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Breast Cancer Care in Malaysia: Access to Early Detection, Diagnosis and Optimal Treatment

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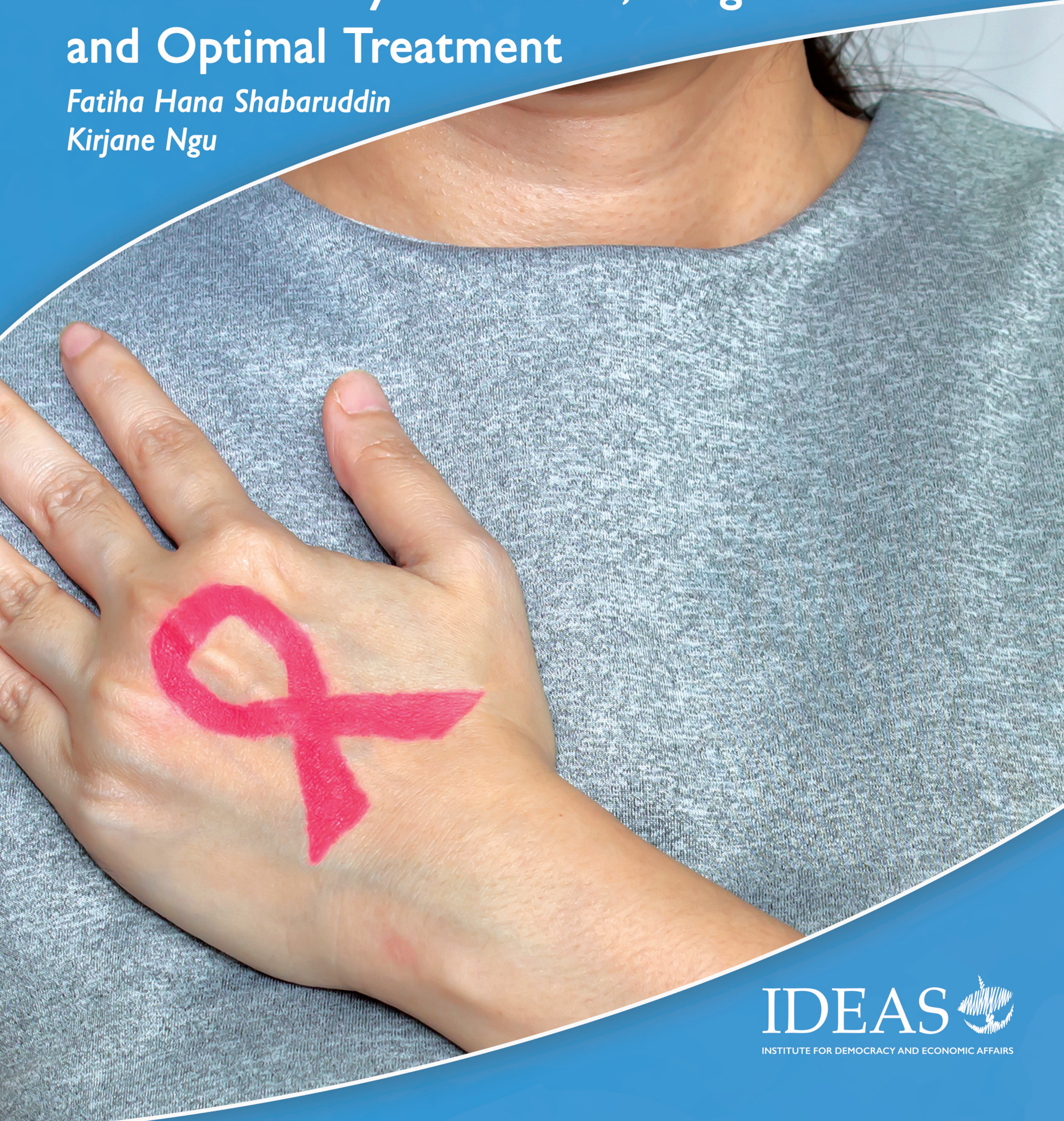

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Executive Summary

48% of breast cancer cases recorded in Malaysia were diagnosed at the advanced-stages such as Stage III and Stage IV

Breast cancer is one of the most prevalent cancers among females in the world and in Malaysia, with an age-standardised incidence rate of 34.1 per 100,000 between 2012 to 2016. Public health efforts towards reducing the burden of breast cancer in Malaysia have been focused on early detection through opportunistic mammography screening and clinical breast examinations (CBE) in government clinics and hospitals, as reflected in the National Strategic Plan for Cancer Control Programme (NSP-CCP, 2021-2025).[1] While CBE and mammogram uptake have notably increased from 52% to 65% and 8% to 24% respectively between 2006 to 2014, the significant proportion of advanced-stage breast cancer remains an issue as nearly half (48%) of breast cancer cases were only diagnosed at the advanced-stage (Stage III and Stage IV).

Malaysia lags behind most developed nations in terms of survival outcomes of breast cancer, recording a 5-year relative survival rate of 66.8% as compared to breast cancer survival in other developed nations that range from 80% to 90%. This highlights that there are significant gaps in breast cancer management in Malaysia. In this report, the authors evaluated the gaps in breast cancer care in terms of patients' access to early presentation (presentation interval), timely diagnosis (diagnostic interval) and optimal treatment (treatment interval). These gaps are evaluated by assessing publicly available government data and policy documents, existing literature as well as through focus group discussions with patients and survivors and roundtable discussions with key stakeholders and service providers.

The low mammogram uptake is primarily due to the limited availability of mammogram facilities and their capacity, especially in rural and suburban areas. While Breast Self Examination (BSE) and CBE uptake were similar across regional states in Malaysia, mammogram uptake nationally ranged between 5.5% and 31.1%, with East Coast Peninsular states such as Terengganu and Kelantan among the lowest. The limited availability of screening facilities in these regions means that women have to bear higher transportation costs and other aspects of out-of-pocket expenditures to get screened, rendering limited access and affordability to these services. Besides the limited availability of mammogram screening, the lack of culturally appropriate breast health screening services also hinders early detection. For instance, the presence of male doctors, nurses or radiologists during screening was reported as a significant barrier for some women.

Even when mammography screening services are available, patient utilisation of screening services is hindered by the lack of awareness of breast cancer and poor health literacy. Given that most early stages of breast cancer have non-visible symptoms, patients often dismiss the seriousness of symptoms especially when breast pain is absent. Furthermore, patients are often not aware of the risk factors associated with breast cancer as well as information regarding available screening services. In addition, cultural beliefs towards healthcare as well as the knowledge and awareness of patients' social networks also influence symptom interpretation, and subsequently utilisation of screening. This highlights

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[1] Ministry of Health Malaysia (2021). National Strategic Plan for Cancer Control Programme 2021-2025.

the need to develop culturally sensitive, widespread breast cancer awareness campaigns and BSE education.

Prompt diagnostic follow-up is crucial as screening does not end at early recognition of mammographic abnormalities. However, prompt diagnostic follow-up can be hindered by complicated referral processes, leading to delayed diagnosis. Due to long wait times and limited availability of government breast cancer screening facilities, women may opt to get screened at private hospitals or non-governmental organisation (NGO) clinics. For patients who wished to be referred to public hospitals for further investigations at an affordable rate upon detection of suspicious breast abnormalities at private or NGO facilities, these patients were subsequently charged at higher rates due to them being referred by private institutions. In some cases, patients were required to repeat the screening procedure before proceeding with further diagnostic testing within the public system, which subsequently led to delayed diagnosis. In addition, the lack of awareness of lump and non-lump symptoms among primary healthcare workers and patients also contributes to referral delays. Hence, this highlights the need to streamline referral processes between public and private healthcare systems as well as to implement comprehensive breast health education for primary healthcare workers.

Access to best practices options for breast cancer surgery is limited by the lack of specialist surgical expertise and the limited availability of radiotherapy treatment nationally. There are only 22 breast and endocrine specialist surgeons and 9 public oncology centres that offer both systematic chemotherapy and radiotherapy treatment in Malaysia, which are mainly concentrated on the west coast of Peninsular Malaysia. The lack of resources limits patients' options for breast conserving surgery. In some cases, surgical treatment may also be delayed due to patients refusing to undergo surgery and opting for alternative treatments due to cultural beliefs and misinformation about surgical treatments.

Limited availability of radiotherapy, chemotherapy and targeted biological treatment within public healthcare centres hinder the continuum of care. The relatively small number of oncology specialists and the limited availability of radiotherapy and chemotherapy treatment within public health facilities nationally are among the key barriers in the breast cancer continuum of care. In the face of the rising incidence of breast cancer in Malaysia and the increasing number of patients who require treatment, this could contribute to treatment delay, lower uptake and poor adherence to treatment, which can subsequently lower survival rates. Targeted biological therapy faces similar challenges as chemotherapy and radiotherapy treatment as well as additional challenges due to their high acquisition costs. Patients who are clinically eligible for targeted biological treatments for breast cancer may incur significant out-of-pocket expenditure as there is limited availability of these drugs within public healthcare institutions. Hence, this gives rise to the potential development of Patient Access Schemes (PASc) to be developed to increase patients' access to targeted treatment and provide innovative care within finite budgets.

Recommendations:

1. Public-private partnership

- To set up a National Breast Cancer Committee to systematically address the gaps in breast cancer care nationwide and to foster collaborative efforts among various stakeholders.

- To facilitate efforts by NGOs and civil societies within the presentation and diagnostic intervals.

- To develop a collaborative database that maps out existing resources provided by partnering organizations and pathways to accessing breast health screening and clinical care.

- To streamline referral processes between public and private systems to avoid delayed diagnosis and treatment.

- To formalise collaborative care between public and private institutions in order to expand the provision of psychosocial support for breast cancer patients and survivors.

2. Data management

- To measure regular and repeated CBE and mammography screening according to the CPG as indicators of screening uptake nationwide.

- To improve data collection and management of the incidence and survival of breast cancer cases through Electronic Health Records across public and private systems.

3. Financing

- To increase the resource and budgetary allocation for cancer care to improve the availability and accessibility of screening and diagnostic facilities as well as optimal cancer treatment.

- To review policies mandating higher charges for patients referred from private health institutions for treatment in public health facilities.

- To regulate charges to access cancer treatment in private health facilities to relieve the burden of the public healthcare system.

- To develop Patient Access Schemes to address consumer demands and alleviate the pressure of rising costs while increasing access to innovative care.

4. Awareness and literacy

- To produce a cohesive and comprehensive message for breast cancer through a nationwide awareness campaign.

- To partner with religious institutions and schools for the implementation of culturally sensitive breast cancer awareness programmes.

- To provide comprehensive education for primary healthcare workers in public and private healthcare facilities on non-lump symptoms and risk factors associated with breast cancer.

Introduction

Breast cancer is the most prevalent cancer in the world, affecting the lives of 7.8 million women globally in the past 5 years, as of the end of 2020[2]. Breast cancer also has a significantly higher disease burden as compared to other types of cancer, demonstrated by the higher lost disability-adjusted life years (DALYs[3]) of women to breast cancer globally as compared to other types of cancer. Furthermore, the World Health Organisation - International Agency for Research on Cancer (WHO-IARC) reports increasing breast cancer trends worldwide. The increase in new cases is due to population growth and ageing rates, which contribute an additional 13% and 15% respectively. The burden of mortality for breast cancer also varies based on countries' economic status whereby lower and middle-income countries (LMIC) have lower incidence ratios of 0.44 as compared to 0.29 in more developed countries.

As a middle-income country, the growing burden of breast cancer globally is very much a reality for Malaysia. Over the past 5 decades, Malaysia has seen much progress in improving overall health outcomes for its population, as the life expectancy rose from 65.6% to 77.6% for women and 61.6% to 72.6% for men[4]. Since then, the mortality rates in Malaysia have mainly shifted from communicable to non-communicable diseases, with breast cancer being the second leading cause of cancer-related deaths in

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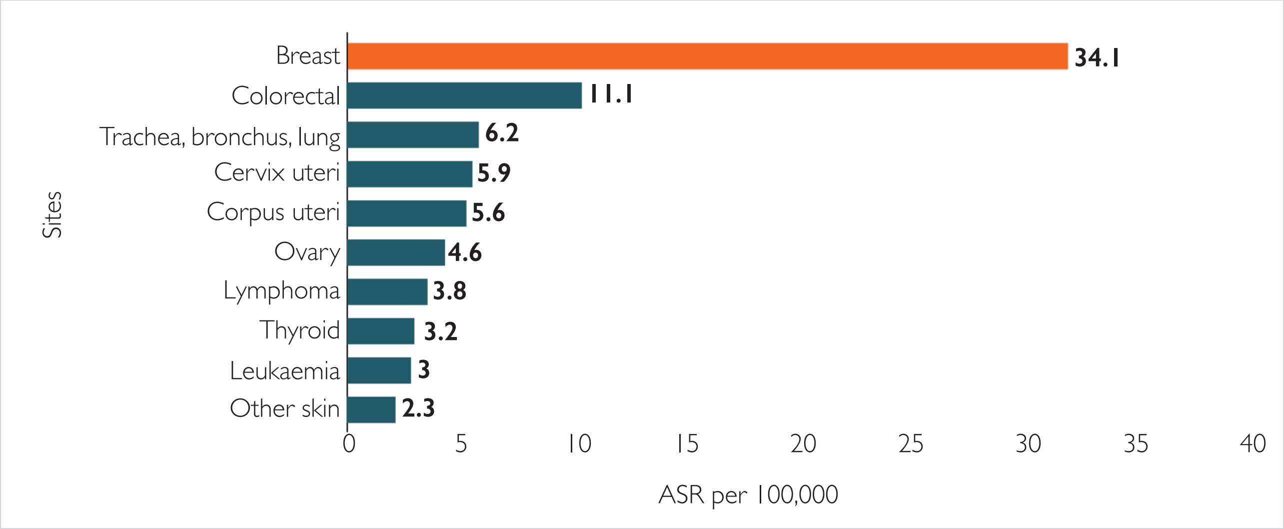
[2] World Health Organization (2021). "Breast cancer." Retrieved from https://www.who.int/news-room/fact-sheets/detail/breast-cancer

[3] Disability-adjusted life-year (DALYs) is a common metric overall disease burden that combines duration and quality of life. DALYs for a disease or health condition are the sum of the years of life lost due to premature mortality and the years lived with a disability due to prevalent cases of the disease or condition in a population.

[4] DOS. 2020b. Malaysia Economics Statistics - Time Series 2019: Population. Putrajaya: Department of Statistics Malaysia.

Malaysia[5]. In Malaysia, breast cancer has an age-standardised incidence rate of 34.1 per 100,000 between 2012 to 2016, which is higher than other cancer types (see Figure 1).[6]

Figure 1: Age-standardised incidence rates for the 10 most common cancers in Malaysia, 2012 to 2016



In line with Sustainable Development Goal 3: *"to reduce, by one-third premature mortality from non-communicable diseases through prevention and treatment, by 2030"*, public health efforts have been focused on improving the early detection of breast cancer, as reflected in the National Cancer Control Plan (2021-2025). Despite this, late-stage presentation and relatively poor survival rates for breast cancer remain significant public health issues. Hence, this report aims to evaluate breast cancer care in Malaysia by examining the barriers to accessing early detection, diagnosis and optimal treatment.

This report evaluates breast cancer care in Malaysia by drawing on publicly available data from the Ministry of Health (MOH) and the Ministry of Women, Family and Community Development (MOWFC), policy documents as well as secondary quantitative and qualitative data from existing literature. In addition, a focus group discussion and a roundtable discussion were convened in September 2022 to discuss issues related to breast cancer care in Malaysia with an emphasis on access to early detection and optimal treatment. These closed-door discussions engaged key stakeholders including cancer healthcare professionals from public and private healthcare institutions, patient advocacy groups and cancer patients. This report was further developed based on these discussions.

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[5] National Cancer Registry (2018). Malaysian Study on Cancer Survival (MySCan): National Cancer Registry, National Cancer Institute, Ministry of Health Malaysia

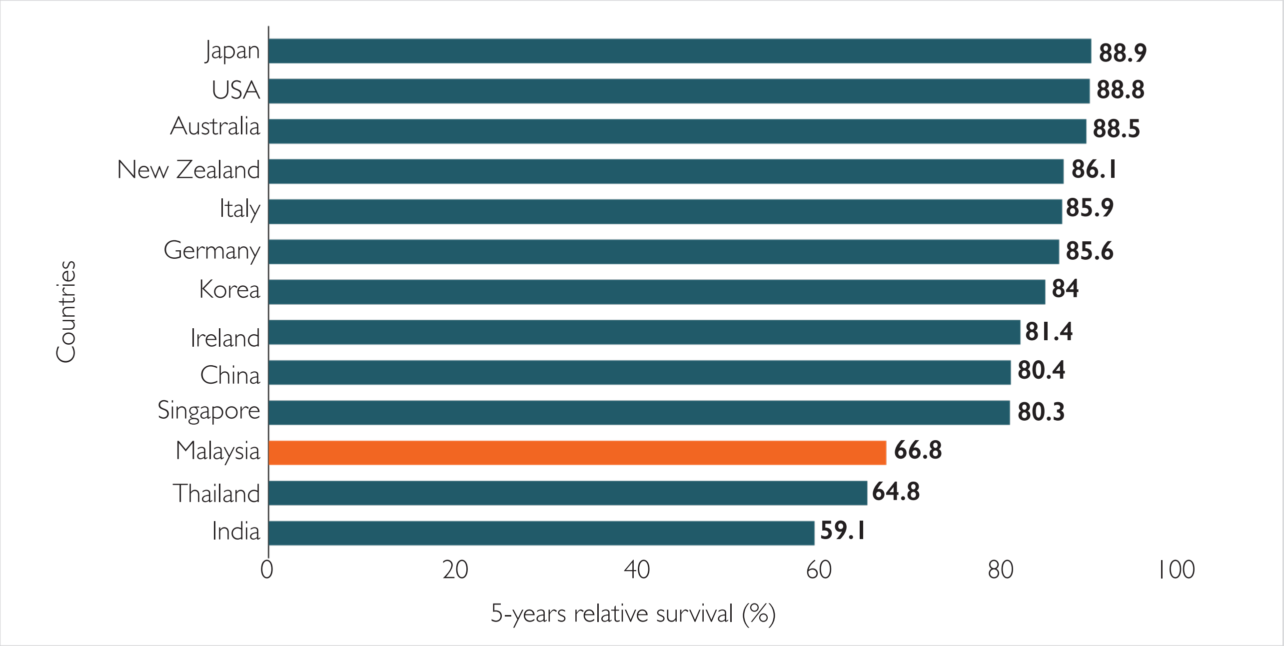
[6] Ministry of Health Malaysia (2019). Malaysia National Cancer Registry Report (2012-2016), Putrajaya, Malaysia: National Cancer Registry Department, National Cancer Institute, Ministry of Health, Malaysia

Breast Cancer Care in Malaysia

Epidemiology

Malaysia lags behind most developed nations when it comes to survival outcomes of breast cancer. According to the MyScan report, the 5-year relative survival[7] for breast cancer in Malaysia was recorded at 66.8%, which is lower than most developed nations such as the United States of America, Japan, New Zealand and Singapore where their relative survival rates range between 80% to 90%[8] (Figure 2).

Figure 2: Breast cancer: International comparison of 5-year relative survival, period of diagnosis 2007-2011, and followed up to 2016.



Survival outcomes vary by stage of diagnosis, ethnicity and age

Survival rates from breast cancer vary by ethnicity, age and stage of diagnosis, with advance-stage diagnosis being the most significant determinant for poor cancer survival.

Among the major ethnic groups in Malaysia, the highest incidence rate was recorded among Chinese women (1 in 22), followed by Indian women (1 in 23), and Malay women (1 in 30; see Figure 3)[9]. However, Malay women have the lowest 5-year relative survival rates of 57.9%, as compared to Indian (70.5%) and Chinese (76.5%) women[10] (Figure 4). This was replicated in other studies whereby Malays

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[7] International comparison of 5-year relative survival, period of diagnosis between 2007 and 2011, and followed up to 2016. Relative survival is the probability of being alive for a given amount of time after diagnosis compared with all mortality in the general population. Relative survival is calculated by dividing observed survival by the expected survival for the general population.

[8] National Cancer Registry (2018). Malaysian Study on Cancer Survival (MySCan): National Cancer Registry, National Cancer Institute, Ministry of Health Malaysia

[9] Ministry of Health Malaysia (2019). Malaysia National Cancer Registry Report (2012-2016), Putrajaya, Malaysia: National Cancer Registry Department, National Cancer Institute, Ministry of Health, Malaysia

[10] Ministry of Health Malaysia (2019). Malaysia National Cancer Registry Report (2012-2016), Putrajaya, Malaysia: National Cancer Registry Department, National Cancer Institute, Ministry of Health, Malaysia

were associated with a significantly higher risk of all-cause mortality, even after controlling for age, stage of diagnosis, tumour characteristics and treatment.[11] The poorer survival rate among Malay women was found to be associated with factors such as late-stage presentation, larger tumour size, and more lymph nodes affected.[12] Besides delay in seeking treatment, other reasons behind the racial discrepancy in survival rates could be due to differing screening practices, health-seeking behaviour, treatment compliance, health resources available, population structure and socioeconomic status[13 14].

Figure 3: Age-standardised incidence rates by major ethnic groups in Malaysia, 2012-2016

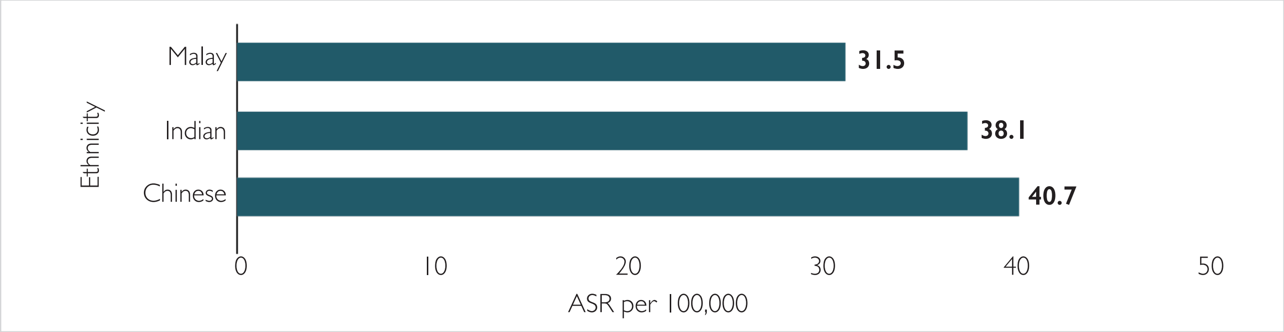
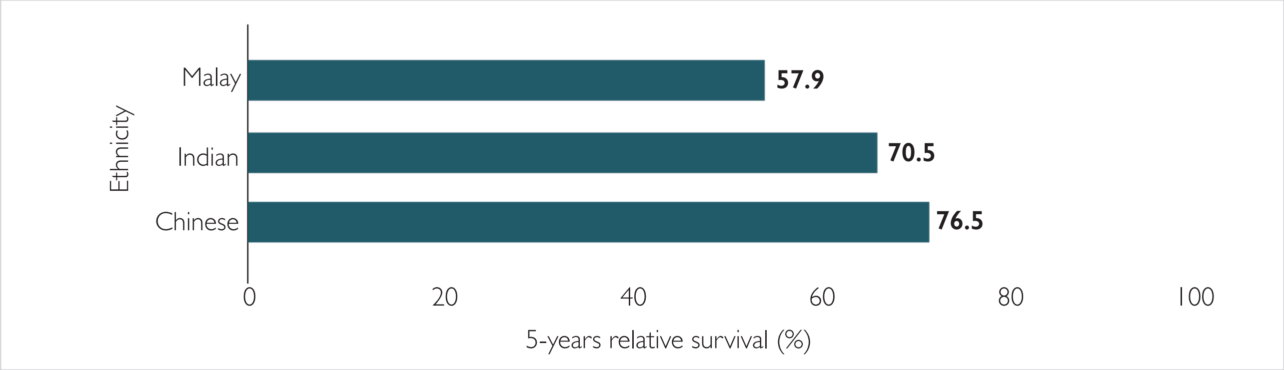


Figure 4: 5-year relative survival by major ethnic groups, period of diagnosis 2007-2011 and followed up to 2016



In terms of age groups, the majority of breast cancer cases were recorded in the age group of 45-54 years (34.9%), followed by 15-44 years (26.1%) and 55-64 years (24.4%)[15]. While studies have shown that the elderly have significantly lower survival rates compared to young and middle-aged women[16], the MyScan reported that women diagnosed with breast cancer between the age of 15 to 44 years had the

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[11] Bhoo-Pathy et al.

[12] Ibrahim, N. I., Dahlui, M., Aina, E. N., & Al-Sadat, N. (2012). Who are the breast cancer survivors in Malaysia?. *Asian Pacific journal of cancer prevention*, 13(5), 2213-2218.

[13] Yip, C. H., Taib, N. A., & Mohamed, I. (2006). Epidemiology of breast cancer in Malaysia. *Asian Pacific Journal of Cancer Prevention*, 7(3), 369.

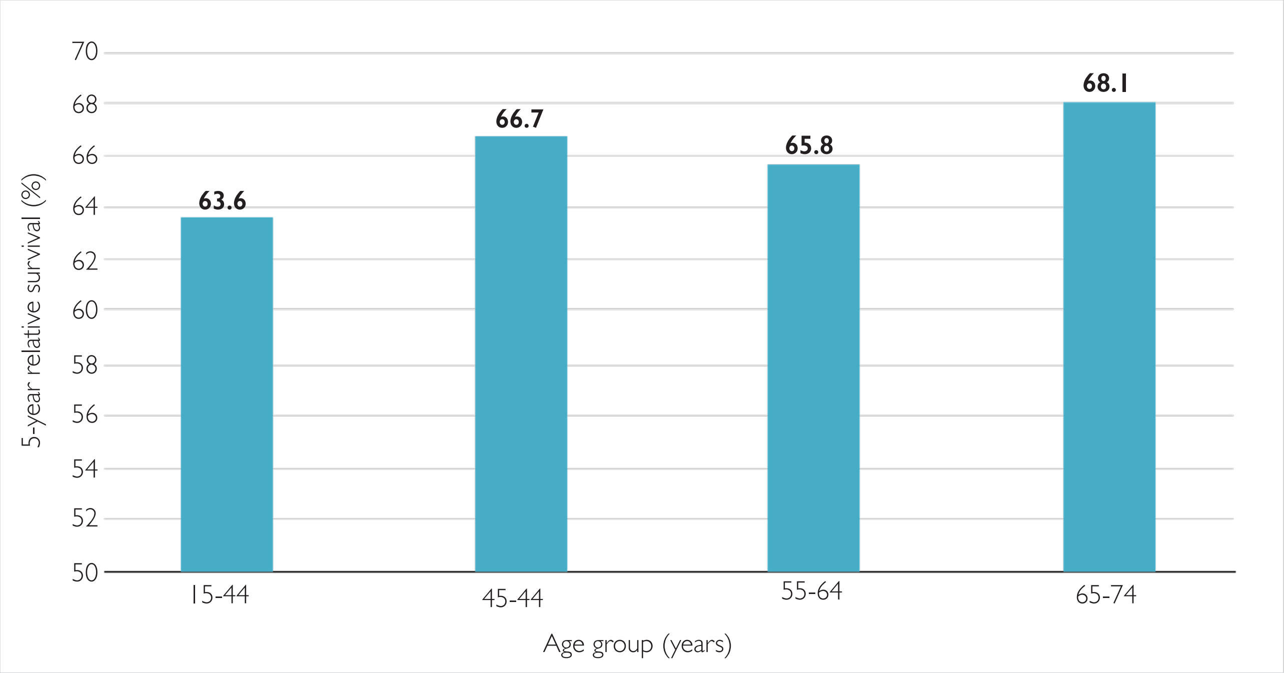
[14] Taib, N. A., Yip, C. H., Ibrahim, M., Ng, C. J., & Farizah, H. (2007). Breast cancer in Malaysia: are our women getting the right message? 10 year-experience in a single institution in Malaysia. *Asian Pacific Journal of Cancer Prevention*, 8(1), 141.

[15] Ministry of Health Malaysia (2019). Malaysia National Cancer Registry Report (2012-2016), Putrajaya, Malaysia: National Cancer Registry Department, National Cancer Institute, Ministry of Health, Malaysia

[16] Tan, K. F., Adam, F., Hussin, H., & Mujar, N. M. M. (2021). A comparison of breast cancer survival across different age groups: a multicentric database study in Penang, Malaysia. *Epidemiology and Health*, 43.

lowest 5-year survival rate out of all age groups (Figure 5).[17] The age at diagnosis had minimal impact on the net survival rates as compared to the stage of diagnosis.[18]

Figure 5: 5-year relative survival by age groups, period of diagnosis 2007-2011 and followed up to 2016, Malaysia



The stage of diagnosis is the most prominent prognostic factor for survival. Women who were diagnosed with advanced breast cancer have a significantly lower 5-year relative rate of 17.3% (Stage IV) and 55.6% (Stage III), as compared to 72.5% (Stage II) and 75.8% (Stage I) for the earlier stages (see Figure 6). However, nearly half of the breast cancer cases recorded by the National Cancer Registry were diagnosed in advanced stages (Stage III and Stage IV). Furthermore, data also demonstrated an increase in advanced-stage diagnosis between the intervals of 2007-2011 and 2012-2016[19] (see Figure 7), suggesting that late-stage presentation remains an issue.

[17.] National Cancer Registry (2018). Malaysian Study on Cancer Survival (MySCan): National Cancer Registry, National Cancer Institute, Ministry of Health Malaysia

[18.] Hanis, T. M., Yaacob, N. M., Hairon, S. M., & Abdullah, S. (2021). Net survival differences of breast cancer between stages at diagnosis and age groups in the east coast region of West Malaysia: a retrospective cohort study. *BMJ open,* 11(5), e043642.

[19.] National Cancer Registry (2018). Malaysian Study on Cancer Survival (MySCan): National Cancer Registry, National Cancer Institute, Ministry of Health Malaysia

Figure 6: 5-year relative survival by stage at diagnosis, period of diagnosis 2007-2011 and followed up to 2016, Malaysia

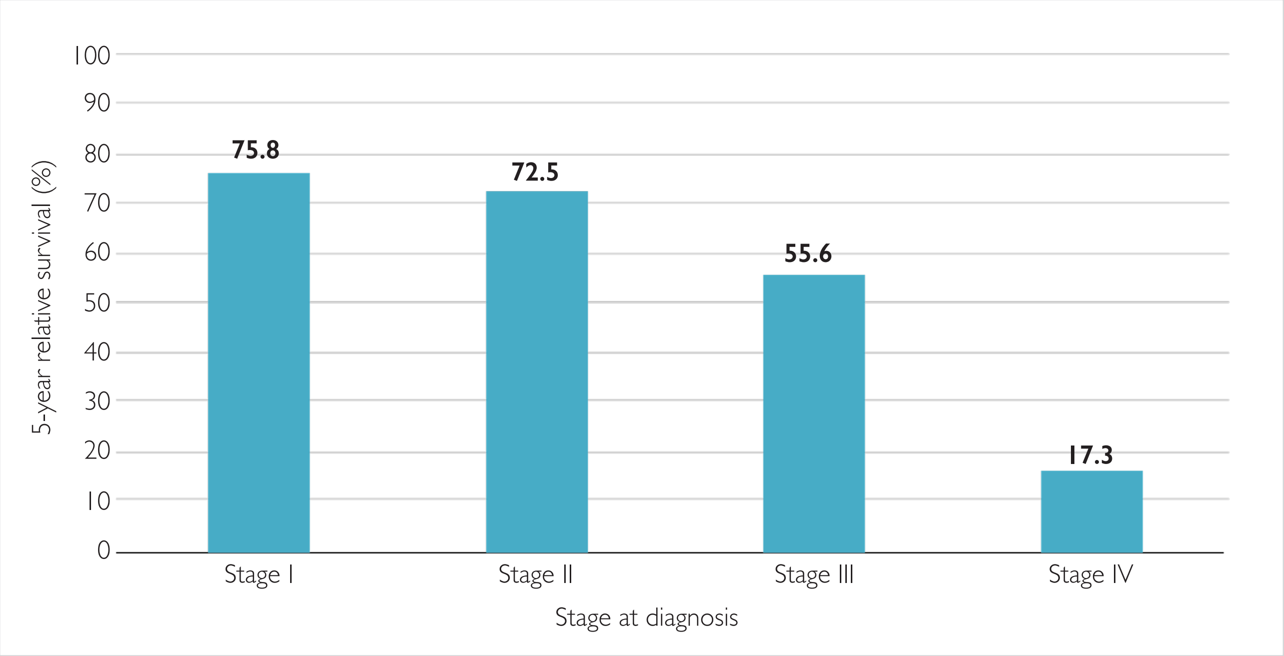
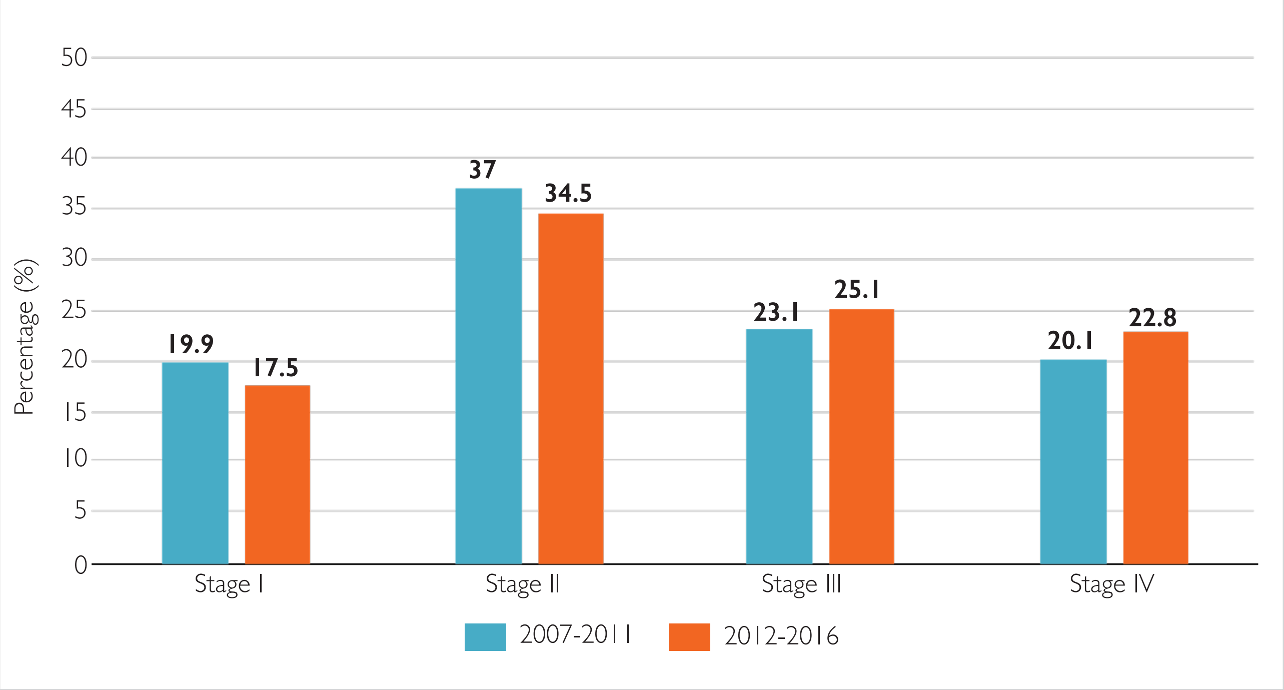


Figure 7: Incidence rates by stage at diagnosis in Malaysia, comparison between 2007-2011 and 2012-2016



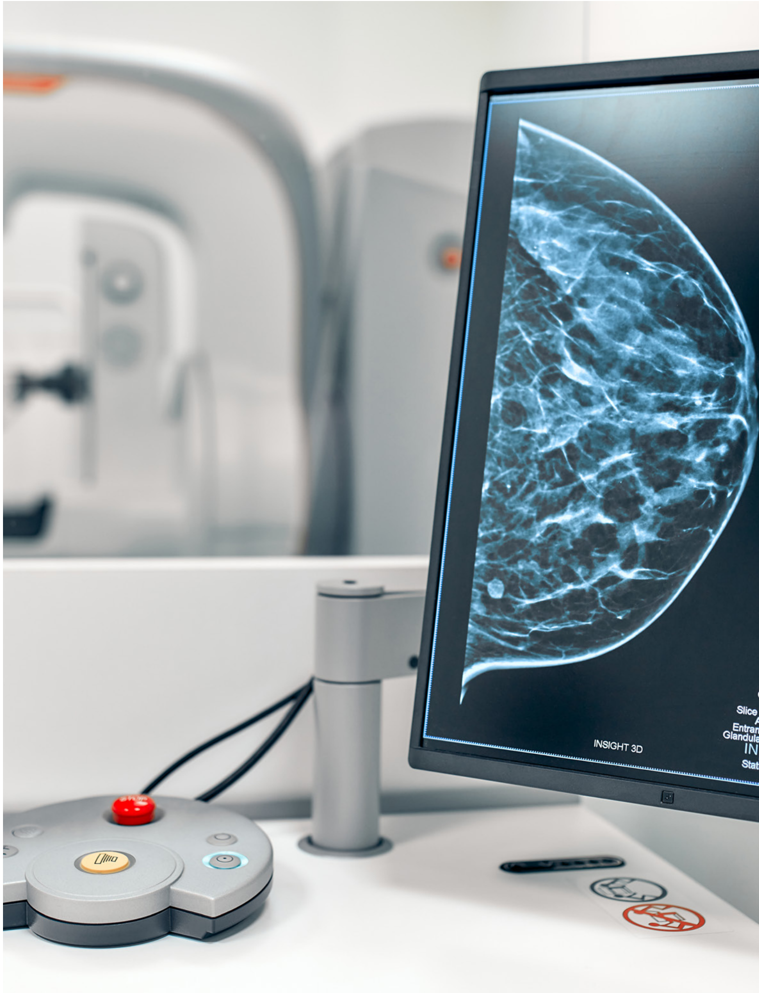
There are data limitations with the existing National Cancer Registry

The Malaysian National Cancer Registry was established in 2007 with the first Malaysian National Cancer Registry report published in 2015. The national cancer registry is the main data source on cancer in Malaysia with data on the age-ethnic composition and cancer stage distribution. However, there is considerable under-reporting of cases due to the voluntary requirement for reporting , thus the true incidence of cancer in Malaysia is likely higher than the data from the national registry. It has been estimated from drug utilisation data, including anti-cancer hormonal drugs utilisation, that 74% of breast cancer patients nationally were treated in public hospitals in 2012[20].

Breast cancer policies in Malaysia

The National Strategic Plan for Cancer Control Program (NSP-CPP) aimed to downstage breast cancer at the time of diagnosis by 25% by the year 2030. The main strategy adopted to achieve this goal is through breast cancer screening, which is an evidence-based strategy to promote early diagnosis and reduce mortality. Breast cancer screening in Malaysia is currently opportunistic, with the Malaysian Clinical Practice Guidelines recommending that biennial mammograms should be performed among women aged 50 to 74 years, while women aged 40 to 49 years are not offered mammograms routinely. Meanwhile, BSE is only recommended as a breast awareness measure. The Malaysian government provides subsidised mammograms through the MOWFC and state government programmes.

Aside from screening programmes, this NSP-CPP also highlighted the government's plans to address the shortage of breast surgeons, oncologists, breast radiologists and pathologists as well as the need to develop additional expertise such as clinical geneticists, genetic counsellors, breast cancer nurses and dedicated mammographers. Furthermore, emphasis also has been given to the improvement of infrastructure and equipment, the reinforcement of effective referral pathways as well as the improvement of breast health awareness and literacy among healthcare providers and women.



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[20] Ho, G. F., Taib, N. A., Pritam Singh, R. K., Yip, C. H., Abdullah, M. M., & Lim, T. O. (2017). What if all patients with breast cancer in Malaysia have access to the best available care: How many deaths are avoidable? *Global Journal of Health Science*, 9(8), 32.

Patient-pathway

It was estimated that 88% of excess deaths due to breast cancer in Malaysia were avoidable[21], with 57% attributable to late-stage presentation and 43% due to lack of access to optimal treatment.[22] Delays in breast cancer diagnosis and treatment are associated with larger tumours, late-stage diagnosis, lower cure rates, disease progression, poorer prognosis and lower survival rates.[23] [24] Hence, it is important to evaluate breast cancer care in Malaysia with regards to its timeliness across the patient pathway[25]. The time intervals serve not only as an indicator of the accessibility of healthcare but also identify the inequalities of care in patient management.[26]

The universal patient pathway for breast cancer care can be divided into 3 sequential intervals of care[27]: the presentation interval, diagnostic interval and treatment interval.[28] The presentation interval spans the time from the initial presentation at a primary care facility based on the onset of clinical symptoms or asymptomatic screening to the detection of a breast abnormality that warrants further evaluation. The diagnostic interval spans the period when the identified breast abnormality undergoes the "triple test" workup based on clinical evaluation, imaging and tissue sampling to arrive at a definitive diagnosis. The treatment interval spans the time from diagnosis resolution to initial treatment. During the treatment interval, each patient undergoes individualised evaluation and treatment planning for curative therapy or palliative management, depending on the extent of the disease and potential meaningful clinical improvement based on the application and available resources.

It is important to note that help-seeking behaviour throughout the patient-pathway is shaped by the complex interplay between cultural values, family relationships, structural conditions of people's lives and the availability of healthcare.[29]

The following sections adopt the breast cancer care timeliness framework by Mujar et al. (2022) to identify health system and patient barriers to early presentation (presentation interval), diagnosis (diagnostic

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[21] Avoidable deaths due to breast cancer was based on estimated survival if all patients had access to the best available care in Malaysia. The number of avoidable deaths is the difference between the number of cancer deaths estimated for the general population in Malaysia and the expected number of deaths if all cancer patients had experienced the age-ethnic and stage specific survival outcomes observed in a reference population in Malaysia. Data for the general population were based on multiple data sources of breast cancer population from the local cancer registry and public hospitals while the reference population were based on patients treated at a leading cancer centre in Malaysia that could accomplish survival outcomes comparable to those observed in leading centres in developed countries

[22] Ho, G. F., Taib, N. A., Pritam Singh, R. K., Yip, C. H., Abdullah, M. M., & Lim, T. O. (2017). What if all patients with breast cancer in Malaysia have access to the best available care: How many deaths are avoidable? Global Journal of Health Science, 9(8), 32.

[23] McLaughlin JM, Anderson RT, Ferketich AK, et al: Effect on survival of longer intervals between confirmed diagnosis and treatment initiation among low-income women with breast cancer. J Clin Oncol 30:4493-4500, 2012

[24] Kothari, A., & Fentiman, I. S. (2003). 22. Diagnostic delays in breast cancer and impact on survival. International journal of clinical practice, 57(3), 200-203.

[25] Mohd Mujar, N. M., Dahlui, M., Emran, N. A., Hadi, I. A., Yan, Y. W., Arulanantham, S., ... & Mohd Taib, N. A. (2022). Breast Cancer Care Timeliness Framework: A Quality Framework for Cancer Control. *JCO Global Oncology*, 8, e2100250.

[26] Ibid.

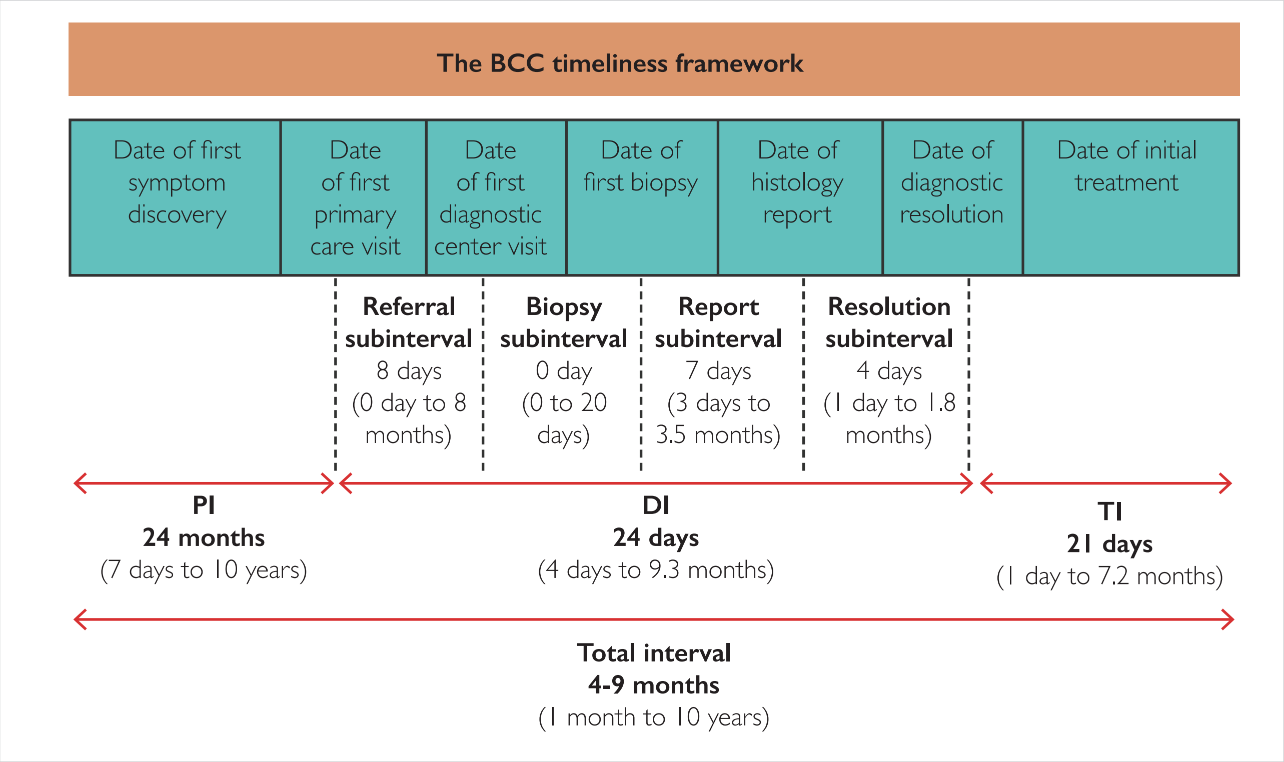
[27] Horton, S., Camacho Rodriguez, R., Anderson, B. O., Aung, S., Awuah, B., Delgado Pebe, L., ... & Gelband, H. (2020). Health system strengthening: Integration of breast cancer care for improved outcomes. *Cancer,* 126, 2353-2364.

[28] see footnote 25.

[29] Unger-Saldaña, K., & Infante-Castañeda, C. B. (2011). Breast cancer delay: a grounded model of help-seeking behaviour. *Social science & medicine*, 72(7), 1096-1104.

interval) and treatment (treatment interval) for timely interventions (Figure 8).

Figure 8: Breast cancer care timeliness[30] framework



Note: BCC, Breast Cancer Care; DI, diagnostic interval; PI, presentation interval; TI, treatment interval

Presentation Interval: Access to Early Detection

The presentation interval spans the time from an initial presentation at a primary care facility based on the onset of clinical symptoms or asymptomatic screening to the detection of a breast abnormality that warrants further evaluation. Previous studies reported a median interval ranging from 2 to 4 months after patients first discovered their symptoms[31] [32] [33], suggesting that the time taken to seek medical care is delayed and varies between institutions and geographic locations (urban or rural).

There is a wide spectrum of patients' health-seeking behaviours reflected in the presentation interval, ranging from presentation to clinical care through breast cancer screening to presentation from self-detected symptoms of breast cancer. In order to promote health-seeking behaviour and early detection, efforts need to be targeted at both ends of the spectrum to remove barriers from the systemic level as well as the patient level.

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[30] Mohd Mujar, N. M., Dahlui, M., Emran, N. A., Hadi, I. A., Yan, Y. W., Arulanantham, S., ... & Mohd Taib, N. A. (2022). Breast Cancer Care Timeliness Framework: A Quality Framework for Cancer Control. JCO Global Oncology, 8, e2100250.

[31] Yip, C. H., Taib, N. A., & Mohamed, I. (2006). Epidemiology of breast cancer in Malaysia. Asian Pacific Journal of Cancer Prevention, 7(3), 369.

[32] Lim et al. (2014). Closing the global cancer divide-performance of breast cancer care services in a middle income developing country. BMC cancer, 14(1), 1-7.

[33] Yeoh et al. (2018). Feasibility of patient navigation to improve breast cancer care in Malaysia. Journal of global oncology, 4, 1-13.

> **"For certain areas yes, maybe screening might be the best thing. For other areas, pushing for early detection might be a better thing. Yes, there are nuances between screening and early detection, but there are vast differences between these two things." - Dr. S, NGO practitioner**

Availability, Accessibility and Utilisation of Screening

Screening efforts have not translated to improved early detection of breast cancer

Malaysia's approach to addressing the issue of late-stage presentation of breast cancer involves prevention measures such as clinical breast examinations (CBE) and opportunistic mammography screening in both public (government-funded) and private healthcare facilities. Since 2010, Malaysia's approach has shifted from targeted screening of high-risk women to opportunistic screening for the general population, as evident from the Clinical Practice Guidelines (CPG) and the NSP-CCP (Table 1). Since 2014, the National Population and Family Development Board (NPFDB) started providing subsidised mammography screening and/or CBE through 49 Nur Sejahtera clinics and 15 family mobile centres to improve the accessibility of screening, especially in rural areas.[34] As of 2022, there is a total of 78 Nur Sejahtera clinics nationwide.

Table 1: Summary of Guidelines and Strategic Plan on Cancer Control in Malaysia

Guidelines and Strategic Plans	Year	Recommendations related to cancer
Clinical Practice Guidelines (CPG): Management of breast cancer	2002 (1st edition)	Screening recommendations for early detection among the high-risk group and management of breast cancer patients
Clinical Practice Guidelines (CPG): Management of breast cancer	2010 (2nd edition)	Screening recommendations for early detection in the general population, high-risk groups, and management of breast cancer patients
Garis Panduan Program Pengesanan Awal Kanser Payudara Kebangsaan	2011	National breast cancer screening guidelines for the general population and high-risk group
Clinical Practice Guidelines (CPG): Management of breast cancer	2019 (3rd edition)	Screening recommendations for early detection in the general population, risk groups, and management of breast cancer patients
National Strategic Plans for NCDs (NSP-NCD)	2010-2014	To reduce the prevalence of NCDs (i.e. cardiovascular disease, diabetes and cancer)
National Strategic Plans for NCDs (NSP-NCD)	2016-2025	To reduce the burden of NCDs in Malaysia; including cancer
National Cancer Control Blueprint Master Plan (NCCB)	2008-2015	To reduce the burden of cancer by reducing mortality and morbidity, and improving quality of life among cancer patients and families
National Strategic Plan for Cancer Control Program (NSP-CCP)	2016-2020	Primary prevention, screening, early detection, management, and cancer research

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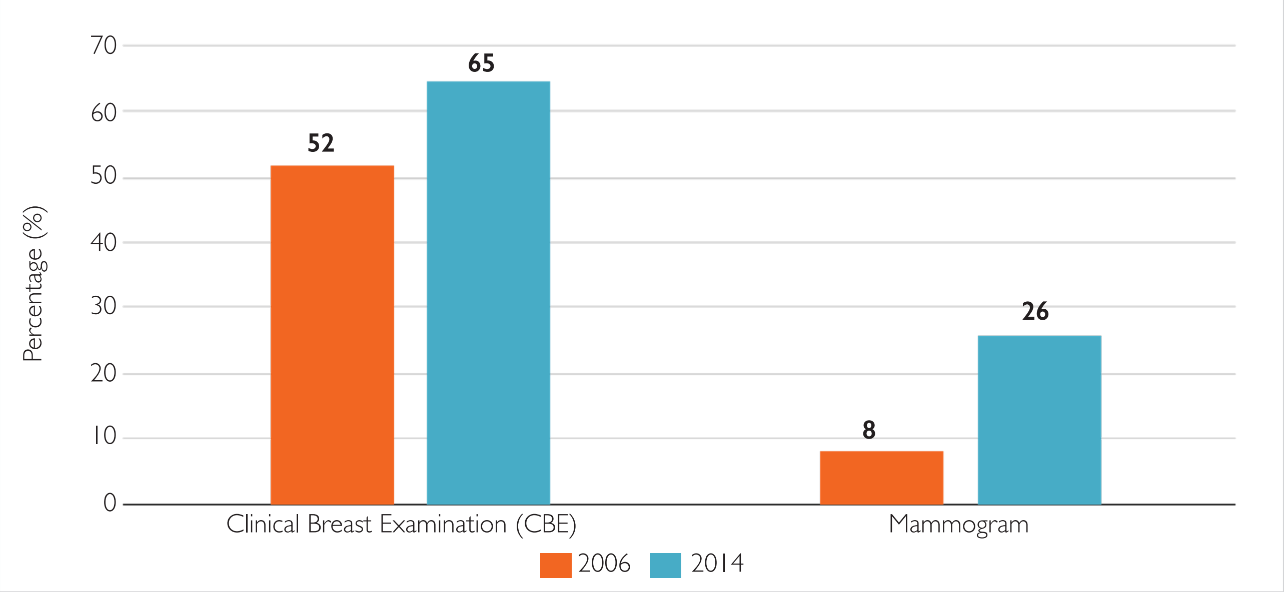
[34] Senarai Klinik Nur Sejahtera LPPKN. Available at http://mamogram.lppkn.gov.my/KlinikLPPKNList.aspx

Since the implementation of screening programmes nationwide, breast health screening uptake has noticeably increased from 52% (2006) to 65% (2014) for CBE and from 8% (2006) to 26% (2014) for a mammogram[35] (see Figure 9). These data only capture whether women had ever undergone CBE and mammograms. Current data shows that screening uptake did not correspond with the downstaging of breast cancer in Malaysia[36] (see Figure 7), indicating that efforts to promote screening have not translated to improved early detection of breast cancer.

Figure 9: Mammogram uptake among women aged 15-59 in Malaysia, as measured by "ever" done breast health screening



Downstaging breast cancer in Malaysia is challenging

Downstaging breast cancer nationally will rely on the increased uptake of regular breast cancer screening through CBE and mammogram, which are life-saving, evidence-based screening strategies, as well as increasing access to clinical care upon self-discovery of breast cancer symptoms. Persistent poor early detection nationally despite screening efforts could be linked to poor mammogram uptake due to various factors. Mammography has been established as the primary and standard imaging screening modality for breast cancer detection. Compared to CBE and BSE, mammographic screening is the only evidence-based screening modality that reduces breast cancer mortality[37]. A systematic review of 18 multinational randomised controlled trials (RCT) showed mammography screening reduces breast cancer mortality by approximately 15% for women aged 39 to 69 years, while no significant benefit has

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[35] Ministry of Women, Family and Community Development, National Population and Family Development Board, Malaysia (2017). Breast Cancer in Malaysia: National Population and Family Development Board, Malaysia. Available at: http://familyrepository.lppkn.gov.my/692/.

[36] National Cancer Registry (2018). Malaysian Study on Cancer Survival (MySCan): National Cancer Registry, National Cancer Institute, Ministry of Health MalaysiaMOH/P/ IKN/04.18 (RR). Available at: http://www.moh.gov.my/ resources/index/Penerbitan/Laporan/Malaysian_Study_ on_Cancer_Survival_MySCan_2018.pdf

[37] Lee, M., Mariapun, S., Rajaram, N., Teo, S. H., & Yip, C. H. (2017). Performance of a subsidised mammographic screening programme in Malaysia, a middle-income Asian country. BMC Public Health, 17(1), 1-7.

been shown for CBE or BSE.[38] Similarly, large prospective cohort studies in Norway and Sweden found that modern mammography screening among women aged 50 to 69 years may reduce deaths from breast cancer by about 28%.[39] This indicates that mammography screening is crucial to any breast cancer screening strategies and efforts are needed to increase equitable access to mammography screening nationally. Despite evidence that mammographic screening reduces morbidity and mortality, mammogram uptake is still significantly lower as compared to CBE uptake (see Figure 9). Low mammogram uptake has been among the key findings of several local studies in Malaysia[40 41].

There are significant disparities in mammogram uptake across states

While BSE and CBE uptake was similar across regional states in Malaysia (Figure 10), mammogram uptake ranged approximately five-fold from 5.5% to 31.3% of women having ever had a mammogram. Mammogram uptake was lower in the East Coast Peninsular states, such as Terengganu and Kelantan. It is possible that this is largely due to the lack of screening infrastructure, facilities and resources in these regions, leading to the disparity in mammogram uptake across states. For instance, Hospital Kuala Krai and Hospital Raja Perempuan Zainab II in Kelantan, and Hospital Sultanah Nur Zahirah in Terengganu are the only government-funded hospitals within these two east coast of Peninsular states with mammogram and ultrasound facilities available for breast cancer screening. It has been reported that women from rural areas face higher travel burden to mammogram facilities than in urban areas, which presents a significant barrier to physically accessing screening facilities[42]. Furthermore, transportation costs[43] and other aspects of out-of-pocket expenditure incurred due to geographical barriers can render limited access and affordability to these services.

> ***"If you ask people to go for mammograms, they give a lot of excuses: looking after grandchildren, unable to get off work…People will cancel [mammogram] appointments because they don't have transportation, or the money for transportation….I have already approached whoever who can come for screening, but turns out they have no transport. I have cases where women got their appointments, but they do not have the money to pay for transportation…" - Senior nurse heading an NGO breast cancer screening unit***

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[38] Myers, E. R., Moorman, P., Gierisch, J. M., Havrilesky, L. J., Grimm, L. J., Ghate, S., ... & Sanders, G. D. (2015). Benefits and harms of breast cancer screening: a systematic review. *Jama*, 314(15), 1615-1634.

[39] Duffy et al. (2020). Mammography screening reduces rates of advanced and fatal breast cancers: Results in 549,091 women. Cancer, 126(13), 2971-2979.

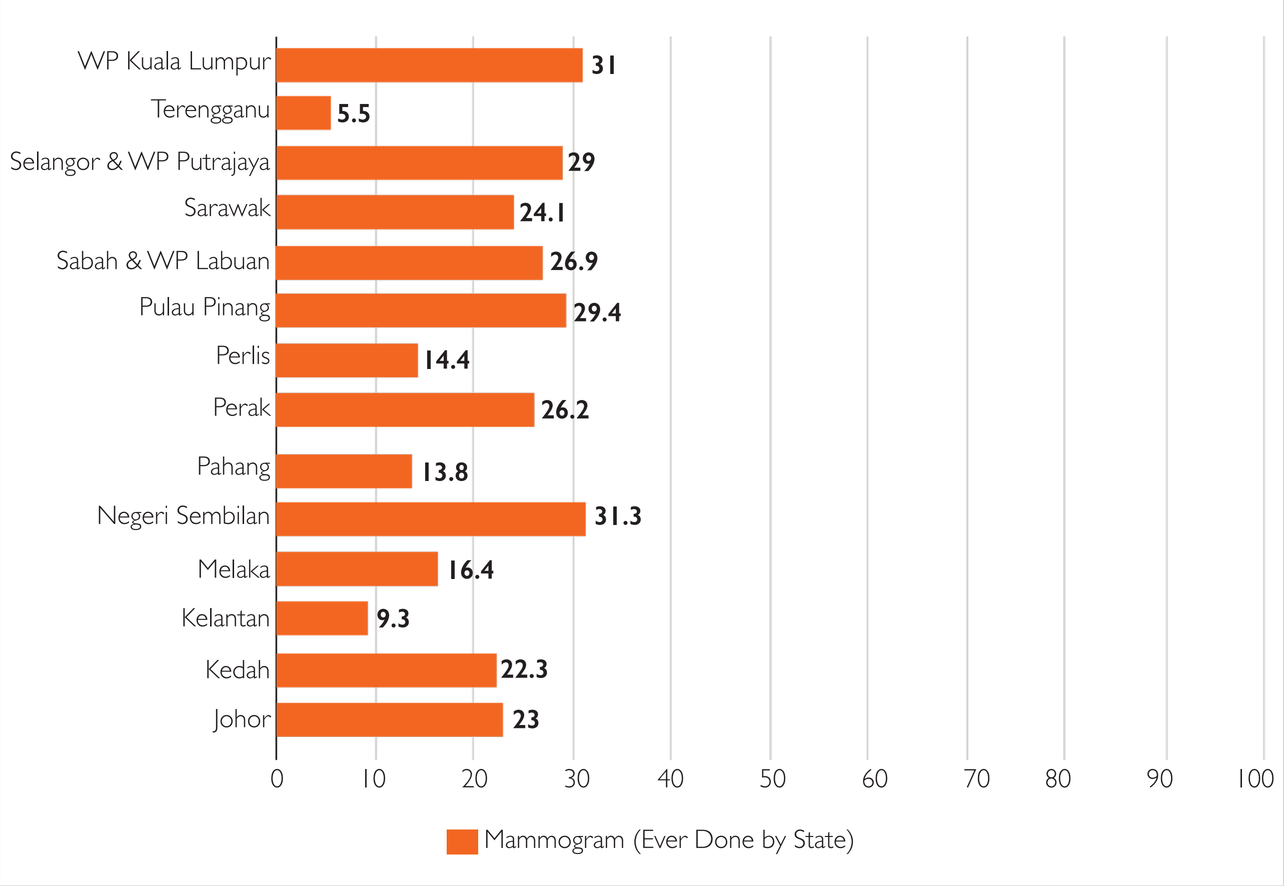
[40] Dahlui, M., Gan, D. E. H., Taib, N. A., & Lim, J. N. W. (2013). Breast screening and health issues among rural females in Malaysia: how much do they know and practice?. Preventive medicine, 57, S18-S20.

[41] Mohan et al. (2021). Breast cancer screening in semi-rural Malaysia: Utilisation and barriers. International Journal of Environmental Research and Public Health, 18(23), 12293.

[42] Aidalina, M., & ASJ, S. M. (2018). The uptake of Mammogram screening in Malaysia and its associated factors: A systematic review. The Medical Journal of Malaysia, 73(4), 202-211.

[43] Alexandraki, I., & Mooradian, A. D. (2010). Barriers related to mammography use for breast cancer screening among minority women. Journal of the National Medical Association, 102(3), 206-218.

Figure 10: Mammogram uptake across states, as measured by "ever" done breast health screening



Gender sensitivities influence the utilisation of breast cancer screening

Furthermore, studies reported that the discomfort of seeking care from male doctors or the presence of male staff were significant barriers to screening, especially among Malay women.[44] It was also found that rural and suburban Asian women are less receptive to revealing their private parts to healthcare providers, hindering them from going for breast screening.[45] [46] [47] This emphasises the importance of prioritising female healthcare workers at breast screening facilities to consider gender sensitivities. This could be done by prioritising the sub-specialty training and upskilling for female nurses and radiographers.

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[44] Mohan et al. (2021). Breast cancer screening in semi-rural Malaysia: Utilisation and barriers. International Journal of Environmental Research and Public Health, 18(23), 12293.

[45] Norsa'adah, B., Rahmah, M. A., Rampal, K. G., & Knight, A. (2012). Understanding barriers to Malaysian women with breast cancer seeking help. Asian Pacific Journal of Cancer Prevention, 13(8), 3723-3730.

[46] Pruitt et al. (2015). Social barriers to diagnosis and treatment of breast cancer in patients presenting at a teaching hospital in Ibadan, Nigeria. Global public health, 10(3), 331-344.

[47] Rastad, H., Khanjani, N., & Khandani, B. K. (2012). Causes of delay in seeking treatment in patients with breast cancer in Iran: a qualitative content analysis study. Asian Pacific Journal of Cancer Prevention, 13(9), 4511-4515.

Monitoring and evaluation of breast cancer screening programmes need to account for regular screening

Screening efforts have not translated to improved early detection of breast cancer. Data from the literature indicate that there are two key components to early detection: i) increased uptake of screening, ii) presentation to clinical care upon self-discovery of symptoms. One way to improve outcomes from breast cancer screening is to improve on how mammogram uptake and utilisation is being measured. While existing data showed increased uptake of screening programmes, uptake was often measured using the indicator of 'ever done'. These statistics do not capture the proportion of women in Malaysia who are adherent to evidence-based breast cancer screening schedule that is recommended by the CPG. Instead, it only measures the proportion of women who have ever undergone a mammography screening at least once through the MOWFC screening programme. In other words, existing indicators for mammography screening are not reliable measures of adherence to evidence-based mammography programmes and as such, are unlikely to lead to the desired life-saving clinical outcomes.

Based on existing literature, most studies define mammography screening as "ever" having a mammogram, with a few defining it as having a mammogram within the "past 12 months", and fewer measuring "repeated or regular" screening. Studies have shown that regular mammography utilisation is most likely to yield early breast cancer detection. Furthermore, the factors associated with ever having a mammogram are not the same as those correlating with current and repeated/regular mammography use. Therefore, it is necessary to identify the factors that predict current and more importantly *regular or repeated* mammography screening as it is the most effective in reducing morbidity and mortality. This allows policymakers and researchers to identify and implement targeted interventions for women who may engage in mammography screening but are not regular users of this procedure.[49] Similarly, regular (monthly) BSEs complement regular mammography screenings. Therefore, identifying the factors that reliably encourage monthly BSE is also important to encourage healthy breast cancer screening practices and effectively promote early detection.

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[48] Laing, S. S., & Makambi, K. (2008). Predicting regular breast cancer screening in African-American women with a family history of breast cancer. *Journal of the National Medical Association*, 100(11), 1309-1317.

Awareness and Literacy of Screening

Patients' health awareness and literacy influences their decision to get screened

Across demographics and localities, poor breast health literacy is a significant barrier to screening and early detection. Poor breast health literacy can be reflected in the i) lack of knowledge in symptom appraisal, ii) non-recognition of the seriousness of symptoms, iii) lack of awareness of being at risk and iv) lack of information on screening services.

For instance, studies found that young women who delayed presentation of breast cancer admitted that they had no knowledge and understanding of breast cancer and its symptoms.[49] [50] [51] Furthermore, studies also reported that delayed presentation was associated with women's perception about the seriousness of the symptoms, especially in cases when breast pain is absent or where the lump is small.[52]

> ***"I find that the lack of awareness is alarmingly horrible, they say "it is not painful, it is okay", I'm sorry to say it's not only the public; it's the medical fraternity as well"***
> ***– Dr A, Specialist breast surgeon***

Pain is the most common symptom to trigger medical help-seeking, especially when it interferes with daily-life activities.[53] Other triggers usually include symptom visibility such as nipple discharge and the enlargement of breast. However, pain and visible symptoms usually appear in advanced stages of breast cancer. Given that most early-stages of breast cancer have non-visible symptoms, there needs to be an added emphasis on encouraging regular BSE and mammography screening in order to increase early detection.

It is important to note that some patients dismiss the seriousness of symptoms due to situational factors such as pregnancy and lactation as breast changes are commonly observed during pregnancy or breastfeeding. Furthermore, with the lack of knowledge of breast cancer and its related risk factors, many women are not aware of their high-risk status, and hence do not see the need to go for regular screening.[54]

The lack of information regarding the availability of breast cancer screening services is another barrier to early detection.[55] It was reported in our study that while there are various mammography screening programmes nationwide as well as incentives and financial assistance provided by government ministries and NGOs, there is no consolidated information about the available services. Hence, this necessitates

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[49] Taib, N. A., Yip, C. H., & Low, W.Y. (2011). Recognising symptoms of breast cancer as a reason for delayed presentation in Asian women—the psycho-socio-cultural model for breast symptom appraisal: opportunities for intervention. *Asian Pac J Cancer Prev*, 12(6), 1601-8.

[50.] Yusuf, A., Ab Hadi, I. S., Mahamood, Z., Ahmad, Z., & Keng, S. L. (2013). Understanding the breast cancer experience: a qualitative study of Malaysian women. *Asian Pacific Journal of Cancer Prevention*, 14(6), 3689-3698.

[51.] Norsa'adah, B., Rahmah, M. A., Rampal, K. G., & Knight, A. (2012). Understanding barriers to Malaysian women with breast cancer seeking help. *Asian Pacific Journal of Cancer Prevention*, 13(8), 3723-3730.

[52] see footnote 49

[53..] Yusoff, N., Taib, N. A. M., & Ahmad, A. (2011). The health seeking trajectories of Malaysian women and their husbands in delay cases of breast cancer: a qualitative study. *Asian Pac J Cancer Prev*, 12(10), 2563-70.

[54.] Yu, F. Q., Murugiah, M. K., Khan, A. H., & Mehmood, T. (2015). Meta-synthesis exploring barriers to health seeking behaviour among Malaysian breast cancer patients. *Asian Pacific Journal of Cancer Prevention*, 16(1), 145-152.

[55.] *Ibid.*

more investments into developing breast cancer awareness campaigns and outreach to improve the level of knowledge and awareness nationwide. Such campaigns should aim to disseminate information about the range of breast cancer symptoms and risk factors, the importance of regular screening, techniques on BSE as well as a clear directory of available screening services and assistance across localities.

> ***"[Breast health] education is important…We don't have a singular message that we are sending out to people. Previously, we had a national campaign against smoking - the Tak Nak campaign. There isn't something similar for breast cancer. Each organisation presents their own data, facts and messages and it [the message] gets muddy." - D, NGO doctor***

> ***"I was working in my company and one of our beneficiaries came to our office for (breast cancer) campaign...They asked us to examine our breast and that's when I identified I had a solid lump in my breast"- 39 years old, Johor, diagnosed in 2021 with Stage III breast cancer***

Cultural norms and support systems influences screening utilisation

The patient's locality, ethnicity and culture influence the patients' knowledge and beliefs about breast cancer, which subsequently determines their screening uptake even when screening is available and accessible. Furthermore, the knowledge and awareness of the patient's social networks will also influence symptom interpretation and utilisation of screening.

> ***"When I turned 35 years old, my cousin sister told me that every month from now I should do breast self-examination…So I was doing it every month for nearly 3 years. At the age of 38, I found a very small lump on my breast" - 59 years old, Penang, diagnosed in 2000 with Stage III breast cancer***

For instance, poor uptake of mammography screening and delayed presentation in rural or suburban areas such as Kelantan can be attributed to poor knowledge of cancer, fear of the consequences of cancer, beliefs in complementary alternative medicine, needing support from others, competing priorities (ie. care responsibilities), as well as their perception towards healthcare.[56] [57] Beyond these individual factors, lack of family support in the form of providing information about breast cancer, providing financial and logistical support to access health facilities, and emotional support may also hinder uptake of screening. Family support is especially influential in localities where there are strong cultural norms of firm family reliance, especially the authority of men to make medical decisions within the household.[58] [59] [60] Hence, this highlights the necessity of conducting culturally sensitive breast

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[56] Taib, N. A., Yip, C. H., Ibrahim, M., Ng, C. J., & Farizah, H. (2007). Breast cancer in Malaysia: are our women getting the right message? 10 year-experience in a single institution in Malaysia. Asian Pacific Journal of Cancer Prevention, 8(1), 141.

[57] Norsa'adah, B., Rahmah, M. A., Rampal, K. G., & Knight, A. (2012). Understanding barriers to Malaysian women with breast cancer seeking help. Asian Pacific Journal of Cancer Prevention, 13(8), 3723-3730.

[58] Taib, N. A., Akmal, M. N., Mohamed, I., & Yip, C. H. (2011). Improvement in survival of breast cancer patients—trends in survival over two time periods in a single institution in an Asia Pacific Country, Malaysia. Asian Pac J Cancer Prev, 12, 345-9.

[59] Mohd Taib, N. A., Su, T. T., Al Sadat, N., Dahlui, M., Abdul Majid, H., & Bhoo Pathy, N. (2013). Malaysian breast cancer survivorship cohort (MYBCC) study. J Health Transl Med, 16, 58.

[60] Yu, F. Q., Murugiah, M. K., Khan, A. H., & Mehmood, T. (2015). Meta-synthesis exploring barriers to health seeking behaviour among Malaysian breast cancer patients. Asian Pacific Journal of Cancer Prevention, 16(1), 145-152.

cancer awareness campaign and education programmes for not just women but also men within these communities.

Key recommendations to improve the presentation interval

1. Improving breast cancer awareness through promoting BSE

There is a need to have a singular message for breast cancer, which includes information about the importance of screening, screening facilities and assistance available, and BSE techniques as well as information to educate both women and men about lump and non-lump symptoms, and the risk factors associated with breast cancer. Furthermore, findings highlight the need to implement culturally sensitive breast cancer awareness programmes in partnership with religious institutions and schools, especially for rural and suburban regions in Malaysia.

2. Improving the availability and accessibility of infrastructure and screening facilities

To improve access to mammography screening, there is a need to expand the availability of affordable mammogram programmes through Klinik Nur Sejahtera and Klinik Kesihatan. To address the issue of limited capacity and resources, government must collaborate with NGOs to widen the availability of mobile mammography facilities, especially in rural areas. Furthermore, there is also a need to address the indirect cost of accessing screening through incentives and subsidies, such as through PeKa B40.

3. Improving data availability and the monitoring and evaluation system of screening programmes

Relevant government ministries must collaborate to measure regular and repeated BSEs mammography screenings according to the CPG as indicators to monitor and evaluate the effectiveness and progress of existing breast cancer screening programmes. As current epidemiology data of breast cancer are largely based on the voluntary reporting of cases, there is also a need to improve data collection and management of the incidence and survival of breast cancer cases through a widespread adoption of Electronic Health Records across public and private healthcare system.

Diagnostic Interval: Access to Diagnosis

The diagnostic interval spans the period when the identified breast abnormality undergoes the "triple test" workup based on clinical evaluation, imaging and tissue sampling to arrive at a definitive diagnosis. Studies have reported a median diagnostic interval of 26 days in Malaysia. The interval is not far from the intervals reported in other Asian and high-income countries. This interval is within the recent Breast Health Global Initiative recommendations that health systems should strive to complete diagnostic examinations within 60 days. While this indicates the acceptability of diagnostic interval of breast cancer in Malaysia, the wide range of duration for this interval, with 9.3 months as the upper range, highlights that there are still gaps and room for improvement within our local healthcare system.

Timeliness of Referral Processes

Screening does not end at early recognition of mammographic abnormalities, a prompt diagnostic follow-up is crucial

Currently, breast cancer diagnosis and treatment are provided mainly by 19 trained breast surgeons across 8 government hospitals. A study involving 6 out of 8 of these hospitals found that 42% of breast cancer patients experienced diagnosis delay of more than one month from first presentation at a healthcare facility to diagnosis.[61] Among the diagnosis sub-intervals (referral, biopsy, report, resolution), the referral interval was the longest.[62] This indicates significant gaps between the detection of breast abnormalities during screening and referral for diagnostic tests. The referral delays in this stage can be attributed to various system-level and patient-level factors. Only recently, a recommended time frame of 2 weeks for a referral from primary care facility to diagnostic centre in Malaysia was incorporated into the CPG.

Complicated referral processes led to delayed diagnosis

Aside from breast cancer screening services at MOH hospitals and clinics or Klinik Nur Sejahtera under the MOWFC, women in Malaysia can also get screened at private hospitals and NGO clinics. The reasons for getting screened at private hospitals or NGO clinics are usually attributed to shorter wait time and availability. The *Garis Panduan Pelaksanaan Perintah Fi (Perubatan) (Pindaan)* 2017 states that direct referrals from private hospitals and NGO clinics will be charged the private rate at government hospitals. It was commonly reported that some patients who have detected breast abnormalities suspected to be breast cancer within private or NGO screening facilities would prefer to be referred to public hospitals for further testing due to its affordability. For these patients to not be charged the private rate, patients are required to obtain referral letters from government healthcare providers. In some cases, mammography results provided by NGO clinics were not recognised by government healthcare providers. Hence, patients were required to repeat the screening procedure at government screening facilities in order to continue further diagnostic testing and treatment in government hospitals. These processes have caused significant referral delays, subsequently leading to late diagnosis.

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[61] Mujar NMM, Dahlui M, Taib NA (2018). Presentation, diagnosis, and treatment among patients with breast cancer in Malaysia. Global Oncol, 4, 25s-25s

[62] Mohd Mujar, N. M., Dahlui, M., Emran, N. A., Hadi, I. A., Yan, Y. W., Arulanantham, S., ... & Mohd Taib, N. A. (2022). Breast Cancer Care Timeliness Framework: A Quality Framework for Cancer Control. *JCO Global Oncology*, 8, e2100250.

> ***"NGOs are powerless when it comes to referrals. So if we do all the investigations for a patient and refer them to the Ministry of Health, that patient becomes a private patient. We are servicing mostly the B40 [individuals]. But once they come to us, they become a private patient. We then have to look for kind-hearted souls within the government sector who will see that patient just to write a referral letter so that the patient can go into the government healthcare system, which adds layers and delays." - Dr S, NGO practitioner***

> ***"Even with my ultrasound result and scan from National Cancer Society of Malaysia done by a radiologist, I was asked to do another ultrasound in Hospital Kuala Lumpur. Such move, to me, actually delays a patient's chance to get an appropriate treatment (if needed) as soon as possible. Whether to be scanned in private or governmental hospitals, I believe an ultrasound is an ultrasound, unless the standard medical training of radiologist is varied?" - 39 years old, Kuala Lumpur, diagnosed in 2020 with Stage I breast cancer***

> ***"I got myself transferred to IKN from HUKM. Little did I know that I was more complicated than it was supposed to be. Whatever HUKM informed them, they just put aside…And they wanted to redo the whole biopsy again, which they need to punch on my chest without any anesthesia…They insist to do the biopsy again… It is really painful." - 52 years old, Kuala Lumpur, diagnosed in 2017 with Stage II breast cancer***

Knowledge and Literacy of Diagnosis

Awareness of lump and non-lump symptoms among healthcare practitioners and patients

Studies show that symptoms without a breast lump were significantly associated with diagnosis delay.[62] [63] [64] [65]. This may be attributed to poor awareness of non-lump symptoms among primary healthcare practitioners, leading to these patients not being referred for further investigation.[66] [67] [68] This was also reflected in findings from the roundtable discussion that reported cases of general practitioners or primary care physicians, who are usually the first point of contact for clinical need in the community,

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[62] Mohd Mujar, N. M., Dahlui, M., Emran, N. A., Hadi, I. A., Yan, Y. W., Arulanantham, S., ... & Mohd Taib, N. A. (2022). Breast Cancer Care Timeliness Framework: A Quality Framework for Cancer Control. *JCO Global Oncology*, 8, e2100250.

[63] Plotogea et al. (2014). Clinical and prognostic factors associated with diagnostic wait times by breast cancer detection method. Springerplus, 3(1), 1-10.

[64] Forbes, L. J., Warburton, F., Richards, M. A., & Ramirez, A. J. (2014). Risk factors for delay in symptomatic presentation: a survey of cancer patients. British journal of cancer, 111(3), 581-588.

[65] Jones et al. (2014). A systematic review of barriers to early presentation and diagnosis with breast cancer among black women. BMJ open, 4(2), e004076.

[66] Taib, N. A., Yip, C. H., & Low, W. Y. (2011). Recognising symptoms of breast cancer as a reason for delayed presentation in Asian women—the psycho-socio-cultural model for breast symptom appraisal: opportunities for intervention. Asian Pac J Cancer Prev, 12(6), 1601-8.

[67] Yu, F. Q., Murugiah, M. K., Khan, A. H., & Mehmood, T. (2015). Meta-synthesis exploring barriers to health seeking behaviour among Malaysian breast cancer patients. Asian Pacific Journal of Cancer Prevention, 16(1), 145-152.

[68] Lim, J. N., Potrata, B., Simonella, L., Ng, C. W., Aw, T. C., Dahlui, M., ... & Taib, N. A. (2015). Barriers to early presentation of self-discovered breast cancer in Singapore and Malaysia: a qualitative multicentre study. BMJ open, 5(12), e009863.

not referring patients with breast cancer related symptoms for further investigations. This highlights the importance of comprehensive education to healthcare providers, especially for primary healthcare workers in order to increase their awareness of non-lump symptoms and to avoid referral delays. While cancer care is now an integral part of medical education, prioritising continuous medical education sessions on cancer screening and diagnosis among doctors and other healthcare professionals can increase their awareness of symptoms and the need for prompt referral for further investigations.

Similar to barriers to mammography screening, delayed follow-up post-mammogram may also be associated with women's perception about the seriousness of the symptoms, especially in cases where there is an absence of breast pain.[69] Hence, it is important that information disseminated to the public about breast cancer includes both lump and non-lump symptoms.

Key recommendations to improve the diagnostic interval

1. To streamline referral process between public and private healthcare facilities

To broaden the availability and improve the accessibility of breast cancer screening services, government ministries such as the MOH and MOWFC should partner with private hospitals and NGO clinics to leverage their screening facilities. This will likely increase the uptake of breast cancer screening. However, referral processes between public and private systems must be streamlined to shorten the referral interval and to avoid delayed diagnosis and treatment. These referral procedures must also be communicated and disseminated effectively across various stakeholders to prevent any information gap. A potential strategy to improve the linkage between public and private healthcare services and to improve continuum of care is through a patient-navigation system.

2. Education for primary healthcare workers in public and private healthcare facilities

There is a need to implement comprehensive education for healthcare providers, especially for primary healthcare workers in order to increase their awareness of non-lump symptoms and to avoid referral delays. While cancer care is now an integral part of medical education, prioritising continuous medical education sessions on cancer screening and diagnosis among doctors and other healthcare professionals can increase their awareness of symptoms and the need for prompt referral for further investigations.

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[69] Taib, N. A., Yip, C. H., & Low, W. Y. (2011). Recognising symptoms of breast cancer as a reason for delayed presentation in Asian women—the psycho-socio-cultural model for breast symptom appraisal: opportunities for intervention. Asian Pac J Cancer Prev, 12(6), 1601-8.

Treatment Interval: Access to Optimal Treatment and beyond

Treatment interval (TI) is defined as the time from a diagnosis resolution to initial treatment.[70] For many breast cancer patients, initial treatment is followed by subsequent treatment, in accordance with the national CPG for breast cancer. The main treatment modalities for breast cancer are surgery, radiotherapy, chemotherapy, hormone therapy and targeted biological therapy.[71]

There is a wide spectrum of barriers occurring within the treatment interval, ranging from geographic availability and timely access to optimal treatment and clinical care throughout the breast cancer continuum of care to wide variations in treatment-seeking behaviour of breast cancer patients. Efforts need to be targeted at both ends of the spectrum to remove barriers from the health system level as well as the patient level. There is a lack of guidance regarding the connectivity and patient care pathways between various health facilities through the cancer care system within published policies on breast cancer.

Barriers to optimal surgical treatment

Surgery is the mainstay of treatment for both early and advanced breast cancer. Most women with breast cancer require some type of surgery as part of their treatment.

Generally, there are two types of surgeries that aim to remove as much of the cancer as possible. A mastectomy is a surgery in which the entire breast that is affected by cancer is removed, including all of the breast tissue and sometimes other nearby tissues. A lumpectomy is a breast-conserving surgery where only the part of the breast containing the cancer is removed as well as some surrounding normal tissue close to the cancer. Typically, only women with early-stage breast cancer who meet the clinical criteria would be clinically eligible to undergo a lumpectomy instead of a mastectomy. These criteria include the size and location of the cancer, the extent of lymph nodes involvement as well as other relevant clinical criteria.

For many patients with advanced or metastatic breast cancer, surgery remains a key treatment modality as it may help to slow the spread of the cancer or help prevent or relieve symptoms of advanced cancer. For these patients who are eligible to undergo surgery, mastectomy is the key surgical option, often followed by radiotherapy.

Some patients may also receive breast reconstruction surgery to restore the breast shape after the cancer is removed. Breast reconstruction surgery could be performed separately after a patient has recovered from the initial surgery or immediately after a mastectomy by specialist oncoplastic breast surgeons.[72]

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[70] Mohd Mujar, N. M., Dahlui, M., Emran, N. A., Hadi, I. A., Yan, Y. W., Arulanantham, S., ... & Mohd Taib, N. A. (2022). Breast Cancer Care Timeliness Framework: A Quality Framework for Cancer Control. *JCO Global Oncology*, 8, e2100250.

[71] Ministry of Health Malaysia (2017). National Strategic Plan for Cancer Control Program (2016-2020).

[72] Bertozzi, N., Pesce, M., Santi, P. L., & Raposio, E. (2017). Oncoplastic breast surgery: comprehensive review. European review for medical and pharmacological sciences, 21(11), 2572–2585.

There is varied access to best practice options for breast cancer surgery

Many women with early-stage cancers are clinically eligible to choose between having breast-conserving surgery and mastectomy. The main advantage of breast-conserving surgery is that a woman keeps most of her breast. Most women who undergo breast conserving surgery would require radiotherapy treatment after surgery, depending on the stage of the cancer. Women who have mastectomy for early-stage cancers are less likely to need radiation. Studies for the past three decades involving thousands of women with early-stage cancer who are candidates for both types of surgery showed that when breast-conserving surgery is followed by radiation, the outcome in terms of survival is similar to patients who had mastectomies.[72] As radiation is often required to achieve the best survival for women who receive breast-conserving surgery, women are only offered this option if radiotherapy is available in that locality and if the patient agrees to undergo radiotherapy after surgery.

Other than the availability of radiotherapy, surgical options are also determined by the surgeon's surgical specialty. Oncology surgery services under the MOH are presently available at all state hospitals and several of the larger district hospitals. These services are provided by surgeons in various surgical disciplines. There are currently 10 Breast & Endocrine Surgery Subspecialty Centres within MOH facilities, which are Hospital Kuala Lumpur, Hospital Putrajaya, Hospital Selayang, Hospital Pulau Pinang, Hospital Raja Permaisuri Bainun Ipoh, Hospital Sultan Ismail, Hospital Raja Perempuan Zainab II, Hospital Sultanah Nur Zahirah, Hospital Queen Elizabeth II, and Hospital Umum Sarawak, where there are trained specialists performing breast-conserving surgery. Out of the 56 breast and endocrine specialist surgeons registered in Malaysia, only 22 are working at these centres.[73] Breast cancer patients in other MOH facilities are attended by general surgeons who are often trained to perform mastectomies in face of the clinical need due to the rising burden of breast cancer nationally.

For instance, a study based in Sabah found that mastectomy was the most common surgery performed (69.4%) whereas only 12.3% of the patients in the study had breast-conserving surgery or lumpectomy.[74] Meanwhile, a study based in the University Malaya Medical Centre, Kuala Lumpur had a higher proportion of patients that undergone breast-conserving surgery (27%).[75] Comparing Malaysia to centres in other more developed countries such as Korea (39.1%)[76], Australia (48.7%)[77] and United Kingdom (36.1% - 54.9%)[78], Malaysia has a lower proportion of patients that undergone breast-conserving surgery.

The limited practice of breast-conserving surgery in regions such as Sabah is due to by the lack of expertise, advanced disease presentation, smaller breast volume, and possible preference for mastectomy

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[72] Ye, J. C., Yan, W., Christos, P. J., Nori, D., & Ravi, A. (2015). Equivalent Survival With Mastectomy or Breast-conserving Surgery Plus Radiation in Young Women Aged < 40 Years With Early-Stage Breast Cancer: A National Registry-based Stage-by-Stage Comparison. Clinical breast cancer, 15(5), 390–397.

[73] Ministry of Health Malaysia (2017). National Strategic Plan for Cancer Control Program (2016-2020).

[74] Leong, B. D. K., Chuah, J. A., Kumar, V. M., Rohamini, S., Siti, Z. S., & Yip, C. H. (2009). Trends of breast cancer treatment in Sabah, Malaysia: a problem with lack of awareness. *Singapore medical journal,* 50(8), 772.

[75] Agarwal, G., Pradeep, P.V., Aggarwal, V., Yip, C. H., & Cheung, P. S. (2007). Spectrum of breast cancer in Asian women. *World journal of surgery*, 31(5), 1031-1040.

[76] Son, B. H., Kwak, B. S., Kim, J. K., Kim, H. J., Hong, S. J., Lee, J. S., ... & Ahn, S. H. (2006). Changing patterns in the clinical characteristics of Korean patients with breast cancer during the last 15 years. *Archives of Surgery, 141*(2), 155-160.

[77] Koshy A, Buckingham J, Zhang Y, et al. Surgical management of invasive breast cancer: a 5-year prospective study of treatment in the Australian Capital Territory and South-Eastern New South Wales. ANZ J Surg 2005; 75:757-61.

[78] Hobbs, S., Taylor, A., & Armistead, P. (2003). Patients' choice--or is it. *Ann R Coll. Surg. Engl*, 85, 65

due to locoregional recurrence concerns. In addition, mastectomy will also make subsequent treatment and follow-up easier, especially for patients from rural areas as the usage of modern chemotherapy and hormonal modulating agents are limited by the cost of medication, insufficient healthcare funding and the lack of facilities.

There are delays in undergoing breast cancer surgery due to cultural beliefs and misinformation about surgery

Optimal outcomes from breast cancer treatment are time sensitive with clinical evidence indicating that delays in starting treatment after diagnosis influences patients' survival. A study that assessed whether time from diagnosis to surgery correlated with overall survival (OS) and disease-specific survival (DSS) in two large national data sets in the United States found that longer time from diagnosis to breast cancer surgery was associated with a decline in OS and DSS, when adjusting for patient, tumour and treatment factors.[79] Overall survival declined for each interval increase, with the decline most pronounced in Stages I and II diseases. Although time is required for preoperative evaluation and consideration of options such as reconstruction, efforts to reduce time to surgery should be pursued when possible to enhance survival, followed by timely commencement of chemotherapy and adjuvant treatment.

A study conducted in 6 out of 8 MOH hospitals that provide breast cancer treatment by trained breast surgeons and their teams found that 35% of breast cancer patients experienced treatment delay, more than one month passing from diagnosis to initial treatment.[80] Similarly, it was also found in the Sabah-based study that 20.4% of patients defaulted proper treatment, with surgery being the most common treatment that was refused by patients (55.3%).[81] Most patients who refused treatment opted for alternative or traditional therapy, which are freely available, and returned with more advanced disease after such alternative treatment had failed. The reason for refusing surgery and opting for alternative treatments may be due to cultural beliefs and misinformation. For instance, some women may develop a strong sense of denial as they perceive breast cancer to be a threat to their identity as a wife, mother and a woman, which will then affect their relationship with their husbands and their children. Some may also be misinformed that mastectomy is the only surgery option or fear that surgery will disturb the tumour and accelerate the spread.

While these barriers exist and there is room for improvement, national efforts to increase access and lower barriers to treatment have resulted in positive experiences for some breast cancer patients. There is a need for strategies to ensure that all patients in need of care will receive timely and optimal treatment, as well as proper education on about the surgical treatment options available to ensure the best outcomes for breast cancer nationally.

> ***I didn't have to wait long for an appointment. It was about two weeks later I got an appointment to see a specialist in Putrajaya. And that's how I started my journey with mastectomy and the treatment that followed" - 54 years old, Selangor, diagnosed in 2020 with Stage I breast cancer***

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[80] Bleicher, R. J., Ruth, K., Sigurdson, E. R., Beck, J. R., Ross, E., Wong, Y. N., ... & Egleston, B. L. (2016). Time to surgery and breast cancer survival in the United States. *JAMA oncology*, 2(3), 330-339.

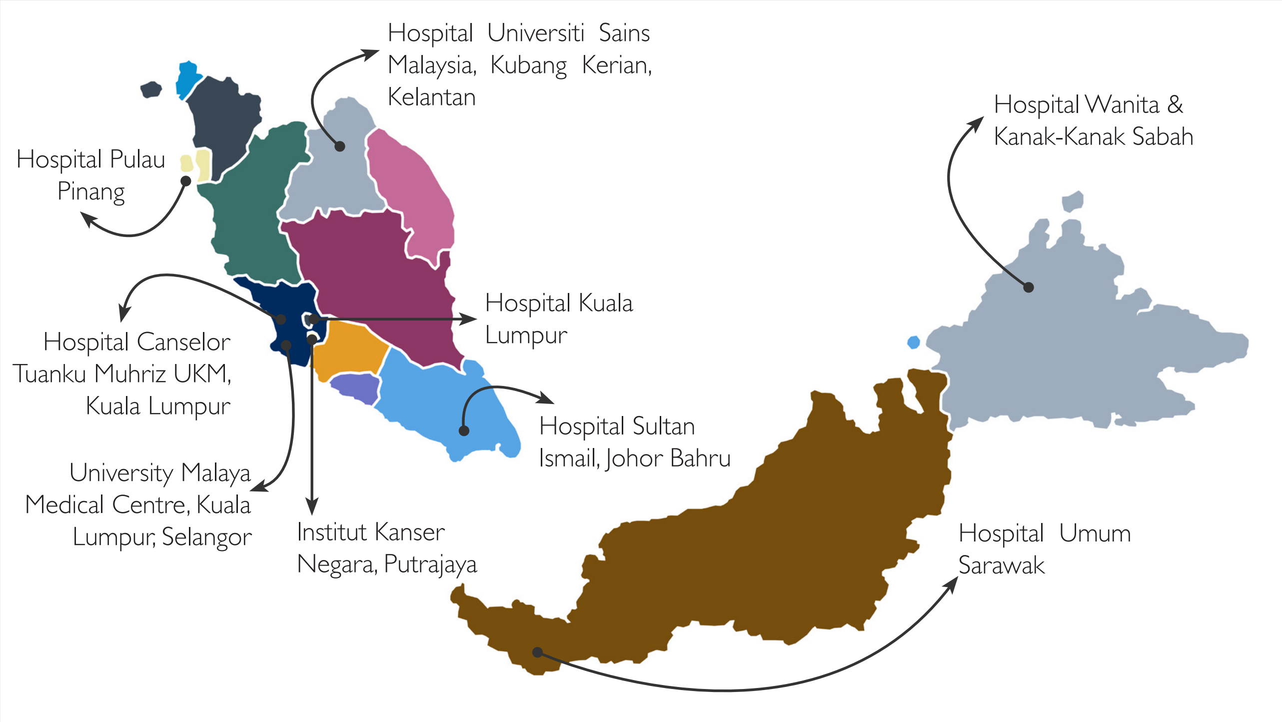
[81] Mohd Mujar, N. M., Dahlui, M., Emran, N. A., Hadi, I. A., Yan, Y. W., Arulanantham, S., ... & Mohd Taib, N. A. (2022). Breast Cancer Care Timeliness Framework: A Quality Framework for Cancer Control. *JCO Global Oncology*, 8, e2100250.

[82] Leong, B. D. K., Chuah, J. A., Kumar, V. M., Rohamini, S., Siti, Z. S., & Yip, C. H. (2009). Trends of breast cancer treatment in Sabah, Malaysia: a problem with lack of awareness. *Singapore medical journal*, 50(8), 772.

Barriers to optimal radiotherapy treatment

Radiation therapy for breast cancer uses high-energy X-rays, protons or other particles to kill cancer cells. Rapidly growing cells, such as cancer cells, are more susceptible to the effects of radiation therapy than are normal cells. The X-rays or particles are painless and invisible. Radiotherapy may be used to treat breast cancer at almost every stage. Cancer treatment is provided by both public and private hospitals and mainly concentrated on the west coast of Peninsular Malaysia. There are currently nine public oncology centres in 6 out of 13 states, and 2 out of 3 federal territories nationwide that offer both systemic chemotherapy and radiotherapy treatment of cancer (see Figure 11), excluding states such as Kedah, Melaka, Negeri Sembilan, Pahang, Perak, Perlis and Wilayah Persekutuan Labuan.[83]

Figure 11: Geographical location (by state) of public oncology centres that offer both systematic chemotherapy and rediotherapy treatment in Malaysia



The limited access to radiotherapy treatment within public hospitals limits surgical options for breast cancer

Most women who receive breast-conserving surgery will need radiotherapy after their surgery. Radiotherapy reduces the risk of breast cancer recurrence after surgery. This has a direct implication on the surgical options for patients with early stage cancer in the states without radiotherapy centres. Without access to radiotherapy, patients are often required to undergo mastectomy even when they are clinically eligible for breast-conserving surgery as radiotherapy is crucial for breast-conserving surgery to achieve survival rates similar to mastectomies. Survival from breast-conserving surgery without subsequent radiotherapy is lower than survival from mastectomies.

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[83] Ministry of Health Malaysia (2017). National Strategic Plan for Cancer Control Program (2016-2020).

For patients with advanced cancer, patients may also need radiotherapy after undergoing mastectomy as there are usually cancerous lymph nodes in the armpit, unclear surgical margins or locally advanced cancer. Radiotherapy can also help ease the symptoms caused by metastatic cancer that has spread to other parts of the body.

The limited availability of radiotherapy treatment within public hospitals compromises clinical outcomes of breast cancer patients

Radiotherapy is a key treatment modality for breast cancer. Radiotherapy has a role within the breast cancer treatment pathway for every stage of breast cancer, with many patients requiring radiotherapy to achieve optimal clinical outcomes according to best practice guidelines. Radiotherapy is commonly used to treat locally advanced cancer that could not be removed by surgery as well as metastatic breast cancer as radiotherapy can ease the symptoms caused by breast cancer that has spread to other parts of the body.

Patients in states and geographic locations without radiotherapy services available within MOH facilities would need to either travel to the nearest facility with radiotherapy, receive radiotherapy in private healthcare facilities or forgo this evidence-based life-saving treatment. Given the pivotal role of radiotherapy within breast cancer continuum of care, it is expected that the limited availability of this treatment within MOH facilities has a direct adverse impact on survival and related clinical outcomes of breast cancer.

Barriers to optimal chemotherapy treatment

Chemotherapy is a cancer treatment where medicine is used to kill cancer cells. Chemotherapy stops cancer cells reproducing, which prevents them from growing and spreading in the body. Chemotherapy is a mainstay of breast cancer treatment, with various evidence-based regimens commonly used in MOH centres. Chemotherapy can be given after surgery, known as adjuvant chemotherapy or before surgery, known as neo-adjuvant chemotherapy. Patients with advanced breast cancer who are not eligible for surgery may also receive chemotherapy with or without radiotherapy to slow the progression of breast cancer.

Long duration of chemotherapy treatment required for optimal outcomes

The average duration of treatment for a complete chemotherapy regimen generally requires six cycles of chemotherapy at three-weekly intervals, which spans approximately four and a half months.[84] Clinical evidence indicates that patients who complete the chemotherapy regimen have higher chances of benefiting from treatment in terms of disease-free progression and survival.[85] It is also important for patients to receive chemotherapy according to the chemotherapy dose schedule in order to maintain the dose intensity.

The inclusion of incentives to complete cancer treatment within the PeKa B40 financial assistance scheme for patients from low-income B40 households highlights the pressing need to address this barrier

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[84] Clinical Practice Guidelines (CPG): Management of Breast Cancer (2010) Second Edition

[85] Nielson et al (2021) Relative Dose Intensity of Chemotherapy and Survival in Patients with Advanced Stage Solid Tumor Cancer: A Systematic Review and Meta-Analysis. The Oncologist. 26 (9)e1609-e1618

to chemotherapy treatment, especially within this population.

> ***"….Interestingly we also offer cancer treatment incentives for our B40……we offer a completing cancer treatment incentive whereby we offer RM 1,000 cash given to beneficiary accounts upon the completion of the cancer treatment which we define as our amount of completing cancer treatment and at least to visit doctors in public hospitals. And for those receiving benefits to having health aid and also for completing their cancer treatment incentive, we also offer them transport incentives based on diagnosis, so therefore the patient usually has two types of transport incentives—RM 500 to peninsular Malaysians and RM 1000 for East Malaysians (Sabah and Sarawak) per diagnosis." – Dr. Y, MOH subsidiary***

There is limited access to chemotherapy treatment within the public health system

Generally, chemotherapy for breast cancer is delivered by oncologists. There is an acute shortage of oncology specialists within the public health system, with more than half of the estimated 150 oncologists nationally practising in the private health facilities. The high patient load alongside the long waiting time for chemotherapy services in the public health system can lead to lower uptake and completion of chemotherapy treatment, which can adversely impact breast cancer survival. There are only 6 MOH oncology centres treating the majority of cancer patients in Malaysia. The limitations in terms of facilities, human resource and funding currently pose huge challenges. Thus, strategies need to be put in place to reduce long waiting time for curative radiation treatment, better access to formulary drugs, decentralise the current oncology centres as well as improve access to oncologist's consultation.[86] With more than half of oncology specialists in Malaysia working in private health centres, the high cost of accessing private chemotherapy treatment in private facilities impedes access to most patients.

Barriers to optimal hormone treatment

Long-term treatment is required for optimal outcomes of hormone treatment for breast cancer

The availability of hormone treatment for breast cancer, also known as endocrine therapy, is less limited within the public health system compared to the other treatment modalities. These oral treatments for breast cancer are generally prescribed to all eligible patients, with acquisition costs that are lower than other breast cancer treatment modalities. Patients with hormone positive breast cancer can benefit from hormone treatment with improved survival. Clinical data indicate that these surviving patients would benefit from long term treatment ranging from five to seven years for individual patients.[87] This necessitates long term follow up and retention of patients within clinical care for optimal outcomes from this treatment modality.

There is a need for long-term adherence to hormone treatment for breast cancer

The long-term hormone treatment needed by patients, who can be relatively symptom-free, can lead to challenges in treatment retention, with low adherence to medicine intake well-documented among patients who are on long term medical treatment. Cancer survivors who are on hormone treatment

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[86] Ministry of Health Malaysia (2017). National Strategic Plan for Cancer Control Program (2016-2020).

[87] Gnant et al. (2021)

face similar challenges to patients of chronic disease who require long term pharmacotherapy. A systematic review found that adherence to adjuvant endocrine therapy decreased from the first to fifth year of treatment.[88] On average, one-third of patients were not adherent to treatment by the fifth year. This indicates a need to enhance strategies to retain breast cancer patients within clinical care and to identify and lower barriers to retention within clinical care.

Adverse side effects from hormone treatment, such as sleep disturbance, hot flashes, pain and anxiety, impair quality of life and increase the likelihood of participants becoming non-adherent to hormone treatment medication.[89] In order to maximise hormone treatment adherence and reduce breast cancer mortality, side effects from hormone treatment should be closely monitored to identify individuals who would benefit from individualised intervention strategies aimed at alleviating these side effects.

Barriers to provision and access to targeted biological treatment

There is limited availability of high cost targeted biological treatment within public healthcare centres

Targeted therapy, also called biological therapy, uses the body's immune system or hormonal system to fight breast cancer cells by interfering with processes in the cells that help cancer grow. Similar to chemotherapy, targeted therapy is given as multiple cycles of treatment over several months, with the duration of treatment crucial in optimising clinical outcomes. Targeted treatment can be given after surgery to reduce the chances of breast cancer recurrence or given before surgery to shrink a larger cancer before it is surgically removed. Targeted therapies can also be used to treat metastatic breast cancer to slow down the spread of cancer.

The most commonly used targeted therapy for breast cancer is trastuzumab. It is used to treat breast cancer that is HER2 positive. There are various other targeted therapy drugs to treat HER2 positive breast cancer as well as HER2 negative, oestrogen receptor (ER) positive breast cancer and triple negative breast cancer.[90]

While many of these targeted biological therapy drugs have been registered for use in Malaysia, their availability and use within MOH centres are still limited, mainly due to their high cost. There are increasing demands from oncologists and patients to increase access to these drugs within the MOH system, particularly in oncology centres.

> ***"…..after I finish my radiation, my oncologist told me in the final week that I need to go through targeted therapy, and …….I have to go through 12 cycles. I am paying myself for all these treatment… They keep on adding and adding…So I realised there is no transparency at all. They should have told me 'Ok, this is what you expect to go through…along the way you probably need to add on radiation or targeted therapy…and probably you need to have around RM300,000', so that I***

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[88] Yussof, I., Tahir, N. A. M., Hatah, E., & Shah, N. M. (2022). Factors influencing five-year adherence to adjuvant endocrine therapy in breast cancer patients: A systematic review. *The Breast (62) 22-35.*

[89] Ibrar, M., Peddie, N., Agnew, S., Diserholt, A., & Fleming, L. (2022). Breast cancer survivors' lived experience of adjuvant hormone therapy: a thematic analysis of medication side effects and their impact on adherence. *Frontiers in Psychology,* 13.

[90] Łukasiewicz et al (2021) Breast Cancer-Epidemiology, Risk Factors, Classification, Prognostic Markers, and Current Treatment Strategies-An Updated Review. Cancers 13(17):4287.

> ***am well prepared. Because of this, I suddenly feel anxiety because I am not working anymore, I start to think I am a burden to my family. I start to think to myself… there is only two options, either I continue living or I accept my mortality." - 39 years old, Johor, diagnosed in 2021 with Stage 3***
>
> ***"My case was very unfortunate, I had it (breast cancer) during pandemic time. I had my operation done in UMMC. The breast was only Stage I but it had spread to the liver….so it was Stage IV. By the time I wanted to have my chemo, the whole UMMC was full of COVID…I don't blame them, COVID comes first. But I was so worried because my cancer is Stage IV. In the end, my siblings and my son managed to get me to a private hospital to have it (chemotherapy) done immediately. I have finished my targeted treatment, which consisted of 18 (cycles), that was the first targeted treatment. Then there was the second, which I have completed too. Now they want me to do another one, which is the third…I will be in financial problem isn't it? So I just don't know what am I going to do." - 73 years old, Selangor, diagnosed in 2020 with Stage IV breast cancer***

Access and availability to targeted biological therapy for breast cancer within the public system is even more limited compared to the availability of radiotherapy and chemotherapy, mainly due to its high costs. The high costs of these treatments limit access even to patients who are willing to pay out-of-pocket for cancer treatment. In some cases, it was also reported by patients that the estimated cost for targeted biological treatment were not transparently communicated prior to treatment. It is important to outline the expected financial implications of any health treatment through policies adopted by healthcare institutions. There is an urgent need to increase access to and affordability of targeted treatments nationally. Many countries in Europe have developed patient access schemes to increase access to innovative cancer treatment.[91] Options and models that have been applied in these countries could be adapted to increase access in other countries.[92] Here in Malaysia, the Pharmacy Practice & Development Division, Ministry of Health Malaysia has developed a guideline to encourage the development of Patient Access Scheme (PASc), defined as a scheme proposed by pharmaceutical companies and agreed upon by the Ministry of Health (MOH), Malaysia in order to improve access to medicines likely to have high budget impact either due to high treatment cost per patient and/or large volumes of use. This scheme involves innovative pricing agreements designed to improve cost effectiveness and facilitate patient access to specific medicines. This scheme may address the rising cost pressure, consumer demands and uncertainties, while attempting to provide patient access to innovative care within finite budgets. These strategies could potentially increase access to targeted biological therapy within the public health system. Further assessments are vital as data indicate that, while early experiences in Asia show that patient access schemes can be effective in achieving intermediate national drug policy objectives on drug utilisation and cost-savings, their long-term impact on containing healthcare costs and improving clinical outcomes remains uncertain.[93]

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[91] Lawlor, R., Wilsdon, T., Darquennes, E., Hemelsoet, D., Huismans, J., Normand, R., & Roediger, A. (2021). Accelerating patient access to oncology medicines with multiple indications in Europe. Journal of market access & health policy, 9(1), 1964791.

[92] Sruamsiri, R., Ross-Degnan, D., Lu, C.Y., Chaiyakunapruk, N., & Wagner, A. K. (2015). Policies and programs to facilitate access to targeted cancer therapies in Thailand. PloS one, 10(3), e0119945.

[93] Guce, K., Liu, C., Lawrence, A., & Mckendrick, J. (2020). PCN69 The IMPACT of Patient Access Schemes for Innovative Cancer Therapies in FOUR Asian Countries: A MIXED-Method Review. Value in Health Regional Issues, 22, S18.

The need to optimise palliative care services within public health centres

Limited availability of palliative care services within public healthcare centres

Palliative care is an approach that improves the quality of life of patients and their families through the prevention and relief of suffering from issues associated with life threatening illness. Specialised palliative care services within public hospitals are available in several state and major specialist hospitals. There are hospices run by NGOs in almost all states across the nation. The National Palliative Care Policy and Strategic Plan 2019-2030 provides a framework for the development of a nationwide palliative care program that is more out-reaching and equitable for the entire population.[94] The increasing prevalence of patients living with cancer, which is partly due to efforts to increase cancer survival by improving screening and treatment outcomes, highlights the need to provide a minimum standard of palliative care within the public health system nationally.

> ***"We want our patients to be admitted to patient-centred care services in hospitals. We need to put palliative care into any of these strategies. Hospice Malaysia only looks after 10 patients at one time. But, people don't know about us, so there is a huge power in collaboration. But who coordinates that?" - SL, NGO practitioner***

Key recommendations to improve the treatment interval

There is a need to increase access to optimal breast cancer treatment, especially to the currently limited surgical and radiotherapy treatment options within public healthcare centres. It is crucial to develop strategies that acknowledge and address the limitations within the public health systems. One study found that there was a significant difference in breast cancer outcomes for those who are treated in a leading private cancer centre compared to public centres.[95] Part of the challenge likely relates to the need to develop policies to increase equitable access to breast cancer care. During the peak of the COVID pandemic, there were temporary strategies developed to allow public healthcare patients to be treated within private health facilities for fee structures that were agreed upon by both parties. Those arrangements were made in face of acute constraints within public healthcare due to the increased patient load that exceeded the public system's capacity during the pandemic. Similar arrangements could be considered for cancer care, which can accelerate improvements in cancer outcomes nationally.

Financial Barriers

There is a wide spectrum of financial challenges that breast cancer patients and survivors face, depending on their personal and economic circumstances. These challenges can occur at any stage of the breast cancer patient pathway, from the presentation interval to the diagnostic interval as well as the treatment interval. Financial barriers for breast cancer patients vary according to their socioeconomic groups, with patients from lower income groups likely to experience financial barriers to access the continuum of care from the early phases of the presentation and diagnostic intervals while patients from higher income groups likely to experience financial barriers in accessing sequential lines of high-cost treatment,

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[94] Ministry of Health Malaysia (2019). National Palliative Care Policy and Strategic Plan 2019-2030.

[95] Ho, G. F., Taib, N. A., Pritam Singh, R. K., Yip, C. H., Abdullah, M. M., & Lim, T. O. (2017). What if all patients with breast cancer in Malaysia have access to the best available care: how many deaths are avoidable. *Glob J Health Sci*, 9(8), 32-39.

such as novel regimens of chemotherapy and targeted therapy.

Beyond financial barriers that patients are facing, there are also funding constraints within the healthcare budget that needs to be acknowledged. The rise of the incidence and prevalence of non-communicable diseases nationally need to correspond with increased funding for healthcare at the national level.

Financial challenges for health-related expenditure among patients from low- and middle-income households

In Malaysia, there is healthcare-related financial assistance available for citizens from low- and middle-income households, on top of the availability of partially subsidised healthcare for all citizens in government-run healthcare facilities nationally. National policies in Malaysia often target specific income groups, defined based on households' monthly income, comprising the low-income B40 households (monthly household income of less than RM4,850), middle-income M40 households (monthly household income of RM4,850 to RM10,959), and high-income T20 households (monthly household income of more than RM10,959). The two national healthcare-related financial assistance schemes are the MySalam and the PeKa B40 schemes, which were implemented by the government within the past 5 years to assist patients from B40 and M40 households. The MySalam scheme offers one-off financial assistance to adult patients up to 65 years old from low- and middle-income households who have been diagnosed with any of the diseases listed as a critical illness, which include cancer. The MySalam scheme also provides recipients with hospitalisation allowances for up to 14 days per annum for admissions in government-run health facilities. In addition to MySalam, the PeKa B40 scheme also provides financial assistance for patients from low-income B40 households with their health-related expenditures when they receive treatment in public hospitals run by the MOH. The PeKa B40 financial assistance includes medical equipment assistance, cancer treatment incentives and transport incentives. Considering the income threshold for M40 households, it is important to also consider the financial challenges faced by this population.

> ***"I'd like to speak as a cancer patient. There's been lots of work being done for B40s, but not for M40s. We are a very disadvantaged group; only 30%, from what I know, have insurance. I'd just like to urge you to take into consideration M40s as well." - N, NGO practitioner***

High out-of-pocket expenditure among breast cancer patients

Data indicate that many breast cancer patients incur substantial out-of-pocket expenditure for a prolonged period after diagnosis.[96] The multiple treatment modalities often needed for breast cancer include chemotherapy, radiotherapy, surgery and hormonal therapy, with optimal treatment often involving multiple lines of treatment with subsequently prolonged and lengthy duration. Nearly all treatment modalities required as optimal treatment for breast cancer are high-cost treatment, with the costs of surgery, radiotherapy, chemotherapy and biological therapy within private health facilities amounting to hundreds of thousands of ringgit, more than what the majority of Malaysians can afford

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[96] Yusoff and Ismail (2021) Out of pockets spending among breast cancer women receiving outpatient treatment in a tertiary teaching hospital in Kuala Lumpur Malaysia. Malaysian Journal of Public Health Medicine. Vol. 21(3): 240-24

without third party coverage, such as from medical insurance. With more than half of oncology specialists in Malaysia working in private health centres, the high cost of accessing private radiotherapy and radiotherapy treatment in private facilities limits access for most patients.

> *"They did the biopsy and confirmed there were cancer cells there. With that…. financially I couldn't afford to be looked after in a private hospital. So I was referred to Putrajaya." - 54 years old, Selangor, diagnosed in 2020 with Stage I breast cancer*
>
> *"I am paying myself for all these treatment… They keep on adding and adding…So I realised there is no transparency at all. They should have told me 'Ok, this is what you expect to go through…along the way you probably need to add on radiation or targeted therapy…and probably you need to have around RM300,000'. - 39 years old, Johor, diagnosed in 2021 with Stage III breast cancer*
>
> *"I was on stage II because 3 of my lymph nodes was affected. I went through 6 cycles of chemo and 25 fractions of radiotherapy. So everything was done. I did my yearly check-up, took Tamoxifen for 5 years. My oncologist was telling me to add another 5 years. On the 6th year in 2022, I had my yearly check-up and the result was not good. They found nodules in my lungs. So apparently it has spread to my lungs…. So now, I have to go through another cycle of treatment, this time it is going to cost me bomb…I have maxed out all my insurance and everything. I have done my chemotherapy and everything in Gleneagles. Then after that I got myself transferred to HUKM because I couldn't afford Gleneagles anymore…" - 52 years old, Kuala Lumpur, diagnosed in 2017 with Stage II breast cancer*

The cross-sectional study conducted by Yusoff & Ismail (2021) assessed out-of-pocket spending among 172 breast cancer women in 2017. The highest percentage of financial component was out of pocket expenditure on adjuvant therapy, RM 334,056.00 (30.2%, n=67/172) comprising adjuvant therapy (other than chemotherapy) such as radiotherapy, hormonal or biological/targeted therapy. Out-of-pocket expenditures related to breast cancer are a burden for women and their families. Financial support, especially to receive clinical treatment other than surgery and chemotherapy, could provide financial assistance to the out-of-pocket spending related to breast cancer, thereby reducing the financial burden among patients and their families.

Financial consequences to patients due to the poor linkage between private and public healthcare centres

Despite attempts to assist with financial challenges at the presentation and diagnosis intervals, such as breast cancer screening programmes, the lack of linkage between screening and diagnosis in private facilities and subsequent access to treatment in public healthcare centres have presented an additional challenge to patients. Based on current policies and practices, patients who were referred from a private institution and not from a MOH facility, such as from private primary care clinics when they first presented with self-discovered symptoms as well as those who were first screened and diagnosed in private health facilities, appear to be at a disadvantage. The current policy dictated that patients who were referred from private facilities are charged at higher rates compared to patients who were referred from public healthcare centres. This policy does not take into account the patients' financial status and their ability to pay for treatment. It also penalises patients who were screened or diagnosed with breast cancer through various breast cancer screening efforts that are run by NGOs and private health facilities. This policy on patient charges and fees in MOH facilities further exacerbates the challenges faced by breast cancer NGOs in referring breast cancer patients to clinical treatment, especially those that collaborate with private health facilities in their breast cancer screening efforts.

> ***"The other thing is that we are NGOs, and yes, MOH collaborates with NGOs, but we are powerless when it comes to referrals. So if we do all the investigations for a patient and we refer them to MOH, that patient becomes a private patient, because we are not part of the service. We are servicing B40 but once they come to us, they become a private patient and we have to look for kind-hearted souls within the government sector who will see that patient just to write a referral letter so that the patient can go into the governmental sector, which adds layers and delays. So it's the little things like this which makes a huge difference" - Dr. S, NGO practitioner***

There is a need to reassess policies on the treatment charges of patients who were referred for suspected breast cancer from private health centres. Charging patients for treatment in MOH facilities based on their financial status and ability to pay could encourage patients to start treatment and remain within clinical care. This is a necessary step in improving the clinical outcomes of breast cancer patients nationally. This can also help divert the resources incurred within the screening and diagnosis intervals towards private health facilities and allow public health centres to focus resources and efforts towards treatment of breast cancer.

Financial implications of long-term breast cancer treatment required for optimal outcomes

While the national healthcare-related financial assistance schemes may alleviate some of the financial burden of breast cancer patients, cancer is often an expensive diagnosis. Financial challenges can occur as early as at the presentation interval, when women first discover symptoms of breast cancer, such as when women cannot afford the initial medical check up, taking time away from formal or informal work, or the transportation costs required for first presentation to clinical care. Financial challenges due to those aspects can also occur during the diagnostic interval, which can delay women from obtaining a breast cancer diagnosis after first presentation to clinical care. These financial challenges can reduce access and delay diagnosis, even when subsidised clinical investigations for a breast cancer diagnosis are available. These financial barriers during the presentation and diagnosis intervals can result in delays in starting treatment which subsequently lead to poorer prognosis.

> ***"Not only early detection is important; it's also about continuation of care." - Dr S, NGO practitioner***

Many women are being diagnosed with advanced cancer in Malaysia, which often require long-term treatment to optimise clinical outcomes. The sequential treatment for advanced breast cancer may comprise years of treatment and could continue until palliative care is indicated. The financial implications of the lengthy treatment of advanced breast cancer to patients and their families can be significant, in terms of medical expenditure, as well as other health-related out-of-pocket expenditure. This can also impact their employment status and ability to perform daily activities.

"I am Stage 4, HER2-positive with lung mets. They told me it's aggressive and I have to go to treatment immediately. In my family, no one knows anything so we rely 100% on the doctors and what they say. Initially they told me I have to go through chemotherapy and then mastectomy. So that is the first thing I agreed to. After 5 cycles of chemotherapy, because I have very bad side effects…After I met my oncologist he said I need to go for mastectomy immediately. And I thought that was it, probably I just need to rely on the pills, which is Tamoxifen. But then after after I finish my mastectomy, I gone through 2 months break, and then the doctor to me that they decided for me to go for radiotherapy, which is 15 cycles. But then after I finish my radiation, my oncologist told me in the final week that I need to go through targeted therapy, and …….I have to go through 12 cycles." - 39 years old, Johor, diagnosed in 2021 with Stage 3

Conclusion and Recommendations for Collaborative Strategies

In order to downstage breast cancer at the time of diagnosis by 25% by the year 2030, as aspired in the NSP-CPP, there needs to be collaboration between the public and the private sector in order to reduce system inefficiencies, address resource constraints, improve data management, as well as to increase awareness of breast cancer among the general public.

Facilitating public-private partnerships to increase access and optimise breast cancer care

The roundtable executed revealed that many organisations are working on the ground to facilitate and improve breast cancer care. There is an acute need for structured public-private partnerships where all parties work together to address the needs of breast cancer patients. While informal collaborations have been indispensable given the pressing needs witnessed on the ground, all parties agreed that having a structured body that is systematically addressing breast cancer, and bridging the link between different organisations is the way forward.

> ***"....individually as organisations, we're doing brilliantly. But we need to have a body out there that is systematically looking at this and approaching all of us together, to collaborate and to go out there and push our expertise and only are we going to change things. " - Dr S, NGO practitioner***

While MOH has developed strategies for cancer care, there is a need to reach out to organisations outside the MOH to facilitate implementation of these policies. An organised committee could develop collaborative databases and map the resources and paths to access clinical care including programmes, services and organisations that could assist patients in acquiring treatment.

> ***"Private clinicians must be asked to work with public clinicians in the care of patients, this way time is shortened when patients go from private to public or vice versa" - 61 years old, Kuala Lumpur, diagnosed with Stage I breast cancer***

There are various efforts by NGOs and civil societies who are working to alleviate barriers within the presentation and diagnosis intervals. These include programmes by MAKNA with efforts to bring screening programmes including mobile mammograms to patients, collaborative efforts between NGOS such as BCWA which allows patients' access to subsidised screening at participating mammogram centres, which are being subsidised by the public sector. Many patients who are screened and diagnosed by NGOs and civil societies' programmes face financial barriers in accessing treatment in public health facilities, as they are subsequently charged higher fees because they were referred by private centres. Clear policies need to be in place to facilitate public-private partnerships. Immediate efforts are needed to resolve this barrier and optimise breast cancer continuum of care nationally by supporting the efforts on the ground by breast cancer NGOs and civil societies.

Collaborative care for psychosocial support between private and public institutions

The MOH goals are generally focused on the provision of healthcare nationally. Breast cancer patients are often in need of social support in psychosocial situations. Most MOH centres do liaise with social welfare teams, but their capacity is often limited.

> ***"As an oncologist, we want to explore social support with other parties. We only have one social worker for breast cancer. It's very difficult for her to tackle psychosocial situations. One thing we want to explore is to get assistance to ensure that we can minimise this." - Dr. C, Ministry of Health***

This is an area which NGOs are currently supplementing for cancer patients. There are NGOs who run helplines with social workers, counsellors and dieticians who are able to assist with free of charge psychosocial support. It is important to develop formal structures to allow these collaborative care frameworks to thrive within the public health system.

Increasing the resource and budgetary allocation for cancer care in public healthcare facilities

The increased incidence and prevalence of cancer alongside incremental improvements in outcomes wherein breast cancer patients have higher life expectancy following multiple lines of treatment highlights the need to increase the funding allocation for cancer care.

> ***"We have gaps everywhere at all levels: prevention, screening, diagnosis, palliative care. Communication is important; it's the gist of everything. We need more, but it's not simple. It isn't easy to have all this implemented: we need financial and human resources." - Dr S, NGO practitioner***

Lowering barriers to access cancer treatment in private health facilities

The limited capacity to provide optimal breast cancer treatment within the public healthcare system indicates a need for private healthcare centres to contribute to national breast cancer care strategies. This is especially important in view of the distribution of breast cancer specialists within clinical practice, with most endocrine breast surgeons and oncology specialists in Malaysia practising in private healthcare centres.[97]

Currently in Malaysia, there are regulated fee structures on clinician's fees in private practice, but there are no regulations on the other medical fees incurred within private health facilities. A recent study in the US found that medical supplies and nonphysician services contributed the most to cancer care spending.[98] An analysis by Ministry of Health in the NSPC acknowledged the need to buy services from

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[97] Ministry of Health Malaysia (2021). National Strategic Plan for Cancer Control Programme 2021-2025.

[98] Zaorsky, N. G., Khunsriraksakul, C., Acri, S. L., Liu, D. J., Ba, D. M., Lin, J. L., ... & Leslie, D. L. (2021). Medical Service Use and Charges for Cancer Care in 2018 for Privately Insured Patients Younger Than 65 Years in the US. JAMA network open, 4(10), e2127784-e2127784.

private healthcare providers due to the limited capacity within the public system. Such arrangements would need to be regulated and structured to optimise patients' outcomes and cost consequences. This could increase access to clinical care for breast cancer from the presentation interval, diagnosis interval throughout the treatment interval in private centres and reduce the patient load within public hospitals. Considering the critical need for comprehensive breast cancer care to improve survival outcomes nationally, expanding such efforts to regulate charges for cancer care in private health centres could also improve the affordability of cancer care for patients in private centres if such arrangements were to be expanded beyond public-private agreements to include individual patients' fee structures.

Cancer registry with real time data availability and reporting

Transparent collection and reporting of data on cancer incidence, clinical management and outcomes across both public and private systems within Malaysia is crucial to identify and monitor improvements and gaps from the collective efforts made nationally. Participation towards reporting to the cancer registry must be a commitment for all healthcare professionals within the public and private healthcare systems to ensure that the data accurately reflects the reality of everyday clinical practice. It is necessary to ensure that the collected data are available in real time, which will encourage concurrent improvements within clinical care.

Notes

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