

Background

- By 2030, developing countries will account for 70 per cent of cancer cases in the world!
- It will not be long before cancer becomes the leading cause of morbidity and mortality **in Asia** overtaking infectious diseases.

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Our Problem

- Healthcare budgets are stressed and traditionally, the focus has been on infectious disease, and over the past decade on cardiovascular diseases.
- Cancer is not a priority area.
- However, if we are not prepared, we are going to be hit hard. It is time for ACTION!

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What is needed?

- Cancer should be **'in the agenda'** when aligning health policies → or it creates a vicious cycle
- Currently, a majority of treatment expenditures in Asian countries are paid privately or from out-of-pocket health-care systems. ➤
- It is potentially a major cause of economic hardship and poverty to the patients and families. ➤
- Weakening national economic development ➤

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How to get cancer into the 'agenda'?

- **Quantify** the impact of cancer in Malaysian households not only in terms of dollar and cents but also in terms of quality of life.
- Facilitates policy makers to make 'evidence-based' decision!

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Outline

- ASEAN Phase 2 study
 - Objectives
 - Methods
 - Outcomes
- Timelines
- Role of Regional Investigators
- Policy and practice implications

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Objectives of ASEAN Phase 2

To assess in the 8 ASEAN countries:

1. the economic impact of cancer on households
2. variation in the management and the costs of hospital and non-hospital treatment for cancer
3. the social and quality of life impact of cancer on patients

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Methods

- Prospective study of patients in the ASEAN countries admitted or receiving treatment for the cancer.
- Baseline
 - Interview
 - Patient standard form
- Follow-up interviews
 - 3 months
 - 12 months

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Patient population

- A cross-section of hospitals across the 8 ASEAN countries (1000-1500 patients per country)

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Participants

- 18 years and older
- Receiving treatment in hospital for a newly diagnosed cancer (6 weeks)
- All stages of cancer, consecutive patients
- Conscious and with sufficient cognitive capacity to complete an interview

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Baseline interview

- Administered in person at the clinic during initial treatment.
- Case report form
 - Demographics
 - Quality of life
 - Socioeconomic status
 - Employment status
 - Household economic hardship and stress.
 - Contact details for follow-up interviews will be collected.

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Questionnaire

Questionnaire domain	Items
Demographic	Age, sex, education, medical history, insurance status, occupation, number of dependants, initial household income, wealth
Quality of life, disease progression	Generic and cancer specific
Socioeconomic	Economic hardship, household income
Use of health services and direct health <i>out of pocket</i> costs in past 3 months	Hospital treatment, non-hospital based care, medications, diagnostics, palliative care, complementary and alternative medicines and treatments
Direct non-health services related to illness and <i>out of pocket</i> in past 3 months	Accommodation (nursing home, hospice care), assistance (paid)

Patient-specific standard form

- Upon discharge research officer extracts from individual patient files and records on a standard form the following details regarding admission :
 - length of stay
 - investigations
 - medications
 - procedures

3 and 12 month interviews

- Based on a similar interview administered at baseline.
- Carried out at a follow-up visit or where such a visit is not possible, at participants' homes.

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Primary outcome

Incidence of financial catastrophe following treatment for cancer.

- Financial catastrophe: out of pocket direct health care expenditure at 12 months exceeding 30% of household income as assessed over the 12 months of follow-up.

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Secondary outcomes

- Poverty induced illness.
- Quality of life (generic)
- Quality of life (cancer specific)
- Hospital costs
- Non-hospital health care costs
- Out-of pocket costs
- Indirect costs
- Economic hardship

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Issues addressed by analyses

- Impact of different cancer types on quality of life, household economic and social outcomes
- Influence of insurance status, hospital type, region and socioeconomic status on these outcomes
- Variations in costs, outcomes and treatment patterns for cancer across hospitals, regions and countries
- Non hospital direct costs, non-health care costs and indirect costs incurred by patients with cancer

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ASEAN Phase 2 -Timeline

An indicative timeline:

- July 2011- March 2012:
 - initial start up and KOL meetings
 - establishment of database
 - training
 - recruitment to achieve an overall target number of 10,000 patients
 - data collection: baseline and follow-up
- April 2012-March 2013:
 - Data collection – follow up for all patients
- April 2013 – July 2013
 - analyses
 - writing up
 - dissemination including meetings with KOLs

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Role of regional investigators

- Input into study design / questions
- Translation
- Recruit sites / patients
- Data collection
 - Baseline interviews
 - Patient standard form
 - Follow-up interviews (3 and 12 months)
- Data input (data management and analysis at George Institute)
- Input into interpretation of findings
- Dissemination and policy change

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Local Steering Committee

- Prof Yip Cheng Har
- Dr Nirmala Bhoo Pathy
- Dr Jamaiyah
- Dr Gerard Lim / representative
- Ms Shridevi

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Executive Committee

- Principal investigator:
Prof Mark Woodward
- Investigators from George Institute (4)
- One representative from each country (8)

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Sydney, AUSTRALIA | Beijing, CHINA | Hyderabad, INDIA | London, UK



Affiliated with the University of Sydney

Potential policy and practice implications

- Advocacy
 - Cancer burden to families, the community and government
- Health system reform and health insurance
 - Financial barriers to care treatment
 - Level of financial protection available through different health systems
- Planning and financing of health care
 - Variations in treatment patterns, costs and outcomes by facility type, region and country

Benefits for CRC

- Research is sponsored by Roche:
 - Free training for our research officers
Skills acquired maybe used for future research of our own
 - ROs get paid for their work
 - Patients are paid honorarium for their time
 - Ownership of research output is shared with all countries

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More importantly

- Data ownership: belongs to each country. We will get to keep our data!
- Future studies using the above data is possible without restriction. Only need to inform the executive committee

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In the pipeline

- Investigator initiated research using data from ACTION study:

Prevalence and type of complementary and alternative medicine use among cancer patients in South East Asia

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Background

- A major obstacle in cancer control particularly in low and middle income Asian nations is late presentation of cancer patients.
- A qualitative study to explore reasons for late stage presentation among women with breast cancer (i.e. patient delay) attending a tertiary academic hospital in Malaysia, had identified three emerging themes.

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Why patients present late?

1. Fatalism
2. Prevailing belief in alternative therapy as an active form of treatment and acceptable option
3. Lack of autonomy in decision making

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Complementary/Alternative medicine (CAM) therapy

Use of medical and health care systems, practices, and products that are not generally considered part of conventional medicine, either **together** , or **in place of** conventional medicine

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What we know of CAM use?

- About 30% of cancer patients in Western settings, seek complementary and alternative medicine use.
- We do not know the magnitude of CAM use in Asia except in small hospital series from China, Taiwan, and Singapore.

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What we know?

1. A study of 328 breast cancer patients from urban and rural settings in Malaysia found that more than 40% of patients opted for alternative therapy. In this population, the use of alternative therapy was associated with **80% increase** in the delay of diagnosis of breast cancer **by approximately 6 months**

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What we know?

2. Study in HKL showed that 5% of breast cancer patients default further treatment to seek alternative therapy

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Therefore....

Research Objectives

1. To determine the prevalence of complementary and alternative medicine use among South East Asian cancer patients
2. To identify types of complementary and alternative medicine use in the different participating countries
3. To assess the associations between complementary and alternative medicine use and patient demography, and clinical characteristics in South East Asia

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So what?

Potential impact

1. Quantifying the extent of CAM use in South East Asian nations, may aid in planning patient education and awareness creation programs.
2. Findings may be conveyed to policymakers to realign health priorities.
3. This knowledge may aid in planning further studies on assessing the impact of use of CAM on cancer patients in Asia.

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Research Protocol

- On the way...

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