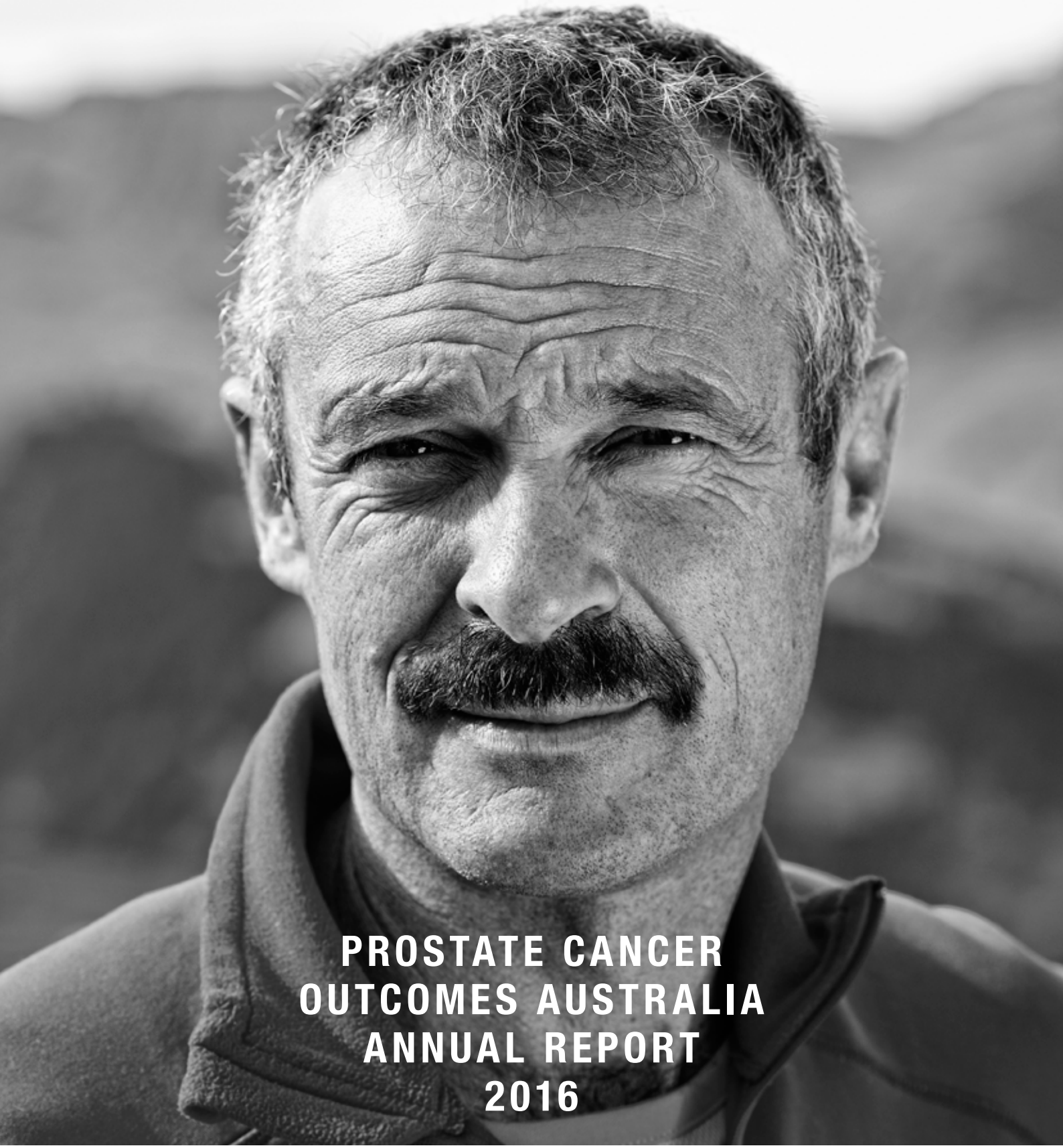
PROSTATE CANCER OUTCOMES

REGISTRY AUSTRALIA & NEW ZEALAND



PROSTATE CANCER OUTCOMES AUSTRALIA ANNUAL REPORT 2016

MONASH University Medicine, Nursing and Health Sciences

SAHMRI South Australian Health & Medical Research Institute

University of South Australia

ACKNOWLEDGEMENTS

The Chair, the Steering Committee and the Movember Foundation would first and foremost like to thank the men who have agreed to contribute their data for this project. Without their willingness to provide their information, we would not be able to work with the clinical community towards further improvements in the quality of care for all men diagnosed with prostate cancer, not just within Australia, but globally.

Likewise, the Chair, the Steering Committee and the Movember Foundation acknowledge the clinical community who has agreed to contribute to the project. Their willingness to embrace the project has seen strong implementation so far and provides a great foundation for population-wide data capture targets.

This report includes quotes from men diagnosed with, and treated for, prostate cancer. We are grateful to those men who have given a voice to the challenges faced by men diagnosed with prostate cancer.

The Movember Foundation would like to thank the members of the Prostate Cancer Outcomes Registry – Australia and New Zealand Steering Committee and, in particular, the leadership of Professor David Roder, the Committee's Chair. This team has contributed many hours on a voluntary basis and is truly collaborative. Their passion for the project and determination to drive improvements in clinical practice is inspirational.

We would also like to thank Dr Rasa Ruseckaite, Ms Fanny Sampurno and Dr Kerri Beckman for undertaking the analyses that inform this report.

We also thank the:

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Finally, the Movember Foundation would like to thank A/Professor Sue Evans, Professor John McNeil and A/Professor Jeremy Millar from Monash University, and A/Professor Kim Moretti from South Australia for their leadership, management and ongoing support for this project, and their support as we develop similar programs around the world.

CHAIR'S REPORT

Prostate cancer is by far the most common cancer among men that is reported to Australian cancer registries, with an estimated 18,138 newly diagnosed cases in 2016 [1]. Fortunately, the trend is downwards, with about 5% fewer diagnoses per year over the past 5 years. Of greater reassurance is the age-adjusted reduction in prostate cancer–related deaths of around 22% over 10 years.

Survival from prostate cancer in Australia is now about 94% at five years and 85% at 10 years after diagnosis. This is very high by world standards. Global data indicate that prostate cancer survivals in Australia are among the highest in the world, with only North America having an equivalent or slightly higher survivals.

Surviving cancer is important, but so is the quality of life and functional status of survivors. However, registries have rarely collected such data, which limits the opportunities to learn from experience in selecting the best treatment options and providing appropriate supportive care services. The Movember Foundation is to be commended for addressing this important gap by working with men affected by the disease and clinicians to improve wellbeing as well as survival. Through systematic registry data analysis and research, this global effort promotes the quality of life of men affected by prostate cancer by reducing negative effects on urinary, bowel and sexual function, and increasing general physical and mental wellbeing. The enthusiastic support given to these initiatives by men affected by prostate cancer and the clinical community has been outstanding.

A key component of this global initiative has been the support for introducing prostate cancer outcomes registries to monitor patient-reported outcomes and patterns of care. Men and clinicians are able to make an informed choice about participating in this monitoring and research. Steps to introduce a national Australian registry were initiated in 2013, and in 2014 New Zealand also expressed interest in contributing to this initiative. A bi-national registry is now under active development at Monash University, with all Australian states and territories and New Zealand electing to participate. In parallel, the Prostate Cancer Health Outcomes Research Unit (PCHORU) is being supported by the Movember Foundation in partnership with Monash University, the University of South Australia and the South Australian Health & Medical Research Institute. PCHORU is analysing registry data, researching risk stratification and psychosocial outcomes, and investigating the roles of general practitioners in caring for men with this cancer.

Establishing a national population-based registry is a major undertaking, involving negotiations and system development across eight Australian states and territories, and New Zealand. Good headway is being made that reflects the hard work of the Monash registry team and the goodwill of States and Territories. Reporting of prospective national registry data is intended to start in 2017. In the meantime, data from two established registries in South Australia and Victoria are providing early output, and this report includes these results. This report illustrates the contribution that registry data can bring, by showing trends and variations in diagnostic and treatment practices, and survival and patient-reported survivorship outcomes. The importance of this reporting is highlighted, along with the value of a mixed qualitative and quantitative approach for advancing survivorship. For me, it is a great privilege to be involved in this important collaboration.

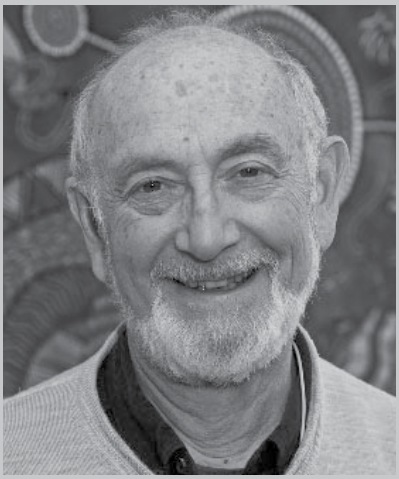
PROFESSOR DAVID RODER
CHAIR, PROSTATE CANCER OUTCOMES REGISTRY-AUSTRALIA AND NEW ZEALAND

CONSUMER REPORT

I joined the Prostate Cancer Outcomes Registry as a consumer representative in early 2016. I was diagnosed with prostate cancer 5 years ago at the age of 47, and looked to available outcome data to help me make an informed decision about treatment options. 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.

It is fantastic that my input is actively sought by the committee, and it is very gratifying to be part of a group so deeply committed to improving prostate cancer outcomes across Australia.

ASSOCIATE PROFESSOR TONY WALKER ASM, CONSUMER REPRESENTATIVE



I am very excited at the prospect of a National Prostate Cancer Outcomes Registry and proud that Australia is a world leader in this field. It is critical that these data are available for research, to provide accurate information on the outcomes of treatment (and non-treatment) for men across Australia.

As a patient, and as a facilitator of a prostate cancer support group, I am aware of the importance to men of having accurate information available to them about the outcome of different treatments. I am also reassured that the registry is tracking treatment and providing reports back to hospitals and to specialists. It is only through monitoring that you can improve. I hope this report helps men understand their options and make informed decisions.

MAX SHUB,
PROSTATE CANCER OUTCOMES REGISTRY – VICTORIA,
PATIENT ADVOCATE

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GLOSSARY AND SHORTENED FORMS

Unless otherwise specified, definitions have been taken from the Cancer Council. [2]

ACTIVE SURVEILLANCE	When a person does not receive immediate treatment; rather, they have their health monitored regularly.
ADVANCED PROSTATE CANCER	Prostate cancer that has spread to other parts of the body.
ANDROGEN DEPRIVATION THERAPY (ADT)	A treatment that blocks the body's natural hormones that help cancer grow. Also called hormone therapy or hormone treatment.
BIOPSY	The removal of a small sample of tissue from the body, for examination under a microscope, to help diagnose a disease.
BRACHYTHERAPY	A type of radiotherapy treatment that involves implanting radioactive material, which is sealed in needles or seeds, into or near cancerous cells.
EPIC-26	Expanded Prostate Cancer Index Composite (26 items).[3] EPIC-26 is a survey that men complete to help healthcare workers and researchers understand how men are coping with the symptoms commonly present when living with prostate cancer. The survey asks about incontinence, bowel problems, impotence and levels of vitality.
ERECTILE DYSFUNCTION	The inability to obtain or maintain an erection firm enough for penetration. Also called impotence.
EXTRA-PROSTATIC CANCER	Cancer that has spread to other organs from the prostate. Also known as advanced prostate cancer.
GLEASON SCORE	The Gleason grading system is usually used to indicate how aggressive the prostate cancer is. Scores range between 1 and 10; the higher the score, the more likely the cancer will grow and spread quickly. Scores are grouped according to the NCCN risk category (Appendix A). Scores of 2–6 are low grade, a score of 7 is intermediate grade and scores of 8–10 are high grade.
HORMONE THERAPY	A treatment that blocks the body's natural hormones that help cancer grow, such as androgen-deprivation therapy (ADT). Also called hormone treatment.
INCONTINENCE	The inability to hold or control the loss of urine or faeces.
INTERQUARTILE RANGE	Quartiles divide a rank-ordered dataset into four equal parts. The values that divide each part are called the first, second and third quartiles. First, second and third quartiles correspond to the observation at the 25th, 50th and 75th percentiles, respectively. The observation from the 25th percentile to the 75th percentile is referred as the interquartile range. An observation at the 50th percentile corresponds to the median value in the dataset.

GLOSSARY AND SHORTENED FORMS

LAPAROSCOPY	Surgery that uses a thin telescopic instrument (laparoscope), which is inserted into the body through a small cut. Also called keyhole surgery.
LOCALISED PROSTATE CANCER	Prostate cancer that has not spread beyond the prostate gland. Also known as early prostate cancer.
MEDIAN	The middle value in a series of values that are arranged from smallest to largest.
METASTASIS	Cancer that has spread from another part of the body. Also known as secondary cancer.
NCCN	National Comprehensive Cancer Network
NCCN RISK GROUP	The NCCN risk criteria for disease progression used to classify patients into low-, intermediate- and high-risk disease (refer to Appendix A).[4]
POSITIVE SURGICAL MARGIN	After a prostatectomy, the cancerous cells that may be left behind.
PROSTATECTOMY	Surgery that removes all or part of the prostate.
PROSTATE-SPECIFIC ANTIGEN (PSA)	A protein produced by prostate cells. It may indicate prostate cancer and can be used to monitor its recurrence post-treatment.
PCHORU	Prostate Cancer Health Outcomes Research Unit
PCOR-ANZ	Prostate Cancer Outcomes Registry – Australia and New Zealand
PCOR-VIC	Prostate Cancer Outcomes Registry – Victoria. Formerly known as the Victorian Prostate Cancer Clinical Registry (Vic PCR). It is the registry from which Victorian data from this report was derived and provides its data to the PCOR-ANZ
PCOR-SA-PCCOC	Prostate Cancer Outcome Registry-South Australia- South Australian Prostate Cancer Clinical Outcomes Collaborative. It is the group overseeing the South Australian registry from which data for this report was derived. PCOR-SA-PCCOC provides its data to the PCOR-ANZ.
PROGRESSION OF DISEASE	Cancer that continues to grow or spread.
PROM	patient-reported outcome measure
QI	quality indicator
RADIOTHERAPY (EXTERNAL-BEAM RADIOTHERAPY)	Therapy that uses high-energy X-rays to kill cancer cells or injure them so they cannot grow and multiply.
SAHMRI	South Australia Health & Medical Research Institute

GLOSSARY AND SHORTENED FORMS

SF-12 HEALTH SURVEY	A survey that people complete to help healthcare workers and researchers to understand the state of people's general physical and mental health. The measure ranges from 0 to 100.[5]
STAGING	Determining how far a cancer has spread using tests.
TRANSURETHRAL RESECTION OF THE PROSTATE (TURP)	A surgical procedure to remove tissue from the prostate that is restricting urinary flow.
TRUS	transrectal ultrasound
URINARY OBSTRUCTION	A blockage of the flow of urine out of the body.
VIC PCR	Victorian Prostate Cancer Clinical Registry
WATCHFUL WAITING	A way of monitoring prostate cancer that is not causing any symptoms or problems.

EXECUTIVE SUMMARY

Prostate cancer is currently the most common cancer diagnosed in Australian men. The survival rate is very good – more than 94 percent of men diagnosed with prostate cancer are alive five years later[6] – but the treatments can affect men and those close to them long after the therapies have finished.

Registry data can provide researchers with the tools and information necessary to improve outcomes for men with prostate cancer, by understanding areas of unmet need, implementing strategies to address these needs and tracking progress over time to see if these strategies are successful.

The Prostate Cancer Health Outcomes Research Unit (PCHORU), supported by the Movember Foundation, has established and analysed data from the Prostate Cancer Outcomes Registry – Australia and New Zealand, to address some of the unmet needs of men with prostate cancer. This report collates and evaluates patient-reported and clinical outcomes, and patterns of care. It also reveals why collecting registry data is so important for continuing to improve prostate cancer care.

PATIENT-REPORTED OUTCOMES

Patient-reported outcomes are important to the men with prostate cancer and their families, and these outcomes are often different to clinical outcomes. Importantly, patient-reported outcomes reflect men's views of their quality of life after cancer treatment, which is becoming more important as survival rates for prostate cancer improve.

Registry data show that fewer men who are diagnosed with low-risk prostate cancer are receiving immediate curative treatment. Curative treatment such as surgery and radiotherapy, and androgen deprivation therapy (ADT) which controls the disease, can have side effects such as urinary, sexual and bowel bother and lowered mental wellbeing. Men with low-risk disease benefit from not having these types of treatments if it is not necessary, as it means avoiding the side effects that can reduce quality of life.

More aggressive cancers do need to be treated. Men who have had a prostatectomy are likely to experience some initial decline in urinary continence and sexual functioning, which, for some men improves with time after surgery. Men who have had radiotherapy may experience urinary, bowel and sexual problems. Some men may struggle with the psychological and emotional side effects of some treatments.

Ideally men should be informed about the possibility of decreased urinary continence, and bowel and sexual functioning when making treatment decisions. These have implications in the human aspect of treatment – how the man feels about his disease and quality of life. This is something that the Movember Foundation will be focusing on, to see how we can help men improve their quality of life after treatment.

DEMOGRAPHICS AND CLINICAL OUTCOMES

The average age of men diagnosed with prostate cancer in South Australia and Victoria from 2009 to 2013 was 65 years, and trends in South Australia show that the average age at diagnosis is decreasing.

Most men are being diagnosed with prostate cancer by a trans-rectal ultrasound (TRUS) biopsy. TRUS biopsies are performed when there is a suggestion of prostate cancer after initial screening tests have been performed. For this procedure, men are informed that the biopsy is to look for prostate cancer. A declining percent of men are being diagnosed incidentally through transurethral resection of the prostate (TURP), which is undertaken to remove tissue restricting urinary flow. This trend reflects an increase in PSA blood-test case finding, as absolute numbers of men undergoing TURP has remained relatively constant.

Overall prognosis is very good for men diagnosed with localised prostate cancer, and men who are diagnosed with prostate cancer are more likely to die from something other than cancer. This is likely because of a combination of early detection through screening programs and clinical outcome improvements – such as lower positive surgical margins, which means less chance of disease recurrence.

PATTERNS OF CARE

Prostate cancer management is complex. Active surveillance is an appropriate approach for many men with low-risk prostate cancer. Prostatectomies are becoming more common as the first choice for curative treatment, and we have seen a decline in the use of ADT as a first-line management approach.

Understanding patterns of care is important for all involved, from patients and clinicians, to healthcare managers and policy makers. Men and their families, together with their clinicians, should be aware of and discuss all treatment options, including active surveillance, after a diagnosis. Men may make treatment decisions based on their risk of disease progression, side effects and cost (e.g. some treatment options may result in out-of-pocket expenses).

Healthcare managers, funding bodies and policy makers need to be familiar with patterns of care for various reasons, including:

- financial or economic
- population and epidemiological trends
- current structural and organisational arrangements
- expert evidence-based pronouncements on treatment options
- community opinion
- workforce considerations.

ADVANCING THE USE OF REGISTRIES

Population registries operating within each Australian State and Territory and in New Zealand are notified when a cancer diagnosis has been confirmed. These registries track the incidence of different cancers, including prostate cancer and they link with national and state-based registries which capture data on all deaths. They have, to varying extents, the ability to capture treatment information. Clinical Quality Registries, such as the Prostate Cancer Outcomes Registry-Australia and New Zealand (PCOR-ANZ) work closely with and extend the work of the population cancer registries in each state and in New Zealand to provide a greater understanding of the stage of disease at diagnosis, treatments being provided and the longer-term quality of life of patients.

PCOR-ANZ provides benchmarking information, which provides a strong impetus for clinicians and hospitals to continuously improve clinical quality and quality of care, which in turn improves health outcomes for patients. PCOR-ANZ provides feedback to hospitals and clinicians, so they can compare their performance and management of prostate cancer with their peers. The PCOR-ANZ Steering Committee and registry leaders in Ireland have used registry data to help developed a set of quality indicators (QIs). These QIs will be used to continually improve prostate cancer care in Australia.

FUTURE OF PROSTATE CANCER CARE

The PCOR-ANZ is still in its implementation phase, with prospective aggregate data to be reported publicly in 2017. The PCOR-ANZ aims to follow men for 5-, 10- and 15-years after diagnosis to better understand their prostate cancer journey, as well as issues such as management of advanced disease through use of androgen deprivation therapy (ADT) and chemotherapy. With longer-term follow-up through PCOR-ANZ, research can begin to focus on treatments and outcomes for men who develop more advanced disease over the longer term. The registry will also provide data for treatment options for men with low-risk or less-advanced cancer.

Also funded by the Movember Foundation, some exciting explorative research is underway using the PCOR-ANZ to not just identify men who are not doing so well throughout their journey, but to provide additional care and support to improve their health outcomes. The research has already revealed valuable information, and will continue to improve outcomes for all men diagnosed with prostate cancer and improve treatment decision making in the short- and long-term future.

ABOUT THE MOVEMBER FOUNDATION

THE MOVEMBER FOUNDATION IS A GLOBAL CHARITY COMMITTED TO HELP MEN WHO HAVE BEEN DIAGNOSED WITH PROSTATE CANCER TO LIVE HAPPIER, HEALTHIER AND LONGER LIVES. SINCE 2003, MILLIONS OF PEOPLE HAVE JOINED THE MEN'S HEALTH MOVEMENT, WHICH HAS RAISED AU$685 MILLION. PART OF THIS FUNDRAISING HAS PROVIDED FINANCIAL SUPPORT FOR MORE THAN 1,000 PROJECTS THAT FOCUS ON PROSTATE CANCER, TESTICULAR CANCER AND SUICIDE PREVENTION.

Following extensive consultation with relevant stakeholders in 2011, the Movember Foundation made three critical investment decisions in the allocation of funding for prostate cancer care and quality improvement programs:

- Define a set of indicators of outcomes that really matter to men diagnosed with prostate cancer, and use this information to drive program investments (see the Movember Foundation Prostate Cancer Outcomes Statements in Appendix B).
- Establish and invest in a collaborative network to develop and implement holistic solutions that address the greatest unmet needs of men diagnosed with prostate cancer.
- Invest in national clinical registries to understand where we are now, and to track changes the outcomes of men over time.

As a result of these investments, the Movember Foundation has now committed more than AUD$40 million to the TrueNTH program across Australia, Canada, Ireland, New Zealand, the United Kingdom and the United States. TrueNTH is a revolutionary new care intervention program that will help men living with prostate cancer to access care and support that will improve their quality of life. This care and support includes treatment information, lifestyle advice, the chance to share experiences with other prostate cancer survivors and better access to healthcare professionals.

In addition, the Movember Foundation has committed AUD$22 million to prostate cancer outcomes initiatives. These initiatives involve collecting data and reporting on how men are doing throughout their prostate cancer journey, together with research designed to assess and reduce the variation in treatment and health outcomes for men diagnosed with prostate cancer. The aim is to provide information to enable rapid and population-wide improvements in clinical quality, leading to improvement in the outcomes that matter to men diagnosed with prostate cancer and their partners, family and carers.

MOVEMBER FOUNDATION AND REGISTRIES

There has been a worldwide drive to improve the transparency of health outcomes and, as a result, patient, provider and treatment choice are beginning to be shaped by these data.

PCOR-ANZ and the PCHORU are two investments seeking to improve outcomes for men diagnosed with prostate cancer in Australia. The Movember Foundation committed AUD$5.5 million to the PCOR-ANZ and the PCHORU to understand how men are doing after their treatment, and use this information to set new benchmarks and drive quality improvement in clinical and patient-reported outcomes.

The important part of the registry is the regular and risk-adjusted reports that are provided to clinicians, hospitals and decision makers about clinical practice and outcomes for men. This reporting fosters improved quality of treatment and care for men diagnosed with prostate cancer.

PROSTATE CANCER INCIDENCE

In 2016, an estimated 18,138 men in Australia will be diagnosed with prostate cancer.[7] It is the most common cancer diagnosed in men; almost double the number of the next most-common cancer (colorectal cancer). One in nine men under 75 years will be diagnosed with prostate cancer, and one in six men aged under 85 years will be diagnosed with the disease.

For the past 20 years, there has been a 40% increase in the number of men diagnosed with prostate cancer. This is thought to be, in large part, because of the increased case-finding of asymptomatic men with the Prostate Specific Antigen (PSA) test. An estimated 185,700 to 201,700 men diagnosed with prostate cancer will be living in Australia in 2017.

PROSTATE CANCER PROGNOSIS

An individual's prognosis depends on several things, including the stage of cancer, and age and general health at the time of diagnosis. Based on national cancer registry data, the 5-year survival for men diagnosed with prostate cancer is 94%, considering all stages combined. For men who are diagnosed before cancer has spread beyond the prostate, survival is much higher, with the 5-year survival being around 97%.[8]

ABOUT THIS REPORT

This report aims to provide information on the patterns of care for men with prostate cancer in Australia, and to describe the impact of a diagnosis and subsequent treatment on physical functioning and quality of life, as reported by men themselves.

While PCOR-ANZ is being established, the Movember Foundation funded the PCHORU to examine patterns of care and patient outcomes using data from the two existing state-based prostate cancer registries:

- The Victorian Prostate Cancer Clinical Registry, (henceforth referred to in this report as PCOR – Vic,) which was established in 2008; and
- The Prostate Cancer Outcome Registry- South Australian Prostate Cancer Clinical Outcomes Collaborative (henceforth referred to in this report as PCOR-SA-PCCOC) which was established in 1998.

Both registries collect similar data on patient characteristics, clinical presentation and the treatments provided. More detail about these data sources is in Appendix C. This report mostly presents combined data from the PCOR-Vic and PCOR-SA-PCCOC for men diagnosed from 2009 to 2013. Common data items from the two clinical registries were merged to develop a combined dataset, which comprised data on 13,598 men with prostate cancer. The majority of participants (74%) in the combined dataset were from Victoria with 26% from South Australia. This reflects the respective population size in each state. This report also includes data analysis from the PCOR-SA-PCCOC over a 16-year period to identify longer-term changes in patterns of clinical presentation, treatment and outcomes. These analyses included all men in the PCOR-SA-PCCOC who were diagnosed between 1998 and 2013 (7168 men).

Patient-reported outcomes on physical functioning and quality of life are also collected by both registries, but in different ways, which made it difficult to combine some items. Results relating to patient-reported outcomes are therefore presented for each state separately. See Appendix D formore detail about the collection of patient-reported outcomes.

This report also includes some quotes from men with prostate cancer, which were gathered through interviews undertaken in two other Movember Foundation–funded studies, one in South Australia (the SAHMRI study) and one in regional Victoria (the Gippsland study). Both of these studies examined men's experiences following a diagnosis of prostate cancer. These studies are described further in Appendix D.

This report has limited data that describe the management of men with advanced stage prostate cancer disease. The PCOR-Vic recruits men at diagnosis and follows them up for 24 months, so only captured details of advanced disease management if this was evident in the first 24 months after diagnosis. The PCOR-SA-PCCOC follows men for longer, to determine whether the cancer returns or spreads, but data on subsequent treatments, particularly for ADT, are not always available. Currently, we do not have a complete picture of patterns of care after prostate cancer returns or spreads, and we cannot say how this impacts on men's physical health and wellbeing.

PATIENT-REPORTED OUTCOMES

KEY MESSAGES

MEN UNDERGOING A PROSTATECTOMY ARE LIKELY TO EXPERIENCE SOME INITIAL DECLINE IN URINARY CONTINENCE AND SEXUAL FUNCTIONING, WHICH GENERALLY IMPROVES WITH TIME AFTER SURGERY. HOWEVER, THEY ARE UNLIKELY TO REGAIN THE LEVEL OF URINARY CONTINENCE OR SEXUAL FUNCTION THEY HAD BEFORE THEIR PROSTATECTOMY.

SOME MEN MAY STRUGGLE WITH THE MENTAL AND PHYSICAL WELLBEING SIDE EFFECTS OF SOME TREATMENTS.

IDEALLY, MEN SHOULD BE INFORMED ABOUT THE POSSIBILITY OF DECREASED URINARY CONTINENCE AND BOWEL AND SEXUAL FUNCTIONING WHEN MAKING TREATMENT DECISIONS.

IMPORTANCE OF PATIENT-REPORTED QUALITY-OF-LIFE OUTCOMES

Patient-reported outcome measures (PROMs) come from a patient's own assessment of their health and wellbeing without interpretation from anyone, including a clinician. This is important, because these outcomes may differ from those of their treating clinician. We know that treatment for prostate cancer can have long-term side effects, which can have a major effect on quality of life.

By combining PROMs with clinical information, and by considering risk categories such as age at diagnosis and stage of disease, we can better understand how treatments may affect men. Understanding these effects can also provide opportunities for men to take action to improve their outcomes.

In terms of reporting to clinicians and hospitals, PROMs are now recognised as an important measure of quality of care, and provide a broader perspective to determine the success of treatment than the conventional measures such as 5-year survival. By providing information about physical health and mental wellbeing back to clinicians, comparisons can be made between different treatments and techniques. Audit and feedback of this kind has been shown to drive quality improvement in patient care and outcomes.[9]

The methods and tools used to collect patient-reported outcomes in the PCOR-SA-PCCOC and PCOR-Vic are described in Appendix D.

TREATMENT OPTIONS AND SIDE EFFECTS

Prostate cancer is staged according to level of risk based on tumour characteristics (Appendix A). Treatment options for prostate cancer vary according to risk classification.

In low-risk disease, cancer is confined to the prostate and therefore, less likely to spread. More recently, because of side effects associated with treatment, men with low-risk disease are often advised to start 'active surveillance' or 'watchful waiting' if their disease is not causing symptoms.[10] Men on active surveillance are monitored for any progression of the cancer.

Men with intermediate or high-risk prostate cancer disease may require surgery or radiotherapy because of the increased risk of the cancer spreading to other organs. Surgery that intends to cure the cancer will involve removal of the whole prostate (radical prostatectomy). The main side effects of radical prostatectomy can include urinary problems such as urine leakage, and sexual functioning problems such as difficulty getting an erection.

Radiotherapy may also be used to treat prostate cancer, with either external radiation or brachytherapy common options. Side effects of radiotherapy and brachytherapy can include bowel, urinary and sexual functioning problems.

ADT may be used in men with high and very high-risk prostate cancer. ADT reduces the stimulus of the male hormone testosterone. ADT can stabilise the disease for a number of years, and may improve outcomes if given with radiation early after diagnosis in men whose prostate cancer has a high risk of spreading.[11]

Even if men choose to not have treatment, they may experience psychological issues such as depression, anxiety and regret about the decision path they have chosen. Mental health side effects may also be felt by men undergoing treatment.

Since the risk of prostate cancer diagnosis is related to ageing, some of the reported outcomes may be also related ageing (such as decreases in sexual function and urinary continence).

Based on the research undertaken to develop the Movember Foundation Prostate Cancer Outcomes Statements (Appendix B), we know that there are a number of areas that affect the outcomes of men who are diagnosed with prostate cancer and who undergo different treatment options. Given the retrospective nature of this report and the challenges associated with collecting large amounts of data, this report will focus on five outcomes – urinary, bowel and sexual functioning, and mental and physical wellbeing.

URINARY BOTHER

Figure 1 illustrates the proportion of Victorian men reporting urinary bother in the 24 months (as measured every 3 months) after three different primary treatment options.

More men reported a moderate or big urinary bother in the first 3 months after surgery and radiotherapy compared to later time points, but less bother was reported with time.

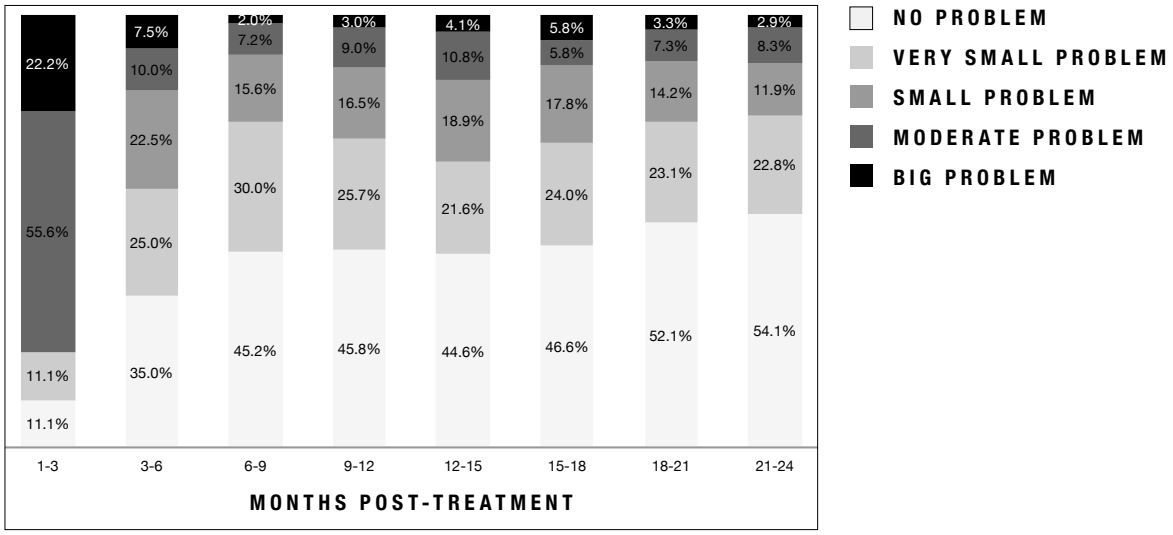
The proportion of men who reported a moderate or big urinary bother after commencing on ADT in the absence of any other treatment (monotherapy) has remained unchanged, even two years post-hormone treatment (22%). However, as more time passes post-treatment, more men reported a very small problem or no problem at all, the same as for other treatment options. The Victorian registry does not collect data to understand the extent to which men had urinary bother before treatment began, so it is not clear whether the 22% of men reporting moderate or big bother after commencing ADT had problems before it was commenced. According to the PCOR-Vic, men receiving ADT as monotherapy are, on average, 13 years older than those receiving active treatment (surgery or radiotherapy), and advanced age is associated with more urinary problems.

A large study in the United States identified that elderly men with prostate cancer who were on ADT had a two-fold higher rate of daily urinary leakage and one-and-a-half fold higher rate of urinary bother compared to men without prostate cancer[12]. A New South Wales study showed that men diagnosed with prostate cancer receiving ADT as monotherapy had worse urinary bother even before treatment began compared with those who went on to receive active treatment and those who were not diagnosed with prostate cancer[13].

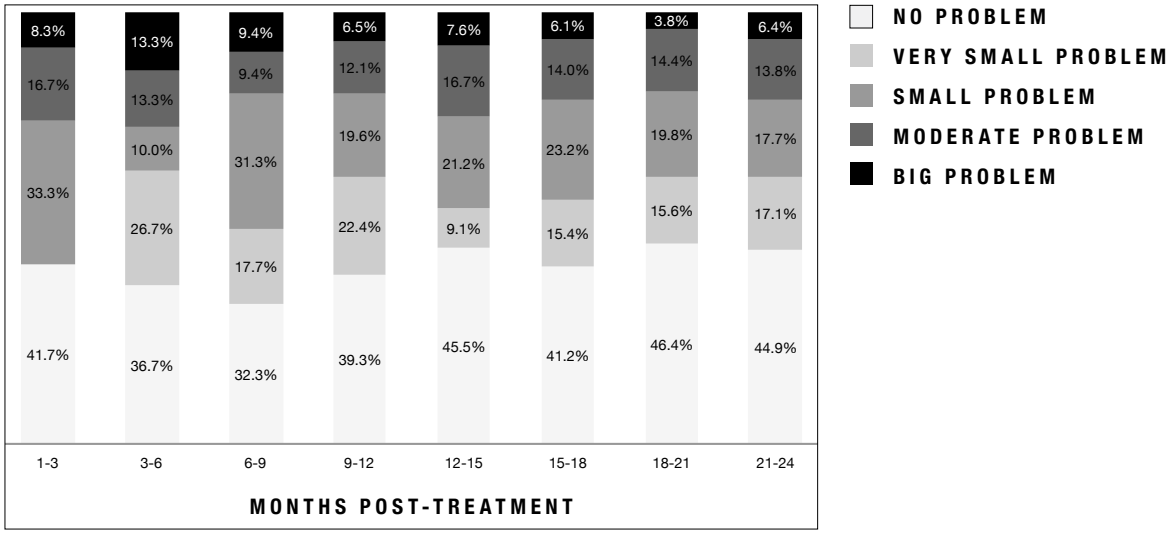
FIGURE 1

URINARY BOTHER IN MEN WITH PROSTATE CANCER, 1–24 MONTHS AFTER DIFFERENT PRIMARY TREATMENT OPTIONS (SURGERY, RADIOTHERAPY AND HORMONAL MONOTHERAPY), VICTORIA

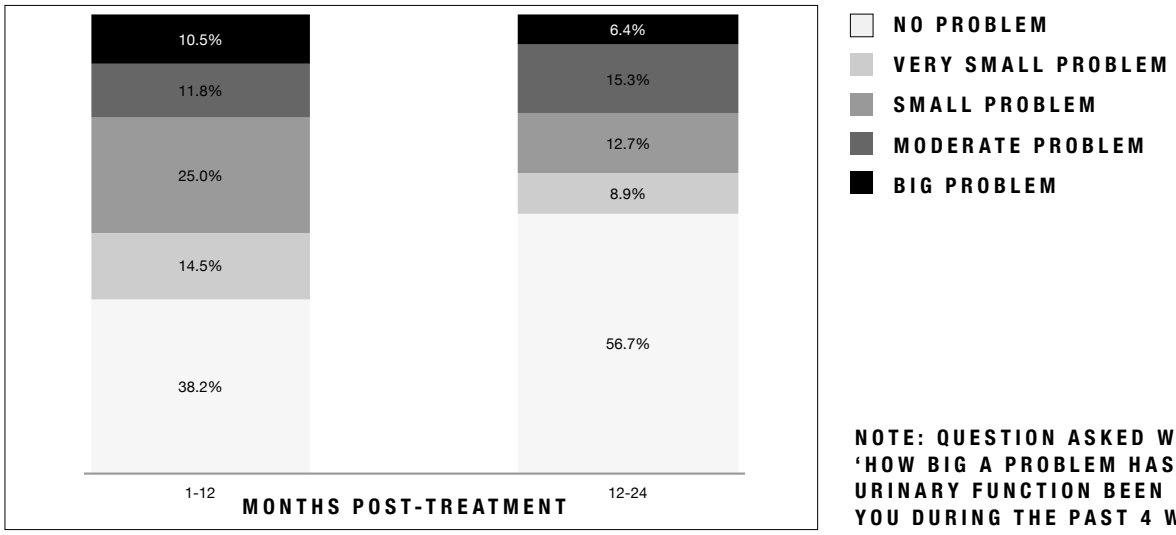
SURGERY



RADIOTHERAPY



ANDROGEN DEPRIVATION THERAPY (ADT) AS MONOTHERAPY



NOTE: QUESTION ASKED WAS 'HOW BIG A PROBLEM HAS YOUR URINARY FUNCTION BEEN FOR YOU DURING THE PAST 4 WEEKS?'

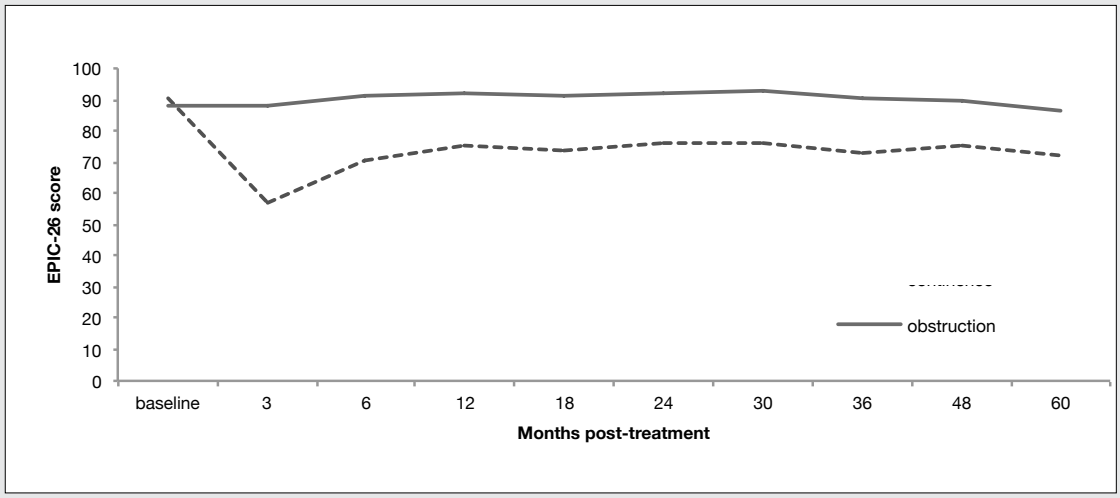
The tool used to collect PROMs in South Australia, the Expanded Prostate Cancer Index Composite (EPIC-26) quality-of-life survey[14] measures both urinary incontinence (e.g. problems with leaking urine) and urinary obstruction (e.g. problems with weak flow, incomplete emptying or needing to urinate frequently). Higher scores indicate better functioning and/or fewer symptoms. Results reflect the reported experiences of approximately 1000 mean, who collectively returned 2800 surveys between 2009 and 2014.

URINARY FUNCTION

Trends from PCOR-SA-PCCOC data indicate that urinary continence declined in the initial 3 months after having a radical prostatectomy, but got better steadily thereafter (see Figure 2). Urinary continence scores remained lower than the baseline level, which means that not all men recover their original level of urinary control. Problems with urinary obstruction were not affected by treatment.

FIGURE 2

CHANGES IN URINARY CONTINENCE AND URINARY OBSTRUCTION SCORES AFTER PROSTATECTOMY, SOUTH AUSTRALIA



Note: Higher EPIC-26 scores indicate better function/fewer symptoms.

Interviews with men revealed that having to use incontinence pads affected their mental wellbeing. This was related to a sense of embarrassment and a perception that using these pads compromised their masculinity:

The nominating factor is the total lack of urinary control, it just pretty much destroyed your life for 12 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.

I never felt like a man when I had pads on. It was always, like I limited what sort of social contact I had when I had to wear pads. That was psychological as much as anything.

BOWEL BOTHER

Figure 3 illustrates the proportion of Victorian men who report bowel bother in the 24 months after three different treatments. Bowel bother was measured every three months for surgery and radiotherapy, and every 12 months for hormonal monotherapy.

In the first three months after surgery, a higher proportion of Victorian men reported a moderate bowel bother, compared with later time points. As more time passed after treatment, men reported a very small problem or no problem at all. South Australian men who underwent surgery reported very little impact of a prostatectomy on bowel function.

However, radiotherapy and ADT resulted in more bowel bother compared with prostatectomies. As more time passed after radiotherapy and ADT, more men reported a moderate or big bowel bother (Figure 3).

As with the urinary bother, the proportion of men reported as having moderate and big bowel bother remained the same, even after two years post-ADT (16%). ADT affects everybody differently and, generally, does not affect bowel functioning directly. However, bowel problems might result from other issues. Interviews revealed that some men did struggle with bowel-related side effects from hormone treatment:

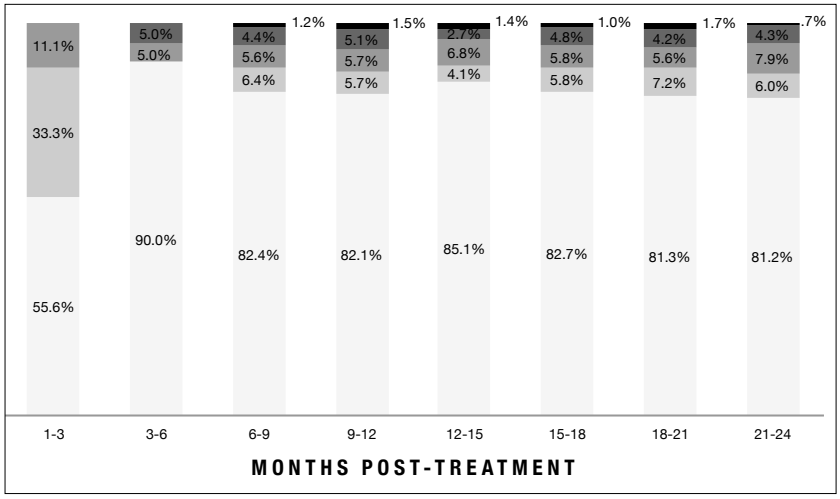
… the side effects of the hormone treatment have probably been the worst thing to handle. I have had after effects, and I believe that it's probably through the radiation. I have bowel problems. I will go to the toilet and use my bowels first thing in the morning, and then within 5 or 10 minutes, I've got to race back again, sometimes three times, so that didn't happen before

… because of the radiation and the bowel, I believe that it's caused problems there, so there are those risks in it. With anything, I think you've just got to face up to it.

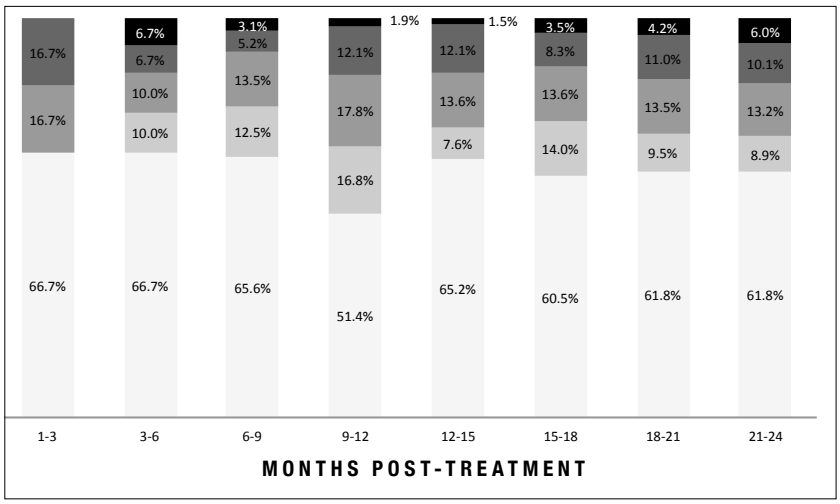
FIGURE 3

BOWEL BOTHER IN MEN WITH PROSTATE CANCER, 1–24 MONTHS AFTER DIFFERENT PRIMARY TREATMENT OPTIONS (SURGERY, RADIOTHERAPY AND HORMONAL MONOTHERAPY), VICTORIA

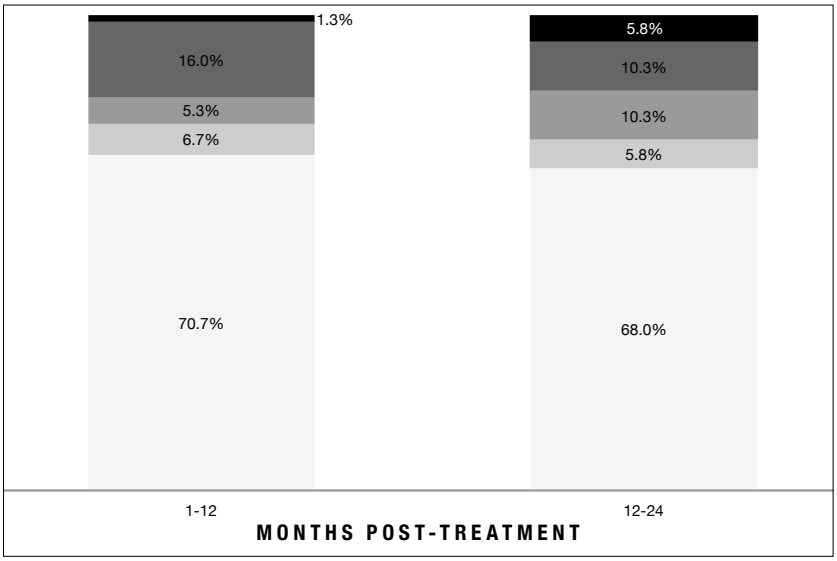
SURGERY



RADIOTHERAPY



ANDROGEN DEPRIVATION THERAPY (ADT) AS MONOTHERAPY



NOTE: QUESTION ASKED WAS 'HOW BIG A PROBLEM HAS YOUR URINARY FUNCTION BEEN FOR YOU DURING THE PAST 4 WEEKS?'THOSE WHO WERE NOT DIAGNOSED WITH PROSTATE CANCER.

SEXUAL BOTHER

Figure 4 illustrates the proportion of Victorian men who report sexual bother in the 24 months after three different treatments. Sexual bother has been reported in three-monthly time periods post-surgery and radiotherapy treatments, and in the initial and subsequent 12 month time periods following ADT.

In the first 6 months after surgery, half of all men reported a lot of sexual bother, but function did improve with time (Figure 4). Surgery resulted in more men reporting a big or moderate sexual bother compared with radiotherapy or hormonal monotherapy.

Less sexual bother was reported by men as time passed after their ADT – that is, 26% in the first 12 months compared with 21% in the subsequent 12 month period after ADT (see Figure 4).

ADT is known to decrease sexual functioning. This may be because blocked androgen hormone receptors or decreased normal hormone production could lead to decreased libido or to cardiovascular effects that contribute to erectile dysfunction. These effects obviously bother some men. ADT may also affect men's psychological wellbeing (i.e. through increased mood swings), which may make men more vulnerable to feeling grief about the loss of their masculinity. The use of intermittent, rather than continuous, ADT may serve to minimise the impact of ADT on sexual functioning.

Men reported that the sexual decline could be very difficult to deal with, especially for those who were not in a long-term relationship at the time of their diagnosis:

It just doesn't work … That is a real, umm, a real downer. Yeah. I did find a lady and [long pause] all the feelings were there, but when the time came [gestured to indicate no erection].

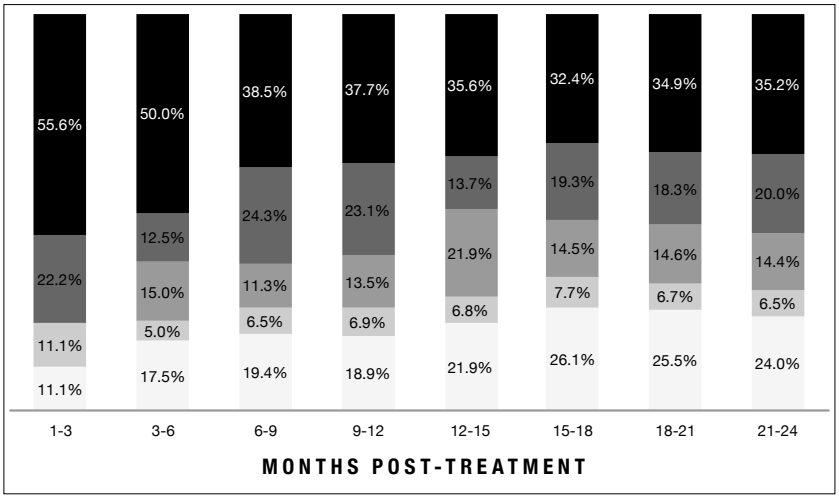
It really knocked me around. Just the lack of confidence and you know, self-esteem and everything. It just, yeah. I don't know. All my female friends umm, now, [laughs] or at least if I'm looking, I'm looking at somebody who's out of that, too old for that you know … So I sort of shy away from anything that, any mention of sleeping together or anything like that.

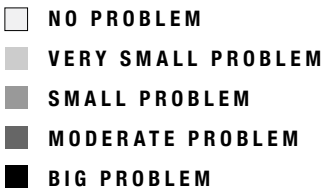
I didn't feel like a man, anymore. That was the hardest part and time got rid of that, time cured that and I just feel like, I feel like I was less than a man for a while. Probably the first 6 months, 12 months. After the treatment I think yeah … [it changed] with knowing that every now and then it does work.

FIGURE 4

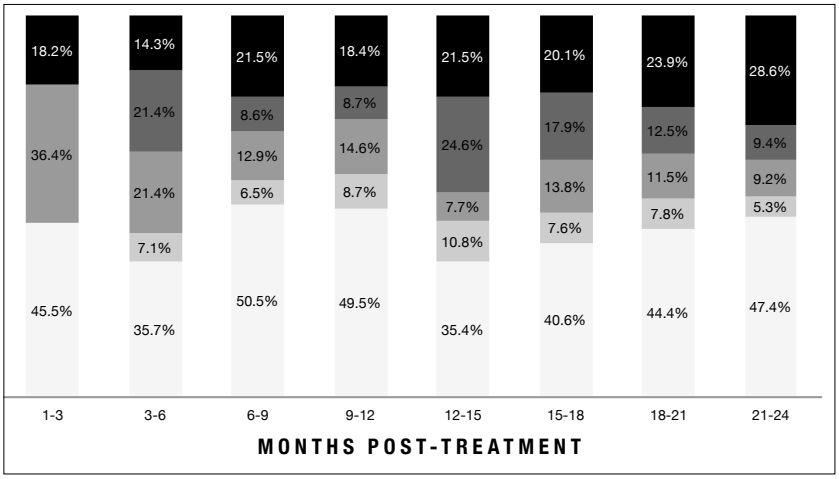
SEXUAL BOTHER IN MEN WITH PROSTATE CANCER, 1–24 MONTHS AFTER DIFFERENT PRIMARY TREATMENT OPTIONS (SURGERY, RADIOTHERAPY AND ANDROGEN DEPRIVATION THERAPY (ADT) AS MONOTHERAPY), VICTORIA

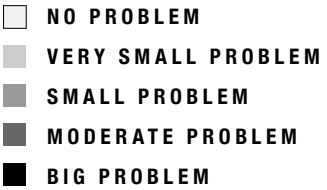
SURGERY



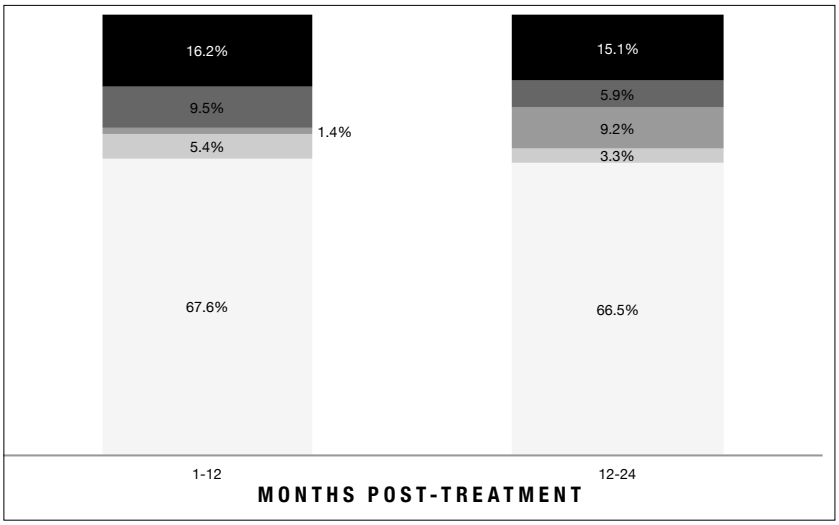


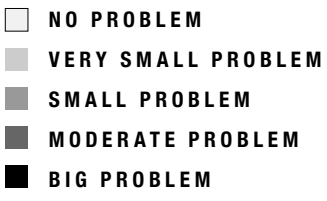
RADIOTHERAPY





ANDROGEN DEPRIVATION THERAPY (ADT) AS MONOTHERAPY





NOTE: QUESTION ASKED WAS 'HOW BIG A PROBLEM HAS YOUR SEXUAL FUNCTION BEEN FOR YOU DURING THE PAST 4 WEEKS?'

SEXUAL FUNCTION

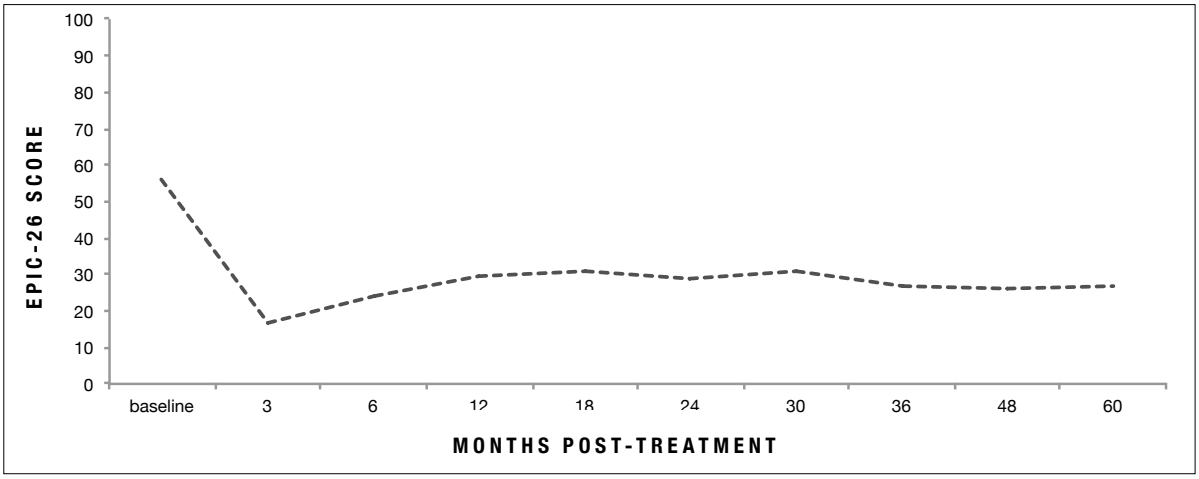
South Australian men responding to the EPIC-26 survey also reported decreased sexual functioning after a prostatectomy (see Figure 5).

Because sexual functioning declines with increasing age and diagnosis of prostate cancer increases with age, sexual functioning before treatment (baseline) starts at a somewhat lower point than other areas of physical functioning. Immediately after surgery, men commonly experienced problems with sexual functioning as seen by the sharp decrease in average sexual function score. Although there was some improvement with time after treatment, on average, sexual functioning remained at levels much lower than they were before treatment.

Results for sexual functioning after a radical prostatectomy reflect the reported experiences of approximately 870 South Australian men who collectively returned 2500 surveys between 2009 and 2014.

FIGURE 5

CHANGES IN SEXUAL FUNCTIONING AFTER A PROSTATECTOMY, SOUTH AUSTRALIA



Note: Higher scores indicate fewer symptoms.

MENTAL WELLBEING

In Victorian men, mental wellbeing was measured at 12 and 24 months after being diagnosed with prostate cancer. Mental wellbeing score is computed using the scores of 12 questions from the SF12 Health Survey. Scores range from 0 to 100; a score of 0 indicates the lowest level of health and 100 indicates the highest level of health.[15]

Figure 6 illustrates the average mental wellbeing of Victorian men by disease risk groups. The median (or value of the person in the middle of all those who answered the survey) of the mental wellbeing score is indicated by the horizontal line that separates the light and dark shades in each group being compared. The lower and upper body of the box represents the 25th and 75th percentiles of the mental wellbeing scores as illustrated below

WELLBEING SCORES AS ILLUSTRATED BELOW

TOP 75TH PERCENT	25%	Upper 25% range of patients' score
		Middle (median) score
BOTTOM 25TH PERCENT	25%	Lower 25% range of patients' score

Overall, mental wellbeing scores were similar across the risk groups. Men with low-risk disease experienced slightly poorer mental health before receiving treatment; however, this result was not demonstrated in other risk groups. This might reflect the fact that men in the low-risk disease group were, on average, younger than men in the intermediate- and high-risk groups. A study has shown that younger patients were more likely to report concerns regarding waiting time to treatment.[16]

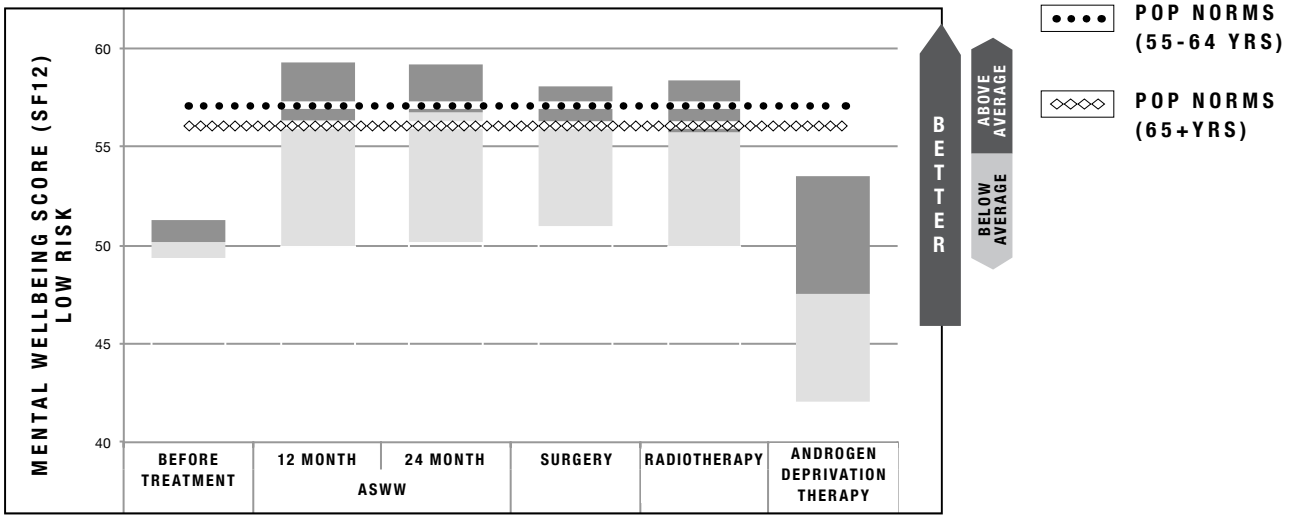
Although greater variability in scores is observed in men receiving ADT in the low and intermediate-risk groups, it is important to note that the proportion of men who received ADT in the low-risk group was less than 1%.

On average, 12 and 24 months after diagnosis, men with prostate cancer did not have poorer mental health when compared with men in the general population. The median mental scores for men aged 55–64 years, 65–74 years and ≥75 years are 57, 56 and 56, respectively.[17]

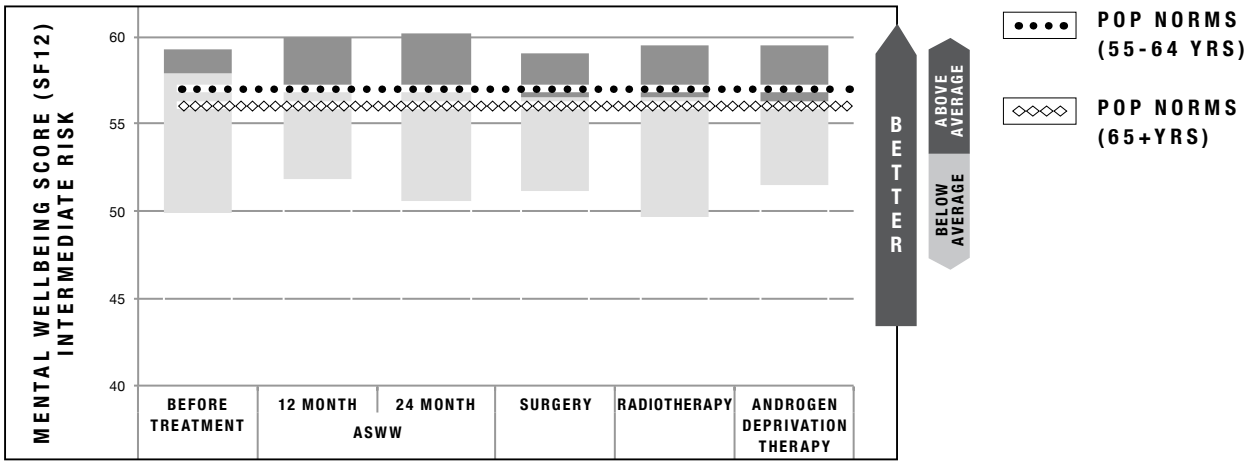
FIGURE 6

PATIENT-REPORTED MENTAL WELLBEING SCORE BEFORE AND AFTER DIFFERENT PRIMARY TREATMENT OPTIONS, VICTORIA

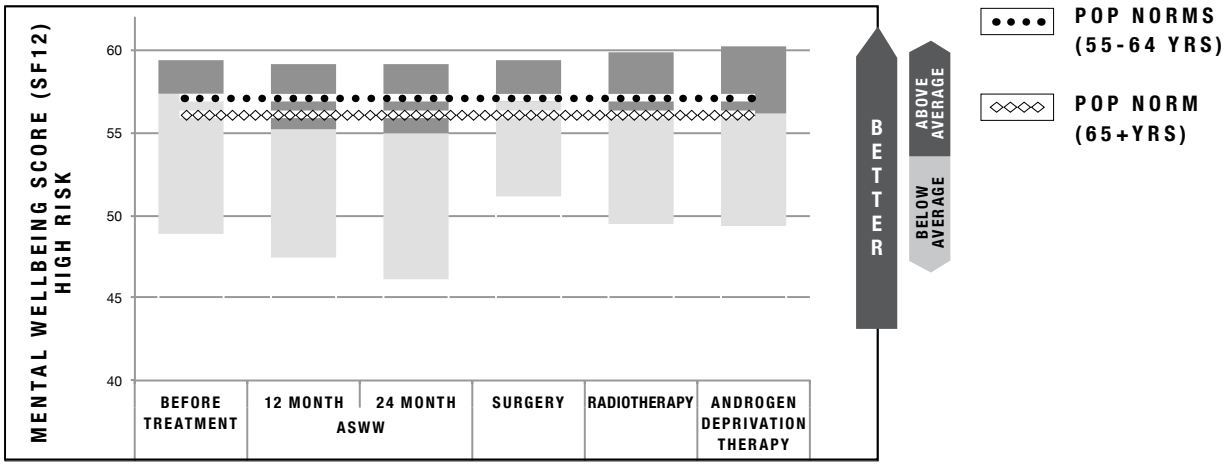
LOW-RISK GROUP



INTERMEDIATE-RISK GROUP



HIGH-RISK GROUP



ASWW = active surveillance or watchful waiting
Note: A higher score indicates better mental wellbeing.
Source: Avery, Dal Grande and Taylor (2004)[18]

Mental wellbeing among South Australian men following radical prostatectomy, assessed using the SF12 survey, also showed very little change from baseline to five years (data not shown). One participant from the SAHMRI study specifically talked about feeling depressed as a consequence of treatment, and that this experience had kept him isolated from others for a period. He believed that the depression was related to the hormone treatment he had undergone:

Yeah once again, in the early days, it was an embarrassment and I didn't want to tell anyone, I didn't want to see anyone. That was probably an effect of the initial onslaught of hormone therapy I had. It was sort of like I don't want to see anyone, I don't want to talk about anything to anyone and there were, there were friends that rang me and said geez, I haven't heard from you in ages, sometimes you just want to hide under the doona.

You sort of laugh about everything and you smile about everything but there's some hard yards in there.

PHYSICAL WELLBEING

As with mental health assessment, the SF12 was used to score physical wellbeing.[19]

Figure 7 illustrates the average physical wellbeing of Victorian men by disease risk groups. The median of physical wellbeing score is indicated by the horizontal line that separates the light and dark shades in each group being compared. The lower and upper body of the box represents the 25th and 75th percentiles of the physical wellbeing scores.

There is a steady decline in the physical wellbeing scores (poorer physical health) as the risk of the disease progressed. Better physical wellbeing is demonstrated in men who had surgery across all disease groups. Conversely, poorer physical health is reported by men receiving ADT. This might reflect the fact that men treated with ADT are, on average, older. In addition, ADT is also associated with numerous adverse effects including hot flashes, fatigue, anaemia, loss of bone density, muscle atrophy and sexual dysfunction.[20] These effects may contribute to a loss of physical function.

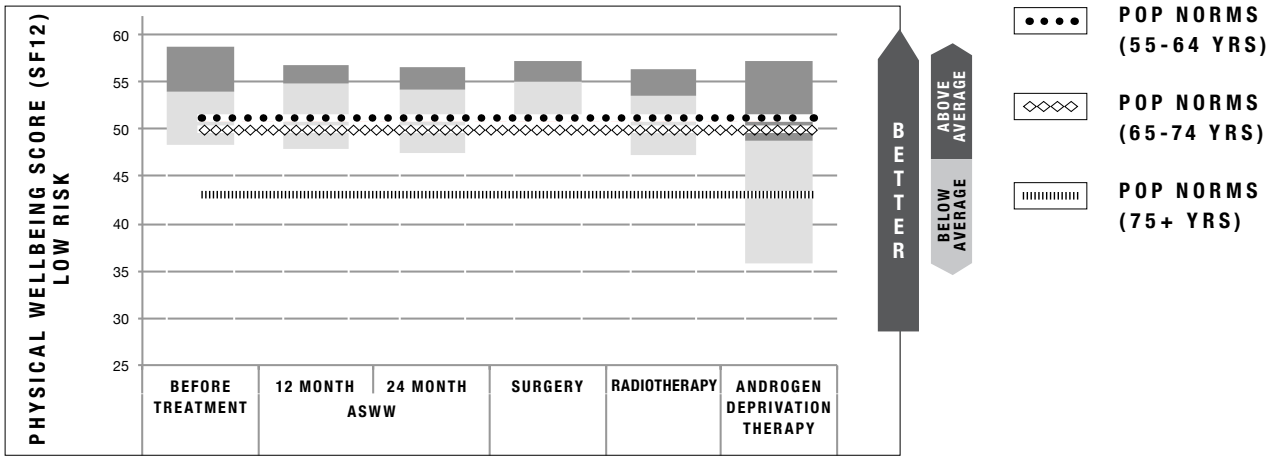
On average, 12 and 24 months after diagnosis, men with low and intermediate-risk of prostate cancer did not have poorer physical health than the general population, with the exception of those who had received ADT. On the other hand, most men in the high-risk group reported worse physical wellbeing than the general population. The median physical scores for men aged 55–64 years, 65–74 years and ≥75 years are 51, 50 and 43, respectively.[21]

Physical wellbeing in South Australian men was also assessed using SF12's physical health domain (see Appendix D). Overall, physical wellbeing remained similar to that reported at baseline and changed little in the post-treatment period (data not shown).

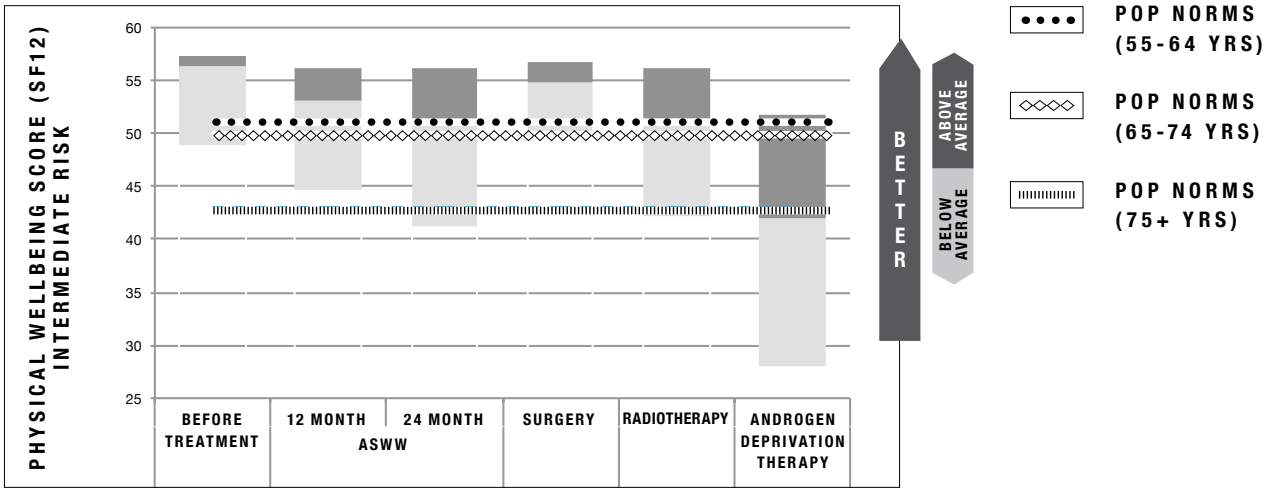
FIGURE 7

PATIENT-REPORTED PHYSICAL WELLBEING SCORE BEFORE AND AFTER DIFFERENT PRIMARY TREATMENT OPTIONS, VICTORIA

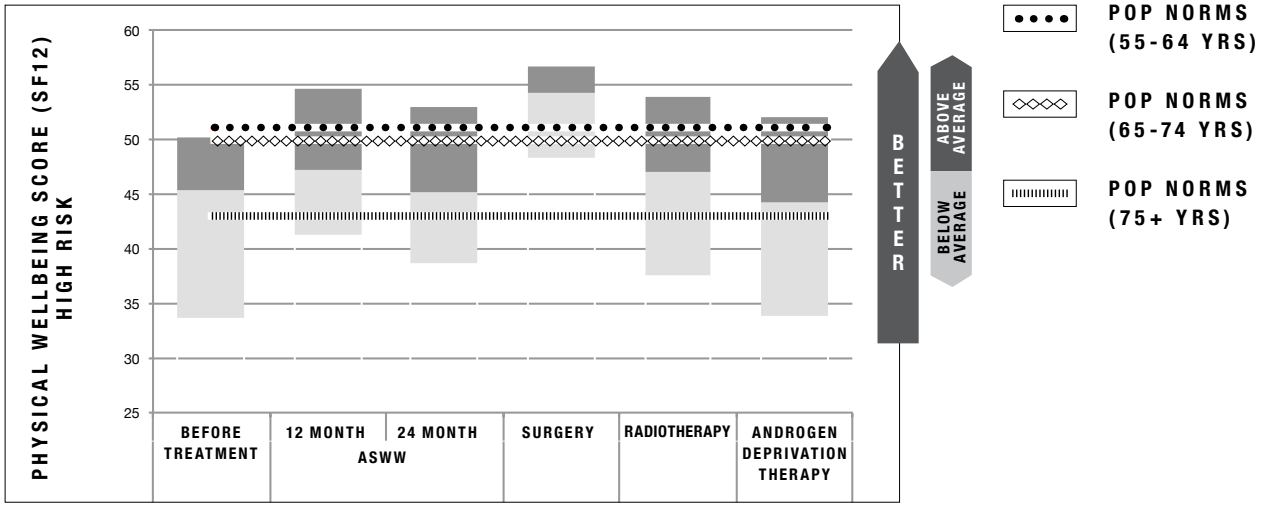
LOW-RISK GROUP



INTERMEDIATE-RISK GROUP



HIGH-RISK GROUP



ASWW = active surveillance or watchful waiting
Note: A higher score indicates better mental wellbeing.
Source: Avery, Dal Grande and Taylor (2004)[22]

DEMOGRAPHICS AND CLINICAL OUTCOMES

KEY MESSAGES

THE AVERAGE AGE OF MEN DIAGNOSED WITH PROSTATE CANCER IN SOUTH AUSTRALIA AND VICTORIA FROM 2009 TO 2013 WAS 65 YEARS. TRENDS IN SOUTH AUSTRALIA INDICATE A SIGNIFICANT DECREASE OVER TIME IN THE AVERAGE AGE AT DIAGNOSIS, FROM 72 YEARS IN 1998–99 TO 68 YEARS IN 2011–2013.

TRENDS INDICATE AN INCREASE IN THE DIAGNOSIS OF PROSTATE CANCER THROUGH TRANSRECTAL ULTRASOUND BIOPSY PROCEDURES AND A CORRESPONDING DECREASE IN 'INCIDENTAL FINDINGS' BECAUSE OF TRANSURETHRAL RESECTION OF THE PROSTATE (TURP) PROCEDURES.

OVERALL PROGNOSIS IS VERY GOOD FOR MEN DIAGNOSED WITH LOCALISED PROSTATE CANCER.

IMPORTANCE OF MONITORING CLINICAL CHARACTERISTICS AND OUTCOMES

An individual's prognosis largely depends on the clinical characteristics of the cancer at diagnosis, such as the extent of disease (how much the tumour has spread) and grade (how fast the tumour grows). These factors are taken into account when planning treatment and management options for those diagnosed with prostate cancer. Timely and accurate diagnosis is important to ensure good treatment planning and favourable outcomes, which, in turn, may be influenced by awareness of symptoms, decisions to participate in prostate-specific antigen (PSA) testing and access to health care.

Socioeconomic status and where people live has been associated with variation in screening practices, treatment and follow up for men with prostate cancer. Men aged between 50 and 79 years and living in rural areas have been shown to be 16% less likely to be screened for prostate cancer, 29% less likely to receive prostatectomy once diagnosed and 20% more likely to die from their prostate cancer compared with men who live in capital cities.[23]

This section describes the demographic and clinical profile of men in the PCOR-SA-PCCOC and PCOR-Vic, as well as changes over time for three factors: characteristics of disease, mode of presentation and methods of diagnosis. Changes in prostate cancer survival and disease-free survival (i.e. being free of any evidence of prostate cancer returning after curative treatment) are also presented for South Australia where data have been collected for a longer period to monitor survival.

DEMOGRAPHICS

This work describes clinical and treatment characteristics for men diagnosed with prostate cancer in the PCOR-SA-PCCOC from 1998 to 2013 and the PCOR-Vic from 2009 to 2013.

Socioeconomic advantage/disadvantage

Neither PCOR-SA-PCCOC nor PCOR-Vic collect individual level data on income, education levels or occupation. However, an indication of the level of advantage or disadvantage of men within the registry can be gained from Australian Bureau of Statistics' Socio-Economic Index for Areas[24] using the postcode of the area in which men live at the time of their diagnosis.

Table 1 shows the distribution of men in the PCOR-Vic and PCOR-SA-PCCOC according to the socioeconomic profile of the areas in which they live. These results indicate that there were more men than would be expected from highly advantaged areas and fewer than expected from disadvantaged areas diagnosed with prostate cancer. Reasons for this are not clear. It may be that, compared to men living in less advantaged areas, men from advantaged areas are better informed about prostate cancer screening or see GPs who are more informed and are more likely to offer prostate cancer screening to men. It may reflect better access to healthcare or perhaps that men in more affluent areas have greater predisposition for prostate cancer (e.g. genetic factors, race/ethnicity).

TABLE 1

DISTRIBUTION OF MEN WITHIN THE VICTORIAN AND SOUTH AUSTRALIAN PROSTATE CANCER CLINICAL REGISTRIES ACCORDING TO SOCIOECONOMIC INDEX FOR AREAS (SEIFA) CATEGORIES

SEIFA	Proportion of prostate cancer diagnoses in the South Australian and Victorian registries
81–100% (i.e. the most advantaged 20%)	33
61–80%	21
41-60%	16
20–40%	17
<20% (i.e. the least advantaged 20%)	13

Figures from the Cancer Council Victoria have shown that men in Gippsland, Victoria, were less likely to survive 5 years after diagnosis than men in most other Victorian regions.[25] PCOR-Vic has helped the Prostate Cancer Foundation of Australia to shed some light on this issue through the 'Gippsland study'. Findings from this study have shown that men diagnosed in this region had considerably lower socioeconomic advantage than men living in other regions of Victoria. A systematic review study also suggests that urban–rural disparities in the prostate cancer incidence and mortality may result from differences in demographic and socioeconomic characteristics of the two groups, which may influence access to, and use of, diagnostic and treatment services.[26]

The Movember Foundation is currently funding the next phase of the Gippsland study, which aims to explore the perceptions and experiences of prostate cancer screening, diagnosis, treatment and care of general practitioners, prostate cancer patients and their partners, and men with no history of prostate cancer in regional–rural and metropolitan areas in Victoria.

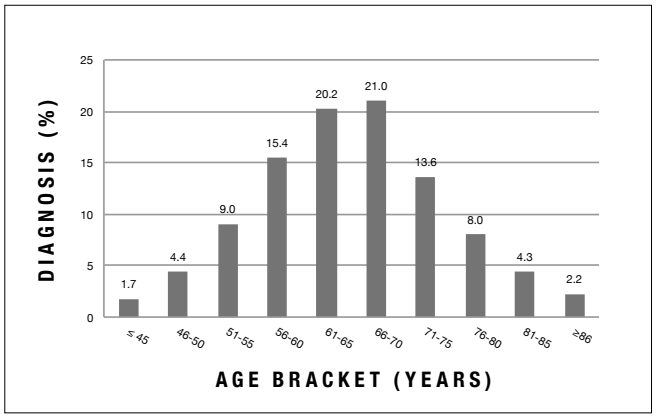
Age at diagnosis

The median age of men diagnosed with prostate cancer in South Australia and Victoria from 2009 to 2013 was 65 years (interquartile range is 59–71 years).

Figure 8 summarises men's profile by age. About 40% of men were diagnosed between 60 and 70 years old.

FIGURE 8

AGE DISTRIBUTION OF MEN AT DIAGNOSIS WITH PROSTATE CANCER, SOUTH AUSTRALIA AND VICTORIA

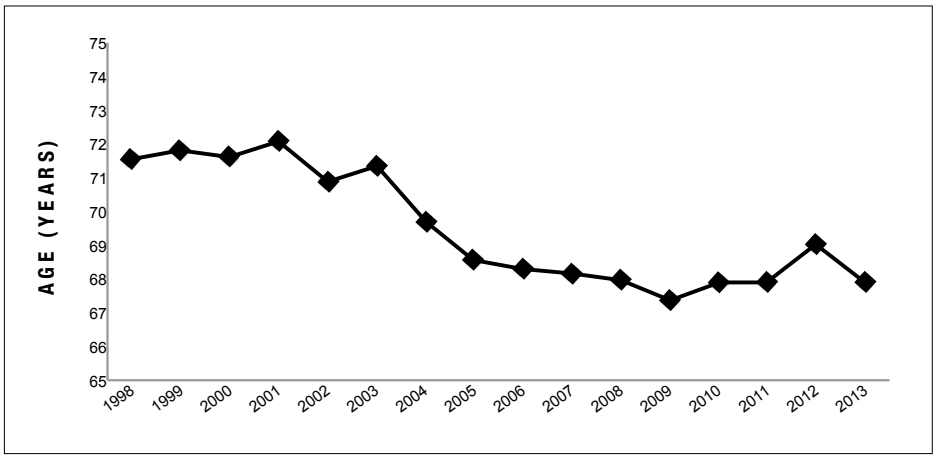


Trends for PCOR-Vic and PCOR-SA-PCCOC combined data show that fewer younger men (i.e. under 65 years) are diagnosed with prostate cancer each year (data not shown).

PCOR-SA-PCCOC data show that there has been a significant decline in the average age of men at diagnosis, from 72 years of age in 1998–2000 to 68 years in 2011–13 (Figure 9), suggesting the number of elderly men diagnosed also decreased.

FIGURE 9

TRENDS IN AGE AT DIAGNOSIS FOR SOUTH AUSTRALIAN MEN, 1998–2013



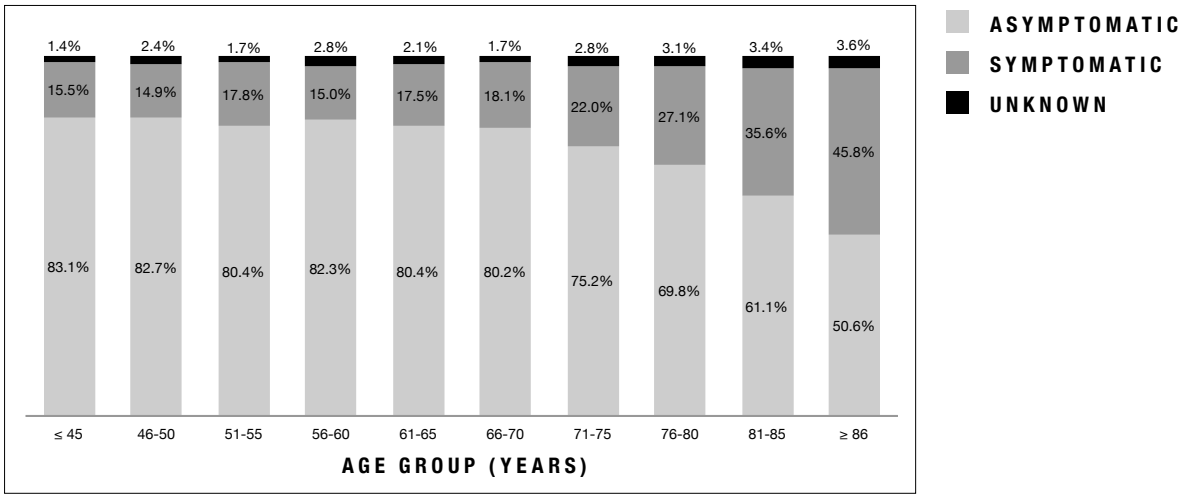
PRIMARY REASON FOR REFERRAL

The reason for referral to a urologist for initial investigation for prostate cancer was collected using different approaches in the PCOR-Vic and PCOR-SA-PCCOC.

Men participating in PCOR-Vic were telephoned at 12 months after their prostate cancer diagnoses and asked 'How was your prostate cancer first-detected? Was it through a screening test such as a PSA blood test or digital rectal examination (asymptomatic), or was it because you went to see your doctor about some particular symptoms (symptomatic)?' 78% of men reported that their cancer was detected though routine case-finding, 20% of men reported that they presented with symptoms and 2% were unknown. Nearly half of the men who reported having prostate symptoms (such as lower urinary tract symptoms [LUTS]) were more than 66 years old (Figure 10).

FIGURE 10

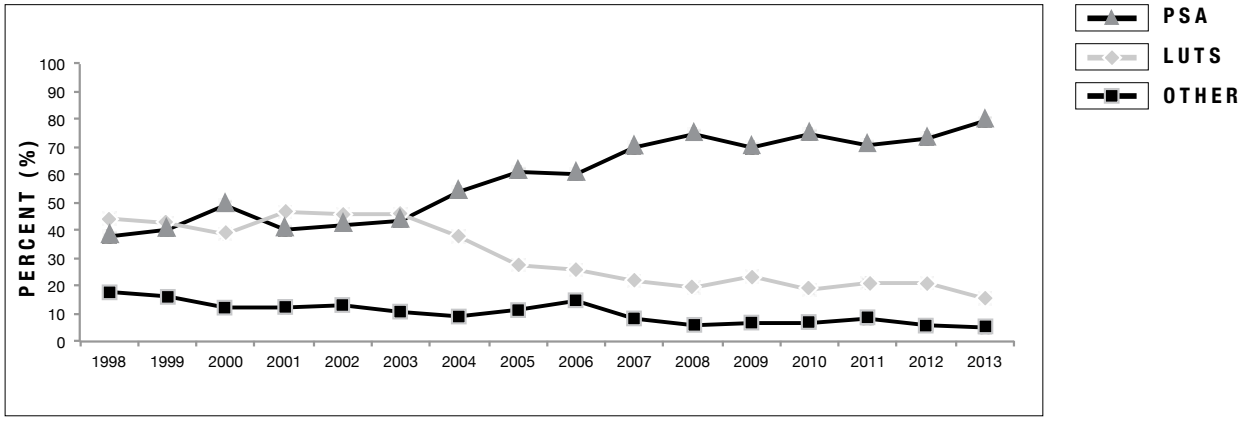
REASON FOR REFERRAL REPORTED BY VICTORIAN MEN BY AGE AT DIAGNOSIS, 2009–13



In South Australia, the reason for referral to a urologist for initial investigation was collected from clinical notes. Trends indicate that reason for referral has changed substantially during the past 15 years. In 1998–2000, similar proportions of men were referred to a Urologist because of lower urinary tract symptoms and elevated PSA levels (each about 45%). In 2011–13, elevated PSA levels were the primary reason from referral in 75% of cases; far fewer were referred because of urinary tract symptoms (Figure 11). The proportion referred because of other symptoms (e.g. bone pain suggesting prostate cancer that had already spread) has also declined slightly during this period.

FIGURE 11

TRENDS IN PRIMARY REASON FOR REFERRAL AT DIAGNOSIS FOR SOUTH AUSTRALIAN MEN, 1998–2013



LUTS = lower urinary tract symptoms; **PSA =** prostate-specific antigen

DIAGNOSTIC CHARACTERISTICS

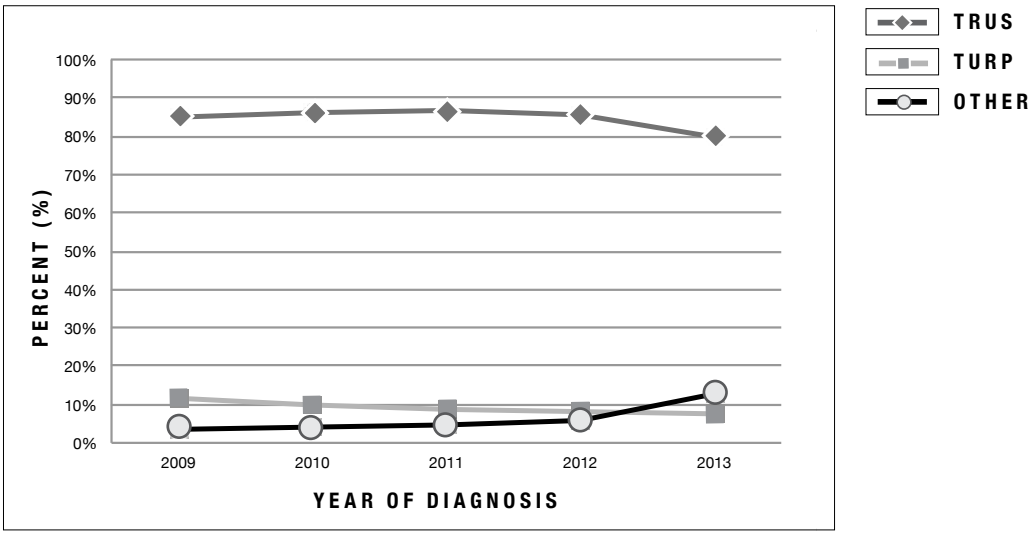
Method of diagnosis

The vast majority of men in both Victoria and South Australia were diagnosed using transrectal ultrasound (TRUS)–guided biopsy. Trends indicate a 5% decrease of TRUS procedures during a 5-year period (Figure 12). This is because of a substantial increase in the use of transperineal template biopsy procedures in a number of diagnostic settings in Victoria in 2012–13, which is evidenced by the increase in 'other' methods of diagnosis. Transperineal biopsy is a fairly new biopsy procedure that offers a safe and, potentially more accurate, method of diagnosis. This procedure allows for more systematic sampling of the whole prostate gland; however, it needs to be done in an operating theatre, thus potentially requiring more time and finances than the standard TRUS procedure.[27] Studies are under way to compare outcomes of different biopsy methods.

Although most men with prostate cancer are initially diagnosed through a biopsy, in some cases, prostate cancer is diagnosed incidentally during procedures to treat other prostatic disease. Transurethral resection of the prostate (TURP) procedures are often done to relieve symptoms of an enlarged prostate. The tissue removed is then sent to pathology for analysis. In men more than 76 years, approximately one-third were diagnosed because of incidental findings following TURP since 2009 (Figure 13).

FIGURE 12

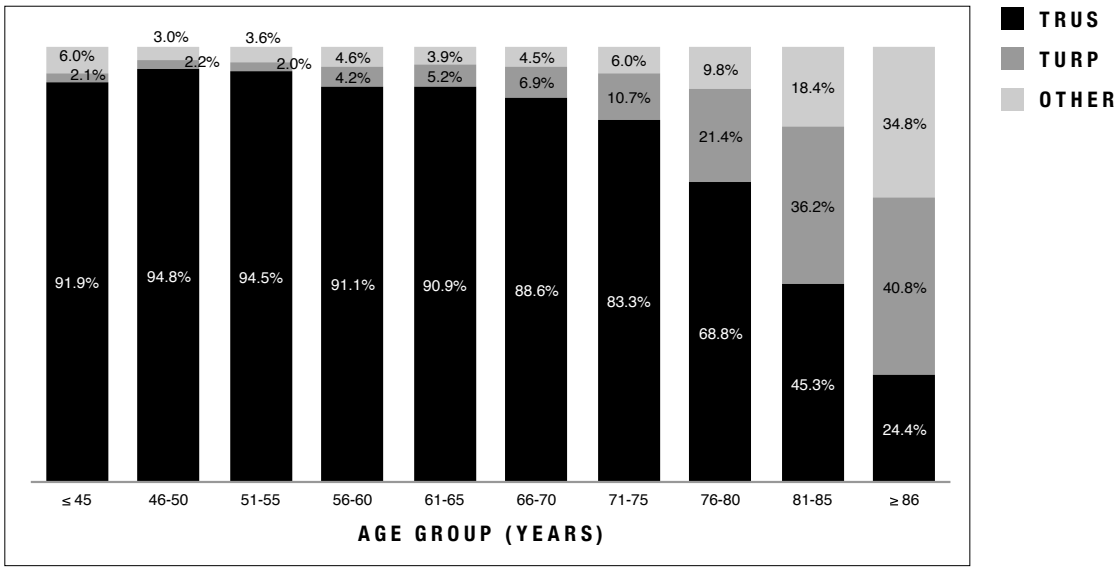
METHOD OF DIAGNOSIS OF MEN WITH PROSTATE CANCER, SOUTH AUSTRALIAN AND VICTORIAN MEN



TRUS = transrectal ultrasound; **TURP =** transurethral resection of the prostate
Note: 'Other' methods of diagnosis included clinical investigation, histology of metastatic site, holium laser enucleation of prostate and transperineal template biopsy.

FIGURE 13

METHOD OF DIAGNOSIS OF MEN WITH PROSTATE CANCER, BY AGE, SOUTH AUSTRALIA AND VICTORIA

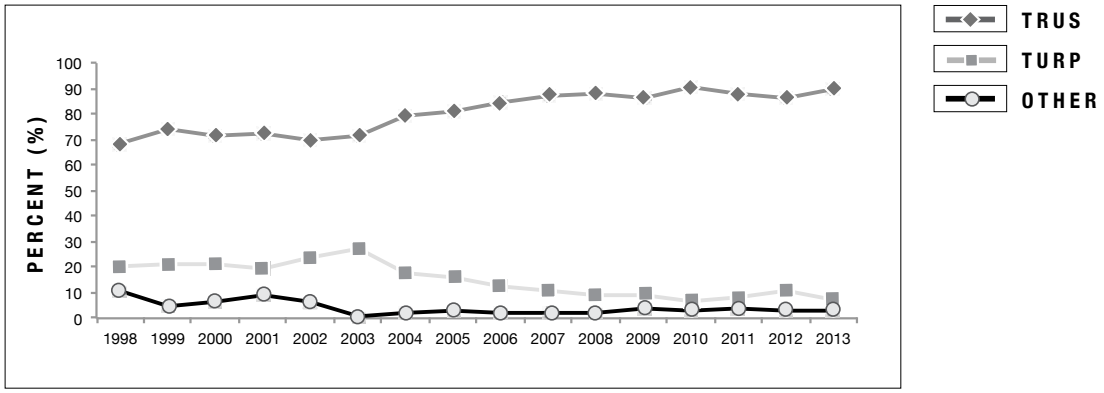


TRUS = transrectal ultrasound; **TURP =** transurethral resection of the prostate
Note: 'Other' methods of diagnosis included clinical investigation, histology of metastatic site, holium laser enucleation of prostate and transperineal template biopsy.

Trends from PCOR-SA-PCCOC indicate an increase in the diagnosis of prostate cancer through TRUS biopsy procedures and a corresponding decrease in 'incidental findings' in TURP procedures, which are generally done to treat lower urinary tract symptoms (Figure 14). Among those having TRUS biopsies, there was clear evidence of an increase in the average number of cores (samples of prostate tissue) taken at biopsy, up from 6 to about 14 in 2011–13 (Figure 15). The increase in number of cores should mean greater diagnostic precision, with fewer missed cancers and more accurate grading. Ultimately, this will lead to better treatment planning and improved outcomes. Transperineal template biopsies are becoming more frequent in South Australia, but a substantial increase in its use began after 2013.

FIGURE 14

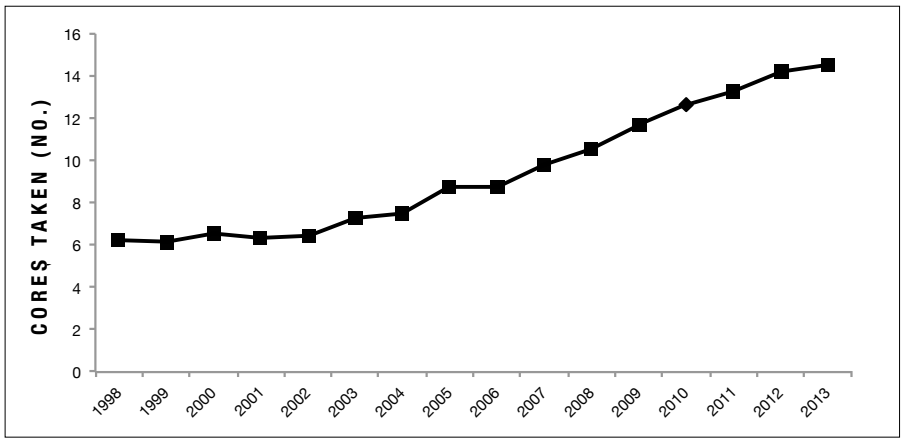
TRENDS IN METHOD OF DIAGNOSIS FOR SOUTH AUSTRALIAN MEN, 1998–2013



TRUS = transrectal ultrasound; **TURP =** transurethral resection of the prostate
Note: 'Other' methods of diagnosis included clinical investigation, histology of metastatic site, holium laser enucleation of prostate and transperineal template biopsy.

FIGURE 15

TRENDS IN THE MEAN NUMBER OF CORES TAKEN AT BIOPSY FOR SOUTH AUSTRALIAN MEN, 1998–2013



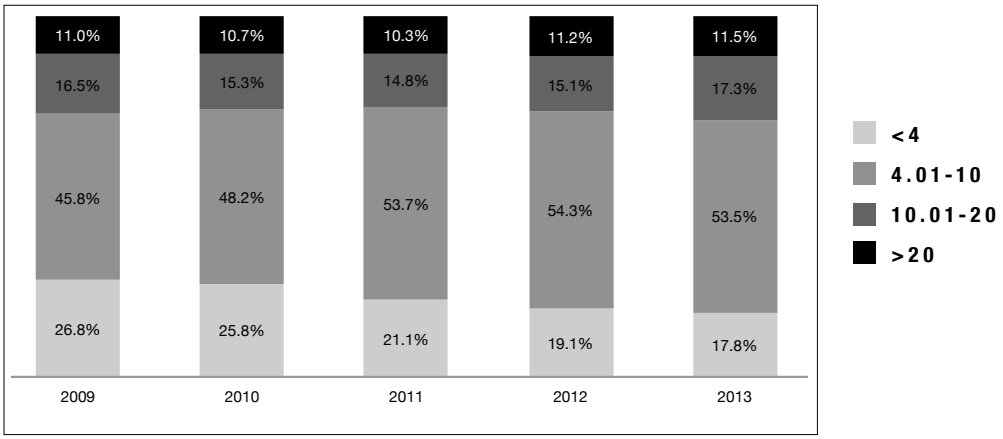
PROSTATE-SPECIFIC ANTIGEN LEVEL AT DIAGNOSIS

A PSA test measures the level of prostate-specific antigen in the blood. The normal range for PSA levels vary with age; however, the standard normal range cut off is 4 nanograms/millilitre (ng/mL).[28] Higher than normal PSA levels can signal that a tumour is present, but they can also indicate benign disease. When cancer is found, higher PSA levels generally indicate more advanced disease. In Figures 16–19, we have grouped PSA levels according to the National Comprehensive Cancer Network (NCCN) risk categories: <10 ng/mL, 10–20 ng/mL and >20 ng/mL (see Appendix A). We further reclassified PSA <10 ng/mL into ≤4 ng/mL and 4.01–10.00 ng/mL subcategories, because the PSA threshold for referral to prostate biopsy is 4 ng/mL.[29]

The median PSA level at diagnosis in men from both states was 6.1 ng/mL (interquartile range of 3.6–10.0 ng/mL). Figure 16 shows the changes in the proportion of men in each of the PSA groupings over time. The majority of men in South Australia and Victoria were diagnosed with a PSA level of <10 ng/mL.

FIGURE 16

AVERAGE PROSTATE-SPECIFIC ANTIGEN LEVEL AT DIAGNOSIS OF MEN WITH PROSTATE CANCER, SOUTH AUSTRALIA AND VICTORIA

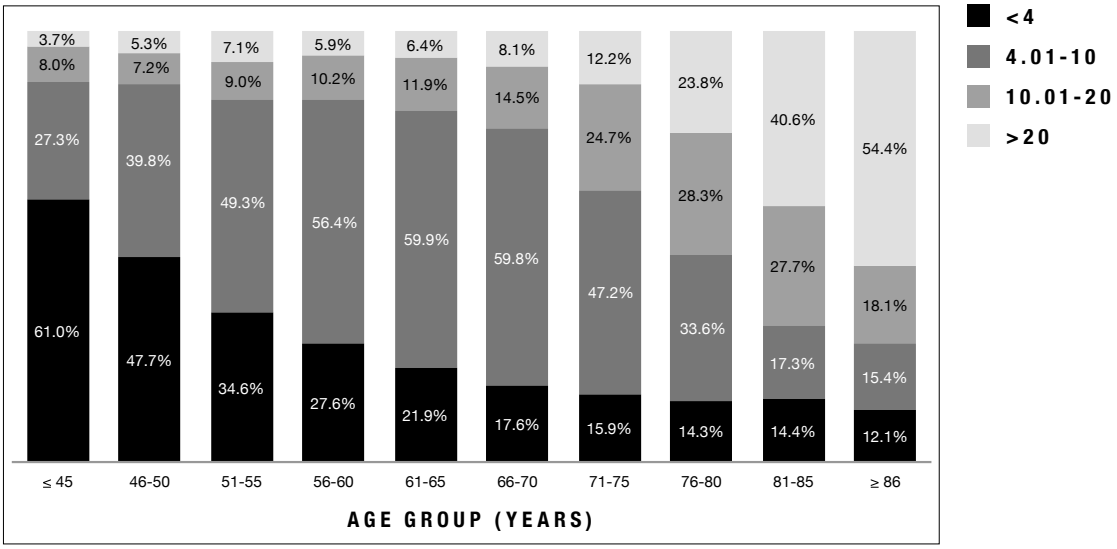


ng/mL = nanograms per millilitre

Men diagnosed with prostate cancer who were aged more than 76 years were at least three times more likely than those aged less than 65 years to have a PSA level of greater than 20ng/mL (Figure 17).

FIGURE 17

AVERAGE PROSTATE-SPECIFIC ANTIGEN LEVEL (NG/ML) BY AGE AT DIAGNOSIS OF MEN WITH PROSTATE CANCER, SOUTH AUSTRALIA AND VICTORIA

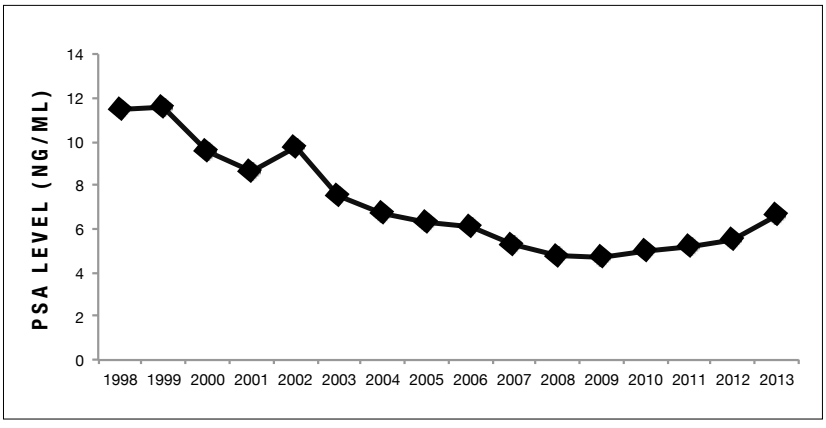


ng/mL = nanograms per millilitre

Trends in PCOR-SA-PCCOC indicate a significant decrease over time in the average PSA levels at diagnosis, from a median level of 12 ng/mL in 1998–99 to about 6 ng/mL in 2012–13 (Figure 18). In the 2012-13 period, 70% of men had PSA levels <10 ng/mL at diagnosis and about 10% of men had PSA levels >20 ng/mL compared with 50% and 30%, respectively, in the 1998-99 time period. Data indicate a decrease in the proportion of men with very low levels (≤4 ng/mL) in the most recent period (Figure 19).

FIGURE 18

TRENDS IN MEDIAN PROSTATE-SPECIFIC ANTIGEN LEVEL AT DIAGNOSIS FOR SOUTH AUSTRALIAN MEN, 1998–2013



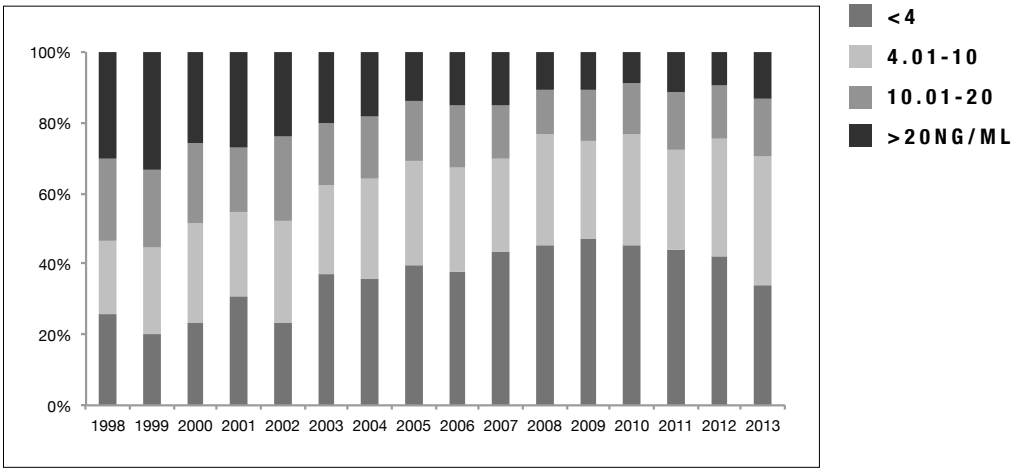
ng/mL = nanograms per millilitre; **PSA** = prostate-specific

Figure 19 shows that the level of the average PSA of men at the time of prostate cancer diagnosis has changed markedly over time. The median PSA at diagnosis of prostate cancer in South Australian men decreased by more than half between 1998–99 and 2008–09; since that time there has been an increasing trend:

- From 1998–99 to 2008–09, there was a steady decrease in the proportion of men with PSA levels of more than 10 ng/mL, and a concomitant increase in the proportion of men with PSA levels less than 10 ng/mL.
- Since 2009, the largest decreases have been in the proportion of men with PSA levels of <4 ng/mL, with the proportionate increase occurring in men with PSA levels of 4–10 ng/mL. Men with PSA levels of 10–20 ng/mL or >20 ng/mL stayed relatively constant.

FIGURE 19

TRENDS IN PROSTATE-SPECIFIC ANTIGEN LEVELS (GROUPED) AT DIAGNOSIS FOR SOUTH AUSTRALIAN MEN, 1998–2013



ng/mL = nanograms per millilitre;

The decreasing PSA levels at diagnosis during the early 2000s likely reflects the changing trends in case-finding practices for prostate cancer. During the early 2000s, men aged over 55 years, and especially those with a family history of prostate cancer, were encouraged to have a PSA test, even if they had no symptoms of the disease. This screening often picked up men with low PSA levels and with such early stage disease that it may not have impacted their life-expectancy if it hadn't been detected.

In the mid-to-later 2000s there was increasing debate over the 'over-diagnosis' of early stage prostate cancer. There was recognition that treating men with early stage disease might lead to more harm than benefit (i.e. unnecessary treatment causing unwanted side effects and higher costs). Accumulating evidence, such as through the Prostate Cancer Prevention Trial, demonstrated the association between PSA level and risk of prostate cancer disease[30]. PSA testing guidelines were developed to better target men more likely to have disease requiring curative treatment. Management guidelines recommended that biopsy be indicated in men with a PSA level of >3ng/mL. PCOR-SA-PCCOC data demonstrates a progressive reduction in the number of men being diagnosed with PSA levels of <4ng/mL from 2009 onwards.

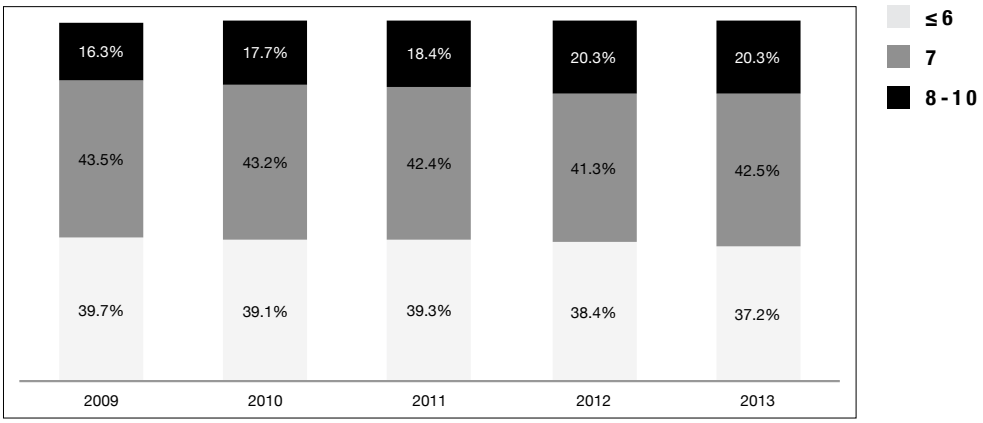
Gleason score at diagnosis

The Gleason grading system is usually used to indicate the level of aggressiveness of the cancer. Scores are grouped according to the NCCN risk category (Appendix A), with scores of 2–6 considered to be low grade, 7 considered to be intermediate grade and 8–10 considered to be high grade.

Between 2009 and 2013, approximately 80% of the men presented with low or intermediate-grade prostate cancer (39% and 42%, respectively). Figure 20 shows the changes in the proportion of men in each of the Gleason groupings over time.

FIGURE 20

GLEASON SCORE AT DIAGNOSIS OF MEN WITH PROSTATE CANCER, SOUTH AUSTRALIA AND VICTORIA

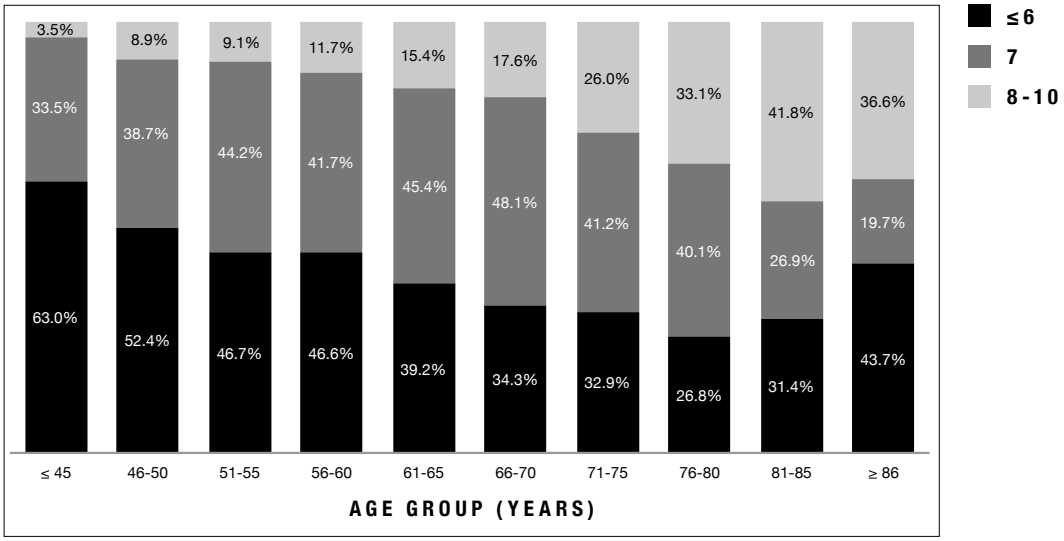


Note: Higher Gleason scores indicate more aggressive cancer.

Nearly half of men at aged 55 years and younger were diagnosed with a Gleason score of ≤6; however, Gleason scores tend to increase with the age and about one-third of older men had Gleason scores of ≥8 (Figure 21).

FIGURE 21

GLEASON SCORE BY AGE AT DIAGNOSIS OF MEN WITH PROSTATE CANCER, SOUTH AUSTRALIA AND VICTORIA

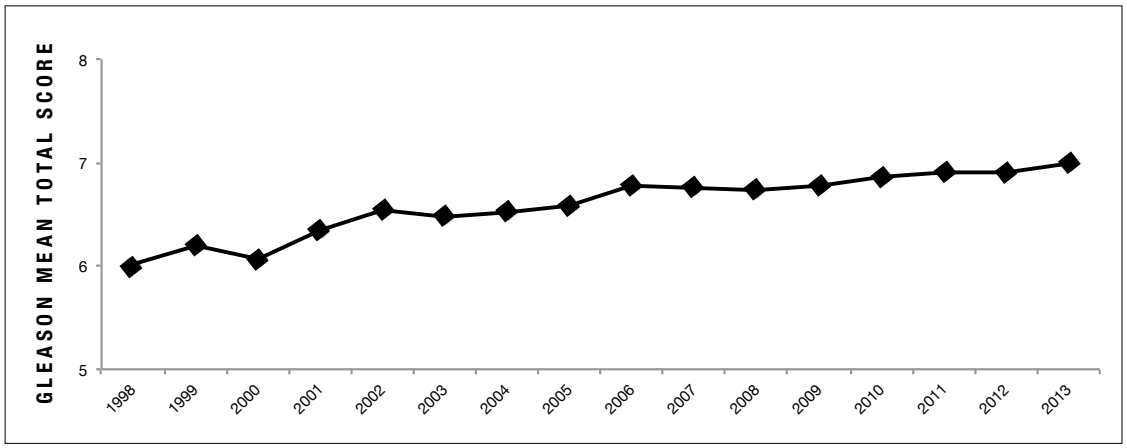


Note: Higher Gleason scores indicate more aggressive cancer.

There has been a gradual shift in Gleason grading, from a mean score of 6 to a mean score of 7 across the 15-year period among South Australian men (Figures 22 and 23). The proportion of men with a high Gleason score (8–10) remained relatively stable over time, at around 20%. The proportion of men with a Gleason score of 7 increased, and the proportion of men with a total score of ≤ 6 decreased over time. The increase in moderate Gleason scores (7) is likely to be because of changes in criteria for Gleason grading, which were introduced in 2005.[31]

FIGURE 22

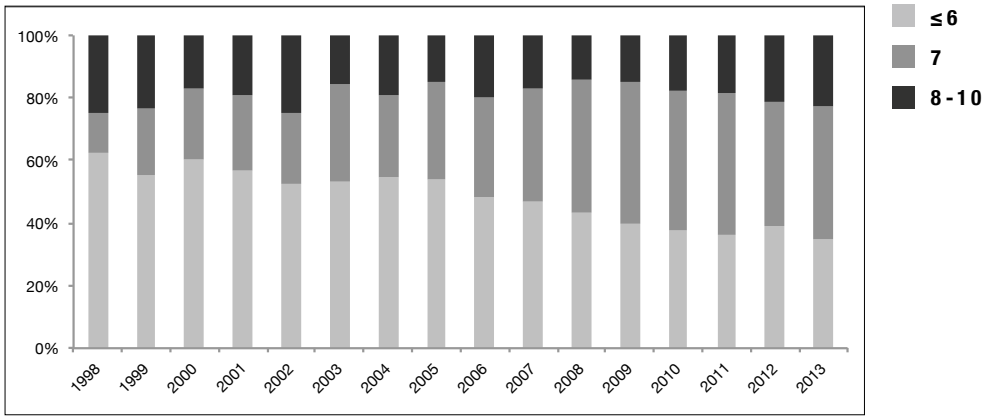
TRENDS IN GLEASON SCORE AT DIAGNOSIS AMONG SOUTH AUSTRALIAN MEN, 1998–2013



Note: Higher Gleason scores indicate more aggressive cancer.

FIGURE 23

TRENDS IN GLEASON SCORE CATEGORIES AT DIAGNOSIS AMONG SOUTH AUSTRALIAN MEN, 1998–2013



Note: Higher Gleason scores indicate more aggressive cancer.

RISK OF DISEASE PROGRESSION

To help determine treatment options, men with prostate cancer are grouped according to the risk of their disease progressing. Risk levels are usually determined from a combination of 3 variables: (1) the PSA level; (2) the Gleason score; and (3) the clinical stage, which is determined by the specialist by feeling the prostate when a digital rectal examination is undertaken and increasingly through the assistance of radiological findings such as magnetic resonance imaging (MRI) scans. This report groups risks according to NCCN risk groupings (see Appendix A).

Most men had intermediate risk disease at diagnosis. Older men were more likely to have high-risk disease (26%) than younger men (10.7%) (Figure 24).

FIGURE 24

RISK OF DISEASE PROGRESSION AT DIAGNOSIS OF MEN WITH PROSTATE CANCER, SOUTH AUSTRALIA AND VICTORIA

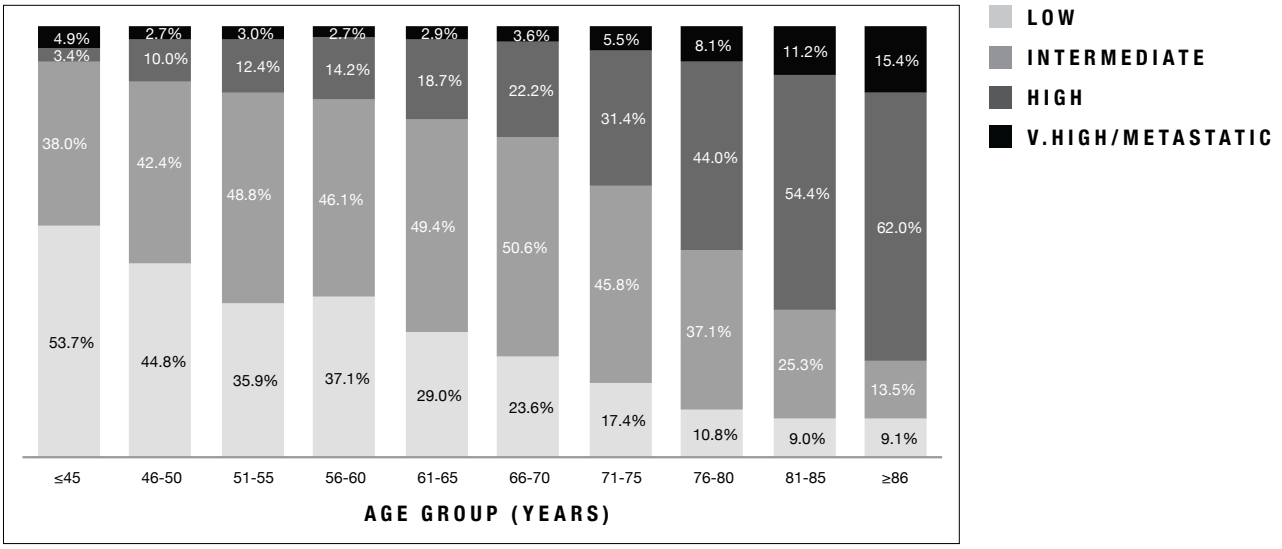
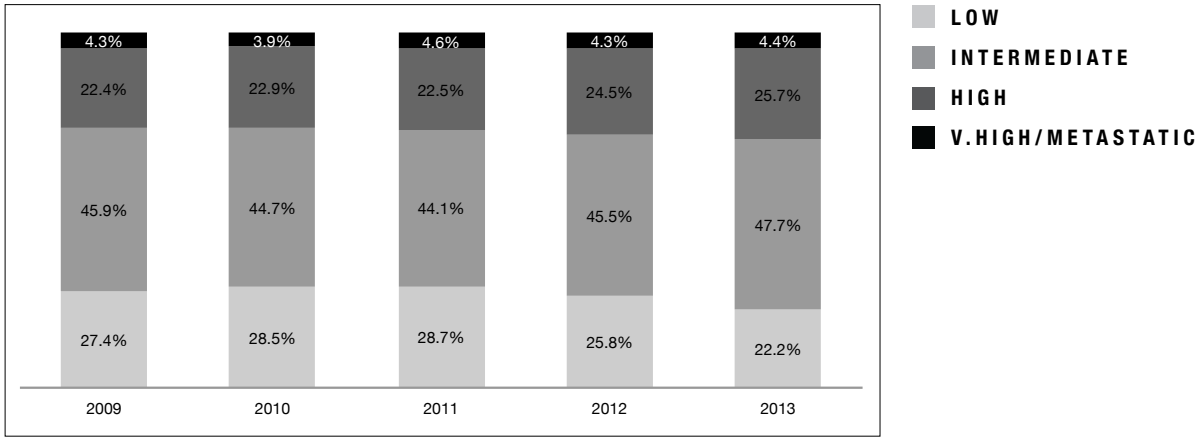


Figure 25 shows an increasing trend of intermediate- and high-risk disease at diagnosis for men from the combined PCOR-SA-PCCOC and PCOR-Vic. This increase may be the result of decreased screening which might result in men being diagnosed with more advanced disease.

FIGURE 25

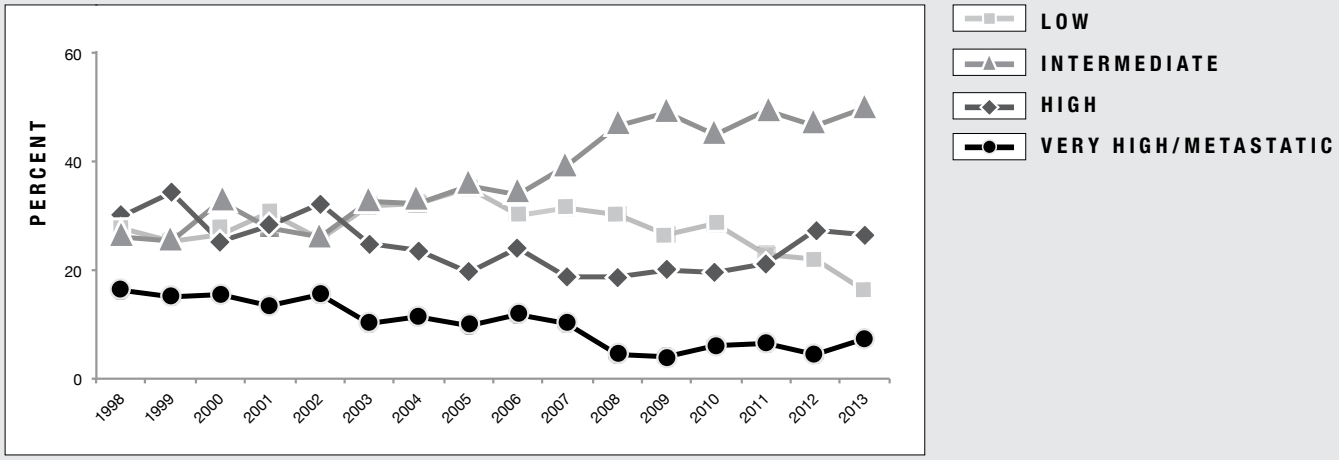
RISK OF DISEASE PROGRESSION OF MEN AT DIAGNOSIS BY YEAR OF DIAGNOSIS, SOUTH AUSTRALIA AND VICTORIA



Data from South Australia also show that there has been a substantial increase in the proportion of men classified as having intermediate-risk disease at diagnosis, from <30% in 1998–2000 to 50% in 2011–13 (Figure 26). There has been a corresponding decrease in the proportion classified as having low risk disease. In addition, the proportions classified as having high- or very high–risk metastatic disease have declined during the entire period. However, trends suggest a recent upturn in high-risk disease. This may be because of increased use of diagnostic imaging e.g. MRI scans which can more easily detect extra-prostatic disease. Having extra-prostatic disease will assign men to a clinical stage of T3a, which puts a man in a high risk group for disease progression (see Appendix A).

FIGURE 26

TRENDS IN RISK GROUPS FOR SOUTH AUSTRALIA MEN, 1998–2013



Notes: 1. Based on Gleason grade and prostate-specific antigen only when clinical stage was not reported.

TRENDS IN SURVIVAL

Overall prognosis is very good for men diagnosed with localised prostate cancer. Trends from South Australia indicate significant improvements in prostate cancer survival and in overall survival over time. Five-year prostate cancer survival has improved from 84% for men diagnosed in 1998–2000 to 96% for men diagnosed in 2010–13. Importantly, men diagnosed with prostate cancer have an equal or greater chance of dying from other causes than from their cancer.

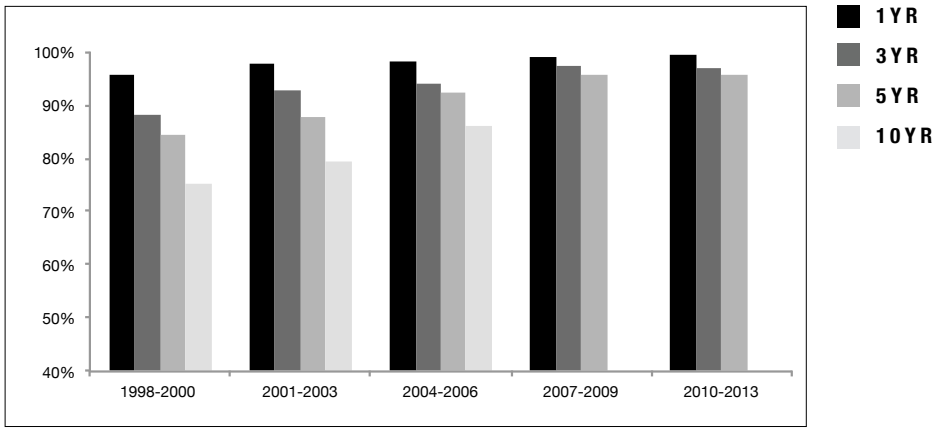
Prostate cancer–specific survival

Figure 27 shows the proportion of men who did not die from prostate cancer (i.e. survival) at 1, 3, 5 and 10 years after diagnosis for different time periods.

Prostate cancer–specific survival has improved significantly over the past 15 years. These trends likely reflect a number of things. Firstly, it likely reflects the impact of screening which has detected disease that might otherwise never have been detected. Detection of prostate cancer through screening has added a large number of "years with disease" to the statistics, thereby improving the survival statistics. Secondly, identification of earlier stage disease has enabled initiation of earlier treatment with concomitant survival benefit. Thirdly, improved survival may also reflect improvements in the management of prostate cancer during this 15-year period.

FIGURE 27

TRENDS IN PROSTATE CANCER–SPECIFIC SURVIVAL FOR SOUTH AUSTRALIAN MEN DIAGNOSED IN DIFFERENT PERIODS, 1998–2013



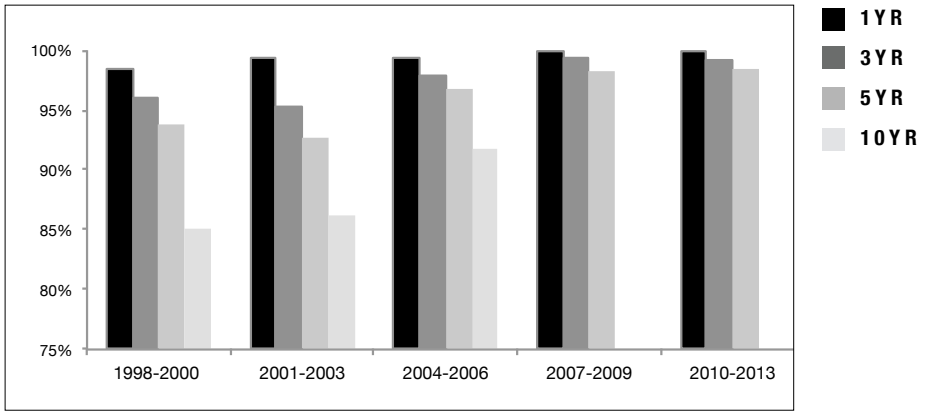
Disease-free survival following curative treatment

Figure 28 shows trends in disease-free survival following curative treatment for prostate cancer (i.e. radical prostatectomy or radiotherapy with curative intent) for men in the PCOR-SA-PCCOC. Disease-free survival is considered to be living free of evidence of disease recurrence. Recurrence is indicated by increased PSA levels after prostatectomy or radiotherapy (known as biochemical recurrence), or evidence of metastatic disease or death from prostate cancer. These analyses only included those who had curative treatment (4189 men), since delayed and non-curative approaches are aimed at monitoring signs of disease progression rather than removing prostate cancer.

Trends show significant improvement in disease-free survival over time, meaning that there were fewer cases of treatment failure over time or that the time to recurrence has increased, or both.

FIGURE 28

TRENDS IN DISEASE-FREE SURVIVAL FOR SOUTH AUSTRALIAN MEN DIAGNOSED IN DIFFERENT PERIODS, 1998–2013



PATTERNS OF CARE

KEY MESSAGES

THE MANAGEMENT OF PROSTATE CANCER IS COMPLEX.	ACTIVE SURVEILLANCE IS AN APPROPRIATE APPROACH FOR MANY MEN WITH LOW-GRADE PROSTATE CANCER.	PROSTATECTOMIES ARE BECOMING MORE COMMON AS THE FIRST CHOICE FOR CURATIVE TREATMENT.	THERE HAS BEEN A DECLINE IN THE USE OF ADT AS A FIRST-LINE TREATMENT.

Management of prostate cancer is complex and depends on patient factors such as personal preferences, lifestyle, existing comorbidities, distance to treatment centres and age; and also on disease characteristics such as stage of the disease at diagnosis. Treatment options include active surveillance, watchful waiting, surgery, radiotherapy, brachytherapy and ADT, and the decision on which treatment to use depends largely on stage of disease at diagnosis. Chemotherapy may be provided for palliative treatment of late-stage prostate cancer.

Research shows that active surveillance is an appropriate approach for many men with low-risk disease compared with having immediate invasive treatment.[32] The Prostate Cancer Research International Surveillance (PRIAS) project was initiated in 2006 to describe patterns of care for men on active surveillance and provide guidance on the active surveillance regimen.[33] Active surveillance aims to individualise the management of early prostate cancer by selecting only those men with cancer that is at risk of spreading for curative treatment.

IMPORTANCE OF PATTERNS OF CARE

Current Australian and international evidence-based guidelines recognise a wide variety of treatment options that aim to cure localised prostate cancer:

- surgery (radical prostatectomy, which might be open radical prostatectomy, laparoscopic prostatectomy or robot-assisted laparoscopic prostatectomy)
- external-beam radiation therapy
- brachytherapy
- ADT by itself offers survival benefit but is not generally considered curative.

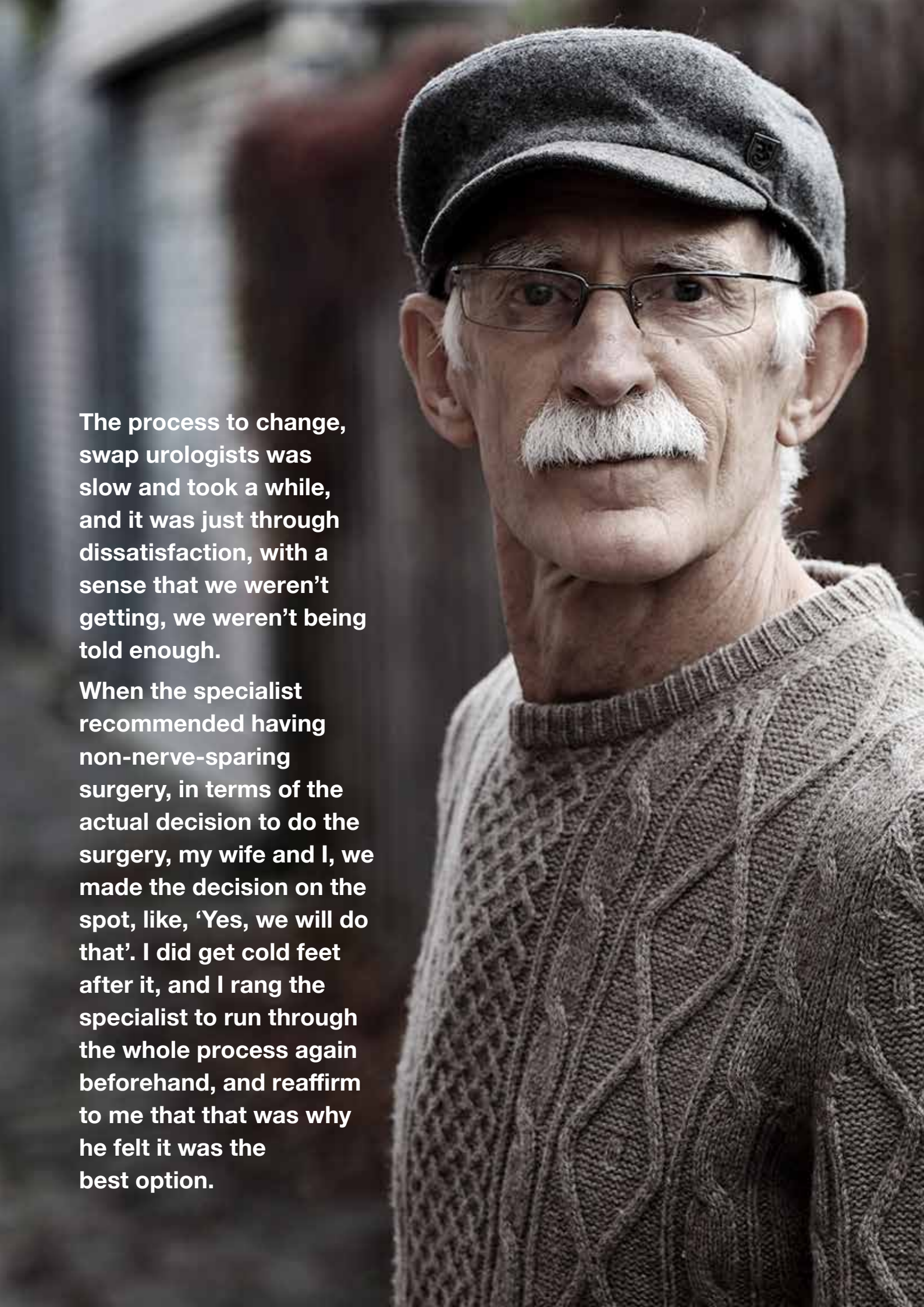
Patterns-of-care data provided by our prostate cancer registries provide fundamental information that is not – perhaps surprisingly – available from other sources. The data are critical at all levels of health care, from the individual men, to government planners and funders. It is impossible for any of these people to decide where they should be going without a good understanding of where they are now. This is what understanding patterns of care can provide.

For men with prostate cancer

All treatment options are different in the nature of the procedure for the men, the potential short and long-term side effects, and in some cases, cost (some men have out-of-pocket expenses that can create financial hardship and distress[34]). It is this variation and the inevitable choices for patients, clinicians, health service institutions, policy makers and funders in a setting of rapid evolution of treatments that make accurate timely record of the patterns-of-care so important.

For men facing the choice of the best treatment, knowledge of the contemporary patterns-of-care provides them with an understanding of the full range of options available. There is evidence that men with localised prostate cancer disproportionately select the treatment according to the type of specialist they consult regarding treatment. If they see a radiation oncologist, they are more likely to undergo radiotherapy, and if they see a urologist, they are more likely to have surgery. For this reason, it is important that men are informed of the treatment options, and the risks and benefits of each approach[35].

The Gippsland study showed that decision making by men was influenced by various factors, including their specialist's recommendations, their knowledge of what had happened to people they knew who had had cancer, and their own preferences for minimising side effects or aggressive treatments. Some changed doctors until they were satisfied.



The process to change, swap urologists was slow and took a while, and it was just through dissatisfaction, with a sense that we weren't getting, we weren't being told enough.

When the specialist recommended having non-nerve-sparing surgery, in terms of the actual decision to do the surgery, my wife and I, we made the decision on the spot, like, 'Yes, we will do that'. I did get cold feet after it, and I rang the specialist to run through the whole process again beforehand, and reaffirm to me that that was why he felt it was the best option.

For clinicians

The patterns of care also provide insight for clinicians. The population base for these prostate cancer registries allows an overview of the full range of practice in regions, and can provide an understanding that is not easily available from personal clinical experience.

For healthcare organisations, funders and policy makers

Health service institutions, funders and policy makers each benefit from accurate and timely descriptions of the patterns of care for planning purposes.

Funders and policy makers are in a position to consider a wider range of factors to form a view as to what patterns of care they fund and what support for a population should look like. These factors include:

- financial or economic data and constraints
- population and epidemiological trends
- current structural and organisational arrangements
- expert evidence-based pronouncements on treatment options
- community opinion
- workforce considerations

The patterns of care available from prostate cancer quality registries allow a gap analysis between the care that funders and policy makers think ought to be provided and what actually is provided.

PRIMARY TREATMENT CHARACTERISTICS

Table 2 summarises primary treatment characteristics in men with prostate cancer diagnosed between 2009 and 2013 in South Australia and Victoria. A majority of men (45%) underwent surgery (prostatectomy), followed by radiotherapy (23%). Approximately 19% of men were under either watchful waiting or active surveillance.

TABLE 2

PRIMARY TREATMENT CHARACTERISTICS OF MEN WITH PROSTATE CANCER DIAGNOSED IN SOUTH AUSTRALIA AND VICTORIA, 2009–13

TREATMENT TYPE	PROPORTION OF MEN (%)
Surgery	45
Radiotherapy	23
Androgen deprivation therapy	7
Watchful waiting/active surveillance[a]	19
Other	6

a For simplicity, watchful waiting and active surveillance were grouped together for this study.

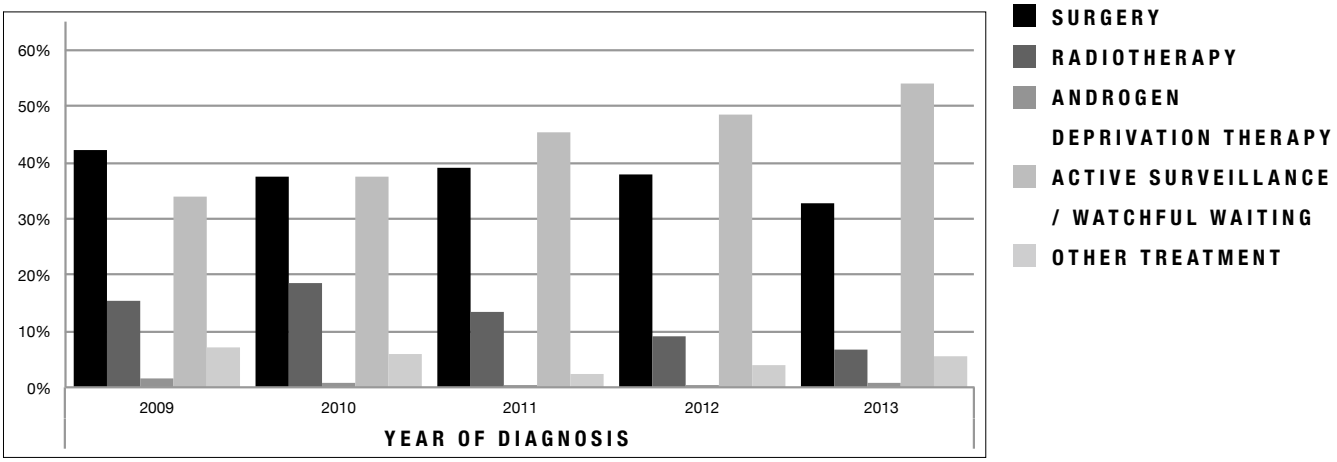
Primary treatment type by risk of the disease progression

Data for the PCOR-SA-PCCOC and PCOR-Vic combined show that the type of primary treatment varied according to disease risk groupings. Figure 29 shows that there were more men in the low-risk category who underwent active surveillance or watchful waiting between 2009 and 2013 (34% in 2009 to 54% in 2013). Most men with intermediate-risk disease had surgery. Radiotherapy and surgery remains to be the most common treatments for men with high-risk disease. There is an increasing trend in radiotherapy treatment among men with very high–risk or metastatic disease. The majority of men with high-risk or metastatic disease received ADT.

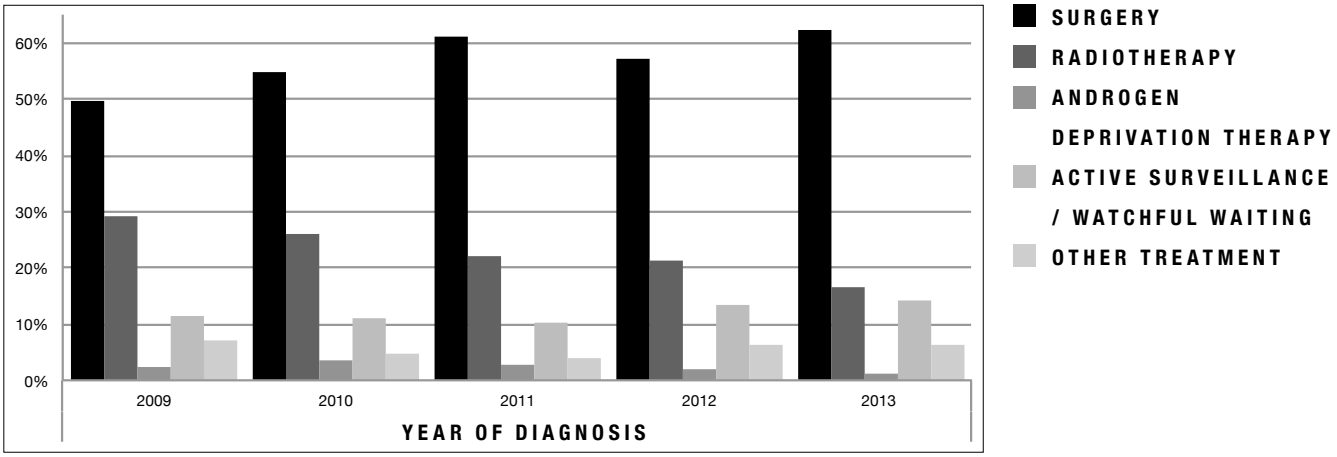
FIGURE 29

PRIMARY TREATMENT CHARACTERISTICS BY PROSTATE CANCER RISK GROUPS, SOUTH AUSTRALIA AND VICTORIA, 2009–2013

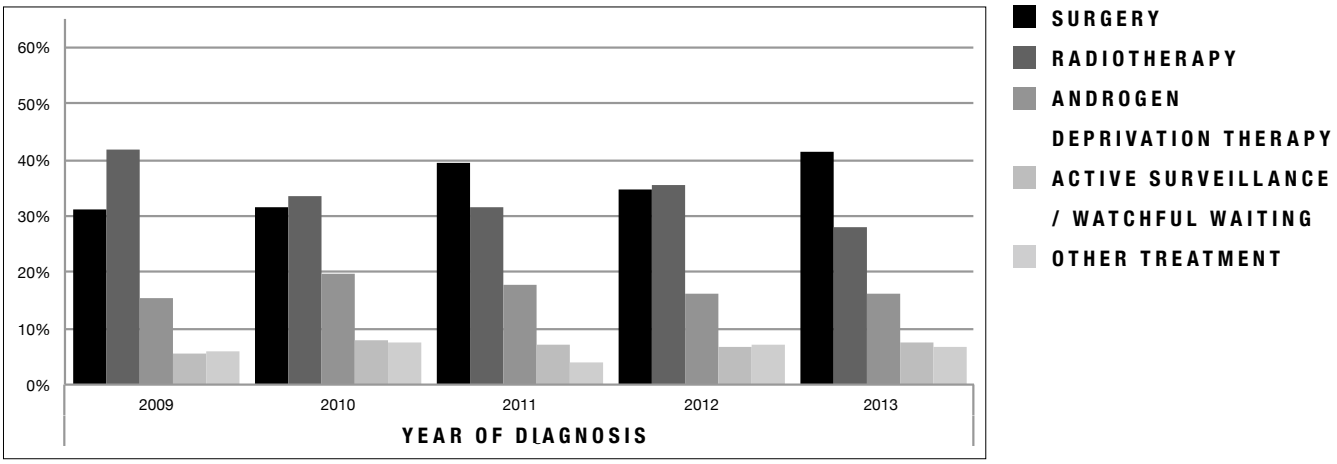
LOW-RISK GROUP



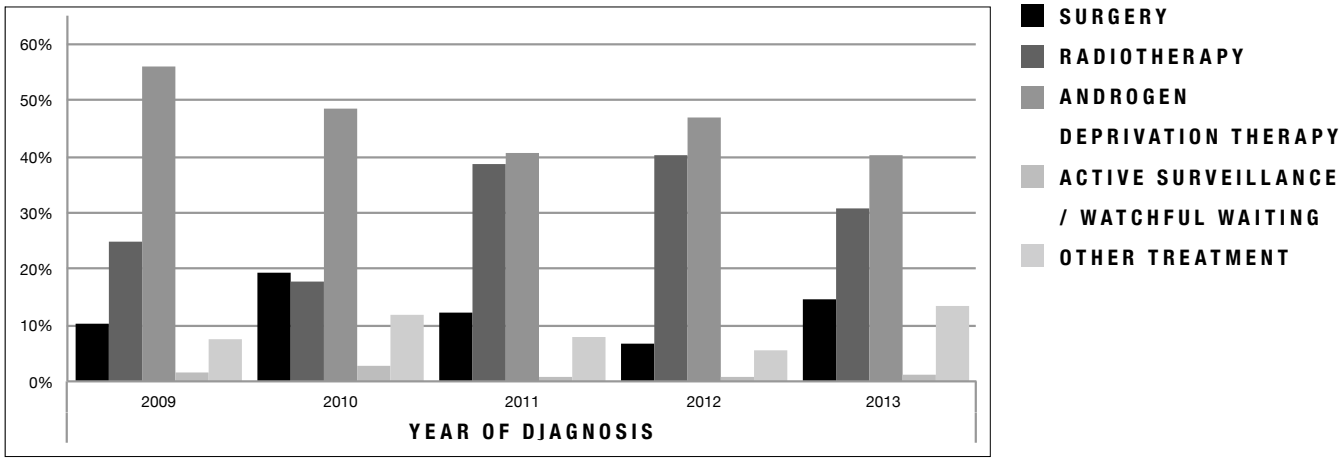
INTERMEDIATE-RISK GROUP



HIGH-RISK GROUP



VERY HIGH-RISK OR METASTATIC GROUP



Trends in prostate cancer treatment

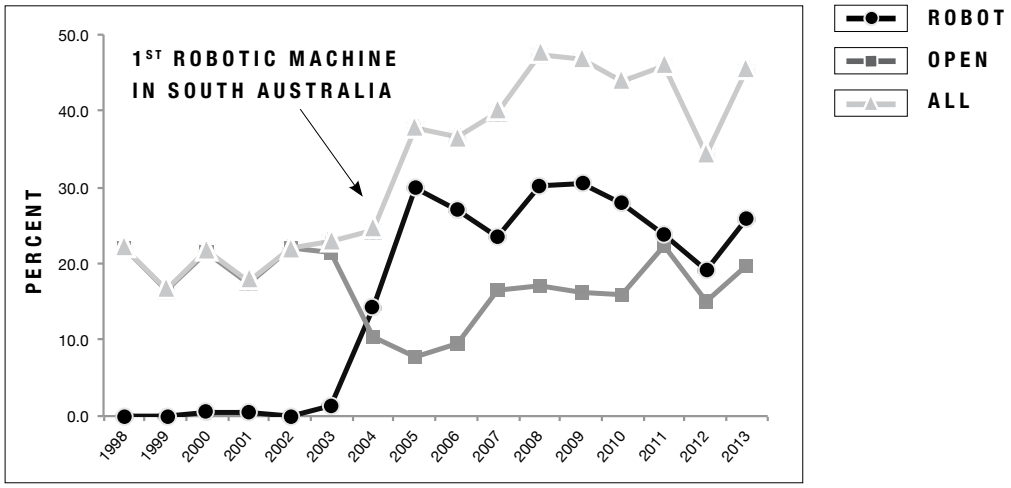
Figure 30 shows trends in primary treatment for prostate cancer among men recorded on the PCOR-SA-PCCOC during the longer term. These trends indicate that there has been an increase in the proportion of men undergoing radical prostatectomy – from 20% in 1998–2000 to about 40% in 2010–12. Robot-assisted surgery became available in 2004 and is now used in more than 50% of prostatectomies performed in the PCOR-SA-PCCOC cohort.

The use of radiotherapy as the primary treatment has been relatively stable from 1998 to 2013 (Figure 30). Among men undergoing radiotherapy, between 15 and 20% had brachytherapy. Brachytherapy became available in South Australia from around 2003.

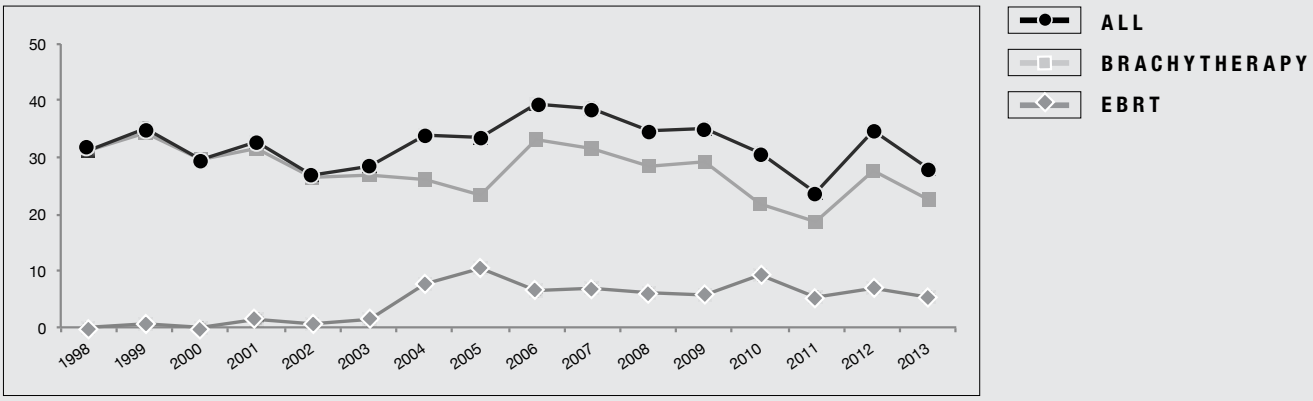
FIGURE 30

TRENDS IN CURATIVE TREATMENT (SURGERY AND RADIOTHERAPY) AS PRIMARY TREATMENT FOR PROSTATE CANCER FOR SOUTH AUSTRALIAN MEN, 1998–2013

RADICAL PROSTATECTOMIES



RADIOTHERAPY



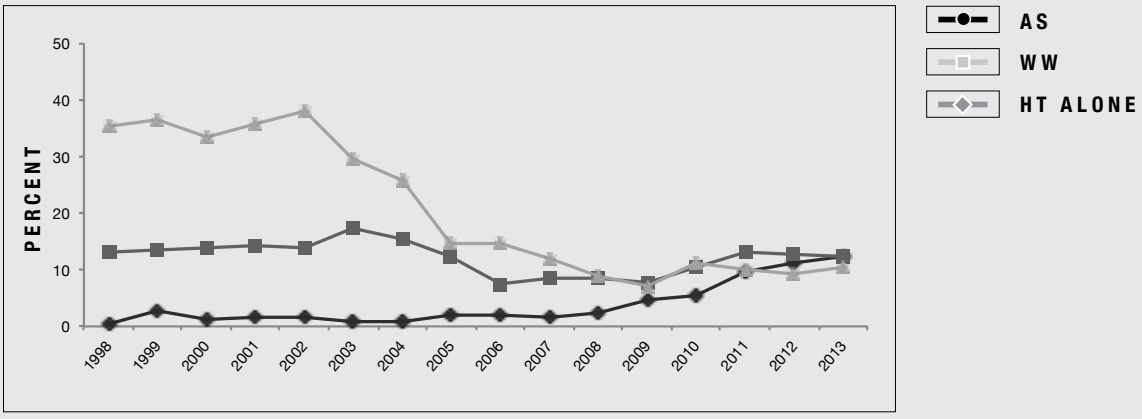
EBRT = external beam radiotherapy

Among the PCOR-SA-PCCOC cohort, there has been a substantial decline in the use of ADT as the primary management approach (Figure 31). This is consistent with international trends, and may be because of the decrease in the proportion of men who are diagnosed with or develop advanced prostate cancer over time, as ADT is more commonly used in advanced disease.

There has been a recent increase in active surveillance as a reported treatment option, although the proportion of men using this treatment option was still relatively low in 2013 in South Australia.

FIGURE 31

TRENDS IN DELAYED (ACTIVE SURVEILLANCE) AND NON-CURATIVE (WATCHFUL WAITING AND ADT) APPROACHES AS PRIMARY TREATMENT FOR PROSTATE CANCER FOR SOUTH AUSTRALIAN MEN, 1998–2013



ADT = Androgen deprivation therapy; AS = active surveillance; WW = watchful waiting

Table 3 shows changes in primary treatment for prostate cancer among men diagnosed in 1993 recorded in the Victorian Cancer Registry compared to with men diagnosed between 2009 and 2013 recorded by the PCOR-Vic. Compared to with the 1993 Victorian patterns of management, the proportion of men treated with surgery between 2009 and 2013 has increased from 14% to 47%. This increasing trend was also shown in men treated with radiotherapy (11% to 22% over the same period). We identified a 6-fold decline in ADT use as front-line treatment for prostate cancer compared with the 1993 Victorian Cancer Registry study (39% to 6%).

TABLE 3

PRIMARY TREATMENT FOR PROSTATE CANCER DIAGNOSED IN VICTORIA, 1993 AND 2009–2013

	DIAGNOSED IN 1993	DIAGNOSED IN 2009 - 2013
SOURCE OF DATA	**VICTORIAN CANCER REGISTRY[36]**	**VICTORIAN PROSTATE CANCER OUTCOMES REGISTRY**
Number of men	1038	9910
Primary treatment		
Surgery	14%	47%
Radiotherapy	11%	22%
Androgen deprivation therapy (ADT)	39%	6%
Active surveillance or watchful waiting	36%	22%

TIME FROM DIAGNOSIS TO INITIAL TREATMENT

Among South Australian and Victorian men diagnosed in 2009–13, the median number of days (interquartile range is shown in brackets) between diagnosis and primary treatment (excluding active surveillance/watchful waiting) according to risk group were:

- 119 days (63–222) for men with low-risk disease
- 80 days (48–137) for men with intermediate-risk disease
- 49 days (29–96) for men with high-risk disease
- 31 days (12–72) for men with very high–risk or metastatic disease.

Trends of median days (interquartile range) in time to the initial treatment by year and National Comprehensive Cancer Network (NCCN) risk groups are shown in Figure 32. The median number of days between diagnosis and primary treatment (excluding active surveillance or watchful waiting) is indicated by the horizontal line that runs across the box. The lower and upper body of the box represents 25th and 75th percentiles of the number of days (interquartile range).

The data show that:

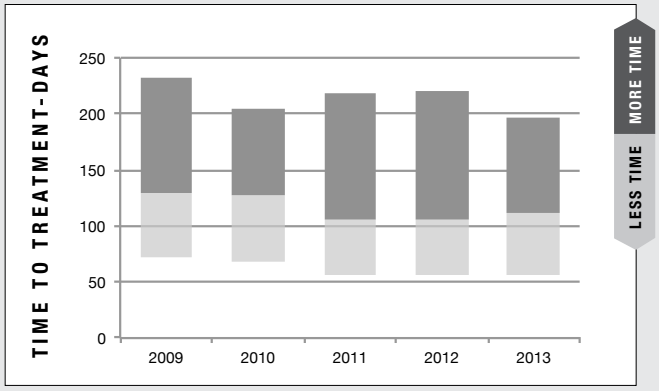
- average time to treatment in the low-risk disease category dropped from 130 days in 2009 to 111 days in 2013
- average time to treatment in the intermediate-risk disease category dropped from 98 days in 2009 to 71 days in 2013
- average time to treatment in the high-risk disease category dropped from 60 days in 2009 to 42 days in 2013
- average time to treatment in the very high-risk or metastatic disease category varied from 36 days in 2009 and 28 days in 2013.

Overall, time to treatment has become shorter. This may mean that there is better access to treatments, including more healthcare organisations offering cancer services and emerging medical technologies.

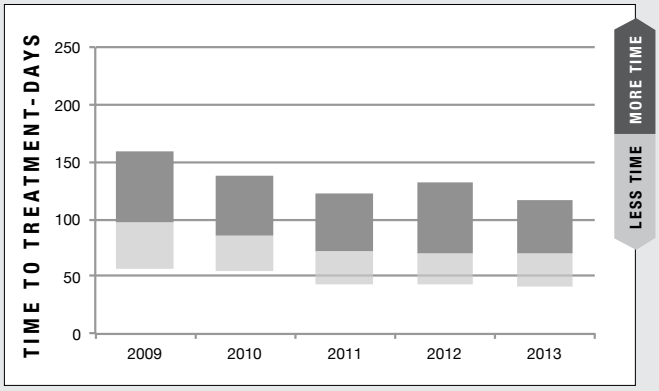
FIGURE 32

MEDIAN NUMBER OF DAYS (INTERQUARTILE RANGE) BETWEEN DIAGNOSIS AND INITIAL TREATMENT IN PATIENTS IN DIFFERENT NCCN RISK PROGRESSION CATEGORIES, 2009–13

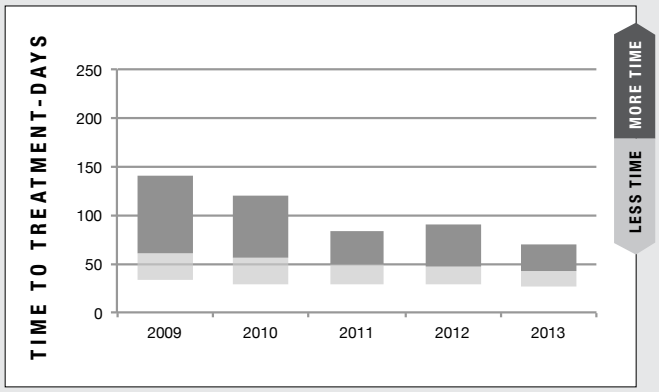
LOW-RISK DISEASE



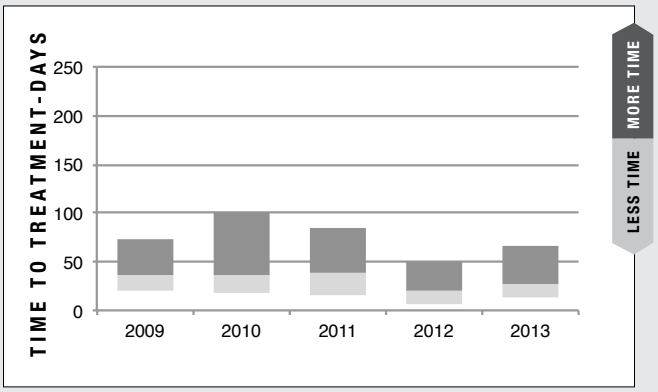
INTERMEDIATE-RISK DISEASE



HIGH-RISK DISEASE



VERY HIGH–RISK OR METASTATIC DISEASE



ADVANCING THE USE OF REGISTRIES

KEY MESSAGES

BENCHMARKING INFORMATION PROVIDED BY CLINICAL QUALITY REGISTRIES PROVIDES A STRONG IMPETUS FOR CLINICIANS AND HOSPITALS TO CONTINUOUSLY IMPROVE CLINICAL QUALITY AND QUALITY OF CARE, WHICH IMPROVES HEALTH OUTCOMES FOR PATIENTS.

THE PCOR-VIC HAS BEEN PROVIDING CLINICIANS AND HOSPITALS WITH ONGOING FEEDBACK ON THEIR PERFORMANCE. THESE REPORTS HAVE ALLOWED THEM TO COMPARE THEIR RESULTS WITH THOSE OF OTHER PROVIDERS, VISUALISE VARIATION IN COMPLIANCE WITH INDICATORS AND STIMULATE 'COMPETITION' TO IMPROVE OUTCOMES OF MEN WITH PROSTATE CANCER.

BENCHMARKING REPORTS SUCH AS THOSE PROVIDED BY PCOR-VIC HAVE FACILITATED A CYCLE OF CONTINUOUS QUALITY IMPROVEMENT IN PROSTATE CANCER CARE IN VICTORIA.

HOW AND WHY DATA ARE REPORTED BACK TO HOSPITALS AND CLINICIANS

One of the most effective ways of improving quality of care is to compare findings and benchmark clinical outcomes across health service providers. This fosters competition and a desire to be the best.[37] The PCOR-ANZ is committed to providing feedback to hospitals and doctors, comparing their performance and management of prostate cancer with their peers. During 2015, the PCOR-ANZ Steering Committee and registry leaders in Ireland have developed a set of quality indicators (QIs). The final agreed-to QIs for PCOR-ANZ are: [38]

QI-1: Number of patients treated at institution per year (by treatment).

QI-2: Positive surgical margins rate after radical prostatectomy for organ-confined pathological T2 disease.

QI-3: Prostate-specific antigen (PSA) level recorded at diagnosis.

QI-4: Documentation of clinical T stage in the medical record.

QI-5: Active surveillance or watchful waiting for men with low-risk disease.

QI-6: Evidence that patients in the high-risk disease group received active treatment.

QI-7: Time from biopsy-confirmed diagnosis to first treatment (risk adjusted).

QI-8: 5-, 10- and 15-year overall survival.

QI-9: Clinical and/or biochemical disease-free survival after primary treatment by radiation therapy or radical prostatectomy.

QI-10: Patient assessment of urinary incontinence and obstruction, and erectile and bowel dysfunction.

QI-11: Patient assessment of urinary, sexual and bowel bother.

QI-12: Rate of in-hospital death from surgical complications.

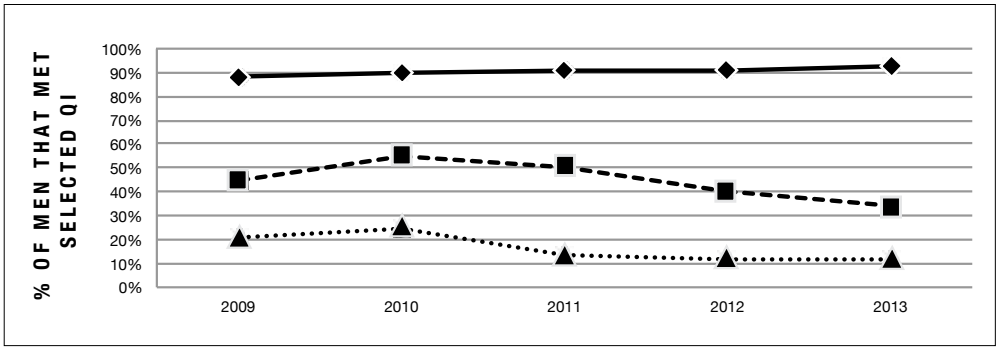
QUALITY OF CARE ACHIEVEMENTS IN VICTORIA

The PCOR-Vic provides clinicians and hospitals with feedback on their performance every 6 months. These benchmarking reports allow them to monitor and compare their results with those of other providers. QIs are reported in a number of ways. For example, patients who are identified as meeting QI-5 and QI-6 selection criteria (see above for definitions) are alerted to their treating/diagnosing clinicians and hospitals. QI-2 and QI-11 are reported to hospitals and clinicians in a form of risk-adjusted funnel plots. These funnel plots are de-identified in regard to other clinicians and hospitals. They provide a visual representation of how each clinician and hospital compares to its peers. (To read more about funnel plots and the data they provide, see Appendix E). Units whose performance has deviated below par have been seen to engage outside consultants to identify areas for improvement.

In 2015, an evaluation was performed on the process-of-care indicators collected and reported by the PCOR-Vic (QI-2, QI-5 and QI-6). These three indicators were selected because the hospital and clinician reports focused heavily on reporting against these indicators and benchmark reports were provided comparing their results against peers. Outcome indicators were not benchmarked. Survival and recurrence rates were not benchmarked because rates were too low to be meaningful. Quality of life was not benchmarked because the intent was to provide clinicians and hospitals with an understanding of men who had poor quality of life so that they could be followed up. The science of benchmarking quality of life is not well advanced at this point in time. Results for the process-of-care indicators are outlined in Figure 33 and described below.

FIGURE 33

TREND IN QUALITY CARE IMPROVEMENT IN VICTORIA



QI = quality indicator

Positive surgical margins for organ-confined pathological T2 disease

Men with low-risk group who underwent prostate cancer treatment

Men with high and locally advanced disease group who underwent prostate cancer treatment within 12 months post diagnosis

QI-2: POSITIVE MARGINS RATE AFTER RADICAL PROSTATECTOMY FOR ORGAN-CONFINED PATHOLOGICAL T2 DISEASE

Positive surgical margin status is important for evaluating quality of care in the management of prostate cancer because it has been associated with increased risk of biochemical recurrence after radical prostatectomy.[39] It is also a significant predictor of the need for additional radiotherapy and/or androgen deprivation therapy, even taking stage of disease into consideration.[40]

The percentage of positive surgical margins for men with organ-confined (pT2) prostate cancer in 2009 was 24% and had climbed up slightly by 3.4% in 2010 (see Appendix A for information about tumour staging). Significant decline was first shown in 2011, when the percentage of pT2 positive surgical margins after prostatectomy was reduced by 7%. Further significant improvements were shown for radical prostatectomies performed between 2012 and 2013, where positive surgical margins remained steady at 12% for both years.

QI-5: ACTIVE SURVEILLANCE OR WATCHFUL WAITING FOR MEN WITH LOW-RISK DISEASE

There is now good evidence that active surveillance is an appropriate approach for many men with low-risk prostate cancer compared with having immediate invasive treatment.[41] The PRIAS project was initiated in 2006 to describe patterns of care for men on active surveillance and provide guidance on the active surveillance regimen.[42] The Urological Society of Australia and New Zealand has formally endorsed the PRIAS criteria for active surveillance, and has been supporting the recruitment of patients for PRIAS since 2010.[43]

Overall, there has been a downward trend in the percentage of men with low-risk disease who undertook active treatment (PRIAS non-compliance) between 2009 and 2013. The mean percentage of PRIAS non-compliance decreased from 45% in 2009 to 40% and 34% in 2012 and 2013.

QI-6: EVIDENCE THAT PATIENTS IN THE HIGH-RISK DISEASE GROUP RECEIVED ACTIVE TREATMENT

The standard approach to treatment of high-risk prostate cancer disease (to increase the survival rates post-diagnosis) is prompt initiation of surgery, or radiation therapy with androgen deprivation therapy.[44] Delay from the date of biopsy to the date of surgery, particularly for high-risk men, may be associated with poorer outcomes.[45]

There was a gradual increase in the percentage of men with high-risk and locally advanced disease having treatment within the first 12 months of their prostate cancer diagnosis during the past 5 years. 88% of men in these risk disease groups received immediate active treatment when the registry commenced in 2009 and there was a trend for this percentage to continue to climb (89%, 91%, 91% and 93% in 2010, 2011, 2012 and 2013, respectively).

The overall improvements we report across the three QIs are likely to be because of a combination of factors, including:

- an improved knowledge and acceptance of management for low- and high-risk prostate cancer
- technical advances and refinements in surgical techniques
- an ongoing QI program by PCOR-Vic aimed at monitoring and improving compliance with evidence-based prostate cancer guidelines.

FUTURE OF PROSTATE CANCER CARE

This report highlighted some very positive findings for men diagnosed and living with prostate cancer. Overall, the prognosis for men diagnosed with prostate cancer is very good. Disease-free survival is increasing, as is prostate cancer specific survival.

There are some less positive findings as well. The side effects from treatment – such as bowel, urinary and sexual bother – are not just short-term effects, and some men are experiencing the effects these have on quality of life well after the treatment finishes. Some men are also having trouble coping with mental and physical wellbeing after diagnosis and treatment. However, changes in patterns of care appear to be starting to reflect these concerns. More men diagnosed with low-risk disease are undergoing active surveillance or watchful waiting, rather than undergoing radical, curative treatment prior to it being necessary. Further, the use of ADT as a first-line treatment was diminishing, thus sparing more men from some of the unnecessary negative side effects of this treatment.

Registries are important for improving cancer care in Australia. Large datasets can reveal important trends, and can be used to set benchmarking standards for clinicians and hospitals so they can see how well they are performing against other similar units in the country. The PCOR-ANZ will provide regular and risk-adjusted reports to clinicians and hospitals decision makers. Twelve quality indicators have been set for Australia, which in turn will drive 'competition', resulting in improvements in prostate cancer care and outcomes for men.

The PCOR-ANZ is still in its implementation phase, with prospective data to be reported publicly in 2017. The PCOR-ANZ aims to follow men for 5-, 10- and 15-years after diagnosis to better understand their prostate cancer journey, as well as issues such as management of advanced disease through use of ADT and chemotherapy. With longer-term follow-up through PCOR-ANZ, research can begin to focus on treatments and outcomes for men who develop more advanced disease over the longer term. The registry will also provide data for treatment options for men with low-risk or less-advanced cancer.

The PCOR-ANZ team are working together to ensure the long-term sustainability of the registry. The project will identify men who are not doing so well throughout their journey, to provide additional care and support to improve their health outcomes. The project has already revealed valuable information, and will continue to improve outcomes for all men diagnosed with prostate cancer and improve treatment decision making in the short- and long-term future.

APPENDIX A
NCCN RISK CATEGORIES

Table A1 provides an outline of the variables used to derive the National Comprehensive Cancer Network (NCCN) risk categories.[46] These measures have been validated and extensively used when evaluating prostate cancer outcomes.[47]

TABLE A1
NCCN RISK CATEGORIES

Prognostic Group: Primary tumour clinical stage only (T)		PSA level (ng/mL)		Gleason score		NCCN Risk categories
T1	Clinically in-apparent tumour neither palpable nor visible by imaging	<10		2-6		Low risk disease
T1a	Tumour incidental histological finding in 5% or less of tissue resected	AND		AND	=	
T1b	Tumour incidental histological finding					
T1c	Tumour identified by needle biopsy					
T2	Tumour confined within prostate					
T2a	Tumour involved one-half of one lobe or less					
T2b	Tumour involved more than one-half of one lobe but not both lobes	10-20		7		Intermediate risk disease
T2c	Tumour involves both lobes	OR		OR	=	
T3	Tumour extends through the prostate capsule	>20				High risk disease
T3a	Extracapsular extension (unilateral or bilateral)	OR		OR	=	
T3b	Tumour invades seminal vesicle(s)					Locally advanced/very high risk
T4	Tumour is fixed or invades adjacent structures other than seminal vesicles					
N1	Tumour has spread to nearby nodes					Metastatic disease
M1	Tumour has metastasized to other sites					

ng/mL = nanograms per millilitre; PSA = prostate-specific antigen
TNM score is a method used by the American Joint Committee on Cancer and derives a score from three components: T = rating of the size and extant of the tumour; N = reflects if the cancer has spread to the nearby nodes; and M = if the cancer has metastasised to other sites.

APPENDIX B
MOVEMBER FOUNDATION PROSTATE CANCER OUTCOMES STATEMENTS

MEN LIVING WITH PROSTATE CANCER CAN SAY:		INDICATORS	
A	My information, treatment, care and support needs have been met	A1	I had access to well-coordinated advice treatment and care
		A2	I made a well-informed treatment decision that I do not regret
		A3	I had access to the treatment of my choice
		A4	The practical support needs of my partner, family, caregivers and I have been met
B	I am physically well	B1	I have fully recovered from any urinary dysfunction that I had
		B2	My partner and I are satisfied with the level of sexual function
		B3	I have fully recovered from any bowel dysfunction that I had
		B4	My partner, family, caregivers and I are effectively managing any pain, fatigue, nausea and other symptoms experienced
C	I am mentally well	C1	My partner, family, caregivers and I are not depressed or anxious
		C2	My partner, family, caregivers and I know what to expect during and after treatment, including when and where to seek help if specific issues arise
		C3	My partner, family, caregivers and I are able to live a meaningful life in the community of our choice
		C4	I have accepted and am prepared for the possible consequences and possible outcomes of my cancer and my treatment(s)

APPENDIX C
REGISTRIES AND BACKGROUND DATA

REGISTRIES

The data sources for the results presented in this report are the Prostate Cancer Outcomes Registry-Victoria (PCOR-Vic), based at Monash University (Victoria), and the Prostate Cancer Outcomes Registry-South Australian Prostate Cancer Clinical Outcomes Collaborative (PCOR-SA-PCCOC) database, a multi-institutional clinical registry based at the Repatriation General Hospital in Adelaide.

The data items collected in both the Victorian and South Australian registries include:

- initial diagnosis and staging items
- prostate-specific antigen (PSA) levels at diagnosis, before each treatment, and at 12 and 24 months after diagnosis
- clinical examination results
- treatment details in the initial 24 months after diagnosis

Follow-up data include:

- clinical evidence of recurrence
- further biopsy events and reported pathology
- patient-reported symptoms and quality of life.

Prostate Cancer Outcomes Registry-Victoria

A pilot prostate cancer clinical registry (Vic-PCR) was established in 2008.[48] Its purpose was to collect information systematically on all men with prostate cancer to assess patterns of diagnosis, care and outcomes, and quality of care and outcomes, and investigate causes of variations in outcomes. Data on prostate cancer cases are currently collected from 33 metropolitan and regional public and private hospitals in Victoria. The registry currently contains data for more than 10,000 men with prostate cancer, and gathers data from about 75% of the newly diagnosed prostate cancer cases each year in Victoria. Registry recruitment is linked with mandatory notification of prostate cancer to the population-based Victorian Cancer Registry.

Prostate Cancer Outcome Registry - South Australian Prostate Cancer Clinical Outcomes Collaborative

The PCOR-SA-PCCOC was established in 1998 and initially included men with prostate cancer treated at one of the three major teaching hospitals in South Australia.[49] The database has been expanded more recently to include private treatment facilities.

The overall objective of the PCOR-SA-PCCOC is to evaluate the standard of care for men with prostate cancer in South Australia by monitoring patterns and outcomes of that care over time. The registry records clinical and demographic characteristics, clinical management, patient-reported outcomes, cancer recurrence and survival outcomes, with ongoing follow-up until death. The registry now follows more than 10,000 patients. In addition to the data items collected by the Vic PCR, SA-PCCOC collects PSA data, as well as patient-reported urinary and bowel symptoms, erectile function, and mental and physical wellbeing before and after treatment.

APPENDIX D
PATIENT-REPORTED OUTCOMES

SOUTH AUSTRALIAN DATA

In the South Australian registry, patient-reported outcomes were collected using validated surveys (self-completed postal survey) before treatment started (i.e. baseline) and at various time points after treatment (3–60 months).

The surveys included the Expanded Prostate Cancer Index Composite (26 items) (EPIC-26) tool, which measures the impact of treatment on physical function and on quality of life. Outcomes are described as mean scores in several domains: urinary function, sexual function, bowel function and hormonal symptoms. Functional scores for each subcategory range from 0 to 100, with a higher score indicating better functioning/fewer symptoms. These surveys also collect a measure of patient-reported health-related quality of life, using a tool known as the SF-12 Health Survey, which provides an indication of general physical and mental wellbeing. Again, higher scores indicate better physical or mental health.

Results presented in this report cover the period when the EPIC-26 survey was used, and include all surveys returned between 2009 and 2014. Since the majority of patients surveyed were those who underwent surgery, the analysis of South Australian patient-reported outcomes has been restricted to only those who had radical prostatectomy. Analysis includes more than 2800 returned surveys completed by around 1000 men who underwent prostatectomy.

The survey results presented in this report show changes in functional outcomes and quality of life from baseline across time after treatment for prostate cancer up to 5 years. Patterns reflect the average experience of men who responded to the survey at each time point.

VICTORIAN DATA

In Victoria, trained registry staff routinely collected patient-reported health-related quality of life (using the SF-12 Health Survey) and complications data from participating men, via a structured telephone interview at 12 and 24 months post-diagnosis. This was done as part of the clinical and research data collected by the Victorian Prostate Cancer Clinical Registry (Vic PCR). Staff used three questions from the EPIC-26 survey. Patient-reported outcomes will be collected in the future, at 12 and 24 months post-treatment, in alignment with international standards.

For the disease-specific quality of life, men were asked the following three questions relating to bowel, urinary and sexual bother:

- ‘How big a problem has your urinary function been for you during the past 4 weeks?’
- ‘How big a problem have your bowel habits been for you during the past 4 weeks?’
- ‘How big a problem has your sexual function or lack of sexual function been for you during the past 4 weeks?’

For each of the questions above, men were given an option from a 5-point ordinal response scale:

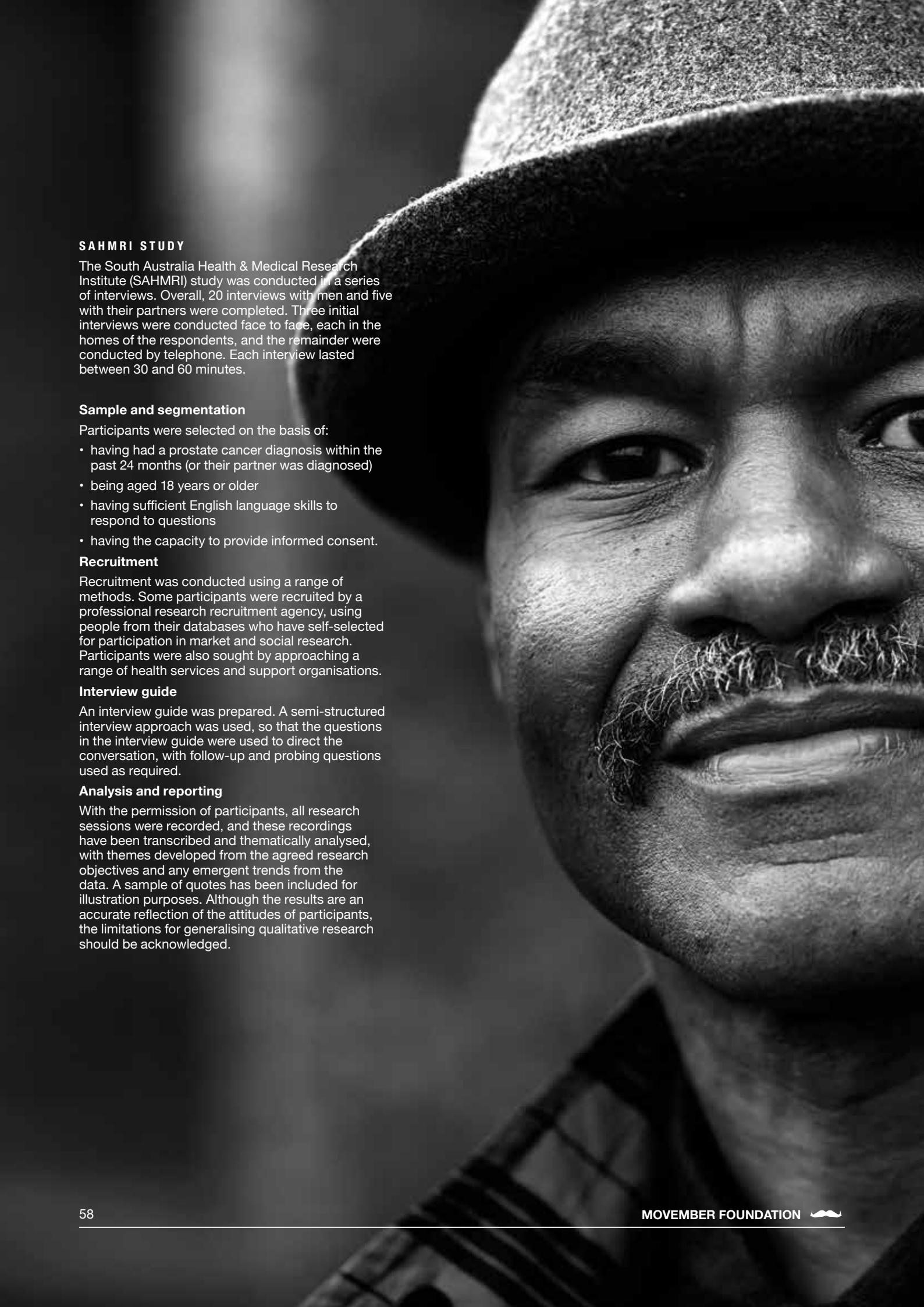
- ‘no problem’
- ‘very small problem’
- ‘small problem’
- ‘moderate problem’
- ‘big problem’.

These questions were asked in relation to outcomes after surgery (prostatectomy), radiotherapy and hormone treatments.

GIPPSLAND STUDY

Gippsland is located in south-eastern Victoria and covers more than 18% of Victoria’s total landmass. Some existing data show that men diagnosed in Gippsland have poorer 5-year survival rate than the rest of Victoria.

Research aimed to evaluate factors associated with poorer survival outcomes for men with prostate cancer in Gippsland compared with the rest of Victoria. To do this, the Prostate Cancer Health Outcomes Research Unit analysed data from Vic PCR. We also sought to understand the perceptions and experiences of prostate cancer diagnoses, treatment and care among men who have been diagnosed with prostate cancer and men who have not been diagnosed with prostate cancer, and to ascertain the perceptions of general practitioners (GPs) on these matters. Therefore, we interviewed men and GPs in regional and metropolitan Victoria.



SAHMRI STUDY

The South Australia Health & Medical Research Institute (SAHMRI) study was conducted in a series of interviews. Overall, 20 interviews with men and five with their partners were completed. Three initial interviews were conducted face to face, each in the homes of the respondents, and the remainder were conducted by telephone. Each interview lasted between 30 and 60 minutes.

Sample and segmentation

Participants were selected on the basis of:

- having had a prostate cancer diagnosis within the past 24 months (or their partner was diagnosed)
- being aged 18 years or older
- having sufficient English language skills to respond to questions
- having the capacity to provide informed consent.

Recruitment

Recruitment was conducted using a range of methods. Some participants were recruited by a professional research recruitment agency, using people from their databases who have self-selected for participation in market and social research. Participants were also sought by approaching a range of health services and support organisations.

Interview guide

An interview guide was prepared. A semi-structured interview approach was used, so that the questions in the interview guide were used to direct the conversation, with follow-up and probing questions used as required.

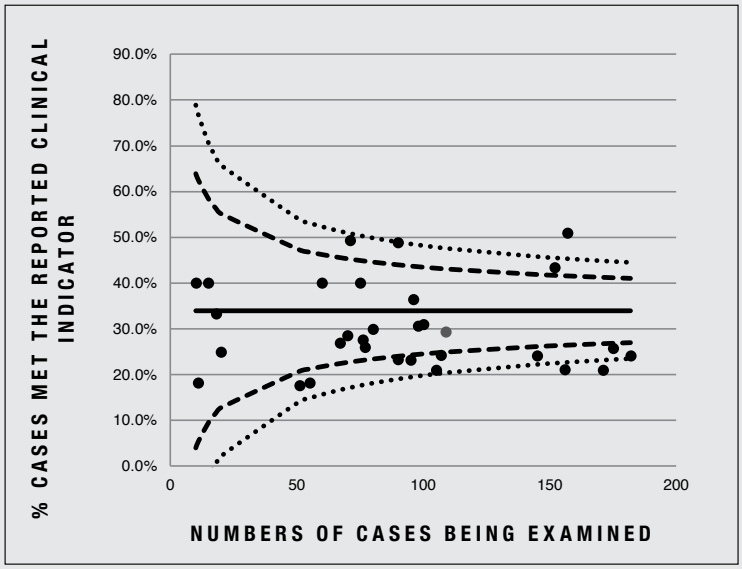
Analysis and reporting

With the permission of participants, all research sessions were recorded, and these recordings have been transcribed and thematically analysed, with themes developed from the agreed research objectives and any emergent trends from the data. A sample of quotes has been included for illustration purposes. Although the results are an accurate reflection of the attitudes of participants, the limitations for generalising qualitative research should be acknowledged.

APPENDIX E
INTERPRETING A FUNNEL PLOT

Benchmarking results are commonly presented in the form of funnel plots (see Figure A1), where results of a unit are compared with the risk-adjusted results from other similar units.

TABLE A1
NCCN RISK CATEGORIES



% cases met the reported clinical indicator (by hospital /clinician)

Pooled average % cases met the reported clinical indicator (for hospitals/ clinicains combined)

Lower 99.8% Limit

Upper 99.8% Limit

Lower 95% Limit

The horizontal axis (x-axis) measures the number of cases being examined. The vertical axis (y-axis) measures the percentage of cases that meet the reported clinical quality indicators.

A point estimate (black dot), which represents the percentage of observed cases, is then plotted for each clinician or hospital contributing to the registry. The larger number of cases (volume) notified to the registry, the further to the right will be its figure; the smaller the volume, the further to the left its black dot will be. The clinician's or hospital's own data are represented as a grey dot.

The black line represents the pooled average (%) observed cases for all clinicians/hospitals combined.

As sample numbers get larger, the closer to the pooled estimate they become, as represented by the convergence of dashed contour lines (themselves representing 5% and 1%, or 0.2% significance, respectively).

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