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## History of Contemporary Medicine

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### Cancer Registry in Iran: a Brief Overview

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#### Abstract

Cancer registry is an important tool for any successful cancer control program. The first formal cancer related data from Iran were published in 1956. In 1969, observations documenting a high incidence of esophageal cancer in the Caspian Littoral, urged researchers to set up the first population-based cancer registry in this region. This cancer registry was established jointly by University of Tehran and the International Agency for Research on Cancer (IARC). In 1976, another cancer registry started its activities in Fars Province. In 1984, the Parliament passed a bill mandating the report of all tissues "diagnosed or suspected as cancer tissue" to the Ministry of Health. While only 18% of all estimated cancer cases were reported in first reports, this rate increased to 81% in 2005. In 1998, Tehran Population-Based Cancer Registry started to collect data from cases of cancer referred to the treatment and diagnostic facilities throughout the Tehran metropolis. Digestive Disease Research Center, Tehran University of Medical Sciences, established four new population-based cancer registries in Northern Iran and another in Kerman Province in the south. These five provinces have a total population of about 9.5 million, and constitute about 16% of the total population of Iran. While the pathology-based cancer registration is in place, we hope that the addition of the population-based cancer registries, and establishment of new registries in poorly-covered areas, will improve cancer reporting in the country.

**Keywords:** Cancer registry • esophageal cancer  
• Iran • population-based cancer registry

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#### Introduction

During the past century, chronic diseases, including cancers, have emerged as among the most challenging problems for public health systems in medium- and low-resource countries. One of the first steps in controlling the cancer burden is to collect information about the incidence, type, and location of cancers, and this is best done within the framework of cancer registries.<sup>1</sup>

#### Cancer registry in the world

In 1930, cancer registry was perceived as an effective preventing and controlling tool for cancers. As a result, the first population based cancer registry units covering data derived from whole countries initiated in Hamburg (1927), New York (1940), Connecticut (1941) and Denmark (1942).<sup>1</sup> The first cancer registry conference based on population resources was organized in 1946.<sup>2</sup> The conference offered several ideas to support local and global establishment of cancer registry units to WHO. These included the following: 1. Data collection from cancer patients are very profitable, 2. Data collection should be obtained in an organized manner, and 3. Establishment of an international headquarters is an essential bridge to make linkage of national and international statistical flow. In 1950, WHO organized a committee to support cancer registry programming.<sup>3</sup> In 1965, International Agency for Research on Cancer (IARC) was established in order to specify cancer related research topics by WHO and in 1966, the International Association of Cancer Registries (IACR) started its work officially and published its first global report, "cancer in five continents". Nowadays there are more than 200 cancer registry centers all over the world, but there is considerable difference in coverage across the world, for instance 99% of the population in North America is covered by cancer

registries, while this is about 8% in Asia.<sup>1</sup>

### Cancer registry in Iran

The first activities in Iran aiming at organizing cancer reporting were initiated in 1955, by the establishment of Cancer Institute in University of Tehran (now the Institute is part of Tehran University of Medical Sciences). The first formal cancer related data from Iran were published by Habibi in 1956.<sup>4</sup> This report included data obtained from years 1945–1956. Based on this report the prevalence rates of cancers were 28/100,000 in south and 42/100,000 in north part of the country. In 1969, observations documenting a high incidence of esophageal cancer in the Caspian Littoral, urged researchers to set up the first population-based cancer registry in this region.<sup>5</sup> This cancer registry was established jointly by University of Tehran and the International Agency for Research on Cancer (IARC). It started in the city of Babol in Mazandaran province, on the Eastern side of the Caspian Littoral, and subsequently extended to the Western province of Gilan.<sup>6</sup> Based on the data from this registry, Mahboubi et al<sup>7</sup> reported an incidence rate of higher than 100 per 100,000 person-years for esophageal cancer in the eastern portion close to Turkmenistan (now Golestan Province), particularly in the semidesert plain settled mainly by people of Turkmen ethnicity (109 per 100,000 among men and 174 per 100,000 among women).

In 1968, another cancer registry started its activities in Fars Province.<sup>8</sup> This registry collects data on all cases of cancer in Shiraz, which is situated in the south of the country.<sup>9</sup> These efforts were interrupted in the early 1980s due to the sociopolitical events in Iran, including the revolution and the war with Iraq.

In 1984, the Parliament passed a bill mandating the report of all tissues “diagnosed or suspected as cancer tissue” to the Ministry of Health.<sup>10</sup> The purpose of the bill was mentioned as promotion of “conducting epidemiologic research, regional prevention programs, and extracting statistical data on cancer patients”. Pathology centers are required by law to report all cancer cases according to International Classification of Diseases-Oncology (ICD-O). The reports have been published regularly in Persian since 1999, and while in its first year, only 18% of all estimated cancer cases were reported, this rate increased to 81% in 2005<sup>11</sup>.

In 1998, Tehran Population-Based Cancer

Registry (TPBCR), also known as Tehran Metropolitan Area Cancer Registry (TMACR), started to collect data from cases of cancer referred to the treatment and diagnostic facilities throughout the Tehran metropolis.<sup>12</sup> This registry is a collaborative program of the Cancer Institute Research Centre and the International Agency for Research on Cancer, and is funded by different research centers and Tehran University of Medical Sciences.<sup>13</sup>

In 1992, Digestive Disease Research Center (DDRC), was established in Tehran University of Medical Sciences. The Center had investigations on upper GI cancers as one of its main missions,<sup>14,15</sup> and was recognized as a WHO collaborating Center for research on Gastrointestinal Cancer in the year 2006. DDRC established new population-based cancer registries in Northern Iran in collaboration with IARC, Center for Disease Control in Iranian Ministry of Health and local medical sciences universities. The first of these registries was set up in Ardabil in the Northwest. The Ardabil Cancer Registry office is currently run by Ardabil University of Medical Sciences and supervised by the DDRC, and it has been a member of IACR since 2005.<sup>16</sup> This registry was extended to the east, including Gilan, Mazandaran<sup>17</sup> and Golestan<sup>18</sup> provinces. Northern Provinces were selected for 2 main reasons: the high incidence of upper GI cancers reported in these provinces and the availability of cancer registry data of this region from the 1970s.<sup>17,19</sup> Another center was established in Kerman Province in the south-central part of Iran. This registry aimed at providing a comparison site for cancer risk with the registries located in the North.<sup>20</sup> These five provinces have a total population of about 9.5 million, and constitute about 16% of the total population of Iran. They also include three major ethnic groups in the country: Persian, Azari Turk, and Turkmen.<sup>21</sup> All of these registries are now run by the local universities of medical sciences. In addition, other population based cancer registries in central and southern provinces have been established by Shiraz and Semnan Universities of Medical Sciences.<sup>9,22</sup>

A series of reports from these registries have been published showing a declining incidence of squamous cell cancer of esophagus and small bowel lymphoma (immunoproliferative small intestinal disease) with concomitant rise in the incidence of colon, breast and distal esophageal

adenocarcinoma. Another important finding has been a high incidence of gastric cardia adenocarcinoma especially in North western provinces.<sup>18-28</sup>

### Conclusion

Population-based cancer registries, by definition, use multiple sources (including hospital records, records from diagnostic facilities and even death certificates) to collect cancer data.<sup>1</sup> While this is usually easier to achieve in smaller countries, a vast geographical territory such as Iran, with its climate and cultural diversity, may pose technical and logistic problems to this objective. Legislations in place are indeed helpful in establishing pathology-based registries, but they lack direct support for multiple-source, population-based cancer registries. While the pathology-based cancer registration is in place, we hope that the addition of the population-based cancer registries, and establishment of new registries in poorly-covered areas, will improve cancer reporting in the country. One problem the authors faced while composing this overview was the scarcity of published sources regarding cancer registration in Iran. Almost none of the registries named in this overview have an active website and most of them publish their results infrequently (if ever), or at least their publications are not easily accessible.

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