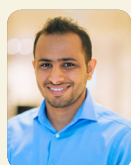


Cancer surveillance in the Eastern Mediterranean Region

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Cancer is a major cause of morbidity and mortality in the Eastern Mediterranean Region (EMR). Population-based cancer registration is vital to guide cancer prevention, care and policies. Although cancer registries have improved in the EMR, they still face many obstacles including political instability, shortage of human and technical resources, lack of sustainable funding, and regulatory processes. In this review, we provide an overview on the population-based cancer registration status in the EMR and shed light on the future directions towards high quality data. We envisioned that this review would provide policy-makers and health planners with the initiatives that would improve and empower population-based cancer registration in the EMR.

The Eastern Mediterranean region (EMR), with a population over 700 million, faces many health challenges (1). Cancer is one of the biggest public health challenges with a tremendous health and economic burden in the EMR. The latest GLOBOCAN estimation of cancer incidence in the EMR is over 730,000, and mortality over 450,000 cancer-related deaths in 2020 (Figures 1, 2) (2). Health systems and cancer care in the EMR vary by sub-region and country based on several factors including structure of the healthcare system, emergencies and conflicts, and economy status (3). Moreover almost half of countries in the region are in state of emergency or/and in conflict (3).

Cancer registration is a process of collecting high quality patient's identifications and tumour characteristics and ensuring secured storage for such data to be properly analyzed

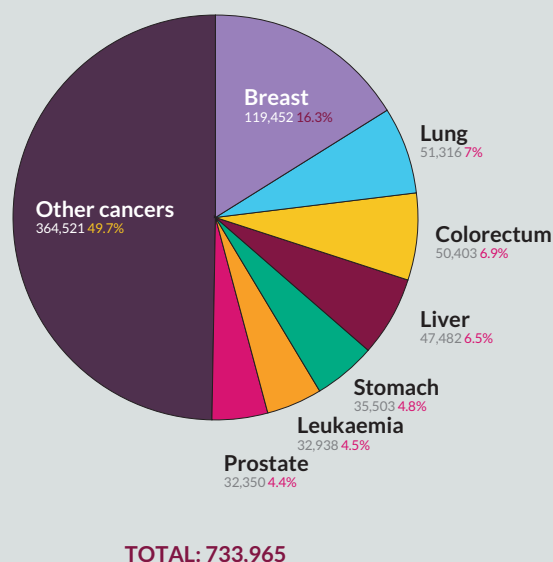
and used. There are two types of cancer registries: hospital-based and population-based registries. Hospital-based registries focus on collecting information on cancer patients in a particular hospital for hospital policy development or the assessment of cancer treatment outcomes. Whereas, population-based cancer registration plays a crucial role in the planning of national cancer control and prevention strategies, monitoring and evaluation of cancer care services, and epidemiological and clinical research (4). Reliable population-based cancer registry data are widely used to monitor cancer incidence and trends, patterns of geographical distribution, and survival at population level (5, 7).

Population-based cancer registration coverage has increased in the last two decades in the EMR despite many obstacles (6). Yet there are some limitations to cancer registration in

Table 1: Cancer registries in the EMR by type and year of foundation. Adapted from (3, 7)

Registry name	Country	Year founded	Type
Bahrain Cancer Registry	Bahrain	1998	Population based
Egypt National Population-based Cancer Registry	Egypt	2007	Population based
Ministry of Health, Iraqi Cancer Board, Iraqi Cancer Registration Section	Iraq	1974	Hospital and population based
The King Hussein Cancer Centre Tumour Registry	Jordan	2006	Hospital based
Jordan Cancer Registry	Jordan	1996	Population based
Saudi Cancer Registry	Saudi Arabia	1992	Population based
Kuwait Cancer Registry	Kuwait	1970	Population based
National Cancer Registry	Lebanon	2002	Population based
Benghazi Cancer Registry	Libya	2003	Population based
Casablanca Cancer Registry	Morocco	2004	Population based
Oman Cancer National Registry	Oman	1996	Population based
The Palestinian National Cancer Registry	Palestine	1998	Population based
National Centre for Cancer Care and Research Registry	Qatar	unknown	Hospital based
Qatar National Cancer Registry (QNCR)	Qatar	2012	Population based
Sudan National Cancer Registry	Sudan	2009	Hospital based
Syrian National Cancer Registry	Syria	2001	Hospital based
North Tunisian Cancer Registry	Tunisia	1996	Population based
United Arab Emirates National Cancer Registry	UAE	2013	Population based
Iranian National Cancer Registry	Iran	2016	Population based
Golestan Population-based Cancer Registry	Iran	2006	Population based

Figure 1: Estimated number of cancer cases by type in 2020 in both sexes across all ages for the WHO Eastern Mediterranean Region. Adapted from GLOBOCAN 2020



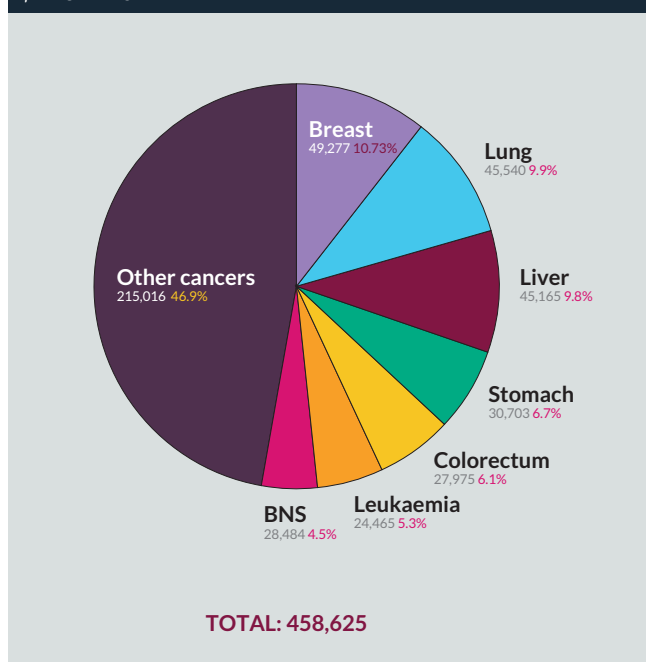
the region due to the shortage of funding and poor quality of data, population mobility and instability due to political disputes that involve several EMR countries (3). Therefore many improvements are needed to help cancer registries in the region to provide accurate and reliable data that would help to formulate evidence-based cancer care policies (6). This review provides an overview on the cancer registration status in the EMR and sheds light on the future directions for improvement.

Cancer registration status in EMR

According to Cancer Incidence in Five Continents (CI5) report, there is considerable variation across the region, both in terms of cancer registry coverage and data quality reflecting the varying degrees of maturation (7). Fourteen out of the 20 have functional cancer registries in place (either subnational or national), Afghanistan, Djibouti and Somalia do not have any type of cancer registration system yet.

Table 1 shows a list of cancer registries in the EMR by their type and year of foundation, as reported in recent publications that detailed and compared all cancer

Figure 2: Estimated number of cancer related death by type in 2020 in both sexes across all ages for the WHO Eastern Mediterranean Region. Adapted from GLOBOCAN 2020



registration in the EMR (3, 6).

In the Gulf Cooperation Council (GCC) States, health ministers issued a joint resolution to emphasize the importance of launching national cancer prevention and control programmes in each member state, which includes Kuwait, Saudi Arabia, Bahrain, Qatar, United Arab Emirates and Oman). In response to that, the Gulf Centre for Cancer Registration (GCCR) was established in 1998 to provide technical support to the newly established population-based cancer registries in the Gulf region, to provide cancer incidence statistics among GCC States, and to encourage epidemiological and clinical cancer research (8). The GCCR data was the main source for the Gulf region's strategic cancer control and prevention action plans for more than 20 years. Unfortunately, most of the EMR countries are now affected by halted or chronic states of conflict and instability (3). For example, healthcare systems including cancer care and registration in Syria, Yemen, Lebanon, Iraq and Palestine have been largely affected by these conflicts (3, 9).

One of the major limitations in most EMR countries is related to access to cancer patients details from the private and semi-governmental healthcare sectors, which greatly affect population cancer incidence and survival statistics (9). In cancer registration, mortality data is an important independent data source for the assessment of the cancer burden. Despite the pivotal role of mortality data in cancer registration and in policy-making, outcome monitoring and efficient use of cancer care resources, such important data are either suboptimal or not available. Absence of a national multisectoral framework

that brings all stakeholders in the decision loop, in addition to financial constraints and a shortage of skilled staff are the main reasons for the poor quality of data in most EMR countries. For example, conflicts and refugee mobility across some areas of Syria, Iraq, Lebanon and Libya have doubled the challenges in these areas in terms of a lack of accurate census and mortality data (3, 9). Despite the development of healthcare systems and advances in health information systems in the GCC, the GCC States still face challenges in updating vital status data on cancer incidence among expatriates due to their high mobility, and subsequently a large proportion of the GCC population are lost to follow-up (9, 10). Unique patient identification numbers are essential to ensure data collection from different sources and to eliminate duplicates, however, many EMR registries do not collect them, which subsequently increases the workload by registry staff to collect required data while ensuring accuracy and completeness. Such practices limits data linkage between different national data repositories.

Future direction in cancer registration

Cancer registries in the EMR need to be empowered to play their role in national cancer control programmes. For example, population-based registries in some developed countries have been a reliable source for cancer statistics, monitoring screening programmes (11), and cancer care outcomes (12, 14). Whereas some EMR registries still need to expand their role in order to provide reliable cancer statistics. Besides their crucial role in cancer control policies, data from population-based cancer registries can be expanded to link with other national datasets. Advances in data collection methods, bioinformatics, and data quality assurance have allowed for further enhancements to include more data on cancer management, patient experience and measures on quality of life to be collected and linked with the national cancer registry (15). For example, in England in the United Kingdom, several datasets have been established and then linked to the National Cancer Registration and Analysis Service hosted by Public Health England. These data include information on patients' diagnosis, treatment including chemotherapy and radiotherapy, socioeconomic status, quality of life, patient experience with cancer care and Patient Reported Outcomes Measures (PROMs) (16). The National Cancer Institute in the United States have linked large cancer registration data from SEER to patient satisfaction, medical expenditures, Medicare data and Medicaid (17). In Scandinavian cancer registries, years of collected clinical data have been linked to the population-based cancer registration to allow for detailed analysis of cancer care quality, clinical studies, cancer patients diagnosis and subsequent care outcomes (18). These registries have shown to be effective in updating cancer care-related

policies and benchmark comparisons to provide high quality and equitable cancer care (14, 18, 19).

There is a need to develop a roadmap for reliable sources of data, clear governance, and well-defined data collection pathways to enable healthcare planners, clinicians and researchers to use cancer registry data to improve cancer care policies and enhance cancer care outcomes. The EMR efforts in cancer control are now well supported and acknowledged by the World Health Organization (WHO) and the International Agency for Research on Cancer (IARC). The Global Initiative for Cancer Registry Development (GICR) programme was established to further support countries to develop, maintain, and sustain their population-based registries (20, 21). Nowadays, several countries in the region have been included in the latest CI5 and more submissions are expected for Volume XII, compiling data from 2017–2023.

Moreover, ensuring permanent staffing for cancer registration is a key step for sustainable population-based registries, as an adequately trained workforce is vitally important to ensure high quality cancer registration. It is therefore important to establish continuous staff training programmes through courses and workshops, e-learning and mentoring using resources provided by GICR (20). Countries with limited technical resources are encouraged to take advantage of the GICR, which is a partnership led by IARC that aims to assist low- and middle-income countries in building cancer registry capacities, including technical training, advocacy and building regional networks (22). Those countries with existing cancer registries that are not population-based cancer registries should focus on raising standards for registration quality and building on or extending existing registry activities to a population-based cancer registry and improve data quality and coverage without compromising data accuracy standards (20).

The regulatory and governance aspects of setting up and sustaining a population-based cancer registry requires a high level of commitment at national level. Mandating cancer as a reportable disease is strongly recommended for population-based cancer registries (24). Regulatory and governance aspects are also significant in strengthening cancer research, with national and international groups with mutual interests that would enhance collaboration and advance data utilization (20). This is particularly important for countries with limited resources to exchange experiences in building local capacities.

Despite these recent achievements in population-based cancer registries in several countries in the EMR, there are still exciting challenges. Countries are therefore encouraged to explore new ways to translate evidence generated from cancer data to create policy changes in cancer prevention and management. This calls for the need to provide high quality

data and bring policy-makers on board to recognize existing gaps and challenges in cancer surveillance, as well as in the evidence-based solutions.

Workshops and courses, such as those provided by IARC and WHO EMRO, that emphasize the effectiveness of population-based cancer registry use for cancer control and prevention activities (23), are of great help in building capacity and should also allow policy-makers and key stakeholders to make informed decisions. Countries with functional population-based cancer registries in the region such as GCC States should also take the lead in supporting countries with limited capacities to develop and maintain their cancer surveillance activities. Experts and professionals working with cancer registries are also encouraged to share their expertise through site visits, regional workshops and liaising with IARC hubs and other regional efforts.

Finally, besides the disruption that the COVID-19 pandemic has imposed to cancer care services, it has also caused collateral damage to population-based cancer registration (24). This disruption was most pronounced in low- and middle-income countries (24). It is therefore important to ensure policy-makers' continue their commitment to supporting cancer registration. Migration from paper-based to paperless electronic data flow whenever possible would be a breakthrough evolution in cancer registration and would ultimately benefit countries in achieving their national strategic goals for cancer control and prevention. ■

Disclaimer

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