



## Transforming cancer care in Southeast Asia: The ACTION study.

The George Institute  
for Global Health



Better treatments  
Better care  
Healthier societies

***The ACTION (Asean CostS In Oncology) study aimed to generate unprecedented data to help policymakers protect their people and economies from cancer's catastrophic impact. Since 2015, ACTION has provided policymakers with the evidence needed to remove financial barriers to lifesaving diagnoses and treatments, giving cancer patients in Southeast Asia a voice, improving their lives and those of their families for generations to come.***

### ***The inequitable impact of cancer***

Each year, cancer kills around 9.6 million people globally and costs over US\$1.1 trillion. Approximately 70% of these deaths are in low- and middle-income countries where cancer is often diagnosed at a late stage or left untreated because diagnosis and treatment are unaffordable.

In Southeast Asia, cancer can quickly devastate families. For the poor and under-insured who must disproportionately spend household income on treatment, it is a difficult choice: skip treatment or go into potentially catastrophic debt to pay for it.

Aung, a breast cancer survivor in Myanmar, had to borrow money from neighbours and relatives to pay for treatment.

"Cancer has changed my life completely because in the past I would go to work regularly and I had no worries for money," says Aung. "Now I cannot work and if I work hard, I feel very tired."

Sadly, Aung's brother, who struggled to help pay for her medical bills, died of liver cancer a year after his diagnosis, unable to pay for his own treatment.

***"The burden of cancer would grow enormously beyond what these economies could bear – we needed data that showed the scale of the problem"***

**Professor Stephen Jan**

### ***New data for better policy***

Only 20% of low- and middle-income countries have reliable data to enable decision makers to improve cancer care policies. In 2011, a group of researchers at The George Institute for Global Health began to change this.

"Until then, most studies on the economic burden of cancer had only been done in high-income countries, little was known about its impact in low- and middle-income countries where people had to pay for most of their health care out of their own pocket," says Professor Stephen Jan, Co-Director of Health Systems Science at The George Institute.

"Treating cancer was getting more expensive with new medicines and technology. The burden of cancer would grow enormously beyond what these economies could bear – we needed data that showed the scale of the problem," says Stephen.

The landmark ACTION study, the biggest and first of its kind in Southeast Asia, followed 9,513 cancer patients from public and private hospitals in the first year after

## Cancer in Southeast Asia

- In 2012, it was estimated that there were over 770,000 new cases of cancer and 527,000 cancer deaths in the Southeast Asia region, making it the region's number one killer.
- New cases are expected to rise by about 70% to reach 1.3 million by 2030.
- The average cost a year for treatment for a breast cancer in Southeast Asia in 2014 was US\$15,000, compared to the average GDP of US\$3,550. Some treatments cost hundreds of times the minimum wage in Southeast Asia.



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diagnosis, across eight countries: Cambodia, Indonesia, Laos, Malaysia, Myanmar, the Philippines, Thailand and Vietnam.

"We had a mix of countries at different stages of introducing universal health coverage and were able to get a real-time snapshot of the burden of cancer in the region," reflects Stephen.

A combination of factors were examined: household economic well-being, patient survival and quality of life, economic hardship, patients who stopped treatment, and links between health insurance, social economic status and patients stopping or not undertaking treatment.

### ***The catastrophic cost of cancer***

Published in August 2015 in the European Journal of Cancer, the findings provided a compelling case for making cancer care more accessible and affordable.

"We had the data that could help governments financially protect their citizens and help their economies, and it told a grim story," says Professor Mark Woodward, Senior Professorial Fellow at The George Institute.

The cost of cancer was a significant driver of poverty in the region, with the poorest hit hardest. A year after diagnosis, 75% of cancer patients either died or had suffered financial catastrophe. For many, medical costs exceeded their annual household incomes.

"Once diagnosed with cancer, people faced devastating financial hurdles to get treatment, and a late-stage diagnosis accounted for the high rates of financial ruin and death," says Mark.

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**Professor Mark Woodward**

Marites, a cancer survivor in the Philippines, used her life-savings, sold her family property, and her relatives re-mortgaged their homes to help pay for treatment.

"My only wish is for the Philippines government to allocate budget for free cancer medical services because there are many poor and sick Filipinos who need assistance," said Marites at the time of the study.

### ***Working locally for regional change***

From the start of the project until after it finished, local partnerships and stakeholder consultation were key to its success and subsequent impact.

"To challenge the status quo, we needed to work with local experts, decision makers, industry, and patient advocacy groups," says Helen Monaghan, Global Director Operations at The George Institute.

"Throughout the study we held three policy roundtables with our local partners so country experts and government representatives could contribute to the study's direction and agree on priorities for action based on the data," says Helen.

In 2012, during a policy roundtable on future access to cancer care, participants issued the Jakarta Call for Action on Cancer Control Declaration. This was subsequently endorsed by the Association of Southeast Asian Nations Taskforce on Non-Communicable Diseases in 2013.



Singapore, July 2011: The ACTION study was launched at the 1st Association of Southeast Asian Nations (ASEAN) Cancer Stakeholders Meeting, hosted by the ASEAN Foundation, The George Institute and Roche, with 80 government and health officials from 11 countries in Southeast Asia.



Indonesia, August 2015: International experts and health officials from the Southeast Asia region discuss the region's readiness in cancer control and implementing the Jakarta Call For Action on Cancer Control Declaration following the publication of the ACTION study results.

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Helen Monaghan

During the final roundtable in 2015, international experts and health officials agreed on priorities for tackling the catastrophic cost of cancer in the region based on the ACTION study results.

Speaking at the event, Associate Professor Nirmala Bhoo-Pathy, Principal Investigator on the study in Malaysia, highlighted that cancer is an under-appreciated cause of poverty.

“Thanks to the ACTION study, the economic and health impact of cancer in the region is now known. To effectively combat cancer, countries must implement national cancer control programs, prioritising early detection,” said Nirmala.

**Better care and economic wellbeing**

Since 2015, policymakers, government officials, patient advocacy groups, health experts and industry have used ACTION study data to advocate for equitable cancer care policies and affordable care. This has contributed to substantial progress toward universal health coverage in Southeast Asia – one of the United Nations Sustainable Development Goals.

“The ACTION study continues to be quoted extensively in the region’s media, and the data used to increase understanding of the impact of cancer in the region,” explains Dr. Merel Kimman, one of the lead researchers on the study.

Most recently, in November 2018 in the Philippines, the study helped pass the National Integrated Cancer Control Act in the Senate. Senator Juna Edgardo Angara, co-sponsor of the successful bill, cited the study in Parliament to highlight the economic reality of cancer for many Filipino cancer patients.

The far-ranging Act will strengthen cancer care programs, as well as research and prevention to improve survival rates. It will provide financial protection with a Cancer Assistance Fund, which will complement the Philippines Universal Health Coverage Act, and ensure a steady supply of cancer drugs and cancer control related vaccines. The Act also significantly expands health insurance benefits and compensation for those who cannot work due to treatment.

A Philippine Cancer Centre, as well as regional cancer centres, will be established to treat and care for cancer patients, and train doctors, nurses and other medical professionals. A cancer registry will also be established to keep track of the burden of cancer.

“The new cancer legislation in the Philippines gives cancer patients hope and most importantly a choice, especially the underprivileged and marginalised,” says Stephen.

Since 2015, the ACTION study has helped improve cancer care policy and priorities in other countries in Southeast Asia.

In Indonesia, the government implemented early cancer detection programs at local health clinics and primary health care service providers; basic cancer care has been included in the country’s universal health coverage program, despite the fiscal implications; and patient advocacy groups are now empowered to not only actively participate in the cancer policy process but also aid real-time decision making.

In Malaysia, more patients are included in a national health insurance scheme for lower socioeconomic groups. Cancer patient group, Together Against Cancer Malaysia, used our data to lobby for a Cancer Drug Fund to make cancer drugs more affordable, and health experts and government officials have often cited the study in the media, for example, to highlight gaps in specialist care.

Our study remains one of the few on the burden of cancer in Vietnam and found it had the highest rate of financial catastrophe in Southeast Asia. In 2015, it helped shape policy commitments in the National Cancer Control Planning for 2015-2025, and in 2017, it informed a comprehensive plan to improve the quality and access to breast cancer care for the 2020-2025 period.

The ACTION findings have also been used to frame the financial merits of new health insurance policies in Vietnam and Malaysia.

Through media coverage at time of publication and as recently as 2019, ACTION has helped raise public awareness throughout Southeast Asia of the impact of cancer on households, and supported calls for more funding for early detection and treatment.

Follow-up studies have been conducted that build on ACTION’s initial findings and impact, providing governments with more evidence to drive better cancer care policies, prevent poverty due to treatment costs, and give cancer patients a choice. In 2019, The George Institute expanded this approach beyond Southeast Asia with the launch of a pilot study to examine the cost of cancer care and adverse health outcomes in women diagnosed with breast, cervical and ovarian cancer.

*This case study is part of The PRISM Initiative, an ongoing series that highlights the impact of The George Institute’s key research achievements.*





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**Project:** ACTION study (Asean CoSTs In Oncology)

**Executive Committee:** Professor Mark Woodward (Australia), Professor Stephen Jan (Australia), Dr Merel Kimman (Australia), Dr David Kingston (Australia), Helen Monaghan (Australia), Dr Eav Sokha (Cambodia), Professor Thabrany Hasbullah (Indonesia), Dr Bounthaphany Bounxouei (Laos), Dr Nirmala Bhoo-Pathy (Malaysia), Dr Myo Khin (Myanmar), Dr Gloria Christal-Luna (Philippines), Dr Thiravud Khuhaprema (Thailand), Professor Nguyen Chan Hung (Vietnam).

**Project Cycle:** 2011–2014

**Partners and supporters:** The impact of ACTION was possible due to multi-country and cross-sector collaborations, and local partnerships. We are especially thankful to our collaborators: The ASEAN Foundation, George Clinical, Dr Ait-Allah Mejri and others at Roche Asia Pacific, and country principal investigators.

### **About The George Institute for Global Health:**

The George Institute for Global Health is focused on generating robust evidence to create better treatments, better care and healthier societies. This means not only generating evidence to determine what works, and doesn't work, but also which health service or treatment is value for money and where the cost of healthcare can be reduced. Paramount to our work is finding new ways to fund healthcare so health systems can become more sustainable, as well as operate more equitably.

### **About The PRISM Initiative:**

Through interviews with investigators and research partners, project staff and peers in the research community, The Project & Research Impact Story Mapping (PRISM) Initiative examines key research milestones of The George Institute and explores the impact of its projects on health sectors and systems, government policies, communities and more. Join us as we explore key research achievements of the past 20 years, examine how conventional thinking was challenged, who benefitted and what led the research to be transformed into practice.

### **ACTION's evidence at a glance**

- 9,513 cancer patients from 47 sites across eight Southeast Asian countries followed throughout the first year after their cancer diagnosis.
- A year after diagnosis:
  - 75% of cancer patients either died or had suffered financial catastrophe because their medical costs exceeded 30% of their annual household income.
  - 29% of cancer patients died, 48% had financial catastrophe, and only 23% were alive with no financial catastrophe.
- Those without some form of health insurance were most likely to experience financial catastrophe, those without health insurance were at higher risk of death.
- 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.