

**POPULATION CANCER REGISTRY IMPLEMENTATION RELEVANCE IN THE
REPUBLIC OF UZBEKISTAN****Djanklich S.M., Tillyashaikhov M.N., Berkinov A.A., Ibragimov Sh.N., Imamov.O.A., Sabirjanova Z.R.**

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SUMMARY

Cancer registration is the organization of the systematic collection, storage, analysis and provision of data about subjects with cancer. Population cancer registries collect data on all new cases of malignant tumors that are detected in a geographically well-defined population, for example, the population of a region or a republic. CanReg5 is open source software developed by the International Agency for Research on Cancer (IARC) specifically designed to capture, store, validate, and analyze population-level reported cancer data. In the Republic of Uzbekistan, it is planned to introduce a cancer registry in a pilot mode in one of the regions of the Republic, and subsequently in all regions, with the subsequent formation of a single database in the Republican Specialized Scientific Practical Medical Center of Oncology and Radiology.

KEYWORDS: Population cancer registry, malignant neoplasms.**Cancer registration history**

The registration of cancer patients has a long and complex history. The first known attempt to compile a census of cancer patients was made in Great Britain in 1728, and was unsuccessful. In the next two centuries, similar attempts were repeated, but the data obtained were not very reliable. By the end of the 19th century, German and English scientists came to the conclusion that it was necessary to obtain information on the prevalence of cancer. Beginning in 1900, in Germany, and then in a number of other European countries, attempts were made to obtain information about all cancer patients receiving treatment by interviewing doctors, but no more than half of the doctors filled out the questionnaires, and these attempts were also recognized as unsuccessful [12,15, sixteen]. The first serious attempts to count the number of new and existing cancer cases in a given population were made at the turn of the 19th and 20th centuries. However, the first population cancer registries in the world were organized at the beginning of the 20th century: in Canada, the USA, Scotland - in the 30s, in Australia, Denmark - in the 40s, in Japan, Finland and Sweden - in the 50s, in Israel and China - in the 60s.^[3] Namely, the first register approaching modern in structure can be considered the Hamburg register, formed in 1926 first as a private enterprise, and by 1929 passed under the auspices of the Hamburg Ministry of Public Health. Three nurses at regular intervals visited the Hamburg clinics and private doctors, wrote down the names of new cancer patients and transferred them to the archive. All the names of the

archive were checked weekly with the official list of the deceased, on the basis of which the register was formed. Already in 1935, the first ever population cancer registry was launched in the United States, and in 1942 in Denmark, the first national cancer registry covering the entire population of the country. Today the Danish Cancer Registry is the oldest operating cancer registry in the world.^[10,13,17-19] On this occasion, a conference was held in Copenhagen in 1946, in which leading experts in the epidemiology and treatment of cancer decided to recommend the creation of an Interim Commission for the Development and Distribution of Cancer Cancer Registries at the World Health Organization (WHO). After 4 years, a WHO committee for registration of cases of cancer and statistical processing of these data was created, which developed recommendations for the creation of cancer registries. By 1954, there were already 18 population cancer registries in the world, including in the USSR since 1953. Today, there are more than 700 population cancer registries in the world, and almost a quarter of them record individual oncological diseases, for example: the American Registry of Brain Tumors, the French Registry of Breast and Female Reproductive System Tumors, and the Pediatric Cancer Registry.^[1]

It is essential for the normal functioning of the registry to have supporters who can show decision-makers the value of cancer statistics and how they can be used to improve the delivery of health services. To this aim, at the UN Summit on Noncommunicable Diseases, which took place in October 2011, the World Declaration of Cancer

and the Global Initiative for the Development of Cancer Registries were developed, signed by heads of state around the world, which impose obligations on states to "support the development and implementation of the necessary multidisciplinary national programs and plans for the prevention and control of noncommunicable diseases".^[11,19,20,21] As part of this initiative, five training courses on basic cancer registration were conducted with the support of IARC in Russia and the countries of the former Soviet Union (Astana, Bishkek). This allowed many registers to re-evaluate their data, some to participate in international projects.^[1,3]

Basic information about cancer registration.

Cancer registration is the organization of the systematic collection, storage, analysis and provision of data about subjects with cancer. There are two types of cancer registries: hospital and population-based. Hospital registries are working to record information about cancer patients observed in a particular medical institution. The main purpose of such registries is to provide accessible information on patients with malignant tumors, their treatment and outcomes. These data are used mainly for administrative purposes and also to assess the quality of treatment in hospital departments. They can be used to a limited extent for epidemiological purposes in individual cases, but in general they cannot be used to measure the cancer burden, since they cover only an unknown part of the general population of cancer patients in a certain area in which this hospital is located.^[1,2,3]

Population cancer registries collect data on all new cases of malignant tumors that are detected in a geographically well-defined population, for example, the population of a region or a republic. As a result, there is an opportunity, unavailable in the hospital register, to conduct a statistical assessment of cancer incidence and cancer prevalence in a given area and to assess the survival rate and control the spread of malignant neoplasms in society. This is the main purpose of population registers and determines their importance in epidemiology and public health.^[1]

The main task of the Cancer Registry is the formation of a database on cancer patients, on the basis of which it becomes possible to carry out an adequate assessment of the state of cancer care in quantitative criteria, the possibility of monitoring (optimization) of the treatment process and dispensary observation, greater accuracy in conducting epidemiological studies and analyzing long-term results.^[2,3,11,16,22]

According to the research of many authors, in manual preparation, the calculation of indicators is very laborious and routine. In addition, it is almost impossible to check the quality of data and control duplicates. In addition, with this technology, there is no flexibility in obtaining new indicators, except for those included in standard statistical reports. All this leads to mistrust and unsatisfactory attitude towards medical statistics.^[4,5,7,8]

The volume of data entered into the register depends on the primary documents used by the register to obtain high-quality medical information. In the hospital register, such a document is the "Case history", in the population register - special registration forms. In the case of unqualified or incomplete filling of the primary documents, the possibilities of the register to conduct scientific research and obtain reliable results are reduced. Cancer is chronic in nature; the treatment process often takes several years. Even after the end of treatment, the monitoring of cancer patients does not stop. All information not only about the primary, but also about the subsequent treatment, about the occurrence of complications, relapses or metastases, about the death of the patient (from cancer or from other causes) is also entered into the register. This makes it possible to assess the long-term (5-, 10-years) survival rate of patients. But obtaining such information requires a proven technology for monitoring patients.^[3,5]

All statistical processing of the accumulated data consisted in the annual receipt of State Statistics Reports, until only paper forms were stored. At the same time, it was impossible to analyze the data in cases where the corresponding column was not provided for the groups of patients of interest to us. It was also impossible to move from the numbers in the statistical table to the constituent cases of the disease, for example, for verification or refinement, without repeating all the work of calculating the table. All this led to the fact that more attention by statisticians was paid not to obtaining high-quality information, but to making the statistical reports submitted to higher authorities look more attractive.

The modern information technologies implementation makes it possible to automate the counting process of any tables and indicators, instead paying more attention to the quality of primary medical information and the conduct of scientific research.^[6,8,9,10]

The informatization of processes ensures a decrease in the amount of paper circulation, ensures the speed of servicing patients, the accuracy and reliability of the information provided, and its storage on electronic media. With the correct and complete filling of the program, a large amount of statistical material can be obtained, on the basis of which it is possible to carry out various scientific developments with the conduct and analysis of observations of patients in dynamics.^[2,9,23-25]

Initially, in 2009, in the Republic of Uzbekistan, a database of patients who underwent treatment and diagnosis at the Republican Specialized Scientific Practical Medical Center of Oncology and Radiology was created on the basis of Access. This database consisted of the following modules: passport part, anamnestic data, diagnostics, types of treatment (surgical, radiation, chemotherapy, combined, complex) and outcome. This base was installed in all departments of the Republican Specialized Scientific Practical

Medical Center of Oncology and Radiology in order to carry out the test work with the subsequent elimination of the identified deficiencies.

After the test work, it was revealed that the program did not fully meet the requirements of the Ministry for the Development of Information Technologies and Communications of the Republic of Uzbekistan and required correction. In this connection, in 2012, a new software was created based on MS SQL, the cancer-register information system, which was installed with technical difficulties in almost all regional departments of the oncological service and in clinical departments of the Republican Specialized Scientific Practical Medical Center of Oncology and Radiology. However, over time, it turned out that this cancer registry also turned out to be inconsistent to the generally recognized international standards for cancer registration.

The main aim of the cancer registry is to improve qualified and specialized oncological care in the Republic, to study the reliability of statistical indicators on oncological services, their timely and high-quality collection and assessment, which will improve the level and quality of care, thereby contributing to a decrease in morbidity and mortality rates in the Republic Uzbekistan.

The CanReg5 program is an open source software developed by the International Agency for Research on Cancer (IARC) specifically designed to capture, store, validate and analyze data on reported cancer cases at the population level. The program was downloaded from the official IARC website and adapted, i.e. the necessary variables for qualitative collection of information were included, as well as to facilitate data analysis, many variables were coded (localization and histological type according to ICD 03, tumor staging using TNM classification, tumor behavior, method of diagnosis, etc.) and all the variables with the codifier were translated from English into Uzbek and Russian languages. About 20 variables were included to this software. These variables have key importance for the cancer registry operation and which should be collected for each case of malignant neoplasm.^[10,11,12,15-17,21-24]

The formation of a single information space that allows for multivariate analysis of the incidence of malignant neoplasms and mortality from them, the state of specialized care for cancer patients is possible only in the system of automated population cancer registries based on the corporate network of oncological institutions operating on a single methodological basis.^[4,5,7,8]

Long-term following-up of patients in the cancer registry is the only reliable method for studying the survival of cancer patients. The modern approach assumes that population monitoring of malignant neoplasms includes not only medical and scientific, but also economic and social aspects. The significance of the register is

determined by the quality of the stored information and the range of its use in research and in the development of the medical care system, increasing with the accumulation of information.^[6,7,8,14,25]

Cancer registries can be used

1. To describe the prevalence and properties of malignant tumors in general and for individual nosologies, which allows you to determine the priorities in the anti-cancer fight.
2. As a basic source for research on the cancer etiology.
3. To monitor and evaluate the effectiveness of measures to combat malignant tumors.^[1]

Prospects for further development

The formation of a unified population cancer registry in the Republic of Uzbekistan based on the interaction of existing branches of the oncological service will exchange information at the level of district oncologists, with their subsequent accumulation and transfer it to the head server of the Republican Specialized Scientific Practical Medical Center of Oncology and Radiology. The creation of a network of territorial cancer registries working according to a unified ideology and unified codifiers will make it possible to fundamentally change the degree of information support for decision-making at various administrative levels, create a central database of generalized data on patients with malignant neoplasms as a source of adequate information for governing bodies and system analysis of information.

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