PROSTATE CANCER OUTCOMES | REGISTRY AUSTRALIA & NEW ZEALAND

ANNUAL REPORT 2018

REPORTING ON DATA 2015–2016

MOVEMBER® FOUNDATION | MONASH University

ACKNOWLEDGEMENTS

Above all, the Chair, the Steering Committee and The Movember Foundation would like to extend their thanks to the men who have contributed their time and their data to this project. Without their support and willingness to allow us to use their information, we would not be able to achieve any of the outcomes that the Prostate Cancer Outcomes Registry – Australia and New Zealand (PCOR-ANZ) is striving towards; namely, improving all aspects of the quality of care for men diagnosed with prostate cancer, within Australia and New Zealand, and globally.

We would particularly like to thank those men who have contributed their thoughts to the qualitative research in this report. Their quotes, which they have generously allowed us to use throughout, serve to shine a light on the deeply personal nature of the challenges these men face every day when tackling prostate cancer. We hope they will generate a greater understanding of the data this project produces; underlining the importance of continuing to uncover actionable project outcomes.

Similarly, the enthusiasm and professionalism shown by members of the clinical community who have agreed to participate in PCOR-ANZ is gratefully acknowledged. They form the front line in our data-collection efforts and the continued success of the registry depends entirely on their generosity in being involved, reflecting an unceasing dedication within that community to improving the lives of their current and future patients.

The Chair and the Steering Committee would particularly like to acknowledge the generous contribution of The Movember Foundation to the establishment and ongoing operation of PCOR-ANZ, without whom, none of this would be possible. Similarly, we are grateful for the important work undertaken by ethics committees and the Aboriginal Program Development Committee to ensure that our registry operates in an ethically responsible and culturally appropriate manner.

The Movember Foundation would like to thank the members of the PCOR-ANZ Steering Committee and, in particular, the leadership of the outgoing Chair, Professor David Roder. This team has contributed many hours on a voluntary basis to provide thoughtful stewardship of the activities of PCOR-ANZ and is truly collaborative. Their passion for the project and determination to drive improvements in clinical practice is inspirational. We also warmly welcome Professor Sanchia Aranda to the committee. Professor Aranda took up the position of Chair in November 2018 and we have no doubt that under her leadership, PCOR-ANZ will continue to strengthen in this next phase as we progress with our development of a population-based prostate cancer clinical registry to improve quality of care and transform outcomes for men living with prostate cancer.

We all would also like to extend our appreciation to our endorsing societies who have put their weight behind the initiative and recognised the significant impact the registry will have on clinical quality in Australia and New Zealand. These include: the Urological Society of Australia and New Zealand (USANZ), the Medical Oncology Group of Australia (MOGA), the Royal Australian and New Zealand College of Radiologists (RANZCR), the Société Internationale d'Urologie (SIU), and the Royal College of Pathologists of Australia (RCPA).

Find out who's involved and how to get involved; and access information about our contributors, governance, publications and more at https://prostatecancerregistry.org

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MESSAGE FROM THE CHAIR

Being diagnosed with cancer is a major life event and this is no different for men with prostate cancer, their partners, and families. Treatment side effects are often silent, private and long term, but can profoundly affect men and their close relationships. Out-of-pocket costs to individuals treated for cancer are becoming more burdensome and the increasing economic cost to the healthcare system for new surgical, pharmaceutical, or radiation treatments cannot continue without significant change in the way we fund and arrange healthcare. Prostate cancer sits at the centre of these contemporary issues, not just in the management of the cancer itself but also in the physical, emotional, social and financial toll it can take.

PCOR-ANZ is a fundamental mechanism to enable and encourage rational action against all aspects of diagnosis, treatment and care of men treated for prostate cancer and their families. Never before has such a dashboard of data, including large-scale overviews that drill down to clinician-level reports, been available to guide and drive improvements in prostate cancer outcomes. The data collected provide an impressive system-wide view of prostate cancer treatment, care and outcomes in Australia and New Zealand. In turn, the registry becomes an extremely valuable resource for patients, clinicians and policy makers and can assist, guide and inform decision making.

PCOR-ANZ has come a long way. It started in five hospitals in Melbourne ten years ago, before linking with similar South Australian efforts. In the past five years, the registry has matured off the back of a system designed to capture population data on prostate cancer diagnosis, management, and outcomes. To date, we have been able to recruit over a third of all patients with prostate cancer from Australia and New Zealand. By December 2019, we expect to increase this to 85% in most jurisdictions. The scale of this clinical data collection is unparalleled within Australia and New Zealand and continues to set an international standard. This report is a tribute to, and summary of, the rich data made available by this registry and is a credit to the willing clinicians and patients who have made it possible.

One of the important differences for PCOR-ANZ is the focus on understanding outcomes that matter to patients. From the outset, PCOR-ANZ leadership could see the way in which Michael Porter's idea of "value" could transform healthcare. The registry was very early to contribute to and adopt the standard datasets promoted by Porter's International Collaboration on Outcome Measurement (ICHOM). These ideas are gaining traction globally and PCOR-ANZ is very well positioned to make a meaningful contribution to this model as a mechanism to improve health care.

Much remains to be done. We must expand data collection to reach at least 90% population coverage. Just as we are working to improve data accrual, the registry is working to improve, and widen the quality of its feedback to patients, clinicians, health services, and policy-makers. Improvements in these two-way channels will enable improvements in care delivery to improve the lives of men with prostate cancer. Finally, the model provided by PCOR-ANZ needs to be considered and adapted for other cancers: the power of PCOR-ANZ, and the concept behind it, needs to be more widely appreciated.

PCOR-ANZ receives generous support from funders who care, are visionary, and are strategic. The universal support received from everyone that contributes to the PCOR-ANZ effort is breathtaking and vital. The Steering Committee have been tireless in their efforts to ensure that PCOR-ANZ is both successful and sustainable now and into the future. With the appointment of Professor Sanchia Aranda

to the position of Chair of the PCOR-ANZ Steering Committee in November 2018, we are confident that she will be an able successor to the design and establishment efforts led so ably by Professor David Roder. As she takes up her position, Sanchia is clearly excited about the possibilities PCOR-ANZ provides. She is passionately committed to a comprehensive cancer and health data system that will be the backbone of improving the performance of our healthcare system with a particular focus on ensuring that all men in Australian and New Zealand benefit from world-leading cancer outcomes.

PCOR-ANZ is at the cutting edge of developing a comprehensive cancer and health data system, which will see it at the forefront of global innovation, and this is truly exciting for all involved.

JEREMY MILLAR

ACTING CHAIR, PCOR-ANZ STEERING COMMITTEE

THE MOVEMBER FOUNDATION REPORT

We want fewer men to die from prostate cancer. We also want men living with, and beyond, prostate cancer to have the treatment and care they need to be well, both physically and mentally. Our ambitions are big – that's why we invest in the most innovative projects we can find.

We are proud to be the principal funder of PCOR-ANZ and have demonstrated our commitment with over AUD11.5M of investment to date. We are proud because this initiative is transforming prostate cancer healthcare in the most profound ways. Through the systematic collection of clinical and patient-reported outcomes data, we are now able to report on how men are doing throughout their prostate cancer journey and build a better understanding of men's experiences. Alongside this, our recently launched Clinical Quality Research Program, is enabling research designed to leverage the dataset to assess and reduce variation in treatment and health outcomes. Through the Stamp initiative, we are able to positively acknowledge the significant contribution of the participating clinicians and hospitals who are so integral to the success of PCOR-ANZ.

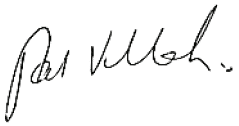
In registry terms, PCOR-ANZ is still in its infancy. The effort involved in establishing a population-based registry such as this is staggering, and the true benefits of this initiative will only be realised over the coming years and well into the future. As we look towards 2019, we remain mindful of the great challenge we face in improving the outcomes of men treated for prostate cancer. Fortunately, we are assembling an incredibly committed group of researchers, clinicians and hospitals who are as dedicated to changing the face of men's health as we are here at The Movember Foundation. As the registry continues to mature, our ability to report, influence and improve the lives of men and their families going through the prostate cancer journey will go from strength to strength.

In 2019, The Movember Foundation's TrueNTH digital health platform will begin rolling out, and there are exciting synergies to be leveraged by clinicians and hospitals participating in PCOR-ANZ. The platform provides health trackers and resources for men with prostate cancer and their families so they can manage their own condition from home. Through the collection of patient-reported outcomes, the platform will also enable men participating in PCOR-ANZ to complete their patient-reported outcome measures (PROMs) questionnaires online.

This year, The Movember Foundation will also make a significant investment in the underlying infrastructure that supports PCOR-ANZ. This upgrade in technology will enable us to respond to the changing landscape of prostate cancer diagnosis and treatment more rapidly and enable data-linkage endeavours that leverage and expand on the valuable data set already established.

We are excited about the future for PCOR-ANZ and I look forward to continued success in 2019 with great optimism.

PAUL VILLANTI



EXECUTIVE DIRECTOR - PROGRAMS

GLOSSARY

ADT	Androgen-deprivation therapy
AS	Active surveillance
CaPSURE	Cancer of the Prostate Strategic Urologic Research Endeavor
CEASAR	Comparative Effectiveness Analysis of Surgery and Radiation
DRE	Digital rectal examination
EBRT	External beam radiation therapy
EPIC-26	Extended Prostate Cancer Index Composite-26 questions
GP	General practitioner
HDR	High dose rate (brachytherapy)
HR-QOL	Health-related quality of life
ICHOM	International Consortium for Health Outcome Measures
ISUP	International Society of Urological Pathology
LDR	Low dose rate (brachytherapy)
MBS	Medicare Benefits Scheme
MOGA	Medical Oncology Group of Australia
MRI	Magnetic resonance imaging
NCCN	National Comprehensive Cancer Network
NSW-PCCR	New South Wales Prostate Clinical Cancer Registry
PBS	Pharmaceutical Benefits Scheme
PCOR	Prostate Cancer Outcomes Registry
PCOR-ANZ	Prostate Cancer Outcomes Registry – Australia and New Zealand
PRIAS	Prostate Cancer Research International: Active Surveillance
PROMs	Patient-reported outcome measures
PSA	Prostate-specific antigen
QoL	Quality of life
RCPA	Royal College of Pathologists of Australia
SA-PCCOC	South Australia Prostate Cancer Clinical Outcomes Collaborative
SIU	Société Internationale d'Urologie
SUN-SF	Survivorship Unmet Need Survey-Short Form
TRUS	Trans-rectal ultrasound
TURP	Transurethral resection of the prostate
TURBT	Transurethral Resection of Bladder Tumour
USANZ	Urological Society of Australia and New Zealand
WW	Watchful waiting

... I was driving to work and I just ran off the road and I just couldn't stop crying... it just sort of hit me like a truck"

(61 years, 1 month after diagnosis, SA study)

... waiting from the time I had my biopsy 'til the time I was told that I had prostate cancer... that was terrible, because your imagination plays havoc with you, and you're not up to the stage of having the support or the acceptance that you have it.

(77 years, regional Victoria, Vic study)

I think I've been helping him [friend with prostate cancer] with it because I've been talking very openly about it... He's a very popular chap and he talked about his prostate cancer that he's had, and that he's still having the treatment... That's a good attitude to have, rather than not talk about it.

(77 years, regional Victoria, Vic study)

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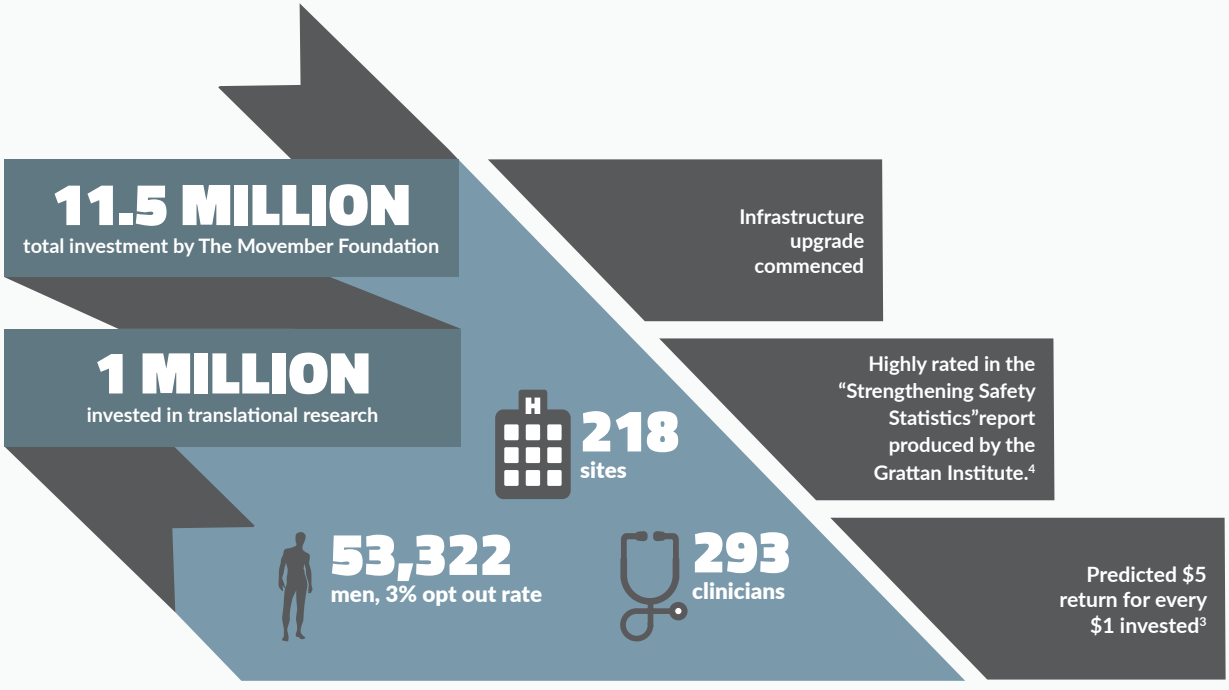
EXECUTIVE SUMMARY

PCOR-ANZ is now in its fourth year of operation as a bi-national registry and we are pleased to present, for the first time, clinical and patient-reported outcomes from the registry-wide data set. The information reported here represents historical data from men diagnosed in South Australia and Victoria for the period January 2008 to December 2016 and data from other jurisdictions from January 2015 to December 2016. For the period 2015–2016, PCOR-ANZ captured 36% of all new prostate cancer diagnoses registered within Australia and New Zealand.

Our ultimate recruitment goal is to reach 90% population coverage across all contributing jurisdictions, which will allow us to draw clinically reliable conclusions about treatment trends and patient-reported outcomes for men across Australia and New Zealand. More immediately, our next target is to reach 85% population coverage by December 2019. With this in mind, the jurisdictional PCOR teams have been working hard to recruit more clinicians and hospitals to the database, and as of November 30th 2018, we have 218 sites and 293 clinicians enrolled in the registry. This represents a huge effort from the jurisdictional teams and a sincere commitment from all our contributors, who share our vision of improving the quality of care for all men diagnosed with prostate cancer.

Much of the early stages of development of PCOR-ANZ have been spent in establishing a robust governance framework, and processes for effective data collection. These efforts have been well recognised. Our researchers have worked with the International Consortium for Health Outcome Measures (ICHOM) to develop standardised datasets for localised[1] and advanced[2] prostate cancer. PCOR-Victoria (PCOR-VIC), one of our more mature registries, was able to demonstrate a return of $2 for every $1 invested, when it underwent an economic analysis by the Australian Commission on Safety and Quality in Health Care in 2016. This return is predicted to rise to $5 for every $1 invested when we national coverage is reached.[3] And when reviewed by the "Strengthening Safety Statistics" report produced by the Grattan Institute,[4] PCOR-ANZ attained the highest possible score on all parameters other than coverage.



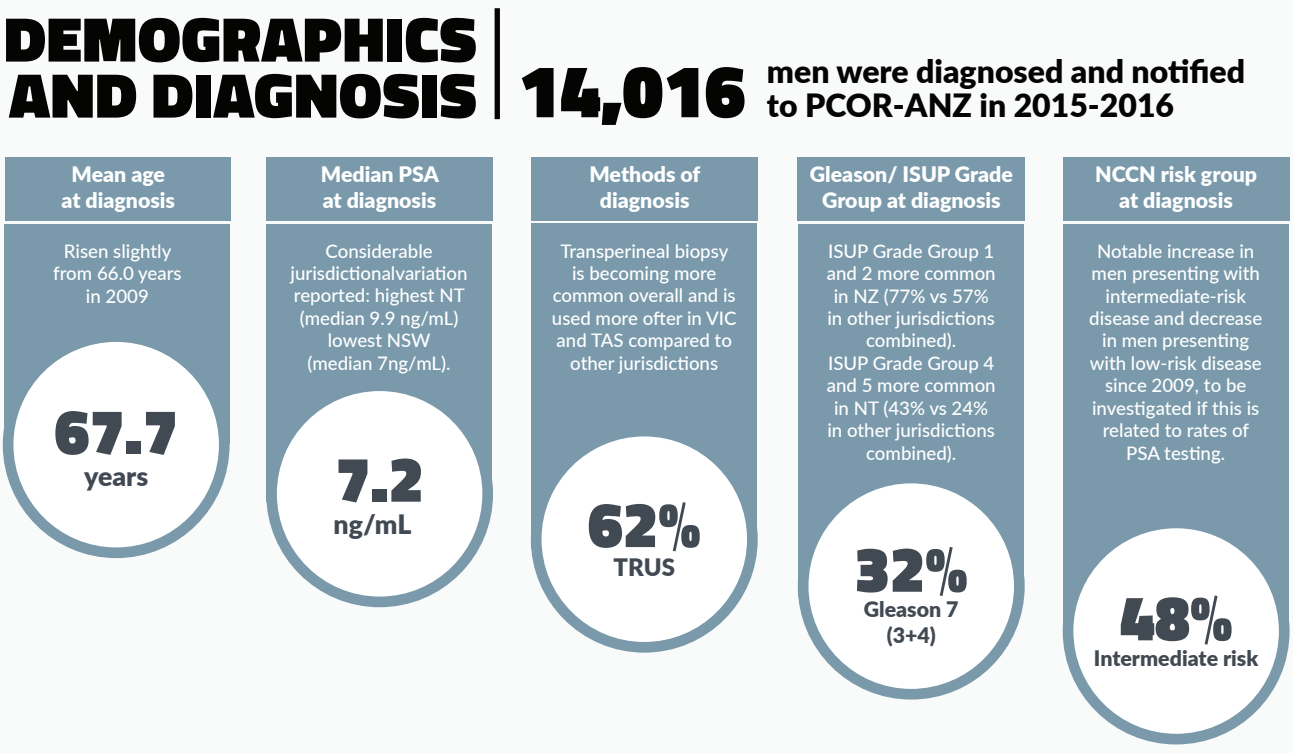
A key part of our vision is to be able to provide actionable recommendations to decision makers that can inform healthcare policy in relation to prostate cancer, and we are already seeing results. PCOR-ANZ data from Victoria and South Australia were used by the Australian Government to understand the number of men on active surveillance and the likely impact that introducing a rebate for magnetic resonance imaging (MRI) scans into practice would have on clinical outcomes and the economy. As a result, it was announced that, from July 1st 2018, men having an MRI scan at diagnosis, or as part of active surveillance, will be eligible for a $400 Medicare rebate off the cost of the scan. As the registry matures and our funded research projects progress, we hope to be able to influence important changes in practice such as this across all areas of prostate cancer care.

A diagnosis of prostate cancer can place an enormous psychological burden on men and on their relationship with others. Navigating the various complex treatment options can be difficult for both patients, partners and family members. The patient-reported outcomes we collect will provide deeper insights into the issues that men face, and in 2015–2016 we captured responses from 50% of the men in our registry (6,953 PROMs). Our hope is that the information PCOR-ANZ provides about the risks and benefits of different treatments will assist men and their families in their decision-making as they go through their journey with prostate cancer.

DEMOGRAPHICS AND DIAGNOSIS

For men diagnosed with prostate cancer and notified to PCOR-ANZ in 2015–2016, the mean age at diagnosis was 67.7 years, which represents a slight rise since our earliest reported data in 2009 (66.0 years). Most men (62%) were diagnosed by trans-rectal ultrasound (TRUS)-guided biopsy, but transperineal biopsy is becoming more common over time and is used much more often in sites from Victoria and Tasmania, compared to other jurisdictions.

We observed significant geographical differences in risk groups at diagnosis. Men were much more likely to be diagnosed with earlier-stage disease – International Society of Urological Pathology (ISUP) Grade Group 1 or 2 – in New Zealand compared to other areas (77% vs 57% across other jurisdictions



combined, p<0.001); and much more likely to be diagnosed with later-stage disease (ISUP Grade Group 4 or 5) in the Northern Territory (43% vs 24% across other jurisdictions combined, p<0.001). There has also been an overall increasing trend between 2009 and 2016 in men presenting with intermediate-risk disease – categorised by the National Comprehensive Cancer Network (NCCN) risk groups – and a corresponding decrease in men presenting with low-risk disease. As New Zealand coverage is currently only 9% of all men diagnosed in New Zealand, it is not clear whether this is representative of the broader New Zealand population of men with prostate cancer. Further investigation into the reasons for these differences is warranted.

TREATMENT CHOICES

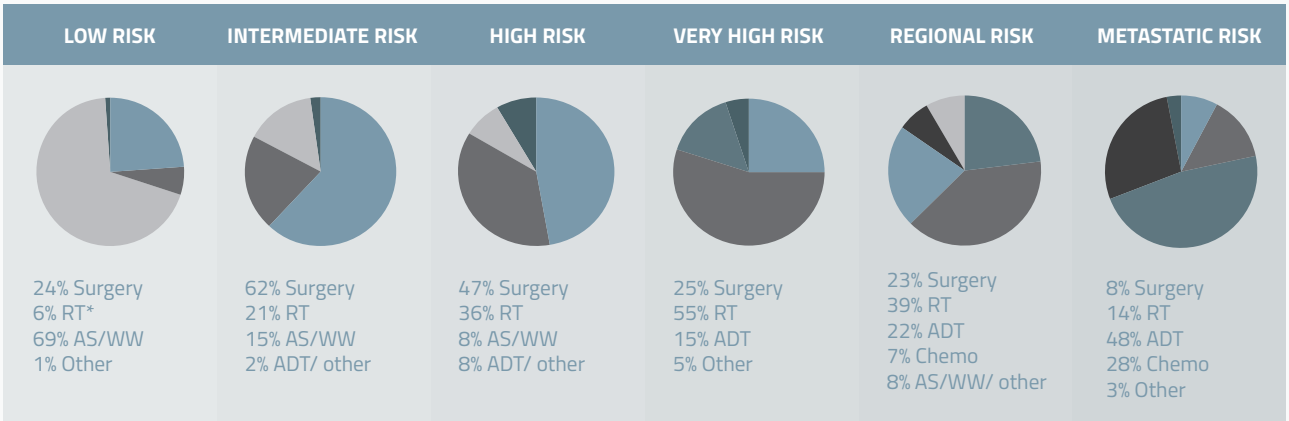
Uptake of active surveillance/watchful waiting is on the rise overall in our PCOR-ANZ cohort of men with low-risk disease, which is reflective of current treatment guidelines.[5,6] However, a large proportion of men with low-risk disease still receive radical treatment (31%, excluding missing data), and this is especially concerning in men under 60 years of age, of whom 42% (354/840) underwent immediate surgery or radiotherapy in 2015–2016. It will be important to monitor this trend over time and investigate why so many men are undergoing immediate curative treatment (rather than active surveillance), which may cause severe side effects, but which has a low likelihood of clinical benefit.

Conversely, 7% (181/2704) of men diagnosed with high-risk disease and 15% (16/105) of men diagnosed with very high-risk disease underwent androgen-deprivation therapy (ADT) monotherapy in 2015–2016. Given that this will only slow their disease, and that radical treatment can be curative in these groups, understanding why these men do not choose more aggressive treatment is another area that warrants further examination.

PATIENT-REPORTED OUTCOMES

Encouragingly low numbers of men (≤3%) reported big problems with either urinary or bowel bother in this first registry-wide analysis of patient-reported outcomes. It is clear however, that sexual bother and function are significant concerns. Around 1 in 5 men have a big problem with sexual bother 12 months after surgery or external beam radiation therapy (EBRT; 22% and 20%, p=0.162).

TREATMENT CHOICES | 43% of men overall underwent radical surgery (5,716/13,336)



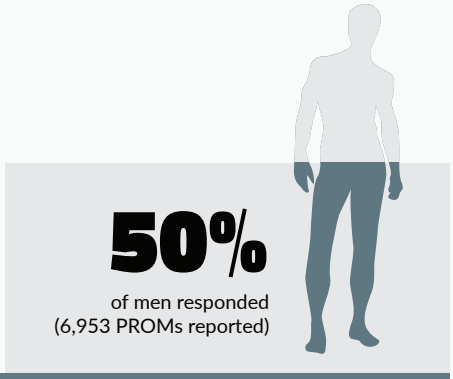
Key questions for investigation on treatment choice

Why are 31% of men with low-risk disease undergoing active treatment rather than AS/WW? Especially concerning is that, in men under 60 with low-risk disease, the rate rises to 42%.

Why are 7% of men with high-risk, and 15% of men with very high-risk, disease having ADT monotherapy when they could be undergoing potentially curative treatment?

*RT: radiotherapy (incorporates external beam radiotherapy and low and high-dose brachytherapy.)

PATIENT-REPORTED OUTCOMES



Urinary and bowel bother
<3% of men report that urinary or bowel function is a 'big problem' 12 months after treatment.

Sexual bother
1 in 5 men have a big problem with sexual function after surgery (22%) or EBRT (20%).

Urinary and bowel function
Urinary incontinence after surgery and bowel function issues after EBRT are notable problems.

Sexual function
Sexual function is the biggest problem, even for men on AS/WW. Men on ADT reported the lowest sexual function score.

The collective bother category of moderate-to-big problems was significantly more frequently reported after surgery compared to EBRT (42% vs 32%, p<0.001). ADT monotherapy was associated with moderate-to-big bother with sexual function for around 1 in 4 men (24%) when assessed 12 months after diagnosis. These are not surprising findings, and The Movember Foundation is already funding a care coordination study under the TrueNTH program to address the needs of men who report that they have problems with their urinary, bowel or sexual function (see Examining quality of life in Chapter 5).

LOOKING TO THE FUTURE

Many changes are occurring across PCOR-ANZ over the next 12 months. We are making a large-scale investment into upgrading the infrastructure of our database and are working towards improved data-collection standards by facilitating an audit of data quality. Simultaneously, our jurisdictional coordinators are continuing their work on recruiting hospitals and clinicians to get us closer to population coverage. In 2019, it is our intent to provide hospital and clinician-level reports back to all contributors across Australia and New Zealand. For the first time, clinicians will be able to compare their clinical approach and outcomes of their treatments with those of other clinicians treating similar patients across Australia and New Zealand. Previously, these reports were only delivered to clinicians and hospitals in Victoria. A bi-national approach will provide unprecedented ability to compare and reduce variation in quality of care.

This national dataset is now available for researchers to use and a range of new translational research projects will be funded through our Clinical Quality Research Program. In the future, we intend to use the data from PCOR-ANZ to develop and test hypotheses across the spectrum of prostate cancer care, with an emphasis on cross-jurisdiction collaboration. Underlying all our activity is the principal aim of ensuring that men with prostate cancer receive high-quality, appropriate and safe care, irrespective of their location, insurance status or healthcare provider. Working together with our contributors, we are committed to driving continuing improvement in the outcomes that matter to men diagnosed with prostate cancer and their partners, family and carers.

ABOUT THIS REPORT

This annual report provides a summary of data collected during the period 2015–2016, which have been gathered by seven jurisdictions across Australia and New Zealand. Further demographic detail can be found in the Supplementary File that accompanies this document. Details of the research conducted by PCOR-ANZ in 2017 and 2018 are also included in Chapter 8.

It should be noted that, within this timeframe, several jurisdictions were in the early stages of data collection, resulting in some outcome endpoints having very low patient numbers. The Movember Foundation and PCOR-ANZ value the privacy of the contributors to the registry extremely highly. So, for jurisdictional comparisons that included very low numbers of men – meaning there may be a possibility that an individual could be identified by the reported characteristics – the data will not be publicly released. While PCOR-ANZ has in-built validation checks to optimise the quality of the data entered into the registry, independent audit of the data has not been widely performed across all the jurisdictions at this stage.

Chapters within this annual report have been organised to provide initial information on prostate cancer and then to provide a summary of research findings according to the patient journey. We then provide details on our activities and future direction. Additional information to support the data can be found in the Supplementary File. An outline of the chapters is provided below.

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

Provides an overview of how the registry works, including its approach and objectives, governance structure and how data find their way into the registry.

2. WHAT DO WE KNOW ABOUT PROSTATE CANCER IN AUSTRALIA AND NEW ZEALAND?

Summarises incidence, prevalence and survival statistics for prostate cancer. Australian and New Zealand data have been collated by the Australian Institute of Health and Welfare for Australian statistics and the Ministry of Health New Zealand, for New Zealand statistics.

3. DIAGNOSING PROSTATE CANCER

Outlines statistics relating to diagnosis method and initial disease stage. Trend data are provided to demonstrate how quickly this landscape is changing. Qualitative research with men and GPs on prostate cancer diagnosis is also included.

4. TREATING PROSTATE CANCER

Summarises treatment men receive after a diagnosis of prostate cancer, including details on uptake and adherence to active surveillance. Published qualitative research undertaken with men undergoing radiotherapy and surgery is also summarised here.

5. PATIENT-REPORTED OUTCOMES

Summarises our data in regard to longer-term outcomes of prostate cancer. Research examining quality of life from the perspective of men undergoing treatment is also included.

6. WORKING WITH CLINICIANS AND HOSPITALS

Describes how we work with clinicians and presents an overview of the feedback we have had regarding the quality of care reports. Reviews the work we are currently undertaking to improve the registry itself and lists the collaborating clinicians, hospitals and registry staff who are making all this possible.

7. FUTURE DIRECTIONS

Demonstrates how the work being conducted by PCOR-ANZ and the data collected by PCOR-ANZ jurisdictions is contributing to a wider global movement to improve health outcomes for men diagnosed with prostate cancer.

8. PUBLICATIONS

Lists published peer-reviewed publications from the period 2017–2018. A full list of publications and abstracts can be found on our website prostatecancerregistry.org.

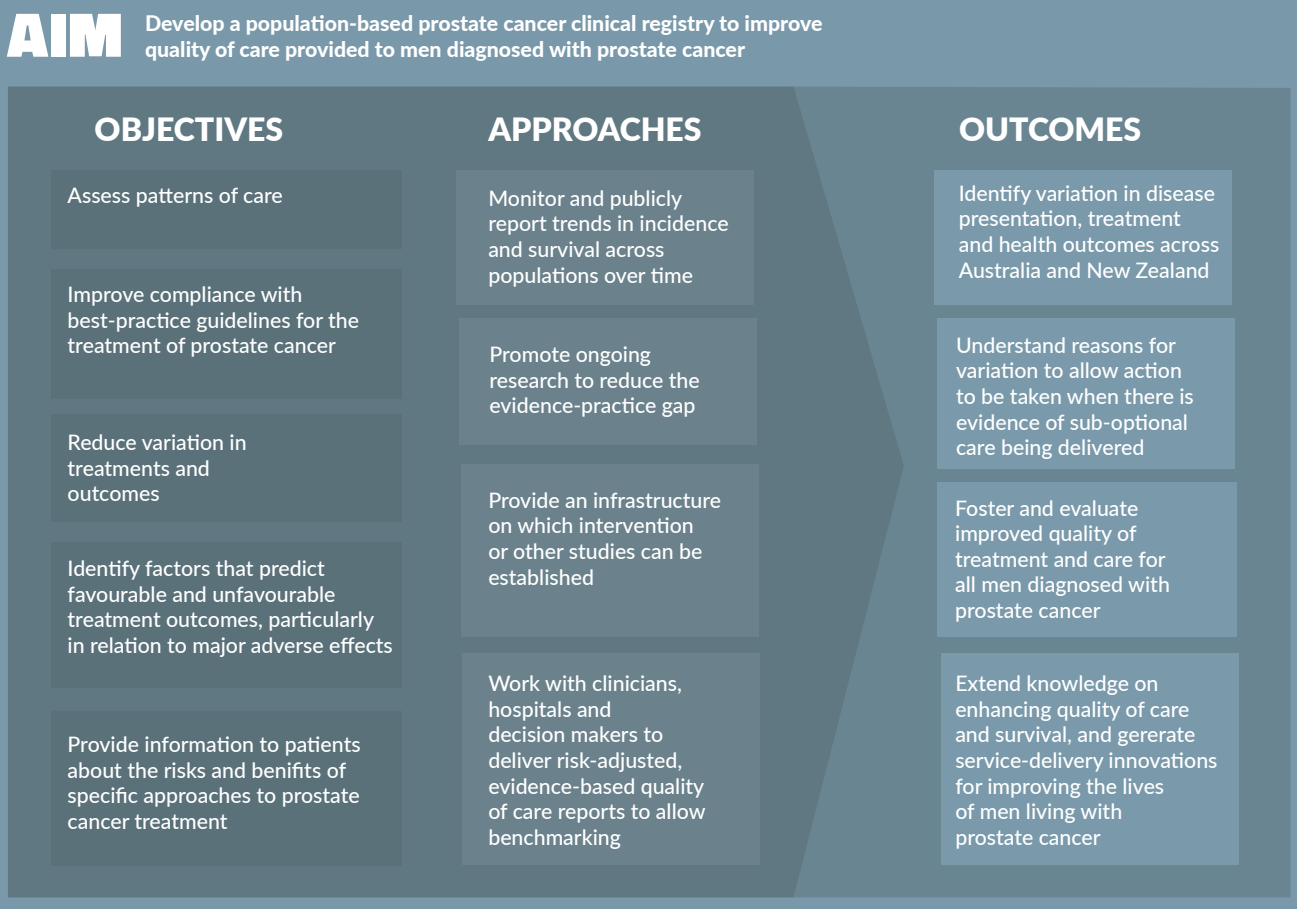
1. THE PROSTATE CANCER OUTCOMES REGISTRY

AUSTRALIA AND NEW ZEALAND (PCOR-ANZ)

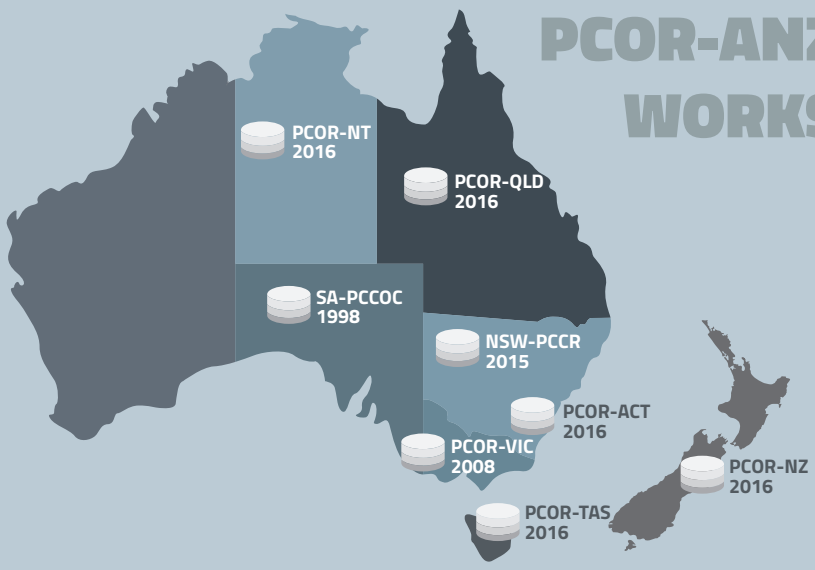
PCOR-ANZ is a clinical quality registry[7] with a goal to help achieve the best possible health outcomes for men who have been diagnosed with prostate cancer. Clinical quality registries systematically monitor the quality of healthcare by routinely collecting and reporting health-related information. Information is used by clinical quality registries to benchmark performance and identify variation in clinical processes of care and health outcomes.[3] PCOR-ANZ has been reviewed and approved by ethics committees in New Zealand and each Australian jurisdiction, and by the Aboriginal Health and Medical Research Council Ethics Committee for data collection in New South Wales. Further details are provided in Appendix 1. The registry uses an opt-out approach to patient recruitment. Nationally, 97% of men approached to contribute to the registry have accepted (2.7% opt-out rate).

We aim to generate insights that will contribute to improving the quality as well as the extent of prostate cancer survival across Australia and New Zealand through a multi-pronged approach **(Figure 1)**.

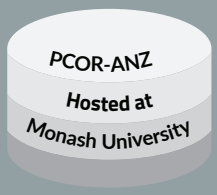
FIGURE 1: PCOR-ANZ AIMS AND OBJECTIVES.



HOW PCOR-ANZ WORKS



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



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

Approved by jurisdictional ethics committees

PCOR-ANZ has been approved by ethics committees from each jurisdiction and by the Aboriginal Health and Medical Research Council Ethics Committee. Each ethics committee has approved an opt-out recruitment approach.

Governance by Steering Committee

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

Runs with bank-level security and a standardised data dictionary

see Appendix 3 for more information and details on missing data).

RECRUITMENT IS PROGRESSING RAPIDLY

218 sites

Represents 59% of public and 41% of private hospitals. Hospitals are progressively invited to join, but can also join by contacting their jurisdictional data coordinator

293 clinicians

Clinicians are progressively being approached directly, and may also be identified via pathology reports from participating hospitals. You can sign up to participate by contacting your jurisdictional data coordinator

53,322 men

53,322 men have consented. Nationally there is an opt out rate of 2.7%. Only men who are diagnosed by participating clinicians are invited to contribute to PCOR-ANZ. They can opt out at any time by calling 1800 771 410 in Australia or 0800 008 436 in New Zealand

HELP US

reach our goal of population coverage. Contact your PCOR jurisdictional coordinator under 'Who's involved' at **https://prostatecancerregistry.org**

NSW-PCCR, New South Wales Prostate Clinical Cancer Registry; PCOR, Prostate Cancer Outcomes Registry; SA-PCCOC, South Australia Prostate Cancer Clinical Outcomes Collaborative.

WORKING TOWARDS OUR GOALS

Worldwide, there is an ongoing drive to improve the transparency of health outcomes. Through our systematic collection of clinical data as well as PROMs (collected 12 months after treatment), PCOR-ANZ is building a highly valuable trans-Tasman dataset. As PCOR-ANZ continues to evolve into a mature clinical-quality registry with 90% population coverage, we seek to provide policy and decision makers at the highest levels of government with evidence-based recommendations that can inform health policy in Australia and New Zealand. But we gratefully acknowledge that it is the engagement we have with our contributing clinicians, hospitals and patients that forms the backbone of our approach and allows us to aspire to these goals.

The confidential, bi-annual benchmark reports that we deliver to clinicians and hospitals are evaluated against an agreed set of clinical-quality indicators. These reports have been distributed to hospitals and clinicians in Victoria since 2012; and in 2019 they will be made available to clinicians and hospitals across Australia and New Zealand. For the first time, treating clinicians are being provided with evidence-based outcomes data that they can use to inform positive changes in clinical practice and improve outcomes for the patients they serve. These reports have been well received by the clinical community, and we are continuing to collect and act on feedback from our contributors to make them as informative and easy to use as possible (read more about the clinical quality of care reports in Chapter 6).

A second central role of PCOR-ANZ is to listen to the voices of men living with prostate cancer by collecting information directly from them. These PROMs will give us deeper insights into their quality of life and are being used to understand what type of care delivers the best results, according to men themselves. This year, we are able to present the first PROMs data from a registry-wide dataset. We envisage that these PROMs will become steadily more informative and actionable over time as the registry gains 90% population coverage. Our PROMs data from the 2015–2016 dataset can be reviewed in Chapter 5.
See Appendix 2 for information on PROMs data collection and Supplementary File, Table 21, to see the Extended Prostate Cancer Index Composite-26 (EPIC-26) survey.[8]

As someone successfully treated for prostate cancer at the age of 47, I know only too well the impact that this disease, and the frequent side effects of treatment, can have on our physical and psychological wellbeing. Not to mention their impact on those we love and who care for us. As a health professional, I was fortunate to be diagnosed early and was able to make informed decisions about my treatment. But I know this is not the case for all men. This is where the Prostate Cancer Outcomes Registry comes in. By monitoring prostate cancer outcomes, this national registry promotes better quality of life for the men and their families that are affected by this disease; and I am pleased to be able to provide a patient lens to the great work being undertaken by those passionately committed to improving prostate cancer outcomes across Australia and New Zealand.

ASSOCIATE PROFESSOR TONY WALKER ASM
(PATIENT REPRESENTATIVE)

POPULATION COVERAGE

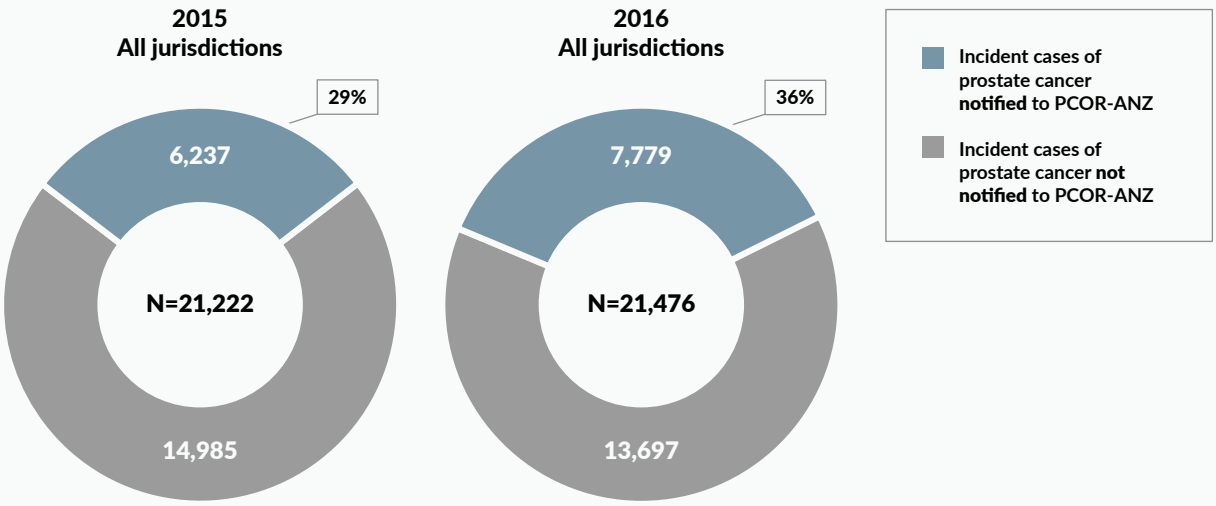
Achieving population coverage is a key goal for PCOR-ANZ as it will allow us to draw clinically reliable conclusions using high-quality data. It will also allow more reliable, and effective, inter-jurisdictional and international comparisons to be made regarding treatments, clinical practice and patient-reported outcomes.[9]

As of November 2018, coverage ranges from ~9% in the New Zealand registry to >90% in our smaller or more established jurisdictional registries. Western Australia have not yet joined PCOR-ANZ. Our immediate aim is to reach at least 85% population coverage in contributing jurisdictions by December 2019. Jurisdictional PCOR teams are continuing to recruit clinicians and hospitals while they also manage data collection and ethics/governance applications.

Ultimately, it is envisaged that prostate cancer clinical information and patient-reported outcomes will be provided to PCOR-ANZ from all Australian and New Zealand jurisdictions.

Figure 2 provides an overview of recruitment numbers and estimated total population incidence of prostate cancer for the period 1 January 2015 to 31 December 2016 in all contributing jurisdictions. Further details on recruitment and how population coverage was calculated, including population coverage by jurisdiction, can be found in Appendix 4 and a summary of population coverage for the period 2015–2016 by jurisdiction is outlined in the Supplementary File, Table 2.

FIGURE 2: POPULATION COVERAGE OF PROSTATE CANCER IN PCOR-ANZ
– TOTAL INCIDENCE OF PROSTATE CANCER ANALYSED BY NOTIFICATION TO PCOR-ANZ ACROSS ALL JURISDICTIONS (2015–2016).



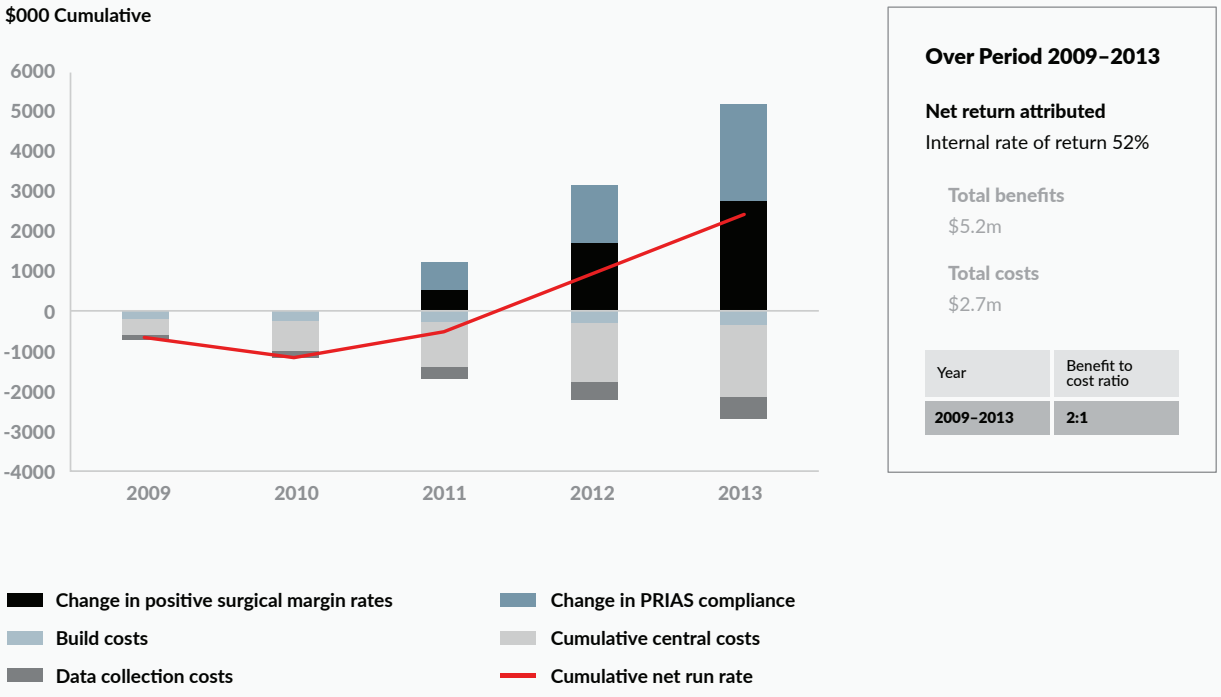
DEMONSTRATING THE VALUE OF PCOR-ANZ

An economic review of clinical quality registries was undertaken by the Australian Commission on Safety and Quality in Health Care to assess whether such registries provided a good return on investment.[3] PCOR-VIC, one of the more mature PCOR registries, was included as one of the five clinical quality registries examined.

Despite being the youngest of the five registries examined, in just its first five years of operation PCOR-VIC was able to demonstrate a return of $2 for every $1 invested. This was calculated using improvements in only two out of the ten quality indicators that are reported back to health services and clinicians. It was estimated that if the registry had national coverage, it would provide a $5 return for each $1 invested.

Figure 3 has been taken from the report. It demonstrates improvement in both quality indicators. One of the indicators assessed is change in positive surgical margin rate, with a reduction in margins having the economic benefit of not requiring additional radiotherapy. Our data showed that positive surgical margins was an independent predictor of men going on to have EBRT.[10] The other indicator assessed in the economic evaluation related to change in pattern of treatment for men with low-risk disease. Increased uptake of active surveillance for men with low-risk disease reduced over-treatment, and this has an economic benefit. This indicator is denoted as "Change in PRIAS compliance" in **Figure 3**. PRIAS (Prostate Cancer Research International: Active Surveillance) is the protocol used to assess whether men with low-risk disease are appropriate for management on active surveillance.

FIGURE 3: COST-BENEFIT ANALYSIS OF THE PCOR-VIC REGISTRY (2009–2013).[5]



Note: discounted by 3% p.a.; cost units in 2014 dollars. VSLY unit calculated per annum. Values may not exactly sum due to rounding.
Reproduced with permission from Australian commission on Safety and Quality in Health Care.[5]

PCOR-ANZ was also favourably reviewed in the "Strengthening Safety Statistics" report produced by the Grattan Institute.[4] The South Australian PCOR registry (SA-PCCOC) was one of only a few to achieve the highest possible score in terms of coverage, nature of the data, public reporting and feedback to clinicians. PCOR-ANZ attained the highest possible score on all parameters other than coverage, which we aim to achieve in the next three years.

THE PCOR-ANZ STEERING COMMITTEE AND JURISDICTIONAL COORDINATORS

Below are the members of the PCOR-ANZ Steering Committee who were in their roles as of 30th November 2018. The Steering Committee has been designed to encompass members from each jurisdiction and funding body, as well as from a range of essential disciplines and clinical specialities.

PROFESSOR SANCHIA ARANDA

Chair

CEO, Cancer Council Australia

ASSOCIATE PROFESSOR ANDREW BROOKS

PCOR-NSW Representative

Head of the Urology Department at Western Sydney Local Health District

PROFESSOR DAVID CURROW

Quality of Care Expert

Chief Cancer Officer and CEO, Cancer Institute

PROFESSOR IAN DAVIS

Medical Oncology Representative

Senior Oncologist, Eastern Health

MR PAOLO DE IESO

PCOR-NT Representative

Radiation Oncologist, Northern Territory Radiation Oncology

ADJUNCT PROFESSOR WARICK DELPRADO

Pathology Representative

Director (Histopathology), Douglass Hanly Moir Pathology

ASSOCIATE PROFESSOR HANY ELSALEH

PCOR-ACT Representative

Staff Specialist Canberra Hospital, Australian National University

PROFESSOR SUE EVANS

Project and Data Coordination Centre Representative

Head of Clinical Registries Unit, Monash University

PROFESSOR FRANK FRIZELLE

PCOR-NZ Representative

Head of Department – Department of Surgery, University of Otago, Christchurch

PROFESSOR MARK FRYDENBERG

Custodian Representative

Chair of the Department of Urology, Monash Medical Centre

PROFESSOR JEREMY MILLAR

PCOR-VIC Representative

Director of Radiation Oncology, Alfred Health

ASSOCIATE PROFESSOR KIM MORETTI

PCOR-SA Representative

Head of Urology, Queen Elizabeth Hospital

DR DAVID PRYOR

PCOR-QLD Representative

Radiation Oncologist, Greenslopes Private Hospital and Princess Alexandra Hospital

DR MARKETA SKALA

RANZCR and PCOR-TAS Representative

Senior Radiation Oncologist, Royal Hobart Hospital

ASSOCIATE PROFESSOR DAVID SMITH

Epidemiologist

Research Fellow, Cancer Council

MR PAUL VILLANTI

Movember Representative

Executive Director of Programs, Movember Foundation

ASSOCIATE PROFESSOR TONY WALKER

Patient Representative

Chief Executive Officer, Ambulance Victoria

DR CRAIG WHITE

Medical Administrator

Consultant

DR PETER HEATHCOTE

USANZ Representative

President Elect, Urological Society of Australia and New Zealand

PROFESSOR JOHN MCNEIL

Custodian Representative

Head of Department of Epidemiology and Preventive Medicine, Monash University

DR JEFFERY THAVASEELAN

PCOR-WA Representative

Perth Urology Clinic

Each jurisdiction also has its own registry team responsible for ensuring that data are collected, stored and used in accordance with the PCOR-ANZ policies and protocol. They each report to their respective jurisdiction-based steering committee and/or lead clinician. Jurisdictional coordinators oversee registry operations **(Table 1)**. Members of our PCOR-ANZ team are listed in Appendix 5.

TABLE 1: REGISTRY COORDINATORS IN EACH JURISDICTION

REGISTRY COORDINATORS IN EACH JURISDICTION	
ANZ	Gabriella Tikellis
ACT	Rebekah Smith, Mirka Smith
NSW	Serina Teuss
NT	Lisa Smith
NZ	Judith Clarke
QLD	Heather Day
SA	Michael O'Callaghan, Tina Kopsaftis
TAS	Zoe Stephens
VIC	Melanie Evans
WA	Angela Ives

2. WHAT DO WE KNOW ABOUT PROSTATE CANCER IN AUSTRALIA AND NEW ZEALAND?

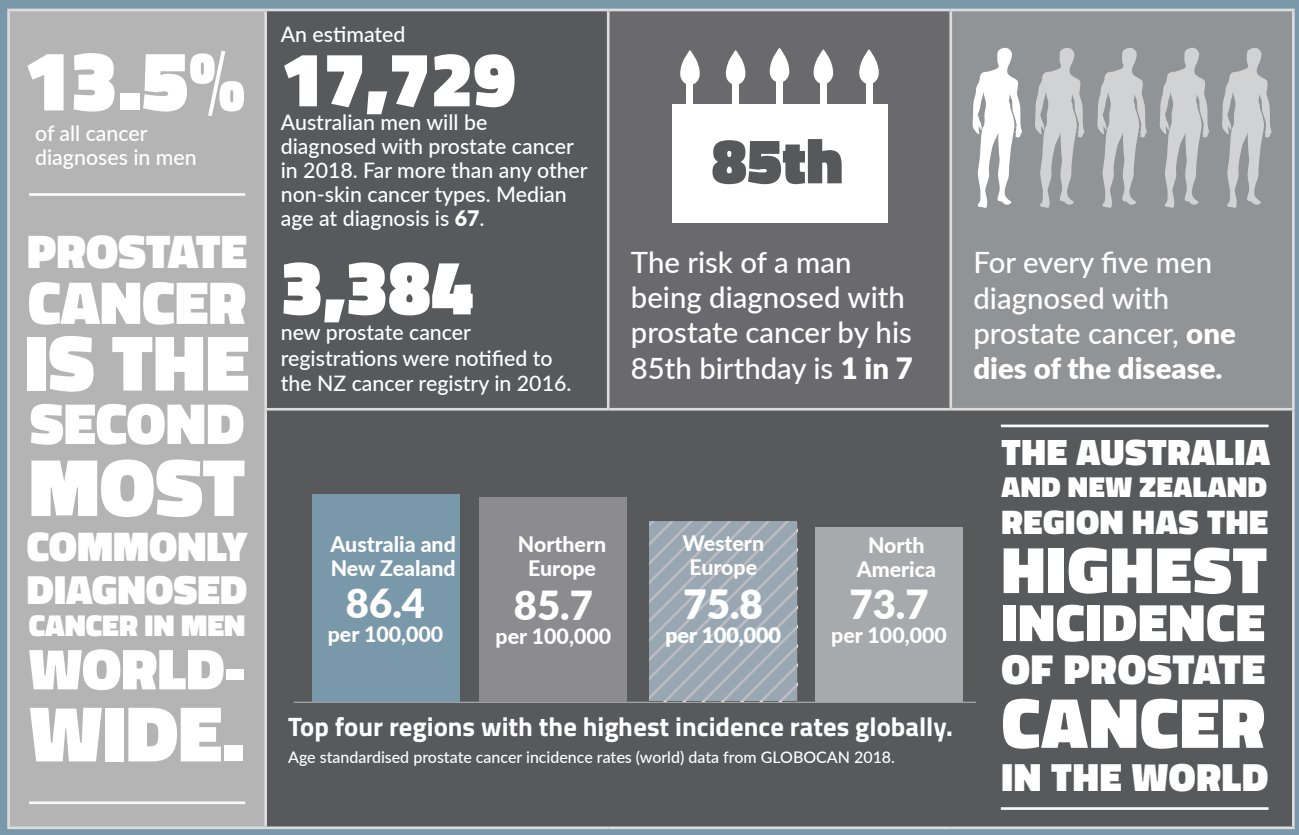
INCIDENCE (NEW CASES)

Globally, prostate cancer is the second most commonly diagnosed cancer among men (excluding non-melanoma skin cancer), accounting for 13.5% of cancer diagnoses.[11] Australia and New Zealand have the highest incidence of prostate cancer in the world, and in our region it is currently the most commonly diagnosed non-skin cancer in men **(Figure 4)**.[12–14]

Australian incidence rates increased more than two-fold from the early 1980s to 2009, with a significant peak in the mid-1990s being attributed to asymptomatic cases that were uncovered by the introduction of prostate-specific antigen (PSA) testing.[12,15] In 2018, it was estimated that approximately 17,729 new cases would be diagnosed in Australia.[12] New Zealand data available to 2016 show that incidence rates have increased 7% over the three years from 2014 to 2016; 3,384 cases were notified to the New Zealand cancer registry in 2016.[13]

Incidence rates are not uniform across the populations of Australia and New Zealand. In Australia, incidence rates are higher in regional areas than in major cities, where immigrant groups from low-risk countries more commonly reside.[15] The disease is also known to have an upper socioeconomic gradient in Australia such that the highest rates are found in higher socioeconomic areas.[15] In New Zealand, data from 31 general practices captured between 2007 and 2010 demonstrated that men being managed in rural general practices were 32% less likely have a PSA blood test, twice as likely to have prostate cancer detected following case-finding (6 per 1,000 for rural men vs 3 per 1,000 for urban men) and twice as likely to have a Gleason score of 9 on biopsy (18.3% vs 9.1%) compared with their counterparts being managed in urban general practices.[16]

FIGURE 4: PROSTATE CANCER INCIDENCE IN AUSTRALIA AND NEW ZEALAND AND GLOBALLY.[11-14]



Furthermore, there is quite a different profile of diagnosis and mortality among Indigenous Australians and Māori compared with other Australians and New Zealanders. For non-Indigenous men from Australia and for both Indigenous and non-Indigenous men from New Zealand, prostate cancer is the most commonly diagnosed cancer.[13,14] For indigenous men from Australia, prostate cancer is the fourth most commonly diagnosed cancer.[14] However, incidence rates among Aboriginal and Torres Strait Islander men are approximately 30% lower than for other Australian men,[14] and among Māori men are approximately 18% lower compared with non-Māori New Zealanders.[17] This variation may reflect differences in case-finding practices between populations. Research demonstrates that Māori men are almost half as likely to be tested for prostate cancer as non-Māori men.[17] It is unclear whether, in Australia, this is the result of PSA testing rate differences between Indigenous and non-Indigenous populations.

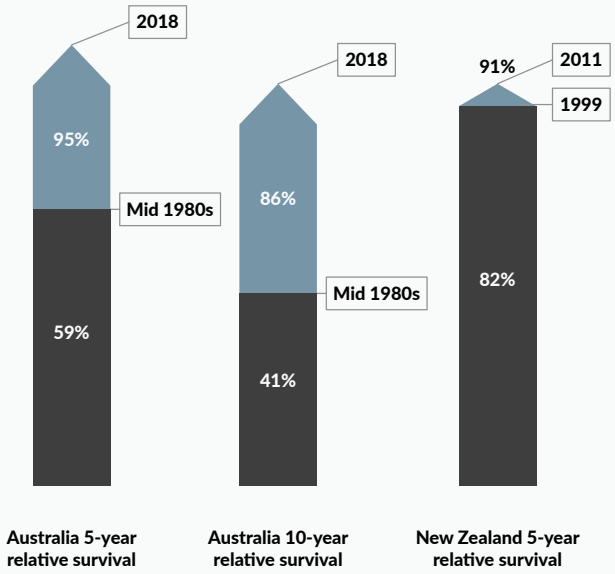
Jurisdictional differences in trends and potential discrepancies in care such as these are areas that PCOR-ANZ aims to shed more light on, allowing us to contribute to finding improved solutions for men who are currently being underdiagnosed.

SURVIVAL

Survival rates are improving across both Australia and New Zealand **(Figure 5)**.[12,18] But while survival improves, mortality attributable to prostate cancer differs across populations. Regional areas of Australia have a 30% higher five-year mortality rate than do urban areas.[19] Prostate-cancer-specific mortality is also much higher in Indigenous Australians and the Māori population compared with other Australians and New Zealanders. For example, New South Wales data have shown that Aboriginal and Torres Strait Islander men have a 35% higher five-year mortality rate compared with other Australians.[20] While in New Zealand, Māori men have a 54% higher five-year mortality rate compared with other male New Zealanders.[21] These differences may relate to biological factors (e.g. risk factors) or to the health system (e.g. later diagnosis, differences in management of the disease) – questions we will also be able to address as the database matures.

Prostate cancer survival is lowest in men in the oldest age groups measured. In Australia, men aged 80 years or more have a five-year survival rate of 72% compared to >85% in all other age groups;[15] in New Zealand, men aged 75 years or more have a 5-year survival rate of 73% compared to >96% in all other age groups.[18] This is because clinical management and broader social support can be complicated by multiple chronic co-morbidities and frailty, and sometimes, by isolated living environments.

FIGURE 5: PROSTATE CANCER RELATIVE SURVIVAL AND RELATIVE MORTALITY RATES, AUSTRALIA AND NEW ZEALAND.[12,18]



5-year relative prostate cancer mortality compared between selected populations		
Australian men from regional areas	12.3%	30% DIFFERENCE
Australian men from urban areas	8.6%	
Aboriginal and Torres Strait Islander men (NSW)	17.5%	35% DIFFERENCE
Other male Australians (NSW)	11.4%	
Māori Men	19.7%	54% DIFFERENCE
Other male New Zealanders	9.1%	

MANAGEMENT CHALLENGES

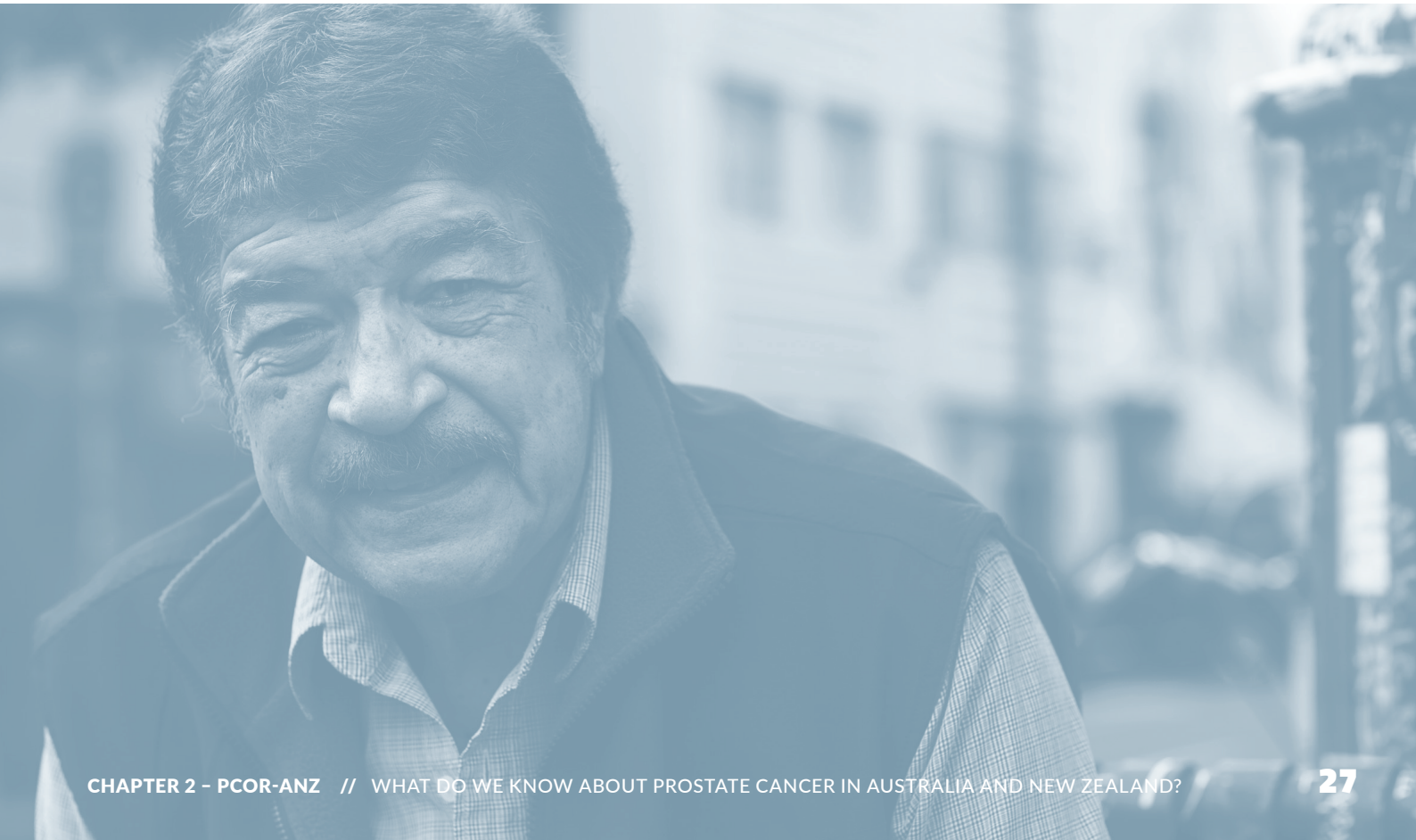
The total estimated cost of prostate cancer treatment in Australia is anticipated to rise by 42% in the next nine years, from $383.6 million in 2016 to $543.9 million in 2025.[22] Estimated costs to the New Zealand health system are not known, but will likely reflect the percentage increase estimated in Australia. To manage costs, it is important to ensure that treatment is provided only to men who are likely to achieve a survival benefit from it.

The advent and increase in availability of PSA testing, coupled with rising disease awareness, have led to earlier diagnosis of more localised, low-volume prostate cancers for which surgery and radiotherapy can be curative.[23] This has brought with it the significant challenge of avoiding overtreatment of indolent disease, to ensure that men do not suffer treatment side effects when they are unlikely to experience clinical benefit.[24] Two key prostate cancer management goals therefore continue to be the early – and accurate – identification and treatment of aggressive disease, coupled with improvements in treatment to reduce the side-effect profile.

By contrast, some men with high-risk localised or locally advanced prostate cancer may be under-treated.[24] Aggressive treatment of such disease with combined treatment modalities can be curative. But research shows that otherwise healthy men, particularly if they are in an older age group or ethnic minority, are often being undertreated, for example, with hormone therapy alone.[20,25,26]

Despite the high prevalence of prostate cancer within our community, we still do not know enough about its aetiology. Advanced age, family history and ethnicity are known risk factors. Diet, exercise and body mass are all thought to be related to risk of prostate cancer.[27] Yet, we do not have sufficient information at present to make confident recommendations about disease prevention.

Finally, it is more than clear that a diagnosis of prostate cancer, coupled with the side effects of treatment can be significantly challenging, both emotionally and physically, for the men involved. Effective implementation of strategies to address psychological and physical burden as soon as possible after they become apparent, are therefore also crucial for effective disease management. Through comprehensive data collection and a focus on patient-reported outcomes, these challenges are areas in which PCOR-ANZ is poised to generate valuable data that can help inform clinical solutions.



3. DIAGNOSING PROSTATE CANCER

Data from PCOR-ANZ provide insights into current practice in the diagnosis of prostate cancer across Australia and New Zealand. We know from other studies that there are variations across different sub-populations in prostate cancer diagnostic practices in our region. It is particularly notable that Indigenous populations in Australia and New Zealand have lower rates of diagnosis than their non-indigenous counterparts.[14,17] As we get closer to population coverage, we hope to be able to demonstrate more clearly where and when variations such as these are occurring, with the aim of guiding solutions that will drive more equitable diagnostic practices. As data collection across several of our component registries is in its infancy, we cannot draw suitably robust conclusions about these variations as yet. But we aim to do so in future reports.

For the period 1 January 2015 to 30 December 2016 (two calendar years) there were 14,016 new (incident) cases of prostate cancer included in PCOR-ANZ. Trend data are provided for the period 2009 to 2016. It should be noted that longer-term trends prior to 2015 represent data from Victoria and South Australia only, as data collection did not commence in other jurisdictions until 2015.

STATISTICS AND TRENDS AT A GLANCE: DIAGNOSIS 2015–2016

Average age at diagnosis (mean): 67.7 years

Men in New Zealand were on average, slightly younger (66.4 years) while men in South Australia were on average slightly older (69.0 years) than average.

Mean age at diagnosis has risen slightly over the past seven years from 66.0 years in 2009 to 67.7 in 2016.

Most common method of diagnosis: TRUS, 62% of all men

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

As men age, transurethral resection of the prostate (TURP) becomes more common.

Median PSA level at diagnosis: 7.2 ng/mL

Median PSA at diagnosis has not significantly altered over time, but there was considerable variation across jurisdictions with the highest level in the Northern Territory (median 9.9 ng/mL) and the lowest in New South Wales (median 7.0 ng/mL).

STATISTICS AND TRENDS AT A GLANCE: DIAGNOSIS 2015–2016

Most common Gleason score at diagnosis:
Gleason score 7 (3 + 4); ISUP Group 2, 32% of all men (excluding missing data)

There is a notably high rate of ISUP Grade group 1 and 2 cases being diagnosed in New Zealand relative to other jurisdictions (77% of cases vs 57% in other jurisdictions combined, excluding missing data).

Northern Territory has a significantly higher rate of men being diagnosed with ISUP Grade Group 4 and 5 disease (43% vs 24% in other jurisdictions combined, excluding missing data).

Most common NCCN risk group at diagnosis:
intermediate, 48% of all men, excluding those for whom NCCN cannot be determined

Since 2009, there has been an increase in men presenting with intermediate-risk disease and a decrease in men presenting with low-risk disease.

My experience of some years as a consumer representative of the Steering Committee of the well-established SA-PCCOC has enforced for me the great value in having a national prostate cancer outcomes registry. The availability of accurate data for research to direct future treatment regimens indicates exciting progress for clinicians and will give patients decision-making choices for best treatment outcomes. As a patient, confirmation of my disease status 16 years ago was extended over 5 years before an adenocarcinoma was finally confirmed. Radiotherapy 2 years after radical surgery resulted in a positive outcome, however the value of registry research may have influenced a different treatment path with improved side effect issues. In my Support Group mentoring role, I am exposed to men living with complex post-treatment problems and fears, who would be reassured by the awareness that their treating clinician had access to the optimal research applications available. I am truly gratified that improvement in prostate cancer outcomes across Australia and New Zealand will result from the essential role of the registry.

DAVID MERRY
(SA REGISTRY REPRESENTATIVE).

AGE AT DIAGNOSIS

Of the 14,016 men who were diagnosed with prostate cancer and notified to PCOR-ANZ during 2015–2016, data on age were available for 13,870 men (99% of all men) **(Figure 6)**. The mean age at diagnosis was 67.7 years. The median age at diagnosis was 67.8 years, which correlates well with the 2018 Australian Government statistics (median age, 67 years).[12]

Age at diagnosis differed between jurisdictions with men in New Zealand being on average, slightly younger (66.4 years) while men in South Australia were on average slightly older (69.0 years) **(Figure 7)**. This may reflect differences in case-finding practices across jurisdictions. There has also been an increase in age at diagnosis over the past seven years from a mean age of 66 years in 2009 to 67.7 years in 2016.

When we compare our statistics to global data, men in Australia and New Zealand are on average, being diagnosed at a younger age than their counterparts in the United Kingdom. Results from the National Prostate Cancer Audit on men diagnosed between 2015 and 2016 found that 45% of men in the United Kingdom were aged less than 70 years at diagnosis,[24] while for our cohort, 61% of men were aged less than 70 years at diagnosis. By contrast, men in the United States appear to be diagnosed at an earlier age than our cohort. According to the United States National Institutes of Health, the median age at diagnosis is 66 years (period 2011–2015).[28] This correlates with a study of 10,472 men contributing to the Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE) registry, which found that the average age at diagnosis between 1990 and 2013 was 65.7 years (the registry accrued men with prostate cancer diagnosed at 45 urology practices across the United States).[29]

FIGURE 6: AGE AT DIAGNOSIS, TOTAL PCOR-ANZ POPULATION ACROSS ALL JURISDICTIONS (2015–2016).

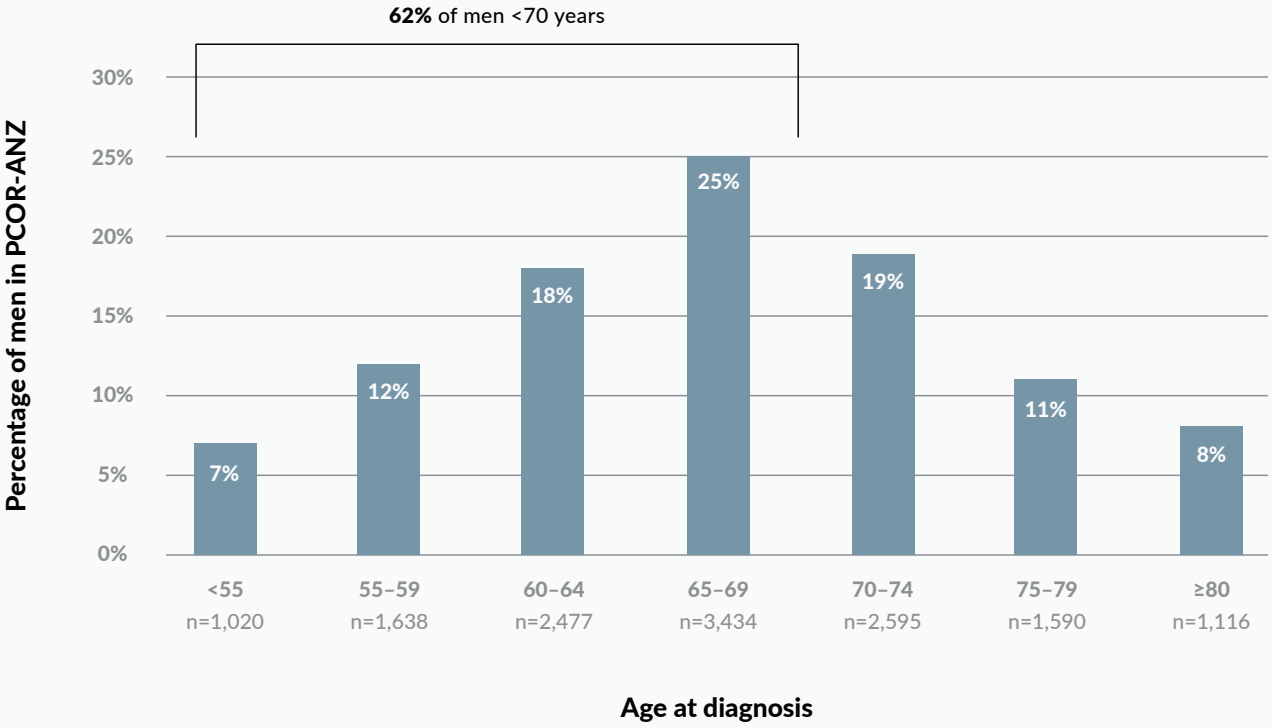
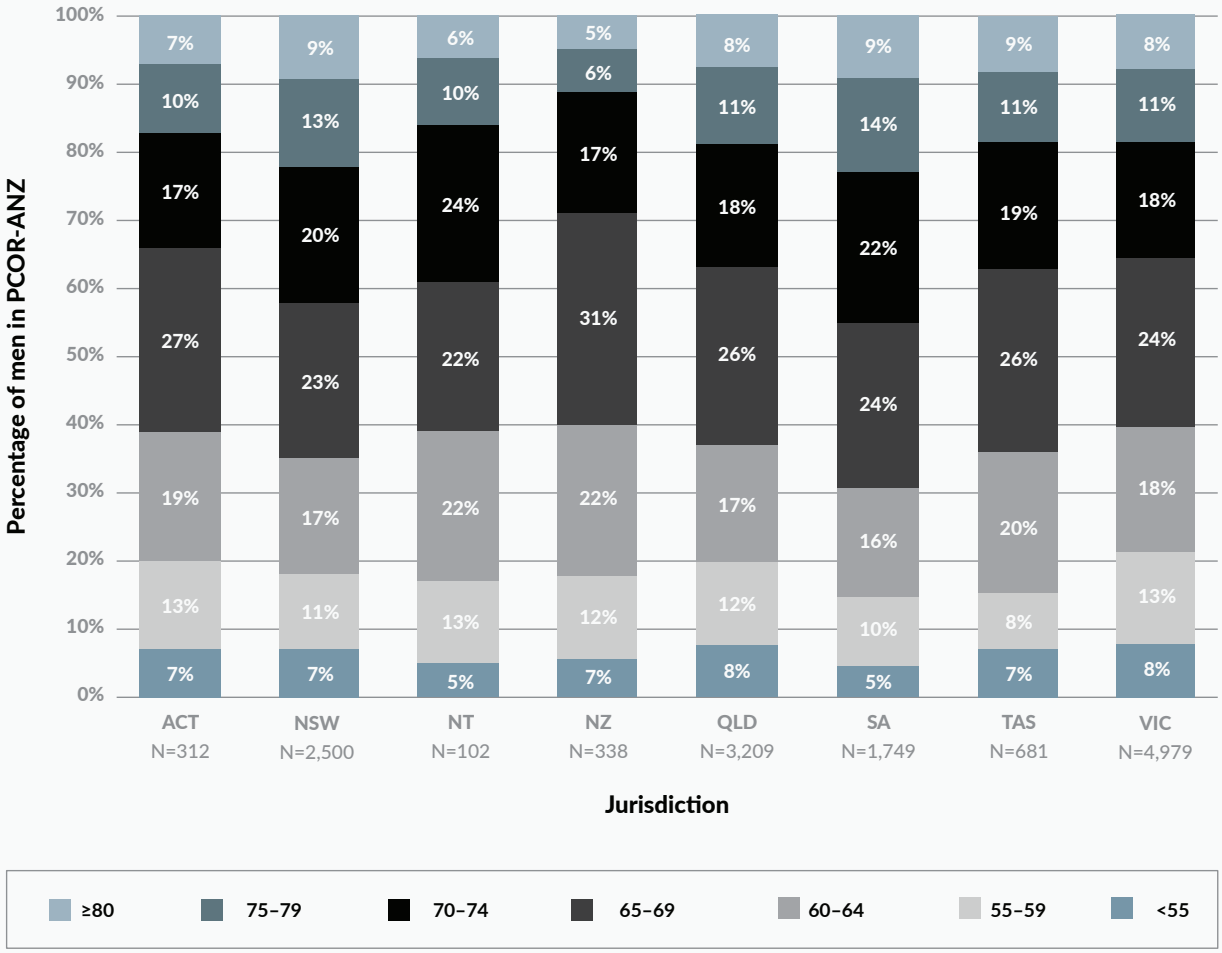


FIGURE 7: AGE AT DIAGNOSIS BY JURISDICTION (2015–2016).



METHOD OF DIAGNOSIS

For the reporting period of 2015–2016, TRUS was the most common method (62%) used to diagnose prostate cancer in PCOR-ANZ **(Figure 8)**. Comparatively, in the United Kingdom, a larger proportion of men (88%) are being diagnosed by TRUS.[24]

There were marked differences in method of diagnosis across jurisdictions, with transperineal biopsies used to diagnose approximately half of all men in Tasmania and Victoria, but used to diagnose only a minority of men in other jurisdictions **(Figure 9)**.

Transperineal biopsy via ultrasound guidance was first reported in 1981,[30] and outcomes have been reported for men diagnosed via transperineal biopsy in Australia from as early as 2006.[31] Our data show an increase in the use of this technique over time, particularly since 2013 **(Figure 10)**. This is a trend also seen in the United Kingdom where approximately 12% of men diagnosed in 2015–2016 had perineal sampling or template-guided biopsy to diagnose their prostate cancer.[24]

The method of diagnosis varies according to the age group of men at diagnosis **(Figure 11)**. Older men are more likely than younger men to require TURP to relieve urinary problems. Pathology analysis is taken on tissue excised during this procedure. As such, it is not surprising to see that as men age, the proportion diagnosed via TURP increases.

FIGURE 8: SUMMARY OF METHOD OF DIAGNOSIS ACROSS JURISDICTIONS (2015–2016).

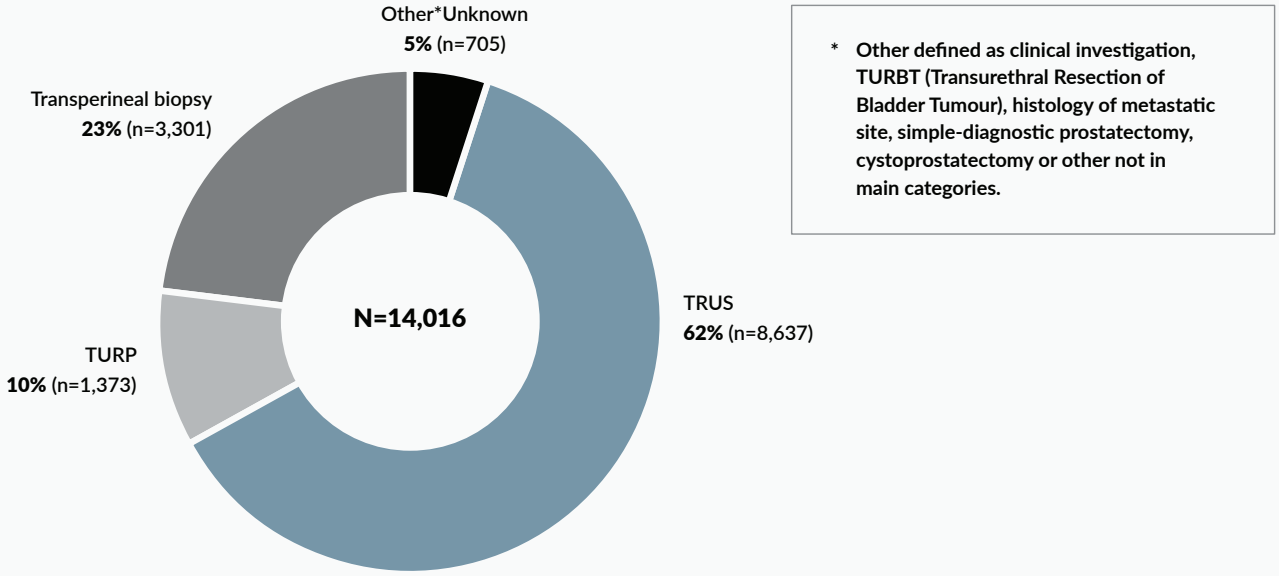
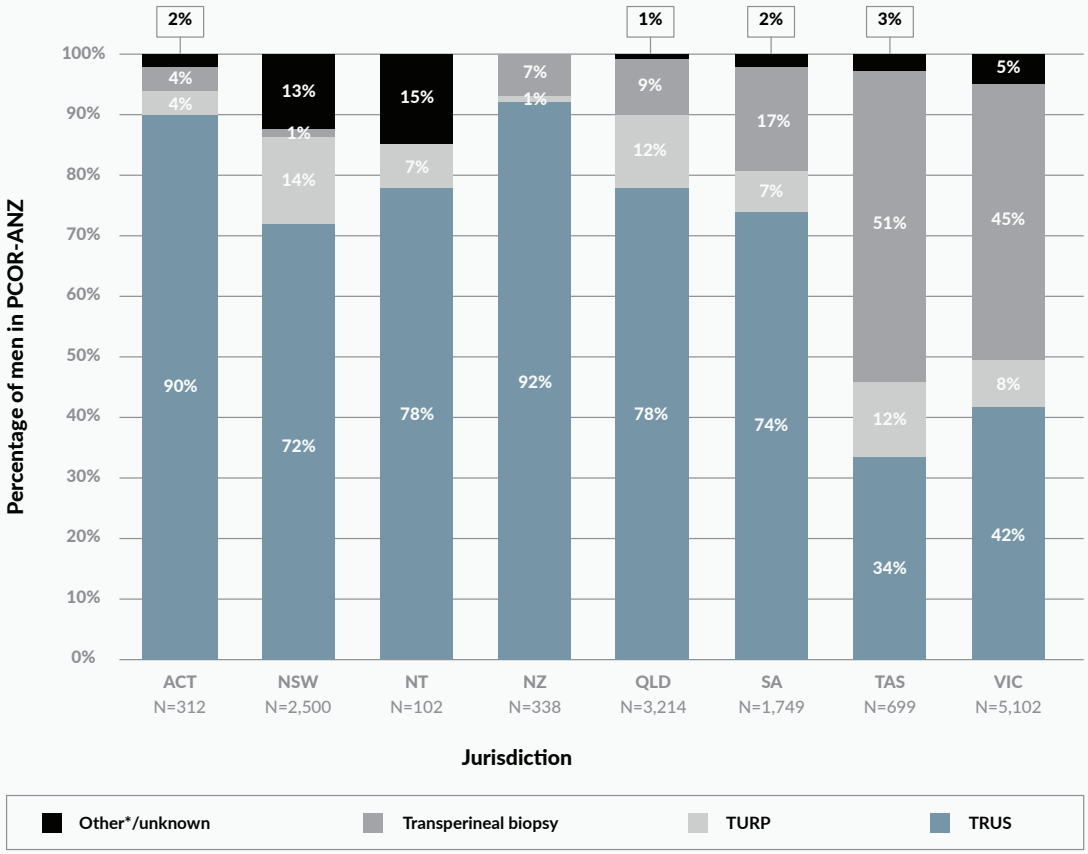


FIGURE 9: METHOD OF DIAGNOSIS BY JURISDICTION (2015–2016).

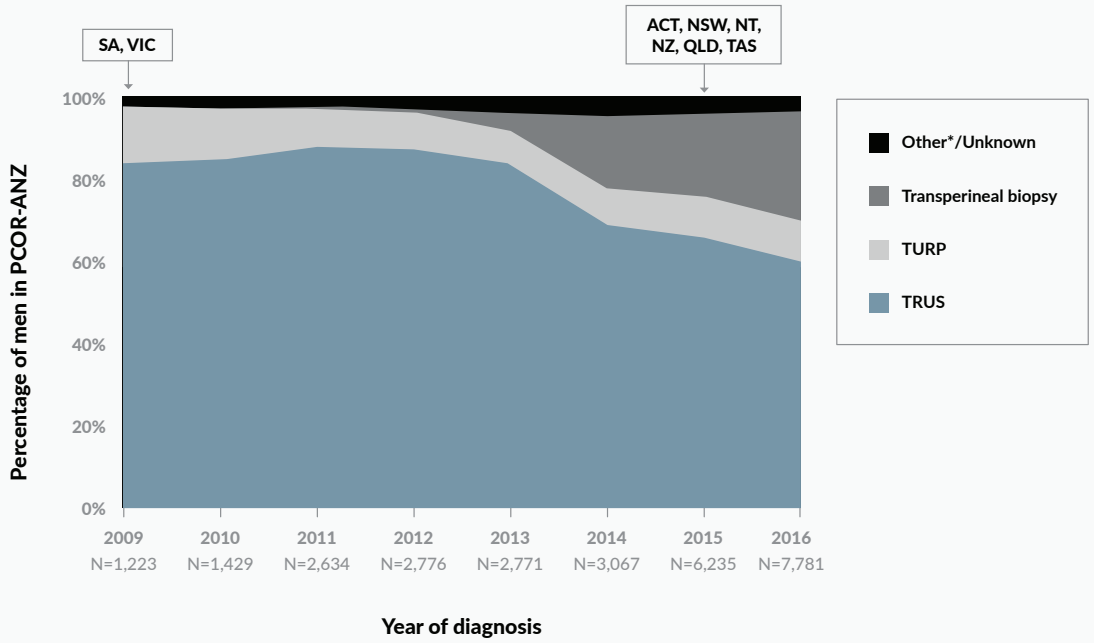


* Other defined as clinical investigation, TURBT (Transurethral Research of Bladder Tumour), histology of metastic site, simple-diagnostic prostatectomy, cystoprostatectomy or other not in main categories.

It is important to take into account that the registry does not have population coverage in most jurisdictions and coverage is biased towards capturing men diagnosed and treated in large, metropolitan hospitals. It will be interesting to evaluate these data when coverage occurs uniformly across Australia and New Zealand.

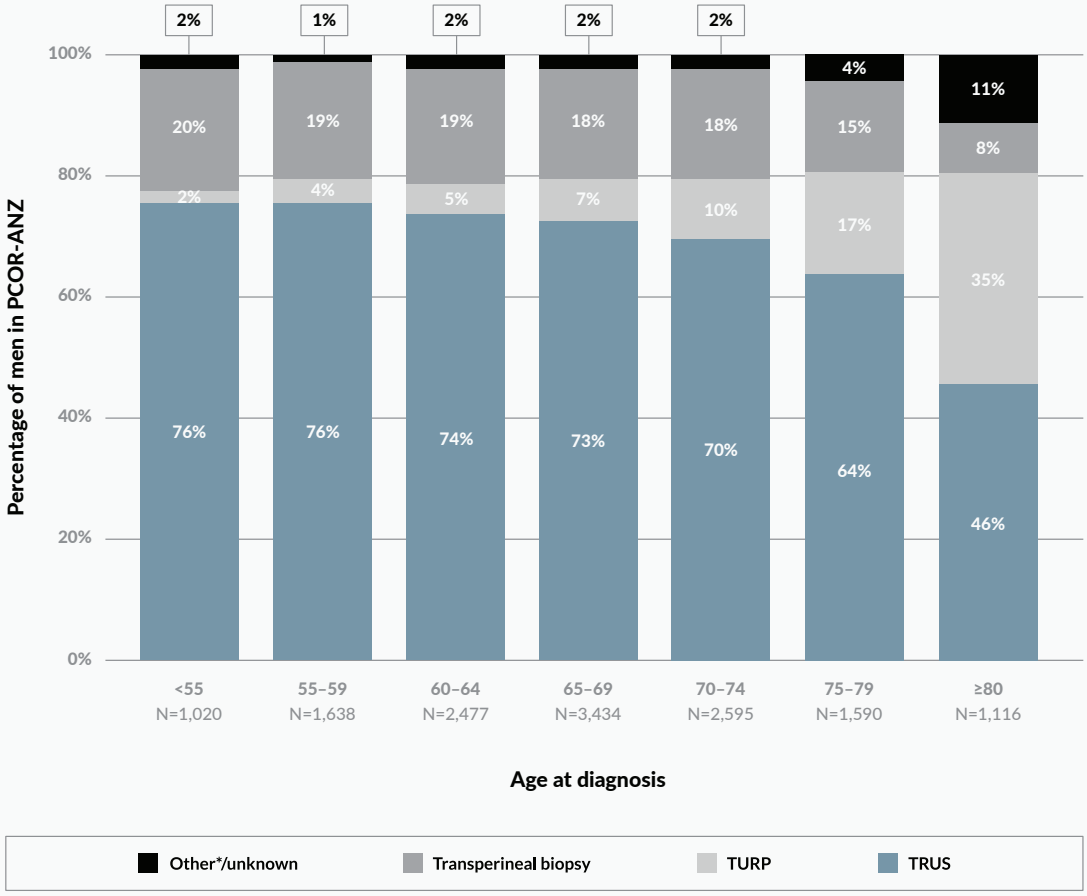
PCOR-ANZ has commenced capturing the use of MRI scans in the diagnosis and ongoing surveillance of men with prostate cancer. A systematic review is underway by PCOR-ANZ researchers to compare MRI scan plus TRUS biopsy, with MRI scan plus transperineal biopsy in terms of diagnostic accuracy, complications, and disease progression.

FIGURE 10: TREND IN METHOD OF DIAGNOSIS (2009–2016).



Year that data were first populated in thregistry, by jurisdiction, is indicated above the graph.

FIGURE 11: METHOD OF DIAGNOSIS BY AGE AT DIAGNOSIS ACROSS ALL JURISDICTIONS (2015–2016).

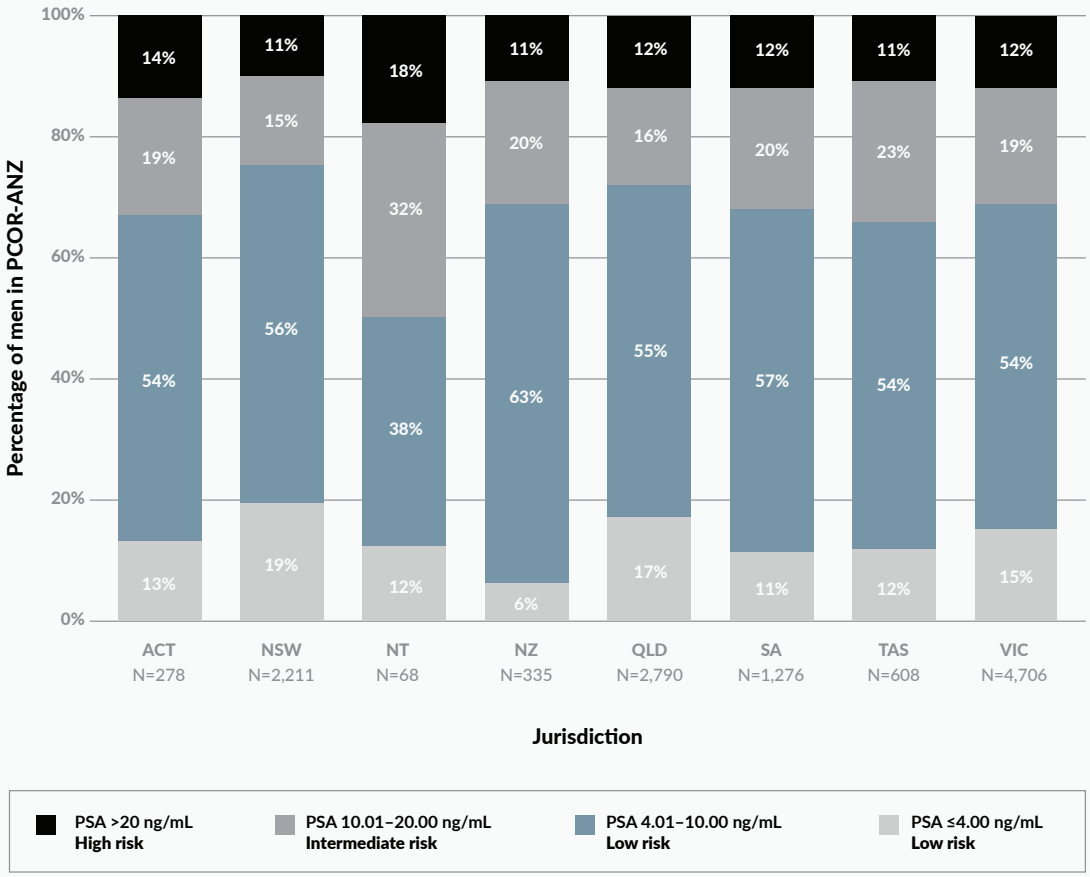


PSA LEVEL AT DIAGNOSIS

The median PSA level at diagnosis was 7.2 ng/mL, and readings were available for 12,263/12,847 (95.5%) men where PSA was recorded as having been taken. There were some notable variations by jurisdiction **(Figure 12)**. PSA level was highest in the Northern Territory (median level of 9.9 ng/mL) and lowest in New South Wales (median level of 7.0 ng/mL). Future research conducted by PCOR-ANZ researchers will help us better understand the reasons for this difference.

The overall median PSA level has not significantly altered over time, with the median rate around 7 ng/mL since 2009. In 2009, the median PSA level at diagnosis was 7.1 ng/mL and in 2016 it was 7.3 ng/mL, a difference that is clinically insignificant.

FIGURE 12: PSA LEVEL (ng/mL) AT DIAGNOSIS BY JURISDICTION (2015–2016).



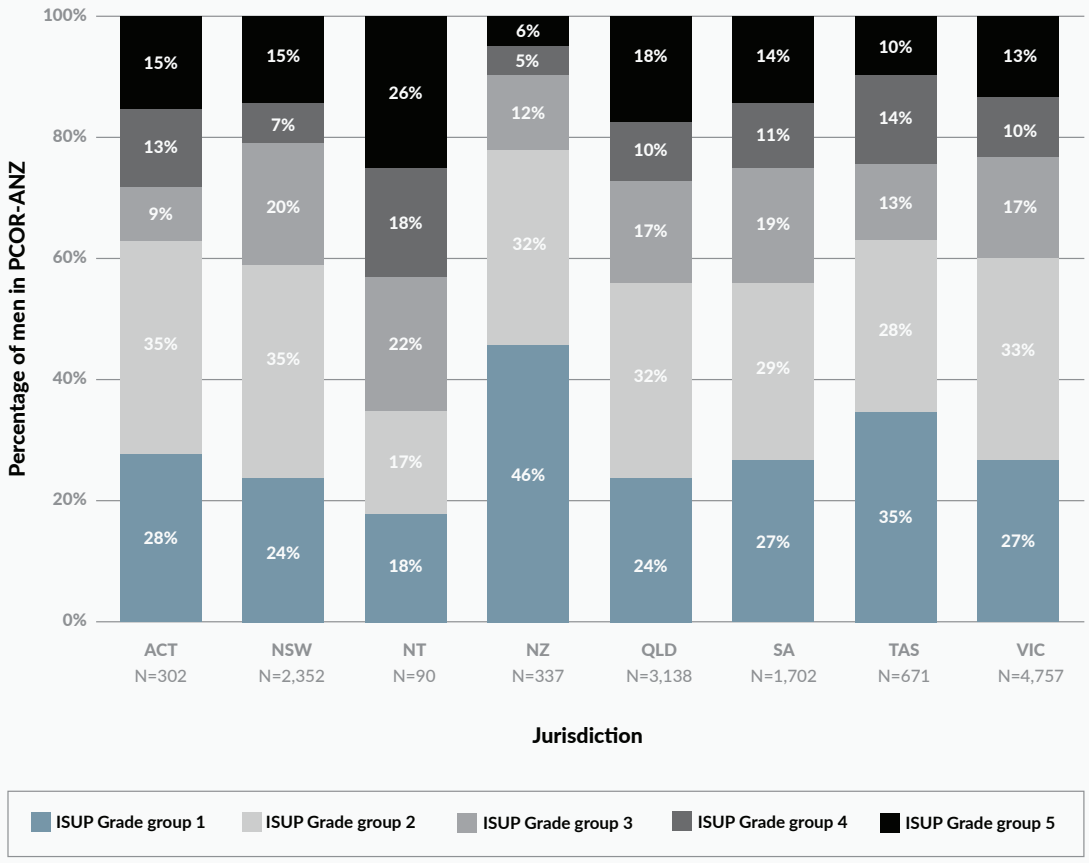
GLEASON SCORE AND ISUP GRADE AT DIAGNOSIS

A description of how the ISUP grade groups compare to the traditional Gleason Grading system is outlined in Appendix 6. Men in PCOR-ANZ were most commonly diagnosed with a Gleason score of 7 (3 + 4) – equivalent to ISUP Grade Group 2 – accounting for 32% of men for whom a Gleason Grade Group was available. Notably, there is a high rate of ISUP Grade Group 1 and 2 cases being diagnosed in men from New Zealand relative to other jurisdictions (77% of cases in New Zealand vs 57% in other jurisdictions combined, excluding missing data, p<0.001, Fisher's exact test).

It is unclear whether differences in population-wide approaches to PSA testing[32,33] may influence the observed stage of disease at diagnosis.

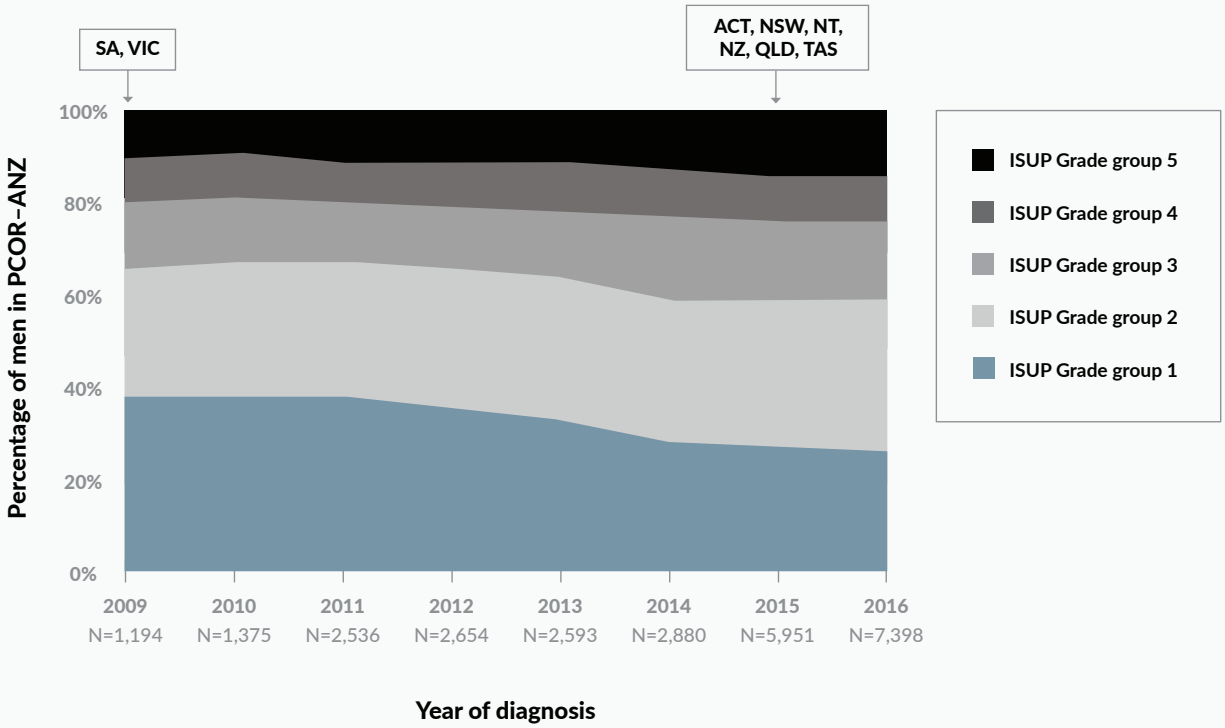
By contrast, the Northern Territory had a significantly higher rate of men being diagnosed with ISUP Grade Group 4 and 5 disease relative to other jurisdictions (43% vs 24% in other jurisdictions combined, excluding missing data, p<0.001, Fisher's exact test; **Figure 13**). Further research is required to understand whether men are more likely to present with symptomatic disease in the Northern Territory relative to other jurisdictions.

FIGURE 13: ISUP GRADE GROUP AT DIAGNOSIS BY JURISDICTION (2015–2016).



When assessing trend over time **(Figure 14)**, we observed more Grade Group 4 and 5 men in recent years. This represents data from jurisdictions other than South Australia and Victoria joining the registry from 2015 onwards e.g. the Northern Territory joined the registry in 2015 and has a higher proportion of men with high-grade disease. It will be important to monitor this closely over coming years to see if this trend continues as the registry moves towards population coverage. It will also be important to assess whether this increasing trend towards diagnosing men with higher-stage disease correlates with an increase in age-standardised disease-specific mortality. It is envisaged that PCOR-ANZ will have an ongoing important role to play in informing policy development of prostate cancer case-finding recommendations.

FIGURE 14: TREND IN ISUP GRADE GROUP (2009–2016).



Year that data were first populated in the registry, by jurisdiction, is indicated above the graph.

NCCN RISK GROUP AT DIAGNOSIS

PCOR-ANZ uses the risk prediction model developed by the NCCN in the United States.[6] We use this model because it has been validated in Australian men and uses the same model across all management approaches. It is therefore easy to understand and apply. Details of how the NCCN risk groups are calculated are outlined in Appendix 7.

Across all jurisdictions, men were most likely to present with intermediate risk prostate cancer (**Figure 15**). A slightly higher percentage of men were diagnosed with localised disease in this Australian–New Zealand cohort when compared with a large cohort of 751,565 men from the United States between 2004 and 2007 (86% vs 82%, respectively).[29]

NCCN risk groups are unable to be calculated in 5% of cases. Because of the way in which the risk groups are defined, it is highly likely that these men will have low-risk disease (data not shown due to small numbers).

FIGURE 15: NCCN RISK GROUP AT DIAGNOSIS ACROSS ALL JURISDICTIONS.

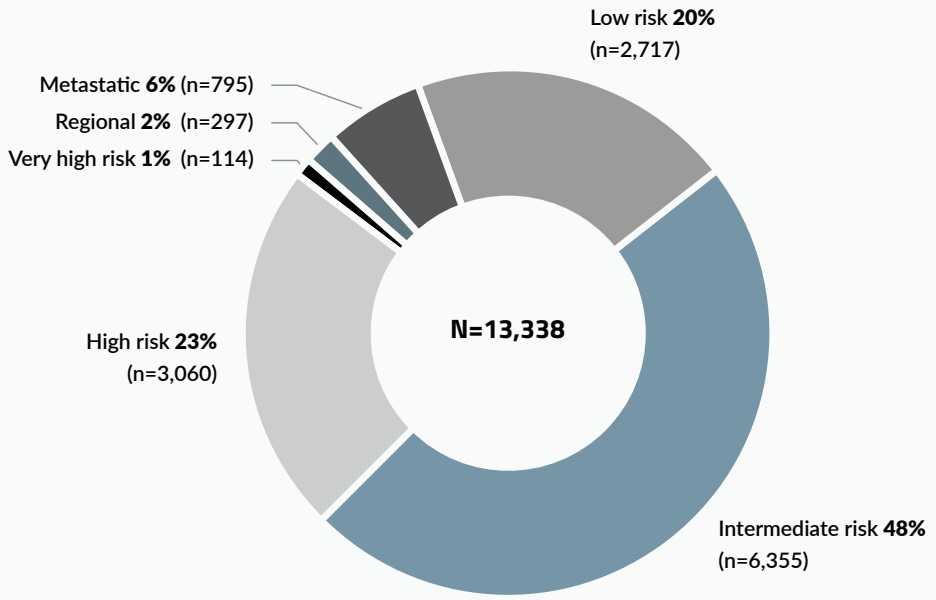


FIGURE 16: NCCN RISK GROUP AT DIAGNOSIS BY AGE AT DIAGNOSIS (2015–2016).

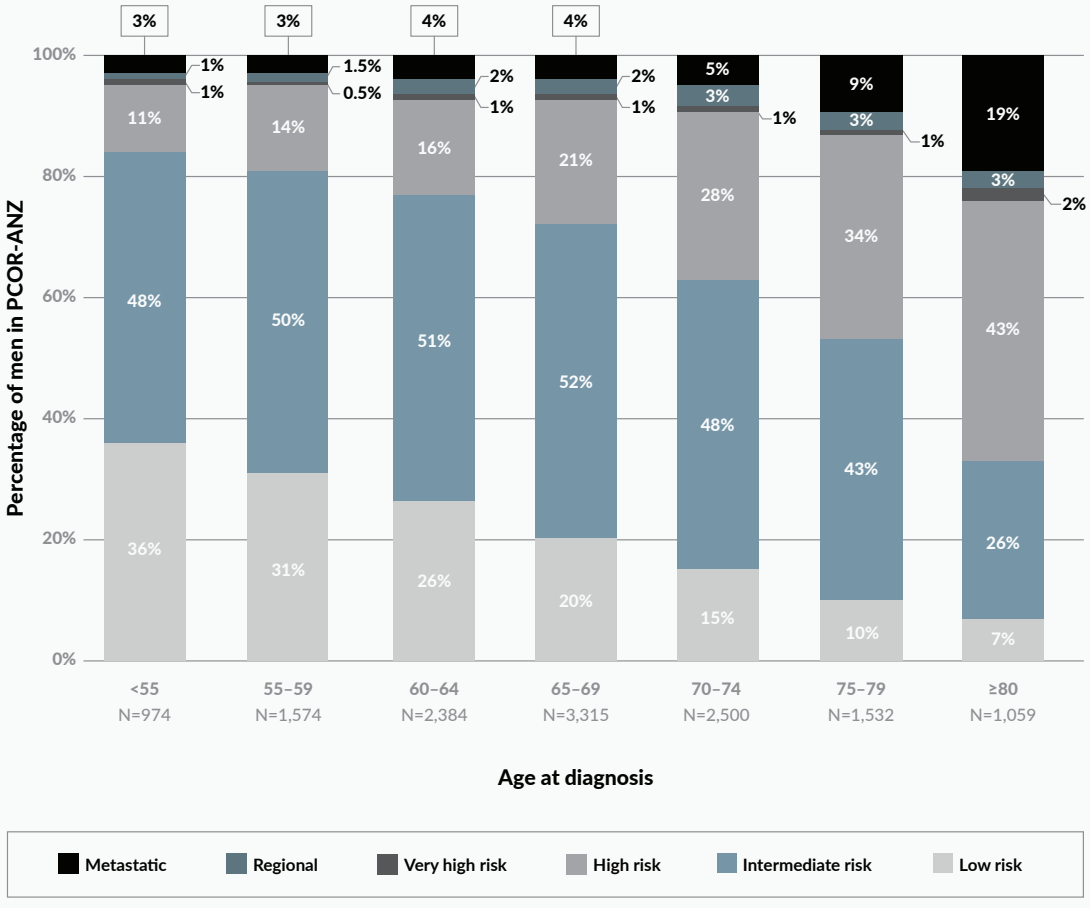


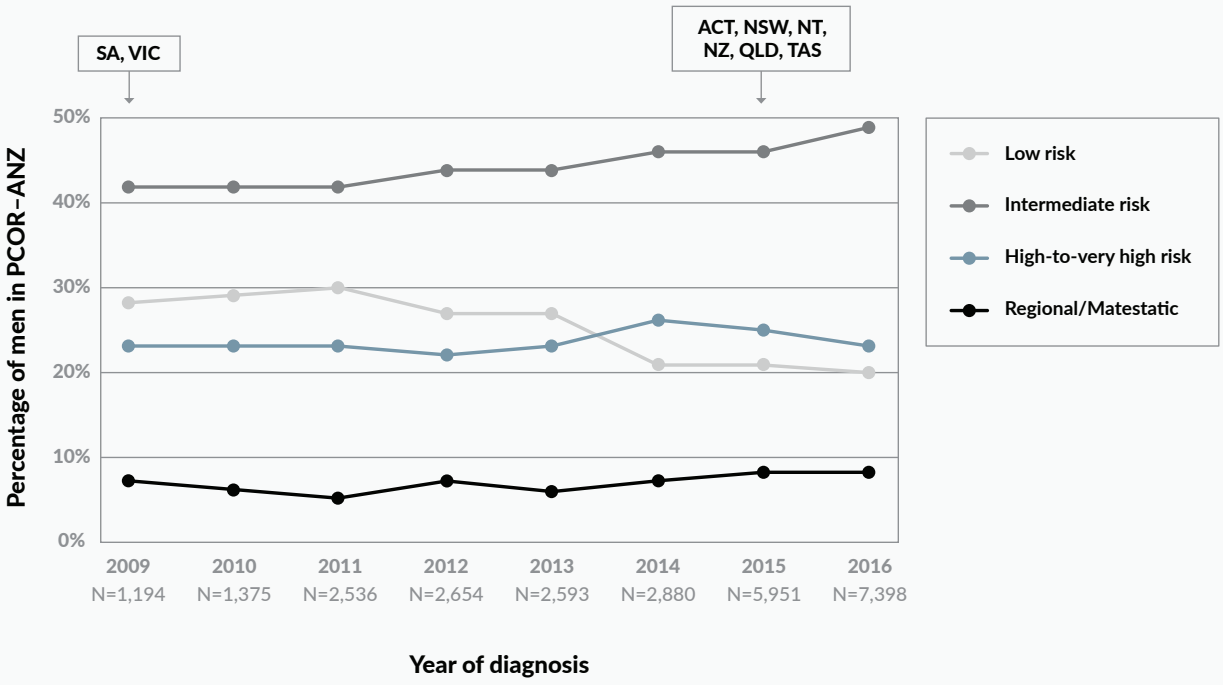
Figure 16 summarises risk groups by age at diagnosis. Men aged over 75 years were significantly more likely to be diagnosed with high-to-very high disease risk or above, compared with men aged 75 years or below. Not surprisingly, younger men are more likely to be diagnosed with early-stage disease compared to older men, as these represent the group most likely to be detected through case finding.

Of interest is the changing profile of risk group over the past eight years, displayed in **Figure 17**.

We observed an increase in intermediate-risk disease and a decrease in low-risk disease, likely reflecting change in case finding practices across Australia and New Zealand.

The quantitative statistics provided in this section of Chapter 3 give an indication of age and stage at diagnosis. The psychosocial burden of a prostate cancer diagnosis is discussed in the following section, through our qualitative research projects.

FIGURE 17: TREND IN NCCN RISK GROUP ACROSS ALL JURISDICTIONS (2009–2016).



Year that data were first populated in the registry, by jurisdiction, is indicated above the graph.

QUALITATIVE RESEARCH AT DIAGNOSIS

Qualitative research improves our understanding of the needs and experiences of men with prostate cancer and complements the statistical data the registry collects. It is important to appreciate that every man's journey is different, and that aggregating data in reports can sometimes de-personalise the individual nature of the journey.

The qualitative research presented here was undertaken by PCOR-ANZ researchers in South Australia[34] and Victoria[35] (South Australia, N=20 men diagnosed with prostate cancer; Victoria, N=10 interviews with men and GPs in regional and metropolitan areas, plus N=10 interviews with men who had received radiotherapy).

THE IMPACT OF A PROSTATE CANCER DIAGNOSIS

Emotional effects of diagnosis

Many men did not specifically report that their prostate cancer had impacted their emotional well-being as such. However, the emotional impact was apparent indirectly when their feedback was analysed. For example, several men described feelings of anxiety, loneliness, social isolation, anger, questioning ("why me?"), fear of dying and distress.

"Yes, once you deal with the big bad guy, that's when you deal with this, it's emotionally almost as bad but it's not going to kill you."

(52 years, 6 months after diagnosis, SA study)

Stigma

Some men felt there was stigma attached to prostate cancer. This view was more common among younger men, as prostate cancer was less familiar within their friend groups. These men believed that other people were reluctant to talk to them about their illness because of this sense of stigma.

Some men found a sense of embarrassment or awkwardness towards prostate cancer because of the side effects, such as sexual dysfunction, and because of its genital proximity. Some were reluctant to talk to others because they were embarrassed and fearful of others' reactions towards them, and some were reluctant to talk to others as they preferred to keep health issues private.

"Yeah, that's because it's involved with the sexual organs and as such, people don't like … to ask questions… it ends up being a, 'oh we can't talk about it', type issue".

(45 years, interviewed 4 months after diagnosis, SA study)

"I kind of wonder whether that's actually because of the, a stigma attached to prostate cancer, and oh like secret men's business, it's a bit downstairs, a bit yucky, and not considered, like breast cancer is very much out in the open … Prostate cancer is far more hidden."

(52 years, 6 months after diagnosis, SA study)

Seeking information

It seemed that information seeking was a common 'coping mechanism' to reduce anxiety. Men actively sought out information, particularly after diagnosis, and prior to treatment, from multiple sources, e.g., medical professionals (urologists/doctors/surgeons), websites, and friends, and to a lesser extent, from nurses, written information (pamphlets or books), and support groups.

"I've done my own research through the net and I've also talked to people who have also been through the same journey … you get to know who are the good oncologists, who are the good urologists and I've spoken to people who have had different treatment options and got their information as well."

(50 years, 2 months after diagnosis, SA study)

The waiting period

Interviews with men living in regional Victoria identified some difficulties they faced in waiting for a diagnosis after their biopsy.

"I think the worst part of the whole affair was waiting from the time I had my biopsy 'til the time I was told that I had prostate cancer … over a month, I think it was … so that was terrible, because your imagination plays havoc with you."

(77 years, regional Victoria, Vic study)

MANAGING AFTER A PROSTATE CANCER DIAGNOSIS

Regardless of which treatment men choose, treating prostate cancer is likely to have both a clinical and psychosocial impact. It may impact relationships, finances, and how men perceive themselves. In their interviews with men, PCOR-ANZ researchers from South Australia and Victoria discussed the process of decision making, treatment choices and the impact of this treatment on their quality of life. Below we discuss some key themes which emerged.

Effects on relationships

Some men felt that, at times, they were overburdening their partners emotionally. Sexual problems as a consequence of treatment impacted on relationships for many of them. This was particularly difficult for single men as they felt it prevented them from seeking sexual intimacy.

"I mean obviously being impotent is not great, that's not good for a relationship… Because you don't get the same intimacy with your partner. I guess it's an important part of your life and just, I feel like I've let her down."

(59 years, 13 months after diagnosis, SA study)

"I'm just concerned I suppose, whether you know you might meet someone and be expected to sleep with them it might be an issue."

(61 years, 1 month after diagnosis)

Effects on how men saw themselves

For some men, having prostate cancer and experiencing treatment side effects (e.g., impotence and/or urinary incontinence) resulted in feelings of lost manhood.

"Well as yeah, a status thing, you know, you are no longer a bull in the paddock, you know, you're cast out as a heifer … like a gelding in horse racing terms. And you know, definitely affects your sense of self."

(52 years, 6 months after diagnosis, SA study)

"I never felt like a man when I had pads on."

(54 years, 11 months after diagnosis, SA study)

Some men felt being diagnosed with a disease associated with older age was challenging to their sense of mortality and invincibility.

"…even though I'm 64, I still retain vestiges of a teenage male sense of invincibility… so this is kind of a reminder that I'm human. So that was a blow to my ego if nothing else."

(64 years, 18 months after diagnosis, SA study)

"I think it's only normal to say that everybody goes through that questioning of 'well, is this it?' Is this the beginnings of a slow but sure decline into immortality, being no longer…?' "

(61 years, 6 months after diagnosis, SA study)

Effects on finances and planning for the future

Some men experienced financial burdens and had concerns regarding providing for their family.

"So hopefully I'll still be able to provide reasonable support for my son and my wife, when I'm gone, but yeah it depends how long I last and how expensive it is."

(59 years, 13 months after diagnosis, SA study)

Not typically seeking emotional support

Men typically did not seek formal support, although there were indications that it may have been valuable. A few mentioned that medical professionals had suggested counselling, but this was not common, and some men had little awareness of the support that was available.

"…I'm not very happy … the fact that there is not much information distributed, concerning localised prostate cancer, and as a matter of fact any cancer that's available… The treatment, the hospital treatment, the medical side of it, it's okay, it's just the relevant information to keep people from going outside and stepping in front of a bus."

(73 years, 2 months after diagnosis, SA study)

"…But nothing has ever been suggested to me. 'Do you feel you need help, or would you like to go to a support group?' It's never been offered."

(82 years, 2 months after diagnosis, SA study)

Support groups appeared to be an important source of support for some men, although awareness of support groups varied considerably. One man stated:

"I reckon you should go off to a support group straight away… Just to know you're not the only one."

(54 years, 11 months after diagnosis, SA study)

Some men were hesitant to talk to anyone, including friends or family. Reasons for this ranged from anticipated awkwardness from others, not wanting to burden others with their problems, not wanting to attract sympathy (uncomfortable), and because they felt the issue was private. Some men (generally single men) felt that they could or should deal with things themselves. Several men felt that they would not seek emotional support in any context, and suggested that seeking emotional support or help was not characteristic of men.

"I figure, well other people have got their own problems. They don't want to know my problems."

(67, 27 months after diagnosis, SA study)

DIAGNOSING PROSTATE CANCER FROM THE GPs' PERSPECTIVE

PCOR-ANZ data showed that, in some regional areas of Victoria, men are more likely to be diagnosed with later-stage disease than in other areas.[36]

In one region, it was particularly troubling; not only were men being diagnosed with later-stage disease, they were also waiting longer for definitive active treatment. This research sparked investigation of the attitude of GPs in this region and in metropolitan Melbourne to prostate cancer testing and management. (Ten GPs were interviewed, four from the regional area of concern, six from metropolitan Melbourne, six were female and four male).[37]

Issues raised by the GPs included a perception that men would prefer to see a male GP than a female GP, and that in some regional areas there was a shortage of male GPs.

"I think, like a lot of practices, it really depends on the demographics of the doctors at the time, so I think our prostate cancer care was much better when we had a 55-year-old [male] GP working here. So, I have to say that I think that decreased when he left the practice."

(Regional GP, female)

GPs faced time constraints and information deficits in undertaking the testing. They felt they had an important role to play in case finding and diagnosis, but that it was difficult to engage men in thinking about it. Promoting testing through posters was thought to be effective. Additionally, GPs in regional areas were often well known to their community, making broaching the subject of prostate cancer somewhat awkward.

"You're the first port of call, and, if you can prompt it, and the patient is agreeable for further investigations, I think that's the most important thing for a GP to do: first of all to raise the issue, and then to do something about it."

(Regional GP, male)

"[Unlike] women who come in and say, 'I'm here for my Pap smear,' men don't say, 'I'm here to talk to you about prostate cancer.' The only people who ever do that are those with a very strong history of prostate cancer."

(Metropolitan GP, male)

"[Some GPs] wouldn't be bothered to [educate men] anyway because of the time factor."

(Regional GP, female)

"I tend to make lots of phone calls to urologists … I don't really feel confident in making a decision about any PSA results."

(Regional GP, female)

"I think we need much more clear guidelines as to whether we go the PSA pathway or the digital rectal exam pathway. I know that one college, the College of Pathologists, traditionally has said one thing, and then the College of GPs has said another."

(Metropolitan GP, male)

"The reason why [there are poorer outcomes in regional areas] is because country folk – look, you've only got a small number of GPs. They know you very well. They've probably known you for a very long time, and it's maybe just a tad too intimate to somebody you know very well offering to put a finger up your bottom."

(Metropolitan GP, male)

Through interviews with GPs, a number of strategies to improve outcomes for men in regional areas were suggested. It was suggested that because men in regional areas often do not have regular visits to their GP, educational material about prostate cancer could be provided through sports clubs and 'men's sheds', which have been established to improve men's health and wellbeing.

"[We need] easy printout material … in a brochure form or something to give to the patient."

(Regional GP, female)

"… people often respond to all sorts of posters, even things that you think no-one would be interested in. But someone will say, 'I just saw that poster outside,' and they want to talk about it. So, I think a poster is a very quiet but powerful way, and a very cost-effective way, of bringing that up."

(Metropolitan GP, female)

CONCLUSION

Collection of clinical details on method of diagnosis is important. Equally important, is understanding the impact of a prostate cancer diagnosis on men's wellbeing. Qualitative research provides the ability to capture the 'lived experiences' of participants and assists in providing an understanding of issues impacting people living with, and those caring for, people with prostate cancer.

In addressing the significant issues raised by men early after their diagnosis, a focus for PCOR-ANZ over the next few years will be to initiate contact with men as soon as possible after their diagnosis. This will provide baseline information on health and quality of life, and the ability to provide information support to assist in this turbulent journey.

The relationship between men and their GP is important in the management of their overall health. Yet, there remain a number of complex issues which prevent GPs from testing men for prostate cancer. Through the provision of data on prostate cancer trends and health outcomes, PCOR-ANZ will help inform development of policy guidelines for testing and management of the disease.

4. TREATING PROSTATE CANCER

The most significant decision that men must make when faced with a prostate cancer diagnosis is what treatment to have; and a key part of that decision is based on their disease stage and level of risk. Over-treatment of low-risk disease and under-treatment of high-risk localised or locally advanced disease are recognised clinical challenges.[24] And it is clear that there are inequalities in treatment delivery and outcomes between different populations across Australia and New Zealand.[16,17,19,20]

For example, data from the Victorian PCOR-ANZ registry have revealed significant discrepancies in treatment patterns and patient outcomes between metropolitan Melbourne and other areas of Victoria.[36] Studies in New Zealand have also shown that rural men do not receive the same level of care as their urban counterparts.[16]

A key goal for PCOR-ANZ is to gain the population coverage needed to facilitate systematic analyses that will identify where and when such discrepancies in treatment occur. Allowing us to help define solutions that will provide more equitable standards of treatment across, and within, all jurisdictions in our region.

I have been battling advanced prostate cancer for 15 years now. My current PSA is about 1 so I'm in a good place. I've been heavily involved in support, awareness, advocacy and research since 2010, and I'm particularly interested in advanced disease and am a founding member of the Advanced PC Support Group.

Ultimately, research is the route to the medical aspects of that help. I have been involved with The Movember Foundation's TrueNth program since its inception and, more recently, in their Ironman Registry proposal for advanced guys. I see registries as important to provide general peer comparisons for clinicians and most importantly as generators of hypotheses for researchers. Guiding research in fruitful directions will be a great benefit amidst the complexities of cancer. That's why I joined the committee.

TONY MAXWELL
(NSW PCCR PATIENT REPRESENTATIVE)

NOTES ON TREATMENT DATA 2015–2016

In the 2015–2016 dataset, population coverage was not sufficient to allow meaningful inter-jurisdictional comparisons due to low patient numbers in some of the younger databases. This analysis has therefore been completed on an 'all jurisdictions' regional level.

Data on active surveillance and watchful waiting management groups have been combined in this report because there is sometimes ambiguity in documentation as to whether men are receiving one or the other. However, it should be noted that even though both result in men not having immediate surgery or radiotherapy, the management approach of watchful waiting and active surveillance is quite different.[38]

Data on salvage ADT were not available from either the South Australia or Northern Territory databases for this analysis. Patient-reported outcome data from the Northern Territory were not available for inclusion in this report.

STATISTICS AND TRENDS AT A GLANCE: TREATMENT 2015–2016

In all calculations missing data have been excluded.

Low risk

69% of men with low-risk disease had either active surveillance or watchful waiting.

31% of men across Australia and New Zealand chose active treatment (surgery, radiotherapy or 'other').

In men under 60 years of age, 42% (354/840) underwent immediate surgery or radiotherapy.

Intermediate risk

62% of men with intermediate-risk disease had surgery, 21% had radiotherapy and 15% commenced on active surveillance or watchful waiting.

High risk

83% of men received treatment with curative intent (47% of men received surgery, 36% received radiotherapy).

15% of men received non-curative treatment (8% received watchful waiting or active surveillance and 7% received ADT as monotherapy).

Very high risk

Very high-risk disease accounted for only 1% of new prostate cancer cases.

80% of men with very high-risk disease received either surgery or radiotherapy and 15% received ADT monotherapy.

Regional disease

Regional disease accounted for 2% of new prostate cancer cases.

62% of men received radical (surgery or radiotherapy) treatment.

Metastatic disease

6% of newly diagnosed cases of prostate cancer had disease that extended to the lymph nodes (N1) or other distant sites (M1).

48% of men underwent ADT monotherapy and 28% underwent chemotherapy-monotherapy.

PROSTATE CANCER TREATMENT ACROSS ALL PCOR-ANZ JURISDICTIONS

Data on treatment by risk group were available for 13,336 men from the database, of whom, the majority (43%) had surgery to treat their prostate cancer, with active surveillance/watchful waiting (21%) and then radiotherapy (19%) being the second most popular treatment decisions overall (Table 2). Other treatments included cystoprostectomy, green light laser therapy (n=9), and focal treatments (n=8).

TABLE 2: SUMMARY OF MANAGEMENT PROVIDED TO MEN BY NCCN RISK GROUP IN AUSTRALIA AND NEW ZEALAND ACROSS ALL JURISDICTIONS (2015–2016).

	NCCN RISK GROUP						
PRIMARY TREATMENT	**LOW RISK n (%)**	**INTERMEDIATE RISK n (%)**	**HIGH RISK n (%)**	**VERY HIGH RISK n (%)**	**REGIONAL n (%)**	**METASTATIC n (%)**	**LOW RISK n (%)**
Surgery*	596 (22)	3,708 (58)	1,274 (42)	26 (23)	60 (20)	52 (7)	5,716 (43)
Radiotherapy**	159 (6)	1,238 (20)	980 (32)	58 (51)	105 (35)	94 (12)	2,634 (20)
Chemotherapy-monotherapy	0 (0)	0 (0)	13 (0.4)	2 (1)	20 (7)	191 (24)	226 (2)
ADT - monotherapy***	2 (0.1)	54 (1)	181 (6)	16 (14)	59 (20)	332 (42)	644 (5)
Watchful waiting / active surveillance	1,708 (63)	873 (14)	225 (7)	3 (3)	17 (6)	11 (1)	2,837 (21)
Other treatments#	18 (1)	65 (1)	31 (1)	0 (0)	6 (2)	6 (1)	126 (1)
Missing	234 (8)	415 (6)	356 (12)	9 (8)	30 (10)	109 (14)	1,153 (9)
TOTAL	2,717 (100)	6,355 (100)	3,060 (100)	114 (100)	297 (100)	795 (100)	13,336 (100)

*Excludes men on active surveillance who then had surgery.

**Radiotherapy includes EBRT, high dose rate (HDR) and low dose rate (LDR) brachytherapy, and radiotherapy type unknown.

***ADT data not available for SA and NT at time of data analysis.

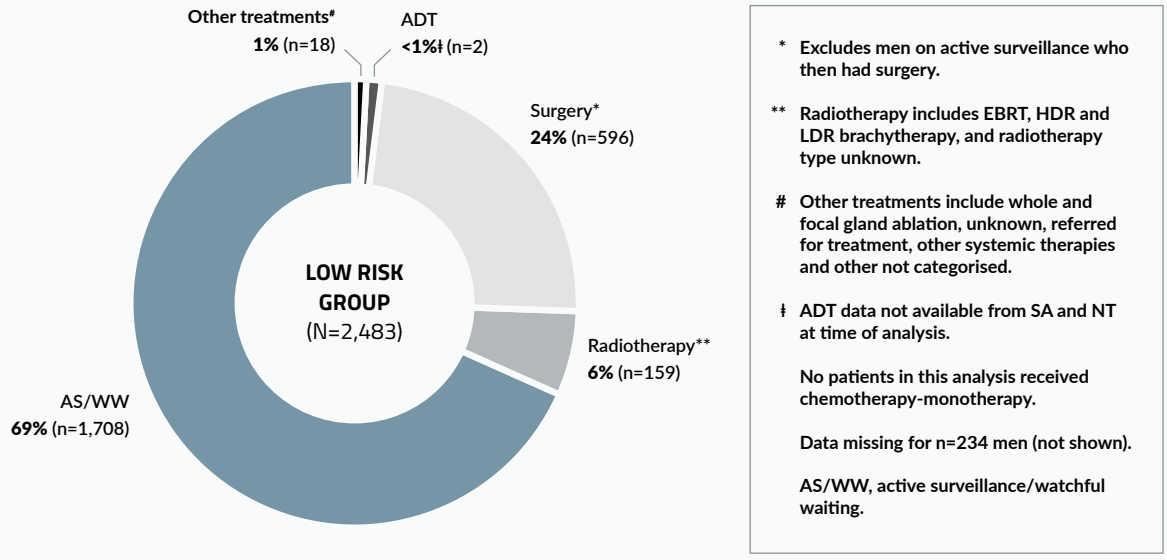
#Other treatments include whole and focal gland ablation, referred for treatment, other systemic therapies and other not categorised.

LOW-RISK GROUP

To avoid unnecessary treatment burden in patients for whom there is likely to be little benefit, Australian and International guidelines recommend the use of active surveillance for all men with low-risk prostate cancer.[5,39] Across all PCOR-ANZ jurisdictions, 69% of men with low-risk disease had either watchful waiting or active surveillance (excluding missing data). This indicates that, across our region, up to 31% of men were potentially being over treated in 2015–2016 (excluding missing data; **Figure 18**). There is work to be done here in reducing overtreatment of men with low-risk disease, as there is international evidence that we can achieve better results.

In the United Kingdom, the 2015–2016 National Prostate Cancer Audit demonstrated that only 8% of men with low-risk disease underwent radical treatment. This signalled a decline from 12% the year prior.[24] In Sweden between 2009 and 2014, active surveillance increased from 57% (380/665) to 91% (939/1027) for very-low-risk prostate cancer and from 40% (1159/ 2895) to 74% (1951/2644) for low-risk prostate cancer, with the strongest increase occurring from 2011 onward. Among Swedish men aged 50 to 59 years, 88% (211/240) with very-low-risk and 68% (351/518) with low-risk disease chose active surveillance in 2014.[40]

FIGURE 18: PRIMARY TREATMENT IN THE LOW-RISK GROUP (2015–2016).

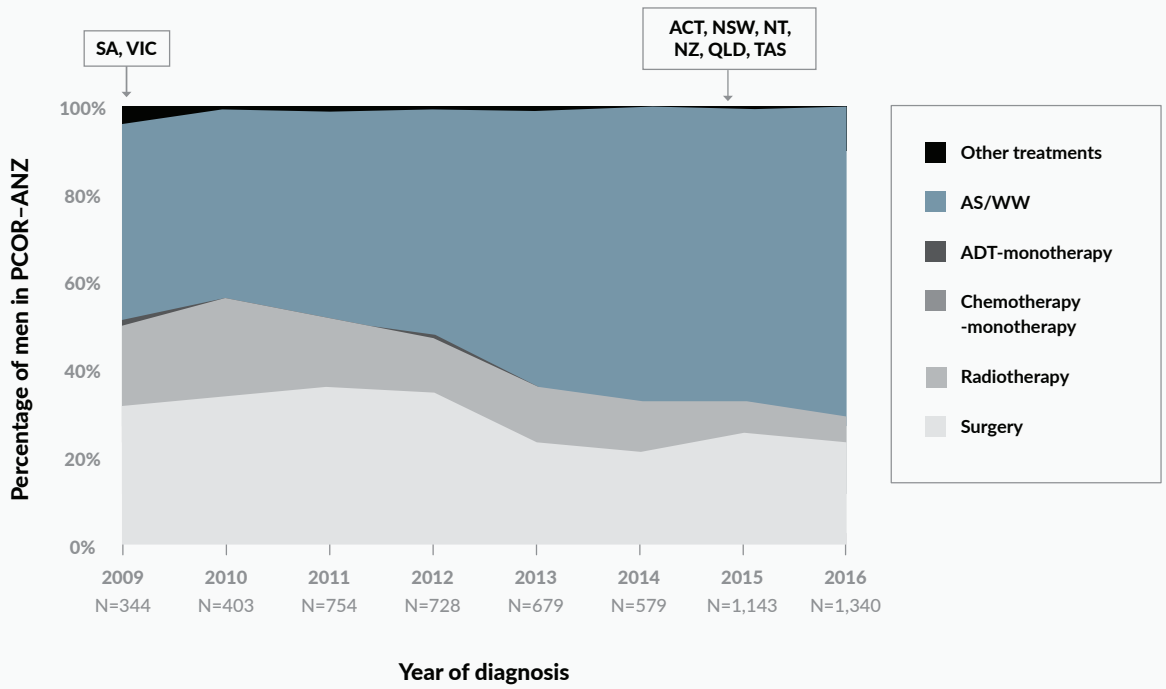


However, among men in PCOR-ANZ diagnosed before the age of 60 with low-risk disease, 42% (354/840) underwent radiotherapy or surgery. Choosing more aggressive treatment modalities to treat low-risk disease may be particularly impactful on younger men, as they will have to live for many years with the potential side effects they bring. Encouragingly, there are early indications that there is an increasing trend in our region towards choosing active surveillance/watchful waiting among men with low-risk disease **(Figure 19)**. It will be important to monitor this as the registry approaches population coverage. We anticipate seeing this rate increase to above 85% in line with contemporary practice in other countries.

INTERMEDIATE-RISK GROUP

The widely-employed NCCN risk grouping for prostate cancer subdivided the original 'intermediate-risk' group, recognising the heterogeneity in the prognosis and treatment recommendations for men previously 'lumped together' in one risk grouping. A favourable-risk category of intermediate risk men was defined as men with no more than 50% of biopsies containing cancer, no higher grade than ISUP 2, and one of T2a-b, PSA 10–20 ng/mL or grade group 2. Men in the intermediate-risk group are usually offered surgery or radiotherapy as radical (curative) treatment. However, active surveillance may be recommended to men with favourable intermediate-risk disease.[39] While acceptable outcomes have been reported in men with intermediate disease managed on active surveillance, there is also evidence that they have higher rates of progression, adverse disease and metastatic disease.[41] It has been recommended that before initiating men on active surveillance and during follow up, assessments such as multiparametric MRI, PSA levels, biopsy factors, urinary, tissue and genetic markers should be used to identify individuals who are at risk of clinical progression.[42]

FIGURE 19: TREND IN PRIMARY TREATMENT FOR THE LOW-RISK GROUP (2009–2016).



Year that data were first populated in the registry, by jurisdiction, is indicated above the graph. AS/WW=active surveillance/watchful waiting.

Across all PCOR-ANZ jurisdictions, 62% of men with intermediate-risk disease had surgery, 21% had radiotherapy and 15% commenced on active surveillance or watchful waiting (excluding missing data) **(Figure 20)**. The trend in management of men with intermediate-risk disease seems to be reasonably stable since 2009 **(Figure 21)**.

FIGURE 20: PRIMARY TREATMENT IN THE INTERMEDIATE-RISK GROUP (2015–2016).

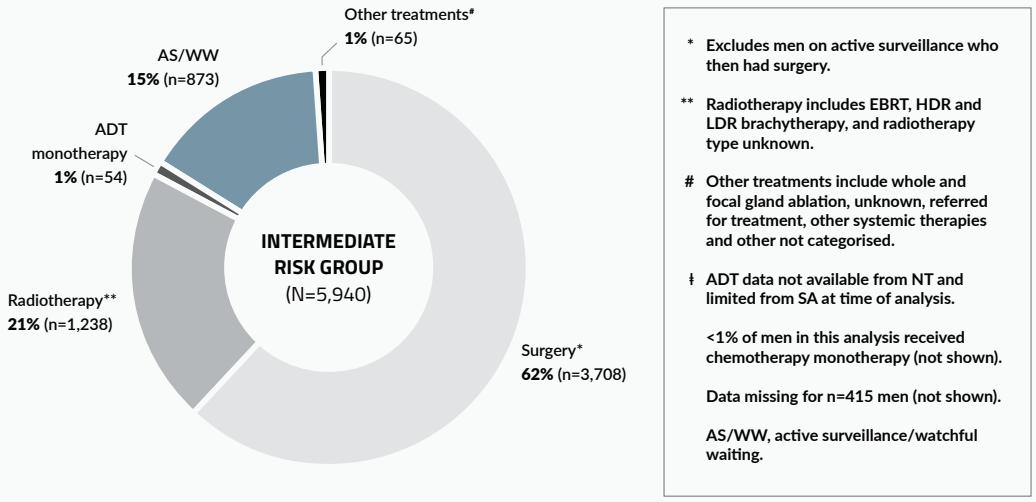
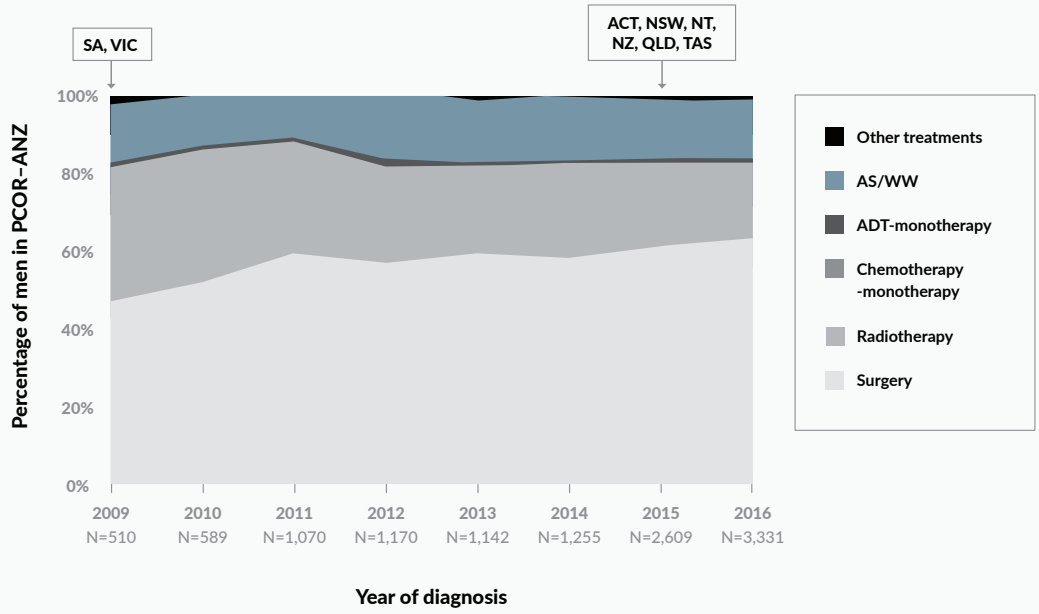


FIGURE 21: TREND IN PRIMARY TREATMENT FOR THE INTERMEDIATE-RISK GROUP (2009–2016).



Year that data were first populated in the registry, by jurisdiction, is indicated above the graph. AS/WW=active surveillance/watchful waiting.

HIGH-RISK GROUP

Men with high-risk disease contained within the prostate gland are generally offered curative treatment if they are in good health. Across Australia and New Zealand, we see that 83% of men received either surgery or radiotherapy, excluding missing data **(Figure 22)**. Seven percent of men received ADT as monotherapy, which is not curative treatment, but is intended to slow the spread of the cancer. As the database matures, we will analyse whether this figure remains stable, and whether any men in this category could be classed as being unnecessarily 'under treated'. The rate of active treatment reported in this cohort (83%) is higher than the 73% reported in the UK National Prostate Cancer Audit.[24] **Figure 23** assesses primary treatment trend over time in men with high-risk disease.

FIGURE 22: PRIMARY TREATMENT IN THE HIGH-RISK GROUP (2015–2016).

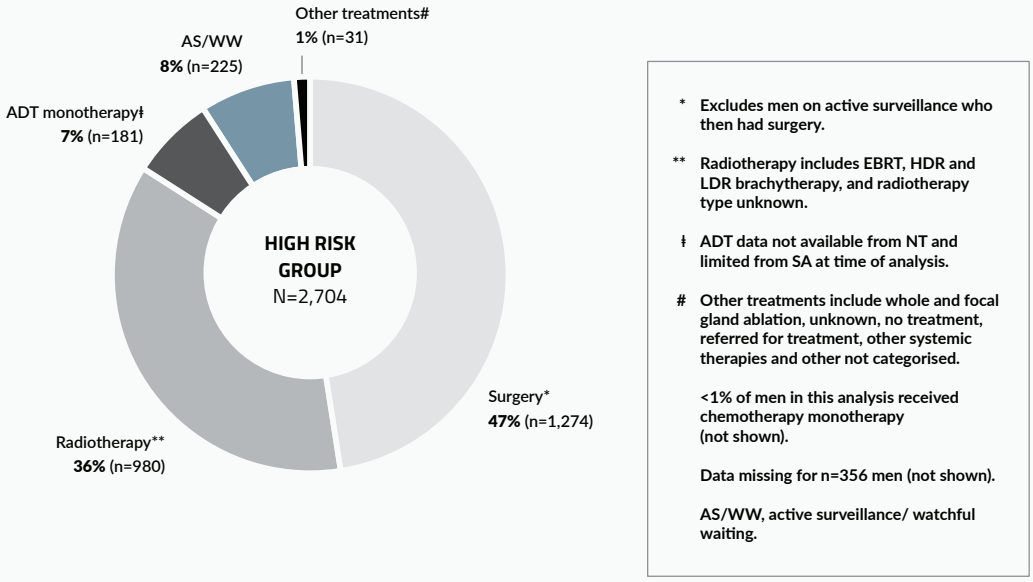
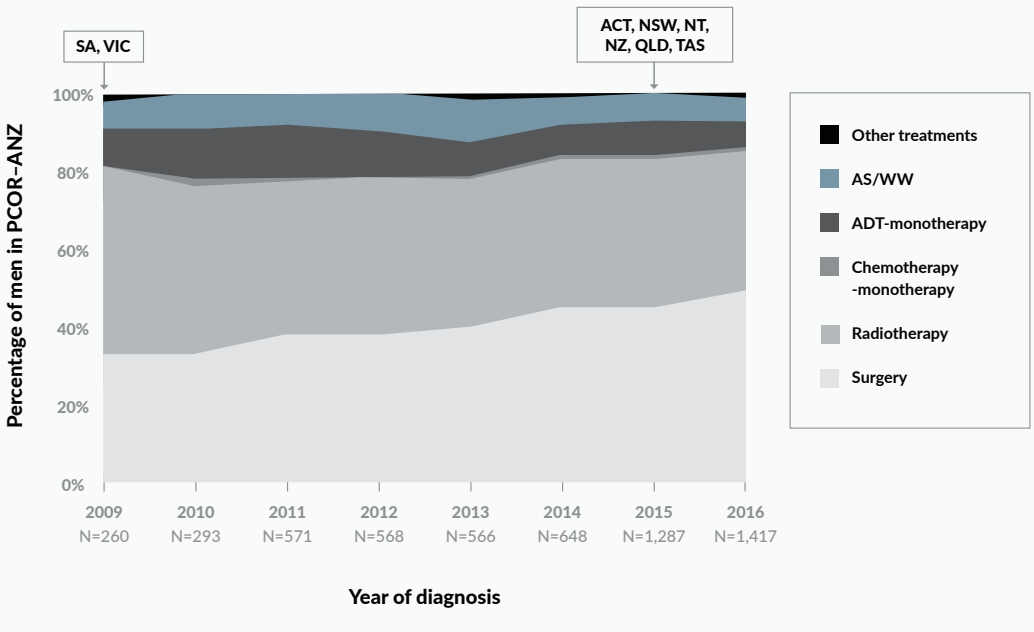


FIGURE 23: TREND IN PRIMARY TREATMENT FOR THE HIGH-RISK GROUP (2009–2016).



Year that data were first populated in the registry, by jurisdiction, is indicated above the graph. AS/WW=active surveillance/watchful waiting.

VERY HIGH-RISK GROUP

Very high-risk disease accounted for only 1% of new prostate cancer cases across men in the PCOR-ANZ database in 2015–2016. Men classified as being at very high risk for disease progression have a tumour which has invaded seminal vesicles or structures adjacent to the prostate. For those with a life expectancy greater than five years, evidence-based guidelines recommend curative treatment with radiotherapy and ADT, or surgery with pelvic lymph-node dissection.[6]

Across all jurisdictions in Australia and New Zealand, 80% of men with very high-risk disease received either surgery or radiotherapy and 15% received ADT monotherapy, excluding missing data; **Figure 24**. Our data show that the percentage of very high-risk men receiving ADT monotherapy has decreased in recent years. It will be important to monitor these trends over time to assess if any of these men should be receiving curative treatment **(Figure 25)**.

FIGURE 24: PRIMARY TREATMENT IN THE VERY HIGH-RISK GROUP (2015–2016).

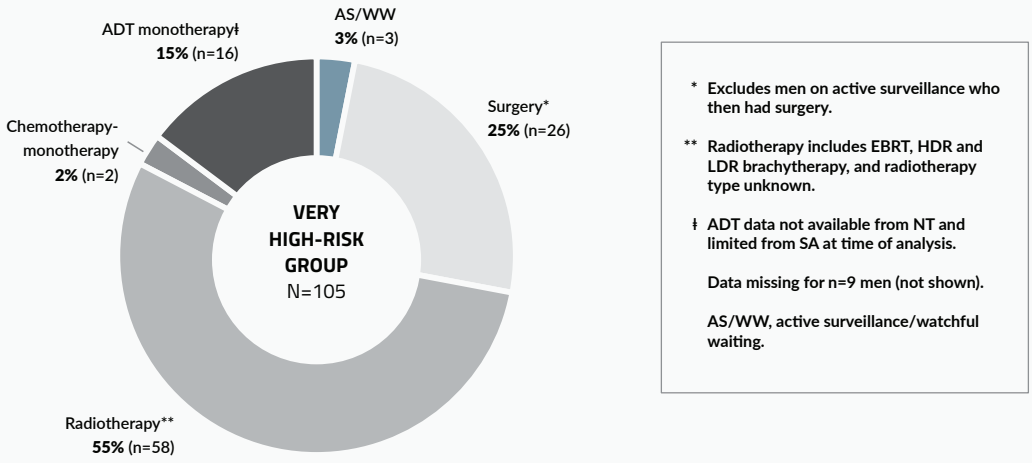
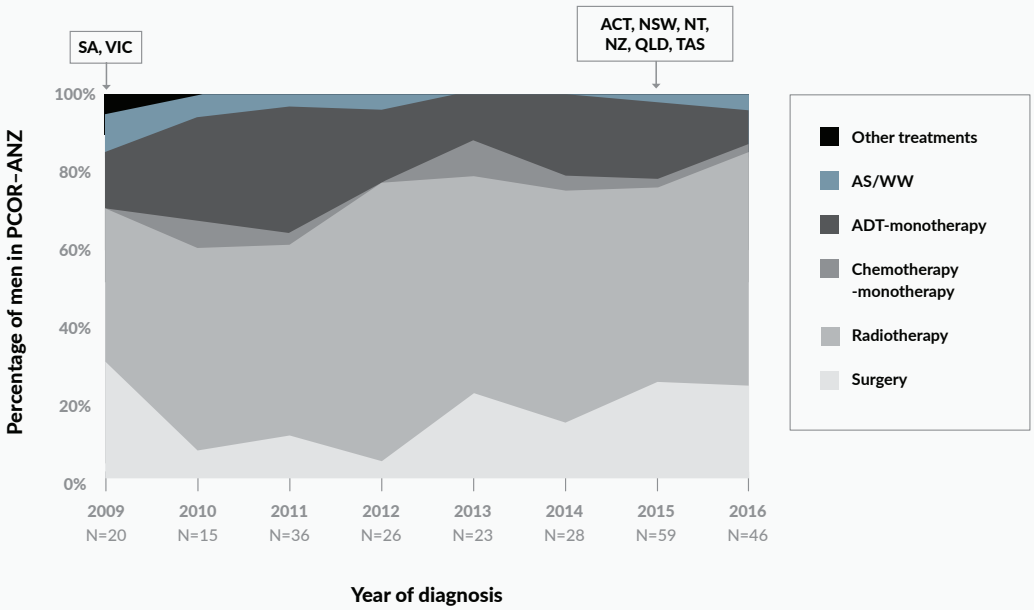


FIGURE 25: TREND IN PRIMARY TREATMENT FOR THE VERY HIGH-RISK GROUP (2009–2016).



Year that data were first populated in the registry, by jurisdiction, is indicated above the graph. AS/WW=active surveillance/watchful waiting.

REGIONAL DISEASE

Prostate cancer that has spread to regional lymph nodes accounts for only 2% of men diagnosed within PCOR-ANZ. Guidelines suggest that men with regional disease and with a life expectancy of greater than five years be offered radiotherapy and ADT, or ADT plus abiraterone and prednisolone.[6]

In Australia and New Zealand, the PCOR-ANZ data show that radiotherapy was the most commonly administered primary treatment for these men **(Figure 26)**. In total, 39% of men with regional involvement received radiotherapy and 22% received surgery (excluding missing data). The trend in management of men with regional disease is outlined in **Figure 27**. The variability in management of men prior to 2015 reflects the small number of men diagnosed with regional disease during these earlier years across the South Australian and Victorian databases only.

FIGURE 26: PRIMARY TREATMENT IN THE REGIONAL DISEASE GROUP (2015–2016).

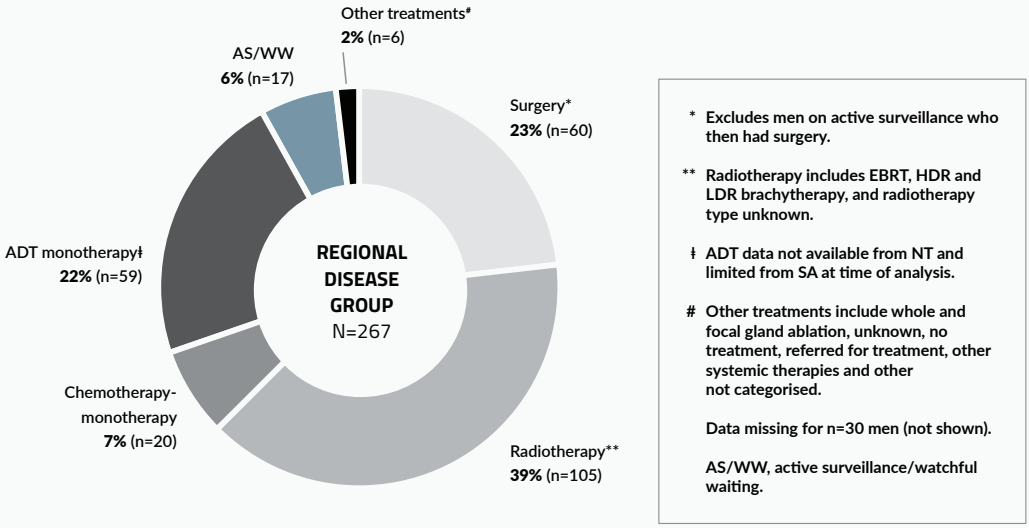
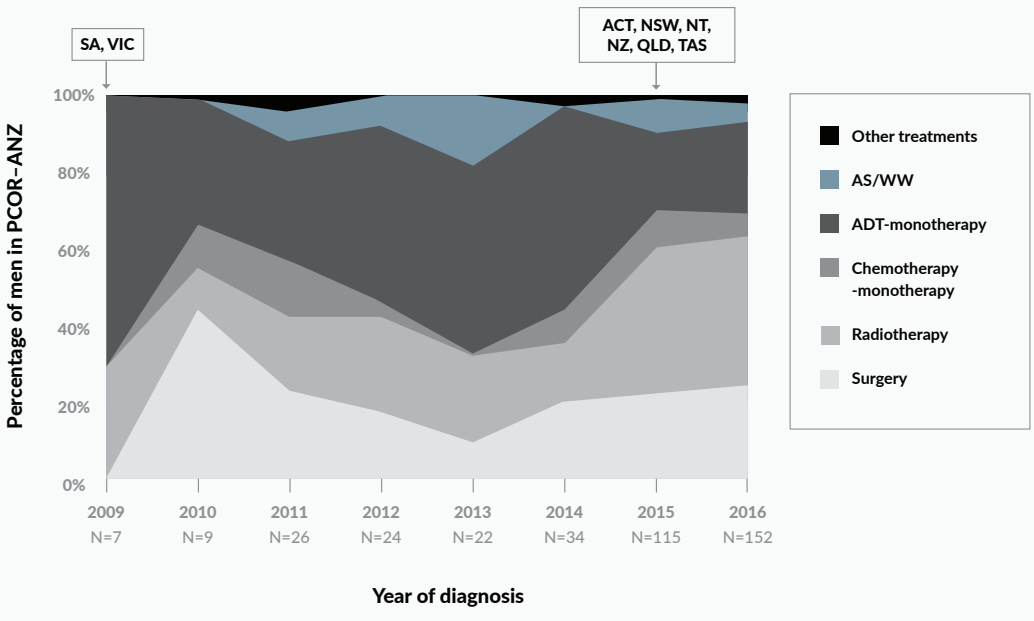


FIGURE 27: TREND IN PRIMARY TREATMENT FOR THE REGIONAL DISEASE GROUP (2009–2016).



Year that data were first populated in the registry, by jurisdiction, is indicated above the graph. AS/WW=active surveillance/watchful waiting.

METASTATIC DISEASE

Management of men with metastatic disease depends on the extent of disease spread, castrate-resistant status and life expectancy.[6] There were 795 men who were diagnosed with prostate cancer that had extended to the lymph nodes (N1) or other distant sites (M1). Together, this accounts for 6% of newly diagnosed cases of prostate cancer between 2015 and 2016 across all PCOR-ANZ jurisdictions **(Figure 28)**. In this group, ADT monotherapy was delivered to 48% of men as their primary management (excluding missing data). However, ADT monotherapy has decreased in this risk group as a treatment choice over time (2009–2016), and 'other treatments', radiotherapy and chemotherapy-monotherapy are increasing **(Figure 29)**.

FIGURE 28: PRIMARY TREATMENT IN THE METASTATIC DISEASE GROUP (2015–2016).

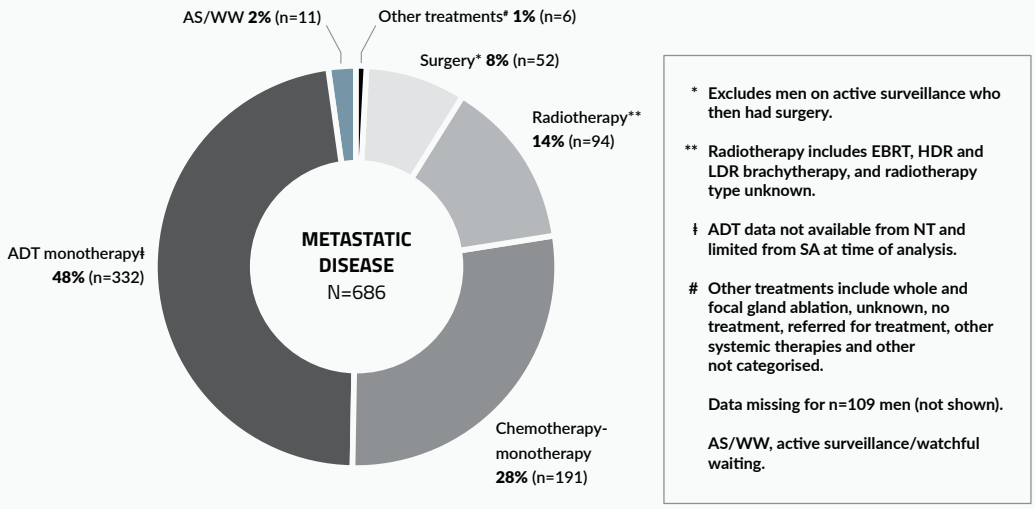
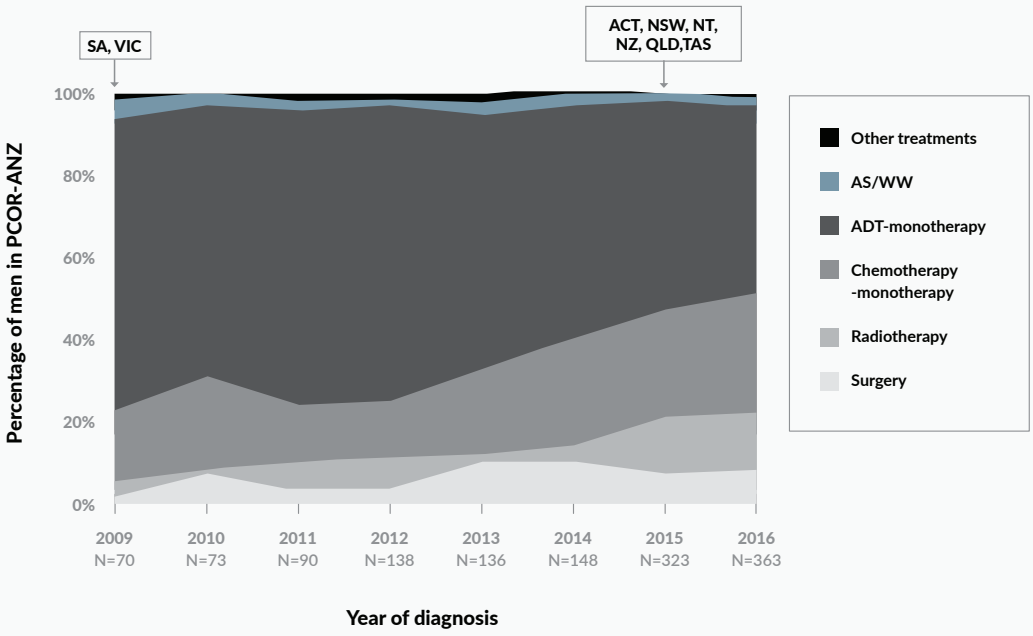


FIGURE 29: TREND IN PRIMARY TREATMENT FOR THE METASTATIC DISEASE GROUP (2009–2016).



Year that data were first populated in the registry, by jurisdiction, is indicated above the graph. AS/WW=active surveillance/watchful waiting.

PCOR-ANZ PUBLISHED HIGHLIGHTS: ADHERENCE TO ACTIVE SURVEILLANCE

For men who have been initiated on active surveillance, it is important that a regimen is followed to prevent disease from progressing beyond the point where it can be cured.

Results from the Victorian PCOR-ANZ database showed, disturbingly, that 3 in 4 men on active surveillance (N=1,635) were not receiving the level of follow up that is recommended by international and national clinical guidelines.[43] The recommendation for follow-up regimens from these guidelines are summarised in **Table 3**.

TABLE 3: PUBLISHED PEER-REVIEWED ACTIVE SURVEILLANCE PROTOCOLS FOR MEN WITH LOW-RISK PROSTATE CANCER.

PROTOCOL OR GUIDELINE	PSA ASSESSMENT FREQUENCY	BIOPSY FREQUENCY
Dall'Era et al.[44]	Every 3-4 months	12 months, then every 1–2 years as indicated by PSA result examination
National Institute for Clinical Effectiveness (NICE)[45]	Every 3–4 months during first year, then every 3–6 months	12 months after diagnosis
Prostate Cancer Research International Active Surveillance (PRIAS)[46]	Every 3 months for first 2 years, then every 6 months	12 months, 4, 7 years after diagnosis
Cancer Council Australia Wiki[39]	Offer monitoring with PSA testing every 3 months	Reclassification biopsy 6–12 months after starting active surveillance; then every 2–3 years
European Association of Urology (EAU)[47]	Timing not defined*	Annually*
National Comprehensive Cancer Network[6]	Every 6 months	Within 6 months, then annually
UpToDate[48]	Every 3–6 months	12 months after diagnosis, then every 2–5 years

The study, published in the Medical Journal of Australia[43] identified that men were more at risk of not being followed up in accordance with recommended guidelines if they were:

- diagnosed in public hospitals (83% higher risk compared to those diagnosed in private hospitals),
- diagnosed by trans-perineal biopsy (nearly 70% higher risk compared to those diagnosed via the traditional transrectal biopsy),
- or in the older age bracket (45% less likely if aged over 65 years compared to men aged less than 55 years).

PCOR-ANZ researchers are currently investigating why men are not having the recommended level of 'surveillance', with results expected at the end of 2018. Our plan is to develop a solution to address this problem, but before embarking on a solution we need to understand the problem further by asking whether:

- men are being advised to have a biopsy and/or PSA check but are not taking it up?
- tests are being performed but are not being updated in the patients' medical record?
- there is a breakdown in the process to arrange tests?
- treating clinicians are not recommending a biopsy and or PSA level in line with the clinical practice guidelines?

Armed with this knowledge, we will develop strategies to address information, system or person-related factors impacting adequate surveillance.

PCOR-ANZ PUBLISHED HIGHLIGHTS: INSIGHTS INTO RADIOTHERAPY CARE

PCOR-ANZ researchers have been examining care delivered to men receiving radiotherapy through analysis of registry data and interviews with men, in part, to assist in the development of quality indicators specifically for radiotherapy.[49] These quality indicators monitor whether radiotherapy-related care is in line with evidence-based guidelines. They will be incorporated into Quality of Care Reports, which will be distributed to radiotherapy centres in 2019. These reports are intended to ensure that all men receive optimal radiotherapy care.

Researchers interviewed twelve men who received care in both the private and public sector. Several key themes emerged regarding the pre-treatment phase of their care.

Information needs

All participants reported they wanted to know more about what to expect. Meeting these information needs appeared to be linked to addressing fear and anxiety relating to the uncertainty of their future health outcomes. For some men, there was a need to actively search for information, while others were content not to be so actively engaged in the process. While one participant stated "when it affects you, you start looking at any information you can get" (PT 5, 72yrs) another man described "I don't need all that information… I was suffering information overload…" (PT 10, 69yrs). Men sought information from healthcare providers, other men with prostate cancer and via their own research.

"I felt that it was all controllable, and it wasn't going to actually be fatal, you know, not like other forms of cancer of course."

(70 years, Vic study)

"I saw a nurse when I first came in here and she sort of gave me background you know, from the floor so to speak, of what could happen and you know how it will affect you or could affect you and it just gives you all possibilities of what can happen, and it was good to know that…"

(54 years, 11 months after diagnosis, SA study)

"…a few groups of my friends I could talk to about it and get their side as well, there's a whole range of treatments they've got … so, it's just talking about it and getting a feel for it."

(72 years, Vic study)

Decision-making

All men commented on their consideration of quality of life (QoL) and side effects versus survival and length of life as critical factors driving their treatment choice. While younger men in this study tended to preference quality of life, with the loss of sexual function influencing their treatment choice, for older men, concern about length of life and surviving was the main motivator of the treatment decision.

"I'm not afraid of dying or of prostate cancer … the quality of life after the treatment is what's seriously directed me in the way I've gone."

(70 years, Vic study)

Trusted relationship

Participants commented on the importance of establishing a trusting relationship with their radiation oncologists, with honesty and patience an integral component. Of importance, was the need to have open communication and to not feel rushed into making a decision. Participants' experience of care was improved when clinicians and other staff took the time to listen and when the "[staff] spent a lot of time explaining stuff…" 67 yrs, Vic Study). Contrary to this, some participants described their negative experiences as 'rushed' when physicians were not giving their full attention.

"To me, it's very important that I have a doctor that's very good at explaining things."

(69 years, Vic Study)

This research has identified areas of unmet need in a small cohort of men receiving radiotherapy. Our next step is to survey in a wider cohort of men the level of unmet need and work with services to understand how to rectify identified issues.

5. PATIENT-REPORTED OUTCOMES

PCOR-ANZ actively seeks to engage with men and understand their journey so that we can identify areas for quality improvement. PROMs provide an important, gauge of the success of treatment, and can therefore deliver valuable insights into any areas that may need to be improved. By collecting information across the population, PCOR-ANZ can also provide an average estimate of where men might expect to be at this point in time on their prostate cancer journey.

To understand quality of life as impacted by treatment, we use the validated EPIC-26 survey.[8,50] Men are contacted 12 months after their diagnosis; or if they have treatment, 12 months post treatment. PROMs data were collected from 50% of all men enrolled in PCOR-ANZ over 2015–2016 (6,953/14,016 men; see Appendix 2 for more details).

URINARY, BOWEL AND SEXUAL BOTHER

When reporting on quality of life in men diagnosed with prostate cancer, both the function men experience and the extent to which it bothers them should be considered. In this first section of Chapter 5, the focus is on the bother component of the self-reported survey. To give an idea how the data from our region compares to global trends in PROMs, where possible, we have drawn comprisons with the Comparative Effectiveness Analysis of Surgery and Radiation (CEASAR) study. This prospective, longitudinal, population-based cohort study from the United States reported on PROMs at 12 months from 2,550 men aged <80 years, with cT1-2 disease and PSA <50 ng/mL.[51]

NOTES ON PROMS DATA 2015-2016

When outcomes are compared across management modalities it is important to consider that the most influential factor predicting good or bad function and bother after treatment is the degree of function or bother before treatment. The registry is currently unable to capture the quality of life of men prior to treatment at a population level, because pre-treatment (or baseline) data are not collected using the EPIC-26. But this is something we are working towards.

As active surveillance/watchful waiting does not involve treatment intervention, the level of functional problems those men experience likely reflects the underlying prevalence of these problems in men in general.

It should also be noted that the population characteristics of men may vary widely between different treatment modalities, so between-treatment comparisons should be treated with caution.

PATIENT-REPORTED OUTCOMES AT A GLANCE: EPIC-26 DATA, 2015-2016

Urinary bother

≤3% of men report that urinary function is a 'big problem' 12 months after treatment, regardless of what treatment choice they make.

Bowel bother

Only 3% of men who undergo EBRT report 'big problems' with bowel function, but this is significantly more than the number of men undergoing surgery (1%, $p<0.001$).

Sexual bother

Around 1 in 5 men have a big problem with sexual function after surgery (22%) or EBRT (20%).

Overall, men are more likely to have a moderate-to-big problem after surgery than they are after EBRT (42% vs 32%, $p<0.001$).

After ADT monotherapy, around 1 in 5 men (24%) report a moderate-to-big problem with sexual function.

Urinary function

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

After surgery, men report lower function scores for incontinence (i.e. more incontinence 'problems') compared to other treatment modalities, but higher function scores for irritation/obstruction (i.e. less irritation or obstructive 'problems').

Bowel function

Men report higher dysfunction scores after EBRT compared to surgery and active surveillance/watchful waiting, which is expected as radiation can cause inflammation of the bowel lining.

Higher levels of bowel dysfunction and bother after ADT therapy were reported by our cohort.

Sexual function

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

Men having surgery, EBRT and ADT all report low sexual function scores compared with active surveillance/watchful waiting.

Men on ADT reported the lowest sexual function score.

I started my particular journey with prostate cancer back in 2012, at age 52, when I was first diagnosed. Like most men when first told that they have this disease, I was desperate for information so that I could make informed decisions about my treatment, and by so doing exert some form of control in a situation where the patient often feels that things are very much outside his control. Prostate cancer support groups and forums provided much of this information, however it quickly became clear that there was a wide range of outcomes experienced by men, both in the side effects from various treatments, and in the ultimate outcome.

Now as the patient advocate on the PCOR-NZ steering committee I see the high value of the patient-reported outcomes for researchers, clinicians and ultimately the patients themselves. The work of gathering and correlating data from men both before and after treatment is vital to the ongoing efforts of researchers and clinicians to provide the best possible care and treatment to every man and the family of every man who faces this disease.

BRYAN WILSON
(NEW ZEALAND PATIENT REPRESENTATIVE)

SELF-REPORTED URINARY PROBLEMS

The treatment men receive for prostate cancer can cause problems with urinary function, for example, incontinence after surgery (radical prostatectomy) and/or EBRT (radiotherapy) can be a problem. However, across all treatment types, including surgery and EBRT, <3% of men reported that their urinary function was causing them a big problem 12 months after treatment **(Figure 30)**. Moderate problems were reported in 5% to 8% of men across all treatment types; but it is notable that 8% of men on active surveillance/watchful waiting – who received no treatment intervention – and 8% of men on ADT reported moderate problems with urinary function (excluding those who declined to answer).

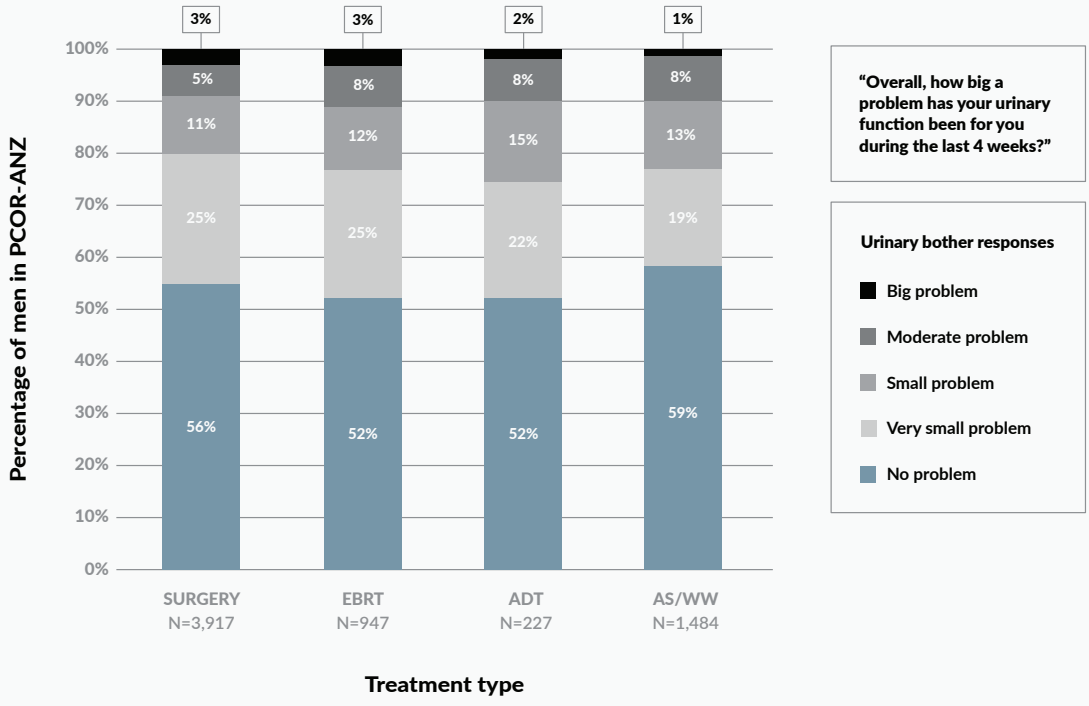
Trends in urinary bother 12 months after each different treatment type are reported in **Figure 31** to **Figure 34**. There were no notable trends in any of the examined treatment types over the timeframe reported (2009–2016).

URINARY BOTHER AFTER SURGERY AND EBRT

Surgery and EBRT are the treatment types most likely to cause problems with urinary function. So we focused on these two treatment types for comparison with data from the CEASAR study (2,550 men, aged <80 years, with cT1-2 disease and PSA <50 ng/mL).

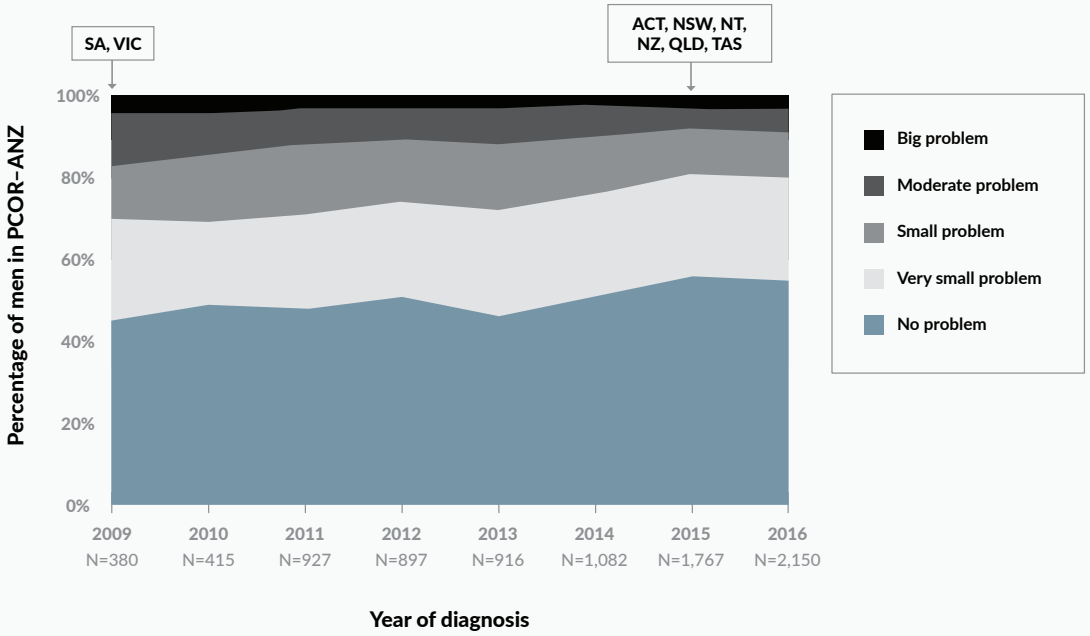
In PCOR-ANZ, we found that 7% (128/1737) of men aged <80 years, with cT1-2 disease and PSA <50 ng/mL had moderate-to-big problems with urinary function 12 months after surgery, which compares favourably with the 12% reported in CEASAR.[51] For EBRT, there was about the same rate of moderate-to-big problems in PCOR-ANZ (11%) as reported in CEASAR (10%).

FIGURE 30: PATIENT-REPORTED URINARY BOTHER 12 MONTHS AFTER TREATMENT ACROSS ALL JURISDICTIONS (2015–2016).



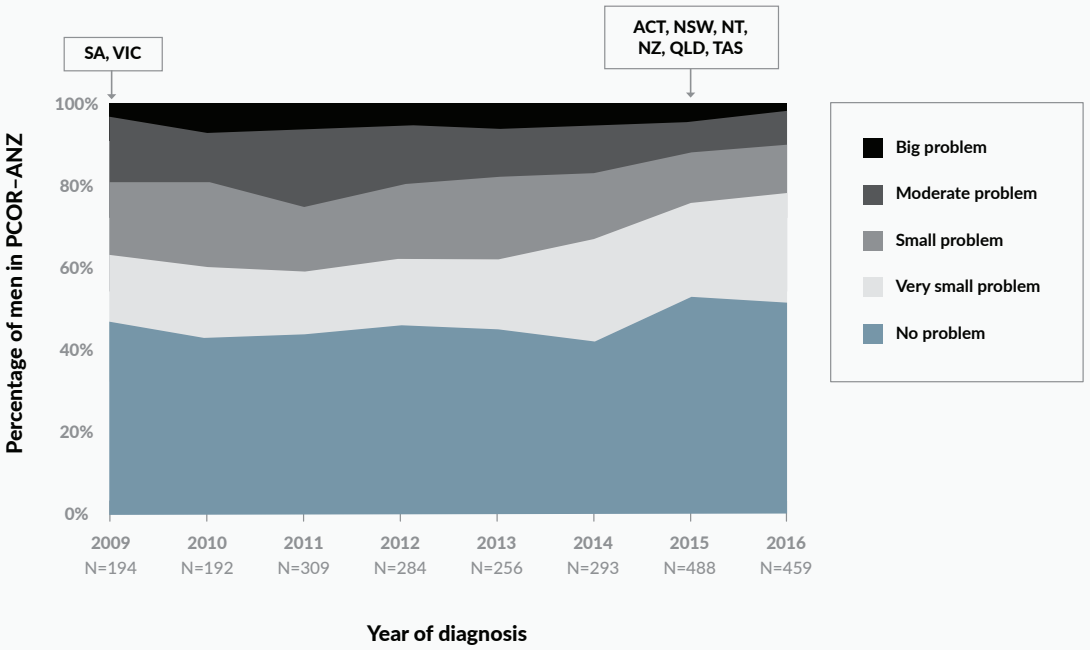
Based on numbers where 12-month EPIC-26 survey was completed. ADT data not available for NT and limited for SA at time of analysis. 'Participant declined to owner' excluded. AS/WW, active surveillance/watchful waiting.

FIGURE 31: TREND IN PATIENT-REPORTED URINARY BOTHER 12 MONTHS AFTER SURGERY (2009–2016).



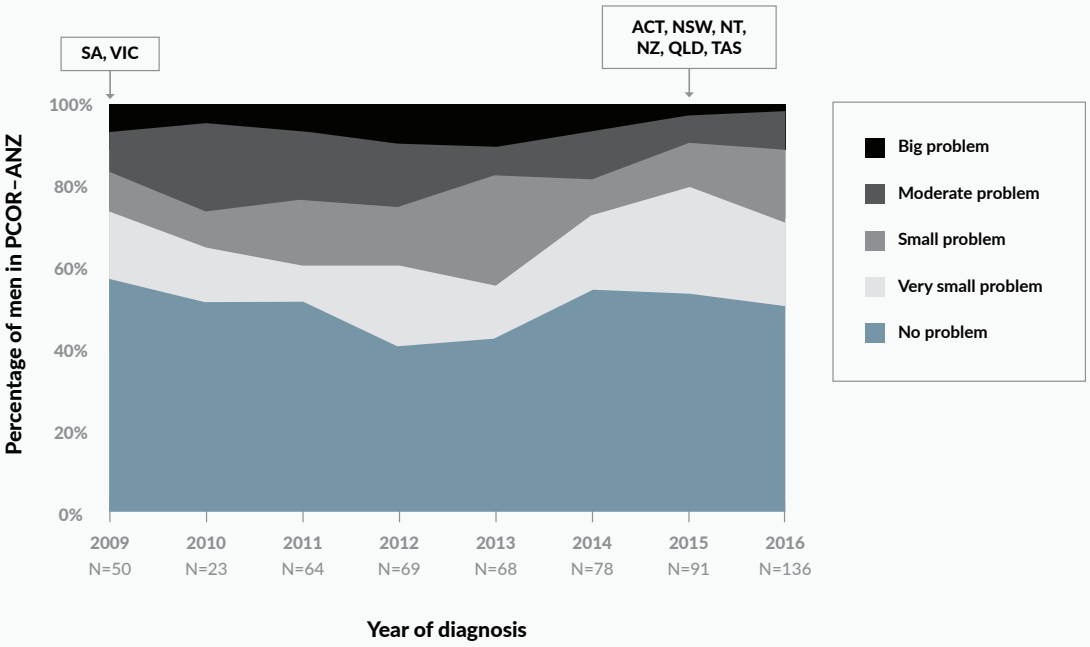
Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in the registry, by jurisdiction, is indicated above the graph.

FIGURE 32: TREND IN PATIENT-REPORTED URINARY BOTHER 12 MONTHS AFTER EBRT (2009–2016).



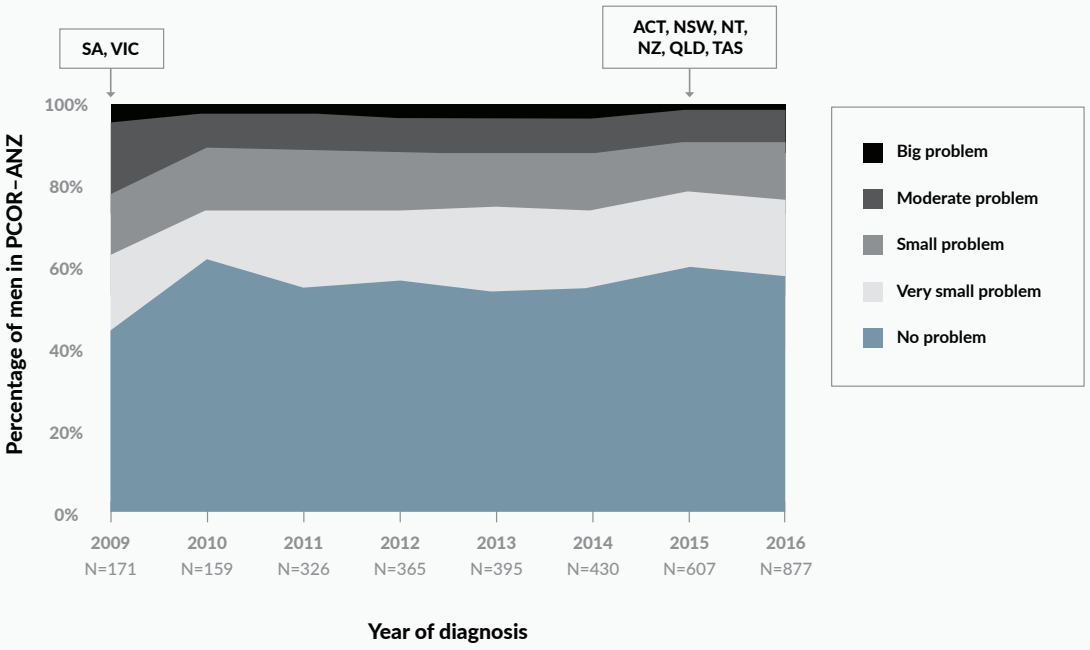
Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in the registry, by jurisdiction, is indicated above the graph.

FIGURE 33: TREND IN PATIENT-REPORTED URINARY BOTHER 12 MONTHS AFTER ADT MONOTHERAPY (2009–2016).



Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in the registry, by jurisdiction, is indicated above the graph.

FIGURE 34: TREND IN PATIENT-REPORTED URINARY BOTHER 12 MONTHS AFTER ACTIVE SURVEILLANCE/WATCHFUL WAITING (2009–2016).



Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in registry, by jurisdiction, is indicated above the graph

SELF REPORTED BOWEL PROBLEMS

Bowel problems were principally reported among men who had received either EBRT or ADT as monotherapy; moderate or big problems were reported by 9% of men receiving EBRT and 7% of men receiving ADT (excluding those who declined to answer). **Figure 35** provides the side-effect profile of patient-reported bowel bother across each of the four management groups. Trends in bowel bother 12 months after each different treatment type are reported in **Figure 36** to **Figure 39**.

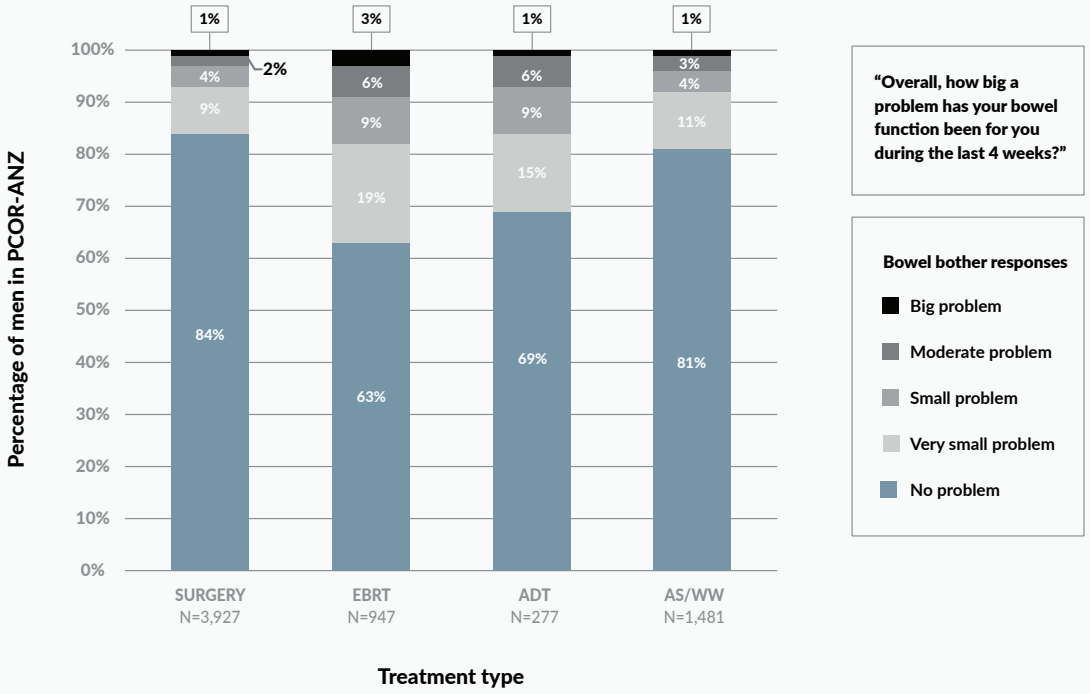
BOWEL BOTHER AFTER SURGERY

Radical prostatectomy rarely causes damage to the gastrointesinal tract and, as expected, few men in PCOR-ANZ (3%) reported bowel problems post surgery **(Figure 35)**, excluding those who declined to answer. The rates of 'big problems' with bowel function are also similar for both ADT (2%) and active surveillance/watchful waiting (1%). This is likely to represent the percentage of men in the community who self-report 'big' bowel problems.

In the PCOR-ANZ cohort of men aged <80 years, with clinical stage cT1-2 disease and PSA <50 ng/mL (similar to those in the CEASAR study) only 2% reported that their bowel function was causing them either a moderate or a big problem 12 months after surgery. This was slightly lower than the 3% reported in the CEASAR study at 12 months post surgery.[51]

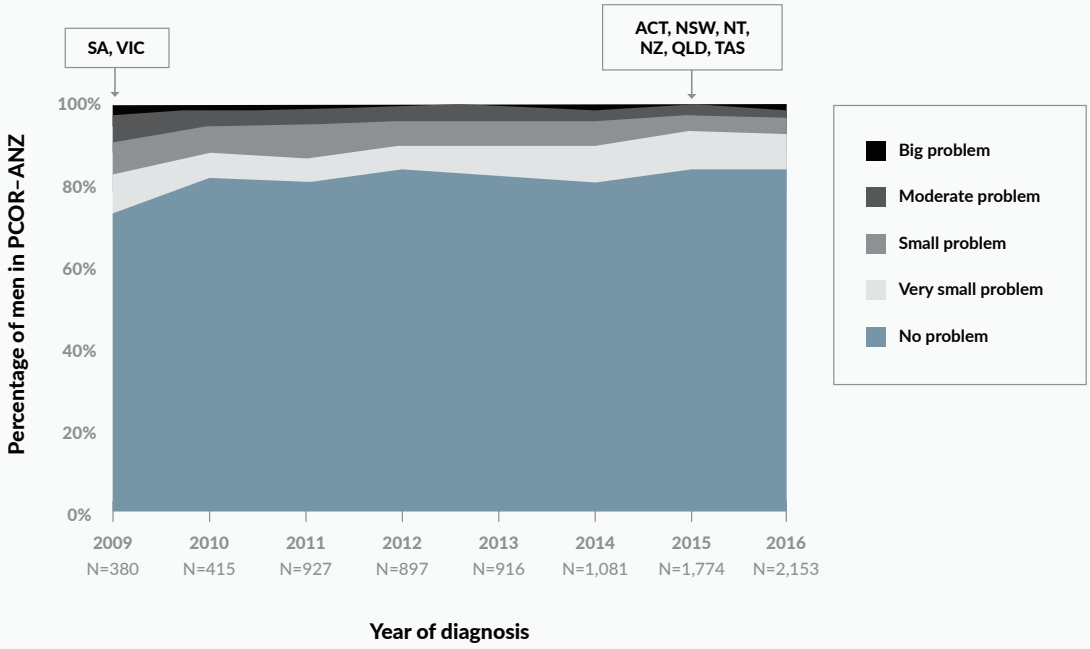
The trend in bowel bother 12 months after surgery has remained relatively stable over time (2009–2016; **Figure 36**).

FIGURE 35: PATIENT-REPORTED BOWEL BOTHER 12 MONTHS AFTER TREATMENT ACROSS ALL JURISDICTIONS (2015–2016).



Based on numbers where 12-month EPIC-26 survey was completed. ADT data not available for NT and limited for SA at time of analysis. 'Participant declined to answer' excluded. AS/WW, active surveillance/watchful waiting.

FIGURE 36: TREND IN PATIENT-REPORTED BOWEL BOTHER 12 MONTHS AFTER SURGERY (2009–2016).



Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in registry, by jurisdiction, is indicated above the graph.

BOWEL BOTHER AFTER EBRT

Bowel problems most commonly occur in men who have received radiotherapy to treat the prostate. Radiation can cause the lining of the bowel to become inflamed (proctitis) which then leads to symptoms such as bowel incontinence (also known as faecal incontinence). Accidental leaking of faeces may be minor or may result in total loss of bowel control.

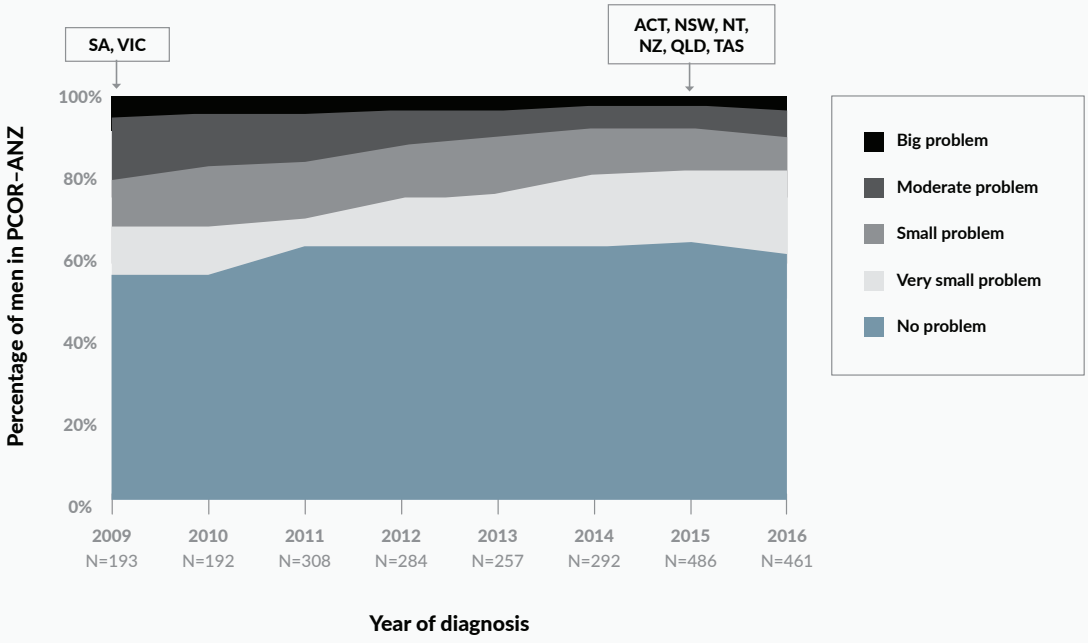
Men were more likely to self-report having a big problem with bowel function post-EBRT compared to post surgery (3% vs 1%, p<0.001; Fisher's exact test). When comparing responses for those who reported either a moderate or a big problem (and excluding those who declined to respond), men having EBRT were more likely to have poorer bowel quality of life at 12 months compared to men undergoing surgery (86/497 (9%) vs 105/3927 (2.6%), p<0.001 Fisher's exact test).

Moderate-to-big bowel function bother was reported in 8% of men 12 months after EBRT in the CAESAR study.[51] When compared with a similar population of men from PCOR-ANZ (men <80 years, cT1-2 disease and PSA <50 ng/mL), 9% of men reported that their bowel function was causing them moderate to big function bother 12 months after radiotherapy.

Our results are also consistent with those reported in an early study of quality of life following prostate cancer treatment in Australia. Smith *et al.* reported that bowel bother was persistently worse in all treatment groups relative to controls, with the greatest impact at 12 months in the groups who received EBRT with or without ADT.[52]

Trend in bowel function bother 12 months post EBRT has remained reasonably consistent over time **(Figure 37)**.

FIGURE 37: TREND IN PATIENT-REPORTED BOWEL BOTHER 12 MONTHS AFTER EBRT (2009–2016)



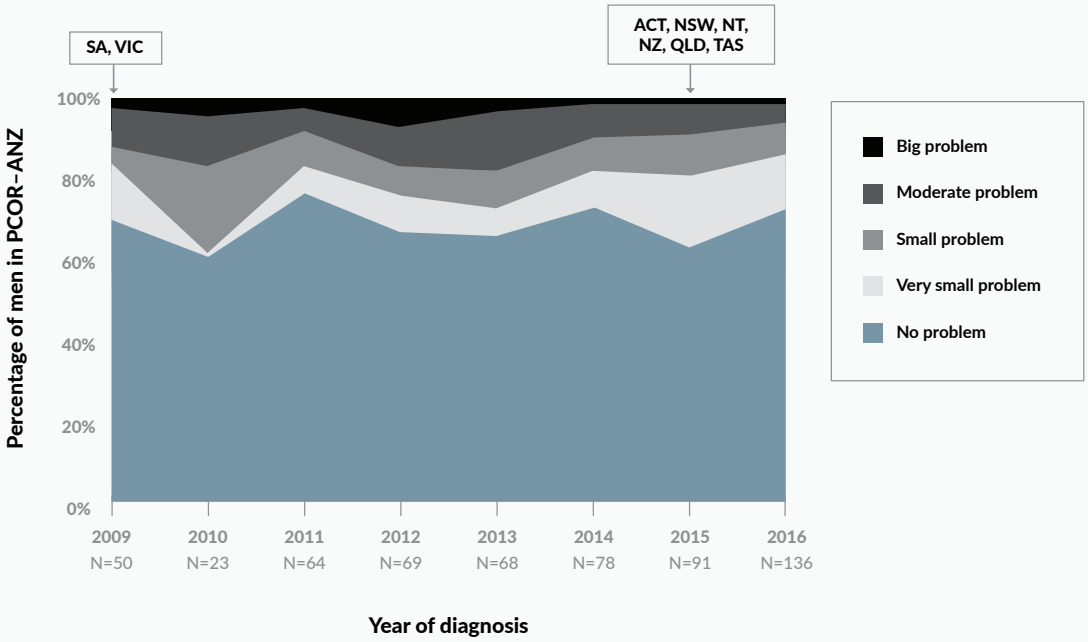
Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in registry, by jurisdiction, is indicated above the graph.

BOWEL BOTHER AFTER ADT

Of those men who had ADT as monotherapy and answered the survey question (n=227), 7% reported either moderate or big problems with their bowel function. This compared to only 4% of men who reported the same extent of bother and who were on active surveillance or watchful waiting; a statistically significant difference (Fisher's exact test, p=0.022). ADT is associated with a number of side effects (cardiovascular disease, osteopenia and osteoporosis, hot flushes, gynaecomastia/mastalgia, depression, loss of libido/sexual dysfunction/decreased genital size, and metabolic syndrome); yet bowel dysfunction is not a widely reported side effect of treatment.[53,54]

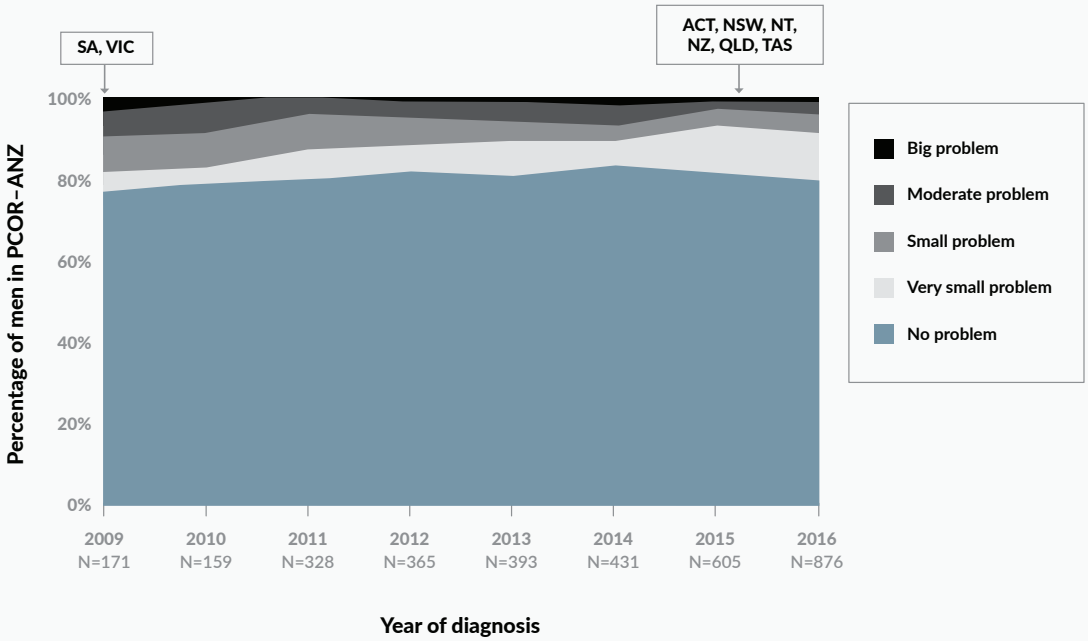
Observed impairment of bowel function associated with ADT treatment for has been reported in a large North American practice-based prostate cancer registry project, CaPSURE.[55] This registry accrued men with prostate cancer treated with various modalities followed for a median period of over six years to report on differences in long-term quality of life. In this cohort of 3,294 patients, the bowel function and bother associated with primary ADT treatment was worse than most other modalities of treatment – including EBRT – at most time points (even more notably with "bother" compared with "function"). The baseline bother and function for those receiving primary ADT was worse than for those receiving surgery, radiotherapy and watchful waiting, and showed a decline in the first two years. It would seem plausible that most of the explanation for the effect we saw is that men receiving ADT as monotherapy have worse function and bother at the outset, prior to treatment. ADT does have an impact on "general quality of life" and it might also be that the "general" effects of ADT on physical and mental quality of life also affect men's responses to questions regarding bowel bother.

FIGURE 38: TREND IN PATIENT-REPORTED BOWEL BOTHER 12 MONTHS AFTER ADT MONOTHERAPY (2009–2016).



Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in registry, by jurisdiction, is indicated above the graph.

FIGURE 39: TREND IN PATIENT-REPORTED BOWEL BOTHER 12 MONTHS AFTER DIAGNOSIS AND FOLLOWING INITIATION OF ACTIVE SURVEILLANCE/WATCHFUL WAITING (2009–2016).

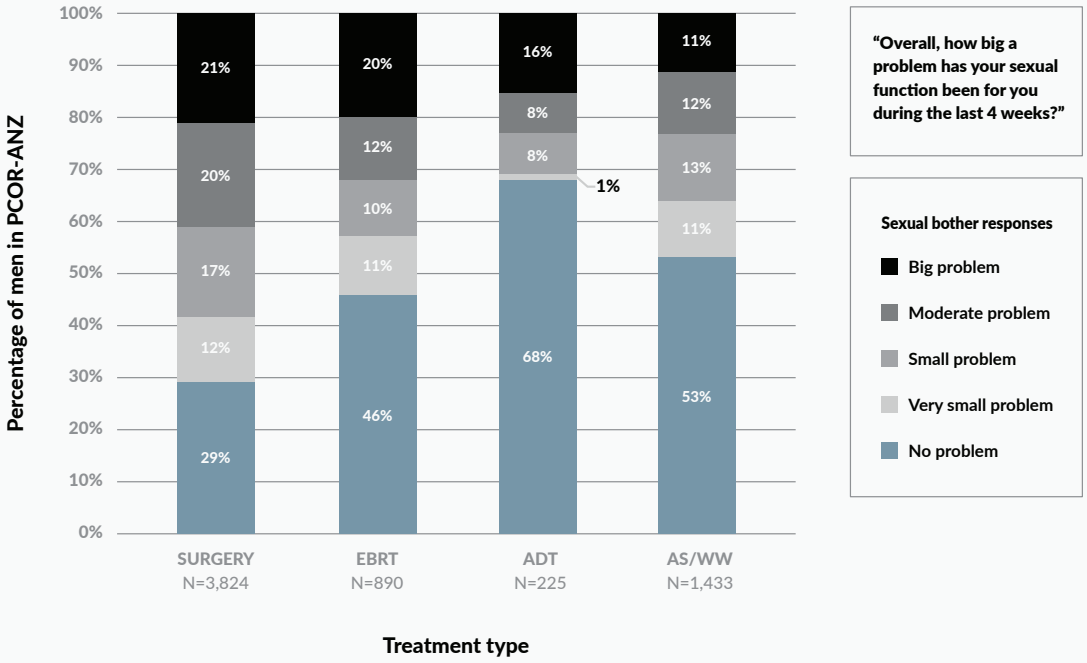


Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in registry, by jurisdiction, is indicated above the graph.

SELF-REPORTED SEXUAL PROBLEMS

Sexual problems are the category of problems that men most commonly reported after any form of treatment for prostate cancer **(Figure 40)**. Surgery, radiotherapy, brachytherapy and focal gland ablation can damage the nerves and blood vessels needed for an erection; and hormone therapy can lower the desire for sex. Men who enter active surveillance or watchful waiting receive no treatment interventions so the distribution of their responses are likely to reflect the usual distribution of reports of men in society regarding sexual function, as a 'control group'. In this control group at 12 months, 23% of these men report, without any treatment, moderate or big problems. After EBRT, this proportion was 32% and after surgery 41%. Men treated with ADT alone had rates of self-reported moderate or big problems with sexual function at rates very similar to men receiving no treatment (24% vs 23%). This similar rate might be explained by the manner in which ADT suppresses sexual desire and so the associated decrease in actual sexual function is not perceived as a 'problem'.

FIGURE 40: PATIENT-REPORTED SEXUAL BOTHER 12 MONTHS AFTER TREATMENT ACROSS ALL JURISDICTIONS (2015–2016).



Based on numbers where 12-month EPIC-26 survey was completed. ADT data not available for NT and limited for SA at time of analysis. 'Participant declined to answer' excluded. AS/WW, active surveillance/ watchful waiting.

SEXUAL BOTHER AFTER SURGERY

One in five men (22%) reported a big problem and slightly fewer (20%) reported a moderate problem with their sexual function 12 months after surgery, excluding those who declined to answer **(Figure 40)**. When restricted to men aged less than 80 years and with clinical stage cT1-2 disease disease and PSA <50 ng/mL, as in the CEASAR study, the total number of men reporting moderate-to-big problems altered very little (from 40% to 39%). This is more favourable than the 50% of men reporting on this survey question in CAESAR at 12 months post prostatectomy.[51]

Over time, there has been a slight trend towards reduced levels of sexual bother following surgery (2009–2016), but the trend has remained relatively stable in recent years as the newer jurisdictions came online and more men have joined the database **(Figure 41)**.

SEXUAL BOTHER AFTER EBRT

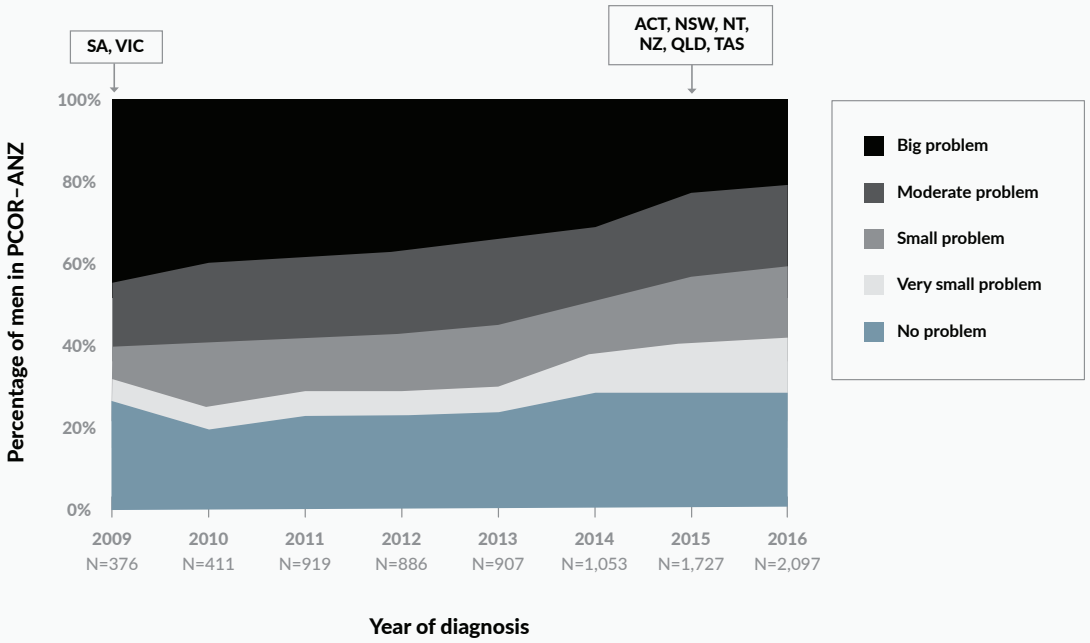
A slightly smaller percentage of men (20%) reported a big problem with their sexual function compared to those receiving surgery (22%, **Figure 40**). However, when comparing responses for those who reported either a moderate or a big problem (and excluding those who declined to answer), men having surgery were more likely to have poorer sexual quality of life at 12 months compared to men undergoing EBRT [1,613/3,824 (42%) vs 289/890 (32%), p<0.001 χ^2 test].

While 32% of men reported a moderate-to-big problem with sexual function post EBRT in our full PCOR-ANZ cohort, fewer men with earlier-stage disease and younger age (<80 years, clinical stage cT1-2 disease and PSA <50 ng/mL) reported this to be a problem (27%). These results compare favourably to the CAESAR study group, in which 39% of men reported a moderate or big problem 12 months after radiotherapy.[51] **Figure 42** shows trend in problems with sexual function following EBRT.

SEXUAL BOTHER AFTER ADT MONOTHERAPY

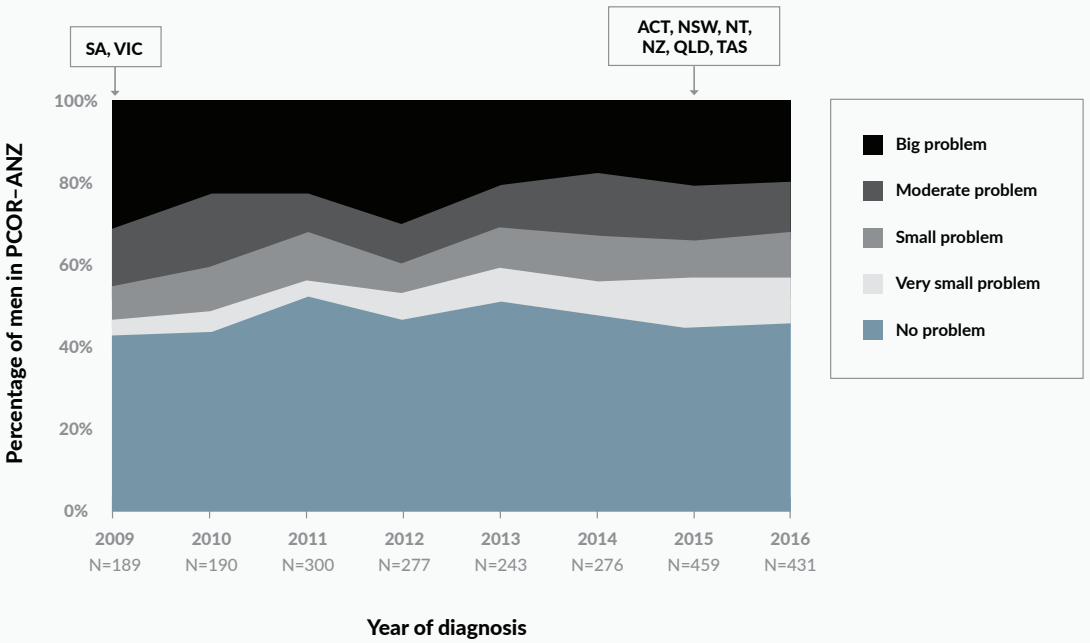
Loss of libido and erectile dysfunction (ED) are well-known side effects of ADT and are usually attributed to the decrease in testosterone levels.[53] ADT is indicated for first-line treatment for symptomatic metastatic prostate cancer, and as neoadjuvant therapy prior to radiotherapy. It is also given as a treatment for patients with biochemical recurrence after first-line treatment, or to patients who present with locally advanced disease, lymph-node metastasis or metastatic disease. As seen in **Figure 40** 12 months after commencing ADT, 16% of men reported a big problem with their sexual function and 8% reported a moderate-big problem, excluding those who declined to answer. **Figure 43** shows that the trend over the time period 2009 to 2016 remains relatively stable.

FIGURE 41: TREND IN PATIENT-REPORTED SEXUAL BOTHER 12 MONTHS AFTER SURGERY (2009–2016).



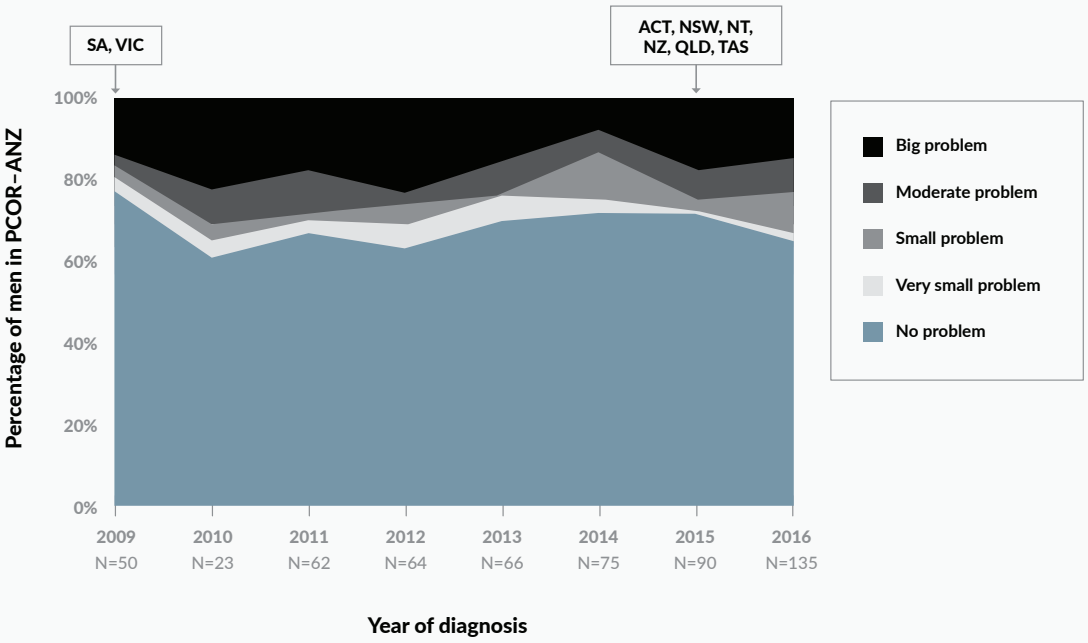
Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in the registry, by jurisdiction, is indicated above the graph.

FIGURE 42: TREND IN PATIENT-REPORTED SEXUAL BOTHER 12 MONTHS AFTER EBRT (2009–2016).



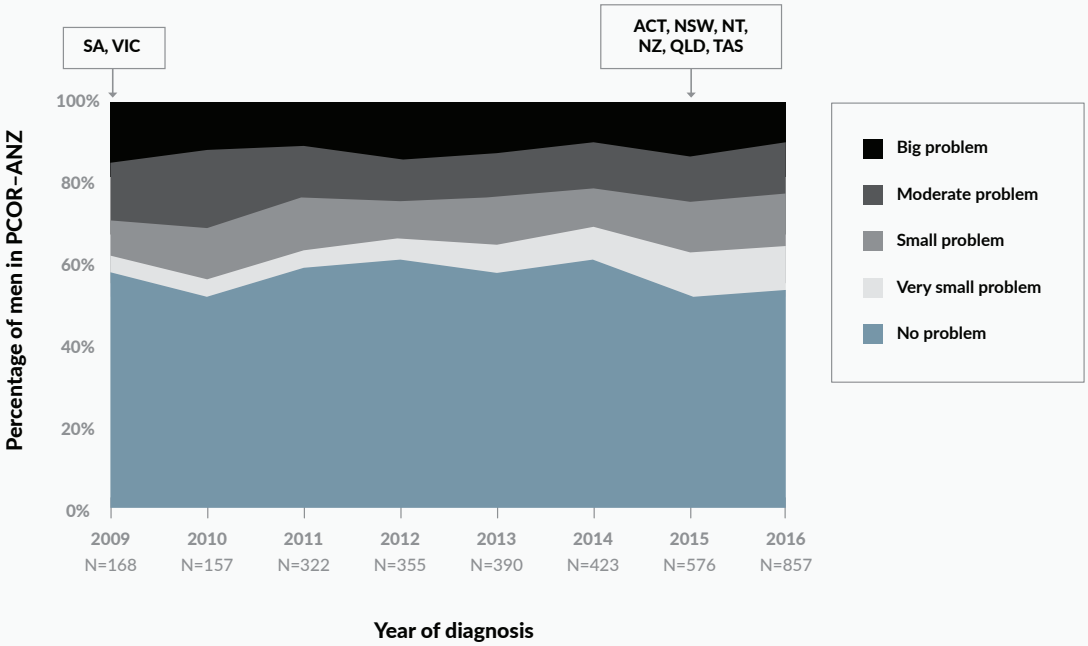
Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in the registry, by jurisdiction, is indicated above the graph.

FIGURE 43: TREND IN PATIENT-REPORTED SEXUAL BOTHER 12 MONTHS AFTER ADT MONOTHERAPY (2009–2016).



Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in the registry, by jurisdiction, is indicated above the graph.

FIGURE 44: TREND IN PATIENT-REPORTED SEXUAL BOTHER 12 MONTHS AFTER ACTIVE SURVEILLANCE/WATCHFUL WAITING (2009–2016).



Trend graph does not include 'participant declines to answer'. Year that data for this figure were first populated in the registry, by jurisdiction, is indicated above the graph.

URINARY, BOWEL AND SEXUAL FUNCTION

In this section of Chapter 5, we assess urinary, bowel and sexual function 12 months after treatment. The EPIC-26 quality of life instrument has been developed on a scale of 0 to 100, where 0 is equivalent to no function and 100 equals perfect function. Threshold and cutoffs for symptom severity have not been calculated for the EPIC-26 instrument.[8,50] However, a lower function score indicates a poorer quality of life reported by men. Boxplots have been used to indicate the dispersion of the urinary, bowel and sexual function 12 months after the various treatments. The boxplot provides the median function score, the interquartile range (IQR) and the minimum and maximum points. It also provides an indication of 'outliers' or scores which fall well outside the normal range. **Figure 45** provides a description of how the boxplots should be interpreted.

URINARY FUNCTION

Urinary function is divided into two components; urinary irritation/obstruction and urinary incontinence. The questions which assess urinary irritation/obstruction are outlined in Appendix 1. Urinary incontinence focuses on the extent to which men self-report having leakage of urine, control of urine, the number of pads required per day and dripping. Urinary irritation or obstruction is assessed through questions relating to pain or burning on urination, bleeding on urination, weakness of the urine stream and the need to urinate frequently during the day.

Figure 46 and **Figure 47** detail quality of urinary function 12 months after treatment for men who undergo surgery and radiotherapy, and for those who receive ADT as monotherapy or are managed on active surveillance or watchful waiting. Men undergoing surgery reported higher scores (higher function) for urinary irritation/obstruction than those undergoing either radiotherapy or ADT **(Figure 48)**. Urinary incontinence however, seemed to be marginally more of a problem after surgery than it was after other treatment modalities, with men reporting lower function scores for incontinence in comparison to other treatment modalities. Incontience was a particular problem for some men receiving active surveillance/watchful waiting, as evidenced by their outlier status **(Figure 47)**.

PCOR-ANZ researchers are currently investigating differences in urinary, bowel and sexual function scores across treating institutions to understand whether there are services, supports or programs that men are accessing in hospitals where the scores are considerably higher than in other hospitals. These data will be analysed in a future report.

FIGURE 45: DESCRIPTION OF HOW BOXPLOTS ARE CALCULATED.

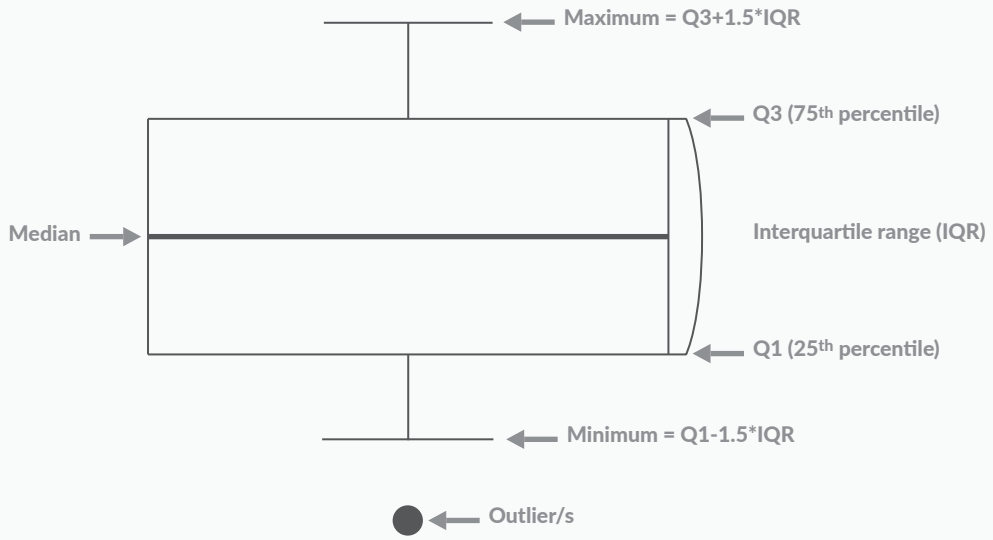
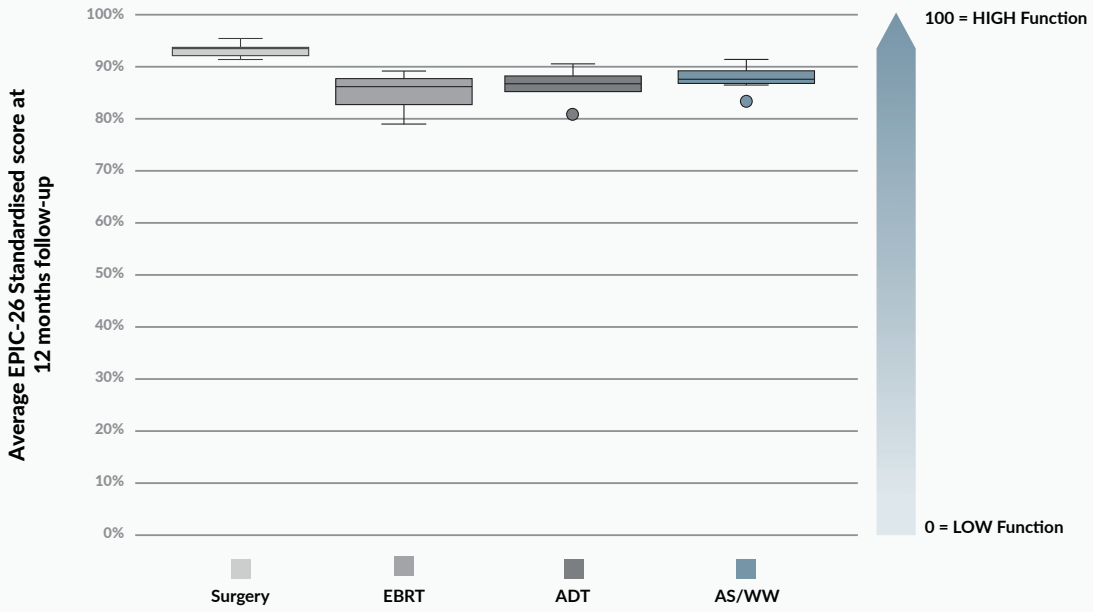
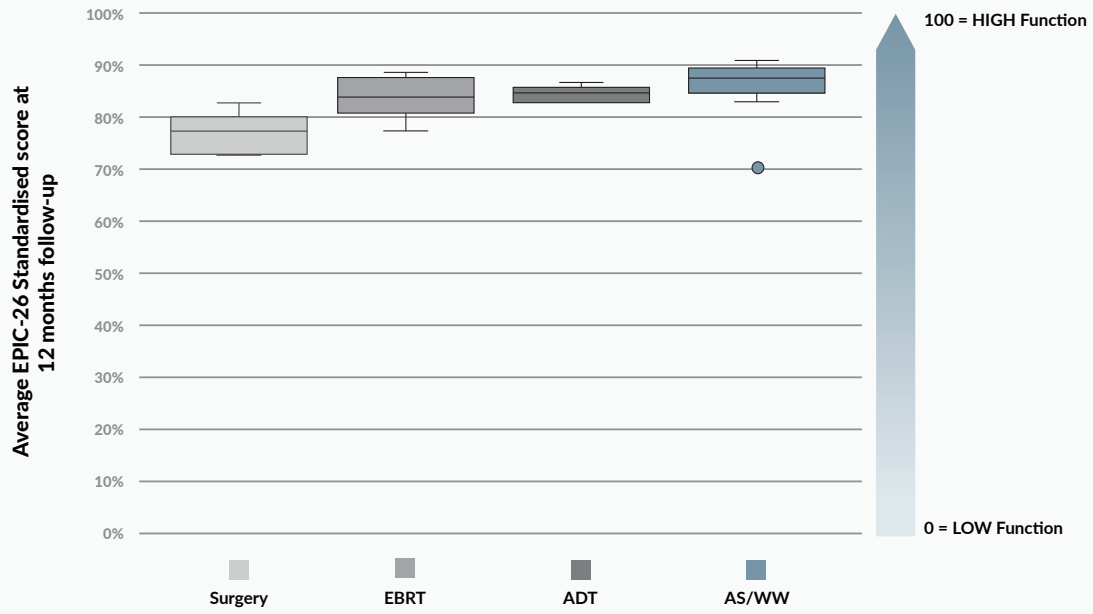


FIGURE 46: PATIENT-REPORTED URINARY IRRITATION/OBSTRUCTION FOLLOWING TREATMENT (SURGERY, EBRT, ADT, AS/WW; 2015–2016).



Based on numbers where 12-month EPIC-26 survey was completed. ADT data not available for NT and limited for SA at time of analysis.
AS/WW, active surveillance/watchful waiting.

FIGURE 47: PATIENT-REPORTED URINARY INCONTINENCE FOLLOWING TREATMENT (SURGERY, EBRT, ADT, AS/WW; 2015–2016).

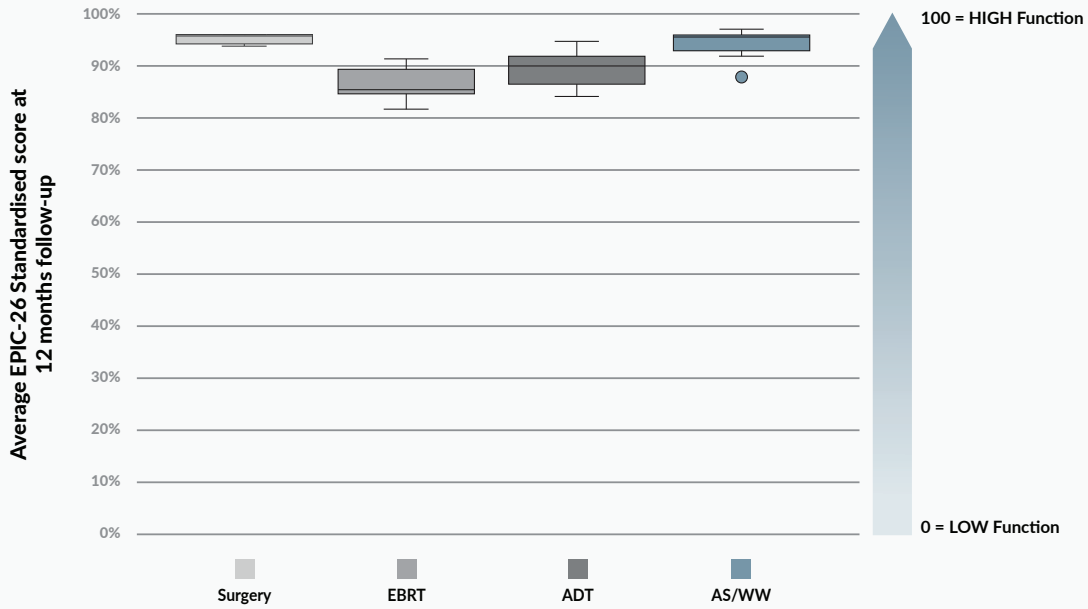


Based on numbers where 12-month EPIC-26 survey was completed. ADT data for NT not available and limited for SA at time of analysis.
AS/WW, active surveillance/watchful waiting.

BOWEL FUNCTION

Figure 48 provides an overview of bowel function after surgery, radiotherapy, ADT and active surveillance/watchful waiting. Bowel function assesses the extent to which men report urgency to have a bowel movement, increased frequency of bowel movements, losing control of stools, bloody stools, and abdominal, rectal or pelvic pain. Low function at 12 months is reported in men who have received radiotherapy. This reflects the fact that radiation can cause proctitis (inflammation of the rectum) which then leads to bowel dysfunction. Of interest was the high number of men receiving ADT who reported bowel dysfunction, but as discussed in relation to bowel bother, this is likely to reflect the observation that men on ADT have overall poorer quality of life than men on active surveillance or watchful waiting.

FIGURE 48: PATIENT-REPORTED BOWEL FUNCTION FOLLOWING TREATMENT (SURGERY, EBRT, ADT, AS/WW; 2015–2016).



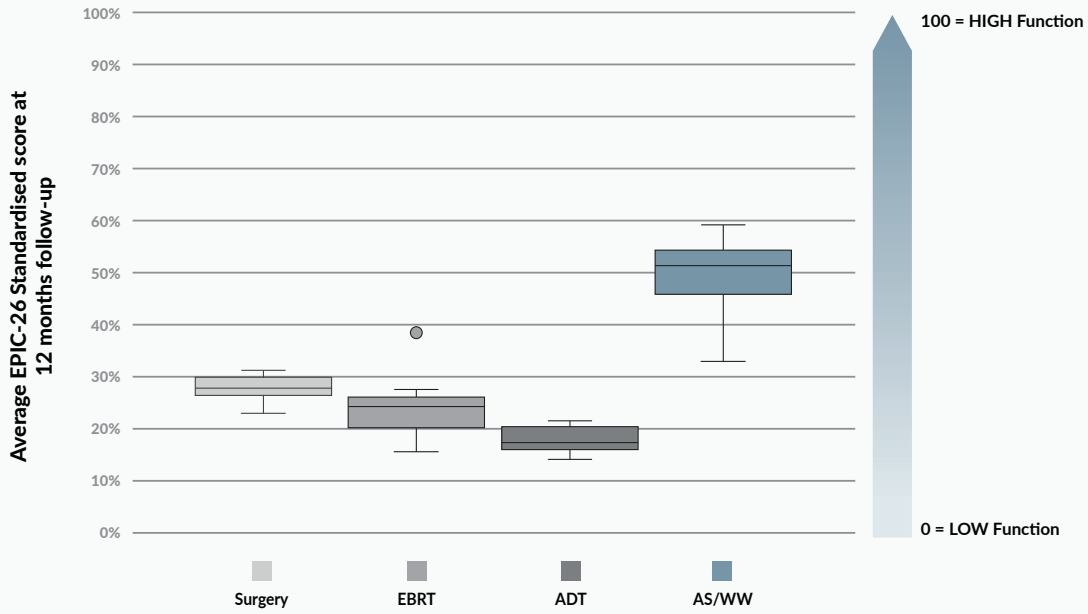
Based on numbers where 12-month EPIC-26 survey was completed. ADT data not available for NT and limited for SA at time of analysis.
AS/WW, active surveillance/watchful waiting.

SEXUAL FUNCTION

Figure 49 provides a summary of sexual function 12 months after surgery, radiotherapy, ADT and initiation on active surveillance/watchul wating. Sexual function is calculated taking into account the extent to which men self-report problems associated with having an erection, reaching orgasm, as well as the quality and frequency of erections.

It is clear that sexual function is often impacted after treatment, and that this occurs across surgery, radiotherapy and ADT. Even men who have no active treatment report function scores that are much lower than those reported for either urinary or bowel function at 12 months. Overall, ADT appears to affect men the most in terms of sexual function.

FIGURE 49: PATIENT-REPORTED SEXUAL FUNCTION FOLLOWING TREATMENT (SURGERY, EBRT, ADT, AS/WW; 2015–2016).



Based on numbers where 12-month EPIC-26 survey was completed. ADT data not available for NT and limited for SA at time of analysis.
AS/WW, active surveillance/watchful waiting.

QUALITATIVE RESEARCH FOLLOWING TREATMENT

The side effects of treatment such as urinary and bowel symptoms and erectile dysfunction can be substantial and psychologically damaging. The need to avoid or minimise these symptoms as far as possible is important to sustaining a reasonable quality of life.

TREATMENT SIDE-EFFECTS CAUSING MEN TO FEEL SHAME AND EMBARRASSMENT

Men felt a sense of shame or embarrassment with the known side effects of treatment (sexual dysfunction and urinary incontinence). Some men felt that they might be judged to be impotent and/or incontinent if they spoke about their prostate cancer to others, and the men who were actually experiencing these symptoms indeed felt some degree of embarrassment or shame.

"I think it's the fear of the unknown, it's 'Are they well are they not?' 'Are they wearing a pad or are they not?' 'Can they wet themselves?' "

(45 years, 4 months)

"...particularly blokes, and particularly middle-aged blokes, do tend to make funny faces. Uncomfortable and pained expressions, like oh really, you are kidding, is that what you had, kind of thing. Oh geez really!?"

(52 years, 6 months)

LONELINESS AND ISOLATION

Many men expressed feelings of loneliness and social isolation, particularly younger men and those living alone and without family members close by. Some men were reluctant to talk with people close to them about their anxieties about prostate cancer. Some mentioned that they felt isolated because some of their friends did not know how to deal with their diagnosis. Some men reported feeling isolated because they were not able to socialise as before, due to poor health, negative effects of surgery and treatment, including urinary incontinence.

"The nominating factor is the total lack of urinary control; it just pretty much destroyed your life for twelve months... You really can't go anywhere much because when you do try and go anywhere, you finish up having overflows and it's just not worth even going down that path."

(74 years, 27 months after diagnosis, SA study)

UNMET NEED DIRECTLY AFTER TREATMENT

Many men felt they had unmet needs directly after treatment for prostate cancer. These ranged from gaining sufficient information, support or care from a physical or emotional perspective. Some men felt they were unprepared for the recovery process and side-effects after they had treatment.

"...it's kind of like something's been given to you in a sense and then taken away, so you've got the support and then it's been taken away all of a sudden."

(28 years, 16 months after diagnosis)

"It's a little kind of 'look, well you know I've cured you of the cancer so that's the big job,' you know."

(52 years, 6 months after diagnosis)

NEXT STEPS

These qualitative studies have revealed some issues that PCOR-ANZ researchers are currently addressing through targeted programs.

The extent of unmet need 12 months after treatment in men with prostate cancer is being assessed by PCOR-ANZ researchers in Victoria. Men will be asked to report on their unmet needs using the validated Survivorship Unmet Need Survey-Short Form (SUNS-SF), with results reported back to health services. This will assist in tailoring strategies to meet local gaps.

A care coordination study is underway to address the needs of men who report that they have problems with their urinary, bowel or sexual function. PCOR-ANZ plays a crucial role in the delivery of this trial program. Men who self-report having a moderate or big problem with their urinary, bowel or sexual function are invited to have a care coordinator work with them to understand if there are services which might assist them in improving their quality of life. Members of the TrueNTH care coordination team communicate with men over the phone and assist them with advice and access to local support services or provide telephone-based education and support.

Early results are promising. In a pilot study, 33 men who reported a moderate-to-big problem with their sexual function at baseline entered into the 12-month program. They were recruited 12 months after diagnosis and the intervention concluded 24 months after diagnosis. Results were compared with 85 men who resided in the same geographic region as those in the study, but did not receive the intervention. These 85 men were 'historical controls', they were diagnosed at least two years before the intervention commenced. At 24 months post diagnosis, men who received the intervention were almost 60% less likely to report moderate or big problems than the historical controls (Odds ratio 0.38, 95% confidence interval 0.14-0.98, p=0.047). These results will be described in detail in a future report.

6. WORKING WITH CLINICIANS AND HOSPITALS

The primary goal of PCOR-ANZ is to improve the quality of care provided to men diagnosed and treated for prostate cancer. As a clinical quality registry, our focus is on strengthening health services delivery and supportive care by engaging with and working alongside the clinical community. Our primary mechanism to achieve this is through the provision of confidential quality of care reports distributed bi-annually to our participating hospitals and clinicians. These confidential, risk-adjusted, evidence-based reports provide feedback on a set of quality of care standards. Currently, we have 218 public and private hospitals and 293 treating clinicians who have registered with PCOR-ANZ and making a commitment to the quality of care of their patients. The names of all contributing clinicians by jurisdiction are listed below in the Contributing Clinicians and Hospitals section of this report.

QUALITY OF CARE REPORTS

National-level quality of care reports will soon be distributed to participating hospitals and clinicians. These reports will be released bi-annually and will document performance against a core set of quality indicators. The following indicators are currently being reported but this number will increase in the next two years to cover the full composite of indicators as voted by clinicians and researchers:

- **INDICATOR 1:** Mortality
- **INDICATOR 2:** PSA taken post prostatectomy
- **INDICATOR 3:** Documentation of cT in medical record
- **INDICATOR 4:** Advanced disease and active surveillance (risk adjusted)
- **INDICATOR 5:** Patients who met PRIAS criteria and had radical prostatectomy
- **INDICATOR 6:** Positive margin post prostatectomy (risk adjusted)
- **INDICATOR 7**: Disease-specific quality of life - Urinary bother (12-month follow-up)
- **INDICATOR 8:** Disease-specific quality of life - Sexual bother (12-month follow-up)
- **INDICATOR 9:** Disease-specific quality of life - Bowel bother (12-month follow-up)

We are constantly working towards improving the quality of care reports that we provide in order to give clinicians and hospitals the data they need in the format that is most useful to them. PCOR-ANZ researchers in Victoria have been conducting interviews with urologists to understand their views on the reports and how they could be improved.[56] Some comments by consultant urologists are outlined on the next page in regard to the current report format.

"... I think the report is very good, I think the format is excellent and it serves an excellent purpose. Those funnel plots are fairly standard for depiction of epidemiological and certainly surgical/quality of care data so made a lot of sense to me."

Consultant urologist 1, 15 years' experience

"I think the reports are excellent. I find it extremely useful ... I look very carefully at my own data to see how my own results are by comparison with the general. So not only do I get the reports for myself, I also get the reports for [hospital], so I also get a chance to look at the outcome for these institutions, which we monitor very closely."

Consultant urologist 2, 20+ years' experience

"I look at it, the hospital executives look at it, if necessary we'll take it to one of the committee meetings to discuss whether it's appropriate or not, I guess we are still in the early stages of deciding how best to make use of it, but we do look at it very closely and find it very important to have. Because it is an audit, and we regard audit as very important, so to have this audit done for us is excellent"

Consultant urologist 3, 20+ years' experience

"I find it very useful, I think it's a really, really good format, and it's a fantastic way to benchmark yourself against your colleagues and against the state average for various indicators"

Consultant urologist 4, 12 years' experience

Suggestions for improvement that we are taking on board include developing summary reports, providing a summary of data completeness/ missing data, examining aspects of the surgical indicators in more detail, and making reports available electronically or accessible online.

"It's very detailed, probably a bit more detailed than it needs to be, maybe at six months you could have an abbreviated report and then a full report at 12 months."

Consultant urologist 2, 15 years' experience

"Now we have a data manager that comes here every few months ... and updates our raw data for the registry. I asked her what effort is made to go back and try and retrieve this missing data and she said nobody is trying to retrieve the missing data."

Consultant urologist 5, 20+ years experience

"Margin rates aren't given over time so it's actually very hard to know how we are tracking because if someone has a higher than average margin rate... he can't really tell whether they are improving or not improving"

Consultant urologist 6, 20+ years' experience

"Having online access to these would be much better, as we always hoped we would have a website that people could log into and see how they're performing in real time and print out reports yourselves, I mean I think we would still love to see that in the registry, having online ccess to kind of up-to-date data."

Consultant urologist 3, 20+ years' experience

Over the next 12 months, Quality of Care reports will be distributed to all contributing hospitals across Australia and New Zealand. We will continually strive to improve the reports and will expand the quality indicators against which we report on an ongoing basis, to ensure that we monitor areas that need closer attention and where we wish to motivate change.

THE STAMP INITIATIVE

PCOR-ANZ is made possible through our strong collaboration with participating clinicians and hospitals across Australia and New Zealand. The participation of healthcare providers who treat and care for men throughout their prostate cancer journey is critical to the success of PCOR-ANZ. We highly value our collaborating health professionals who enable us to:

- Support research at a population level and identify trends across Australia and New Zealand.
- Provide risk-adjusted, evidence-based reports to clinicians and hospitals on a bi-annual cycle, based on a common set of clinical quality indicators.
- Increase the implementation of best practice guidelines for treatment.
- Assess patterns of care.
- Reduce variation in patient outcomes.
- Identify factors that predict better treatment outcomes.
- Provide information to patients about the risks and benefits of specific approaches to prostate cancer treatment.

In November 2017, we launched the Stamp initiative, which is designed to positively acknowledge the highly valuable contribution participating clinicians and hospitals are making to PCOR-ANZ. In presenting our collaborating participants with a licence to use the Stamp, we publicly acknowledge the active contribution they are making to the registry. By signing on to the registry, participants have agreed to:

- Provide contact information for patients diagnosed with prostate cancer in their hospital/practice.
- Provide explanatory information to patients and carers about the registry and its purpose.
- Ensure data managers have access to clinical records stored in their hospital/practice.
- Act on information provided back from the registry regarding quality of care.

Furthermore, each participant is presented with a Certificate of Participation, which can be displayed in waiting or consulting rooms. This is another way that PCOR-ANZ enables participants to signal to their patients that they are committed to quality treatment and outcomes in prostate cancer.

Calvary Mater, Newcastle

Dr Mark Louie-Johnsun, is part of the NSW PCCR

Participation in the Registry is about quality.

Dr Peter Chong, Lake Macquarie Urology,
Belmont District Hospital and Royal Newcastle Centrek

It's part of our professional responsibility to the community to ensure we provide the best service possible – measuring outcomes is essential.

A/Prof Andrew Brooks, Westmead Hospital,
Western Sydney Local Health District

From an educational, professional and public responsibility point of view, it is essential...

Prof Phil Stricker, St Vincent's Private Hospital,
part of the St Vincent's Health Network

The Registry is the coal-face of prostate cancer care. Understanding real-world effectiveness allows me to give people better treatment.

A/Prof Anthony Joshua, St Vincent's Public Hospital,
part of the St Vincent's Health Network

CONTRIBUTING CLINICIANS AND HOSPITALS

We are grateful to the following clinicians and hospitals for their ongoing participation and support for PCOR-ANZ. We positively acknowledge the contribution that each and every participant is making to improve the lives of men and their families who are going through, or will go through, a prostate cancer treatment journey. Patients will be invited to join the registry if both their treating clinician and the hospital or site in which they are diagnosed contribute to the registry. A list of contributing sites and clinicians, categorised by jurisdictions, can be found below.

Note: The following lists of participating clinicians and hospitals are accurate as of the 30th November 2018.

ACT RECRUITING SITES	
Barton Private	National Capital Private Hospital
Calvary Bruce Private Hospital	Calvary Public Hospital Bruce
Calvary John James Hospital	The Canberra Hospital
Canberra Private	

ACT CLINICIANS	SPECIALTY	ACT CLINICIANS	SPECIALTY
Ahmad Al-Sameraaii	Urologist	Muhammad Kahloon	Urologist
Rex Chan	Urologist	Laeeq Malik	Medical Oncologist
Hany Elsaleh	Radiation Oncologist	Simon McCredie	Urologist
Hodo Haxhimolla	Urologist	Maurice Mulcahy	Urologist
		Ganesalingham Pranavan	Medical Oncologist

NSW RECRUITING SITES			
The St Vincent's Prostate Cancer Centre (St Vincent's Clinic)	Calvary Mater Hospital	Lismore Hospital	Shoalhaven District Memorial Hospital
Riverina Cancer Care Centre	Campbelltown Hospital	Liverpool Hospital	St George Hospital
St Vincent's Private Hospital	Cobar District Hospital	Maitland Hospital	St Vincent's Hospital Sydney
Sydney Adventist Hospital	Coffs Harbour Hospital	Manning Rural Referral Hospital	Tamworth Rural Referral Hospital
Garvan Institute of Medical Research	Coonabarabran District Hospital	Mudgee District Hospital	Wagga Wagga Base Hospital
Armidale Rural Referral Hospital	Dubbo Hospital	Nepean Hospital	Walgett Health Service
Bankstown-Lidcombe Hospital	Gosford Hospital	Orange Health Service	Westmead Hospital
Bathurst Base Hospital	Grafton Base Hospital	Port Macquarie Base Hospital	Wollongong Hospital
Belmont Hospital	Griffith Hospital	Prince of Wales Hospital	Wyong Hospital
Blacktown Hospital	John Hunter Hospital (Royal Newcastle Centre)	Royal North Shore Hospital	

NSW CLINICIANS	SPECIALTY	NSW CLINICIANS	SPECIALTY
Diana Adams	Medical Oncologist	Bavanth Balakrishnar	Medical Oncologist
Gias Ahmed	Urologist	Simon Bariol	Urologist
Paul Ainsworth	Urologist	Martin Berry	Radiation Oncologist
Mohan Arianayagam	Urologist	Andrew Brooks	Urologist
Nader Awad	Urologist	David JG Brown	Urologist

Table continues over page

NSW CLINICIANS	SPECIALTY	NSW CLINICIANS	SPECIALTY
Joseph Bucci	Radiation Oncologist	Kenny Low	Urologist
Alistair Cameron-Strange	Urologist	William Lynch	Urologist
Venu Chalasani	Urologist	Finlay Macneil	Urologist
Matthew Chan	Medical Oncologist	David Malouf	Urologist
Christopher Chee	Urologist	Pascal Mancuso	Urologist
Peter Chin	Urologist	Nicholas McLeod	Urologist
Peter Chong	Urologist	Andrew Mitterdorfer	Urologist
Wei Chua	Medical Oncologist	Marianne Morgan	Medical Oncologist
Elizabeth Dally	Urologist	Spencer Murray	Urologist
Stephen Della-Fiorentina	Medical Oncologist	Timothy Nicholson	Urologist
Norbert Doeuk	Urologist	Gordon O'Neill	Urologist
Stuart Ehsman	Urologist	Lisa Osgood	Urologist
David Eisinger	Urologist	Rupert Ouyang	Urologist
David Ende	Urologist	Manish Patel	Urologist
Richard Ferguson	Urologist	Kesley Pedler	Urologist
Andrew Fong	Radiation Oncologist	Prem Rashid	Urologist
Paul Gassner	Urologist	Krishan Rasiah	Urologist
David Gillatt	Urologist	Prem Rathore	Urologist
Alexander Grant	Urologist	Andrew Richards	Urologist
Howard Gurney	Medical Oncologist	Rahul Rindani	Urologist
Kayvan Haghighi	Urologist	Stephen Ruthven	Urologist
Lawrence Hayden	Urologist	Timothy Skyring	Urologist
Chi Can Huynh	Urologist	Steven Sowter	Urologist
Thomas Jarvis	Urologist	Raymond Stanton	Urologist
Neil Joshi	Urologist	Phillip Stricker	Urologist
David Kerle	Urologist	Edward Sun	Radiation Oncologist
Mohamed Khadra	Urologist	James Symons	Urologist
Lawrence Kim	Urologist	Ruban Thanigasalam	Urologist
Raymond Ko	Urologist	Robert Thomas	Urologist
Paul Kovac	Urologist	Matthew Threadgate	Urologist
Craig Kukard	Medical Oncologist	Celi Varol	Urologist
Benjamin Kwok	Urologist	Justin Vass	Urologist
Andre Lalak	Urologist	Kenneth Vaux	Urologist
Howard Lau	Urologist	Clair Whelan	Urologist
Enzo Lazzaro	Urologist	Michael Wines	Urologist
Dominic Lee	Urologist	Lee Hao (Eddy) Wong	Urologist
Mark Louie-Johnsun	Urologist	Henry Woo	Urologist
		Robert Zielinski	Medical Oncologist

NZ RECRUITING SITES	
North Shore Urology	Dunedin Hospital
Andy Malcolm Urology	Greenlane Clinical Centre
Hawke Urology	Grey Base Hospital
Merrilees Dawson Ltd	Manukau Super Clinic
Mischel Neill Urology	Middlemore Hospital
OneSixOne	Nelson Hospital
UA Central Otago	North Shore Hospital
Urology Associates	Southland Hospital
Urology BOP	Timaru Hospital
Urology Care Wellington	Wairarapa Hospital
Waikato Hospital	Wairau Hospital
Southland Hospital	Waitakere Hosptial
Auckland City Hospital	Palmerston North Hospital
Christchurch Hospital	Wellington Regional Hospital

NZ CLINICIANS	SPECIALTY	NZ CLINICIANS	SPECIALTY
Brendon Anderson	Radiation Oncologist	Quentin King	Urologist
Chris Atkinson	Radiation Oncologist	Madhu Koya	Urologist
Kevin Bax	Urologist	Andrew Lienert	Urologist
Suzanne Beuker	Urologist	Giovanni Losco	Urologist
Nicholas Buchan	Urologist	Serge Luke	Urologist
Peter Davidson	Urologist	Douglas Iupati	Radiation Oncologist
James Duthie	Urologist	Jane Macdonald	Urologist
Sharon English	Urologist	Michael Mackey	Urologist
Mark Fraundorfer	Urologist	Andy Malcolm	Urologist
Adrian Folwell	Urologist	Stephen Mark	Urologist
Peter Gilling	Urologist	David Merrilees	Urologist
Eva Fong	Urologist	Mischel Neill	Urologist
Mark Heinau	Urologist	Tony Nixon	Urologist
Alistair Hepburn	Urologist	Avtar Rainer	Radiation Oncologist
Chris Hawke	Urologist	Guiseppe Sasso	Radiation Oncologist
Ben Hindson	Radiation Oncologist	Rod Studd	Urologist
Carmel Jacobs	Medical Oncologist	Simon Van-Rij	Urologist
Lisa Johannson	Radiation Oncologist	Andrew Williams	Urologist
Michael Holmes	Urologist	Liam Wilson	Urologist
Andrew Kennedy-Smith	Urologist	Chris Wynne	Radiation Oncologist
Frank Keuppers	Urologist	Michael Stotzer	Urologist

NT RECRUITING SITES
Darwin Private Hospital
Alice Springs Hospital (ASH)
Royal Darwin Hospital

NT CLINICIANS	SPECIALTY
Paolo De Ieso	Radiation Oncologist
Henry Duncan	Urologist

QLD RECRUITING SITES	
Toowoomba Urology	Urology South Brisbane
Brisbane Private Hospital	Wesley Hospital
Brisbane Urology Clinic	Wesley Urology Clinic
Cairns Private Hospital	Ipswich Urology
East Coast Urology	Jamie Reynolds Urology
Genesis Care	John Flynn Private Hospital
Gold Coast Urology	Mackay Urology
Gold Coast Private Hospital	Mater Hospital Brisbane
Greenslopes Private Hospital	Mater Hospital Mackay
Greenslopes Urology Clinic	Cairns Hospital
Holy Spirit Northside Private Hospital	Gold Coast University Hospital
Mater Private Hospital Townsville	Ipswich Hospital
Northern Urology	Mackay Base Hospital
Northern Urology Clinic	Princess Alexandra Hospital
Patrick Dunne Urology	QE II Jubilee Hospital
Pindara Private Hospital	Redcliffe Hospital
St Andrews Hospital Toowoomba	Rockhampton Hospital
St Andrews Private Hospital Ipswich	Royal Brisbane and Women's Hospital
Sunshine Coast Urology Clinic	Toowoomba Base Hospital
Townsville Urology	Townsville Hospital

QLD CLINICIANS	SPECIALTY	QLD CLINICIANS	SPECIALTY
Ahmad Ali	Urologist	Ian McKenzie	Urologist
Stefan Antoniou	Urologist	Jason Paterdis	Urologist
Sanjeev Bandi	Urologist	Stuart Philip	Urologist
Stephen Bourne	Urologist	John Preston	Urologist
William Bowes	Urologist	David Pryor	Radiation Oncologist
Peter Burke	Urologist	Jamie Reynolds	Urologist
Alistair Campbell	Urologist	Jo Schoeman	Urologist
Adrian Clubb	Urologist	David Sillar	Urologist
Stuart Collins	Urologist	Philip Smith	Urologist
Geoffrey Coughlin	Urologist	Daryl Stephens	Urologist
Katharine Cuff	Medical Oncologist	Yang Sun	Urologist
Patrick Dunne	Urologist	Peter Swindle	Urologist
Garrath Evans	Urologist	Alex Tan	Radiation Oncologist
Tony Gianduzzo	Urologist	Hee Soo Teng	Urologist
Jacob Gleeson	Urologist	Christopher Tracey	Urologist
Katherine Gray	Urologist	Paul Vasey	Medical Oncologist
Kiran Hazratwala	Urologist	Ian Vela	Urologist
Peter Heathcote	Urologist	Euan Walpole	Medical Oncologist
Wesley Hii	Urologist	Roger Watson	Urologist
Malcolm Lawson	Urologist	Glen Wood	Urologist
Margot Lehman	Radiation Oncologist	Simon Wood	Urologist
Steven Lun	Urologist	Hin-Wai Yap	Urologist
James Mackean	Radiation Oncologist	John Yaxley	Urologist
Greg Malone	Urologist		

SA RECRUITING SITES	
Ashford Hospital	Western Hospital
Calvary Central Districts Hospital (CCDH)	Flinders Medical Centre
Calvary North Adelaide Hospital	Lyell McEwin Hospital
Flinders Private Hospital (FPH)	Modbury Hospital
Genesis Care - Adelaide Radiotherapy Centre, CCDH	Naracoorte Hospital
Genesis Care - Adelaide Radiotherapy Centre, FPH	Noarlunga Hospital
Genesis Care - Adelaide Radiotherapy Centre, St Andrew's Hospital	Repatriation General Hospital
Genesis Care - Adelaide Radiotherapy Centre, Tennyson Centre	Royal Adelaide Hospital
St Andrew's Hospital	The Queen Elizabeth Hospital

SA CLINICIANS	SPECIALTY	SA CLINICIANS	SPECIALTY
John Bolt	Urologist	Jason Lee	Urologist
Nick Brook	Urologist	John Miller	Urologist
Rick Catterwell	Urologist	Kim Moretti	Urologist
Michael Chong	Urologist	Kim Pese	Urologist
David Elder	Urologist	Adrian Porter	Urologist
Darren Foreman	Urologist	Raj Singh-Rai	Urologist
Andrew Fuller	Urologist	Alan Stapleton	Urologist
Kym Horsell	Urologist	Denby Steele	Urologist
Alex Jay	Urologist	Peter Sutherland	Urologist
Jimmy Lam	Urologist	Richard Wells	Urologist

TAS RECRUITING SITES	
Calvary Hospital - St Luke's Campus	Hobart Private Hospital
Calvary Hospital - St Vincent's Campus	North Tas Urology
Calvary Hospital - Lenah Valley Campus	Launceston General Hospital
Calvary Hospital - St John's Campus	Royal Hobart Hospital

TAS CLINICIANS	SPECIALTY	TAS CLINICIANS	SPECIALTY
Stephen Brough	Urologist	Fadi Nuwayhid	Urologist
Anthony Eaton	Urologist	Frank Redwig	Urologist
Robert Jensen	Urologist	Marketa Skala	Radiation Oncologist
Ian Middleton	Urologist	Michael Vaughan	Urologist
Michael Monsour	Urologist		

VIC RECRUITING SITES	
Cabrini Hospital Malvern	Footscray Hospital (Western Health)
Cabrini Hospital Brighton	Frankston Hospital (Peninsula Health)
Epworth Eastern	Gippsland Radiation Oncology
Epworth Freemasons	Gippsland Southern Health Service
Epworth Richmond	Goulburn Valley Health
Geelong Private Hospital	Healesville Hospital (Eastern Health)
GenesisCare Albury Wondonga	Heidelberg Repatriation Hospital (Austin Health)
GenesisCare Epping	Kerang and District Health
GenesisCare Footscray	Kyabram District Health Services
GenesisCare St Vincent's	Kyneton District Health Service
GenesisCare Cabrini	Latrobe Regional Hospital
GenesisCare Ringwood	Maroondah Hospital (Eastern Health)
GenesisCare Berwick	Mildura Base Hospital
GenesisCare Franskton	Monash Medical Centre Clayton (Monash Health)
Maryvale Private Hospital	Moorabbin Hospital (Monash Health)
Masada Private Hospital	Northern Health
Mildura Private Hospital	Peter MacCallum Cancer Centre - Parkville
St John Of God - Ballarat	Peter MacCallum Cancer Centre - Moorabbin
St John Of God - Bendigo	Peter MacCallum Cancer Centre - Bendigo
St John Of God - Geelong	Peter MacCallum Cancer Centre - Box Hill
St John Of God - Warrnambool	Peter MacCallum Cancer Centre - Sunshine
The Bays Private Hospital	Portland District Health
The Valley Private Hospital	Rochester And Elmore District Health Service
Angliss Hospital (Eastern Health)	Rosebud Hospital (Peninsula Health)
Alfred Hospital (Alfred Health)	Royal Melbourne Hospital (Melbourne Health)
Alfred Radiation Oncology (Alfred Health)	Sandringham Hospital (Alfred Health)
Austin Hospital (Austin Health)	South Gippsland Hospital
Bairnsdale Regional Health Service	South West Healthcare
Ballarat Health Service	St Vincent's Hospital Melbourne
Bass Coast Health	Sunshine Hospital (Western Health)
Bendigo Health	Swan Hill District Hospital
Box Hill Hospital (Eastern Health)	University Hospital Geelong
Casey Hospital (Monash Health)	Wantirna Health (Eastern Health)
Caulfield Hospital (Alfred Health)	West Gippsland Healthcare Group
Central Gippsland Health Service	Western District Health Service
Colac Area Health	Williamstown Hospital (Western Health)
Dandenong Hospital (Monash Health)	Yarra Ranges Health (Eastern Health)
Echuca Regional Health	

VIC CLINICIANS	SPECIALTY	VIC CLINICIANS	SPECIALTY
Dinesh Agarwal	Urologist	Adam Landau	Urologist
Paul Anderson	Urologist	Nathan Lawrentschuk	Urologist
David Angus	Urologist	Daniel Lenaghan	Urologist
Sree Appu	Urologist	Stephen Lindsay	Urologist
Ravi Asopa	Urologist	Peter Liodakis	Urologist
Conrad Bishop	Urologist	Christopher Love	Urologist
Damien Bolton	Urologist	Philip McCahy	Urologist
Janelle Brennan	Urologist	Michael McClatchey	Urologist
Nicholas Campbell	Urologist	Kathryn McLeod	Urologist
Alexander Cato	Urologist	Richard McMullin	Urologist
Chee Wee Cham	Urologist	Daniel Moon	Urologist
Yee Chan	Urologist	Peter Mortensen	Urologist
Christopher Chang	Urologist	Declan Murphy	Urologist
Anita Clarke	Urologist	Greg Neerhut	Urologist
Laurence Cleeve	Urologist	Bradley Newell	Urologist
David Cook	Urologist	Owen Niall	Urologist
Niall Corcoran	Urologist	Briony Norris	Urologist
Anthony Costello	Urologist	Fadi Nuwayhid	Urologist
Alan Crosthwaite	Urologist	Jason Ooi	Urologist
David Dangerfield	Urologist	David Pan	Urologist
Lachlan Dodds	Urologist	Justin Peters	Urologist
Scott Donnellan	Urologist	Trung Pham	Urologist
Philip Dundee	Urologist	Ranjit Rao	Urologist
Robert Forsyth	Urologist	Nicholas Redgrave	Urologist
Mark Frydenberg	Urologist	Peter Royce	Urologist
Johan Gani	Urologist	Paul Ruljancich	Urologist
Jeremy Goad	Urologist	Prassanah Satasivam	Urologist
Richard Grills	Urologist	Andrew See	Radiation Oncologist
Jeremy Grummet	Urologist	Shomik Sengupta	Urologist
Dennis Gyomber	Urologist	Ross Snow	Urologist
Rohan Hall	Urologist	Daniel Steiner	Urologist
Uri Hanegbi	Urologist	Joseph Thomas	Urologist
Laurence Harewood	Urologist	Raymond Tong	Urologist
Matthew Harper	Urologist	Ben Tran	Medical Oncologist
Anu Jayathillake	Urologist	Andrew Troy	Urologist
Lydia Johns-Putra	Urologist	David Webb	Urologist
Paul Kearns	Urologist	Geoffrey Wells	Urologist
Jamie Kearsley	Urologist	Lih-Ming Wong	Urologist
Dennis King	Urologist	Peter Wong	Urologist
John Kourambas	Urologist		

7: FUTURE DIRECTIONS

In just its first four years of operation, PCOR-ANZ has already proven itself a valuable resource to the prostate cancer community. Twenty-nine peer-reviewed publications have been released to date (see https://prostatecancerregistry.org/ for more details) and economic analysis has demonstrated that there is a clear return on investment, which is expected to reach $5 per $1 dollar investment when we achieve population coverage.[4] Over the next 12 months, we are looking forward to continuing our role of monitoring patterns of care across Australia and New Zealand, with a summary of our plans described below.

DATABASE	RECRUITMENT	We will be aiming to increase recruitment of our eligible population over the next 12 months to reach 85% population coverage overall by December 2019.
	DATA INTEGRITY	We will continue to search for more efficient and effective methods for obtaining clinical information and an audit will be undertaken focusing on ensuring accurate abstraction of data from the medical record. We will pursue initiatives to undertake data linkage with external administrative dataset such as the Pharmaceutical Benefits Scheme (PBS) and the Medicare Benefits Scheme (MBS) datasets.
	BENCHMARKING REPORTS	Increasing emphasis is to be placed on the production and dissemination of benchmark reports across all contributing sites. We are progressively moving towards real-time reporting of registry data and to providing regular feedback to sites on timeliness, accuracy and completeness of data used in the production of their benchmark reports.
DIAGNOSIS AND TREATMENT	BIOPSY	Work is underway by PCOR-ANZ researchers to understand the impact of the biopsy approach, with and without an accompanying MRI scan, on ability to identify clinically significant prostate cancer, side-effect profile such as infection and pain, and cancer survival (PROSPERO REGISTRATION 91028).
	MRI	We are now collecting details of MRI scans so that we can better understand how it is being used and its impact on disease management, progression and on men's perception of their health.
	ACTIVE SURVEILLANCE	We will undertake research to explore reasons for poor adherence to active surveillance, so that strategies may be developed to address this emerging problem.
	RADIOTHERAPY	We will be linking high-quality radiotherapy data to PCOR-ANZ to more accurately understand longer-term management of prostate cancer, particularly salvage treatment.
PATIENTS	PROMs	We are investigating approaches to collect patient-reported outcomes beyond 12 months post diagnosis or treatment, and new patient-reported measures will be introduced to assess unmet needs of men with prostate cancer and the associated needs of their partners and families.
	QUALITY OF LIFE	There appears to be considerable variability in quality of life across sites. In the next 12 months, we intend to examine attributes of health services which are achieving good or excellent results, to identify if there are lessons to be learned. It is through benchmarking and learning from exemplars that the bar can be raised for all. We will strengthen linkages with The Movember Foundation's TrueNTH program, which provides both telehealth and digital health interventions.

RESEARCH	RESEARCH	The national dataset is available for use by researchers whose projects are approved by an authorised ethics committee and have the support of the PCOR-ANZ Steering Committee. Future research will explore using PCOR-ANZ to recruit men to clinical trials and linkage to biorepositories in order to improve the targeting of therapy according to genetic and other biomarkers.
	CROSS-COLLABORATION	A research program will foster cross-jurisdiction collaboration using PCOR-ANZ data. This will ensure that projects are co-designed to address problems which have widespread relevance.

As we move out of the implementation phase of our first few years, we will expand our capabilities to allow us to follow men for 5, 10 and 15 years. This will help us construct a more accurate picture of the journey men, their families and carers undergo when faced with a prostate cancer diagnosis.

We see PCOR-ANZ as the structure within which doctors, researchers and men and their families can work together to improve the wellbeing of all those affected by the disease. We are fully committed to working side by side with our contributors to continue positively impacting prostate cancer health outcomes in three very important ways

- **REDUCE VARIATION:**
  Reduce the current variation in treatment and outcomes, by benchmarking outcomes that matter to men.

- **PROVIDE INFORMATION:**
  Provide helpful information to men about the risks and benefits of different treatment options available.

- **SUPPORT RESEARCH:**
  Support research to advance the treatment options for men diagnosed with prostate cancer.

8: PUBLICATIONS

A full list of publications and abstracts can be found on the PCOR-ANZ website (https://prostatecancerregistry.org). Peer-reviewed publications for the period to 2017–2018 are reported below.

Beckmann K, O'Callaghan M, Vincent A, Roder D, Millar J, Evans S, McNeil J, Moretti K. Australian validation of the Cancer of the Prostate Risk Assessment Post-Surgical score to predict biochemical recurrence after radical prostatectomy. ANZ J Surg. 2018 Mar;88(3):E183–E188. doi: 10.1111/ans.13954. Epub 2017 May 4.

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Campbell JM, Raymond E, O'Callaghan ME, Vincent AD, Beckmann KR, Roder D, Evans S, McNeil J, Millar J, Zalcberg J, Borg M, Moretti KL. Optimum Tools for Predicting Clinical Outcomes in Prostate Cancer Patients Undergoing Radical Prostatectomy: A Systematic Review of Prognostic Accuracy and Validity. Clin Genitourin Cancer. 2017 Oct;15(5):e827–e834. doi: 10.1016/j.clgc.2017.06.001. Epub 2017 Jun 8.

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Moretti, KL, Shi Z, Kopsaftis T, O'Callaghan ME. Delays in radical prostatectomy for prostate cancer and survival outcomes World J Urol 2018 Aug:36(8);1337–1338. doi: 10.1007/s00345-018-2265-z. Epub 2018 Mar 16.

Moretti K, Vatandoust S, Kichenadasse G, et al. Prostate cancer mortality is high in the elderly and can be reduced by selective individualized curative treatment. World J Urol 2018 Nov;36(11):1799–1800. doi: 10.1007/s00345-018-2312-9. Epub 2018 May 10.

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APPENDICES

APPENDIX 1: ETHICS

PCOR-ANZ has been reviewed and approved by ethics committees in New Zealand and each Australian jurisdiction and by the Aboriginal Health and Medical Research Council Ethics Committee (for data collection in New South Wales).
Each ethics committee has approved an opt-out approach to recruitment. This is sometimes also called an opt-off approach. The opt-out approach is a method used in the recruitment of participants into research where information is provided to the potential participant regarding the research and their involvement and where their participation is presumed unless they take action to decline to participate.[57] In being given approval to use an opt-out approach, PCOR registries across Australia and New Zealand provide assurance that

- an explanatory statement will be sent to each man;
- it will be in a format and language which is easy to understand;
- and men can decline to participate at no personal financial cost to them.

A 1800 (freecall) number is available and recorded on the explanatory statement in large bold text. Nationally, the opt-out rate is 2.7%.

The Aboriginal Health and Medical Research Council Ethics Committee approved data collection for Aboriginal men in 2016 after an extensive consultative process. Prior to seeking approval, a request was made by PCOR to seek input and culturally specific advice on how PCOR should operate in recruitment of Aboriginal men. This request was made to the Cancer Institute NSW's Aboriginal Program Development Committee. Three members of the Cancer Institute NSW's Aboriginal Program Development Committee met with PCOR staff to understand the aims of the registry, its recruitment process and how men were contacted to administer the follow up survey. The three Committee members were Clarke Scott, the Aboriginal Health Promotion Officer, Close the Gap Team, Nepean Blue Mountains Local Health District (pictured below in Error! Reference source not found., to the right); Leslie Jenkins, the Aboriginal Health Service Manager, Budyari Aboriginal Community Health Centre, South West Sydney Local Health District; and Rose Wadell, the Aboriginal Cancer Project Officer, Hunter New England Local Health District.

This consultation process resulted in some changes to the script used by PCOR staff. Following a review process by Committee members, the final script was reviewed and approved by Jim Lord, an Aboriginal man diagnosed with prostate cancer (pictured below in **Figure 50**, to the left).

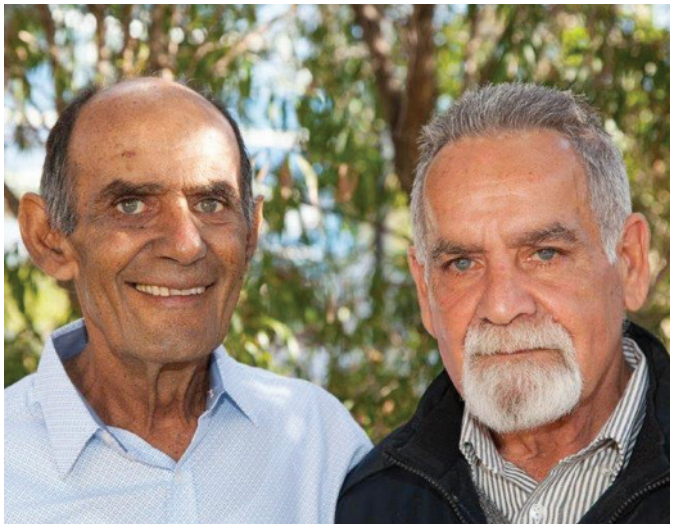
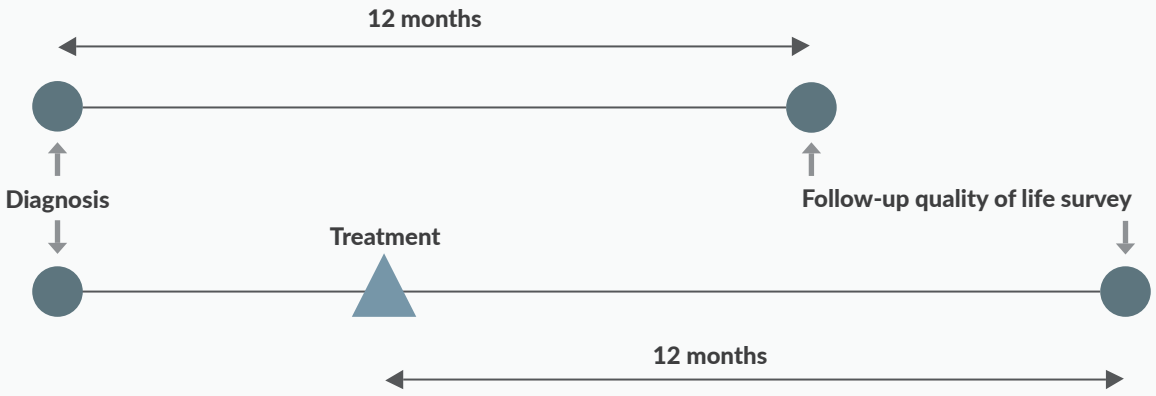


FIGURE 50:
MR JIM LORD (LEFT, A CONSUMER REPRESENTATIVE) AND **MR CLARKE SCOTT** (RIGHT, A CANCER INSTITUTE NSW ABORIGINAL PROGRAM DEVELOPMENT COMMITTEE MEMBER).

APPENDIX 2: THE EXTENDED PROSTATE CANCER INDEX COMPOSITE-26 (EPIC-26) QUALITY OF LIFE INSTRUMENT COLLECTED BY PCOR-ANZ

To assess patient-reported outcomes from the men registered with PCOR-ANZ, men are contacted 12 months after their diagnosis to ask them a set of questions about their quality of life.
If men have treatment, this 12-months follow up is re-set to the date of the treatment (**Figure 51**).

FIGURE 51: TIMELINE FOR COLLECTION OF PATIENT-REPORTED OUTCOMES IN PCOR-ANZ.



The EPIC survey is used by PCOR-ANZ to evaluate men's quality of life at the 12-month follow-up time point.[8,50] The EPIC survey was developed by researchers at University of Michigan and the University of California, Los Angeles, to measure health-related quality of life among men with prostate cancer. It has been validated in men with localised prostate cancer who underwent surgery, EBRT, or brachytherapy with or without the use of hormonal adjuvants.

EPIC-26 was developed as a short-form version of the full EPIC survey. This version contains 26 items and 5 domains: urinary incontinence, urinary irritative/obstructive, bowel, sexual, and hormonal.

Response options for each EPIC item form a Likert scale, and multi-item scale scores are transformed linearly to a 0-100 scale with higher scores representing better HRQOL.

This survey focuses on urinary, bowel and sexual problems, the most common side effects of treatment. It also asks men about their mental health. With these data, the outcomes of different treatments can be assessed that include quality as well as duration of survival. The results of these patient-reported outcomes for men receiving various treatments are shown in Chapter 5 of this report and the full questionnaire can be reviewed in the Supplementary File.

SURVEY RESPONSE RATE

The completeness of PROMs data depends on how data are collected (e.g. capacity for a proxy); the mode of data collection (self-administered or interview-administered); the method of data collection a (paper-based questionnaire/ telephone/ electronic mail (email); and the setting of administration (clinic, home).[58] Survey completeness is also influenced by the number of items in the instrument, the perceived relevance and usefulness of the items, and the perceived ease of understanding the items and the response scale.[59] Response rate by telephone is generally found superior to both mail and email although it may be more expensive to administer.

Jurisdictions employ a variety of techniques to capture quality of life surveys from men. The different approaches used and the completion rates are documented in **Table 4**.

In the early stages of the registry's development there have been some challenges in collecting PROMs. In some jurisdictions, PROM data collection was not collected continuously over the entire two-year period. PCOR-ANZ researchers have been evaluating the best approach to capture patient-reported outcomes. This is discussed briefly in Chapter 6 of this report.

In total, PCOR-ANZ has captured information directly from 50% of all men enrolled on the registry (**Table 4**). Lessons from the implementation of PROM data collection in Victoria are being distributed to other jurisdictions in an effort to improve the response rate. This includes an initial telephone call followed by email distribution of the survey. The aim is to improve response rates to above 80% in 2019.

TABLE 4: FOLLOW-UP METHODOLOGY AND QUALITY OF LIFE SURVEY COMPLETION RATE BY JURISDICTION (2015–2016).

	JURISDICTION								
12 MONTH PROMs (2015-2016)	**ACT**	**NSW**	**NT**	**NZ**	**QLD**	**SA**	**TAS**	**VIC**	**TOTAL**
Approach used to collect survey data from men	Phone Email Letter	Phone Email Letter	Letter	Letter	Letter	Letter	Phone Email Letter	Phone Email Letter	----
EPIC-26 response rate* n (%)	91/312 (29)	981/ 2,500 (39)	39/ 102 (38)	253/ 338 (76)	1,118/ 3,214 (35	523/ 1,749 (30)	243/ 699 (35)	3,705/ 5102 (73)	6,953/ 14,016 (50)

*Numerator denotes number of men who had a 12-month follow up and completed the EPIC-26.

*Denominator denotes the number of men diagnosed with prostate cancer and notified to PCOR-ANZ between 2015 to 2016, by jurisdiction.

APPENDIX 3:
DATA SECURITY AND DATA QUALITY

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

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

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

Data completeness: In each table we have included details of fields where data are missing. As the registry achieves greater population coverage, these gaps will reduce and outstanding data will be collected. We anticipate that missing data rates will reduce markedly over the next three years, but will monitor this closely.

Among the most important variables reported by PCOR-ANZ are those required to calculate the risk of disease progression (NCCN risk groups). NCCN risk groups (see **Appendix 7**) require three variables to be calculated; the clinical T stage, PSA level and Gleason sum.

Table 5 details the extent to which these variables have been collected in the registry. The clinical T stage is the most difficult variable to collect, as it is often not clearly documented as such in the medical record. Due to the way in which the risk categories are structured, a missing clinical t stage does not necessarily mean that a risk category cannot be assigned. It only becomes an issue if men have a low PSA level (<10ng/mL) and a Gleason score of <6. This is because all three variables are required to determine that men are at low risk of disease progression.

In total, 678 /14016 (5%) of cases could not be classified because of missing values.

TABLE 5: SUMMARY OF THE MISSING DATA FIELDS REQUIRED TO CALCULATE THE NCCN RISK GROUPS

Missing data for calculating NCCN Risk Group at diagnosis	TOTAL across all Jurisdictions n (%)
Clinical T category	4095/13,910 (29)
PSA level*	584/12,847 (5)
Gleason sum	667/14,016 (5)

* The denominator includes only men for whom a PSA was recorded as having been taken. In some situations e.g. diagnosis via TURP, it is likely that a PSA may not have been taken.

APPENDIX 4: POPULATION COVERAGE

CALCULATING POPULATION COVERAGE

The process of determining what percentage of the eligible population was recruited in each jurisdiction during the 2015 and 2016 report period is complex, principally because of delays in collating data by relevant government agencies and reporting it consistently across New Zealand and all Australian states and territories.

To obtain consistent estimates on population coverage, members of the PCOR-ANZ team sourced National, State and Territory publicly available data on total numbers of new cases of prostate cancer from Australia and New Zealand. Some assumptions were made on the trend in prostate cancer incidence based on historical data.

Two central sources of data provide the most up to date and robust publicly available data for National, State and Territory numbers of new cases of prostate cancer. These are:

1. Australian Institute of Health and Welfare (AIHW) 2017 Australian Cancer Incidence and Mortality (ACIM) books: prostate cancer Canberra: AIHW.[60]
2. New Zealand Ministry of Health. New Cancer Registrations 2015.[13,61]

ACIM books provide Australian State and Territory incidence data up to and including 2014.

Actual NSW data are not available but are estimated in the accompanying AIHW publication, Cancer in Australia 2017.[62] Estimates for NSW are based on the actual 2014 data for each of the other Australian States and Territories. Based on these sources we estimated numbers of new cases using:

- The total number of prostate cancer cases estimated by AIHW for Australia in 2017 and 2018 were disaggregated by State and Territory using the state-based proportions observed in 2011–2013 as the basis for this disaggregation. Australian data were obtained from the AIHW ACIM books.
- New Zealand data on incidence cases were available up to 2016. The trend in incidence had been relatively stable between 2011 and 2015 so a linear regression was applied to project the numbers based on these five years of data through to 2018. Incidence figures used in this report were obtained from the New Zealand Ministry of Health (updated April 2018) at the following web pages:
- **https://www.health.govt.nz/publication/cancer-historical-summary-1948-2015**
- **https://www.health.govt.nz/publication/selected-cancers-2014-2015-2016**

Figure 52 summarises data sources used to calculate population coverage for the periods 2015 and 2016.

FIGURE 52: SUMMARY OF DATA SOURCES USED TO CALCULATE POPULATION COVERAGE

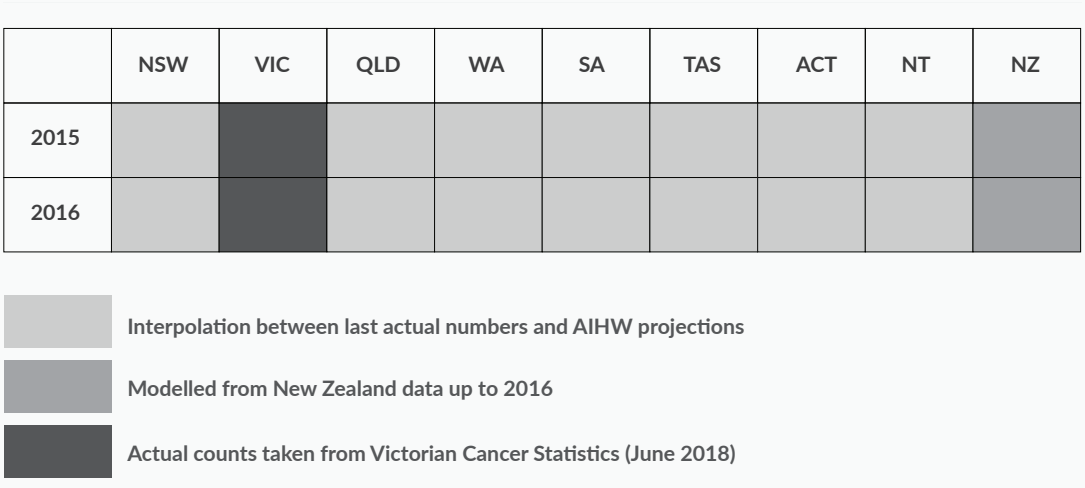


Figure 53 provides a summary of the population coverage across each of the eight jurisdictions contributing to PCOR-ANZ as reported at December 31st 2016.

FIGURE 53: POPULATION COVERAGE BY JURISDICTION
– TOTAL INCIDENCE OF PROSTATE CANCER ANALYSED BY NOTIFICATION TO PCOR-ANZ (2015–2016).

Incident cases of prostate cancer **notified** to PCOR-ANZ

Incident cases of prostate cancer not **notified** to PCOR-ANZ

***NSW population coverage may be under-estimated as the data is being migrated across to the PCOR system and therefore, not complete at the time this report was generated.**

†Due to data mapping differences, this is likely to be an under-estimate.

SITE RECRUITMENT, COVERAGE BY JURISDICTION

We encourage clinicians wishing to have their hospitals 'sign up' to contribute to the registry to contact the PCOR-ANZ research team in their jurisdiction. Alternatively, clinicians may ask their hospital Director of Medical Services or Chief Executive to contact the PCOR-ANZ coordinator in their jurisdiction to discuss how the registry works and to facilitate the hospital's enrolment to the registry.
A summary of site recruitment is outlined in **Table 6**.

TABLE 6: TOTAL NUMBER OF PARTICIPATING SITES WITHIN EACH JURISDICTION BY NUMBER OF PUBLIC AND PRIVATE SITES.

Jurisdiction	Total no. recruiting sites	PUBLIC sites recruited	PUBLIC % of total	PRIVATE sites recruited	PRIVATE % of total
ACT	7	2	29%	5	71%
NSW	39	34	87%	5	13%
NT	3	2	67%	1	33%
NZ	28	18	64%	10	36%
QLD	40	11	28%	29	73%
SA	18	8	44%	10	56%
TAS	8	2	25%	6	75%
VIC	75	52	69%	23	31%
OVERALL TOTAL	218	129	59%	89	41%

PATIENT RECRUITMENT

Only men treated by participating clinicians are recruited into PCOR-ANZ. Notifications of men diagnosed with prostate cancer are received from the following data sources:

- Australia: incident cases are identified through the admitting hospital when a diagnosis of prostate cancer is entered in the medical record OR through the pathology service that processes the positive prostate biopsy OR through the jurisdictional cancer registry.

- New Zealand: incident cases are identified through the diagnosing or treating site when a diagnosis of prostate cancer is entered in the medical record OR through the pathology service that processes the positive prostate biopsy.

An invitation to contribute to PCOR-ANZ is sent to patients by the PCOR team in each jurisdiction. This invitation is made either soon after men have been diagnosed or at about 10–11 months after a confirmed diagnosis of prostate cancer. Most men do not opt-off the registry. In fact, the opt-out rate is only 2.7% of all men who are contacted and invited to participate.

Men are contacted to undertake the survey 12 months after diagnosis (if they have not had surgery or radiotherapy) or 12 months after surgery or radiotherapy. More frequent follow-up is undertaken in some settings. The purpose of this contact is to understand the frequency of the men's self-reported symptoms.

Men are asked a series of questions about their quality of life using the Extended Prostate Cancer Index Composite (EPIC-26, see Supplementary file).[8,50]

APPENDIX 5: PCOR-ANZ PERSONNEL

JURISDICTIONAL STAFF AND STEERING COMMITTEE MEMBERS

PCOR-ANZ STAFF	
Gabriella Tikellis	PCOR-ANZ Coordinator
Sue Evans	Academic Lead
Ellie Tsiamis	PCOR-ANZ Research Manager

PCOR-ACT STAFF	
Rebekah Smith	PCOR-ACT Coordinator
Leah Newman	Manager
Hany Elsaleh	Clinical Lead

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Kiran Hazratwala	Peter Heathcote	Colleen Nelson	Jamie Reynolds
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Roger Watson	Patsy Yates		

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Kim Moretti		Clinical Lead	
Scott Walsh		Data Manager	
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Braden Higgs	Ganessan Kichenadasse	Tina Kopsaftis	David Merry
Scott Walsh			

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Brian Stokes		Manager, Tasmanian Cancer Registry	
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Liesel Fitzgerald	Brian Stokes	Rossa King	

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Ellie Tsiamis		PCOR-Vic Research Manager	
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Sam Kleverlaan	Joanie McPhee	Dawn Hevey	Lisa Selbie
Maggie Johnson	Katrina Hall	Kate Crough	Ellie Tsiamis
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Max Shrub	Colin O'Brien	Helen Farrugia	Damien Bolton
John McNeil	Ian Davis	Mark Frydenberg	Kathryn Whitfield
Albert Frauman	Lachlan Dodds		

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Angela Ives	PCOR-WA Coordinator
Jeff Thavaseelan	Clinical Lead

APPENDIX 6: GLEASON SCORES AND ISUP GRADES

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

Prostate cancer grades are described according to the Gleason Score that describes the distinct patterns of the prostate cells as they change from normal cells to cancerous cells. The cells are scored on a scale of 1 to 5 with scores close to 1 considered "low-grade" tumour cells and tend to look similar to normal cells while those close to 5 are considered "high-grade". The pathologist examining the biopsy sample will assign one Gleason grade to the most predominant pattern and a second Gleason grade to the second most predominant pattern to give the Gleason score (e.g. 3 + 4).

In 2014, the International Society of Urological Pathologists (ISUP) released a new prostate cancer grading system, called the ISUP Grade Groups. The ISUP Grade Group system grades the prostate cancer on a scale from one to five.

Cancers classified in the lower ISUP Grade Groups or with the lowest Gleason scores tend to be less aggressive, while cancers with higher Gleason scores (7–10) tend to be more aggressive. **Table 7** compares the 2005 modified Gleason grading system with the 2015 ISUP grade groups.

TABLE 7: COMPARING TRADITIONAL GLEASON GRADE GROUPS (2005)63 WITH THE ISUP GRADE GROUPS (2016)[64]

2005 MODIFIED GLEASON GRADING SYSTEM	2015 ISUP GRADING SYSTEM
3+3, 3+2, 2+3, 2+2	1
3+4	2
4+3	3
4+4, 3+5, 5+3	4
4+5, 5+4, 5+5	5

APPENDIX 7: NCCN RISK GROUP CLASSIFICATION

TABLE 8: NCCN RISK OF DISEASE PROGRESSION CHART USED IN THIS REPORT

NCCN RISK CATEGORY	T	PRIMARY TUMOUR CLINICAL STAGE	GLEASON PATTERN		PSA LEVEL (ng/mL)		GLEASON SCORE
LOW	T1	Clinically in-apparent tumour neither palpable nor visible by imaging	≤3 + 3	AND	<10	AND	≤6
	T1a	Tumour incidental histological finding in ≤5% tissue					
	T1b	Tumour incidental histological finding in >5% tissue					
	T1c	Tumour identified by needle biopsy in one or both sides, but not palpable					
	T2	Tumour is palpable and confined within the prostate					
	T2a	Tumour involves one-half of one side or less					
FAVOURABLE INTERMEDIATE	T2b*	Tumour involves more than one-half of one side but not both sides	3 + 4	OR	10-20	OR	7
UNFAVOURABLE INTERMEDIATE	T2c*	Tumour involves both sides	4 + 3				
HIGH	T3	Extraprostatic tumour that is not fixed or does not invade adjacent structures	4 + 4 (3 + 5/ 5 + 3)	OR	>20	OR	8 to 10
	T3a	Extraprostatic extension (unilateral or bilateral)	4 + 5, 5 + 4, 5 + 5				
LOCALLY ADVANCED/ VERY HIGH	T3b	Tumour invades seminal vesicle(s)	ANY		ANY		ANY
	T4	Tumour is fixed or invades adjacent structures other than seminal vesicles, such as external sphincter, rectum, bladder, levator muscles, and/or pelvic wall					
REGIONAL	N1	Metastases in regional lymph node(s)	ANY		ANY		ANY
METASTATIC	M1	Distant metastasis including non-regional lymph node (M1a), bones (M1b) and other site(s) with or without bone disease (M1c)					

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REPORTING ON DATA 2015–2016
SUPPLEMENTARY DATA

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Table 1: Number of men notified to, and consented to, PCOR-ANZ (2017–2018).

	ACT	NSW	NT	NZ	QLD	SA	TAS	VIC	TOTAL across all jurisdictions
Eligible men to 30 Nov 2018	644	6,140	267	2,702	6,633	14,429	1,265	22,840	**54,920**
Men consented to 30 Nov 2018	628	6,043	254	2660	6,583	13,811	1225	22,118	**53,322**
Opt-out rate to 30 Nov 2018	2.5%	1.6%	4.9%	1.6%	0.8%	4.2%	3.2%	3.2%	**2.7%**

*For SA, data refers to timeframe 01 January 1998 to 30 November 2018.

Table 2: Estimated population coverage of PCOR-ANZ for the period 2015 and 2016 by jurisdiction.

Year men diagnosed with prostate cancer	NSW*	VIC	QLD	WA	SA	TAS	ACT	NT	NZ	TOTAL across all jurisdictions
PCOR-ANZ 2015	584	2,466	1,801	-	877	298	95	38	78	6,237
Population diagnosed with prostate cancer 2015	6,036	4,387	3,714	1,889	1,365	419	250	82	3,080	21,222
% population coverage	9.7	56.2	48.5		64.2	71.1	38.0	46.3	2.5	**29%**
PCOR-ANZ 2016	1,916	2,636	1,413	-	872	401	217	64	260	7,779
Population diagnosed with prostate cancer 2016	5,915	4,779	3,544	1,803	1,334	403	237	78	3,383	21,476
% population coverage	32.4	55.2	39.9		65.4	99.5	91.6	82.1	7.7	**36%**

*NSW population coverage may be under-estimated as the data is being migrated across to the PCOR system and therefore, not complete at the time this report was generated.

Table 3: Age at diagnosis by jurisdiction (2015–2016).

	JURISDICTION								
AGE GROUP (years)	ACT Number of men (%)	NSW Number of men (%)	NT Number of men (%)	NZ Number of men (%)	QLD Number of men (%)	SA Number of men (%)	TAS Number of men (%)	VIC Number of men (%)	TOTAL across all jurisdictions n (%)
<55	22 (7)	174 (7)	5 (5)	22 (6)	248 (8)	91 (5)	50 (7)	408 (8)	1,020 (7)
55–59	41 (13)	280 (11)	13 (12)	39 (12)	389 (12)	174 (10)	57 (8)	645 (13)	1,638 (12)
60–64	60 (19)	430 (17)	22 (22)	76 (22)	553 (17)	285 (16)	138 (20)	913 (18)	2,477 (18)
65–69	84 (27)	574 (23)	22 (22)	105 (31)	848 (26)	418 (24)	178 (26)	1,205 (24)	3,434 (24)
70–74	53 (17)	499 (20)	24 (23)	59 (18)	569 (18)	382 (22)	126 (18)	883 (17)	2,595 (19)
75–79	31 (10)	328 (13)	10 (10)	19 (6)	359 (11)	237 (14)	73 (10)	533(10)	1,590 (11)
≥80	21 (7)	215 (9)	6 (6)	18 (5)	243 (8)	162 (9)	59 (8)	392 (8)	1,116 (8)
Missing	0 (0)	0 (0)	0 (0)	0 (0)	5 (0.2)	0 (0)	18 (3)	123 (2)	146 (1)
Mean age ±SD	67.21 ± 8.46	68.12 ± 8.83	67.41 ± 7.72	66.41± 7.54	67.45 ± 8.73	68.97 ± 8.54	68.06 ± 8.42	67.28± 8.92	67.70 ± 8.76
Median age (IQR)	67.34 (11.14)	68.34 (11.86)	67.36 (11.99)	66.44 (8.65)	67.60 (11.35)	69.05 (10.96)	67.97 (10.41)	67.42 (11.61)	67.84 (11.41)
TOTAL	312	2,500	102	338	3214	1,749	699	5,102	**14,016**

Table 4: Method of diagnosis by jurisdiction (2015–2016).

	JURISDICTION								
METHOD	ACT Number of men (%)	NSW Number of men (%)	NT Number of men (%)	NZ Number of men (%)	QLD Number of men (%)	SA Number of men (%)	TAS Number of men (%)	VIC Number of men (%)	TOTAL across all jurisdictions n (%)
TRUS	280 (90)	1,802 (72)	80 (78)	311 (92)	2,496 (78)	1,290 (74)	243 (34)	2,135 (42)	8,637 (62)
TURP	13 (4)	352 (14)	7 (7)	2 (1)	393 (12)	117 (7)	84(12)	405 (8)	1,373 (10)
Transperineal biopsy	13 (4)	24 (1)	0 (0)	25 (7)	281 (9)	298 (17)	354 (51)	2,306 (45)	3,301 (23)
Other*/Unknown	6 (2)	322 (13)	15 (15)	0 (0)	44 (1)	44 (2)	18 (3)	256 (5)	705 (5)
TOTAL	312 (100)	2,500 (100)	102 (100)	338 (100)	3,214 (100)	1,749 (100)	699 (100)	5,102 (100)	**14,016 (100)**

*Other defined as clinical investigation, TURBT (Transurethral Resection of Bladder Tumour), histology of metastatic site, simple-diagnostic prostatectomy, cystoprostatectomy or other not in main categories.

Table 5: PSA level at diagnosis by Jurisdiction (2015–2016) based on numbers where PSA status was reported as 'taken'.

	JURISDICTION								
PSA level at diagnosis (ng/mL)	**ACT** Number of men (%)	**NSW** Number of men (%)	**NT** Number of men (%)	**NZ** Number of men (%)	**QLD** Number of men (%)	**SA** Number of men (%)	**TAS** Number of men (%)	**VIC** Number of men (%)	**TOTAL across all jurisdictions n (%)**
≤4	36 (13)	406 (18)	8 (8)	20 (6)	465 (17)	142 (11)	74 (12)	699 (15)	1,850 (14)
4.01 – 10.00	151 (54)	1,238 (56)	26 (27)	212 (63)	1,543 (55)	719 (57)	328 (54)	2,556 (54)	6,773 (53)
10.01 – 20.00	52 (19)	329 (15)	22 (23)	65 (19)	455 (16)	253 (20)	139 (23)	868 (18)	2,183 (17)
>20	38 (14)	238 (11)	12 (12)	38 (11)	327 (12)	153 (12)	67 (11)	583 (12)	1,457 (11)
Missing	6 (3)	6 (0.3)	29 (30)	0 (0)	32 (1)	411 (24)	50 (8)	50 (1)	584 (5)
Median PSA level	7.8	7.0	9.9	7.2	7.2	7.8	7.9	7.2	7.3
TOTAL	284 (100)	2,217 (100)	97 (100)	335 (100)	2,822 (100)	1,678 (100)	658 (100)	4,756 (100)	**12,847 (100)**

Table 6: Gleason ISUP Grade Group at diagnosis by jurisdiction (2015–2016).

	JURISDICTION								
Gleason score by ISUP Grade group	**ACT Number of men (%)**	**NSW Number of men (%)**	**NT Number of men (%)**	**NZ Number of men (%)**	**QLD Number of men (%)**	**SA Number of men (%)**	**TAS Number of men (%)**	**VIC Number of men (%)**	**TOTAL across all jurisdictions n (%)**
Group 1: ≤6	85 (27)	551 (22)	16 (16)	154 (46)	757 (24)	461 (26)	236 (34)	1,294 (25)	3,554 (25)
Group 2: 3+4	106 (34)	814 (32)	15 (15)	107 (31)	1,014 (32)	498 (28)	186 (27)	1,555 (30)	4,295 (31)
Group 3: 4+3	26 (8)	471 (19)	20 (20)	40 (12)	519 (17)	320 (18)	88 (12)	800 (16)	2,284 (16)
Group 4: 4+4 or 3+5 or 5+3	40 (13)	172 (7)	16 (16)	17 (5)	298 (10)	192 (11)	92 (13)	496 (10)	1,323 (9)
Group 5: 9 or 10	45 (14)	344 (14)	23 (23)	19 (6)	550 (18)	231 (13)	69 (10)	612 (12)	1,893 (14)
Missing Gleason score at diagnosis*	10 (3)	148 (6)	12 (12)	1 (0.1)	76 (2)	47 (3)	28 (4)	345 (7)	667 (5)
TOTAL	312 (100)	2, 500 (100)	102 (100)	338 (100)	3,124 (100)	1,749 (100)	699 (100)	5,102 (100)	**14,016 (100)**

*Missing due to no pathology report, insufficient pathology sample to score or not reported.

Table 7: Risk group at diagnosis across all jurisdictions.

NCCN Risk Group at diagnosis	TOTAL across all jurisdictions n (%)
Low risk	2,717 (19)
Intermediate risk	6,355 (45)
High risk	3,060 (22)
Very high risk	114 (1)
Regional	297 (2)
Metastatic	795 (6)
Cannot be determined	678 (5)
TOTAL	**14,016**

Table 8: Summary of management provided to men by NCCN risk group in Australia and New Zealand (2015–2016).

	NCCN RISK GROUP						
PRIMARY TREATMENT	**LOW RISK n (%)**	**INTERMEDIATE RISK n (%)**	**HIGH RISK n (%)**	**VERY HIGH RISK n (%)**	**REGIONAL n (%)**	**METASTATIC n (%)**	**TOTAL across all jurisdictions n (%)**
Surgery*	596 (22)	3,708 (58)	1,274 (42)	26 (23)	60 (20)	52 (7)	5,716 (43)
Radiotherapy**	159 (6)	1,238 (20)	980 (32)	58 (51)	105 (35)	94 (12)	2,634 (20)
Chemotherapy-monotherapy	0 (0)	0 (0)	13 (0.4)	2 (1)	20 (7)	191 (24)	226 (2)
ADT - monotherapy‡	2 (0.1)	54 (1)	181 (6)	16 (14)	59 (20)	332 (42)	644 (5)
Watchful waiting /active surveillance	1,708 (63)	873 (14)	225 (7)	3 (3)	17 (6)	11 (1)	2,837 (21)
Other treatments#	18 (1)	65 (1)	31 (1)	0 (0)	6 (2)	6 (1)	126 (1)
Missing	234 (8)	415 (6)	356 (12)	9 (8)	30 (10)	109 (14)	1,153 (9)
TOTAL	2,717 (100)	6,355 (100)	3,060 (100)	114 (100)	297 (100)	795 (100)	**13,336 (100)**

*Excludes men on active surveillance who then had surgery.

**Radiotherapy includes external beam (EBRT), high-dose (HDR) and low-dose (LDR) brachytherapy and radiotherapy type unknown.

‡ADT data not available for SA and NT at time of data analysis.

#Other treatments include whole and focal gland ablation, referred for treatment, other systemic therapies and other not categorised.

Table 9: Patient-reported urinary bother* 12 months after SURGERY across all jurisdictions (2015–2016).

URINARY BOTHER after surgery "Overall, how big a problem has your urinary function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	2,181 (54)
Very small problem	966 (24)
Small problem	436 (11)
Moderate problem	212 (5)
Big problem	122 (3)
Participant declined to answer	110 (3)
TOTAL*	**4,027**

*Based on numbers where 12-month EPIC-26 survey was completed.

Table 10: Patient-reported urinary bother* 12 months after EBRT across all jurisdictions (2015–2016).

URINARY BOTHER after EBRT "Overall, how big a problem has your urinary function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	496 (51)
Very small problem	234 (24)
Small problem	113 (12)
Moderate problem	73 (7)
Big problem	31 (3)
Participant declined to answer	33 (3)
TOTAL*	**980**

*Based on numbers where 12-month EPIC-26 survey was completed.

Table 11: Patient-reported urinary bother* 12 months after ADT MONOTHERAPY across all jurisdictions (2015–2016).

URINARY BOTHER after ADT monotherapy** "Overall, how big a problem has your urinary function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	119 (51)
Very small problem	51 (22)
Small problem	34 (15)
Moderate problem	19 (8)
Big problem	4 (2)
Participant declined to answer	6 (3)
TOTAL*	**233**

*Based on numbers where 12-month EPIC-26 survey was completed. **ADT data for NT not available at time of analysis and limited for SA.

Table 12: Patient-reported urinary bother* 12 months after ACTIVE SURVEILLANCE/WATCHFUL WAITING across all jurisdictions (2015–2016).

URINARY BOTHER after active surveillance/watchful waiting "Overall, how big a problem has your urinary function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	871 (58)
Very small problem	276 (18)
Small problem	193 (13)
Moderate problem	123 (8)
Big problem	21 (1)
Participant declined to answer	22 (1)
TOTAL*	**1,506**

*Based on numbers where 12-month EPIC-26 survey was completed.

Table 13: Patient-reported bowel bother* 12 months after SURGERY across all jurisdictions (2015–2016).

BOWEL BOTHER after surgery "Overall, how big a problem has your bowel function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	3,296 (82)
Very small problem	370 (9)
Small problem	156 (4)
Moderate problem	80 (2)
Big problem	25 (1)
Participant declined to answer	99 (2)
TOTAL*	**4,026**

*Based on numbers where 12-month EPIC-26 survey was completed.

Table 14: Patient-reported bowel bother* 12 months after EBRT across all jurisdictions (2015–2016).

BOWEL BOTHER after EBRT "Overall, how big a problem has your bowel function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	594 (61)
Very small problem	183 (19)
Small problem	84 (9)
Moderate problem	61 (6)
Big problem	25 (3)
Participant declined to answer	34 (3)
TOTAL*	**981**

*Based on numbers where 12-month EPIC-26 survey was completed.

Table 15: Patient-reported bowel bother* 12 months after ADT MONOTHERAPY across all jurisdictions (2015–2016).

BOWEL BOTHER after ADT monotherapy** "Overall, how big a problem has your bowel function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	157 (67)
Very small problem	33 (14)
Small problem	20 (9)
Moderate problem	14 (6)
Big problem	3 (1)
Participant declined to answer	6 (3)
TOTAL*	**233**

*Based on numbers where 12-month EPIC-26 survey was completed. **ADT data for NT not available at time of analysis and limited for SA.

Table 16: Patient-reported bowel bother* 12 months after ACTIVE SURVEILLANCE/WATCHFUL WAITING across all jurisdictions (2015–2016).

BOWEL BOTHER and active surveillance/watchful waiting "Overall, how big a problem has your bowel function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	1,195 (79)
Very small problem	163 (11)
Small problem	65 (4)
Moderate problem	45 (3)
Big problem	13 (1)
Participant declined to answer	26 (2)
TOTAL*	**1,507**

*Based on numbers where 12-month EPIC-26 survey was completed.

Table 17: Patient-reported sexual bother* 12 months after SURGERY across all jurisdictions (2015–2016).

SEXUAL BOTHER after surgery "Overall, how big a problem has your sexual function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	1,094 (27)
Very small problem	466 (12)
Small problem	651 (16)
Moderate problem	764 (19)
Big problem	849 (21)
Participant declined to answer	196 (5)
TOTAL*	**4,020**

*Based on numbers where 12-month EPIC-26 survey was completed.

Table 18: Patient-reported sexual bother* 12 months after EBRT across all jurisdictions (2015–2016).

SEXUAL BOTHER after EBRT "Overall, how big a problem has your sexual function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	407 (42)
Very small problem	102 (10)
Small problem	92 (9)
Moderate problem	111 (11)
Big problem	178 (18)
Participant declined to answer	84 (9)
TOTAL*	**974**

*Based on numbers where 12-month EPIC-26 survey was completed.

Table 19: Patient-reported sexual bother* 12 months after ADT MONOTHERAPY across all jurisdictions (2015–2016).

SEXUAL BOTHER after ADT monotherapy** "Overall, how big a problem has your sexual function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	153 (66)
Very small problem	2 (1)
Small problem	17 (7)
Moderate problem	17 (7)
Big problem	36 (15)
Participant declined to answer	8 (3)
TOTAL*	**233**

*Based on numbers where 12-month EPIC-26 survey was completed. **ADT data for NT not available at time of analysis and limited for SA.

Table 20: Patient-reported sexual bother* 12 months after ACTIVE SURVEILLANCE/WATCHFUL WAITING across all jurisdictions (2015–2016).

SEXUAL BOTHER and active surveillance/watchful waiting "Overall, how big a problem has your sexual function been for you during the last 4 weeks" RESPONSES	TOTAL across all jurisdictions n (%)
No problem	760 (51)
Very small problem	152 (10)
Small problem	183 (12)
Moderate problem	174 (12)
Big problem	164 (11)
Participant declined to answer	67 (4)
TOTAL*	**1,500**

*Based on numbers where 12-month EPIC-26 survey was completed.

Table 21: EPIC-26 survey used in this report.

What it measures	Question	Response choices
URINARY FUNCTION: This section is about your urinary habits. Please consider ONLY THE LAST 4 WEEKS.		
UI	Over the past 4 weeks, how often have you leaked urine?	More than once a day About once a day More than once a week one About once a week Rarely or never Participant declines to answer
	Over the past 4 weeks, how often have you urinated blood?	
	Over the past 4 weeks, how often have you had pain or burning with urination?	
UI	Which of the following best describes your urinary control during the last 4 weeks?	No urinary control whatsoever Frequent dribbling Occasional dribbling Total control Participant declines to answer
UI	How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks?	None 1 pad per day 2 pads per day 3 or more pads per day Participant declines to answer
	How big a problem, if any, has each of the following been for you during the last 4 weeks? (Circle one number on each line)	
UI	• Dripping or leaking urine	No problem Very small problem Small problem Moderate problem Big problem Participant declines to answer
UI/O	• Pain or burning on urination	
UI/O	• Bleeding with urination	
UI/O	• Weak urine stream or incomplete emptying	
UI/O	• Need to urinate frequently during the day	
Urinary bother	Overall, how big a problem has your urinary function been for you during the last 4 weeks?	No problem Very small problem Small problem Moderate problem Big problem Participant declines to answer

Survey continues over page.

BOWEL HABITS: The next section is about your bowel habits and abdominal pain. Please consider ONLY THE LAST 4 WEEKS.		
	How big a problem, if any, has each of the following been for you? (Circle one number on each line)	
B	• Urgency to have a bowel movement	No problem Very small problem Small problem Moderate problem Big problem Participant declines to answer
B	• Increased frequency of bowel movements	
B	• Losing control of your stools	
B	• Bloody stools	
B	• Abdominal/ Pelvic/Rectal pain	
Bowel bother	Overall, how big a problem have your bowel habits been for you during the last 4 weeks?	No problem Very small problem Small problem Moderate problem Big problem Participant declines to answer
SEXUAL FUNCTION: The next section is about your current sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, THIS SURVEY INFORMATION IS COMPLETELY CONFIDENTIAL. Please answer honestly about THE LAST 4 WEEKS ONLY.		
	How would you rate each of the following during the last 4 weeks? (Circle one number on each line)	
S	Your ability to have an erection?	Very poor to none Poor Fair Good Very good Participant declines to answer
S	Your ability to reach orgasm (climax)?	
S	How would you describe the usual QUALITY of your erections during the last 4 weeks?	None at all Not firm enough for any sexual activity Firm enough for masturbation and foreplay only Firm enough for intercourse
S	How would you describe the FREQUENCY of your erections during the last 4 weeks?	I NEVER had an erection when I wanted one I had an erection LESS THAN HALF the time I wanted one I had an erection ABOUT HALF the time I wanted one I had an erection MORE THAN HALF the time I wanted one I had an erection WHENEVER I wanted one

Survey continues over page.

S	Overall, how would you rate your ability to function sexually during the last 4 weeks?	Very poor Poor Fair Good Very good
Sexual bother	Overall, how big a problem has your sexual function or lack of sexual function been for you during the last 4 weeks?	No problem Very small problem Small problem Moderate problem Big problem Participant declines to answer
HORMONAL FUNCTION The next section is about your hormonal function. Please consider ONLY THE LAST 4 WEEKS		
	How big a problem during the last 4 weeks, if any, has each of the following been for you? (Circle one number on each line)	
H	• Hot flashes/flushes	No problem Very small problem Small problem Moderate problem Big problem Participant declines to answer
H	• Breast tenderness/enlargement	
H	• Loss of Body Hair	
H	• Feeling depressed	
H	• Lack of energy	
H	• Change in body weight	

Legend

- UI=Urinary Incontinence question
- UI/O= Urinary irritative/obstruction question
- S= Sexual function question
- B=Bowel function question
- H= Hormone-related impact question

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