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A Rare Cancers Australia Initiative

PATHWAYS FOR TRANSFORMING THE CANCER ECOSYSTEM

A PATIENT CENTRED FRAMEWORK

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CONTENTS

INTRODUCTION AND OVERVIEW

The way we view, talk about, prevent, and treat cancer has been evolving globally. Thankfully, increased access to care and major recent advancements mean that more people are surviving cancer, and they, their families and carers are wanting to share their experiences and help others. And this is just the beginning. Thought leaders and experts believe we are entering a major turning point for cancer care, with exponential potential to better understand, prevent, treat and cure cancers.

Scope of this report

This report outlines how we can all do more to improve cancer survivorship in the Asia-Pacific region, which has more than half of the world's population and more than half of global cancer deaths. Rare Cancers Australia (RCA) facilitated the development of this collaborative report with a highly regarded advisory board and more than 100 interviews with a range of stakeholders including patients, patient support organisations and other community groups, clinicians, researchers, multiple industries, and healthcare decision-makers (see list in the Appendix).

This report explores relevant trends, opportunities and tangible ways to collaboratively drive positive changes, with the patient voice being critical to identifying the best opportunities for investment of resources and time. We came across many positive trends in the region, including:

- ✓ the growing voice of patients, carers, and the community
- ✓ overall improved community understanding that cancer is survivable
- ✓ support through global and regional collaboration initiatives
- ✓ more local research and clinical leadership
- ✓ a better recognition of the value of health (post COVID-19)
- ✓ greater use of telehealth technologies to reach more people (post COVID-19).

The region is diverse with many geographical, cultural, political, funding and structural differences, however there are valuable themes and positive examples relevant for all. The many inspiring examples shared in this report show great change is possible and happening already, and that working together, with patient representatives and others, will lead to better outcomes.

Opportunities and realities

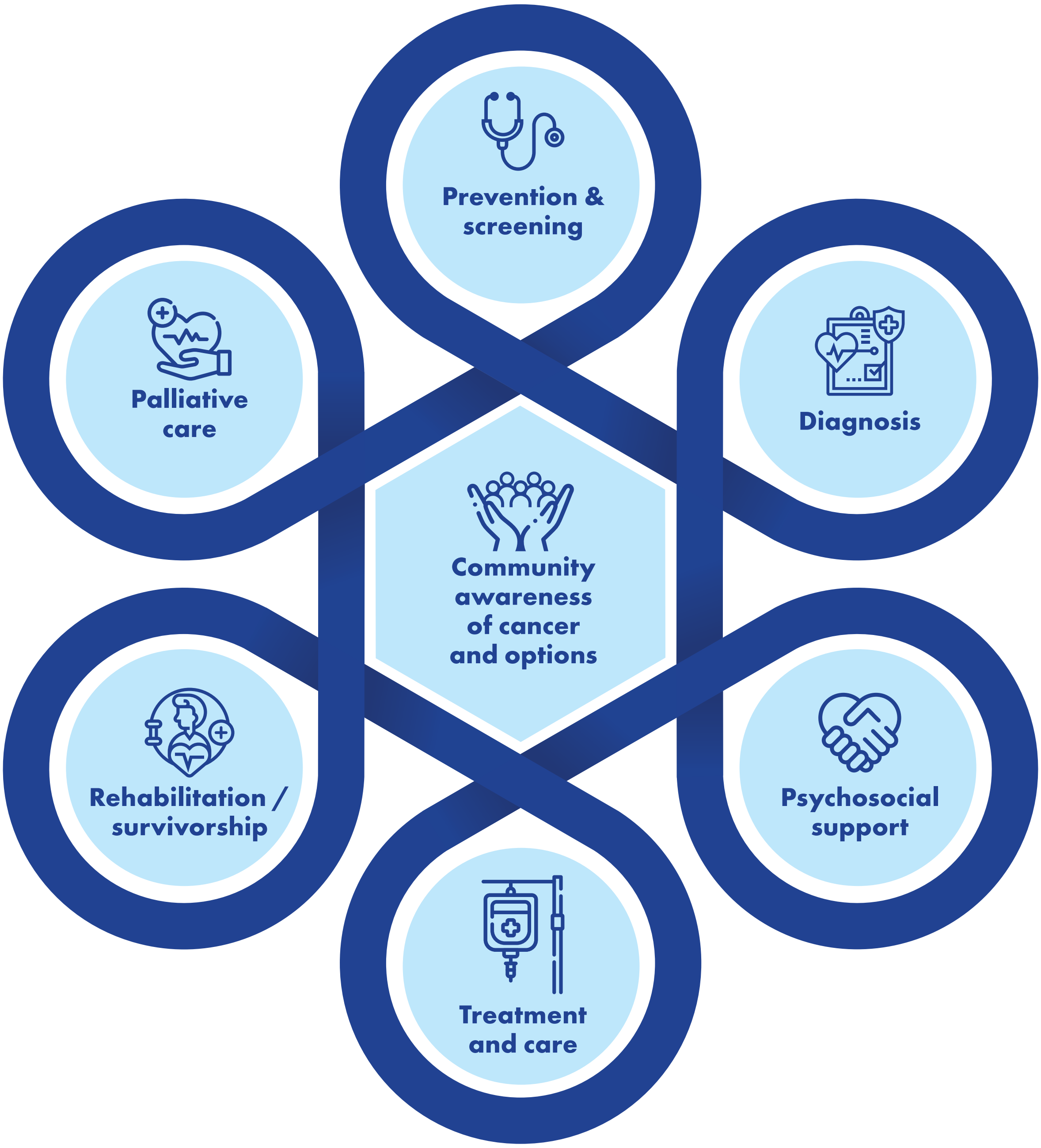
The global shift in perceptions and reality of cancer has a number of implications and considerations for the Asia-Pacific region, including:

- the need for equitable access to diagnostic and treatment options
- growing health and cancer care costs
- the need for patient representatives to help lead positive changes
- opportunities to prevent more cancers
- benefits of earlier detection and diagnosis
- increasing demand for psychosocial and supportive care.

Many experts interviewed for this report argue that funding healthcare and saving lives should be considered an investment in the community and the economy, not merely a cost. There are major economic and social benefits to treating cancer. Premature death has longer-term flow-on impacts to families and communities and many cancer diagnoses lead to financial toxicity for patients and families in the region.

However, there are realities that mean each country (and market) in the region will need to have a strategy for how to sustainably provide better cancer prevention and care services for the community. Health systems are grappling with growing healthcare expenditures, ageing populations, chronic diseases and relatively high costs for new technologies. Sustainability and value for money are clear questions in this context.

Figure 1: Cancer care continuum components



Maximising community benefits

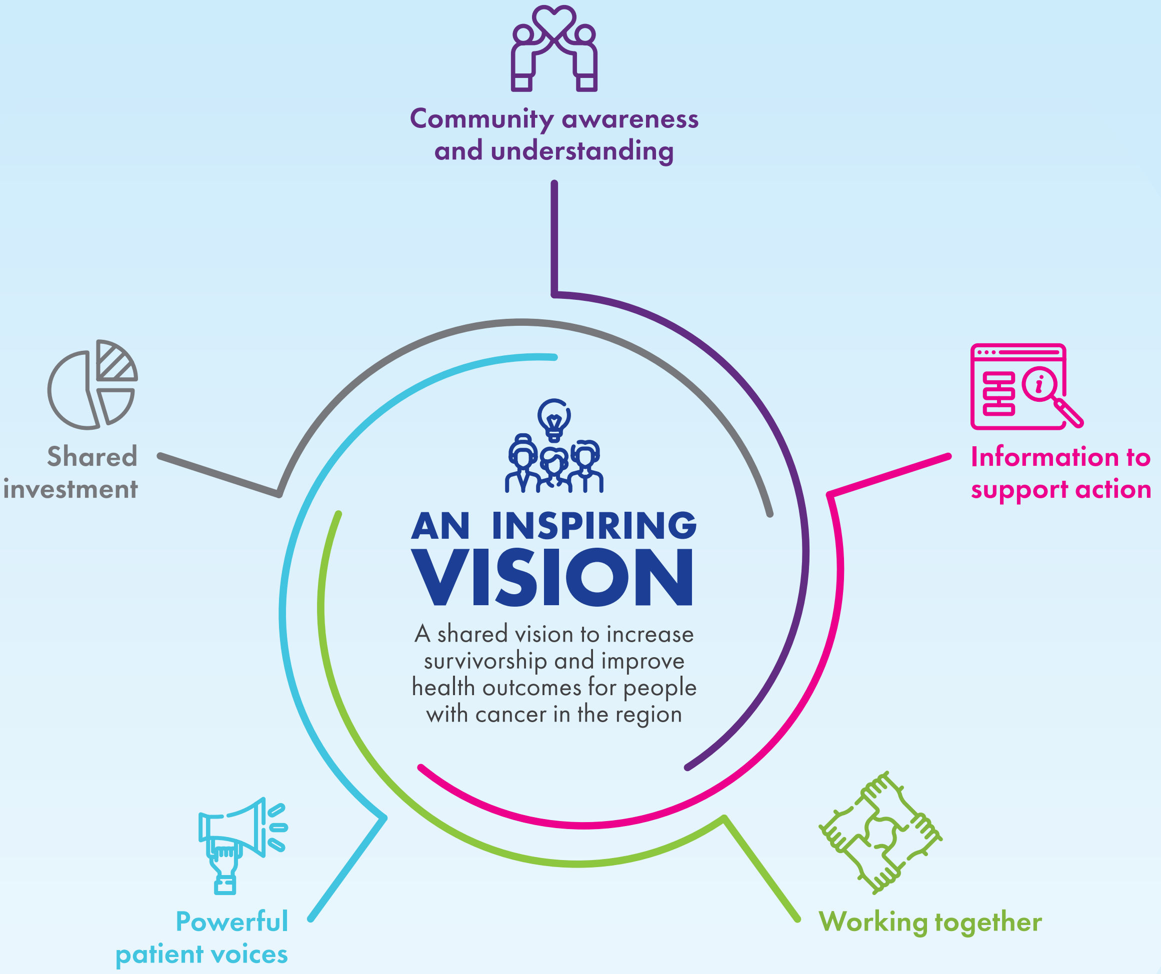
There is a great opportunity for further positive change in the region to benefit patients with cancer and their families, building on the existing positive momentum. Further improvements to cancer prevention, treatment and care, and psychosocial support require more than just funding to be successful (although funding is still critical). In the context of growing health budgets and other urgent political priorities, funding and resources will need wise management to achieve maximum community benefits in health.

Significant improvements will need systems thinking and change based on the local needs, context, and leadership, so standard or 'one size fits all' solutions risk inefficient and inappropriate use of resources. Sustainable systems changes require shifts in policies, practices and resource flows, relationships and connections, and beliefs. These shifts cannot be done in isolation and require collaboration. Importantly, the patient voice is a critical piece of the puzzle. Globally, the world is waking up to the value patient representatives provide to the community, how patient voices can help improve systems, and that patient engagement leads to better health outcomes and potentially more efficient healthcare. These insights are not just relevant for cancer, but cancer is a leading cause of death in the region and so a good place to focus.

Harnessing local collaboration can help to avoid inefficiencies and help initiate, scope and prioritise action, considering:

- an inspiring vision for change
- information to support action
- working together through collaboration and shared leadership
- powerful patient voices
- broader community engagement with civil society
- shared investments and actions from different sectors.

Figure 2: Collaborative framework for systems action



Community awareness and understanding

Information to support action

Working together

Powerful patient voices

Shared investment

AN INSPIRING VISION

A shared vision to increase survivorship and improve health outcomes for people with cancer in the region

Broader community engagement with civil society

- Promoting widespread information on cancer
- Breaking myths and misconceptions
- Reshaping public perceptions, and expectations of care
- Reducing stigma and discrimination
- Engaging media, political leaders, families of patients and survivors, and scaling up their involvement

Evidence and strategic information

- Understanding the current situation and opportunities
- Knowing how the system works, recognising important gaps and emerging challenges
- Identifying relevant evidences, research, best practice and key players
- Harnessing technology and data

Collaboration and shared leadership

- Shared leadership to improve outcomes for patients
- Experts, patient organisations, development partners, civil society organisations, decision makers and industry have collaborative relationships to drive and create momentum for change
- Local research is promoted and supported

Powerful patient voices

- Patients are valued, organised, communicating needs and concerns
- Patients lived experiences, ideas and insights inform systems changes
- Patients are meaningfully involved and shape policy and program design, research/ data generation

Investment and action from various sectors

- Sustainable and innovative financing to drive change and improvements
- Investments of time and expertise
- Market shaping interventions for greater access, availability and affordability

The report outlines further what is meant by these concepts with case studies to highlight examples of successes already happening in the Asia-Pacific region.

Recognition of the many voices involved

Thank you for the valuable input from our Advisory Board who had an active role in developing the scope, plan and key messages for this report.

Carmen Auste
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Vice President, Cancer Coalition Philippines

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Thank you to the many passionate experts and community leaders who contributed their time, insights and ideas during interviews for this report (see list in the Appendix). A special thanks to the project team, Tiffany Petre, Christina Cho and Eri Nishiuchi, for their efforts in conducting the many interviews and creating this collaborative report.

We are also incredibly grateful for the support of our sponsors of the Pinnacle Program and APOA.

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RARE CANCERS AUSTRALIA AND PINNACLE

About Rare Cancers Australia

Rare Cancers Australia (RCA) was founded in 2012 by Kate and Richard Vines. RCA works to improve the lives and health outcomes of Australians living with rare, less common and complex cancers – today and into the future. Before RCA, there was little to no support for rare cancer patients and no understanding of rare cancer issues in Australia. Over the last 11 years, we have:

- changed the game for patient voices being involved in research, policy and health systems pathways
- raised over $5m to cover out of pocket costs for patients
- enabled major policy reform and investment for rare cancers in Australia
- written 16 policy shaping and thought leadership reports
- supported thousands of patients by delivering a 360 degree model of navigation that truly puts people at the centre of their own healthcare experience
- hosted over 20 to raise funds and awareness for rare cancers.

The RCA team started Pinnacle because we want to share our successes and learning by creating a platform of shared experiences and mentoring so we can all learn from each other. Through our work, we have a reservoir of intellectual property we're committed to sharing with our fellow patient organisations.

About the Pinnacle Program

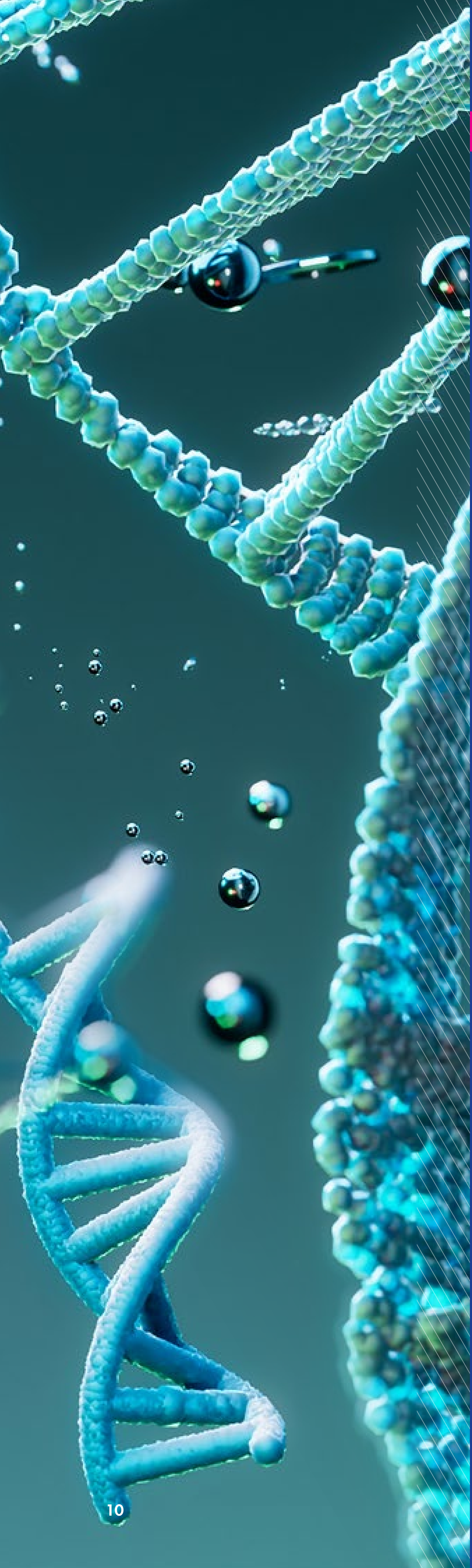
The Pinnacle Program is a peer-to-peer mentoring program developed by RCA for patient support organisations (PSOs) across the globe. The mission of the Pinnacle Program is to **support, connect and empower** PSOs and improve the health outcomes of patients across the Asia-Pacific region.

It is based on the principles of ethnographic teaching and aims to create a community for learning, connecting, collaborating and sharing across PSOs internationally so that we can all learn, grow and better support our patients. Capacity building initiatives need to specifically consider the local context, cultural and linguistic factors relevant for patient organisations in the Asia-Pacific (APAC) region and the Pinnacle program is designed to work in that way.

The Asia-Pacific Oncology Alliance (APOA) is an initiative of the Pinnacle Program. The relationship between RCA, the Pinnacle Program and APOA is outlined in Figure 3.

APOA is a network of stakeholders (comprising of patients, patient organisations, clinicians, researchers, multiple industries, and healthcare decision-makers) from across the cancer continuum who are committed to improving cancer survivorship in the Asia-Pacific region.

Figure 3: RCA, Pinnacle Program and APOA



A NEW ERA IN CANCER CARE GLOBALLY

The way we think about and treat cancer has changed dramatically in the last 20 years. Cancer has been shifting from generally being considered a terminal disease to one that can be increasingly treated and managed.

Major recent advancements include:

- ✓ learnings about the molecular pathology of cancers and underlying genetic drivers
- ✓ identifying rarer subtypes and recognising how each person's cancer can have unique characteristics
- ✓ discovering biomarkers to better diagnose and treat cancer
- ✓ introduction of newer treatments such as targeted, gene and immuno-oncology therapies that have a more focused approach to fighting cancer
- ✓ adoption of tele and digital health solutions to improve access to services and for better prevention, early diagnosis, treatment, and survivorship
- ✓ increased recognition and support of the patient, carer and family voice and recognition of the need to consider the whole person in care planning
- ✓ use of artificial intelligence (AI) to help diagnose cancer, and manage and analyse large datasets (e.g. genetic data)
- ✓ use of new devices and robotics making surgeries more precise.

The newest precision therapies are fundamentally different from the traditionally used chemo and radiation therapies, which poison the cancer but also affect healthy cells, leading to many side effects. Newer treatments are tailored to the patient's own DNA or the molecular characteristics of their cancer. They block the action of enzymes, proteins and other molecules that promote the growth of cancer cells, or they harness the immune system to kill cancer cells. For patients, the side effects are often much more manageable, but also more importantly for some patients, these treatments offer hope for survival that wasn't possible in the past.

In the last 20-30 years, the pharmaceutical and health care industries have invested substantially in improving screening, diagnosis, and treatment of cancer. More than 100 new cancer drugs were approved by the European Medicines Agency between 2010-2020 alone, although it is recognised that only a portion of these would be considered 'innovative' therapeutics.[1]

And this is just the beginning. Thought leaders and experts believe that we are entering a major turning point for cancer care, with the potential to better understand and cure cancers. Most cancer therapies in development now are considered 'innovative personalised treatments'.[2]

> The perceptions of the Chinese population have changed in the last 10 years. People used to associate cancer with fear and wanting to run away because of the harsh reality of limited treatment options, no money for treatment and no confidence. Now we can face cancer and more people hope to live with cancer. We have more access to medicine, the means to afford treatment and the confidence to fight. For most people, a lot has changed.
>
> **Jenny Zhang**
> Director of International Affairs, House086 China

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[1] Hofmarcher, T., Keel, G., Lindgren, P. (2021). Cancer Care and Access to Cancer Drugs in Asia-Pacific. Available: https://ihe.se/wp-content/uploads/2021/11/IHE-Report-2021_3b_.pdf

[2] Rare Cancers Australia. (2020). Vision20-30 Building an Australian Cancer Futures Framework

This fundamental shift in how cancer is and will be treated has a wide range of implications for the Asia-Pacific region.

Access

Globally, access to cancer prevention, research, diagnostics, treatment, and psychosocial support vary considerably across countries and regions. Most countries in Europe and North America generally benefit from better access. It is estimated that by 2030 about 75% of all cancer deaths will occur in low- and middle-income countries (LMICs).[3] Unfortunately, LMICs have the lowest survival rates[4] and according to a 2018 World Health Organization (WHO) study, LMICs received less than 5% of global resources for fighting cancer.[5] In addition, LMICs are often dealing with infectious diseases and health systems with limited budgets that aren't yet adequate to manage and finance the complexities of cancer prevention and care.

A number of countries in the APAC region have very limited access to diagnostic and treatment options for everyone. Some experts interviewed commented on the ethical challenges of increasing cancer screening and diagnosis, or raising awareness of groundbreaking treatment options, if they are neither available nor affordable in some countries. Other experts noted that even if diagnostics and medicines were available through certain donations, assistance, or special access programs, this isn't a feasible or sustainable solution if the healthcare infrastructure is not yet in place and ready to deliver care.

Cancer care costs

While breakthrough innovations give us great reason for hope, they are generally expensive and not affordable for most patients and their families. A cancer diagnosis can lead to financial ruin for families in many LMICs. Many countries also have rapidly ageing populations and inflating healthcare costs. With rising costs to treat cancer, every country in the next 5-10 years has the challenge of sustainably providing improved cancer prevention and care.

Prevention

The WHO estimates that 30-50% of cancer cases are preventable[6] (e.g. through changes to diet and physical activity and reducing exposure to tobacco, infections, pollution and radiation) and that prevention is a cost-effective long-term strategy. For example, two common cancers in Southeast Asia are oral and lung cancers which are associated with tobacco and betel nut use and thereby considered preventable.[7]

Prevention is important for improved and sustainable cancer control in the region. However, considerable investments in health promotion and prevention infrastructure and initiatives would be needed to reap future benefits. It might prove difficult to prioritise these investments given the growing urgent care needs.

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[3] World Health Organization. (n.d.). Cancer Tomorrow. Available: https://gco.iarc.fr/tomorrow/en

[4] World Health Organization. (2020). WHO outlines steps to save 7 million lives from cancer. Available: https://www.who.int/news/item/04-02-2020-who-outlines-steps-to-save-7-million-lives-from-cancer

[5] World Health Organization. (2018). Technical Report: Pricing of Cancer Medicines and its Impacts: A Comprehensive Technical Report for the World Health Assembly Resolution 70.12: Operative Paragraph 2.9 on Pricing Approaches and Their Impacts on Availability and Affordability of Medicines.

[6] World Health Organization. (2023). Preventing cancer. Available: https://www.who.int/activities/preventing-cancer#:~:text=Between%2030%E2%80%9350%25%20of%20all,for%20the%20control%20of%20cancer

[7] World Health Organization. (2022). Urgently address gaps in cancer care: WHO. Available: https://www.who.int/southeastasia/news/detail/04-02-2022-urgently-address-gaps-in-cancer-care-who

Screening and early diagnosis

Early diagnosis has a range of benefits including: higher likelihood of successful treatment and survivorship, less treatment needed, lower costs, and improved quality of life. Unfortunately, many cancer cases in Asia are diagnosed at later stages which negatively affects mortality rates.[8] Opportunities to facilitate screening and early detection (and therefore more timely treatment) include addressing health literacy, personal beliefs and community awareness, infrastructure for screening and referral pathways, costs, fear, and recruitment strategies.[9]

Psychosocial and supportive care

With improved diagnostic and treatment options, people are living longer and with a better quality of life, again mostly in higher income countries. Many cancers can be managed longer term, similar to a chronic illness. This has increased the need for ongoing support of patients, carers and their families beyond solely clinical care, with greater and more tailored psychosocial and supportive services around:

- information and healthcare system navigation needs
- shared decision-making
- managing effects of medication, treatment and care
- family, social and practical needs, including financial support
- emotional and psychological needs
- living beyond cancer
- reintegration into community and society
- return to work and community roles
- palliative care and pain management.

Need for patient representatives/supportive civil society organisations

Patient and carer representatives, patient support organisations and community groups (summarised as 'patient voice' or 'patient representatives' for this report) are needed to help navigate the complexities of access, care, support services and financial impacts. The positive effect of more survivors means that people are giving back, sharing their voice, supporting each other, and advocating for others. Additionally, these advocates can help identify areas of research and more effective, efficient and responsive health system changes to better meet the needs of local patients, survivors and their families.

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[8] Lim, Y., Lim, Z., Ho, P., Li, J. (2022). Breast Cancer in Asia: Breast Cancer in Asia: Incidence, Mortality, Early Detection, Mammography Programs, and Risk-Based Screening Initiatives. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9454998/; Martina, D., Segelov, E. (2023). Improving Equity Across Cancer Care Continuum in Asia Pacific. Available: https://ascopubs.org/doi/full/10.1200/GO.23.00056

[9] Lim, Y., Lim, Z., Ho, P., Li, J. (2022). Breast Cancer in Asia: Breast Cancer in Asia: Incidence, Mortality, Early Detection, Mammography Programs, and Risk-Based Screening Initiatives. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9454998/; Nightingale, c., et al. (2023). Lung Cancer Screening: Implementation Challenges and Health Equity Considerations For the Western Pacific Region. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10166439/

Economic benefits of better cancer care

With the growing costs of cancer care, sustainable health spending is obviously a necessary consideration. There are major economic and social benefits to treating cancer. Premature death has negative effects on productivity, overall wellbeing, and the economy. Healthy and well people are valuable to society, for example through caring for their families, contributing to their communities, and being able to work and pay taxes. A cancer diagnosis impacts the patient, their family, caregivers and friends, employers, communities, and governments. A cancer diagnosis can be emotionally and financially devastating to the individual and their family. Parents struggle with how to balance the rigours of treatment with working to support their family. Some must make impossible choices between treatment or work, in other words, deciding between their survival and being able to afford essentials for their family.

Economic costs of cancer (beyond treatment costs) include:[10]

- workforce participation and contributions to Gross Domestic Product (GDP) and taxes
- workforce productivity through absenteeism and presenteeism
- productivity losses of carers
- disruption to education for childhood cancers
- social care costs from financial toxicity
- loss of unpaid contributions to society (e.g. community, volunteering).

Social costs are more difficult to estimate, but the influence on families' wellbeing is easily recognisable. Premature death has longer-term flow-on impacts to families and communities. Rare Cancers Australia commissioned an analysis of the impacts of a non-curative cancer diagnosis on individuals and their families, and the economic and societal benefits of preventing death. The Social Return on Investment analysis showed for every $1 invested in cancer treatments, there is $3.06 of social and economic value created.[11]

Some examples include:

- losing a parent in the prime of life devastates families; the disruption and trauma to children is severe and long-lasting, and the societal implications can last for generations
- young people dealing with a parent's cancer diagnosis are three to six times more likely to experience high, or very high, levels of psychological distress than their peers
- the death of a child from cancer also has catastrophic effects on loved ones, placing bereaved parents and siblings at risk for both physical and psychosocial morbidities
- patients are faced with desperately searching for funding options to stay alive, which may include mortgaging or selling their home or accumulating considerable debt to access and complete necessary treatment.

Understanding these costs to families and society clarifies the arguments for improved access to care and illustrates the impacts on families and society more broadly. Many experts interviewed argue funding healthcare and saving lives should be considered an investment in the community and the economy, not merely a cost.

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[10] Desai, A., Gyawali, B. (2020). Financial toxicity of cancer treatment: Moving the discussion from acknowledgement of the problem to identifying solutions . Available: https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370%2820%2930013-4/fulltext

[11] Rare Cancers Australia. (2022). Counting the Cost: The true value of investing in cancer treatment. Available: https://rcararecancers.blob.core.windows.net/assets/contentpage_htmlcontent/RCA4279%20Counting%20the%20Cost%20Report-final.pdf; Rare Cancers Australia. (2023). Counting the Cost: How we can assess the true value of investing in cancer treatment. Available: https://rcararecancers.blob.core.windows.net/assets/contentpage_htmlcontent/RCA4603%20Counting%20the%20Cost%20Summary%20Report%20FA.pdf

ACTION (ASEAN CosTs In Oncology) Study[12]

A team from the George Institute and international collaborators conducted a study on the economic impact of cancer on households across eight countries in Southeast Asia. The research team worked collaboratively with local experts, decision makers, industry, and patient advocacy groups. The impacts on the almost 10,000 patients followed highlighted how cancer diagnoses are devastating to families and often lead to financial ruin. It found that:

- a year after diagnosis, 29% of cancer patients died, 48% had financial catastrophe, and only 23% were alive with no financial catastrophe
- almost half (44%) of those who survived 12 months after diagnosis used their entire life savings
- diagnosis at a more advanced stage of cancer leads to a patient being five times more likely to die within 12 months, and a 50% higher chance of financial catastrophe
- the average cost for breast cancer treatment in Southeast Asia in 2014 was USD$15,000, compared to the average GDP of USD$3,550. Some treatments cost hundreds of times the minimum wage in Southeast Asia.

These stark findings helped make an economic and social case for better cancer care that is more affordable. These findings influenced positive changes to policies across the region, some examples including:

- the National Integrated Cancer Control Act (NICCA) in the Philippines
- in Indonesia, the government has invested in early detection programs and more cancer care coverage
- in Malaysia, there is more insurance coverage for lower socioeconomic groups
- in Vietnam, the findings helped shared cancer control planning.

This study is a brilliant example of how collaborative approaches, highlighting the patient experience and voice, and powerful evidence can be important puzzle pieces needed to instigate positive change.

Find out more: https://www.georgeinstitute.org.au/our-impact/case-studies/improving-cancer-care-in-south-east-asia-the-action-case-study

Contributing factors for its impact on meaningful change:

An inspiring vision

Developing evidence of the financial burden of a cancer diagnosis on patients and families

Information to support action

Providing tangible data highlighting the impact of cancer to enact change

Powerful patient voices

Following almost 10,000 patients

Working together

Collaboration between researchers, local experts, decision makers, industry and patient support organisations

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[12] Jan, S., Woodward, M. (2021). Improving Cancer Care in South East Asia: The ACTION case Study. Available: www.georgeinstitute.org.au/our-impact/case-studies/improving-cancer-care-in-south-east-asia-the-action-case-study

Opportunities to increase survivorship across the continuum of care

The full cancer continuum needs to be considered for the goal of improving cancer outcomes and increasing survivorship in the Asia-Pacific region. The continuum ranges from education, prevention, screening, diagnosis, treatment, survivorship, rehabilitation, and end-of-life care. These are often not strictly linear experiences when considering overlaps of recurrence, preventive behaviours along the way, how diagnoses can evolve with treatment and information, and the value of planning for rehabilitation from diagnosis.

Figure 4: Cancer care continuum components

To improve services across the cancer care continuum, there are a range of enablers needed, including:

- funding for services, screening, diagnostics, and treatment across the continuum
- strategic investments and planning for health system capability, capacity, integration and infrastructure
- recognition of the value of non-treatment focused quality-of-life services such as education, psychosocial support, rehabilitation, palliative care and pain management
- local expertise, clinical leadership, and research
- quality information for decision making for patients and their families, funders, researchers, and health service providers
- support and engagement from patient support organisations and community groups
- a broader public understanding of cancer and person-centred care.

In summary, the ability to increase survivorship and improve cancer outcomes more equitably in the region requires complex changes across a range of factors. Increased health system funding is an important enabler of change, **however solutions also require a strategic understanding of local needs, resources and systems, shared leadership and collaboration, empowerment of patient and community representatives, and cultural sensitivity.**

CANCER IN THE APAC REGION

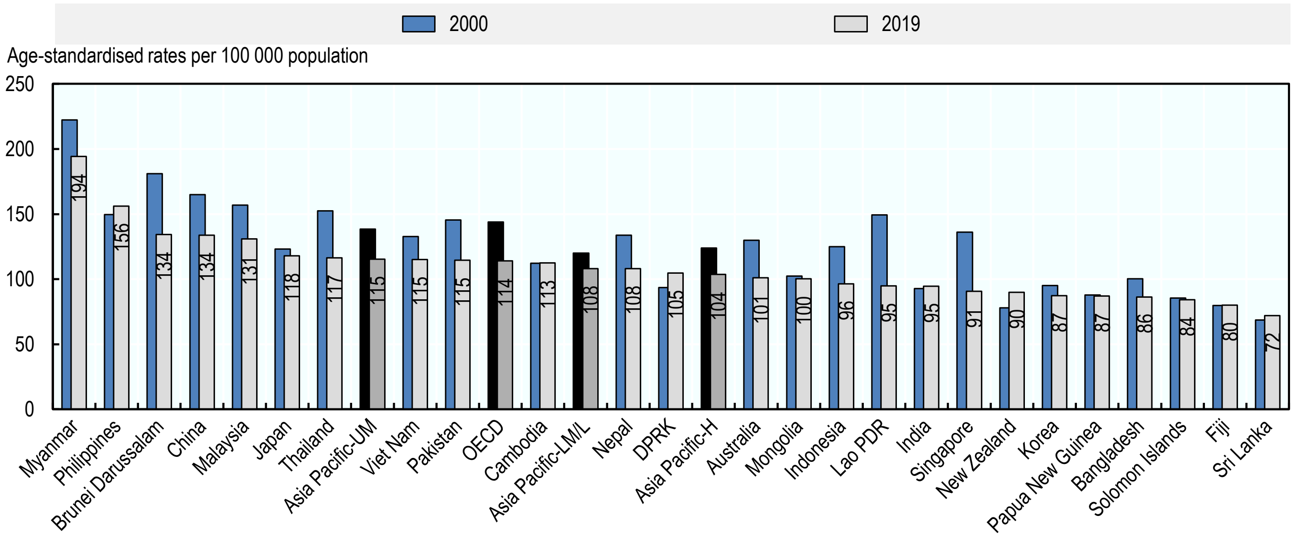
More than half of the world's population live in the Asia-Pacific region, and more than half of global cancer deaths occur in the region. According to a recent American Society of Clinical Oncology (ASCO) publication, the region bears the heaviest burden of cancer worldwide.[13] It is a diverse region with varying:

- community understanding and perceptions of cancer
- cultures and communication styles around health and healthcare, with often hierarchical and paternalistic health systems and cultures in many locations, making it difficult to challenge and change
- health coverage, resources, and health system capacity, with most high-income countries having a form of comprehensive cancer treatment services, while most lower-income countries do not[14]
- local risk factors for cancers
- levels of engagement with patient representatives for health system improvements and with patients in shared decision-making about care
- geography, with some countries having large rural populations
- political systems and structures.

Note: There are different global definitions and borders for the Asia Pacific region. For this report the scope has been mainly focused on countries in the WHO categories of the South-East Asia and Western Pacific regions.[15]

The chart below from the WHO Global Health Estimates shows a broad range of estimated cancer mortality rates for countries across the region. For the most part, it appears that mortality rates per age-standardised 100,000 population improved between 2000 and 2019.[16]

Figure 5: All cancers, estimated mortality rates, 2000 and 2019



Note: OECD is a simple average calculated with data from WHO 2019 GHE.
Source: WHO 2019 Global Health Estimates.

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[13] Martina, D., Segelov, E. (2023). Improving Equity Across Cancer Care Continuum in Asia Pacific. Available: https://ascopubs.org/doi/full/10.1200/GO.23.00056

[14] World Health Organization. (2020). WHO outlines steps to save 7 million lives from cancer. Available: https://www.who.int/news/item/04-02-2020-who-outlines-steps-to-save-7-million-lives-from-cancer

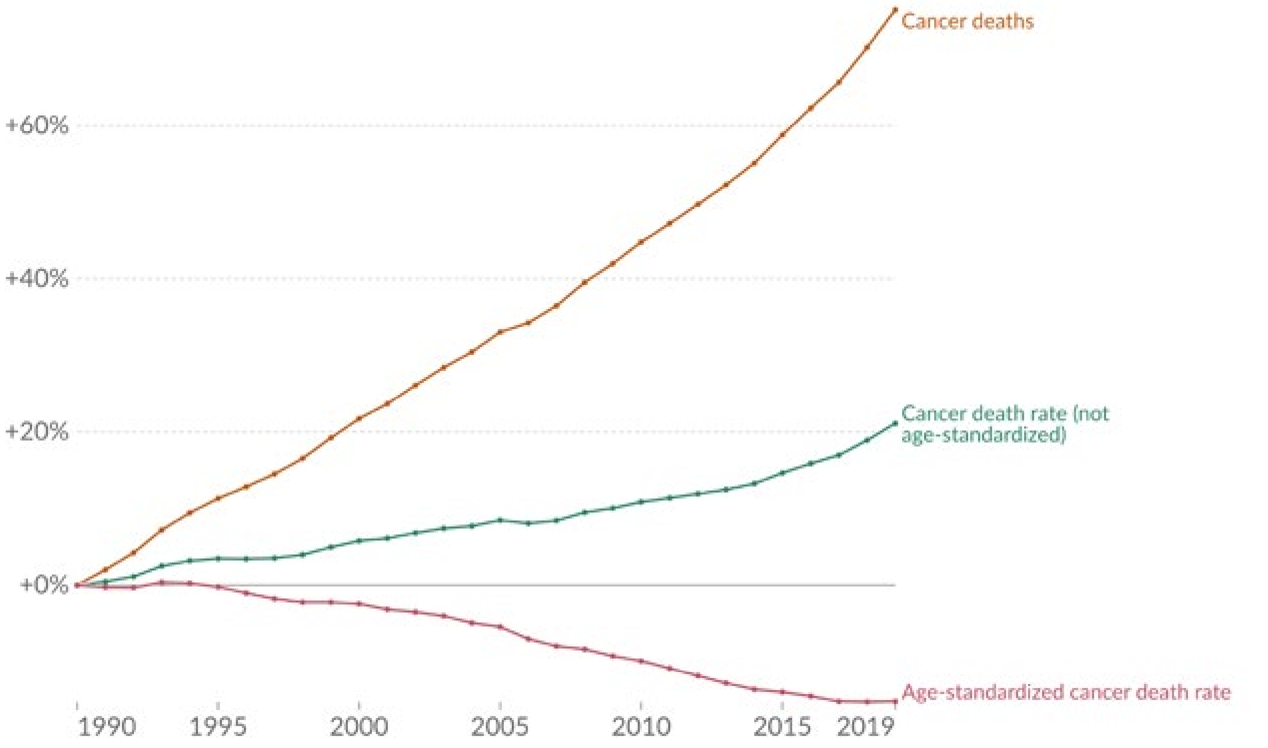
[15] World Health Organization. (n.d.). Countries. Available: https://www.who.int/countries

[16] OECD/WHO. (2022). Mortality from cancer. Available: https://doi.org/10.1787/3dc086db-en

It is important to note the effects of age standardisation on statistics with ageing populations. Globally, cancer deaths and cancer death rates have increased significantly since 2000, while the age standardised rates have decreased in that time (due to ageing population trends).[17] This shows that globally, and in the region, communities are actually having to deal with increasing cancer incidences and deaths.

Figure 6: Change in three measures of cancer mortality, World, 1990 to 2019

This chart compares cancer deaths, crude cancer death rates, and age-standardised* death rates.



Data source: IHME, Global Burden of Disease (2019)

OurWorldInData.org/cancer | CC BY

* Age standardisation: Age standardisation is an adjustment that makes it possible to compare populations with different age structures, by standardising them to a common reference population.

There are major differences in access to affordable essential health services and cancer care across the region, driving high levels of catastrophic out-of-pocket costs for some countries.[18] The following sections summarise some of the high-level differences in access to health workforce, infrastructure, and treatment options across the region.

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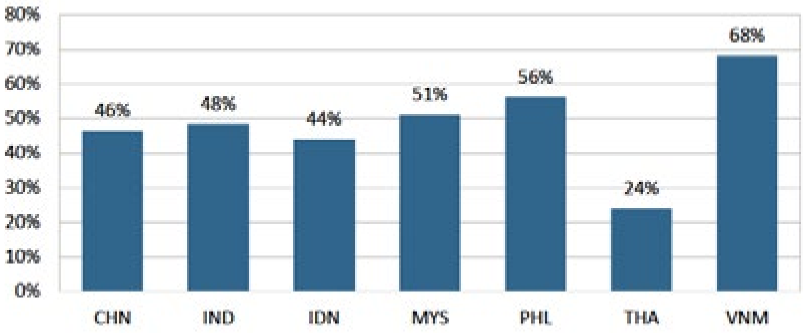
[17] Roser, M., Ritchie, H. (2019). Cancer. Available: https://ourworldindata.org/cancer

[18] OECD/WHO. (2022). Health at a Glance: Asia/Pacific 2022: Measuring Progress Towards Universal Health Coverage. Available: https://doi.org/10.1787/c7467f62-en

Figure 7: Proportion of households in financial catastrophe due to household member having cancer



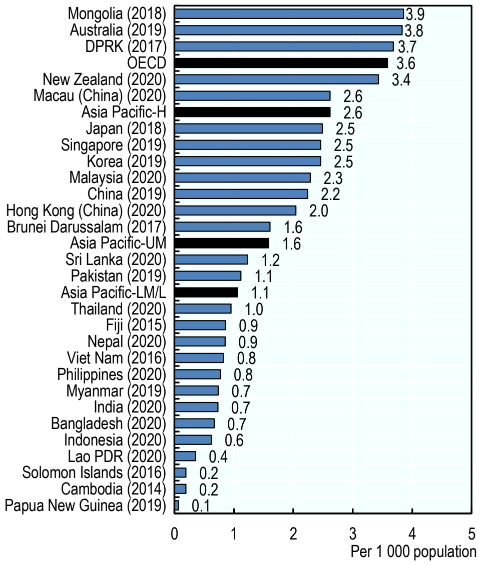
Notes:
Financial catastrophe is defined as out-of-pockets payments for medical services and non-medical services exceeding annual household income by 30%. This follows the definition used in the ACTION study that covered many member states of the Association of Southeast Asian Nations.

Chart source: Hofmarcher, T., Keel, G., Lindgren, P. (2021). Cancer Care and Access to Cancer Drugs in Asia-Pacific. Available: https://ihe.se/wp-content/uploads/2021/11/IHE-Report-2021_3b_.pdf

Workforce and infrastructure

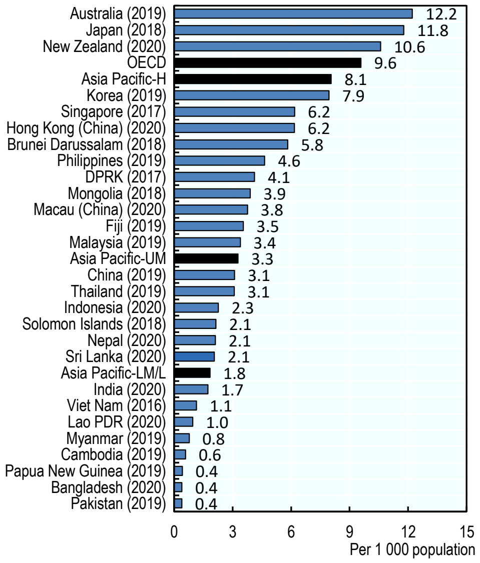
The capacity of a health system to prevent and treat cancer depends on multiple factors including the health workforce capacity and capabilities, and available infrastructure.[19] The charts below illustrate the availability of doctors, nurses, CT scanners, MRI units, mammographs and radiation therapy equipment per population across a range of countries in the Asia-Pacific region, with an obvious trend of higher income countries commonly having more resources available.[20] Generally, the higher income countries can devote greater investment to healthcare.[21]

Figure 8: Doctors per 1000 population, latest available year



Note: Denominator for Hong Kong (China) is based on mid-year population; for Macau (China) on end of year population.
Source: OECD Health Statistics 2022; WHO GHO, 2022; National Data Sources (see Annex A).

Figure 9: Nurses per 1000 population, latest year available



Note: Denominator for Hong Kong (China) is based on mid-year population; for Macau (China) on end of year population.
Source: OECD Health Statistics 2022; WHO GHO, 2022; National Data Sources (see Annex A).

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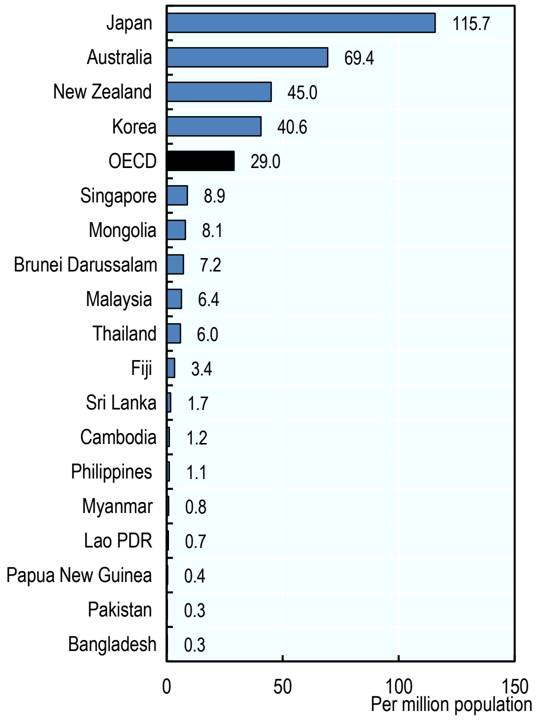
[19] OECD/WHO. (2022). "Doctors and nurses" in Health at a Glance: Asia/Pacific 2022: Measuring Progress Towards Universal Health Coverage. Available: https://doi.org/10.1787/c7467f62-en

[20] OECD/WHO. (2022). "Mortality from cancer" in Health at a Glance: Asia/Pacific 2022: Measuring Progress Towards Universal Health Coverage. Available: https://doi.org/10.1787/c7467f62-en

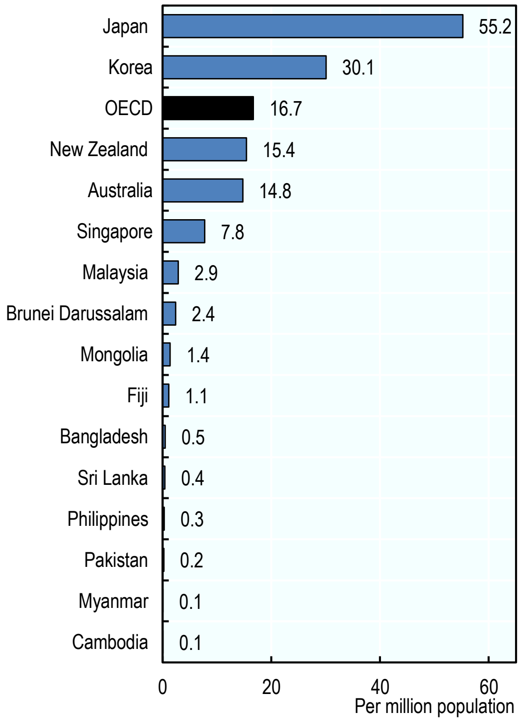
[21] OECD/WHO. (2022). "Health expenditure per capita and in relation to GDP" in Health at a Glance: Asia/Pacific 2022: Measuring Progress Towards Universal Health Coverage. Available: https://doi.org/10.1787/c7467f62-en

Figure 10: Computed tomography scanners, latest year available



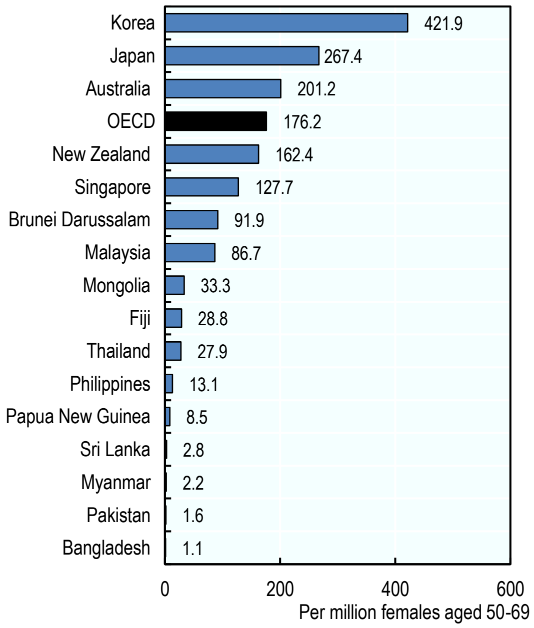
Source: OECD Health Statistics 2022;
WHO Global atlas of medical devices 2022 (forthcoming).

Figure 11: MRI units, latest year available



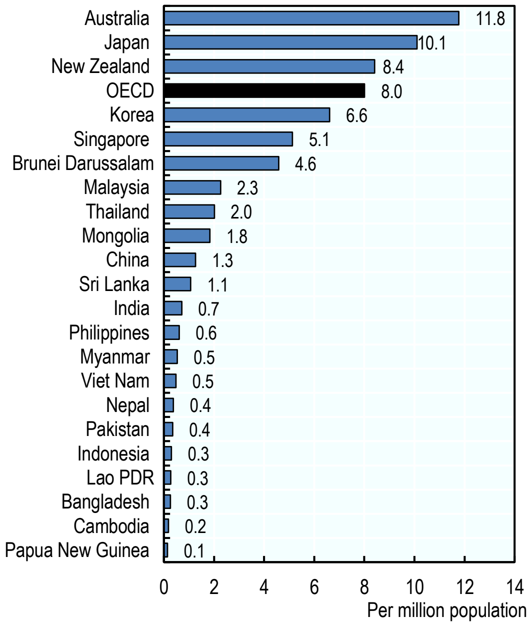
Source: OECD Health Statistics 2022;
WHO Global atlas of medical devices 2022 (forthcoming).

Figure 12: Mammographs, latest year available



Source: OECD Health Statistics 2022;
WHO Global atlas of medical devices 2022 (forthcoming).

Figure 13: Radiation therapy equipment, latest year available



Source: OECD Health Statistics 2022;
WHO Global atlas of medical devices 2022 (forthcoming).

Equipment and technology have become increasingly relevant for newer diagnostic and therapeutic breakthroughs and the expansion of information and communications technology in health care.[22] However, without a skilled workforce to operate and maintain the technology, capital investments or donations could be wasted.

Many experts interviewed noted that their health systems were under pressure with long patient wait lists, overloaded hospitals, and doctors and nurses not having sufficient time to meet the informational needs of patients and their families. The COVID-19 pandemic led to major disruptions in healthcare services,[23] likely causing additional pressure on health systems with backlogged demand, delayed diagnoses, and discontinuity of care.

An ongoing challenge for many countries is providing access to health services in rural and geographically inaccessible and disadvantaged areas (GIDA). Some experts interviewed observed that concerted efforts to decentralise cancer care services and create more capacity and connections with regional centres have been beneficial. This helps create access to cancer care and reduces travel costs for patients and their families.

Telehealth and technology

The COVID-19 pandemic set back a number of health initiatives in the region, but it also led to a surge in use of telemedicine platforms, which were already on an upwards trend prior to the pandemic.[24] This is in line with interviews conducted for this report, where people stated that patients are more comfortable with digital tools, websites for information and wearables for health and self-care since the onset of the pandemic. This has the potential to improve access to experts and quality information for many people and can be particularly valuable for providing some services in more rural and underserved GIDA areas. However, there are still challenges surrounding access for people without devices, internet, or the skills to engage in this way. Also, some countries lack legislation to support telehealth care, which can be a risk for practitioners.

Artificial intelligence (AI) was a theme in interviews for this report, with some experts hoping the technology would help with more efficient diagnosis of cancer, particularly where nationwide screening resources are not yet available. For example, some companies are using AI to help detect lung cancer nodules in historical CT scans taken for COVID-19, to explore the possibility of earlier detection.[25]

> We are at a crossroads where we have a lot of medicines and patients who are from different parts of the world and have different cancers. We need diagnostic tools and capacities across the cancer spectrum in order to get medicines to patients and save lives.
>
> **Dr Dan Milner**
> Executive Director, Access To Oncology Medicines (ATOM)

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[22] OECD/WHO. (2022). "Health expenditure per capita and in relation to GDP" in Health at a Glance: Asia/Pacific 2022: Measuring Progress Towards Universal Health Coverage. Available: https://doi.org/10.1787/c7467f62-en

[23] OECD/WHO. (2022). Health at a Glance: Asia/Pacific 2022: Measuring Progress Towards Universal Health Coverage. Available: https://doi.org/10.1787/c7467f62-en

[24] Kapur, V., Boulton, A. (2020). Covid-19 Accelerates the Adoption of Telemedicine in Asia-Pacific Countries. Available: https://www.bain.com/insights/covid-19-accelerates-the-adoption-of-telemedicine-in-asia-pacific-countries/#:~:text=In%20Bain's%202019%20Asia%2DPacific,provider%20(see%20Figure%201)

[25] Mandal, S., et al. (2023). PP01.58 Multi City Opportunistic Screening of Lung Nodules amidst COVID-19. Available: https://www.jto.org/article/S1556-0864(22)01670-7/fulltext

Project ECHO Pilot – Indonesian Breast Cancer Foundation

Project ECHO is a global organisation with a mission to empower professionals in rural and underserved areas to address disparities and improve community well-being. Using a free telementoring model, Project ECHO aims to tackle various challenges in healthcare and education, striving to impact 1 billion lives by 2025.

A pilot of Project ECHO was recently completed in Indonesia, led by the Indonesian Breast Cancer Foundation: ECHO Breast Cancer Early Detection in the district of Tangerang. Despite being a country of over 17,000 islands and 270 million inhabitants, Indonesia only has around 140 medical oncologists and 200 surgical oncologists. For this pilot, the IBCF collaborated with primary health care centres, women's community organisations and other stakeholders, with the ECHO team in India and the US supporting them.

The pilot was a telementoring training program on breast health, breast cancer early detection and the referral ecosystem. It was attended by 100 participants which consisted of 50 healthcare workers and 50 laywomen from two primary health centres in the Tangerang District.

From the data, 18 people identified a lump through self breast examination for breast cancer early detection education during the six months of the program. These findings were referred to the Primary Health Centres to be followed up by clinical breast examination and the results showed that eight of the women identified had benign tumours, while 10 cases showed suspected breast cancer. They were referred to the hospital for further check-up by an oncologist.

The pilot has shown promising opportunities to replicate this model in other areas of Indonesia, and IBCF is currently finalising the monitoring and evaluation report for the Ministry of Health. This example also highlights the importance of decentralised health care in the region.

Find out more: https://hsc.unm.edu/echo/

Contributing factors for its impact on meaningful change:

An inspiring vision

Improve community wellbeing in rural and underserved areas

Community Awareness

Reaching broader community via virtual networks

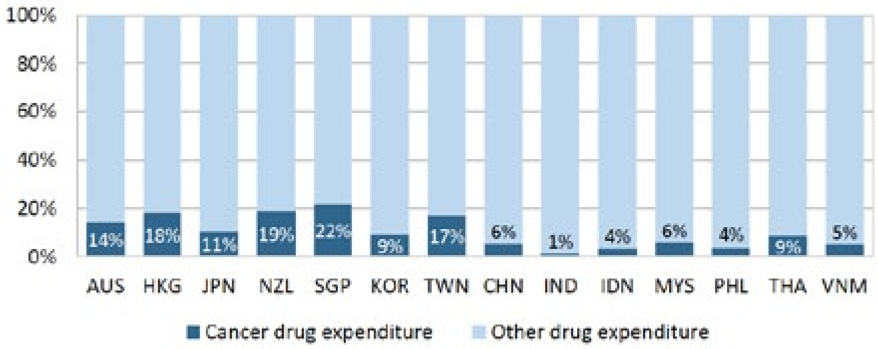
Working together

Collaboration between organisations, community, healthcare providers

Access to treatment options

Countries have different financial capacity to invest in new treatments. Governments need to strategically invest considering costs, benefits, and feasibility, and recognising that many established, less costly diagnostic and treatment approaches are still effective and affordable.[26] There are varying levels of relative investment in cancer medicines, unsurprisingly with higher income countries generally able to invest more.[27]

Figure 14: Cancer drug expenditure as % of total pharmaceutical expenditure, 2019

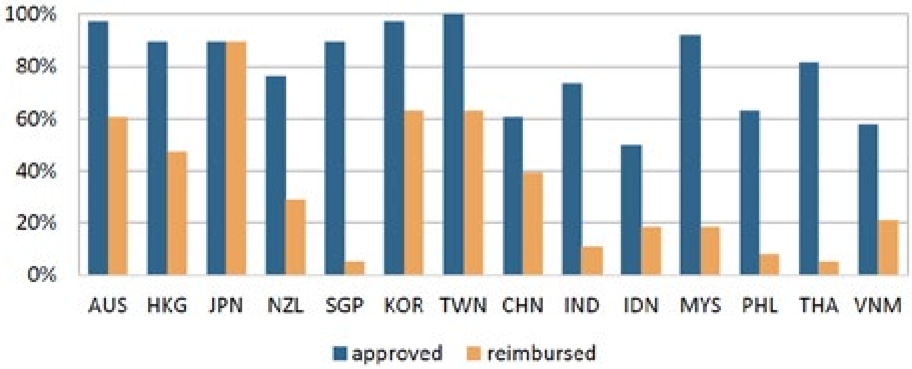


Notes: Underlying sales data from IQVIA do not fully capture confidential rebates and arrangements granted by drug manufacturers to payers, which would overestimate the proportion of cancer drug expenditure if the size of rebates for cancer drugs is greater than for other pharmaceuticals.[28]

For example, one analysis of access in the region found that while 38 'innovative' drugs were US FDA approved between 1998 and 2020, 80% of those had regulatory approvals across APAC in 2020 but only 35% were reimbursed.[29] Reimbursement has major impacts on accessibility. Access to treatment includes more than innovative medicines and these analyses help to highlight the differences in access across the region for one indicator.

Some experts interviewed suggested that international collaborations across regulatory bodies could speed up regulatory approval and registration processes. For example, if a treatment has been approved in the EU, US and Australia, then it could go through a faster approval process in countries with fewer resources for evaluation.

Figure 15: Proportion of innovative cancer drug-indications approved/reimbursed relative to US FDA approvals (as of Sept 30, 2020)



Notes: In Singapore, the proportion of reimbursed drug-indications only refers to drugs on the SDL or MAF while patient's expenditure for approved drugs are mostly covered through the 3M schemes. In India, no reimbursement scheme exists for the whole population and drugs listed in the NLEM are considered here instead.[30]

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[26] World Health Organization. (2020). WHO outlines steps to save 7 million lives from cancer. Available: https://www.who.int/news/item/04-02-2020-who-outlines-steps-to-save-7-million-lives-from-cancer

[27] Hofmarcher, T., Keel, G., Lindgren, P. (2021). Cancer Care and Access to Cancer Drugs in Asia-Pacific. Available: https://ihe.se/wp-content/uploads/2021/11/IHE-Report-2021_3b_.pdf

[28] Hofmarcher, T., Keel, G., Lindgren, P. (2021). Cancer Care and Access to Cancer Drugs in Asia-Pacific. Available: https://ihe.se/wp-content/uploads/2021/11/IHE-Report-2021_3b_.pdf

[29] Ibid

[30] Hofmarcher, T., Keel, G., Lindgren, P. (2021). Cancer Care and Access to Cancer Drugs in Asia-Pacific. Available: https://ihe.se/wp-content/uploads/2021/11/IHE-Report-2021_3b_.pdf

Establishment of decentralised health care systems – Japan

In Japan, the designation of Regional Cancer Treatment Core hospitals began in 2001, with the aim of equitable cancer care. "Core Hospitals" were allocated at various levels, and served as medical institutions that provide multidisciplinary treatment with the goal of having one Core Hospital in every secondary medical care region.

The levels of cancer care services in Japan include:

- **National Cancer Centre**
  The core institution for cancer control in Japan as a whole.
- **Provincial Core Hospitals**
  Play a central role in providing quality cancer care in Japan's provinces.
- **Regional Core Hospitals**
  One regional Core Hospital is planned to be established in each cancer treatment area, responsible for providing specialised cancer care. There are requirements to be met with respect to the system of medical care, medical personnel, medical performance, provision of training, and system for collecting and providing information.
- **Core Hospitals for specific fields of cancer treatment**
  Designated medical institutions that treat the largest number of patients in the province for a specific cancer.
- **Regional cancer hospitals**
  Hospitals that collaborate with Core Hospitals for cancer treatment in adjacent cancer medical regions.

This decentralised approach to cancer care is intended to provide quality cancer care for all patients in Japan, regardless of their location.

Find out more: www.mhlw.go.jp/stf/seisakunitsuite/bunya/kenkou_iryou/kenkou/gan/gan_byoin.html

Contributing factors for its impact on meaningful change:

An inspiring vision

Provide equitable cancer care across Japan

Working together

Collaboration between government, health care systems across different levels

Further trends

Public perceptions: Misinformation and stigma

Misinformation is a major concern and barrier to quality healthcare globally. This challenge came up consistently in interviews with local experts. In some countries there is a distrust of 'Western medicine' and people turn to social media, word of mouth or scam treatments.

The internet and social media have made it easier for people to amplify misinformation and offer scams. Much of the information shared online about cancer is inaccurate and can be harmful. Unfortunately, false information seems to garner greater engagement, spreading further and faster than accurate information.[31]

Stigma can also be harmful with its effects on mental health, treatment choices and social connection.[32] Stigma varies across countries and cultures. In some countries, cancer stigma can have extreme consequences with a family and community shunning or giving up on cancer patients, even believing that cancer is contagious. However, based on interviews for this report, it does seem that in the last 5-10 years stigma and discrimination generally have reduced in the region. This is likely due to better awareness and understanding of cancer thanks to the initiatives of patient and community groups. This positive momentum needs to continue to further reduce harmful stigma.

High mortality rates help perpetuate stigma. Better services for earlier diagnosis and treatment of cancer can help boost public trust that cancer is survivable. Also, open public conversations about cancer can help educate people to identify and act on symptoms. Education and awareness campaigns are critical to breaking down existing stigmas.[33]

Stigma and misinformation are also significant barriers to better cancer prevention and care in the region and should be a priority for action. Enhanced public understanding of cancer, reliable information sources, and positive stories about survival can help reduce stigma.[34] Patient representatives, community organisations and local healthcare leaders can educate about cancer, connect with the community, and share powerful personal survival stories. Healthcare leaders also need to be engaged to help fight misinformation online.[35]

> We can use social media to disseminate accurate health information. I post about topics that I think are important and interesting and now have more than 1 million followers and am an outspoken advocate for reliable healthcare information. As a doctor, I intend to use my expertise to help others. If information has been presented incorrectly, I will point it out, regardless of who said it.
>
> **Dr Amalina Bakri**
> Imperial College London

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[31] Ben-Ari, E. (2021). Addressing the Challenges of Cancer Misinformation on Social Media. Available: https://www.cancer.gov/news-events/cancer-currents-blog/2021/cancer-misinformation-social-media; Johnson, S. (2022). Cancer Misinformation: Its impact on Patients and Migration Strategies. Available: https://www.ilcn.org/cancer-misinformation-its-impact-on-patients-and-mitigation-strategies/

[32] Teo, I., et al. (2022). Perceived stigma and its correlates among Asian patients with advanced cancer: A multi-country APPROACH study. Available: https://pubmed.ncbi.nlm.nih.gov/35048471/; Pham, N. et al. (2021). The prevalence of perceived stigma and self-blame and their associations with depression, emotional well-being and social well-being among advanced cancer patients: evidence from the APPROACH cross-sectional study in Vietnam. Available: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-021-00803-5

[33] UICC. (2023). Breaking down the stigma: women and cancer care. Available: https://www.uicc.org/news/breaking-down-stigma-women-and-cancer-care

[34] Loh, S. (2020). Reducing Stigma of Cancer in Asia-An Important Strategy for Cancer Control. Available: https://www.researchgate.net/publication/341977655_Reducing_Stigma_of_Cancer_in_Asia-An_Important_Strategy_for_Cancer_Control

[35] Johnson, S. (2022). Cancer Misinformation: Its impact on Patients and Migration Strategies. Available: https://www.ilcn.org/cancer-misinformation-its-impact-on-patients-and-mitigation-strategies/

Fighting misinformation through social media

Dr Nur Amalina Che Bakri

Dr Nur Amalina Che Bakri is a medical professional specialising in general surgery and a clinical research fellow in breast cancer surgery at Imperial College, London. Her research focus lies in leveraging existing technology to enhance breast cancer treatment, particularly interested in using wearable technology to objectively monitor post-surgery physical activities, allowing for personalised rehabilitation programs.

Dr Nur Amalina has an active presence on social media, with over 1 million followers across platforms like Twitter, Instagram and TikTok. She uses her online influence to advocate for accurate healthcare information, fight misinformation, and educate the public about important health topics, including the COVID-19 vaccines, women's health, and surgical issues. She has a strong following in her home country of Malaysia. Through her online presence, she has also been involved in impactful initiatives, such as a viral crowdfunding campaign to help a baby with a germ cell tumor receive life-saving surgery in London. Her commitment to providing evidence-based information, her advocacy for women's empowerment through Girls for Girls UK, and her personal journey from a student to a surgeon, researcher and a mother serve as an inspiration to young women worldwide.

Find out more: www.dramalina.com

Contributing factors for her impact on meaningful change:

An inspiring vision

Empowering young women worldwide and fighting misinformation online as a clinical leader

Community Awareness

Educating the public and enhancing community awareness

Information to support action

Using an evidence-based approach

International support

Based on interviews, it appears that in the last 5-10 years there has been a considerable increase in support and interest from international organisations working in the region to collaboratively support better cancer control. Some include:

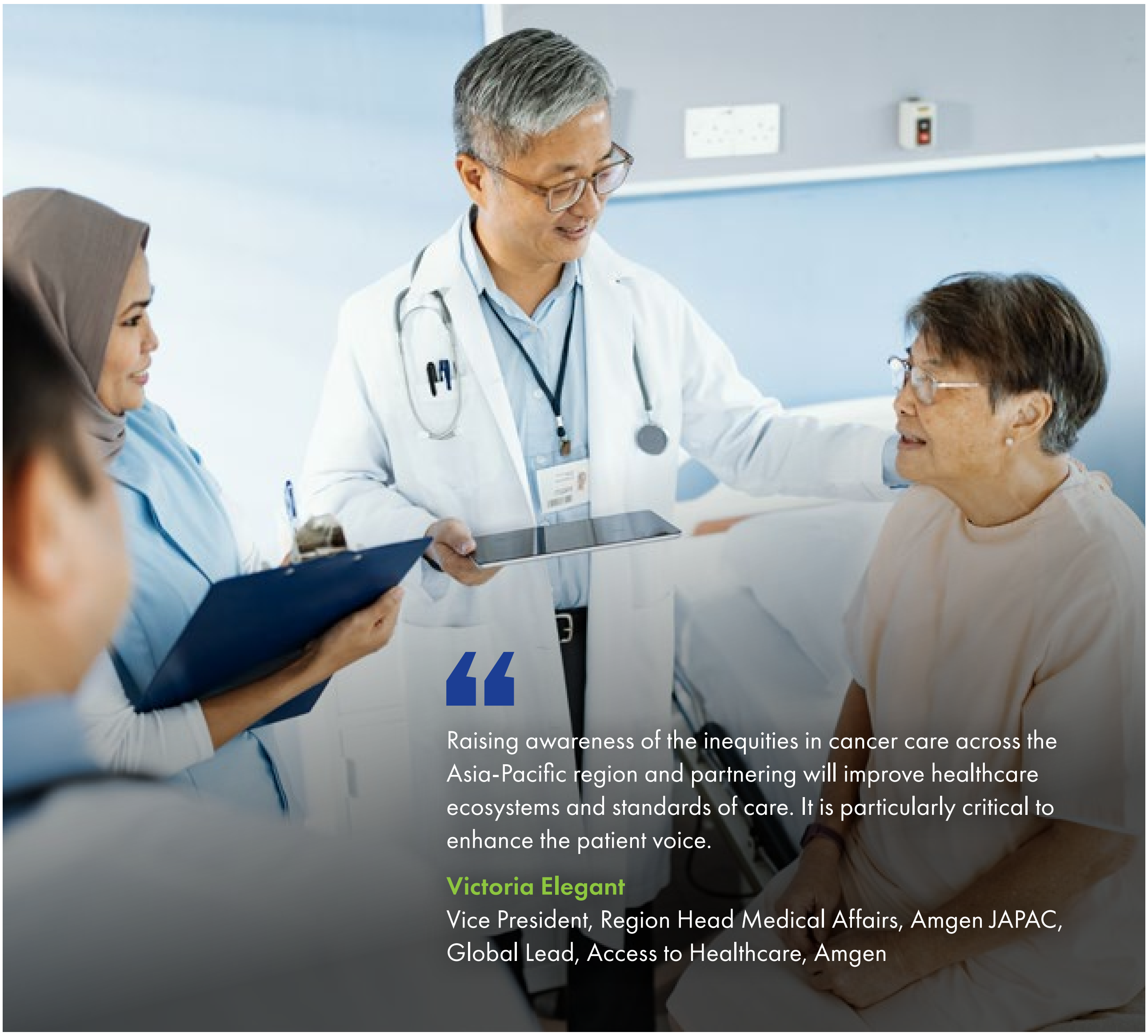
- Access to Medicine Foundation
- Access to Oncology Medicines (ATOM)
- American Lebanese Syrian Associated Charities (ALSAC)
- APAC drug consortium
- ASCO leadership program
- Asia Pacific Coalition Against Lung Cancer
- Asian National Cancer Centers Alliance (ANCCA)
- Asia-Pacific Economic Cooperation
- Bill and Melinda Gates Foundation
- Centre for Regulatory Excellence (CoRE), Duke-NUS
- Chai Foundation
- Childhood Cancer International
- City Cancer Challenge
- Clinton Global Initiatives
- Direct Relief
- ESMO Asia
- Global Focus on Cancer and Southeast Asia Breast Cancer Symposium (SEABCS)
- Global Initiative for Childhood Cancer
- The Max Foundation
- National Cancer Grid
- RCA's Pinnacle Program
- The Alliance & Partnerships for Patient Innovation & Solutions (APPIS) platform
- TogetHER for Health
- Union for International Cancer Control (UICC)
- VIVA Foundation
- Women's Cancer Coalition: Asia Pacific
- World Child Cancer.

Some experts have also observed that with the increased interest in the region, some organisations and local leaders are experiencing an overload of requests for action and engagement, with some work being duplicative. They noted that greater collaboration across initiatives could be valuable.

> I really feel because of that communication with my doctor about cancer that I am capable and I feel like I have power. I can participate in making decisions and that is important. Open communication between doctors and patients can give power to both parties.
>
> **Hataitip (Tor) Jirathun**
> Member, Thailand Breast Cancer Community

Stronger patient voices

In numerous interviews it was noted that overall, in the last five years, the voice of patients and their families is stronger and more present than in the past. This is related to more people surviving cancer and a greater understanding of cancer. Some experts interviewed observed that people are more willing to publicly share their stories, participate in research, assist others, and advocate for change. Complementary to that, there appears to be an increasing interest and recognition amongst decision-makers, clinicians, researchers, and the treatment industry to include patients as co-partners to develop more patient centred care, research and services.



> Raising awareness of the inequities in cancer care across the Asia-Pacific region and partnering will improve healthcare ecosystems and standards of care. It is particularly critical to enhance the patient voice.
>
> **Victoria Elegant**
> Vice President, Region Head Medical Affairs, Amgen JAPAC,
> Global Lead, Access to Healthcare, Amgen

VALUE OF THE PATIENT VOICE IN IMPROVING SYSTEMS

Our health systems exist to improve outcomes for patients. However, this focus can sometimes be lost among the details of conducting research, providing health services, and managing time constraints and budgets. Patients, carers, their families, and patient support organisations (considered together as patient representatives) can help maintain focus on what is important and needed for citizens.

Globally, the world is waking up to the value that patient representatives provide to the community, how patient voices can help improve systems, and that patient engagement leads to better health outcomes and potentially more efficient healthcare.[36] In 2023, the WHO launched a *Framework for Meaningful Engagement for People Living with Non-Communicable Diseases (NCDs) and Mental Health and Neurological Conditions* in recognition that participation in health is a human right and that the lived experience "is invaluable for understanding barriers, identifying solutions, and planning policies, programmes and services, while aiding accountability".[37]

There are, however, still important structural, cultural, capacity and resource challenges to realising the full benefit of engaging with patients.

Patient representatives, organisations, and community groups

Patient support organisations (PSOs) and similar community groups/non-government organisations (NGOs) have the great responsibility of sharing the patient and carer perspectives and experiences to improve outcomes for those they represent. These organisations achieve incredible positive change and can be a beacon of hope, often with very limited resources and official power.

PSOs work to:

- provide high-quality, credible information for patients and their families, and work to dispel harmful stigma, misinformation and discrimination
- share and amplify the voices and perspectives of those with a lived experience of cancer to help improve the health system
- assist patients and their families to navigate the health and social care systems
- create a community where people can find hope and support
- improve access to treatment and care
- provide services to support patients and their families, including psychosocial support and ways to manage financial difficulties that often arise with healthcare costs
- raise awareness in the community about cancer, its risk factors, early warning signs and symptoms
- advocate for policies and health system changes that improve outcomes for patients
- support research and create insights, data and information for decision-makers
- influence health policies and secure patient rights.

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[36] James, J. (2013). Patient Engagement. Available: https://www.healthaffairs.org/do/10.1377/hpb20130214.898775; World Health Organization. (2023). WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions. Available: https://www.who.int/publications/i/item/9789240073074

[37] World Health Organization. (2023). WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions. Available: https://www.who.int/publications/i/item/9789240073074

> Improving literacy about cancer and treatment in the community is very important. So many patients ignore or delay standard treatment because of fake news which become more serious with the internet, mobile devices and social networks. We are working to improve literacy and fight misinformation in Vietnam through resources and collaboration to improve the quality of care.
>
> **Dr Quy Pham Nguyen**
> Y Hoc Cong Dong Organisation, Vietnam
> and Kyoto Miniren Central Hospital,
> Kyoto University, Japan.

PSO teams need to be educated about relevant cancer(s), treatment options and evidence around outcomes, national clinical experts and services, research and evolving technology, cost and access challenges, physical and emotional impacts and legal challenges for patients and their families. They become valuable experts in understanding and communicating the comprehensive picture of the cancer landscape in their communities. In the Asia-Pacific region, these organisations also help manage positive developments such as patients who are more engaged and connected digitally, have higher expectations of care, are more willing to share their voice and story and want to advocate for solutions.[38]

How PSOs operate in providing this value to the community is impacted by local contexts such as culture, regulations, resources, and recognition of the value of the patient voice. Based on interviews for this report, there appears to be a broad spectrum and varying levels of recognition and engagement with PSOs across the region. It should also be noted that PSOs are not always the only or best route to convey the patient voice. Individual patients, survivors, carers, family members and sectoral representatives and advocates also provide valuable insights and diverse points of view alongside PSOs, so pathways for engagement with these individuals should also be considered as best practice.

PSOs and patient representatives should be acknowledged by all cancer stakeholders and compensated for their contributions to patients and their families, the health system, the broader community, and the economy.

> Patients are end users of medicines and experts in their medical condition. With powerful insights and perspectives others cannot replicate, their lived experience can inform various stages of cancer treatment options, including research priorities, clinical trial design, regulatory approvals, health technology assessment (HTA), and post-approval monitoring. So, they should be informed, involved, and treated as partners in their own care as well as in healthcare decision making.
>
> **Dr Khoo Yoong Khean**
> Scientific Officer, Duke-National University of Singapore Medical School (Duke-NUS) Centre of Regulatory Excellence (CoRE), SingHealth Duke-NUS Global Health Institute

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[38] Asia Pacific Patient Innovation Summit. (2021). Partnering with Patient Organizations to Address the Unmet Needs of Patient Communities in the Asia Pacific Region and Beyond

Working with patients and patient support organisations

Governments, clinicians, researchers, health service providers and the diagnostic and treatment industries would benefit from better understanding and recognising that PSOs are high value community assets that have an important role to play as experts in identifying, designing, and disseminating health solutions. A recent Lancet Commission on Women, Power and Cancer found that:[39]

- policy-makers and academic and medical institutions must fully recognise the value of patient advocates and patient support organisations and integrate them into all aspects of the cancer care continuum
- progress can only happen when the intersection of research, policy, and advocacy are considered as essential and equal partners.

High-level guidance for working well with patient representatives includes:

Organisational/structural supports

- understanding the value of shared decision-making and sharing power with patient representatives
- storytelling is powerful, but we also need to move beyond that with more formal mechanisms for engagement
- developing processes and established leadership for organisations to engage with patient representatives
- identifying and supporting champions at different levels of power
- including patient representatives in decision making committees and panels etc
- considering sustainable funding options for engagement with patient representatives, and consider and manage conflicts of interest in funding mechanisms
- providing technical training to both patient representatives and those who engage with patients
- formally recognising the value of PSOs by governments, medical bodies and clinical groups, research organisations and treatment industry groups.

> Policy makers, academic and medical institutions need to recognise the value and importance of patient advocates and patient organisations as essential and equal partners and integrate them into all aspects of cancer care.
>
> **Carolyn Taylor**
> Founder and Executive Director of
> Global Focus on Cancer

Engagement experiences

- considering patients as an expert group and active partners, just like other stakeholders, where time is respected and compensated
- including patient representatives in discussions and planning from the beginning instead of requesting endorsement for decisions that have already been developed without their input
- recognising that patients often understand system barriers but shouldn't be expected to also be technical experts (e.g. HTA, clinical trials, clinical pathways) for engagement to be appropriate and valuable. Technical experts need to learn how to integrate the patient voice meaningfully into their work (not vice versa)
- including patient representatives in clinical trial design and educational programs
- supporting PSOs to collect and own data on the patient perspectives and experiences
- allowing for and planning sufficient time for engagement, feedback and discussions
- not assuming that other stakeholders (e.g. health care providers) can speak for patient and carer experiences
- providing patient advocates access to data, research results, and peer reviewed materials
- communicating using accessible language and frameworks and consider adjustments for different cultures and languages to support communication and exchange
- closing the feedback loop with patients to explain how their contributions have had an impact on decision-making.

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[39] Ginsburg, O., et al. (2023). Women, power, and cancer: a Lancet Commission. Available: https://www.thelancet.com/commissions/women-power-and-cancer

CASE STUDY

Patient Focused Medicine Development (PFMD)

PFMD is a global, non-profit, non-competitive coalition to improve global health by co-designing the future of healthcare for patients, with patients.

Its mission is to bring together initiatives and best practices that integrate the voice of the patient, thereby speeding up the creation and implementation of an effective, globally standardised framework – that involves patients as partners – as well as the necessary tools, services and support to allow the adoption of the framework by various stakeholders.

PFMD's three strategic objectives are:

- scaling patient engagement (PE) in drug development deeper and wider
- building conditions and enablers for patient engagement
- building PE in digital health and data.

PFMD is working on a range of projects to support these objectives. One project is collaboratively exploring how patient engagement can be incorporated into environmental, social, and governance (ESG) and sustainability strategies for organisations.

PFMD has also partnered with Japanese Partners for Patient-Centric Care (JPPAC) on the Patient-Centered Medicines Project, which aims to contribute to the discovery and development of patient centred medicines in Japan by raising awareness of PE. This includes the translation of key PFMD resources, such as the Patient Engagement Quality Guidance, into the Japanese language and context to help amplify the local conversation about the value of patient engagement and what good patient engagement looks like.

Find out more: www.patientfocusedmedicine.org

Contributing factors for its impact on meaningful change:

An inspiring vision

Improving global health through co-designing healthcare with patients

Information to support action

Bringing together best practices and initiatives that integrate the patient voice & building PE in digital health and data

Powerful patient voices

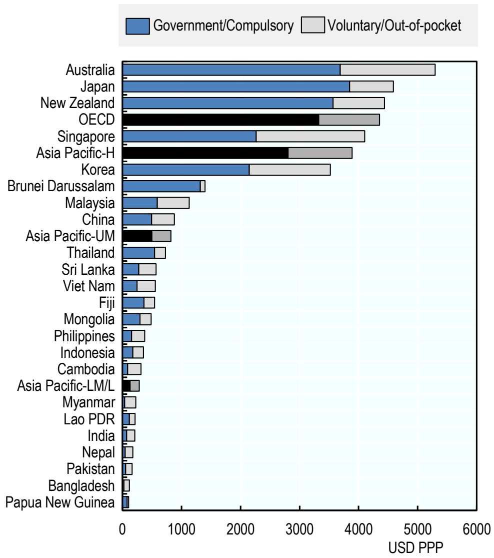
Co-designing healthcare with patients

HEALTH TECHNOLOGY ASSESSMENT (HTA) IS EVOLVING IN THE REGION

Health systems globally and across the region are grappling with growing healthcare expenditures from trends of ageing populations, chronic diseases and costs for new technologies. These trends are expected to continue. OECD analyses[40] of per capita health spending in countries across the Asia-Pacific region showed that between 2010 and 2019, spending increased by:

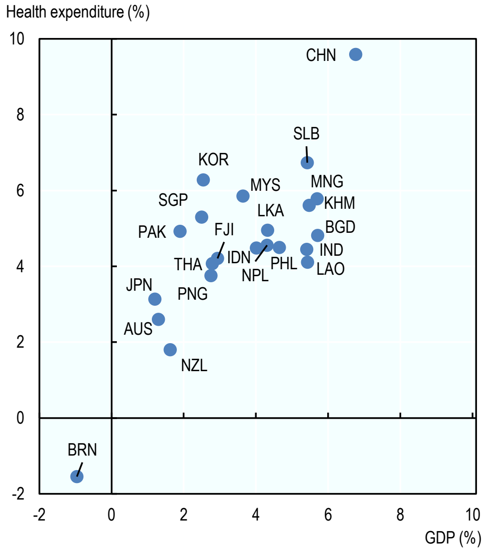
- 65% in low- and lower-middle-income countries
- 76% in upper-middle-income countries
- 33% in high-income countries.

Figure 16: Health expenditure per capita, 2019



Source: WHO Global Health Expenditure Database; OECD Health Statistics 2022.

Figure 17: Annual average growth rate in per capita health expenditure and GDP, real terms, 2010-19



Source: WHO Global Health Expenditure Database.

Health expenditure relative to GDP has also grown during that timeframe across most countries in the region.[41] In addition, COVID-19 measures have likely impacted health spending and fiscal balance in the years since 2019.[42] Some estimates project declines in global governments' expenditures on health post the pandemic, with increasing interest rates being an important factor.[43] Sustainability and value for money are clear questions in this context.

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[40] OECD/WHO. (2022). "Health expenditure per capita and in relation to GDP" in Health at a Glance: Asia/Pacific 2022: Measuring Progress Towards Universal Health Coverage. Available: https://doi.org/10.1787/c7467f62-en

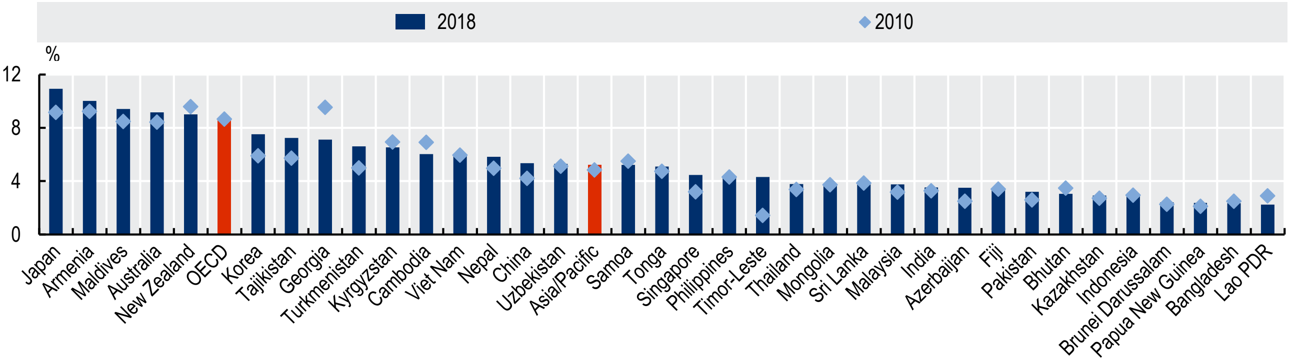
[41] Ibid

[42] Asian Development Bank. (2021). ADB Data Show the Impact of COVID-19 on Government Finance in Developing Asia. Available: https://www.adb.org/news/features/adb-data-show-impact-covid-19-government-finance-developing-asia; Gadsden, T., et al. (2022). Health financing policy responses to the COVID-19 pandemic: a review of the first stages in the WHO South-East Asia Region. Available: https://academic.oup.com/heapol/article/37/10/1317/6692678; The World Bank. (2023). From Double Shock to Double Recovery. Available: https://www.worldbank.org/en/topic/health/publication/from-double-shock-to-double-recovery-health-financing-in-the-time-of-covid-19

[43] The World Bank. (2023). From Double Shock to Double Recovery. Available: https://www.worldbank.org/en/topic/health/publication/from-double-shock-to-double-recovery-health-financing-in-the-time-of-covid-19

Figure 18: Health expenditure-to-GDP-ratios increased in many Asia-Pacific countries

Current health expenditure (%) of Gross domestic product (GDP) in 2010 and 2018



Source: WHO (2021), Global Health Expenditure Database; OECD (2021), OECD Health Statistics. StatLink https://stat.link/p7o4yb

The WHO supports broader use of Health Technology Assessment (HTA), as part of universal health coverage, evidence-based policy development and decision-making, and sustainable and effective health systems.[44] HTA is a form of policy research used to determine the value and potential impacts of a new health technology, such as a treatments, devices, procedures or diagnostics. The assessment generally includes evidence around safety, clinical effectiveness, and cost effectiveness to better understand the potential value and benefits of a new 'technology' to a society compared to existing alternatives, and to help inform decision-making on whether a treatment should be made available and/or subsidised, and at what cost.

HTA is officially used by more than 40 jurisdictions around the world. In the last 5-10 years, more Asian governments are interested in HTA or evolving their HTA approach.[45] HTAsiaLink, a collaborative research network of HTA agencies in the Asia-Pacific region, was established in 2010 with the common objective of HTA competency improvement. The network currently has representation from 16 countries across the region.[46] Additionally, since 2013, Health Technology Assessment International (HTAi)'s Asia Policy Forum has been bringing together senior representatives from HTA stakeholders across Asia-Pacific annually to engage in strategic discussions informed by the perspectives of their different organisations without the constraints associated with discussions of specific products or organisational policies.[47]

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[44] World Health Organization. (n.d.). Health technology assessment. Available: https://www.who.int/health-topics/health-technology-assessment#tab=tab_3

[45] Liu, G., et al. (2020). The Development of Health Technology Assessment in Asia: Current Status and Future Trends. Available: https://www.sciencedirect.com/science/article/pii/S2212109919305783

[46] HTAsiaLink. (2023). HTAsiaLink Members. Available: https://htasialink.com/about-us/htasialink-members

[47] HTAi. (n.d.). Asia Policy Forum. Available: https://past.htai.org/policy-forum/asia-policy-forum-2/

Just like in other parts of the world, APAC countries have varying approaches and experience in HTA implementation and use of the patient voice. One published analysis found considerable differences across the region and that "Advanced HTA programs have independent HTA agencies with a broad remit, explicit process and methods, network of researchers, and routine use of HTA," and that "Political will, technical expertise, and sustained financing remain challenges for sustainable HTA programs."[48]

The HTA discipline is continuously evolving to better meet the needs of people affected by cancer and to be prepared for high-cost technologies, small patient populations, and emerging advancements including diagnostics, genetic testing, digital solutions, data, medicines, services and devices.[49]

There are a range of ways that patient engagement approaches in HTA are being used across the region, including:

- nomination of topics for assessment
- prioritisation of topics for assessment
- meetings/consultations with HTA committees
- surveys to provide lived experience
- workshops
- official evidence submissions
- qualitative interviews
- representation on HTA committees, including as full voting members
- appeals on HTA decisions
- dissemination of outcomes
- strategy input on engagement processes and communication efforts
- development of guidelines and implementation plans for healthcare decisions
- launch events/communication for the broader patient community.

Considerations for future evolution of HTA

As HTA continues to evolve in the region, it could improve by:

- having more local research from the region to support HTA decisions using local context, patient preferences, data and expertise
- considering the broader impacts on patients, society and the economy in HTA assessments
- international collaborations to share best practice approaches, results and lessons learned, in culturally appropriate ways
- special access arrangements for rarer subpopulations, where standard clinical trials and evidence are not possible
- including the patient voice in meaningful and structured ways in research and in HTA processes.

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48 Kumar, R., et al. (2022). Assessing progression of health technology assessment implementation in Asia: a balanced scorecard for cross comparison of selected countries in Asia. Available: https://pubmed.ncbi.nlm.nih.gov/35858879/

49 HTAi 2023 summary report

Including the patient voice in HTA

More work is needed to better incorporate the patient voice in HTA globally. Some of the standard challenges and opportunities for better engagement in HTA include health literacy, resource constraints, capacity to engage, diversity in views from patients and trust that the decision-makers will use the insights shared in meaningful ways. Below are some ideas on how to collaboratively create better opportunities for engagement:

- patient involvement in co-designing HTA engagement approaches can help build trust for all involved and ensure processes reflect the needs of patients
- investing in robust research into patients' needs, preferences and experiences (patient-based evidence) and qualitative skills within HTA bodies
- collaboration across the region, sharing insights and practices around patient involvement
- greater transparency around how the patient voice is valued and included
- creating structured approaches for engagement including standard processes and leadership (e.g. someone who oversees and is responsible for engagement with patients in appropriate, clear and efficient ways, based on best practice)
- additional resourcing for patients and HTA teams to engage as standard practice
- capacity building/training among patient communities to participate in HTA
- capacity building within HTA bodies and with other relevant stakeholders to improve understanding and use of patient insights and patient-based evidence
- support PSOs to collect and own data on the patient perspectives and experiences
- co-design patient involvement strategies and frameworks for individual HTA bodies
- working with priority populations (who are lacking equity in healthcare) to improve the representativeness of the HTA and better meet their unmet needs
- further support for experienced patient representatives who have established trust, relationships and a more in-depth understanding of the systems and stakeholders, to help, mentor, include and represent a broader range of patients
- involvement of patients in clinical trial design means that outcomes measured represent what patients identify as important.

Patient perspectives can add specific and valuable insights on:

- what outcomes are important to them
- what a health condition means for their daily life, including impacts on their family and work
- unmet needs
- challenges in managing their disease with current healthcare/social resources
- how the treatment may change their quality of life compared to what happens without it
- experiences of accessing or using a current and/or new treatment or service
- burden of treatment
- pathways to diagnosis and treatment
- preferences and trade-offs regarding side effects
- financial consequences
- suitability of the comparator
- needs of particular sub-groups
- variation in services and local context
- rules about stopping and starting treatment
- applicability of trial data to local patients/context
- fill gaps or uncertainties in the evidence base.

CASE STUDY

Patient involvement in HTA – Agency for Care Effectiveness (ACE) Singapore

The Agency for Care Effectiveness (ACE) is Singapore's national HTA agency, established in 2015. In 2021, ACE established the Consumer Engagement and Education (CEE) team to support patient involvement in ACE's work. All patient involvement processes have been co-developed with local patient organisations in Singapore.

The CEE team are responsible for co-developing, implementing and improving methods and processes to enable patients to meaningfully contribute to ACE's HTAs. To begin with, they conducted a comprehensive mapping exercise to identify all patient organisations in Singapore, and formed a Consumer Panel, comprising 15 members from local patient organisations to represent a collective voice of healthcare consumers and provide strategic advice to ACE on patient involvement initiatives. Each year they have expanded opportunities for patients to be involved in ACE's work and have begun co-developing educational resources and training workshops with patient organisations, which improve health literacy and empower patients to make evidence-based decisions about their healthcare needs.

Find out more: www.ace-hta.gov.sg/Patients-And-Community/opportunities-for-patient-involvement

Contributing factors for its impact on meaningful change:

An inspiring vision

Enhancing patient involvement in HTA processes

Powerful patient voices

Forming a Consumer Panel of patient organisations to represent patients

Shared investment

Investment from government in setting up a dedicated team to involve patients

Patients included as key stakeholders at the HTAi Annual Meeting

Health Technology Assessment International (HTAi) is a global society championing equitable, responsive, and cutting-edge HTA. It is a community of multidisciplinary advisors, academics, scientists, professionals, public and private organisations, students, and patient members. Patient involvement in HTA overall and at Annual Meetings is a priority with the Patient and Citizen Involvement in HTA Interest Group (PCIG) specifically focusing on practical approaches to progress patient engagement in HTA globally.

In June 2023, the HTAi Annual Meeting was held in Adelaide, Australia with considerable patient representation. There was the largest number of patients in person at an HTAi Annual Meeting with more than 70 patients participating, including many from across the APAC region. Patients were also heavily involved in planning for the conference, presentations and panel events and discussions on the future of HTA. The HTAi meeting is a great example of a collaborative approach, shared investment, and shared understanding of the need for systems change and for patients to be part of the conversation.

This was possible because of the support from a range of organisations, but also because patient representatives were willing to invest their time, energy and funding (in many cases) to actively participate and learn more about how they can be involved in HTA.

Find out more: www.htai.org

Contributing factors for its impact on meaningful change:

An inspiring vision

Highlighting patient perspectives and involving them in HTA processes

Working together

Community of multidisciplinary advisors, academics, scientists, professionals, public and private organisations, students, and patient members

Powerful patient voices

Focusing on the patient voice in HTA processes

LOCAL RESEARCH, EXPERTISE, CLINICAL LEADERSHIP AND DATA

Local research and clinical trials are beneficial to the community in many ways. Research conducted in the context of local cultures, health systems and populations will create more accurate insights as it is based on a more real-world local situation. Clinical trials data is typically the major input for approvals for access and subsidies, including with HTA. It was estimated that previously (2011-2016), only 17% of global clinical trials included Asian patients and this underrepresentation can affect generalisability of global trial results to local contexts and delays in decision-making.[50]

There has been a major increase in the volume of registered clinical trials in the APAC region with considerable year-on-year growth rates since 2016, faster than Europe and North America.[51]

One industry report estimated that the APAC clinical trials market in 2020 was over USD$7 billion (with over one third related to oncology) and will grow to more than USD$12 billion by 2027.[52]

> Genomic information about cancer is leading to better diagnosis and matched treatment strategies that are tailored to patients' tumours. This is called precision medicine. The rapid development of Next Generation Sequencing has led to improved accuracy for precision medicine.
>
> **Dr Toshio Shimizu**
> Professor, Wakayama Medical University Hospital

This rapid growth is likely due to a range of factors:

- lower costs of conducting studies (relative to other locations)
- large and diverse patient population pools to recruit from
- increasing challenges in conducting trials in other parts of the world
- improving healthcare infrastructure and quality standards
- ease of regulatory compliance (relative to other locations)
- many treatment companies have implemented a mandate to include more emerging markets in trials.

Research helps upskill and retain local experts and create more local data, boosting the potential for more local innovation opportunities. The science is moving fast, and we are learning that cancers can be more personalised and based on someone's DNA and local settings, making local research and innovation all the more important for meeting local needs. These opportunities can also support local healthcare professionals to have a broader view of opportunities for better cancer care and changes needed.

Local research can also mean access to innovative diagnostics and treatment options for some patients who may not be able to afford or access them otherwise. Importantly, there is an opportunity for greater engagement in clinical trial design from patient representatives in the region.

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[50] Fashoyin-Aje, L., et al. (2017). Asian representation in clinical trials of new drugs for the treatment of cancer. Available: https://ascopubs.org/doi/10.1200/JCO.2017.35.15_suppl.6564; Lin, LW., et al. (2020). Use of Real-World Data and Real-World Evidence to Support Drug Reimbursement Decision-Making in Asia. Available: https://hiper.nus.edu.sg/wp-content/uploads/2021/03/REALISE-Full-guidance-post-feedback_20201211-version-1.1.pdf

[51] Novotech. (2022). Evolution of Clinical Trials in the Asia Pacific Region Compared to the US and EU5. Available: https://novotech-cro.com/whitepapers/evolution-clinical-trials-asia-pacific-region-compared-us-and-eu5; Siu, A., Benson, A. (2022). APAC As A Clinical Trial Powerhouse. Available: https://invivo.pharmaintelligence.informa.com/IV146738/APAC-As-A-Clinical-Trial-Powerhouse; Ali, S., et al. (2019). Clinical trials in Asia: A World Health Organization database study. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6647899/

[52] Graphical Research. (2021). Asia Pacific Clinical Trials Market. Available: https://www.graphicalresearch.com/industry-insights/2004/asia-pacific-clinical-trials-market

Considerations for future growth in local research

As the APAC region becomes a global leader in research and evidence development, there are important considerations, including more equitable access to research, regulatory approvals, data, and involving patient representatives.

More equitable access

The growth in local research is something to celebrate, however more work needs to be done for equitable access across the region. Collaboratively addressing relevant barriers can help reduce global health inequity.

Low- and middle-income countries

Fewer studies are conducted in LMICs.[53] One systematic review found the major barriers for international clinical trials in developing countries include lack of financial and human capacity and capability, ethical and regulatory system obstacles, lack of research environment, operational barriers, and competing demands.[54] Some of the new technologies require costly equipment for participation, such as Next Generation Sequencing machines.

In addition, where clinical trials had reached LMICs, some experts interviewed expressed concerns around realising sufficient community benefits.

One example is locations being used to boost trial numbers for FDA approval, with little additional collaboration potential, and questions were raised around access to new medicines in a country after global clinical trials had been conducted there.[55]

It is important to build local evidence and leadership because cancer-control strategies that work in high resource settings are not necessarily applicable to low-resource settings or among more vulnerable populations for a range of reasons. These can include disease characteristics, health systems capacity, sociocultural factors, treatment completion rates, access to medicines, ethnic variations and particularly the high costs of approaches developed in higher-income countries can be impossible to directly implement in lower-resource settings. In addition, effective local leadership will need to be developed based on culturally sensitive leadership styles, behaviors, and communications.[56]

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[53] Pramesh, CS., et al. (2022). Priorities for cancer research in low- and middle-income countries: a global perspective. Available: https://www.nature.com/articles/s41591-022-01738-x

[54] Alemayehu, C., Mitchell, G., Nikles, J. (2018). Barriers for conducting clinical trials in developing countries – a systematic review. Available: https://equityhealthj.biomedcentral.com/articles/10.1186/s12939-018-0748-6#:~:text=Barriers%20to%20conducting%20clinical%20trials%20in%20developing%20countries%20were%3A%20lack,demands%20(see%20Table%202)

[55] Miller, JE., et al. (2021). Evaluation of Drug Trials in High-, Middle-, and Low-Income Countries and Local Commercial Availability of Newly Approved Drugs. JAMA Network

[56] De Guzman, R., et al. (2023). ASCO's Leadership Development Program: Focusing on the Next Generation of Leaders in Asia Pacific. Available: https://pubmed.ncbi.nlm.nih.gov/36812447/

Remote/regional communities

Patients in more regional and remote locations often have inequitable access to healthcare in general, including the ability to participate in clinical trials. Research is generally conducted at major hospitals in larger cities leaving patients with difficult decisions such as investing in travel and time off work in order to participate. Patient support programs could help with logistics and funding to support transport options and accommodation, however more sustainable investment approaches are needed.

Some countries have instituted a telehealth approach to clinical trials. For example, a trial in Japan is partnering with rural hospitals to provide in-person check-ups and delivering instructions and medicines directly to participant's homes for the trial.[57] In Australia, the Teletrial Program uses telehealth to connect regional and rural clinical trial site clusters.[58]

Rare cancers

People living with a rare cancer have a range of challenges such as delays in diagnosis, limited treatment options and difficulty in finding clinicians that can help. Rare cancer survival rates haven't improved at the same rate as more common cancers over the last 20 years. More research is needed to provide equitable care for patients with rare cancers. Due to smaller population sizes, it is almost impossible to conduct a standard clinical trial. International collaborations are needed to increase patient participation numbers, create evidence, and share progress to improve the situation.

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[57] The Japan Times. (2023). Rare cancer drug trials to go online in Japan. Available: https://www.japantimes.co.jp/news/2023/06/27/national/science-health/cancer-drug-trials-online-japan/

[58] Australian Teletrial Program. (2022). The Australian Teletrial Program. Available: https://australianteletrialprogram.com.au/about/

MASTER KEY Asia Project – ATLAS

MASTER KEY Asia is an international collaborative research project of the Asian Clinical Trials Network for Cancers (ATLAS) led by the National Cancer Center in Japan, launched in 2021. ATLAS focuses on building infrastructure and clinical trials networks in Asia, including capacity building programs for clinical trial procedures and genomic cancer medicine. This approach supports more investigator-initiated research.

ATLAS is a collaborative effort involving existing networks across Japan, Korea, Taiwan, Singapore, and China (Hong Kong) and has been expanding to other ASEAN countries including Thailand, Malaysia, Philippines, Vietnam and Indonesia.

The MASTER KEY Asia project helps to collaboratively develop valuable datasets for rare cancers (in Asia) to better understand the cancers and develop treatment options, which is a known challenge because of the smaller patient population groups with rare cancers. The team now has the largest registry for rare cancers in the region.

The MASTER KEY Asia project aims to:

- gather genomic information, treatment details and prognoses into a comprehensive database
- address the scarcity of genomic medicine for cancer patients in Asia, and along with MASTER KEY Japan, aims to enrol 1,000 patients annually from the region
- collaborate across Asia to develop effective treatments for rare cancers in Asia
- collaborate with local patient organisations for information sharing and recruitment.

The project aligns with ATLAS's goal of working towards establishing a clinical trial infrastructure in Asia while accelerating clinical research for the benefit of Asian patients with rare cancers.

In addition to this project, the National Cancer Center in Japan has also introduced online clinical trials for rare cancers, aiming to enhance access for patients residing in remote areas. A central hospital in Tokyo has launched online trials for physician-led trials, allowing patients to participate through local healthcare institutions.

Find out more: https://en.atlas.ncc.go.jp/MK_Asia

Contributing factors for its impact on meaningful change:

An inspiring vision

Accelerating clinical research for rare cancer patients in Asia-Pacific region

Powerful patient voices

Listening to the demand for high-level treatments for rare cancer patients

Working together

Collaboration between local patient support organisations, patients, and hospitals

Information to support action

Forming a genomic database to support clinical trials and treatment decision-making

Regulatory approvals for international research

Coordinating research across the region can be complex with the range of health systems, languages, cultures and regulatory approval processes. Streamlining regulatory approvals across the region using international standards could help create more efficient and effective research programs, boost regional investments,[59] and support a more balanced flow of research investment into emerging markets. Collaboration across researchers/trial groups, regulators, and healthcare decision makers could help identify opportunities for harmonisation.[60] Including patient representatives in these collaborations could help with ethical and process considerations. The collaborations could also consider how more local investigator trials (designed by local researchers) can be supported for local leadership and innovation.

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[59] Day, D., et al. (2023). Operational Challenges of an Asia-Pacific Academic Oncology Clinical Trial. Available: https://ascopubs.org/doi/full/10.1200/GO.23.00040

[60] Tang, M., et al. (2019). Challenges of international oncology trial collaboration – a call to action. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6889481/

Data for decision making

With cancer care becoming more personalised and based on an individual's situation and biomarkers (biological indicators), data collection and analysis is increasingly relevant for cancer research and care.[61] 'Big data' (large and complex data sets) and Artificial Intelligence/machine learning can help with risk identification, diagnosis, prognosis, and treatment selection.[62] There is also a global trend of increasing focus on tracking and researching 'real world outcomes' for patients to better understand the impacts of new cancer treatments on people in the mainstream health system, to add to the clinical trial evidence.[63] Local registries are one way to collaboratively collect health outcomes for research.

These advancements will be relevant for the future of cancer control in the region with great opportunities for improving care and efficiency. There are however important ethical considerations such as:

- privacy and data ownership
- patient consent for participation
- investments in high quality data storage (including local registries)
- sharing information for research
- handling of patient-reported outcomes
- impacts on clinical decision-making and access
- sharing data/insights with patient representatives and community organisations.

Local clinical leaders will be crucial to understanding and navigating these opportunities and complexities. It will be important for them to collaborate with other clinical stakeholders, patient representatives, and decision-makers to do so. For example, many countries don't allow for data or samples to be shared internationally, making some international research projects too difficult to implement.

Regional centres of excellence could help to support clinical leaders and researchers to identify best practices for the region and opportunities for research and data sharing harmonisation, balancing ethical and patient benefit considerations.

Engaging patient representatives

The patient voice and perspective is valuable for the full development cycle of new health technologies and services, from pre-clinical trial to real world evidence and post market reviews. Involvement of patient representatives in clinical trial design means that the evidence developed better represents what patients feel is important. Engagement can also help improve study designs, participation, applicability to different countries' healthcare systems and delivery.

In addition, patient representatives can assist with:

- considering the most important health outcomes (end points)
- recognising important health system and process hurdles for participation
- identifying overly burdensome protocols
- accessible communication
- peer support for participants
- ethical considerations
- patients as active partners in research, with a framework for ethical guidelines for research.

For patient representatives to have the opportunity to provide such value, they need to be seen as valuable experts for engagement. The earlier patient representatives can be involved as collaborative partners, the better.

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[61] Sweeney, SM., et al. (2023). Challenges to Using Big Data in Cancer. Available: https://pubmed.ncbi.nlm.nih.gov/36625843/#:~:text=Abstract,%2C%20wearables%2C%20and%20medical%20devices

[62] Zhang, B., Shi, H., Wang, H. (2023). Machine Learning and AI in Cancer Prognosis, Prediction, and Treatment Selection: A Critical Approach. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10312208/

[63] Tang, M., Pearson, S., Simes, R., Chua, B. (2023). Harnessing Real-World Evidence to Advance Cancer Research. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9955401/

Regional Leadership Development Program, ASCO

ASCO launched the Asia Pacific Regional Council (APRC) in 2019 to advise on member needs and encourage the involvement of regional cancer health care professionals in ASCO's global activities. Highly prioritised was the need to create leaders in the region. Understanding that the traditional Western leadership program may not be well suited to an Asian context, a culturally modified training program was deemed essential.

ASCO's Regional Leadership Development Program represents a pivotal initiative aimed at nurturing emerging leaders in the field of oncology across various regions, including the Asia-Pacific region. Its overarching goal is to prepare the next generation of oncology leaders by developing the knowledge and skills for effectively navigating cancer care. There is a growing demand for high-quality and comprehensive oncology care globally and the critical role that effective leadership plays in addressing these challenges.

A significant aspect of the program involves project-based learning, where participants work in teams on projects relevant to cancer care in the region. This approach is intended to foster teamwork, leadership skills, and collaboration.

Find out more: www.ascopubs.org/go/special/series/cancer-care-asia-pacific

Contributing factors for its impact on meaningful change:

An inspiring vision

Developing future oncology leaders

Working together

Organisation leaders and healthcare professionals working together across borders

Shared investment

Investment from clinicians and the clinical community

Information to support action

Program content driven by needs of the region

Asia Pacific Oncology Drug Development Consortium (APODDC)

The Asia Pacific Oncology Drug Development Consortium (APODDC), established in 2021, works to foster education and collaboration between key stakeholders of oncology drug development within the Asia Pacific region. By emphasising the importance of data sharing, streamlining regulatory aspects, and exploring the potential for medical trial tourism, APODDC aims to create solutions for improved treatment access for patients. The team includes a range of research and clinical leaders from across the region and is growing.

One study conducted by APODDC was on the use of Next Generation Sequencing (NGS) in metastatic cancer patients in the APAC region. The study evaluated the applicability of NGS in nine cancer types within the Asia-Pacific region, considering factors like Asian ethnicity, accessibility of NGS testing, reimbursement, and local practice characteristics. The study provides practical guidance on the clinical utility of NGS in specific cancer indications, offering valuable insights from the APAC region perspective.

Contributing factors for its impact on meaningful change:

An inspiring vision

Improving oncology drug development and accessibility in the region

Working together

Fostering collaboration with stakeholders across the region

Information to support action

Emphasising importance in data sharing and research for better care

SUPPORTIVE CARE SERVICES

There is increasing global recognition of the need to include physical and psychological wellbeing during and after cancer care, moving from strictly medical care to aiming to improve wellbeing more holistically through additional support services.[64]

Cancer is disruptive to ways of life, plans, physical and mental states, relationships, and work and can cause psychological distress.[65] Supportive services can help people navigate and address these changes and challenges, however such services may not routinely be delivered in some countries.[66]

Psychosocial support

Several interviewees mentioned an increasing demand for psychosocial support services to help people better deal with the impacts of cancer. Psychosocial oncology is a multidisciplinary field in cancer care that focuses on mental wellbeing in dealing with the difficulties of treatment and uncertainty regarding prognosis.[67]

Services to support mental wellbeing can include:

- counselling/therapy
- information/education including financial and legal support
- navigation
- group/peer support
- spiritual support.

> We underestimate the power of community and peer support in cancer care. We can learn a lot from how other countries in the region are providing these valuable models of care in lower resourced environments where peer support is critical for care delivery.
>
> **Professor Bogda Koczwara**
> Medical Oncologist, Flinders Medical Centre and Flinders Health and Medical Research Institute, Flinders University Australia

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[64] Chan, RJ., Chang, A., Yates, P., Molassiotis, A. (2017). A step forward in addressing cancer survivorship in the Asia-Pacific region. Available: https://escholarship.org/uc/item/1vf7g4wm

[65] Weis, J. (2015). Psychosocial Care for Cancer Patients. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4463789/

[66] Kaasa, S., Knaul, FM., Mwangi-Powell, F., Rodin, G. (2018). Supportive care in cancer: new directions to achieve universal access to psychosocial, palliative, and end-of-life care. Available: https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(18)30086-X/fulltext

[67] Tack, L., et al. (2022). Psychosocial Care after Cancer Diagnosis: Recent Advances and Challenges. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9739074/

These services can be valuable for patients and their families and can be delivered by a wide range of health and social care professionals or patient and community groups. They can be relevant for most of the cancer care continuum, from diagnosis to palliative care.[68]

The International Psycho-Oncology Society proposes an international quality standard for psychosocial support:[69]

- psychosocial cancer care should be recognised as a universal human right
- quality cancer care must integrate the psychosocial domain into routine care
- distress should be measured as the sixth vital sign after temperature, blood pressure, pulse, respiratory rate and pain.

Psychosocial care is part of providing rehabilitation, survivorship, and palliative care services.

> In the National Cancer Control Act, the institutionalisation of psychosocial care for paediatric patients is mandatory. This will help lower anxiety, stress and fear, heighten compliance and ensure better treatment outcomes for children. Despite the long road ahead, there is much to be hopeful about.
>
> **Dr Angie Sievert-Fernandez**
> Ex-Executive Director,
> Kythe Foundation Inc. Philippines

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CASE STUDY

Stronger Together – A peer-to-peer psychosocial intervention for women

Stronger Together is a peer-to-peer support program that uses trained, supervised volunteers with a lived experience of cancer to assist newly diagnosed cancer patients and their families navigate their treatment and provide emotional support.

The goals of the program are to:

- provide emotional and navigational support
- inform patients and care partners about cancer related topics
- decrease distress for patients and their families
- increase adherence to treatment
- build a sense of community and purpose among the cancer survivor population.

The program is either embedded in hospital structure and services and/or has strong clinical affiliations and is managed by a trained program coordinator. They work with the medical team to coordinate the activities of the peer mentors to best meet patient needs. Cancer survivors are screened and receive rigorous training on practical peer mentoring skills. Peer mentors are carefully matched and monitored by the program coordinator to newly diagnosed patients based on cancer type, stage, age, language/culture and patient preferences.

The program has been piloted at four sites in Vietnam. The approach is highly acceptable, feasible and successful at reducing psychological distress among participants and it does not require significant healthcare resources. To assist in the sustainability and replication of the program, Global Focus on Cancer has developed a Toolkit to guide the implementation of this model of peer-to-peer support.

Contributing factors for its impact on meaningful change:

An inspiring vision

Empowering and supporting patients and families/carers through their cancer journey

Powerful patient voices

Incorporating lived experience of cancer into the program

Working together

Hospitals, volunteers, international organisations working together

Survivorship and rehabilitation

People not only want to survive but also thrive after cancer. Survivorship focuses on care to maximise health and wellbeing for survivors of cancer and can include rehabilitation services.[70]

Rehabilitation helps people deal with the physical (side effects) and psychosocial impacts of cancer after treatment (or with ongoing treatment). Rehabilitation is one of the essential health services included in the WHO's definition of universal health coverage and can have a range of benefits including shortening recovery time, preventing complications, and improving physical and mental functioning and well-being.[71]

The recently released WHO 'Package of interventions for rehabilitation' outlines the most essential interventions for rehabilitation across seven disease areas including cancer (malignant neoplasm) which has categories for assessment of:[72]

- mental/cognitive function
- pain management
- bowel/bladder management
- sexual function
- cardiovascular and immunological function
- motor function and mobility
- exercise and fitness
- activities of daily living
- interpersonal interactions and relationships
- education and vocation
- community and social life
- lifestyle modification
- self-management
- carer and family support
- mental health
- osteoporosis
- malnutrition.

Rehabilitation can help people to return to work and engage more in their community and interpersonal relationships. There is great opportunity to improve rehabilitation-focused care in the region, particularly in LMICs.[73]

Fertility

Cancer treatments can affect people's ability to have children, which is often a major concern for younger cancer patients. Fertility preservation is an emerging field in the region that may include the harvesting and storing of sperm and eggs prior to beginning treatment. Opportunities to improve care include funding, locally developed models of care and research and better information for healthcare professionals, cancer patients and the broader society.[74] A positive example in Australia is the Government's recent announcement of support for cancer patients of reproductive age with funding to subsidise costs of storage for future use of eggs, sperm or embryos.[75]

> The burden of cancer is rising in the low and middle income countries and many of the health systems are trying to lay out plans to improve access to treatment but not enough is being done for supportive and survivorship care. Needs assessment tools help to identify unmet needs in an evidence based way, for people living with cancer based on their situation and culture.
>
> **Dr Nirmala Bhoo Pathy**
> Professor of Epidemiology and Public Health, Department of Social and Preventive Medicine, Faculty of Medicine, Universiti Malaya

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Fertility support for cancer patients – Hope Foundation for Cancer Care Taiwan

The Hope Foundation is a patient organisation in Taiwan dedicated to supporting cancer patients. One of its goals is to create an informed and supportive environment for cancer patients facing fertility challenges in Taiwan, emphasising the importance of safeguarding fertility health alongside cancer care. It was found that nearly 60% of cancer patients wished to have children after treatment, with 40% reporting inadequate access to fertility information.

With the number of cancer patients of childbearing age in Taiwan reaching 22,000, a significant challenge lies in fertility preservation, as cancer patients often find themselves navigating these sensitive issues with limited guidance due to a lack of formal communication requirements in Taiwan's medical policy.

To address this issue, HOPE launched Cancer and Fertility in 2020, a fertility website for cancer patients in Taiwan. The platform offers personalised guidance, shares inspirational patient stories, and provides essential reproductive and health information.

HOPE aims to further enhance the website, strengthen communication with medical professionals, and solidify its role as the primary resource for fertility health concerns among cancer patients in Taiwan. HOPE also seeks to integrate fertility preservation information into professional training courses, raising physician awareness and promoting patient-centric reproductive decisions alongside cancer treatment.

In 2021, the HOPE Foundation was granted funding from the Pinnacle Program of US$8,500 to support this project through the Pitch for Pinnacle competition.

Find out more: www.ecancer.org.tw

Contributing factors for its impact on meaningful change:

An inspiring vision

Highlighting fertility challenges in Taiwan for cancer patients

Powerful patient voices

Incorporating unique needs of young cancer patients

Working together

Working with patients and clinicians

Community awareness

Providing a platform for cancer patients with fertility needs

Return to work

Impacts on employment can be a major concern for cancer patients and their families, especially when coupled with high treatment costs. Helping people return to work is important for the economy and for the patient's quality of life, self-esteem, social connections, and economic stability.[76] Social stigma related to cancer, fears around the ability to work, and potential cancer recurrence can affect someone's ability to work during and after treatment.[77]

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[76] Xu, J., et al. (2023). Cancer patients' return-to-work adaptation experience and coping resources: a grounded theory study. Available: https://bmcnurs.biomedcentral.com/articles/10.1186/s12912-023-01219-7#:~:text=Return%20to%20work%20is%20regarded,and%20mental%20health%20%5B10%5D

[77] Lee, SE., Park, EY. (2023). Employees' attitudes toward cancer, cancer survivors, and cancer survivors' return to work. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9995287/; So, S., et al. (2022). Return to Work and Work Productivity During the First Year After Cancer Treatment. Available: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.866346/full; Lo, SY. (2020). Reducing Stigma of Cancer in Asia – An Important Strategy for Cancer Control. Available: https://www.researchgate.net/publication/341977655_Reducing_Stigma_of_Cancer_in_Asia-An_Important_Strategy_for_Cancer_Control

CASE STUDY

Employment support for cancer patients – Japan

In Japan, comprehensive support systems have been established to assist cancer patients in balancing their medical treatment and work responsibilities. Approximately one in three cancer patients in Japan are aged between 20 and 60 and continue to work while undergoing treatment. Around 20% of working individuals had to leave their jobs due to their diagnosis. Among these, 57% left their jobs before receiving their initial treatment.

In response to these challenges, several key initiatives have been implemented by the Ministry of Health, Labor and Welfare to facilitate work-life balance for cancer patients and survivors. Key changes include:

Creating an environment in which cancer patients can more easily balance treatment and work:

- creation and dissemination of guidelines and manuals to support balancing work and medical treatment at workplaces
- training and deployment of dual support coordinators
- support and guidance for companies from the Comprehensive Support Center for Occupational Health Promotion
- utilisation of subsidies to support balancing work with medical treatment and other costs.

Counselling support for cancer patients from the time cancer is diagnosed:

- from employment specialists such as labour and social security attorneys
- through coordinators and guides for advice on re-employment after leaving a job
- with employment support navigators.

This approach ensures people do not miss out on treatment opportunities due to work obligations and are not hindered from sustaining their employment due to the imperative for medical care.

Find out more: www.mhlw.go.jp/content/11200000/001088186.pdf

Contributing factors for its impact on meaningful change:

An inspiring vision

Creating of an environment to support patients in balancing medical treatment and work

Powerful patient voices

Patient experiences help frame solutions

Working together

Government, patients and employers working together to support patient employment

Community awareness

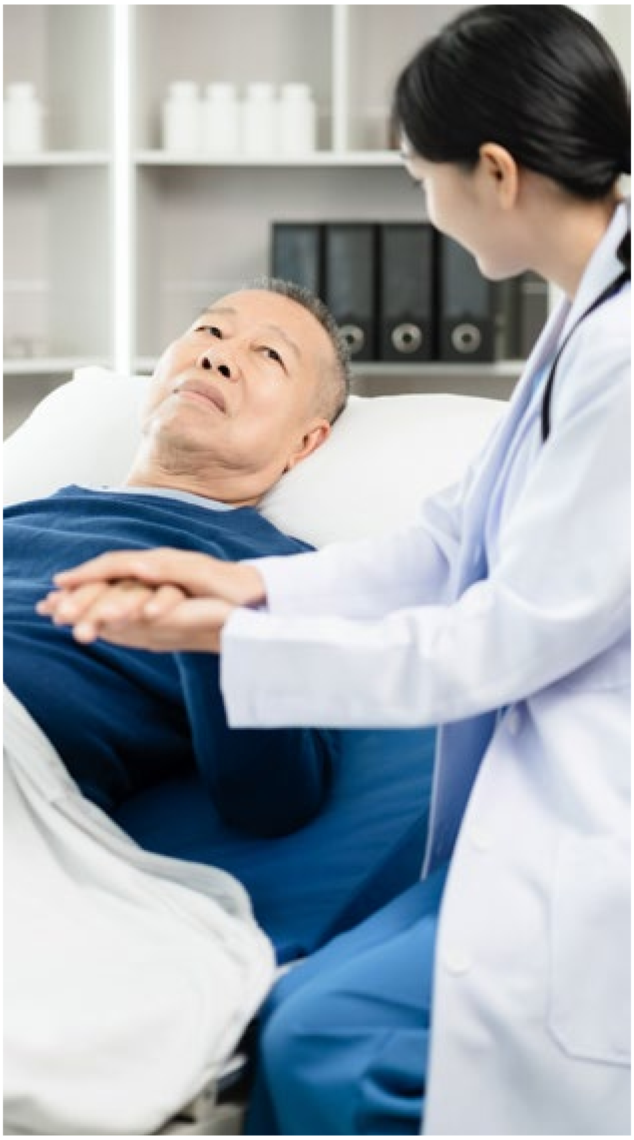
Creating guidelines and manuals to increase awareness and support

Palliative care

The WHO states that palliative care is a crucial part of integrated, people-centred health services and is a global ethical responsibility.[78] Palliative care can help people manage physical symptoms and emotional impacts from cancer and treatment. It helps improve quality of life for patients and their families and can lead to better coping with bereavement.[79]

Societal perceptions of cancer and palliative care are important.[80] It is valuable for people to understand that cancer is not necessarily a death sentence and that even if not curable, people can live well with cancer. It is a common misconception that palliative care is solely for end-of-life care. Palliative care can be more about enhancing quality of life and helping people live longer and more comfortably with cancer. Palliative supports can be provided at any time during someone's experience.

There is a clear need for better and more integrated palliative care services in the region, especially as many cancers are diagnosed late stage. It is estimated that globally only 14% of patients who need palliative care receive it[81] and there are major disparities in the quality of end-of-life care delivered across the region, especially between the highest-income countries and others.[82] Research on palliative care models in the region is also mostly conducted in higher-income countries.[83] Education and training on palliative care is needed as a starting point from which to improve access.[84]



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[78] World Health Organization. (2023). Expanding palliative care. Available: https://www.who.int/southeastasia/activities/expanding-palliative-care

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[80] Liu, MF., et al. (2021). Palliative Care Development in the Asia Pacific Region: A Review of Assessment Indicators. Available: https://www.jpsmjournal.com/article/S0885-3924(21)00317-1/fulltext

[81] World Health Organization. (2023). Expanding palliative care. Available: https://www.who.int/southeastasia/activities/expanding-palliative-care

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[83] Cheong, WL., Mohan, D., Warren, N., Reidpath, D. (2019). Palliative Care Research in the Asia Pacific Region: A Systematic Review and Bibliometric Analysis of Peer-Reviewed Publications. Available: https://www.liebertpub.com/doi/10.1089/jpm.2018.0447

[84] Spruyt, O. (2018). The Status of Palliative Care in the Asia-Pacific Region. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5763429/; Cheong, WL., Mohan, D., Warren, N., Reidpath, D. (2019). Palliative Care Research in the Asia Pacific Region: A Systematic Review and Bibliometric Analysis of Peer-Reviewed Publications. Available: https://www.liebertpub.com/doi/10.1089/jpm.2018.0447

Asia Pacific Hospice Palliative Care Network and Lien Collaborative

The Asia Pacific Hospice Palliative Care Network (APHN) is committed to advancing palliative care in the Asia-Pacific region, aiming to empower and support individuals and organisations dedicated to easing the suffering caused by life-threatening illnesses. APHN's efforts encompass education, skills development, raising awareness, fostering communication and promoting research and collaboration.

The Lien Collaborative for Palliative Care (Lien Collab) was co-developed by the Asia Pacific Hospice Palliative Care Network (APHN) and the Lien Foundation in 2012 and draws on philanthropy, health institutions, palliative care service providers, individuals and more to strengthen leadership and capacity in bringing pain relief to all. It envisions a world where access to quality palliative care services is a basic human right for all individuals and communities facing life-limiting conditions in Asia.

The Lien Collab program was initiated in Myanmar in 2013 and later expanded to countries such as Bangladesh, Sri Lanka, India, China, Bhutan, Timor-Leste, and Laos. The program has played a pivotal role in advocating for palliative care in countries with limited access to such services. With a presence in 139 institutions and the training of over 450 individuals, its In-Country Training of Trainers program stands out as a valuable initiative for building local expertise.

Key activities include:

- engaging key government institutions and emphasising the essential role of pain medications
- advocating for improved accessibility and affordability
- promoting knowledge exchange and capacity building among healthcare professionals, through overseas clinical fellowships.

By transforming knowledge into action, this collaborative initiative aims to reduce suffering and improve the quality of life for millions facing serious illnesses in the region.

Find out more: www.aphn.org

Contributing factors for its impact on meaningful change:

An inspiring vision

Access to quality palliative care is a basic human right

Working together

Joint efforts of international specialists and local stakeholders

Community awareness

Advocating and educating in networks and collaboratives, knowledge exchange

Powerful patient voices

Aiming to empower and support individuals

Shared investment

Using international philanthropy to support improvements

Considerations to enhance supportive services in the region

The scope of services needed for more supportive care (psychosocial, rehabilitation and palliative) are considerable and complex, and require more than just funding. The integration of these services will require community engagement, needs assessment and the collaboration of leaders across health systems, funders, patient and community organisations, researchers and the broader community (e.g. employers).

Opportunities to work together to improve care include:[85]

- developing services based on local cultures, patient experiences and needs and health system contexts
- planning for integration of services into routine cancer care and primary care
- providing clarity and training for healthcare professionals on what is needed and shared care requirements, communication and care coordination
- education for clinical care teams on how psychosocial, rehabilitation and palliative care services improve outcomes for patients and their families
- recognition that people have different needs at different points in the cancer care continuum
- development of minimum standards and guidance
- considering the value and integration of community and peer support
- recognition of patient representatives and community groups as important stakeholders
- research collaborations to better understand needs and benefits of services
- evaluation of care models for quality of life and health economic impacts
- embedding survivorship and support services in cancer control plans, national strategies etc
- considering telehealth options to support patients in remote and rural areas.

Patient and community organisations are critical to help identify and articulate needs, and provide important services like navigation, psychosocial support, and peer network services.

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[85] Koczwara, B., et al. (2023). Cancer Survivorship in the Indo-Pacific: Priorities for Progress. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10166466/; Chan, RJ., Chang, A., Yates, P., Molassiotis, A. (2017). A step forward in addressing cancer survivorship in the Asia-Pacific region. Available: https://escholarship.org/uc/item/1vf7g4wm; Liste, S. (2023). Package of interventions for rehabilitation. Available: https://www.who.int/activities/integrating-rehabilitation-into-health-systems/service-delivery/package-of-interventions-for-rehabilitation; Tack, L., et al. (2022). Psychosocial Care after Cancer Diagnosis: Recent Advances and Challenges. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9739074/

CASE STUDY

Needs Assessment Tool for Breast Cancer (NeAT-BC) – Malaysia

A Needs Assessment Tool for Breast Cancer (NeAT-BC) was developed in Malaysia, covering five domains: emotional support, social and intimate relationships, hospital appointments, personal care and health, and information and services. A co-design approach was taken to develop the NeAT-BC, involving patients, caregivers, community workers, patient support organisations, and healthcare professionals.

Compared to other existing tools, there are three key differences:

1. specifically designed for people living with and beyond breast cancer
2. catering for patients who are newly diagnosed to assess needs around the time of diagnosis
3. includes items on financial needs, employment needs, needs related to traditional and complementary medicine, fertility needs, religious and spiritual support, needs related to diet, and medical aid or equipment including mastectomy bras and breast prostheses.

This tool can be used both within the clinical setting to understand where patients need particular assistance, and in the community (e.g. by patient support organisations) to evaluate how patients' needs are being met and highlight areas for new services to be developed to address any gaps.

This tool is useful for many cancer care stakeholders to monitor, evaluate and improve their care services for patients. The tool is available to use free of charge for not-for-profit organisations. For access, please email: Dr Nirmala Bhoo Pathy at nirmala.bhoopathy@ummc.edu.my.

Find out more: www.ncbi.nlm.nih.gov/pmc/articles/PMC9858119

Contributing factors for its impact on meaningful change:

An inspiring vision

Better understand un-met patient needs

Working together

Co-designed with multiple stakeholders

Information to support action

Based on a scientific process and research

Follow Up Care in the Community Programme – Singapore

Access to cancer survivorship care can be a challenge across the Asia-Pacific region. In the case of Singapore, many cancer survivorship programs are traditionally provided by publicly funded national cancer centres and are usually small in scale, targeting specific health issues and populations. Lack of awareness, shortage of survivorship expertise, and integration of survivorship care into routine cancer care are some barriers to people living with cancer receiving quality survivorship care.

Working with primary healthcare providers and empowering them to provide follow up cancer care can help to reduce these barriers and also lessen the load on other parts of the health care system and most importantly, provide patients with continuity of care after treatment.

In 2018, the National University Cancer Institute of Singapore launched the "Follow Up Cancer Care in the Community Programme" for breast and colorectal cancer survivors, which focuses on follow-up care in the community, provided by primary care providers. The programme aims to integrate and provide continuity of care in the communities where cancer survivors live.

Find out more: www.ncis.com.sg/Our-Services/Home-and-Community-Programmes/Pages/Follow%20Up%20Cancer%20Care%20in%20the%20Community.aspx

Contributing factors for its impact on meaningful change:

An inspiring vision

Providing quality continuity of care for cancer survivors

Working together

Primary care providers working with national cancer institute to support cancer survivors

OPPORTUNITIES FOR FURTHER TRANSFORMATIONAL CHANGE

There is a great opportunity for further positive change in the region to benefit patients with cancer and their families, leveraging positive momentum around:

- breakthroughs in diagnostics and treatments
- the growing voice of patients, carers, and the community
- overall improved community understanding that cancer is survivable
- understanding the value of prevention and early detection to save lives
- support through global and regional collaboration initiatives
- more local research and clinical leadership
- a better recognition of the value of health globally (post COVID-19)
- greater use of telehealth technologies to reach more people (post COVID-19).

Further improvements to cancer prevention, treatment and care, and psychosocial support require more than just funding to be successful. In the context of growing health budgets, ageing populations and other urgent political priorities, funding and resources will need wise management to achieve maximum community benefits in health. Many countries have a national strategy or cancer control plan that identify key areas for action. Where to start and how to proceed are important considerations for meeting these national goals. Sustainable systems change to improve health equity require shifts:[86]

- structural – policies, practices, and resource flows
- relational – relationships and connections
- mental models – beliefs.

These shifts cannot be done in isolation and require collaboration.

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[86] Kania, J., Kramer, M., Senge, P. (2018). The Water of Systems Change. Available: https://www.fsg.org/resource/water_of_systems_change/

Significant improvements will require systems thinking and change based on the local needs, context, and leadership, so standard or 'one size fits all' solutions risk inefficient and inappropriate use of resources. Examples identified in interviews of investments in the region that could have benefited from better collaboration and understanding of the local context and system included:

- providing resources, medicines and machines that can't be utilised with the current system capacity and skills
- not considering the challenges and restraints for lower-resource health systems
- training that didn't lead to supporting local capacity
- developing health system pathways and services in isolation
- duplication of efforts
- one-off events with no follow-up support
- research with recruitment challenges and unnecessary inconvenience/discomfort for patients.

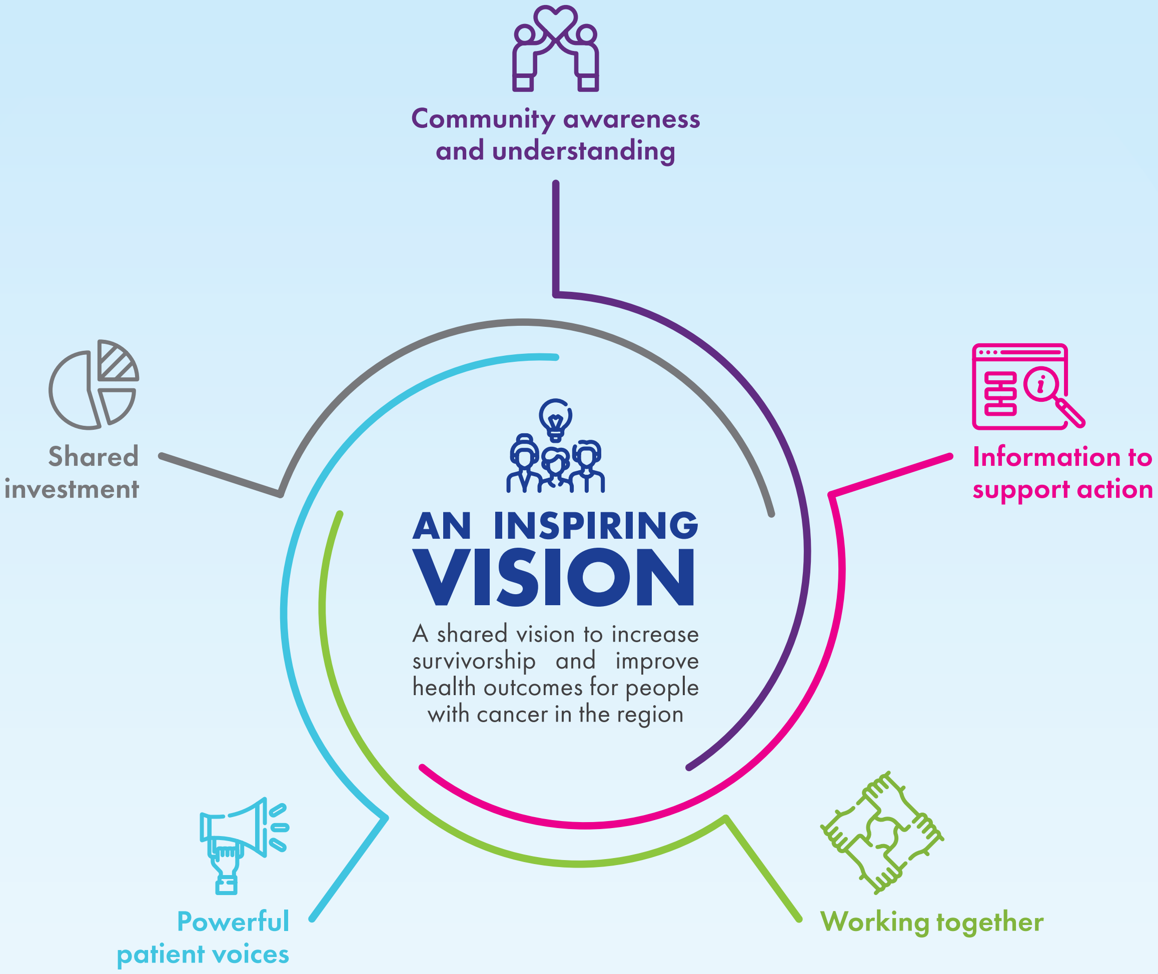
A patient centred framework for change

Harnessing local collaboration can avoid inefficiencies and help initiate, scope and prioritise action, considering:

- an inspiring vision for change
- information to support action – evidence and strategic information
- working together – collaboration and shared leadership
- powerful patient voices
- broader community engagement with civil society
- shared investments and actions from different sectors.

The following sections outline further what is meant by these concepts with great examples of successes already happening in the region. Patient representatives play a critical role however all stakeholders could benefit from considering a collaborative framework for action.

Figure 5: Collaborative framework for systems action



Broader community engagement with civil society

- Promoting widespread information on cancer
- Breaking myths and misconceptions
- Reshaping public perceptions, and expectations of care
- Reducing stigma and discrimination
- Engaging media, political leaders, families of patients and survivors, and scaling up their involvement

Evidence and strategic information

- Understanding the current situation and opportunities
- Knowing how the system works, recognising important gaps and emerging challenges
- Identifying relevant evidences, research, best practice and key players
- Harnessing technology and data

Collaboration and shared leadership

- Shared leadership to improve outcomes for patients
- Experts, patient organisations, development partners, civil society organisations and industry have collaborative relationships to drive and create momentum for change
- Local research is promoted and supported

Powerful patient voices

- Patients are valued, organised, communicating needs and concerns
- Patients lived experiences, ideas and insights inform systems changes
- Patients are meaningfully involved and shape policy and program design, research/ data generation

Investment and action from various sectors

- Sustainable and innovative financing to drive change and improvements
- Investments of time and expertise
- Market shaping interventions for greater access, availability and affordability

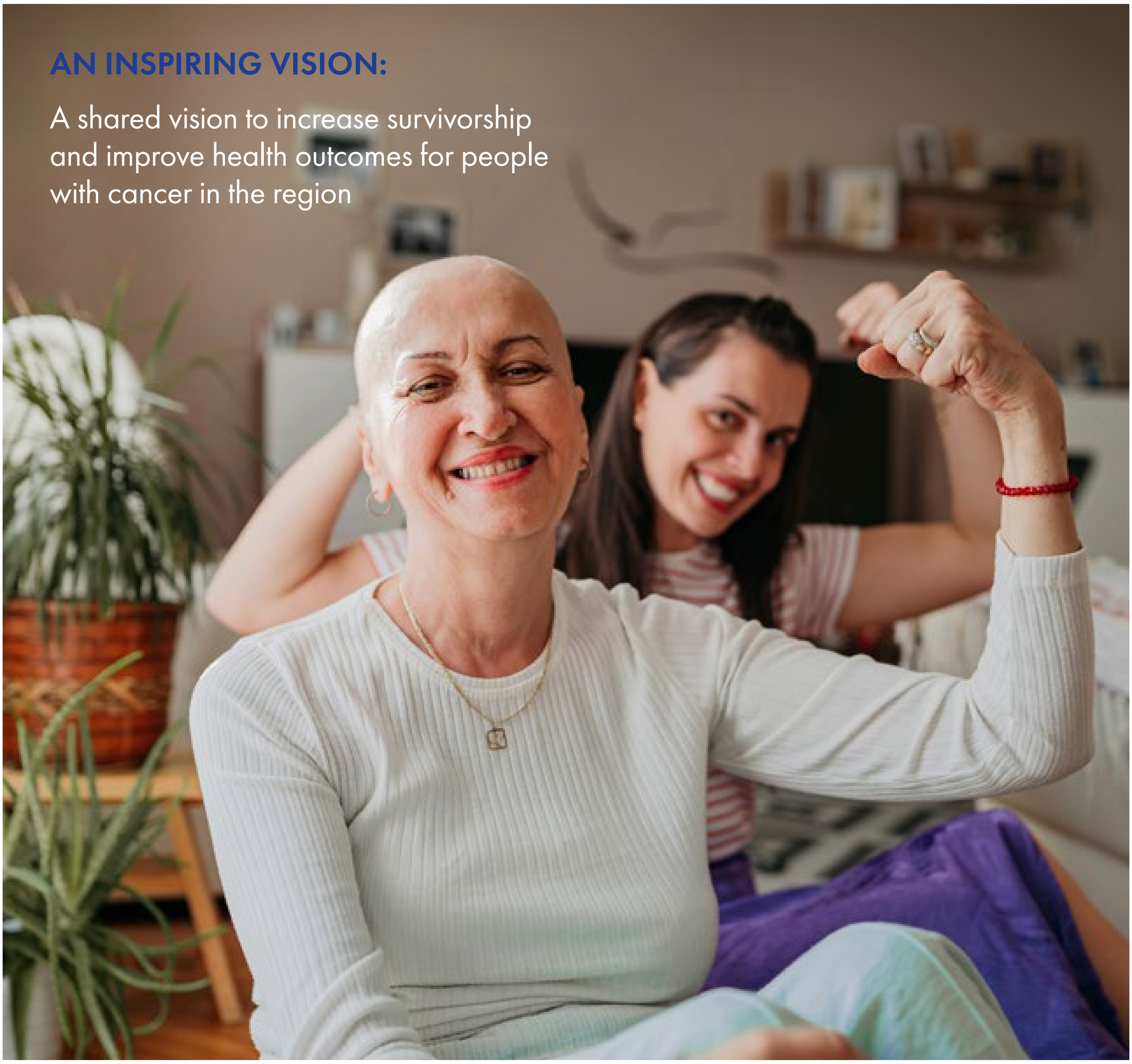
An inspiring vision for change

This is a unifying and inspiring statement that articulates what is needed and why. Change requires energy, mobilisation of resources and hope. A clear statement of purpose for what needs to change can help provide direction, focus and important communication to build trust with others and gain important support and engagement. The right vision can bring people together, across silos and standard ways of working. It humanises the topic and brings out values.

For example, most people can understand and support the need to:

- save people's lives so they can continue to participate in families and communities
- help people be more comfortable and supported in painful and difficult times
- avoid financial toxicity and trauma for families
- allow patients to have more of a say in the care they receive
- support people to feel valuable in the community and return to work and the community after cancer.

Comprehensive and clear information can support the vision and case for change.



AN INSPIRING VISION:

A shared vision to increase survivorship and improve health outcomes for people with cancer in the region

Information to support action

A good understanding of the current situation locally, gaps in care, and information to support change can help identify and clarify opportunties, as well as who to involve. It can also communicate the benefits of change (that is, make the case for change). This helps focus efforts on evidence based, efficient and feasible action. It also helps identify information for key messages, to communicate the vision and inspire change.

Questions to ask could include:

- What is the major challenge/barrier that needs to be addressed?
- How can patient outcomes be improved? How would we measure success? Can researchers help prove this?
- What would happen if nothing changed?
- Can PSOs provide valuable data on the patient needs and experience to enhance the case for change?
- What information is available to support the case?
- Has someone already tried this? If so, why wasn't it successful? Or how has the situation changed since?
- Who is involved in this? Who are decision makers and what are their incentives in the system? What do they care about?
- Are there technical, clinical, political, patient experts who can help?
- Are there global or local trends that are important to understand?
- Are there international examples to learn from?
- How much will it cost to make a change? Can it be done more efficiently?
- What is the first thing that needs to happen to start the change?
- How would you communicate what needs to happen?

Evidence and strategic information:

- understanding the current situation and opportunities
- knowing how the system works, recognising important gaps and emerging challenges
- identifying relevant evidence, research, best practice, and key players
- harnessing technology and data.

Important sources of information could include:

- current national strategies and plans
- prevalence rates and cancer registries
- impacts on patients and their families, including social and financial
- costs of care and changes
- current global and local research and evidence
- steps and decisions needed for the positive change to happen, considering all involved.

> When supporting capacity building, we have to work to develop long term relationships with local clinicians, health administrators and leaders to help deliver what they require. It is helpful to have a needs analysis done from their country's point of view, not your own. Recommendations need to be tailored to what resource limited countries can deliver.
>
> **Prof Desmond Yip**
> Medical Oncologist, The Canberra Hospital

Access to Medicine Foundation and Index

The Access to Medicine Foundation guides and incentivises essential healthcare companies to do more for the people living in low- and middle-income countries by defining the actions that, for example, innovative pharmaceutical companies can and should be taking to improve access to medicine.

The Foundation assesses 20 of the world's largest innovative pharmaceutical companies (accounting for more than half of global pharmaceutical revenue) on their access-to-medicine performance across 83 diseases, pathogens and conditions, including cancer, in their biennial Access to Medicine Index. Companies are analysed based on 31 indicators spread across three technical areas: Governance of Access, Research & Development, and Product Delivery.

As a tool to drive change, the Index identifies best practice, tracks progress and shows opportunities for critical action to improve access to medicine. By ranking companies every two years, it spurs them to improve and collaborate on priority access-to-medicine topics. It shows which companies are leading the way, as better performers rise in the ranking. There is progress to celebrate for each index reporting period. Companies are increasingly using strategies to expand access to more of their products such as the use of equitable pricing strategies, patient assistance programs, or voluntary licenses, and manufacturing capacity building.

Find out more:
www.accesstomedicinefoundation.org

Contributing factors for its impact on meaningful change:

An inspiring vision

Improving access to medicines in low- and middle-income countries

Working together

Collaborating with essential healthcare companies and other key stakeholders

Shared investment

Expanding access to low- and middle-income countries through shared contributions

Information to support action

Understanding access measures, best practice guidelines and tracking progress

‘Twinning’ partnerships – Australia & Solomon Islands

Picture: Oncology Multidisciplinary Team from Australia with National Referral Hospital Staff, Honiara, October 2023

‘Twinning’ partnerships have been recognised as a collaborative and effective means of training and knowledge transfer. Many health professionals are motivated to support progress in other nations overseas. There is a lot of goodwill to build on, however the approach is important. It is critical that solutions are developed based on local needs, capacity and infrastructure. Many models in higher income countries may not be directly translatable.

One example is with Dr Desmond Yip’s (The Canberra Hospital) work in 2016 to help establish the first oncology unit with the Solomon Islands government. In the Twinning project, the team reviewed the chemotherapy protocols in the context of limited resources. The team did a needs analysis, interviewed healthcare professionals and developed a recommendation report with resources, which was implemented immediately after the review.

Some lessons learned from the Twinning experience include:

- conducting needs analyses from the perspective of the host country (rather than our own) is invaluable. What do they think is most important?
- trust and longer-term relationships with local healthcare professionals and community leaders are important for good collaboration, communication and understanding the local situation
- it is important to highlight the workforce training needs and capacity as part of planning
- aim for more sustainable approaches of reducing reliance on overseas staff or patient transfers for treatment abroad if possible
- recommendations must align with the resources available in countries, even if they do not represent the world’s best treatments.

Find out more: https://ascopubs.org/doi/full/10.1200/GO.22.00325

Contributing factors for its impact on meaningful change:

An inspiring vision

Building capabilities locally in a sustainable manner

Community awareness

Providing education to local clinicians, health administrators, and leaders

Working together

International collaboration between local hospitals, healthcare professionals

Shared investment

Investment of expertise through international support

Information to support action

Using a needs analysis and international expertise to focus efforts

reach52 – Singapore

reach52 is a healthtech social enterprise that focuses on improving healthcare access and health outcomes in underserved and rural communities, particularly in low- and middle-income countries (LMICs). Operating across six diverse countries, the reach52 team comprises experts in healthcare, technology, data insights, community engagement, social services, and strategy.

reach52 uses a data-driven approach, effectively leveraging health information gathered from the communities they serve. This data not only facilitates the identification of health trends but also empowers the organisation to run cost-efficient and hyper-targeted health engagements. In addition, the organisation thrives on community collaboration by forming important partnerships with local governments and communities, working hand-in-hand with community health workers and local organisations. These community health workers play a pivotal role as trusted intermediaries, using reach52's offline-first app to connect individuals in need with critical healthcare services and information.

reach52 uses a holistic, data-informed, and community-centred approach to healthcare access, affirming its commitment to creating a world where healthcare has no geographic barriers and reaches all who need it most.

Find out more: www.reach52.com

Contributing factors for its impact on meaningful change:

An inspiring vision

Improve healthcare access and outcomes in underserved and rural communities

Working together

Partnership between local communities, community health workers, and local organisations

Community awareness

Entrenched community involvement

Information to support action

Data-driven approach, with community-based information

Working together

No one organisation or sector has all of the information, insights and resources to considerably improve cancer survivorship and outcomes; we have to work together. Local and international organisations and stakeholders operate more efficiently and create better solutions by working collaboratively. Collaborations are sustainable when they are developed from a shared vision, have shared power, are culturally respectful, interests are aligned and actions are agreed with shared contributions. Importantly, people need to feel they can make a difference together and a more unified voice is more powerful.

Each collaborative relationship and project is different, but some best practice considerations include:

- Who is affected by or might care about change? Who should be involved and why would they want to be?
- What are some principles or ways of working that people can agree on?
- What is the shared value or vision that everyone in the group can support? What are people passionate about?
- How can different people or groups contribute to the cause utilising their respective strengths?
- How long will we need to work together? Can we plan for achievement within a certain timeframe?
- How can we build trust with each other over time?
- Who can provide the right leadership to inspire and keep things on track?
- What are the power dynamics to consider and try to balance?
- How can patient representatives be meaningfully involved?
- What information needs to be communicated to keep people informed and engaged?
- Who will do the work of keeping the collaboration connected and functioning?

Collaboration and shared leadership

- Shared leadership to improve outcomes for patients
- Experts, patient organisations, development partners, civil society organisations and industry have collaborative relationships to drive and create momentum for change
- Local research is promoted and supported

> One of the most important points is the ability to get companies as well as other key stakeholders who might not be around the same table together, outside of silos, discussing important topics, and hopefully coming to pragmatic, solution oriented conclusions that are able to increase access to medicine for those who need it.

James Hazel
Research Programme Manager
for the Access to Medicine Index,
Access to Medicine Foundation

> Coalitions bring power. They also enhance creativity and your network, reduce duplication of efforts and use of resources. It really means we can reach further together and help ensure that there are better health outcomes and futures for people. The coalition is the way to go.

Carmen Auste
CEO, Cancer Warriors Foundation and
Vice President, Cancer Coalition Philippines

City Cancer Challenge

The City Cancer Challenge (C/Can) is a global not-for-profit organisation driving local innovation for global impact, dedicated to strengthening the health system to improve access to quality, equitable cancer care in lower- and middle-income countries. C/Can adopts a bottom-up approach, listening to and supporting cities as they assess their own needs, and build tailor-made, scalable cancer-care solutions. C/Can invests in strengthening the connections between people, policies and processes to build local ownership, sustainability and scalability.

C/Can employs an innovative approach known as the City Engagement Process Framework (CEPF), enabling cities to submit applications to participate in the initiative. Following comprehensive due diligence and needs assessments, C/Can extends invitations to cities for collaborative efforts in developing and executing customised cancer care solutions that address their specific needs and challenges. This effort involves a multi-stakeholder collaboration connecting local and national governments, healthcare providers, civil society organisations, and patient advocacy groups. To bolster access to high-quality cancer care, C/Can strategically leverages technical and industry partners, mobilising their resources and expertise.

C/Can operates in 14 cities worldwide, including three cities in the Asia region: Yangon* (Myanmar), Phnom Penh (Cambodia), and Greater Petaling (Malaysia). Drawing from its experience in supporting and partnering with cities, C/Can has identified common challenges and solutions. The organisation actively shares its knowledge and expertise with cancer care professionals in new cities. City Projects within C/Can cities typically focus on strengthening healthcare systems, encompassing areas such as service delivery, workforce development, health financing, leadership and governance, and health information systems.

This approach allows C/Can to adapt and apply its proven methods and best practices to improve cancer care in diverse cities and regions across the globe.

*C/Can has temporarily suspended its operations in Yangon due to the ongoing situation impacting Myanmar.

Find out more: www.citycancerchallenge.org

Contributing factors for its impact on meaningful change:

An inspiring vision

Improving access to quality care based on local needs and context

Powerful patient voices

Local patient support organisations are collaborative partners

Working together

Cities, communities, governments, healthcare providers, industry partners working together

Community awareness

Multisectoral collaboration approach

Shared investment

Considering sustainable funding from different stakeholders

Information to support action

Evidence-informed approach using due diligence and needs assessments

CASE STUDY

Global Focus on Cancer

Global Focus on Cancer (GFC) is a US-based not-for-profit organisation founded in 2011, with a mission to raise cancer awareness, provide support, and create a global network among cancer patients, caregivers, and medical professionals. GFC's approach involves partnering with local organisations, customising effective cancer awareness and education strategies to align with the cultural and resource context of each region.

GFC collaborates with more than 100 local organisations globally to link them with global cancer resources. They customise cancer awareness and education materials for cultural and resource compatibility, aiming to boost awareness and early treatment options. GFC relies on partnerships with healthcare professionals, hospitals, cancer organisations and international companies to produce and distribute tailored materials and host cancer awareness events. They also help establish and enhance cancer support programs by adapting successful models to suit each country's unique needs.

A key program run by GFC in the APAC region is the South-East Asia Breast Cancer Symposium (SEABCS), a flagship program started in 2016, bridging the gap between advocacy, clinician, and academia. SEABCS conducted advocacy/networking conferences in six different South-East Asian countries so far, addressing regional challenges and opportunities in areas of breast cancer, and promoting partnerships among advocates, academics and clinicians. The program shares experiences, opportunities and best practices to foster mutual learning and progress.

Find out more: www.globalfocusoncancer.org

Contributing factors for its impact on meaningful change:

An inspiring vision

Improve cancer outcomes and awareness

Powerful patient voices

Programs that put patients and patient support organisations at its core

Working together

Collaboration between clinicians, researchers, patient support organisations, and patients

Community awareness

Culturally and regionally appropriate cancer awareness strategies

Information to support action

Collecting and publishing data and research

Remote training and capacity building of local workforce – ICON Group

Icon Group is a large Australian cancer care provider that brings together all aspects of quality cancer care, including medical oncology, radiation oncology, haematology, pharmacy and chemotherapy compounding.

In 2019, Icon Group became the first Australian healthcare company to deliver cancer care in China at the Icon Cancer Centre in Jiangxian in the Shanxi province. Jiangxian was the first Icon Cancer Centre that commenced face to face training, however due to the COVID-19 pandemic, the go live implementation support was provided remotely. Since then, five more centres were established completely virtually (including all training of local workforce for oncology nurses and radiation technicians).

Despite COVID-19 related challenges, Icon successfully set up five radiation oncology departments during this time, and there were a few key factors for its success, including:

- training the local workforce in local places virtually
- focusing on the foundation and fundamentals of specialty oncology services
- working with local policies and procedures, and considering the cultural differences between the Australian and Chinese health care systems
- adapting and contextualising the training materials to the local context through consultation with local experts and regulation
- use of technology (e.g. Realwear) that allowed visual, real-time demonstrations and communication of training materials between various locations across the globe.

Find out more: https://icongroup.global/en/our-services/cancer-services-asia/mainland-china/

Contributing factors for its impact on meaningful change:

An inspiring vision

Set up a comprehensive cancer centre in China

Working together

Local and Australian cancer experts working together

CASE STUDY

‘Closing the Care Gap’ documentary on outreach programs – Society for Cancer Advocacy and Awareness (SCAN)

The Society of Cancer Advocacy and Awareness Kuching (SCAN) was founded in July 2017 with the aim of being the unified voice for all cancer patients, working to improve access to high-quality healthcare. In 2023, SCAN, in collaboration with the Sarawak Breast Cancer Support Group, Sarawak Heart Foundation, and the Ministry of Health, has taken a significant step in expanding its early cancer detection program to rural Sarawak, Borneo.

SCAN has made a documentary of these outreach programs, with the goal of closing the gap in disseminating breast cancer awareness, early detection and screening of breast cancer in marginalised populations. The documentary also aims to promote the importance of early breast cancer detection, and call attention to the needs of marginalised communities.

The outreach programs reached 169 women throughout four different rural locations. Despite the challenges associated with stigma, the team successfully interviewed about 10 cancer survivors and three caregivers for the documentary. Their outreach activities include sharing sessions by breast cancer survivors, educational talks by breast surgeons from SCAN, and counselling using “Know Your Lemons” leaflets.

Through sharing real-life patient stories and challenges in this documentary, SCAN hopes it will serve as a powerful tool for awareness and advocacy, not only to the general public, but for policy makers and international affiliations. It can inform policy makers on the major gaps in cancer care, and highlight the urgent need to reform the health care system to improve patient outcomes in rural Malaysia. Watch the full documentary here: https://youtu.be/fni3hN1FyOc?si=IredjZE1bMOGzGRs

The program was awarded a grant by Union for International Cancer Control (UICC) as part of its Breast Cancer programme.

Find out more: www.scan.org.my

Contributing factors for its impact on meaningful change:

An inspiring vision

Promoting early detection and facilitating breast cancer screening in rural areas

Working together

Collaboration between patient organisations, patients and the government

Powerful patient voices

Highlight patient voice to drive policy change

Community awareness

Drive breast cancer awareness in rural communities

Shared investment

Grant awarded by the UICC to support early detection of breast cancer

Powerful patient voices

Governments, clinicians, researchers, health service providers and the diagnostic and treatment industries would benefit from better understanding and recognising that PSOs are high-value community assets that play an important role as experts in identifying, designing and disseminating health solutions. Patients and patient support organisations can collaborate to understand how they can be most valuable and communicate that effectively.

Some considerations for meaningful engagement:

- What are the insights and experiences that patients can bring to the challenge?
- How can the patient voice be promoted or shared more directly with decision-makers?
- How can services and research be designed with patient satisfaction and preferences being major indicators for success?
- What is being asked of patients and patient groups? Is it ethical? Are conflicts of interest relevant?
- Recognise that many patient representatives bring skills as well as their insights.
- What are patients' preferences for engagement? How can patient representatives engage in a sustainable way?
- How can patient representatives be compensated for their time or contributions in a way that reflects their relevance and value?
- How can sharing of important information and decision making become a standard in engagement?
- What education, training and resources could further support patient representatives to build their capacity?

Powerful patient voices

Patients are meaningfully involved and shape policy and program design, research/data generation

Patients are valued and organised, communicating needs and concerns

Patients lived experiences, ideas and insights inform systems changes

> It is encouraging to see so many initiatives taking place that promote patient involvement in different aspects of healthcare decision-making. This is a fantastic advancement, but there is still a lot more we can do to promote structured collaboration and partnership among all stakeholders involved in health policy and ensure that patients are given the same opportunities to effect change.

Fiona Pearce
Senior Advisor, Agency for Care Effectiveness, HTA and Consumer Engagement and Education, Ministry of Health Singapore

> With participatory approaches, it's really about transforming the patient from a passive recipient of care and of the policy as a user, into an active agent, a driver of change, systemic change in all the policies designed and also implemented within the health system. Everyone agrees on the principle. However, there are still a lot of barriers to do so. We need to institutionalise and formalise participatory approaches in developing policies.

Mélanie Samson
Senior Manager, Capacity Building, Union for International Cancer Control (UICC)

CASE STUDY

National Integrated Cancer Control Act (NICCA) – Philippines

The National Integrated Cancer Control Act (NICCA) was signed into law by President Duterte in February 2019 as the framework for government-led cancer control initiatives. The primary aim of NICCA is to enhance cancer control efforts in the Philippines, with a focus on improving cancer survivorship and reducing the financial burden on both families and cancer patients.

The Cancer Coalition Philippines (CCP), a coalition of organisations committed to addressing the needs of both adult and paediatric cancer patients, played a pivotal role in shaping and advancing NICCA. The development and passage of NICCA resulted from robust advocacy efforts involving government, civil society organisations, political "champions", the private sector, and international organisations. This collaborative approach underscores the significance of involving civil society and multiple stakeholders in shaping public health policies like NICCA.

The CCP has developed the '12 promises of NICCA' which documents the key promises in accessible terms. They are using this document to keep track of the progress in cancer care to ensure effective implementation of the Act.

Find out more: www.uicc.org/case-studies/cancer-and-universal-health-coverage-Philippines

Contributing factors for its impact on meaningful change:

An inspiring vision

Enhance cancer control efforts in the Philippines

Powerful patient voices

Patients and patient support organisations being leaders in shaping change

Working together

Patients, patient support organisations, governments working together

Shared investment

Government policy changes and investments

Thailand Breast Cancer Community (TBCC) – Thailand

The Thailand Breast Cancer Community brings together breast cancer patients, family members, survivors, nurses, and volunteers from various hospitals to collaborate and support one another. Founded in 2012, it operates under the guidance and consultation of the Breast Disease Association of Thailand. TBCC has since become a catalyst for change in Thailand's breast cancer landscape.

Many patients face challenges in understanding their cancer and their treatment options, leading some to seek alternative and less evidence-based treatments. TBCC aims to educate about breast cancer and enhance support for breast cancer patients nationwide. Some of their work includes:

- hosting networking events with various communities and clubs to assist patients and clinicians in fostering open communication
- workshops with role-playing exercises that show the dynamics of doctor-patient interactions with open communication
- developing comprehensive manuals for clinicians and patients – offering guidance on effective communication when delivering a cancer diagnosis, as well as for patients and caregivers, equipping them with essential questions to ask doctors and nurses.

Furthermore, during Breast Cancer Awareness Month, TBCC hosts an art exhibition that vividly communicates the emotions and experiences of cancer patients, using artwork to help promote the value of understanding and communication.

Find out more: www.tbcc-community.com

Contributing factors for its impact on meaningful change:

An inspiring vision

Enabling good communication and person-centred care for patients with breast cancer

Powerful patient voices

Helping empower patients to have open conversations related to cancer care

Working together

Working collaboratively with patients and healthcare professionals

Community awareness

Increasing awareness in the Thai breast cancer community

House086 – China

House086 is a patient support organisation in China founded in 2011, serving as China's exclusive online communication community for lymphoma patients, with registered members exceeding 120,000 individuals (as of October 2023).

Patient support organisations like House086 have played an important role in the transformation of cancer care in China, evolving from simple support networks to influential advocates for unmet patient needs. These organisations focus on advancing science-based, standardised treatments and serve as bridges between patients and healthcare professionals. They provide education, advocate for patients' rights, raise public awareness, promote clinical trial participation, and foster international collaborations. Additionally, they contribute to healthcare policies, conduct research influencing drug coverage decisions, and enhance health literacy through digital platforms and collaborations with healthcare providers. The collaborative efforts between the government, industry, and patient support organisations are significantly improving the lives of cancer patients in China.

In recent years, there has been a notable transformation in how the Chinese public perceives cancer. Previously, cancer was associated with fear and death due to limited treatment options and high costs, and it was generally difficult for doctors to directly inform patients of their diagnosis. Patients also felt a significant sense of shame. However, progressive policies and medical advancements have brought a positive shift. Some of these changes include:

- the "Healthy China 2030 Plan" aims to increase the five-year survival rate for cancer patients by 15%, and there has already been a nearly 10% master improvement in this rate, now at 40.5%
- patient centred care, annual negotiations for medical insurance coverage, and the introduction of innovative drugs have expanded treatment options with reduced financial burdens and improved access to patient education and awareness.

This transformation reflects a healthcare system increasingly aligned to patients' needs, empowering individuals to confront cancer with hope and confidence.

Find out more: www.house086.com

Contributing factors for its impact on meaningful change:

An inspiring vision

Advocating for unmet patient needs

Powerful patient voices

Patient voice helping lead change

Working together

Patients, patient support organisations, governments, healthcare providers working together

Community awareness

Increasing public awareness and advocacy

Shared investment

Government policy changes, international collaborations and industry support

Cancer Control Promotion Council – Japan

In Japan, the ongoing efforts to combat cancer have led to significant milestones, including the implementation of comprehensive strategies and the enactment of important laws. These achievements include the introduction of the Ten-Year Comprehensive Cancer Control Strategy in 1984, the establishment of the Cancer Control Basic Law in 2006, and the formulation of the Basic Plan to Promote Cancer Control Promotion Programmes in 2007. In line with this plan, the Cancer Control Promotion Council has been established.

The Council is responsible for formulating and implementing cancer control policies and plans, conducting research and analysis on cancer-related issues, and coordinating activities among various stakeholders, including government agencies, medical professionals, researchers, and patient advocacy groups. Comprising a maximum of 20 members, with a two-year term, the council brings together individuals who are cancer patients and their families or bereaved families, those engaged in cancer medicine, and individuals with expertise.

The Cancer Control Promotion Council is a great example of empowering and meaningfully involving patients and patient organisations in health care decision making.

In 2023, the Fourth Stage of the Cancer Control Promotion Basic Plan was formulated. This plan aims to leave no one behind in cancer control and maintains the three pillars of the previous stage while addressing current challenges. The three pillars include cancer prevention, cancer care, and coexistence with cancer.

Find out more: www.mhlw.go.jp/english/wp/wp-hw3/dl/2-077.pdf

Contributing factors for its impact on meaningful change:

An inspiring vision

Comprehensive strategies and laws to combat cancer

Powerful patient voices

Active involvement of patients and patient organisations in decision making

Working together

Government agencies, medical professionals, patients, patient families to work together

Community awareness and understanding

The broader community awareness and understanding of cancer can be critical for preventing cancer, early diagnosis, reducing stigma, getting timely access to treatment, advocating for change and supporting patients better (e.g. navigation) in the community. Governments and the health system can't always do everything when it comes to engagement and awareness for cancer. Local community leaders and volunteers are important allies for cancer control, can help with community engagement services and are needed to help fight the growing levels of misinformation being shared.

Some considerations for broader community engagement:

- Where are people getting information about cancer?
- How can communications be accessible and easy to understand?
- How can we engage people to care and be part of the solution? What is important to them?
- How can the media help shape/share important messages and opportunities?
- How can accurate information about cancer and services be shared in different channels?
- How can we fight misinformation?
- Are there decision-makers, famous people or influencers who can help? Maybe some with personal experience?
- Could social media be used more effectively?
- Can powerful patient stories help the cause?
- How could volunteers be empowered to be part of the solution for engaging with communities?

Broader community engagement with civil society

- Promoting widespread information on cancer
- Breaking myths and misconceptions
- Reshaping public perceptions, and expectations of care
- Reducing stigma and discrimination
- Engaging media, political leaders, families of patients and survivors, and scaling up their involvement

> In order to better reach and support people, it is crucial for us to work with the broader community besides patient organisations, such as, healthcare providers, policy makers, local community leaders, local residents, individuals with lived experience and not forgetting students of higher education in healthcare, social work, law and so on.
>
> **Ranjit Kaur**
> Immediate past president of the Breast Cancer Welfare Association Malaysia

‘Dying to Survive’ film – China

Dying to Survive (我不是药神) is a 2018 Chinese comedy-drama film based on the real-life story of Lu Yong, a real-life Chinese leukaemia patient who was arrested for smuggling cheap generic cancer medicine from India for many Chinese leukaemia patients.

The impact of the film on cancer in China was profound. Liu Zhengchen, the founder of the New Sunshine Charity Foundation, led public welfare efforts to support the “price reduction and supply” of anticancer drugs in China. Inspired by the movie and his personal battle with chronic myeloid leukaemia, he established the first private bone marrow bank in the country and established the charity foundation.

The film’s success generated significant donations and resulted in a nationwide conversation about the challenges faced by cancer patients, drawing attention to the lack of accessibility to affordable medicine. The Chinese government took notice of the film and the movement it created, and responded by:

- considering measures to lower the prices of cancer drugs
- revising the Drug Administration Law of the People’s Republic of China in 2019, whereby “illegally imported drugs” are no longer considered counterfeit drugs (and thus do not constitute the crime of producing and selling counterfeit drugs).

These changes were not solely the result of the film itself, but were also facilitated by collaboration among various stakeholders. The movie inspired policymakers to prioritise cancer care initiatives, and its success acted as a catalyst for change, promoting collaboration to improve cancer treatment accessibility and affordability nationwide.

Find out more: www.imdb.com/title/tt7362036, www.ncbi.nlm.nih.gov/pmc/articles/PMC6929591

Contributing factors for its impact on meaningful change:

An inspiring vision

Highlighting patient perspectives and lack of affordable treatment

Powerful patient voices

Patient story being a catalyst for change

Community awareness

Increasing community awareness and advocacy

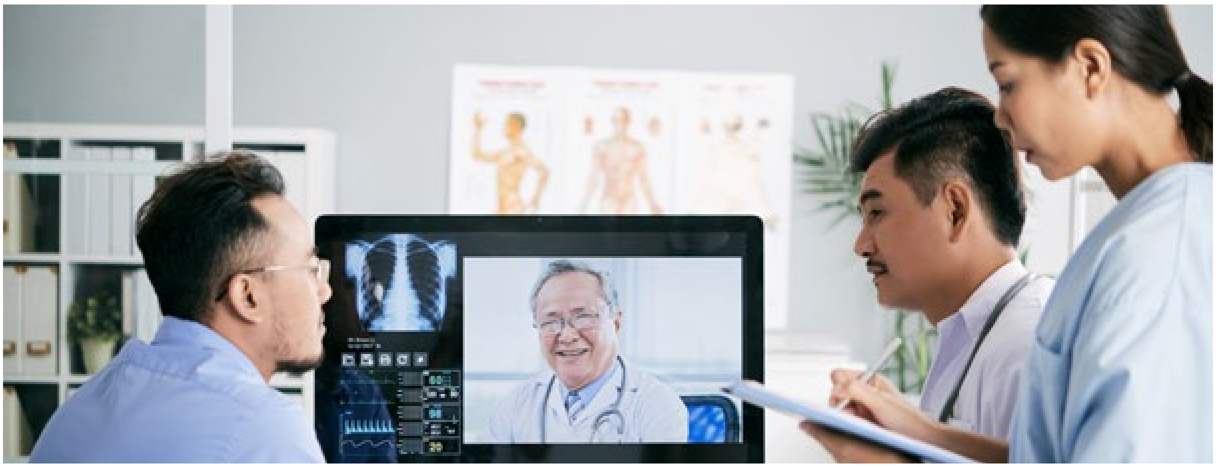
Shared investment

Government policy changes, donations from different stakeholders

Working together

Patients, patient support organisations, governments working together

Improving cancer literacy – Y Hoc Cong Dong – Vietnam



In Vietnam, a large number of cancer patients do not follow standard treatment due to word-of-mouth recommendations and inappropriate content on the internet and social media. Low cancer literacy is significantly and independently associated with worse prognosis and poor quality of life. Therefore, it is important to improve cancer-related literacy at the community level.

Y Hoc Cong Dong (YHCD) is a network of 400+ doctors, medical students and volunteers established in 2012 to improve health literacy in Vietnam. To do this, they have built a collaborative network to produce over 4,000 doctor-approved articles, patient handbooks and operate some fanpages and cancer support groups. They also organise e-learning programs and informational webinars for cancer patients and families. These efforts help patients better understand their cancer based on scientific evidence, and their rights as patients.

With support from the National Academies of Sciences, Engineering and Medicine in the US, and in collaboration with Hue University of Medicine and Pharmacy, YHCD have also established the "Kvengers Project" which identifies and combats cancer-related misinformation in Vietnam. Through this project, they have shared webinars, articles and videos to correct misinformation and provide evidence-based information to patients.

Find out more: www.yhoccongdong.com

Contributing factors for its impact on meaningful change:

An inspiring vision

Improving cancer-related health literacy

Community awareness

Building community awareness of misinformation and providing reliable information

Information to support action

Driven by evidence-based information to support patients

Working together

Collaboration between health care professionals, the cancer community, international organisations and hospitals

KOSPEN Wellness of Workers (WOW) – Ministry of Health Malaysia

The Ministry of Health, Malaysia (MOH), launched the Komuniti Sihat Pembina Negara (KOSPEN) program — which translates to "Healthy Communities, Building the Nation" — in 2013 to to help address the issue of growing rates of chronic disease. This initiative trained volunteers to serve as health agents of change, promoting healthy lifestyles within their communities based on five major pillars (healthy eating, active lifestyle, quit smoking, weight management and early detection of non-communicable diseases through health screening). KOSPEN received positive feedback from implementers, volunteers, and local communities. The program started with diabetes and hypertension screening, and now includes colorectal cancer screening. Colorectal cancer incidence in Malaysia is increasing and many patients are diagnosed at a late stage. Some barriers to screening include trust, lack of awareness, and concerns with sending a stool sample (ref: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9799312/). The KOSPEN volunteers and outreach program can help overcome some of these barriers to screening uptake.

Building on the success of KOSPEN in communities, the MOH extended the program to workplaces in 2016, introducing KOSPEN Plus (later KOSPEN WOW- Wellness of Workers [2020]). This initiative aimed to prevent NCDs and related risk factors among targeted workers by creating supportive environments and encouraging healthy behaviors. The program identifies individuals at risk and encourages them to undergo clinical screenings, thereby addressing potential health concerns at an early stage. KOSPEN WOW offered eight scopes of activities: 1. Health Screening, 2.Healthy Eating, 3. Quit smoking, 4. Active lifestyle, 5. Weight loss management, 6. Mental Health, 7. Healthy work environment, and 8. Prevention of harmful use of alcohol.

Find out more: https://iku.gov.my/research/iku/kospen-plus

Contributing factors for its impact on meaningful change:

An inspiring vision

Working with community volunteers to improve health

Community awareness

Training volunteers to engage with the community

Working together

Collaboration between government, communities and volunteers

Shared investment

Investment from MOH to implement this program, donation of time from volunteers

CASE STUDY

Community mobilisation in palliative care – Kerala, India

Dr Divya Valsala Somasekharannair, Kerala, India

Kerala, India, has made significant strides in palliative care, primarily due to its network of community initiatives. In 1999, four non-governmental organisations (Malappuram Initiative in Palliative Care, Pain and Palliative Care Society in Kozhikode, Alpha Palliative Care Clinic in Thrissur, and Justice Sivaraman Foundation) collaborated to establish the Neighbourhood Support in Palliative Care program, emphasising active volunteer engagement.

This initiative paved the way for community-level efforts in the palliative care movement, acting as a catalyst for official activities and marking a pioneering paradigm shift in Kerala's approach. The Government of Kerala furthered these efforts by introducing the Pain and Palliative Care Policy in 2008. This policy declared palliative care an integral part of primary health care and promoted community-based home care through local self-governments.

Kerala uniquely integrated the National Rural Health Mission (NRHM) into palliative care, resulting in projects like Arogya Keralam. This collaborative initiative between the government and local self-governments significantly expanded the network's coverage. Initially implemented in 400 panchayaths (village councils) in 2008, the program now extends its services in collaboration with primary health centres, student volunteers and local field staff, marking the second phase of a transformative paradigm shift in Kerala's palliative care movement. It has been noted that these efforts lead to whole-of-community involvement and awareness, including from taxi drivers and barbers in the community who provided support to patients receiving palliative care.

Find out more: www.core.ac.uk/download/pdf/214005255.pdf

Contributing factors for its impact on meaningful change:

An inspiring vision

Emphasising the importance of palliative care in India

Community awareness

Recruiting volunteer groups from local community to raise awareness

Working together

Collaboration between government, communities and volunteers

Shared investment

Considering the global financial pressure on healthcare spending, we need creative ways to capitalise on limited resources. In addition to government funding for projects, reform and access, there needs to be more shared investment to improve outcomes faster and achieve sustainable access. The cost burden on patients and families needs to be reduced through efficiencies and collaborative solutions.

Some considerations for shared investments:

- Can changes happen with current resources? Are there potential efficiencies?
- Can locally developed models of cancer care be more efficient (than international gold standards)?
- Can support workers take some of the responsibility off doctors?
- Are there lower cost/volunteer options to consider?
- How can global resources/funding be used to support change in the region?
- Are there risk sharing agreements or other approaches to share the costs/risks of accessing new therapies?
- How can local organisations and corporations be engaged to support solutions?

Investment and action from various sectors

- Sustainable and innovative financing to drive change and improvements
- Market shaping interventions for greater access, availability and affordability
- Investments of time and expertise

CASE STUDY

Patient access programs – Axios International

With a global presence spanning more than 100 countries, Axios International offers affordable and accessible healthcare to patients.

Collaborating closely with pharmaceutical companies, Axios International plays a pivotal role in strategising and implementing healthcare access solutions that have a meaningful impact on patients, especially in Low and Middle-Income Countries (LMICs).

With the support of its partners, the company designs and implements Patient Assistance Programs (PAPs) to help patients overcome treatment affordability challenges. These cost-sharing solutions focus on providing the full treatment course, which can be implemented as bridging or standalone access to treatment solutions using a multi-stakeholder collaborative approach.

For cancer patients, these programs are not just about providing a temporary lifeline; they are about ensuring that patients can continue their treatment over the long term. Axios International's proprietary tool, the Patient Financial Eligibility Tool (PFET), is the cornerstone of this patient-centric approach. PFET takes into account an individual's income, expenditures, and assets to determine their ability to pay for treatment. Axios has over 40 active PAPs globally in South-East Asia, Europe, the Middle East and North Africa, and Latin American regions covering disease areas such as oncology, hematology, pulmonology, rheumatology, gastroenterology, and immunology.

Find out more: www.axiosint.com

Contributing factors for its impact on meaningful change:

An inspiring vision

Enhance patient access to treatment in LMICs

Shared investment

Collaboration and investment from both patients and pharmaceutical companies

Working together

Private organisations, pharmaceutical companies and patients working together

Information to support action

Driven by the Patient Financial Eligibility Tool

Supportive Fund for Cancer Patients – Bright Future Foundation (Vietnam)

The Supportive Fund for Cancer Patients – Bright Future Foundation (BFF) provides support to cancer patients in Vietnam. It provides a bridge between cancer patients and doctors, policy makers, and other organisations.

The BFF is a partnership of the National Cancer Control Program in Vietnam. BFF organises campaigns to improve community awareness of cancer control, support screening of common cancers, support cancer clubs at oncology hospitals, and improve capacity for healthcare professionals at different levels of the health care system. They also collaborate with industry partners to support access to medicines for cancer patients.

Since its establishment to now, BFF supported has for more than 35,000 cancer patients, screening for nearly 100,000 people. The BFF was the first organisation running the patient access program (PAP).

One notable activity is the first pilot program in Vietnam regarding access to drugs. The BFF collaborates with hospitals and the pharmaceutical industry to provide better access to treatments for cancer patients. This program is running in over 30 hospitals.

Find out more: www.uicc.org/membership/supportive-fund-cancer-patients-bright-future

Contributing factors for its impact on meaningful change:

An inspiring vision

Improving cancer care and awareness in Vietnam

Shared investment

A range of donations from industry and corporate funders help improve access to treatment and care

Working together

Collaborating with industry partners, hospitals, pharmaceutical companies

Community awareness

Campaigns to improve community awareness

CASE STUDY

Voluntary Licensing – Access to Oncology Medicines (ATOM)

Led by the Union for International Cancer Control (UICC), the Access to Oncology Medicines Coalition (ATOM Coalition) was launched in May 2022 with the aim of reducing the suffering and deaths caused by cancer in low- and lower–middle income countries by improving access to essential cancer medicines. It has since grown to 40 global partners, including pharmaceutical and diagnostics companies, NGOs and civil society organisations, professional associations, and research and academic institutions.

The ATOM Coalition focuses on three key areas: (1) strengthening country capacity to receive and use cancer medicines, (2) improving the availability of generic and biosimilar cancer medicines, and (3) increasing the number of patented and new medicines in ATOM Coalition target countries. By pooling resources, improving negotiation mechanisms, enlarging the market, and creating compelling access options, the ATOM Coalition is working with partners, governments and local stakeholders to sustainably increase the availability, affordability, and appropriate use of cancer medicines.

As part of these efforts, the ATOM Coalition facilitated the first ever voluntary license agreement for a cancer medicine by two of its partners, Medicines Patent Pool (MPP) and Novartis. This is the first license that MPP has signed for a non-communicable disease and cancer treatment, and the first time a company is licensing a patented cancer medicine through a public health-oriented voluntary licensing mechanism. Through such a licensing mechanism, generic companies are granted permission to develop, manufacture and supply generic versions in ATOM Coalition target countries, offering a more sustainable solution that fosters broader, more affordable access to generic cancer medicines.

Find out more: www.uicc.org/atom/atom-coalition-home

Contributing factors for its impact on meaningful change:

An inspiring vision

Reducing the suffering and deaths caused by cancer in low- and lower–middle income countries

Shared investment

Innovative financing to support LMICs access treatments

Working together

Global partners working together

CASE STUDY

An Accord for a Healthier World – Pfizer Inc.

In May 2022, Pfizer launched an initiative (the Accord) to reduce health inequities in lower-income countries, with an initial commitment for access to all patented Pfizer medicines and vaccines available in the U.S. or EU on a not-for-profit basis in 45 lower-income countries.

In January 2023, Pfizer expanded this offering to now include off-patent medicines, bringing its total offering from 23 to around 500 products. These include chemotherapies and oral cancer treatments, as well as other medicines and vaccines to treat or prevent infectious and non-communicable diseases. New medicines and vaccines to be launched will also be included in the Accord portfolio.

Through this initiative, Pfizer's hope is to "empower country governments and co-create solutions with them and other multi-sector partners to break down many of the system-level barriers to better health."

Find out more: www.pfizer.com/about/responsibility/global-impact/accord

Contributing factors for its impact on meaningful change:

An inspiring vision

Reducing health inequities in lower-income countries

Shared investment

Investment from Pfizer to provide their products on a not-for-profit basis to lower income countries

Working together

Collaboration between local governments, multi-sector partners and industry

CASE STUDY

The Max Foundation

Founded in 1997, The Max Foundation is dedicated to accelerating health equity by delivering medication, technology, and services to patients facing cancer and other critical illnesses. They work with local oncologists and hematologists and their institutions to ensure that people in resource-constrained areas have access to essential medications and proper medical care.

A great example of this is their cancer programs, where they provide access to treatments (11 drugs for 12 cancer types) in over 75 low- and middle-income countries. The Max Foundation collaborates with various pharmaceutical companies, healthcare institutions, governments, NGOs, and shipping and logistics partners to facilitate access to essential medications and improve the quality of care for patients.

Beyond access to treatments, The Max Foundation helps people with cancer via providing access to diagnostic services in under-resourced settings, and access to care and support through emotional support services, disease education and connection to patient communities.

Find out more: www.themaxfoundation.org/

Contributing factors for its impact on meaningful change:

An inspiring vision

Vision to support patients in resource-limited countries

Shared investment

Receive support and resources from various organisations and individual donors

Working together

Collaborate with in-country HCPs and institutions, governments, NGOs, patient organisations and pharma

Powerful patient voices

Listening and empowering the patient voices

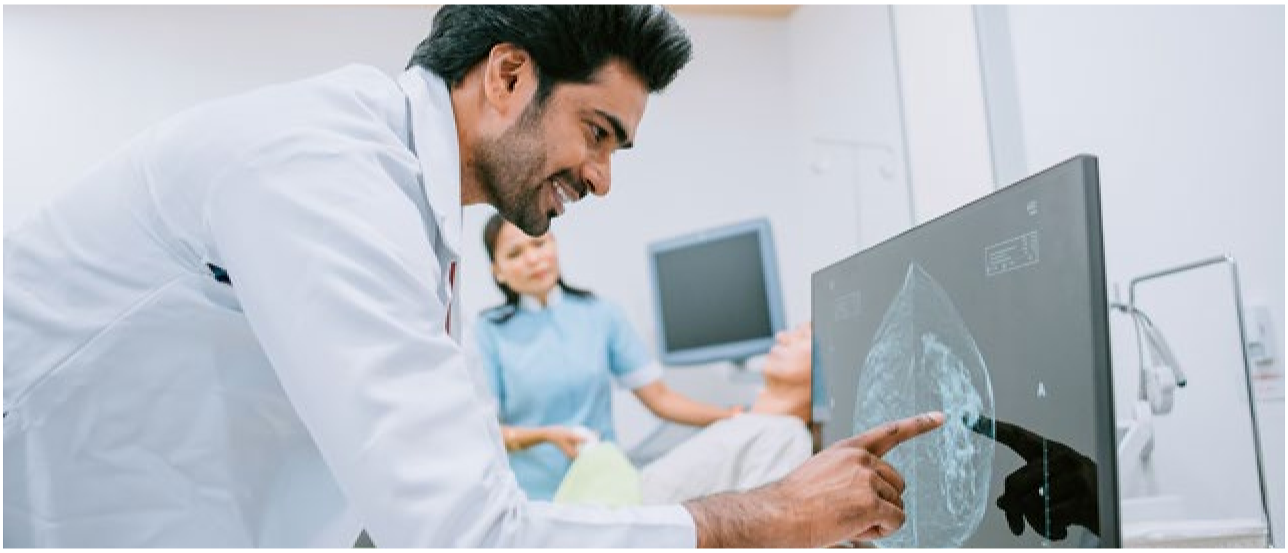
NEXT STEPS TO SUPPORT TRANSFORMATIONAL ACTION

Financial and political commitments are critical for positive change, but more is needed. Further improvements to cancer prevention, treatment/care and psychosocial support across the region will require more than just funding to be successful. Health systems are complex, and positive systems changes are often not linear, so simple cause and effect logic is often not sufficient.[87] To help drive further positive system and transformational changes in the region and improve health equity, we need to harness more collaboration, use valuable information to communicate and plan, and foster shared leadership.

Investing in the right dynamics, capability and relationships are enablers of productive and sustainable changes to improve survivorship and cancer health outcomes in the region. Global and regional leaders can support:

- initiatives that are based on the local context, needs, resources and culture, recognising that international generic solutions will need to be tailored or may not be appropriate
- collaborative relationships, organisations and networks with shared values and trust
- local leaders in healthcare and government, patient support organisations and community groups, research, and industry who are passionate, interested in collaboration and working outside of formal silos
- empowered and sustainable patient support organisations and community groups to participate as experts with independent voices
- commitments to knowledge and information sharing and open feedback
- codesign approaches to understanding opportunities and solutions from different perspectives and among different stakeholders
- sustainable investments in education, training, engagement and action initiatives, as most transformational changes take time
- use of the Collaborative Framework for Systems Action (in this report) to help discuss and workshop change initiatives at regional conferences, national summits, symposiums and other collaborative events.

It is an important time; there is positive momentum in many areas across the region. There are many ways to approach improved cancer control in the region. No matter what the starting point, goal or level of investment, the above considerations can help guide how to create sustainable local leaders and initiatives that are better suited to local opportunities and meeting patient needs.



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[87] Braithwaite, J. (2018). Changing how we think about healthcare improvement. Available: https://www.bmj.com/content/361/bmj.k2014

WHAT WOULD SUCCESS LOOK LIKE IN 10 YEARS?

More sustainable, collaborative, and patient centred change in the region could lead to considerable benefits for society. Supported and high-performing patient support organisations and community groups could more actively, independently, and consistently provide valuable insights on what is needed to better prevent and treat cancer and support patients with cancer, through and after treatment.

Strong collaborations with local healthcare professionals, patient support organisations and community groups, decision-makers, researchers, and industry help identify the best investments locally to implement strategies and plans efficiently, considering limited resources and the cultural context. International collaborations help identify opportunities, build networks, and mobilise resources to develop locally adapted and relevant solutions. Where feasible, new technologies like AI may help identify the best actions and interventions for limited resources.

Through shared leadership and investment, the cost barriers in access to treatment can be reduced to save more lives in the region. Better prevention and more equitable healthcare access would mean that fewer families are left devastated by a cancer diagnosis, succumbing to financial toxicity and experiencing premature death.

These benefits would have positive flow on impacts for thriving communities and healthy economies.

APPENDIX

APOA Advisory Board Members

Carmen Auste
CEO, Cancer Warriors Foundation Philippines and
Vice President, Cancer Coalition Philippines

Adjunct Professor Victoria Elegant
Vice President, Region Head Medical Affairs Amgen
JAPAC, Global Lead, Access to Healthcare, Amgen

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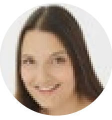

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Neil Wildman
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APAC & Africa Middle East, Pfizer Inc.

Jenny Zhang
Brand Communication and
International Cooperation Lead
House086 China

> The APOA report demonstrates what can be achieved through a genuine multi-stakeholder collaborative approach and a shared desire to positively impact the lives of cancer patients across the Asia Pacific region. I am humbled to have been part of the report's advisory committee and congratulate Rare Cancers Australia for their ongoing vision and leadership.
>
> **Neil Wildman**
> Senior Director Patient Advocacy
> APAC & Africa Middle East, Pfizer Inc.

Interviewees

We would like to acknowledge the many individuals who helped make this report possible. The following list includes individuals interviewed for this report who agreed to be named. This report is an amalgamation of the views of many interviewees and should not be attributed to any particular individual. It should not be assumed that any interviewee endorses any key messages.

NAME	TITLE	ORGANISATION
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Diana Aron	Program Manager	The Synergist
Dr Thet Ko Aung	Senior Manager Technical Cooperation	City Cancer Challenge
Carmen Auste	CEO	Cancer Warriors Foundation
Omair Azam	Associate Director	Crowell & Moring International
Dr Amalina Bakri	Specialty Registrar, Clinical Research Fellow	Imperial College of London, NHS England, Genomics England
Kavita Berger	Director, Board on Life Sciences and co-Director, Board on Animal Health Sciences, Conservation, and Research	U.S. National Academies of Sciences, Engineering, and Medicine
Alex Best	Director, Regional Market Access Policy, Asia-Pacific	Janssen
Dr Nirmala Bhoo Pathy	Professor of Epidemiology and Public Health, Department of Social and Preventive Medicine, Faculty of Medicine	Universiti Malaya
Dr Muhammad Fikri Bin Azmi	Public Health Medicine Specialist, Senior Principal Assistant Director Cancer Prevention and Control Unit, Disease Control Division	Ministry of Health Malaysia
Dr Divya Valsala Somasekharannair	Oncologist	Kerala India
Edward Booty	CEO	reach52
Dr Ros Suzanna Binti Ahmad Bustamam	Head of Department, Department of Radiotherapy & Oncology	Ministry of Health Malaysia
Louise Carter	Head of Corporate Affairs	BeiGene
Sook Mei Chang		SingHealth
Chris Cheng	President	Society for Cancer Advocacy and Awareness

NAME	TITLE	ORGANISATION
Kim Soon Chew	Co-Chair	SingHealth Patient Advocacy Network (SPAN)
Phoebe Chi	CEO	Taiwan Association of Cancer Patients
Dr Imjai Chitapanarux	Professor Chair	Chiang Mai University Suandok Breast Cancer Network
Dr Wonyoung Choi	Staff Physician (Medical Oncology) / Research Scientist	National Cancer Center Korea
Dr Melvin Chua	Head of Department, Head Neck and Thoracic Cancers, Division of Radiation Oncology	National Cancer Centre Singapore
Dr Roselle De Guzman	Medical Oncologist and Associate Professor	Manila Central University-FDTMF Hospital
Morgan Dean	Associate Director, International Membership Programs	American Society of Clinical Oncology (ASCO)
Michaela Dinboeck	Head PE Disease Strategy and Science	Novartis
Dr Rolando Enrique Domingo	Coordinator, Management of Noncommunicable Diseases	World Health Organization (WHO)
Adjunct Professor Victoria Elegant	Vice President, Region Head Medical Affairs Amgen JAPAC, Global Lead, Access to Healthcare	Amgen
Jack Fisher	Participatory Researcher	Technical University of Munich
Dr Guy Fones	Head, Global Coordination Mechanism for the prevention and control of Noncommunicable Diseases	World Health Organization (WHO)
Prof David Goldstein	Conjoint Clinical Professor	University of New South Wales
Begoña Gomez	Global Executive Director, Patient Engagement	Novartis
Vandana Gupta	Founder	V Care Foundation
Ms Le Thu Ha	Member	Bright Future Foundation
James Hazel	Research Programme Manager, Access to Medicine Index Programme	Access to Medicine Foundation
Chris Hourigan	Company Group Chairman, Pharmaceuticals, Asia Pacific	Janssen
Prof Yin Yin Htun (Rose)	President	Shwe Yaung Hnin Si Cancer Foundation Myanmar
Dr Li Ying (Grace) Huang	Director and pharmacist	Health Technology Assessment, Center for Drug Evaluation, Taiwan (CDE/HTA)

NAME	TITLE	ORGANISATION
Dr Lina Inagaki	Staff, Department of International Clinical Development	National Cancer Centre Hospital, Japan
Prof Stephen Jan	Head of Health Economics and Process Evaluation Program	The George Institute
Roshel Jayasundera	Managing Partner	Axios International
Hataitip Jirathun	Member	Thailand Breast Cancer Community
Ranjit Kaur	Immediate past president and patient advocate leader	Breast Cancer Welfare Association Malaysia
Jamie Kebely	Vice President, APJ Government Affairs	Siemens Healthineers/Varian Medical Systems
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Dr Young Saing Kim	Medical Oncologist	Gachon University Gil Medical Center
Ji Won Kim	Secretary	Korea Blood Disease & Cancer Association (KBDCA)
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Prof Bogda Koczwara	Medical Oncologist, Senior Staff Specialist	Flinders Medical Centre and Flinders Health and Medical Research Institute, Flinders University
Bella Sirintip Kudtiyakarn	President	Thai Cancer Society
Aurora Lancha	Associate Program Manager	The Synergist
Prof John CW Lim	Executive Director Lead (Policy)	Duke-National University of Singapore Medical School (Duke-NUS) Centre of Regulatory Excellence (CoRE) SingHealth Duke-NUS Global Health Institute
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Dr Herbert Loong	Clinical Associate Professor	Department of Clinical Oncology at the Chinese University of Hong Kong Asia Pacific Oncology Drug Development Consortium (APODDC)

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Hien Mi Nguyen	President	Salt Cancer Initiative
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Dr Dan Milner	Executive Director	Access to Oncology Medicines (ATOM)
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Ms Giang Nguyen	Member	Bright Future Foundation
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Eric Obscherning	Associate Director	Crowell & Moring International
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Dr Wimrak Onchan	Assistant Professor	Chiang Mai University, Suandok Breast Cancer Network
Mei Ching Ong	Region Head for Asia Pacific, Eastern Europe and Central Asia	The Max Foundation
Jung Sook Park	Director	Korea Blood Disease & Cancer Association (KBDCA)
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Fiona Pearce	Senior Advisor	Agency for Care Effectiveness (ACE) Singapore
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NAME	TITLE	ORGANISATION
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Anna Reilly	Director, Asia Area Government Affairs and Policy	AstraZeneca
Adam Roach	Vice President, Head of Asia Pacific	BeiGene
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Mélanie Samson	Senior Manager, Capacity Building	Union for International Cancer Control (UICC)
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Dr Tokuaki Shobayashi	Health Policy Advisor	Ministry of Health Vietnam, Ex-Ministry of Health Labor and Welfare Japan
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Ann Single	Vice-President Coordinator	HTAi Patient Voice Initiative
Lishan Soon	Corporate Affairs Lead – Southeast Asia, Hong Kong and India	Amgen
Ayesha Tahir	Consultant	Axios International
Ms Tanapat Sangmanee	Officer	Thai Cancer Society
Carolyn Taylor	Founder and Executive Director	Global Focus on Cancer

NAME	TITLE	ORGANISATION
Prof David Thomas	CEO	Omico
Miss Hoang Thi Dieu Thuan	Founder	Children's Cancer Network
Ms Hiromi Todoroki	Chairperson	Kibounokai
Mr Dung Tran	Member	Bright Future Foundation
A/Prof Thi Thanh Huong Tran	Chair, Department of Ethics and Medical Psychology	Hanoi Medical University Bright Future Foundation/ National Cancer Institute
Sammy Tsai	Director, Advocacy & Development Department	HOPE FOUNDATION for CANCER CARE
Marijn Verhoef	Director of Operations and Research	Access to Medicine Foundation
Nathan Walters	General Manager, ANZ	Prospection
Dr Jerry C.H. Wang	Chairman, Oncologist	HOPE FOUNDATION for CANCER CARE
Dr Iain Ward	Co-Chair Radiation Oncologist	Asia Pacific Radiation Oncology Special Interest Group (APROSIG) of Royal Australian and New Zealand College of Radiologists (RANZCR) Christchurch Hospital
Pasusant Wattanaboonya	Founder	MPN Patient Advocacy Group Thailand
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Neil Wildman	Senior Director Patient Advocacy Team Lead, Asia Pacific & Africa Middle East	Pfizer Inc.
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Amy Wu	President	Taiwan Association of Cancer Patients
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Jenny Zhang	Brand Communication and International Cooperation Lead	House086

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PINNACLE
A Rare Cancers Australia Initiative