



RESEARCH BLOG

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Low awareness can be lethal

Alarming new research has revealed about 70 per cent of Australians don't know the signs and symptoms of prostate cancer, prompting Prostate Cancer Foundation of Australia to call for greater public investment in targeted community awareness activities.

The findings have been reported in the *Not All Prostate Cancer is the Same* report, released by the Prostate Cancer Patient Coalition – Asia Pacific (PCPC).

Prostate Cancer in the Asia Pacific: A concerning picture

Prostate cancer is the second most commonly occurring cancer in men worldwide and the fifth leading cause of cancer death globally. In the Asia Pacific region, including Australia, the incidence of prostate cancer has increased sharply over recent decades and is expected to almost double by 2030, due primarily to an aging population, increasing urbanisation, and associated lifestyle changes. Of concern, men diagnosed in later stages of the disease experience poorer prognoses and a higher incidence to mortality ratio.

A united voice

In response to the significant and growing burden of prostate cancer, the Prostate Cancer Patient Coalition – Asia Pacific (PCPC) formed in 2017 to support a collaborative approach and create a united voice to drive change across the region. With PCFA as Australia's representative, the group identified four goals to prioritise efforts to improve outcomes and support for men living with prostate cancer:

1. Improve public awareness of prostate cancer and its impact through stakeholder and community education.
2. Improve health care delivery and consistency of management of prostate cancer and shared decision making between patients and their healthcare professionals.
3. Advocate for prostate cancer becoming a priority area in national health policy.
4. Improve public awareness of the importance of testing for prostate cancer, especially amongst high risk groups such as people with a family history of the disease.

The Not All Prostate Cancer is the Same Report

The *Not All Prostate Cancer is the Same* Report seeks to build on the Coalition's earlier work to provide new insights into the needs of men and communities affected by prostate cancer as a means to advance change in the region. It represents the first instance where an assessment of prostate cancer awareness and understanding has been conducted across the Asia Pacific region.

There are stark differences in how people with prostate cancer in Asia Pacific feel about their condition, depending on the stage of their disease – whereby those with earlier stage disease are most concerned about disease progression and treatment options, while those with advanced prostate cancer are most concerned about pain and physical changes to their body. These concerns may appear, at face value, to be somewhat obvious, but in light of the connection between stage of disease and prognosis, the findings highlight the importance of providing tailored support and information to people with prostate cancer based on their stage of disease, and provide a basis for strengthening prevailing low levels of community awareness.



Poor understanding of prostate cancer delays diagnosis

Critically, the study found the majority of people with prostate cancer across Asia Pacific were either not aware of prostate cancer or had limited knowledge about it. Early diagnosis of prostate cancer is a fundamental aspect of ensuring people with prostate cancer get the best outcomes. If people are able to recognize the symptoms of prostate cancer, in either themselves or a family member, and critically, understand the importance of seeing a healthcare professional promptly once they notice symptoms, they are more likely to receive an early diagnosis and have better outcomes.

Alarmingly, in the Asia Pacific region 60% to 80% of people have no knowledge of prostate cancer prior to diagnosis, and misperceptions of prostate cancer are common.

A call to action

Prostate Cancer Foundation of Australia CEO, Professor Jeff Dunn AO, says the research is a call to action.

“With a growing Australian population and increasing life expectancy, the number of men diagnosed with prostate cancer will continue to increase. It’s vitally important that we do more to improve awareness of the disease and raise understanding of options for early detection and treatment, while supporting survivors with the long-term side effects of their illness.”

The report is based on first-of-its-kind patient perception research just published in the [British Journal of Urology International](#) (BJUI).

“The detailed findings suggest that low awareness of the different stages of prostate cancer and available management options at each stage of the disease can adversely impact each patient’s ability to make informed decisions about their care,” Jeff says.

“Concerningly, right across the Asia Pacific region, recognition of prostate cancer symptoms is extremely poor, whereby up to nine in ten men do not know the symptoms of prostate cancer before they are diagnosed.

“In the Australian context, 70 per cent of men did not know the symptoms and 67 per cent of men reported unmet needs for information on prostate cancer prior to their diagnosis, saying they wished they had known more about it.

“Of particular concern, only 13 per cent of the Australian men surveyed said they knew how to distinguish between the different stages of prostate cancer, a lack of understanding that can be detrimental to early diagnosis and effective care.”

While 53 per cent of Australian men surveyed indicated their doctor provided in-depth information on the stages of prostate cancer at diagnosis, many reported feeling overwhelmed at the time and unable to recall the information provided.

A long way to go

PCPC Co-Chair and Clinical Urologist at the Japan Community Health Care Organization and Tokyo Shinjuku Medical Center, Dr Koichiro Akakura, says the incidence of prostate cancer in the Asia Pacific has increased over the past few decades.

“Incidence of prostate cancer is expected to almost double by 2030 in the Asia Pacific region. These findings clearly demonstrate that we have a long way to go if we want to raise awareness of prostate cancer to the same level we see in breast cancer, where increased awareness has had a significantly positive impact on diagnosis rates and overall survival.”



Fellow Co-Chair and Clinical Professor of Urology at the University of Melbourne, Department of Surgery and Head of Austin Urology Unit, Professor Damien Bolton, emphasised the significance of the findings.

“This is the first time that the disparity in levels of knowledge and support across the Asia Pacific region has been quantified, drawing from patient perception research that has uncovered significant differences in the experiences of prostate cancer patients across the region.

“The findings highlight just how important it is that we improve levels of knowledge and understanding of the symptoms and disease stages of prostate cancer if we want to improve early detection and ultimately impact patient outcomes in the Asia Pacific region.

“The report clearly shows that a significant number of men with prostate cancer experience delays in their diagnosis due to their limited understanding of prostate cancer symptoms,” he says.

The time to act is now

It’s a finding that has prompted Prostate Cancer Foundation of Australia’s CEO Professor Jeff Dunn AO to step up calls for a review of the PSA Test Guidelines and increased public funding for targeted prostate cancer awareness campaign.

“By 2040 we predict there will be 372,000 men living with or beyond prostate cancer in Australia, representing a 76 per cent increase from 211,000 today and the greatest number of men or women diagnosed with any single cancer,” he says.

“Without investment in new campaigns to reach men at risk, many thousands of men face the risk of late diagnosis with advanced disease, with unacceptably poor prospects for survival.

“Of concern to the growing burden of prostate cancer on the Australian community, 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 per cent higher risk of death – investment in awareness is vital to ensure our fathers and sons don’t die before their time.”

Australia has one of the highest rates of prostate cancer in the world, with one in every six Australian men likely to be diagnosed by age 85.

Review of the PSA Test Guidelines

PCFA has written to Federal Health Minister Greg Hunt to seek public funding support for a review of Australia's current PSA Test Guidelines and public awareness activity.

“For Aussie blokes with a family history of prostate cancer, knowing your risks and screening options is key,” Professor Dunn says.

“The current guidelines were published in 2016 and remain highly controversial and poorly understood by the majority of Australians.

“A recent PCFA survey found that 75 per cent of Australians do not know the guidelines, an alarmingly high level of unawareness that impedes early detection and diminishes population-wide survival prospects.”

It is a disease that also takes a heavy toll on men’s mental health.



“About one in five men with prostate cancer experience long-term anxiety and depression and some will have an increased risk of suicide, although few seek support for their mental health needs,” says the Professor.

“Few Australians realise exactly how tough it is to live with a diagnosis of prostate cancer. It’s common for patients to struggle with understanding their treatment options and many are unable to access evidence-based information about the pros and cons of surgery, chemotherapy, and radiation treatment or hormonal therapy. It’s a tragic fact that on any given day men with prostate cancer are already at a 70 per cent increased risk of suicide compared to the general population.

“Every 25 minutes, one of our fathers, sons or friends will hear the news he has prostate cancer – these men deserve our support,” he said.

Prostate Cancer Foundation of Australia has written to the Federal Health Minister to request public funding for a review of the Guidelines and a new public awareness campaign for at-risk men.

To find out more, [email](#) our team or [click here](#) to donate.

ENDS.

Contact

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About Prostate Cancer Foundation of Australia

We were formed nearly 25 years ago, when a group of men banded together with their partners and friends to do something about this deadly disease. Today, we are Australia’s leading charity for Australian-based prostate cancer research and support - all funds raised go towards helping Aussie blokes impacted by the disease and their families. 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 is threefold: (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 and their families.

About the *Not All Prostate Cancer is the Same* report

The report is a result of the *Not All Prostate Cancer is the Same* patient perception research study, both of which were commissioned by Janssen Asia Pacific, a division of Johnson & Johnson Pte. Ltd. and executed by SenateSHJ. Both the research study and the report were prepared in consultation with the co-Chairs of the Prostate Cancer Patient Coalition – Asia Pacific™ - Dr. Koichiro Akakura, Department of Urology, Japan Community Health Care Organization, Tokyo Shinjuku Medical Center, Japan and Professor Damien Bolton, Clinical Professor at the University of Melbourne, Department of Surgery and Head of Austin Urology Unit, Australia.

The Not All Prostate Cancer is the Same patient perception research includes responses from 150 patients diagnosed with different stages of prostate cancer across Australia, China, Japan, Taiwan and Korea.



About the Prostate Cancer Patient Coalition – Asia Pacific™

The Prostate Cancer Patient Coalition – Asia Pacific™ aims to address the challenges faced by patients living with prostate cancer in the Asia Pacific region.

As one united patient voice, our objective is to drive change to improve the quality of life and the outcomes for patients living with prostate cancer in the region by:

- Increasing the awareness and understanding of prostate cancer
- Educating communities, healthcare professionals and governments about the needs of patients living with prostate cancer and their carers
- Advocating for prostate cancer to be a health priority
- Empowering patients and their families.

Members of the Prostate Cancer Patient Coalition – Asia Pacific™ include:

(in alphabetical order of representative name)

- Prostate Cancer Patient Association, Korea as represented by Mr Dong Soo Chun
- China Primary Health Care Foundation as represented by Ms Ningning Hu and Ms Liu Xiu
- Senyu Club, Japan, as represented by Mr. Tsutomu Takeuchi
- Prostate Cancer Prevention, Taiwan as represented by Ms Hsu Tsai-Yun
- Prostate Cancer Foundation of Australia, as represented by Jeff Dunn

Since its inception in 2017, Janssen Asia Pacific, a division of Johnson & Johnson Pte Ltd, has supported the Prostate Cancer Patient Coalition – Asia Pacific (PCPC) in their efforts to improve the lives of those living with prostate cancer. The company respects and upholds the independence of all participating groups.

References:

1. Chen R, Ren S, Yiu MK, *et al.* (2014) Prostate cancer in Asia: A collaborative report, Asian Journal of Urology, 1, 15-29.
2. Akakura K, Bolton D, Grillo V, Mermod N. (2019) Not All Prostate Cancer is the Same - Patient perceptions: An Asia-Pacific study. Available online: <https://bjui-journals.onlinelibrary.wiley.com/doi/abs/10.1111/bju.15129>
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