

# The Cancer Care Working Group



## Cancer Policy Recommendations for Parliamentarians & Policy Makers

### **Improving Cancer Treatment and Care In Malaysia**

September 2018



## SUMMARY

A multi-sectoral stakeholder consultation meeting on cancer was convened in July 2018 to compile key policy recommendations towards improving cancer treatment and care for consideration by the Government of Malaysia.

**Five policy recommendations were identified as being short-term** which can be achieved with minimal effort (low hanging fruit): benchmarking cancer care provision performance based on existing World Health Organisation (WHO) standards, removal of dual referral charges and standardization of treatment fees across public healthcare, improving the quality and availability of national cancer data, and providing medical and non-medical support to low-income and resource-limited patients.

**Eight areas for long-term recommendations were also identified** which require greater reforms to policies, strategies and services on cancer care: ensuring stronger and improved government accountability, monitoring and evaluation over the implementation of the National Strategic Action Plan for Cancer Control Programmes (NSPCCP), establishing multi-sectoral consultative and partnership mechanisms, decentralising cancer care, adopting sustainable healthcare financing strategies, reforming Social Security Organisation (SOCSO) legislation and regulations relating to cancer, improving policies related to public drug procurement, increasing coverage of oncology and cancer treatment-related services and availability of relevant healthcare professionals, and establishment of cancer survivorship services as part of cancer care.

### Short Term

<b>Benchmark Malaysia's cancer care effort against international standards</b>	<ul style="list-style-type: none"><li>• Establish benchmark and evaluate performance of national and state-level cancer care programmes based on World Health Organisation's recommendations for low or middle-resource countries</li></ul>
<b>Remove dual referral charges and standardize fees across public healthcare</b>	<ul style="list-style-type: none"><li>• Introduce legislative amendment to the Fees (Medical) (Amendment) Order 2017</li><li>• Standardise the fee structure in all public hospitals (i.e. MOH &amp; MOE)</li></ul>
<b>Improve national data on cancer</b>	<ul style="list-style-type: none"><li>• The Malaysian National Cancer Registry must be updated at least once every 5 years</li><li>• Improve the coverage of the National Cancer Registry.</li><li>• Make registration of incident cancer cases mandatory</li></ul>
<b>Provide medical and non-medical support to patients from lower income households</b>	<ul style="list-style-type: none"><li>• Integrate cancer diagnosis and care as part of the Skim Peduli Sihat initiative</li><li>• Provide financial counselling early in the treatment pathway</li><li>• Design and establish a non-medical financial support programme</li></ul>
<b>Improve supportive care for cancer patients through collaboration with external stakeholders</b>	<ul style="list-style-type: none"><li>• Actively engage civil societies organisations for provision of effective cancer survivorship services</li><li>• Public hospitals to have formalized partnerships with civil society organisations</li></ul>

## Long Term

<p><b>Strengthen governance of the National Strategic Action Plan for Cancer Control Programme</b></p>	<ul style="list-style-type: none"> <li>• Appoint steering committee members of the NSPCCP from among healthcare professionals with prior experience in cancer control planning</li> <li>• Reconvene the Cabinet Committee on Healthy Environment and ensure the inclusion of cancer</li> </ul>
<p><b>Establish multisectoral consultative mechanisms</b></p>	<ul style="list-style-type: none"> <li>• Establish a consultation and partnership mechanism that includes other ministries, healthcare professionals and patient advocates</li> </ul>
<p><b>Decentralise cancer care</b></p>	<ul style="list-style-type: none"> <li>• Develop a holistic, comprehensive patient navigation system, focusing on referral networks and treatment pathways aimed at eliminating barriers to care</li> <li>• Establish a sustainable network of community-based preventive and hospice services</li> <li>• Invest in the training of allied health professionals</li> <li>• Introduce domiciliary care</li> <li>• Provide health education and training, better communication materials and information</li> </ul>
<p><b>Adopt sustainable public healthcare financing strategies</b></p>	<ul style="list-style-type: none"> <li>• Adopt a needs-based approach towards cancer funding.</li> <li>• Establish a compulsory national social health insurance scheme.</li> <li>• Earmark sin taxes (e.g. from alcohol, tobacco, gambling) to finance cancer treatment and care</li> <li>• Establish joint public-private partnerships with pharmaceutical sectors and permit public promotion of the patient assistance schemes</li> </ul>
<p><b>Reform Social Security Organisation (SOCSO) legislation and regulations</b></p>	<ul style="list-style-type: none"> <li>• Amend the Employees' Social Security Act 1969 to introduce a chronic diseases scheme, to include cancer</li> <li>• Review existing schemes to ensure cancer treatment subsidies are accessible regardless of stage</li> </ul>
<p><b>Improve policies related to public drug procurement</b></p>	<ul style="list-style-type: none"> <li>• Improve adherence and consistent application of policies and processes in evaluating and procuring innovative and generic drugs.</li> <li>• Establish a partnership with the UK's National Institute for Health and Care Excellence (NICE) to improve health technology assessments.</li> <li>• Increase drug procurement allocations under the national health budget</li> </ul>
<p><b>Increase coverage of cancer services and availability of relevant healthcare professionals</b></p>	<ul style="list-style-type: none"> <li>• The building of future hospitals capable of surgical, oncological and diagnostic services must take into account the proposed location, demography and coverage.</li> <li>• Invest in increasing the specialist (e.g. oncologists, surgeons, psycho-oncologists) to patient ratio.</li> <li>• Reform and restructure the career track for allied health professionals in the public health system</li> </ul>
<p><b>Establishment of cancer survivorship services as part of cancer care</b></p>	<ul style="list-style-type: none"> <li>• Inclusion of cancer survivorship as a core action area in the National Strategic Action Plan for Cancer Control Programme</li> <li>• Establishment of cancer survivorship services within hospital and community settings</li> <li>• build formalized partnership with civil societies</li> </ul>

## BACKGROUND

Cancer is the 4<sup>th</sup> most common cause of death in Malaysia, with approximately 37,000 cases of cancer reported every year and 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. Reasons for this are varied, including late presentation of disease, insufficient facilities and specialists (particularly outside urban areas), lack of access to innovative surgical, radiotherapeutic and oncological treatments, etc. Compounding these factors are complications caused by financial catastrophe and the lack of allied health professional networks.

A multi-sectoral stakeholder consultation meeting on cancer in Malaysia was held on 26 July 2018. The consultation was organized to compliment ongoing efforts in strengthening engagement and harnessing existing efforts to improve access to quality cancer care services. Key policy recommendations would be compiled and a multi-sectoral working group formed to assist in pushing forward the aforementioned recommendations at the policymaker and decision-maker level.

Participants of the consultation consisted of public and private cancer specialists, patient groups, academicians, allied health professionals and representatives of non-governmental organisations. The recommendations contained within this paper were derived from the discussions of that meeting. More than 80 percent of these recommendations came from patients and their caregivers.

This paper is intended to provide concrete, **short-term and long-term policy recommendations** in addressing specific challenges relating to cancer treatment and care in Malaysia

## SHORT-TERM

### 1. Benchmark Malaysia's cancer care effort against international standards

**ISSUE:** The National Strategic Action Plan for Cancer Control Programmes (NSPCCP) 2016 – 2020 acts as an aspirational roadmap and primary guidance document for responding to cancer in Malaysia. However, the country's performance (e.g. progress made, achievements, challenges and gaps) has yet to be properly benchmarked against internationally recognized standards of cancer care.

Benchmarking would enable for a comparison to be made to those standards as well as a firm understanding of the country's efforts in providing and improving the continuum of care for people living with cancer as

compared to those of other countries. It would also enable for resource and capacity gaps to be properly identified and responded to with the necessary support needed.

## Recommendation

- **Establish benchmark and evaluate performance of national and state-level cancer care programmes based on World Health Organisation's recommendations for low or middle-resource countries**

Each state to identify gaps in its existing provision of cancer care and set concrete goals to achieve the next level of global standards within a reasonable, specific timeframe. For example, if Sarawak has yet to achieve WHO's recommendations for low-resource countries, they must work to achieve all recommendations for low-resource countries within 3-5 years.

WHO provides detailed recommendations, adjusted according to low and middle-resource countries, or divided into different stages of implementation, such as core, expanded and desired levels of interventions. Using a global benchmark could begin to recognize and address disparities in service coverage across the country, individual states and realistically draw a national roadmap for the country's cancer care to move forward.

### 2. Remove dual referral charges and standardize fees across public healthcare

**ISSUE 1:** The Fees (Medical) (Amendment) Order 2017 states that oncology patients referred from private to public healthcare services must be charged at First Class treatment rates. These rates are significantly higher than those to patients referred from the public sector, who pay much lower charges and whose treatment is mostly subsidised. This rests on the premise and misconception that those who go to private healthcare would be able afford the higher rates.

Such disparity appears to be punitive for those seeking treatment through private healthcare and increases the risk of financial catastrophe for patients and families.

**ISSUE 2:** The disparity in medical charges at university hospitals (which are under the Ministry of Education) have led to larger numbers of cancer patients

experiencing financial catastrophe compared to those in Ministry of Health hospitals.

### Recommendations

- **Introduce legislative amendment to the Fees (Medical) (Amendment) Order 2017**

Remove provisions under the treatment fee schedule which imposes patients referred from private healthcare to the public health system with First Class level charges.

- **Standardise the fee structure in all public hospitals (i.e. MOH & MOE)**

Implement a common fee structure across all public hospitals (including university hospitals currently under the Ministry of Education) to ensure that there is equity of care in the two systems.

### 3. Improve national data on cancer

**ISSUE:** Local, comprehensive and current data on cancer are essential in driving informed and well targeted policies. The International Agency for Cancer Registration currently has classified that Malaysia has high quality regional data, with only less than 10% of its population is being covered.

To the best of our knowledge, only the Penang Cancer Registry has been providing data for global cancer incidence and mortality surveillance to international bodies. The quality and coverage of cancer registration in other Malaysian states are lagging.

There is currently an urgent need to improve the collection and access to high-updated, quality and comprehensive national data on cancer.

### Recommendations

- **The Malaysian National Cancer Registry must be updated at least once every 5 years**
- **Improve the coverage of the National Cancer Registry.**

In order to improve the quality and coverage of cancer registration in Malaysia, we need policies to ensure that cancer registries exist as independent entities within the state healthcare system and receive sustainable funding to train and keep its staff.

- **Make registration of incident cancer cases mandatory**

Once resources for cancer registration is made available, the law should be amended to make it mandatory to register all new cancer cases, somewhat similar to mandatory notification of infectious diseases in Malaysia, under the Prevention and Control of Infectious Diseases Act 1988.

### 4. Provide medical and non-medical support to patients from lower income households

**ISSUE:** The ASEAN Costs in Oncology Study evaluated the economic impact of cancer on patients and families in Malaysia. In this study, 51% of cancer-stricken families had experienced catastrophic expenditures (defined as out-of-pocket illness-related costs at 12 months, equal to or exceeding 30% of the annual household income) just within a year after diagnosis. A closer look at the cost drivers within the affected households revealed that risk of catastrophic expenditures attributed to conventional medical care alone was 18%. Inclusion of expenditures on non-medical good and services (transportation, meals, parking fees, lodging etc.), on top of payments for medical care further inflated the risk of excessive out-of-pocket payments.

### Recommendations

- **Integrate cancer screening programmes as part of the Skim Peduli Sihat initiative** to encourage prevention, early diagnosis and detection, particularly among B40 households. Emphasis should be on cancers where early detection has an impact on survival, e.g. breast, cervical and colorectal cancer.
- **Provide financial counselling early in the treatment pathway** to help patients assess their financial situation and options
- **Design and establish a non-medical financial support programme**

This is to subsidise or co-pay costs related to transport, childcare and patient/family accommodations for patients from lower income households and remote locations, where long-distance travel frequently occurs.

A potential model that could be used is where the state welfare department pays half the logistic cost, while individuals pay the remaining half. This is to incentivise health-seeking behaviours as well as adherence to treatment.

If and when the Employees' Social Security Act 1969 is amended to introduce a scheme specifically for chronic diseases, including cancer, the Social Security Organization (SOCSO), will be able to share the task of providing social assistance to cancer patients, by providing coverage to their contributors.

## 5. Improve supportive care for cancer patients through collaboration with external stakeholders

**ISSUE:** The country specific findings of the ASEAN Costs in Oncology Study revealed that cancer survivors in Malaysia have persistently impaired health-related quality of life and high levels of psychological distress up till one year after their diagnosis. However, there is a currently a lack of mental health professionals, including psychiatrists and psychologists to cater to the psychological needs of cancer patients.

### Recommendations

- International guidelines have recommended some pragmatic alternatives for resource limited settings. Health professionals are for instance encouraged to refer affected patients for peer support by trained volunteers. **Provision of effective cancer survivorship services in low-income and middle-income countries require active engagement of civil societies** including patient support groups, nongovernmental organizations, philanthropic foundations, faith-based organizations, and professional associations to reduce the burden on health systems.
- **All public hospitals are encouraged to have formalized partnership with civil societies**, to systematically screen for psychological distress and provide psycho-oncology support to cancer patients within the hospital and the community settings.

# LONG-TERM

## 1. Strengthen governance of the National Strategic Action Plan for Cancer Control Programme

**ISSUE:** The steering and technical working committee members of the National Strategic Action Plan for Cancer Control Programme (NSPCCP) are currently drawn and appointed from different divisions in the Ministry of Health (MOH). This role is additional to their existing job functions. The committees are also self-governed, with performance being evaluated from within.

The NSPCCP has also never been costed. There is no clear evaluation of the resource gap between the stated aims under the NSPCCP and the actual annual work plans. Execution capacity is therefore limited as the plan can only be implemented based on the annual budget of the respective departments in the Ministry of Health.

### Recommendations

- **Appoint committee members of the NSPCCP from among healthcare professionals with prior experience in cancer control planning**

Representatives from cancer patient advocacy organisations should also be members. The performance of these committees must be evaluated by a third and independent party to gauge the effectiveness and progress made in implementing the plan.

- **Reconvene the Cabinet Committee on Healthy Environment and ensure the inclusion of cancer**

## 2. Establish multi-sectoral consultative mechanisms

**ISSUE:** Discussions surrounding policies related to cancer care in the previous administration are often decided without consultation with allied health professionals, patient advocates and grassroots services. The result is policies that are less holistic, not well targeted and lack effectiveness in tackling issues such as access, coverage and treatment adherence.

### Recommendation

- **Establish a consultation and partnership mechanism that includes other ministries, healthcare professionals and patient advocates**

A committee comprising representatives from different sectors and ministries to ensure the inclusion of different views and perspectives regarding progress in implementation of the NSP. An existing model which could be adopted is the Ministry of Health's Country Coordinating Mechanism used to govern and monitor implementation of HIV projects under the Global Fund for AIDS, Tuberculosis and Malaria.

## 3. Decentralise cancer care

**ISSUE:** Many patients diagnosed with cancer experience difficulty in accessing treatment information and support, in particular low-income and/or less educated patients and their families. This could cause significant distress and confusion to patients and families, and may even delay or obstruct access to treatment.

Cancer care is currently very centralized and restricted to oncological units in a small number of hospitals. The large amount of time spent away from the community acts as a deterrent and a barrier to treatment for lower income and rural patients in seeking, adhering to and completing treatment. There are also currently almost no support networks to bring treatment into the community.

### Recommendations

- **Develop a holistic, comprehensive patient navigation system, focusing on referral networks and treatment pathways aimed at eliminating barriers to care** and integrate across all layers of the healthcare system, from diagnosis to post-cancer care as part of continuum of care.
- **Establish a sustainable network of community-based preventive and hospice services**, consisting of patient navigation systems, allied health professionals and strong referral networks.
- **Invest in the training of allied health professionals** to enable the provision and support of comprehensive care that does not heavily rely on doctors.

- **Introduce domiciliary care** through non-governmental organisations and community clinics where care is provided in a person's community (e.g. in-home visits and follow-ups).
- **Provide health education and training, better communication materials and information** on cancer to health professionals.

#### 4. Adopt sustainable public healthcare financing strategies

**ISSUE:** The Malaysian public health financing system lacks long term sustainability, depending on funding sourced from the annual national budget. Structural reforms to the financing mechanism must be made to ensure sustainability and best possible care.

##### Recommendations

- **Adopt a needs-based approach towards cancer funding.**
- **Establish a compulsory national social health insurance scheme.**
- **Earmark sin taxes (e.g. from alcohol, tobacco, gambling) to finance cancer treatment and care.**
- **Establish joint public-private partnerships with pharmaceutical sectors and permit public promotion of the patient assistance schemes.**

This would help increase patient awareness of these schemes and provide patients with a means to benefit from opportunities in accessing drugs currently not in the Ministry of Health Medicines Formulary.

#### 5. Reform Social Security Organisation (SOCSCO) legislation and regulations

**ISSUE:** Difficulty or inability in claiming benefits from the Social Security Organisation (SOCSCO) as it falls under the Invalidity Pension Scheme (Pencen Ilat). Under this scheme, the eligibility criterion is that the cancer must be at Stage IV or terminal. Success of claiming SOCSCO is also inconsistent. A person in later stages is more likely to obtain SOCSCO compensation than those in early stages of cancer, affecting survivorship.

#### Recommendations

- **Amend the Employees' Social Security Act 1969** to introduce a scheme specifically for chronic diseases, including cancer.
- **Review and improve schemes provided** to ensure all forms of cancer treatment are wholly subsidized and patients should be able to claim SOCSCO benefits regardless of cancer stage: ideal if patients could receive up to 12 months of financial support.

#### 6. Improve policies related to public drug procurement

**ISSUE 1:** Generic and biosimilar oncology drugs are available in the market but pharmaceutical regulatory policies are slow in evaluating and registering them into the Malaysian system. This deprives patients from having the range of treatment options similar to that of neighbouring countries.

**ISSUE 2:** Health technology assessments (HTA) are important elements in drug procurement as it informs the kinds of health intervention, technology and drugs to purchase. However, consistently updating HTA on innovative medicines may prove difficult.

##### Recommendations

- **Improve adherence and consistent application of policies and processes in evaluating and procuring innovative and generic drugs.**
- **Establish a partnership with the UK's National Institute for Health and Care Excellence (NICE) to improve health technology assessments.**

A partnership with NICE would assist in strengthening existing HTAs and increase the negotiating capacity of the government to obtain the latest innovative medicines at competitive prices, improving patient access to quality medicines.

- **Increase drug procurement allocations under the national health budget**

## 7. Increase coverage of cancer services and availability of relevant healthcare professionals

**ISSUE 1:** Surgical oncology and diagnostic services, both public and private, in Malaysia are unequally distributed, with the majority located in urban areas on the west coast of Peninsular Malaysia. The east coast and east Malaysia suffer from a scarcity of adequate surgical, oncological and diagnostic services. There is an urgent and immediate need to provide local-based cancer services in these areas. However, the building of specialised facilities incurs high cost and requires years to reach completion.

There is also inadequate coverage for populations living in large geographical areas (e.g. Pahang, Sabah and Sarawak), where patients have to travel far distances to obtain treatment. This incurs high non-medical expenditures and decreases the likelihood of health and treatment-seeking behaviour.

**ISSUE 2:** Malaysia needs more oncologists, radiologists and other medical professionals. It needs at least 240 oncologists to meet existing demands. It currently has half that number, with only 26 (~25%) working in public healthcare. There is also a severe lack of allied health professionals to assist in providing holistic services to cancer patients.

### Recommendations

- **The building of future hospitals capable of surgical, oncological and diagnostic services must take into account the proposed location, demography and coverage**, to ensure that health services reach and benefit the most number of people in a particular region.

One suggestion has been the expansion of oncological services across the country by establishing standardized oncology units in existing major public hospitals. Besides being a simpler and possibly cost-effective approach, this method of decentralisation could also ensure wider coverage of oncological services using existing public healthcare infrastructure.

- **Invest in increasing the specialist (e.g. oncologists, surgeons, psycho-oncologists) to patient ratio.**

The Ministry of Health needs to identify and provide suitable incentives and appropriate strategies to retain healthcare professionals within the public sector and to pursue training in cancer-related specialisations.

- **Reform and restructure the career track for allied health professionals in the public health system**, such as nurses, social workers, psychologists, genetic counsellors, in order to retain their expertise.

## 8. Establishment of cancer survivorship services as part of cancer care

**ISSUE:** The ASEAN Costs in Oncology Study in Malaysia showed that one year after diagnosis, the mean EORTC QLQ-C30 Global Health score of the cancer patients remained low at 53.0 over 100. Fifty-four percent of the survivors reported at least moderate levels of anxiety, while 27% had at least moderate levels of depression.

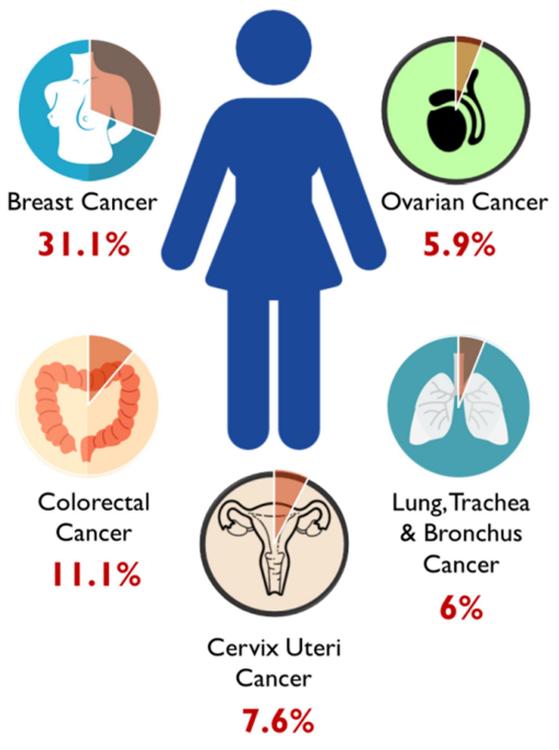
It appears that currently, the delivery of cancer care in Malaysia seems to be heavily focused on treatment alone rather than the after-care of cancer patients. With the increasing number of cancer survivors, there is now an urgent need for development of a holistic national cancer survivorship care plan that can lead to improvement in the quality of life of cancer survivors.

### Recommendations

- **Inclusion of cancer survivorship as a core action area in the National Cancer Control Plan** and be given similar importance as cancer prevention, screening, treatment, etc.
- **Establishment of cancer survivorship services within hospital and community settings** should therefore be considered as high priority, and it is important that these services comprise supportive interventions addressing wider aspects of well-being encompassing the psychological, physical, informational, financial, employment, practical, and spiritual needs of cancer survivors.
- To achieve the above, there is a need to **build formalized partnership with civil societies** including patient support groups, nongovernmental organizations, philanthropic foundations, faith-based organizations, and professional associations, who are able to share the task of providing supportive services to cancer survivors hence reducing the burden on health systems.

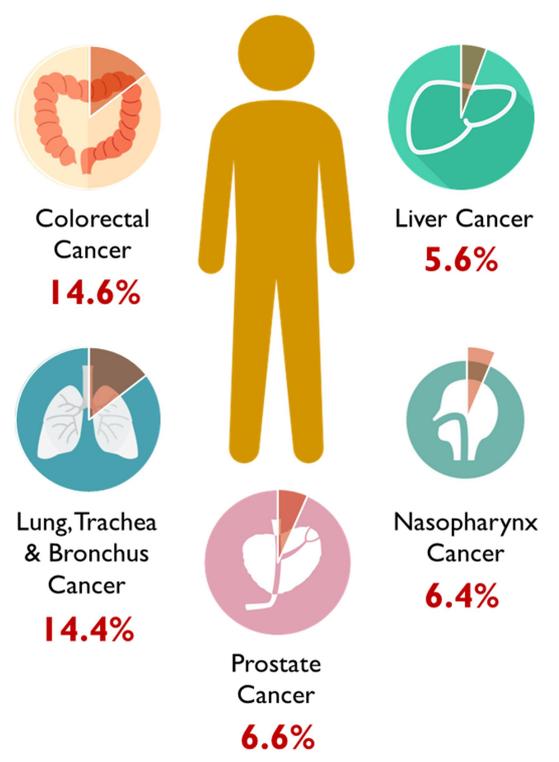
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### MOST COMMON CANCERS AMONG MALAYSIAN WOMEN



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### MOST COMMON CANCERS AMONG MALAYSIAN MEN



## Health & Social Impacts

Cancer has an adverse impact on mental health

#### Post-Traumatic Stress Disorder

22% of patients reported PTSD symptoms 6 months after diagnosis



#### Depression

70.2% of patients were reported to have depression

#### Anxiety

A study found that 92.6% of patients had generalized anxiety disorder (GAD).

1 in 10 caregivers were found to have at least one diagnosable anxiety disorder.



60% women separate or divorce from partners within 6 months after cancer diagnosis

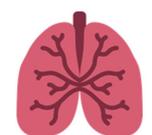
Treatment side effects, pain, later cancer stages have been associated with lower quality of life and self-esteem



## Late Cancer Diagnosis

Late presentation (Stage III & IV) is a key barrier to survivorship across all cancers

## Presentation based on cancer type



Lung Cancer  
75% - 88%



Colorectal Cancer  
63.8%

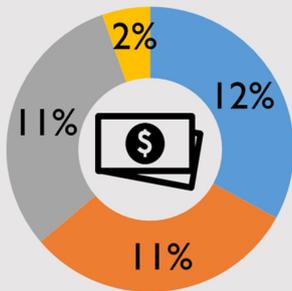


Breast Cancer  
41.3%



Cervical Cancer  
38.5%

## Economic Impact



**12%** could not pay for medicines/drugs

**11%** could not pay for medical consultations

**11%** could not pay rent/mortgage

**2%** could not pay for health insurance

## Coping Mechanisms of Families

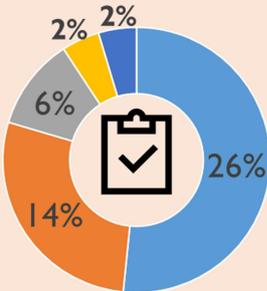
**26%** used savings set aside for other uses

**14%** ask for financial assistance from **family/friends**

**6%** ask for financial assistance from **govt/ community**

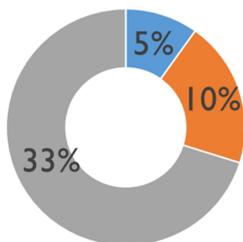
**2%** sold assets for other properties

**2%** took out a personal loan

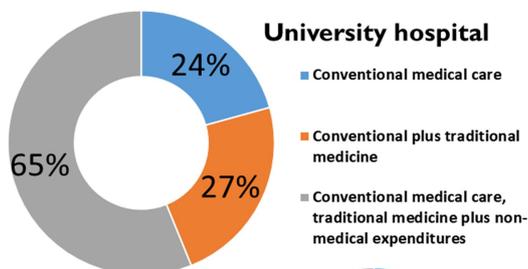


## Incidence of Financial Catastrophe

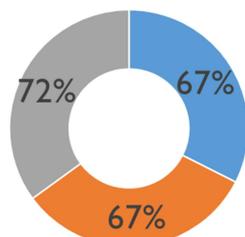
### Ministry of Health hospitals



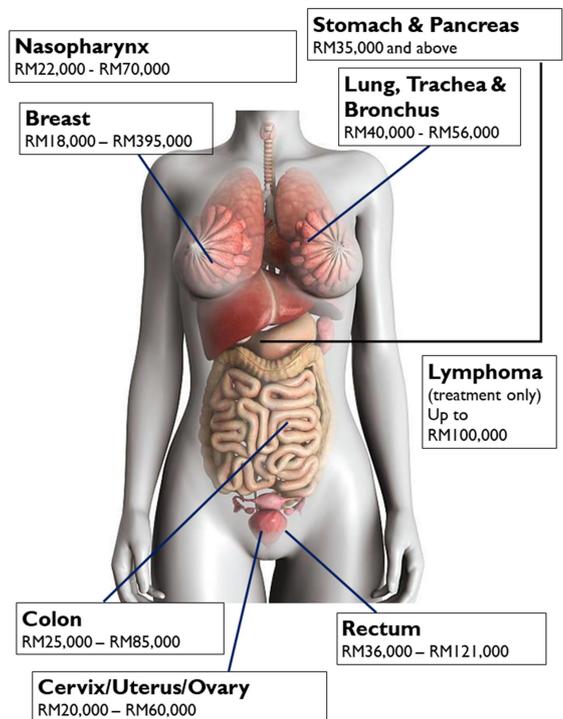
### University hospital



### Private hospital



## Cost of Cancer Treatment



## Sources

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## The Cancer Care Working Group

The Cancer Care Working Group is a coalition of individuals working for improvements in outcomes, treatment and care of cancer in Malaysia. We are a diverse group of people, some representing organisations or themselves, with different areas of focus, including service delivery, research, prevention, information and support, care and treatment, and patient involvement. Together, we work towards influencing cancer policy in Malaysia.

### Objectives

- To enhance and add value to the debate and ongoing campaigning for change in cancer policy.
- To advocate for or influence changes to health and social policies and legislation affecting cancer, including but not limited to, prevention, research, early diagnosis, primary care, secondary care, access to treatments, living with and beyond cancer, and end of life care.
- To promote the empowerment and meaningful participation of patient groups to participate in public policy consultations and discussions.

The Working Group is supported by an independent secretariat. The secretariat is currently the Galen Centre for Health and Social Policy.