











ABOUT US

We are Australia's leading community-based organisation for prostate cancer research, awareness, and support. As the nation's predominant charity fund for Australian-based prostate cancer research, we exist to protect the health of existing and future generations of men in Australia and to improve quality of life for Australian men and families impacted by prostate cancer.

Our vision is a future where no man dies of prostate cancer and Australian men and their families get the support they need.

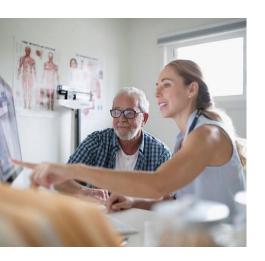
Our focus:

- 1. To be Australia's leading charity fund for Australian-based prostate cancer research.
- 2. To protect the health of existing and future generations of men in Australia.
- 3. To improve quality of life for Australian men diagnosed with prostate cancer.

Prostate cancer in Australia QUICK FACTS

- Most common cancer diagnosed in men
- 16,741 diagnoses per year, 3,152 deaths
- 220,000 men alive today after a diagnosis
- 1 in 6 will be diagnosed by age 85
- 95% five-year relative survival rate
- 24% higher risk of death in regional areas
- 67% of men diagnosed over age 65
- 15% of cases detected at Stages III or IV
- Number of cases set to rise 70% by 2040







Prostate Cancer Foundation of Australia Transforming and saving men's lives

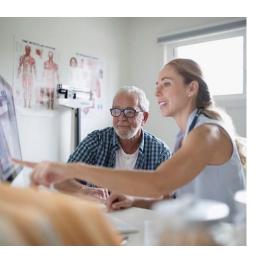
This report provides a brief overview of the activities delivered in 2020 and planned in 2021 by Prostate Cancer Foundation of Australia (PCFA). We are pleased to report we have significantly increased our reach in 2020, raising prostate cancer awareness and engaging the community in conversations to help save lives.

In 2019-20 we dedicated more than \$2M towards life-saving prostate cancer research, distributed 14,000 information packs to the community, supported 6,000 men in our Online Community, connected thousands of men in our Support Network, and delivered life-changing care to more than 12,000 *new* patients via our Specialist Nursing Service, while continuing our care for thousands of *existing* patients and their families.

By June 2021 we'll have 83 Prostate Cancer Specialist Nurses around Australia, and will begin recruiting new specialist nurses at 15 additional sites, in a service expansion that will ensure no man walks alone.

In March 2021 we'll also launch a new Prostate Cancer Specialist Telenursing Service, enabling all men and families to access expert care without having to leave home.



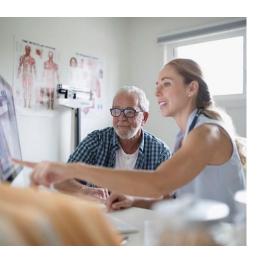




Prostate Cancer Foundation of Australia 2021 Advocacy Priorities

- 1. Review of the NHMRC-endorsed PSA Test Guidelines.
- 2. Action to support the approval of new medicines and treatments.
- 3. Public health awareness activity on prostate cancer risks and family history, via The STARGATE Project.
- 4. Improving engagement with men who have a high risk of prostate cancer, to raise their awareness of relevant risk factors.
- 5. Enhancing support for men with high-risk forms of prostate cancer, including advocacy for new prostate cancer research and treatment.





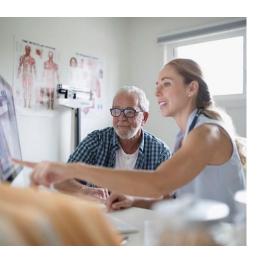


Prostate Cancer Foundation of Australia 2021 Service Priorities

- 1. Expansion of the Prostate Cancer Specialist Nursing Service.
- 2. Launch of a new Prostate Cancer Specialist Telenursing Service.
- 3. Growth of the Support Group Network, Ambassadors Program, and associated peer support innovations, such as MatesCONNECT.
- 4. Engagement of the community in our work through campaigns such as The Long Run and Big Aussie Barbie.
- 5. Strengthen community outreach through the distribution of evidence-based information, our magazine Blue Sky News, and other media.









The STARGATE Project Taking action today that can save lives tomorrow

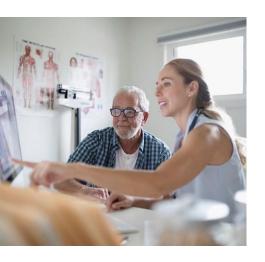
Why do men in regional areas face a 24% increased risk of dying from prostate cancer?

Why are rates of diagnosis <u>higher</u> in some areas?

Why are men more likely to be diagnosed with <u>more advanced</u> <u>disease</u> in regional and poor areas?

What local actions can we take <u>today</u> to improve outcomes for all Australian men tomorrow?







The STARGATE Project Taking action today that can save lives tomorrow

The STARGATE project aims to improve prostate cancer awareness by providing the Australian community with fact sheets on the burden of disease at a regional level, nationwide. The suite of resources will include 89 fact sheets of different regional areas.

Using a new website, people will be able to search by postcode or area name for information on specific Australian regions and share the fact sheets to help improve community understanding and save lives. Importantly, it will help us to identify geographic areas where prostate cancers are being diagnosed at later stages, in order to improve earlier detection.

The data includes diagnoses, deaths, and prostate cancer stage at diagnosis, unlocking information that has not previously been shared with the community.

https://atlas.cancer.org.au/

Patterns of cancer burden across Australia

AUSTRALIAN CANCER ATLAS

LAUNCH ATLAS



2019 WINNER

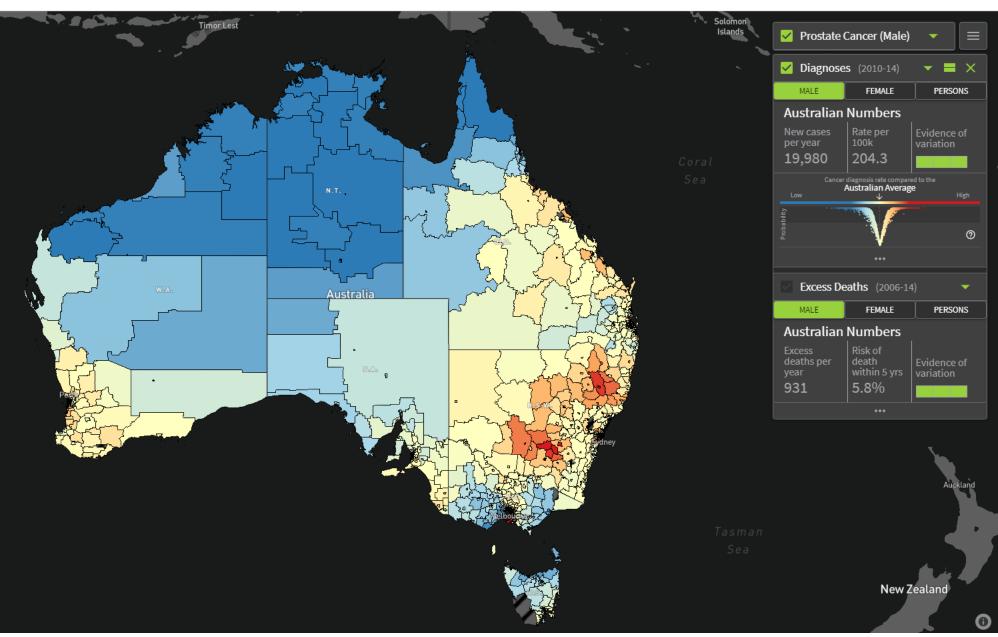
Regional (QLD) winner of the

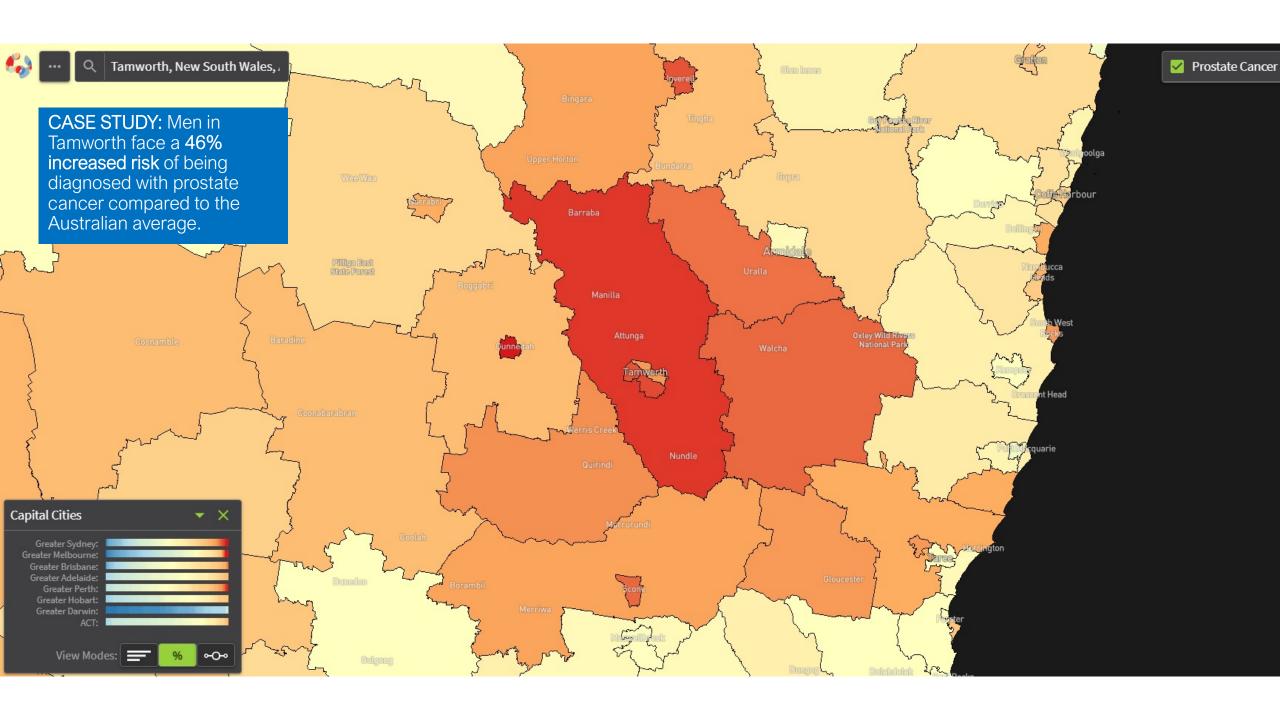
2019 Asia Pacific Spatial Excellence Award for Spatial Enablement

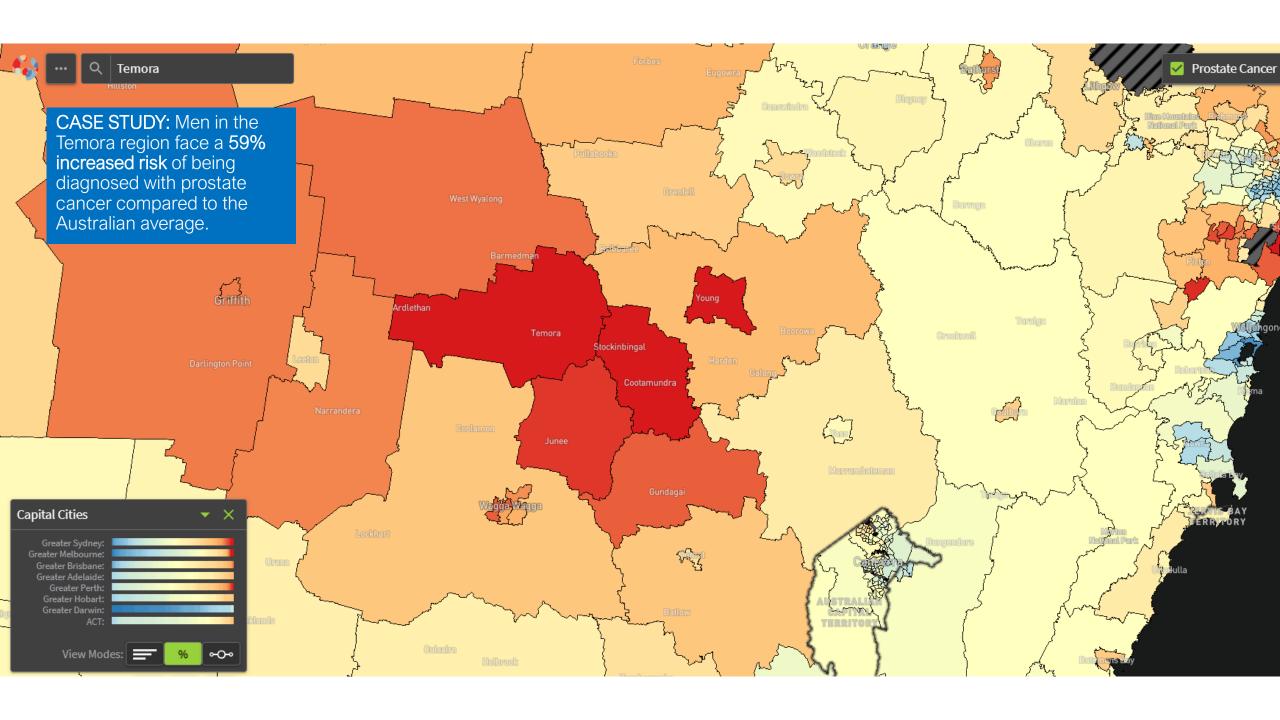


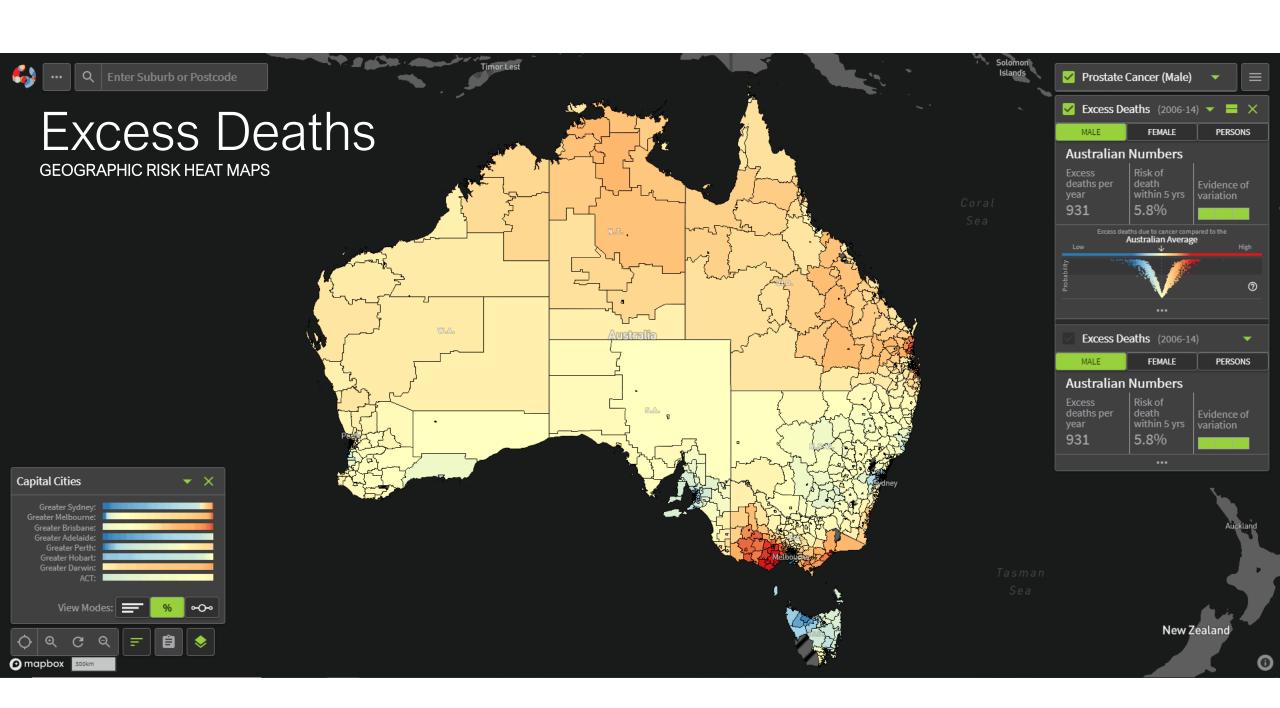
GEOGRAPHIC RISK HEAT MAPS

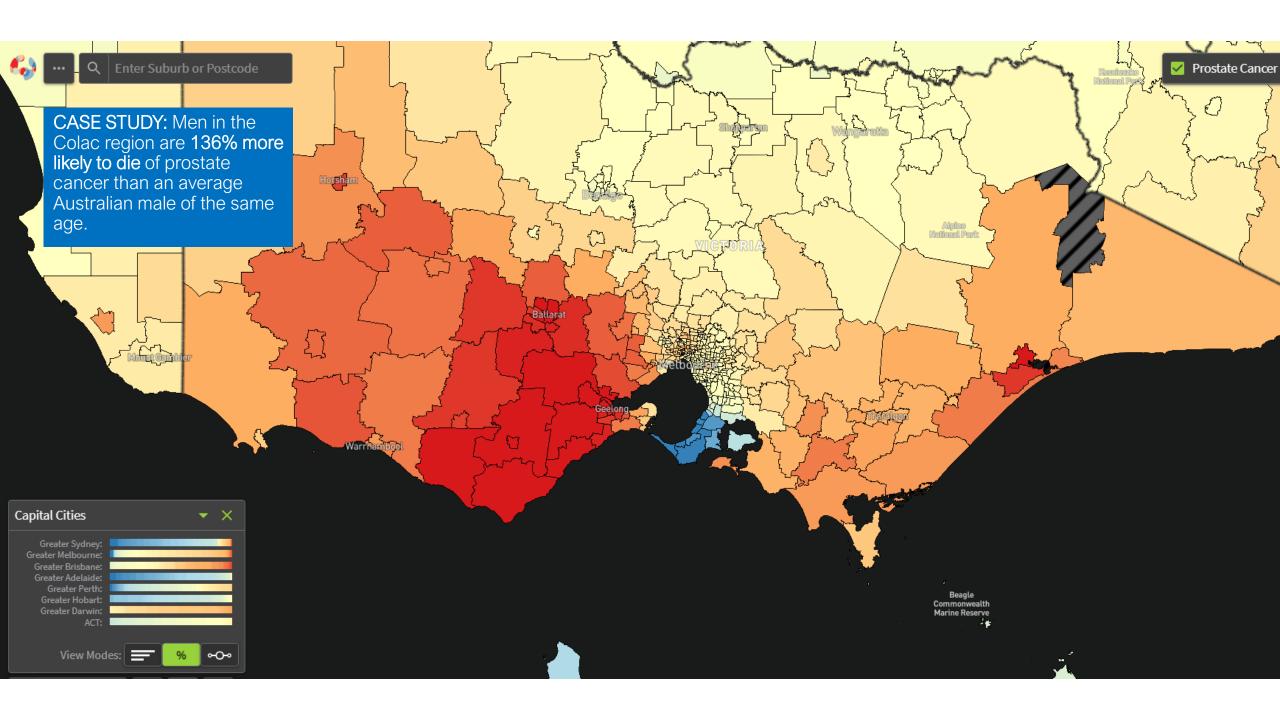


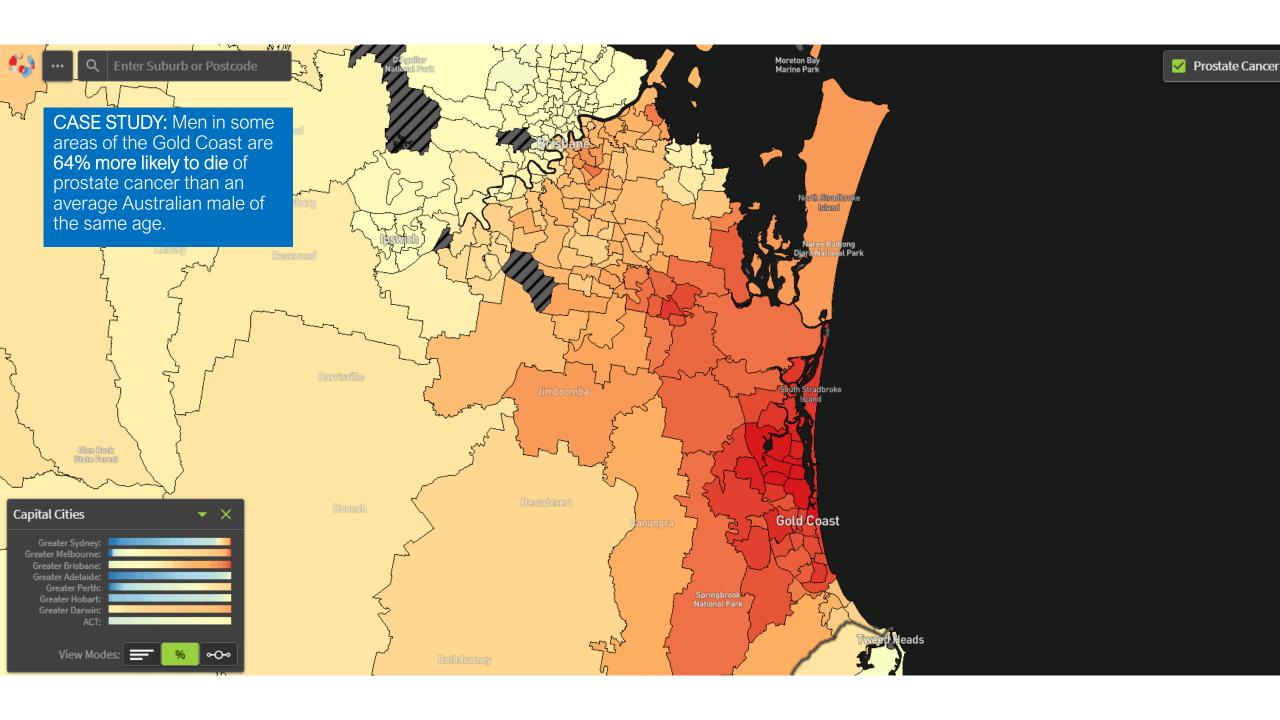














"Men with a family history of prostate cancer have double the risk of being diagnosed, and men in regional and rural areas of Australia face a 24% higher risk of death. Investment in new solutions is urgently needed." Professor Jeff Dunn AO, PCFA













PROSTATE CANCER IN AUSTRALIA A major challenge for men's health

- 70% of men and women don't know the symptoms of prostate cancer.
- 75% of Australians don't understand the PSA Test Guidelines.
- 1 in 5 men with prostate cancer will develop anxiety and depression.
- 72% of men with prostate cancer will not seek help for distress.
- 67% of men with prostate cancer have unmet information needs.
- 87% of Australians don't understand prostate cancer stages at diagnosis.

Men with prostate cancer face a 70% increased risk of suicide.

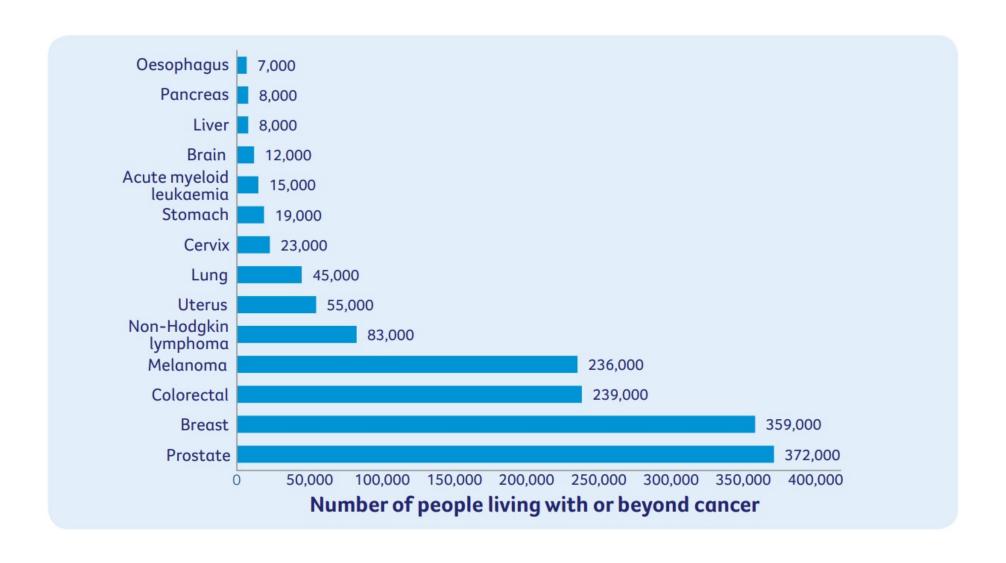


2040: The forecast for prostate cancer











5 years & \$31M for research







6 GAME-CHANGING PROJECTS

1. \$5,250,000

Exploiting alterations in lipid metabolism to improve diagnosis, treatment and imaging of prostate cancer

Despite advances in treatment, we still can't tell which cancers will be slow-growing and which cancers will be aggressive. This project focuses on predicting tumour behaviours and monitoring patients' treatment responses, in order to improve outcomes from treatment.

2. \$1,527,658

A prospective multicentre study of the impact of Ga-68 PSMA PET imaging in prostate cancer management

This trial investigates a new technology PSMA PET/CT. If PSMA-PET/CT proves effective, the scan could become a first-line test for staging prior to surgery or radiotherapy, with significant benefits for patients worldwide.

3. \$1,525,000

A prospective phase II randomised controlled trial of Lutetium-177 PSMA radionuclide therapy in men with metastatic prostate cancer

In this clinical trial, called TheraP, attaching the Lutetium-177 radioactive isotope to PSMA provides a way of locating and killing cancer cells that have travelled to other parts of the body. If TheraP proves effective, it will have major benefits for men with advanced prostate cancer.

4. \$6,250,000

Adaptive Response to Targeting the Androgen Axis: A Strategic Offensive on Resistance

This project will investigate the best approach, in conjunction with Androgen Deprivation Therapy, to halt the spread of prostate cancer, with great potential to improve clinical outcomes and quality of life for men with metastatic disease.

5. \$5,000,000

Prostate Cancer Bone Metastasis (ProMis): New Opportunities for Therapeutic Development

This project will investigate ways to stop prostate cancer cells spreading to bone and growing in bone. Breakthroughs here would be a game-changer for all men impacted by prostate cancer.

6. \$1,040,370

A phase II randomised controlled trial of high dose Vitamin D in localised prostate cancer (Pros-D)

This clinical trial aims to establish whether high-dose vitamin D supplementation helps prevent prostate cancer progression.

OVER \$31 MILLION FUNDED IN RESEARCH OVER THE PAST FIVE YEARS

Here are six of our highest value projects, each worth over \$1 million.



NEW RESEARCH – \$600k Young Investigator Grants







Priority Research Area 1:

Research that uses existing Australian repositories of biological samples from men with prostate cancer to better predict prostate cancer's progression.

Priority Research Area 2:

Research to develop less invasive prostate cancer diagnostics that show promise but need more evidence.

Priority Research Area 5:

Research that advances knowledge and understanding of the impact of prostate cancer on men's lives and the lives of their partners and their families.

Program Launch Date

Monday 19 October 2020

Application Submission Deadline

Monday 16 November 2020 at 5:00 PM AEDT

Expert Panel Review and Deliberations

November to December 2020

Anticipated Award Announcement

February 2021



Colleagues,

On behalf of Prostate Cancer Foundation of Australia's National Board and the thousands of Australians who support our work, I am delighted to announce our 2020 Research Grants are now open.

FIND OUT MORE HERE

As many of you know, every 30 minutes one of our fathers or sons will be diagnosed with prostate cancer. Of particular concern to PCFA, the predicted number of Australian men living with or beyond prostate cancer is set to increase from about 220,000 today to 372,000 by 2040, making it the most prevalent cancer in Australia.

Alarmingly, only 36% of Australian men are diagnosed at Stage 1 of the disease, and the mortality rate in regional areas is 24% higher than the Australian average.

The burden of disease is high. Compared with men in the general population, men with prostate cancer have a 70% higher risk of suicide. A study of men's help-seeking in the first year after diagnosis found 82% of men reported unmet supportive care needs relating to sexuality, psychological, and health system and information issues.

Ten years post-diagnosis, research has found that 35 to 40% of men experience poorer physical and mental quality of life outcomes and lower life satisfaction, with impacts on workforce participation and engagement in community life.



Major Research Investments







Grant ID	PI	Fdg Rnd	Grant Title	Req Budget	Start Date	End Date
BCG 0110 Top-Up	Clements, Judith	2014	PCFA support for the APCC Bioresource	\$200,000.00	01-Jan-15	31-Dec-19
CA 1088878	Hollier, Brett	2014	Targeting neuropilin-1 to inhibit prostate cancer metastasis and therapy resistance	\$63,870.00	15-Jun-15	31-Dec-17
NCG 0215	Ho, Ken	2015	A novel liver-targeted testosterone therapy for sarcopenia in androgen- deprived men with prostate cancer: anabolism without peripheral androgenism	\$100,000.00	01-Jan-16	31-Dec-17
YI 0715	Bock, Nathalie	2015	Using Bioengineered 3D In Vitro Models To Replicate the Tumour Microenvironment in Prostate Cancer Bone Metastasis	\$100,000.00	01-Jan-16	28-Feb-18
NCG 3215	Alexandrov, Kirill	2015	Development of highly sensitive diagnostic test for active form of prostate specific antigen	\$100,000.00	01-Jan-16	31-Dec-16
NCG 1715	Clements, Judith	2015	KLK14 as a novel therapeutic target in muscle wasting induced by androgen deprivation therapy.	\$99,732.00	01-Jan-16	30-Apr-17
CTA 0116	Hofman, Michael	2016	A prospective phase II randomised controlled of Lutetium-177 PSMA radionuclide therapy in metastatic prostate cancer patients	\$1,525,000.00	31-Mar-16	31-Dec-20
YI 0416	Volpert, Marianna	2016	Targeting Neuropilin-1 to inhibit the adaptive response to androgen deprivation	\$99,167.90	01-Jan-17	31-Dec-17
NCG 3216	Richard, Derek	2016	Targeting Genomic Stability in Prostate Cancer	\$99,601.00	01-Jan-17	31-Dec-17
NCG 2416	Davis, Rohan	2016	High-content screening of small molecule inhibitors from nature that target prostate cancer metabolism	\$99,618.00	01-Jan-17	25-Mar-18
NCG 1217	Hollier, Brett	2017	Targeting N-myc-driven Neuroendocrine Prostate Cancer	\$100,000.00	01-Jan-18	31-Dec-18
YI 1017	Srinivasan, Srilakshmi	2017	Deciphering the biological impact of prostate cancer risk associated PSA coding variant	\$75,000.00	01-Jan-18	31-Dec-19
NCG 0217	Teng, Michele	2017	Combination of immune checkpoint inhibitors with denosumab to treat primary and metastatic prostate cancer	\$100,000.00	01-Jan-18	30-Jun-19
PIRA 0819	Southey, Melissa	2019	Evidence-based translation of epigenetic testing to increase the precision of prostate cancer risk and progression prediction.	\$521,884.46	01-Oct-19	30-Sep-22
PIRA 1619	Paterson, Catherine	2019	In men choosing radical prostatectomy for localised prostate cancer, does a multimodal pre-habilitation intervention give better functional and quality of life outcomes than usual care?	\$119,058.60	01-Jan-20	31-Dec-21
PIRA 1519	Taylor, Renea	2019	Inherited pathogenic mutations in prostate cancer: the next generation.	\$599,896.00	01-Jan-20	31-Dec-22



PCFA ANZUP Clinical Trials Partnership





The TheraP Trial

A randomised phase II trial of 177Lu-PSMA617 theranostic versus cabazitaxel in men with progressive metastatic castration resistant prostate cancer

Chief Investigator: Professor Michael Hofman

TheraP is the first randomized trial comparing 177Lu-PSMA-617 (Lu-PSMA), a novel radioactive treatment, to the current standard-of-care chemotherapy, cabazitaxel, for men with metastatic castration-resistant prostate cancer.

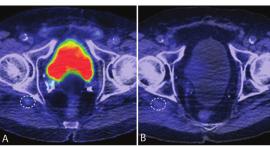
The results are now being evaluated to determine how effective Lu-PSMA is, compared to cabazitaxel, in eradicating prostate cancer, reducing pain, and delaying the growth of tumours. The initial findings provide compelling evidence that Lu-PSMA represents

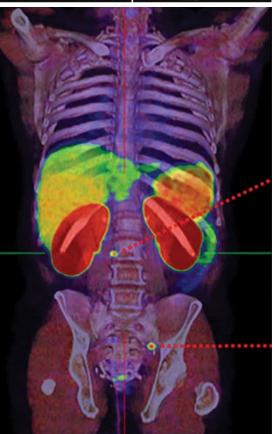
a new class of effective therapy for men with advanced prostate cancer.

PCFA contributed \$1.5 million to this groundbreaking multi-year project, involving more than 200 patients and 10 Australian cancer centres.



PCFA Clinician Trial Awards





The ProPSMA Study

A prospective multicentre study of the impact of Ga-68 PSMA-PET/CT imaging in the management of prostate cancer

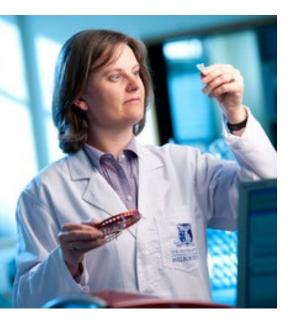
Chief Investigator: Professor Michael Hofman

The aim of the ProPSMA trial was to investigate whether PSMA PET/CT scans are more accurate for detecting metastatic tumours than the current CT and bone scans used at diagnosis. The study also tested whether the scans influenced decisions regarding clinical treatment pathways and reduced radiation exposure. The trial recruited men diagnosed with high-risk localised disease. The study involved 302 men at 10 different treatment centres around Australia. Those involved in the trial had been recently diagnosed with a biopsy showing high-risk prostate cancer. They were considering surgery or radiotherapy to treat their cancer. The researchers found PSMA PET/CT scanning was 92% accurate in detecting metastatic tumours, compared to only 65% accuracy for CT and bone scans.

PCFA was proud to co-fund the ProPSMA project, which has helped to prompt a review of standard imaging for the management of prostate cancer. PCFA is now using the findings to advocate strongly for the subsidization of PSMA PET/CT scanning as standard clinical care.



PCFA Priority Impact Research Award





Epigenetics and prostate cancer risk

Using new epigenetic information to better predict which men are most likely to develop aggressive prostate cancer

Chief Investigator: Professor Melissa Southey

Professor Melissa Southey is using epigenetic information to better predict which men are most likely to develop aggressive prostate cancer. Epigenetics is the study of how the expression of DNA can be changed without changing the structure of DNA itself. Some families are more susceptible to prostate cancer than others, but we don't understand the reasons for this very well. It could be due to inherited DNA (genetics) or the modified expression of DNA (epigenetics). Professor Southey and her team are applying new understandings of inherited DNA modifications that occur in families with high rates of prostate cancer to develop risk prediction models and molecular testing strategies to improve prostate cancer risk prediction for all men. If we can identify aggressive prostate cancers early, we can beat it.

PCFA was proud to provide funding for the full three-year project cost of \$521,885 for Professor Southey's important work, along with two other major research grants in 2019, worth a total of more than \$1 million.













PCFA SERVICES & OUTREACH

- Prostate Cancer Specialist Nursing Service
- New Prostate Cancer Specialist Telenursing Service
- National Prostate Cancer Support Group Network
- PCFA Online Community and Member Forum
- MatesCONNECT Pilot Peer Support Program
- Webcast Educational Series & Research Blog
- Pathfinder Research Registry for consumers
- Free information materials for men and families

Prostate cancer in Australia COMMUNITY CONCERNS

- 70% don't know the symptoms
- 75% don't know PSA Test Guidelines
- 1 in 5 develop anxiety and depression
- 72% don't seek help for distress
- 70% increased risk of suicide
- 67% have unmet information needs
- Only 13% understand cancer stages













PATIENT RESEARCH PROJECT

In 2020, we brought together a multi-disciplinary expert panel to better understand the nature of **prostate cancer survivorship** in the Australian context.

The panel reached a consensus view that the experience remains a challenging one, and must be addressed through integrated quality care. Prostate cancer survivorship care encompasses the health and wellbeing of men from the point of diagnosis onwards.

Quality care recognises the physical, psychosocial, spiritual and economic impacts of cancer, which can be long-lasting, and addresses these so that the patient and his loved ones can achieve optimal quality of life.

Prostate cancer in Australia SURVIVORSHIP PRIORITIES

- 1. Better patient clinician communication
- 2. Developing a survivorship toolkit
- 3. Increasing access to multi-modal care
- 4. Reducing out-of-pocket costs
- 5. Promoting the uptake of exercise
- 6. Harnessing technology
- 7. Greater reach of specialist nurses

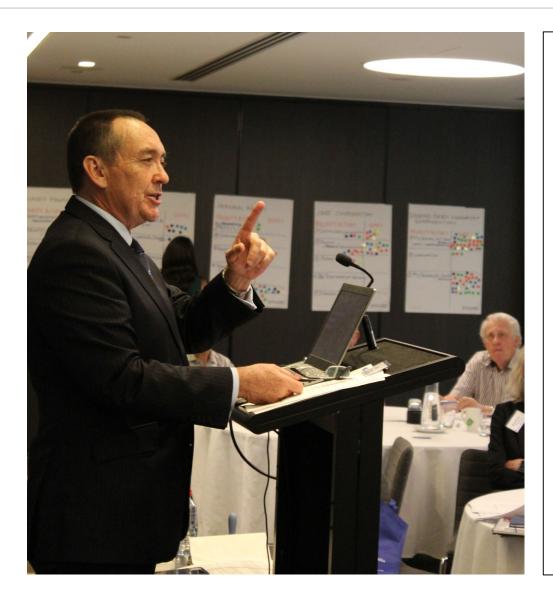


Survivorship Essentials Roundtable Meeting









BJU Int 2020 doi:10.1111/biu.15159

Original Article



Prostate cancer survivorship essentials framework: guidelines for practitioners

Jeff Dunn^{1,2,3,4}, Anna Green⁴, Nicholas Ralph^{2,3,4,5}, Robert U. Newton^{6,7}, Andrew Kneebone^{8,9}, Mark Frydenberg¹⁰ and Suzanne K. Chambers^{2,4,6,1}

¹Prostate Cancer Foundation of Australia, Sydney, NSW, ²Division of Research and Innovation, University of Southern Queensland, Springfield, Qld, ³Cancer Council Queensland, Brisbarne, Qld, ⁴Faculty of Health, University of Technology Sydney, Ultimo, NSW, ⁵School of Nursing and Midwifery, University of Southern Queensland, Toowoomba, Qld, ⁶Exercise Medicine Research Institute, Edith Cowan University, Perth, WA, ⁷School of Human Movement and Nutrition Sciences, University of Queensland, Brisbane, Qld, ⁸Royal North Shore Hospital, Sydney, NSW, ⁹School of Medicine, University of Sydney, Sydney, INSW, ¹⁰Monash University, Melbourne, Vic., and ¹¹Menzies Health Institute Queensland, Gold Coast, Qld, Australia

Objective

To develop contemporary and inclusive prostate cancer survivorship guidelines for the Australian setting.

Participants and Methods

A four-round iterative policy Delphi was used, with a 47-member expert panel that included leaders from key Australian and New Zealand clinical and community groups and consumers from diverse backgrounds, including LGBTQIA per and those from regional, rural and urban settings. The first three rounds were undertaken using an online survey (94–96% response) followed by a fourth final face-to-face panel meeting. Descriptors for men's current prostate cancer survivorship experience were generated, along with survivorship elements that were assessed for importance and feasibility. From these, survivorship domains were generated for consideration.

Results

Six key descriptors for men's current prostate cancer survivorship experience that emerged were: dealing with side effects; challenging; medically focused; uncoordinated; unmet needs; and anxious. In all, 26 survivorship elements were identified within six domains: health promotion and advocacy; shared management; vigilance; personal aero; care coordination; and evidence-based survivorship interventions. Consensus was high for all domains as being essential. All elements were rated high on importance but consensus was mixed for feasibility. Seven priorities were derived for immediate action.

Conclusion

The policy Delphi allowed a uniquely inclusive expert clinical and community group to develop prostate cancer survivorship domains that extend beyond traditional healthcare parameters. These domains provide guidance for policymakers, clinicians, community and consumers on what is essential for step change in prostate cancer survivorship outcomes.

Keyword:

prostate cancer, survivorship, quality of life, implementation, #PCSM, #ProstateCancer

Introduction

In 2018 over 1.2 million men were diagnosed with prostate cancer globally, with overall incidence expected to increase a further 42% by 2030 [1]. As incidence rises, advances in detection and treatment have led to improved survival rates in many countries, with Australia reporting 90.6% 10-year

survival [2], the USA 98% [3], and the UK 84% [4]. Hence the prevalence of prostate cancer continues to rise: in Australia, more than 200 000 men are living with a previous diagnosis [2.5]; 3 000 000 in the USA [6.7], and over 300 000 men in the UK [8]. Problematically, after diagnosis and treatment many men (up to 40%) experience poorer quality of life and satisfaction with life over the long term (10 years)



Survivorship Essentials – 6 DOMAINS







PROSTATE CANCER
SURVIVORSHIP ESSENTIALS
FRAMEWORK

Prostate cancer is the most prevalent male cancer in the world, excluding non-melanoma skin cancer.

In Australia, there are now over 230,000 men living with a diagnosis of prostate cancer. Prostate cancer survivorship care encompasses the health and wellbeing of men from the point of diagnosis and is essential to cancer care. Survivorship care recognises the physical, psychosocial, spiritual and economic impacts of cancer, which can be long-lasting, and addresses these so that the patient can achieve optimal quality of life. The Prostate Cancer Survivorship Essentials Framework places the man and his family at the centre of care.





Survivorship Essentials – 7 PRIORITY ACTIONS







7 PRIORITY ACTIONS FOR MEN WITH PROSTATE CANCER

Action on each priority can be expected to have impact for men across the six survivorship domains, and cumulatively could make a measurable difference in the face of prostate cancer in this country:



Enhance patient-clinician communication



Develop a comprehensive survivorship toolkit



Grow the availability of multi-modal care



Reduce out-of-pocket costs



Promote the uptake of exercise



Harness technology to increase access



Build the capacity and outreach of specialist nurses

New partnerships across disciplines, fully involving consumers, are needed in order to respond to these challenges.







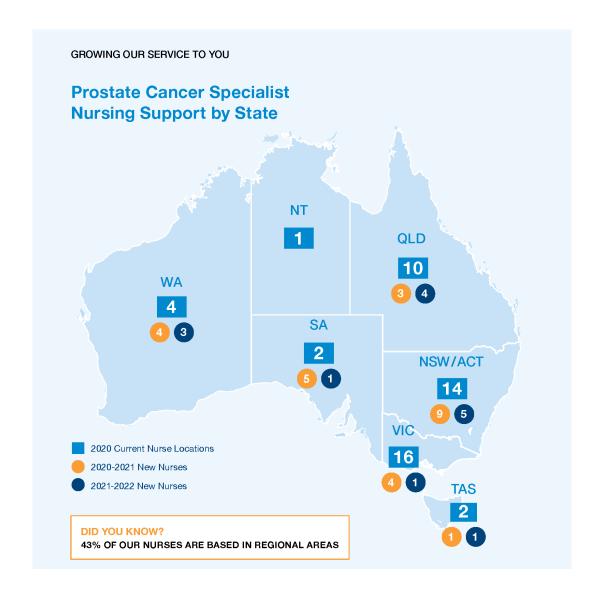


Expansion of PCFA Specialist Nursing Service











Only 36% of Aussie men are diagnosed at Stage 1 when prostate cancer is easier to beat and survival is higher.







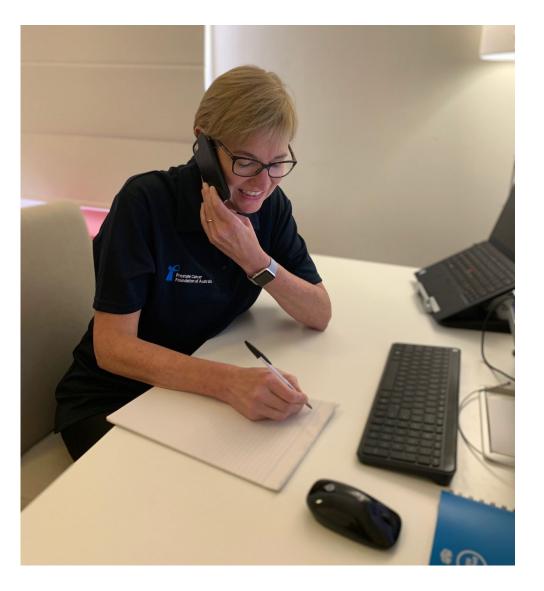


2021: Australian-first Telenursing Service





















Dry July funds provide for prostate cancer telenurse

Service will help

Jane Hanna heard her purt- the Prostate Cancer Founda- cancer.

Throughout the past 14 launch the new telemining. Rigged a high PSA level. The she said.

Now, the Dubbo couple be it through information, aware, now yours later that.

taggreative product cancer, she wished per summer services of the condition of the conditio

Jame said she went unto au- "It was a complete shock,"



Nationwide Prostate Cancer Support Groups











The Online Community & Patient Forum









This Online Community is proudly brought to you by the Prostate Cancer Foundation of Australia. We are committed to working with you and our Online Community to create a future where no man dies of prostate cancer. Regularly check the Announcements tab to see all of the updates from the Prostate Cancer Foundation of Australia.

Latest updates



Merry Christmas from the Online Community Team!

On behalf of the PCFA Online Community team, I would like to thank you for your considerable contributions to the community throughout 2020 in maintai...



Chris_McNamara Community Manager

in Announcements · yesterday







Community Dashboard

Community Admin

Community Analytics

Spam Quarantine

Administrator FAQ

Publishing





Major appeals: Telenursing

















Major appeals: Research







HELP FUND RESEARCH
TO END THE PAIN OF
PROSTATE CANCER.



FUNDING FOR LIFE-SAVING RESEARCH IS UNDER THREAT.







Major appeals: Christmas









"All four of my brothers, and two of my nephews, have faced prostate cancer. I've got two sons. I worry they'll be next." Kathy.











Major appeals: Christmas







"The news hit my family hard.

My wife Michelle burst into tears.

There were so many questions 'should we have the operation?'

and 'what are the chances it

might spread?""

Pete



Pete & Michelle



Campaigns: Big Aussie Barbie











Awareness: Blue Sky News











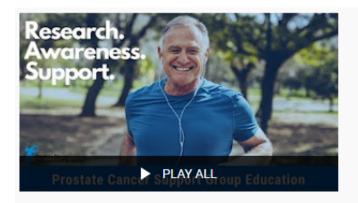


Education: Support Network Webinars









Prostate Cancer Support Group Education Sessions

67 videos • 2,084 views • Updated 4 days ago

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Prostate Cancer Support Group Education.



Prostate Cancer Foundation of Australia





PSA Guidelines: A Prostate Cancer Support Group Education Webinar

Prostate Cancer Foundation of Australia



Funded research - ProPSMA PET/CT: A Prostate Cancer Support Group Webinar.

Prostate Cancer Foundation of Australia



'To Leak or not To Leak' after Prostate surgery - by Kim Toyer

Prostate Cancer Foundation of Australia



Healthy Eating for those with Prostate Cancer - by Jennifer Calacoci

Prostate Cancer Foundation of Australia



Prostate Cancer and inherited risk - by Dr Hilda High

Prostate Cancer Foundation of Australia



Advanced Prostate Cancer Progress to 2017 - A/Prof Gavin Marx

Prostate Cancer Foundation of Australia

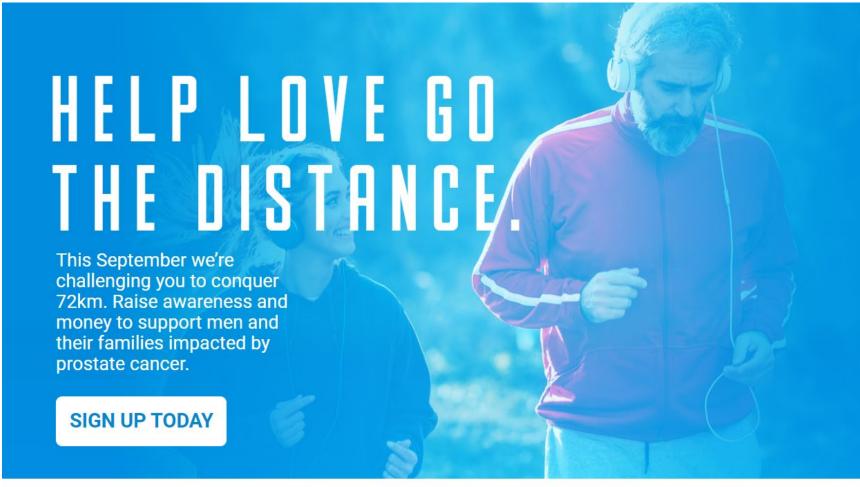


Community fundraising: The Long Run















Engagement: PCFA Social Media









This is Ben Jenkins, his wife Stacey, and their son Bryn.

Ben was hit by prostate cancer when he was just 36, before he'd met Stacey. He had to tackle major questions like not knowing whether he'd be able to have a family.

He went on to do just that (as you can see!) and has just signed up for our new awareness and fundraising event, The Long Run:

"I want blokes reading this, with a similar story to mine, to know they are loved and needed. None of what you're going through and nothing that you've lost physically makes you any less of a man. We need to lose the old preconceived ideas of what a "real man" looks and acts like. Experiences like this will change you. And it should change you. Nothing in life can stay constant."

Onya Ben, we luvya mate. 2 💜



Register now folks 👉 https://www.thelongrun.org.au See Less







Advocacy: Prostate cancer awareness







Features

Monday 27 July 2020 AFR The Australian Financial Review | www.afr.com

Monday 27 July 2020 www.afr.com | The Australian Financial Review

WHEN ALL TESTS FAIL

Health Like most Australian men, Tony Webber didn't have a clue that his symptoms might signal prostate cancer and the system didn't help him, writes Jill Margo.

lthough badly let down by all the measures designed to protect him. Tony Webber blames no one but himself for his stage IV prostate cancer. This is the most advanced stage of the disease and he is willing to disclose the details of his case in the hope that it might enlighten other men. His disclosure comes at a time when two important initiaves are under way in pro-

These will bookend the cancer experience. One is a push to reform the testing guidelines and the other is a push to mprove the survivorship experience.

cancer have the level of PSA, prostate specific antigen, measured in their blood.

A rising or high level of this protein is a red flag. While there has been much public concern about the potential of the PSA test to over-diagnose this cancer, there is much less interest in its potential for under-

The guidelines for PSA testing were revised in 2016, but have remained highly controversial and poorly understood.

The Prostate Cancer Foundation of Australia has been monitoring its members' responses to them and has written to the Federal Health Minister, Greg Hunt, to request they be reviewed.

Professor Jeff Dunn, CEO of the PCFA. says recent research also shows an alarmingly high lack of unawareness about prostate cancer, which is impeding early detection and diminishing population-wide survival prospects.

He says a new report, Not All Prostate a sense of incomplete emptying. Cancer is the Same, found 70 per cent of Australians don't know the signs and symptoms of this cancer.

Based on patient perceptions and published in the British Journal of Urology International (BJUI), the report shows a significant number of men experience delays in diagnosis because of limited understanding of symptoms.

Webber is a case in point. Despite his high level of education and his position, it didn't enter his mind that his problem might be related to cancer. And he couldn't tell the system was failing him.

Now he is in "survivorship", which is the focus of the second initiative. This is a push to create a new way of managing survival that extends beyond traditional care.

In 2011, Dr Webber was chief economist at Qantas when the company decided to sent Men who take their first test for prostate its top 100 executives for a full medical check-up.

While he was told he was in exceptional good health, his CEO, Alan Joyce, was not so fortunate. He was diagnosed with prostate cancer, about which he has since been very

Webber moved on from Qantas and set up Airline Intelligence and Research, a consultancy that houses one of the biggest private aviation operational and financial databases in the world.

He also wrote for The Sydney Morning Herald and, as an associate professor, taught on the MBA program at Sydney University's Business School.

Webber had been to the doctor perhaps a dozen times in his whole life and never thought about his health again, until November 2018, when he realised he was living with a waterworks problem. He was relieving himself much more often, and volumes were notably low, leaving him with

"I'd put on weight and I thought those few kilos were probably putting pressure on my bladder. So, I started taking them off. It



What Tony Webber (above and right, in hospital after his biopsy) had to go through is a cautionary tale for everyone, PHOTO: DOMINIC LORRIMER



didn't help and by January 2019, I thought I'd better do something about it."

With that, he began falling towards a prostate cancer diagnosis, missing the traditional cautions that can catch men before their cancer gets to an advanced stage.

A family history of prostate or related cancers is a warning sign, as is age. Webber was relatively young and had no such history. His PSA was low, his scans missed the cancer and when his GP gave him a digital rectal examination, he missed it too.

"What happened to me reminds me of how a sequence of low probability events can generate a fatal air crash, "he says.

At the GP's behest, in January 2019,

What happened to me reminds me of how a sequence of low probability events can generate a fatal air crash.

Tony Webber

Webber had a series of tests but there was nothing to see

"The results showed my prostate was a bit enlarged, which was normal for a man of 51, My PSA was low and although my kidney function was a little outside the normal range, the GP said it was nothing to worry about. I should go home and the problem would sort itself out."

"The PSA is not foolproof, all my medica people missed it initially," says Webber,

Rather than sorting itself out, his problem persisted on and off. As he was busy and travelling, he lived with it.

"But it took a turn for the worst in Istan bul in March. During the day, the urgency to pee every half an hour was extreme and the volumes were small. Back in Australia, I had a business trip to Bangkok in May and in June my wife was overseas and I had to look after the kids during school holidays.

"My peeing situation deteriorated dramatically and sometimes I was up eight times at night. I also couldn't ejaculate. It just dried up and that really freaked me out because I was pretty good at doing it before.

"And I was oozing weird stuff out of my backside which also caused massive anxiety. Eventually, to pee I had to contort my body and push as hard as I could to get out a

For the second time, he'd left things too long - which is why he blames only himself. By the time he got to the GP in July, there

was a swelling along his pelvic bone and down the left side of his groin. More tests were ordered

"The woman doing the ultrasound said I had a blockage down my left side, likely my prostate, and that I should run back to the doctor, not walk.

"In response, the GP hesitantly performed the digital exam but he couldn't find anything. After three weeks of back and forth with tests, he finally sent me to a urologist because he was completely baffled.

"It was early August and the first thing the urologist did was digital exam. Immediately, he said there was something abnormal about my prostate.

his was a lesson. I discovered it is important to have this exam done by someone who does many of them."

A prostate biopsy followed and by mid-August, he knew he had prostate cancer. That men with this cancer generally have a 95 per cent chance of surviving for five years, was reassuring.

But there was more. He needed stents, small plastic tubes, to keep open the channels that allow urine to flow from the kidneys to the bladder. He also needed CT and MRI scans to see if the cancer had spread.

A short while later he got the call. There had been aggressive spread and he would need "full body treatment", code for chemo-

The next morning, he and his wife, Cecilia, met the urologist and the radiologist. They learned his cancer had spread to his lymph system, through his pelvis, bladder, pelvic bones and into his lower spine.

"Your PSA should have been screaming like there is no tomorrow," the radiologist said to him, before adding "and don't Google this mate, what you've got is probably one of

They also learned that when the new and for step change.

needed a review but I didn't find the time. I old scans were compared, the disease had been visible earlier. "My urologist insisted the company rewrite its report for the January 2019 results to reflect this.

> The hard moment came when they heard that, with stage IV, the likelihood of surviving five years was 30 per cent.

> "I broke down emotionally. I felt I'd been hit by a Mack truck. After the appointment, we sat in the car crying. It was awful.

"But at least we knew they had consulted internationally and had a plan of attack."

For Webber, stage one of the plan was anti-hormone treatment to turn off his testosterone. "It was like going through menopause. I had hot flushes and a private area that basically shrivelled up - not great for my manhood but for me survival was utmost on my mind."

Next came chemotherapy, less daunting than he expected.

"I went to a building nearby, sat on a chair with a view of Sydney's CBD and had a drip in my arm. It involved a 90-minute treatment, six times every three weeks, and was over by Christmas. My cancer was obliterated but I was still dealing with nerve damage, mouth ulcers and other side-effects.

"Today, my hair has grown back grey and although breathing still troubles me, I'm on my way back to normality.

"The most important pieces of intelligence I received were to stay in touch with my GP and seek advice from a mental health specialist. A stage IV cancer diagnosis is nearly impossible to get through without mental health help - and I was fortunate enough to have my absolutely amazing wife

Men's health care has specific challenges that are seldom addressed in mainstream health care delivery. While much of the attention on prostate cancer has been on diagnosis and treatment, little has been directed to life afterwards. This year, the PCFA commissioned a multi-disciplinary panel of experts to analyse survivorship in Australian men with prostate cancer.

The panel concluded the focus was too narrowly concentrated on clinical care and that the framework needed to be extended.

Its findings, published in the BJUI, identified areas for action which cumulatively, it

says, could make a measurable difference. These included improving men's per-

sonal agency and the communication between them and their doctors. There should be more shared management and increased access to care. Technology could be improved to access care and more specialist urology comunity nurses should be trained. The panel laid out what is necessary



Advocacy: Family and genetic risks

COURIERMAIL.COM.AU WEDNESDAY FEBRUARY 5 2020

NEWS 19

Prostate ills tied to family

JANELLE MILES MEDICAL REPORTER

MEN who have a family history of breast and ovarian cancers are at higher risk of being diagnosed with prostate cancer, experts warn.

The Prostate Cancer Foundation of Australia said that while having a family history of prostate cancer significantly increased a man's chances of getting the disease, those with

Links to breast and ovarian cancer increase risk

relatives diagnosed with breast or ovarian cancer were also more vulnerable.

Foundation CEO Jeff Dunn yesterday urged men with a family history of prostate, breast or ovarian cancer to be particularly vigilant about talking to a general practitioner about their risks.

Professor Dunn said about

20,000 Australian men would be newly diagnosed with prostate cancer this year.

About 3300 Australians die from the cancer each year.

"There's no question there are avoidable deaths from prostate cancer," Prof Dunn said. "If their fathers, uncles or brothers have had prostate cancer, they've got to pay attention to that. We want to pick up this cancer as early as possible so we can treat it as effectively as possible to improve survival rates."

Prof Dunn said men also needed to take heed of a family history of breast or ovarian cancers, particularly those caused by a BRCA1 or BRCA2 genetic mutation. "We simply must take action to support these men and their families by arming them with information and providing necessary support," he said.

"Australia has one of the highest incidence rates of prostate cancer internationally, with one-in-six Australian men likely to be diagnosed during their lifetime." The Prostate Cancer Foundation of Australia will this year pump more than \$1 million into three new research projects to better detect prostate cancer's progression and further knowledge into how the disease impacts men's lives.

Side effects of treatment can include erectile dysfunction and incontinence.

FOR INFORMATION AND TO SUP-PORT PROSTATE CANCER RE-SEARCH: PCFA.ORG.AU



Advocacy: COVID downturn







News | Australia shutdown

Wednesday 18 March 2020
The Australian Financial Review | www.afr.com

Charities cruelled in hour of need

Philanthropy

Jill Margo

Health editor

Australia's charity and not-for-profit sector is succumbing to the coronavirus. Already weakened by drought, floods and bushfires, it is now having to cancel major fundraising events and activities.

As funds diminish, capacity is challenged and services are reduced, more people, anxious about the virus, need these services.

This is particularly felt by healthrelated charities, which account for more than 7300 of the 57,675 registered charities in Australia.

Queensland Eye Institute CEO Professor Mark Radford estimates the sector is already easily down 35 per cent over the past six months. He predicts a greater downturn as the virus compounds the problem, complicating staffing arrangements, research and funding over the next 12 months.

Hospitals and clinics are rearranging normal routines, which creates anxiety and uncertainty.

People who might have gone to cancer support groups now find these unavailable because of social distancing or lack of funds.

The Prostate Cancer Foundation of Australia is getting distress calls from men worried about the consequences of delayed treatment.

Its chief executive, Professor Jeff Dunn, says the combination of funding pressure and shallow reserves is likely to lead to the closure of some organisations.

He has written to Prime Minister Scott Morrison describing the risk, seeking a stimulus package and outlining what it could look like.

The sector contributes about \$129 billion to the economy each year, directly employing about 840,000 full-time workers and another 470,000 upstream. Almost 80 per cent of this workforce is female.

As major events are cancelled, donations diminish, activities are constrained and supply chains disrupted, the sector is in crisis.

"This sector is an expression, a community mobilisation, of good deeds to make our world a better place, and we need it," Professor Dunn said.

He would like to see an NFP Employment Protection Provision to provide non-profit employers with a percentage-based or lump sum payment to offset salary costs and safeguard jobs.

There is also a need for a corporate

giving tax offset for companies that donate to registered charities, with donation and offset thresholds to incentivise contributions from small, medium, and large enterprises.

Professor Dunn would like a temporary bonus charity tax deduction incentive for individual taxpayers, providing a 150 per cent tax deduction on donations before June 30.

And, he says, a digital innovation rebate scheme to fund digital and webbased innovations designed to provide community services and programs online would be very helpful.

An official at the Australian Charities and Not-for-profits Commission, which regulates charities, says there is a risk that some charities may be overwhelmed by demand for services, some may not be able to provide services, and some may have to close temporarily because of the outbreaks.



Advocacy: Survivorship care

PROSTATE CANCER RETHINK

Men's health Australia is poised to lead the world in a new way of managing this disease, writes Jill Margo.

he power behind prostate cancer was revealed in Canberra this week. Prime Minister Scott Morrison talked about being tested and how his father had survived more than a decade since his diagnosis.

Federal health minister Greg Hunt disclosed he had a family history of the disease, too, and Opposition Leader Anthony Albanese said because he'd had a high reading on a test he was now being tested every three months.

All were talking before the annual Parliamentary Big Aussie Barbie, run by the Prostate Cancer Foundation of Australia (PCFA).

AFRGA1 0042

Given that one in seven Australian men will be diagnosed with this cancer, many more politicians could have joined them.

Australia is poised to transform the way this cancer is managed.

If it pulls it off, it will be the first country to do so.

This new push is being led by Professor Jeff Dunn, recently appointed chief executive of the PCFA, who has been working on it for about 15 years.

He already has support from all clinical groups associated with prostate cancer and at the barbecue on Wednesday he formally received bipartisan political support too.

So, what is it?



It's a radical approach aimed at ensuring that men with this cancer not only live long, but live well too.

Dunn says it is not enough to treat this cancer as just a physical disease. The heavy emotional, social and personal payload it carries requires serious attention too.

The new push involves routinely screening patients for distress and offering those in need quality help.

"This is the new frontier in innovative care. It's not just defeating prostate cancer, but restoring hope in a future free from both physical and psychological pain," he says.

Before and after treatment, up to one in four men experience anxiety and up to one in five report depression.

Australian men diagnosed with this cancer are at a 70 per cent increased risk of suicide compared with their peers.

Dunn believes such distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiration and pain. This is the consensus view of international psychologists who specialise in cancer, and a view which he helped form.

His plan is ground-breaking because survival rates are now so high that men are living with the fallout for decades. More than 200,000 Australian men live with it and as the population ages and grows the pool of survivors will continue to grow.

On Wednesday, Hunt launched The PCFA Position Statement for Distress Screening and Psychosocial Care for Men with Prostate Cancer, which describes the plan.

It, and a monograph launched with it, are products of the Centre for Research Excellence in Prostate Cancer Survivorship, funded by the government through the National Health and Medical Research Council. The monograph provides a model for psychosocial care.

The real challenge for Dunn now is to roll out the plan and see if he can change practice and make attention to psychological wellbeing part of standard care.

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Advocacy: Mental health









CORMAC PEARSON

AUSTRALIAN cricket legend Matthew Hayden has opened up to shine a light on Men's Health and the importance of

The 48-year-old has been an advocate for men's health since his father was diagnosed with prostate cancer in 2014.

He watched helplessly as Lawrie fought through the many symptoms of the disease. Now the father of three has revealed his own challenges, with a hope it encourages men to go to the doctor, seek help and speak up.

"The walls were closing in at a thousand different times during my career with cricket, at times I felt alone and isolated," Hayden told The Courier-Mail.

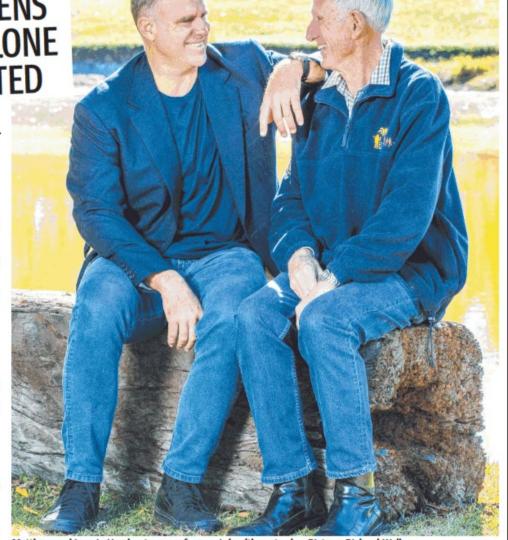
"It's not any disrespect to post traumatic stress disorder, but the symptoms of pressure and professional sport can be very similar to that."

"There was sleeplessness, you can't think straight, you're not hungry, you're erratic, there were so many times during my career when I felt really under pressure."

Hayden is heading the Every Man Can campaign, which aims to raise awareness the lower life expectancy for men, higher risks of suicide, and premature death during Men's Health Week.

"It's a silent disease, it's not dissimilar to having a sore back, you still can walk but no one can see your pain," he said.

"When you suffer in silence it creates a very big hole and it doesn't feel very good. it feels dark."



Matthew and Lawrie Hayden team up for men's health yesterday. Picture: Richard Walker

Plea for prostate cancer support

JACKIE SINNERTON

THE first 10-year study of Australian men affected by prostate cancer has found many have long-term impairments to quality of life, spark- Cancer Survivorship, said suping a call by experts for a portive care programs needed change in the management of to be accessible to men in the the insidious disease

Cancer Council Queensland and University of South- highest incidence rates interern Oueensland lead nationally of prostate cancer. researcher. Associate Professor Nicholas Ralph, said, lian men likely to be diagnosed more needed to be done to during their lifetime," Prosupport Australian men with prostate cancer survivorship.

"Although men with pros tate cancer are living longer. they are not necessarily living a major life stress that is often well, with symptom burden increasing and quality of life de-

"We found that 35-40 per cent of men experience poorer physical and mental quality of in five report depression, with ife outcomes and life satisfac- an increased risk of suicide. tion 10 years after the diagnosis and treatment of prostate cancer. These symptoms were more pronounced for men with multiple conditions, those treated with androgen deprivation therapy, and those from

The study followed men for Dunn AO reiterated the call. a decade after a diagnosis of Clinical Oncology Society of said. Australia Annual Scientific

Co-author Professor Suzanne Chambers AO. Dean of University of Technology Syd ney's Faculty of Health and Chair of the Centre for Research Excellence in Prostate vears after treatment.

"Australia has one of the with one in every six Austra-Chambers said.

"While survival rates for prostate cancer are high, the diagnosis of prostate cancer is followed by challenging treatment-related symptoms and heightened distress

"Up to one in four men experience anxiety and up to one

"Health service providers and policymakers need to prioritise and fund new models of care to ensure men are not suffering through their symp toms in silence"

Prostate Cancer Foun dation of Australia (PCFA) chief executive Professor Jeff

"We must transform the prostate cancer. The findings way Australia manages this will be presented today at the insidious disease," Prof Dunn

"For most men, a diagnosis Meeting and has been pub- of prostate cancer generates lished in the latest edition of strong feelings and a life permanently changed." he said













THANK YOU!

Thank you for your support of Australian men and families impacted by prostate cancer this year.

We look forward to partnering with you in 2021 to deliver on our vision of a future where no man dies of prostate cancer.

Please don't hesitate to contact our team for more information about our plans in 2021.

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