



THE GEORGE INSTITUTE  
for Global Health

THE GEORGE INSTITUTE FOR GLOBAL HEALTH  
POLICY ROUNDTABLE ON SOUTHEAST ASIA COUNTRIES  
READINESS IN CANCER CONTROL

# “TURNING ACTION RESULTS INTO POLICY ACTIONS”

BALI, INDONESIA  
20 AUGUST 2015

## MEETING REPORT



# Policy Roundtable on Southeast Asia Countries' Readiness in Cancer Control "Turning ACTION Results into Policy Actions"



**Policy Roundtable on Southeast Asia Countries Readiness in Cancer Control  
"Turning ACTION Results into Policy Actions"**  
Bali - Indonesia, 20 August 2015

The Policy Roundtable on Southeast Asia Countries' Readiness in Cancer Control "Turning ACTION Results into Policy Actions" held in Bali, Indonesia on 20 August 2015 brought together international experts and health officials from the Southeast Asia region to further discuss the region's readiness in cancer control and to put into action the Jakarta Call For Action on Cancer Control Declaration following the publication of the ACTION Study results.

## Introduction to the ACTION Study

The Asean CosTs In ONcology (ACTION) study is the largest prospective study on the financial costs of cancer ever conducted in Asia, and in the world. With 47 participating centres, 8 countries (Cambodia, Indonesia, Laos, Malaysia, Myanmar, Thailand, the Philippines and Vietnam) involved and 9,513 patients recruited, ACTION offers unique perspectives on the socioeconomic burden of cancer for both the person with cancer and for society as a whole in the Southeast Asia region.

The ACTION study was conducted by researchers from The George Institute for Global Health and funded by Roche. The longitudinal cohort study involved 9,513 hospital patients with a first time diagnosis of cancer. Patients were followed throughout the first year after their cancer diagnosis, with interviews conducted at baseline (after diagnosis), three and 12 months.

The ACTION Study delved into the economic impact of cancer on households in Southeast Asia countries. Firstly, the study measured the incidence of financial catastrophe following treatment for cancer, defined as out-of-pocket health care expenditure at 12 months exceeding 30% of household income. The study also included secondary outcomes of recording the incidences of economic hardship and death resulting from cancer.

The study aims to gather information to plug the gaps in knowledge relating to the burden of cancer in Southeast Asia and how inequitable access to services influences cancer incidence and outcomes. It supplements knowledge with evidence to help policymakers develop methods to effectively meet these needs and improve health outcomes.

The George Institute for Global Health was selected to conduct the study on the basis of its reputation as one of the most renowned health and medical research institutes in the world. Their work in providing the best evidence to guide critical health decisions and engaging with decision makers to enact real change particularly in chronic diseases is well established. With a research portfolio that encompasses mainly cardiovascular diseases and diabetes, the ACTION study is The George Institute for Global Health's first large-scale research in cancer.

# THE LEAD-UP TO THE ROUNDTABLE

## The Lead-Up to the Roundtable

The burden of cancer is increasing in the Southeast Asia region, due to an ageing population and increase in lifestyle behaviours that can contribute to the prevalence of cancer. In 2012<sup>1</sup>, it was estimated that there were over 770,000 new cases of cancer and 527,000 cancer deaths in the Southeast Asia region, with new cases expected to rise by about 70% to reach 1.3 million by 2030. Yet, cancer treatment is estimated to receive less than 0.5% of public health funding, and economic policymakers continue to see cancer as a solely healthcare issue.

Survival rates for most cancers, especially when diagnosed at late stages, are poor and quality of life is greatly impaired. In addition to this significant disease burden, cancer can have a profound economic effect on individuals and their households, especially among the poor and under-insured. Across Southeast Asia, there is a wide disparity in healthcare coverage for cancer – from less than 10% in Laos to almost full coverage in Malaysia.

The financial burden of cancer is heavy – in countries with little coverage as well as in countries with wide coverage. Out-of-pocket payments are often the principal means of financing health care, not just for primary treatment, but also including the long-term costs of adjuvant therapy and follow-up care. A cancer diagnosis can quickly result in catastrophic payments for a household, causing disproportionate amount of household income to be spent on cancer treatment. With cancer patients also often stopping work due to the illness, the family's financial burden is further increased.

Despite the risk of a cancer epidemic overwhelming the region, governments have been slow to react to the health consequences of socioeconomic and demographic changes. Without immediate intervention, the burden of cancer will grow enormously in the Southeast Asia region, with demands on health care systems and economic costs that are more than these emerging economies can bear.

Hence, in 2011, two regional initiatives were launched to increase cancer awareness and inform priority setting. First, a series of roundtable meetings of key stakeholders and experts were organised to generate knowledge and interest through engagement with the media, and secondly, the ACTION Study was initiated.

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<sup>1</sup>Ferlay J, Soerjomataram I, Ervik M, Dikshit R, Eser S, Mathers C, et al. Cancer incidence and mortality worldwide: IARC CancerBase No. 11 [Internet]. GLOBOCAN 2012 v1.0. Lyon: International Agency for Research on Cancer; 2013.

## The 1st Roundtable

At the 1st ASEAN Cancer Stakeholders Meeting co-organised by the ASEAN Foundation, The George Institute and Roche in July 2011 in Singapore, the ACTION study was first announced. After this, cancer centre leaders, investigators and research staff in individual countries were contacted.

The First Policy Roundtable on Future access to Cancer Care in ASEAN Member States was held on 23 November 2012 in Jakarta, Indonesia, and attended by Cambodia, Indonesia, Laos, Malaysia, Myanmar, the Philippines, Thailand and Vietnam. Here, a group of experts in the field was assembled under the auspices of the ASEAN Foundation to review the state of cancer treatment and services in Southeast Asia. At this meeting, the participants issued the Jakarta Call for Action on Cancer Control Declaration, which highlighted the various factors involved in cancer control, including Health Policy, Prevention and Early Detection, Diagnosis, Treatment and Palliative Care, and Surveillance and Research.

In order to track progress towards adoption of the principles of the Jakarta Call for Action on Cancer Control Declaration and the ACTION study, a second roundtable was held.

## The 2nd Roundtable

The 2nd ASEAN Stakeholder Policy Roundtable held in Kuala Lumpur, Malaysia on 25 April 2014 brought together international experts and health officials from the Southeast Asia region to further deliberate on the progress of the Jakarta Call for Action on Cancer Control Declaration. The call to action aimed to identify policy opportunities to accelerate and broaden access to cancer care through a regional roadmap for cancer control. At the meeting, participants had the opportunity to hear experiences of neighbouring countries relating to cancer control programmes, learn more about the ACTION study and view preliminary results, gain a better understanding of the burden of cancer worldwide, and discuss strategies to ensure cancer is a priority in government policies.

From the roundtable, the participants agreed that to further the progress already made and to ensure the implementation of the Jakarta Call for Action on Cancer Control Declaration, the Southeast Asia countries required:

- ▶ A concrete roadmap to guide member states in establishing local cancer control programmes, as well as a Southeast Asia regional cancer roadmap.
- ▶ More evidence-based toolkits and information, such as the ACTION study and State of Oncology report, for member states to use as advocacy materials to empower their respective government officials to raise cancer on the national agenda.
- ▶ Cross-country collaboration in terms of training and sharing of resources to maximise healthcare resources in the region.
- ▶ Transparency in data collection and sharing of information between the public and private sectors, in order to shape the cancer care agenda for the region.

## The Latest Roundtable

The Policy Roundtable on Southeast Asia Countries' Readiness in Cancer Control "Turning ACTION Results into Policy Actions" was held in Bali, Indonesia on 20 August 2015. The event brought together international experts and health officials from the Southeast Asia region to further discuss the region's readiness in cancer control and to put action behind the Jakarta Call For Action on Cancer Control Declaration, following the publication of the ACTION Study results.

In the plenary session, participants learned about the challenges faced by patients and the need to educate them on cancer, as well as to help them access healthcare and financial support, all of which help towards lowering the cancer mortality rate. Afterwards, participants received the final results from the ACTION Study, which would support their dialogue with government stakeholders to highlight the economic impact of the disease.

Armed with the study results as evidence, participants were further equipped with best practices in creating a successful plan for a national cancer control programme as well as key strategies on how stakeholders can help governments make effective policies.

The meeting then broke into four working groups to discuss the following key topics:

- ▶ Group 1: Mobilising Society for Effective Cancer Control
- ▶ Group 2: Multi Population-Based Cancer Registry - Planning for National Cancer Surveillance Estimates
- ▶ Group 3: Choosing Priority Objectives from the Jakarta Call for Action on Cancer Control Declaration
- ▶ Group 4: Building Regional Cooperation within ASEAN to Face the New Reality of Cancer

Across the working groups, the participants reached a consensus that in order to further the progress already made, the Jakarta Call for Action on Cancer Control Declaration needed to be prioritised and implemented to urgently address the potential catastrophe arising from the cancer epidemic in each country and in the region.

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# PLENARY SESSIONS

## Plenary Sessions

**Professor Mark Woodward** from The George Institute kicked off the Plenary Sessions by reiterating that cancer is an increasing problem for many governments and societies, especially in the Southeast Asia region. Highlighting that the latest roundtable follows the progress from the Jakarta Call for Action on Cancer Control Declaration and the 2nd ASEAN Stakeholder Policy Roundtable, he emphasised that the results of the ACTION study is an important milestone in policy shaping for many key stakeholders and gives them a better understanding of the burden and the impact of cancer to the economy, society, and the government.

**Ms Samantha Barbara**, a breast cancer survivor from NGO Lovepink Indonesia, shared her cancer journey – from her struggle with the disease and learning about cancer from scratch to later working to raise awareness. She stressed on the importance of having support for cancer patients to help them shoulder their burden, including educating them on the disease, providing financial support and access to care centres, as well as having health policies to support them.

She elaborated that education is necessary in order to address issues and stigma arising from society's lack of information on cancer. Financial support is needed because there are many patients with low income and do not have insurance coverage. The lack of financial support leads patients to seek alternative treatment methods, which then causes a higher cancer mortality rate. She also highlighted that Indonesia currently lacks cancer centres and has an insufficient number of physicians specialising in the disease, which in turn leads to longer waiting periods for consultation and treatment and a higher mortality rate.

During the Plenary Sessions, Professor Mark Woodward also presented the ACTION Study results. Before going into the results of the ACTION Study, Professor Woodward shared the background of the study, providing statistics on the incidence and cancer mortality in the Southeast Asia region. He noted that while there remains a lack of data specific to the region, Globocan (2012), forecasts that by 2030, all cancers, excluding non-melanoma skin cancer, will increase by 70%.

*...Southeast Asia's aging populations, population increase, and deteriorating lifestyles will only add to the burden of cancer...urgent action is needed to protect people from the financial burden of the disease and to reduce the impact of productivity loss in the region.*



## Plenary Sessions *(continued)*

Professor Woodward highlighted that the primary outcome of the study is that patients in the study experienced financial catastrophe at month 12 of treatment, while the key secondary outcome is the patient's survival with economic hardship, with illness-induced poverty, changes in quality of life, psychological distress, and disease status as other non-key secondary outcomes. He indicated that for some cancers, the 1-year death rate in parts of Southeast Asia is much higher than in Western countries. From the study, it was revealed that over 75% of the newly diagnosed cancer patients are expected to die or suffer financial catastrophe within 1 year of diagnosis.



In closing, Professor Woodward stressed that Southeast Asia's aging populations, population increase, and deteriorating lifestyles will only add to the burden of cancer. Therefore, urgent action is needed to protect people from the financial burden of the disease and to reduce the impact of productivity loss in the region.

**Associate Professor Nirmala Bhoo-Pathy** from the University of Malaya presented on the economic impact of cancer in Southeast Asia. She started by highlighting that cancer is an under-appreciated cause of poverty, particularly through the costs associated with treatment and the impact on people's ability to work. She also noted that the economic and health impact of cancer in the region are known, thanks to the ACTION Study.



Highlighting the study results in each country, Professor Nirmala noted that death was allowed as a competing risk to financial catastrophe at 1-year, but it remains possible that financial catastrophe may have been underestimated, particularly in countries with high death rates, as patients experiencing financial catastrophe who subsequently died may have been missed. Nevertheless, the current results indicate that financial catastrophe was experienced by close to 50% of patients in most countries.

## Plenary Sessions *(continued)*

Prof Nirmala then explained that the study also looked at the solutions patients took to address challenges. She presented data on demographics, availability of health insurance, cancer stages, and treatment type to demonstrate the impact on financial catastrophe and death. The data showed that low income patients remained vulnerable to incurring catastrophic expenditure and death, even when diagnosed at very early cancer stages.

In summary, Professor Nirmala stressed four take home messages from the ACTION results, namely:

- ▶ Cancer down staging via early detection may provide the best avenue to favourably influence economic and disease outcomes in cancer patients in low- and middle-income Southeast Asia countries.
- ▶ Down staging results in a larger proportion of patients presenting with cancer stages that are more amenable to (cheaper) curative treatment options such as surgery.
- ▶ Providing access to prompt administration of (affordable) treatment for cancer patients may potentially reduce financial loss, and premature deaths.
- ▶ Governments need to improve financial risk protection for cancer patients.

Professor Nirmala concluded with three future directions:

- ▶ to enhance cancer registration
- ▶ to establish primary prevention in terms of policy and action
- ▶ to be more creative in developing awareness about cancer



## Plenary Sessions *(continued)*

Dr Simon B. Sutcliffe from the Canadian Partnership Against Cancer shared on the approach and strategy for moving from evidence to practice in establishing a cancer control programme. He highlighted that readiness in addressing the challenges starts with having committed political leadership. Afterwards, all parties, including the government, must accept that cancer is a social challenge and needs a committed clinical leadership. Lastly, resources need to be allocated and/or reallocated to address non-communicable diseases, including cancer.

Dr Sutcliffe explained that the cancer control framework should derive from a population-based cancer plan, including the improvement of human development, promotion and management of health, and the improvement of care for the illness. He shared that there are nine elements to be included in a successful plan, based on real-life experience, namely:

- ▶ Government commitment and national policies
- ▶ Societal ownership of projects and plans
- ▶ Country-based, not institution-based
- ▶ Prioritisation of selected areas
- ▶ A realistic approach (needs : capacity : performance : resources)
- ▶ Coordination of partners (internal and external)
- ▶ Composition of steering groups
- ▶ Secure funding
- ▶ Continuity, stability of leadership and sustainability

In closing, Dr Sutcliffe underlined the importance of a population-based strategy that addresses incidence, mortality, and quality of life in cancer control, which includes three aspects – Content, Relationships and Collaborations and Performance and Strategy

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groups*
- ▶ *Secure funding*
- ▶ *Continuity, stability of  
leadership and sustainability*

## Plenary Sessions *(continued)*

Dr Madeleine de Rosas-Valera, formerly of the Philippines' Department of Health, an expert in developing partnerships, shared the recommended approaches whereby researchers, clinicians, and advocates can help governments make effective policies. She explained that policymakers at all levels want to make healthcare decisions based on the best available evidence on what works well and what does not. Research on comparative effectiveness and patient-centred outcomes can help decision makers plan their public health programmes, design health insurance coverage, and initiate wellness or advocacy programmes that educate people with the best possible information about different healthcare treatment options. She also stressed that policymakers should listen to the patient's voice.

Dr de Rosas-Valera indicated that an effective healthcare programme depends heavily on the roles of the stakeholders, which are broken down into the following elements:

- ▶ suggesting a research topic
- ▶ providing insight on research priorities
- ▶ informing the refinement of research topics
- ▶ developing key questions
- ▶ helping develop a research approach
- ▶ reviewing initial research findings
- ▶ improving research products and tools through evaluation and feedback
- ▶ distributing research reports and products  
and leading the implementation

For effective collaboration, Dr de Rosas-Valera said there are four important pillars:

*Pillar 1:  
an open and  
responsive  
government*

*Pillar 2:  
organised and  
capable citizen  
groups*

*Pillar 3:  
open access to  
information*

*Pillar 4:  
context and  
cultural  
appropriateness*

Dr de Rosas-Valera also emphasised that citizens need to be organised, empowered, and educated with skills, knowledge, values and orientation, and assertiveness.

*Research on comparative effectiveness and patient-centred outcomes can help decision makers plan their public health programmes, design health insurance coverage, and initiate wellness or advocacy programmes that educate people with the best possible information about different healthcare treatment options.*

# BREAKOUT SESSIONS

# Working Group 1: Mobilising Society for Effective Cancer Control

Dr Simon B. Sutcliffe of the Canadian Partnership Against Cancer shared that in Canada's cancer control programme, US\$50 million is allocated per year based on the people's request to the Government for a cancer control plan. However, in Canada, the people's wishes are prioritised over the opinions of healthcare professionals, who are only consulted on issues related to medicine. He posed four questions to the representatives from Indonesia, the Philippines, Malaysia, Cambodia, Thailand, and Myanmar, as follows:

- ▶ Q1: How do we get the Government to listen to healthcare professionals?
- ▶ Q2: How do we integrate across sectors, constituencies, cultures, and countries?
- ▶ Q3: How do we identify leaders for our cause, and how do they achieve support and a following?
- ▶ Q4: What programmes existed in your country, and how can local expertise be used to support the programme?

## Results

There were four key points identified in the discussion, answering the question on how to mobilise society to establish an effective cancer control programme. The key points are as follows:

- ▶ Engage politicians to support and enact appropriate legislation and allocate appropriate resources to the national cancer control programme by providing them compelling reasons to change.
- ▶ Project cancer as one disease with one voice, delivering a common message.
- ▶ Communicate the message across all platforms (political, professional, and social).
- ▶ Utilise expertise to disseminate messages through all tools and available technology.

The participants acknowledged that it is their responsibility to get the action going. They have to make the first step towards an effective national cancer control programme.

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## Working Group 2: Multi Population-Based Cancer Registry-Planning for National Cancer Surveillance Estimate

All participants agreed that with no reliable data, it would be very difficult to convince the Government that there are indeed cancer-related problems. The big question is what steps should be taken in order to convince the Government to develop a national cancer registry – the system for obtaining reliable data on cancer.

### Results

The four key points identified from the discussion were:

- ▶ Get political commitment from the Government to establish a population-based cancer registry.
- ▶ Improve capacity building, including through skill training, in Southeast Asia countries in relation to the cancer registry.
- ▶ Establish a strong collaboration among Southeast Asia countries to share information about cancer findings.
- ▶ Standardise data collection on cancer cases.

The data from the ACTION Study may provide the Government with a preliminary description of the cancer problem. However, to encourage the government to develop a national cancer registry, all healthcare professionals still have to work very hard.

*The big question is what steps should be taken in order to convince the Government to develop a national cancer registry – the system for obtaining reliable data on cancer.*



## Working Group 3: Choosing Priority Objectives from the Jakarta Call for Action on Cancer Control Declaration

The panellists highlighted two aspects. Firstly, there must be adequate resources available - both money and human resources. For example, several countries lack qualified personnel, and therefore those countries are recommended to hold integrated training for general practitioners or internal medicine residents. Additionally, access factors including distance, transportation costs and goods distribution are other aspects that need to be taken into account.

All parties have to work together to inform society about the current state of cancer, and effect a change. Priorities need to be taken from the current objectives of the Jakarta Call for Action on Cancer Control Declaration.

### Results

There were targeted strategies put together by the stakeholders in order to realise the Jakarta Call for Action on Cancer Control Declaration. Although the policy was made four years ago, real steps have yet to be taken. Targets and priorities identified based on experiences by people from various fields are as follows:

#### 1. Targeted health education and awareness

Health education is especially important. There are four health myths that a healthcare professional needs to clarify, as follows:

Myth One: Cancer is just a health issue. Not true - in reality, cancer affects a country's economy, society and overall development.

Myth Two: Cancer is a disease of the wealthy, elderly and developed countries. False - cancer can affect all people, regardless of socioeconomic status, nationality and age.

Myth Three: Cancer is a death sentence. Wrong! These days, many cancers can be managed and cured with effective treatments.

Myth Four: Cancer is my fate. No - preventative measures can reduce the likelihood of many people developing cancer in the first place.

*Targets and priorities identified...*

*1. Targeted health education and awareness*

*2. Adequate prevention*

*3. Specific Protection*

*4. Cost-Effective and Safe Treatment*

*5. Good Healthcare Financing*



## Working Group 3: Choosing Priority Objectives from the Jakarta Call for Action on Cancer Control Declaration *(continued)*

### 2. Adequate prevention

Prevention should specially cater to preventable diseases. There are a number of preventable cancers, such as lung cancer and colorectal cancer. All sectors need to focus on those diseases only. Therefore, a regulation on tobacco control is strongly recommended. In the middle to high income countries, it is recommended to undergo vaccination for a more targeted approach. On the other hand, a specific study to prove the effectiveness in low-income countries has not been done.

### 3. Specific Protection

Mass screening is a very vital aspect when it comes to cancer. In order to make this specific protection effort feasible, adequate manpower and equipment is highly required. In countries where resources are insufficient, redelegation to general practitioners is recommended. Regional cooperation is also another key point for countries that have less equipment, especially in Southeast Asia.

### 4. Cost-Effective and Safe Treatment

A guideline that clearly states the method of staging, treatment referral and the treatment regimen is needed. The treatment stated in the guideline has to be cost-effective and efficient. For example, in Indonesia, it is much cheaper to redelegate mass screening to the general practitioner and relieve the primary health centres, allowing patients to be referred to a trained surgical oncologist for immediate surgery.

It is particularly noted that other than a good referral system, a multi-discipline approach is vital. When a late-stage cancer patient not only needs a chemotherapist, but also a radiotherapist for treatment, it is better to immediately refer the patient to a centre that has multi-discipline doctors (a tertiary health centre). Also, the patient's safety aspect has to be taken care of.

*Targets and priorities identified...*

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## Working Group 3: Choosing Priority Objectives from the Jakarta Call for Action on Cancer Control Declaration *(continued)*

### 5. Good Healthcare Financing

Healthcare financing is a very wide area to address, as it involves people from many sectors – from the government as stakeholders; the patients as people who are affected the most by the system; pharmacies as they determine the price of the drugs; and doctors as this would affect their payment.

In countries that already have a national insurance programme like Indonesia and Thailand, talking about healthcare financing is a lot easier. Most of the payment comes from health insurance, except for second or third-line drugs. On the patient's side, financial catastrophe can be prevented since only a little out-of-pocket funding is required from the family.

On the other hand, the insurance does not pay for specific protections, such as mass screening. For that, especially if the general practitioner is trained to do so, there needs to be additional payment, which is not included in the capitation system.

The Government as a stakeholder needs to effect concrete actions, such as increasing healthcare expenditure. The current cancer scenario is alarming, and with the increase in incidence of up to 70% per year, allocating more money for the issue is something that has to be done. These are aspects that need to be taken care of when it comes to good healthcare financing.

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*5. Good Healthcare Financing*

## Working Group 4: Building Regional Cooperation within ASEAN to Face the New Reality of Cancer

Concerns were highlighted that the ASEAN Post-2015 Health Development Agenda does not explicitly mention NCDs in its strategies. Many agreements emerging from regional meetings are also not reported as written statements. Officials have responded to the concerns, and stated that unwritten agreements do not mean that the issues are neglected, but only implies that each country has a different level of engagement with civil society.

Another problem highlighted related to the cancer data registry in some ASEAN member countries, such as Indonesia, Laos, and Cambodia. The ASEAN Cancer Data and Registry Information System Networking is in progress but is still exclusively between Malaysia, Singapore and Brunei Darussalam. The lack of full participation in integrated and transparent data sharing creates a disparity between Southeast Asia countries, which affects the quality of multi-centre healthcare research and hinders the adoption of regional healthcare policies.

Additionally, the development of the inventory of experts on NCDs is considered an important strategy in the ASEAN Post-2015 Health Development Agenda. However, progress is yet to be reported, and the initiative has yet to be integrated on a regional level.

### Results

The issues that arise relating to the healthcare development agenda present opportunities for improvement. The following are the recommendations derived from the Third Policy Roundtable on ASEAN Member States' Readiness in Cancer Control themed "Turning ACTION results into Policy Actions" held on 20 August 2015, in Bali, Indonesia:

- ▶ Using existing structures instead of creating new ones with open selection, to be supported by the Government and other sectors (eg establishment of coordinating structures for NCDs at the national and regional level with cancer at the sub-coordinating level)
- ▶ Implementing transparent data sharing between Southeast Asia countries to create a good data registry
- ▶ Conducting multi-centre research and using existing data to emulate regional policies
- ▶ Establishing an inventory of experts to be shared on the regional level
- ▶ Listing priorities and formulating legible action plans are vital for building regional cooperation towards better management of NCDs, specifically cancer, in Southeast Asia.

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## Meeting Takeaways

The in-depth dialogues that took place in the four group discussions resulted in key approaches and strategies for different stakeholders groups – to address issues regarding Southeast Asia countries' readiness in cancer control.

- ▶ From the meeting, it is clear that it is important to have all parties, locally and regionally, aligned with the same level of understanding regarding cancer as a major problem faced by society, and which brings economic loss to a country due to productivity loss. Thus, it is necessary to have all stakeholders, especially Governments, playing an active role in establishing a national cancer control plan.
- ▶ Though the ACTION Study results have been published, participants agree that it would be very difficult to convince the Government on the existence of cancer-related problems without the necessary system to obtain reliable population-based data on cancer. Therefore, getting political commitment from the Government to establish a population-based cancer registry is the first priority, followed by improving the capacity of skilled resources in relation to the cancer registry and establishing a stronger collaboration among ASEAN member countries in terms of sharing information on cancer findings. All participants believe they still need to work very hard to encourage the Government to develop a national cancer registry, though the data from the ACTION Study may provide Governments with a preliminary description of the cancer problem in the region.
- ▶ Though the Jakarta Call for Action on Cancer Control Declaration was officially made in 2011, all participants acknowledged that no real action has been taken yet by stakeholders to realise the call. Therefore, all participants agreed on the need to prioritise the call, starting with making available adequate resources – both money and human resources. They agreed to implement strategies targeted towards health education and awareness building, adequate prevention and specific protection, ensuring cost-effective and safe treatment, and creating good healthcare financing.
- ▶ Participants acknowledged that with the help of the Jakarta Call for Action on Cancer Control Declaration, stakeholders are able to take action. Nevertheless, the real homework is making each country and the region realise the state of urgency in taking action on cancer. To make a stronger impact, all have agreed on the importance of projecting cancer as one disease under one voice, while delivering a common message across all platforms.

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## Beyond the Last Roundtable

From the Policy Roundtable on Southeast Asia Countries' Readiness in Cancer Control "Turning ACTION Results into Policy Actions", it can be observed that healthcare professionals are in agreement on the catastrophic impact the disease can have on the economy of nations and across all levels of society if nothing is done. They are unanimous in calling for commitment from the Governments of all ASEAN member countries to urgently implement policies and plans to arrest the growth in cancer cases. There is an urgent need for all Governments to integrate national cancer-control programmes into existing health systems, in line with the Jakarta Call for Action on Cancer Control Declaration.

Recognising that many Governments are not prioritising the cancer problem, there is still much to do and far to go to obtain the necessary resources to aid early detection, to promote policies aimed to provide adequate financial protection from the costs of cancer, and to improve access to cancer care in a socially equitable manner – for all cancer patients across Southeast Asia.

With the ACTION Study, healthcare professional pushing for more focus on cancer care and control now have a little more information to support their cause. With greater awareness of the extent of the cancer problem in Southeast Asia and its breadth in terms of its implications for households and the communities in which cancer patients live, this can help identify priorities for further research and catalyse political action to put in place effective cancer control policies.

It is hoped that the findings will assist ASEAN Governments in making informed choices on cancer control policies and resource allocations, as a coordinated regional response from ASEAN Governments is crucial for confronting the cancer crisis. The findings can contribute to the design of healthcare systems programmes and health insurance schemes, and the implementation of measures to ensure cancer patients have access to appropriate care.

Ultimately, the way forward is to:

- ▶ ensure that evidence from the ACTION study is recognised then incorporated into policymaking - from agenda-setting to formulation to implementation.
- ▶ identify the other factors which influence cancer policymaking and can ultimately limit the extent in which evidence from the ACTION study is used to change policy.
- ▶ realize that policymaking is neither objective nor neutral - it is an inherently political process, and hence, 100% local!

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# APPENDIX

## About the George Institute

The George Institute for Global Health is a health and medical research institute whose mission is to improve the health of millions of people worldwide. Its vision is to be the world's leading research centre dedicated to developing effective and affordable solutions for the healthcare challenges of the 21st century, especially in resource-poor environments.

Through its research, The George Institute provides the best evidence to guide critical health decisions, engages with decision makers to enact real change, targets global epidemics, particularly of chronic diseases and injury, and focuses on vulnerable populations in both rich and poor countries.

With projects in more than 50 countries, The George Institute has raised over \$500 million for global health research since 1999 and has been ranked among the top 10 research institutions in the world for scientific impact by the SCImago Institution Rankings World Report in 2011, 2012, 2013 & 2014. For the past 15 years, research by The George Institute has resulted in changes to medical guidelines and ways of thinking about some of the most common medical treatments around the world.

For more information, visit: <http://www.georgeinstitute.org/>

## Speakers

- ▶ Dr Dyah Erti Mustikawati, Head of Sub-Directorate of Diabetes Mellitus Management under the Directorate of Non-Communicable Diseases/Focal Point of Task Force for Non-Communicable Diseases (ATFNCD), Ministry of Health of the Republic of Indonesia
- ▶ Professor Dr Hasbullah Thabrany, Head, Center for Health Economics and Policy Studies, School of Public Health, University of Indonesia
- ▶ Professor Mark Woodward, Professor of Biostatistics, George Institute, Australia
- ▶ Dr Madeleine de Rosas-Valera, Former Undersecretary for Health Policy, Finance and Research Development, Department of Health Philippines
- ▶ Associate Professor Dr Nirmala Bhoo-Pathy, Principal Investigator, ACTION Study Malaysia, Faculty of Medicine, University Malaya
- ▶ Dr Pattarawin Attasara, Advisor, Bureau of Medical Services Inspection, Department of Medical Services, Ministry of Public Health
- ▶ Ms Samantha Barbara, Chairman, Lovepink Indonesia
- ▶ Dr Saunthari Somasundaram, President/Medical Director, National Cancer Society of Malaysia/Board Member, Union for International Cancer Control
- ▶ Dr Simon B. Sutcliffe, Chair, Canadian Partnership Against Cancer

## Speaker Profiles

***Dr Dyah Erti Mustikawati***  
*Head, Sub-Directorate of Diabetes Mellitus Management under the Directorate of Non-Communicable Diseases/Focal Point of Task Force for Non-Communicable Diseases (ATFNCD), Ministry of Health of the Republic of Indonesia*

Dr Dyah Erti Mustikawati has long been passionate about providing quality healthcare to the citizens of Indonesia. Her focus has been at the nexus of behaviour and a range of research topics. She attended both Airlangga University (1981-1987) - where she completed a Doctorate in Dental Surgery, and Tulane University (1996-1998) - where completed both a Masters of Public Health in International Health and a Doctorate in Public Health.

She has been involved in various research projects and clinical trials since the early 1990s and has covered topics ranging from sexual health to HIV/AIDS, from tuberculosis to dentistry, and from nutrition to non-communicable diseases.

She has worked with the Indonesian Ministry of Health since 2010. She is also involved in the Global TB Programme's Paediatric TB Expert Working Group and the National HIV/AIDS Costing Working Group.



## Speaker Profiles

### *Professor Dr Hasbullah Thabrany* *Head, Center for Health Economics and Policy Studies,* *School of Public Health, University of Indonesia*

Professor Dr Hasbullah Thabrany was born in Jakarta in 1954 and has been awarded the Bakti Utama Kesra medal for his valuable contribution to the welfare of Indonesia, from the Coordinating Ministry of Peoples' Welfare (Menko Kesra). As a native of Jakarta, Dr Thabrany has paid a lot of attention to improving human resource capacity in the Betawi population. In 1982, together with General Eddy M. Nalapraya and Wim Salamun of the Democratic Party, Dr Thabrany established the unified Council of Betawi Organizations (Bamus Betawi). Dr Thabrany has been working actively to improve the social security system starting with universal health coverage in Indonesia and pensions for all Indonesians starting July 2015.

Dr Thabrany obtained his MD degree (1980) from the University of Indonesia and his PhD (1995) from the University of California at Berkeley, USA. From his graduation from the Medical School of the University of Indonesia until the present, Dr Thabrany has been actively serving in the Indonesian Medical Association, including as Secretary General (1997-2000) and Chairman of the Collegium of General Practitioners (2014). He received recognition as a Health Insurance Professional (HIA) and Managed Health Care Professional (MHP) from the Health Insurance Association of America, now the American Health Insurance Plans.

He was the founder of the Indonesian Association of Health Insurance Managers (PAMJAKI) and has served as the Chairman of the Association (1998-2010) and as the Chairman of the Examiners' Board of PAMJAKI (2010-2014). Dr Thabrany was a key contributor of the Presidential Task Force to reform the social security system (SJSN). He was the dean of the School of Public Health at the University of Indonesia (2004-2008) and President of the South East Asian Public Health Institutions Network (2009-2011). At present, he is a professor in Health Economics and the Chairman of the Center for Health Economics and Policy Studies at the University of Indonesia.



## Speaker Profiles

### *Professor Mark Woodward* *Professor of Biostatistics, George Institute, Australia*

Working in the Professorial Advisory Unit of The George Institute, Professor Mark Woodward is also a Professor of Biostatistics at the University of Sydney, Professor of Statistics and Epidemiology at the University of Oxford and Adjunct Professor of Epidemiology at Johns Hopkins University.

He is the author of 400+ peer-reviewed publications and two text-books on statistical methods in medical research, one of which had its third edition published in January 2014. In the five year period from January 2009 to December 2013 he published 161 (>40% of his total) peer-reviewed publications, including seven in *The Lancet*, two in *NEJM* and one in *JAMA*. Three of his papers have over a thousand citations.

Professor Woodward has led four major international studies and directed the analytical research on three landmark collaborative studies worldwide. His work on cardiovascular risk scores formed the basis of national guidelines in Scotland, and his recent work on kidney disease was used to produce new staging criteria for this disease. His total career grant awards are over \$93 million from 39 successful applications.

He also has extensive experience in student teaching, postgraduate supervision and mentoring including 14 PhD and 19 MSc students successfully completed. He has given training workshops in Korea and Thailand, and has taught at least 25 other research training courses.

Professor Woodward served on the governing council of the Institute of Statisticians and the Royal Statistical Society (RSS) and is currently a fellow of the RSS, the European Society of Cardiology, the New York Academy of Medicine and the Royal Society of Medicine.

He has wide experience of development aid work in Africa and Asia, having undertaken 25 missions for aid agencies, such as the WHO. He has also assessed grants for six national medical research councils (including NHMRC) and served on the editorial boards of seven international journals.



## Speaker Profiles

### *Dr Madeleine de Rosas-Valera*

*Former Undersecretary for Health Policy, Finance and Research Development, Department of Health Philippines*

Dr Madeleine de Rosas-Valera was formerly the Undersecretary of Health in charge of the Cluster on Health Policy, Financing, Research, International Health and the National Center for Pharmaceutical Management. She is also the Chairperson for the Formulary Executive Committee and Co-Chair for the DOH Research Hub.

She is a senior health care service professional with more than two decades of professional expertise in health system and primary health care service delivery, financing and management in the public and private sectors. She has served in senior level positions with a national social health insurance organisation, the Philippine Health Insurance Corporation (PHIC), responsible for Health Financing, Payment Mechanism, Contracting, Policy Development, Developing Standards of Accreditation, developing the health care benefits package covering TB, Maternity Care and Non-Communicable Diseases, and outpatient basic care packages, drug and contraceptives devices reimbursement.

Dr de Rosas-Valera is considered a champion of quality assurance in the health sector, having been the leading figure in the implementation of PhilHealth's mandate of quality assurance. She has made quality assurance her vehicle towards serving the public interest. She was a Patient Safety Technical Officer of the WHO Western Pacific Regional Office from 2009-2012.

Dr de Rosas-Valera, being an outspoken advocate for rational drug use, has been recognised for her leadership in advocating the importance of cost-benefit and cost-effectiveness analyses of drugs within the Philippine health care system. She has emphasised rational drug use in PhilHealth's quality assurance programme by supporting the Generics Act and adopting the Philippine National Drug Formulary in PhilHealth's benefits payment scheme. She has also promoted the use of evidence-based medicine and HTA, particularly the clinical practice guidelines in identifying drugs and procedures that can be included in the National Health Insurance Program (NHIP) benefit, based on scientific evidence. She established and strengthened linkages with the different stakeholders of NHIP especially the academe whose expertise she recruited for health technology assessment for PhilHealth.



## Speaker Profiles

### *Associate Professor Dr Nirmala Bhoo-Pathy Principal Investigator, ACTION Study Malaysia, Faculty of Medicine, University Malaya*

Associate Professor Dr Nirmala Bhoo-Pathy graduated from the University of Malaya in 2001 with an MBBS (MD) and subsequently obtained an MPH with distinction in 2008. In the same year, she obtained a scholarship from the European Union to pursue her doctoral training in at the Utrecht University Medical Center, Netherlands. Dr Nirmala completed her Masters in Clinical Epidemiology with cum laude, followed by a PhD in Cancer Epidemiology from Utrecht University in 2011.

Her research interests include treatment outcomes and cancer prognostication in Asian women, as well as ethnic differences, and lifestyle determinants of cancer risk and outcomes. She currently coordinates the Singapore-Malaysia Breast Cancer Working Group, comprising epidemiologists, breast surgeons, and oncologists from Malaysia, Singapore, Hong Kong, and the Netherlands, which aims to improve the understanding on breast cancer in Asian women.

Dr Nirmala is also an active working member of the European Prospective Investigation into Cancer and Nutrition (EPIC) Cohort Study, which is coordinated by the International Agency for Research on Cancer (IARC, Lyon, France), investigating the association between diet, nutrition and physical activity, and risk of cancer. Over the past two years, Dr Nirmala has also been involved in a global cancer survival surveillance study – CONCORD 2, working with researchers from the London School of Hygiene and Tropical Medicine.

Currently employed as an associate professor in the Faculty of Medicine, University Malaya, she is tasked to teach clinical epidemiology and epidemiological methods to medical undergraduates and postgraduates, and also serves as a research consultant to health professionals. Dr Nirmala also conducts research workshops in the Ministry of Health Malaysia and undertakes part-time teaching in Queen's University, Belfast, United Kingdom.



## Speaker Profiles

### *Dr Pattarawin Attasara*

*Advisor, Bureau of Medical Services Inspection,  
Department of Medical Services, Ministry of Public  
Health*

Dr Pattarawin Attasara is presently the Chief of the National Cancer Database and the Chief of Cancer Informatics at the National Cancer Institute of Thailand. He is also the present Advisor of the Bureau of Medical Services Inspection, Ministry of Public Health, Thailand. His involvement in the development of a cancer registry dates back to 2003 when he was then heading the Cancer Registration and Informatics Division.

Dr Pattarawin plays an integral role in the development of more than twenty cancer registries running in all regions in the country. Registry reports and the estimates of cancer statistics for the country have been published with his expert knowledge and contribution. Amongst his notable publications is the 'Cancer in Thailand' report, which is regularly published every three years.



## Speaker Profiles

### *Ms Samantha Barbara* *Chairman, Lovepink Indonesia*

Ms Samantha Barbara, the Chairman of Indonesian breast cancer NGO Lovepink Indonesia is herself a breast cancer survivor. Samantha was diagnosed with breast cancer in April 2013 and underwent a mastectomy in May 2013. Samantha has written about living with breast cancer, managing the chemotherapy experience as a patient, and coming to terms and accepting the cancer diagnosis and having to undergo chemotherapy. She believes it is important for survivors to share their stories to help patients with newly-detected breast cancer.



## Speaker Profiles

### *Dr Saunthari Somasundaram*

*President/Medical Director, National Cancer Society of Malaysia/Board Member, Union for International Cancer Control*

Dr Saunthari Somasundaram was educated in New South Wales, Australia in 1983 and thereafter, studied medicine at the Royal College of Surgeons in Dublin, Ireland / National University of Ireland in 1990. She proceeded to pursue her postgraduate studies and obtained her Master's in Business Administration at the Malaysian Institute of Management / University of Bath, United Kingdom in 2001.

She was attached to the Paediatric Institute of Hospital Kuala Lumpur, and was a Registrar with the Department of Paediatrics of Lister Hospital, Stevenage, United Kingdom. In 2000, she became the Medical Officer at the National Cancer Society of Malaysia's Cancer and Health Screening Clinic. During this period, she also established the Children's Home of Hope, which provides child-friendly accommodation for children undergoing treatment in hospitals.

In 2010, Dr Saunthari was elected the President of the National Cancer Society of Malaysia where she is responsible for the overall strategic direction and vision of the Society. As President, Dr Saunthari oversees the overall direction of the NCSM. As the Medical Director, she manages the operations of the Cancer Control Division in both the clinical and educational services. On the support front, Dr Saunthari actively participates in counselling and talking to individuals with cancer and their caregivers.

Dr Saunthari is also a Board Member of the Union for International Cancer Control (UICC), an international professional non-government organisation dedicated to the global control of cancer. UICC membership comprises more than 760 member organisations in 155 countries.

In June 2015, she was appointed a Board Member of the International Cancer Information Service Group (ICISG), a worldwide network of more than 70 organisations that deliver cancer information.



## Speaker Profiles

### *Dr Simon B. Sutcliffe* *Chair, Canadian Partnership Against Cancer*

Dr Simon B. Sutcliffe is a distinguished clinician, scientist and leading visionary in cancer control in Canada and internationally. A graduate of St. Bartholomew's Hospital, London, England, Dr Sutcliffe's training encompassed internal medicine, scientific research, medical and radiation oncology in the United Kingdom, South Africa, US and Canada.

He has published extensively in the areas of radiation and medical oncology as applied to the treatment of lymphoma, leukaemia and cellular immuno-deficiency and immuno-modulation in cancer. Dr Sutcliffe has been President and CEO of the Ontario Cancer Institute and Princess Margaret Hospital (1994-96) and the BC Cancer Agency (2000-09). Dr Sutcliffe was the inaugural Chair of the Governing Council of the Canadian Strategy for Cancer Control, a past member of the NCIC Board of Directors, and past chair of the Canadian Partnership against Cancer, the Canadian Cancer Society/National Cancer Institute of Canada Joint Advisory Committee on Cancer Control and the National Medical Advisory Committee.

He has also served on the boards of the Michael Smith Foundation for Health Research and Genome BC. Dr Sutcliffe is currently the President of the International Cancer Control Congress Association, President of Two Worlds Cancer Collaboration (the Canadian Branch of the International Network for Cancer Treatment and Research), and Board Chair, Institute for Health Systems Sustainability. He is also a senior advisor to the Terry Fox Research Institute. Dr Sutcliffe was awarded the Queen Elizabeth 50th Jubilee Gold Medal in 2003 and the Terry Fox Award (of the B.C. Medical Association) in 2009 for his lifetime services to cancer control.



# Participants

## Cambodia

- ▶ Dr Heng Viroath, Medical Oncology, Khmer-Soviet Friendship Hospital
- ▶ Dr Kouy Samnang, Head of Department - Oncology, Khmer-Soviet Friendship Hospital
- ▶ Dr Seang Pharin, Medical Oncology, Calmette Hospital

## Indonesia

- ▶ Mr Andi Afdal Abdullah, Group Head, Primary Healthcare Management, Social Security Agency
- ▶ Dr Atikah M Zaki, Coordinator of Health and Social Welfare, Aisyiyah
- ▶ Dr Drajat R. Suardi, Hasan Sadikin Hospital
- ▶ Dr Dyah Erti Mustikawati, Head of Sub-Directorate of Diabetes Mellitus Management under the Directorate of Non-Communicable Diseases/Focal Point of Task Force for Non-Communicable Diseases (ATFNCD), Ministry of Health of the Republic of Indonesia
- ▶ Ms Eviati Adawiyah, Assistant to the Principal, School of Public Health, University of Indonesia
- ▶ Professor Dr Harryanto Reksodiputro, President, Indonesian Society of Hematology-Medical Oncology
- ▶ Professor Dr Hasbullah Thabrany, Head, Center for Health Economics and Policy Studies, School of Public Health, University of Indonesia
- ▶ Dr John Prawira, Researcher for Non-Communicable Diseases Policy, Centre for Health Policy & Management, Faculty of Medicine, Gadjah Mada University
- ▶ Professor Dr Laksono Trisnantoro, Center for Health Policy and Management, Faculty of Medicine, Gadjah Mada University
- ▶ Dr Lily Sulistyowati, Director, Directorate of Non-Communicable Diseases, Ministry of Health of the Republic of Indonesia
- ▶ Dr Niken Wastu Palupi, Chief of Sub Directorate, National Cancer Control Program, Directorate of Non-Communicable Diseases, Ministry of Health of the Republic of Indonesia
- ▶ Professor Dr Soehartati A. Gondhowiardjo, Chairwoman, National Cancer Control Committee (NCCC)
- ▶ Dr Sri Mutya Sekarutami, Radiation Oncologist, Cipto Mangunkusumo Hospital
- ▶ Dr Tubagus Djumhana Atmakusuma, Head, Division of Hematology-Medical Oncology, Department of Internal Medicine, University of Indonesia

## Laos

- ▶ Dr Phetsamone Arounlangsy, Deputy Director of Cancer Center, Cancer Center, Mittaphab Hospital, Lao PDR
- ▶ Associate Professor Bounnack Saysanasongkham, Deputy General Director, Department of Health Care, Ministry of Health, Lao PDR

## Malaysia

- ▶ Dr Azizah Ab Manan, State Epidemiologist (Non-Communicable Diseases Control), Penang, Ministry of Health Malaysia
- ▶ Dr Faridah Aryani Md Yusof, Deputy Director, Formulary & Pharmacoeconomic, Ministry of Health Malaysia
- ▶ Professor Dr Fuad Ismail, Head, Department of Radiology & Oncology, National University of Malaysia Medical Centre
- ▶ Associate Professor Dr Nirmala Bhoo-Pathy, Principal Investigator, ACTION Study Malaysia, Faculty of Medicine, University Malaya
- ▶ Dr Noor Hashimah Abdullah, State Epidemiologist (Non-Communicable Diseases Control), Kelantan, Ministry of Health Malaysia
- ▶ Dr Nor Saleha Ibrahim Tamin, Senior Principal Assistant Director, Cancer Unit, Non-Communicable Diseases Section, Disease Control Division, Ministry of Health Malaysia
- ▶ Dr Rozlan Ishak, Deputy Director, Non-Communicable Diseases, Disease Control Division, Ministry of Health Malaysia
- ▶ Dr Saunthari Somasundaram, President/Medical Director, National Cancer Society of Malaysia/Board Member, Union for International Cancer Control
- ▶ Professor Dato' Dr Yip Cheng Har, Principal Investigator, ACTION Study Malaysia, Sime Darby Medical Centre

# Participants

## Myanmar

- ▶ Professor Htun Lwin Nyein, Investigator/Head of Department of Haematology, Yangon General Hospital
- ▶ Dr Myint Shwe, Director for Non-Communicable Diseases, Department of Public Health (DOPH), Ministry of Health
- ▶ Dr Myo Khin, Primary Investigator, Department of Medical Research
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## Philippines

- ▶ Dr Clarito U. Cairo, Jr, Program Manager, National Cancer Control, Dept. of Health, Disease Prevention and Control Bureau
- ▶ Dr Corazon A. Ngelangel, ACTION Study Principal Investigator, Philippine General Hospital, Taft Avenue, Manila
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- ▶ Dr Marvin Galvez, Medical Specialist III, Philippine Healthcare Insurance Corporation (PhilHealth), Ortigas City, Manila
- ▶ Dr Madeleine de Rosas-Valera, Former Undersecretary for Health Policy, Finance and Research Development, Department of Health Philippines

## Thailand

- ▶ Mrs Nitaya Bhanuwate, Bureau of Non Communicable Diseases, Department of Disease Control, Ministry of Public Health
- ▶ Ms Tarinee Pangjunan, Bureau of Non Communicable Diseases, Department of Disease Control, Ministry of Public Health
- ▶ Dr Pattarawin Attasara, Advisor, Bureau of Medical Services Inspection, Department of Medical Services, Ministry of Public Health

## Vietnam

- ▶ Dr Nguyen Tien Quang, ACTION Investigator, National Cancer Hospital
- ▶ Dr Nguyen Thi Hoai Nga, ACTION Investigator, National Cancer Hospital
- ▶ Associate Professor Tran Thi Thanh Huong, National Institute for Cancer Control

# STUDY FINDINGS

Catastrophic health expenditure and 12-month mortality associated with cancer in Southeast Asia: results from a longitudinal study in eight countries



RESEARCH ARTICLE

Open Access



# Catastrophic health expenditure and 12-month mortality associated with cancer in Southeast Asia: results from a longitudinal study in eight countries

The ACTION Study Group

## Abstract

**Background:** One of the biggest obstacles to developing policies in cancer care in Southeast Asia is lack of reliable data on disease burden and economic consequences. In 2012, we instigated a study of new cancer patients in the Association of Southeast Asian Nations (ASEAN) region – the Asean CosTs In ONcology (ACTION) study – to assess the economic impact of cancer.

**Methods:** The ACTION study is a prospective longitudinal study of 9,513 consecutively recruited adult patients with an initial diagnosis of cancer. Twelve months after diagnosis, we recorded death and household financial catastrophe (out-of-pocket medical costs exceeding 30 % of annual household income). We assessed the effect on these two outcomes of a range of socio-demographic, clinical, and economic predictors using a multinomial regression model.

**Results:** The mean age of participants was 52 years; 64 % were women. A year after diagnosis, 29 % had died, 48 % experienced financial catastrophe, and just 23 % were alive with no financial catastrophe. The risk of dying from cancer and facing catastrophic payments was associated with clinical variables, such as a more advanced disease stage at diagnosis, and socioeconomic status pre-diagnosis. Participants in the low income category within each country had significantly higher odds of financial catastrophe (odds ratio, 5.86; 95 % confidence interval, 4.76–7.23) and death (5.52; 4.34–7.02) than participants with high income. Those without insurance were also more likely to experience financial catastrophe (1.27; 1.05–1.52) and die (1.51; 1.21–1.88) than participants with insurance.

**Conclusions:** A cancer diagnosis in Southeast Asia is potentially disastrous, with over 75 % of patients experiencing death or financial catastrophe within one year. This study adds compelling evidence to the argument for policies that improve access to care and provide adequate financial protection from the costs of illness.

## Background

The Association of Southeast Asian Nations (ASEAN) region consists of ten countries – Brunei, Cambodia, Indonesia, Laos, Malaysia, Myanmar, the Philippines, Singapore, Thailand, and Vietnam – and is home to over half a billion people. The burden of cancer is increasing in the ASEAN region, due to population ageing and growth and the adoption of cancer-associated lifestyle behaviours [1]. In 2012, there were estimated to be over

750,000 new cases of cancer, and incidence is expected to rise to 1.3 million per year by 2030 [2]. Survival rates for most cancers are poor and quality of life is greatly impaired [2–4]. In addition to this significant disease burden, cancer can have a profound economic effect on individuals and their households, especially among the poor and under-insured [5].

Most studies examining the economic burden of cancer have, however, been conducted in high-income settings. Little is known about its economic impact in low- and middle-income settings, where the financial implication of a cancer diagnosis may not be equitable because out-of-pocket (OOP) payments are the principal means of

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financing health care [6]. This not only relates to primary treatment, but may include long-term costs of adjuvant therapy and follow-up care [7–9]. Hence, a cancer diagnosis can quickly result in catastrophic payments for a household; that is, spending a disproportionate amount of household income on cancer treatment [10]. Furthermore, patients may be unable to continue working due to the burden of their symptoms, treatment, or side-effects, leading to poorer economic circumstances [11].

Health insurance is seen as an important means in offering households protection from catastrophic payments for illness. However, the extent of financial protection through insurance depends on which health services are covered and the level of subsidy offered. In the ASEAN region, while population coverage varies between 8 % (Laos) and 100 % (Malaysia), all countries – including those with universal health coverage – rely heavily on OOP financing [12, 13].

Despite the risk of a cancer epidemic overwhelming the region, governments have been slow to react to the health consequences of socioeconomic and demographic changes. Hence, in 2011, two regional initiatives were launched to increase cancer awareness and inform priority setting. First, a series of roundtable meetings of key stakeholders and experts were organised to generate knowledge and interest through engagement with the media [14, 15]. Second, a study of new cancer patients in eight countries in the ASEAN region (Cambodia, Indonesia, Laos, Malaysia, Myanmar, the Philippines, Thailand, and Vietnam) was instigated – the Asean CoTs In ONcology (ACTION) study – to assess the economic and health impact of cancer. This paper presents the main results.

## Methods

### Ethical approval

The ACTION study was approved by the University of Sydney's Human Research Ethics Committee. Approvals from local institutional ethics committees and other regional or national regulatory bodies were obtained prior to the initiation of the study in all centres (Additional file 1). Written informed consent, complying with local, regional, and national requirements, was obtained from all participants prior to entry into the study.

### Study design

ACTION was a prospective longitudinal study; detailed methods have been published previously [16]. In brief, patients diagnosed with a first time cancer were consecutively recruited (within 12 weeks from initial date of diagnosis) from 47 sites, including public and private hospitals and cancer centres. Patients were aged 18 years and older, aware of their cancer diagnosis, and willing to participate in follow-up interviews. Participants were interviewed (face-to-face or by telephone) at baseline, 3,

and 12 months after diagnosis. Questionnaires were translated into local languages.

### Baseline measures and key outcomes

Data were collected on age, sex, marital status, country of residence, highest level of education attained, employment status, recent experience of economic hardship (whether in the previous 12 months they were unable to make any necessary household payments (for example, food, housing) or needed assistance to do so) [17], annual household income, and health insurance status. Clinical characteristics, cancer site, and cancer stage (TNM classification) were obtained from medical records. Health-related quality of life was assessed using the EuroQol (EQ-5D) [18]. Further details are given in the study protocol [16].

The primary outcome at 12 months was financial catastrophe (FC) following treatment for cancer, defined as OOP costs at 12 months equal to or exceeding 30 % of annual household income [19, 20]. OOP costs represented hospital and non-hospital health care costs which were directly incurred by patients at point of delivery and not reimbursed by insurance. Participants prospectively completed a cost diary for the duration of the study. The second key outcome was all-cause mortality. FC and death were recorded at both follow-up interviews.

### Statistical analyses

Multinomial regression models were used to estimate odds ratios (ORs) and 95 % confidence intervals (CIs) for death and FC, relative to being alive without experiencing FC, thus allowing for death as a competing risk to FC. Baseline characteristics considered for association with these joint outcomes were socio-demographic (age, sex, and level of education), economic (household income grouped into low (0–75 % of mean national income), middle (75–125 %), and high income (>125 %), insurance status (yes or no), experience of economic hardship, and paid work status), and clinical (baseline health-related quality of life, cancer site – separately by sex – and cancer stage) [21]. Due to small numbers for some cancer sites, sites were grouped into body location or system: digestive/gastrointestinal; breast; gynaecological; head and neck; haematological/blood; respiratory/thoracic; and other cancers. Analyses were adjusted for age, sex, cancer stage, and geographic region, grouped as low (Cambodia, Myanmar), low-middle (Indonesia, Laos, Vietnam, the Philippines), and upper-middle income (Thailand, Malaysia). Participants who experienced FC at 3 months, but could not be contacted at 12 months, were coded as having experienced FC at 12 months. Primary analyses were conducted on participants with complete data on outcome status at 12 months. More extreme cut-offs for household income

groups were tested in a sensitivity analysis: low (0–50 % of mean national income); middle (50–150 %); and high income (>150 %). Furthermore, multiple imputation ( $m = 5$ ) using predictive mean matching was carried out to impute the missing data on the outcome variables. The imputation models included the outcome variables themselves, all socio-demographic, clinical, and economic predictors examined, and country [22]. Analyses were performed using STATA, version 12.0 (Stata, College Station, TX, USA), and R, version 2.15.3 (R Foundation for Statistical Computing, Vienna, Austria).

## Results

Between March 2012 and September 2013, after exclusions due to patient or doctor refusals, 9,513 patients were recruited into the study. The mean age was 52 years, 64 % were women, 61 % had attained at least secondary education, and 45 % had some form of health insurance. The most common cancer site recorded was breast (26 %); the greatest number was recruited in Indonesia (Table 1). For patients with available data on cancer stage ( $n = 5,159$ ), 11 % presented with stage I, 31 % with stage II, 33 % with stage III, and 24 % with stage IV cancers. Haematological cancers were diagnosed in 825 patients (Additional file 2: Table S1).

The follow-up interviews at 3 and 12 months were completed by 7,245 (76 %) and 5,245 (55 %) participants, respectively. At 12 months, 1,993 (29 %) participants had died. Complete outcome data (data on FC and death) were available for 6,787 participants (71 %) (Fig. 1).

Participants with incomplete outcome data ( $n = 2,726$ ) were slightly younger (51 versus 52 years), more likely to be male (38 versus 33 %), and less likely to have a high income (17 versus 38 %), compared to those with complete outcome data (all  $P$  values <0.001). There were no significant differences in other socio-demographic, clinical, or economic characteristics.

At 12 months, 3,248 participants (48 % of those with complete outcome data) experienced FC and 1,546 (23 %) were alive and did not experience FC. Survival without FC was most frequent in participants with haematological cancer (37 %), gynaecological cancer (27 %), and breast cancer (26 %) (Fig. 2).

After controlling for confounding variables, women had lower odds of death (OR, 0.62; 95 % CI, 0.51–0.75) than men, but sex was not significantly associated with FC, relative to the reference outcome (alive and no FC) (Table 2). Age of >65 years was associated with a higher odds of FC (1.51; 1.17–1.94) and death (2.64; 2.00–3.49), compared to age <45 years. Being unmarried was also associated with a higher odds of FC (1.09; 1.09–1.60) and death (1.42; 1.15–1.77), compared to participants who were married. Having completed primary education only, compared to tertiary education, was significantly

associated with a higher odds of FC (1.45; 1.16–1.82) and death (2.50; 1.93–3.25).

Participants in the low income category within each country had significantly higher odds of FC (5.86; 4.76–7.23) and death (5.52; 4.34–7.02) than participants with high income, relative to being alive and no FC. Using more extreme cut-offs for low and high household income (0–50 % of the mean national income for a low income and >150 % for a high income) resulted in higher odds of FC (9.16; 7.07–11.87) and death (9.30; 6.95–12.44) for the low income category. The country-region specific analysis showed that a low income is especially a factor in predicting FC in the upper-middle income countries (13.75; 10.21–18.51) and less so in lower-middle income countries (1.97; 1.38–2.82) (Additional file 2: Table S2a and S2b). Not having paid work also increased the odds of FC (1.32; 1.11–1.56) and death (1.60; 1.31–1.94). Having some form of health insurance provided protection from FC; those without insurance were more likely to experience FC than those with insurance (1.27; 1.05–1.52). Participants without health insurance were more likely to die (1.51; 1.21–1.88), relative to being alive and not experiencing FC; health insurance was inversely related to FC in upper-middle income countries only.

Cancer stage IV at diagnosis was significantly associated with a higher odds of FC (1.52; 1.12–2.05) and death (5.43; 3.76–7.82), compared to stage I. In terms of health-related quality of life, a decrement of 0.1 point as assessed on the EQ-5D was associated with higher odds of FC (1.11; 1.07–1.16) and death (1.24; 1.18–1.30).

In females, cancer site was not associated with FC. In males, cancer in the head and neck region (0.54; 0.36–0.80) and haematological cancers (0.56; 0.42–0.76) were associated with a lower odds of FC compared to digestive cancers (reference group).

Sensitivity analyses employing missing value imputation (Additional file 2: Table S3) did not change the inferences, except that the effect of health insurance on the odds of FC became non-significant at the conventional 5 % level.

## Discussion

To our knowledge, the ACTION study is the largest observational study of the household burden of cancer yet conducted in Asia. A year after diagnosis, almost a third of patients affected by cancer in the ASEAN region died and almost a half of their households faced catastrophic health care expenses. Patients with advanced stages of cancer at diagnosis and socioeconomically disadvantaged cancer patients, including those with primary education only, low income, and no health insurance, were more likely to experience FC or die within 12 months.

**Table 1** Demographic, socioeconomic, and clinical characteristics of the study population (n = 9,513)

Characteristic	n	%
Age (years)		
<45	2,780	29
45–54	2,801	30
55–64	2,463	26
≥65	1,467	15
Missing	2	<1
Sex		
Male	3,470	37
Female	6,043	63
Marital status		
Married	7,352	77
Not married	2,154	23
Missing	7	<1
Level of education		
0–6 years (primary)	3,693	39
7–12 years (secondary)	3,817	40
>12 years (tertiary)	1,992	21
Missing	11	<1
Country of residence		
Cambodia	206	2
Indonesia	2,335	25
Laos	101	1
Malaysia	1,662	18
Myanmar	1,178	12
Philippines	909	10
Thailand	1,206	13
Vietnam	1,916	20
Household size		
1–2	1,337	14
3–5	5,555	58
>5	2,570	27
Missing	9	<1
Household income (of mean national income)		
0–25 %	1,103	12
25–50 %	1,185	13
50–75 %	1,031	11
75–100 %	1,020	11
100–125 %	767	8
125–150 %	381	4
150–175 %	427	5
175–200 %	417	4
>200 %	1,819	19

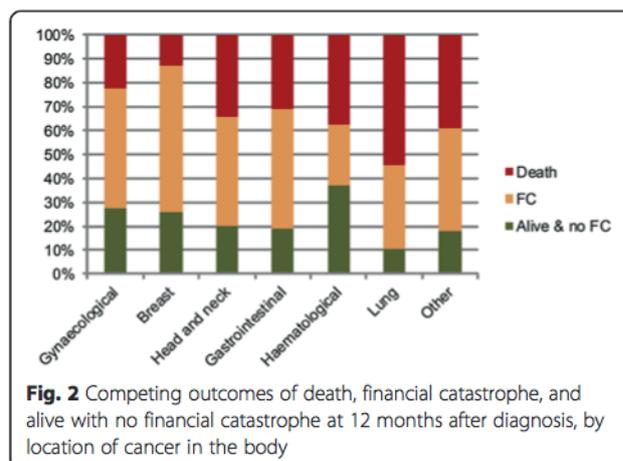
**Table 1** Demographic, socioeconomic, and clinical characteristics of the study population (n = 9,513) (Continued)

Not known	1,336	14
Missing	27	<1
Main source of household income		
Crops and agricultural sidelines	1,965	21
Family business	1,287	14
Wages	4,568	48
Remittances and gifts	455	5
Other income	1,213	13
Missing	25	<1
Health insurance status		
Government-provided insurance	3,061	32
Employment-based insurance	568	6
Private insurance	857	9
Other community insurance	65	<1
None	5,237	55
Missing	11	<1
Type of hospital		
Public	8,760	92
Private	610	6
Other (for example, military)	143	2
Experienced economic hardship in the year before diagnosis		
Yes	5,146	54
No	4,352	46
Missing	15	<1
Paid work (patient level) before diagnosis (self-employed or for a wage)		
Yes	4,512	47
No	4,992	53
Missing	9	<1
Cancer site		
Mouth and pharynx	1,063	11
Oesophagus	160	2
Stomach	305	3
Colon and rectum	910	10
Liver	83	1
Pancreas	53	<1
Trachea, bronchus, and lung	623	7
Melanoma	40	<1
Female breast	2,445	26
Cervix	1,005	11
Uterus	177	2
Ovary	242	3
Prostate	47	<1

**Table 1** Demographic, socioeconomic, and clinical characteristics of the study population (n = 9,513) (Continued)

Bladder	60	<1
Lymphomas and multiple myeloma	454	5
Leukaemia	371	4
Other malignant neoplasms	1,295	14
Missing	179	2
Cancer stage		
Stage I	590	6
Stage II	1,613	17
Stage III	1,696	18
Stage IV	1,260	13
None (haematological cancers)	825	9
Missing	3,529	37

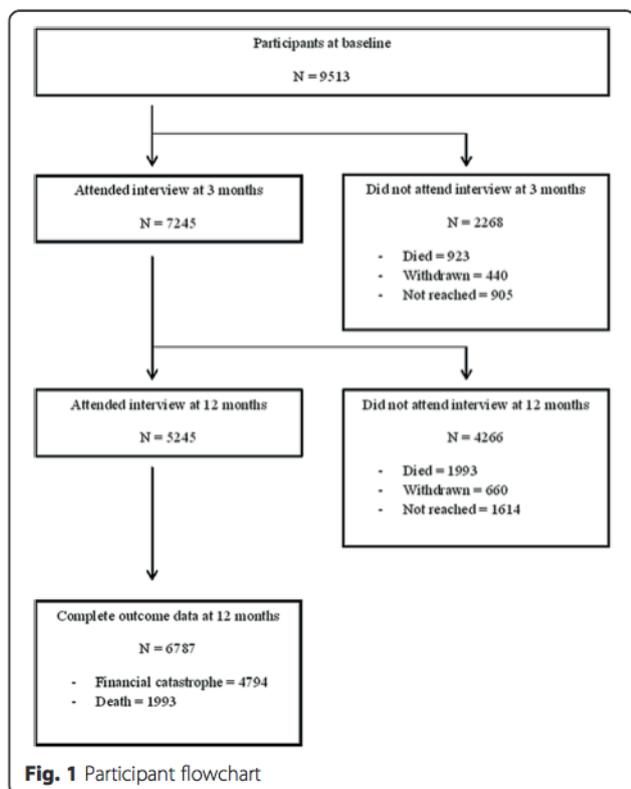
This research adds compelling evidence to the argument for effective cancer control policies and timely access to affordable treatment in low- and middle-income countries. Previously, evidence of significant household economic burden due to cancer has come from only a few, small cross-sectional studies [23, 24]. There has, however, been increasing attention given to the economic impact of non-communicable diseases in low- and middle-income settings, with two recent reviews



**Fig. 2** Competing outcomes of death, financial catastrophe, and alive with no financial catastrophe at 12 months after diagnosis, by location of cancer in the body

highlighting the heavy financial burden that such diseases pose on affected households [25, 26]. In a review of studies that reported on expenditures on chronic diseases, mean expenditures ranged from 5 % to 59 % of household income, household total health expenditure, and household non-food expenditure, but results on catastrophic health expenditures were not reported [26]. A literature review on the costs imposed by non-communicable diseases in low- and middle-income settings included 19 studies that reported on OOP health expenditure as a percentage of capacity to pay or total household expenditure due to health shocks, and found that between 0 % and 34 % of the study population experienced FC, depending on the methods used [25]. Comparison of these findings with our results is difficult due to differences in defining catastrophic spending: some studies used a threshold OOP share of total household expenditure; others of household ‘capacity to pay’; or of ‘non-food expenditure’. In addition, the threshold used also varies, ranging from 10 % to 40 %. Furthermore, in the majority of the above-mentioned studies, OOP estimates were based on retrospective recall of health care utilisation in household surveys, while our study used a prospective cost diary. Studies have shown that OOP estimates depend heavily on the measures used and length of recall periods [27, 28]. Compared to prospective cost diaries, health care utilisation is generally under-reported in household surveys [27]. Nonetheless, results from this study, taken together with other studies, signal the potential for cancer to result in a significant economic burden.

Women were less likely to die in the year following a cancer diagnosis than men, but no significant association between the patient’s sex and their household’s odds of experiencing FC was found. Better survival rates for female cancers may be explained by the high proportion of breast cancer in this population, and its relatively good prognosis, while colorectal, mouth and lung cancers, with a generally poor prognosis [29], were most common in men.



**Fig. 1** Participant flowchart

**Table 2** Odds ratios (and 95 % confidence intervals) for financial catastrophe and death, relative to no financial catastrophe (reference) in all participants with complete outcome data (n = 6,787), adjusted for age, sex, cancer stage, and geographic region

Characteristic		Financial catastrophe	Death
Age (years)	<45	Reference	Reference
	45–54	1.05 (0.85–1.30)	1.08 (0.84–1.38)
	55–64	1.41 (1.13–1.75)	1.59 (1.23–2.04)
	≥65	1.51 (1.17–1.94)	2.64 (2.00–3.49)
Sex	Men	Reference	Reference
	Women	1.14 (0.96–1.36)	0.62 (0.51–0.75)
Highest level of education	Tertiary	Reference	Reference
	Secondary	1.44 (1.16–1.79)	1.43 (1.11–1.85)
	Primary	1.45 (1.16–1.82)	2.50 (1.93–3.25)
Marital status	Married	Reference	Reference
	Unmarried	1.32 (1.09–1.60)	1.42 (1.15–1.77)
Health insurance	Yes	Reference	Reference
	No	1.27 (1.05–1.52)	1.51 (1.21–1.88)
Economic hardship	No	Reference	Reference
	Yes	1.40 (1.19–1.64)	1.82 (1.51–2.20)
Income level	High	Reference	Reference
	Middle	2.15 (1.73–2.67)	1.91 (1.47–2.47)
	Low	5.86 (4.76–7.23)	5.52 (4.34–7.02)
Paid work	Yes	Reference	Reference
	No	1.32 (1.11–1.56)	1.60 (1.31–1.94)
Cancer region: females	Digestive/gastrointestinal	Reference	Reference
	Breast	0.99 (0.69–1.41)	0.45 (0.29–0.69)
	Gynaecological	0.73 (0.49–1.08)	0.69 (0.43–1.11)
	Head and neck	0.69 (0.40–1.19)	0.65 (0.35–1.18)
	Haematological/blood	0.90 (0.69–1.19)	1.93 (1.39–2.69)
	Respiratory/thoracic	1.36 (0.65–2.85)	2.28 (1.07–4.86)
	Other	0.83 (0.48–1.41)	0.99 (0.54–1.83)
Cancer region: males	Digestive/gastrointestinal	Reference	Reference
	Head and neck	0.54 (0.36–0.80)	0.36 (0.24–0.55)
	Haematological/blood	0.56 (0.42–0.76)	1.10 (0.80–1.51)
	Respiratory/thoracic	1.18 (0.67–2.09)	1.88 (1.07–3.31)
	Other	0.56 (0.37–0.86)	0.65 (0.41–1.01)
Cancer stage	I	Reference	Reference
	II	1.23 (0.94–1.60)	0.93 (0.65–1.34)
	III	1.23 (0.94–1.62)	2.34 (1.65–3.33)
	IV	1.52 (1.12–2.05)	5.43 (3.77–7.82)
	None (haematological cancers)	0.68 (0.49–0.95)	3.04 (2.07–4.46)
EQ-5D score (per 0.1 decrement)		1.11 (1.07–1.16)	1.24 (1.18–1.30)

The risk of FC increases with age, perhaps due to increasing co-morbidities which result in greater complexity of the illness and treatment. As expected, age was significantly associated with the risk of death at

12 months. A more advanced cancer stage at diagnosis was associated with higher odds of FC and death.

We found that having a below average income, no health insurance, not having paid work, having experienced

economic hardship prior to diagnosis, and having experienced no more than primary education, were all associated with a higher odds of experiencing FC. Household income showed the strongest association, with these patients having more than five times the odds of FC when an income <75 % of the mean national income was considered a low income, and even nine times the odds when an income <50 % was used as the threshold. That this gradient was found to be more pronounced in upper-middle compared to lower-middle income countries suggests that the risk of FC posed by having a low income is as much based on relative as opposed to absolute disadvantage.

The relationship between health insurance and FC found in the primary analyses of this study was not particularly strong, and was non-significant in the sensitivity analysis where missing data were imputed. Analyses by level of economic development provided some explanation to these inconclusive results: in upper-middle income countries (Malaysia and Thailand) health insurance did provide significant protection from FC; but in lower-middle income countries it did not. This may be explained by the limitations of benefit packages available through health insurance programs in some of the participating lower-middle income countries, which has been well-recognised as a problem in Vietnam and the Philippines [13]. Since health insurance status was assessed as a categorical variable it was not possible to take into account variations in level of coverage.

The findings in relation to the socioeconomic variables reinforce the well-founded conclusions that can be drawn from the social determinants literature – those at greater levels of disadvantage tend to have higher risks of financial hardship and poor health [30]. Reflecting this was the strong relationship of various socioeconomic indicators and death within 12 months. This, and the observed association between low quality of life and higher odds of FC, underscores the relationship between underlying economic disadvantage, health, and economic outcomes in cancer.

The study has a number of limitations. We did not recruit a random cross-section of people with incident cancer in the region due to a variety of reasons. First, as we could only identify cases once individuals presented to hospital, we potentially excluded individuals who did not seek hospital treatment due to geographical isolation, poverty, or socio-cultural barriers [31]. Second, clinicians responsible for enrolling patients into the study appear to have under-recruited those with the most virulent types of cancer, such as lung and liver cancers. Third, public awareness of some types of cancer, specifically breast cancer, was greater than for others, which is likely to have additionally motivated certain cancer patients, particularly women, to agree to participate in the

study. Furthermore, patients treated in private hospitals were under-represented in the study (6 %) and it is unclear whether this has introduced a bias in our estimates of the level of FC. Although private hospitals have often been observed to generate the highest OOP expenses [25] they also tend to attract patients with a higher income. All these factors compromise the generalisability of some of our results, and probably means that we have underestimated the 12-month rate of death from all cancers, but is unlikely to invalidate the main conclusions. Another drawback is that 2,767 participants (29 %) lacked at least one component of data on death, household income, or OOP costs required to compute the study outcomes. The challenges of eliciting income and other socioeconomic data have been well-documented [32], and incomplete follow-up due to being unable to contact many subjects in rural areas, despite repeated telephone calls and field visits, is inevitable in the region studied. The findings from the sensitivity analysis, in which multiple imputation was used to impute the missing data, did not vary substantially from the non-imputed findings, and would not alter conclusions.

These drawbacks have to be considered in the light of the paucity of cancer statistics from the region sampled [2, 15, 33]. The study benefited from having a large sample of patients with various cancer sites and cancer stages from eight countries which have disparate health systems. Due to the large size of the study, it was possible to produce reliable estimates of the influence of a range of demographic, socioeconomic, and clinical predictors. In addition, the study's longitudinal approach improved on most previous economic studies which used cross-sectional surveys based on retrospective reporting of costs, as well as much smaller sample sizes, with subsequent jeopardy for both bias and sampling error. Furthermore, using a multinomial logistic regression model, we were able to adjust FC for the competing outcome of death. This is important as studies that have previously examined the burden to households associated with illnesses have generally focused exclusively on 'economic' outcomes in terms of OOP costs and FC [10, 25, 26], but have overlooked a crucial reason why patients may avoid, or not report incurring, high OOP costs, that is, they may die, and this is unlikely to be non-informative censoring.

## Conclusions

This study provides the type of precise evidence that is required to develop effective policies and programs to address the overall burden of cancer care in the ASEAN region, with potential generalisation elsewhere in the developing world. The results show that a cancer diagnosis is disastrous, even within only 12 months, for over 75 %

**Table 2** Odds ratios (and 95 % confidence intervals) for financial catastrophe and death, relative to no financial catastrophe (reference) in all participants with complete outcome data (n = 6,787), adjusted for age, sex, cancer stage, and geographic region

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	Respiratory/thoracic	1.18 (0.67–2.09)	1.88 (1.07–3.31)
	Other	0.56 (0.37–0.86)	0.65 (0.41–1.01)
Cancer stage	I	Reference	Reference
	II	1.23 (0.94–1.60)	0.93 (0.65–1.34)
	III	1.23 (0.94–1.62)	2.34 (1.65–3.33)
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We found that having a below average income, no health insurance, not having paid work, having experienced

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## **Additional files**

**Additional file 1: Overview approvals local ethics boards ACTION Study.** (DOCX 14 kb)

**Additional file 2: Table S1.** Cancer stage by cancer site (n = 5,984).

Cancer stage was not available for 3,529 participants. Table S2a. Odds ratios (and 95 % confidence intervals) for financial catastrophe and death,

relative to no financial catastrophe (reference) in participants from lower-middle income countries, adjusted for age, sex, cancer stage, and geographic region. Table S2b. Odds ratios (and 95 % confidence intervals) for financial catastrophe and death, relative to no financial catastrophe (reference) in participants from upper-middle income countries, adjusted for age, sex, cancer stage, and geographic region. Table S3. Odds ratios (and 95 % confidence intervals) for financial catastrophe and death, relative to no financial catastrophe (reference) in all participants ( $n = 9,513$ ), using missing value imputation and adjusted for age, sex, cancer stage, and geographic region. (DOCX 36 kb)

#### Abbreviations

ACTION: Asean CoTs In Oncology; ASEAN: Association of Southeast Asian Nations; CI: Confidence interval; FC: Financial catastrophe; OOP: Out-of-pocket; OR: Odds ratio.

#### Competing interests

The authors declare that they have no conflicts of interest, other than the source of funding for this study.

#### Authors' contributions

Principal investigators assisted with the design of the questionnaires and were responsible for patient recruitment and data collection at participating sites. Other contributors assisted with data collection, patient interviews, and data entry. Contributions of members of the writing committee: MK, SJ, and MW designed the study; NBP, CHY, and HT collected data; MK wrote the first draft; and NBP, SJ, SP, HT, MW, and CHY made critical revisions to the manuscript. SP conducted the statistical analysis. All members approved the final manuscript.

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# STUDY FINDINGS

The Societal and Economic Impact of  
Cancer in the Southeast Asian Region

# The Societal and Economic Impact of Cancer in the Southeast Asian Region

It is estimated that there were over 770,000 new cases of cancer and 527,000 cancer deaths in the Southeast Asian region in the year 2012. The number of new cases is expected to rise by about 70% by 2030 to reach 1.3 million.<sup>1</sup>

The ACTION (ASEAN Costs in Oncology) study, conducted by the George Institute for Global Health, examined the human cost of cancer to populations across eight countries in Southeast Asia (SEA) : Cambodia, Indonesia, Laos, Malaysia, Myanmar, Philippines, Thailand and Vietnam.<sup>2</sup>

The study was designed to assess the impact of cancer on household economic wellbeing and patients' survival and quality of life. The study provides evidence for countries in the region to put in place policies that can improve access to cancer care and provide adequate financial protection from the burden of costs of illness.<sup>2</sup>

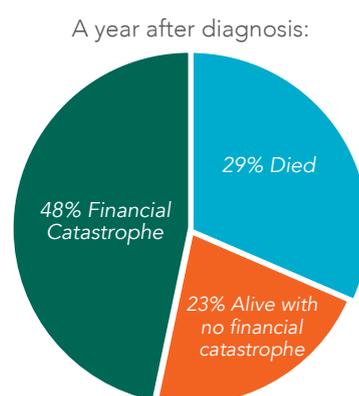
## Study Highlights

### Key points

- Ageing populations and rising cancer burden are leading to the risk of cancer becoming an epidemic that will overwhelm the region.<sup>2</sup>
- Cancer diagnosis in the SEA region is potentially disastrous, with over 75% of patients experiencing death or financial catastrophe within one year of diagnosis.<sup>2</sup>
- Cancer has a compounding effect on existing poverty, with low income patients facing the worst outcomes in the study.<sup>2</sup>
- Once diagnosed with cancer, SEA populations face devastating hurdles in receiving treatment.<sup>2</sup>
- With the growing burden of all cancers in the SEA region, urgent action is needed to protect populations from the financial burden of disease and to reduce the impact of loss of economic productivity.<sup>2</sup>

### Key statistics

Being diagnosed with cancer in SEA is potentially disastrous, as over 75% of patients will experience death or financial catastrophe 12 months after diagnosis.<sup>2</sup>



44% of patients who were alive and who had no hardship at baseline had some hardship at 12 months.<sup>2</sup>

Of this 44%:



## Key Findings

Factors associated with greater chances of financial catastrophe or death:<sup>2</sup>

- **Age:** Older patients (>65 years) were more likely to experience financial catastrophe and death than patients under 45 years.
- **Income level:** Low income is a key factor in predicting financial catastrophe, particularly in upper-middle income countries.
- **Education levels:** Lower education levels were significantly associated with higher odds of death and financial catastrophe.
- **Health Insurance:** Those without some form of health insurance were more likely to experience financial catastrophe than those with insurance. Participants without insurance were at higher risk of death, relative to being alive and not experiencing financial catastrophe.

Presentation stage at point of diagnosis (for available data on cancer stage)



**Cancer stage:** A more advanced cancer stage at diagnosis is associated with more than five times the odds of death and 50% higher odds of financial catastrophe.<sup>2</sup>

## Patient Experience: Malaysia

Mei\* is a very busy 32 year old mother of three from Kuala Lumpur, Malaysia. She first noticed a lump when she was breast feeding with her second child. Worried, she was unsure who to consult or where to seek help. She went to her gynecologist several times and was told repeatedly that nothing was wrong. It wasn't until she was heavily pregnant with her third child that her symptoms were taken seriously and she was referred to a breast surgeon. A biopsy revealed, to her shock, that she had breast cancer. Because the diagnosis was delayed, by that stage, it had also spread to her lymph nodes. She was angry and scared.

To make matters worse, Mei had a long and anxious wait until her baby was born until she could be treated. Two weeks after the birth, and still in post-natal recovery, Mei started chemotherapy to shrink the tumour. She later underwent surgery and later, radiotherapy for six weeks alongside targeted therapy.

A busy mum, with infants, the emotional stress weighed heavily on Mei and she attributes the support of her mum, husband and wider support network for getting her through.

Mei's journey continues to be a struggle, but despite this she considers herself one of the lucky ones; firstly because her pregnancy made her a priority case for doctors and secondly because insurance covered the costs of her expensive treatment. Despite this, Mei still sees an impact on her household income from health supplements and other out of pockets which were burdensome especially with three small children.

\*The patient name has been changed

“ I used to be a caretaker, now I am the patient too. ”

## Why was the study conducted?

Cancer has been cited as the biggest cause of mortality worldwide, with 8.2 million deaths in 2012 (IARC Global Cancer Report).<sup>1</sup> The cancer challenge in SEA is particularly pronounced, with 70% of global mortality in the next two decades predicted to occur in low and middle income countries.

The economic burden of cancer treatments to health systems, individuals and their households will grow as the availability of medical technologies and treatments expands across regions. These impacts will be felt most strongly in socioeconomically disadvantaged groups, particularly those in low and middle

income countries where social safety nets are less likely to be present. Cancer can therefore be a major cause of economic hardship, because treatments are costly and the disease impacts people's ability to work. In addition, economic hardship can have a devastating effect on cancer outcomes.

Little evidence exists about the economic impact of cancer on households in low and middle income settings and its relationship to treatment patterns and health outcomes.

## Patient Experience: Myanmar

Aung\* is 52 years old and lives in Yangon, Myanmar. She was diagnosed with Stage 2 breast cancer at the age of 50.

Having never been married, when her symptoms first arose, it was Aung's neighbours who urged her to see an oncologist. Her brother and cousin helped her arrange it. At first, her family didn't let her know the result of her test as they wanted to protect her from the news.

After finding out her diagnosis, Aung received treatment at a private hospital, which was much cleaner than a public hospital. The cost of treatment exceeded her income, so she borrowed money from neighbours and relatives. Aung also had to leave her job at a kitchenware stall at the local market and rent out her space to others in order to pay for treatment.

Aung's younger brother, a key part of her support network passed away himself from liver cancer after she was diagnosed. He survived less than a year after his diagnosis, after struggling to help pay to cure his sister's cancer. He didn't want her to know his financial struggles and tried to manage it all himself.

Aung's biggest priority is to get well so that she can care for her elderly mother.

\*The patient name has been changed

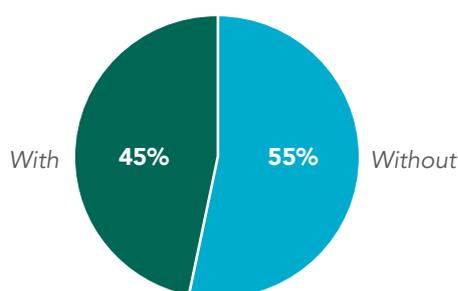
**“ Cancer has changed my life completely because in the past I would go to work regularly and I had no worries for money. Now I can't work and if I work hard I feel very tired. ”**

## How the study was conducted

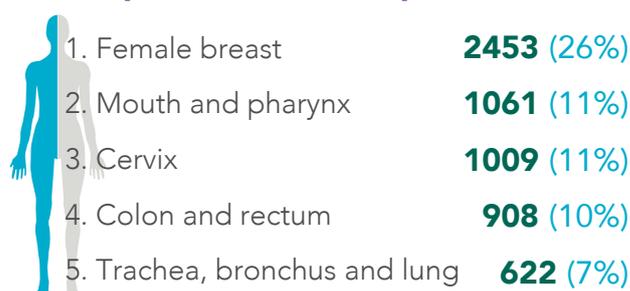
The longitudinal cohort study followed 9513 cancer patients through their first year following diagnosis, and involved a mix of public and private hospitals. The study represented a broad, partly working-age population with a mean age of 52 years. Previous data from the SEA region were limited, and only relate to incidence and prevalence, which portrayed only a crude indication of the burden of cancer on people's lives.<sup>2</sup>

Patient interviews took place at baseline diagnosis, 3 months and 12 months. The primary outcome was financial catastrophe, defined as more than 30% of household income spent on out-of-pocket expenses for cancer treatment at 12 months following the cancer diagnosis. Secondary outcomes included death, quality of life, psychological distress and disease status.<sup>2</sup>

### Patients who had health insurance<sup>2</sup>



### Top 5 cancer sites represented<sup>2</sup>



## Patient Experience: Philippines

Marites\* is from the Philippines, is 61 years old, single and living with her sister. She was diagnosed with Stage 3B ductal carcinoma, a type of breast cancer when she was 58.

When Marites was told that she had carcinoma, she did not understand that it refers to cancer and that she had a malignant tumor. She asked family, relatives, friends, and searched online about the diagnosis. She sought medical advice from doctors who explained her treatment plan.

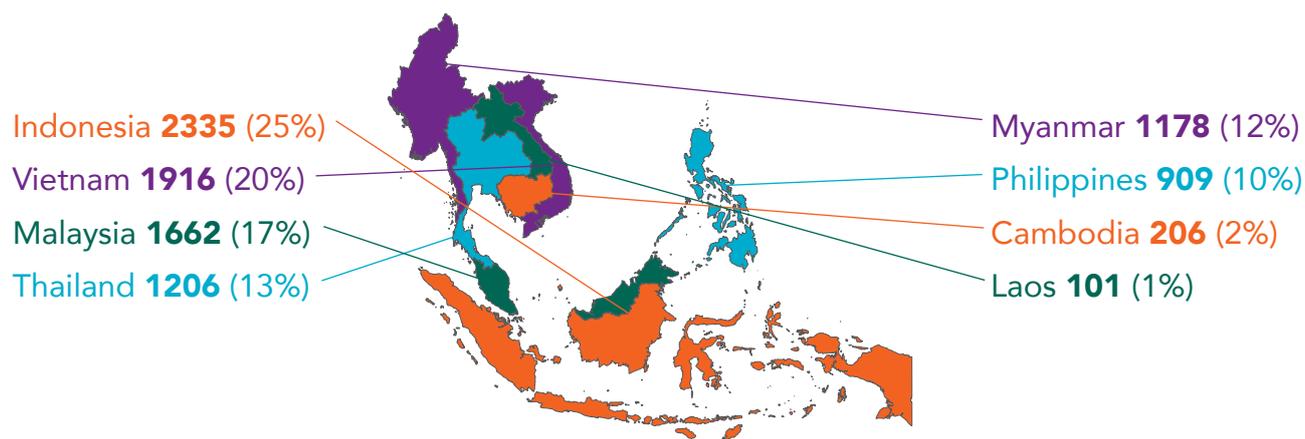
Marites had her left breast removed through mastectomy, followed by chemotherapy and radiotherapy. Her tests showed that she was ER/PR positive and HER2 negative. She paid for her surgery out of her savings; sold the small property that she inherited from her deceased parents; and, aunts and uncles had to remortgage their homes to help her pay for treatment. It was her cousin (a doctor) who provided most of the medical supplies needed for the operation. Thankfully, the Philippine Charity Sweepstakes Office (PCSO), the national lottery agency, provided funding for her one-month, daily radiotherapy sessions.

Marites' cancer prevented her from continuing work in selling insurance policies and left her dependent on her brother and sister. Luckily after treatment, she has been able to slowly return to ballroom dancing and non-rigid exercises, but is still unable to work.

\*The patient name has been changed

“ My only wish is for the Philippine government to allocate budget for free cancer medical services because there are many poor and sick Filipinos who need assistance. ”

## Countries involved & sample size



64% Female  
36% Male



Mean age 52 years



Public and  
private mix



9513 patients



47 study sites



Baseline, 3 month &  
12 month interviews

## Patient Experience: Indonesia

Melati\* is 52 years old and lives in Jakarta, Indonesia. From when she first noticed symptoms, a lump in the breast, it took two years and five check ups with five different doctors until a biopsy confirmed she had stage 2 breast cancer.

Frustrated the cancer was not caught earlier, Melati underwent surgery and several courses of chemotherapy, at one of the main hospitals in Jakarta. Conditions in the wards were crowded and consequently, patients have to wait long periods of time. The oncologist had limited time to converse about her diagnosis and outlook. Given the situation, Melati understood that the doctor would not have enough time to explain more about her disease. For this reason, she decided to proactively ask questions to her doctor to get a better understanding of her condition.

Now in remission, Melati has been able to get back to a relatively normal life taking care of the family home and her husband. She feels very fortunate that cancer treatment was covered by insurance but despite this her children, who are in their 20s, still needed to support with some out of pockets.

\*The patient name has been changed

**“ Patients need to be proactive when speaking with their doctor and should not just stay silent. If they don’t ask questions, the doctor will not say much either. ”**

## Action plan

- There is a clear need for governments to extend financial protection through social health insurance and publicly-supported cancer care to better protect citizens from the costs associated with cancer treatment.
- There is an urgent need to create and better utilise existing social safety nets to prevent citizens from poverty and economic hardship after cancer diagnosis, particularly in socioeconomically disadvantaged communities.
- Outcomes can be improved and costs minimised through high-quality screening programmes that achieve high uptake and cover large numbers of the population. Earlier detection will reduce the costs of treating cancer to government, individuals and households, and will increase economic productivity.
- Understanding the impact of effective and more efficient efforts to tackle cancer outcomes including raising awareness of the cancer burden, should contribute to the improvement of outcomes.
- Governments across SEA need to invest more heavily in efforts to increase early detection of cancer, as the risk of dying from cancer and facing catastrophic costs was associated with a more advanced disease stage at diagnosis. Prioritising cancer as a major health issue will improve survival rates and reduce the economic burden of cancer through reduced management costs (personal and systemic) and loss of economic productivity.
- Governments in the region need to recognise that the costs associated with non-communicable diseases such as cancer are a significant driver of poverty in SEA.
- There is a need to strengthen financial protection from all costs of treatment through universal health coverage, which shall be an economic and health sector priority in the region.
- Cancer must be recognised and prioritised, and seen as a cross-governmental national issue affecting households, society and the economy, rather than limited to health.
- Governments must integrate national cancer-control programmes in existing health systems, in line with the Jakarta Call for Action on Cancer Control.

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2. The George Institute, ASEAN Costs In Oncology “Cancer and its economic impact on households in the ASEAN countries” (ACTION) study



# OTHERS

A Consensus Plan for Action  
to Improve Access to Cancer Care  
in the Association of Southeast  
Asian Nations (ASEAN) Region

## COMMENTARY

# A Consensus Plan for Action to Improve Access to Cancer Care in the Association of Southeast Asian Nations (ASEAN) Region

Mark Woodward

### Abstract

In many countries of the Association of Southeast Asian Nations (ASEAN), cancer is an increasing problem due to ageing and a transition to Western lifestyles. Governments have been slow to react to the health consequences of these socioeconomic changes, leading to the risk of a cancer epidemic overwhelming the region. A major limitation to motivating change is the paucity of high-quality data on cancer, and its socioeconomic repercussions, in ASEAN. Two initiatives have been launched to address these issues. First, a study of over 9000 new cancer patients in ASEAN - the ACTION study - which records information on financial difficulties, as well as clinical outcomes, subsequent to the diagnosis. Second, a series of roundtable meetings of key stakeholders and experts, with the broad aim of producing advice for governments in ASEAN to take appropriate account of issues relating to cancer, as well as to generate knowledge and interest through engagement with the media. An important product of these roundtables has been the Jakarta Call to Action on Cancer Control. The growth and ageing of populations is a global challenge for cancer services. In the less developed parts of Asia, and elsewhere, these problems are compounded by the epidemiological transition to Western lifestyles and lack of awareness of cancer at the government level. For many years, health services in less developed countries have concentrated on infectious diseases and mother-and-child health; despite a recent wake-up call (United Nations, 2010), these health services have so far failed to allow for the huge increase in cancer cases to come. It has been estimated that, in Asia, the number of new cancer cases per year will grow from 6.1 million in 2008 to 10.6 million in 2030 (Sankaranarayanan et al., 2014). In the countries of the Association of Southeast Asian Nations (ASEAN), corresponding figures are 770 thousand in 2012 (Figure 1), rising to 1.3 million in 2030 (Ferlay et al., 2012). ASEAN consists of Brunei Darussalam, Cambodia, Indonesia, Lao, Malaysia, Myanmar, the Philippines, Singapore, Thailand and Viet Nam. It, thus, includes low- and middle-income countries where the double whammy of infectious and chronic diseases will pose an enormous challenge in allocating limited resources to competing health issues. Cancer statistics, even at the sub-national level, only tell part of the story. Many individuals who contract cancer in poor countries have no medical insurance and no, or limited, expectation of public assistance. Whilst any person who has a family member with cancer can expect to bear some consequential burden of care or expense, in a poor family in a poor environment the burden will surely be greater. This additional burden from cancer is rarely considered, and even more rarely quantified, even in developed nations.

**Keywords:** Cancer incidence - cancer mortality - ASEAN

*Asian Pac J Cancer Prev*, 15 (19), 8521-8526

### Policy Roundtable in Jakarta

In November 2012, a group of experts in the field was assembled in Jakarta, under the auspices of the ASEAN Foundation, to review the state of cancer treatment and services in ASEAN, with the exception of Brunei Darussalam and Singapore. This meeting produced the Jakarta Call for Action on Cancer Control (Box 1), which was subsequently endorsed at the Second Meeting of the ASEAN Task Force on Non-communicable Diseases (NCD) in Manila in October 2013. In broad terms,

this document summarises the current situation in the cancer arena and articulates broad plans to strengthen health policy; prevention and early detection; diagnosis, treatment and palliative care; and surveillance and research. This builds upon the significant, but generally under-resourced and narrowly focused, programmes that already exist in member nations.

### Shortfalls in Data

Perhaps the biggest obstacle to developing future

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WE, THE PARTICIPANTS of the First Policy Roundtable on Future access to Cancer Care in ASEAN Member States from the Kingdom of Cambodia, the Republic of Indonesia, the Lao People's Democratic Republic, Malaysia, the Republic of Union of Myanmar, the Republic of the Philippines, the Kingdom of Thailand and the Socialist Republic of Viet Nam, held in Jakarta, Indonesia on 23 November 2012,

NOTED WITH CONCERN THAT:

1. There were over 700,000 new cases of cancer and 500,000 cancer deaths in ASEAN in the year 2008, leading to approximately 7.5 million DALYs lost in one year.
2. The burden of cancer in ASEAN continues to increase largely because of the aging and growth of the population alongside an increasing adoption of cancer-causing behaviours, particularly smoking.
3. The decline in productivity due to illness and deaths from cancer will undermine physical and human capital in ASEAN. Cancer will evolve into a staggering economic burden in the coming years and will constitute a significant impediment to mitigation of poverty in ASEAN.
4. Economic policy makers see cancer as an issue confined only to the health sector.

ACKNOWLEDGED THAT:

1. WHO has been the global leader in promoting and providing guidance for cancer control planning and programme.
2. In May 2005, the 192 WHO Member States attending the 58th World Health Assembly, the governing body of WHO, approved a resolution that calls on all WHO Member States to develop national cancer programmes covering preventive measures, early detection and screening, and improved treatment and palliative care.
3. The vision of the "Healthy ASEAN 2020" adopted at the 5th ASEAN Health Ministers Meeting held in April 2000 in Yogyakarta, Indonesia, is envisioned that by 2020, health shall be at the centre of development and ASEAN cooperation in health shall be strengthened to ensure that our peoples are healthy in mind and body, and living in harmony in safe environments.
4. The Ministers of Health of ASEAN Member States have prioritised cancer as one of the non-communicable diseases to be addressed, following the 6th ASEAN Health Ministers Meeting on Healthy ASEAN Lifestyles (Vientiane Declaration) in 2002.
5. The ASEAN Cancer Stakeholders Forum, held in July 2011 in Singapore, has addressed the issue of the cancer burden in all ASEAN Member States and established a sense of urgency regarding the need to take immediate action.
6. The Joint Statements of the 11th ASEAN Health Ministers Meeting, the 5th ASEAN Plus Three Health Ministers Meeting and the 4th ASEAN-China Health Ministers Meeting, 5-6 July 2012 in Phuket, Thailand recognised cancer together with cardiovascular diseases, chronic respiratory diseases and diabetes as one of four principal NCDs to be tackled.
7. ASEAN Task Force on Non Communicable Diseases is the health subsidiary body to develop and implement the ASEAN Workplan on Non-Communicable Diseases, including concerns on cancer.

RECOGNISED THAT:

1. ASEAN Member States have developed programmes to prevent and control cancer based on countries' situations.
2. Academic institutions, scientists, researchers in ASEAN are contributing significantly in understanding the disease which in turn can be widely used as the basis for evidence-based management.
3. More concerted, strategic, focused and multi-sectoral policy approaches, underpinned by solid researches, are essential to help reverse the negative trends in the regional incidence of cancer.
4. There has been progress in public-private partnerships.

CALL upon all stakeholders of ASEAN in health policy:

1. To strengthen technical leadership in the region to control cancer by demonstrating that a country's investment is dealing with the cancer burden.
2. To recommend to incorporate cancer control issues in regional/international platforms concerning ASEAN Health Cooperation.
3. To increase collaboration with development partners, private sector and concerned civil societies to invest in cancer control efforts, including cancer database.
4. To mobilise stakeholders to ensure that strategies to control cancer regionally reach the targeted population.

Prevention and Early Detection

1. To increase efforts to reduce tobacco consumption by implementing national regulations as well as encouraging governments to implement the Framework Convention on Tobacco Control (FCTC).
2. To raise public awareness regarding the need for campaign to reduce culturally sensitive cancer risk factors and promote risk factors reduction strategies at the community level.
3. To implement efforts to reduce exposure to carcinogens.
4. To promote access to adequate and affordable screening and treatment for the detectable cancers and vaccines to prevent cancer-related infections.

Diagnosis, Treatment and Palliative Care

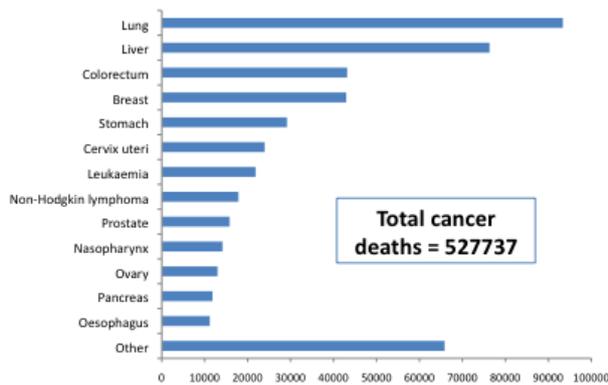
1. To develop cancer diagnosis and treatment guidelines that are relevant to country needs and resources.
2. To gradually meet the need for sufficient equipment and facilities on diagnosis, treatment, palliative, and rehabilitation and well-trained staff for patients and survivors.
3. To increase access to affordable, quality and adequate health care facilities and medical services, including medication for cancer.
4. To increase the number of health professionals with expertise in cancer control by providing specialist training opportunities and fellowships to enable professionals to study in specialised settings.
5. To raise public awareness about the impact of health professionals emigration on the ability of receiving countries to provide adequate levels of cancer care and work collectively to address shortages of health professionals nationally and regionally as well as the resultant deepening of inequity.

Surveillance and Research

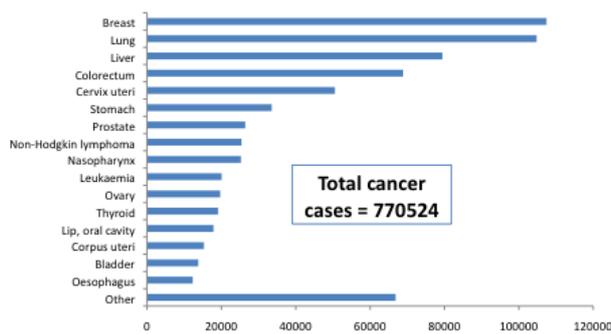
1. To develop and strengthen cancer surveillance through population-based cancer registries.
2. To increase investment in independent basic and applied cancer research and accelerate the translation of research findings into clinical and public health practice.
3. To encourage cancer research organisations among ASEAN Member States to share information, collaborate and define complementary research objectives to optimise the use of the limited funds available for cancer research and avoid duplication of efforts.

AND TO THIS END, WE resolved to submit this Jakarta Call for Action on Cancer Control for further deliberation by the relevant sectors and subsidiary bodies involved in the ASEAN Health Cooperation. 23 November 2012 Jakarta, Indonesia

### Box 1. Jakarta Call for Action on Cancer Control



**Figure 1. Cancer Incidence in The ASEAN Region, 2012. Source of Data: GLOBOCAN (April 16, 2014)**



**Figure 2. Deaths from Cancer in The ASEAN Region, 2012. Source of Data: GLOBOCAN (April 16, 2014)**

policies in cancer care in ASEAN is the lack of reliable data and, for this reason, the Jakarta Call encourages the proliferation of cancer registries. The essential source of international statistics on cancer is GLOBOCAN (Ferlay et al., 2012), which (for 2012 data) places three ASEAN countries in the set of countries that, globally, have the worst quality data on cancer incidence, and four ASEAN countries in the set having the worst quality data on cancer mortality. National death registries are sometimes incomplete, cause of death may be made by unqualified arbitrators, such as through a verbal autopsy, and the range of cancers listed in official compilations may be limited (Kimman et al., 2012a; Moore et al., 2010a; Moore et al., 2010b). In contrast, Singapore has the best quality data of both types.

For most ASEAN countries, GLOBOCAN estimates of cancer incidence (such as those shown in Figure 1) and deaths (such as those shown in Figure 2) are based on data from other ('similar') countries or from sub-national (typically urban) cancer registries. Statistics on the prevalence of cancer in ASEAN (excepting Brunei Darussalam and Singapore) are even more likely to be flawed, due to lack of national data on survival after a diagnosis. In addition, cancer prevents the living of a full life, which is not captured by 'head counts', but data on the quality of life lived with cancer are lacking in ASEAN.

## The ACTION Study

In order to address some of these knowledge gaps in most countries in ASEAN, the Asean CosTs In ONcology (ACTION) study was launched in 2012 (Kimman et al.,

2012b). This study selected consecutive patients with a first time diagnosis of cancer from 47 hospitals (general and specialist, public and private) within ASEAN, except Brunei Darussalam and Singapore. After exclusions due to patient or doctor refusals, 9513 patients were recruited into the study. The primary outcome for this study is financial catastrophe following treatment for cancer during the first year after diagnosis, defined as out-of-pocket expenditure exceeding 30% of household income. Secondary outcomes are survival, disease status, quality of life and psychological distress after one year. Funding to extend the study beyond a year is being sought.

## Policy Roundtable in Kuala Lumpur

In order to track progress towards adoption of the principles of the Jakarta call to action, and the ACTION study, a further meeting of cancer experts was held in Kuala Lumpur on April 24/5, 2014. At this meeting participants had the opportunity to hear experiences of cancer control programmes in Indonesia, Japan and Thailand, to learn more about the ACTION study and see baseline results, to gain a better understanding of the burden of cancer worldwide and to discuss strategies to ensure cancer is a priority in government policies. A senior representative from the ASEAN Secretariat stressed the importance ASEAN gives to non-communicable diseases and highlighted the importance of identifying local champions to lead key activities and advocate cancer control programmes through evidence-based policies. Breakout sessions were held in order to engage participants in small group discussions around strategies for establishing a framework for cancer policy development and programme management that could be adapted for various socioeconomic and cultural contexts in ASEAN.

Following the background presentations, attendees were divided into three working groups to discuss pre-defined specific issues, with a view to achieving a consensus on the way forward in a subsequent plenary session. The questions to be addressed and the results of these discussions follow.

*How can cross-country cooperation within ASEAN member states help them face the new reality of cancer care?*

An understanding of how to work within the ASEAN structure was seen as vital to the advancement of cancer care in the region. However, the group was concerned that the focus on cancer may be diluted within the ASEAN Non-Communicable Disease (NCD) Taskforce, since NCD covers a multitude of diseases. It was agreed that there needs to be better access to pharmaceuticals and health technology assessment, for example, in decision making around the human papillomavirus vaccine. It was further agreed that healthcare budgets would be more efficiently and effectively dispersed by sharing resources amongst member states.

The following actions were agreed:

- A roadmap should be established to guide member states on clear, concrete steps to engage policy

stakeholders in their respective countries.

- Each country should develop its own work plan for cancer care. Common elements from these work plans would then be brought together to establish the overarching roadmap that is applicable to all member states.

- Evidence-based policies, cancer registries and research outcomes should be developed and strengthened.

- The ACTION study can become a basis for cancer advocacy.

- Public discourse on cancer should be encouraged through use of the media. It was noted, however, that the context in which the media operates varies across the ASEAN region, with press freedom more apparent in some countries than others.

- National champions should be identified, to meet under the umbrella of the ASEAN Secretariat which will lead cancer advocacy programmes in the region.

- A cancer registry network should be developed (Moore et al., 2014), where member states are able to transfer knowledge amongst themselves in terms of training, experience, best practices, sharing of resources, expertise and human resources.

- A specific cancer-type should be identified for a pilot project: lung cancer was unanimously agreed, since it is a leading type of cancer across ASEAN.

*What is the value of public-private partnerships in improving outcomes in oncology and what are the conditions for the success of such partnerships?*

A general example cited for public-private partnerships is a community intervention programme which surveys the public on their knowledge of the risk of cancer, and uses the information to formulate a cancer control programme. An example of a public-private partnership model in Malaysia was provided: public hospitals engage private oncology, services due to limited cancer care services in the public sector and the government refers patients from the public sector to receive treatment in private practice. Additionally, in Malaysia, hospices are scarce. Palliative care in the public sector is practically non-existent, prompting non-government organisations (NGOs) to take charge. Further, private clinics and NGOs in Malaysia offer some key services, such as cervical cancer screening, which the public sector is unable to provide. Similarly, in Cambodia NGOs organise home palliative care services for cancer patients. This ensures that care initiated in public sector hospitals can be continued at home.

The group opined that public-private partnerships are difficult to foster in the ASEAN region due to different operational systems in the public and private sectors. The group suggested a 'build, operate and transfer' mechanism, based on experiences in the Philippines. This would entail the private sector building a cancer care system, typically a hospital or healthcare facility, and managing the system until there is commercial success. The system would then be transferred to the public sector. To ensure success of public-private partnerships, the group agreed that the public sector must share data and information with the private sector in a transparent fashion. The sharing of information, however, must have strict guidelines. For

example, an outline of each sector's role, and how much information is to be released, should be agreed, so as to ensure successful partnerships.

*How can we best mobilise stakeholders at the regional level?*

Similar to working group 1, this group agreed that each country needs to establish its own cancer care system, since different countries have different levels of cancer support. Also in agreement with the first group, this group agreed that there should be a roadmap - a regional action plan providing a detailed framework for each country to improve cancer care systems. This road map should include:

- Data generation to support cancer care policies. It was suggested that data should be collected from two avenues: governments and at grassroots level (NGOs, rural stakeholders, oncologists, patients and their families and youth groups).

- Guidelines on diagnosis and cancer treatment, with the ability for member states to share resources such as best practices, training and education.

- Public awareness programmes mobilising grassroots movements to influence policy makers.

- Screening models that can be adapted into local systems.

- Viable insurance coverage and payment models.

- Establishment of a National Cancer Institute in each country. This Institute should function as a cancer 'hub' that provides education, treatment, training, research and guidance in diagnosis.

To make the roadmap a reality, the group agreed that cancer care programmes need to be endorsed by national governments at the top level, and that cancer needs to be recognised as a societal issue that is not confined to health. Stakeholders, mainly identified as Ministry of Health officials and grassroots communities, need science-based education and evidence-based toolkits to feel empowered and ultimately to be successful in gaining buy-in from governments. As a national agenda priority, a grassroots movement should be encouraged to provide a unified voice that creates a sense of urgency amongst government officials to recognise the importance of cancer. Additionally, the media should be mobilised to amplify the need for national cancer care programmes.

*Plenary session*

The expert group, as a whole, reached consensus that the following are needed:

- A concrete roadmap to guide member states in establishing local cancer control programmes, as well as an ASEAN regional cancer roadmap.

- More evidence-based toolkits and information, such as the ACTION study and the State of Oncology report (Boyle et al., 2013), for member states to use as advocacy materials to empower their respective government officials to raise cancer on the national agenda (Moore, 2013).

- Cross-country collaboration in terms of training and sharing of resources, to optimise the impact of cancer care in the region.

- Transparency in data collection and sharing of information between the public and private sectors, which is imperative to shape the cancer care agenda for the region.
- ASEAN countries should capitalise on the opportunity presented by the 12<sup>th</sup> ASEAN Health Ministers Meeting in September 2014, to elucidate the need for a regional cancer care roadmap as member states convene to discuss the ASEAN health agenda post-2015.
- A follow-up meeting in one year to further discuss the details of the roadmap, to help maintain momentum.

## Conclusions

The current state of cancer care and prevention in ASEAN is incompatible with the socioeconomic changes taking place in the region. Mounting lifestyle-related cancer risks are fuelling a cancer epidemic that threatens to overwhelm the region unless governments take urgent action. The Jakarta call for action on cancer control and the ACTION study provide a rich foundation on which to build comprehensive, evidence-based cancer control programmes in the region, and provide important exemplars for other under-developed parts of the world. There is clear enthusiasm to capitalise on these initiatives amongst those who understand the huge burden conferred by cancer. The meeting of ASEAN cancer experts in Kuala Lumpur produced a strong consensus on the best ways forward, but the challenge now is to progress cancer control through advocacy of the cancer agenda at all levels of society and the development of sound, affordable policy guidelines.

## Acknowledgements

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## Appendix 1: Participants at the First Policy Roundtable Discussion on Future Access to Cancer Care in ASEAN (Jakarta, 23 Nov 2012)

### Speakers

- Dr. Peter Boyle, President, International Prevention Research Institute, Lyon, France
- Dr. Panos Kanavos, London School of Economics, Social Policy and LSE Health, UK
- Prof. Mark Woodward, The George Institute for Global Health, University of Sydney, Australia

### ASEAN Foundation

- Makarim Wibisono, Executive Director
- Septania Hanawati, Head of Programs

### ASEAN Secretariat

- Dr. Surin Pitsuwan, Secretary General of ASEAN
- Mr. Larry Maramis, Director for Cross-Sectoral Cooperation, and Dr. Ferdinal M. Fernando MD, MDM, Head, Health and Communicable Diseases Division, ASEAN Socio-Cultural Community

### Cambodia

- Dr. Yos Phanita, Deputy Director General, Ministry of Health
- Dr. Prak Piseth Raingsey, Director, Preventive Medicine Department, Ministry of Health
- Dr. Mao Reasey, Assistant Director General, Calmette Hospital
- Prof. Eav Sokha, Head of Department, Oncology and Hematology, Calmette Hospital
- Dr. Thach Varoeun, Deputy Director, Department of Preventive Medicine, Ministry of Health
- Dr. Heang Korng, Deputy Director, Oncology Department, Khmer Soviet Friendship Hospital

### Indonesia

- H.E. Dr. Nafsiah Mboi, Minister of Health
- Dr. Ratna Rosita Hendarji, Secretary General, Ministry of Health
- Prof. Dr. Tjandra Yoga Aditama, SpP(K), MARS, DTM&H, DTCE, Director General, Disease Control and Environmental Health, Ministry of Health
- Doddy Izwardi, Department of Health
- Prof. Dr. Hasbullah Thabrany, Vice Head, Center of Economic and Health Policy, Public Health Faculty, University of Indonesia
- Dr. Tubagus Djumhana Atmakusuma, Head, Haematology and Medical Oncology Division, Department of Internal Medicine, University Of Indonesia, Cipto Mangunkusumo Hospital, Jakarta
- Prof. Dr Rukmini Mangunkusumo, Wakil Ketua Umum, Yayasan Kanker Indonesia
- Dr. Djohan Kurnianda, Head of Tulip Oncology Clinic, Yogyakarta, Hematology Oncology Division, Department of Internal Medicine, Sardjito General Hospital, Yogyakarta
- Dr. Lukiarti Rukmini, Sekretaris Umum, Yayasan Kanker Indonesia
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Mark Woodward

Dr. Ekowatir Rahajeng, SKM, Mkes

#### **Laos**

Assoc. Prof. Dr. Bounnack Saysanasongkham, Deputy General Director, Department of Health Care, Department of Health Care, Ministry of Health

Assoc. Prof. Dr. Bounthaphany Bounxouei, Director, Mahosot Hospital

Dr. Daovone Thepsouvanh, Director, Oncology Center

#### **Malaysia**

Puan Sri Maniseh Adam, Patron and Ms. Yong Lee Lee, Founder and Chief Executive Officer, Pink Ribbon Wellness Foundation

#### **Myanmar**

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Prof. Swe Swe Win, Head, Department of Oral Cancer, University of Dental Medicine

Prof. Soe Aung, Consultant Medical Oncologist, President, Myanmar Oncology Society, Myanmar Center of Chemotherapy

#### **Philippines**

Dr. Gloria Cristal-Luna, Head, Section of Medical Oncology, National Kidney and Transplant Institute

Dr. Melanie Coronel Santillan, Team Leader, Special Benefits Product Team, Philippine Health Insurance Corporation

#### **Thailand**

Dr. Pattarawin Attasara, Chief, National Cancer Database and Chief, Cancer Informatics, National Cancer Institute

Dr. Wilawan Juengprasert, Director General, Department of Medical Services, Ministry of Public Health

Dr. Wanchai Sattayawuthipong, Deputy Director General, Department of Medical Services, Ministry of Public Health

Dr. Thiravud Khuhaprema, Director, National Cancer Institute

Dr. Suleeporn Sanglajrang, Researcher, National Cancer Institute

### **Appendix 2: Participants at the Second Policy Roundtable Discussion on Future Access to Cancer Care in ASEAN (Kuala Lumpur, April 24/25, 2014)**

#### **Speakers**

Dr. Pattarawin Attasara, Chief, National Cancer Database and Chief, Cancer Informatics, National Cancer Institute, Thailand

Prof. Peter Boyle, International Prevention Research Institute, France

Dr. Tomohiro Matsuda, Section Head (population based cancer registry), National Cancer Centre, Japan

Dr. Jintana Sriwongsa, ASEAN Secretariat

Prof. Hasbullah Thabrany, Head, Center of Economic and Health Policy, University of Indonesia

Dr. Tran Van Thuan, Director, Institute of Cancer Prevention Research, Vietnam

Prof. Mark Woodward, George Institute for Global Health, University of Sydney, Australia/University of Oxford, UK

Miss Kajsa Wilhelmsson, Head, Health Policy and Market Access Europe & CIS, A&R Edelman (facilitator)

#### **Cambodia**

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Dr. Thach Varoeun, Deputy Director, Dept of Preventive Medicine, MOH

Prof. Eav. Sokha, Head, Dept Oncology and Hematology,

Calmette Hospital

Dr. Chhom Sakborey, Calmette Hospital

Dr. Touch Socheat and Dr. Heng Viroath Oncologists, Khmer Soviet Friendship Hospital

Dr. Huy Meng Hut, Ministry of Health

#### **Indonesia**

Mrs. Sylvia Mardiana Sarwani, Indonesian Cancer Foundation  
Dr. Tubagus Djumhana Atmakusuma, Head, Hematology and Medical Oncology Division, University of Indonesia

Dr. Esti Widiastuti, Head, Counselling and Evaluation Section, Sub Directorate of Cancer Control, Ministry of Health

#### **Laos**

Prof. Bounnack Saysanasongkham, Deputy General Director, Department of Health Care, Ministry of Health

Dr. Daovone Thepsouvanh, Head, Oncology Center

Prof. Bounthaphany Bounxouei, Director, Mahosot Hospital

#### **Malaysia**

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Dr. Zainal Ariffin Omar, Deputy Director, NCD Section Disease Control Division, MOH

Dr. Mastura Md Yusof, Clinical Oncologist, University Malaya Medical Centre

Dr. Saunthari Somasundaram, President and Medical Director, National Cancer Society

Miss Ranjit Kaur Pritam Singh, President, Together Against Cancer

Miss Yoon Sook Yee and Datin Dr. Amyza Saleh, Cancer Research Initiatives Foundation

Dr. Ho Gwo Fuang, Clinical Oncologist, University Malaya Medical Centre

#### **Myanmar**

Dr. Myo Khin, Primary Investigator and Dr. Win Pa Naing, Co-Investigator, Department of Medical Research

Prof. Htun Lwin Nyein, Co-Investigator, Yangon General Hospital

Dr. Myo Myint Maw, Head, Medical Oncology Department, Yangon General Hospital

Prof. Soe Aung, Co-Investigator, Witorira Hospital

#### **Philippines**

Dr. Corazon Ngelangel, Principal Investigator, Philippine General Hospital

Dr. Gloria Cristal-Luna, Principal Investigator, National Kidney and Transplant Institute

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Dr. Chereлина Santiago-Ferreras, Principal Investigator, Veterans Memorial Medical Center

Miss Merla Rose Reyes, Senior Social Insurance Specialist, PhilHealth

Dr. Jennifer Raca, Senior Manager, Benefits Development and Research Department, PhilHealth

Dr. Mary Claire Soliman, Department Head, Oncology Department - National Center for Pharmaceutical Access Management, Department of Health

Mr. Michael Junsay, Pharmacist, National Center for Pharmaceutical Access Management, Department of Health

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Dr. Ngo Thuy Trang, Coordinator, Bach Mai Hospital

Mr. Pham Quang Huy and Miss Dao Que Phuong, Coordinators, Hospital K

Prof. Nguyen Ba Duc, Vice President, Vietnam Cancer Association

Dr. Quach Thanh Khanh, Coordinator, Ho Chi Minh City Oncology Hospital.





