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The History of Cancer Registration System in Uzbekistan

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Abstract A population-based cancer registry is an ongoing surveillance system that collects, stores, manages, analyses, and disseminates information on cancer occurrence in a defined population. Population-based cancer registry data are a cornerstone of cancer control, enabling planning, monitoring, and evaluating preventive activities and cancer care. In Uzbekistan, a cancer data collection system was established in the 1950s as part of the Union of Soviet Socialist Republics cancer surveillance system. The system has changed to the present day but is based still on passive reporting.

Keywords Cancer registry, Malignant tumors, Registration, Reporting

1. Introduction

Cancer registration 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. Similar attempts were repeated over the next two centuries, but the resulting data were not very reliable. By the end of the 19th century, German and English scientists concluded that it was necessary to obtain information on the cancer prevalence. In 1900, in Germany, and then in several other European countries, there were several attempts to obtain information on all cancer patients treated by surveying physicians. However, these attempts were also considered unsuccessful [1-3,12,15,16].

The first serious attempt to calculate the number of new and existing cancer cases in a given population were made at the turn of the 20th century. However, the first population-based cancer registries in the world were organized at the beginning of the 20th century: in Canada, USA and Scotland in the 1930; in Australia and Denmark in the 1940; in Japan, Finland, and Sweden in the 1950; and in Israel and China in the 1960 [4-6].

The first registry that approximated the structure of modern registries was considered to be the Hamburg Registry, founded in 1926 initially as a private enterprise, but by 1929 coming under the auspices of the Hamburg Ministry of Public Health. Three nurses visited Hamburg clinics and private physicians at regular intervals, recorded the names of new cancer patients, and transferred them to the archive. All names in the archive were checked weekly against the official list of the deceased, on the basis of which the registry was formed.

In the early 1935, the first population-based cancer registry was launched in the United States, and in 1942, the first national cancer registry covering the entire population was launched in Denmark. Today, the Danish Cancer Registry is the oldest of all active cancer registries in the world [10,13,17-19]. On this occasion, a conference was held in Copenhagen in 1946, at which leading experts in the field of epidemiology and cancer treatment decided to recommend the creation of Commission on the Development and Dissemination of Cancer Registries at the World Health Organization (WHO). Just 4 years later, it was established WHO Committee on Cancer Registration and Statistical Processing, which developed recommendations for the creation of cancer registries.

By 1954, there were already 18 population-based cancer registries worldwide. Today, there are more than 700 population-based cancer registries in the world, and almost a quarter of them record individual oncological diseases, for example: the American Brain Tumor Registry, the French Registry of Tumors of the Breast and Female Reproductive System, and the Children's Cancer Registry [1,13,14].

Cancer registration system is the systematic collection, storage, analysis, and reporting of data on cancer. There are two types of cancer registries: hospital-based and population-based. Hospital-based registries record information on cancer patients at specific medical hospital. The primary objective of such registries is to provide accessible information on cancer patients, their treatment, and outcomes. This information is used primarily for administrative purposes and to assess the quality of care within hospital departments. They may have limited epidemiological use in individual cases, but generally cannot be used to measure cancer burden, as they cover only an unknown portion of the overall cancer patient population in the specific area where the hospital is located [1,2,3,11].

Population-based cancer registries collect data on all new cases of malignant tumors diagnosed in a well-defined

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population, such as a region or republic. This provides the opportunity, unavailable through hospital-based registries, to conduct a statistical assessment of cancer incidence and prevalence, thereby enabling survival assessment [6,7,8,14]. This is the primary goal of population-based registries and determines their importance in epidemiology and public health.

The primary objective of a cancer registry is to develop a database of cancer patients, enabling an adequate quantitative assessment of the state of cancer care, the ability to monitor treatment and follow-up, and greater accuracy in epidemiological studies and the analysis of long-term outcomes [11,16,20].

Aim of this study is to evaluate the current state of cancer registration system in Uzbekistan.

2. Material and Methods

This study was conducted by a method classified as a qualitative study, without experimental methods and without data processing. Information on the cancer registration system was obtained from official reports and orders of the Republican Specialized Scientific-Practical Medical Center of Oncology and Radiology, its branches, and district oncologists (RSSPMCOR). In Uzbekistan there are 15 regional branches of RSSPMCOR. The Cancer registry department (CRD) in RSSPMCOR is mandated to collect data on cancer patients and act as the National Cancer Registry. Cancer registry department has at least 12 medical specialists and medical registrars. There are several positions at the CRD that are labelled: medical statistician, medical registrar, medical technician. At least two specialists are working at the CRD in each of the regional branches responsible for cancer registration.

3. Results and Discussion

In Uzbekistan, a cancer data collection system was established in the 1950s as part of the USSR cancer surveillance system. The system has remained virtually unchanged to the present day and is based on passive reporting using paper-based forms (Form 027-1, Form 090, Form 030). Then, aggregated data is reported in the set of tables (Forms 7) to the Cancer Registry Department at the Republican Specialized Scientific and Practical Medical Centre of Oncology and Radiology (CRD).

Initially in 2010 it was created a database of patients treated and diagnosed at the National Cancer Center in Uzbekistan. This database consisted of the following modules: patient information, anamnestic data, diagnostics, treatment types (surgery, radiation, chemotherapy, combined, and comprehensive), and outcome. This database was implemented in all departments of the National Cancer Center for testing purposes, followed by the elimination of any identified deficiencies.

After testing, it was discovered that the program did not fully comply with the requirements of the Ministry of Information Technology and Communications of the Republic of Uzbekistan for software products and required modification. Therefore, in 2013 it was developed new software - Cancer Registry information system. It was implemented in almost all regional oncology departments and in the clinical departments of the RSSPMCOR. The RSSPMCOR was partially equipped with the necessary equipment (server, computers, uninterruptible power supply) and local area networks (switch, fiber-optic cable) to implement this program at the regional oncology department level. However, over time, it became clear that this cancer registry also did not meet recognized international standards for cancer registration.

In 2017 following the issuance of Presidential Decree №2866 and in accordance with IARC recommendations, there was attempt to use CanReg5 information system, which is open-source software developed by the International Agency for Research on Cancer (IARC) and specifically designed for entering, storing, verifying, and analyzing data on registered cancer cases at the population level. In accordance with international guidelines, the CanReg5 program contains procedures for checking the consistency of information for the following combinations of attributes: Age/Dates of diagnosis and birth; Age/Localization/Histology (International Classification of Diseases for Oncology, 3rd edition [ICD-O-3]); Localization/Histology (ICD-O-3); Behavior/Localization (ICD-O-3); Behavior/Histology (ICD-O-3); Method of diagnosis/Histology (ICD-O-3). The staff of the National Cancer Center translated all reference books and codifiers, as well as all software fields, into Russian and Uzbek. In 2019, recommendation letter was received from IARC and WHO regarding the CanReg5 software product for use in the Republic of Uzbekistan.

To obtain official approval for the use of the foreign-language CanReg5 program, the National Cancer Center contacted the Center for the Development of Electronic Healthcare to review the program's functionality and further implementation. In response, the Center requested technical documentation for the CanReg5 program, including the technical specifications, the concept for creating information systems, and the feasibility study. However, it was impossible to find the relevant documentation for the foreign-language program. Work on implementing the cancer registry information system was suspended.

Over the past few years, a series of measures has been launched to create modern software for data collection, quality assessment, and reporting in accordance with international recommendations. In 2024, the IT company Uzinfocom, the Republican Scientific and Practical Medical Center of Oncology and Radiology (RSPMCOR), with IARC and WHO guidance, created a new information system for cancer registration. The system is automatically linked to the Republic of Uzbekistan's mortality and birth database. The program includes data entry modules, as well as functionality for data consolidation, analysis, and reporting. During 2024, all branches of the RSPMCOR were equipped with the necessary equipment for cancer registration. In November 2024 and September 2025, training seminars on the basics of cancer registration and the use of cancer registry software were held (approximately 50 registrars all over the Republic). The cancer registration system in Uzbekistan was gradually launched in January 2025. Currently, almost all branches of the RSPMCOR and the Republican Center for Pediatric Oncology, Hematology, and Immunology are involved in the cancer registration process. Today, more than 100,000 patients have been registered in the system, including approximately 23,000 new cases in 2025.

In October 2025, the Ministry of Health of the Republic of Uzbekistan, together with the Republican Scientific and Practical Medical Center of Oncology and Radiology, developed and approved an official document (Order №332 on the Registration of Cancer in the Republic of Uzbekistan). For the first time in Uzbekistan, all cancer registration procedures was described in this legal document (database, software, additional tools, personnel). Also, RSPMCOR with the help of IARC formed standard operating procedure for cancer registration, which describes both the technical and medical aspects of cancer registration.

4. Study Limitations

This study has several limitations that should be acknowledged. First, the analysis is based primarily on qualitative assessment of the cancer registration system using official reports and official documents, without quantitative evaluation of data completeness, accuracy, or timeliness. Second, due to the historical reliance on passive reporting and paper-based forms, there may be underreporting and inconsistencies in cancer data across different regions of Uzbekistan. Third, the absence of standardized nationwide digital data collection in earlier periods limits the ability to perform comparisons and other statistical analyses. Finally, as the modern electronic cancer registry system has only recently been implemented (2025y), its performance, data quality, and long-term sustainability require further evaluation through future studies.

5. Conclusions

Long-term patient tracking in a population-based cancer registry is the only reliable method for studying cancer patient survival. A modern approach assumes that population -based monitoring of malignant neoplasms includes not only medical and scientific aspects, but also economic and social ones. The registry's importance is determined by the quality of the information stored and the range of its use in research and the development of the healthcare system, increasing as information accumulates.

The creation of a unified population-based cancer registry in the Republic of Uzbekistan, based on the interaction of existing oncology service branches across the country, will facilitate the exchange of information at the district oncology level, with subsequent accumulation in its database and transmission to the main server of the Republican Scientific and Practical Medical Center of Oncology and Radiology. The creation of a network of territorial cancer registries operating under a unified ideology and standard codifiers will fundamentally improve the level of information support for decision-making at various administrative levels and create a central database of summarized data on patients with malignant neoplasms as a source of adequate information for governing bodies and for systemic analysis.

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