

MEETING REPORT

The Socioeconomic Burden of Cancer in Member Countries of the Association of Southeast Asian Nations (ASEAN) - Stakeholder Meeting Report

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Abstract

The ACTION (Asean CosTs In ONcology) Study will be one of the largest observational studies of the burden of cancer ever conducted in Asia. The study will involve 10,000 newly diagnosed patients with cancer and will be carried out across eight low- and middle income countries within the ASEAN region (Indonesia, Thailand, Malaysia, Cambodia, Myanmar, Viet Nam, Laos and the Philippines). Patients will be interviewed three times over 12 months to assess their health, use of health care services, out of pocket costs related to their illness, social and quality of life issues. The project is a collaboration between the George Institute for Global Health, the ASEAN Foundation and Roche. The aim of the study is to assess the health and socioeconomic impact of cancer on patients in ASEAN communities, and the factors that may impact on these outcomes.

Keywords: Cancer - burden - costs - ASEAN - low/middle income countries

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Introduction

As part of the ACTION (Asean CosTs In ONcology) study a stakeholder meeting was held in Singapore on 7 July 2011. More than 80 key government decision-makers and health officials from ASEAN member states, leading regional and international experts gathered at the meeting. The focus of the meeting was to present cancer rates and the burden of cancer in the ASEAN region (Kimman et al., 2012b); identify priority areas for research in the interview and data collection phase of the project (ACTION study) (Kimman et al., 2012a); and identify avenues for adapting the research to better inform local and regional policy.

Context

Cancer has been cited as the leading cause of mortality, globally accounting for 13 % (or 7.4 million) of all deaths annually with 70% of these occurring in low- and middle-income countries (WHO 2010). It is projected that mortality from cancer will increase significantly over the coming years with 30 million deaths per year worldwide expected by 2030 (WHO 2010). The trend is even more striking in Asia where the number of deaths per year in 2002 of 2.1 million is expected to increase to 8.1 million by 2020 (Lancet 2010). As the availability of medical technologies and treatments expands across regions, the



Figure 1. The Participants of the Meeting from a Total of 11 Countries of South-East Asia and Australia

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economic burden of cancer treatments, not only to health systems but to individuals and their households, will inevitably become more pronounced. These impacts will be felt most strongly in socioeconomically disadvantaged groups particularly (although not exclusively) those in low- and middle-income countries where social safety nets such as universal health insurance are less likely to be present. A consequence of this is that such illness, particularly through the costs associated with its treatment and its impact on people's ability to work, can be a major cause of poverty. Studies such as the ACTION study potentially play an important role in assessing the broader implications of illness for individuals and their families.

Presentations

The meeting was opened by Dr Makarim Wibisono, Executive Director of the ASEAN Foundation. Opening keynote addresses were given by Dr Derrick Heng, Director of the Epidemiology and Disease Control Division, from the Ministry of Health, Singapore (on behalf of the Minister for Health, Mr Gan Kim Yong) and Dr Surin Pitsuwan, Secretary General of ASEAN. Both presenters emphasised the immense policy challenges associated with planning and providing care for an increasing number of people in Asia who will be afflicted by cancer over the coming decades. Dr Pitsuwan also highlighted the severe burdens that, on a personal level, individuals and families encounter with the disease and emphasised the ASEAN Foundation's commitment to further research into this area.

Dr Malcolm Moore, Head of the UICC Asian Regional Office and Chief Editor of the Asian Pacific Journal of Cancer Prevention, reviewed evidence on the costs of cancer treatment and prevention in Asia. His presentation highlighted the growing evidence base around the cost-effectiveness of interventions in cervical and breast cancer in Asia, and in particular the strong evidence of cost-effectiveness emerging in relation to cervical cancer vaccination programs.

Professor Jean-Jacques Zambrowski, Senior Consulting Physician in Internal Medicine and Cardiology at Bichat University Hospital (Paris) highlighted the ideal features of a comprehensive national cancer control strategy. As an example he used the French system, which consistently ranks at the top of international comparisons of health system performance. Some of the reasons why France does so well in cancer care include its high levels of expenditure on treatments, the lack of delay in radiotherapy, good access to doctors and a fast approval and reimbursement process for innovative drugs.

Professor Mark Woodward from the George Institute for Global Health presented the most recent data on cancer rates and the burden of cancer in the ASEAN region. GLOBOCAN 2008 incidence and mortality data were used to estimate the burden of cancer in the countries of ASEAN using the standard methodology developed within the WHO Burden of Disease study. The main findings were that in 2008 there were estimated to have been over 700,000 new cases and 500,000 deaths in ASEAN, leading to approximately 7.5 million Disability Adjusted Life

Years lost (for a full report of the findings see Kimman et al., 2012b).

Associate Professor Stephen Jan from the George Institute for Global Health presented plans for the main observational study, including its rationale, aims and hypotheses and methods. As illustration of the type of evidence that will be generated from this study, he presented the example of a previously conducted study of the household economic impact of stroke in China. The key findings from that work were that the out of pocket costs of hospitalisation for stroke resulted in financial catastrophe in 71% of patients (when 30% or more of annual incomes for were spent on health care expenses), 37 % of patients were pushed into poverty and health insurance provided some, although by no means complete, protection from such impacts (see Heeley et al., 2008). The discussion that followed the presentation centred largely on the feasibility of the current project and the role of investigators in each country.

Priority Areas Going Forward

Following these presentations four breakout sessions were convened about priority areas for research through ASEAN. Two main themes explored were:

1. Logistics of conducting large scale cross-country studies of cancer in Asia.

One of the complexities of the study in ASEAN is that it is conducted across eight countries and therefore spans not only national boundaries but numerous language, cultural and ethnic groupings.

The main points to arise from this discussion were:

- The need for sensitivity in ensuring that patients included in the study are aware of their diagnosis.
- Understanding the complexity of insurance arrangements. This means that assessing insurance status cannot often be addressed simply by the question, 'do you have health insurance?' A more appropriate method of addressing this issue is to ask who is paying for treatment.
- Patients may often not be aware of the costs of treatment, so self-reporting of costs is only possible for out of pocket expenditures. To record out of pocket costs, patients would be asked to record health care use and expenditure in a diary. To ascertain the full costs of cancer treatment, hospital costs would be to elicit information retrospectively from hospitals.
- The small populations in some of the countries will make it difficult to achieve equal numbers of patients across countries within the timeframe for recruitment. Therefore, some flexibility about patient quotas is needed from each country.
- The previous issue is exacerbated by the limited human resource capacity in some of the lower income countries which is likely to impact on the rate of recruitment and follow-up.
- There is likely to be stigma associated with eliciting personal financial and economic information, particularly in settings where there may be distrust of government. Socioeconomic questions therefore will need to be as non-intrusive as possible (e.g. use of indirect measures



Figure 2. The Organizers and Representatives of the Sponsors

of socioeconomic status such as employment).

2. Policy and practice

The importance was highlighted of incorporating into a policy and practice dialogue all potential stakeholders including Non-government organisations, governments and the World Health Organisation. Individual Ministries of Health potentially have crucial roles in moderating and prioritising national programs. Such programs would include the entire spectrum of prevention, screening, treatment and care. Some of the barriers in this process include the stigma associated with the label of cancer, the often high cost of treatment which can often extend for long periods, low levels of health insurance coverage in many of the countries in the region, limited resources, and disease prioritisation processes within many countries and individual hospitals which are often not commensurate with disease burden.

The role of studies such as the ACTION study in assessing the economic and social burden is important in helping to identify priorities as well as in broader advocacy. The ASEAN Foundation can play a key role in increasing awareness of the issues raised and in lobbying for greater priority within national health plans. In this respect, it is important that individual success stories within the ASEAN region are highlighted and publicised; as such narratives can often strongly influence policy decisions.

Conclusions

The ACTION study represents landmark research into the health and economic impact of cancer in South East Asia. It has been designed and will be implemented through genuine partnerships and consultation across academia, industry, civil society and government. The initial stakeholder meeting of the ACTION study produced commitment from the ASEAN stakeholders to work together to ensure that cancer is recognised as an imminent health challenge, and is seriously addressed as a development, health and equity issue in ASEAN. Also, in particular, the attending ASEAN stakeholders committed to support the implementation of the ACTION study. Meetings such as this initial stakeholder meeting in Singapore- which will be repeated at the conclusion of the study- are crucial in facilitating necessary and continuing dialogue between these stakeholders. Such consultation is

the key to how cancer research in this region can be geared toward assisting ASEAN decision-makers at different levels to best answer questions that are relevant to policy and practice, and ultimately in improving the well-being of both cancer patients and their carers.

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