

## Effectiveness of Cancer Registries

Review Article

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### Abstract

Cancer is identified as one of the greatest morbidity and mortality causes throughout the world. The purpose of this work is to show the importance and impact of cancer registries on identification and treatment of cancers. Cancer registries are instrumental in identifying distribution of incidence and burden, risk factors, and at risk populations. By understanding its efficiency and cost effectiveness, policy makers, private stakeholders, and health ministries can implement these high quality data collection methods throughout expanding locations.

**Keywords:** Cancer; Registry; Morbidity; Mortality.

## Introduction

Cancer, also known as malignant neoplasm, is defined as an abnormal division of cells that may spread throughout the body and affect or destroy normal tissue [1, 2]. This generic term encompasses many diseases arising from different cell types and locations. These diseases account for one of the greatest morbidity and mortality causes throughout the world. According to the World Cancer Report, in 2012 the incidence of the disease was approximately 14 million; 8.2 million cases were fatal [3]. Over the next 20 years, the incidence rate is expected to increase by 70% [4]. In the United States it is projected that in this year alone over 1.5 million new cases will be diagnosed. Nearly 600,000 individuals will find the disease fatal this year as well [5].

In 1728, the first systematic collection of cancer diagnoses was described in London as the “General Census of Cancer” [6]. Later in the early 1900s the first modern cancer registries began developing in the United States and Europe. In 1965 hospital based registries were encouraged by the American College of Surgeons. Their thoughts behind developing this program was that by using the data collected by these registries, physicians may increase their knowledge of the disease and the most effective treatment. Most of the information was originally stored on cards in basements and near inaccessible. After the development of computer based registries in the 1980s, accessibility became

increasingly available to physicians and researchers. Diagnoses were standardized as well as the data. Information from many registries were able to be combined to form cumulative data pools [7]. In 1992, the National Program of Cancer Registries (NPCR) was established by the Centers for Disease Control and Prevention (CDC) through the Cancer Registries Amendment Act [8]. Today, global registries are being attempted through the implementation of standardized systems even in lesser-developed countries [7].

Currently, according to the National Institute of Health, the purpose of cancer registries is “to establish and maintain a cancer incidence reporting system; to be an informational resource for the investigation of cancer and its causes; and to provide information to assist public health officials and agencies in the planning and evaluation of cancer prevention and cancer control programs” [9]. The data collected is a “primary source for unbiased population-based case control studies, the end points for cohort studies and clinical trials -- and perhaps most importantly, the beginning point for survival analysis” [9].

## Revealing Distribution of Incidence and Burden

Due to the location, standardization of case definition, and credibility received via the use of major agencies, cancer registries are an efficient, cost-effective method for revealing distribution of incidence and burden of this disease.

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Received: February 01, 2018

Accepted: February 15, 2018

Published: February 19, 2018

Citation: Pichainarongk S, Bidaisee S. Effectiveness of Cancer Registries. *Int J Chronic Dis Ther.* 2018;4(1):67-69. doi: <http://dx.doi.org/10.19070/2572-7613-18000013>

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The NPCR maintains registries representing 96% of the population in the United States. The remaining population is covered by the National Cancer Institute's (NCI's) Surveillance, Epidemiology, and End Results (SEER) Program, allowing for 100% coverage. There is a large disparity in the amount of the population covered by registries in developed versus developing countries [8]. North America has 83% of their population covered while only 6% of Central and South America. 80% of Australia is represented compared to 1% of the entire population within Africa [10].

Many studies are able to use different cancer registries as a source for their data to allow a better estimation of disease burden and incidence. These researchers can organize the information to reveal information about incidence and prevalence of the disease based on many different factors. These factors often include region, gender and age but may also have information on the ethnicity, socioeconomic status, and other demographics.

An example of a study efficiently using different registries to perform reliable research is titled, "Using surveillance data to understand cancer trends: an overview in Morocco". Because there is not one central database, two population based registries were utilized to determine distribution of cancer. One was region based and accounted for approximately 12% of the population in Morocco. The second was a specific registry for the region of Rabat and accounted for approximately 2.1% of the population in Morocco. These registries included data on "date of diagnosis, confirmation of diagnosis, histological type and differentiation, extension of the tumor, classification, stage and treatment, as well as socio-demographic information". Incidence and prevalence of regions were then easily determined [11]. Because a standardized case definition is used by registries internationally, comparison of burden is easily performed.

The International Agency for Research on Cancer (IARC) is an agency maintained by the World Health Organization (WHO) [3]. They are great advocates for cancer registries used as effective methods for identifying disease burden. In their recently published *Cancer patterns, trends, and burden* registries worldwide were used as their data source [12]. It showed how the incidence of certain cancers were rampant in certain regions and near absent in others. An example of this was that of gastrointestinal cancers; in southern Europe the incidence was extensive but rare in northern Europe while. The opposite was found true for lung cancer incidence, being more prominent in the north and less in the south. Understanding the distribution allows registries to begin identifying possible risk factors localized to these areas.

## Identifying Risk Factors and at Risk Populations

After understanding the distribution of the incidence and prevalence of certain cancers, risk factors and at risk populations may be identified via these registries. Even if the registry does not collect information on the specific risk factor or vulnerable population of interest, it may be used in conjunction with other research to form a proper hypothesis.

If observing by region, different data on the region may be interlaid so that ideas and hypotheses may be extrapolated. For

example, if an organization or individual proposes that those living in urban areas in the United States have a higher incidence of cancer, data of cancer incidence in the United States may be superimposed on data of rural regions to identify the possibility of a relationship.

An example of a study that used a cancer registry as their data source for cancer diagnoses was *Identifying risk factors for disparities in breast cancer mortality among African-American and Hispanic women*. This study used data from 3 different sources: female breast cancer cases were obtained from the Texas Cancer Registry, socioeconomic and demographic data were from Census 2000, and network distance and driving times to mammography facilities were estimated using Geographic Information System techniques. This information was used in conjunction with each other to determine that "late-stage diagnosis, poverty factors, and demographic factors were found to be significant predictors of a census tract showing significant racial disparities in breast cancer mortality" [13].

Risk factors and at risk populations may be determined simply by using information from just the registries as in a comparative study on thyroid cancer. The aim of the study was to compare the two populations, one in the United States and one in Sicily to determine risk factors and incidence. The registries not only included information about the malignancy but about the demographics of the individuals diagnosed. The data was organized in a way to determine that incidence was double in Sicily compared to the United States and twice as high in volcanic areas of Sicily than non-volcanic. Identification of volcanoes being a risk factor for the disease allows these registries to then assist in performing appropriate, efficient interventions [14].

## Discussion

Data quality, quantity, and distribution of cancer registries are improving, allowing better understanding of cancer statistics and treatment in areas otherwise unknown. These registries are necessary to efficiently and cost-effectively plan and evaluate interventions.

By identifying vulnerable populations, cancer registries can be instrumental when determining the details of an intervention. The registries show which population the intervention would be most effective for. As suggested by a study in China that used cancer registries as their data source and found a sharp division between rural and urban incidence of cancer, interventions should be tailored based on practicality on each population [15]. They are also a source of data for long term studies that are evaluating interventions. By monitoring the incidence rate for the cancer of interest over years, the effectiveness of the intervention can be properly evaluated.

The IARC under the WHO has developed the Global Initiative for Cancer Registry Development (GICR). It is a coordinated movement to create and maintain cancer registries so that low and middle-income countries have the tools and data to create policies and interventions via understanding cancer incidence, burden, risk factors and vulnerable populations [16]. They have developed six Regional Hubs and their mission is to have 20 active registries in low and middle-income countries by 2020 and by

2025 an additional 30 [17].

## Conclusion

Cancer registries are a simple organized system, but their existence allows a pool of data with vast knowledge and capability to understand this deadly disease. Through proper record keeping of high quality data, specific cancer's distribution of incidence and prevalence can be determined. After doing so, the data can either be compared to the demographic data already collected by the registry, or extrapolated with other research to understand and identify risk factors and vulnerable populations. Planning and evaluating interventions is the landmark feature of proper cancer registry systems. The long term existence of these agencies allow the replacement of expensive, extensive case control, cohort, or evaluative studies, to be as simple as long term follow-up with the cancer registries themselves to determine impact of the intervention. By understanding its efficiency and cost effectiveness, policy makers, private stakeholders, and health ministries can implement these high quality data collection methods within their locations.

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