

# HEALTH LITERACY IN ASIA-PACIFIC

## NATIONAL HEALTH LITERACY POLICIES & STRATEGIES IN THE REGION

2023





#### **About Lymphoma Coalition**

Lymphoma Coalition (LC) is a worldwide network of patient organisations with a full or partial focus on providing support to those affected by lymphoma, including chronic lymphocytic leukaemia (CLL). The need for a central hub of consistent, reliable, and current information was recognized, as well as the need for lymphoma patient organisations to share resources, best practices, and policies and procedures. With this in mind, four lymphoma organisations started LC in 2002 and it incorporated as a not-for-profit organisation in 2010. Today, there are more than 80 member organisations from over 50 countries.

As the organization grew, an additional workstream was added dedicated to advocating for equitable care globally. LC's current strategy remains focused on ensuring impact within two key pillars: information and advocacy.

#### Vision

Equity in lymphoma outcomes across borders.

#### Mission

Enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.

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## **Overview**

#### **Purpose**

#### This report aims to provide an overview of the current health literacy landscape in Asia-Pacific.

This is achieved by examining current health literacy policies at the national level across the region and exploring potential directions for advocacy and policy action to improve health literacy and affect sustainable system-level change.

The Health Literacy in Asia-Pacific report is part of a broader Lymphoma Coalition global strategy to address issues related to health literacy. This report will help further build capacity for member organisations by providing an introductory synopsis of the health literacy landscape in Asia-Pacific and identifying some of the key issues that impact patient outcomes.

#### Additionally, this report provides:

- Relevant data and information to support the identification of health literacy priorities in the region.
- Policy profiles on the state of health literacy in ten countries where there are Lymphoma Coalition member organisations.
- Suggestions to support policy-based actions, improve systemic issues and reduce health literacy inequities and disparities.

It is anticipated this report will help to support patient advocates in the development of health literacy advocacy strategies aimed towards improving patient outcomes and reducing health inequities as well as:

- Further inform healthcare professionals and other stakeholders engaged in policy and decision-making about the importance of health literacy.
- Present a detailed policy overview to highlight the role country-level health literacy policies play in affecting micro and macro changes at the health system level.

#### **Objectives**

#### This report aims to:

- 1. Outline the key issues, challenges and barriers patients experience in relation to health literacy by providing an in-depth analysis of policies and/or practices that address health literacy in national health or policy agendas at country level.
- 2. Inform advocacy efforts, promote strategies to improve health literacy and support the identification of health literacy policy priorities at community, national and regional levels.

#### Methodology

#### The content found in this report was informed by the following methods:

#### **Literature Search**

Initially, a literature search was conducted using key search phrases and word strings that identified articles published in several databases, including ProQuest and PubMed. Similarly, a literature search on Google Scholar also produced articles of relevant and/or general interest. The search parameters focused on materials published in English in the last 5 years with further supplemental literature including grey articles or information sourced from credible websites.

#### **Global Patient Survey**

The biennial Lymphoma Coalition 2022 Global Patient Survey on Lymphomas and CLL (GPS 2022) provided data and information specific to the region of Asia-Pacific, drawing on patient and caregiver responses from the following countries: Australia, China, Hong Kong, India, Indonesia, Japan, Lao People's Democratic Republic, Malaysia, Nepal, New Zealand, North Korea, Philippines, Singapore, South Korean, Tonga, Turkey, and Vanuatu.

#### **Community Advisory Board**

Key learnings and insights from a Lymphoma Coalition Asia-Pacific Health Literacy Community Advisory Board meeting held in 2021 included information on the key barriers, issues and cultural challenges patients with lymphoma experience when making informed decisions about their health and informational needs.

Community Advisory Board (CAB) members are those who are living with the specific condition or alternatively, may be a close family member, carer/caregiver, or member of a patient organisation that works within the disease to advance key priorities or address patient outcomes. CAB members use their professional and/or personal knowledge and expertise to discuss and advise on the latest developments, challenges, and issues related to medical treatments and procedures under development in their respective disease area.

The Asia-Pacific Health Literacy CAB was comprised of Lymphoma Coalition member organisations and representatives from other patient groups across the region. These included participants from Australia, China, the Special Administrative Region of Hong Kong, India, Indonesia, Japan, Malaysia, New Zealand, Philippines, Korea, Singapore and Taiwan. This process of engaging patient experts in discussion identified key factors that contribute to improved patient understanding of treatment and promotion of shared patient-doctor decision-making in a clinical setting.

#### **Health Literacy Policy Research**

Following the Asia-Pacific Health Literacy CAB meeting in 2021, and to better understand the complex policy and health systems landscape in specific countries across the region, Lymphoma Coalition engaged an external Health Policy Consultant in 2022 to conduct research in ten pre-selected countries to identify where health literacy is integrated into national health agendas in the region.

A literature search was conducted as part of the research to identify grey literature followed by a subsequent search to identify peer-reviewed literature of relevance published in the English language within the past 5-year period.

## To guide the literature review and research protocols, the following policy research questions were defined:

- 1. What is the state of health literacy (in the respective country)?
- 2. How is the country addressing health literacy?
- 3. What is the key area of focus in health literacy for the country?
- 4. Who is responsible for implementing policies and/or programmes in health literacy?
- 5. What are the measurement mechanisms in health literacy in the country?

#### **Acknowledgments**

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A special thank you to the Lymphoma Coalition Members and patient advocates in Asia-Pacific who took the time to share their insights and engage in health literacy discussions and to the patients and caregivers who completed the 2022 Global Patient Survey on Lymphomas and CLL.

#### **Disclaimer**

Every effort has been taken to verify the accuracy of the research and information presented in this report. The information contained in the report is taken from various public and private sources. No responsibility can be assumed by LC for the accuracy or timeliness of this information.





## Introduction

#### Why Health Literacy Matters

The integration of health literacy as a key health promotion pillar and driver of health outcomes is not a new concept. On the global health stage, health literacy has been recognised as a priority for almost two decades, through the leadership of the World Health Organisation (WHO).<sup>1</sup>

WHO established a global mandate for prioritising health literacy, promoting it as the role and responsibility of governments, and positioning it as one of the three pillars for achieving sustainable development and health equity in the Shanghai Declaration on Health Promotion (2016).<sup>2</sup>

Health literacy plays a pivotal role in terms of improving the socio-economic status of communities and impacting personal and community health.<sup>4</sup> Adopted by the General Assembly of the United Nations, the 2030 Agenda for Sustainable Development Goals (SDGs) comprise a global call to action that addresses challenges and aims to achieve a better future for all across 17 SDGs and 169 defined targets, with success measured in how the gap between people and national policy setting is addressed, and how the commitment to leave no one behind is achieved.<sup>4</sup>

Health literacy has been steadily gaining global attention by researchers and policymakers.¹ Over the last two decades, there has been exponential growth in the number of stakeholders working in health literacy, and in establishing health literacy in policy agendas.¹ The definition and concept of health literacy continues to evolve, oftentimes with differing views or perspectives advancing from the early fundamental characterization of the ability to read and understand health literacy in a clinical setting to focusing on how to support individuals in reaching informed decisions that improve health outcomes. This expanded understanding of health literacy may be further influenced by the set of skills or competencies that people possess and in which healthcare systems they operate; the means or methods by which health professionals share information, and the practical delivery of information or, how patients receive and understand health-related information.¹

Today, health literacy reflects a much more comprehensive and multidimensional concept - one that encompasses fundamental elements including cultural perspectives, patient-centric knowledge translation, best practices, and a focus on understanding and meeting patient needs with respect to how health information in a healthcare setting is presented and shared.

Health literacy is a vital aspect to patient care. While health literacy focuses on the ability of people to read and understand medical information, the manner that information is shared (or the way in which healthcare professionals and organisations deliver information) is equally important. Despite different published definitions of health literacy, there appears to be a consensus-based shift towards approaching health literacy from two core dimensions:<sup>1</sup>

- Individual or personal health literacy: Considered the ability to find, understand and use health information and understand how to navigate the healthcare system.<sup>1</sup>
- Organisational literacy or the health literacy environment: Considered to be the policies, processes and/or materials that directly affect how people engage with the health system.<sup>1</sup>

For instance, the Australian Commission on Safety and Quality in Health Care defines individual or personal health literacy as the skills, knowledge, motivation, and capacity of a person to "access, understand, appraise, and apply information." The second dimension, organisational health literacy, focuses on the environment and its relation to the policies, processes, and infrastructure that define the health system, as well as the way in which individuals effectively access information or services. Both approaches are equally important as they directly intersect and correlate to the other.



#### Social Determinants of Health

Health literacy is a social determinant of health that supports the social ability and cognitive competencies necessary for individuals to process, inform and apply information aimed at health promotion and the improvement of personal health outcomes.<sup>4</sup>

Studies show a strong relationship exists between health outcomes and literacy, with health literacy known to help patients gain and exert greater control over healthcare decision-making and increase self-management of their individual health.<sup>5</sup> People with higher levels of health literacy often experience increased involvement in shared decision-making while in contrast, those with low health literacy are more likely to experience poorer health outcomes as well as lower engagement with health services, higher hospital re-admission rates, and a decreased understanding of how to manage complex medication regimes.<sup>1</sup>



#### Health Literacy Measurement

Health literacy is a key driver and factor in addressing the glaring disparities and inequities prevalent in health. Addressing gaps in health literacy, more specifically health literacy measurement, is critical to removing health literacy barriers. Other factors that adversely impact health literacy are socioeconomic barriers and the inability to address unmet language needs or communication requirements in healthcare environments.



#### Information and Communication

Interventions to reduce the organisational complexities of health systems and improve organisational health literacy are integral to enable individuals to understand and navigate health information, as well as improve health outcomes.<sup>1</sup> At the healthcare level, the implementation of measures that simplify processes can improve information and communication. For instance, scheduling clinician appointments to ensure communications consider patient reading levels, changing the format or choice of information delivery based on patient needs, and carefully considering cultural or language needs are all key factors in health literacy.

Emerging digital technologies in the context of health provide both opportunities and challenges and while these rapid changes in technologies allow people to have the most up-to-date information, they also highlight the inequities due to lower levels of health literacy.<sup>1</sup>

With respect to education, the integration of health information in educational curriculums may help to enable students to acquire the key competencies necessary to promote health. This may also be extended to apply to vulnerable populations or adult populations to improve health literacy levels.

#### **National Health Literacy Statistics**

The implementation of effective health literacy policies and actions at country-level play integral roles in helping to address health literacy levels and work toward improving patient outcomes. Leveraging evidence-based information and best practices requires an understanding of existing health literacy policies – where they exist and where they are lacking.

Health literacy policies help to frame the current health literacy landscape in Asia-Pacific and provide context necessary to understand policy-based directives, the influence of health policy development, implementation of robust literacy measurement strategies, and health literacy priorities to address challenges and affect sustainable change.

#### Australia

In Australia, almost 60% of adults have low health literacy.<sup>3 25</sup> Consequently, only 40% of adults have the level of individual health literacy needed to effectively exercise their choice or voice in healthcare decisions. In Australia, low health literacy is estimated to account for 3% to 5% of total health system costs.<sup>26</sup>

#### China

Health literacy levels vary significantly among the 25 provinces or municipalities of China.<sup>6</sup> Health literacy in China is improving and the proportion of Chinese residents with adequate health literacy has increased from 6.48% in 2008, to 23.15% in 2020.<sup>7</sup>

#### Hong Kong

There is a lack of population-level data on health literacy in Hong Kong.<sup>8</sup> A study conducted in 2020 on a sample of 486 community-dwelling older adults in Hong Kong, found 50.9% of the participants had inadequate health literacy, suggesting that the prevalence of limited health literacy among older adults was quite high – especially in the ability to evaluate health information.<sup>9</sup>

#### India

The lack of population level data makes it difficult to understand the extent of low health literacy in the country. A study at a tertiary care hospital in Karnataka, India, found that 77% of patients surveyed had very low health literacy and another study at an outpatient department at a dental hospital in Bangalore found that 60.4% had low health literacy.<sup>10 11</sup>

#### Japan

There has not been a population-level assessment of health literacy in Japan to date. <sup>12</sup> A smaller scale study using The European Health Literacy Survey (HLS-EU) adapted for local use measured the health literacy level of 1054 Japanese adults in 2013. <sup>12</sup> These data are most often referenced in the scientific literate as the measure of population health literacy in Japan. <sup>12</sup> The survey found that the level of inadequate health literacy was 49.9%; and 85.4% of the population fell in the "limited" health literacy category (a combination of "inadequate" and "problematic" health literacy). <sup>12</sup>

#### South Korea

Research on health literacy is limited in South Korea.<sup>71</sup> The most recent estimate of Korean health literacy is from a survey in 2020 conducted by the Korea Institute for Health and Social Affairs, surveying 1002 adults aged 19-69 using the HLS-EU-Q16 questionnaire. Findings showed that 70.9% of survey respondents had inadequate or problematic levels of health literacy, and only 29.1% were sufficiently health-literate.<sup>72</sup>

#### Malaysia

In 2015, the first population study was conducted to assess health literacy in adults.<sup>85 19</sup> It found that only 6.6% of Malaysian adults have adequate health literacy, with the urban population reporting significantly higher adequate health literacy (7.8%) compared to the rural population (2.3%).<sup>85 19 86</sup> In 2019, a more comprehensive version of the same survey was repeated, and showed that a majority of the population had sufficient or excellent health literacy.<sup>19</sup> The 2019 survey found that 40.7% of Malaysians had sufficient health literacy, 24.3% had excellent health literacy and 35% had limited health literacy.<sup>81</sup>

#### New 7ealand

More than half (56%) of adult New Zealanders have low health literacy – equating to 1.8 million people.<sup>95</sup> Populations with lower health literacy include the poor, elderly, rural, Pacific peoples, and Māori with studies showing that almost 90% of Pacific adults and 72% of Māori adults, have low health literacy.<sup>95 97</sup>

#### **Philippines**

The first national health literacy survey on the prevalence of health literacy in the Philippines was conducted in 2018-2019 and found low levels of health literacy in the population.<sup>13</sup> The *National Health Literacy Survey* involved 2303 randomly selected Filipino residents aged 15 to 70 years.<sup>13</sup> It found 51.5% of the study participants had limited health literacy.<sup>13</sup>

#### Singapore

The most comprehensive study of population health literacy was conducted in 2021 surveying a sample of 2895 adults aged 18 years and above. This study found most of the population had adequate health literacy with 80.5% having high functional health literacy, meaning the population is able to function efficiently in a health care context, and read, understand and respond adequately to healthcare communications.



The social determinants of health are non-medical factors that influence health outcomes and are often considered in parallel to influential factors such as economic policies, health agendas, social norms, healthcare systems and political systems.<sup>5</sup>

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# **Chapter 1**Health Literacy Landscape

#### **Disparities and Inequities**

Health literacy is a global issue that contributes to growing health care inequities and widespread health disparities between countries, populations, and individuals. Despite advancements in healthcare and an increased understanding of the role of health literacy in affecting health outcomes, people continue to experience disproportionate burdens and inequities in relation to healthcare services because of low levels of health literacy. Despite well-intentioned policies and policy interventions to reduce health inequalities, they persist and are likely to worsen due to the underlying structural or environmental social determinants of health and their direct impact on health policy, health disparities and public health practices.

The social determinants of health are non-medical factors that influence health outcomes and are often considered in parallel to influential factors such as economic policies, health agendas, social norms, healthcare systems and political systems. Fundamentally, health status is determined by the impact of social and environmental conditions, namely the conditions by which people are born, grow, live, and age. As a result, the conditions found in the physical environment are often considered alongside individual characteristics and behaviours that have a role in determining variations in personal health outcomes.

Studies suggest that communication using a culturally tailored approach is important. In New Zealand, Pacific peoples experience an inequitable burden with respect to noncommunicable diseases, with Pacific adults having the highest prevalence compared to their non-Pacific counterparts, with low health literacy considered a contributing factor.<sup>15</sup>

As the social and cultural determinants of health must be addressed in relation to the underlying factors that are directly related to poor health outcomes, applying effective communication between health practitioners and patients requires using culturally and ethnically tailored approaches to support increased understanding.<sup>15</sup>

#### In Brief

- New Zealand began their work on health literacy in more recent years, compared to other countries. The motivation to improve health literacy was largely driven by the need to reduce health inequalities and inequities for Māori, New Zealand's indigenous population. In 2010, the Ministry of Health published New Zealand's first health literacy research report Kōrero Mārama: Health literacy and Māori.
- In Korea, policy recommendations have been suggested to improve health literacy. These include developing a national approach to health literacy by implementing a national survey on a regular basis; linking efforts in health literacy across sectors to promote life-course approach to health literacy, developing tailored health literacy interventions for target groups and developing health literacy guidelines for distributing information and educating healthcare professionals.<sup>72 73</sup>

#### **Urban, Rural and Remote Populations**

Geographically, Asia-Pacific is a vastly dispersed region comprised of diverse cultures and populations. According to the 2022 Global Patient Survey conducted by Lymphoma Coalition, 55% of patients in Asia-Pacific reported living in city or urban areas, with 14% describing the area they live in as rural.

Urban populations appear to have higher health literacy than rural populations with differences in health literacy levels more likely to occur in developing countries.<sup>16</sup> Evidence suggests there may be factors other than rurality to consider when developing policies to reduce rural-urban and clinical levels where access to health services could improve.<sup>16</sup>

In Australia, for instance, there is a disparity in survival rates for patients in regional and metropolitan Australia. According to a 2017 report published by the Australian Cancer Council, patients with cancer living in remote areas are "more likely to die than those living in the city" due in part to contributing factors such as the excessive geographical distance patients must travel to access medical services and treatment, reduced local or community access to health professionals that often results in later tumour stage at the time of diagnosis, and socio-economic disadvantages that are worsened when patients incur out-of-pocket expenses.<sup>17</sup>

In China, relatively little is known about the health literacy differences between urban and rural populations. In 2020, a cross-sectional study with more than 78,000 participants assessed health literacy status and explored determinants to gain a better understanding of the differences. The cross-sectional study used the Chinese Resident Health Literacy Scale to measure health literacy, validating that overall, lower levels of health literacy correlated to lower levels of education.

With lower health literacy more prominent amongst those in rural areas compared to their urban counterparts, the study concluded that "a reorientation of the health policy-making for Chinese rural areas" was recommended, and that health literacy disparities should be considered in health promotion interventions to address health literacy moving forward.<sup>18</sup>

#### In Brief

- In Malaysia, the first population study was conducted to assess health literacy in adults in 2015.<sup>85 19</sup> It found that **only 6.6% of Malaysian adults have adequate health literacy**, with the urban population reporting significantly higher adequate health literacy (7.8%) compared to the rural population (2.3%).<sup>85 19</sup>
- More than half (56%) of adult New Zealanders have low health literacy equating to 1.8 million people.<sup>95</sup> Populations with lower health literacy include the poor, elderly, rural, Pacific peoples, and Māori with studies showing that almost 90% of Pacific adults and 72% of Māori adults, have low health literacy.<sup>94,97</sup>

#### **Policy Development**

Reducing gaps and disparities in health literacy requires an investment into resources and a commitment to not only implementing sustainable policy directives but to allocating appropriate funding as well.

In the last decade alone, health literacy has gained increasing prominence in policy agendas influenced in part by the direct correlation of health literacy as a key determinant of health. As policymakers, healthcare professionals, patient advocates and others actively seek solutions that address healthcare inequities and disparities, it is critical that health literacy remain a firm commitment on policy development agendas. 1

The promotion of health literacy in parallel with driving collaborative action toward identifying policy goals may help to improve equity. At a systems level, studies show that efforts to improve health literacy and address systemic issues can be impeded by a wide range of factors including the prevalence of socioeconomic inequalities, geographic isolation experienced by rural and remote populations, and challenges associated with cultural, language and policy-related barriers, among others.<sup>20</sup>

Although health literacy levels vary considerably across sociodemographic groupings, policy development to address health literacy requires the environment to be responsive to the different barriers and needs of populations.<sup>20</sup>

#### In Brief

- In China, health literacy has become increasingly embedded into national policy. In 2014 the National Health Commission issued the Health Literacy Promotion Action Plan (2014-2020) with the goal of increasing adequate health literacy to 20% of the population by 2020.<sup>37 38</sup> Most recently, health literacy was included as an evaluation indicator in Healthy China 2030 China's national health plan.<sup>34 38</sup>
- In Korea, national policy on health literacy is in its infancy compared to other countries.<sup>71</sup> Health literacy was first introduced as a concept in 2005; but only recently has health literacy become a subject of policy attention, with implementation in the National Health Plan 2030 officially announced in 2021.<sup>7172</sup>



In 2022, participation of patients and caregivers spanned 72 countries around the globe with survey questions translated from English into 18 languages.

# Chapter 2 Patient and Caregiver Experiences

### Global Patient Survey on Lymphomas and CLL

In 2008, Lymphoma Coalition launched its first web-based Global Patient Survey (GPS). The GPS is held every second year to help understand the patient and caregiver experience in lymphomas, including chronic lymphocytic leukaemia (CLL), and the impact of treatment and care. Global responses continue to provide rich datasets that foster a culture of collaboration and knowledge sharing. The data generated from the GPS help drive planning and policy, bridge knowledge gaps, and advocate for equitable care across the globe. Additionally, the data serves as the foundation for scientific abstracts, joint research initiatives, policy papers, and other international collaborations and presentations.

Lymphoma Coalition publishes the GPS report online with strict adherence to privacy and confidentiality measures to ensure no patient identifiers are collected. The Survey Research Centre (SRC) at the University of Waterloo, Ontario, Canada, was commissioned by Lymphoma Coalition to run the 2022 survey. The data dissemination and data preservation plan of Lymphoma Coalition follows best practices and ethical guidelines ensuring the preservation of all critical data and documentation files produced during the data collection process.

In 2022, participation of patients and caregivers spanned 72 countries around the globe with survey questions translated from English into 18 languages by an approved language translation service. There were 18 countries that had over 100+ responses to the GPS 2022. Patients responding to the 2022 GPS in Asia-Pacific expanded across 13 countries, with 7 countries receiving 100+ patient responses.

#### Overview: 2022 GPS Key Findings and Highlights, Asia-Pacific



## 3206 people responded

to the 2022 survey from the Asia-Pacific region

- 2218 patients
- 988 caregivers



## Top 3 countries for responses:

- 1. China (47%)
- 2. Australia (20%)
- 3. India (8%)



## 43% male 57% female

represented the cohort of patient respondents



#### 77%

of patients preferred

#### info from doctors

as their preferred sources of information



#### 13%

of patients felt

## very well informed

about the processes/stages of their healthcare



#### 82%

of patients were

## satisfied with the information

given to them by patient organisations



#### 71%

of patients reported completing

## post-secondary education

60% completed college/ university, 11% postgraduate



#### 62%

of patients experienced

#### fear of relapse

because of their diagnosis



#### 68%

of patients were told their

#### lymphoma subtype



#### 48%

of caregivers

#### use websites

from patient organisations for information



#### 62%

reported experiencing

#### fatigue

making it the most commonly reported symptom by patients



#### 12%

of patients are currently, or have been in,

#### a clinical trial

for lymphoma or CLL

#### 2022 GPS Results: Asia-Pacific

#### Information, Guidance, and Support

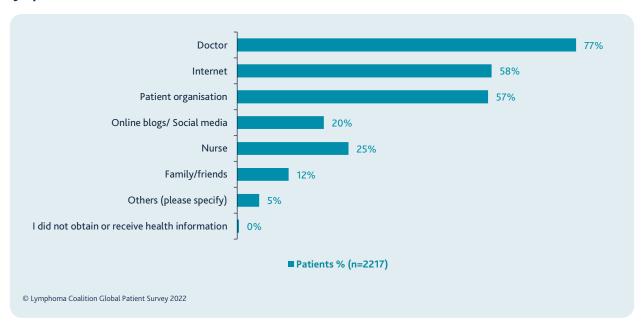
Patients who report having adequate information is correlated with more self-reported positive healthcare experiences. When a patient has knowledge surrounding their condition, treatment options, and self-care practices, doctor-patient communication is more fluid, patient experience is improved, and patients are more inclined to be confident in taking a sustained active role in managing their health and condition.<sup>21</sup>

In addition to information, patients need help and support to help them cope with the challenges they face during their care processes.

Clear information, communication and support for self-care are important aspects of person-centred care that contribute to a successful patient experience.

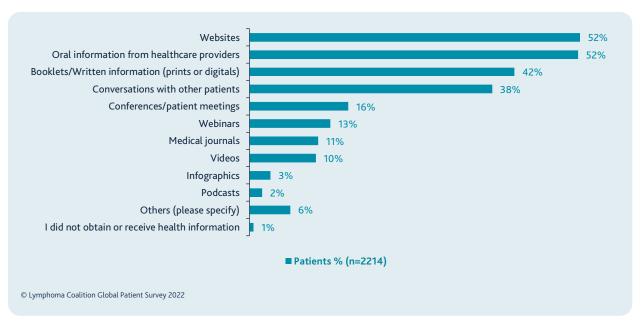
With respect to the patient experience with information, 77% of patients preferred doctors as their source of lymphoma or CLL information.

Figure 1. Given your experience with lymphoma or CLL so far, what are your preferred sources, if any, for lymphoma or CLL information?



Further, patients indicated their preferred method for obtaining or receiving health information about lymphoma or CLL was through websites and oral information from healthcare providers (both 52%).

Figure 2. What is your preferred method for obtaining or receiving health information about lymphoma or CLL?



#### Survey respondents from Asia-Pacific reported:

- 17% of caregivers reported being very well informed about the processes and stages of the patients' healthcare.
- 74% of caregivers preferred sources of information on lymphoma and CLL are doctors, followed by internet searches (72%) and patient organisations (67%).
- Half of the patients (50%) felt the results they had received about their diagnostic tests were explained, and that they understood the results.
- 34% of patients were given more than one treatment option before their current or last therapy for lymphoma.

#### Healthcare Involvement and Decision-Making Support

Patient-centeredness is a key part of providing high-quality cancer care as it takes into consideration the goals and expectations of patients and their families. Patients should be seen by healthcare providers as individuals and not just a diagnosis and doctors should respond to the needs, preferences and concerns of patients and their families. This implies that healthcare providers should ensure a collaborative approach to healthcare decision-making with patients and their families.

The 2022 GPS included a section on healthcare involvement and decision-making support, with the aim of exploring the experience of patients with lymphoma or CLL in this area.

#### Survey respondents from Asia-Pacific reported:

- 63% of patients want their doctors to tell the full truth about the diagnosis even though it may be uncomfortable or unpleasant.
- 52% of patients reporting feeling involved in decisions about their care and treatment.
- 52% of caregivers reported not receiving contact details of a patient organization, support group, and/or information provided by a patient organisation from the doctor or any member of the medical team.
- 34% of patients were given more than one treatment option before their current or last therapy for lymphoma.
- 41% of patients were never presented with an opportunity to take part in a clinical trial.
- 72% of caregivers reported the internet was a preferred source of information, with 70% indicating they get their lymphoma or CLL information from patient organisation websites.
- 40% of patients would like the doctor and patient to be jointly involved in the final decision on healthcare, with an additional 37% wanting their caregiver involved as well.
- 33% of patients felt that they had somewhat adequate time to think about the treatment before the treatment decision was made and 27% said the time was very adequate.

#### Effects of Lymphoma/CLL

In understanding people's experiences of healthcare conditions, it is vital to consider the symptoms and side effects of the disease and associated treatment, including the impact it has upon a person's daily life.

In previous LC Global Patient Surveys, cancer-related fatigue (CRF) was the leading physical symptom affecting the quality of life reported by respondents, regardless of whether the patient was newly diagnosed, in treatment, was in remission or had relapsed disease. However, patients were not being educated about their fatigue or directed to further information/support by their doctors.

### The 2022 GPS included a section on the physical effects of lymphoma, treatment experience and side effects of treatment. Survey respondents from Asia-Pacific reported:

- 62% of patients experienced fatigue as a symptom of lymphoma.
- Fatigue was also the most reported side effect from treatment (62%).

#### With respect to fatigue, and according to the 2022 GPS, global survey respondents reported that:

- 50% of patients discussed their fatigue with their doctor over the last two years while 40% had not. Of those who discussed fatigue, 53% were not followed up by their doctor. <sup>21</sup>
- 36% of patients were not provided with information (relevant to fatigue management, for instance) from their doctors.<sup>21</sup>

## Asia-Pacific Health Literacy Community Advisory Board

#### **Key Learnings**

In 2021, Lymphoma Coalition hosted a virtual Asia-Pacific Community Advisory Board (CAB) meeting. Patient experts participated from the following countries across Asia-Pacific, namely Australia, China, Hong Kong, India, Indonesia, Japan, Malaysia, New Zealand, Philippines, Taiwan, Singapore, and South Korea.

By definition, Lymphoma Coalition Community Advisory Board members are those who are living with the specific condition or alternatively, may be a close family member, carer/caregiver, or member of a patient organisation that works within the disease to advance key priorities or address patient outcomes. Lymphoma Coalition CAB members use their professional and/or personal knowledge and expertise to discuss and advise on the latest developments, challenges, and issues related to medical treatments and procedures under development in their respective disease area.

The primary objective of the 2021 Asia Pacific CAB meeting was to explore the implications associated with understanding health information in addition to discussing culturally appropriate resources and related informational needs that more closely reflect the respective health systems, populations, and experiences in the Asia-Pacific region. Additionally, participants explored practical actions and sustainable solutions to address health literacy issues, challenges, and barriers. Participants also discussed the importance of health literacy in the context of informational needs and resources specific to Asia-Pacific.

### Prior to the Asia-Pacific CAB meeting, participants completed an online survey. Facilitated by an external third party, the survey questions explored areas that included:

- Key barriers and/or issues and cultural challenges patients experience when making informed decisions about their health.
- The role of health professionals, and what support they might need.
- Informational needs that patients may want and/or need, including what information contributes to shared patient-doctor decision-making while better informing patients about their treatment.
- Resources or methods of providing information that are effective, including an evaluation of Lymphoma Coalition resources in key topics of interest like fear of cancer recurrence.

#### Overview: Members Survey Lymphoma Coalition Community Advisory Board Meeting, 2021



#### 69%

believed there are gaps in information specific to clinical trials, followed by 53% who feel there are information gaps in relation to treatment



#### 100%

indicated that limited time with the doctor and other health professionals is a barrier to people receiving and understanding information about their cancer



#### 69%

indicated patients prefer to be communicated with using websites, followed by printed materials and in-person (61%)



#### 38%

indicated the biggest barrier that prevents people from accessing information digitally is connectivity and the ability to use the device



#### 33%

indicated the most popular type of information provided digitally are talks by doctors and health professionals



#### 69%

indicated that a barrier to patients receiving and understanding information about their cancer is the information being too technical and hard to understand

Asia-Pacific Community Advisory Board (CAB) Meeting, 2021.

Perspectives shared during the CAB meeting included the persistence of country-level barriers that impede the overall ability for individuals to receive and understand information about their specific cancer. Further, the implications of low health literacy on patients may be influenced or affected by experiences within the healthcare system or with the delivery of care. These may include challenges with respect to language barriers, cultural differences, or functional and/or cognitive disability.

Additional insights from CAB members included the following:

Table 1. Reasons for Gaps in Information. Lymphoma Coalition Community Advisory Board Meeting.

#### **Reasons for Gaps in Information**

- Limited capability of understanding the information from healthcare professionals
- · Existing language barriers
- Lack of understanding due to low health literacy
- · Different subtypes of lymphoma make it difficult for patients and caregivers to understand the disease
- · Lack of uniform protocols for onboarding patients leaves to deal with the disease on their own
- Unaware of the disease due to a lack of exposure and education

### Table 2. Barriers to Receiving and Understanding Information. Lymphoma Coalition Community Advisory Board Meeting.

#### **Barriers to Receiving and Understanding Information**

- Information dissemination can by driven by different stakeholders whose efforts may not be well coordinated
- In rural areas, activities by volunteers and non-governmental organisations may be dependent on the location
- Social media and mobile apps play a key role in disseminating information in urban areas, but may be a barrier to accessing information if/when unavailable

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## Table 3. How Health Literacy is Perceived by Community Advisory Board Members. Lymphoma Coalition Community Advisory Board Meeting.



## How Health Literacy is Perceived by Community Advisory Board Members

"Health literacy is seen as a way of empowering consumers, patients, and family members to ensure they get the best possible treatment and care, and to give them the confidence to speak out."

"The growth in the range of therapies available for lymphoma makes literacy increasingly important. Treatments, such as CAR-T, for example, are far removed from standard chemotherapy or radiotherapy approaches and understanding how they work varies accordingly."

"Information was not only relevant for the patients but also for the carers and families so that when someone they know is diagnosed, they can also access the relevant information. It can also help patients access the correct medical treatment through the correct channels."

"Health literacy is important for all primarily because it can prevent so many health problems. It allows people to take greater responsibility for their own health and the health of their families."

"Patients from different socioeconomic backgrounds had different communication needs to take care of different educational and cultural backgrounds."

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In addition, the following table highlights additional learnings and insights as shared by CAB members during the meeting.

Table 4. Key Takeaways by Country.

Lymphoma Coalition Community Advisory Board Meeting: Members Insights.

Country	Key Learnings and Insights
Australia	For newly diagnosed patients, there may be a lack of awareness about treatments or questions to ask doctors during appointments. This may be further complicated by doctors tending to rotate through clinical areas without specialisation.
China	Information aimed toward patients may be too technical, contributing to gaps in knowledge due to limited understanding of information.
India	In busy public hospitals, time with a doctor is limited. Often, other patients are in the room which affects the ability to openly communicate or ask questions. In contrast, private hospitals offer ample time for discussion and addressing any patient questions. With more than 200 commonly used languages, resources may only be available in select languages for patients and therefore, contributing to low understanding or levels of health literacy.
Indonesia	As there are very few haematologists practicing in Indonesia, patients do not have sufficient time for discussions with a specialist and when information is sought outside of the clinical environment, it may not be verified or dependable.
Malaysia	Urban populations tend to have a greater trust level in their doctors and a better understanding of health issues while rural populations may have received less education, have less exposure to disease topics, or have an inclination toward the use of alternative medicines for treatment.
Philippines	As the health system is automated, patients move rapidly from initial diagnosis to prescription. Patients may hesitate or refrain from asking questions of their doctors. Further, patients may turn to their communities for alternative medicines and support services that may not be provided by the health system.
Taiwan	Patients view doctors as figures of authority and as such, may be less likely to ask questions for fear of implying mistrust.
Singapore	Patients are expected to absorb significant amounts of information in short timelines, contributing to added stress and anxiety.
South Korea	Where patients experience a trust issue with a doctor, patients may see other doctors until they feel satisfied with the diagnosis and treatment plan.

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Current policies and strategies vary according to the way in which different countries conceptualise and define health literacy, perceive population need, and the healthcare system structures.<sup>2</sup>

## **Chapter 3**Health Literacy Policy in Asia-Pacific

Health literacy has been gaining global attention by researchers and policymakers.<sup>1</sup> Over the last two decades, there has been exponential growth in the number of stakeholders working in health literacy, and in establishing health literacy in policy agendas.<sup>1</sup>

On the global health stage, health literacy has been recognised as a priority for almost two decades, through the leadership of the World Health Organisation (WHO). Most recently, the WHO established a global mandate for prioritising health literacy, promoting it as the role and responsibility of governments, and positioning it as one of the three pillars for achieving sustainable development and health equity in the Shanghai Declaration on Health Promotion (2016).<sup>2</sup>

Many countries have already established heath literacy in policies and strategies. Current policies and strategies vary according to the way in which different countries conceptualise and define health literacy, perceive population need, and the healthcare system structures.<sup>2</sup> Policies may take the shape of broad informal policy statements, or more formalised documents such as frameworks, strategic plans or action plans.<sup>2</sup> Policies should also establish a clear purpose, measurable goals and objectives, actionable strategies, targets, and mechanisms for monitoring, evaluating progress, and reporting on outcomes – however, the reality is that inclusion of these elements are highly variable across countries.<sup>2</sup>

The research conducted to inform this paper aimed to understand the state of national policies and strategies for health literacy across 10 countries in the Asia-Pacific region. Further, a series of pre-determined questions helped to inform the comparative analysis in four key areas:

- 1. **National Policy:** Does the country have a dedicated national health literacy plan, strategy, and framework? If not, is health literacy embedded into other national health plans? Who is the initiator of the national policy?
- 2. **Policy Priority or Focus:** Who are the beneficiaries of the policy? What is the focus area of the policy? Does the policy have clear health literacy goals?
- 3. **Funding:** Is there dedicated funding for the policy? If not, how is the policy expected to be funded and/or implemented?
- 4. **Measurements:** Is health literacy being tracked and measured at a population level? If yes, when, and how often? If not, does the country have a national benchmark of population health literacy through smaller scale research?

Table 5. Comparative Health Literacy Policy Analysis of Countries in Asia-Pacific.

Country and Policy	Focus	Funding	Measurement
Australia  The National Statement on Health Literacy (2014), drafted by the Australian Commission on Safety and Quality in Healthcare (ACSQHC), provides a national approach to embedding health literacy in Australian healthcare and education systems.	The focus is on improving individual health literacy and creating health literate environments.  Concrete actions to improve health literacy (individual and environments) are specified for different stakeholders in the Australian system.	The statement is not legally binding, nor accompanied by funding. Each state is responsible for localising the policy. Most states have created or are creating their own strategy, based on the national policy.	A national health literacy survey was completed in 2006, and 2018, by the Australian Bureau of Statistics.  Health literacy of healthcare providers is re-assessed through the national healthcare quality standards every three years (e.g., the National Safety and Quality Health Service Standards).
China  The National Health Commission of the People's Republic of China issued the Health Literacy Promotion Action Plan from 2014- 2020. Most recently, health literacy was included as an evaluation indicator in Healthy China 2030 – China's current national health plan.	The focus of China's policies is on improving individual health literacy of its citizens.  The National Health Literacy Promotion Action Plan (2014-2020) aimed to increase adequate health literacy to 20% of the population by 2020. The plan focused on women, children, elderly, disabled and migrants.  Healthy China 2030 aims to increase adequate health literacy to 30% of the population by 2030. It will be achieved through a series of 'special initiative' covering a variety of contexts and populations.	Upwards of 40 million USD per year was said to fund China's past health literacy promotion initiatives. No information was found on the funding dedicated to Healthy China 2030 health literacy initiatives.	Population health literacy is assessed annually in China, beginning in 2008. This is the only country found to monitor health literacy annually.

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Table 5. Comparative Health Literacy Policy Analysis of Countries in Asia-Pacific, continued.

Country and Policy	Focus	Funding	Measurement
Hong Kong Hong Kong does not have a national health literacy policy. However, health literacy is recognised in the latest non- communicable disease (NCD) strategy called: Towards 2025: Strategy and Action Plan to Prevent and Control Non- Communicable Diseases in Hong Kong (2018-2025).	The strategy explicitly mentions health literacy as an enabler for reducing the burden of NCDs. Strengthening health literacy of individuals is indicated as an objective.	No information found	Hong Kong lacks population- level data on health literacy.
India India does not have a national health literacy policy; however, recent actions have been taken to improve access to reliable health information and improve health promotion.	Health literacy is currently addressed indirectly through targeted health promotion programmes, and by a new initiative by the government to make health information more accessible, reliable, and trustworthy.  A National Health Portal was recently established, to serve as an online access point for authenticated health information.	No information found	India lacks population- level data on health literacy.
Japan Japan does not have a national health literacy policy. However, health literacy was briefly recognised in the most recent healthcare strategic plan, called: The Japan Vision: Health Care 2035 – published in 2015 by the Ministry of Health, Labour, and Welfare.	Health literacy is mentioned twice in the action items of the health strategy; within the context of empowering people to make healthcare choices, and to improve sustainable healthcare system financing.	No information found	Japan lacks population- level data on health literacy.

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Table 5. Comparative Health Literacy Policy Analysis of Countries in Asia-Pacific, continued.

Country and Policy	Focus	Funding	Measurement
Korea  Health literacy is included in the National Health Plan 2030 (HP2030), launched in 2021 by the Ministry of Health and Welfare, setting the direction of national health policy for the next 10-years.	Improving individual health literacy of Koreans is one of the main goals of the health plan. The target is to achieve adequate health literacy in 70% of Koreans by 2030, and there are 7 indicators set to measure improvements in health literacy in HP2030.	A total budget of 2.5 trillion Korean won is dedicated to implementing the health plan.	Korea lacks population-level data on health literacy.  Developing a tool to assess population health literacy, and regularly monitoring population levels, is indicated as an indicator in HP2030.
Malaysia  Malaysia does not have a national health literacy policy, but the government is currently developing one, so it can be expected in the coming years.  Health literacy was recognised in the Country Health Plan 2011-2015; and most recently in the Twelfth Malaysia Plan 2021-2025 produced by the Prime Minister's Department, outlining a strategic country vision spanning all sectors.	In the Twelfth Malaysia Plan (2021-2025), the intention to create a national health literacy policy is clearly stated as a country priority.  The new policy will include creating a health literacy surveillance system, and health awareness programmes that will be implemented across all levels. Schools will be expected to improve health literacy among students.	No information found	A national survey of health literacy was conducted in 2015, followed by a more comprehensive survey repeated in 2019.  A new surveillance system to monitor population health literacy is expected to be created with the new health literacy policy.
New Zealand  Health literacy is a key priority in New Zealand's current Health Strategy (2016-2026). There are several action items dedicated to health literacy. In 2015, the Ministry of Health developed a Health Literacy Framework.	The strategy has two actions to promote health literacy. The first action focuses on providing individuals with health information, and the second, focuses on making the health system more responsive to people.  The framework conceptualises how each part of the health system contributes to building health literacy and provides guidance to all stakeholders for embedding health literacy in their systems.	No information found	A national health literacy survey was conducted in 1996, and 2006.

Table 5. Comparative Health Literacy Policy Analysis of Countries in Asia-Pacific, continued.

Country and Policy	Focus	Funding	Measurement
Philippines  There is no dedicated national health literacy policy. However, in 2020 the National Health Promotion Framework Strategy 2030 (HPFS2030) was launched and included health literacy.	A goal of the strategy is to ensure that 'Filipinos are health literate, settings are health-enabling and public policies are health-supporting,' demonstrating a strong commitment to health literacy. Health literacy is framed as a 'key concept' guiding the implementation of the strategy.	The budget for implementation of health promotion programmes should be no less than 1% of the Department of Health's total budget. The budget is said to be increasing year over year.	A national survey to assess population health literacy was performed from 2018-2019. Health literacy will be measured more regularly from 2022.
Singapore In 2010, the Health Promotion Board developed the Action Plan to Improve Health Literacy in Singapore.	The action plan defined health literacy for the first time in Singapore and included key priorities: to develop a standard measurement tool for health literacy in Singapore, develop plain language guidelines for the health sector, and include health literacy training in healthcare professional curriculum.  There is limited information available on the implementation of the action plan since it was published.	No information found	Singapore lacks population-level data on health literacy.

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## Country Profiles: Health Literacy Policies





- Australia
- China
- Hong Kong
- India
- Japan
- South Korea
- Malaysia
- New Zealand
- Philippines
- Singapore



In Australia, almost 60% of adults have low health literacy.<sup>3 25</sup> Consequently, only 40% of adults have the level of individual health literacy needed to effectively exercise their choice or voice in healthcare decisions.

Low health literacy in Australia has a devastating impact on patient outcomes and cost of care. The Australian Commission on Safety and Quality in Health Care (ACSQHC) estimates that people with low health literacy are between one-and-a-half and three times more likely to experience an adverse health outcome than those with higher health literacy. Low health literacy is estimated to account for 3% to 5% of total health system costs in Australia.26

## **Findings:**Heath Literacy in Australia

Health literacy has been a priority in Australia for more than three decades.<sup>3</sup> Health literacy is recognised nationally as being fundamental to good health and high-quality care.<sup>3</sup> Health literacy was first recognised as a national priority in 1993, when it was added to Australia's first set of national health goals and targets.<sup>3</sup> Since then, health literacy continues to gain prominence in national policies; and in 2007, health literacy garnered greater attention from the National Health and Hospital Reforms Commission, being identified as a key factor driving consumer engagement in health.<sup>3</sup>

In the years that follow, health literacy was increasingly acknowledged in Australia's national approach to safety and quality improvement in health. This included *The Australian Charter of Healthcare Rights in 2008; The Australian Safety and Quality Framework for Health in 2010; The Australian Safety and Quality Goals for Health Care in 2012;* and *The National Safety and Quality of Health Service Standards in 2012.*<sup>3 22</sup>
<sup>23</sup> Alongside these national policies, health literacy began to appear in states and territory government policies.<sup>23</sup>

Recognising the growing prominence of health literacy in Australian health policies, and the desire for a nationally coordinated approach, The National Statement on Health Literacy was launched in 2014.<sup>3</sup> This statement was drafted by the Australian Commission on Safety and Quality in Healthcare (ACSQHC), who now leads on all policy efforts in health literacy nationally. The National Statement on Health Literacy, which was endorsed by all Health Ministers, provides the strategic direction and a structured approach for embedding health literacy into education and health systems across Australia.

#### The National Statement on Health Literacy (2014)

Notably, Australia is one of the few countries to have a national approach to health literacy. The National Statement on Health Literacy is seen as an immense policy achievement, helping to systematically embed health literacy into health and education sectors.

The National Statement does not constitute a formal (legally-binding) government policy.<sup>2</sup> In Australia, the federal, state and territory, and local governments have a shared responsibility for health governance, including policy development and implementation, and the management of healthcare systems.<sup>2</sup> The federal government develops policies that set a national public health agenda, whereas state and territory governments set the public health agenda for their jurisdictions,

as well as develop the program and funding guidelines that mandate the way services are expected to operate, including specific targets for service delivery.<sup>2</sup>

While the National Statement on Health Literacy is not legally binding, it was endorsed by all federal, state and territory health ministers, signalling a commitment to addressing health literacy.<sup>2</sup> The Statement outlines actions for different stakeholders - divided into the role of consumers, healthcare providers, healthcare organisations, government organisations and policymakers (including regulatory and advisory bodies). Nevertheless, the Statement has since been a driver for health literacy at the local level, with Local Health Networks, Primary Health Networks and community organisations designing and implementing locally appropriate health literacy interventions.<sup>24</sup>

The National Statement on Health Literacy serves three useful functions: it highlights the importance of health literacy to ensure safe and high-quality care; it promotes and supports a coordinated and collaborative approach within the health sector and across sectors to systematically address health literacy; and it describes the possible actions taken by organisations and individuals working in the health sectors to address health literacy.<sup>25</sup>

#### In the statement, health literacy has two distinct components:25

#### Individual health literacy

The skills, knowledge, motivation, and capacity of a person to gain access to, understand, appraise, and apply information to make effective decisions about health and health care, and take appropriate action.<sup>3</sup>

#### · Health literacy environment

The infrastructure, policies, processes, materials, people, and relationships that make up the healthcare system and affect the way that people gain access to, understand, appraise, and apply health-related information and services.<sup>3</sup>

#### The Statement has three strategic priorities:25

#### Embedding health literacy into systems

By developing and implementing systems and policies at an organisational and societal level that support action to address health literacy. This may include funding mechanisms, implementing policies that encourage health literacy in programme planning, and designing healthcare organisations in a way that makes it easier for people to find their way.<sup>25</sup>

#### Ensuring effective communication

By providing print, electronic and other communications that are appropriate for the needs of consumers. It involves creating partnerships, communication channels and relationships between consumers, healthcare providers, managers, administrative staff, and others.<sup>25</sup>

#### · Integrating health literacy into education

By educating consumers and healthcare providers through population health programmes, health promotion, education strategies, school health education, and social marketing campaigns. It also involves formal education and training of healthcare providers.<sup>25</sup>

The statement is not accompanied by dedicated federal funding, a time frame for achieving actions, or monitoring and evaluating frameworks.<sup>2</sup>

#### State-Level Implementation of Health Literacy Policies

There has been significant state-led implementation of health literacy policies. Four Australian states have their own strategy, action plan and/or framework on health literacy - New South Wales, Northern Territory, Queensland, and Tasmania.<sup>26</sup> Whereas the remaining states mention health literacy as a part of their wider health strategies.<sup>27 28</sup> The state-level strategies on health literacy, where they exist, are summarised below.

#### New South Wales Health Literacy Framework (2019-2024)

This framework was developed for the New South Wales (NWS) Health system in 2019. The framework provides a guide to action, by defining or outlining strategies to improve individual and organisational health literacy.<sup>29</sup>

#### The Northern Territory Health Literacy Strategy (2018-2021)

The primary goal of the strategy is to improve the health of residents by enhancing health literacy of consumers and health professionals across the Northern Territory.<sup>30</sup> It was created in alignment with the national priorities in health literacy.<sup>30</sup> The strategy was developed in 2018, as a three-year plan, with 10 key performance indicators (with timelines) that can be used to monitor the outcomes from the strategy and its activities.<sup>30</sup>

#### Tasmanian Government's Health Literacy Action Plan 2019-2024

This document sets achievable goals for healthcare and community providers across the state to help improve health literacy for individuals, communities, and organisations.<sup>31</sup> The action plan outlines four specific priorities: to improve community health literacy awareness, increase health literate organisations, develop a health literate workforce, and create partnerships to improve health outcomes.<sup>31</sup>

#### The Queensland Health literacy strategy and action plan 2020-2024

The strategy and action plan is brief compared to those from other States/Territories.<sup>32</sup> It provides a table of actions for embedding health literacy into systems, ensuring effective communication, and integrating health literacy into education.<sup>32</sup> It is not accompanied by timelines for achieving the desired actions; nevertheless, it demonstrates a commitment to embedding health literacy into the local health system as priority.<sup>32</sup>

#### Measuring Health Literacy in the Country

Australia has a National Health Literacy Survey which measures population health literacy levels. The Health Literacy Survey is part of the Australian National Health Survey that provides a benchmark for population-level health literacy. The most recent survey was conducted in 2018 using the Health Literacy Questionnaire. Prior to 2018, health literacy levels were accessed in 2006 using the Adult Literacy and Life Skills survey. 26

Health literacy has also been incorporated into national healthcare quality standards. Australia takes a structured national approach for monitoring health system quality standards, backed by an accreditation process that is assessed every three years. Health literacy has been incorporated into the National Safety and Quality Health Service Standards that are created and managed by The Australian Commission on Safety and Quality in Healthcare.<sup>2 33</sup> These quality standards define the performance requirements of healthcare services in Australia and are mandatory across hospitals, day procedure services and public dental services.<sup>123 33</sup> The inclusion of health literacy in the standards represents a shift towards health literacy being positioned as a quality and safety issue on the policy agendas of state and territory governments.<sup>23</sup>

#### National Actors and Key Stakeholder(s)

Key stakeholder(s)	Description	Links
The Australian Commission on Safety and Quality in Healthcare (ACSQHC)	The ACSQHC is a corporate Commonwealth entity, jointly funded by the federal and state and territory governments in Australia.  Established in 2006, its role is to ensure safe and high-quality health systems, including through the establishment of the National Safety and Quality Health Service Standards and the ongoing accreditation of healthcare services. National health literacy policy in Australia is within the remit of the ACSQHC. They drafted the National Statement on Health Literacy in 2014.  The ACSQHC plays a significant role in shaping the priorities and direction of healthcare in Australia, and in monitoring the performance of healthcare system.	<ul> <li>The National Statement on Health Literacy</li> <li>The National Safety and Quality Health Service Standards</li> </ul>

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The Chinese population has low level of health literacy with disparities between regions and groups.<sup>34</sup>

Health literacy in China is improving and the proportion of Chinese residents with adequate health literacy has increased from 6.48% in 2008, to 23.15% in 2020.7

## **Findings:** Health Literacy in China

China has demonstrated a commitment to addressing low population health literacy by developing and implementing a series of specific policies and actions, starting in the late 2000s.<sup>34</sup> In 2008, China established a comprehensive National Plan of Health Literacy Promotion Initiatives for Chinese Citizens (2008-2010) – publishing an initial policy paper titled Health Literacy for Chinese Citizens: Basic Knowledge and Skills (Trial); and a guiding document for implementing health literacy promotion initiatives across the country.<sup>35</sup>

As part of this work, health literacy was defined, and a national health literacy survey was established to monitor population health literacy levels for the first time. The image of 40 million USD per year is provided alongside this work to fund China's health literacy promotion initiatives. The image of the image. The image of the image of

Health literacy has become increasingly embedded into national policy. In 2014 the National Health Commission issued the Health Literacy Promotion Action Plan (2014-2020) with the goal of increasing adequate health literacy to 20% of the population by 2020.<sup>37 38</sup> Most recently, health literacy was included as an evaluation indicator in Healthy China 2030 – China's national health plan.<sup>34 38</sup>

## National Plan of Health Literacy Promotion Initiatives for Chinese Citizens (2008-2010)

In 2008, China released its first health literacy focused plan called *National Plan of Health Literacy Promotion Initiatives for Chinese Citizens (2008-2010)*. The plan included two key documents: a policy paper on health literacy, and, a guiding document for implementing health literacy initiatives. This represented the first government document to define health literacy in the Chinese setting, spearheading health promotion work in health literacy in the years to come. Phe policy paper defined the need for a national health literacy survey, and defined a local Chinese National Health Literacy Survey, which kick-started the annual survey of health literacy in the Chinese population.

Key targets and action areas in health literacy were set, and the plan covered the full country and a variety of settings.<sup>35</sup> Expectations for implementing the health literacy were clearly set for different stakeholders in the Chinese healthcare system - by administrative departments at county, city and district levels.<sup>35</sup> The project is centrally funded through the government, and health administrative departments at all levels are also required to incorporate local Health Literacy Promotion Initiatives into the health sector's annual budget to ensure their implementation.<sup>35</sup>

### Health Literacy Promotion Action Plan (2014-2020)

Building on this work, the Chinese government published a health literacy action plan in early 2014. The National Health Literacy Promotion Action Plan (2014-2020) aimed to increase adequate health literacy to 20% of the population by 2020.<sup>38</sup> The Action Plan mandated all health-related government departments and institutes to deliver health education in chronic diseases, infectious diseases, occupational diseases, mental health, reproductive, maternal and child health care, and public emergency to improve health literacy among the public.<sup>40</sup> It also focused on women, children, the aged, the disabled, and migrants.<sup>40</sup>

### Healthy China 2030

Healthy China 2030 is China's newest national health strategy. Health literacy has been positioned as a strategic goal with clearly defined outcomes for improving health literacy by 2030, to be achieved through a programme of special initiatives (e.g. Healthy China Initiatives 2019-2030).<sup>134</sup> The desired outcomes indicated in Healthy China 2030 for health literacy are even more ambitious than previous policies – aiming for adequate health literacy to be obtained in 30% of the population by 2030.<sup>34</sup>

There are several initiatives indicated in Healthy China to meet the health literacy targets.<sup>34</sup> The special initiatives cover a variety of contexts (e.g. communities, healthcare institutions, and schools) and populations (e.g. general populations, non-communicable disease (NCD) patients, healthcare workers, children, and the elderly); and support achieving the desired outcomes in health literacy by 2030.<sup>34</sup> Each special initiative is accompanied by a set of dedicated actions for implementation.<sup>34</sup>

### Measuring Health Literacy in the Country

Heath literacy has been assessed annually in China from 2008.<sup>35</sup> China is the only country found to undertake population health surveys on an annual basis allowing them to track continuing gains in health knowledge and skills.<sup>35</sup> As such, notable improvements in health literacy among the population has been measured, from 6.48% of the population having an adequate level of health literacy in 2008, to 23.15% in 2020 – and improvements have been attributed to their intensive efforts and programme of work on health literacy promotion.<sup>735</sup>

#### National Actors and Key Stakeholder(s)

Key stakeholder(s)	Description	Links
The National Health Commission of the People's Republic of China	Responsible for health legislation, formulating health policies and administration in China.  Oversees healthcare delivery, including quality and safety, and administration of the Center for Disease Control and Prevention.  Published China's national health literacy plans and strategies and commissioned the creation of the Chinese National Health Literacy Surveillance Survey.	<ul> <li>National Plan of Health         Literacy Promotion         Initiatives for Chinese         Citizens 2008–2010</li> <li>Health Literacy for Chinese         Citizens - Basic Knowledge         and Skills (Trial) (2008)</li> <li>Health Literacy Promotion         Action Plan (2014-2020)</li> <li>Healthy China 2030</li> </ul>

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Hong Kong lacks population-level data on health literacy among its nationals.<sup>8</sup>

Despite the lack of population-level data, several studies have assessed health literacy of various populations – pointing to low health literacy.

A study conducted in 2020, on a sample of 486 community-dwelling older adults in Hong Kong, found 50.9% of the participants had inadequate health literacy, suggesting that the prevalence of limited health literacy among older adults was quite high – especially in the ability to evaluate health information.<sup>9</sup>

# **Findings:**Health Literacy in Hong Kong

In Hong Kong, the approach to improving health literacy is said to be scattered, having limited impact.<sup>8</sup> Hong Kong lacks a standalone national approach, strategy, framework and/or action plan on health literacy. However, health literacy as a concept is recognised in non-communicable disease (NCD) strategies – specifically, the 2008 and 2018-2025 framework and action plan to prevent and control NCDs in Hong Kong explicitly mentions health literacy as an enabler for reducing the burden.<sup>4142</sup> Moreover, health literacy is promoted in Hong Kong's Health Promoting Schools accreditation system; and furthermore, by disseminating health information through its Centre for Health Protection.

## Health Literacy in the National NCD Strategy and Action Plan

Health literacy is used as a conceptual basis for the prevention and control of NCDs in Hong Kong. In the 2008 publication by the Department of Health called Promoting Health in Hong Kong: Strategic Framework for Prevention and Control of Non-communicable Diseases, health literacy is recognised as a guiding public health concept for NCD prevention and control.<sup>42</sup> Health literacy is defined as "the ability to read, understand, and act on healthcare information".<sup>42</sup> One action in the strategic framework is dedicated to health literacy, stating the intention to: develop health literacy in the general public with appropriate information and tools, as a means to build capacity and capability to combat NCDs.<sup>42</sup>

Health literacy was also strongly embedded into the latest strategic plan for non-communicable diseases in Hong Kong, published in 2018. The Department of Health released a new strategy called: Towards 2025: Strategy and Action Plan to Prevent and Control Non-communicable Diseases in Hong Kong. <sup>41</sup> The strategy and action plan aims to reduce NCD burden in Hong Kong by 2025, by achieving several objectives – including one on strengthening health literacy in individuals. <sup>41</sup>

### Health Literacy in Schools

Hong Kong has built a comprehensive school-based approach to improving health. Since 2001, they have adopted and scaled the model of health promoting schools (HPS) – a concept initiated by the World Health Organisation, aiming to move beyond individual behavioural change, and consider organisational and structural changes, such as improving schools physical and social environment, curricula, teaching and learning methods.<sup>43</sup>

The HPS framework provides a holistic approach to promoting the health of children, including developing health literacy. 44 Schools that adopt the HPS framework can become accredited and are awarded with the Hong Kong Healthy Schools Award based on how well they meet the criteria in the HPS framework. 44 This school-based model for improved health has been deemed successful at improving the health and well-being of students – for example, in Hong Kong, research has shown that schools who received healthy school awards had significant improvements in personal hygiene, knowledge on health and hygiene, and health information. 44 45

### Measuring Health Literacy in the Country

There have been no studies to date assessing the population health literacy level in Hong Kong.

Key stakeholder(s)	Description	Links
Department of Health, The Hong Kong Special Administrative Region of the People's Republic of China	Authored the national strategies on NCD control and prevention.	<ul> <li>Towards 2025: Strategy and Action Plan to Prevent and Control Non-communicable Diseases in Hong Kong (2018)</li> <li>Promoting Health in Hong Kong: A Strategic Framework for Prevention and Control of Non-communicable Diseases (2008)</li> </ul>
The Hong Kong Office of the Asia Health Literacy Association	Aims to understand health literacy levels across Asia from a research, education, and policy perspective. The Hong Kong Health Literacy Association aims to improve people health literacy skills and promote better understanding and utilisation of health literacy strategies among health professionals to reduce health inequalities. An annual health literacy conference is held, and members work together to discuss/collaborate on current health literacy issues, research and practices, projects, publications, etc.	More about the HK     Office

### National Actors and Key Stakeholder(s), Continued

Key stakeholder(s)	Description	Links
The Centre of Health Protection of Hong Kong (CHP)	The Centre for Health Protection is an agency under the Department of Health in Hong Kong responsible for disease prevention and control.	More about CHP
	They lead efforts on raising public awareness of health issues - using a variety of methods including printed materials, websites, telephone hotlines, briefing sessions, public television announcements and media interviews, along with large-scale publicity campaigns to promote personal and environmental hygiene, and various vaccination programs.	
Centre for Health Education and Health Promotion of the Chinese University of Hong Kong (CHEP)	Established the Hong Kong Healthy School Awards Scheme (HKHSA). CHEP was commissioned by Quality Education Fund of Hong Kong SAR Government.	More about CHEP

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# **Findings:**Health Literacy in India

India does not have a dedicated strategy for national health literacy; and only recently has there been an increased focus on health literacy as a concept.<sup>1</sup> The health literacy movement in India is gaining momentum, through implementation of a mix of government, media and digital initiatives are supporting improved health literacy.<sup>46</sup>

The government of India has recently made health information more accessible, reliable, and trustworthy. In October 2022, the Ministry of Health in India officially launched an online platform called the *National Health Portal* to serve as a single point of access for authenticated health information; in a bid to improve health literacy.<sup>47</sup> The National Institute of Health and Family Welfare (NIHFW) has established the Centre for Health Informatics to be the secretariat for managing the activities of the portal.<sup>47</sup>

Health literacy is also indirectly addressed through targeted health promotion programmes. In India, health literacy is often promoted through specific health promotion campaigns and community-based programmes. Community activists are appointed to lead health education and promotion initiatives, and the government-run programme called "Accredited Social Health Activists". Moreover, "Mitra" (meaning friend) are individuals who support people with low-income to access health services and understand health information – some are employed by health insurance schemes to help facilitate interactions with healthcare services.

There are also several school-based programmes for health promotion. The "Fit India Movement" promotes fitness and wellness among the population and includes protocols and guidelines for implementation in schools; and the "Swachh Bharat Clean School" initiative promotes sanitation and hygiene across schools to raise awareness about hygiene in students.<sup>1</sup>

Health literacy in India has been studied in different diseases and populations. This includes in maternal health literacy in a community-setting,<sup>55</sup> non-communicable diseases<sup>49</sup>, mental health literacy<sup>50</sup>, hypertension<sup>51</sup>, cancer<sup>52</sup>, diabetes<sup>53</sup> and also in validating measurement instruments.<sup>54</sup>



India does not have a national survey to assess health literacy in its population.<sup>1</sup>

The lack of population level data makes it difficult to understand the extent of low health literacy; however, several smaller-scale studies have provided an estimate.

A study at a tertiary care hospital in Karnataka, India, found that 77% of patients surveyed had very low health literacy; another study at an outpatient department at a dental hospital in Bangalore found that 60.4% had low health literacy; and another studying students (graduates and postgraduates) found that 53.7% of graduates and 57.8% of postgraduates had low health literacy. 10 11

## Measuring Health Literacy in the Country

There is no suitable and validated tool to measure health literacy in the Indian population.<sup>154</sup>

Key stakeholder(s)	Description	Links
The National Institute of Health and Family Welfare (NIHFW)	Established the National Health Portal and appointed the Centre for Health Informatics to be the secretariat for managing the activities of the Portal.	National Health Portal
Manipal Health Literacy Unit, Prasanna School of Public Health	Manipal Health Literacy Unit was started on January 15, 2015, with an overall vision to excel in Health Literacy research, policy, and practice.	More about Manipal     Health Literacy Unit

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# **Findings:**Health Literacy in Japan

The concept of health literacy has only recently gained attention, but the concept remains largely unexplored in the Japanese context.<sup>55 56</sup> The COVID-19 pandemic most recently has shed a light on the need to improve health literacy in Japan – due to the misinformation and conspiracy theories that ran rife.<sup>56</sup>

Japan does not have a national health literacy plan, framework, or strategy; however, health literacy was briefly included in the most recent healthcare strategic plan published in 2015 by the Ministry of Health, Labour and Welfare, called *The Japan Vision: Health Care 2035.* 57

Japan has one of the most rapidly aging populations in the world, and faces an increase in lifestyle-related diseases, healthcare costs and the burden of nursing care for older adults. <sup>58</sup> As such, healthy aging is a strong national policy focus, and is embedded within national health promotion programmes, such as *Health Japan 21st Century (HJ21)*, and, *The Smart Life Project.* <sup>58</sup> Both projects focus on healthy ageing and disease prevention through health promotion and concepts in health literacy (although not explicitly mentioned). <sup>58</sup> These programmes aim to provide citizens with opportunities to live healthy and meaningful lives, while also decreasing the societal and monetary burden of healthcare in a rapidly ageing society. <sup>58</sup>

Despite the lack of national policy focus in health literacy, several studies have investigated the possible impact of focusing on health literacy in Japanese healthcare. There is an overall lack of research studies on health literacy in the community setting – with most studies having been conducted in the clinical or vocational setting in Japan. <sup>56 59</sup> Health literacy has been studied in the context of health-related communication to foreign nationals <sup>60</sup>, multimorbidity <sup>61</sup>, preconception care <sup>62</sup>, glycaemic control <sup>63</sup>, COVID-19 <sup>64</sup>, smoking behaviours <sup>65</sup>, and healthcare utilisation <sup>66</sup>, among others. Recognising that health literacy research in Japan was lagging behind internationally, a group of health communication scholars in Japan established the Japanese Health Literacy Association, which held its first meeting in October 2021. <sup>56</sup>

Japan is said to be among the top 10 countries contributing to research on health literacy – ranked tenth in the world, behind South Korea.<sup>67</sup>

### The Japan Vision: Health Care 2035 (2015)

The Japan Vision: Health Care 2035, is the national strategic healthcare plan and mentions health literacy twice in its action items. First, health literacy is mentioned



In Japan, there has not been a population-level assessment of health literacy to date.<sup>12</sup>

A smaller scale study using The European Health Literacy Survey (HLS-EU) adapted for local use measured the health literacy level of 1054 Japanese adults in 2013.<sup>12</sup> These data are most often referenced in the scientific literate as the measure of population health literacy in Japan.<sup>12</sup>

The survey found that the level of inadequate health literacy was 49.9%; and 85.4% of the population fell in the "limited" health literacy category (a combination of "inadequate" and "problematic" health literacy). The same study compared the Japanese health literacy level to European countries, finding it to be lower.<sup>12</sup>

as a tool to support empowering people to make health care choices that are right for them, stating "the lack of patient engagement and the patient-provider information gap have, in some cases, led to unreasonable expectations and responses to health care. This can be addressed by increasing health literacy through efforts of the educational system, providers, government, organizations, and insurers".<sup>68</sup>

In addition, health literacy is mentioned a second time as a strategy to improve sustainable healthcare system financing in Japan. More specifically, health literacy is mentioned as a tool to strengthen financial governance, stating that: "insurers in 2035 will be asked to balance the benefits they provide with the fees they collect while contributing to a sustainable insurance system. The system should comprehensively support the insured by providing prevention and health management services and implementing initiatives that increase health literacy and improve health care quality using tools, such as ICT".<sup>68</sup>

### Health Japan 21st Century (HJ21) and the Smart Life Project

In 2000, the Japanese government launched the National Health Promotion Movement known as Health Japan 21 (HJ21).<sup>69</sup> HJ21 is a 13-year national health promotion policy (2000–2012) aimed at preventing and controlling non-communicable diseases (NCDs) and underlying risk factors.<sup>69</sup> The programme was revised in 2013 for a second term lasting from 2013-2023; and the third term is currently being developed, scheduled to start in 2024.<sup>69</sup> Each plan has several dedicated targets related to NCD control and prevention; and these are monitored throughout the programme.<sup>69</sup>

The Smart Life Project is a project run by the Ministry of Health, Labour, and Welfare to support people's health promotion. It aims to make Japan a healthy country through providing useful health information (on their website) on four topics: diet, exercise, fitness, and smoking cessation. The project hosts various events and campaigns to support health promotion in the Japanese population.<sup>70</sup>

### Measuring Health Literacy in the Country

Japan does not have a national survey to assess population health literacy.

Key stakeholder(s)	Description	Links
The Japanese Health Literacy Association (JHLA)	Recognising that health literacy research in Japan was lagging behind internationally, a group of health communication scholars in Japan established the Japanese Health Literacy Association, which held its first meeting in 2021.	More about JHLA
Ministry of Health, Labour, and Welfare	Set the strategic direction of healthcare in Japan. They produced the Japanese strategic plan for health called The Japan Vision: Health Care 2035, which provides a vision of future health care policies. They also established The Smart Life Project and Health Japan 21st Century – to tackle NCDs through health promotion.	<ul> <li>The Japan Vision: Health Care 2035</li> <li>The Smart Life Project</li> <li>Health Japan 21st Century (HJ21)</li> </ul>

# **Findings:**Health Literacy in South Korea

In Korea, national policy on health literacy is in its infancy compared to other countries.<sup>71</sup> Health literacy was first introduced as a concept in 2005; but only recently has health literacy become a subject of policy attention, with implementation in the *National Health Plan 2030* – officially announced in 2021.<sup>7172</sup> One of the main goals of this policy is to raise people's understanding of health information, and this is expected to serve as a foothold for lifting national health literacy levels.<sup>72</sup>

Despite the new policy focus on health literacy, researchers have been calling on health literacy to receive greater attention in national policy for many years. Pecific policy recommendations have been suggested for the Korean context to improve health literacy, such as: developing a national approach to health literacy by implementing a national survey on a regular basis; linking efforts in health literacy across sectors including diverse stakeholders, including government bodies, health and medical circles, the education sector, and communities, to promote lifecourse approach to health literacy; developing tailored health literacy interventions for target groups; developing a monitoring and evaluation framework for tracking effectiveness of health literacy programmes; and developing health literacy guidelines for distributing information and educating healthcare professionals.

Korea also has many clinical studies investigating the impact of focusing on health literacy. South Korea is said to be in the top 10 countries contributing to research on health literacy – ranked ninth in the world, ahead of Japan.<sup>67</sup> Health literacy has been studied in the context of health-promoting behaviours<sup>74</sup>, COVID-19<sup>75</sup>, immigrant health<sup>76</sup>, frailty in older populations<sup>77</sup>, patient-centred care by nurses<sup>78</sup>, among others.

### National Health Plan 2030

Health literacy has recently been embedded in the *Korean National Health Plan 2030* (*HP2030*) – setting the direction of the national health policy in Korea for the next 10 years.<sup>79</sup>

HP2030 has 6 main policy goals, 28 topic areas, and it will continue to expand investments in health with a total budget of 2.5 trillion Korean won.<sup>80</sup> Improving health literacy is included in the plan under the establishment of the policy goal to create "health-friendly environments".<sup>7180</sup> The target level for adequate health literacy in Koreans is set for 70% to be achieved by 2030, and there are 7 indicators set to measure improvements in health literacy in HP2030 (summarised below):<sup>7180</sup>



Research on the health literacy of South Koreans is limited, and there has never been a population-wide survey of health literacy in Korea.<sup>71</sup>

A few small scale studies have investigated health literacy levels in Koreans, but there are less than 1000 people in the sample size.<sup>71</sup> However, these studies suggest that the limited health literacy level of Koreans ranges between 43.2-70.9% of the population.<sup>71</sup>

The most recent estimate of Korean health literacy is from a survey in 2020, that is said to have the most rigorous scientific methodology.<sup>71</sup> The study was conducted by the Korea Institute for Health and Social Affairs, surveying 1,002 adults aged 19-69 using the HLS-EU-Q16 questionnaire.<sup>72</sup>

#### Findings showed that:

- 70.9% of survey respondents had inadequate and/or problematic levels of health literacy.<sup>72</sup>
- Only 29.1%
   were sufficiently
   health-literate.<sup>72</sup>

Table 6. Indicators for Improving Health Literacy in HP2030.

Sub-objectives of health literacy	Indicators
Periodical monitoring for health literacy	Development of monitoring tool for health literacy in Korea and periodical monitoring.      Development of evidence base and effective delivery method for health.
	<ul> <li>Development of evidence base and effective delivery method for health information.</li> </ul>
Construction of education system for health information	Development of education material to increase health literacy according to population group and provision of educational program connected to public health centres, public hospitals, and schools.
	Development of core message healthy living practice and campaigning.
Construction of health information delivery	<ul> <li>Provision of verified health information through national health information portal.</li> </ul>
and monitoring system	<ul> <li>Making standard distribution guideline for health information from public institution, integrated operation system and serviceability improvement for information diffusion.</li> </ul>
	<ul> <li>Quality assurance and construction of monitoring system for inadequate health information through establishment of standard management guideline for private health information sites.</li> </ul>

This table has been adapted from Park et al 2022  $^{71}$ 

## Measuring Health Literacy in the Country

South Korea does not have a national survey to regularly assess population health literacy levels; although this is a key indicator put forward in HP2030 therefore it is expected to be developed in the next decade.

### National Actors and Key Stakeholder(s)

Key stakeholder(s)	Description	Links
The Ministry of Health and Welfare	Established the National Health Plan, which reflects the directions and tasks of health policy for the next 10 years, is revised every 10 years and supplemented every 5 years.	• National Health Plan 2030 (HP2030)

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# Findings: Health Literacy in Malaysia

Malaysia does not have a specific and dedicated national Health Literacy policy.<sup>81</sup> Despite this, health literacy has been incorporated into national policymaking since 2011, when it was included as a priority area in the Ministry of Health's Country Health Plan 2011-2015.<sup>82 83</sup> The plan set the priority to increase health literacy among the general population, and called upon strategies to be implemented that would increase health literacy.<sup>83</sup> The health literacy percentage in the Malaysian population was set as a key performance indicator to measure success of the plan, and the Ministry of Health commissioned baseline data on health literacy levels to be gathered for the first time.<sup>83</sup>

Health literacy has been gaining national policy attention in recent years. In 2021, the Malaysian Government published a vision document for the country called Twelfth Malaysia Plan 2021-2025 spanning various sectors, including healthcare. He report provided a status update on projects and initiatives to improve health literacy among the general public – reaffirming the government's commitment to improve health literacy. The intention to create a national health literacy policy was announced in this plan, including a health literacy surveillance system.

The Malaysian government is currently working to develop a specific national health literacy policy. In 2022, the Malaysian Government published a call for proposals on the United Nations Global Marketplace, to find a contractor that could develop a strategic plan and framework for establishing the National Health Literacy Policy for Malaysia.<sup>81</sup> The work to develop a strategic plan is expected to conclude at the end of 2022; hinting that Malaysia will have a dedicated national Health Literacy policy in the years to come.<sup>81</sup>

Research on health literacy in Malaysia appears to be quite limited.<sup>85</sup> Health literacy has been studied in the context of validation of health literacy tools<sup>85</sup>, Urban Malaysian Elders<sup>86</sup>, age and healthcare utilisation<sup>82</sup>, diabetes<sup>87</sup>, comprehending medication labels<sup>88</sup>, sociodemographic factors<sup>89</sup>, digital health literacy<sup>90</sup>, mental health literacy<sup>91</sup>, asthma self-management<sup>92</sup>, among others.



In 2015, the first population study was conducted to assess health literacy in adults. It found that only 6.6% of Malaysian adults have adequate health literacy, with the urban population reporting significantly higher adequate health literacy (7.8%) compared to the rural population (2.3%).<sup>19 85</sup>

In 2019, a more comprehensive version of the same survey was repeated and showed that a majority of the population had sufficient or excellent health literacy.<sup>19</sup>

The 2019 survey found that 40.7% of Malaysians had sufficient health literacy, 24.3% had excellent health literacy and 35% had limited health literacy.<sup>81</sup>

### Health Literacy in the Twelfth Malaysia Plan 2021-2025

Health literacy was a key focus in the Twelfth Malaysia Plan 2021-2025.<sup>84</sup> Published by the government, the plan outlines that a national health literacy policy will be introduced to improve the knowledge and understanding of the public on the basic health information and services needed, and to facilitate agencies in planning for better programme implementation.<sup>84</sup> They will create a new health literacy surveillance system to support the implementation of this policy, and implement health awareness programmes across all levels, including in workplaces, government agencies, to combat non-communicable disease (NCDs).<sup>84</sup> Schools were indicated as a key priority stakeholder for improving health literacy among students.<sup>84</sup>

### Measuring Health Literacy in the Country

Health literacy is not regularly measured at the population level in Malaysia. Population health literacy was measured in 2015 and 2019, in a survey initiated by Malaysia's Institute for Public Health, using the National Health and Morbidity Survey (NHMS) - an important survey for monitoring the health of the population in Malaysia established in 1986.<sup>94</sup> In addition, a health literacy surveillance system is being developed with the health literacy national policy – however it is not currently active.<sup>84</sup>

Key stakeholder(s)	Description	Links
Ministry of Health Malaysia, Institute for Public Health	Conducted the 2015 and 2019 National Health and Morbidity Survey (NHMS), that measured the population health literacy level in Malaysia. The Ministry also leads on country health plans.	<ul> <li>More about the NHMS (2015 &amp; 2019)</li> <li>Country Health Plan 2011-2015</li> </ul>
Economic Planning Unit, Prime Minister's Department, Malaysia	Leading the national priority to improve health literacy policy and data infrastructure through the Malaysia Plan 2021-2025.	Twelfth Malaysia Plan,     2021-2025

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# **Findings:**Health Literacy in New Zealand

New Zealand began their work on health literacy in more recent years, compared to other countries. The motivation to improve health literacy was largely driven by the need to reduce health inequalities and inequities for Māori, New Zealand's Indigenous population.<sup>95</sup>

In 2010, the Ministry of Health published New Zealand's first health literacy research report *Kōrero Mārama: Health literacy and Māori*<sup>96</sup>. The report was a defining moment for health literacy, as it showed the scale and size of the challenge locally and illuminated the need to address health literacy as a nation.<sup>95</sup> Health literacy was defined in the report for the first time in New Zealand, as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions".<sup>95</sup>

Health literacy in New Zealand is positioned as a system and health equity issue (rather than individual) and they take a provider-focused approach to driving improvement. 95 97 Their strategic focus is on how health systems and providers can support consumers to access and understand health services. 98 Rather than viewing health literacy as a challenge for individual patients or even individual clinicians, the solution lies in a concerted effort across sectors, including schools, social welfare, ACC and other government agencies, and the entire health care system. 97

The New Zealand Ministry of Health is striving to create more health-literate providers. In 2015 the New Zealand Ministry of Health released two publications on health literacy: *The Health Literacy Review: A Guide, and, A Framework for Health Literacy.* <sup>98 99</sup> These resources were created to support health providers and organisations across New Zealand carry out a health literacy review, and build a health literate organisation to reduce demands on consumers. <sup>100 101</sup>

In 2016, health literacy was embedded as a key priority in the *New Zealand Health Strategy 2016-2026*. The strategy provides a framework for delivery of all health services, and is comprised of two components – the main document, establishing the future direction for the health system, and a second document, providing a detailed roadmap with action items. There are several action items dedicated to health literacy in the health strategy.



More than half (56%) of adult New Zealanders have low health literacy – equating to 1.8 million people.<sup>95</sup>

Populations with lower health literacy include the poor, elderly, rural, Pacific peoples, and Māori, with studies showing that almost 90% of Pacific adults and 72% of Māori adults, have low health literacy. 95 97

Most recently, there have been nationally led efforts to create a more health literate workforce. In 2022 The Health Quality and Safety Commission New Zealand published a report called the *Three steps to meeting health literacy needs*. The guide is intended for healthcare professionals and provides a three-step process for them to follow with every person in healthcare discussions, supporting the role of the health workforce in building health literacy. The supporting the role of the health workforce in building health literacy.

### The Health Literacy Review: A Guide (2015)

Health Literacy Review: A Guide (2015) was created by the Ministry of Health in 2015 to support the creation of health-literate organisations. The guide outlines a step-by-step approach to conducting a health literacy review and provides templates for doing so. The review allows organisations to gain a better understanding of the health literacy demands placed on consumers and families. The guide was informed by international best practice approaches, tailored to the New Zealand health setting and has six dimensions to evaluating the health-literacy level of an organisation. Health organisations are encouraged to conduct a health literacy review of their organisation, and use the findings to form an action plan for creating a more health-literate organisation.

The total number of district health boards (DHBs) who have implemented the health literacy review is currently unclear. However, some sources have indicated that several DHBs are using the health literacy review guide to carry out a review of healthcare provision across region.<sup>95</sup> Some have developed or are developing strategic action plans for health literacy.<sup>95</sup> It has been noted in some cases that current resources do not allow for full implementation of comprehensive health literacy reviews, and associated programmes of work.<sup>105</sup> 106

### A Framework for Health Literacy (2015)

A Framework for Health Literacy was developed by the Ministry of Health in 2015.<sup>99</sup> The framework conceptualises how each part of the health system contributes to building health literacy and provides actions for the health system, health organisations, the health workforce and individuals/their families.<sup>101 107</sup> The actions aim to support a 'culture shift' so that health literacy is core business at all levels of the health system; and reduce health literacy demands on individuals, to contribute to improved health outcomes and reduced health costs.<sup>101</sup>

The Framework is currently not mandated by the Ministry of Health.<sup>106</sup> Instead, it defines expectations and provides guidance to organisations who are encouraged to use the Framework.<sup>106</sup> New Zealand is the only country to have developed a framework that outlines expectations for the health system, health organisations and the health workforce to support health literacy being core business at all levels of the health system. The framework represents the Ministry's commitment to creating a health system that enables everyone living in New Zealand to live well and be healthy.<sup>99</sup>

### The New Zealand Health Strategy (2016-2026) and Roadmap Actions

The currently active New Zealand Health Strategy 2016-2026 recognises health literacy as a key pillar.<sup>2</sup> It has five strategic themes, and health literacy is recognised in the 'people-powered' theme.<sup>2</sup> The roadmap that accompanies the strategy specifies two actions to promote health literacy.<sup>103</sup> The first action focuses on providing individuals with health information to support self-management, including harnessing digital technologies such a social media, mobile applications and video games.<sup>2103</sup> The second action focuses on making the health system more responsive to people, through shared decision-making, cultural competencies, and increased engagement with people.<sup>2103</sup>

### Measuring Health Literacy in the Country

In 2006, a population-based survey was carried out to measure health literacy in New Zealand. The Adult Literacy and Life Skills Survey was conducted on a representative national sample of 7,131 New Zealanders aged 16–65 years. The survey contained 191 health-related questions across four domains: prose literacy, document literacy, numeracy and problem solving. Questions addressed health promotion (60 items); health protection (64 items); disease prevention (18 items); health care maintenance (16 items); system navigation (32 items). The results showed some improvement has been achieved in adult literacy and numeracy since the 1996 International Adult Literacy Survey (IALS). There has not been another survey conducted since 2006 on population health literacy levels.

Key stakeholder(s)	Description	Links
Ministry of Health, New Zealand	Set the national policy agenda for health literacy and have embedded health literacy into the National Health Strategy 2016-2026.  They are also supporting health organisations to become more health-literacy conscious by providing the tools and resources to do so – including the Health Literacy Review Guide, and the Health Literacy Framework.	<ul> <li>Health Literacy Review: A Guide (2016)</li> <li>A Framework for Health Literacy (2016)</li> <li>New Zealand Health Strategy: Future Directions (2016-2026)</li> <li>New Zealand Health Strategy Roadmap of Actions (2016)</li> </ul>
Health Quality and Safety Commission New Zealand	Created a national resource for health professionals to become more health-literate.	Three steps to meeting     health literacy needs     here (2022)
District Health Boards (DHBs)	There are 20 DHBs in New Zealand who organise health services in a geographic area. DHBs are responsible for implementing health literacy programmes, including implementing the health literacy review and framework created by the Ministry of Health in New Zealand.	DHBs are listed here

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The first national health literacy survey in the Philippines was conducted in 2018-2019 and found low levels of health literacy in the population.<sup>13</sup>

The National Health Literacy Survey is the first nationwide survey on the prevalence of health literacy in the Philippines, involving 2303 randomly selected Filipino residents aged 15 to 70 years.<sup>13</sup> It found 51.5% of the study participants had limited health literacy.<sup>13</sup>

# Findings: Health Literacy in the Philippines

In the Philippines, significant progress has been made in the past 5 years with regards to policies in health literacy. In 2010, lawmakers put forward a Health Literacy Act, but were unsuccessful in succeeding to bring it into national law. However, in 2019, the Universal Health Care (UHC) Act came into national law, prescribing reforms to the healthcare system and significantly positioning health literacy as a national priority within health promotion initiatives. However, in 2019, the Universal Health Care (UHC) are came into national law, prescribing reforms to the healthcare system and significantly positioning health literacy as a national priority within health promotion initiatives.

Following the establishment of the UHC Act, all citizens were automatically enrolled in the National Health Insurance Programme for the first time. The UHC Act included a strong focus on healthcare promotion, and mandated the creation of a national framework for health promotion. In 2020, the National Health Promotion Framework Strategy (HPFS) 2030 was officially launched by the Department of Health, to guide national and local implementation of health promotion policies, including health literacy.

## Universal Health Care Act (2019) and Health Promotion Framework Strategy 2030

The UHC Act laid the foundation for embedding health literacy into national policy in the Philippines. Section 30 of the Act - dedicated to National Health Promotion – called on the Department of Health, via a newly formed Health Promotion Bureau (HPB), to pursue improved health literacy, and on the Department of Education to integrate health literacy into school curricula. 109

The Act also stipulated that local governments, guided by a health promotion framework strategy, shall issue and implement effective health promotion policies and programmes. The Act specified that within two years from its commencement, the implementation budget for health promotion programmes should be no less than 1% of the Department of Health's total budget. 109 The Department of Health and Department of Education were also required to begin submitting annual implementation reports on health promotion and health literacy programmes. 109

As specified in the UHC Act, a Health Promotion Framework Strategy (HPFS) 2030 was created and launched in 2020. It provided a roadmap and basis for national and local policies, programmes, and activities on health promotion lasting from 2021-2030.<sup>112</sup> The key goal described in the strategy is to ensure 'Filipinos are health literate, settings are health-enabling and public policies are health-

supporting', demonstrating a strong commitment to health literacy.<sup>112</sup> In addition, HPFS 2030 provides three implementation strategies, namely: healthy governance, healthy settings, and health literacy, which shall guide the implementation of all health promotion policies, programs, plans, and activities.<sup>112</sup>

The first annual report on implementation of the UHC Act was published in 2021, called Health Promotion Implementation Report, detailing significant policy progress in the Philippines. The report shows that the budget to implement health promotion activities has been increasing year over year, and that there is ongoing work to measure health literacy in all UHC provider sites from 2022 onwards – as part of an annual assessment on health promotion.

### Measuring Health Literacy in the Country

Health literacy has been measured once in the Philippines using the National Health Literacy Survey, conducted from 2018-2019. There are plans to measure health literacy levels of individuals across all UHC sites annually, from 2022 onwards.<sup>112</sup>

Key stakeholder(s)	Description	Links
Congress of the Republic of the Philippines	Passed the Universal Healthcare Act in 2018 – establishing the law mandating healthcare for all Filipinos.	<ul> <li>National Health Literacy Act (2010)</li> <li>The Universal Healthcare Act (2018)</li> </ul>
Health Promotion Bureau (HPB), Department of Health	Leads the implementation of health promotion-related policies, plans and programs for the attainment of Universal Health Care and a Healthy Filipinos.	<ul> <li>Health promotion         accomplishment report         (2020-2021)</li> <li>Health Promotion Framework         Strategy 2030</li> </ul>

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To date, no studies have been conducted in Singapore to assess health literacy in the population.<sup>113</sup>

The studies that do exist are mostly small-scale studies conducted on specific disease areas, with limited applicability to the full population.<sup>113</sup>

The most comprehensive study of population health literacy was conducted in 2021 by Asharani et al, surveying a sample of 2895 adults 18 years and above.113 This study found most of the population had adequate health literacy - with 80.5% having high functional health literacy, meaning the population is able to function efficiently in a health care context, and read, understand and respond adequately to healthcare

# **Findings:**Health Literacy in Singapore

There is limited national policy work in Singapore on Health Literacy. In 2010, the Health Promotion Board (HPB) developed the Action Plan to Improve Health Literacy in Singapore. In the Action Plan defined health literacy for the first time in Singapore as "the degree to which people have the ability to obtain, understand, assess and communicate the health information and services needed to guide them in making health-related decisions." These decisions occur at home, at work, and in schools, the healthcare system and society as a whole.

The Action Plan provided a health literacy framework, as well as goals and priority actions for implementation.<sup>114</sup>

The key priorities for improving health literacy in the plan were stated as: 1) developing a health literacy measurement tool to establish standards of health literacy in Singapore, 2) issuing plain language guidelines to all health-related sectors, and, 3) including health literacy in training curriculum for all health and allied health professionals. 114 115 Unfortunately, national policy on health literacy in Singapore remains stagnant since the Action Plan was published in 2010. No further information was found on implementation of the Action Plan since it was originally published.

Singapore has trained a group of health ambassadors to support health education and health promotion in the community setting. For example, the HPB stated their intentions to train 10,000 advocates of healthy living by 2015, as part of its new Health Ambassador Network. The ambassadors will include youths, young adults, parents and seniors, and will take a peer mentoring approach to share healthy lifestyle tips with their family, friends, peers, neighbours and colleagues. The state of the state

Additionally, few scientific studies exist on health literacy in Singapore. In the few identified, health literacy was studied in the context of chronic diseases self-management<sup>116</sup>, digital health literacy<sup>117</sup>, COVID-19 pandemic<sup>118</sup>, mental health<sup>119</sup> and diabetes.<sup>113</sup>

### Measuring Health Literacy in the Country

In 2011, researchers validated the use of the Health Literacy Test for Singapore (HLTS) which is an adapted version of the Short-Test of Functional Health Literacy in Adults, to measure the health literacy of the general population. However, there is no evidence that a national survey was ever conducted following its validation; and no studies exist on population health literacy levels in Singapore.

Key stakeholder(s)	Description	Links
Health Promotion Board (HPB)	Passed the Universal Healthcare Act in 2018 – establishing the law mandating healthcare for all Singaporeans.	<ul> <li>More about HPB here</li> <li>The Singapore Action Plan to Improve Health Literacy (2010)</li> </ul>

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## Conclusion

The early definition of health literacy as put forward by the WHO in 1998, notably "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health" has since evolved. Today, health literacy has progressed from a focus on individual health literacy towards a more broad definition that considers the social and environmental factors that are shown to impact the health literacy of individuals.

While health literacy is continuing to gain global attention and interest, and despite advancements in the definition of health literacy and the emergence of health literacy on policy agendas, health literacy is not a clearly defined priority in the national health policies or health plans of many countries in Asia-Pacific.

In those countries that have health literacy policies and measurement strategies embedded at the national level, there are champions in place to promote health literacy as a priority area of focus. Further, in countries where policies exist there is a lack of consistency with some lacking more formalised frameworks or strategic plans that clearly define measurable goals, actionable strategies, and avenues to monitor, evaluate and report progress.

Additionally, those countries with health literacy integrated into national plans or strategies also have some population-based health literacy data. Not surprisingly, where health literacy policies or strategies are lacking, population health literacy data is either unavailable or sparse.

Health literacy is viewed as part of education in some countries, either embedded in the curriculum or in the context of a policy. However, despite a clear focus on education, there may not be programmes available to meet the needs of vulnerable populations. As well, there may not be training on health literacy available to health professionals working in the healthcare sector.

Although some countries in Asia-Pacific have begun to focus on individual health literacy with policy development or efforts to improve health literacy environments, very little information about how these efforts are funded are readily available. In some countries, funding is in place to implement a broader health plan but little to no information is available with respect to the percentage of budget (if any) that is allocated to health literacy initiatives.

Some countries in the region have prioritised and implemented heath literacy in their national policies and strategies however, the national policies vary based on the way in which different countries conceptualise and define health literacy with factors, such as how countries perceive population need as well as the healthcare system structures, playing influential roles.

## **Key takeaways**

## Informed by research into the state of health literacy in Asia-Pacific, key takeaways include:

- · Health literacy should be embedded in policies.
- Health literacy should be addressed as a social determinant of health.
- Health literacy should be consistently measured and reported.
- Health literacy frameworks should be introduced and championed.
- Health literacy should be integrated into healthcare planning and educational curriculums.



## Health literacy should be embedded in policies.

Of the ten countries where the state of health literacy was examined, very few have established health literacy policies. Where policies exist, they are geared towards population or specific contexts of national health plans.

There are opportunities to build capacity at national levels for policy development, leadership, and knowledge in relation to health literacy. This may be further supported by advocating for a national focus on health literacy as well as utilizing best practices and/or policy strategies from other countries or regions.



## Health literacy should be addressed as a social determinant of health.

Health literacy contributes to inequities and widespread health disparities between countries, populations, and individuals. Many people experience disproportionate burdens and inequities in terms of healthcare services. This is worsened by the underlying structural or environmental social determinants of health. As the health status of individuals is influenced by the impact of social and environmental conditions, the social determinants of health play an important role in determining personal health outcomes. There is a strong relationship between personal health outcomes and literacy. More specifically, health literacy is essential to helping patients gain and exert greater control over healthcare decision-making and self-management.

There is a need at the system-level to integrate health literacy in policies that aim to concurrently address or take into consideration the broader underlying social determinants of health — in particular, those determinants that impact the ability for people to understand health information, navigate complex healthcare systems and services and access the resources necessary to achieve better health outcomes.



# Health literacy should be consistently measured and reported.

Many countries lack a consistent or universal literacy measurement strategy despite the value of producing national population data as a benchmark and the value of using the data to help inform strategies and present a case for budgetary allocation in national health plans. Of the countries profiled, only China is assessing population health literacy on an annual basis as of 2008. In some instances, countries like Australia and Malaysia and New Zealand have each implemented intermittent national surveys that provide benchmark population data. More recently, Malaysia has defined health literacy as a country priority with the intention of creating a new health literacy surveillance system to monitor population health literacy and support the development of health awareness programmes.

Population data is critical to supporting evidence-based policy development and interventions. There is a need for policymakers, system leaders and key stakeholders to collaboratively advocate for national health literacy data collection and reporting. This may include, for instance, the implementation of regular health literacy surveys with attention given to ensuring surveys are culturally and linguistically appropriate. Further, from an advocacy perspective, there are opportunities to leverage health literacy data, including training patient advocates on how to influence health literacy policy development in their respective countries to help ensure their active participation in health system and policy design.



# Health literacy frameworks should be introduced and championed.

There are some countries, such as Australia, which have established a body to serve as a champion of health literacy. Others, such as China, are aiming to increase health literacy in the population by allocating funding and incorporating health literacy in longer term national health agendas.

There are opportunities for stakeholders, including patient organisations and patient advocates, to work in collaboration to champion national frameworks that guide strategic priorities and support ongoing allocation of core funding for short and longer-term health agendas that incorporate health literacy. This may also include detailed mapping to further improve knowledge of health literacy initiatives and strategic directives, as well as help to further identify inequities and existing gaps in the system.



# Health literacy should be integrated into healthcare planning and educational curriculums.

Very few countries to date have embedded health literacy in healthcare and education systems to create health literate environments. There are a handful of countries that have included health literacy in national action plans as, for instance: a health evaluation indicator; an enabler for reducing the burden of non-communicable diseases, to further advance broader non-communicable disease strategies, or to support action to improve access to reliable health information and improve health promotion.

There are opportunities for system leaders and others to advocate for the inclusion of earlier population-based health literacy initiatives (or programmes). For instance, in educational curriculums that promote general literacy and in healthcare settings to help increase understanding of information.



# Health literacy should aim to improve communications across healthcare services and delivery.

Health literacy is a multi-dimensional concept that incorporates cultural perspectives, best practices, and patient-centric knowledge translation. This includes understanding and meeting the needs of patients in terms of how health information in a healthcare setting is shared and the manner and format in which information is shared.

There are opportunities for policy development and the implementation of best practices across all of healthcare to address the core dimensions of health literacy. This may be from an individual (or personal) health literacy perspective or from the health literacy environment. A policy focus on organisational health literacy – namely the policies, processes and materials that affect how people engage at the system level – is essential. Further, policies that focus on improving communications across healthcare services and delivery, including practices that involve communication between patients and healthcare professionals, are likely to have the greatest impact.



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Let's all ensure patients with lymphoma have access to accurate information on their specific subtype, their treatment options – including clinical trials – and are involved in the decision-making process when determining the course of their treatments.

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