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Editorial

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We cannot prevent cancer, detect it early, diagnose, treat, and palliate it without reliable data. Continuous, systematic collection, analysis, and interpretation of cancer-related data are essential to effectively plan, implement and evaluate cancer control activities and policies. Enhancing routine health information systems to ensure that cancer-related data are well captured

is essential, just as fostering functioning cancer surveillance systems, particularly population-based cancer registries (1,2). Population-based cancer registries play a critical role in the planning of national cancer control and prevention strategies, monitoring and evaluation of cancer care services, as well as cancer epidemiological and clinical research (1).

In the WHO Eastern Mediterranean Region (EMR) cancer is the second most common cause of death, after heart disease. Based on the International Agency for Research on Cancer (IARC) data, approximately 733 965 new cancer cases and over 458 625 deaths were documented in the EMR in 2020, and this number is projected to double by 2040, making EMR the region with the highest estimated cancer burden globally (3).

EMR accounts for the highest lifestyle-related risk factor prevalence for cancer, namely, tobacco smoking, which has shown a steady increase since 2000 (4,5), in addition to physical inactivity, high caloric diet and obesity (5). The prevalence of obesity among adults in the EMR remains high and this is expected to cause an increase in the incidence of colorectal, liver and gastric carcinoma, particularly among males, and breast cancer incidence among females (6,7).

It remains pivotal, therefore, to watch and monitor the burden of cancer and the related risk factors in the region to detect windows for intervention and control of the disease. This can principally be achieved through cancer registration, a process of collecting high-quality patient identification and tumour characteristics, and ensuring secure storage of such data for proper analysis and use.

There are 2 types of cancer registries: hospital- and population-based. Hospital-based registries focus on collecting information on cancer patients in a particular hospital for institutional policy development or the assessment of cancer treatment outcomes. Reliable population-based data are now the gold standard

to monitor cancer incidence, trends, patterns of geographical distribution, and survival at population level (1).

Although almost two-thirds (68%) of the 22 countries in the EMR have population-based cancer registries, there is a considerable variation in registry coverage and the quality of data collected.

Important limitations to cancer registration in the region remain political instability and insecurity. For instance, Afghanistan, Djibouti and Somalia do not have any type of cancer registration system, due to challenges in their health information systems (8,9). On the other hand, and despite a strong development of healthcare and advances in health information systems in the Gulf Cooperation Council (GCC) countries, including Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, and United Arab Emirates, there are still challenges. For example, it has been difficult to update vital status data on cancer incidence among expatriates due to their high mobility. Consequently, a large proportion of the population is lost to follow-up (10).

Considering the increasing burden of cancer in the EMR, a regional framework for action on cancer prevention and control was endorsed by the regional committee in 2017 and was updated in 2019 (11). The framework provides a roadmap for EMR countries to develop and implement national plans and highlights strategic interventions and indicators, including surveillance and research interventions. It emphasises the urgency of prioritising early diagnosis and establishing and strengthening monitoring and evaluation systems. However, the absence of a national multisectoral monitoring framework, in addition to financial constraints and a shortage of skilled staff, have resulted in poor quality data in most of the countries (10,12).

Civil registration and vital statistics programmes provide key information on mortality and causes of death (2). In cancer registration, mortality data is an important independent source for the assessment of the cancer burden. Despite the central role, those data often remain either suboptimal or are not available. Unique patient identification numbers are essential to be able to link data collected from different sources and eliminate duplication. However, despite improvements in the last few years, data on mortality and causes of death in several EMR countries remain suboptimal and are probably not being adequately used by the cancer registries to complement and assess cancer-related data (9).

Another limitation in many EMR countries is the limited access to cancer patients' details from the private and semi-governmental healthcare sectors, which greatly affects population-based cancer incidence and survival statistics (12). Again, this is a key challenge that cannot be

addressed adequately unless the national health information systems adequately cover all the health facilities across the country.

The Global Initiative for Cancer Registry Development is a key WHO initiative to further support countries in developing, maintaining, and sustaining their population-based cancer registries (1,12). Cancer registries in the EMR need to be strengthened to play their role in national cancer control programmes and as a key element of the national health information systems. Cancer registries should benefit from advancements made within the health information systems including digitalization and linkages, and their enhancement should be included in the national health information strategies.

A clear roadmap for the establishment of reliable sources of data and well-defined data collection pathways is essential to enable healthcare planners, clinicians and researchers to use cancer registry data to improve cancer care policies and enhance cancer care outcomes.

Regulatory and governance aspects of setting up and sustaining a population-based cancer registry require high-level commitment at national level, and mandating cancer as a reportable disease is strongly recommended for population-based cancer registries. Countries with existing cancer registries that are not population-based should scale-up population-based registries and raise their registration standards as well as data quality, building on, or extending, existing registry activities (1). Countries should train their staff adequately for cancer registration as a key step toward sustainable population-based registries. Strengthening cancer research, jointly with national and international groups that have mutual interests, would further advance cancer data use (10,12,13).

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