



# Prostate Cancer Asia Pacific Whitepaper Report

**A united voice for change**

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Priorities to improve outcomes and support for men  
living with prostate cancer in the Asia Pacific region

# Founding Members

## of the Prostate Cancer Patient Coalition – Asia Pacific™

*(in alphabetical order)*

### **Prostate Cancer Patient Association, Korea,**

as represented by Dar Sook Lee, Chairman and Founder

### **Prostate Cancer Foundation of Australia,**

as represented by Associate Professor Anthony Lowe, Chief Executive Officer

### **China Primary Health Care Foundation,**

as represented by Hu Ningning, Deputy Secretary-General

### **Senyu Club, Japan,**

as represented by Tsutomu Takeuchi, Board Chairperson

### **Prostate Cancer Prevention Association, Taiwan,**

as represented by Hsu Tsai-Yun, Secretary General

The founding members extend their gratitude to the following co-chairs of the inaugural meeting of the Prostate Cancer Patient Coalition – Asia Pacific, which took place in Tokyo in March 2017:

#### **Dr. Koichiro Akakura**

Department of Urology,  
Japan Community Health Care Organisation,  
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Clinical Professor,  
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# Foreword

Prostate cancer is on the rise in the Asia Pacific region and will become a major health issue over the coming years. Concerningly, low screening rates and inefficiencies in the delivery of care are leading to delayed diagnosis and high levels of mortality in some parts of the region. At the same time, many patients and their families are feeling unsupported while they are dealing with the huge impact this devastating disease has on their lives. Yet, there still is a lack of awareness regarding the condition and it is not readily seen as a priority area in healthcare policy or research.

In response, prostate cancer patient organisations from across the Asia Pacific region have come together for the first time to form a unified patient voice to drive change and improve the support for those affected by prostate cancer.

In combining regional reach with local relevance, the newly formed Prostate Cancer Patient Coalition – Asia Pacific aims to support better patient outcomes by educating stakeholders and communities about the gaps in prostate cancer care.

The Coalition's inaugural meeting in March 2017 brought together patient group representatives from Japan, Australia, China, Korea and Taiwan to share local perspectives on the challenges faced by men with prostate cancer, their caregivers and their families. The result of that work is this whitepaper that identifies actions each country should undertake to support men living with prostate cancer and to help reduce the burden of the disease in the region.

As the co-chairs, we are proud to have been part of the first Prostate Cancer Patient Coalition – Asia Pacific meeting and are hopeful that it is the beginning of a long-term effort that strives to advocate for prostate cancer to become a health priority in the region and improve the lives of those with the condition.



**Dr. Koichiro AKAKURA**

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# Executive Summary

Prostate cancer is the second most common cancer and the fifth leading cause of cancer deaths in men worldwide.<sup>1</sup> In Asia, incidence rates have steeply increased over the past decades<sup>2</sup> and are expected to almost double by 2030<sup>3</sup> due to an aging population, increasing urbanisation and associated lifestyle changes.<sup>4,5</sup> In addition, men in Asia tend to get diagnosed in later stages of the disease compared to populations in Australia, Europe or the United States, leading to a poorer prognosis and higher incidence to mortality ratio.<sup>2</sup> While these trends are largely universal across the region, the situation varies between countries, depending on their economic situation and healthcare system.<sup>2,4</sup>

The screening tests and treatment approaches available today mean that men diagnosed with prostate cancer can live for many years.<sup>6</sup> However, most treatments are associated with significant long and short term side effects, including erectile, urinary or bowel dysfunction.<sup>7,8</sup> This can lead to depression, a feeling of 'loss of masculinity' or shame, which have a significant impact on a patient's quality of life.<sup>7</sup> Therefore, it is important that quality of life considerations play a role in the treatment decisions and men living with prostate cancer are provided with the support they need.<sup>7,9</sup>

Despite the significant and growing impact of prostate cancer, it remains a low priority on the healthcare agendas of most Asian countries<sup>10</sup> leaving patients feeling less supported than those suffering from other cancers. Developing national policies and providing increased support for men with prostate cancer is an urgent need that was highlighted in a recent Asian Men's Health Report.<sup>10</sup>

At the inaugural meeting of the Prostate Cancer Patient Coalition – Asia Pacific, held in Japan in March 2017, patient organisations from China, Australia, Japan, Korea and Taiwan identified six core areas that are the most important to improve the lives of those affected by prostate cancer across the region:



**Low awareness of prostate cancer**



**Varying rates of testing for prostate cancer**



**Lack of support for men following treatment**



**Financial burden of treatment**



**Treatment specific challenges**



**Challenges in the delivery of care**

*Prostate Cancer remains a low priority on the healthcare agendas of most Asian countries.<sup>10</sup>*

To address these challenges, the following goals have been identified as priorities:

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

The patient organisations have formed the Prostate Cancer Patient Coalition – Asia Pacific to support a collaborative approach and create a unified voice to drive this change across the region to reduce the burden of prostate cancer.



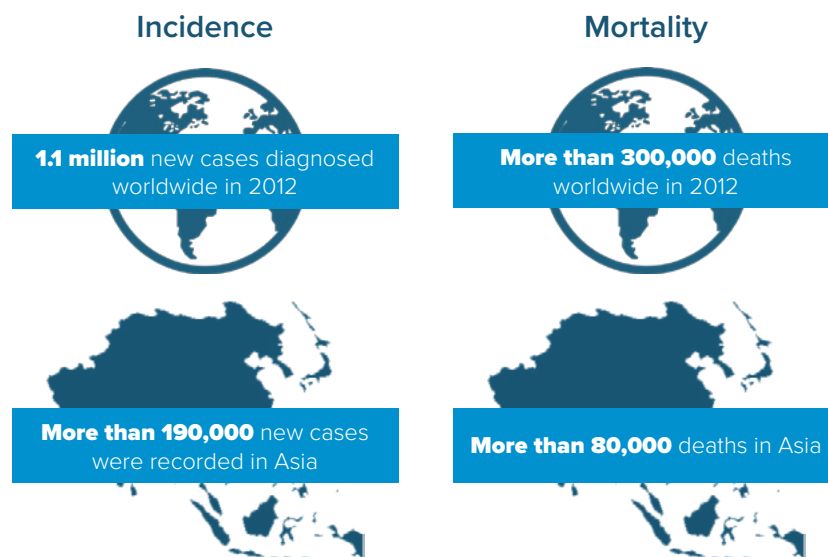
# Prostate cancer in Asia

## The growing impact

Prostate cancer is the second most common cancer and the fifth leading cause of cancer deaths in men worldwide.<sup>1</sup> In Asia, the most recent figures show that over 190,000 new cases are recorded annually and more than 80,000 deaths.<sup>4</sup>

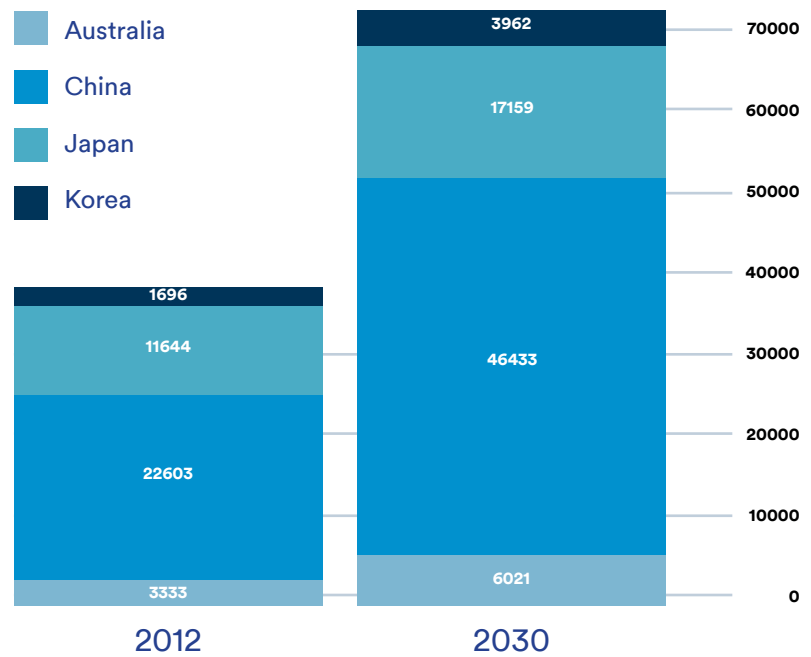
While incidence rates for prostate cancer have historically been lower in Asian countries compared to Australia, North America or Europe, recent decades have seen a steep increase in diagnosis.<sup>2,11</sup> In addition, both incidence and mortality are expected to double by 2030,<sup>3,12</sup> making prostate cancer a major public health issue with a growing impact on the population and the healthcare systems across the region.<sup>4</sup>

**Figure 1.**  
Incidence and mortality of prostate cancer worldwide and in Asia<sup>1,4</sup>





**Figure 2.**  
 Estimated number of deaths from prostate cancer in Australia, China, Japan and Korea between 2012 and 2030<sup>3,12</sup>



*In Asia, the incidence of prostate cancer and mortality rates are expected to double by 2030.*<sup>3,12</sup>

**Two developments are believed to be the key driver of this increase:**



### **Aging population**

Prostate cancer has a higher incidence in older men, with a steep increase in Asian countries in men over 60 years of age.<sup>5</sup> As the population in Asia is aging and the number of elderly people is projected to reach almost 923 million by 2050,<sup>13</sup> the incidence of prostate cancer is set to increase significantly.<sup>4,14</sup>



### **Urbanisation and lifestyle changes**

Economic growth and development is leading to significant changes in many countries. Rising industrialisation and urbanisation are increasing risk factors of prostate cancer, including more animal fats introduced into the diet, less physical activity and higher pollution rates.<sup>2,5</sup>

While these trends are universal across the region, the situation varies from market to market.<sup>2,4</sup> In more developed economies with more mature healthcare systems, the incidence is generally higher and the mortality rates are lower.<sup>2,4,5</sup> For example, Japan, Australia and Korea have some of the highest incidence rates in the region while China and Taiwan report some of the lowest. Yet, almost every second person diagnosed with prostate cancer in China and every fourth in Taiwan dies from the disease, while in Australia the incidence / mortality ratio is around 10%<sup>15,16,17,18,19</sup> One of the reasons for this is that patients in less developed regions in Asia tend to get diagnosed in later stages of the disease, leading to a worse prognosis in most cases. In comparison, patients in more mature healthcare systems get diagnosed in earlier stages of the disease, leading to better outcomes.<sup>2</sup>

*Men in Asia tend to get diagnosed in later stages of the disease, leading to worse prognosis.<sup>2</sup>*

**Figure 3. Incidence and mortality rates of prostate cancer in:**<sup>15,16,17,18,19</sup>





# About prostate cancer

Prostate cancer occurs when abnormal cells develop in the prostate and continue to multiply, forming a malignant tumour (localised disease). When the cancer progresses to an advanced stage, it invades surrounding tissues, including the bladder, rectum, and the peri-prostatic fat (locally advanced disease). The cancer can also spread to lymph nodes, bones and other organs (advanced or metastatic disease).<sup>20</sup>

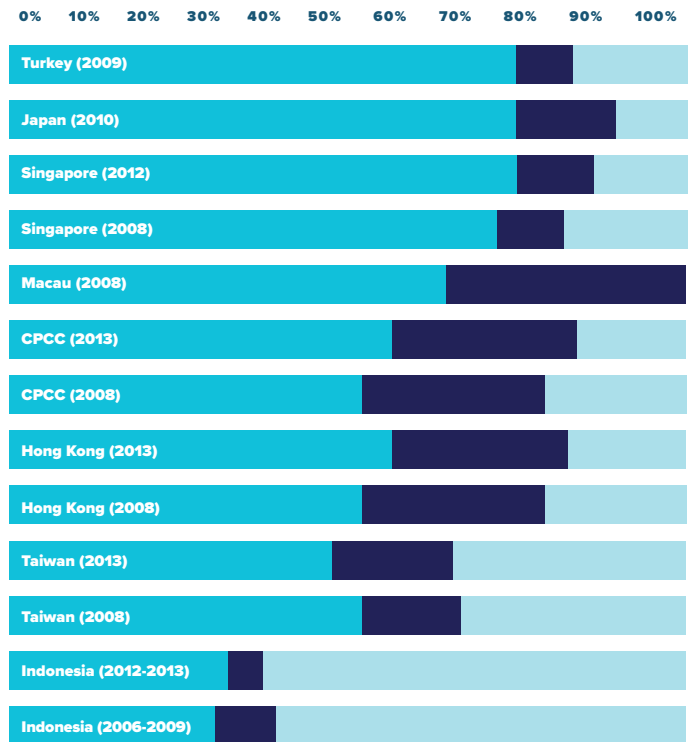
In the early stages of prostate cancer, there may be no or unspecific symptoms. In the later stages, some symptoms of prostate cancer might include:

- **Feeling the frequent or sudden need to urinate**
- **Finding it difficult to urinate**
- **Discomfort when urinating**
- **Finding blood in urine or semen**
- **Pain in the lower back, upper thighs or hips.**<sup>21</sup>

*It is important that quality of life and patient preferences play a role in the treatment decisions.*<sup>20,24</sup>

**Figure 4.**  
Stages of diagnosed prostate cancer in Asian markets<sup>2</sup>

- Localised
- Locally advanced
- Metastasis



Early detection and treatment can significantly improve prostate cancer survival. The tests most commonly used to aid early detection of prostate cancer are digital rectal examination (DRE) and the prostate specific antigen (PSA) blood test that measure a protein produced by prostate and prostate cancer cells. However, neither test is specific to prostate cancer, and a biopsy is required for diagnosis. After diagnosis, DRE, PSA, CT/ MRI tests and bone scans are used to determine cancer stage and grade (measured by the Gleason score).<sup>21,22</sup>

An individual's treatment depends on the cancer stage and their Gleason score as well as their age and overall health.<sup>23</sup> As men diagnosed with prostate cancer today can live for many years and most treatments can be associated with significant long and short-term side effects, it is important that quality of life and patient preferences play a role in the treatment decisions.<sup>20,24</sup>

## Depending on the outcome of the assessment, there are five main treatment approaches:<sup>23</sup>

### Active surveillance

As men with low risk prostate cancer can live many years without their cancer progressing, active surveillance is a viable option. Regular tests are conducted to check if the cancer is progressing and if treatment might be warranted.

### Prostatectomy

The surgical procedure used to remove the prostate is an option for localised prostate cancer in men fit for surgery. Once the cancer has spread, surgery is no longer curative and may not be viable, however in some cases it may be performed to de-bulk the cancer or as a salvage treatment.<sup>20, 26</sup>

### Radiation

To destroy cancer cells, radiation therapy, such as x-rays or particle beams (including heavy particle beam and proton beam)<sup>27</sup> may be recommended to treat localised or advanced prostate cancer, relieve pain, discomfort or other symptoms. Other novel therapies such as Radium 223 can help patients with advanced disease to control symptoms and extend life.<sup>24</sup>

### Androgen deprivation therapy (hormone treatment)

To help slow the growth of the cancer, androgen deprivation therapy involves medication that stops the production of testosterone. This is a common option for advanced disease and may also be used in patients that are unsuitable for surgery or radiation therapy. In combination with other treatments, it is also used to decrease the risk of recurrence.<sup>28</sup>

### Chemotherapy

This treatment option might be used if the cancer spreads and other treatments failed.





## Living with prostate cancer

A diagnosis of prostate cancer can be devastating for the individual and those close to him. In addition to the psychological burden of facing an uncertain future,<sup>29</sup> the side effects of treatment can have a significant impact on the quality of life of men living with prostate cancer – during treatment and after.<sup>7</sup>

Often, erectile dysfunction (ED) is a much feared complication from the cancer itself or from surgery, radiation and hormonal therapy.<sup>7</sup> In many cultures, ED is associated with ‘loss of masculinity’ and can lead to depression as well as relationship problems due to the increased stress.<sup>7</sup> Loss of fertility is another frequent side effect from treatment that is of particular concern for younger men who wish to father children.<sup>30</sup>

Surgery and radiation can also cause urinary and bowel dysfunction. The fear of urine leaking or bowel accidents is humiliating to many men. In fact, urinary incontinence has been rated a worse outcome than ED.<sup>7</sup>

However, despite these side effects, some prefer treatment over active surveillance even in the early stages of disease, due to the distress and anxiety that might be caused by fear of progression.<sup>31</sup>

In addition, the fear of recurrence of cancer following treatment has a significant impact on men’s quality of life and dealing with recurring cancer can be harder than dealing with the initial diagnosis.<sup>20,32</sup>

Even though the impact of prostate cancer is significant, there is limited support available in most countries for men and their families after diagnosis or after treatment.

*“There is limited support available in most countries for men and their families after diagnosis or after treatment.”*

Prostate Cancer Patient Coalition – Asia Pacific

*“Men with prostate cancer feel less supported than men suffering from other types of cancers.”*

Prostate Cancer Patient Coalition – Asia Pacific

## Challenges in the Asia Pacific Region

Despite the significant and growing impact of prostate cancer, the condition remains a low priority on the healthcare agendas of most countries in the Asia Pacific region.<sup>10</sup> Members of the Prostate Cancer Patient Coalition – Asia Pacific report that patients feel less supported than those suffering from other cancers, such as stomach, liver or colorectal, even though they are becoming as significant in numbers.<sup>33</sup>

To provide support to men affected by prostate cancer, patient organisations have formed in many countries to heighten awareness of the disease, educate stakeholders and communities, and advocate for cancer to become a health priority area.

While each group is faced with very specific challenges due to their varying healthcare systems and cultural perceptions towards cancer and men’s health, the Prostate Cancer Patient Coalition – Asia Pacific identified six core areas that are the most important to address to improve the lives of those affected by prostate cancer in their markets and across the region:



**Low awareness of prostate cancer**



**Varying rates of testing for prostate cancer**



**Lack of support for men following treatment**



**Financial burden of treatment**



**Treatment specific challenges**



**Challenges in the delivery of care**



## Low awareness of prostate cancer

As reported by the Prostate Cancer Patient Coalition – Asia Pacific, men with prostate cancer feel less supported than patients with other cancers, such as women with breast cancer, which is largely due to a lack of understanding of the impact of the disease.

**“ Although in Australia, the public profile of prostate cancer has increased markedly over the last 10 years, more needs to be done to improve community awareness and men’s understanding of the disease and the risk factors. ”**

Anthony Lowe, Chief Executive Officer,  
Prostate Cancer Foundation of Australia

**“ The incidence rates of prostate cancer are surpassing those of stomach cancer, the most common cause of cancer in Japan, yet awareness and understanding of the disease is still very low. ”**

Tsutomu Takeuchi, Board  
Chairperson, Senyu Club, Japan

**“ In Korea, men tend not to discuss their health and this is also echoed in the media where there is a higher level of reporting of women’s and child health issues. The rapidly increasing death rates due to prostate cancer is a compelling argument for greater community awareness. ”**

Dar Sook Lee, Chairman and Founder, Prostate Cancer Patient Association, Korea

**“ Men’s health is not commonly discussed in Chinese society and less attention is paid to the needs of men’s health compared to women’s health and care, so public awareness of prostate cancer is low. This is particularly concerning as in China men are diagnosed in the later stages of the disease which significantly impacts their prognosis. ”**

Hu Ningning, Deputy Secretary-  
General, China Primary Health Care  
Foundation

**“ Whilst men’s health has a relatively high profile in Taiwan, the awareness of prostate cancer is quite low and is not generally covered in the media or talked about in communities. Prostate cancer is seen as an old man’s disease and some men see continence issues as a normal part of aging which may be why interest is low. ”**

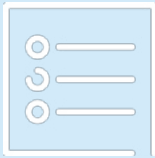
Hsu Tsai-Yun, Secretary General,  
Prostate Cancer Prevention  
Association, Taiwan





## Varying rates of testing for prostate cancer

Prostate cancer testing rates across the region vary significantly,<sup>5</sup> and the Prostate Cancer Patient Coalition – Asia Pacific identified the following factors for the variation in testing practices:



Lack of consensus among governments and clinical bodies on the balance of benefits and harms from PSA testing



Low awareness of prostate cancer testing in some countries



Lack of a sensitive and specific test for prostate cancer i.e. an alternative to DRE and PSA testing



## Lack of support for men following treatment

The Prostate Cancer Patient Coalition – Asia Pacific agrees that more needs to be done in the broader communities to support and help men with prostate cancer deal with the consequences of their diagnosis and treatment.

**“ In Australia, men with prostate cancer might be living 30 years post-treatment, but without support for the problems they are living with, such as continence issues or sexual dysfunction, they often suffer from depression – this is one of areas which we are actively addressing in Australia. ”**

Anthony Lowe, Chief Executive Officer, Prostate Cancer Foundation of Australia

**“ Men with prostate cancer often experience a loss of masculinity or incontinence after surgery, which can be very hard for them in the Korean society. One of our main goals as an organisation is to connect men with each other who have gone through the same experience to ensure they have someone that can help them through this tough time. ”**

Dar Sook Lee, Chairman and Founder, Prostate Cancer Patient Association, Korea

**“ As men in China are often diagnosed at a late stage of the disease and therefore have a poor prognosis, it is important that they receive support to help them and their families understand the diagnosis and the management and treatment options available to them. ”**

Hu Ningning, Deputy Secretary-General, China Primary Health Care Foundation

**“ Before we established the Senyu Club, there was no patient group or peer to peer networks that Japanese men with prostate cancer could turn to for support or information. Now over 600 men reach out to us daily, which shows how desperately they need help, and many still remain without the support they need. ”**

Tsutomu Takeuchi, Board Chairperson, Senyu Club, Japan

**“ At our regular events and through our call line we can see how much patients benefit from the opportunity of talking to us or another about their daily struggles. This proves that having a support network is extremely important and we would like to extend such initiatives to continue to support our patients and members. ”**

Hsu Tsai-Yun, Secretary General, Prostate Cancer Prevention Association, Taiwan



## Financial burden of treatment

Prostate cancer places a financial burden on those affected across the region and the Prostate Cancer Patient Coalition – Asia Pacific believes the following factors contribute to this financial burden:



No or partial reimbursement for prostate cancer treatment



Restricted reimbursement for newer medical treatment options



Out of pocket expenses for surgical procedures



Potential for financial consequences of time away from work to undertake treatment



## Treatment specific challenges

While there are many different prostate cancer treatment options today, treatment decisions and a lack of quality of life considerations are a concern for the Prostate Cancer Patient Coalition – Asia Pacific.

**“ One of the challenges we face in Australia is that the treatment decision is often made without considering all possible options, for example active surveillance, which can be the best option for some men. We see the tendency to prioritise a surgical approach above other possible options and it sometimes seems as if clinical practice is running ahead of the scientific evidence and patient preference in support of new treatments. ”**

Anthony Lowe, Chief Executive Officer,  
Prostate Cancer Foundation of Australia

**“ While 60% of prostate cancer patients in Korea are treated with surgery, robotic surgery is out of the scope of our health insurance system. To ensure Korean men can achieve the best possible treatment outcomes with minimal long-term impact on their lives, one of our main goals as an association is advocate for access to procedures and newer treatments. ”**

Dar Sook Lee, Chairman and Founder,  
Prostate Cancer Patient Association,  
Korea

**“ To serve a patient’s need and to satisfy a patient’s need are two very different things. In China, it will be important to educate patients about the benefits of different treatments and continue to ensure access to a variety of treatment options, so every patient can get the treatment that best suits his disease stage and preference. ”**

Hu Ningning, Deputy Secretary-General, China Primary Health Care Foundation

**“ Men with prostate cancer in Japan have many treatment options available to them. However, we have no patient guidelines and limited information around the different types of prostate cancer. As a result, patients are unsure about their options and treatment decisions are most likely dictated by the physician, who often recommends robotic surgery over active surveillance. ”**

Tsutomu Takeuchi, Board Chairperson, Senyu Club, Japan

**“ As we have National Healthcare Insurance in Taiwan, it is very important for patients living with prostate cancer to have innovative treatments reimbursed as part of this program. For example, a novel hormone therapy finally received reimbursement in September this year and that provides a great opportunity for metastatic patients. However, patients still need accurate diagnostic reports so they could tell who should be on active surveillance, who needs a biopsy and who needs aggressive treatment. ”**

Hsu Tsai-Yun, Secretary General, Prostate Cancer Prevention Association, Taiwan



## Challenges in the delivery of care

As prostate cancer is a complex disease, optimal patient care requires highly-skilled healthcare professionals from different disciplines working together.<sup>34</sup>

**“ While cooperation between urologists, medical oncologists and radiation oncologists is improving, multidisciplinary team meetings and ensuring adequate referrals are still issues we are actively working on. ”**

Anthony Lowe, Chief Executive Officer, Prostate Cancer Foundation of Australia

**“ Patients living with prostate cancer in Taiwan often worry about side effects like continence issues or ED from castration or radiotherapy. Our Association often conducts free educational lectures to assist patients in understanding how to find the right assistance and support and to help them connect to other patients. However the coverage of our Association is limited so this is an area that the healthcare system needs to pay attention to. ”**

Hsu Tsai-Yun, Secretary General, Prostate Cancer Prevention Association, Taiwan

**“ Newly diagnosed patients in Korea are often unsure if they should see an urologist or a radiologist for their treatment. To begin bridging this gap, we are offering information events that specifically address this question. ”**

Dar Sook Lee, Chairman and Founder, Prostate Cancer Patient Association, Korea

**“ Because of China’s growing population, doctors are treating many patients at once. To provide the best possible care for men with prostate cancer, we constantly need to increase the number of doctors that can treat this complex disease and develop specialists to meet the rising demand. ”**

Hu Ningning, Deputy Secretary-General, China Primary Health Care Foundation

**“ In Japan, urologists and radiotherapists rarely work together, so it is difficult for patients to see all their treatment options. ”**

Tsutomu Takeuchi, Board Chairperson, Senyu Club, Japan



# A United Voice for Change

## A Call to Action

Given the increasing impact of prostate cancer in the Asia Pacific region coupled with expectation that incidence rates will almost double by 2030<sup>3</sup> and men living with prostate cancer feel less supported than men living with other types of cancer, The Prostate Cancer Patient Coalition – Asia Pacific believes a united patient voice is critical to drive change to improve the support and care of men with prostate cancer in the region.

As one voice, the Prostate Cancer Patient Coalition – Asia Pacific is calling on communities and the governments across the region to support men with prostate cancer by:

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

The founding members of the Prostate Cancer Patient Coalition – Asia Pacific are committed to delivering on this four-point action plan and supporting men with prostate cancer in their markets and across the region.

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**“ In Australia, we are focusing on improving healthcare services to increase support for men living with prostate cancer. Our goal is to increase the number of Prostate Cancer Specialist Nurses and to develop integrated wellness programs for men who have undergone treatment. ”**

Anthony Lowe, Chief Executive Officer, Prostate Cancer Foundation of Australia

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**“ We continue to work to elevate prostate cancer on the national policy agenda to improve access to and reimbursement of new treatments. The aim is to raise awareness of prostate cancer to support patients and to empower doctors to provide optimal care to men living with the disease in China. ”**

Hu Ningning, Deputy Secretary-General, China Primary Health Care Foundation

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**“ The Senyu Club has two focus areas. One is the continued effort to raise awareness around the impact of prostate cancer on men in Japan. The second is to provide patients and their families with balanced and comprehensive information around treatment options through various channels to ensure informed treatment decisions. ”**

Tsutomu Takeuchi, Board Chairperson, Senyu Club, Japan

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**“ As a priority, the Prostate Cancer Patient Association, Korea aims to increase public awareness of prostate cancer to support screening and early detection. A key component of this will also be to enable information exchange between those affected by the condition. ”**

Dar Sook Lee, Chairman and Founder, Prostate Cancer Patient Association, Korea

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**“ The Prostate Cancer Prevention Association, Taiwan conducts educational lectures based on patients’ needs, and offers balanced and accurate medical information to help patients make the right decisions. We will continue to accompany them throughout what can be a confusing and stressful journey and help them walk out from the dark, enjoy the sunshine and get back to their normal lives. ”**

Hsu Tsai-Yun, Secretary General, Prostate Cancer Prevention Association, Taiwan

# About the Prostate Cancer Patient Coalition – Asia Pacific

The Prostate Cancer Patient Coalition – Asia Pacific aims to address the challenges faced by men living with prostate cancer in the Asia Pacific region. As one united patient voice, the 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 men living with prostate cancer**
- **Advocating for prostate cancer to be a health priority**
- **Empowering patients and their families**

The inaugural meeting of the Prostate Cancer Patient Coalition – Asia Pacific was held on 30th March 2017 in Tokyo, Japan. Co-chaired by Dr. Koichiro Akakura (Tokyo Shinjuku Medical Centre, Japan) and Professor Damien Bolton (University of Melbourne, Australia), the Coalition consists of five patient organisations from markets across the region:

- **Prostate Cancer Foundation of Australia**
- **China Primary Health Care Foundation**
- **Senyu Club, Japan**
- **Prostate Cancer Patient Association, Korea**
- **Prostate Cancer Prevention Association, Taiwan**

The outcome of the inaugural meeting is the ***Prostate Cancer Asia Pacific Whitepaper Report: A united voice for change*** and the contents of this whitepaper reflect the presentations and discussions from the meeting.

The Prostate Cancer Patient Coalition – Asia Pacific has agreed to implement a joint initiative on an annual basis to support patients across the region. It is hoped that this collaborative approach will provide a platform for the founding organisations to learn from each other, develop new ideas and approaches and exchange information on progress and best practice.

The Prostate Cancer Patient Coalition – Asia Pacific is seeking further prostate cancer patient organisations from across the Asia region to join the Coalition and will be seeking additional sponsors to support their work.





# Appendix

# About the Prostate Cancer Patient Coalition – Asia Pacific Founding Member Organisations



## Prostate Cancer Foundation of Australia



Group Representative  
**Associate Professor  
Anthony Lowe,**  
Chief Executive Officer

### **About**

The Prostate Cancer Foundation of Australia is a broad-based community organisation and the peak national body for prostate cancer in Australia.

### **Vision and goals**

We are dedicated to reducing the impact of prostate cancer on Australian men, their partners and families, recognising the diversity of the Australian community.

### **Our activity includes:**

- Promoting and funding world-leading, innovative research into prostate cancer
- Implementing awareness and advocacy campaigns and education programs for the Australian community, health professionals and Government
- Supporting men and their families affected by prostate cancer through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses



# China Primary Health Care Foundation



Group Representative  
**Hu Ningning,**  
**Deputy Secretary-General**

## **About**

The China Primary Health Care Foundation was established in 1996. The Foundation was initiated by the Central Committee of the Chinese Peasants' and Workers' Democratic Party and the National Health and Family Planning Commission.

## **Vision and goals**

- Create an environment where patients have ready access to treatment with a reduced financial burden
- Provide better treatment for patients
- Increase the number of doctors in our treatment networks and empower them to provide optimal care
- Collate useful clinical data on prostate cancer in China



# Senyu Club, Japan



Group Representative  
**Tsutomu Takeuchi,**  
Board Chairperson

## **About**

The Senyu Club was established in 2014. It represents the first and only advocate group for prostate cancer patients. With the support of 400 members, the Senyu Club conducts consultations and supports activities with the objective of providing accurate information on prostate cancer to patients and their families.

## **Vision and goals**

- Promote medical care, preservation of health, and welfare of patients
- Promote information sharing about prostate cancer to patients through social media
- Build disease awareness through academia, culture, the arts, or sports events
- Support the expansion of counseling seminars, learning sessions and some face-to-face sessions



# Prostate Cancer Patient Association, Korea



Group Representative  
**Dar Sook Lee,**  
Chairman and Founder

## **About**

The Prostate Cancer Patient Association was established in March 2017. It was formed from an online community created in 2013.

## **Vision and goals**

- Empower prostate cancer patients
- Increase opportunities to improve patient outcomes
- Recognise challenges prostate cancer patients face
- Share experiences and knowledge among patients



# Prostate Cancer Prevention Association, Taiwan



Group Representative  
**Hsu Tsai-Yun**  
Secretary General

## **About**

The Prostate Cancer Prevention Association was established in 2007 in Taiwan as the first national prostate cancer patient group established.

## **Vision and goals**

Our key objectives are to increase awareness of prostate cancer and to promote the importance of the PSA for early detection.

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