

## History of cancer registration in Georgia

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### Summary

The importance of cancer registries lies in the fact that they collect accurate and complete cancer data that can be used for cancer control and epidemiological research, public health program planning, and patient care improvement. Cancer registration is the basic method by which information about the incidence, type, extent of disease at time of diagnosis, treatment methods used and survival of patients with cancer is systematically collected (Wagner, 1991). Cancer registries play an important role in the fight against cancer. Local, state and national cancer agencies use registry data in defined areas to make important public health decisions that maximize the effectiveness of limited public health funds, such as the placement of screening programs (Yasui et al., 2017). Cancer registries are valuable research tools for those interested in the aetiology, diagnosis and treatment of cancer. Fundamental research on the epidemiology of cancer is initiated using the accumulated data. Lifetime follow-up is an important aspect of the cancer registry (Stiller, 1993). Current patient follow-up serves as a reminder to physicians and patients to schedule regular clinical examinations and provides accurate survival information. The roles of hospital-based, pathology-based, and population-based cancer registries are different and complementary. The first two types of registry serve important administrative and clinical functions, but only PBCRs provide an unbiased profile of the present cancer burden and how it changes over time. PBCRs have a unique role in planning and evaluating population-based cancer control actions aimed at reducing the cancer burden in the community (Parkin, 2006). In 2015, Population-based Cancer Registry, which is an organized system for collecting, storing, analyzing, interpreting and presenting the cancer data, was implemented in Georgia. The Registry plays a significant role in terms of gathering qualitative data of cancer incidence and prevalence. Using this type of registry is important for cancer control programs' assessment, for the defining and planning priority interventions, for cancer screening and for proper implementation other preventive measures, as well as for evaluation of the service effectiveness to determine the oncological patients' medical care dynamic observation. After the introduction of cancer registry in Georgia, the registered incidence of malignant neoplasms almost doubled (NCDC Annual Report 2016, 2015). A review of the latest data obtained from the registry indicates that it records more cancer cases than were known of before it was introduced. The cancer incidence rate derived from this registry is close to the average rates for both the European Region and the CIS (Medical Statistics, 2016).

**Keywords:** cancer registries, cancer prevention, cancer control, cancer screening program, cancer surveillance, cancer history, cancer incidence rate, population-based survival public health planning, SEER.

### Introduction:

Cancer is a leading cause of death worldwide, accounting for 8.8 million deaths in 2015. More than 20 million new cases of cancer are predicted worldwide in 2025, with four fifths of the burden falling on low- and middle-income countries (LMICs) (World Health Organisation, 2017). To understand the local cancer situation and tackle the increasing incidence, there is a pressing need for planners to have relevant and unbiased data on the cancer burden in their communities. Physicians need cancer data to learn more about the causes of cancer and detect cancer earlier, thereby increasing the chance of finding a cure (Parkin, 2006). Cancer specialists make treatment choices based on accurate cancer data from such sources as reports from pathologists and cytologists. Even after treatment, cancer specialists still need cancer data to follow-up with the patient long enough to determine whether the treatment has worked and, if not, to determine why not. Cancer data may

point to environmental risk factors or high risk behaviours, so preventive measures can be taken to reduce the number of cancer cases and resulting deaths (World Health Organisation, 2007).

A cancer registry is an information system designed for the collection, management, and analysis of data on persons with the diagnosis of a malignant or neoplastic disease (cancer) (IARC, n.d.). Cancer registries can be classified into three general types:

- ◇ Healthcare institution registries: maintain data on all patients diagnosed and/or treated for cancer at their facility. Healthcare facilities report cancer cases to the central or state cancer registry as required by law.
- ◇ Central registries: population-based registries that maintain data on all cancer patients within certain geographical areas.
- ◇ Special purpose registries: maintain data on a particular type of cancer, such as brain tumours (IARC, 2015).

### **The history of cancer registration:**

The idea of using a written, catalogued registry of man's afflictions in order to understand them better dates to at least the late 16th century. Prompted by the seemingly random geographic ravages of the plague, the English Crown appointed elderly, epidemic-scarred women to prowl the countryside in search of the dead and dying. These 'Ancient Matrons' published weekly 'Bills of Mortality' for each parish, tabulating deaths by causes such as 'the purples' (probably leukemia), 'ricing of the lights', 'consumption' (often an effect of cancer), and of course, the plague (Bellhouse, 1998). Just how this information was used is not recorded. Perhaps the royalty found it helpful to determine where the plague was active so they could be somewhere else.

Around 1665 a London businessman, John Graunt, created medical history by subjecting decades of mortality data to critical and mathematical analysis. He literally invented the science of medical epidemiology and statistics, publishing a pamphlet with 108 conclusions (Graunt, Mentioned, Upon, Society, & Warden, n.d.). The list included such revolutionary observations as the facts that women saw physicians twice as often as men yet lived longer, and plague epidemics moved outward from swampy areas. Graunt also was the first person to use mortality statistics to project population survival, probably by crudely fitting data samples to a logarithmic curve. For his efforts John Graunt became the first non-scientist appointed to the Royal Academy. A few years later Sir Edmund Halley, of comet fame, used Graunt's inspiration to create the first actuarial tables for an emerging French life insurance industry (Bacaër, 2011). The "life table" concept is now the backbone of the cancer outcomes analysis.

The first cancer registry began in London in 1728 (Wagner, 1991), and the first known hospital devoted to cancer patients opened in France in 1740 (Faguet, 2015). One of the first recorded uses of cancer patient data was the work of Sir Percival Potts in 1775, identifying the cause of scrotal cancer in chimney sweeps (Krush & Krush, 1982). An example of mandatory reporting of cases of specific diseases occurred with the Factory act in 1885 in England and Wales. It made epitheliomas, which were caused by tar and other petroleum products, reportable.

General cancer morbidity data was first collected in Germany, where all physicians and hospitals began to report cancer statistics in 1904. The first population-based cancer registry was set up in Hamburg (Germany) in 1926 (Tsoi, Chan, & Hirai, 2017). Three nurses visited hospitals and medical practitioners in the city at regular intervals. They recorded the names of new cancer patients and transferred data to a central index in the health department. This index was compared once a week with official death certificates (Becker-Hinrichs, 2012).

The first nationwide registrations were made in Norway and Denmark shortly after the war. Zaragosa, Spain, initiated a population based registry in 1960 (Navarro et al., 2010).

In the United States, cancer registration was first attempted in a limited way in 1921 in the bone sarcoma registry of Dr. Ernest Codman. A major problem Dr. Codman experienced were differences in nomenclature and classification of disease. This led to a joint effort by the American Society of Clinical Pathologists and the American College of Surgeons to develop a standard classification and nomenclature to be used by all physicians for cancer cases.

The first hospital registry was established at Yale-New Haven Hospital in New Haven, CT, in 1926, and the first central or state registry was established in Connecticut in 1935. In 1956, the Commission on Cancer of the American College of Surgeons supported the development of hospital-based registries by requiring a cancer registry for approved cancer programs.

In 1971, the National Cancer Act budgeted monies to the National Cancer Institute (NCI) for research, detection, and treatment of cancer and, in 1973, the Surveillance, Epidemiology and End Results (SEER) Program of NCI established the first national cancer registry (Role & Registrars, 2010). In October 1992, Congress established a National Program of Cancer Registries (Public Law 102-515, The Cancer Registries Amendment Act). The National Program of Cancer Registries Act was passed to help states without registries to develop a cancer data system and to assist those state registries already in existence (Galloway, Laimins, Division, & Hutchinson, 2016). In 1993 state laws emerged making cancer a reportable disease.

The International Association of Cancer Registries (IACR) was formed in 1966. The main objective of this association is to develop and standardize the collection methods across registries to make their data as comparable as possible (Whelan, Moore, & Park, 2010).

The legislation authorized the Centre for Disease Control and Prevention (CDC) to provide funds to states and territories to enhance existing cancer registries and to plan and implement registries where they do not exist. In 1995, 42 states and the District of Columbia received CDC support for cancer registries. Today, the CDC supports forty-five states, the District of Columbia, Puerto Rico, and the U.S. Pacific Island jurisdictions.

The advent of microcomputer registry systems in the 1980's created a new window of opportunity for making registry information work to the patient's benefit. Standardization of data collection has made it possible to pool data from multiple registries in such projects as the National Cancer Data Base (NCDB) of the Commission on Cancer (CoC - a division of ACoS).

At present, more than 200 population-based cancer registries exist in various parts of the world. They cover about 5% of the world's population, but the proportion is much greater in developed countries than in developing ones. Moreover, in developing countries, registries are more likely to cover urban areas, where access to diagnostic and treatment services is better. In most countries, however, population-based cancer registries cover only a proportion of the population (e.g., Colombia, India, Italy, United States). Some specialized registries that cover only the registration of specific age groups (e.g., childhood cancers in Oxford, UK) or particular cancer sites (e.g., gastrointestinal cancers in Dijon, France) have also been established. In addition, hospital-based cancer registries have been set up in a large number of hospitals worldwide.

#### **Recorded information:**

Information recorded in the Cancer Registry is divided into personal characteristics (at date of diagnosis) and tumor characteristics. The variables containing personal characteristics are the unique personal identification number, date of birth, sex, age at diagnosis, the municipality and county/region, and the date of death (Chaudhry & Luthra, n.d.) The variables containing tumor characteristics are the diagnosis according to the 10th revision of the International Classification of Disease (ICD-10), modified diagnosis based on the 3th revision of the International Classification of Disease for Oncology (ICD-O-3) for topography, morphology and TNM classification for stage (where T denotes the size of the tumor, N denotes the presence of regional lymph nodes, and M denotes the presence of distant metastases)(Bray et al., 2014).

Information maintained in the cancer registry includes: demographic information, medical history, diagnostic findings, cancer therapy and follow up details. The data is used to evaluate patient outcome, quality of life, provide follow-up information, calculate survival rates, analyze referral pattern, allocate resources at regional or state level, report cancer incidence as required under state law, and evaluate efficacy of treatment modalities (Zachary et al., 2015).

Cancer registration data, however, provide more comprehensive, more valid and more detailed information on patient characteristics than can be obtained from death certificates(Teppo, Pukkala, & Lehtonen, 2009). Moreover, reliable cause-specific mortality data are available in most developed countries but in only a few developing countries. Thus, cancer registries may be the only way of obtaining information on the burden and patterns of cancer in developing countries, as well as providing a focus for research into etiology and prevention (Brawley, 2016).

#### **Incidence rates:**

A major activity of the cancer registries is the calculation of incidence rates. Incidence rate is defined as the number of new cases of disease, which occur in a defined population of disease free individuals, over a specified period of

time (Coleman, Muir, & Menegoz, 1992). The incidence rate of cancer is generally expressed for 100,000 population over one year (or a block of few years)(Jensen & Storm, 1991). The International Agency for Research on Cancer, in its publication on The Cancer Incidence in Five Continents, provides such rates for a period of five years. The cancer registries calculate incidence rates for every 5year age category for each sex (age & sex specific incidence rates). The incidence rate when expressed for all ages is called crude incidence rate, and provides a direct estimate of the probability or risk of the illness for the concerned population. It is well known that cancer does not occur with uniform rate in different age groups. Thus, for comparison of incidence rate in different areas or for the same area over a long period, it is necessary to adjust the rates for variations in the proportion of population in different age groups (Silva, 1999). The generally adopted procedure is that of direct standardization, which applies the age & sex specific incidence rates of the area under consideration, to world standard population, to derive the number of cancer cases expected to occur in the standard population. Such age standardized (or adjusted) incidence rates are useful in international or secular comparisons (IARC, 2015).

#### **Cancer control:**

Cancer control planning without reliable data from cancer registries is prone to misplaced emphasis and wasted investment. This is exactly the position many countries still find themselves in at the beginning of the 21st century. Particularly in low- and middle-income countries, this situation reflects a lack of advocacy for the value of registries, a lack of trained staff and other resources, and a lack of prioritization for "counting cancers" in among the many demands on limited health care services.

Population-based cancer registries (PBCRs) provide such information and are a standard requirement for cancer control planning and evaluation in every country of the world. They are especially valuable in LMICs, where few other population-based data on cancer occurrence and outcome are available.

Hospital-based cancer registries are concerned with the recording of information on the cancer patients seen in a particular hospital. The main purpose of such registries is to contribute to patient care by providing readily accessible information on the subjects with cancer, the treatment they received and its result. The data are used mainly for administrative purposes and for reviewing clinical performance. Although these data may be used, to a certain extent, for epidemiological purposes, these registries cannot provide measures of the occurrence of cancer in a defined population because it is not possible to define their catchment populations, that is the populations from which all the cases arise.

The World Health Organization (WHO) notes that population-based cancer registries (PBCRs) are a core component of cancer control strategy (WHO, 2011). There are important roles for PBCRs in estimating the current cancer burden, examining recent trends, and predicting their probable future evolution. The scale and profile of cancer can be evaluated in terms of incidence and mortality, but other dimensions are often considered, including prevalence, person-years of life lost, and quality- or disability-adjusted life years. An appraisal of the current situation provides a framework for action, and cancer control planning should include the setting of explicit targets, which permits the success (or otherwise) of interventions to be monitored.

### **Cancer registry in Georgia:**

The major causes of death in Georgia are related to non-communicable diseases (NCDs) including circulatory diseases, cancer, diabetes and respiratory diseases. Due to the collapse of the registration system in the country, which interrupted surveillance of cases of some chronic diseases the availability of consistent data on malignant neoplasms and cancer morbidity in Georgia is limited. Reported cancer incidence and mortality rates from malignant neoplasms in Georgia are therefore significantly lower than the average rates for both the CIS and the European Region (2017 The Regional Office for Europe of the WHO, n.d.).

Cancer is becoming a global health problem and the number of cancer cases in Georgia is rising. Being an European country, Georgia has its share of cancer burden. However, population-based data in cancer incidence, prevalence, and mortality in Georgia were not available and most published cancer cases were based on estimates from hospital-based information sources. Most of these sources are maintained by individual health institutions and are mostly paper based.

On 1 January 2015, Georgia established a population-based cancer registry in order to improve the epidemiological surveillance of cancer.

Cancer registration in Georgia follows international standards and recommendations. The Georgian Cancer Registry covers the entire population of Georgia. Doctors in all health care facilities are required to send full details of every new cancer case to the central registry. In each oncologist is responsible for registering incidence, diagnosis, and treatment details. All health care providers in the state of Georgia are required to report specific information on cancer in their patient population to the Georgia Comprehensive Cancer Registry. This includes all facilities providing diagnostic evaluations and/or treatment for cancer patients, including but not limited to: Hospitals, Outpatient surgical facilities, Laboratories. Radiation therapy facilities, Medical oncology facilities, Physicians and Physician's Offices. 210 medical facilities, including 36 labs, were involved in reporting system, 19061 forms were received during one year reporting period. Consultations of the personnel, in-

involved in the cancer registration, correction of the reporting forms, and software support was conducted permanently. Cancer Registry 2015 data analysis was prepared and published.

Data collected within this registry significantly changed perspective regarding cancer morbidity. In 2015, according to the CPR data, there were registered 10506 new cases of malignant neoplasms, including no melanoma skin cancers and cancers in situ. According to recommendations of the International Agency for Research on Cancer (IARC), all cancer cases except no melanoma skin cancers and cancers in situ, must be used for statistical calculations. In 2015, this number constitutes 9598 cases. The incidence rate is 258.2 per 100000 population; this is close to the IARC estimates (NCDC, 2016 Health care). The following cancer stage distribution for all localization of cancers was found: the first stage – 20%, second – 20%, third - 23%, fourth - 28%, unknown - 9%.

Based on the data from population based cancer registries in Georgia the estimated number of new cancer cases for the year 2016 was 10097 The incidence rate for 100,000 population was 271.5, Among them, 44% were men and 46% were women.

### **Implications and future directions:**

Cancer registries are recognized as being more or less indispensable components of national cancer-control programs, and are likely to be founded in countries that implement such programs if they do not already exist. There are several advantages to the ongoing registration of cancers, rather than one-off surveys, but the desirability of national coverage, rather than sample sites, is less obvious. A limited geographic coverage is adequate for many descriptive and surveillance activities, and although national data are clearly superior, especially if follow-up of specific cohorts is required (to avoid losing track of migrating subjects), the costs involved should be weighed against the benefits. The expanding roles of registries in monitoring factors that influence outcome (survival and quality of life), and the nature and quality of the care received by cancer patients, demands a dataset that includes many more variables than has traditionally been collected. Sometimes this can be achieved through linkage to other files; sometimes an in-depth study of sample cases will be the more reasonable approach. Cancer registration has come a long way in the last 60 years, and future expansion in geographic coverage and scope of work seem reasonable predictions, unless registries fall foul of the objections to their work by the informed-consent ethicists.

## Conclusion:

The uses of population-based cancer registration data may be summarized as follows: (1) They describe the extent and nature of the cancer burden in the community and assist in the establishment of public health priorities. (2) They may be used as a source of material for etiological studies. (3) They help in monitoring and assessing the effectiveness of cancer control activities. Some of these functions can be fulfilled using mortality data derived from vital statistics systems.

Population-based cancer registries seek to collect data on all new cases of cancer occurring in a well defined population. Usually, the population is that which is resident in a particular geographical region. As a result, and in contrast to hospital-based registries, the main objective of this type of cancer registry is to produce statistics on the occurrence of cancer in a defined population and to provide a framework for assessing and controlling the impact of cancer in the community. Thus, the emphasis is on epidemiology and public health.

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