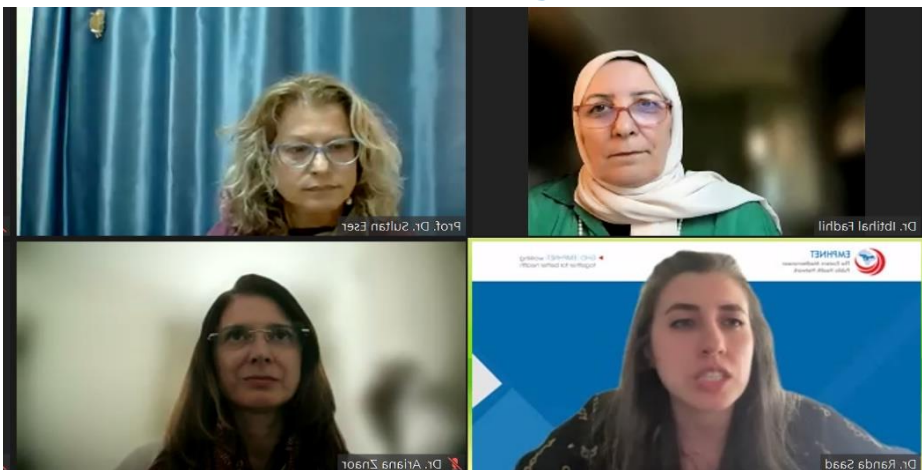




Policy Brief

June 2023

Strengthening Cancer Registries in the Eastern Mediterranean Region



EXECUTIVE SUMMARY

The burden of cancer in the Eastern Mediterranean Region (EMR) is experiencing an alarming surge. Population-Based Cancer Registries (PBCRs) play a vital role in planning national cancer control and prevention strategies, monitoring and evaluating cancer care services, and conducting epidemiological and clinical research. However, the EMR faces several challenges in establishing and maintaining high-quality PBCRs, including limited coverage, poor governance, political instability, shortage of resources, and insufficient funding.

This policy brief outlines the importance of PBCRs in cancer control planning, the existing barriers to their development, and potential solutions to enhance the quality and use of cancer registry data in the region. By addressing these challenges and leveraging available opportunities, the EMR can make significant progress in cancer control and planning, ultimately improving health outcomes for millions of people in the region.

Approach

This policy brief stems from a webinar organized by the Eastern Mediterranean Public Health Network (EMPHNET), facilitated by EMPHNET's technical specialist, Dr. Randa Saad. The session featured distinguished speakers including Dr. Ibtiha Fadhil (the Founder and Chair of the Eastern Mediterranean Non-Communicable Disease Alliance), Dr. Ariana Znaor (Scientist, Cancer Surveillance Branch, International Agency for Research on Cancer (IARC)) and Prof. Sultan Eser (Associate Professor at Balıkesir University, the Principal Investigator for the Regional Hub for Cancer Registration in Northern Africa, Central and Western Asia), each contributing their expertise on cancer registration in the EMR. Their collective insights into the current challenges and potential opportunities for enhancing PBCRs in the EMR form the basis of the recommendations outlined in this brief.



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Key policy recommendations include empowering EMR cancer registries, expanding the use of PBCR data, collaborating with international organizations, establishing continuous staff training programs, encouraging resource sharing among countries, mandating cancer as a reportable disease, promoting regional cooperation, ensuring policymakers' commitment to cancer registration, and migrating to paperless electronic data flow whenever possible.

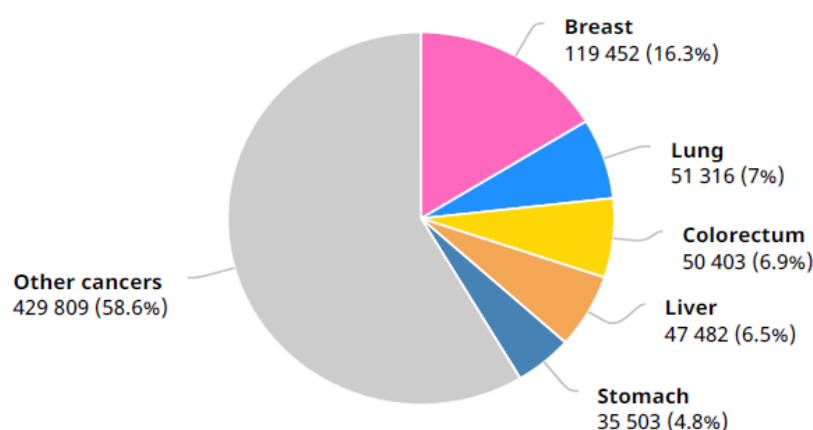
A counterfactual analysis highlights the potential consequences of inaction in cancer registry improvement, the risks and challenges that could arise without intervention, and the imperative for action in cancer control and prevention. Timely implementation of these recommendations will prevent the further widening of health disparities and inequities in the region, ultimately contributing to better cancer outcomes for the EMR's population.

INTRODUCTION

Cancer is one of the most significant public health challenges in the EMR, home to a population of over 700 million people. The burden of cancer in the region is experiencing an alarming surge. The latest Global Cancer Observatory estimation of cancer cases in the EMR are over 730,000, with over 450,000 cancer-related deaths in 2020 (GLOBOCAN, 2020). Cancer care in the region varies by country and it is influenced by factors such as the structure of healthcare systems, emergencies, conflicts affecting almost half the countries in the region, and economic status. Furthermore, prevention, rehabilitation, and palliative care areas are underdeveloped.

While population-based cancer registries (PBCR) coverage has increased in the last two decades in the EMR, several challenges remain, including limited funding, poor data quality, population mobility, and political instability.

Number of new cases in 2020, both sexes, all ages



Total: 733 965

THE PROBLEM

The EMR is facing multifaceted challenges when it comes to the establishment and maintenance of PBCRs. Primarily, there are significant governance and regulatory issues, including a lack of awareness around PBCR data and regulatory processes that hinder the efficient operation and expansion of cancer registries. Financial constraints also pose a major obstacle, with deficient funding diminishing the development and sustenance of these registries. This lack of resources inevitably impacts the coverage and quality of cancer incidence data. By 2020, only 13 countries within the EMR had PBCRs, and among them, merely nine maintained national cancer registries.

Furthermore, the region's political instability, unrest, armed conflicts, and unpredictable conditions, makes the establishment and consistent operation of cancer registries incredibly challenging. The problem is compounded by a scarcity of human and technical resources. The effective functioning of cancer registries is hindered by a lack of skilled personnel and an inadequate technical infrastructure.

Moreover, there is an underrepresentation of migrant workers within the region's cancer registration systems, with a substantial number of these workers often unaccounted for. One of the crucial problems often overlooked is the insufficient awareness of available registry data among policymakers and researchers. This lack of awareness not only limits the potential for data-driven decisions but also hampers the creation and implementation of effective cancer control strategies. It is essential to address these issues to fully leverage the potential of PBCRs and significantly improve cancer prevention, detection, and treatment strategies in the EMR.

ELEMENTS TO ADDRESS THE PROBLEM

Element 1: Strengthening Governance and Regulatory Frameworks

A proactive approach is needed to overcome the issues of poor governance and complex regulatory processes in the region. By raising awareness around PBCR data and streamlining regulatory processes, the operation and expansion of cancer registries can be made more efficient. This could involve the implementation of regional standards and guidelines, as well as targeted awareness campaigns.

Element 2: Securing Sufficient Financial Resources:

To ensure the functionality and continued development of PBCRs, there is a pressing need to secure adequate funding. This could involve advocacy for increased government budget allocations.

Element 3: Increasing Coverage of High-quality Population-based Cancer Incidence Data

As of 2020, 13 EMR countries had PBCRs, and out of these, only nine had national cancer registries. There's a clear need to improve the coverage and quality of PBCR data in the region. This might involve establishing new registries, expanding existing ones, and improving data collection methods.

Element 4: Navigating Political Instability

Political unrest, armed conflicts, and instability pose significant challenges to the establishment and maintenance of cancer registries. Solutions might involve finding ways to operate registries in unstable areas or securing international support for cancer registry efforts in conflict-affected countries.

Element 5: Building Human and Technical Resources

There's a clear need to invest in human resources and technical infrastructure to facilitate the effective functioning of cancer registries. This might involve training programs for registry staff, and investments in the software and hardware needed for modern data collection and analysis.

Element 6: Including Migrant Workers in Cancer Registries

The large number of migrant workers in the region are often unaccounted for in cancer registration systems. Efforts should be made to ensure these populations are included in population data, to enable the data collection by cancer registries and the calculation of incidence rates.

Element 7: Increasing Awareness of Available Registry Data

Policymakers and researchers must be made aware of the rich data that resides within cancer registries. This could involve communication campaigns, training workshops, or the implementation of data access policies that facilitate the use of registry data for cancer control planning and implementation. These activities should target different stakeholders, with outputs such as fact sheets and website summaries for program owners and policy makers and the media, as well as more detailed registry report for academia, clinicians, and broader research community.

Element 8: Improving Accessibility of Registries' Data for Researchers

Ensuring that researchers have efficient and secure access to cancer registry data is vital for advancing cancer research in the region. By improving accessibility, researchers can conduct more comprehensive studies, collaborate more effectively, and contribute to the global

knowledge base on cancer prevention and treatment.

POLICY RECOMMENDATIONS

1. **Standardize Cancer Registration Procedures:** Develop standard operating procedures (SOPs) for cancer registries across the EMR to ensure high-quality morbidity and mortality data.
2. **Strengthen Collaborative Governance:** Create a common legal framework for reporting and registration and facilitate formal governmental connections with the International Agency for Research of Cancer (IARC) with its Global Initiative for Cancer Registry Development (GICR) program. Initiate registry twinning programs to exchange expertise and skills globally and develop a regional cancer registration expert group for scientific coordination and oversight.
3. **Promote Cancer Registration Awareness:** Develop a proactive approach to enhance visibility and awareness of cancer registration in the EMR. Establish an online platform for relevant stakeholders and organize regular regional webinars and workshops on the subject. Utilize social media campaigns and resources to educate both the public and policymakers about the importance of cancer registration.
4. **Build Capacity for Cancer Registration:** Invest in staff training for data entry using electronic systems. Leverage GICR to provide regular capacity-building training sessions covering all aspects of cancer registration. Establish a certification program for cancer registrars and provide advanced training to create a team of peer-to-peer trainers within the region.

5. **Support for Conflict-affected Countries:** Provide additional assistance and resources to conflict-affected countries in the region to support their healthcare systems, particularly for cancer care and registration.

COUNTERFACTUAL ANALYSIS

Consequences of Inaction in Cancer Registry Improvement

Without sufficient standardization and digitalization of cancer registration procedures, there will be increased variability and underreporting. This lack of standardization hinders the ability to effectively plan and execute national cancer control programs, thereby compromising the efficient allocation of resources and the quality of cancer care services. Inadequate collaboration between key stakeholders and international organizations like the International Association of Cancer Registries (IACR), GICR and IARC results in missed opportunities for capacity building, technical training, and advocacy. Moreover, the inability to properly monitor and evaluate cancer trends, screening programs, and cancer care outcomes will prevent the necessary improvements to cancer care quality and patient experiences.

Risks and Challenges Without Intervention

If there is no intervention, the risks and challenges are manifold. We could see an increase in cancer-related morbidity and mortality rates due to inefficient cancer control strategies and insufficient visibility of cancer registration. Health disparities and inequities in access to

and quality of cancer care across the region could worsen. The lack of robust cancer research infrastructure and limited opportunities for collaboration might stunt progress in cancer prevention and treatment. Such circumstances would also hinder progress towards global and regional cancer control targets, making it difficult for countries to achieve their national strategic goals for cancer control and prevention.

The Imperative for Action in Cancer Control and Prevention

However, by implementing the recommended policies, EMR countries can establish robust cancer registries, which are essential for improving cancer care services, reducing cancer-related morbidity and mortality, and achieving national and international cancer control targets. Strengthening collaboration with international organizations and fostering regional cooperation can give EMR countries access to resources, knowledge, and support needed to build their capacity and accelerate progress in cancer control and prevention. Ensuring adequate staffing and continuous training in cancer registration will guarantee the collection of high-quality data, enabling evidence-based policymaking and facilitating the improvement of cancer care quality and patient experiences. Timely action to implement these recommendations will prevent further widening of health disparities and inequities in the region, ultimately contributing to better cancer outcomes for the EMR population.

REFERENCES

Alessy S et al. Cancer surveillance in the Eastern Mediterranean Region. East Mediterr Reg Spec Rep. 2022, 51, 90.

International Agency for Research on Cancer. (n.d.). WHO East Mediterranean (EMRO) - Fact sheets. Global Cancer Observatory. Retrieved May 3, 2023, from <https://gco.iarc.fr/today/data/factsheets/populations/993-who-east-mediterranean-emro-fact-sheets.pdf>

Abdul-Sater Z et al. Cancer registration in the Middle East, North Africa, and Turkey (MENAT) /region: A tale of conflict, challenges, and opportunities. Frontiers in Oncology. 2022, 12.

Znaor A et al. Use of cancer data for cancer control in the Eastern Mediterranean Region: Results of a survey among population-based cancer registries. International Journal of Cancer. 2020, 148, 593 - 600.

Centers for Disease Control and Prevention. (n.d.). National Program of Cancer Registries (NPCR). Retrieved May 17, 2023, from <https://www.cdc.gov/cancer/npcr/index.htm>

Tucker, T. C., Durbin, E. B., McDowell, J. K., & Huang, B. (2019). Unlocking the potential of population-based cancer registries. Cancer, 125(21), 3729-3737.

Marion Piñeros et al, A Global Cancer Surveillance Framework Within Noncommunicable Disease Surveillance: Making the Case for Population-Based Cancer Registries, Epidemiologic Reviews, Volume 39, Issue 1, January 2017, Pages 161–169, <https://doi.org/10.1093/epirev/mxx00>

GHD|EMPHNET: Working Together for Better Health

The Eastern Mediterranean Public Health Network (EMPHNET) is a regional network that focuses on strengthening public health systems in the Eastern Mediterranean Region (EMR) and beyond. EMPHNET works in partnership with ministries of health, non-government organizations, international agencies, private sector, and relevant institutions from the region and the globe to promote public health and applied epidemiology. To advance the work of EMPHNET, Global Health Development (GHD) was initiated to build coordination mechanisms with partners and collaborators. Together, GHD|EMPHNET is dedicated to serving the region by supporting efforts to promote public health policies, strategic planning, sustainable financing, resource mobilization, public health programs, and other related areas.

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