

EVENT REPORT

Advancing an Agenda of Hope and Action on Cancer in Malaysia

30 September 2018

Highlights

The Galen Centre for Health and Social Policy, with the National Cancer Society Malaysia jointly organised the Advancing an Agenda of Hope and Action on Cancer in Malaysia event on 30 September 2018, in conjunction with the World Cancer Congress 2018 held in Kuala Lumpur.

The event included a keynote speech, launch of The Cancer Care Working Group by patients and caregivers, presentation of the cancer policy recommendations and handover to YB Jamaliah Jamaluddin and representatives from YB Maria Chin Abdullah's office, and a public forum discussing the recommendations and mobilising action on cancer care.

The event was attended by 57 participants, including patients, caregivers, public and private cancer specialists, non-governmental organisations, and representatives from government ministries. A third were attendees of the World Cancer Congress 2018.

This summary was developed based on the keynote speech by Datuk Dr. Narimah Awin, the presentation of the cancer policy recommendations by Galen Centre CEO, Azrul Mohd Khalib and the public forum featuring Prof. Dr. Nur Aishah Mohd Taib, Dr. Martin Mellor Abdullah, Dr. Murallitharan Munisamy and Ms. Ranjit Kaur.

Background

Cancer is the fourth most common cause of death in Malaysia, with approximately 37,000 cases of cancer reported every year. This figure is estimated to rise to more than 55,000 newly diagnosed cases by 2030. Malaysia also has one of the highest mortality to incidence ratio for breast cancer in the Southeast Asian region.

It is essential for Malaysian policymakers to hear and take into account the lived realities of accessing healthcare in Malaysia, particularly when it comes to the challenges of cancer, in order to ensure effective healthcare reforms that are beneficial to the public.

Keynote speech

Dr. Narimah Awin shared her insights into cancer care from her unique position as a public health expert and policymaker with the Ministry of Health, researcher, physician and breast cancer survivor.

She noted through the sharing of her experience battling cancer the importance of having a system of call and recall in the public healthcare sector to follow up on screening appointments, and the strong emotional support system she received from peers, friends and family.

She also shared her recommendations to improve Malaysia's healthcare system:

- **Coherent, evidence-based primordial, primary, secondary and tertiary treatment:** Malaysians must be given more information to reduce their risk of cancer with evidence-based methods such as improving diet and exercise. Primary, secondary and tertiary treatments must also be analysed for gaps and further improved.
- **Practice evidence-based medicine:** Diets and supplements must only be recommended if the usage is backed by scientific research.
- **Improving health literacy:** Cancer awareness is still not up to par, and there is strong resistance to health education among the Malaysian public, especially among Malay people.
- **Offer a variety of evidence-based treatment options:** Offer other forms of medicine and therapies other than allopathy. However, the efficacy of these therapies must be rigorously studied like any other allopathic therapies.
- **Policymakers must keep an open mind:** Policymakers must pursue methods that work and not be reliant on current standard operating procedures if they are found to be ineffective.

- **Improved local data collection and surveillance:** Local data collection and surveillance must be improved to enable current policies to be studied thoroughly and help develop future policies. We are currently very dependent on the Union for International Cancer Control for local data.
- **Political commitment to improving cancer care:** Politicians and parliamentarians can significantly influence the media and the people to bring about positive behavioural changes. This is especially evident among women and women politicians.

Launch of The Cancer Care Working Group & Cancer Policy Recommendations

The Cancer Care Working Group, comprising cancer survivors, public and private cancer specialists and non-governmental organisation leaders, was launched by patients and caregivers, together with Datuk Dr. Narimah Awin. The secretariat for the Working Group was also recognised to as the Galen Centre for Health and Social Policy.

The Working Group presented short-term and long-term key policy recommendations towards improving cancer treatment and care for consideration by the Government of Malaysia. These recommendations are:

Short-term recommendations

- Benchmark Malaysia's cancer care effort against international standards
- Remove dual referral charges and standardise fees across public healthcare
- Improve national data on cancer
- Provide medical and non-medical support to patients from lower income households
- Improve supportive care for cancer patients through collaboration with external stakeholders

Long-term recommendations

- Strengthen governance of the National Strategic Action Plan for Cancer Control Programme
- Establish multisectoral consultative mechanisms
- Decentralise cancer care
- Adopt sustainable public healthcare financing strategies
- Reform Social Security Organisation (SOCSO) legislation and regulations
- Improve policies related to public drug procurement
- Increase coverage of cancer services and availability of relevant healthcare professionals

- Establishment of cancer survivorship services as part of cancer care

Panel Discussion

1. There is a need to collect data to ascertain the five-year survival rates of all cancers to check how Malaysia is doing against international standards.
2. Cancer survivorship is better in the private sector compared to public sector. This is mostly attributed to the public healthcare sector being overburdened and constrained by lack of time to properly pay attention to every patient.
3. Survivorship care is currently entirely reliant on support groups and non-governmental organisations (NGOs), who are often unpaid and centred in urban areas. This shows a great lack of survivorship care in areas not covered by these support groups and NGOs who are already stretched thin.
4. Survivorship must be measured based on the quality of life for patients. This includes income, mental health, wait times for treatments, check-ups, tests and scans.
5. The public healthcare system must involve allied healthcare services to address possible patient needs. Patients must also be taught on how to monitor themselves to ensure that concerns are addressed in early stages.
6. Barriers to cancer care also involves non-medical concerns such as distance, childcare, ability to take leave, etc to spend an inordinate amount of time in queues in public healthcare system. All these concerns make going to government hospital a deterrent.
7. Dual referral charges penalise people who are referred from the private healthcare system to the public healthcare system. Some patients access private healthcare to speed up their diagnosis, others have run out of insurance coverage. This charge directly contributes to the financial catastrophe commonly afflicting cancer patients.
8. The public healthcare system is still struggling with early diagnosis. Patients are often blamed for late presentation, but the referred patient could receive an appointment date with a specialist in the public healthcare system that is months away.

Q&A Session

1. Patients are mostly concerned with cost and availability of treatment. Urban and rural patients have the right to receive comparable care.

2. Policymakers must think about how best to collaborate with private healthcare providers to lessen the burden on the public healthcare system and reduce the queue in public hospitals.
3. There is a shortage of public hospitals. Some states only have one public hospital, while public hospitals in urban areas do not have the capacity to service the large populations in their area. Public hospitals in less urban states also lack important cancer care services like radiation. As such, patients have decided to undergo unnecessary surgeries to avoid travelling to better equipped hospitals in national urban centres for treatment.
4. The government should engage in strategic purchasing of medicines from pharmaceutical companies to drive down the cost of medication. Thailand was cited as a good case study.
5. There is a need to look at the cost of medication and supplements to ensure that it is accessible to patients.
6. Cancer care financing must be updated, especially SOCSO as it only covers later stages of cancer. The people must demand details of the upcoming national health insurance scheme to ensure its efficacy.
7. Some measures for healthcare financing were suggested, including long-term care insurance for those aged 40 and above. Other methods of healthcare financing can also be considered including the earmarking of sin taxes.
8. These measures will require pressure and support for policymakers. As such, cancer patients and advocates should engage with their local MPs and ADUNs to demand change and ensure their voices are heard.

Comments

Datuk Dr. Narimah Awin has expressed interest in wanting to be involved in future policy discussions regarding cancer organised by the Working Group.

The political representatives present indicated interest and support for holding further discussions on the issues and recommendations raised by the The Cancer Care Working Group, and specifically on increasing government support for cancer. YB Maria's office has indicated support to help organise the briefing session with parliamentarians in Parliament House. The Galen Centre will follow-up on this.