

Different stages, different perceptions: understanding why not all prostate cancer and patients are the same







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(in alphabetical order of representative)

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This report is a result of the Not All Prostate Cancer is the Same Patient Perception research study, both of which were commissioned by Janssen, a division of Johnson & Johnson Pte. Ltd. and executed by SenateSHJ. Both the research study and this report were prepared in consultation with the co-Chairs of the Prostate Cancer Patient Coalition — Asia Pacific™.

 $\ensuremath{\mathbb{C}}$ Janssen, a division of Johnson & Johnson Pte Ltd. 2019.



Foreword

When we talk about prostate cancer, we are not just talking about one disease, but a number of different disease states that share one thing in common – cancer that originated in the prostate.

Prostate cancer exists in many different forms, and as our understanding of the disease advances, so does our ability to diagnose and treat those affected as early and as effectively as possible.

However, whilst clinicians frequently debate clinical management strategies for different stages of prostate cancer with each other, there tends to be less discussion about this with patients, and even less again with the general public. What this means is that prostate cancer patients and their caregivers can be left without all the information they need to make informed decisions about the management of their disease.

Data shows that patients with better awareness and understanding of their disease are more likely to be diagnosed early and therefore have better survival. We have seen how this can work in the case of breast cancer, where a concerted effort over many years to improve understanding has led to increased knowledge levels amongst the public, a substantial increase in early diagnosis, and improved survival rates.

It is the role of the treating physician to assess the evidence and recommend the best treatment approach. It is also the duty of a treating physician to provide the best possible information to patients and their families, to support them to make informed decisions about their treatment. However, to date, there has been no systematic collection of data in the Asia Pacific region to understand the unique perspectives of our patients with prostate cancer based on disease stage, making it difficult for physicians to provide support that meets their individual needs.

The data contained in this report therefore gives us the first ever insights into prostate cancer patients' needs and preferences in the region, and how they may differ depending on the stage of disease. It also provides some thoughts for how we can work together to address them.

We need to create a more informed public; one that recognizes the signs and symptoms – and potential lack thereof - of prostate cancer across the different stages of the disease to help improve early detection and treatment. We also need to recognize that just as not all prostate cancer is the same, not all patients are the same, and we need to work together to ensure the support we provide takes into consideration their disease stage.

As co-Chairs of the Prostate Cancer Patient Coalition – Asia Pacific (PCPC), we recognize the critical role that patient organizations, in partnership with patients and their families, play in driving positive change. We are honoured to be working with the PCPC to better understand and address the needs of people living with prostate cancer across Asia Pacific. We hope this data and the PCPC's efforts spark continued improvement in both how the disease is managed, and the quality of life of those living with prostate cancer in the region.

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Prostate cancer in Asia Pacific

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. The group identified four goals to prioritize efforts to improve outcomes and support for people living with prostate cancer, which were published in the first report on the impact of prostate cancer in the region.

The Not All Prostate Cancer is the Same report seeks to build on the PCPC's work to date and provide new insights into the needs of people 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.





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. people with a family history of the disease.

A concerning picture



SECOND MOST

commonly occurring cancer in men worldwide.

5TH LEADING

commonly occurring cancer in men worldwide.



In Asia, the incidence of prostate cancer has

INCREASED STEEPLY over the past decades.⁵

It is expected to almost **DOUBLE BY 2030.**⁶

aging population, increasing urbanization and associated lifestyle changes.^{7,8}

This increase is due to an

People in Asia tend to get

DIAGNOSED IN LATER STAGES

of the disease compared to populations in Australia, Europe or the United States.⁵

This leads to a **POORER PROGNOSIS** and higher incidence to mortality ratio.⁵

While these trends are largely universal across the region, the situation varies between locations, depending on their economic situation and healthcare system ^{5,7}



A focus on improving outcomes through awareness and education

Focusing on increasing early detection and treatment can significantly improve prostate cancer survival and is a key priority of the PCPC. As seen in the case of breast cancer, public awareness and education can improve the rate of diagnosis in early stages of the disease and enable people to take greater ownership of their own health and health care.

Recognizing a gap in understanding of the factors influencing time to diagnosis and ability to actively participate in decisions about treatment, the first research into prostate cancer patients' perceptions across the region was undertaken to explore these issues. Given the importance of personal preference and quality of life in treatment decisions, the research sought to identify the information and education needs of people with prostate cancer across the region, based on their stage of the disease. Called Not All Prostate Cancer is the Same – Patient perceptions: An Asia Pacific study, the results of the research were published in June 2020 by the British Journal of Urology International.

Not all prostate cancer is the same

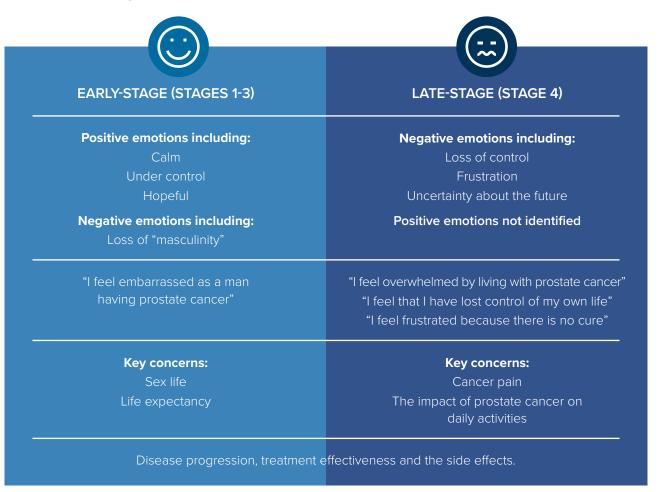
There are stark differences in how people with prostate cancer in Asia Pacific feel about their condition, depending on the stage of their disease.

People's concerns vary depending on their disease state – those with earlier stage disease are most concerned about disease progression and treatment options, whereas those with advanced prostate cancer are most concerned about pain and physical changes to their body.

Whilst these concerns may at face value seem somewhat obvious, in light of their likely prognosis due to the stage of cancer, they nonetheless highlight the importance of providing tailored support and information to people with prostate cancer based on their stage of disease.



Different stage, different state of mind





"It is clear we need to do more to debunk the perception that prostate cancer only impacts the elderly, and to improve recognition of symptoms across all ages. Poor knowledge of prostate cancer symptoms is the primary factor influencing time to diagnosis. There is an urgent need for increased public awareness of prostate cancer symptoms."

PROSTATE CANCER FOUNDATION AUSTRALIA

Poor understanding of prostate cancer delays diagnosis

Critically, the Not All Prostate Cancer is the Same 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 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.

Unfortunately, the Not All Prostate Cancer is the Same study found:

- 60% 80% of patients in Asia Pacific have no knowledge of prostate cancer prior to diagnosis
- People living with prostate cancer in Japan, China, Taiwan and Korea have the lowest levels of knowledge.

Misperceptions of prostate cancer are common amongst people in Asia Pacific. For example, most people believe prostate cancer only affects the elderly (>65 years).

Recognition of prostate cancer symptoms is extremely poor across the region:

- "9 in 10 people in Asia Pacific do not know the symptoms of prostate cancer before being diagnosed:
 - In Australia, where there are higher levels of awareness of prostate cancer prior to diagnosis, 7 in 10 people do not know the symptoms.
 - In China, no patients reported prior knowledge of prostate cancer symptoms,
 - In Japan, Korea and Taiwan, 93% of patients do not know the symptoms of prostate cancer before diagnosis.

"I was not aware of the symptoms at all...I wish I had known the symptoms"

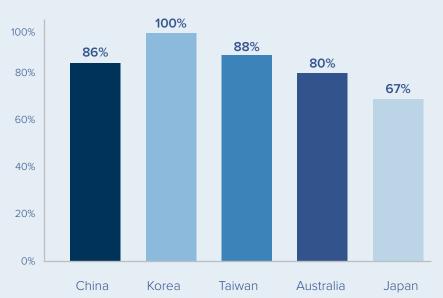
"I do not know the details. I knew some things about high blood pressure and diabetes before I was diagnosed, but not for prostate cancer"





Figure 1.

The perception about prostate cancer: "It's a condition for older men".



Whilst the majority of people with prostate cancer experience symptoms prior to diagnosis (primarily issues with urinating), these symptoms typically do not drive them to see their healthcare professional. The Not All Prostate Cancer is the Same study found people did not realize issues with urination could be related to prostate cancer - they assumed they were just part of getting older and/or were not serious.

Across Asia Pacific, the time from symptoms to diagnosis of prostate cancer varies:

- In Korea and Taiwan, the delay between experiencing symptoms and visiting a healthcare professional was six months.
- In Japan, the delay was up to two years.

"I wish there was an intervention program to help with early detection."

As identified in the Prostate Cancer Asia Pacific Whitepaper Report – A united voice for change, people in less developed regions in Asia tend to get diagnosed in the later stages of the disease, leading to a worse prognosis.

For example:

- Almost every second person diagnosed with prostate cancer in China will die from the disease⁹
- Every fourth person in Taiwan diagnosed with prostate cancer dies from the disease.¹⁰

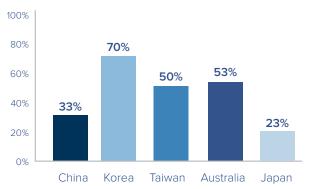
In contrast, whilst Australia has one of the highest rates of prostate cancer incidence in the region, only one in five Australians will die from the disease.¹¹

People with prostate cancer's ability to recall information varies

"To be perfectly honest, doctors could have gone through this info, but at the time you wouldn't be listening. There was a cloud over my head."

There is a significant variation in the percentage of patients reporting their doctor provided clear information on the different stages of prostate cancer across the region:







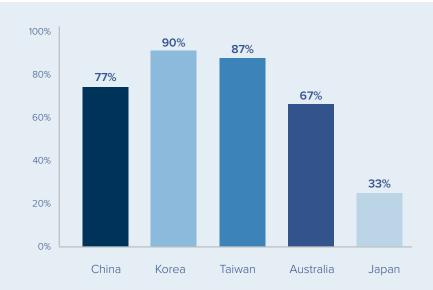
"It is not uncommon for people to feel overwhelmed during consultations with their doctor, particularly when that doctor may be conveying information such as an initial diagnosis of cancer or a progression of cancer. Understandably, this can have an impact on a person's ability to recall the information they are given during a consultation."

SENYU CLUB JAPAN

The research supports the need for more public awareness and knowledge of prostate cancer

Figure 2.
Unmet needs for information

"I wish I had known more about PC prior to diagnosis"





Across the region, the desire for more public awareness of prostate cancer is strong.

The key areas people wanted more knowledge of prostate cancer include:

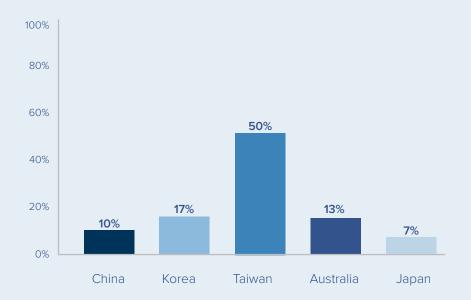
- Symptoms
- · What doctor to visit
- · Prostate-specific antigen (PSA) and what it means
- · The different stages of prostate cancer
- · Disease progression and its impact
- Treatment options per stage of prostate cancer
- How to select treatments.

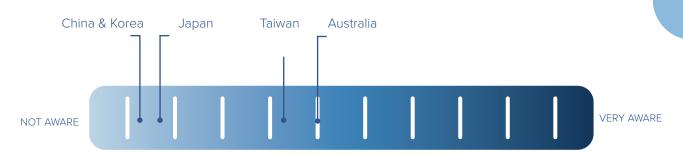
Limited understanding of the different stages of prostate cancer and disease progression impacts people's ability to make informed decisions about their treatment

Most people are aware that prostate cancer has different stages, but the vast majority of people across the region aren't able to distinguish between them.

Figure 3.
Knowledge after diagnosis

"I know how to distinguish different stages of prostate cancer"





AWARENESS OF TREATMENT OPTIONS PER STAGE PER LOCATION

People with prostate cancer in Asia Pacific believe they do not receive enough information about the different stages of prostate cancer or how the disease progresses. They also appear to have limited knowledge of the treatment options available for the different stages of disease.

There is a noticeable difference in the level of understanding of prostate cancer based on a person's disease stage. For example, many patients across the region with localized (stages 1-3) disease did not have a clear understanding of the different disease stages and future treatment options.

Regardless of disease stage, there was a consistent desire for greater knowledge and information

Patients wanted:

- · their healthcare professionals to use simplified language,
- more information and education materials,
- greater psychological support.





Snapshots from the region

Australia

Awareness and knowledge

Australians have high levels of awareness of prostate cancer as a result of public awareness campaigns. Awareness of treatment options and disease progression amongst patients was also higher than other locations in the region.

State of mind

Interestingly, similar to in China, Australians with late stage prostate cancer were especially overwhelmed by negative emotions compared to those with early stage prostate cancer. People whose disease had metastasized felt a strong sense of restriction due to not being able to do what they want, e.g. being physically active, travel without limitation.

Involvement in decision making about treatment

Surgery is a common treatment approach in Australia, and patients in this location felt their doctor involved them sufficiently in decisions about their treatment. They also felt their doctor gave them enough time to make decisions about surgery, which is in contrast to some other locations involved in the study.





China

Awareness and knowledge

Awareness of prostate cancer and knowledge of symptoms is extremely poor in China. None of the patients surveyed in the Not All Prostate Cancer is the Same study had heard of prostate cancer symptoms prior to diagnosis. Interestingly, this did not cause a delay in visiting the doctor once symptoms occur, however it was clear from the study that prostate cancer was not suspected prior to diagnosis.

State of mind

Like patients in Australia, those with late stage of prostate cancer in China were especially overwhelmed by negative emotions compared to those with early stage prostate cancer. The emotions they were most likely to identify with included feeling overwhelmed, that their life is out of their control and frustration at the lack of cure.

Involvement in decision making about treatment

Patients in China had a lower awareness of treatment options and disease progression compared to patients in other locations. Chemotherapy was the most common treatment received by patients in China.

"Reducing prostate cancer mortality in China and increasing survival is our core focus. A significant gap in information and support for people with prostate cancer in China is when they leave hospital and go back into the community. They don't have regular interactions with their doctor, and they need alternative sources of information and support which we are looking to fill by supporting interactions between people living with prostate cancer in China. We are also focused on promoting the benefits of screening and public education as the primary tool to increase early diagnosis and intervention."

Japan

Awareness and knowledge

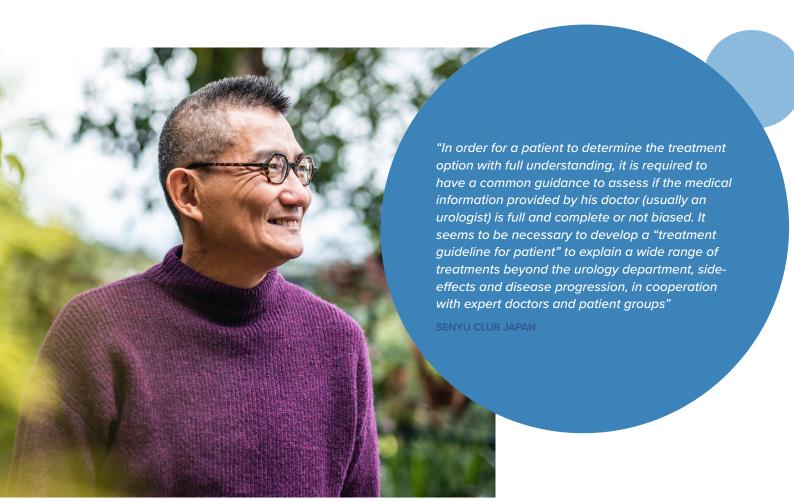
Awareness of prostate cancer, symptoms and disease stages is low in Japan, and the perception that prostate cancer only affects the elderly is common. This lack of knowledge appears to have a significant impact on the delay from onset of symptoms to the first visit to a healthcare professional in Japan, with patients reporting a delay of up to 2 years.

State of mind

Interestingly, Japanese patients experience a wide range of negative emotions regardless of disease stage and had very few positive emotions related to their disease.

Involvement in decision making about treatment

On the one hand, patients in Japan said they did not feel sufficiently involved in the decision-making process with their doctor. On the other hand, less than half of Japanese patients said they were motivated to take control of their condition or wanted more information. These contrasting results may be an indicator of the psychological impact of a cancer diagnosis, and the need to supplement any existing information provided by healthcare professionals.





Korea

Awareness and knowledge

As is the case in other locations in Asia Pacific, Koreans have low awareness of prostate cancer, symptoms and disease stages prior to diagnosis and a perception that prostate cancer is a condition for elderly men.

State of mind

Consistent with other locations in the region, Korean patients showed a greater extent of negative emotions during late stage disease, whereas those with localised disease felt calm, under control and hopeful with few negative emotions.

Involvement in decision making about treatment

Whilst healthcare professional communication was reported to be strong in Korea, including the provision of information on stages of prostate cancer, disease progression and involvement in treatment decisions, Korean patients, particularly with advanced disease, did not have a clear understanding of their treatment options.

"Aside from low awareness amongst the public about prostate cancer, there are a number of other important factors which may be influencing the delay between symptoms appearing and diagnosis.

There are many misconceptions about the cause of prostate cancer in Korea and this can lead to people feeling they are being blamed for the condition or ashamed of their diagnosis. People also don't think prostate cancer is serious in Korea, given our incidence and mortality rates have traditionally been lower than other locations in the region and around the world, so it doesn't receive a lot of public attention. These are all factors we are working to address."

PROSTATE CANCER PATIENT ASSOCIATION, KOREA



Taiwan

Awareness and knowledge

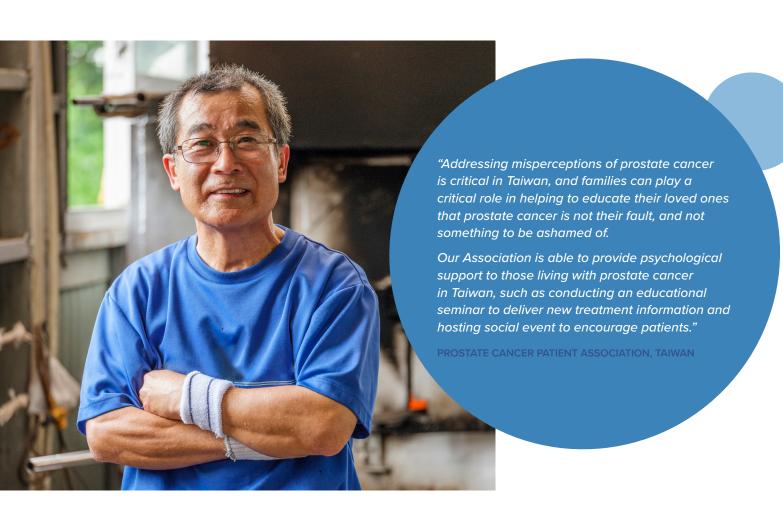
The Taiwanese have low awareness of prostate cancer, symptoms and disease stages prior to diagnosis. The misperception that prostate cancer is a condition for elderly men is commonly held amongst the population. In contrast, awareness of the different stages of prostate cancer and how to distinguish between them is high in Taiwan, which is indicative of the fact that patients in Taiwan tended to receive more in-depth information about prostate cancer and disease progression from their doctors.

State of mind

People with prostate cancer in Taiwan tended to have similar emotional responses based on their disease stage. Those with advanced disease had a greater extent of negative emotions, whereas those with localized disease were more likely to feel calm, under control and hopeful with few negative emotions.

Involvement in decision making about treatment

Fairly high levels of understanding of the treatment options per stage and involvement in treatment decisions was reported by Taiwanese patients. Most reported being given sufficient time to decide on surgery. Of concern, the majority believed they would be cured after surgery.





Summary of responses across locations

	Themes		Australia	China	Japan	Korea	Taiwa
General prostate cancer awareness and knowledge	Awareness of prostate cancer		+++				
	Knowledge of prostate cancer symptoms		++				
	Believe prostate cancer is a condition for older men only		+++		++		
	Delay between onset of symptoms and first visit to healthcare professional		<3 months or immediately	<1 month	1 month - 2 years	1 – 6 months	1 – 6 month
State of mind	Emotions – early stage		Mainly +/ve	Mainly +/ve	Mainly -/ve	Mainly +/ve	Mainl +/ve
	Emotions – late stage		Mainly -/ve	Mainly -/ve	Mainly -/ve	Mainly -/ve	Mainl -/ve
	Concerns – early stage	Disease progression	~	V	~	~	V
		Treatment options	~	V	~	~	
		Life expectancy	-	V	V	~	
		Impact on sexual life	V		V		
		Physical changes to the body	-		~	~	
	Concerns – late stage	Disease progression	~	~	~	~	V
		Treatment options	~	V	~	~	V
		Life expectancy	~	V	~	~	
		Impact on daily life	~	V	~	~	~
		Impact on sexual life	~		-	-	
		Physical changes to the body	~	~	-	~	V
		Pain associated with prostate cancer	~	~	~	~	~
Understanding of disease progression	Awareness of different stages		+++		++	+++	
	Know how to distinguish between stages		+		+	+	
	Know the different treatment options per stage		++		+	+	
	Know what it means when prostate cancer progresses from one stage to another		++		+	+	
Treatment decision making	Involvement in treatment decisions		+++				
	Sufficient time to make decision on surgery		+++		+	+++	
	Consented to undergoing surgery despite voicing reservations		+		++	+++	
	Believe surgery cures prostate cancer		++		+		

Key: +++ High (70–100% of patients) ++ Moderate (30–70% of patients) + Low (<30% of patients)

Definitions: +/ve = positive, -/ve = negative



Evolving our call to action

The Not All Prostate Cancer is the Same research demonstrates a clear and unmet need for greater public information and knowledge of prostate cancer in Asia Pacific, including its symptoms and disease stages. It also highlights the urgent need for psychological support for those affected by prostate cancer, to help them better manage living with cancer. Information and support are critical for patients to make informed decisions about the treatment that best suits them, based on their stage of disease and personal preferences.

Given the needs of people with prostate cancer vary dependent on their stage of disease, prostate cancer should not be thought of as one disease.

Information and support provided to those affected by prostate cancer needs to recognize the differences in mind set and behavior that are common to a disease stage and be tailored accordingly.

Whilst there are a number of common knowledge gaps about prostate cancer, it is important to recognize the unique needs and perspectives of people with prostate cancer per location in Asia Pacific and support efforts to address these locally.

The PCPC reiterates our previous call to action to drive change to improve the support and care of patients with prostate cancer in the region.

We remain committed to our action plan, outlined in the United Voice for Change report and seek to build on this action plan using the insights from the Not All Prostate Cancer is the Same research as follows:



Improve public awareness and understanding of prostate cancer, with a focus on symptoms and disease progression in order to:

- Improve early detection of prostate cancer
- Increase understanding of the potential seriousness of prostate cancer if not diagnosed early.



Improve healthcare delivery, consistency of management of prostate cancer and shared decision making between patients and their healthcare professionals by:

- Supporting the development of education materials that explain the stages of prostate cancer, disease progression, prognosis and treatment options in simplified language for clinicians to share with patients
- Creating a support guide for patient's families and carers, to ensure they have some knowledge and understanding of how best to support their loved one



Advocating for prostate cancer becoming a priority area in national health policy including:

 Improving access to psychological support for those affected by prostate cancer, particularly in later stages of the disease where patients have greater negative emotions and strong feelings of fear and uncertainty.



Improving public awareness of the importance of testing for prostate cancer, especially amongst high risk groups e.g. people with a family history of the disease in order to:

 Target efforts to address the increasing incidence and mortality of prostate cancer in Asia based on the area of greatest need.

About the Prostate Cancer Patient Coalition

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 PC



Educating communities, healthcare professionals and governments about the needs of patients living with PC



Advocating for PC to be a health priority



Empowering patients and their families.

About the Prostate Cancer Patient Association, Korea

The Prostate Cancer Patient Association was founded in March 2013. As of March 2017, the Association has 1,875 members and has successfully carried out 24 patient mentoring seminars.

The Association conducts two regular meetings per year with the aim of reaching the following objectives:

- 1. Empower the Prostate Cancer patients' right
- 2. Increase opportunities to improve patient outcomes
- 3. Recognize challenges prostate cancer patients are faced with
- 4. Share experiences and knowledge among patients.

About the Prostate Cancer Foundation of Australia

The Prostate Cancer Foundation of Australia (PCFA) is a "broad-based community organization and the peak national body for prostate cancer in Australia". The Foundation is dedicated to reducing the impact of prostate cancer on Australian men, their partners and families, recognizing the diversity of the Australian community. They do this by 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 and supporting men and their families affected by prostate cancer through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses.

About the China Primary Health Care Foundation

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. In August 2013, the Foundation set up a "life oasis" patient assistance fund, which was aimed to support and deepen government understanding towards improved medical security, social responsibility, and support patients in order to promote the development of a harmonious society.



About the Senyu Club, Japan

Established in 2014, accredited as an incorporated non-profit organization in 2016, the Senyu Club conducts consultations and supports activities with the objective of providing accurate information regarding prostate cancer to patients and their families. Through the collaboration of 500 members, they work towards the improvement of the medical environment, and promotion of medical care and welfare related to prostate cancer, through educational activities that improve society's level of awareness of prostate cancer in Japan.

The Senyu Club conducts:

- 1. Activities for the purpose of providing medical information, counseling and support to prostate cancer patients and their families.
- 2. Activities for the purpose of raising social awareness towards prostate cancer.
- 3. Activities for the purpose of making policy recommendations in collaboration with organizations related to prostate cancer.

About the Prostate Cancer Prevention Association, Taiwan

The Prostate Cancer Prevention Association is the first prostate cancer patient group established in Taiwan. The Association provides consultation prior to treatment, experience sharing during treatment as well as professional, educational knowledge for patients. They provide medical education to raise disease awareness and deliver the most up-to-date knowledge on treatment to patients. The Association supports, comforts and encourages patients through several engagements and outdoor activities to assist in stepping away from the fear that comes with diagnosis and reclaiming their lives with ease and joy.

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