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## Cancer Registration in the Middle East

There is now extensive knowledge about cancer incidence in the Western and certain other parts of the world. Much of this knowledge comes from high quality population-based registries established in these countries.<sup>1</sup> Such knowledge is not currently available in most developing countries<sup>2</sup> and is particularly sparse in the Middle East.

The Middle East Cancer Consortium (MECC) (with membership comprising Cyprus, Egypt, Israel, Jordan, and the Palestinian Authority (PA)) was established in Geneva on May 20, 1996 through an agreement signed by each member's Ministers of Health and witnessed by the U.S. Secretary of Health and Human Services and by the Director of the U.S. National Cancer Institute (NCI). The goal of this new intergovernmental organization is to increase knowledge and ultimately to decrease the burden of cancer in the Middle East. Among the stated reasons for its creation is the conviction that "multilateral cooperation in the Middle East in medicine and health research will strengthen the bonds of friendship and understanding among their people and will advance the state of public health to the benefit of all parties, as well as mankind generally." One of its first activities is the establishment of cancer registries and development of linkages among them, as a critical step in public health planning, research, and the establishment of effective cancer control programs. The other major activity of the MECC at this time is the conduct of a program of small grants for collaborative research between MECC members.

### Background

At the start of this project, much of the information about the burden of cancer in Middle East populations came from mortality records, cancer specialty hospitals or case series.<sup>3,4</sup> Within MECC, Israel had an established population-based cancer registry

going back more than 40 years, Jordan had established a registry in 1996, and Cyprus established a registry in 1990 that functioned fully only until 1993. Egypt and the Palestinian Authority were proposing to initiate new registries.

The five members of MECC reflect a wide range of ethnicities and cultures, including places of birth (Europe, Asia and Africa are all well represented) and religions (Islam, Judaism and Christianity). Some sections of these populations are thought to be especially inbred and may demonstrate a variety of genetic mutations or unusual distributions of polymorphisms. The best known example at present is that of the Ashkenazi Jews in whom specific mutations of the BRCA1 and BRCA2 genes have recently been identified.<sup>5</sup> This variety makes comparison of cancer rates in the different populations all the more interesting. A central tenet of the MECC registry project is the standardization of data items, definitions, coding and quality control that will enable reliable comparisons to be made.

Although there is a lack of firm information on organ-specific cancer rates within the areas covered by MECC, information from some sources such as death certificates or hospital-based registries is available and indicates that there may be some unusual patterns. For example, El-Bolkainy reported that the most common cancer in Egyptian men is urinary bladder cancer,<sup>3</sup> a site that is comparatively low on the list of cancers in Western countries. This shift is thought to be connected to the widespread prevalence of schistosomiasis in Egypt. At a recent MECC meeting, the Palestinians reported preliminary information on cancer incidence, noting that lymphoma was the second leading type of cancer (after breast cancer) in Gaza and the West Bank. Furthermore it is notable that Israel has a low incidence of lung cancer compared with Western countries, despite a prevalence of cigarette smoking that is not unusually low.<sup>6</sup>

Further light on these and many other questions regarding cancer incidence can be shed by collecting

**TABLE 1. Location of Middle East Cancer Consortium Registries and Population Covered**

Registry	Population covered	Population size (1,000's)	Location
Cyprus	National	645	Nicosia
Egypt	Gharbiya Region	3705	Tanta
Israel	National	5700	Jerusalem
Jordan	National	4140	Amman
PA Gaza	Gaza*	2360*	Gaza City
PA West Bank	West Bank*		Bethlehem

\* The two registries together provide national coverage of the Palestinian Authority (PA) population.

reliable and complete data and making comparisons between incidence and mortality rates of the MECC members, and also with data from Europe and America. A particular hazard in uncontrolled comparisons is the widely different age distributions in the five registry areas (Table 1). The populations of Egypt (Gharbiya region), Jordan and the PA include a much smaller proportion of the elderly (9–13% over 50 years of age), compared with Cyprus and Israel (20–25% over 50 years of age). For this reason alone one would expect to see differences in crude incidence rates of cancers between these countries, and age adjustment is a prerequisite to proper understanding of the comparative data.

### Aims

The immediate aims of the project are to establish population-based registries for each MECC member, to ensure comparability of data, and to conduct comparisons of cancer incidence rates between MECC members and with other population-based registries around the world. There are also several long-term aims associated with the wider use of cancer registries. These include stimulating the use of cancer registry data for estimating the cancer burden, identifying unusual cancer patterns, and for health policy planning; stimulating joint research in cancer epidemiology between MECC members using cancer registry data as a starting point; and developing a cancer control strategy or program with the cancer registry as the focal point.

### Methods

The project opened on January 1, 1998. One of the first tasks was to take steps to achieve data comparability. In the 1st year of the project the MECC members agreed to a Manual of Standards for Cancer Registration that sets out the data collection and coding methods that all registries will use. At the same time a training program was initiated to teach registry staff the principles of cancer registration as laid out in the Manual. Both the writing of the Manual and the training were conducted by two of the authors (Steven Roffers and John Young).

A program to ensure comparability of data among registries requires several elements. First, MECC members have agreed on the definition and codes for 12 basic data items, including age, sex, date of diagnosis, basis of diagnosis, primary site code (ICD-O-2),<sup>7</sup> histologic type/behavior/grade (ICD-O-2),<sup>7</sup> and summary stage (SEER).<sup>8</sup> Second, five of the six registries have agreed to use common software, a version of CANREG developed by the International Agency for Research in Cancer (IARC). (The Israel registry already has a well-established software system and will not adopt the new software.) Third, staff from the various registries have participated in a standardized training course. Since the start of the project, three such courses in the principles of cancer registration have been given to MECC staff. Fourth, exercises are being conducted to evaluate the comparability of medical records abstracting and coding. The same case records are coded by the staff of each registry and the codes are then compared among different staff at the same registry and among registries. Fifth, aside from our training emphasizing the methods required to achieve high levels of completeness and accuracy, external assessors will conduct exercises to assess the levels of completeness and accuracy of the data at each registry. A random sample of treatment institutions in the region will be visited by the assessors, who will review all the records of cancer cases at these institutions and abstract the information required for the basic data items. They will then return to the registry notifications and check the proportion already registered, and the level of agreement between the abstracted information and that in the registry file.

### Comparison of Registry Data

Any project to develop a cancer registry is necessarily a long-term one. It is recognized that some years will pass before the data are of sufficient quality and completeness to provide a basis for reliable comparisons with other registry data. In the interim, MECC is conducting comparisons of the longer-established registries and will gradually increase coverage of the other registries as the project proceeds. The first interim comparison, that of Jordan's and Israel's 1996 data, is now in progress, in collaboration with the NCI.

### Summary

This project signals an advance in cancer registration in the Middle East region. While it is too early to declare a major breakthrough, significant strides have been made toward establishing a basis for reliable information on the cancer burden at a population level and future collaborative efforts in cancer epidemiologic research and prevention.

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## APPENDIX: MECC Organization

MIDDLE EAST CANCER CONSORTIUM BOARD OF GOVERNORS

Cyprus: Charatini Komodiki

Egypt: Amal Ibrahim

Israel: Bracha Rager

Jordan: Samir Al-Kayed

Palestinian Authority: Khamis El-Najjar

United States of America: Richard Klausner

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