The
Cancer Care
Working
Group

Policy For Action
No. 5/ 2021

White Paper

Cancer Care Challenges, Gaps And Opportunities In Malaysia

Galen Centre
for Health and Social Policy

Acknowledgements

Cancer Care - Challenges, Gaps And Opportunities In Malaysia is a report written by Winnie Ong and Azrul Mohd Khalib. With the support of the Malaysian Cancer Care Coalition (M3C) Taskforce and Cancer Care Working Group, this publication has been independently produced by the Galen Centre for Health & Social Policy.

The findings of this policy paper were derived from a review of existing literature, consultations and discussions held in 2019, 2020 and 2021 with persons living with cancer, patient groups, healthcare professionals, policy makers and payers.

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September 2021

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Executive Summary

Non-communicable diseases (NCDs) are estimated to claim the lives of around 41 million people per year, accounting for 71% of all deaths worldwide.[1] The main NCDs, namely cardiovascular diseases, cancers, chronic respiratory disease and diabetes, are among the top 10 leading causes of death.

In Malaysia, there is an estimated 8 million adults living with hypercholesterolemia, 6.4 million with hypertension, 4.1 million with obesity and 3.9 million with diabetes.[2]

1 in 7 Malaysians are now estimated to develop cancer before reaching 75 years of age.[3]

Amidst the COVID-19 crisis, approximately 49,000 people in Malaysia were estimated to be newly diagnosed with cancer in 2020, and this is expected to rise to more than 66,000 new cases annually by 2030.[4]

Over several decades, Malaysia has made progress in universal coverage of cancer care through its health system, particularly through the public healthcare service. However, effective cancer control remains elusive, and the disease still devastates thousands of lives, families, and communities.

Interventions to prevent and treat cancer must address a challenging context which includes late presentation of disease, an ageing population, rapid urbanisation, inactive and sedentary lifestyles, and unhealthy diets.

The late presentation for the disease which has resulted in high prevalence of advanced-stage cancer, has been a barrier since the 1990s, when the Penang Cancer Registry first discovered that 53% of cases were diagnosed in Stage III and IV.[5] This has often led to delays in diagnosis and treatment, resulting in poorer outcomes and low survival rates, for people with certain types of cancer.

In 2020, the redeployment of healthcare workers to frontline efforts and widespread movement restrictions to prevent the spread of SARS-CoV-2 have had knock-on effects to the cancer care landscape, particularly diagnosis and follow-up treatment.

Financial toxicity, particularly for those living with cancer from lower and middle-income households, is expected to deepen and spread due to economic disruptions and rising health costs.

Out-of-pocket payments are increasing as patients discover that they have inadequate insurance coverage or forced to depend on private healthcare due to insufficient access to necessary treatment in the public healthcare system.

Three actions are needed to reduce cancer's devastating impact on Malaysians

- get more people to be screened and detected at an earlier stage of their cancer
- provide timely and effective treatment when it is needed to avoid the burden of undertreated cancer
- optimise financing and governance of cancer care to steer towards better survival and reduced burden

The consequence of late diagnosis often resulting in fewer treatment options available in the latter.

Malaysia has been recognised as having the National Strategic Plan for Cancer Control Programme (2016-2020) which emphasised prevention and is committed to providing treatment access for all.

The successor to this strategic plan covering the period of 2021-2025 is expected to approach cancer care more comprehensively, extending beyond treatment. It will be end-to-end, covering preventative measures to palliative care.

Such a plan requires strong political and institutional support, utilises public-private partnerships, and is sufficiently funded to ensure its successful and effective implementation. However, the lack of sufficient funding, monitoring, reimbursements, and effective governance presents significant challenges to the strategic plan.

Operationalising such plans and producing successful health outcomes require committed resources which are ideally sustained over a multi-year period, utilising both public and private resources.

Increased investments and commitments in health, specifically in cancer, will have a direct impact on overall population health outcomes, particularly reducing the human and financial costs resulting from late-stage presentation of cancer, and premature deaths.

This paper emphasises on three key areas for action to reduce the impact of cancer on Malaysians.

More people need to be screened and diagnosed at an earlier stage of their cancer when treatment is most effective, and the chance of survival is at its highest.

Timely, effective and innovative treatment should be made available when it is needed to avoid the burden of undertreated cancer. Not all cancers can be detected early, and the health system must not leave behind those diagnosed with advanced cancer.

The financing and governance of cancer care needs to be optimised to steer towards better survival, reduced burden from cancer, and overall better health outcomes.

This document has been prepared to raise awareness about the burden of cancer in the country and the challenges faced by people living with this disease.

It outlines feasible and pragmatic policy recommendations that have the potential to produce better outcomes for people living with cancer in Malaysia.

Cancer Policy Recommendations

- Reform health financing for cancer care
- Move towards value-based medicine
- Coordinate stakeholders under a central governance body
- Mainstream patient navigation and psychosocial support
- Strengthen monitoring and application of cancer control data

Burden of cancer in Malaysia

During a time of economic uncertainty and reprioritisation of health services to respond to the COVID-19 pandemic, the burden from cancer continues to climb unabated.

Over the past decade, nearly 250,000 cancer cases and 150,000 deaths from cancer have been reported in Malaysia. [6,7]

Cancer is the second leading cause of premature death behind heart disease in this country.[8] 1 in 7 individuals is expected to develop cancer before reaching 75 years of age.[3]

As sedentary lifestyles, overweight and obesity become more commonplace in Malaysian households, combined with populations that are growing increasingly older, cancer rates are expected to increase.

The numbers of new cancer cases and deaths are expected to rise by 37% and 42% respectively, a greater degree than what has been projected for neighbouring countries such as China, Indonesia, and Thailand.[9, 10]

Breast, colorectal, and lung cancers are currently the most common cancers. Together, they make up nearly 40% of deaths due to cancer.[11]

Despite existing screening programmes, a high proportion of patients with breast cancer (48%) or colorectal cancer (73%) are diagnosed at Stage 3 and 4.[6] Advanced disease is associated with significantly worse outcomes, less effective treatment, and more costly care.

In every Peninsular and East Malaysia state, cancer remains a major health issue (Figure 1).

In the coming years, ageing and rapid urbanisation will drive an increase in new cases, similar to what has been seen in high-income countries such as Japan and Singapore.

1 in 7 individuals is expected to develop cancer before reaching 75 years of age.

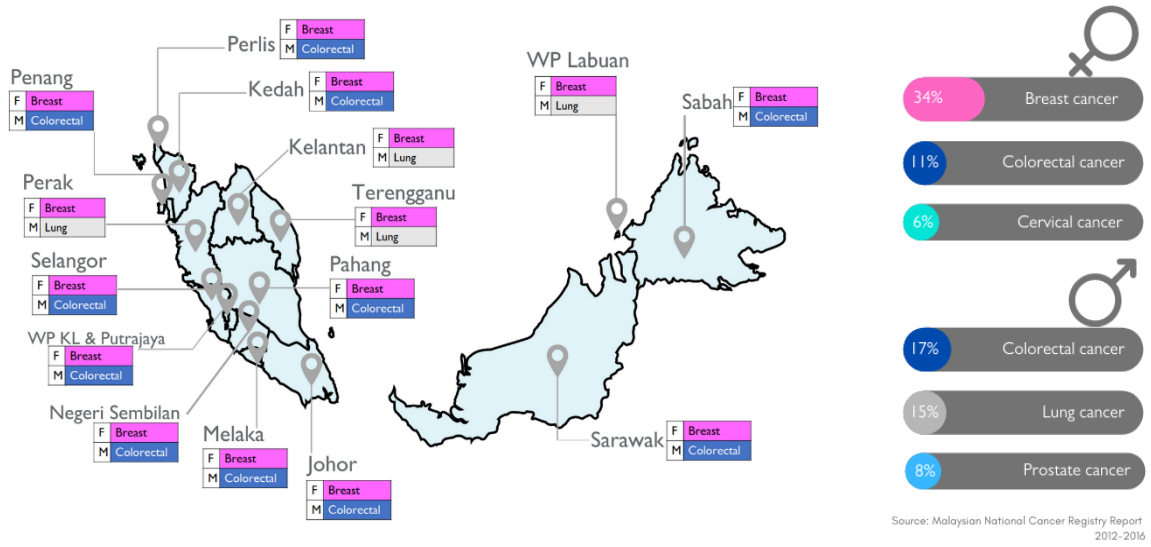

Figure 1 - *Breast cancer is the leading cancer among females (F) across all states, while colorectal and lung cancer top the ranks for males (M) (left). On the right are the top three diagnosed cancer types for each gender are displayed along with the percentage of cases.*

Survival from cancer in Malaysia is currently less than ideal

At 61%, the mortality to incidence ratio is higher than other countries in the upper middle-income bracket and at a similar stage of economic development.[12,13]

Survival rates capture how effectively health systems detect cancer cases and access to treatment. Unfortunately, Malaysia lags other countries which have better survival rates.

At 67%, the country's five-year survival rate for breast cancer is one of the worst in the Asia Pacific region.[6] Lung cancer is at 11%.

For every 5 newly diagnosed cases, 3 deaths from cancer occurred within the same period.

Women between the ages of 30-69 years old died from cancer at a rate of 73.3 per 100,000 population, similar to ischemic heart disease at 75.8 per 100,000 population.[8]

Unfortunately, 64% of all cancer cases are presented late at Stages III and IV.

The available survival data for Malaysia underlines the importance of the link between late advanced stage diagnoses and insufficient access, with receiving effective and relevant treatment, and increased cancer survivorship.

Though newly diagnosed cancer cases in this country are lower than the global average, the relatively higher ratio of deaths makes disease management of cancer a necessary and urgent priority. The situation can be improved upon, and survival rates among those diagnosed with cancer increased.

Nevertheless, surviving any cancer is difficult and may take months to years of treatment. It often involves navigating a maze from getting a diagnosis, treatment, and hospitalisation, to survivorship and end of life.

Financial burdens affect survivorship

Navigating through the cancer care pathway, from screening, diagnosis, treatment, and supportive care, are often fraught with logistical, financial, informational, emotional and system barriers.[16]

A large proportion of cancer patients are also diagnosed during their most productive and economically active ages (Figure 2).[6]

These factors affect survivorship.

Many of those who undergo treatment subsequently face long-term physical side effects, psychosocial distress, and financial hardship.

A diagnosis of cancer brings about losses in income and productivity, limits to daily activity, and costs in time and transportation needed to access regular medical care.[16]

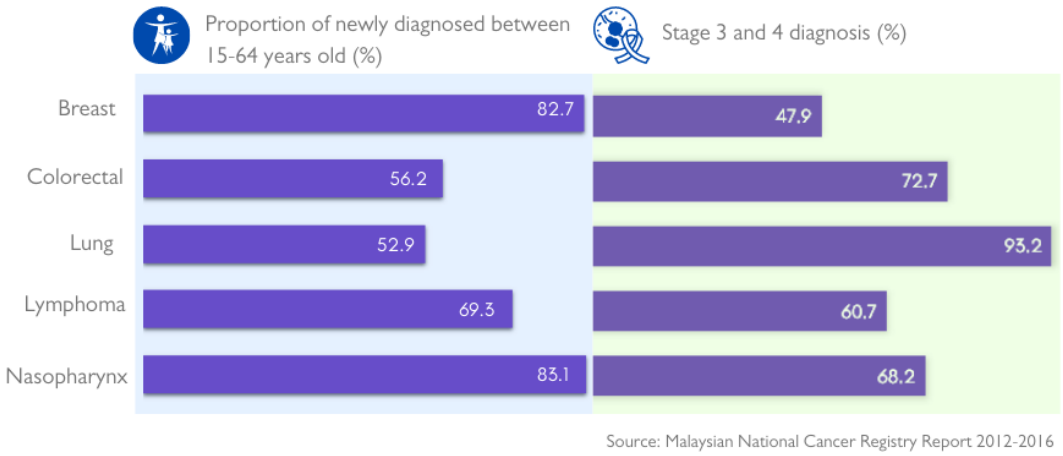

Figure 2 - *Malaysians diagnosed with cancer are often in the most productive periods of their lives (left).*

Among the top five cancers in Malaysia overall, the burden of advanced cancer is substantial (right)

Research from the landmark 2012–2014 ASEAN Costs in Oncology study showed that one in two cancer survivors (51%) in Malaysia would be pushed into economic hardship within the first year of being diagnosed. [16]

49% would have used up the entirety of their personal savings in pursuit of treatment. 39% of respondents could not pay for their medication. Of the respondents, 35% were unable to afford medical consultation fees, 22% could no longer pay for their rents and mortgages. 19% discontinued treatments altogether, as a result of financial harship.

One in three Malaysian households (33%) in the study fell below the national poverty line as a result of a cancer diagnosis.[16]

Despite higher out of pocket payments for medical care in university and private hospitals, patients resort to seeking treatment and care in these settings due to limited treatment options or longer waiting times in public hospitals.[17]

Though medical care is highly subsidised for patients accessing the public healthcare system, indirect costs arising from the process of seeking care and treatment in the hopes of getting better can be substantial. [16]

Cancer impoverishes households and is a major cause of poverty. It causes financial catastrophe and drains resources due to the cost of treatment and managing the disease.

Defaulting medical care or being unable to access or afford effective treatment bears even more devastating consequences in terms of cancer survival.

In 2017, DALY (disability-adjusted life year) losses from cancer in Malaysia was estimated to be around RM 30.73 billion or 2.2% of nominal GDP.[11] Most were among the 50–69 years age group, which accounted for nearly one half (47.9%) of the attributable burden of disease costs.

Trachea, bronchus and lung cancers, accounted for the largest burden of disease losses at 15% of the total DALY from cancer, affecting mostly males. [11] This was followed by breast cancer and cancer of the colon and rectum, each of which accounted for approximately 11.5% of the total DALY burden. Breast cancer formed 25.2% of the female cancer burden.[11]

A large proportion of cancer patients are diagnosed during their most productive and economically active ages.

COVID-19 and its impact on cancer

The burden of COVID-19 on health systems is unprecedented and has serious ramifications for cancer care.

Globally, 42% of countries surveyed by the World Health Organisation experienced disruption in cancer diagnoses and treatment during their pandemic response.[18]

Cancer patients appear to be more vulnerable to COVID-19 complications with increased mortality amongst those who are positive.[19, 20] The fear of infection coupled with the suspension of diagnostic services may cause individuals to be delayed or not be screened at all for cancer. Treatment pathways were modified, and radiotherapy and chemotherapy sessions prioritised according to how likely the treatment will benefit the patient, causing deferment and delays.

Throughout the emergency lockdowns imposed by the Malaysian government, major hospitals rushed to enforce physical distancing, postponing appointments, and delaying elective surgeries to absorb COVID-19 cases.[21, 22] This resulted in many patients with chronic conditions, in this case, those with cancer, not being able to access care, which could lead to poorer health outcomes, including premature loss of life.

The worsening economic conditions in 2020 and 2021 have further exacerbated the financial burden of cancer survivors and made employment conditions even more precarious. Many cancer patients face an impossible choice between complying with medical treatment or putting food on the table.[23] Cancer Research Malaysia found that 1 in 4 breast cancer patients surveyed (25.6%) were in crisis during the March – June 2020 lockdown period due to their inability to meet basic needs such as being able to afford food, water, electricity, and rent, which hindered them from receiving treatment.[24]

The cost of the Movement Control Order (MCO) and of the measures imposed to control the spread of COVID-19 to cancer patients in Malaysia from the perspective of care and disease progression has yet to be fully described. It is likely that their implications will have impact for years to come.

A modelling study from the United Kingdom indicated that a 3-month delay in diagnosis during the lockdown period, triggered a subsequent delay in care and treatment. It predicted that long-term survival would be reduced by 10%.[25]

Challenges and gaps

The National Strategic Plan for Cancer Control Programme 2016-2020 identified many of the gaps existing in cancer care but also highlighted that the previous cancer plans were not properly costed or provided with the necessary resources to commit the country to their implementation. [17]

Efforts to downstage existing cancer cases often run parallel to prevention efforts, resulting in competition for prioritisation and resources. This is a reality that even policy makers themselves have recognised repeatedly. [17]

There are several gaps that have been identified, including coverage and capacity of related services.

In Peninsular Malaysia, cancer care services are concentrated in the urban regions of Klang Valley, Penang, Johor, and Ipoh with limited services along the east coast. The states of East Malaysia, making up 60% of Malaysia's total landmass, are served by a handful of hospitals in the state capital cities of Sabah and Sarawak.

Besides the predominantly urban concentration of facilities, the number of cancer related specialists fall short of the recommended 10 per million population.[26]

For every million people, there are currently only about 3.6 radiotherapy and oncology specialists. The majority are employed by private hospitals (58%), with the remaining in Ministry of Health hospitals (30%) and university hospitals under the Ministry of Higher Education (12%).[26]

Today, people living with cancer and healthcare professionals face a steeper journey than before, as the COVID-19 pandemic continues to exert tremendous pressure on the public healthcare sector, diverting resources and funding, and triggering the loss of private medical insurance coverage and draining of personal savings.[27]

For the next couple of years, the shadow of the COVID-19 crisis will continue to loom large over all efforts to manage public health concerns including non-communicable diseases such as cancer.

Nonetheless, three major challenges which have and continue to exacerbate the burden of cancer in Malaysia:

- late detection and diagnostic delays
- insufficient and disparate access to treatment; and
- unmet needs in the social, psychological, and financial aspects of surviving cancer

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Late detection and delays in diagnosis

A high proportion of cancer in Malaysia, is screened, diagnosed, and treated late. The National Cancer Registry 2012 - 2016 report found that 64% of newly diagnosed cancer cases were at Stages 3 and 4.[6]

Existing treatment options at that point are limited and often costly, particularly those in private healthcare. Managing the disease becomes more expensive and debilitating for individuals and caregivers, which lead to an overall lower chance of survival.

Societal challenges and institutional obstacles at different levels often stand in the way of an earlier diagnosis for the individual.

Dismissal of symptoms as benign or low-priority, fatalism on cancer, reinforced by disjointed pathways to diagnosis in the health system, have contributed to the failure of most cancers being detected earlier.

Persons living with breast cancer reported varying experiences which delayed their presentation for diagnosis.[28-30] This includes:

a.) poor recognition of related symptoms
b.) lack of financial resources to access screening facilities
c.) low awareness of available health advice and social support
d.) negative influences from family members often promoting the use of traditional and alternative therapies.

Figure 3 illustrates Malaysia's position compared to other countries when it comes to diagnosis of breast cancer.

Logistical challenges included living far from the relevant healthcare facilities and being unable to obtain care for dependents or a substitute in the workplace.[31, 32]

Multiple service providers for screening exist including facilities under the Ministry of Health and the National Population and Family Development Board (LPPKN), and Social Security Organisation (SOCSO) panel clinics.[17] These are often either partially or fully subsidised, and available to all.

Despite the availability of subsidised screening services, uptake can nevertheless be poor. In addition to not being population-based, there are major gaps in access, documentation, and coordination between health providers.[33, 34]

Over 200,000 SOCSO beneficiaries qualified for health screenings in 2017, but only 32,000 underwent for screening.[35]

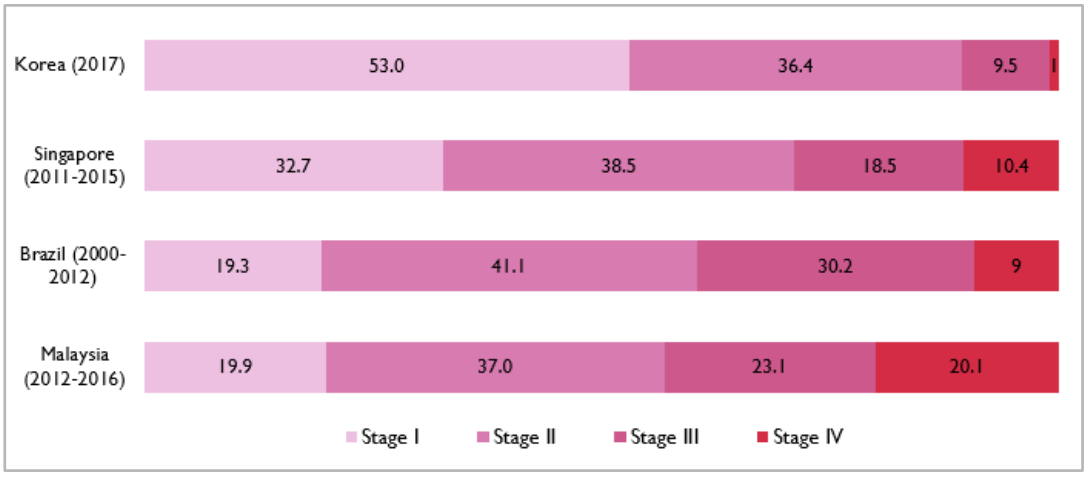

Figure 3 - *Stage distribution of breast cancer compared to other countries with higher five-year survival rates.*

Earlier diagnosis opens up the possibility of better survival, greater treatment effectiveness, and reduced costs.

Findings from studies conducted in urban locations in Terengganu, Selangor and Kuala Lumpur, found that uptake of subsidised mammogram screening was between 10.5% and 31.9% among the general population and 80.3% among hospital staff. However, uptake was less than 10% among women in rural Perak and Pahang.[36]

A pilot study on early lung cancer screening (PEARLS) encountered poor response, likely due to low awareness, refusal to be screened, and fear of receiving a cancer diagnosis.[37] As a result, the study which provided low dose computed tomography (CT) screening, was terminated.

Under employer-provided or personal insurance, screening may not be covered, and it would depend on the individual to request for screening, pay for it out of pocket and follow the recommended schedule over her or his lifetime.

Patients drop out during follow-up after screening and diagnosis or become uncontactable.[38] Many cancer screening programmes face similar challenges and become ineffective due to weak linkages to next stages of care.[30]

In 2018, 12% of Ministry of Health patients who screened positive under the national colorectal cancer screening programme refused referral. [39]

When the patient finally presents herself or himself to the healthcare system, it would usually be in a poor state of health with a less than preferred prognosis, and fewer available treatment options.

Misdiagnosis or late diagnosis at the primary care level can also result in delays in referral. Waiting times for a cancer diagnosis could vary widely due to interdepartmental delays. For breast cancer, under the public healthcare system, this could range from 2 weeks to 6 months.[30]

As a result, there is often an increased risk of cancer progression or loss of patients to follow-up.

More than 70% of the Malaysian population depend on the public healthcare system, particularly primary care facilities.[44] As a result, the latter often experiences tremendous stress due to shortages of manpower, and patient overload, especially those located in urban settings.

There have been serious delays in call and recall of cancer screening. In one study, only 6.7% of newly diagnosed breast cancer patients received their diagnosis within one month. [45] 45.5% were notified more than 6 months after consultation.

Self-paying patients seeking diagnosis in the private sector may experience delays due to fee payment, insurance coverage, or the time-off needed for employer approval.[42]

The COVID-19 crisis which has reduced hospital-based screening services, induced fear of going to a healthcare facility, and created the perception that vague symptoms (such as changes in bowel habits) as a 'non-essential' cause for a hospital visit, is expected to further delay cancer detection efforts.

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Insufficient access to treatment

The current capacity and distribution of oncology services in the public and private healthcare sectors are major hurdles to accessing quality cancer treatment and care (Figure 4).

Major public hospitals, including the National Cancer Institute, are the main providers of cancer care services, managing an estimated two out of three patients in the Malaysian health system.[30]

Along the east coast of Peninsular Malaysia and large stretches of Sabah and Sarawak, patients either do not have access to or are forced to travel long distances for radiotherapy and oncology services. 25% of the Malaysian population live more than 100km away from radiotherapy facilities.[46]

Systemic therapies that have transformed the standard of care have become the cornerstone of cancer treatment. While hormone therapy and chemotherapy are well-established in the public sector, innovative medicines such as targeted therapy and immunotherapy are generally accessed through the private sector.[47-49]

While gradually been taken up into the national formulary, essential cancer therapies such as *trastuzumab, rituximab, erlotinib, bortezomib,* and *abiraterone* are not uniformly accessible.

The number of patients covered by reimbursed medicines are restricted by quota systems, which vary between hospitals. Once those quotas are filled up, it falls on patients to use their personal or household savings, borrow funds and/or apply for financial assistance to access such therapies.[48, 49, 51]

Limited availability and accessibility also deter cancer specialists from recommending these medicines as first or second line treatment in national protocols.[51] The attending clinician, out of concern for a patient's financial wellbeing, may also refrain from suggesting innovative treatment.[47] This could cause patients to forego such treatment.[51]

Despite innovative medicines such as *lapatinib, pertuzumab, crizotinib*, and *cetuximab* being rated highest on the ESMO Magnitude of Clinical Benefits Scale,[53] they may not be available in the national formulary.

When clinicians are unable to prescribe according to the optimal therapeutic strategy, patients with inadequately treated disease face the risk of higher morbidity, productivity loss, and premature death.

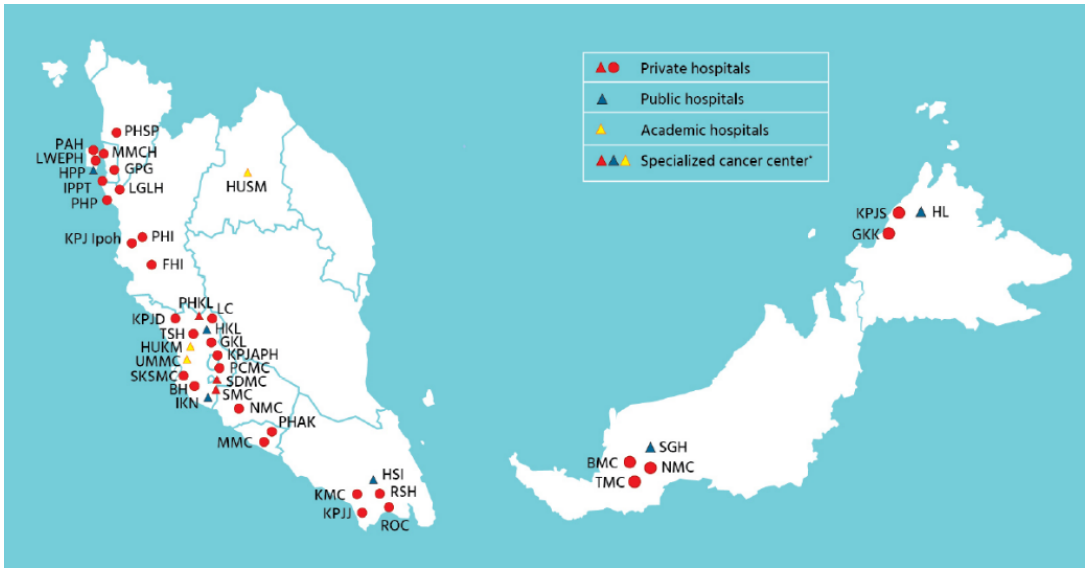

Figure 4 - *Distribution of public and private sector facilities providing cancer care in Peninsular and East Malaysia*

Navigating supportive care and financial burdens

Once diagnosed with cancer, patients often face a long and arduous journey to access care, begin and complete treatment, and adapt to survivorship.

In the Malaysian context, barriers exist which increase the chance of patients foregoing or discontinuing treatment, and cause quality of life to deteriorate, and survival to wane.

Getting treatment for cancer is disruptive to most Malaysian households. Adhering to treatment regimens requires social support and financial resources for a long period of time.[30, 51]

As illustrated in Figure 5, individuals and households often do not have the necessary capacity to navigate the complexity of supportive care needed and to figure out the financial implications from a diagnosis of cancer.

Chemotherapy takes months to complete, as each cycle is followed by a rest period to recover from side effects. Radiotherapy is also given in hospital facilities over a few weeks, usually several times a week, following scans and appointments to plan treatment.

After surgery to remove a tumour, the period of recovery can be prolonged, stretching from weeks to months. It may be followed by physical therapy and rehabilitation to regain daily functional abilities.

During these periods of treatment and convalescence, the absence of supportive care could lead to undesired outcomes such as dropping out or defaulting on treatments.[55]

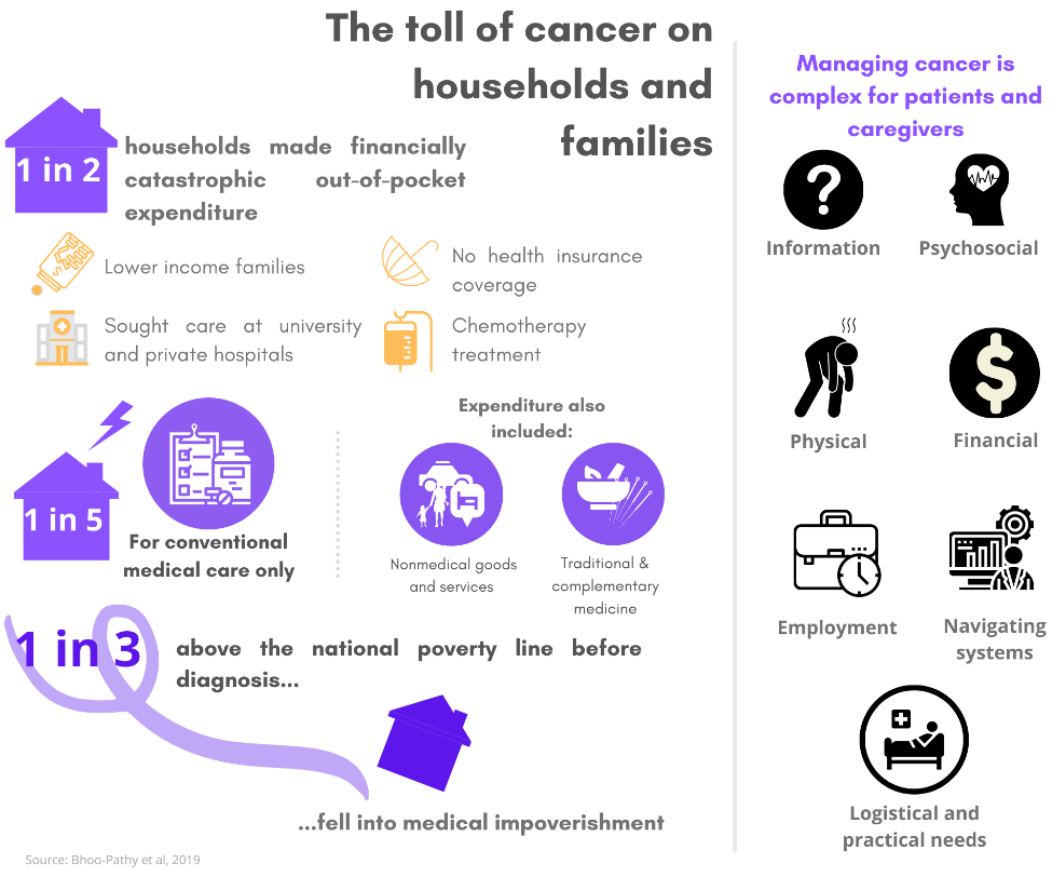

Figure 5 - *Impact of cancer on individuals and households in Malaysia one year after cancer diagnosis*

Despite the need for psycho-oncology support within the cancer care field, it is under-recognised.[55] Patients may not even realise that this kind of care is needed. Unfortunately, there are very few mental health professionals available in Malaysia to support the work of cancer clinicians. [57]

Patients and family members could be influenced to choose traditional or alternative treatments, leading to progression, and worsening of the cancer.

Regardless of initial socioeconomic status, loss of income and unemployment after a cancer diagnosis are major causes of financial hardship.[51, 58]

Many employed individuals are unable to continue working due to prolonged work absence, lack of workplace flexibility, and reduced productivity while going through treatment.[51, 58]

Frequent hospital follow-ups and long waiting time in major public hospitals can quickly lead to substantial parking and transport fees, as well as spending for childcare and household help.[51]

Rural patients who travel long distances to seek treatment, such as in Sabah and Sarawak, struggle to afford transportation, lodging, and nominal treatment fees.

The choices are often stark: stay home and retain your job or get treated and lose at least several days' worth of wages or even become unemployed.[59]

Individuals and households often do not have the necessary capacity to navigate the supportive care needed and to figure out the financial implications from a diagnosis of cancer.

Even among patients who have private health insurance, there can be complications and challenges. Not having the right insurance with sufficient coverage or being underinsured are common problems among cancer patients.

Lack of reimbursement for necessary procedures such as screening and post-surgery items may also lead to additional and unexpected expenditure needing out-of-pocket expenditure.[51]

Seeking financial assistance can be fraught with bureaucratic hurdles. Patients whose condition are not considered severe enough to qualify for SOCSO assistance or their EPF savings are left with little support.

A 2019 incident saw a woman with Stage 4 cancer being brought to the Employee Provident Fund office on a stretcher to enable her to withdraw from her pension fund savings.[60]

Social insecurity and financial problems are likely to deepen while the person is still living with cancer or recovering from it.

After undergoing primary cancer treatment, many patients struggle to return to work or find new jobs. They do so while managing complications, going for follow-up appointments, and taking maintenance treatment.

Survivorship is also affected by discrimination and lack of workplace accommodations for people with serious chronic illnesses.

Opportunities to improve treatment and survive cancer

Registries in high-income countries show cancer patients living longer, even for cancer types with poorer prognosis such as lung and pancreatic cancer.[63]

Since the 1970s, the five-year survival rate in the United Kingdom for all cancers combined doubled.[61]

In Singapore, the past decade has seen more than 50% of male cancer patients survive their disease for five years or longer. For females, more than 60% survived beyond that same period. The rate of cancer death for breast, lung, colorectal, prostate, cervical and stomach cancer, has declined significantly in Singapore over the past three decades. [62]

Effective prevention, detection and treatment have played critical roles in all these achievements.

Where there is earlier detection, access to effective treatment, and working health systems, cancer becomes a chronic disease rather than a fatal condition.

Today, it is possible to survive cancer.

When the World Health Assembly in 2017 called upon countries to prevent and control cancer, it placed a burden of responsibility on governments to ensure the best chance for their citizens to have access to necessary treatment to survive cancer.

Detecting and diagnosing earlier

Being diagnosed at an earlier stage gives people living with cancer, the best prospects for curative treatment and survival with a higher quality of life.

Countries have channelled resources attempting to shift their citizens to an earlier stage at diagnosis, both as a cost-effective strategy as well as to save lives.

One strategy has been to target and screen asymptomatic population groups in order to detect precancerous lesions before they develop into invasive cancer.

Many high-income countries have rolled out population-level screening programmes, which have been shown to save lives[64] and avert future treatment costs[66].

Countries such as Malaysia, with a lower capacity to manage large-scale screening and with varied access to cancer treatment services, opt for opportunistic programmes.

As most cancers are detected outside screening programmes, improving education through public health campaigns to increase early recognition of suspicious signs and symptoms are another crucial strategy, to encourage early presentation, promote downstaging and make cancer more treatable and care cost-effective in the long run.[68]

However, such an approach demands a robust diagnostic and referral pathway to translate increased awareness into improved early diagnosis and hence, survival gains.

Pathways for treatment and care should be monitored by emphasising on cancer waiting time targets, rather than patient volume. Countries such as the United Kingdom and other OECD nations, have adopted similar approaches reflecting the urgency of treating cancer when it is still amenable to interventions.

Ideally, people should start treatment within a month of diagnosis.

The UK's National Health Service places as its target that a person should not wait more than 28 days from referral to finding out whether you have cancer.[69]

In Malaysia, wait times can sometimes be longer than 6 months in the public health system. [45] For colorectal cancer in Thailand, it is around 89 days.[70] The average wait time in breast cancer diagnosis in Taiwan was 27.8 days.[71]

Molecular advances in screening are also increasingly helping to pre-empt or detect early cancers. The ability to test for the BRCA 1 and 2 gene mutations, which increases the risk of breast and ovarian cancer, has enabled earlier surveillance and detection in millions globally.[73]

Major government healthcare facilities such as Ampang and Kuala Lumpur Hospital have such capabilities but may be overburdened and unable to cope with existing demands.

Molecular diagnostic testing for the human papillomavirus (HPV) has also augmented traditional cytology-based methods by making screening convenient for women to perform self-sampling, enabling for earlier assessments of women at risk of cervical cancer.[74]

As survival declines with each stage of cancer (Figure 6), ensuring that people are detected and diagnosed with cancer earlier remains a priority.

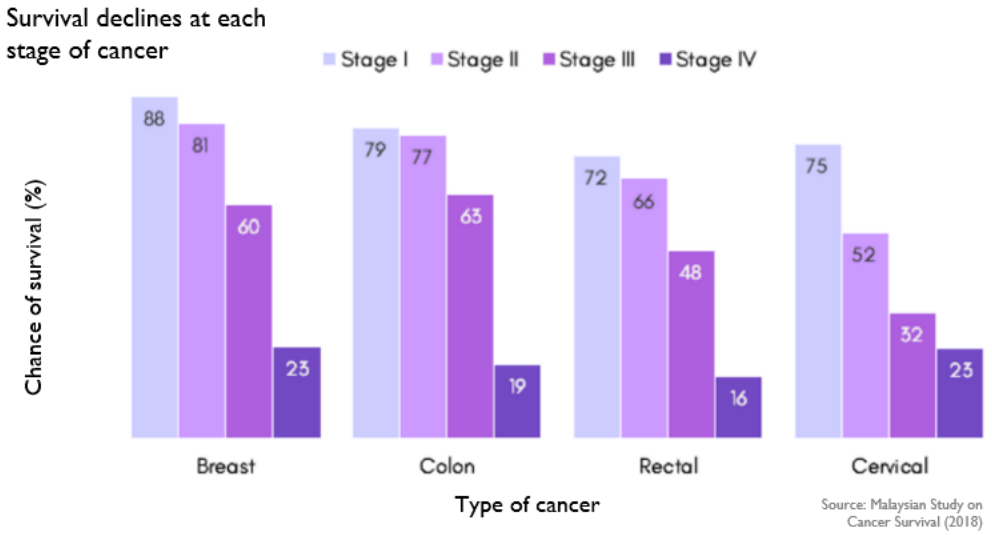

Figure 6 - *The likelihood of five-year survival (%) declines drastically for Stage IV, when cancer has metastasised or spread to other organs and parts of the body.*

Pushing the limits of treatment and care

Not every cancer can be prevented or detected at an early stage through screening. Therefore, access to necessary treatment and care, especially for cancers at an advanced stage, is critical.

Effective treatment ensures that cancer is removed, controlled, or even cured. This includes therapy given after the main treatment to reduce the risk of cancer recurrence, that is now an essential part of cancer care.

The evolution of cancer research, particularly in the last two decades, have led to the addition of targeted therapies, monoclonal antibodies and immunotherapy to treatment regimens, alongside conventional chemotherapy, surgery, and radiotherapy techniques.

Many of the new targeted therapies have the benefit of being both of higher efficacy and lower toxicity, allowing for patients to have better functionality and less discomfort during treatment.[75] This provides an increased chance of surviving their cancer.

These therapies have paved new standards of care for commonly treated cancers and changed the outlook of previously untreatable and advanced-stage cancers, even those with poor prognosis such as lung and pancreatic cancers.[63]

These new treatments are the main reason for increases in life expectancy of people living with cancer.

For people living with chronic myeloid leukaemia, the introduction of tyrosine kinase inhibitors has returned life expectancy to near normal and survival rates have improved 80-90%.[76]

Access to innovative treatment has become an important component of quality cancer care.

The World Health Organisation's List of Essential Medicines includes conventional chemotherapy, hormonal therapies, and targeted therapies as the minimum medicine needs for a basic healthcare system.[77]

Treatment of less common and rare cancers together which make up a significant proportion of cancer incidence and deaths in Malaysia, including cancers in children and adolescents[78], is often dependent on innovative therapies.

For the most part, these therapies are accessible through special access programmes, or participation in clinical trials. However, access remains limited. They are often time bound with strict medical and programme requirements that need to be met prior to approval.[49]

Overcoming obstacles to access these therapies including delayed diagnosis, difficulty accessing clinical expertise, affordability, and smaller patient pools for clinical trials, are critical to improving survival and quality of life.

Access to innovative treatment has become an important component of quality cancer care.

Strengthening governance and leadership

Reducing the burden from cancer is complex and needs multidisciplinary approaches. It is an issue which requires effective governance structures to make a difference in the lives of those affected by cancer.

Due to the long-term nature of the disease, cancer care can be costly and resource-intensive, requiring sustained commitment of institutional and political will.

The shift from a volume-based healthcare system to a value-based system also requires strong leadership, especially if changes or reforms to healthcare delivery and reimbursement models are being proposed.

Institutionally, the transition to value-based care centred around a patient's condition rather than a specific treatment or symptom is challenging the current dependence on separate budget lines.

At the clinical level, effective governance in cancer care requires breaking down the traditional silos that separate oncologists, surgeons, radiologists, nurses, allied health professional providers, social workers and dietitians.

Despite the movement towards more multidisciplinary approaches, the cancer workforce remains a highly siloed profession. For example, when debating the quality of cancer care in Malaysia, the number of oncologists is frequently the focus of discussion.

An increasing number of countries are being guided by their respective national cancer control plan (NCCP) for planning, implementation, evaluation, and investment. Malaysia has its own National Strategic Plan for Cancer Control Programme (2016-2020).

Governance in cancer control, from prevention to end of life care, makes a difference in the lives of individuals living with cancer.

It has been found that the stronger a country's governance and health system, the lower the relative mortality of cancer in the population.[86] In such countries, more people are surviving cancer.

A 2013 OECD analysis found that cancer care resources and governance explained nearly three-quarters of survival differences between member countries.[87]

As Malaysia begins its transition to a high-income economy (expected to be between 2024 and 2028), it is important to take heed a number of key and salient points. High-income countries tend to have low levels of out-of-pocket (OOP) expenditure, higher levels of prepayment and risk pooling, and various innovative payment schemes for cancer medicines.[87]

As Malaysia seeks to address gaps in cancer care, there is an opportunity to address governance structures in cancer care through ongoing proposed health reforms.

Tackling issues such as financial protection will help push back against fatalism and reduce the depletion of savings and resources of people living with cancer and their families. It will also assist in ensuring the continuing sustainability of universal health coverage in Malaysia.

Recommendations

Three key themes which, if addressed strongly and supported consistently, will be able to significantly reduce the devastating impact of cancer in Malaysia.

Earlier is better. Increasing awareness and knowledge of cancer allows for more people to be informed, to decide to be screened, and be detected at a much earlier stage of their cancer. The earlier the cancer is detected, the better the chance of survival as the access and availability of current treatment would be at their most effective.

Leave no patient behind. Not all cancers can be detected early, and the health system must not marginalise those diagnosed with advanced cancer. When necessary and effective treatment options are made available, lives can be saved by treating late-stage cancer properly.

Ensure that cancer care is sufficiently funded. It is possible to ensure that adequate financing of cancer care is available and committed to. When health outcomes are identified and targeted (e.g. better cancer survival), the needs to achieve them can be better understood, properly costed and funding gaps identified. Financing, from both public and private sectors, can then be mobilised and optimised in support.

- Reform health financing for cancer care
- Move towards value-based medicine
- Coordinate stakeholders under a central governance body
- Mainstream patient navigation and psychosocial support
- Strengthen monitoring and application of cancer control data

Introduce innovative cancer care financing

Health financing in Malaysia has long been recognised as an area in need of reform. Malaysia currently spends less than 5% of Gross Domestic Product (GDP) on health expenditure (4.3% in 2019).[88]

Out-of-pocket (OOP) spending on health over the past decade has increased and has resulted in households facing financial catastrophe.[89]

More than 80% of households utilised their current income as a source for payment towards health services. [89] The World Health Organisation has previously recommended reducing the country's OOP from 35% to between 15-20%.

With the COVID-19 pandemic, the Government has a huge burden to keep up with the increasing demand for funding to treat patients, as well as provide vaccines to the population, especially those considered high risk such as people living with non-communicable diseases such as cancer.

The incidences of cancer and specifically, advanced cancer, are expected to grow due to repeated movement restrictions being imposed. As a result of cancer taking on a lower budget priority during this public health emergency, cancer can easily become the most expensive disease for many health systems.

There is a need to transition from the annual budget-based financing framework to public financing or community-based health insurance (CBHI) schemes that enable prepayment and pooling of risks and costs.

Health insurance schemes can be designed to cater to innovative therapies provided by MOH. They could be subsidized at different tiers to accommodate different household income levels. This would allow the government to have more funding flexibility for different population groups.

Based on the National Health and Morbidity Survey 2019, only 22% of Malaysians are covered with at least one type of health insurance [44].

The Government must drive collaboration with the insurance industry to create more awareness and education to empower more Malaysians to have sufficient protection for health expenditure, particularly cancer care.

To improve and sustain the insurance coverage of private sector employees, the introduction of a portable health insurance with cancer-specific coverage would provide for care and treatment, regardless of employment status.

These insurance options increase access for a significant portion of the population through effective pooling and redistribution to reduce catastrophic health costs.

In addition to partnerships with insurance organisations, the Government should also deliberate on other forms of public-private partnership models to alleviate the financial burden of cancer treatments, including the possibility of multi-party co-pay systems.

New sources of financing should also be explored to increase budget for cancer care. Interim tax and non-tax mechanisms should be implemented to cater to current and future unmet needs.

One such mechanism involves earmarking at least 5% of annual revenue from tobacco and alcohol excise duties (so-called "sin taxes") for cancer treatment. The proposed quantum could potentially contribute an additional RM290 million annually to a cancer care budget that could be allocated to provide coverage of molecular diagnostics and innovative treatment, complimenting the existing public funding for cancer[90].

It is highly recommended that such funds are ring-fenced for the purpose of cancer treatments. These funds must be specially governed to ensure that it does not get absorbed into the main Ministry of Health

budget. Doing so would mean that it could be repurposed, negating the purpose and benefits of having a dedicated cancer care fund.

The recent formation of a Parliamentary Select Committee on Health, Science, and Innovation offers an opportunity for greater public-private partnership to explore innovative financing solutions such as co-payment, managed entry agreement and patient assistance schemes.

It offers an opportunity to strengthen political commitment to cancer care within the context of a health financing agenda.

More funding needs to be invested in comprehensive cancer care. However, it can be challenging in a resource-limited setting. Simply increasing the annual budget for cancer incrementally is likely to be unsustainable, and heavily dependent on ongoing political will.

Action Points

- incrementally increase budget for cancer by 10% annually
- explore Public Private Partnerships for innovative financing solutions
- earmark at least 5% of annual revenue from tobacco and alcohol excise duties
- introduce public financing, community-based health insurance (CBHI) schemes or co-pay systems
- introduce portable health insurance with cancer-specific coverage

Shift towards value-based medicine

Studies have shown that despite high spending on cancer, many health systems may fall short of providing consistent, high-quality cancer care.[87]

There are wide variations in the amounts spent on cancer care. However, higher spending does not always correlate with better outcomes.[87] Misaligned costing priorities between payers, suppliers, hospitals and patients result in siloed budgets which are inefficient and wasteful.

There are many variables which may be responsible for the differences in cancer survival rates including age, co-morbidities, stage at detection, and access.

The advances in diagnosis and treatment have generally improved survival rates for cancer.

However, these improvements in survival and new treatments such as targeted therapies and immunotherapies can often be expensive.

Therefore, the discussions concerning financing of cancer care are often challenged by questions centred around whether or the health system can afford these new treatments, and if they are cost-effective.

Value assessment framework

Value should be patient-centric and be guided by a care pathway approach.

The basic framework of a value-based approach is to focus on

- outcomes determined by people living with cancer
- delivery of healthcare services

- cost optimisation to achieve those outcomes, and
- prioritising value rather than volume of care.[93]

This approach is already being used by health systems in other countries such as the United Kingdom to improve outcomes for patients with diabetes, coronary heart disease, and other chronic conditions. It is now being adopted to improve the delivery of cancer care.[95]

The treatment pathway of the average cancer patient, utilising at least one of the more prevalent cancers, should be costed.

This would enable a better understanding of the total cost of delivering care across the patient journey through hospital and clinics. This would significantly help identify inefficiencies and drive improvements.

A value assessment framework can be developed working with technical experts, clinicians, and organisations such as the National Cancer Society of Malaysia (NCSM), and National Cancer Council (MAKNA). It can then be used to evaluate survival, quality of life, adherence to treatment, medicines, and other interventions as part of a holistic approach.[96]

Such a framework would enable the government to negotiate pricing, tailor procurement strategies, and work with the private sector to fine tune patient access schemes (PASc) in order to maximise the societal value of a treatment and increase its availability to those who need it. [96]

Best-practice care pathways need to be established, beginning with one or two of the most common cancers in Malaysia - breast and colorectal cancers. Each pathway should define the best practices for prevention, clinical care delivery, and end-of-life care.

Eventually, this could lead to optimal patient care and treatment pathways being defined and implemented for all oncology services in Malaysia.

Action Points

- adopt patient-centric frameworks to determine and assess value
- establish value assessment framework using care pathways
- identify best-practice care pathways for at least one cancer

Coordinate stakeholders under a central governance body

Malaysia has notably strong cancer control planning and policy, but face challenges in implementation and oversight.[85]

Clear-sighted problem identification and most importantly, leadership are important to address systemic fundamental gaps that lead to low survival rates.

Substantial structural reforms along the cancer control continuum cannot be addressed by the health sector alone.

The burden of addressing cancer in Malaysia should not be shouldered solely by the Ministry of Health or the government. It must also involve those in other ministries such as welfare and finance, as well as the private sector and civil society to address various social determinants of health.

A central governance body, under the National Strategic Plan for Cancer Control Programme, should be given the mandate to have oversight and drive progress in the national cancer control plan through multisectoral action and system-level milestones over a multi-year basis.

It should be populated by representatives of health and non-health stakeholders, as well as representatives from the government, private sector, professional organisations, civil society organisations and patient groups.

What would be critical for this central governance body is have senior representation from the government such as the Deputy Minister of Health. This would empower the body, provide clear key performance indicators, and allow decisions made to be followed through with a high level of accountability.

The intention would be to ensure that the issue of cancer care is effectively championed, guide and sustain discussions within the government, senior leadership of the civil service and across ministries and agencies, as well as provide the impetus for transformation and change in the cancer care space.

Strong government support within such a body would have the potential for stronger collaborations, and more opportunities for meaningful, quality public-private partnerships to improve patient care.

The body could guide or provide oversight on projects to close gaps in early detection, diagnosis, treatment and care, with research support from the National Institutes of Health.

The City Cancer Challenge in the Greater Petaling district in the state of Selangor, provides such an opportunity to test, learn, and scale-up implementation and address current gaps in cancer diagnosis and treatment through collective multisectoral action.[97]

This community-level initiative uses a model which involves health and non-health sectors; local, state, and Federal government representatives; academics, clinicians, and patient advocates.

Governance in cancer control, from prevention to end of life care, makes a difference in the lives of individuals living with cancer.

Action Points

- establish multi-sectoral central governance body for National Strategic Plan for Cancer Control Programme implementation
- involve non-health stakeholders (e.g. businesses, welfare NGOs) in community level initiatives to address cancer

Mainstream patient navigation and psychosocial support

Patient navigation, a process where a person engages with a patient to determine barriers to care and provides information to improve access to components of the health system, is increasingly recognised as an essential element of quality, patient-centred cancer care[98]. It has played a critical role in improving the timeliness of diagnosis and treatment.

Figure 7 illustrates an example of a pathway for a breast cancer patient. However, the experience is rarely linear.

In Malaysia, through an ongoing programme implemented by Cancer Research Malaysia, patient navigation has been instrumental in increasing adherence to care amongst people living with breast cancer.[54]

In that example, dedicated teams work closely with breast cancer patients by understanding them and providing necessary support services to ensure that they get diagnosed on time and complete their recommended treatment.

It has been credited with cutting waiting times for cancer diagnosis from 3-6 months to just 14 days, and reducing the number of treatment defaults.

Patient navigation should be widely integrated as part of cancer management.

However, patient navigation in many cancer programmes is currently absent or limited, mainly due to concerns of increased financial and human resource burdens[99].

The complexity of the cancer care system can be a major barrier to those needing to receive appropriate and timely medical interventions.

To prevent dropout between screening and diagnosis, individuals should receive navigation services to increase the likelihood of attending follow-up investigations and linking patients with required treatment and care.

Mainstreaming patient navigation into existing treatment pathways has enabled reductions in unnecessary resource utilisation such as visits to hospitals and emergency wards, and in reducing the burden on oncology services[99].

Training of navigators from the community should be carried out in conjunction with non-governmental organisations that are well trained in providing navigation services, such as Cancer Research Malaysia and National Cancer Society Malaysia (NCSM).

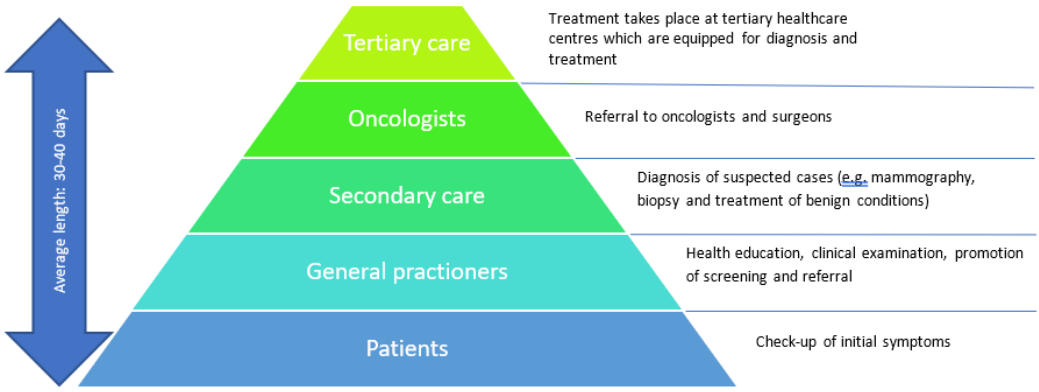

Figure 7 – *An example of pathway for a breast cancer patient at the point of screening and diagnosis*

Cancer casts a heavy shadow over individuals and households. Mental health support, particularly psychosocial support, should be mainstreamed and made an integral part of treatment planning.

By mainstreaming psychosocial needs into cancer management, patients will be more empowered in knowing what they can do about their condition, raise questions and concerns which they may have, and be more active in their diagnosis, treatment, and care. It can improve the management of cancer.

Action Points

Strengthen monitoring and application of cancer control data

The COVID-19 crisis has witnessed the systematic collection of data being channelled towards coordinating a coherent response to the pandemic. This can be replicated within cancer care.

The current cancer control data infrastructure such as the use of the National Cancer Registry has greatly improved. However, there is a need for better linkage to the objectives of the National Strategic Plan for Cancer Control Programme (NSPCCP).

The following actions are proposed:

- Publish key performance indicators for NSPCCP

  Data, including real world evidence, should be used to monitor, measure, and evaluate progress towards achieving objectives. These can assess outcomes, derive actionable insights, and enhance decision-making for policymakers and payers.

- Mandatory reporting for new cases of cancer

  Involvement of Ministry of Higher Education, Ministry of Defence and private hospitals would significantly increase representation of the cancer registry to track incidence and survival outcomes.

- Utilise the Malaysian Health Data Warehouse (MHDW)

  The MHDW was established to ensure trusted health data and information to be utilized in evidence-based decision-making and performance measurement, and financial and resource planning. It can play a crucial role in improving the analysis and application of cancer control data.

Apart from the registration of cases and periodic updates to the National Cancer Registry, it is also vital to strengthen information systems to capture the patient journey throughout treatment and survivorship.

As Malaysia is moving towards digitalization of healthcare by using Electronic Medical Records (EMR) systems and to futureproof cancer care, main hospitals and healthcare facilities should be linked via a robust interoperability online platform. This will improve hospital coordination, personalized cancer treatments and prescriptions leading to better patient outcomes.

Action Points

- utilise and make public key performance indicators aimed to evaluate the performance and implementation of the NSPCCP
- harness the resources of the Malaysian Health Data Warehouse in evaluating cancer care
- make notification of cancer cases mandatory in non-Ministry of Health healthcare facilities
- strengthen regulatory framework and policies to support digital health technologies and innovations in personalized healthcare infrastructure

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Conclusion: The way forward

As Malaysia moves along the trajectory towards high-income nation status, accessibility and quality of cancer care remain concerns.

Although clinicians are doing their best to provide guideline-driven care, the performance of cancer care services across the population has been challenged by the many gaps and challenges which exist.

Cancer screening in Malaysia remains largely opportunistic as opposed to a population-based approach. This should change to help with early detection and screening efforts.

With more people present or are detected at an earlier stage of their cancer, linking them with effective treatment will ensure that the chance of survival is at its highest.

Timely, appropriate, and effective treatment should be made available and expanded as needed to reduce the burden of undertreated cancer.

Mainstreaming patient navigation along with supporting psychosocial services into existing treatment pathways can reduce unnecessary resource utilisation such as visits to hospitals and emergency wards, as well as in treatment defaults or patient dropouts.

There is a need to address the fact that public and private health facilities which provide cancer treatment and care services are concentrated mainly in cities along the West Coast of Peninsular Malaysia, with Sabah and Sarawak having a limited number of facilities. Patients are often forced to travel long distances and at great cost to access treatment.

The health system must also not leave behind those diagnosed with advanced disease. Innovative and life-saving treatments such as targeted therapies and immunotherapies are becoming increasingly available in Malaysia, allowing for options where previously there were few or none.

Wider access for people living with cancer to these therapies is possible with improved and faster product registration, coverage in the national formulary, and innovative approaches to address the challenge of affordability.

Financing and governance of cancer care need to be optimised to ensure better survival and reduced burden from cancer.

The government should establish stronger accountability mechanisms for cancer care within the public health care space, forge stronger collaborations through public-private partnership frameworks, and adopt key performance indicators which drive greater cooperation and collaboration between stakeholders.

Shifting from a volume-based healthcare system to a value-based system to improve patient treatment and care, as well as overall health outcomes, requires strong leadership and better accountability.

Local, comprehensive, and current data on cancer are essential in driving informed and well targeted policies. Systems that measure and evaluate investments made in cancer care need to be built and strengthened.

Health outcomes will be impacted for decades to come unless remedial action is taken, and long-term commitments to cancer care are made.

The COVID-19 pandemic has demonstrated the need to make the necessary investments and commitments in healthcare, as they have a direct implication and impact on overall population health outcomes and resiliency.

In terms of cancer care, this would mean being able to reduce the human toll and financial costs resulting from late-stage presentation of cancer, and premature deaths.

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