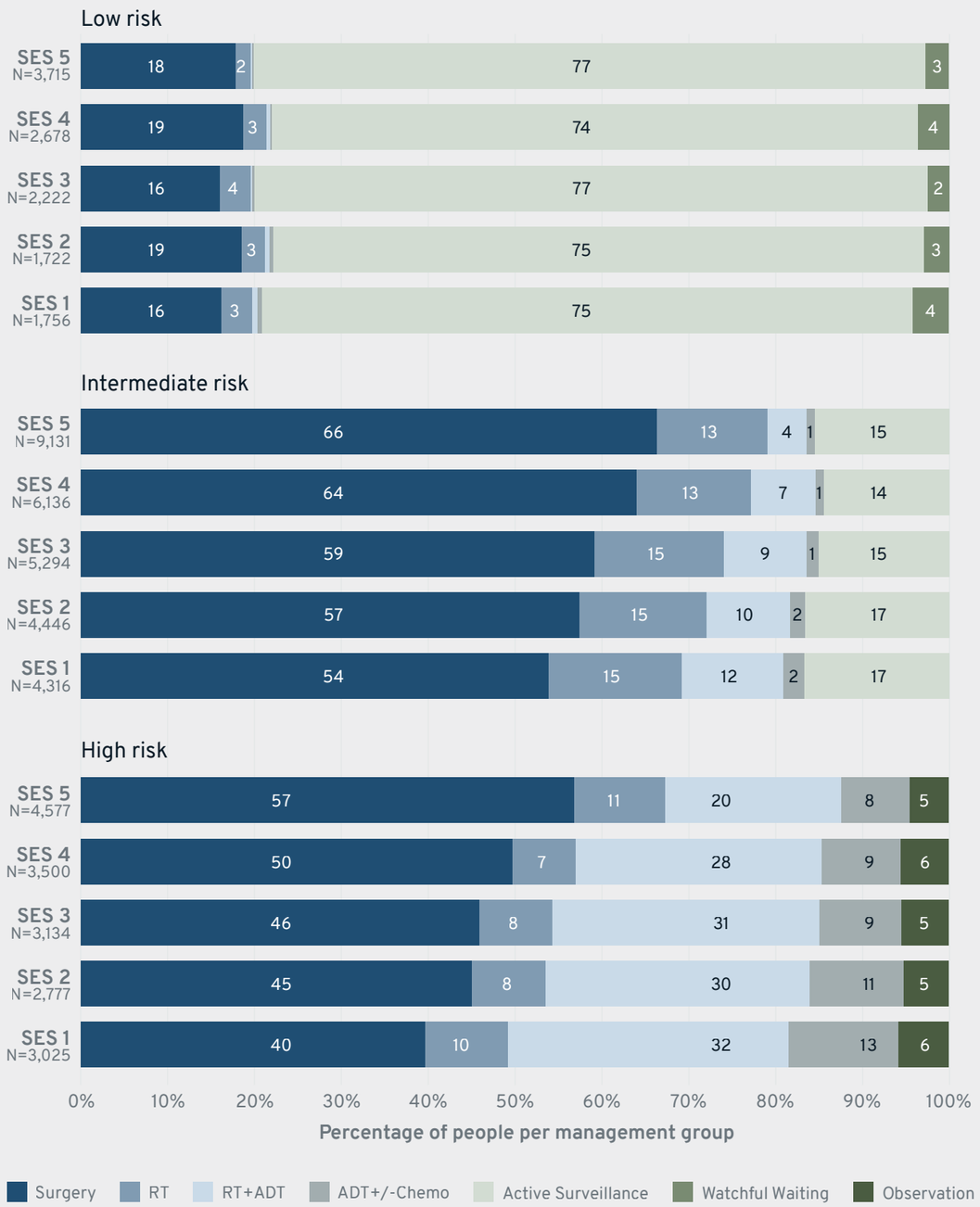
FIGURE 14: INITIAL MANAGEMENT PROVIDED BY NCCN RISK GROUP AND BY JURISDICTION OR COUNTRY (2015–2021)

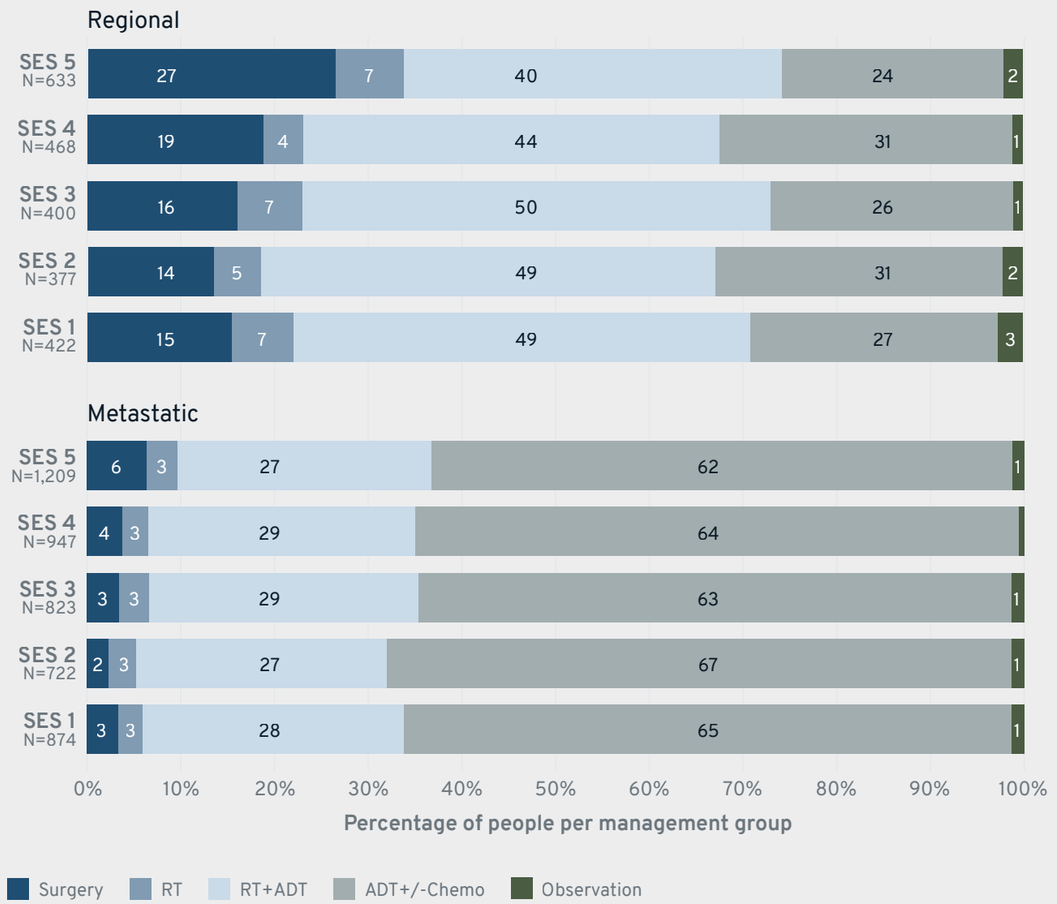




- Proportions per management group per jurisdiction are calculated as a percentage of PCOR-ANZ registrants from that jurisdiction and NCCN risk group who had available management data (from all years combined).
- Information on NCCN risk group designation was available for 87.8% (80,904/92,167) of people in the database; 77,106 of whom had management and jurisdiction data available (95.3% of registrants with NCCN risk group data).
- Percentages are rounded and may not add to 100%; values <1.0% are not annotated.

FIGURE 15: INITIAL MANAGEMENT PROVIDED BY NCCN RISK GROUP AND SES QUINTILE (2015-2021)





- Proportions per management group per SES quintile are calculated as a percentage of PCOR-ANZ registrants from that SES quintile and NCCN risk group who had available management data (from all years combined).
- Information on SES quintile was available for 99.6% of Australian residents (79,319/79,664); 65,354 of whom had both NCCN risk group and management data available (82.4% of Australian residents with SES data).
- Percentages are rounded and may not add to 100%; values <1.0% are not annotated.

CHAPTER 4

PROMS FOR PEOPLE WITH PROSTATE CANCER

Over the seven-year reporting period, our PROMs questionnaires were completed by 50% of people diagnosed with prostate cancer and registered in the database (46,418/92,167, see **Table S2** for more information); or 53% if we consider only those who are eligible to complete questionnaires (46,418/86,913; see Methods for detail on eligibility). However, there were large variations in PROMs completion across different jurisdictions and over time (**see infographic**). The reasons for these variations are likely due to local differences in data-collection methodology, and differences in following up non-returned PROMs questionnaires.

Overall, PROMs completion has been highest in ACT (70%, 1,486/2,124) and Victoria (62%, 15,452/24,974) over the seven-year reporting period. And some jurisdictions have seen a substantial increase in PROMs completion over time:

- Tasmania's PROMs completion rate has changed from 30% in 2015 (88/295) to 71% in 2021 (365/511);
- NT has changed from 14% (17/41) in 2015 to 30% (26/86) in 2021;
- ACT's PROMs completion rate has changed from 8% in 2015 (8/95) to 68% in 2021 (315/460) – although 68% represents a substantial drop since a high of 84% (317/379) in 2019, which could relate to jurisdiction-specific data-collection challenges experienced during the pandemic, but further enquiries would be needed to confirm this.

However, some jurisdictions have experienced an overall decline in PROMs completion rate over time:

- NSW has changed from 48% (403/834) in 2015 to 31% (1,600/5,213) in 2021;
- New Zealand has changed from 85% (66/78) in 2015 to 42% (1,448/3,414) in 2021.

These declines are likely to be related to the logistical challenges experienced when gathering questionnaires on much larger scales as the scope of the database has increased. In New Zealand in particular, this reduction relates to the change from the inclusion of one initial jurisdiction – which had a dedicated local team capturing their regional PROMs – to scaling the PROMs collection process up to the national level.

WHAT PROPORTION OF PEOPLE HAVE BEEN RETURNING PROMS QUESTIONNAIRES?

92,167 PEOPLE REGISTERED IN PCOR-ANZ

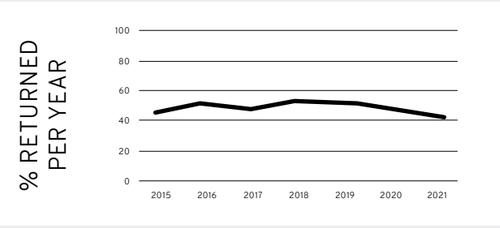
86,913 WERE ELIGIBLE TO COMPLETE PROMS

46,418 PEOPLE RETURNED THEIR PROMS

~50% PROMS COMPLETION OVER TIME

The overall proportion of PCOR-ANZ registrants who return their PROMs questionnaires has remained steady over time

46% OVERALL PROMS COMPLETION IN 2021 (8,189/17,896)



WHAT ABOUT INDIVIDUAL JURISDICTIONS AND COUNTRIES?

SEXUAL DOMAIN AND LIBIDO

Sexual function was commonly reported to be affected following treatment or observation (**Figure 16**), with more than 1-in-3 people (38%, 16,024/42,641) reporting moderate-to-big sexual bother (**Table S12**). When stratified by treatment modalities (**Figure 17**) and age (**Figure 18**), there was a consistently higher proportion of people who had moderate-to-big bother with sexual function after surgery, compared with other treatment modalities. This held true across all age groups. In younger people who had radiation therapy, the addition of ADT was associated with a higher proportion of patients experiencing moderate-to-big bother with their sexual function overall (45% in those <60 years [137/305]; **Figure 18**). In people aged ≥75 years, the proportions who reported moderate-to-big sexual bother were similar between those who had radiation therapy with or without ADT (RT alone 32% [353/1,097]; RT plus ADT 31% [2,305/7,523]). While older people tended to be less likely to report moderate-to-big sexual bother at twelve months after treatment in general, we found that older people who were on observation were more likely to report moderate-to-big sexual bother at twelve months after diagnosis compared with younger people (27% [449/1,671] in those aged ≥75 years versus 18% [327/1,866] in those aged <60 years).

In relation to the specific question about sexual function – which is different to 'bother' with sexual function – 23% (4,878/20,806) of people who had surgery, 35% (1,320/3,816) of people who had radiation therapy, and 59% (5,572/9,443) of people on observation reported fair, good or very good ability to function sexually. However, this was comparatively much lower in people receiving ADT – 10% in those receiving radiation therapy plus ADT (563/5,920) and 6% in those receiving ADT with/without chemotherapy (**Table S12**).

When looking at questions relating to libido across the group as a whole, 34% of people (13,020/38,545) reported to be quite-a-bit or very-much interested in sex, 29% (12,450/43,036) reported the ability to have fair or very-good erections and 57% (24,159/42,555) reported no or very-poor ability to function sexually. There were 38% (14,647/38,746) of respondents who reported the use of medications or devices to aid in their erections. See **Table S12** for more detail per management type.

URINARY DOMAIN

In urinary function, 10% (4,408/44,261) reported moderate-to-big urinary bother. When looking at the urinary domain of the EPIC-26, we found that 14% (6,472/44,454) of people reported leaking urine more than once per day, and 18% (8,159/44,439) reported use of at least one urinary pad per day (**Table S12**). Urinary leakage was most commonly reported in people who had surgery: 20% (4,328/21,323) reported urinary leakage more than once per day, and 31% (6,603/21,303) reported using at least one pad per day. However, overall, only 9% (2,005/21,263) of those who had surgery reported moderate-to-big urinary bother (**Figure 17**). Moderate-to-big urinary bother was most frequently reported by people who had ADT (14%, 388/2,802) across all age groups (**Figure 19**). There was a higher proportion of people who reported moderate-to-big urinary bother out of those having radiation therapy with ADT (12%, 777/6,278), compared with those who had radiation therapy alone (9%, 366/4,015; **Figure 17**). In people who had surgery, there was an increasing proportion who reported moderate-to-big urinary bother with increasing age: 7% (319/4,754) in those aged <60 years and 12% (163/1,305) in those aged ≥75 years. Reported use of at least one urinary pad per day occurred in 31% of people who had surgery (6,603/21,303), 7% of people who had radiation therapy (761/10,378 including RT with/without ADT), and 5% of people who had observation (458/9,949; **Table S12**).

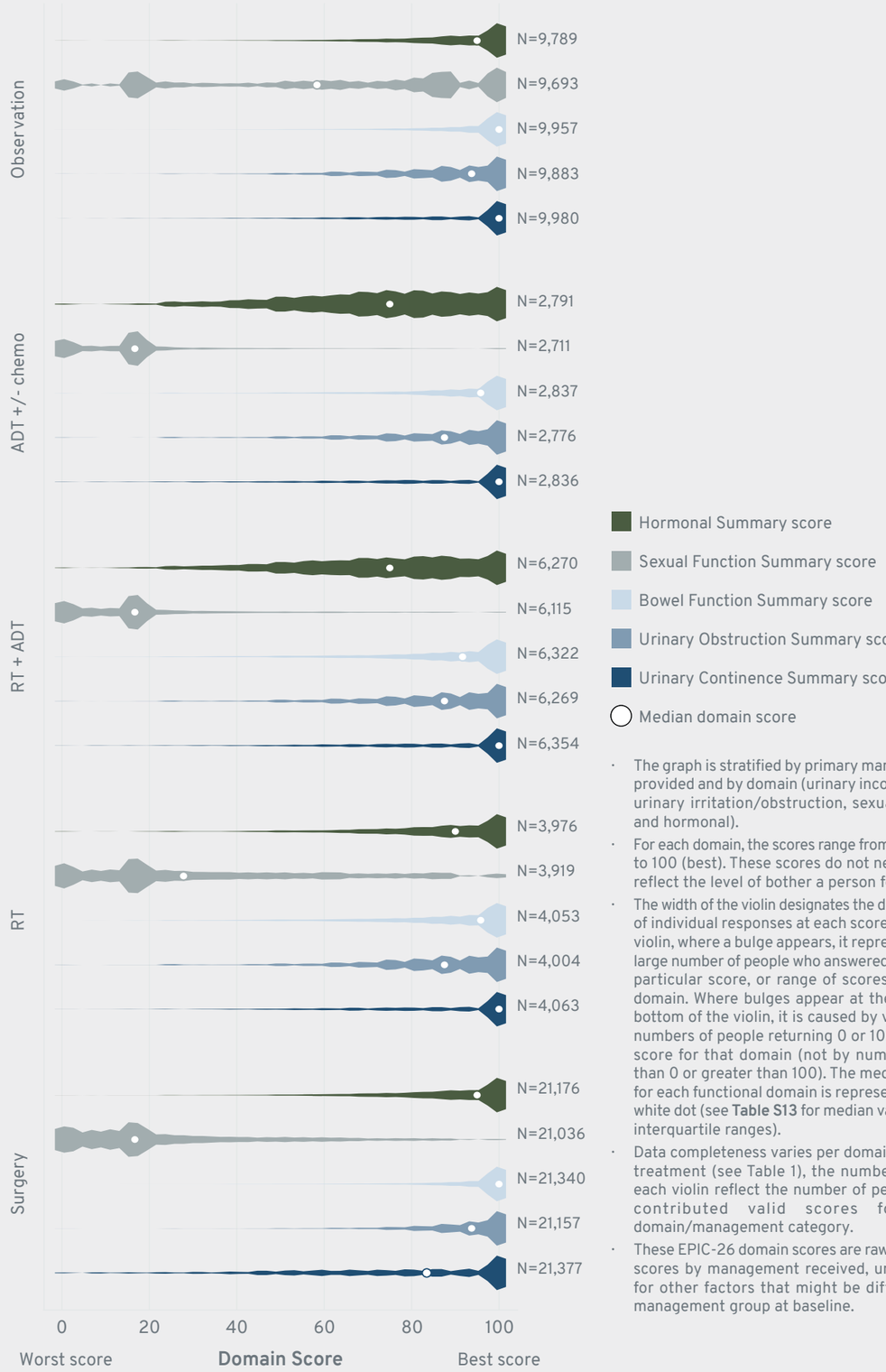
BOWEL DOMAIN

Whilst few people (5%, 2,123/44,296) had moderate-to-big bother in terms of bowel function overall, this outcome was most frequently reported by those who had radiation therapy with ADT (10% [616/6,285]; **Figure 20; Table S12**). Among people who had primary ADT and people on observation, there was a higher proportion who reported moderate-to-big bowel bother with increasing age. When looking at questions on bowel function, 2% (960/43,520) of people reported moderate-to-big problems with losing bowel control overall. Those who had radiation therapy had the highest proportion of moderate-to-big problems with losing bowel control (RT, 4% [160/3,891]; RT with ADT [5%, 330/6,109]; **Table S12**).

HORMONAL DOMAIN

In the hormonal domain (**Table S12**), feelings of depression were reported by 7% (675/9,636) of people on observation. Feelings of depression were more frequent in those treated with regimens containing ADT: radiation with ADT (13%, 800/6,094) and ADT with/without chemotherapy (13%, 361/2,696). Thirteen percent (2,677/21,032) of people treated with surgery reported feeling a lack of energy, comparable with people receiving observation (13%, 1,212/9,714). Feelings of lack of energy were more frequent in ADT regimens: 32% (1,989/6,188) in people treated with radiation therapy and ADT, and 35% (961/2,738) in people receiving ADT with/without chemotherapy.

FIGURE 16: DISTRIBUTION OF RESPONSES TO THE FUNCTIONAL DOMAINS OF THE EPIC-26 PROMS QUESTIONNAIRE BY INITIAL MANAGEMENT PROVIDED (2015-2021)



- The graph is stratified by primary management provided and by domain (urinary incontinence, urinary irritation/obstruction, sexual, bowel, and hormonal).
- For each domain, the scores range from 0 (worst) to 100 (best). These scores do not necessarily reflect the level of bother a person feels.
- The width of the violin designates the distribution of individual responses at each score. On each violin, where a bulge appears, it represents the large number of people who answered with that particular score, or range of scores, for that domain. Where bulges appear at the top and bottom of the violin, it is caused by very large numbers of people returning 0 or 100 as their score for that domain (not by numbers less than 0 or greater than 100). The median value for each functional domain is represented by a white dot (see **Table S13** for median values plus interquartile ranges).
- Data completeness varies per domain and per treatment (see Table 1), the numbers above each violin reflect the number of people who contributed valid scores for that domain/management category.
- These EPIC-26 domain scores are raw reported scores by management received, unadjusted for other factors that might be different by management group at baseline.

FIGURE 17: PATIENT-REPORTED BOTHER 12 MONTHS AFTER INITIAL MANAGEMENT PROVIDED, BY FUNCTIONAL DOMAIN AND TREATMENT TYPE (2015-2021)

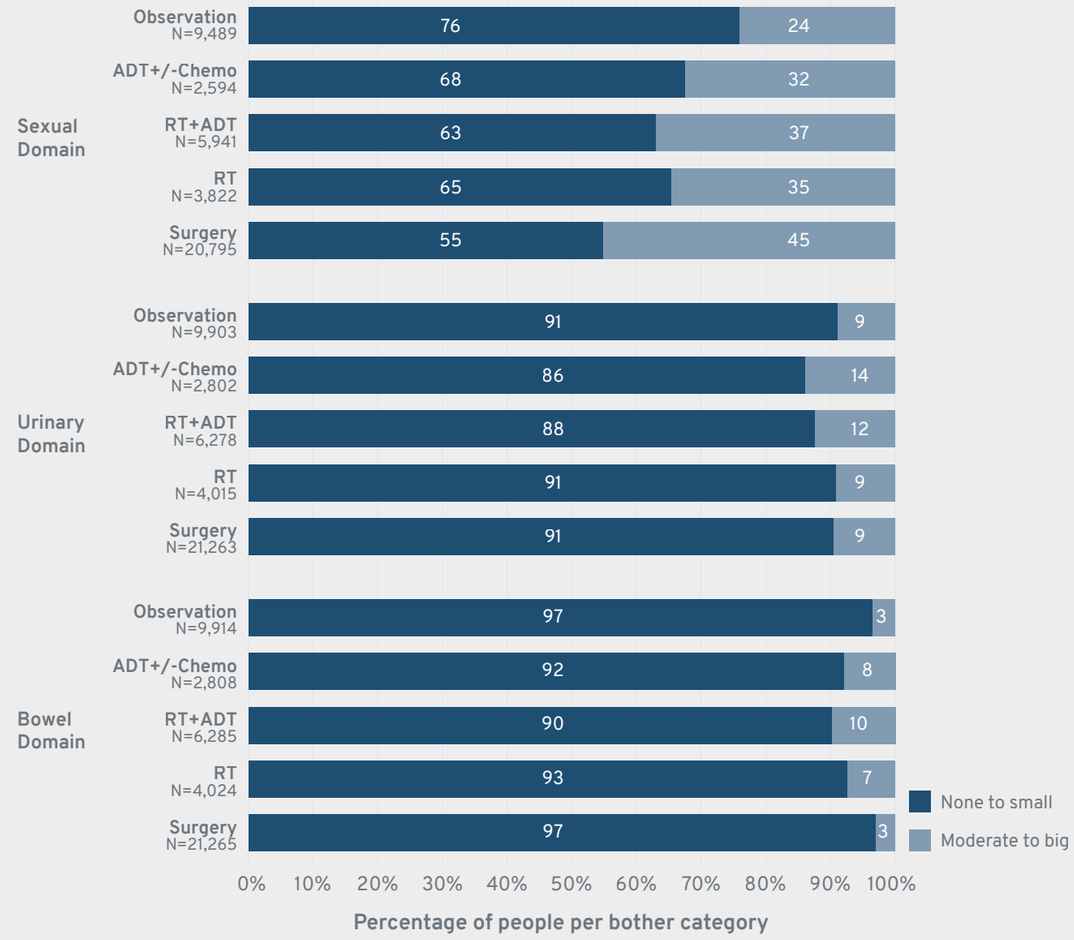
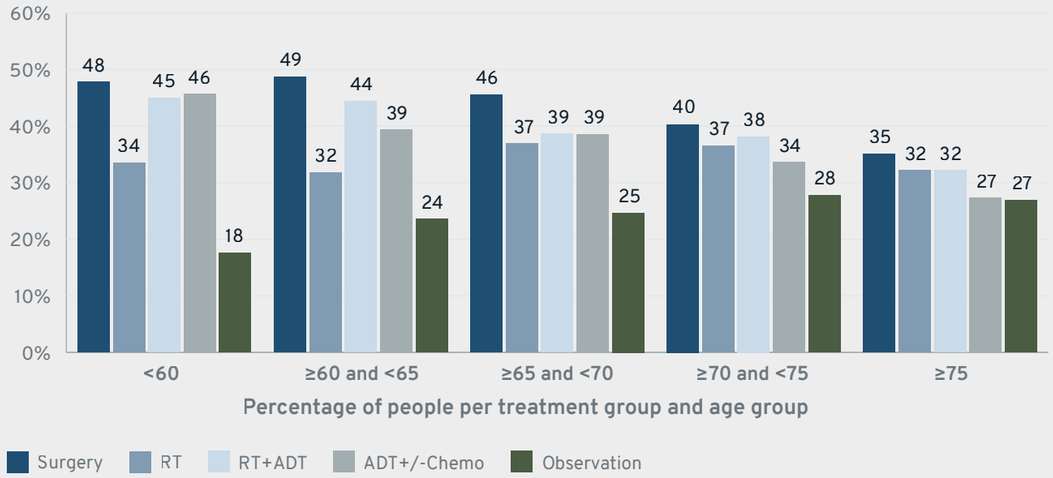
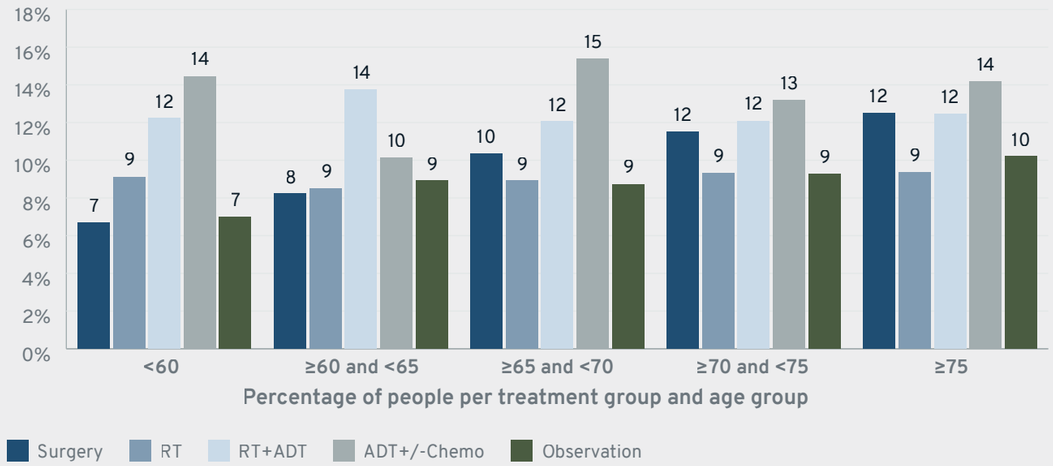


FIGURE 18: PATIENT-REPORTED MODERATE-TO-BIG SEXUAL BOTHER, 12 MONTHS AFTER INITIAL MANAGEMENT PROVIDED, BY MANAGEMENT TYPE AND AGE GROUP



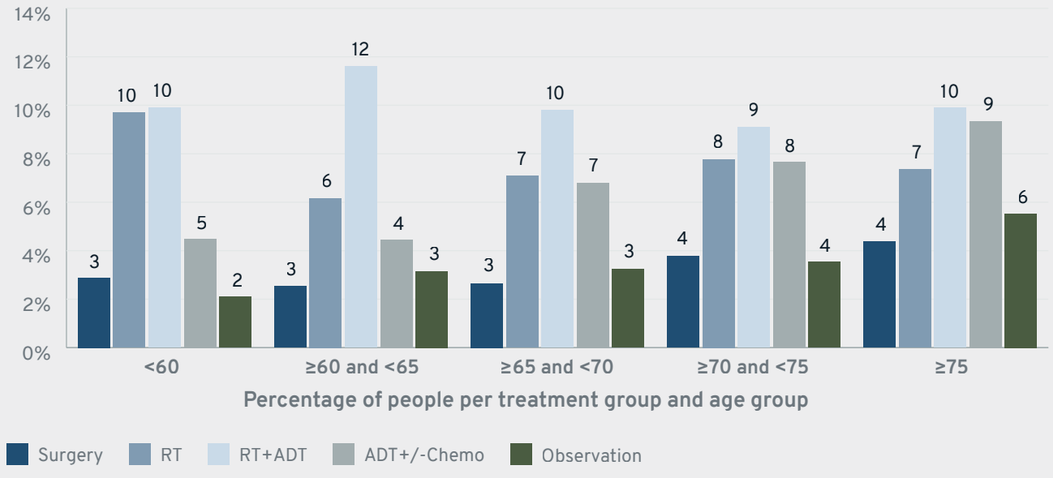
- See **Table S9** for more information on patient-reported moderate-to-big sexual bother.
- Sexual bother questions were completed by 95.0% (44,114/46,418) of people who returned PROMs questionnaires.

FIGURE 19: PATIENT-REPORTED MODERATE-TO-BIG URINARY BOTHER, 12 MONTHS AFTER INITIAL MANAGEMENT PROVIDED, BY MANAGEMENT TYPE AND AGE GROUP



- See **Table S10** for more information on patient-reported moderate-to-big urinary bother.
- Urinary bother questions were completed by 98.9% (45,892/46,418) of people who returned PROMs questionnaires.

FIGURE 20: PATIENT-REPORTED MODERATE-TO-BIG BOWEL BOTHER, 12 MONTHS AFTER INITIAL MANAGEMENT PROVIDED, BY MANAGEMENT TYPE AND AGE GROUP



- See **Table S11** for more information on patient-reported moderate-to-big bowel bother.
- Bowel bother questions were completed by 99.0% (45,940/46,418) of people who returned PROMs questionnaires.

CHAPTER 5

DATA QUALITY

PCOR-ANZ is an expansive registry that can collect a maximum of 993 variables from each registrant. This section reports on the data quality of variables used in this report to better guide interpretation of the data and findings. Data completion for variables included in this report for the 92,167 people in the database is summarised in **Table 1**. Among the 79,664 people diagnosed and registered in PCOR-ANZ in Australia, almost all had valid residential postcodes for derivation of the SES and MMM. The NCCN risk categories were available in 88% of registrants, based on Gleason score (95%), PSA level (87%) and clinical T category (69%). There were 98% people who had a diagnosis method documented, of which 76,733 were documented as either transperineal or transrectal biopsy (83.3% of all registrants). Data relating to the management of prostate cancer was captured for 92% of people registered in PCOR-ANZ (84,417/92,167). There is considerable variation between jurisdictions in data completeness, particularly those surrounding diagnosis and demographics (e.g. country of birth, clinical T category, diagnosis method). These will be target areas for improving the overall data quality and utility of the PCOR-ANZ data set.

In this report we have included data on PROMs returned up to 26th September 2023. Of the 86,913 people who were eligible for PROMs collection at 12 months post diagnosis/treatment between 2015 and 2021, 53.4% returned the PROMs questionnaire (46,418/86,913). This equates to 50% of all registrants within PCOR-ANZ who were included in the 2015-2021 analysis (46,418/92,167). From the returned PROMs questionnaires, data completeness for individual questions ranges from 86% to 99%. It is important to note that PROMs completion is dependent on people receiving timely surveys from jurisdictional registries, and completing (and returning) the surveys (agreeing to participate). Timely PROMs collection is reliant on notification of cancer diagnoses or registrations and treatment data being available, as well as having accurate address details in the case of postal surveys. These factors vary across jurisdictions.

TABLE 1: DATA COMPLETENESS

ANALYSIS PARAMETER	n/d	%
Population characteristics		
Postcode (Aus and NZ)	92,167/92,167	100
Date of Birth	92,167/92,167	100
MMM (Derived variable, Aus Only)	79,556/79,664	99.9
SES (Derived variable, Aus Only)	79,319/79,664	99.6
Diagnosis		
Date of diagnosis	92,167/92,167	100
Method of diagnosis	89,957/92,167	97.6
NCCN risk group	80,904/92,167	87.8
Gleason score	87,107/92,167	94.5
PSA Level	80,017/92,167	86.8
Clinical T category	63,403/92,167	68.8
Management		
12-month Treatment Summary Score	84,417/92,167	91.6
PROMs		
PROMs returned	46,418/86,913	53.4
Sexual Summary Score	44,990/46,418	96.9
Sexual Bother	44,114/46,418	95.0
Ability to have an erection	44,532/46,418	95.9
Quality of erection	44,284/46,418	95.4
Ability to function sexually	44,034/46,418	94.9
Interest in sex	39,495/46,418	85.1
Urinary Continence Summary Score	44,610/46,418	96.1
Urinary Obstruction Summary Score	44,089/46,418	95.0
Use of medications or devices to aid or improve erections (Derived variable)	39,703/46,418	85.5
Urinary Bother	45,892/46,418	98.9
Leaked Urine	46,075/46,418	99.3
Number of urinary pads used	46,069/46,418	99.2
Bowel Bother	45,940/46,418	99.0
Bowel Summary Score	44,519/46,418	95.9
Losing bowel control	45,101/46,418	97.2
Hormonal Summary Score	44,002/46,418	94.8
Feeling depressed	44,846/46,418	96.6
Lack of energy	45,189/46,418	97.3

n, numerator; d, denominator; MMM, Modified Monash Model; SES, Socioeconomic Status; PROMs, Patient-reported outcome measures; NCCN, National Comprehensive Cancer Network; PSA, Prostate-specific antigen.

CHAPTER 6

DISCUSSION AND FUTURE DIRECTIONS

PCOR-ANZ represents a unique, huge, and rich dataset which can be, and should be, optimally utilized to monitor, benchmark, and improve the quality of prostate cancer care in Australia and New Zealand. The data continues to mature over the nine years since the bi-national establishment of PCOR-ANZ, and there are opportunities and possibilities for more research projects as we collect data over a much longer time span and include many more people within the registry. At the same time, we are also expanding the population coverage of PCOR-ANZ, for example, through the establishment of PCOR-WA.

Within the PCOR Data Coordinating Centre, we are continuing to work on and explore more efficient processes for data capture and data dissemination. During the programmed progressive migration of the PCOR-ANZ database to the new DACIMA platform, there has been inevitable lag and complexities in generating and circulating the quality indicator reports to respective institutions. However, we anticipate that, moving forward, the new platform will allow more efficient and automated quality indicator reporting, which can then be circulated in a more timely manner. The past three years have also been impacted by the COVID-19 pandemic in many ways. A companion report evaluating the impact of COVID-19 on people with prostate cancer will be released in 2024.

In the immediate future, our focus is to utilise the PCOR-ANZ dataset to identify inequity in prostate cancer care, from diagnosis to management and outcomes. The planned companion report that is in the pipeline will also highlight disparities in prostate cancer care. However, we recognize the limitations of some of the data captured in PCOR-ANZ. For example, in the current Annual Report, data on socioeconomic status and remoteness of residency are not available for people who reside in New Zealand. Beyond socioeconomic status and remoteness of residency, it is well-recognized that there are inequities in healthcare in certain populations, such as those from Aboriginal and Torres Straits Islander (ATSI), or culturally and linguistically diverse (CALD) backgrounds. However, these data variables cannot currently be comprehensively and accurately captured anywhere, including in PCOR-ANZ. We recognise the need for future work in this area. In New Zealand, we have a full-time research registrar employed in 2024 to assist with analysis of the public hospital PCOR-NZ data. The main goal is to conduct a review of inequity by ethnicity and geography, and leverage the information generated to advocate for change in the New Zealand healthcare system to reduce inequity.

PCOR-ANZ is unique in the scale of capture of PROMs data from patients after cancer treatment. We are dedicated to improving on our current best-in-class performance, recognising the gaps, and making better use of the data we have. Our key aims are to assist, not only with population-level insights, but also – critically – helping highlight individuals who might stand out as having dire quality-of-life impact where we can. The consistent and complete capture of baseline PROMs, before any treatment or management decision is made, is a tough administrative 'nut to crack' on an Australia- and New Zealand-wide basis; but is important to allow us to better understand the impacts of diagnosis and treatment. We are currently exploring options that will allow us to expand PROMs collection to include a baseline questionnaire, this may require a restructuring of the PCOR-ANZ recruitment process; and piloting of the implementation of this process is being undertaken in selected centres. In addition, given that the current post-treatment PROMs completion rate across PCOR-ANZ was only approximately 50%, a more efficient process for PROMs collection overall is also required.

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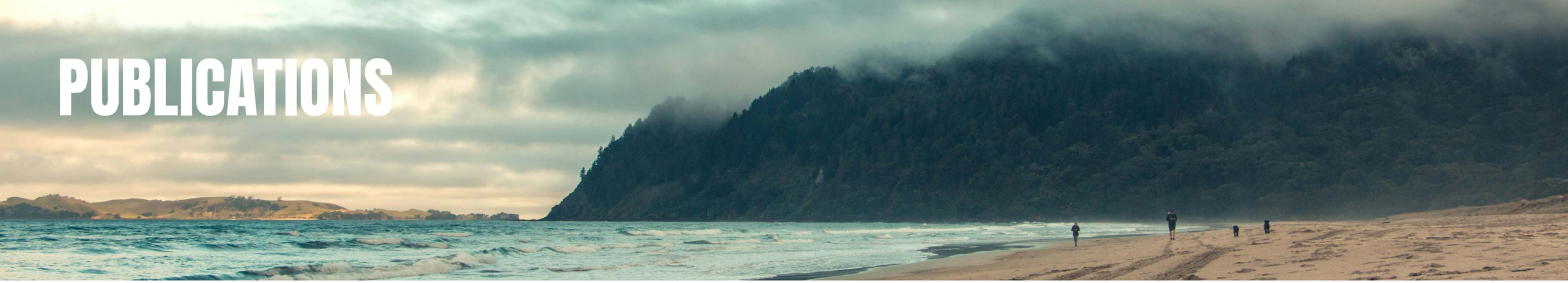

PUBLICATIONS

PCOR-ANZ publications from 2022 and 2023 are listed below. For a historical list of publications please click here

1. 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. doi:10.1186/s41687-022-00426-1
2. Foley GR, Blizzard CL, Stokes B, et al. Urban–rural prostate cancer disparities in a regional state of Australia. Sci Rep. 2022;12(1):3022. doi:10.1038/s41598-022-06958-2
3. Kelly BD, Perera M, Bolton DM, Papa N. Social determinants of health: does socioeconomic status affect access to staging imaging for men with prostate cancer. Prostate Cancer Prostatic Dis. 2023;26(2):429-431. doi:10.1038/s41391-022-00508-7
4. Koo K, Papa N, Evans M, et al. Mapping disadvantage: identifying inequities in functional outcomes for prostate cancer survivors based on geography. BMC Cancer. 2022;22(1):283. doi:10.1186/s12885-022-09389-4
5. Ong WL, Thangasamy I, Murphy D, et al. Large variation in conservative management of low-risk prostate cancer in Australia and New Zealand. BJU International. 2022;130(S1):17-19. doi:10.1111/bju.15698
6. Gondoputro W, Thompson J, Evans M, et al. How does age affect urinary continence following robot-assisted radical prostatectomy? A prospective multi-institutional study using independently collected, validated questionnaires. J Urology. 2022;207(5):1048-1056. doi:10.1097/JU.0000000000002391
7. Rechtman M, Forbes A, Millar JL, 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. doi:10.1186/s12894-022-00966-0
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11. Papa N, Perera M, Bensley JG, et al. A decade of declining prostatectomy margin positivity within a prostate cancer clinical quality registry. Urol Oncol. 2022;40(12):537.e19-537.e24. doi:10.1016/j.urolonc.2022.08.012
12. Chmiel E, Pase M, Evans M, Johnson M, Millar J, Papa N. Development of binational radiation therapy quality indicator reports for prostate cancer treatment using registry data. J Med Imag Rad Onc. 2022;66(8):1097-1105. doi:10.1111/1754-9485.13481
13. Ong WL, Evans M, Papa N, Millar J. Real-world utilisation of brachytherapy boost and patient-reported functional outcomes in men who had external beam radiation therapy for prostate cancer in Australia. Clin Translat Radiat Oncol. 2022;37:19-24. doi:10.1016/j.ctro.2022.08.009
14. Papa N, Roberts MJ, Perera M. The continuing impacts of the COVID-19 pandemic on diagnosis and surgical prostate cancer management: a population-based analysis. ANZ J Surg. 2022;92(5):950-952. doi:10.1111/ans.17646
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28. Tiruye T, Roder D, FitzGerald LM, O'Callaghan M, Moretti K, Beckmann K. Prognostic value of comorbidity measures among Australian men with non-metastatic prostate cancer. Cancer Epidemiol. 2023;87:102482. doi:10.1016/j.canep.2023.102482
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TABLE A1: NCCN RISK GROUP

NCCN risk category*	Low	Intermediate	High	Regional	Metastatic
Gleason score (ISUP Grade Group)	6 (GG1)	7 (GG2-3)	8-10 (GG4-5)	N/A	N/A
PSA level	<10ng/mL	10-20 ng/mL	>20 ng/mL	N/A	N/A
Clinical T Stage	≤cT2a	cT2b/T2c	cT3a/T3b/T4	cT1-4	cT1-4
Clinical N Stage	N0	N0	N0	N1	N1-2
Clinical M Stage	M0	M0	M0	M0	M1

*There is insufficient information (e.g., prostate volume, number or percentage of positive biopsy cores) to differentiate very low risk vs low risk, favourable vs unfavourable intermediate risk, and high vs very high risk. The NCCN risk groups were classified as low risk, intermediate risk, high risk, regional, and metastatic.

TABLE S1: ESTIMATED POPULATION COVERAGE OF PCOR-ANZ BY JURISDICTION (2015-2021)

	ACT	NSW	NT	NZ	QLD	SA	TAS	VIC	WA	Total
PCOR-ANZ 2015	95	834	41	78	1,814	979	295	2,540		6,676
Population diagnosed with prostate cancer in 2015	257	6,616	82	3,163	4,034	1,449	464	4,385	(1,972)	18,478
% population coverage	36.96%	12.61%	50.00%	2.5%	44.97%	67.56%	63.58%	57.92%		36.13%
PCOR-ANZ 2016	218	2,155	82	260	1,519	972	398	2,849		8,453
Population diagnosed with prostate cancer in 2016	259	6,488	85	3,480	3,972	1,370	544	4,800	(1,941)	19,057
% population coverage	84.17%	33.22%	96.47%	7.47%	38.24%	70.95%	73.16%	59.35%		44.36%
PCOR-ANZ 2017	246	2,488	84	811	2,611	1,215	382	3,410		11,247
Population diagnosed with prostate cancer in 2017	267	6,570	88	3,920	4,323	1,641	558	5,190	(2,109)	20,448
% population coverage	92.13%	37.87%	95.45%	20.69%	60.40%	74.04%	68.46%	65.70%		55.00%
PCOR-ANZ 2018	322	3,848	66	1,899	3,147	1,170	356	3,796		14,604
Population diagnosed with prostate cancer in 2018	269	7,023	87	4,249	4,752	1,689	560	5,161	(2,117)	21,673
% population coverage	>100%*	54.79%	75.86%	44.69%	66.22%	69.27%	63.57%	73.55%		67.38%
PCOR-ANZ 2019	379	3,790	97	2,886	3,332	1,410	303	4,329		16,526
Population diagnosed with prostate cancer in 2019	294	6,589	94	4,252	4,837	2,024	562	5,979	(2,300)	22,601
% population coverage	>100%*	55.26%	>100%*	67.87%	68.89%	69.66%	53.91%	72.40%		73.12%

2020	Reported national number†	PCOR-ANZ registrants	Percentage coverage per jurisdiction/country	Overall bi-national population coverage for PCOR-ANZ
New Zealand	4,016	3,155	78.56%	**60.31%**
Australia	23,782	13,610	57.23%	
2021				
New Zealand	4,356	3,414	78.37%	**62.31%**
Australia	24,367	14,482	59.43%	

Estimated population coverage of the PCOR-ANZ data-set is based on the estimated prostate cancer incidence from the AIHW (updated 31st August 2023)[23] and the New Zealand Ministry of Health.[24] The prostate cancer incidence estimation method used by the AIHW was changed in 2022 to better predict and reflect the aging nature of Australia's population, and this method will be the only one available from 2022 onwards. As a result, the data included for Australia in this report should not be compared to previous versions of the PCOR-ANZ annual report. These are only rough estimates and are not suitable for decision making. As of the time of this report, reporting of prostate cancer estimated incidence by individual Australian state/territory was not available for 2020 and 2021. Therefore, for 2020 and 2021, the coverage for is for all of Australia (including Western Australia). The 2020 and 2021 values for New Zealand are correct at the time of writing.

*In smaller jurisdictions (ACT and NT), the apparent coverage rate is >100%, which reflects people seeking care in jurisdictions other than where they ordinarily reside.

†Incidence (NZ) and Predicted/Projection (AUS). The reported number for Australia from the AIHW includes projected numbers for Western Australia within the estimate. However, it should be noted that Western Australia is not yet included as a jurisdiction in the PCOR-ANZ cohort.

TABLE S2: PERCENTAGE OF PROMS COMPLETED BY DIAGNOSIS YEAR, PER JURISDICTION OR COUNTRY

	2015	2016	2017	2018	2019	2020	2021	Total PROMs completion per jurisdiction (2015-2021)
NSW 📞 @ ✉	403/834 48%	1,094/2,155 51%	1,037/2,488 42%	1,806/3,848 47%	1,694/3,790 45%	1,509/4,348 35%	1,600/5,213 31%	9,143/22,676 40%
VIC 📞 @ ✉	1,792/2,540 71%	2,053/2,849 72%	2,364/3,410 69%	2,260/3,796 60%	2,251/4,329 52%	2,146/3,796 57%	2,586/4,254 61%	15,452/24,974 62%
QLD ✉	586/1,814 32%	561/1,519 37%	1,105/2,611 42%	1,701/3,147 54%	1,862/3,332 56%	1,831/3,341 55%	1,298/2,573 50%	8,944/18,337 49%
SA ✉	272/979 28%	273/972 28%	349/1,215 29%	437/1,170 37%	528/1,410 37%	530/1,289 41%	551/1,385 40%	2,940/8,420 35%
TAS 📞 @ ✉	88/295 30%	160/398 40%	91/382 24%	242/356 68%	249/303 82%	271/355 76%	365/511 71%	1,466/2,600 56%
NT 📞 ✉	17/41 41%	23/82 28%	28/84 33%	19/66 29%	37/97 38%	21/77 27%	26/86 30%	171/533 32%
ACT 📞 @ ✉	8/95 8%	88/218 40%	161/246 65%	267/322 83%	317/379 84%	330/404 82%	315/460 68%	1,486/2,124 70%
NZ @ ✉	66/78 85%	192/260 74%	539/811 66%	1,191/1,899 63%	1,752/2,886 61%	1,628/3,155 52%	1,448/3,414 42%	6,816/12,503 55%
AUS	3,166/6,598 48%	4,252/8,193 52%	5,135/10,436 49%	6,732/12,705 53%	6,938/13,640 51%	6,638/13,610 49%	6,741/14,482 47%	39,602/79,664 50%
Total PROMs completion per year (ANZ)	3,232/6,676 48%	4,444/8,453 53%	5,674/11,247 50%	7,923/14,604 54%	8,690/16,526 53%	8,266/16,765 49%	8,189/17,896 46%	46,418/92,167 50% **Overall PROMs completion over time**

Approaches used to collect PROMs: 📞 = phone; @ = e-mail; ✉ = letter.

TABLE S3: AGE AT DIAGNOSIS (CALCULATED)

Year	Mean	95% confidence interval (lower bound - upper bound)	Median	25%	75%	Number of patients per year
2021	68.61	68.48-68.74	68.72	62.73	74.62	17,896
2020	68.41	68.28-68.54	68.56	62.77	74.03	16,765
2019	68.32	68.19-68.45	68.47	62.71	73.98	16,526
2018	68.14	68.00-68.28	68.26	62.45	73.91	14,604
2017	67.81	67.65-67.97	68.04	62.26	73.29	11,247
2016	67.67	67.48-67.86	67.78	61.90	73.41	8,453
2015	67.46	67.25-67.68	67.63	61.69	73.14	6,676

TABLE S4: MODIFIED MONASH MODEL DISTRIBUTION FOR AUSTRALIAN RESIDENTS BY DIAGNOSIS YEAR

	MMM1 - Metropolitan	MMM2 - Regional Centres	MMM3 - Large Rural Towns	MMM4 - Medium Rural Towns	MMM5 - Small Rural Towns	MMM6 - Remote Communities	MMM7 - Very Remote Communities
2015	**4,349/6,587** 66%	**711/6,587** 11%	**313/6,587** 5%	**172/6,587** 3%	**854/6,587** 13%	**150/6,587** 2%	**38/6,587** 1%
2016	**5,310/8,187** 65%	**851/8,187** 10%	**384/8,187** 5%	**265/8,187** 3%	**1,184/8,187** 14%	**137/8,187** 2%	**56/8,187** 1%
2017	**6,369/10,419** 61%	**1,188/10,419** 11%	**528/10,419** 5%	**343/10,419** 3%	**1,727/10,419** 17%	**204/10,419** 2%	**60/10,419** 1%
2018	**7,930/12,687** 63%	**1,310/12,687** 10%	**634/12,687** 5%	**395/12,687** 3%	**2,142/12,687** 17%	**219/12,687** 2%	**57/12,687** 0%
2019	**8,539/13,621** 63%	**1,369/13,621** 10%	**662/13,621** 5%	**465/13,621** 3%	**2,277/13,621** 17%	**227/13,621** 2%	**82/13,621** 1%
2020	**8,541/13,585** 63%	**1,326/13,585** 10%	**755/13,585** 6%	**435/13,585** 3%	**2,221/13,585** 16%	**243/13,585** 2%	**64/13,585** 0%
2021	**9,008/14,470** 62%	**1,330/14,470** 9%	**897/14,470** 6%	**463/14,470** 3%	**2,500/14,470** 17%	**210/14,470** 1%	**62/14,470** 0%

These data relate to the group of Australian residents who are registered in PCOR-ANZ and have MMM data available. Data on remoteness for New Zealand is not freely available from the PCOR-ANZ dataset at this time.

TABLE S5: SOCIOECONOMIC STATUS (SES) QUINTILE DISTRIBUTION FOR AUSTRALIAN RESIDENTS BY DIAGNOSIS YEAR

Year	SES1	SES2	SES3	SES4	SES5
2015	1,119/6,560 17%	1,038/6,560 16%	1,090/6,560 17%	1,516/6,560 23%	1,797/6,560 27%
2016	1,315/8,148 16%	1,207/8,148 15%	1,498/8,148 18%	1,686/8,148 21%	2,442/8,148 30%
2017	1,802/10,376 17%	1,729/10,376 17%	1,913/10,376 18%	2,198/10,376 21%	2,734/10,376 26%
2018	2,015/12,644 16%	1,915/12,644 15%	2,349/12,644 19%	2,660/12,644 21%	3,705/12,644 29%
2019	2,311/13,581 17%	2,065/13,581 15%	2,527/13,581 19%	2,825/13,581 21%	3,853/13,581 28%
2020	2,273/13,568 17%	2,120/13,568 16%	2,509/13,568 18%	2,676/13,568 20%	3,990/13,568 29%
2021	2,241/14,442 16%	2,211/14,442 15%	2,622/14,442 18%	2,955/14,442 20%	4,413/14,442 31%

These data relate to the group of Australian residents who are registered in PCOR-ANZ and have SES data available. SES data is not freely available for NZ at this time.

TABLE S6: PROPORTION OF PEOPLE DIAGNOSED BY TRANSPERINEAL VERSUS TRANSRECTAL BIOPSY, BY JURISDICTION OR COUNTRY, PER YEAR

Year	NSW	VIC	QLD	SA	TAS	NT	ACT	NZ	AUS	ANZ
2015	42% 303/717	43% 962/2,219	10% 156/1,570	9% 78/875	48% 120/250	0% 0/32	3% 3/88	4% 3/77	28% 1,622/5,751	28% 1,625/5,828
2016	39% 706/1,833	60% 1,491/2,472	11% 142/1,304	29% 248/860	73% 257/354	0% 0/70	5% 10/205	8% 22/259	40% 2,854/7,098	39% 2,876/7,357
2017	48% 1,032/2,137	69% 2,034/2,959	11% 249/2,230	50% 556/1,105	79% 265/336	0% 0/76	2% 5/225	19% 153/786	46% 4,141/9,068	44% 4,294/9,854
2018	62% 1,918/3,107	78% 2,525/3,248	31% 867/2,762	68% 710/1,049	82% 252/309	2% 1/53	6% 17/291	16% 284/1,786	58% 6,290/10,819	52% 6,574/12,605
2019	73% 2,072/2,830	87% 3,315/3,816	52% 1,551/3,006	85% 912/1,072	77% 199/260	4% 3/71	12% 41/348	22% 587/2,656	71% 8,093/11,403	62% 8,680/14,059
2020	81% 2,438/3,007	93% 3,080/3,297	66% 1,949/2,954	91% 568/627	92% 278/302	0% 0/65	10% 35/364	24% 691/2,859	79% 8,348/10,616	67% 9,039/13,475
2021	86% 2,766/3,211	96% 3,535/3,685	83% 1,945/2,337	97% 283/292	81% 364/452	13% 10/75	18% 78/434	29% 886/3,069	86% 8,981/10,486	73% 9,867/13,555

These biopsy proportions are derived from the number of transperineal biopsies divided by the pool of transperineal plus transrectal biopsies. Other biopsy methods are not included in these analyses.

TABLE S7: PROPORTION OF PEOPLE DIAGNOSED BY TRANSPERINEAL VERSUS TRANSRECTAL BIOPSY, BY MMM GROUP PER YEAR

Year	MMM1 - Metropolitan	MMM2 - Regional Centres	MMM3 - Large Rural Towns	MMM4 - Medium Rural Towns	MMM5 - Small Rural Towns	MMM6 - Remote Communities	MMM7 - Very Remote Communities	Total
2015	33% 1,250/3,839	17% 110/621	20% 53/269	21% 31/149	22% 157/704	15% 19/125	3% 1/35	28% 1,621/5,742
2016	45% 2,091/4,629	31% 236/754	37% 118/318	31% 71/230	30% 297/1,001	29% 34/116	11% 5/45	40% 2,852/7,093
2017	51% 2,832/5,550	37% 383/1,038	48% 224/464	43% 124/288	35% 523/1,485	23% 40/176	20% 10/51	46% 4,136/9,052
2018	64% 4,367/6,814	44% 504/1,136	62% 319/515	57% 188/330	47% 832/1,772	31% 58/185	28% 14/50	58% 6,282/10,802
2019	76% 5,493/7,233	57% 677/1,184	75% 386/515	62% 229/371	65% 1,178/1,818	47% 92/196	41% 28/68	71% 8,083/11,385
2020	82% 5,461/6,627	66% 742/1,132	84% 457/546	73% 256/349	76% 1,285/1,693	54% 106/197	54% 27/50	79% 8,334/10,594
2021	90% 5,812/6,472	75% 849/1,139	89% 509/571	80% 281/353	79% 1,389/1,753	71% 104/146	66% 27/41	86% 8,971/10,475

These data relate to the group of Australian residents who are registered in PCOR-ANZ and have MMM data available. Data on remoteness for New Zealand is not freely available from the PCOR-ANZ dataset at this time. These biopsy proportions are derived from the number of transperineal biopsies undertaken in the MMM groups divided by the pool of transperineal plus transrectal biopsies undertaken in the MMM groups. Other biopsy methods are not included in these analyses.

TABLE S8: PROPORTION OF PEOPLE DIAGNOSED BY TRANSPERINEAL VERSUS TRANSRECTAL BIOPSY, BY SES QUINTILE PER YEAR

Year	SES 1	SES 2	SES 3	SES 4	SES 5	Total
2015	17% 159/946	18% 158/890	21% 199/950	26% 339/1,325	48% 764/1,604	28% 1,619/5,715
2016	31% 353/1,121	31% 322/1,040	32% 410/1,291	38% 566/1,475	56% 1,198/2,134	40% 2,849/7,061
2017	37% 567/1,544	36% 526/1,472	39% 657/1,666	46% 878/1,923	62% 1,498/2,410	46% 4,126/9,015
2018	47% 782/1,667	50% 804/1,619	52% 1,028/1,995	57% 1,326/2,330	74% 2,327/3,157	58% 6,267/10,768
2019	64% 1,178/1,834	65% 1,122/1,729	66% 1,391/2,116	70% 1,704/2,444	83% 2,670/3,232	71% 8,065/11,355
2020	74% 1,241/1,681	74% 1,228/1,655	78% 1,554/1,986	78% 1,694/2,175	85% 2,608/3,082	79% 8,325/10,579
2021	82% 1,243/1,521	81% 1,259/1,552	86% 1,640/1,907	86% 1,921/2,234	89% 2,893/3,241	86% 8,956/10,455

These data relate to the group of Australian residents who are registered in PCOR-ANZ and have SES data available. SES data is not freely available for NZ at this time. These biopsy proportions are derived from the number of transperineal biopsies undertaken in the SES quintiles divided by the pool of transperineal plus transrectal biopsies undertaken in the SES quintiles. Other biopsy methods are not included in these analyses.

TABLE S9: PATIENT-REPORTED MODERATE-TO-BIG SEXUAL BOTHER, 12 MONTHS AFTER INITIAL MANAGEMENT PROVIDED, BY MANAGEMENT TYPE AND AGE GROUP

	Surgery	RT	RT+ADT	ADT+/- Chemotherapy	Observation	Reported sexual bother* per age group across all treatments
<60	2,253/4,715 48%	99/295 34%	137/305 45%	79/173 46%	327/1,866 18%	2,895/7,354 39%
≥60 and <65	2,229/4,577 49%	150/472 32%	244/549 44%	85/216 39%	423/1,789 24%	3,131/7,603 41%
≥65 and <70	2,858/6,270 46%	350/949 37%	4,552/1,168 39%	147/381 39%	606/2,455 25%	4,413/11,223 39%
≥70 and <75	1,606/3,983 40%	369/1,009 37%	660/1,729 38%	171/509 34%	474/1,708 28%	3,280/8,938 37%
≥75	439/1,250 35%	353/1,097 32%	2,305/7,523 31%	359/1,315 27%	449/1,671 27%	2,305/7,523 31%
Reported sexual bother per treatment type across all age groups*	9,385/20,795 45%	1,321/3,822 35%	2,198/5,941 37%	841/2,594 32%	2,279/9,489 24%	16,024/42,641 38% Overall total sexual bother*

*Bother is defined as those reporting moderate or big bother divided by the total number of people who answered this question.

TABLE S10: PATIENT-REPORTED MODERATE-TO-BIG URINARY BOTHER, 12 MONTHS AFTER INITIAL MANAGEMENT PROVIDED, BY MANAGEMENT TYPE AND AGE GROUP

	Surgery	RT	RT+ADT	ADT+/- Chemotherapy	Observation	Reported urinary bother* per age group across all treatments
<60	319/4,754 7%	27/296 9%	272/310 12%	26/180 14%	133/1,901 7%	543/7,441 7%
≥60 and <65	383/4,662 8%	41/482 9%	78/567 14%	23/227 10%	163/1,828 9%	688/7,766 9%
≥65 and <70	662/6,390 10%	88/986 9%	146/1,212 12%	61/397 15%	221/2,531 9%	1,178/11,516 10%
≥70 and <75	478/4,152 12%	99/1,062 9%	218/1,806 12%	72/546 13%	168/1,815 9%	1,035/9,381 11%
≥75	163/1,305 12%	111/1,189 9%	297/2,383 12%	206/1,452 14%	187/1,828 10%	964/8,157 12%
Reported urinary bother per treatment type across all age groups*	2,005/21,263 9%	366/4,015 9%	777/6,278 12%	388/2,802 14%	872/9,903 9%	4,408/44,261 10% Overall total urinary bother*

*Bother is defined as those reporting moderate or big bother divided by the total number of people who answered this question.

TABLE S11: PATIENT-REPORTED MODERATE-TO-BIG BOWEL BOTHER, 12 MONTHS AFTER INITIAL MANAGEMENT PROVIDED, BY MANAGEMENT TYPE AND AGE GROUP

	Surgery	RT	RT+ADT	ADT+/- Chemotherapy	Observation	Reported bowel bother* per age group across all treatments
<60	137/4,760 3%	29/299 10%	31/313 10%	8/179 4%	40/1,903 2%	245/7,454 3%
≥60 and <65	118/4,660 3%	30/486 6%	66/569 12%	10/225 4%	58/1,833 3%	282/7,773 4%
≥65 and <70	170/6,388 3%	70/989 7%	119/1,214 10%	27/397 7%	82/2,528 3%	468/11,516 4%
≥70 and <75	157/4,154 4%	83/1,067 8%	164/1,803 9%	42/549 8%	64/1,806 4%	510/9,379 5%
≥75	57/1,303 4%	87/1,183 7%	236/2,386 10%	136/1,458 9%	102/1,844 6%	618/8,174 8%
Reported bowel bother per treatment type across all age groups*	639/21,265 3%	299/4,024 7%	616/6,285 10%	223/2,808 8%	346/9,914 3%	2,123/44,296 5% Overall total bowel bother*

*Bother is defined as those reporting moderate or big bother divided by the total number of people who answered this question.

TABLE S12: PROM RESPONSES TO INDIVIDUAL QUESTIONS BY MANAGEMENT GROUP

	Surgery	RT	RT+ADT	ADT +/- Chemotherapy	Observation
Urinary					
Urinary Bother*	**2,005/21,263** 9.43%	**366/4,015** 9.12%	**777/6,278** 12.38%	**388/2,802** 13.85%	**872/9,903** 8.81%
Urinary Pad[$]	**6,603/21,303** 31%	**222/4,048** 5.48%	**539/6,330** 8.52%	**337/2,809** 12.00%	**458/9,949** 4.60%
Leaked Urine[%]	**4,328/21,323** 20.3%	**359/4,050** 8.86%	**680/6,324** 10.75%	**356/2,815** 12.65%	**749/9,942** 7.53%
Bowel					
Bowel Bother*	**639/21,265** 3%	**299/4,024** 7.43%	**616/6,285** 9.8%	**223/2,808** 7.94%	**346/9,914** 3.49%
Losing Bowel Control[#]	**233/21,058** 1.11%	**160/3,891** 4.11%	**330/6,109** 5.4%	**97/2,708** 3.58%	**140/9,754** 1.44%
Sexual					
Sexual Bother*	**9,385/20,795** 45.13%	**1,321/3,822** 34.56%	**2,198/5,941** 37%	**841/2,594** 32.42%	**2,279/9,489** 24.02%
Ability to have an erection[@]	**4,526/20,920** 21.63%	**1,343/3,866** 34.74%	**643/6,031** 10.66%	**193/2,645** 7.3%	**5,745/9,574** 60.01%
Quality of erections[A]	**2,643/20,832** 12.69%	**900/3,835** 23.47%	**371/6,005** 6.18%	**107/2,634** 4.06%	**4,320/9,489** 45.53%
Ability to function sexually[B]	**4,878/20,806** 23.45%	**1,320/3,816** 34.59%	**563/5,920** 9.51%	**159/2,570** 6.19%	**5,572/9,443** 59.01%
Interest in sex[C]	**7,202/18,318** 39.32%	**1,130/3,496** 32.32%	**710/5,717** 12.42%	**168/2,463** 6.82%	**3,810/8,551** 44.56%
Use of sexual aids[D]	**10,735/18,395** 58.36%	**913/3,509** 26.02%	**717/5,766** 12.43%	**267/2,482** 10.76%	**2,015/8,594** 23.45%
Hormonal					
Feeling depressed[#]	**2,102/20,988** 10.02%	**332/3,876** 8.57%	**800/6,094** 13.13%	**361/2,696** 13.39%	**675/9,636** 7.04%
Lack of energy[#]	**2,677/21,032** 12.73%	**717/3,921** 18.29%	**1,989/6,188** 32.14%	**961/2,738** 35.10%	**1,212/9,714** 12.48%

*Moderate-big bother, [#]Moderate-big problem, [$]≥1 pad per day, [%]more than once per day, [@]Fair/good/very good ability to have an erection, [A]Firm enough for intercourse, [B]Fair/good/very good ability to function sexually, [C]Quite a bit/very much interest in sex, [D]Use of medications or devices to aid or improve erections.

TABLE S13: MEDIAN SUMMARY SCORES FOR THE FUNCTIONAL DOMAINS OF THE EPIC-26 PROMS QUESTIONNAIRE BY INITIAL MANAGEMENT PROVIDED (2015-2021)

	Surgery	RT	RT+ADT	ADT +/- Chemotherapy	Observation
Urinary continence summary score (E)	83.5 (58.5-100) N=21,377	100 (79.25-100) N=4,063	100 (75-100) N=6,354	100 (75-100) N=2,836	100 (85-100) N=9,980
Urinary obstruction summary score (E)	93.75 (87.5-100) N=21,157	87.5 (75-100) N=4,004	87.5 (75-100) N=6,269	87.5 (75-100) N=2,776	93.75 (81.25-100) N=9,883
Bowel function summary score (E)	100 (85.83-100) N=21,340	95.83 (83.33-100) N=4,053	91.67 (79.17-100) N=6,332	95.83 (87.5-100) N=2,837	100 (91.67-100) N=9,957
Sexual function summary score (E)	16.67 (8.33-43) N=21,036	27.83 (13.83-61.67) N=3,919	16.67 (4.17-16.67) N=6,115	16.67 (4.17-16.67) N=2,711	58.3 (25-83.33) N=9,693
Hormonal function summary score (E)	95 (80-100) N=21,176	90 (80-100) N=3,976	75 (60-90) n=6,270	75 (58.33-90) N=2,791	95 (85-100) N=9,789

E, median and interquartile range.

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Editorial assistance for the Annual Report 2015-2021 was provided by Lesley Cunliffe (PhD) and funded by Movember.