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

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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

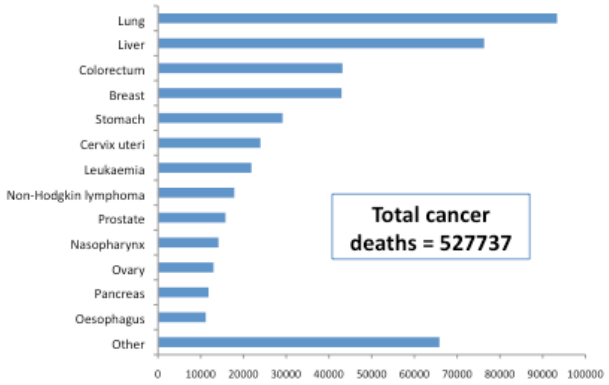

Figure 1. Cancer Incidence in The ASEAN Region, 2012. Source of Data: GLOBOCAN (April 16, 2014)

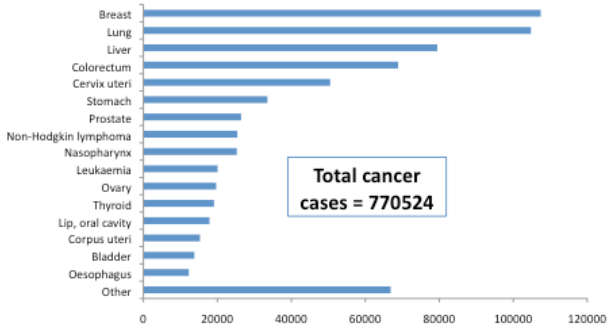

Figure 2. Deaths from Cancer in The ASEAN Region, 2012. Source of Data: GLOBOCAN (April 16, 2014)

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 12th 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

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ASEAN Foundation

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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

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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

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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)

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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

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Prof. Soe Aung, Co-Investigator, Witorira Hospital

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