Health System Strengthening and Breast Cancer Care in the Middle East

IN COLLABORATION WITH

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Health System Strengthening and Breast Cancer Care in the Middle East

Workshop Proceedings

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1 Introduction

Countries in the Middle East are undergoing rapid demographic, economic, nutritional, and socio-cultural transitions. These transitions mirror those encountered by other countries with emerging economies that are also facing rapidly increasing burdens of noncommunicable diseases and rising rates of multimorbidity. An analysis of health system responses to the rising cancer burden can help identify strategies to effectively manage cancer while simultaneously improving health system functions to benefit other conditions through a diagonal approach. To work toward these aims, a group of expert participants from across the region and globe assembled at the Harvard Medical School Center for Global Health Delivery–Dubai on January 22 and 23, 2018 for a meeting entitled Health System Strengthening and Breast Cancer Care in the Middle East: Results of the Harvard Research Study.

1.1 MEETING OBJECTIVES

The meeting’s objectives were to:

- Convene stakeholders in the Middle East to facilitate exchange on health systems strengthening strategies to improve delivery of breast cancer care within the region.

- Present findings from the Harvard Research Study on: (i) the burden of breast cancer, and (ii) the provision of breast cancer care in Jordan, Kuwait, Oman, Saudi Arabia, and United Arab Emirates based on health systems analysis in each country.

- Review findings from two additional studies – the CONCORD study and the Lancet Commission on Global Access to Palliative Care and Pain Relief.

- Review existing challenges to addressing breast cancer care in the Middle East across the continuum of cancer control and care (prevention, screening, diagnosis, treatment, palliation, and survivorship).

- Identify systems-level policy interventions to address challenges to breast cancer care in the Middle East.

- Discuss priority actions based on current challenges and suggested policy interventions to expand access to breast cancer care in the Middle East.

1 Middle East is defined as the noted study countries.

1.2 ORGANIZATION OF THE MEETING

The meeting featured presentations on study findings from each country analyzed in the Harvard Research Study – Jordan, Kuwait, Oman, Saudi Arabia, and United Arab Emirates; presentations on current country-level efforts to strengthen breast cancer care; and moderated panel discussion on future directions. Study presentations provided results on the national burden of breast cancer, a health system overview, a review of health systems performance in comparison to benchmark countries on provision of breast cancer care across the continuum, and policy implications for the cascade of care. Further, the meeting included discussion on the CONCORD study findings as well as recommendations and strategies to improve registries and data collection systems in the region. Moreover, it highlighted results from the Lancet Commission on Palliative Care and Pain Relief and discussion on how to expand access to palliative care in the region. The meeting ended with a review of pathways and priority actions to improve management of the breast cancer burden in the Middle East, as well as plans for dissemination of findings and identify next steps for ongoing knowledge exchange and formation of a collaborative research network to strengthen national and regional efforts.
1.3 ORGANIZATION OF THE REPORT
Following the Introduction, Section 2 provides detailed results of the Harvard study on Health Systems and Breast Cancer Care in Jordan, Kuwait, Oman, Saudi Arabia and the UAE. Section 3 provides a summary of the findings and the deliberations for the Concord-3 study. Section 4 presents the summary of the findings of the Lancet Commission on Palliative Care and Pain Control, with a specific emphasis on the findings pertaining to the Middle East. The report then presents in Section 5 a Framework for Action and a proposed set of activities based on the challenges identified in the studies and the views of the participants along with priority areas that need addressing.

1.4 HARVARD RESEARCH STUDY OVERVIEW AND FRAMEWORK
The Harvard Research Study utilized a proprietary framework developed by Harvard faculty (previously used in single- and multi-country studies2,3) to analyze breast cancer management in Jordan, Kuwait, Oman, Saudi Arabia and United Arab Emirates by tracing cancer care through each system function: stewardship, financing, resource management, and healthcare service delivery. The study also examined how health system functioning influences the provision of services for breast cancer services and outcomes for breast cancer, and vice versa. Finally, the study sought to explore:

- Contextual factors and health systems functions affecting cancer care
- Interaction of factors to influence attainment of health system goals (improved health, financial protection and user satisfaction)
- Impact on production health services (both individual and population levels) that meet
- Health system objectives of efficiency, effectiveness, equity and responsiveness

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2 Breast cancer in the Middle East: Harvard Research Study findings by country and regionally

Box 1 provides the outline by which the report of each country’s study findings was structured (per information available; some countries do not have findings for each category).

Box 1. Structure of report of each country’s study findings

- Demographic and epidemiological trends
- Health system performance
- Health outcomes: cancer burden
  - Financial protection
  - User satisfaction
  - Breast cancer care by health system function
  - Stewardship
  - Financing
- Resource management
  - Health service delivery across the continuum
  - National cancer planning
  - National cancer registry
  - Projections of future burden of cancer
- Policy implications of the study findings

2.1 BREAST CANCER IN THE KINGDOM OF SAUDI ARABIA

KSA was characterized as a showcase for the rest of the region because many of the patterns observed in KSA also apply to the other countries.
2.1.1 Demographic and epidemiological trends

KSA is interesting in that its population is growing unlike in Europe where the population is stable or even declining (see Figure 21). KSA’s population pyramid currently indicates a young population, with a broad base of young people, but a demographic transition is approaching: by 2050 that cohort will have aged and the base will become narrower and by 2100—and probably earlier—there will be a rapidly aging population with lower numbers among the younger population (see Figure 1).
Figure 1. Population projections by age group for the Kingdom of Saudi Arabia (1980-2050)

Source: Study presentation

Data source: United Nations Department of Economic and Social Affairs 2015
This imminent demographic transition in KSA will have a major impact on epidemiological trends in the next 30 years, because along with aging come disability and chronic disease. Many countries around the world are currently struggling to manage similar transitions. To illustrate the epidemiological transition, the respective top-ranking causes of disability-adjusted life years (DALYs) per 100,000 population in 1990 and in 2016—a span of just 30 years can be compared. The top ten disease categories for 2016 were mainly chronic diseases and injuries (unintentional as well as transport injuries) (see Figure 23). The key problems have shifted from maternal and child health issues and infectious diseases, for example, to problems related to noncommunicable diseases. The transition is occurring rapidly.
Figure 3. Rank of disability-adjusted life year causes per 100,000 population in the Kingdom of Saudi Arabia

Epidemiological Trends

The ASR incidence rate of all cancers in KSA is lower compared to other countries in the region, which reflects the transition that the country is going through—that is, KSA probably has a younger population compared to other countries (see Figure 24. Average annual age-standardized incidence rates of all cancers by gender in the Gulf Cooperation Council states (1998-2012)).

2.1.2 Health system performance

KSA was evaluated along two measures of health system performance: health outcomes and financial protection.

2.1.2.1 Health outcomes: cancer burden

Source: Study presentation6

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6 Data source: Institute for Health Metrics and Evaluation (IHME), Global Burden of Disease Data 2016
According to 2000-2004 data, the five-year net survival percentage for breast cancer in KSA (78.4%) is lower than in comparable countries (France: 86.9%; Australia: 86.2%, Canada: 85.8%; Switzerland: 85.5%; Germany: 85.3%; United Kingdom: 81.1%; Turkey: 78.6%). The higher survival being achieved in other countries is an opportunity for KSA to further improve its own survival levels. This is the first health system outcome using survival as the metric for population-level health outcomes.

2.1.2.2 Financial protection

In terms of financial protection—the other important measure of health system performance—KSA does relatively well; its citizens have a right to health and can avail of a fairly comprehensive benefits package. The system in KSA aspires toward universal health coverage (UHC) and there is constitutionally authorized coverage (free of charge) for all citizens and expatriates for needed services in public sector, which has led to high usage of the public system. The government also provides free health services to pilgrims for Hajj. However, private sector insurance coverage is incomprehensive. KSA has relatively low out-of-pocket health expenditure as a percentage of total health expenditure compared to other countries in the region, at 14.3% (see Figure 26. Financial protection indicators: Kingdom of Saudi Arabia and comparable countries (2014)). The

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risk of catastrophic expenditures for surgical care in KSA is relatively high, with 24.4% of people at risk, as is the risk of impoverishing expenditure for surgical care, is relatively higher compared to other countries (14.9% of people at risk). These data come from surgery, and not from cancer care specifically, and call for better understanding of whether cancer can also lead to excess expenditures.

Figure 5. Financial protection indicators: Kingdom of Saudi Arabia and comparable countries (2014)

<table>
<thead>
<tr>
<th>INDICATORS (2014)</th>
<th>KSA</th>
<th>Canada</th>
<th>United Kingdom</th>
<th>France</th>
<th>Germany</th>
<th>Turkey</th>
<th>Lebanon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Out-of-pocket health expenditure (% of total health expenditure)</td>
<td>14.3</td>
<td>13.6</td>
<td>9.7</td>
<td>6.3</td>
<td>13.2</td>
<td>17.8</td>
<td>36.4</td>
</tr>
<tr>
<td>Risk of catastrophic expenditure for surgical care (% of people at risk)</td>
<td>24.4</td>
<td>2.7</td>
<td>0.9</td>
<td>0.5</td>
<td>0.3</td>
<td>4.9</td>
<td>31</td>
</tr>
<tr>
<td>Risk of impoverishing expenditure for surgical care (% of people at risk)</td>
<td>14.9</td>
<td>0.3</td>
<td>0.6</td>
<td>0.2</td>
<td>0</td>
<td>7.4</td>
<td>13.3</td>
</tr>
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</table>

Source: Study presentation

2.1.3 Breast cancer care by health system function

An overview of KSA’s health system functions of stewardship, financing, resource management, and service delivery is summarized below based on discussions.

2.1.3.1 Stewardship

2.1.3.1.1 Governance

In terms of governance, KSA has a fairly centralized system with the Ministry of Health (MoH) as the main governing body and contributor of monetary resources; the MoH also monitors health services in the private sector. The government of KSA is taking a leading role in driving an ambitious major health system transformation under the auspices of the Vision 2030 initiative (which is also aimed at transformation in non-health sectors). Every part of the system is being examined with the view to transformation, and there is a particular focus on noncommunicable diseases (NCDs). Given

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8 World Bank. World Development Indicators, 2016.
that the health system is pluralistic—with both private and public systems—a key challenge is trying to develop information systems that can capture data among all the providers and data systems that interact with one another, and then finding ways to combine data sets to examine what is happening in specific institutions as well as in the system as a whole.

2.1.3.1 Monitoring and evaluation
As part of the health system transformation program, KSA has plans to strengthen the current monitoring and evaluation system to improve data capture and transition to digital systems. Currently, there are different processes used for monitoring and evaluation in the system, with performance indicators that are not linked to outcomes. Among the existing plans to strengthen M&E include the newly established National Center for Health Information, which will function alongside National Cancer Center and National Center for Health Research under the umbrella of the Saudi Health Council.

2.1.3.2 Financing
According to 2014 data from the World Bank, total health expenditure in KSA is 4.7% of the GDP, of which 74.5% is financed from public sources and the remainder from private sources, including insurance and out-of-pocket expenditure. Private health insurance began in 2005 and represented only 15% of the total health expenditure in 2015. Private health care providers in KSA offer limited tertiary services, such as cancer care. As a result, much of the cancer care is provided by the public sector, both for patients from KSA but also for a number of patients who travel overseas for care that is funded by KSA.

2.1.3.3 Resource management
In relation to resource management, there are multiple providers of cancer care, but cancer networks have not yet been systematically established. The ongoing health transformation initiative offers an opportunity for using existing resources more efficiently and effectively, for example, by developing cancer networks to optimize care delivery among different providers, given evidence from other countries that networks are quite effective in delivering care.

2.1.3.4 Health service delivery: access
2.1.3.4.1 Screening
In relation to service delivery access, there is a national breast screening program that has been rolled out mainly in urban areas. Non-governmental organizations (NGOs) are involved in screening, but KSA’s National Breast Cancer Early Detection/Control Program (initiated in 2013) is currently the major provider of screening services. The program delivers patient-centered care with two-pronged approach: health care provider facilities and mobile clinics. Results are provided within ten days and women who are positively diagnosed are followed up within one month; however, there is not yet an integrated health information system in place. Services are now being provided in shopping malls to expand reach. Screening is a key area for improvement because 50%-60% of cases diagnosed via the screening program are advanced stages. The program needs to expand beyond urban areas to rural areas to ensure wider coverage and outreach programs are being tested to increase coverage. Additional challenges faced in screening include cultural barriers, lack of public awareness, stigma, and illiteracy among older women.

2.1.3.4.2 Treatment
Regarding treatment, KSA has very good institutions, including centers of excellence, and care is provided per up-to-date guidelines and treatment protocols. However, there are opportunities for improvement, for example developing improved integrated care pathways to manage the entire care continuum from screening to diagnosis to treatment, as well as post-treatment, as

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9 World Bank. World Development Indicators 2014.
opposed to horizontal management. The primary health care system is not currently focused on breast cancer or other NCDs; there is lack of adherence to evidence-based guidelines, poor prescribing practices, and under-referring of cases. Cancer care is now provided mainly in the public sector, but the quality varies geographically.

Experts advised that: 1) the primary health care system needs to be strengthened to promote earlier diagnosis of cancer and improve management after patients are discharged from centers of excellence following treatment as managing patients in an institutional setting, rather than primary care, is both cumbersome and difficult for patients; 2) the opportunity to use data systems to benchmark and ensure that everyone is providing care to the optimal level should be utilized; and 3) improved pathways for patients to transition from screening to diagnosis to treatment to post-treatment discharge, which could be enhanced by a strengthened referral system and putting cancer care networks in place, are necessary.

Data on out-of-pocket expenditures for breast cancer treatment is not available, but anecdotally, patients receiving care in the private sector have had to make out-of-pocket payments due to the lack of a comprehensive insurance system. This can be an impoverishing expenditure because when someone starts expensive treatment, it cannot simply be interrupted. One of the considerations in relation to the health system transformation program is to think through how the insurance model can be developed to purchase services from both the public and private sector to ensure that individuals are not exposed to surprising out-of-pocket expenditures. This is an opportunity that requires collecting data to understand the extent of expenditure for cancer and for treatment.

Another issue is that treatment facilities need to be more accessible because many women in KSA must travel to seek care in centers of excellence. There is an opportunity to develop cancer care networks that are more accessible. An important facility-related development was a 2013 Cabinet of Ministers Decree that mandated accreditation of all facilities by the Saudi Central Board for Accreditation of Healthcare Institutions, which oversees quality of care for all providers, including breast cancer services.

2.1.4 National cancer planning

Work is ongoing to implement the national strategy on cancer that has been developed in KSA, according to experts. The strategy focuses on outreach for breast cancer screening (given that low current usage of services due to lack of awareness) and is premised on the need to balance demand-side and supply-side factors. It targets current access challenges and is seeking to gradually expand to strengthen tertiary care development, in order to ensure promotion of screening coupled with access to treatment. This needs to be augmented by focusing on the integrated care pathways and the development of networks.

2.1.5 National cancer registry

The Saudi Cancer Registry (SCR) was established in 1992 at King Faisal Specialist Hospital under the authority of the MoH and then transferred to the Department of National Registries at Saudi Health Council in 2014. It has five regional branches in the country that provide data to the central registry, with rigorous systems for data collection, coding, and analysis as well as a strong quality assurance protocol in accordance with WHO and Surveillance, Epidemiology, and End Results (SEER) guidelines. The Council published annual reports on cancer data in KSA. The SCR generates crude and age-standardized incidence rates for cancers in the Kingdom by sex, age group, geographic region, and nationally, and the SCR is playing a leadership role in developing a Gulf Cooperation Council (GCC)-wide registry with regional comparisons.
2.1.6 Projections of future cancer burden

Experts reported that the estimated number of breast cancer deaths in KSA is predicted to double by 2030 compared to 2015, and will then continue to increase (see Figure 27). The estimate (as well as those for other countries analyzed in the project) takes into account changes in age structure, but not other changes such as levels of obesity and diabetes, both of which are contributors to rising breast cancer incidence. The numbers will likely be far larger than currently being projected, so it is very important to model the additional contributions of changing risk factors for breast cancer. For example, a meta-analysis of other countries outside the region indicates that the risk of developing breast cancer increases among women who are overweight and/or have diabetes. Understanding the implications of the changing disease burden in the region is an important area for future research, he noted, to allow for projections that go beyond changes in demographic structure.

Figure 6. Projected estimates for the number of breast cancer deaths in the Kingdom of Saudi Arabia

![Projected estimates for the number of breast cancer deaths in the Kingdom of Saudi Arabia](source: Study presentation10)

2.1.7 Policy implications

KSA’s major health system transformation—in which cancer is a priority area—offers an excellent opportunity to inform policies related to cancer. Experts emphasized that cancer should not be treated as a separate program in these broader health system reforms.

2.2 BREAST CANCER IN THE HASHEMITE KINGDOM OF JORDAN

2.2.1 Demographic trends and epidemiological trends

Jordan has a similar pattern in terms of demographic change as seen in KSA. The population is growing rapidly (see Figure 28).
and by 2100, it is predicted that the proportion of the population over the age of 50 will be greater than the younger population (see Figure 29). The epidemiological trends in Jordan are also similar to KSA in terms of DALY causes per 100,000 population (see Figure 210).

Figure 7. Population projections by age group for Jordan (1980-2050)

Source: Study presentation

Figure 8. Population pyramid for Jordan (1980-2050)

Source: Study presentation

11 Data source: United Nations Department of Economic and Social Affairs 2017
12 Data source: United Nations Department of Economic and Social Affairs 2017
2.2.2 Health system performance

2.2.2.1 Health outcomes: cancer burden

In terms of health system performance with respect to cancer health outcomes, breast cancer was the most commonly reported cancer among women in 2014. Breast cancer represented 39.4% of all reported cases in women, followed by colorectal (9.6%), thyroid (5.8%), corpus uteri (5.4%), and non-Hodgkin lymphoma (4.1%). This rate is higher compared to KSA, which underscores the need to better understand the risk factors that contribute to variation among countries in the region as part of the research agenda moving forward. The age-standardized incidence rate of all cancers in Jordan is relatively high compared with other Eastern Mediterranean countries (see Figure 211).
In terms of breast cancer health outcomes, the trends for breast cancer among women in Jordan reveal a pattern of increase similar to that in KSA. The average annual ASR among women in Jordan is on the rise (see Figure 212) and the age-specific incidence rate of breast cancer among women in Jordan is relatively high compared with other types of cancers (see Figure 212). According to CONCORD-2 data, the five-year net survival for breast cancer in Jordan is lower than KSA (see Five-year net survival (%) for breast cancer: Jordan and comparable countries (1995-2009)). Meeting participants noted the potential inaccuracy of this data, and indicated that this may need to be reviewed.

Figure 10. Age-standardized incidence rate of all cancers in select Eastern Mediterranean countries by gender (2012)

Source: Study presentation

Figure 11. Average annual age-standardized incidence rate* trend for breast cancer among women in Jordan (2000-2012)

*Per 100,000 population
Source: Study presentation

16 Jordan Cancer Registry Report 2012
Figure 12. Age-specific incidence rates of most common cancers among females in Jordan (2012)

Source: Study presentation

Figure 13. Five-year net survival (%) for breast cancer: Jordan and comparable countries (1995-2009)

Notes: KSA: 1995-2004 data only; Jordan data: 2000-2009 only
Source: Study presentation

17 Jordan Cancer Registry Report 2012
18 Data source: Allemani et al Lancet 2015
Jordan has demonstrated a high level of commitment in the fight against cancer, but main areas for improvement are: service management and suitable distribution of services. More resources are needed and the MoH should develop a national cancer control plan due to the urgent need for national coordination of strategies for early detection and for workforce and infrastructure development.

While the government, private medical services, and all other sectors are trying to provide the best possible services, experts warned that the breast cancer burden is increasing among Jordan’s population of around nine million. This is attributed in part to the three million non-nationals who have come to the country in the past five years, placing a large burden on the system and its limited resources in a very short amount of time. Around 80% of the total cases are in Jordan’s three main cities: the central capital city of Amman (58% of cases) as well as the northern city of Irbid (12%) and Zarqa (11%). Most of the services—hospitals, laboratories and all the facilities for diagnosis and treatment—are almost entirely located in those three cities. The rest of the breast cancer cases (around 20%) are distributed through the rest of the country’s other ten governances, where the services are generally very minimal beyond basic diagnosis or referral services, in some instances. Patients who live outside those three cities must travel to Amman or Irbid for diagnosis and treatment.

2.2.2.2 Financial protection
Jordan does relatively well compared with other middle- or upper-middle-income countries with respect to out-of-pocket expenditures (20.9% of total health expenditure) and risk of catastrophic expenditure (23.4% of people at risk), using surgical care as a proxy (see Financial protection indicators: Jordan and comparable countries (2014)). In Jordan, the right to health is constitutionally entitled, but there is no universal health care. The Royal Court provide basic services to uninsured and the MoH covers all citizens >60 years of age. King Hussain Cancer Center (KHCC) provides free cancer treatment to all advanced-stage patients and citizens can apply to Royal Court or Prime Ministry for treatment. An estimated 44% of the population is covered by civil health insurance (including civil servants, dependents, children under the age of six, and individuals classified as poor). Around 27% of the population is covered by medical services military insurance, 1.3% by university hospital insurance, 6.9% by private insurance, and 6.8% by the United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA).
Jordanians with a national identification number are treated at the expense of the government, but only after being diagnosed. Patients who are not insured must pay out of pocket for costly diagnostic tests, which many people cannot afford. People without national identification numbers may not be able to afford treatment.

### 2.2.2.3 User satisfaction

Most cases of breast cancer are dealt with through the Jordan breast cancer program (established around 10 years ago) that provides accreditation to other facilities, facilitates training of doctors, nurses, and technicians, and works to promote early diagnosis and treatment. User satisfaction with cancer services is relatively high in the central area around Amman, but not in remote areas where facilities are lacking. There is no ongoing research in this area (due to lack of resources), but experts suggested that the Harvard Research Study has provided a potential opportunity to drive improvement.

#### 2.2.3 Breast cancer care by health system function

##### 2.2.3.1 Stewardship

##### 2.2.3.1.1 Governance

Jordan’s Higher Health Council governs the health sector and the national strategy for the health sector in Jordan (2015-2019) affirms its commitment to the strategic goal of achieving UHC. The strategy includes a focus on quality care across the life course; NCD control is one of the four main objectives. The MoH houses the National Cancer Registry and National End Stage Renal Disease Registry, as well as the Noncommunicable Diseases Directorate (one of multiple directorates). There are ongoing efforts to make accreditation mandatory with a focus on creating centers of excellence.
However, clinical and implementation science research are lagging and not well integrated. Challenges related to governance involve both management (e.g., lack of political will) and financing. The MoH budget does not specifically allocate money to cancer, among other financing burdens on the MoH.

2.2.3.1.2 Monitoring and evaluation
According to experts, the Quality Assurance Directorate at the MoH conducts tracking activities related to monitoring and evaluation, but quality improvement efforts are not yet institutionalized. Information systems in Jordan are good but need improvement; new technology could facilitate improved monitoring and evaluation. A system was recently set up to electronically aggregate information from remote areas to a center in Amman.

2.2.3.2 Financing
Per World Bank 2014 data, total health expenditure in Jordan is around 7.5% of its GDP. There is no specific tax scheme to finance public health services with the exception of a taxation on tobacco to treat cancer patients at KHCC. The two major insurers are the MoH and Royal Medical Services, which are financed by general tax revenue as well as premium contributions and user fees. Budget allocations approved by Jordanian Parliament, he added, and UNRWA services are funded by international donors.

Financing breast cancer care is an ongoing challenge as there is a shortfall for financing cancer as a whole. Ongoing strategies include the introduction of higher taxation on alcohol and cigarettes, but experts argued that raising taxes cannot be the only solution.

2.2.3.3 Resource management
In terms of resource management, the shortage of health professionals is the greatest challenge for public healthcare service delivery in Jordan. Further, a lack of incentives (i.e., low salaries) has created problems with provider retention, as many seek opportunities overseas. However, Jordan serves as a location for medical tourism, which generates higher demands on the system and creates competition for Jordanians seeking private health care services.

A key challenge facing human resources and infrastructure is the inequity infrastructure country-wide: some areas have five-star infrastructure while others have none at all. Inflexible legislation poses further challenges to resource management that need to be addressed at a policy level. For example, healthcare providers are disincentivized from pursuing further training and education because their salaries would be cut and they would not be supported by the system.

2.2.3.4 Service delivery – access
2.2.3.4.1 Organization of care
KHCC is a regional center of excellence certified by Joint International Commission for oncology program. Other public-sector facilities include the MoH’s Al-Bashir Hospital, the Royal Medical Services (Queen Alia’s Center), University Medical Centers (Jordan University Hospital and King Abdullah Hospital), and Centers for Diabetes and Endocrinology and Genetics. There are also numerous private-sector facilities, including Al Alfieah Center.

The status of integrated care pathways is poor due to the large number of providers, poor communication between the public and private sectors, lack of organizational structure, and pervasive inequities. Experts suggested that treatment guidelines and protocols should be unified and adopted by all providers, noting that the MoH recently required that the KHCC protocols be used in the MoH facilities and hospitals. This also has implications for access care and management of NCSs; although Jordan has launched an NCD national strategy, its implementation has been very minimal.

2.2.3.4.2 Screening
In terms of screening, the only national cancer-specific screening program for breast cancer is the Jordan Breast Cancer Program.
(JBCP), which was established under the directive of the MoH and is governed by National Steering Committee with diverse stakeholders, while being led and supported by KHCC. In 2007, a national situational analysis in 2007 identified four main gaps:

- Low human resource capacity, including trained female technicians and specialized radiologists in mammography
- Inaccessibility and variability of mammography services across the Kingdom, quantity- and quality-wise
- Absence of guidelines and protocols for screening and diagnosing breast cancer
- Limited public awareness and ongoing misconceptions about breast cancer

Because of the analysis, focus shifted from full implementation of universal access to mammography for women aged >40 years to early detection and downstaging of breast cancer. The JBCP’s activities targets include increasing availability of accessibility of screening services (e.g., two mobile mammography units have been acquired and units have been upgraded and newly built), building the capacity of multidisciplinary healthcare providers on mammogram interpretation, quality management, and positioning, and communicating to drive social behavior change.

2.2.3.4.3 Treatment

It is important to centralize services to improve quality of care, increase volume capacity, and improve outcomes. Currently, KHCC serves as the country’s only comprehensive cancer center, caring for two-thirds of breast cancer cases. Al-Bashir is largest government hospital, providing cancer treatment with radiotherapy and chemotherapy departments. King Abdullah is the largest government hospital in north, which is currently under construction and plans to provide radiotherapy services. Ongoing challenges include reaching patients outside of the capital and in remote areas and the disproportionate distribution of health professionals across facilities.

2.2.3.4.4 Palliative care services

Jordan does well in terms of palliative care. Hospice care was first provided by Al Malath Foundation in 1992 and initiated by KHCC as a demonstration project (along with WHO) to emerge as a regional model providing services and certified training. Palliative care is also offered at KHCC, Al-Bashir Hospital, King Abdullah Hospital, and some private facilities. While there is no national palliative care strategy currently in place, several initiatives are underway. The MoH and KHCC established Jordan’s National Pain and Palliative Care Initiative Committee in 2003 to work toward a national palliative care program; the Jordan Palliative Care and Pain Society was founded in 2010 to promote advocacy, education and training; and national palliative care guidelines are being developed. As a result of these initiatives, opioid access has been expanded in the country.

2.2.3.4.5 User engagement

Activities have been carried out in Jordan to increase patients’ and caregivers’ levels of education, awareness, and engagement around breast cancer. Strategies have involved workshops, media campaigns, pamphlets, and educational materials, pitched at both professional and patient levels. Experts suggested that new technology should be utilized in more advanced ways to communicate the necessary messages and obtain the desired outcomes, for patients and the public.

2.2.4 National cancer planning

The National Strategy for Health includes the goal to implement a 3-to-5-year national cancer plan, drafted in coordination with National Cancer Control Committee and currently under review. Additional research being conducted to generate an evidence-based national cancer control plan and the adoption of a national cancer strategy would
be critical step in improving cancer care across the care continuum in Jordan.

2.2.5 National cancer registry

The Jordan Cancer Registry (JCR) is a national population-based registry established in 1996 and housed as a unit of the Cancer Prevention Department, NCD Directorate. Data is collected on cancer incidence and mortality across Jordanian health institutes for citizens and non-citizens, with a combination of active methods (e.g., registry personnel visiting different sources) and passive methods (e.g., submission to registry) employed for case finding and data collection. Quality control measures in place for ongoing validation and CanReg™ (International Agency for Research on Cancer [IARC] registration software) is used to process data. In 2005, a ministerial declaration made cancer reporting mandatory and data collection improvements were made to include the type of treatment provided and mortality data (collected by the Directorate of Information and Research and the MoH). Survival data is expected to be included in the forthcoming JCR report.

2.2.6 Projections of future cancer burden

The number of breast cancer deaths in Jordan is expected to nearly double between 2020 and 2035, in a trend that is similar to that projected for KSA (see Figure 217. Projected estimates for the number of breast cancer deaths in Jordan).

Figure 15. Figure 217. Projected estimates for the number of breast cancer deaths in Jordan

Source: Study presentation

2.2.7 Policy implications

The policy implications for Jordan are also similar to those for KSA. Experts concluded that the main challenges facing the healthcare sector in Jordan are:

- Inequity in standards of care provided
- Duplication of services and poor coordination among major providers
- Unregulated private sector
- Low utilization rates in the private sector
- Limited quality improvement programs
- Inefficient use of available resources

• Poor management and inappropriate health information systems
• Management and financing

2.3 BREAST CANCER IN THE UNITED ARAB EMIRATES

2.3.1 Demographic and epidemiological trends
The demographic trends and transitions taking place in the United Arab Emirates (UAE) are quite remarkable, particularly with respect to the speed of the transition which has been driven in large part by the influx of expatriate workers (see Population projections for the United Arab Emirates by age group (1980-2050) and Population pyramid for the United Arab Emirates (1980-2050)).

The projected population pyramid does not have a stable structure—i.e., a sufficient population base of younger people at the bottom of the pyramid—which has major implications for the health system.

The percentage of the population aged 60 or older is projected to increase from 5% to 20% by 2050. The speed of this demographic transition has far exceeded the trajectory at which a health system can be expected to develop. By the time health policies can be developed and implemented to adjust to the new demographic structure, health systems become misaligned.

Figure 16. Population projections for the United Arab Emirates by age group (1980-2050)

Rank of DALY causes per 100,000 population in the United Arab Emirates illustrates the epidemiological trends in the UAE, which enumerates the most common causes of DALYs per 100,000 population in 1990 versus 2016. As with Jordan and KSA, the most common causes have shifted toward noncommunicable diseases and injuries.

Source: Study presentation

21 Data source: United Nations Department of Economic and Social Affairs 2017
Figure 17. Population pyramid for the United Arab Emirates (1980-2050)

Source: Study presentation

Figure 18. Rank of DALY causes per 100,000 population in the United Arab Emirates

Source: Study presentation

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22 Data source: United Nations Department of Economic and Social Affairs 2017
23 Data source: Institute for Health Metrics and Evaluation (IHME), Global Burden of Disease Data 2016
2.3.2 Health system performance

2.3.2.1 Health outcomes: cancer burden

New demands are being placed on the healthcare system in the UAE due to the growing burden of noncommunicable diseases, with cardiovascular diseases, cancer, chronic obstructive pulmonary diseases, and diabetes being the most common NCDs in the UAE.

Breast cancer is also the most commonly reported cancer among women in the UAE, representing 38.86% of reported female cancers (followed by thyroid [11.93%], colorectal [7.55%], uterus [5.41%], and ovary [3.98%]). Compared with other selected Eastern Mediterranean countries, the age-standardized incidence rates of all cancers in 2012 were lower in the UAE than in Jordan for both males and females, but higher among females in the UAE compared to females in KSA.

In the UAE, breast cancer rates are similar to Jordan. In 2014, breast cancer had the highest age-specific incidence of the most common cancers, peaking at more than 18% of new cases per 100,000 population around the age of 50 years (see Age-specific incidence of most common cancers in the United Arab Emirates (2014)). Per 2014 data on the stage distribution of breast cancer cases reported in the UAE, 26.4% were localized, 29.4% were regional, 10.1% were distant, 6.2% were in-situ, and 27.8% were unknown. Late presentation is a feature of the region, he added, which underscores the need to increase awareness and diagnose cases earlier, which helps to improve outcomes.

Figure 19. Age-specific incidence of most common cancers in the United Arab Emirates (2014)

Source: Study presentation

2.3.2.2 Financial protection

In the UAE, quality health care is mandated by Article 19 of constitution, with health insurance mandatory for citizens and residents and the cost of care covered by the government for citizens and by sponsors for
residents. Non-nationals can obtain health care from Dubai Health Authority (DHA), which launched the Basmah Initiative in 2017 to cover spectrum of care (screening to treatment) for three cancer types under the basic benefit plan of the Dubai Mandatory Health Insurance Scheme. A key challenge is that the complete spectrum of care is not fully covered by insurance companies and the basic insurance scheme for unskilled and lower-paid workers may not cover cancer treatment expenses, although they may be covered by charitable organizations.

Turning to the financial indicators regarding surgery, the UAE has relatively high out-of-pocket expenditures (17.8% of total health expenditure) for a country with such per capita high income levels (see Figure 224. Financial protection indicators: United Arab Emirates and comparable countries (2014)). Out-of-pocket expenditures are a very inefficient way of spending money, and it would be better to capture these expenditures up front as part of an insurance scheme, so they can be invested more effectively. The risk of catastrophic expenditures for surgical care in the UAE is also relatively high for a high-income country, with 9.5% of people at risk, as is the risk of impoverishing expenditures for surgical care (2.2% of people at risk).

Participants discussed the financial indicators and noted that the data probably captures nationals, not expatriates, and that the data comes from private-sector rather than public-sector facilities. It was suggested that better understanding expenditure patterns for cancer is an important research question, because the data are not available, and the number of cases is continuing to increase.

**Figure 20. Figure 224. Financial protection indicators: United Arab Emirates and comparable countries (2014)**

<table>
<thead>
<tr>
<th>INDICATORS (2014)</th>
<th>Jordan</th>
<th>Canada</th>
<th>United Kingdom</th>
<th>France</th>
<th>Germany</th>
<th>Turkey</th>
<th>United Arab Emirates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Out-of-pocket health expenditure (% of total health expenditure)</td>
<td>20.9</td>
<td>13.6</td>
<td>9.7</td>
<td>6.3</td>
<td>13.2</td>
<td>17.8</td>
<td>17.8</td>
</tr>
<tr>
<td>Risk of catastrophic expenditure for surgical care (% of people at risk)</td>
<td>23.4</td>
<td>2.7</td>
<td>0.9</td>
<td>0.5</td>
<td>0.3</td>
<td>4.9</td>
<td>9.5</td>
</tr>
<tr>
<td>Risk of impoverishing expenditure for surgical care (% of people at risk)</td>
<td>17.2</td>
<td>0.3</td>
<td>0.6</td>
<td>0.2</td>
<td>0</td>
<td>7.4</td>
<td>2.2</td>
</tr>
</tbody>
</table>

*Source: Study presentation27*

27 Data source: World Bank 2016
2.3.2.3 User satisfaction
In the UAE, the local health authorities conduct research on patient satisfaction. A survey of 38,000 patients in Abu Dhabi found that health services were rated 8.57/10, with 86% satisfied with outpatient care and 84% satisfied with emergency care. Reported areas for improvement included the registration process, the discharge process, and waiting times at pharmacies in public and private hospitals. The Ministry of Health and Prevention (MOHAP) also conducts various ongoing user satisfaction surveys. Customer satisfaction regarding breast cancer screening services at MOHAP primary healthcare centers increased from 45% in 2015 to 85% in 2016. Experts suggested that more surveys to measure customer satisfaction of early detection and treatment of breast cancer services should be carried out by all the healthcare entities.

2.3.3 Breast cancer care by health system function

2.3.3.1 Stewardship

2.3.3.1.1 Governance
In the UAE, the MOHAP is the federal health authority. Three local governments28 have set their own sub-healthcare systems but are mandated to report to the MOHAP. The UAE National Health Agenda is guided by the Vision 2021 National Agenda, which highlights the need to address NCDs including cancer; 5/10 indicators and targets for health are focused on NCDs and related risk factors. Key performance indicators are in place to reduce number of deaths from cancer per 100,000 population, coupled with commitments to provide UHC to all citizens and to promote preventive medicine. However, there is limited coordination with the private sector.

In terms of governance, the MOHAP’s responsibility is to achieve the national target of reducing number of deaths from cancer per 100,000 populations by 18% by the end of year 2021. This key performance indicator measures the deaths from malignant tumors per 100,000 population. The MOHAP launched executive and government accelerator taskforces to accelerate achievement of the national agenda Vision 2021 targets. The executive committee is multidisciplinary and includes members from all the stakeholders.29

Experts described a cancer initiative in UAE aimed at promoting awareness of early detection of breast cancer, implemented with multiple partners. This demonstrates an increase awareness and early detection as a result of the initiative.

2.3.3.1.2 Monitoring and evaluation
Monitoring is conducted by the MOHAP and each of sub-healthcare systems.

2.3.3.2 Financing
The total health expenditure in the UAE is 3.6% of its GDP, per 2014 World Bank data. The primary sources of healthcare funding in Abu Dhabi and Dubai are tax revenue and petroleum royalties, along with small contributions from debt collections revenue and capital revenue. Aggregate data on financing of UAE’s health system is limited, but improvements are needed in communication and coordination between entities. The UAE Cabinet approved a record Dh51.4 billion federal budget (excluding individual budgets for seven Emirates) for 2018 with a focus on education, healthcare, and community wellbeing and Dh4.5bn (7.4%) earmarked for the health sector.

2.3.3.3 Resource management
Better resource management is needed to expand the capacity and efficiency of healthcare professionals (e.g., through task shifting) in the UAE, suggested experts, as well as gathering publicly available data on health system capacity to ensure the alignment

28 Department of Health-Abu Dhabi (HAAD), Dubai Health Authority (DHA), and Sharjah Health Authority
29 Stakeholders include Dubai Health Authority, Health Authority Abu Dhabi, Ministry of Presidential Affairs / Healthcare Office, Ministry of Presidential Affairs/Sheikh Khalifa Specialty Hospital, the Federal Competitiveness and Statistics Authority, Sharjah Healthcare City, Al Tawam Hospital, Dubai Medical Healthcare City, the private hospital sector, and the Friends of Cancer Patients organization, colleges and universities, women’s associations, and industry partners.
of supply and demand for health services. Experts highlighted the need to measure the ratio of nurses and oncologists to the population, as well as the ratio of Emirati healthcare professionals to all healthcare professionals.

Experts suggested that the ratio of nurses and oncologists to the population needs to be better quantified, as well as the proportion of trained Emirati health professionals to all oncology doctors in UAE. Oncology services and resources need to be better distributed geographically to provide oncology facilities at the primary, secondary, and tertiary levels.

2.3.3.4 Service delivery: access

2.3.3.4.1 Organization of care

In the UAE, the public health system has a network of primary healthcare centers that includes specialty physicians, general physicians, and various cadres of health workers. There are 31 public and 43 private hospitals; SEHA, in Abu Dhabi, is the largest healthcare network operating with public hospitals and clinics. Other networks include: MOHAP for citizens in the Northern Emirates (patients are referred to Sheikh Khalifa for treatment of palliative care services); DHA for residents of Dubai; HAAD for residents of Abu Dhabi; Sheikh Khalifa Specialty Hospital for the Ministry of Presidential Affairs; and Sharjah Health Authority, through the University Hospital, for residents of Sharjah. The private sector and NGOs provide a large proportion of cancer care. Government hospitals, as well as some private hospitals, provide oncology services ranging from surgery, medical oncology, radiation, pathology, palliative care, rehabilitation, to advanced diagnostics.

2.3.3.4.2 Screening

The MoH operates breast cancer screening units and has implemented national guidelines for breast cancer screening and diagnosis; the screening protocol is currently being updated to align with international standards, including:

- Women aged <40 years: no screening
- Women aged 40-49 years: screening every year (subject to capacity building and data collection)
- Women aged 50-69 years: screening every 2 years
- Mandatory control of data (incidence, interval cancer rate, size of tumors, DCIS, and axillary node status)
- The only imaging modality should be mammography without clinical exam

Primary care centers serve as the main point of service for screening with referrals made to secondary and tertiary health centers with oncology care. In 2014, the MOHAP issued National Guidelines for Breast Cancer Screening and Diagnosis (which are currently being upgraded) that were adopted by all the Emirates. They provide comprehensive and systematic guidance for adequate and consistent care, as well as recent updates on screening assessment, the definition of women at high risk of developing breast cancer, and protocols for surveillance of women at high risk. Women receive breast health awareness at primary health clinics. In 2017, an annual national campaign for early detection of breast and cervical cancer was established and rolled out in coordination with the National Program for Early Examination of Breast Cancer; it provides mobile mammogram services to better reach women in remote areas.

2.3.3.4.3 Treatment

Access to care and treatment options vary by geography and healthcare authority. The treatment of breast cancer is designed to follow the National Comprehensive Cancer Network (NCCN) Guidelines. HAAD and DHA have highest number of centers and oncologists, while Tawam Hospital provides the majority of oncology care in Abu Dhabi (however, it has high staff turnover driven by lack of job security and low monetary compensation for salaries). Experts called for more facilities in the Northern Emirates.
and for more investment into radiation treatment in the UAE. Experts highlighted the challenge of adhering to the unified practice guidelines for cancer management set forth by healthcare entities and the international accreditation of healthcare facilities providing oncology services.

2.3.3.4 Palliative care services

In the UAE, varying levels of palliative care are available across public and private facilities. Community-level palliative care has not yet been developed and will be needed to address rising burden of chronic diseases. However, the MOHAP is developing a national palliative care strategy to include guidelines for unified and comprehensive care for cancer patients requiring palliative care services, and some providers have received training in palliative care in Jordan at KHCC.

2.3.4 National cancer planning

The MOHAP is developing a national cancer plan that is linked to the National Agenda, the existing National Guidelines for Breast Cancer Screening and Diagnosis, and the national breast cancer screening program. HAAD has its own cancer control plan. The Vision 2021 target is to reduce cancer mortality from 99 deaths per 100,000 in 2012 to 64.2 deaths per 100,000 by 2021 (a 35% reduction).

2.3.5 National cancer registry

The UAE National Cancer Registry is a population-based cancer registry for the seven Emirates established under the jurisdiction of the MOHAP. It is managed under the auspices of the Statistics and Research Center, with a certified tumor registrar for proper collection, management, and production of cancer registry statistics and annual cancer registry report. The registry receives data from the Abu Dhabi Central Cancer Registry and the Dubai Health Authority Cancer Registry; the cancer registry at Tawam Hospital is responsible for cancer data collection from healthcare facilities under SEHA and submits the data to Abu Dhabi central cancer registry. The UAE National Cancer Registry collects information about cancer patients who are diagnosed and/or treated across all healthcare providers in the country to analyze cancer patterns and trends over time, as well as monitoring cancer incidence and cancer mortality in the country.

2.3.6 Projections of future cancer burden

Like other countries in the region, the number of breast cancer deaths is projected to increase substantially in the next 20 years. The number is expected to nearly double between 2020 and 2035 (see Projected estimates for the number of breast cancer deaths in the United Arab Emirates).
2.3.7 Policy implications

Experts suggested that the UAE has multiple opportunities within its fairly comprehensive system of multiple providers to develop a research agenda to strengthen cancer care. Analysis of financing patterns and trends should ensure that funds are allocated efficiently and effectively, but investments should be balanced across the care continuum—not only in hospitals but also in screening and post-hospital discharge. Further, considering how to ensure the right kind of human resources now and in the future, including the development of multidisciplinary teams will be a necessary task.

2.4 ANALYSIS OF KINGDOM OF SAUDI ARABIA, HASHEMITE KINGDOM OF JORDAN, AND UNITED ARAB EMIRATES

A major challenge going forward (one of many) is the lack of data. In Jordan, Saudi Arabia, and the UAE, there are problems with applying the data that is collected. In countries with limited resources, it needs to be understood and established whether the outcomes of very expensive medications (e.g. immunotherapies) are acceptable. In Jordan, outcome data is only collected at the KHCC, which represents only two-thirds of the breast cancer. Collecting data on the whole country may or may not allow them to achieve what has been done in the West—i.e., a 5-year survival of around 97%—without sufficient resources to subsidize immunotherapies and targeted therapies. The best way of collecting data needs to be identified: at a national level in a governmental agency, or through a targeted center of excellence in each country to make sure the data being captured in various centers actually represents the whole country. Collected data along the care continuum is a common problem among the countries studied. There are pockets of data with limited information in relation to the care continuum. Experts highlighted the importance of measuring outcomes—understanding survival as a starting point and

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then questioning why we are observing what we are.

The lack of logistics and data as a key concern for cancer. UAE government’s national strategy to reduce the number of deaths from cancer by 2020 starts with initiatives for cancer screening, detection, and treatment through collaboration among public and private sectors as well as the pharmaceutical and insurance sectors. The model recently created in Dubai has an insurance mandate for screening as well as coverage for patients from screening to treatment for three types of cancer (including breast cancer). A basic benefit plan is applied to cover people who cannot afford treatment (i.e., who have an income of less than $1100 per month). Around 2.2 million people in the UAE are covered by this health insurance system by the sponsors who are paying for them. However, to cover them completely without charge is a real challenge, but they have created a model that will cover will cover people from screening to treatment for a marginal increase in premiums. They are working to maintain case detection and improve the system of referral from private facilities to centers of excellence. This model has been an achievement for the government of the Dubai and the National Cancer Committee is planning to apply the model to all the Emirates.

The UAE is proactively following all data related to the problem, from detection onward. Screening and monitoring will be carried out for women age 40 and above. Their eClaim system covers all the data related to health insurance claims, so they will have data related to each patient in Dubai—that is, how many patients are seen and how many are screened by age group as a process of care. They will also have data on the outcome of care: how many patients are followed up, their compliance, and so forth, which can feed into the registry. Participants were in agreement that if done appropriately, this would be an incredible resource; it also has the advantage of shifting the burden away from the providers by using the eClaim system. However, the discussion emphasized that this cannot be done with the public sector alone; the private sector needs to be integrated. People with access to private-sector screening will be covered by insurance then referred to a center of excellence. When the model is expanded, there are also three other premises in Dubai that meet established criteria and will be linked to the center of excellence and imaging will be covered.

There are well-established national registries in Saudi Arabia and in many GCC countries, but the quality of the data needs to be examined and challenged, if necessary. Two indicators to measure the effectiveness of registries are incidence rate and survival. Incidence rates have trended upward for that past two decades in the region, but survival data from the region is difficult to find, indicating that that there are major components in the cancer registry that need to be improved. Regarding access to care, it was noted that good quality of care is available only in the large cities. Given that more than 50% of patients present with advanced disease, it was surmised that access to care is not adequate country-wide. Experts suggested that the increase in incidence may be a result of the population’s lack of education on the signs and risk factors for cancer, which highlights the need to increase cancer awareness. Regarding the quality of data on survival, the problem of different patients using the same ID to get free access to care was highlighted.

Participants identified the following key points. The first was the importance of both data collection and analytics to better understand the incidence rates going forward; there are opportunities for modeling studies in the region. The second was the need to raise awareness about cancer to help promote earlier presentation. Thirdly, late presentation could also be addressed by expanding and enhancing the screening programs. Fourth, developing networks is critical; establishing centers of excellence is very important, but they need to be linked to patients outside of major urban areas where those centers are located. Finally, the focus should be placed not
only on the quality of data, but on consistent quality of care.

The region’s level of preparedness for the cancer epidemic that is imminent over the next 20 years or so, given that the population is aging and the risk factors are worsening, was of concern to participants. Further, diagnosis at advanced stages is common. The region will not be prepared in terms of personnel and facilities. The transitions are happening rapidly in countries in the region, but health systems are on a trajectory based on the European models that took 100-150 years (or even longer) to develop. The systems are not ready in spite of the existing good will and relevant policies. The impact of advanced-stage diagnosis as not only a human cost—because those patients do not respond to treatment as effectively as patients who present early—but also a financial cost. The cost of treatment and management for advanced-stage patients is much greater than for early-detected cancers and the outcomes are poor.

Hospice and palliative care programs will be needed to take care of advanced-stage patients, as will survivorships. Many people will survive, who need to be properly monitored and supported going forward. The number of survivors will increase in the region as more effective treatments become available, so planning should include not only 5-year survival, but 10-year survival and beyond.

Participants expressed that primary health care workers and the gatekeepers have to be aware of screening for early detection, given the cost difference between early-detected cases and finding cases late. This facet of professional development is included in the Dubai model through a partnership for early detection. They are training almost every gatekeeper in Dubai about the three types of cancer being screened in the model. This can be viewed as focusing not only on the supply-side measures—which is the focus of most health systems—but also on the demand side, in raising awareness and in actively engaging the population and civil societies.

Further, participants agreed that raising awareness on the difference between incidence and prevalence would help clinicians understand the actual load of patients and the trends in the same aliquots of time.

2.5 COMPARISON OF BREAST CANCER IN OMAN AND KUWAIT

2.5.1 Burden, incidence, and mortality

Oman and Kuwait are two of the smaller countries in the GCC region, which makes breast cancer—and all cancers and diseases in these countries—more manageable. Oman’s registry goes back more than 20 years, with the two most recent years being 2013 and 2014. In Oman, the breast cancer burden has likely increased a small amount since 2014. Kuwait’s registry data disaggregates Kuwaitis and non-Kuwaitis. The age-standardized incidence rates were slightly higher for Kuwaiti women than for non-Kuwaitis.

Contrary to the assumption that the countries in the region were trending in similar ways with respect to the percentage of cases under the age of 40 and the median age for breast cancer, there was variation in the two countries along both indicators. In Oman, the percentage under 40 was 25% in 2013 and then increased to 45% in 2014. The median age of incidence was 49 years in Oman, 49 years for non-Kuwaitis, and 54 years for Kuwaitis. These numbers are much lower than the global levels, which is around 62 years. The potential additional number of incident cases was calculated based on increases in population sizes. In Oman, the number of incident cases is predicted to increase 3.2x by 2035. In Kuwait, the number of potential incident cases is projected to increase 3.5x by 2035.

The female age-standardized breast cancer incidence rate (2011-2013) was 22 in Oman and 59 in Kuwait. Oman’s longitudinal data on breast cancer enabled them to analyze the
age-standardized rates for all ages in Oman over the period from 1996 onward. Between 1998 and 2013, the ASR for all ages increased by 88%. This is a stark contrast to the rates over the same time period in other countries, for example, where the ASR are higher, but the percentage increases were much lower (over even negative) during that time (UK: 28%; France: 8%; Germany).

The breast cancer age-specific incidence (per 100,000 population) in Oman, Kuwait, and the United States were reviewed to examine the age profile for breast cancer within those different populations. The age range in Kuwait is a bit higher than in Oman, and the overall trend in Kuwait is more similar to the US than Oman is: that is, toward younger incident cases (see Breast cancer age-specific incidence (per 100,000 population), Oman and Kuwait). In Oman, the percentage of breast cancer incidence among women under the age of 40 is trending upward, from around 21% in 1998 to more than 45% in 2014.31

**Figure 22. Breast cancer age-specific incidence (per 100,000 population), Oman and Kuwait**

![Graph showing breast cancer age-specific incidence](image)

**Source:** Local Registries

**NOTES:** Median ages: 49 years (Oman), 54 years (Kuwaiti); younger than the global norm (median age 62)

**Source:** Study presentation32

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31. Data source: Oman Cancer Registry
32. Data source: local registries
In 2012, the breast cancer age-standardized mortality rate in Oman was 9.5\textsuperscript{33} and in Kuwait was 17.3\textsuperscript{34}. Breast cancer incidence and mortality projections, Oman and Breast cancer incidence and mortality projections, Kuwait illustrate the incidence and mortality estimates for breast cancer in Oman and Kuwait, respectively, which predict large increases (up to three-fold) in mortality and incidence by 2035.

Figure 23. Breast cancer incidence and mortality projections, Oman

![Projected estimates for incidence and deaths for breast cancer, Oman](image)

Source: Study presentation\textsuperscript{35}


2.5.2 Screening

Screening can vary across the region—and there is not necessarily one “right” way to screen. For context, screening rates in Oman and Kuwait can be compared to five other countries as follows (see Figure 23. Screening rate in seven countries (2004-2014)).

Source: Study presentation\textsuperscript{36}

Figure 25. Screening rate in seven countries (2004-2014)

2.5.2.1 Oman screening program
The MoH in Oman piloted a regional early detection program in 2009 in two governorates (North Sharqia and Dahirah); it has now expanded to six out of 11 governorates. The screening program is based on clinical breast exams annually for Omani women between 40-59 years old, with mammograms for high-risk women or those with abnormal clinical exams. In four of six governorates, the screening rate (clinical breast exam [CBE]) for the target population varies between 21%-78%. Once a woman is initially screened as a potential case, she is referred immediately to the surgeon for a triple assessment that includes a more rigorous clinical breast exam, a mammogram, and a biopsy. Oman also has a mobile unit operated by the Oman Cancer Association (NGO). They provide mammograms in their mobile unit, as well as health education and screening services (11,502 mammograms done between 2010-2014). Within the MoH CBE program in four governorates, 50% of the target population receive CBE screening, 6% of those are referred to surgeons, and 1% of those are diagnosed malignant. Within the Oman Cancer Association (OCA) mammogram program in all governorates, 9% of the target population receives mammography screening, 10% of those are referred to surgeons, and 4% of those are diagnosed malignant.39

Source: Study presentation37,38

39 Data source: Early Detection & Screening program, Oman
2.5.2.2 Kuwait screening program
Kuwait piloted its national mammography screening program for Kuwaitis in 2014, with clinics now running in all five Kuwaiti governorates. The program targets all asymptomatic Kuwaiti women over age 40 and has conducted about 6,933 mammograms (4% of their target). The program diagnosed 83 cases in first two years, with a malignancy rate (number malignant of number screened) of 1%. A positive screen receives expedited referral to facilities for additional imaging, tissue sampling and diagnosis. Within 2.5 years of their initial screen, 0.2% of women had returned for a re-screen.40

2.5.3 Cancer registries
2.5.3.1 Oman cancer registry
The Oman Cancer Registry is a population-based registry that has been in place since 1986, with the last report published for 2014. Data are collected actively via semiweekly visits to the Royal Hospital—one of the main hospitals providing care in Oman for cancer patients—and monthly to other tertiary hospitals. Data are collected passively through notification forms sent to the registry. Data is checked and validated using IARC software; incidence and prevalence is analyzed and published. Cancer mortality data are available, though it is unclear whether it is connected to the registry.

2.5.3.2 Kuwait cancer registry
The Kuwait cancer registry was also established long ago in 1971, with the last report published in 2013. Data are collected for both Kuwaiti and non-Kuwaiti citizens. The data sources are paper-based and come from the Kuwait Cancer Center and other hospital patient records, pathology reports, and MoH data. They receive paper-based reports from 12 facilities (8 public and four private). Data are checked and validated using IARC software.

2.5.4 Health system organization and service delivery for breast cancer
2.5.4.1 Oman health care organization: system level
Oman has a large public sector providing care for locals and expatriates in 14 MoH governorate hospitals, 35 secondary hospitals, 206 primary healthcare centers, and other public facilities (e.g., university, army, and police). The private sector is growing, now encompassing 19 hospitals. Universal health coverage is provided for all Omanis through the MoH or other public facilities; expatriates pay privately and have the option of employer-based, private insurance.

2.5.4.2 Oman breast cancer care pathways
Figure 26 illustrates the system for managing women with breast cancer in Oman. Most women stay within Royal Hospital for treatment, although some of them go abroad and may be reimbursed by the government for the services they receive for breast cancer care. All other Omani residents and expats can flow through the system in the same ways, although they may be charged a fee for services. The pathway through the Sultan Qaboos University Hospital (SQUH) system is mainly for government employees and families of those with a particular referral, but they also do their own screening; women can receive a triple assessment and also treatment through that particular system.

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40 Kuwait National Mammography Screening Program, 2016
Chapter 3

2.5.4.3 Kuwait health care organization/service delivery: breast cancer care

Like Oman’s, Kuwait’s healthcare system organization is also a large public sector providing care for locals and expatriates. Care is free almost everywhere, although more fees are being implemented for expatriates. The Kuwait Cancer Control Center (KCCC) is the only source of cancer treatment in the public sector. Women are referred to KCCC through the opportunistic screening program at six governorate primary health centers. The Rapid Diagnostic Breast Clinic at KCCC (implemented through a partnership with the Canadian government) provides a triple assessment: mammogram, CBE, and biopsy diagnosis within 3 days. The palliative care initiatives in Kuwait are notable: a number of NGOs (e.g., the Cancer Awareness Network and Al Sidra) are working on awareness, fundraising, palliative care, and psychological support for cancer patients.

2.5.4.4 Kuwait referral flow map

Figure 27 illustrates the pathway for Kuwaiti breast cancer patients. Kuwaitis over 40 years of age take part in the national screening program and then flow through the KCCC system for diagnosis, treatment and post-treatment care. All other residence and expatriates can do opportunistic screening—that is, self-present at any facility outside of the auspices of national screening program—and then flow through the system on their own. Many women chose to receive treatment overseas at their own expense after diagnosis in Kuwait.
2.5.5 Financing

Financing for breast cancer is one of the major gaps that has been identified in all the countries. Data is necessary to better understand expenditures on cancer care, understand an individual’s ability to pay for care, and understand any future costs for breast cancer care.

2.5.6 Policy implications

In terms of research, using registry data across regional countries to understand risk factors, link to diagnosis, and then link to outcomes was suggested by participants (for example, in Oman and Kuwait when they screen the women, they also collect risk factors). It is important to establish clear research questions around financing, for both current and projected costs.

Regional-level policies include awareness and primary prevention, training, and research.

Country-specific policies are important, she said, because there is variation across the region in how programs are carried out. Supporting and expanding screening programs can be done at the country-specific level and supporting and expanding registries can be done at the local level. Focusing on prevention efforts in low- and middle-income countries was recommended.

Guidance from the Breast Cancer Gynecological Immunology Conference (BGICC) Consensus Document on breast cancer, which was the output of a recent conference in Egypt, was recommended for use. This as an extremely important document for the region. It provides consensus guidelines on prevention of breast cancer from primary prevention to tertiary care, highlighting guidelines specifically for low- and middle-income countries as well as highlights for the region.

1.1 BREAST CANCER IN OMAN

2.5.7 Health system performance

2.5.7.1 Health outcomes: cancer burden

With respect to the cancer burden, the ASR in 2010 in Oman was 24.3, indicating an upward trend (see Figure 236. Breast cancer ASR for all ages in Oman (1996-2013)).

In terms of distribution, it was noted that breast cancer cases are diagnosed and reported in most regions in the country, but most of the oncology services (including the trained breast oncologist surgeons) are located in Muscat. This poses a barrier to many patients who must travel long distance for care and highlights the need to improve geographic equity in access to care.

2.5.7.2 Financial protection

Non-Omanis are the least protected financially for breast cancer services in the country. They have to pay out-of-pocket for diagnostic services and treatments, although there is some support from NGOs and charities. Omani nationals receive free treatment.

However, it will be difficult to pay for new innovative treatments for all Omani patients, as the cost of the targeted therapy for early and metastatic Her-2 positive as well as TNBG (5% of all patients) is expensive. Furthermore, it can take years for new treatments to become available for patients in Oman for regulatory and financial reasons.

A set of strategies to avoid catastrophic health expenditure for breast cancer have been outlined. The first is to invest in early detection and screening. The second is to collect local data on the total cost and outcomes. For example, given that targeted therapies receive regulatory approval in the West, their efficacy among the population in

Source: Expert presentation42

Figure 28. Figure 236. Breast cancer ASR for all ages in Oman (1996-2013)
Oman is unknown because there have been no studies on the outcomes of these expensive medications to understand if patients are actually benefiting from them. The third is to use health economic evaluation and health technology assessment using risk sharing agreements and multiple criteria decision analysis to evaluate new cancer medications. Finally, encouraging local and private-sector NGOs to contribute in the cost of cancer care (e.g., transport costs, treatment costs, and obtaining new technological equipment) until government policies are enacted to do so were recommended in the discussion.

2.5.7.3 User satisfaction
Oman’s National Oncology Center (NOC) carried out patient satisfaction surveys in 2010 and 2016, as well as a pharmacy patient satisfaction survey. The MoH also used a questionnaire for patient evaluation of health services in the Royal Hospital, including the oncology department.

2.5.8 Breast cancer care by health system function
2.5.8.1 Stewardship
2.5.8.1.1 Governance
An urgent need is a national strategy to control cancer rates, as well as the establishment of a comprehensive national cancer control program through the MoH. The MoH’s national plan must accommodate the increasing numbers of cancer patients beyond the major urban area around Muscat.

The NOC needs to be fully integrated with the inclusion of surgical oncology and palliative care as part of the NOC. The lack of surgical oncologists can have major implications on costs because in some cases, they have to give patients unnecessary and expensive chemotherapy due to incomplete surgery or lymph node dissection, which could have been avoided by proper surgical treatment.

The NOC should also ensure the availability of dedicated clinical psychologists and dietitians, as well as a dedicated research unit.

2.5.8.1.2 Monitoring and evaluation
In terms of monitoring and evaluation, participants recommended establishing a computerized integrative database to capture all important patient data from various health establishments, not just from the MoH. Patient data is not currently being captured from university hospitals, private hospitals, or armed forces hospitals, which is a reason why the reported mortality data are low. That is, all mortality data come from the MoH, but 25% of cancer cases are treated and the university hospitals: when mortality data from university hospitals are incorporated, the rate goes up by more than 9.8%. In addition to improving the collection of mortality and survival data, creating an information gathering system to collect data on cancer economics was suggested.

2.5.8.2 Financing
To address financing challenges, encouraging national investment in cancer care through civil centers and civil societies was suggested. For example, a current program called “Bridging the Gap” addresses the lack of hospices and palliative care in Oman by helping train family members to care for patients at home (which creates more beds in the hospitals). Encouraging the private sector to contribute in cancer care and implementing health economic strategies for negotiation and fair pricing with pharmaceutical companies was advised by the group.

2.5.8.3 Resource management
According to the international standard, one radiation oncologist is needed per 200-250 new cancer cases, and around one medical oncologist per 160-200 new cancer cases. By 2020, Oman will need 10 consultant radiation oncologists and 12 consultant medical oncologists; by year 2030, it will need 15 consultant radiation oncologists and 19 consultant medical oncologists to run the services.

A major challenge related to human resources for breast cancer care is to attract Omani physicians to specialize in medical and
radiation oncology. Other needs include establishing continuing education, training, and development programs for practicing professionals and increasing the number of academic programs for various disciplines related to cancer care. Most important is improving practice standards to enhance professional satisfaction, staff recruitment, and retention after people are trained.

2.5.8.4 Service delivery: access
In relation to access challenges within health service delivery, experts suggested working on long-term secondary oncology centers with the MoH. With the expected increase in the number of new cancer cases, there is a need to improve the satellite oncology centers, of which there are currently nine. A situation analysis was recently carried out aimed at improving these centers.

2.5.8.4.1 Disease management
In terms of disease management, the need for integrated care pathways was highlighted; while there are integrated care pathways in place for surgery, there are not pathways in place for medical or radiation oncology. Work on treatment guidelines and protocols is ongoing. They are in the process of publishing the third version of the management guidelines for breast cancer in Oman and the second edition of guidelines for early detection, screening, and management of breast cancer.

2.5.8.4.2 User engagement
Regarding the engagement component of service delivery, the levels of education and engagement among patients and caregivers is relevant. The wellness community is supported through event participation, for example, by providing speakers and resources and serving on the boards of local non-profit organization OCA to help provide professional guidance and direction. The oncology department partners with community organizations, such as the OCA, in supporting cancer patients. They have established a patient awareness group at the NOC and NOC staff are actively involved in community awareness programs for different cancers, through the media and through OCA.

2.5.9 Policy implications
The priority needs for improving breast cancer needs in Oman were summarized as:

- A national breast cancer screening program with separate budget for cancer screening and prevention
- Participation of other ministries and private sectors in cancer prevention and early detection activities
- Strategies to attract Omani doctors to specialize in medical oncology, radiation, and surgical oncology
- Establishing secondary cancer care centers

Starting a pilot study for breast cancer screening and cost-effectiveness was recommended, as well as increasing collaboration between MoH, NOC, and NGOs on improving cancer awareness. Further, support oncology satellite units with human resources and treatment supplies were recommended. Establishing fair pricing and fundraising should be priorities to cope with the many new innovations and medications for treating breast cancer in addition to escalating costs and inequities in access to care.

2.6 BREAST CANCER IN KUWAIT

2.6.1 Health system performance

2.6.1.1 Health outcomes: cancer burden
The major burdens that breast cancer places on the healthcare system in Kuwait: higher mortality compared to the rest of the world, aggressive biology, and more advanced disease at presentation (i.e., fewer diagnoses of early stage and stage 1 localized breast cancer). An overview of the distribution of breast cancer cases among Kuwaiti and

43 While it would be difficult to provide radiography in all centers, it was noted that it could be centralized in Muscat with secondary centers could providing machine-based treatment to save human resources.
non-Kuwaiti women, according to 2013 data, are as follows:

- Distribution of breast cancer cases according to age group among Kuwaitis: 20-29 years (3%); 30-39 years (9%); 40-49 years (26%); 50-59 years (27%); ≥60 years (35%).
- Distribution of breast cancer cases according to age group among non-Kuwaitis: 20-29 years (3%); 30-39 years (18%); 40-49 years (31%); 50-59 years (30%); ≥60 years (18%).
- Distribution of breast cancer cases according to the extent of disease among Kuwaitis: regional (35%), localized (19%); distant (8%); unknown (38%).
- Distribution of breast cancer cases according to the extent of disease among non-Kuwaitis: regional (41%); localized (20%); distant (8%); unknown (31%).

Almost twice as many non-Kuwaiti women were diagnosed when they were younger than 40 (21%) compared with Kuwaiti women (12%). This has important implications because screening is not generally recommended to patients in that age category, so new strategies will be needed to address this age group. A large proportion—more than one-third—of both Kuwaiti and non-Kuwaiti women were diagnosed with regional disease. The size of the “unknown” category is due to the large numbers of patients who apply for boarding and treatment in overseas countries before they get a tissue or stage diagnosis. They do not know much about those patients until they return with a recommendation for treatment (or are already being treated), which can take up to a year or more.

2.6.1.2 User satisfaction
With respect to the user satisfaction domain of health system performance, the level of user satisfaction is only anecdotal and has not been formally quantified; it is based on asking patients in the clinic if they were satisfied with the process.

2.6.2 Breast cancer care by health system function

2.6.2.1 Stewardship

2.6.2.1.1 Governance
In terms of the health system functions of stewardship and governance, financing is not the main problem in Kuwait, but the lack of breast cancer services provided. Implementing a parliament law and/or agenda for the management of breast cancer including research, screening, diagnosis, treatment, and overseas medical boarding. Given that all nationals and non-nationals in Kuwait have civil identification numbers that are linked to data including birthdates, implementing a program in which women are directly invited to take part in the national screening program when they reach the age of 40 years was suggested. However, it was noted that it would be very difficult to obtain that demographic data because the MoH and other ministries tend to be siloed in relation to data. Human resources are another issue. Breast cancer services are generally understaffed; for example, the screening program does not have enough radiologists to read the images.

2.6.2.1.2 Monitoring and evaluation
In terms of monitoring and evaluation, the need for a unified and centralized system to strengthen the breast cancer information system was suggested. Kuwait is unique in the region in that it has a centralized cancer control center (KCCC). However, the center is not connected to the five major private hospitals. In addition to impacting the monitoring and evaluation system, this lack of integration leads to other issues with coordination. For example, when women are referred to one of the private hospitals, the KCCC does not have access to information about the patient’s pathology, radiology, or other results. In many cases patients have to do much of the coordinating work themselves. It was argued that money that is currently being spent to board patients overseas should
be invested in creating a unified centralized networking system.

2.6.3 Financing

The amount of financing spent on medical boarding for breast cancer patients needs to be reduced. Women can receive approval through a boarding committee to travel for care if they receive a diagnosis. A question that needs research is whether boarding contributes to the high rates of locally advanced cancer in the country, because the process involved in boarding can take 2-3 months to complete after the patient is diagnosed.

Financing for breast cancer care in Kuwait should also be directed toward improving, expanding, and increasing awareness of the national screening program was suggested. This should include research on the optimal screening modality for the younger Kuwaiti women, as 25% of people in Kuwait (around 4 million) are women younger than 40 years old. Mammograms are not necessarily the best screening modality for women under 50, which warrants further research. More investment is needed for cancer research across the board, and there are particular financing shortfalls in the area of human resources.

2.6.4 Service delivery

2.6.4.1 Access

In Kuwait, two groups of people have the least access (or are unaware of the access system) to breast cancer services. Among the first group—expatriates—many people are of lower socioeconomic status with low or minimum wage jobs; this group can be difficult to reach. The second group is the large segment of the population that is relatively uneducated (i.e., has only completed high-school level education). Many in this group lack awareness about breast cancer, which is illustrated by the fact that most patients come to the clinic with a symptomatic diagnosis and not through the screening program. Even for people who are aware about it, actually accessing the program is not easy.

Main challenges for health service delivery include the outdated, bureaucratic method used in the exiting referral system. This would be improved by implementing systematic, unified care pathways across the country to connect all of the multidisciplinary cancer departments; this is entirely feasible. Furthermore, the health delivery system has no unified treatment guidelines and protocols in place; providers are all following different guidelines and it is very difficult to convince people to adhere to them. Finally, Kuwait does not have a navigation cancer nurse service, creating another barrier for patients to gain access to the system that could be mitigated through increased financing.

2.6.4.2 User engagement

There are suboptimal levels of education and engagement among both patients and caregivers which need to be addressed. Most patients are unaware of what cancer is, even after explanation. Awareness and education could be improved by raising awareness, educational sessions, educational booklets, and a patient information website.

2.7 ANALYSIS OF OMAN AND KUWAIT

Key points of discussion centered around the need for managing breast cancer in a different way in the region, because of younger patients, aggressive disease, high mortality, and large numbers of patients presenting with advanced-stage disease. Current screening modalities are based on other types of populations and may not be applicable in the GCC region. Government and policymakers need to be aware of these issues and prioritize them, so that they can allocate funding toward alleviating the impending burden. Funding needs to be channeled into managing the patients, as opposed to the current mindset of sending them abroad where other countries will take care of them. Policies need to be clear on how to manage this. There is no problem in managing tertiary care and palliation, but it is a massive burden on the government. Given the emerging threats of rapid rise in burden,
late presentation, and aggressive disease, the current trajectory in breast cancer management is not sufficiently aligned with the raising burden. Care delivery models need to be underpinned by developing networks, and improving IT systems to capture quality data.

Another key point was that screening is crucial and there are different approaches in different countries, whether it is by law or choice. Screening programs in different countries for breast, cervical, and colon cancer vary greatly in terms of age, frequency, and methods used. Funding and focusing on screening for people age 40 and again after ten years will not solve the problem, because mammogram-only screening is insufficient. Genetic testing, MRI, and the new blood test for circulating DNA need to be integrated into the screening.

Participants expressed various opinions on the best policy intervention. To save money, some participants noted that governments should adopt policies for compulsory screening, similar to those for vaccinations and infectious diseases. Given that expatriates coming to many countries have a compulsory medical examination (chest x-ray, blood tests, hepatitis, HIV), a mammogram might also be included. The same could apply to all women under 40, using the same type of justification as legal requirements to immunize children before school registration: to prevent cost and burden on the system. Some experts warned against making this an optional choice and contended that screening should be a component of national security supported by the government. It was discussed that governments must become aware of the burden so that they can begin to address it now, by implementing laws and funding to mitigate the current expenditure on high-cost treatments.

Convincing the government to make that kind of investment will require the proper data: e.g., mortality rate versus expenditure, and survival rates at different stages at diagnosis. The importance of developing a rigorous and robust evidence base was evident in the discussions.

Some experts considered compulsory screening to be misplaced, because the rationale behind the argument for compulsory vaccination, for example, is that one person can give the disease to another—this is clearly not the case for malignancy. The rationale for making screening for breast cancer (in this case, but possibly other cancer) compulsory by law is also weak when it is based on government expenditure. As far as participants were aware, there is very little evidence for the effectiveness of screening for breast cancer under than age of 50 in reducing mortality. It was argued that if a segment of the population is compelled by law to have a screening exam that does not reduce mortality, then great care should be taken on the fundamental criteria for offering screening in the first place. Compulsory screening was not considered the answer by many because under what constitution would treatment for a person diagnosed with cancer be contingent upon having been screened or not. Participants against compulsory screening warned that these are public health issues, not policy issues, that impact people’s lives and warrant careful consideration. The discussion included the possibility of incentivizing treatment by offering to pay only for patients who take part in the screening program. It was concluded that this is an interesting matter of debate that warrants further consideration about strategies to increase screening rates.

In terms of cost-effectiveness, participants suggested modeling the potential benefits of a robust screening program on earlier diagnosis and improving survival. Participants also emphasized the need to strengthen systems across the care continuum; breast cancer is just one tracer and looking at other conditions will reveal other issues. Through discussion, it was concluded that diabetes and obesity be included in projections, which will make cancer number-one killer in the region.

It was noted that the proportion of women diagnosed with breast cancer under the
age of 40 is a function of the population’s age profile, as much as anything else. If all woman were aged less than 40, for example, then a 100% of breast cancer cases would be diagnosed under that age range. The proportion of women diagnosed under 40 is only relevant if the age profile is known. Measuring that with a percentage of cases under 40 is a clinical reality that must be dealt with in practice, but comparing populations requires the age-specific incidence rates. There is likely much less difference between the populations in the countries presented than the proportions of the women diagnosed under 40. Regarding mortality and incidence, experts suggested that mortality rates are less useful as a guide to the overall effectiveness of the health service than survival, because the women dying of breast cancer in any given year are those who were diagnosed one, five, or even ten years earlier. In terms of the responsiveness of that metric to the effectiveness of a certain health system, mortality is far less useful than survival. Survival indicates the probabilities of living one, five, or ten years after diagnosis for women being diagnosed in a given year—that is what is needed to manage the effectiveness of the health service.

The pathway noted by some experts was to assemble a higher committee for cancer control in each country. The committee should strengthen the cancer registry to accurately understand the magnitude and incidence rates, and then develop guidelines for patients with cancer who are going to be subsidized by either insurance or government. The strategy for cancer control should be based on the WHO pillars.

Breast cancer is often discussed in the spectrum of many different cancers and within the broad range of NCDs, so making breast cancer a priority issue is easier said than done. There was concern that all the resources would be reallocated for screening, at the expense of many other things that need to be done to strengthen the framework of breast cancer control and cancer control in general. It is important to look for evidence for the effectiveness of the early screening.

2.8 REGIONAL SYNTHESIS OF FINDINGS ON BREAST CANCER IN THE MIDDLE EAST

2.8.1 Major achievements and gaps in the Middle East

An overview of major achievements and gaps in breast cancer care in the Middle East include commitment to and prioritization of cancer in national health agendas coupled with ongoing efforts to develop national cancer plans (in countries where they have not already been adopted). Further, there is engagement in activities to strengthen care and encouraging initiatives to develop national screening programs. Emerging centers of excellence for treatment are providing a platform for a comprehensive network, which are bolstered by a growing research network of collaborators.

Gaps in breast cancer care in the region include the lack of consistent and comprehensive data on burden and survival as well as on effectiveness, efficiency, and responsiveness of care. There is great potential to improve breast cancer survival in the region, but it will require more integrated pathways to provide efficient, effective, and targeted care. There is an opportunity to extend capacity and capabilities of current and future human resources. Further gaps include the dearth of implementation science research and the lack of mechanisms to translate locally generated evidence to enhance policy and practice. Additionally, there are missed opportunities for coordination and synergy as well as limited engagement among patients and caregivers (e.g., patient-reported outcomes).

2.8.2 Regional noncommunicable disease burdens

Among the total number of cases of the nine most frequently occurring cancers in the Middle East and North Africa region in 2012,
the percentages of cases among both sexes attributable to excess BMI were:

- Breast (postmenopausal): 31%
- Corpus uteri: 21%
- Colon: 15%
- Kidney: 11%
- Gallbladder: 7%
- Pancreas: 5%
- Rectum: 4%
- Ovary: 3%
- Esophageal adenocarcinoma: 3%

Figure 32. Age-standardized death rate for cardiovascular diseases (per 100,000) in Jordan and comparator countries by gender (2005-2013) depicts the age-standardized death rate for cardiovascular diseases (per 100,000 population) in Jordan and comparator countries by gender between 2005 and 2013. The increase in obesity prevalence rates between 2010 and 2014 among select countries in the region as well as the US, Canada, France, and Germany is presented in Prevalence of obesity (30 kg/m²; aged 18 years or more) (2010 and 2014). The prevalence of diabetes in the adult populations of regional and comparator countries in 2015 is depicted in Diabetes prevalence in adult population (20-79 years) in regional and comparator countries (2015).
2.8.3 Strengthening regional health system capacity

Suggestions aimed at strengthening regional health systems’ capacity with respect to training, to generating, managing, and exchanging knowledge, and to leveraging regional public goods were made through the meeting.

2.8.3.1 Training

In relation to training, participants suggested generating a scholarship program for regional training that draws upon existing successful...
training models, such as KHCC’s program. Systematic utilization of telemedicine within the region as part of ongoing training was recommended. Multiple detector computed tomography (MDCT) scanning also needs to be supported. Training could also be supported by designing shared and openly accessible curricula and modules made available for clinical team members (e.g., for palliative care training). Finally, there is a need to develop a network of training centers focused on specific technical expertise, both cancer-specific and more generally functional expertise, such as monitoring and data analytics.

2.8.3.2 Knowledge generation, management, and exchange
To promote knowledge generation, management, and exchange, the drafting of a regional cancer research agenda was suggested to collaboratively generate knowledge, as well as incorporating and earmarking funding for cancer research in fiscal planning. Low-cost and efficient activities could be conducted for knowledge exchange such as regional webinars and online research forums and investing in building design, implementation, and analytic capacity for rigorous research on care delivery and outcome. Further, regular regional reports on a biannual basis could be generated.

2.8.3.3 Regional public goods
To capitalize on regional public goods, shared technical guidelines on screening, diagnosis, treatment, and care could be developed. Generating public education materials could help to address common barriers, such as stigma around cancer across the region. At the national level, documenting lessons on design and implementation of interventions to strengthen cancer care and at the regional level, designing a pragmatic tool-kit for the development, implementation and evaluation of national cancer plans would be of great value.

2.8.4 Regional coordination in the fight against cancer
To strengthen regional coordination in the fight against cancer, cancer registries could be leveraged and a cancer research network could be created.

2.8.4.1 Cancer registries
Cancer registries could be used to create opportunities for regional exchange of anonymized data for comparative regional analysis and for conducting collaborative monitoring and quality assurance checks. It would also serve to build a knowledge-base on the region that could be used to compare trends with other world regions and globally.

2.8.4.2 Cancer research network
There is great potential to build on existing initiatives (e.g., the Middle East Cancer Consortium, Harvard Study, and CONCORD-3 study) to develop an inclusive research network (e.g., Middle East Cancer Consortium). Such a network could promote regular discourse on cancer care in Middle East region, serve as a repository of knowledge, and provide a platform for development of technical guidance, idea exchange, and more.

2.8.5 Lessons from breast cancer management for chronic care
Lessons can be gleaned from breast cancer management for the care of chronic conditions.

2.8.5.1 Comorbidities
Cancer can be utilized to identify strategies for addressing comorbidities, particularly with other chronic NCDs and risk factors. There is space to create opportunities for joint health promotion and primary prevention activities for cancer and other NCDs, such as tobacco and obesity. Registries provide an opportunity to capture comorbidities with cancer. MDCTs should also be trained to understand how to treat comorbidities.
2.8.5.2 Palliation
The lack of systematic provision of palliative care is a major gap in the region. He called for re-examining resource allocation and budgeting process to ensure adequate investment in palliative care. The joined-up provision of palliative care with other conditions (e.g., COPD and heart failure) both in institutional and home settings should be explored. The aim should be ensuring appropriate pain relief through the whole course of the disease, which will also require developing mechanisms to support caregivers.

2.8.6 Opportunities to improve breast cancer care in the region
Participants observed that it is vital to balance foresight regarding the importance of NCDs in the future with hindsight regarding the transitional period of transformation that all countries in the region are in the midst of experiencing. The fundamental question is how to prioritize people's health within the available health systems by leveraging existing strengths and addressing weaknesses to promote health, quality of life, and life expectancies. Discussions often focus on life expectancies, but not healthy life expectancies, which should be the utmost priority for any health system. Emphasis was placed on how to more efficiently focus on the real priorities for patient care, particularly for cancer and NCDs. In the case of breast cancer, it is particularly important to extend to the overall health of women beyond reproductive health. Breast cancer care has two aspects—NCD care and women's healthcare—which are both priorities for sustainable development, women's rights, and health policies.

In periods of transition, a future-oriented perspective is warranted to consider how cancer and NCDS will evolve with respect to epidemiological transitions in age, cancer types, treatment, survival, and quality of life. Regional strengths and experiences in cancer management and treatment (including breast cancer) can be leveraged to support all countries in setting breast cancer as a priority for health systems strengthening and support. While the countries in the region have similarities, there are also important differences—both socioeconomically and in terms of priorities. The overarching objective of developing a common regional framework to guide national control strategies and priority setting.

The importance of capacity building for systems, countries, and research recurred during the discussions as priority issues for health information systems. Most important is developing the evidence base that will facilitate the adoption of those strategies within countries. The capacities needed are not contingent only upon the research per se, but also upon what it takes to support the research: the funding, the infrastructure, and the evidence. To date, many countries in the region rely on non-national and non-regional evidence that might not accurately reflect the situations they are facing, such as the trends that suggest earlier age of breast cancer onset in the region. Research is urgently needed on national- and regional-level etiology of breast cancer. In addition to strengthening health information systems, Participants emphasized the need for critical analysis of data collected, in order to inform and update strategies and frameworks for action according to any changes in trends that occur. This should be coupled with a future-oriented outlook regarding expected epidemiological or environmental changes that may affect breast cancer.

The spectrum of cancer care starts at promotion and prevention and extends across the spectrum of health and care. Curative services and screening are part of that spectrum, which then moves through WHO's perspective on disease control and management. Improving certain components of the spectrum of care will require reallocating resources and redesigning strategies if the desired outcomes are to be achieved in the future. Another priority should be finding strategies at the regional and national levels to fill in the gaps in service provision, cancer control, and screening. There
are discrepancies and inequities that must be addressed from the human rights perspective as well as the perspective of health system strengthening perspective in order to achieve universal coverage for breast cancer management, access, and quality care. Cost-effectiveness disparities driven by modern technology for breast cancer care will also need to be addressed with systems to cover patients who need care that has high costs. These issues need to be dealt with at both the political level and the implementation level, which needs to be taken into consideration in the proposed regional framework.

Ultimately, the aim should be to create sustainable programs for cancer control in ways that support and strengthen the entire health system—a system that starts with the government, but ends with sufficient financing and the quality of the health workforce. The latter are pervasive issues in the region that need to be prioritized at the policy level. Overall, the need for a human rights perspective for health was noted by participants.

Among the many common challenges faced in the region, the critical challenge of the lack of good quality data to serve as the foundation for research in the region was recurring. Prioritizing improved data collection and data management practices will be essential for the future. There is ongoing research in the region to estimate the population-attributable risks for modifiable cancer risk factors, by trying to calculate the number of cases that would not have occurred if an exposure had been eliminated. From a health policy point of view, this type of research would be helpful in prioritizing actions. There are also issues faced in trying to identify the risk factors in the region because many of the guidelines currently used in the region are generally Westernized and/or based on North American guidelines. Thus the guidelines are based on data, risk factors, and practices specific to North America that do not necessarily apply to countries in the GCC region. Re-evaluating risk factors and identifying new, region-specific risk factors would be helpful in tackling this issue on the grand scheme. Good quality data should also be used to shape and prioritize policies. A scoring system to quantify the magnitude of the issue at hand could be created with parameters including: incidence; prevalence; DALYs; costs of interventions; the length of time to expect the benefits of particular interventions; and the expected positive impacts of particular interventions.

Another challenged highlighted was the need for better infrastructure for research across the region, including randomized, phase III trials. Research is urgently needed to develop a corpus of data of sufficient quantity and quality to develop tailored guidelines for screening and treatment (e.g., Japan has their own guidelines for gastric cancer screening due to their high incidence rates). Country- and region-specific guidelines need to be developed for treatment as well as screening. It is known that some drugs do not work the same way in different populations, so research will need to determine if drugs approved in the West work in the region’s populations.

Research, it was noted, is important not just for the sake of research, but to inform policy and practice, including national and local guidelines.

### 2.8.7 Regional opportunities

Participants explored various opportunities to improve breast cancer care in the region. Regarding the curricula for health professionals, reviewing what is currently available about breast cancer issues and how to further advance those curricula was recommended. In addition to health professionals, programs at the school and undergraduate levels could also focus on the importance of NCDs, risk factors, cancer, and general awareness raising.

Developing research and a local evidence base is critical in developing nuanced guidelines for the specific to the region, but also to specific countries.
Participants highlighted the importance of a global perspective by providing two examples of strategies that can be implemented in practice to improve patient outcomes without pharmaceutical intervention. First, there is good evidence that multidisciplinary team meetings can improve survival outcomes and patient care. Second, proper supportive and palliative care can improve survival figures to a greater extent than introducing targeted treatments (antibodies or immunotherapies, for example) that are not cost-effective in the GCC region’s developing countries. There is good evidence for multidisciplinary teams as an effective organizational intervention to leverage existing human resources.

Participants emphasized that creating local guidelines is not an easy task, for two reasons. Resources in each country are different, and what applies to one area does not necessarily apply to another. Carrying out clinical trials to reflect a specific population is another challenge. The Gulf area, for example, has a very heterogeneous population; in some places local people may not even represent more than 20% of the population, giving rise to questions about how to disaggregate people in clinical study according to their nationality or region of origin. The current guidelines based on Western data are the best available option until enough data is available from cancer registries from the GCC region on outcome measurements, survival, etc. Regional, multi-country, multi-center clinical trials that include homogenous populations as controls need to be carried out.

Given the small size of some of the GCC countries’ populations, the importance of regional research collaboration is essential to improve the quality of data collection, to facilitate expedited hospital accreditation, and to provide the infrastructure for future research. Regional infrastructure for research could include randomized controlled trials as well as policy- and implementation-related research.

Participants agreed that a systems perspective, in that fixing breast cancer issues will have positive benefits on other conditions by strengthening the system as a whole, should be adopted. Breast cancer can serve as a tracer condition to identify synergies.
3 CONCORD Study: improving breast cancer registries and data collection systems in the Middle East

The CONCORD study is a global surveillance program of cancer survival. The CONCORD-3 estimates, the latest edition, are based on real data about what can be seen in countries and should be used when possible. GLOBOCAN estimates can be useful when nothing else is available. The difference between the two was discussed. IARC does not publish survival in GLOBOCAN: it publishes incidence and mortality rates, which are not the same thing. IARC, like many other agents around the world, uses mortality incidence ratios as an indicator of survival—but it is not. The complement—that is, 1 minus the mortality incidence ratios—is not an estimate of 1-, 5-, or 10-year survival. IARC has published studies in the past (called SURVCAN) from selected countries that use the same approach as CONCORD-3; although it does not include net survival, they do have registry-based survival based on individual patient data. GLOBOCAN uses, predicts, projects, and models data for cancer incidence around the world in many countries that do not have a cancer registry. It does that by using mortality incidence ratios, which is the best that can be done. But they do not publish survival.

CONCORD-3 provides estimates for 71 countries, she added. CONCORD-3 includes 42 million cases of individual-level data ("microdata"), characterizing an amazing data set. With modeling, many errors are introduced because people borrow data from other countries in the region. The second important point, is the distinction between mortality rate versus survival. Mortality rate depends on incidence rates: if the latter falls, the former will too. But survival reflects the functioning of the health system. Regardless of how trends are rising or falling, survival illustrates how well cases are managed and the cumulative effect of health system interventions. There is a need to educate the health workforce about the difference between mortality rate and survival.

A number of registries worldwide have and continue to face issues in acquiring detailed and accurate data. This highlights the importance of governments’ supporting registries politically, administratively, and financially so that registries have the right to access up-to-date information on all deaths in order to estimate survival for cancer.

When the cancer registries in the region were established, the main aims were to capture the number of cases and report incidence; the importance of survival and follow-up data were not prioritized. Most registries rely on medical records as the main source of data, not death registries. At the end of the year, incidence rates are reported and most cases are never updated again, which is a barrier to capturing survival data. Another concern is the large percentage of cases of unknown stage—around 20%-30% in the region. This proportion of unknown staging is unacceptable because more than 85% of cases have histopathology, which facilitates proper staging when combined with clinical radiology.

Participants recommended working toward a unified regional registry to enable data exchange. This will require fixed standards for national registries, proscribed definitions for each item in the registry, and a standardized methodology such that a given registry can be adapted to fit any study. Registries should be staffed by certified professional registrars, and clinicians and policymakers need to be educated about how to use the data appropriately (e.g., the difference between

49 There is a GCC registry that currently has six countries contributing to it.
population-based data and other types of data). Even a single ASR curve, for example, provides a wealth of information. Data use also gives rise to issues of confidentiality. The creation of a supreme council for cancer control to which studies submit for release approval was recommended.

An issue in some countries is that pathologists report 99% of the cases. Clinicians do not fill out the form or provide TNM information, which is required for a good cancer registry. Physicians will be reluctant to be burdened with filling out another long, exhaustive form and physicians completing the forms is a drain on resources. Training other professionals to complete it or the use of new technologies might be helpful in building capacity to do so. It was agreed that registrars as well as people to report cases are needed. Shopping around is a hobby of most of the populations in the region. Unless there is a serious reporting program in place, this tendency to shop around will be a problem for cancer patients. A user-friendly reporting system is needed for doctors that avoids complicated forms. More accurate case reporting going forward will require the involvement of everyone, not just pathologists. Registrars should be trained and certified, and use support software available from WHO. Participants emphasized the need for complete medical records.

Participants discussed that the primary information needed from physicians is tumor staging and coding; other staff can fill out the other information. However, all physicians are not oncologists and may encounter some difficulty in determining tumor stage using the various systems of staging.

Participants discussed that the outcome for survival of cancer patients is also a matter of access to medical care and the quality of that care. Even within the same country, different institutions have different standards of care. Standardizing the quality of care gives rise to several challenges.
4 Lancet Commission on palliative care and pain relief: study findings

Findings from the recent Lancet Commission on Palliative Care and Pain Relief 50 highlight palliative care as a priority area for investment. Meeting discussions explored recommendations and policies that could be implemented to expand access to palliative care and pain relief in the region.

The Lancet commissions bring together international experts from very different countries and often expertise. They can be very large collaborations: typically, the group of commissioners ranges from 20-25 people and working groups including researchers and local collaborators can range from 20-100 people. Compared to what is published on a weekly basis in the Lancet, commissions take two to three years to produce a seminal piece that brings together all the evidence and makes suggestions for implementation. The Commission on palliative care is unusual in that, in addition to making suggestions, there is a follow-up that involves working with and supporting countries.51

The development of the Lancet Commission on Palliative Care and Pain Relief took a huge amount of work over more than three years. It is the first Commission to look at palliative care and pain relief in a systematic fashion, by exploring the burden of suffering in relation to cancer and other conditions. It develops a metric to measure the burden, because the current measurements (e.g., DALYs and QALYs) do not take into account the huge burden suffered by individuals due to symptoms such as pain from point of diagnosis through end-of-life,52 and as a result, that burden does not feature in priority-setting discussions and cost-effectiveness analyses.

Therefore, the Commission came up with a new metric- serious health-related suffering, estimated the burden, and considered the core components of a good palliative care model. There was no existing systematic description of what could be included in a benefits package for palliative care. The Commission designed an essential package of interventions and then costed them, so that countries interested in implementing the interventions could add them to their insurance programs. The current coverage levels of these interventions are quite surprising. A diagonal approach was adopted in considering how to translate the Commission’s work into action in health system; that is, to consider how implementation could strengthen not only palliative care programs, but also strengthen the whole system at the same time. Finally, a set of recommendations for actions at the country and regional levels were produced.

The key messages from the Commission are:

(1) 61 million people experience serious health-related suffering and majority of this burden is faced by LMICs, however, this issues is one of the most neglected areas in global health.53

(2) The package of palliative care interventions should be part of universal health care, which is aligned with the SDG3 target of introducing palliative care to address the burden of serious health-related suffering.

(3) The essential package is very affordable. Low and middle-income countries (not to mention high-income countries) of this region can fund this and include it as part of universal health coverage expansion.


51 An implementation working group is working with the International Association for Hospice and Palliative Care to ensure that the recommendations of the commission are implemented.

52 The Commission emphasized that palliative care is important from the point of diagnosis through the end of life.

(4) As well as country-level action, there is a set of international collective actions to make this happen, including surveillance systems, capacity building, and working with countries to develop palliative care plans as part of their national health plans.

(5) Because suffering is typically not measured and not captured in typical cost-effective analyses, priority setting needs rethinking.

With respect to the fifth point, palliative care cannot be included in priority setting using the current tools (i.e., cost-effective analysis and resource allocation) because cost-effective analysis is based on efficiency and the benefit—in economic terms—compared to the cost. This is an important issue for cancer generally, but especially for those who present late. Current metrics do not take into account other important things that physicians care about: dignity, wellbeing of the individual, and wellbeing of society. Cost-effective analysis is very narrow and misses these important dimensions that really matter to humans and to society and which need to be included as part of priority setting. A number of countries have done this already: for example, in Sweden the first criteria is dignity, then equity, then cost-effectiveness. When setting priorities in relation to cancer, these dimensions should be included to ensure that palliation is part of policy making. Otherwise, it results in interventions that focus on treatment of certain conditions, but misses out on many others.

In 2015, a total of 61.1 million people experienced serious health-related suffering, with a total number of 21.2 billion days spent suffering. Much of this suffering is not being adequately addressed—people are in pain that is not adequately alleviated and their families struggle to cope, even in countries with good systems for palliative care. In 2015, 25.5 million deaths were associated with serious health-related suffering, which represents 45% of the 56.2 million deaths worldwide.

The essential package developed by the Commission includes a number of very low-cost, off-patent medicines. Medical equipment includes pressure-reducing mattresses to prevent bedsores and ulcers, nasogastric drainage, some catheters, and oxygen. A number of human resources are also needed as part of a multidisciplinary team to work in the community.

The is significant unmet when in terms of the availability of opioids for pain relief, in the availability of opioids in Canada, USA, Australia, and Western Europe drastically exceed need. In terms of the proportion compared to what is needed, he reported that the USA is the most over-provided (as evidenced by its large opioid problem) and Canada also has very high levels. Estimates of the amount of morphine in mg per patient is very low in the two most populous nations, China (approximately 314 mg per patient) and India (approximately 43 mg per patient), compared with Canada (approximately 68,000 mg per patient), for example. There is also a huge problem in the Middle East region.

Participants discussed that data on patient consumption of morphine is limited and rather data about morphine that has been distributed is utilized as a estimate. Given the currently limited data available, there is no way to understand actual consumption—distributed opioid morphine-equivalent is a proxy for access (not consumption). The estimates of need to address serious health-related suffering are based only on the 20 conditions most associated with need of palliative care, on the calculated burden of serious health-related suffering relates to physical and psychological suffering: a broader framework was utilized by the Commission, acknowledging that spiritual and social suffering are also important, but these were not part of the assessment. A key message is that some countries have overprovision and other countries have under-provision, generating a pain divide. In terms of disaggregation and refinement, it is surprising is how little data there are available. It is also difficult to understand prescribing patterns: the data reflect what is purchased, not what
is being used. There is a substantial research gap in regard to palliative care and pain relief. The Commission also identified strategies for developing palliative care functions within health systems with respect to the functions of stewardship, financing, service delivery, resource generation and management, and information research. The emphasis is not on developing a separate program, but on trying to mainstream and integrate palliative care into the health system at all levels of care through the diagonal approach.

One of the important messages from the Commission is that to effectively deliver palliative care, many countries have effectively used non-governmental or civil society organizations. Some of the best systems have origins entirely in NGOs or civil society, such as the hospice movement. Lebanon is an interesting case study in which civil society was important in initiating national palliative care planning. A national committee for pain and palliative care was charged with the development of a national strategy with a research focus. A number of priority gaps and areas were identified by the committee, but they were not able to implement what they had planned, partly because of the civil unrest and the Syrian crisis that resulted in 2.5 million refugees.

The GCC region does not yet have a regional association for palliative care, which he highlighted as an important opportunity. It fits into a discussion about developing a regional registry, for example, and there could be a regional collaboration on developing a framework for implementing palliative care. A regional association could work with the International Association for Hospice and Palliative Care to establish a set of activities to better understand what is happening in countries, to establish country-level commissions, to generate and disseminate knowledge, and to provide support in creating interdisciplinary and multisectoral linkages to implement palliative care. There are regional already networks in Africa, Asia, Latin America, and the Caribbean: all regions are covered except the Middle East.

There is an opportunity to harness country-level initiatives in a way that is region-specific. Further opportunities include looking at the regional- and country-level burdens and explore what an essential package might cost in each country, so they can be discussed with MoHs for formal inclusion in benefits packages. Participants suggested the combining of resources in the region to build upon what is happening in specific countries, and what WHO Eastern Mediterranean Regional Office (EMRO) is doing to develop joint training programs. Knowledge and experience should also be shared as part of the global network.

Participants discussed that palliative care is partly the responsibility of civil society and partly of institutions. It is difficult for relatives to see someone die; it is hard to explain and for relatives to accept the point at which treatment is no longer an option. This needs to be done in a way that helps the relatives feel informed by building awareness and acknowledging that medical expertise has limitations. No matter what resources are available, there is a limit to what medicine can cure and the patients should be allowed to die with dignity at home, rather than keeping them in hospitals. Palliative care should be a priority action in service delivery.

Dignity is of utmost importance and it is inappropriate to bring someone who is suffering into a hospital to suffer even more. The culture and attitudes of families in the region can be leveraged as an asset to support palliative care, as long as they are provided with the full picture of what is happening with their loved one.

Policies and regulations need to change to ensure safe prescribing of controlled drugs and medicines. Physicians must often fill out extensive paperwork and go through an arduous application process to prescribe opioids; pharmacists encounter similar barriers. Due to these administrative obstacles, physicians are disincentivized.
from prescribing opioids and pharmacies are disinterested in stocking them. In many contexts, pharmacists are also unwilling to handle opioids due to government scrutiny over how much they release and to whom; in many cases, there is also resistance in both doctors and patients to utilizing them due to stigma about opioids leading to addiction. Physicians are uncomfortable prescribing opioids as well; they are often unfamiliar with how to help patients cope with side effects, for example.

To enable the delivery of a full package of services, palliative care needs to be bolstered by societal engagement, education, awareness raising, and overcoming issues related to dignity and right to autonomy end-of-life.
5 Framework for action: pathways to improving management of breast cancer in the Middle East

To identify pathways for improving breast cancer in the Middle East the workshop participants reviewed, three main areas were explored: 1) priority actions (both leadership- and policy-directed) at the regional level to address challenges; 2) specific actions at the country and regional levels in relation to key health system functions, and; 3) priority actions in relation to policy-writing, coordination, planning, monitoring, evaluation, data collection, dissemination, and empowerment.

5.1 PRIORITIZING POLICY INTERVENTIONS AND ACTIONS IN THE REGION

Participants offered the following suggestions for priority policy interventions and actions in the region:

- Improve data networking and mechanisms for information exchange. Systems are fragmented within and between countries; work needs to be integrated and duplicate work prevented.

- Review regional- and country-level policies; find opportunities to work together by registering data; work on unifying legislation, guidelines, and capacity building.

- Create a mechanism for coordinating the development of guidelines tailored to the regional context.

- Address policy issues related to clinical trial patients recruited from Japan and Korea, who are taken into account in publications.

- Facilitate information and policy exchange.

- Create research networks to enable participation in international trials, for example.

- Utilize graduate students to assist with research.

- Carry out systematic reviews, such as a recent review on barriers to access.

- Create collaborative research group for cancer care.

- As a key output of the meeting, build a collaborative research group through joint studies and publications; identify priorities that develop through this work.

- Fund more region-specific research; for example, the scale of operations in the region is different from the US and genetic testing tailored for the region’s unique population is needed.

- Attract funding from companies by offering access to a multicentric network of cancer care facilities.

- Achieve critical mass in the regional research network to compel investment in the region’s future and its growing population.

- Create a platform for collaboration around country-level interventions, such as screening and research, for example, by proposing collaboration at twice-yearly meetings held by World Health Organization’s Eastern Mediterranean Regional Office (WHO EMRO); attention from WHO EMRO can also yield political commitment from leaders.

- Obtain support from authorities in each country.

54 He noted that EMRO’s focus has broadened from infectious disease and vaccinations to NCDs.
• Enact regulations that empower providers in each country.
• Coordinate work across government, private, and civil society sectors (particularly budgeting and funding).
• Ensure regional coordination among national governments to share data and create sharing data and regional-level guidelines.
• Create a voluntary alliance for breast cancer among countries; draft a framework to work jointly on awareness, service delivery, funding opportunities, fundraising, collaborative research, and sharing experiences (such an effort began at a conference in 2015).
• Aggregate information from alliances formed around training and networks; create a document explaining what has already been done and what should be developed.
• Identify the existing platforms that can be harnessed to create a long-term, sustainable initiative rather than one that dies out after the conference.
• Ensure that guidelines are actually adhered to in practice and that recommendations are followed (strengthen governance).
• Prioritize training of registrars so that registries can actually go into effect.
• Use benchmarking and implementation research to measure outcomes and performance; share results among regional research network to improve members’ work through exposure to what others are doing.
• Create a high-level master plan; establish a platform, either through EMRO or the Gulf Cooperation Council (GCC); streamline activities through a trusted party to control and coordinate activities in a sustainable manner in the region, according to benchmarks and with appropriate funds and the commitment to participate.
• Evaluate the outcomes (e.g., tumor size at presentation in the region) of the breast cancer screening and awareness initiative between the US and the Middle East launched ten years ago by the US first lady Michelle Obama.
• Carry out regional research on if/how the increased number of screenings has affected patient outcomes.
• Develop local guidelines on recommended screening age.
• Evaluate the cost-effectiveness of expensive mobile screening vans.
• Use data sets on screening to evaluate effectiveness.
• Address data quality gaps via policy, guidelines, and sharing best practices; establish an overarching professional body because governments do not take the issues seriously enough.

5.2 PUBLICATION AND DISSEMINATION STRATEGIES FOR THE REGION

Participants emphasized the need to increase the volume of published output from the region, which is currently very low—including in countries where there is substantial research funding. Participants discussed challenges and opportunities related to publication and dissemination strategies for the region. It is important to ensure that all countries are generating appropriate data and that research is translated into publications and other outputs. People are not citing research from the region because there is the impression that it is weak. Publications that do exist are not widely indexed and thus difficult to access. Participants discussed the

55 Atun noted that in Sweden, researchers have put together institutions to see what they are achieving regarding certain outcomes—i.e., research through audit.
56 Al Zahran said that EMRO has 22 countries, within which it is difficult to collaborate due to political conflict. The GCC probably can function as an umbrella for actions and plan. There is a 10-year regional strategy for all participating countries, to which some countries are more committed than others.
experience of publications on the region not being accepted due to the geographic focus, even from supervised PhD students who study in the US. Further, researchers from the region are able to publish in European journals, but US journals do not seem to accept work from the region.

Participants agreed that the quality of the research and a measurable contribution must be present—that is, the publication addresses important research questions; it adds to empirical evidence; or it adds to methodology. There was agreement that researchers in the region should focus on research that can contribute to international literature.

Publication and dissemination would be bolstered by prioritizing the creation of a research alliance in the region, as collaboration between the East and the West may serve to bridge the gap in publication.

5.2.1 Improving access to care through technology and outreach

Given that most centers of excellence are located in the capital cities of countries in the region, there are geographic barriers to patients’ access to biopsies and other oncology practices. Leveraging technology (such as telemedicine using webcams) can increase access for patients regardless of where they live, especially for those who cannot pay out-of-pocket to make in-person visits. Funding telemedicine collaborations with colleagues in the US or Canada—e.g., multidisciplinary conferences or virtual clinics—may be much more cost-effective than sending patients abroad. Ontario, Canada, has two such models. One is the multidisciplinary centers of excellence where doctors log in on a weekly basis, for example, and present cases with doctors across different hospitals. The other is an e-consultation model, whereby there is a list of oncologists and surgeons that a patient can consult with or be referred to through their primary care physician. In Canada, the government pays for this through the socialized medicine system, but a private entity could be created to provide this type of low-cost consultation service for a fee.

There are opportunities to invest in services outside of the central infrastructure, by transitioning from single centers of excellence to investing in human and other resources in this age of technology. Future-oriented efforts should to look beyond hospital care as much as possible, because they are very costly centers and structures. Money could be better spent in alternative models of service delivery and in human capital rather than in bricks and mortar, especially in a region with a young population that is technology-enabled.

Outreach is another way to improve equity, for example, through specialists reaching out to secondary or district hospitals. HCare at home is another approach, because immunocompromised patients should not be exposed to infection in hospitals.

5.2.2 Inequity in access to quality care

There are access issues related to equity and physical access, but also access issues that pertain to ensuring an appropriate level of quality. Participants discussed the recommendation of implementing policies which mandate that patients should not receive publicly funded treatment in a hospital that does not meet minimum criteria (e.g., the presence of medical and surgical oncologists) and standards of quality. In cases where those standards are not met, patients would be connected by telemedicine to appropriate specialists and/or be given a choice about the facility in which they will receive their treatment.

Electronic connectivity between healthcare sectors can enhance the follow-up, continuity of care, referrals between sectors, and psychosocial support services for breast cancer patients. Specific gaps are different in each country. A double-reading policy was recommended to enhance diagnostic accuracy and establishing national mammogram reading centers to integrate...
sectors and bridge the gaps of human resources and availability.

5.2.3 Gaps and opportunities related to primary care

Most primary care physicians do not carry out clinical breast exams or refer patients to mammography, even for diagnostic purposes. Awareness and education programs should target not only the public, but also primary care physicians. Some family physicians are unaware that screening guidelines exist, and they do not know how to refer patients. Examples of programs across the region were discussed, including ones to educate people about how cancer can be effectively treated, a program to train GPs on performing breast examinations and how to pick up even very small lumps, and continuing professional development (CPD) programs in all specialties, and seminars about breast cancer.

If physicians are not educated in how to conduct clinical breast examinations, it should be added back into medical training programs. From the perspective of primary care physicians, cancer is rare. Hence, inviting physicians to be trained on breast cancer may not be enough, and training of primary care physicians in a range of common malignancies is likely needed.

5.2.4 Gaps in the spectrum of care

There is a potential misconception about the utility of mammography as a screening modality. Mammography is more useful in the diagnostic setting, because only when staging is based on the breast exam and biopsy is a mammogram helpful in screening to capture those cancers that are small and not palpable. This needs to be clarified in the context of primary care.

Women face barriers such as timing issues if they work late, lack of spare time, worries about the availability of female physicians, or lack of knowledge about where to go to be screened. These barriers need to be addressed

A navigation program should be created to guide individuals through the complex maze of service delivery. A regional alliance for advanced and metastatic breast cancer was suggested, predicting that such an alliance would improve the quality of patients’ outcomes, improve the patients’ quality of life, and help guide decisions about whether patients should be cared for at home, in hospice, or in hospitals.

5.2.5 Clinical governance and quality management

The introduction of quality management programs for breast cancer care in each country, or in each center of excellence, could benefit everyone and address gaps in the spectrum of care that require the most immediate attention. Breast cancer imaging and care have very well-known qualitative indicators. Obtaining accreditation and measuring quality indicators would eliminate wasted resources, more data could become available, and improved quality would benefit patients.

5.2.6 Strategies for outreach and raising community awareness

In terms of service delivery, the focus has tended to be on “supply-side interventions.” An important intervention to improve access is using outreach efforts to raise awareness so that people present early. Comprehensive primary care level should offer these as “demand-side” interventions.

Efforts are needed to directly dispel misconceptions about breast cancer among the population at large—such as mammography causing thyroid cancer—through television or other media. Efforts are also needed to counteract anti-screening campaigns (e.g., “Think Before You Pink”) and to counteract false reassurances from family physicians, who may not be aware of appropriate cancer protocol.

The use of media campaigns in a positive, funny way through Facebook, Instagram, Twitter, WhatsApp, and other social media
networks was reviewed as potentially reaching greater number of people. Participants noted the importance of reaching out to the public using the most (currently) popular social media modality among the specific population. Non-physician members of large healthcare teams, such as nurses, could be trained to perform screenings and raise awareness in hospitals, schools, shopping malls, and the communities at large.

Participants agreed that changing behavior will require reaching the public: ribbons have very limited impact. An example of the use of popular soap operas to deliver public health messages for control of communicable diseases as well as screening of NCDs in Latin America was cited.

To reach out to patients actively through primary care, participants discussed implementing weekly women’s clinics for patients above a certain age that are tied to NCD screening in general but also include specific education for patients about breast cancer screening and cervical screening, for example. Nurses could be trained to do this as well, he added.

5.3 RESULTS OF REAL-TIME PARTICIPANT POLL ON CHALLENGES, OPPORTUNITIES, AND PRIORITIES

At regular intervals throughout the workshop, participants took part in ten real-time polls to capture their perspectives on challenges, opportunities, and priorities with respect to breast cancer care in the Middle East. The following figures display the results of the polls, which were carried out using Mentimeter™ software platform:

- What are the top 5 challenges to providing breast cancer care in the Middle East?
- What are the top 5 opportunities to improve breast cancer care in the Middle East?
- Figure 43. What are the three main policy interventions that should be developed at the country level?
- Figure 44. What are the three main policy interventions that should be developed at the regional level?
- What is one word that best describes the most important challenge?
- What is one word that best describes the greatest opportunity?
- What is one word that best describes your top priority?
- What are three words that best describe the most important challenges?
- Figure 49. What are three words that best describe the greatest opportunities?
- What are three words that best describe your top priorities?

57 Participants noted that in one country, women prefer Instagram, men prefer Twitter, and people do not tend to use Facebook.
**Figure 32. What are the top 5 challenges to providing breast cancer care in the Middle East?**

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Social factors: stigma, awareness. Etc.</td>
<td>order to prioritize incentives for change</td>
</tr>
<tr>
<td>Lack of vision and strategy. Lack of clinical governance. Limited</td>
<td>- Data and information early diagnosis financial coverage. Fragmented system</td>
</tr>
<tr>
<td>resources. Fragmented system. Patient's awareness</td>
<td>. Patient's awareness.</td>
</tr>
<tr>
<td>Data collection. 2. Accessibility to cancer care centers. 3. Lack of</td>
<td>- 1. Lack of good quality data. 2. Access to advanced cancer care. 3. High</td>
</tr>
<tr>
<td>awareness. 4. High cost of cancer care</td>
<td>. Treatment. 4. Increasing demands on cancer services. 5. Unequalized.</td>
</tr>
<tr>
<td>Easy access to facility. Outcome data involving the highest management</td>
<td>- Poor partners coordination. Service inequity. Lack of unified protocols</td>
</tr>
<tr>
<td>for proper decision</td>
<td>. and guidelines. Financing</td>
</tr>
<tr>
<td>Improve data collection both in cancer registries and national statistic</td>
<td>- Lack of data. No political / governance support for screening. Very poor</td>
</tr>
<tr>
<td>Compulsory screening same as immunization</td>
<td>- Government awareness of the problem more important than cancer awareness.</td>
</tr>
<tr>
<td>Lack of cross functional, multi-party consortium to align on challenges</td>
<td>- No complete care pathway, especially in rural financial issues</td>
</tr>
<tr>
<td>and way forward</td>
<td></td>
</tr>
<tr>
<td>Existence and implementation of NCCP Sustainable financing. Disease</td>
<td>- Data availability and quality. Awareness among population. 1. Variance in</td>
</tr>
<tr>
<td>Awareness Financial support</td>
<td>. Good quality data. 2. Access to advanced cancer care. 3. High cost of</td>
</tr>
<tr>
<td>the healthcare system. Training.</td>
<td></td>
</tr>
<tr>
<td>Rapid demographic transition. Lack of integrated care pathways.</td>
<td></td>
</tr>
<tr>
<td>Financial protection. Access gaps in rural areas. Lack of good data</td>
<td></td>
</tr>
</tbody>
</table>
Figure 33. What are the top 5 opportunities to improve breast cancer care in the Middle East?
Figure 34. What are the three main policy interventions that should be developed at the country level?
Figure 35. What are the three main policy interventions that should be developed at the regional level?
Figure 36. What is one word that best describes the greatest opportunity?

Figure 37. What are the three main policy interventions that should be developed at the country level?

Figure 38. What are the three main policy interventions that should be developed at the regional level?

Figure 39. What is one word that best describes the most important challenge?
Figure 40. What is one word that best describes your top priority?

Figure 41. What are three words that best describe the most important challenges?
Figure 42. What are three words that best describe the greatest opportunities?

![Collaboration Word Cloud]

Figure 43. What are three words that best describe your top priorities?

![Awareness Word Cloud]
References


Appendices

APPENDIX A. MEETING AGENDA

Health System Strengthening and Breast Cancer Care in the Middle East: Results of the Harvard Research Study
January 21-23, 2018

FINAL AGENDA

Venue
Harvard Medical School Center for Global Health Delivery–Dubai

Meeting Objectives
1. Convene stakeholders in the Middle East* to facilitate exchange on health systems strengthening strategies to improve delivery of breast cancer care within the region.
2. Present findings from the Harvard Research Study on: (i) the burden of breast cancer, and (ii) the provision of breast cancer care in Jordan, Kuwait, Oman, Saudi Arabia, and United Arab Emirates based on health systems analysis in each country.
3. Review existing challenges to addressing breast cancer care in the Middle East across the continuum of cancer control and care (prevention, screening, diagnosis, treatment, palliation, and survivorship).
4. Identify systems-level policy interventions to address challenges to breast cancer care in the Middle East.
5. Discuss priority actions based on current challenges and suggested policy interventions to expand access to breast cancer care in the Middle East.

Meeting Outcomes
Generate a proceedings paper to summarize discussions that will be published by the Harvard Medical School Center for Global Health Delivery–Dubai.
Build a regional platform for knowledge exchange on breast cancer care in the Middle East.

With special thanks to Harvard Medical School Center for Global Health Delivery–Dubai for providing funding for this meeting.
January 21, 2018
19:30 – 21:00 Dinner on arrival

January 22, 2018
8:30 – 8:45 Opening Session
Opening remarks and objectives

Sessions 1-6
For each country, study presentation on findings, country presentation on current efforts, and moderated panel discussion on future directions. Study presentations to provide results on the national burden of breast cancer, health system overview, review of health systems performance in comparison to benchmark countries on provision of breast cancer care across the continuum, and policy implications for the cascade of care.

8:45 – 10:00 Session 1 – Study Findings: Breast Cancer in Jordan, Saudi Arabia and United Arab Emirates

10:00 – 10:15 Morning Coffee Break

10:15 – 10:45 Session 2 – Panel Discussion: Breast Cancer in Jordan, Saudi Arabia and United Arab Emirates

10:45 – 12:00 Session 3 – Study Findings: Breast Cancer in Oman and Kuwait

12:00 – 12:30 Session 4 – Panel Discussion: Breast Cancer in Oman and Kuwait

12:30 – 13:30 Lunch Break

13:30 – 14:15 Session 5 – Synthesis of Study Findings: Breast Cancer in the Middle East
Present integrated summary results on health systems performance with respect to breast cancer care in Jordan, Kuwait, Saudi Arabia, Oman, and the United Arab Emirates, and provide a regional perspective on lessons from challenges and successes.
Present policy interventions that have a potential to function in country and within the regional policy environment.

14:15 – 14:30 Coffee Break

14:30 – 15:45 Session 6 – Study Findings and Discussion: the CONCORD programme
Present findings from latest CONCORD study and compare to changes from CONCORD-2. Discuss recommendations and strategies to improve registries and data collection systems in the region.

15:45 – 16:00 Coffee break
16:00 – 16:45  **Session 7** – Study Findings and Discussion: Comparative Baseline Needs Assessment for Breast Cancer Awareness and Management in the Middle East

(i)  *Present findings on knowledge, attitudes and perspectives on breast cancer among women and providers.*

(ii)  *Discuss recommendations and opportunities for integrating findings to improve breast cancer care in the region.*

16:45 – 17:00  **Agenda for Day Two and Adjourn**

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**January 23, 2018**

8:45 – 9:15  **Session 8** – Study Findings and Discussion: Lancet Commission on Palliative Care and Pain Relief

Present findings from Commission’s report and highlight palliative care as a priority area for investment.

Discuss recommendations and policies that can be implemented to expand access to palliative care and pain relief in the region.

9:15 – 11:00  **Session 9** – Framework for Action: Prioritizing Interventions to improve management of Breast Cancer burden in the Middle East: small group work

Breakout sessions will be organized by health system function/thematic areas to prioritize policy interventions for implementation within national and regional contexts. Sessions will focus on actions to address the country-specific and regional challenges identified during the previous day of the meeting.

11:00 – 11:15  **Morning Coffee Break**

11:15 – 12:15  **Session 10** – Pathways to Improving management of Breast Cancer burden in the Middle East

Reconvene to review and discuss priority actions from the breakout sessions and develop summary take-aways.

12:15 – 13:00  **Session 11** – Next Steps: Publications, Dissemination and Translation

Discuss plan for dissemination of findings and identify next steps for ongoing knowledge exchange/collaborative research network to strengthen national and regional efforts.

13:00 – 13:15  **Closing Remarks**

13:00 – 14:00  **Adjourn and Lunch**
Health System Strengthening and Breast Cancer Care in the Middle East