

**MAKE
BLOOD
CANCER
VISIBLE**

#MAKEBLOODCANCERVISIBLE



**Perspectives from
Patients & Caregivers**

Asia Pacific

janssen  Oncology

PHARMACEUTICAL COMPANIES OF *Johnson & Johnson*

About the Cover Design

The practice of senbazuru originated in Japan. It was believed that a person who folded 1,000 paper cranes would be granted a wish from the gods. Since then, the practice of folding paper cranes has spread throughout Asia Pacific and it is used to represent the hope for longevity which the crane symbolizes. Paper cranes also have a special link to blood cancer through Sadako Sasaki, a young woman who was diagnosed with leukemia after World War II. It is said that folding cranes gave her focus and hope during treatment.

The image of a hand illuminated by light depicts the importance of bringing patients and their caregivers out from the shadows as we continue to work towards a world where every individual with blood cancer is seen, heard and supported.

Foreword by

Paul Kershaw

Vice President, Medical Affairs, Asia Pacific
Janssen, a division of Johnson & Johnson Pte. Ltd

The prevalence of blood cancer is growing in Asia Pacific and there is currently no cure for the over 140 different forms of the disease.

However, recent developments in how blood cancers are treated have seen dramatic improvements in quality of life and importantly, the amount of time people can live with blood cancer. Despite this, community awareness and understanding of blood cancer remains low and impacts those who live with blood cancer.

Janssen has a strong legacy of leading innovation in the treatment of blood cancers, by developing and providing transformational treatments that prolong and enhance lives, but we recognize that patients require more than treatment. Patients need information and support, they want to be seen and heard.

In response to this, we launched the Make Blood Cancer Visible initiative and commissioned the first-of-its-kind Make Blood Cancer Visible Report in Asia Pacific.

The Report aimed to:

- uncover existing misperceptions and gaps in understanding about blood cancers by the public,
- elevate the voice of people living with blood cancers across Asia Pacific, and
- support those living with blood cancers by supporting a call for action to Make Blood Cancer Visible.

Following the release of the Make Blood Cancer Visible – Asia Pacific Report in 2017, we were overwhelmed by the messages of support received from the public and those affected by blood cancers, so I am honored to introduce the second Report in the series, Make Blood Cancer Visible – Perspectives from Patients and Caregivers.

In this report we revisit some of the misperceptions and explore the impact of low awareness and understanding of blood cancers on patients and their caregivers. The findings present a stark reality.

The Asia Pacific Make Blood Cancer Visible Report Series forms part of Janssen's global commitment to ensure those living with blood cancers are recognized and supported, and to ultimately bring the world one step closer to our aspiration of making blood cancers diseases of the past.

We hope you'll join us and add your voice to the call to make blood cancer more visible.

We won't rest until we do!



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About Blood Cancers

Blood cancer is not one but 140 different cancers that affect the blood, bone marrow, and lymphatic system¹

Blood cancers fall into three main categories:



Leukemia

A cancer of white blood cells

Abnormal white blood cells, usually responsible for fighting infections, block up the bone marrow. They then move quickly into the blood and spread to other areas of the body.

Types of Leukemia include:

- Chronic Lymphocytic Leukemia (CLL)
- Chronic Myeloid Leukemia (CML)
- Acute Lymphocytic Leukemia (ALL)
- Acute Myeloid Leukemia (AML)



Lymphoma

A cancer that starts in the lymphatic system

Abnormal white blood cells block up the lymphatic system, an important part of the immune system.

Types of Lymphoma include:

- Diffuse large B-cell Lymphoma (DLBCL)
- Mantle Cell Lymphoma (MCL)
- Follicular Lymphoma (FL)
- Marginal Zone Lymphoma (MZL)
- Lymphoplasmacytic Lymphoma (LL)
- Mucosa-associated Lymphoid Tissue Lymphoma (MALT)



Myeloma

A cancer of plasma cells in the bone marrow

Bone marrow is blocked up by abnormal plasma cells, usually responsible for making antibodies and responding to an infection.

The Burden of Blood Cancer in Asia Pacific

Across Asia Pacific blood cancers affect between 5-10 percent of the population and they are one of the more fatal types of cancers in the region²

Misconceptions about blood cancer are common, particularly when it comes to the causes of blood cancer and how it is transmitted.



Some **incorrectly** think that **anemia is a cause of cancer.**³

Like other cancers, blood cancer is **perceived to be contagious.**

Understanding about the likely survival with blood cancer is also poor.



Many people believe a **blood cancer** diagnosis equates to a “death sentence” as it is **perceived to be incurable.**³

It is **commonly thought** that those with blood cancer will **not be able to regain their quality of life.**



This is in spite of the fact that survival times for some blood cancers have nearly doubled over the last decade due to the introduction of new targeted drugs.⁴

Understanding the Impact of 'Invisible' Blood Cancers in Asia Pacific⁵

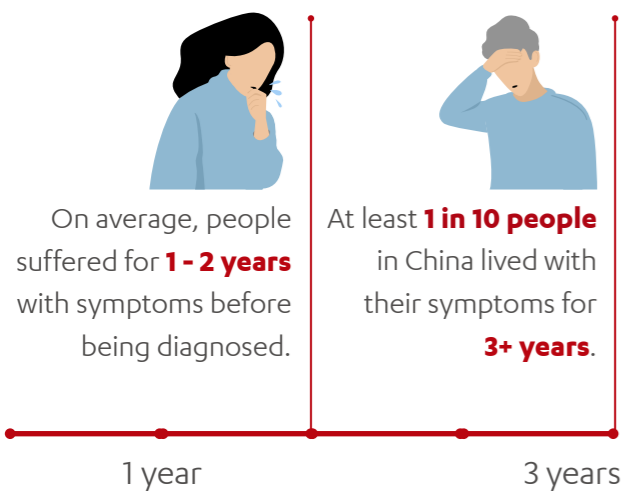
Across the region, access to accurate and up-to-date information about blood cancer can be beneficial throughout a patient's journey with blood cancer, including:

- When symptoms first start
- Following diagnosis
- When making decisions about treatment
- When trying to access treatment



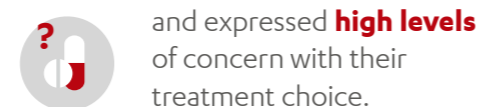
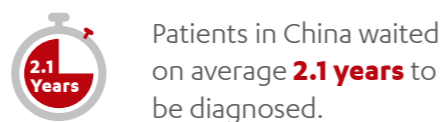
Symptoms

Research into patient and caregiver views across three countries in Asia Pacific show low awareness of blood cancers causes delays in diagnosis



Diagnosis

Delays in diagnosis negatively impact patient experience and perceptions



In Japan, the average diagnosis time is **1 year** and women reported waiting **5x longer** than men for a diagnosis.

Women waited **7 years**
 Men waited **1.5 years**

Treatment Decision

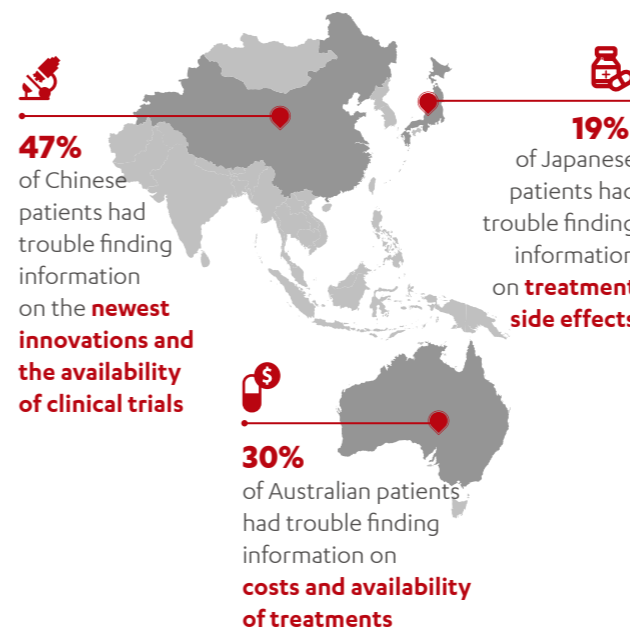
Patients and caregivers need blood cancer information and support to be more visible in Asia Pacific

A blood cancer diagnosis can be overwhelming, and it can be difficult to know where to **find information and support**.

Often, people rely on the **support of a family member or friend** to help them understand their cancer and make decisions about the treatment options available to them.

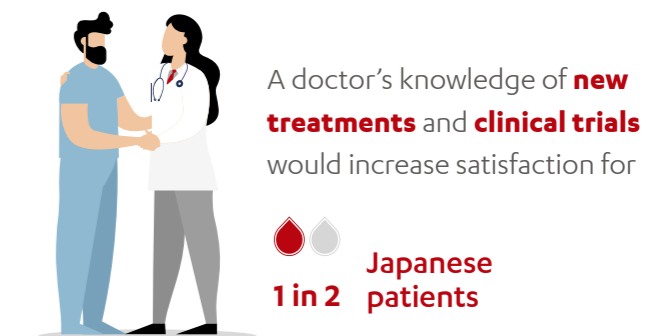
Better information can support confident treatment decision-making

Despite the development of new targeted blood cancer treatments that have shown to **increase survival**, people with blood cancer can find it difficult to access information on the **latest innovations**.



Access

Patients want more information from a range of sources



Caregivers play a critical role in finding information about treatment

In the three countries, the majority of patients had a caregiver who:



More information about lymphoma is needed across the three countries





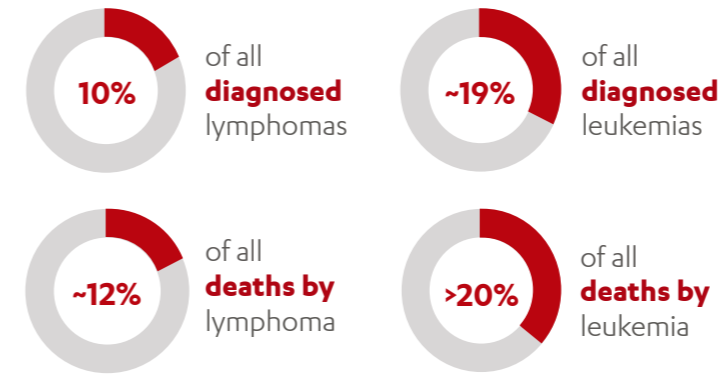
China

Blood Cancer Insights

The Facts

Cancer has been the leading cause of death in China since 2010⁶

Globally,

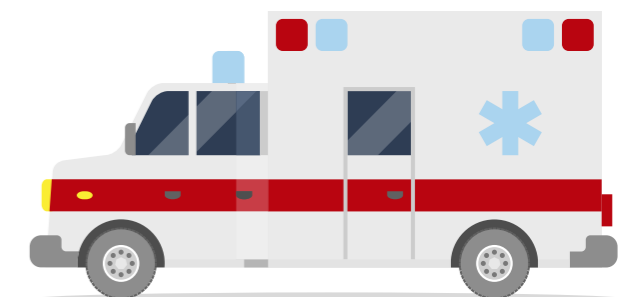
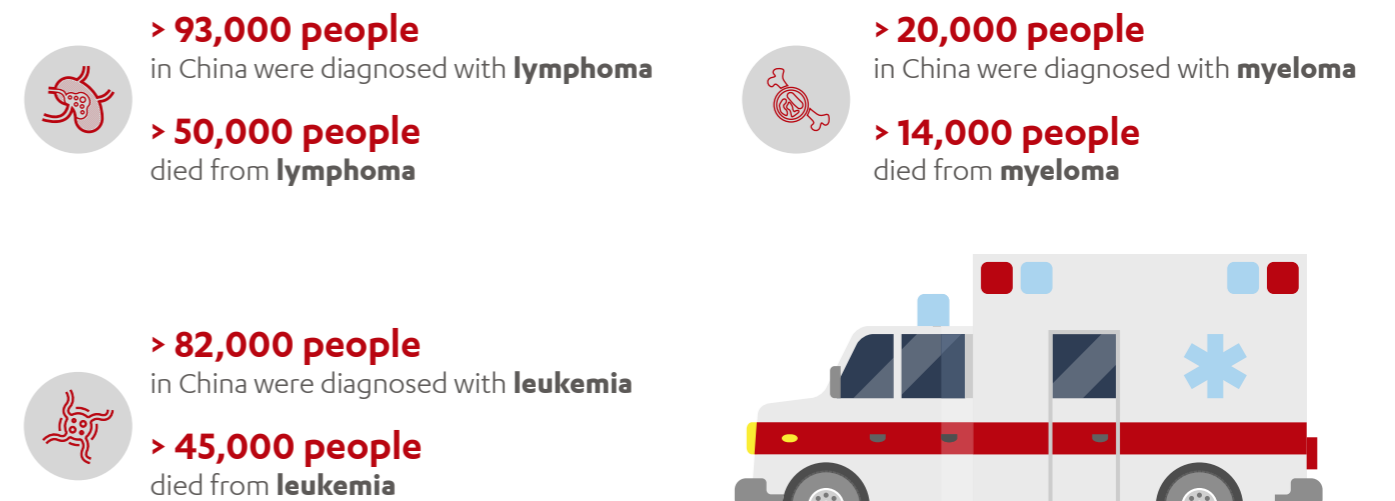


occur in China⁷



In 2018, blood cancers accounted for **4.6%** of the total number of new cancers in the country, and the same percentage of **all cancer deaths**.⁸

Prevalence and lives lost by blood cancer types:⁸



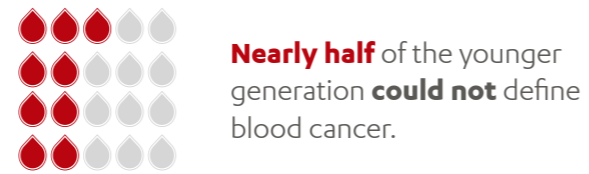
Awareness of blood cancers is extremely limited amongst the general public⁹



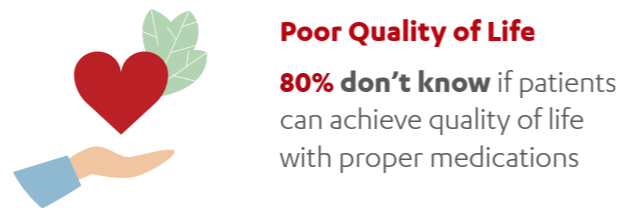
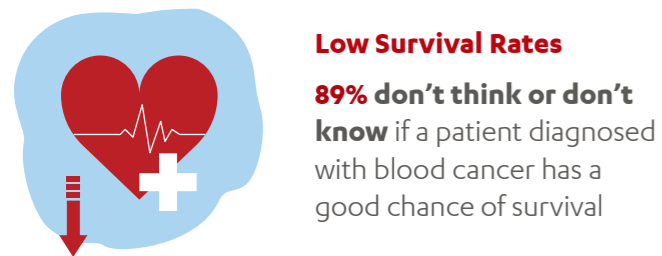
1 in 2 respondents either **don't know anything** about blood cancer or **only know** it by name

1 in 4 respondents could not name a **single symptom** of blood cancer

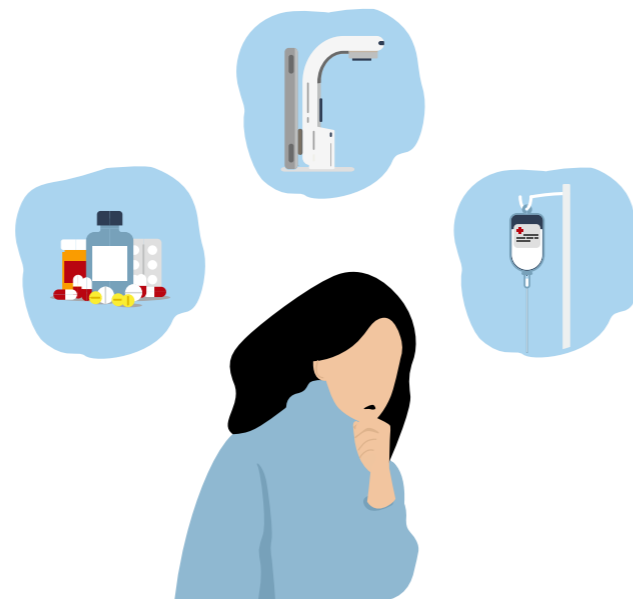
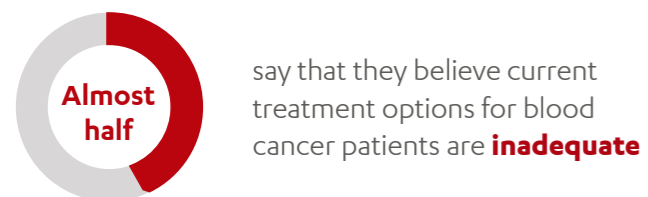
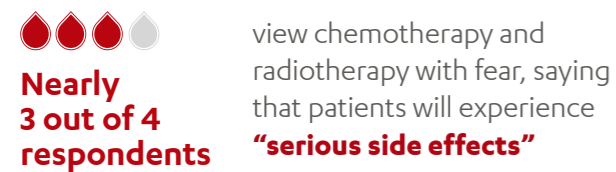
With younger generations and lower income groups, blood cancer is even less understood⁹



Low awareness can lead to a number of fears and misconceptions about the disease⁹



Limited understanding of the treatment options can lead to fears and misconceptions⁹



China Patient and Caregiver Insights


Improving Diagnosis and Patient Experience through Awareness

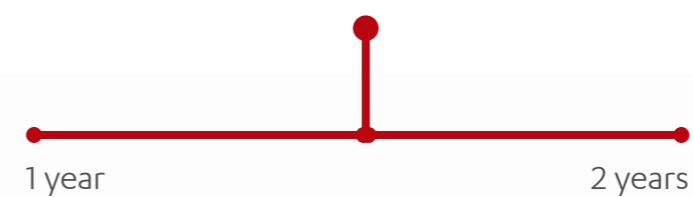


In China, low awareness of blood cancer contributes to delays in diagnosis

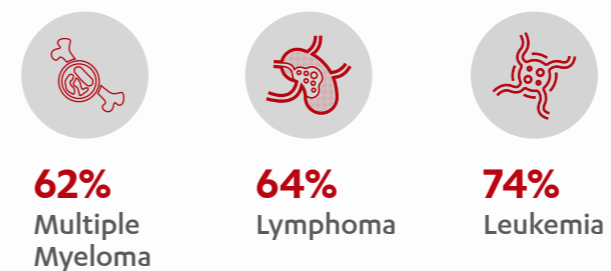
1 in 4 Chinese Patients  knew little or nothing about blood cancer pre-diagnosis.

“ I had no knowledge about lymphoma. While I was aware that my lymph nodes under my jaw and groin had been swelling for years, I never took them seriously or thought I needed medical attention.”

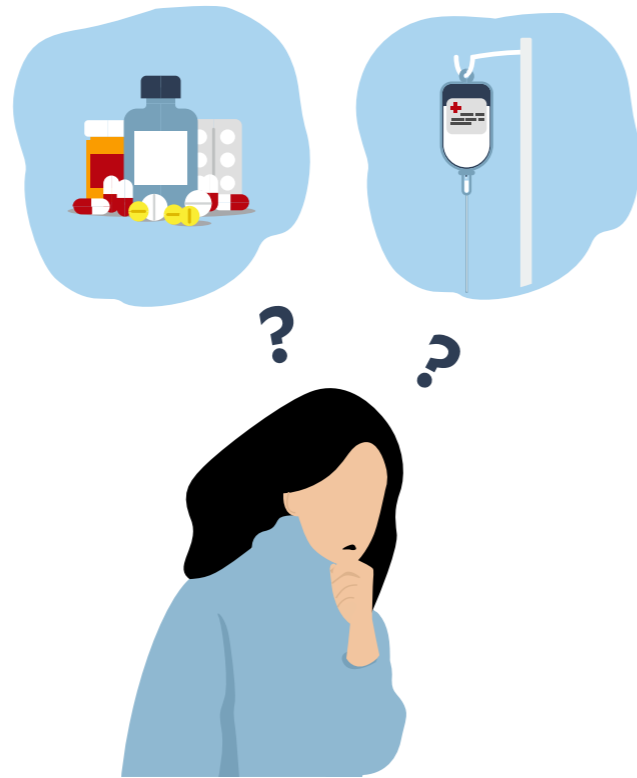
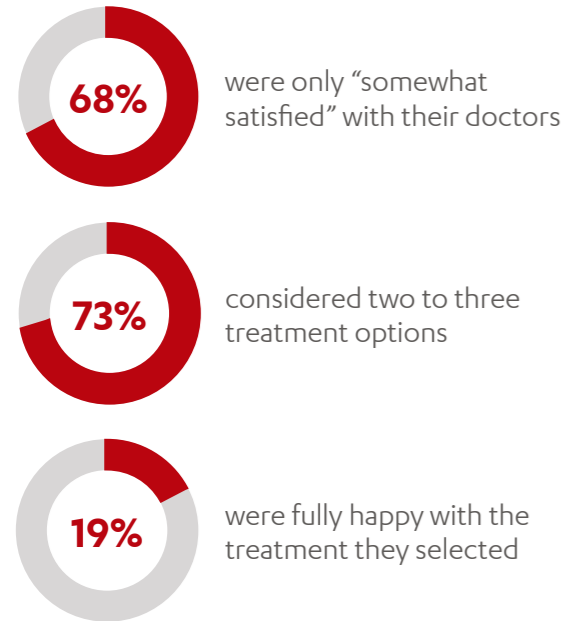
 **69%** took 1-2 years to be diagnosed.




Diagnosis is delayed across blood cancer types:



Delayed diagnosis compromises patient experience and confidence in treatment decisions



After diagnosis, patients and caregivers had difficulty finding information on:

-  Newest treatments
-  Availability of specific treatments close to home
-  Treatment side effects
-  Availability of clinical trials



Blood Cancer Patients and Caregivers Want Blood Cancer To Be More Visible

-  **1 in 2** would have involved their **doctors** more in their journey.
-  **1 in 2** think **patient support groups** should be leading more discussions on blood cancer topics.
-  **1 in 4** think **friends, colleagues, and family members** should share disease information online and in person.



“ I must thank House086.com for building a platform that allows patients to communicate with each other. In the group, we exchange information and share our treatment experiences.”



Comments From Patient Support Groups, Blood Cancer Patients and Caregivers

Hong Fei

Lymphoma patient and Founder of House 086

“Patients are put to a mental test when faced with severe diseases. Many patients give up on themselves and quit treatment because they don’t know much about their disease and there’s the possibility to be cured. If our society, including public platforms such as the media can better contribute to improving the quality of medical information available, they can help to reduce the fear and sense of hopelessness that blood cancer patients have. Ultimately allowing them to feel more positive and optimistic towards their treatment and life ahead.

Greater awareness and understanding from the society can help to remove the stigmatization and psychological pressure that blood cancer patients continually face. This also means being able to recognize and accept us when we return to work to lead a normal life.

On the part of the government, helping them understand the benefits of new drugs for blood cancer patients can accelerate its inclusion in the national reimbursement drug list (NRDL), so that patients can benefit from it.”

“ Many patients give up on themselves and quit treatment because they don’t know much about their disease and there’s the possibility to be cured. ”

Sarah

Caregiver of a leukemia patient

“When we first learned the news of her diagnosis, we felt helpless because we knew little about blood cancer or where to get support. As a caregiver, I feel that if there was more understanding and awareness for blood cancer, we wouldn’t feel alone. The more people understand our situation, the easier it would be to receive the support we need to make the treatment journey less difficult and challenging.”

“ As a caregiver, I feel that if there was more understanding and awareness for blood cancer, we wouldn’t feel alone. ”



Japan

Blood Cancer Insights

The Facts

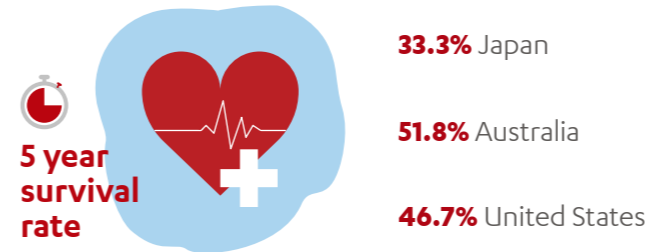
The three types of blood cancer tracked by the National Cancer Centre (malignant lymphoma, multiple myeloma, and leukemia) make up about 5% of all cancers in Japan.¹⁰

In 2018, it was projected that there would be a total of:

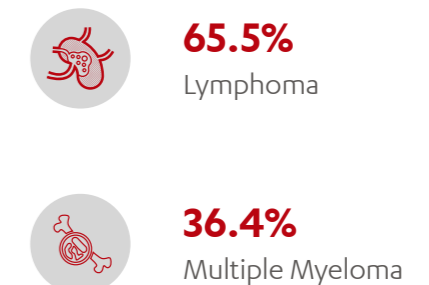
32,400 cases of lymphoma **14,100 cases** of leukemia **7,700 cases** of multiple myeloma

in Japan.¹⁰

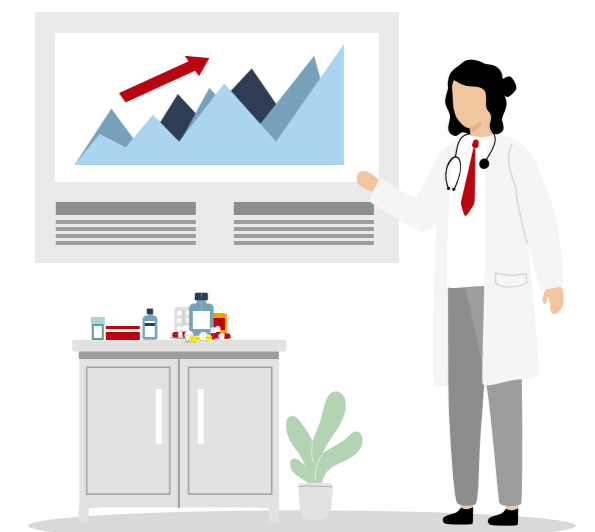
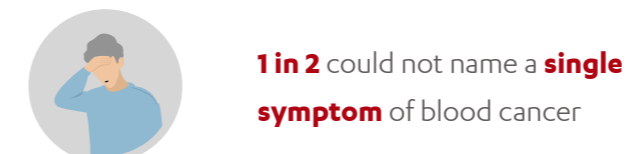
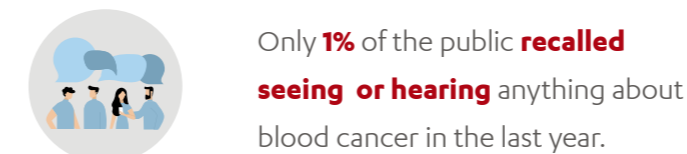
Although Japan's five-year cancer survival rate is at 62.1%,¹⁰ the five-year survival rate for patients with blood cancers like leukemia in adults is lower than other developed nations.¹¹



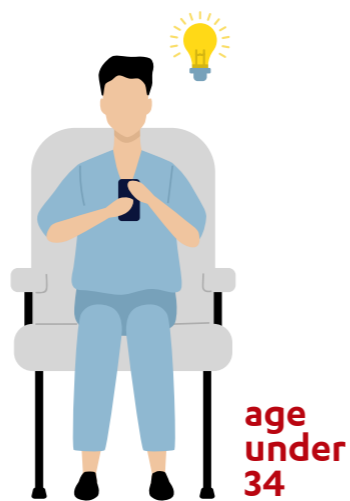
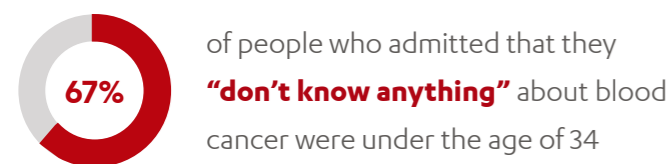
Five-year survival rates of other blood cancer types in Japan.¹⁰



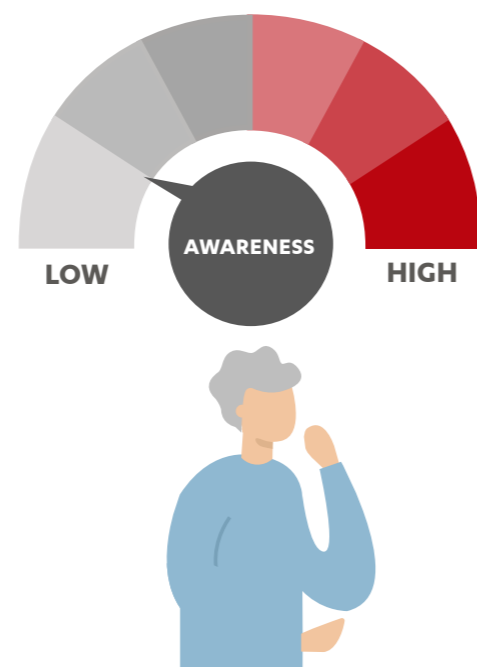
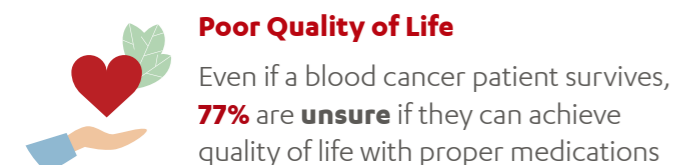
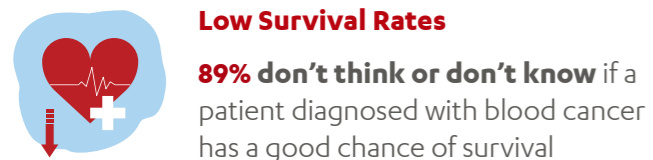
Blood cancer incidence has been growing in Japan,¹² yet overall public awareness is still low.⁹



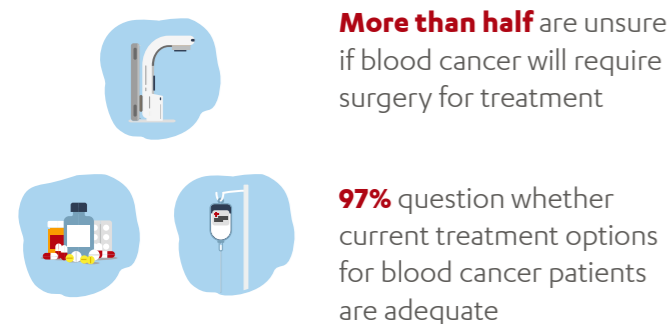
Decline in awareness is more pronounced in the younger generations, which is a potential stumbling block to early detection or prevention efforts.⁹



Low awareness contributes to a very grim outlook on blood cancer, as well as several misconceptions.⁹



Limited understanding of treatment options may lead to fears and misconceptions.⁹



The public is eager to know more

1 in 3 said they could use more information about blood cancer and the **top two** topics of interest are:⁹

- Patient Experiences
- Treatment Options

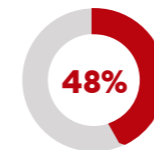


Japan Patient and Caregiver Insights

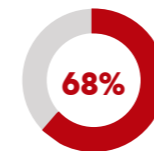
Meeting Changing Expectations for Doctor-Patient Relationships through Education



Patients and caregivers valued the information provided by their doctor



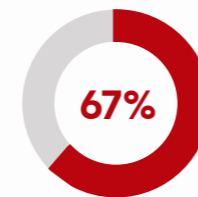
48% considered their doctor the most **useful source** of information about their disease



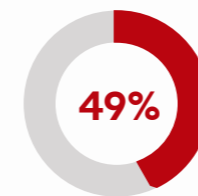
68% said that their **doctor's recommendation** contributed to their treatment choice



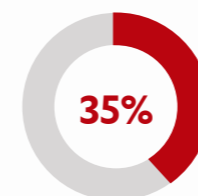
However, their satisfaction in terms of the level of care they received can improve



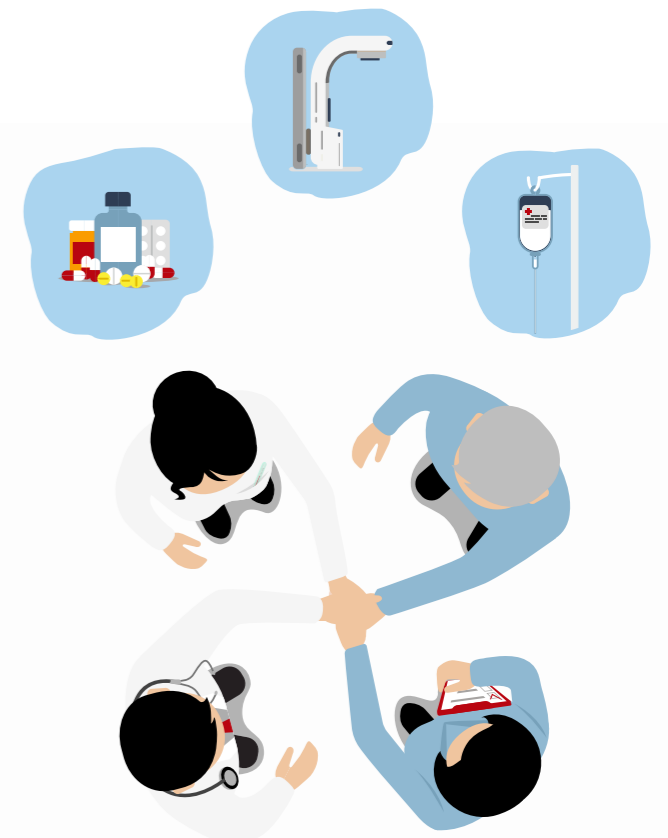
67% wish that their doctor had spent more time **explaining disease treatment options**



49% want doctors to share information on **new treatment options and clinical trials**



35% are **fully happy** with the treatment they selected

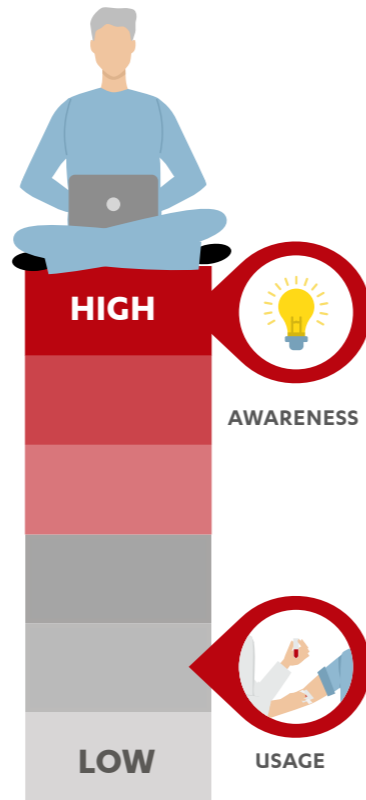
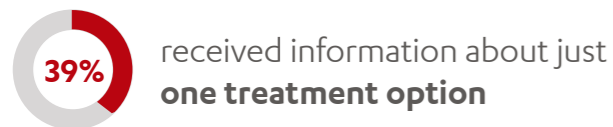


Patients are aware of novel therapies but use them rarely

Chemotherapy:



Targeted Immunotherapy:



Caregivers play a significant role in finding valuable information and improving the doctor-patient relationship



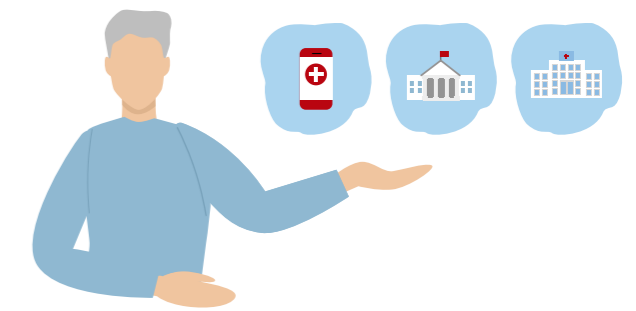
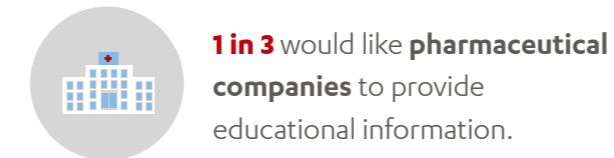
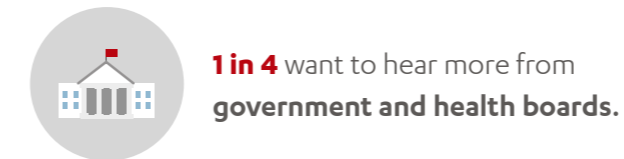
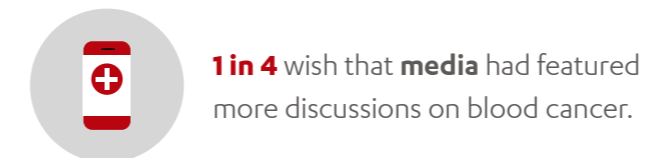
knew about blood cancer before diagnosis

1 in 3 patients had a caregiver who played a key role in **making final decisions** on their treatment options.

1 in 4 had a caregiver who helped them **access new information**.



Blood Cancer Patients and Caregivers Want Blood Cancer To Be More Visible



“ These days, there are many treatment options, so I am confident that I will extend my survival period. Now I focus on spending time with my family.”



Australia

Blood Cancer Insights

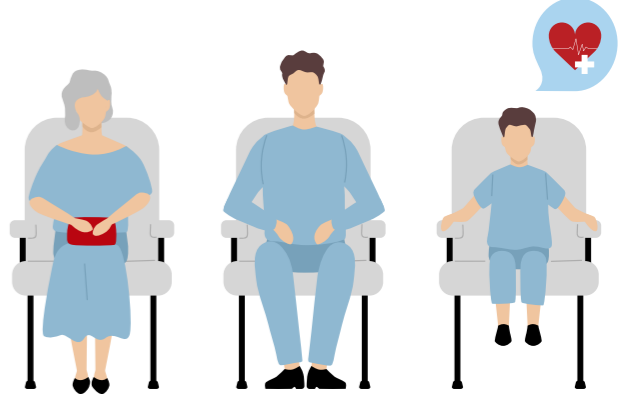


The Facts

In 2017, blood cancer was the third biggest cause of cancer death across Australia.¹³

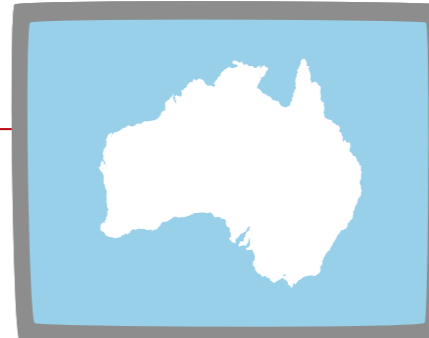


While more children are surviving the disease, **almost half** of adult blood cancer patients will lose their lives.¹⁴



Blood cancer accounts for **around 10%** of all cancers diagnosed each year.¹⁴

> 110,000 Australians currently **live with** a blood cancer.¹⁵



Around 41 Australians are diagnosed **each day** with a blood cancer.¹⁵

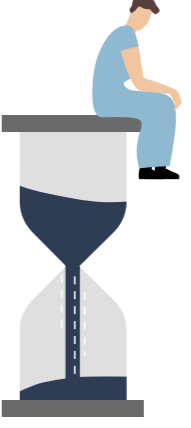
In 2019, the estimated incidence of leukemia, lymphoma and multiple myeloma combined is more than 15,000 in Australia.¹⁵



Lymphoma is the **fifth most common** cancer in Australia.¹⁶



In 2019, it is anticipated that:¹⁷



1, 061 Australians will die from **multiple myeloma**

1, 632 Australians will die from **lymphoma**

2, 039 Australians will die from **leukemia**

Australia Patient and Caregiver Insights

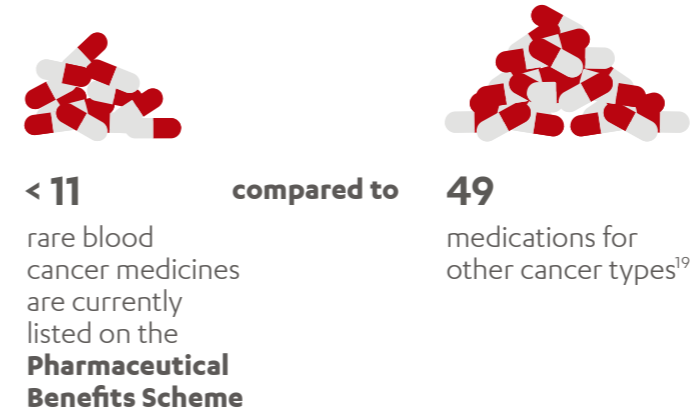
Access to The Latest Treatments is The Most Pressing Issue That Blood Cancer Patients Face



Patients in Australia continue to face inequitable access to medicines and clinical trials¹⁸



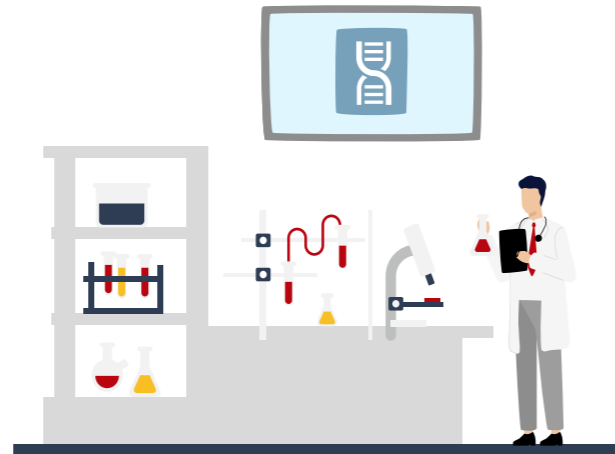
Reimbursement of treatments for rare or less common blood cancer in Australia is low



Patients are using personal savings and selling assets to fund their treatments



“ My best chance was a trial 10,000 miles away. With a shot at a long remission and possibly a cure, I dipped back into my superannuation fund and set off.”



Doctor’s knowledge of new treatments and innovations rank higher than any other factor in patient satisfaction

Top three factors that would improve satisfaction with their doctor:

- 59% Sharing knowledge of **new treatments** and **ongoing clinical trials**
- 51% Time spent **addressing concerns** about the disease
- 49% Ensuring their patients have a **clear understanding** of the disease



“ As a journalist, I needed information. I joined forums, subscribed to medical journals, and sought a number of specialists for second opinions. When it came to available treatment options, whether it was a stem cell transplant (SCT), clinical trials, new drugs or chemotherapy, I would always assess each risk to give myself the best chance to see my children grow up.”

Patients want to hear from healthcare professionals (HCP) outside of their specialist

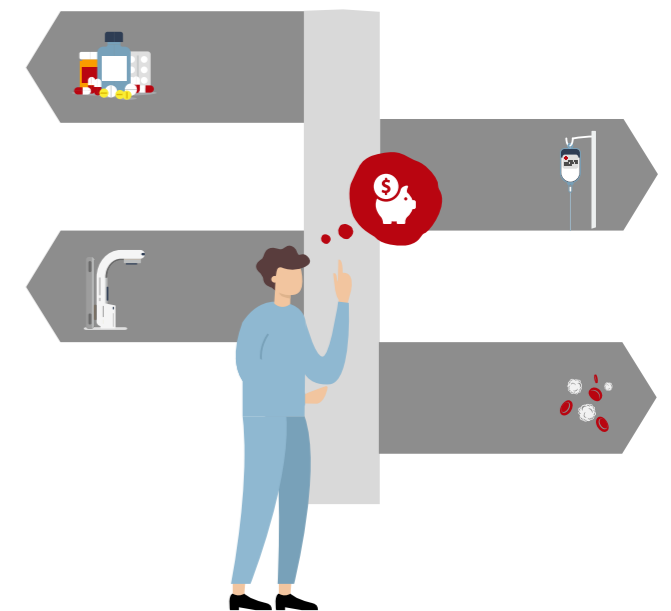


“ National clinical trial databases are not easily navigated, and many patients must therefore rely on outside expertise, if available, to help them find potential trials. As a result, patients can feel isolated, experience delays in treatment or miss critical opportunities to save or extend their lives.”



When it comes to making a decision about treatment

Cost of treatment is of **equal importance** to fewer side effects and **more important** that quality of life.

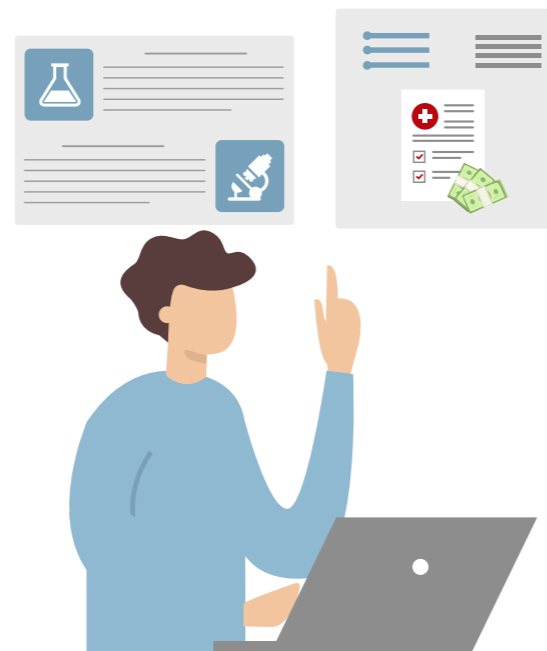


Caregivers play a critical role in treatment decision-making



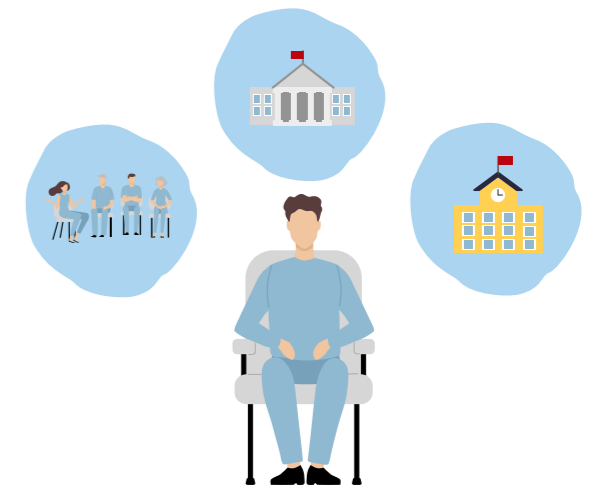
The information needs of blood cancer patients varying depending on cancer type

- Cost of treatment** for Multiple Myeloma patients
- Newest treatment options** for Lymphoma patients
- Availability of specific treatments** for Leukemia patients



Blood Cancer Patients and Caregivers Want Blood Cancer To Be More Visible

- 1 in 2** want to hear more from **government and health boards.**
- 2 in 5** think **patient support groups** should be leading more discussions on blood cancer topics.
- 1 in 3** would like **academic and research institutions** to provide more information.



“ When I can, I join the Leukemia Foundation’s monthly blood cancer support group at the local hospital. ”



Comments From Patient Support Groups, Blood Cancer Patients and Caregivers

Bill Petch

CEO Leukemia Foundation

“Blood cancers as a group, are amongst the most prevalent and deadly cancers affecting Australians today with over 15,000 people diagnosed each year and a 30 percent increase in incidence expected over the next decade. Through the Leukemia Foundation’s research, we have seen how the impact of these cancers on Australians of all ages including their friends and family can be devastating, not to mention the cost to the health system and the broader economy. We also saw that blood cancers are still not well understood and so by shining a light on blood cancer, we can work together as a nation to address the necessary changes that need to be made to save lives.

Awareness and understanding brings with it the power to make changes. The Leukemia Foundation is committed to driving change by working in partnership with the blood cancer community and governments to improve blood cancer survival rates. The key to this is ensuring access to the right information, the best treatments and services, the latest trials, tests and diagnostic tools, to help people not just survive - but to also live well.”

“ Awareness and understanding brings with it the power to make changes. The Leukemia Foundation is committed to driving change by working in partnership with the blood cancer community and governments to improve blood cancer survival rates. ”

Deborah Sims

Chronic lymphocytic leukemia patient

“Around 41 Australians are diagnosed with a blood cancer every day and it’s the third biggest cause of cancer deaths here claiming more lives each year than breast or prostate cancer. When people think of cancer, they generally think of solid tumors and investment in novel therapies for blood cancer has been significantly behind other nations. However, I’m thrilled that there has been an improvement on that front over the past 12 months and we now have more treatment options available to us.

The most important thing for patients who are in a similar position to me – having what is considered to be incurable blood cancers - is to have hope. Hope that scientists will keep ahead of our disease, that there will be government action to help speed up the time from bench to bedside and a public will to make sure funding is properly allocated to help us fight our disease with the best treatments out there.”

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The most important thing for patients who are in a similar position to me – having what is considered to be incurable blood cancers - is to have hope. ”



Closing Remarks by

Mei Ching Ong

Region Head for Asia Pacific, The Max Foundation

Cancer is a complex and challenging journey. From diagnosis, to treatment, to survivorship, no one can do it alone. And no one should have to. That is why we have been creating and managing treatment access programs for people diagnosed with cancer for 20 years.

At the Max Foundation, we believe all people living with cancer deserve access to treatment, care and support. Our vision is a world where all people can face cancer with dignity and hope.

In pursuit of that vision, we have learned the power and importance of shared-value collaborations. They are key to our access programs and to the thousands of people we support. We treasure all partners who share in this journey with us and are grateful for their efforts.

Though we have made great strides together, continued learning is critical to continued progress. We must understand the needs of those living with blood cancers in the region, before we can try to meet them.

I am inspired to do more by the findings outlined in this report and I hope you are as well.

Together, we can Make Blood Cancer Visible, so we can reduce the time from symptoms appearing to diagnosis, giving people with blood cancers across the Asia Pacific region the best chance at fighting their disease.

Together, we can increase the knowledge and confidence of people living with blood cancers and their caregivers to be actively involved in discussions about treatment to get the option that best suits them.

Together, we will do all we can to empower those living with blood cancers to live their best life.

If you are moved to work on behalf of people living with blood cancers in the region, please contact us. The Max Foundation is always seeking new partners and collaborators.

“ Together, we can Make Blood Cancer Visible, so we can reduce the time from symptoms appearing to diagnosis, giving people with blood cancers across the Asia Pacific region the best chance at fighting their disease. ”

About the Study

The Make Blood Cancer Visible – Perspectives from Patients and Caregivers Asia Pacific study asked 431 patients and caregivers in Australia (150), China (131) and Japan (150) about their experiences and perceptions around treatment, support and information.

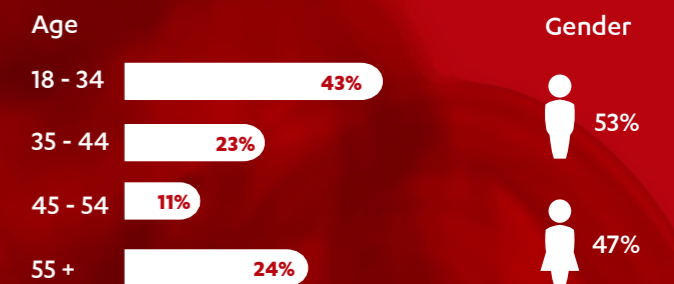
All questions had fixed answer categories and were online, self-administered surveys. To ensure anonymity, all respondents were assigned an anonymous alphanumeric identification to protect their identity.

The study was conducted from 2 November 2018 to 21 November 2018 in all countries. The questionnaire was commissioned by Janssen and executed by WE Communications and YouGov. Questions focused on patient and caregiver understanding and opinions about different elements across the patient journey in their country. Elements included blood cancer treatment options, available information and channels for information, the role of physicians, the relationship between patients and physicians, as well as access barriers and expectations about support across the patient journey.

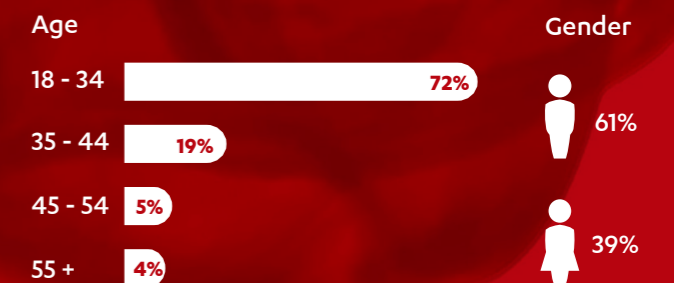
The definition of a caregiver for the purpose of this research is limited to family/relatives and friends only.

Demographic Profiles

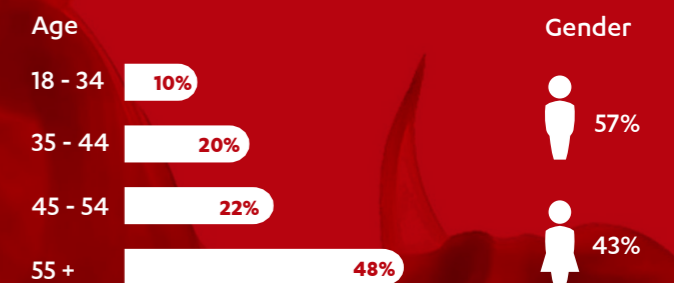
Australia



China



Japan



About the Report

The preparation and launch of the Perspectives from Patients and Caregivers Asia Pacific Report were sponsored by Janssen Asia Pacific, a division of Johnson & Johnson Pte Ltd. The quotes in this report were written and voluntarily submitted by the patients themselves. The opinions expressed in the quotes are those of the patients and do not necessarily reflect the views of the sponsor.

Resources

Australia



Leukaemia Foundation
www.leukaemia.org.au

China



House086
www.house086.com



For more information and support, please visit The Max Foundation website at <https://www.themaxfoundation.org/>.

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