

## SHORT COMMUNICATION

# Population-based registry of cancer patients in the Russian Federation

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## ABSTRACT

The article describes the work of the population cancer registry of the Russian Federation. It outlines developments in the registration of oncological diseases in the country and the main principles that guided the formation of the current system. The registry operates in all constituent entities of the Russian Federation and is implemented as a multi-level system; it is maintained in the information-analytical system that was developed by the P. Hertsen Moscow Oncology Research Institute – branch of the National Medical Research Radiological Centre of the Ministry of Health of the Russian Federation. The registry allows the comparison of statistical indicators and other data from the various regions across time. The system also allows

the monitoring of the status of each patient, cohort and professional group. As a demonstration of the capabilities of the register, indicators of 5-year adjusted survival of women diagnosed with breast cancer C 50 established in 2013 are presented, depending on the stage of the tumour. This article was partially published in Russian in Kaprin A, Chissov V, Starinsky V, Gretsova O, Petrova G, Prostov Y. Information and analytical accounting system for cancer patients in the Russian Federation. *Oncology. Journal of P.A. Herzen.* 2015;4(5):40–3. doi:10.17116/onkolog20154540-43. The material is published for the first time in English.

**Keywords:** CANCER REGISTRATION, DATA QUALITY, CANCER STATISTICS, POPULATION-BASED CANCER REGISTRY.

Monitoring oncological diseases among a population is one of the tasks that must be carried out as part of the fight against noncommunicable diseases. Incidence of cancer can only be properly recorded by maintaining population-based cancer registries.

The International Agency for Research on Cancer (IARC) regularly publishes information about the incidence of cancer in the *Cancer Incidence in Five Continents* series. Volume XI contains information about new cases that were diagnosed from 2008 to 2012 in 343 cancer registries from 65 countries. The Russian Federation is represented in this publication by four regional cancer registries (1).

Regional cancer registries have been created in all the regions of the Russian Federation and together provide information on the registration of cancer for the entire population of the country, including populations residing in remote and sparsely populated territories.

The regulations of the Russian Ministry of Health define uniform rules for the registration of cancer patients and new incidents: medical organizations of all agencies and forms of ownership at which new cases of cancer have been detected, diagnoses have been recorded, cancer patients have received medical care including symptomatic, palliative or other treatment, or are undergoing follow-up monitoring, must report this information to the cancer registry covering the place where each patient is permanently registered. Information on the

detection of cancer incidents must be provided to the registry by pathoanatomical and medicolegal offices. Cancer patients undergo follow-up monitoring at cancer facilities for life.

Considerable attention has been paid to the registration of oncological diseases as far back as 1945, when Decree No. 935 of the USSR Council of People's Commissars "On measures to improve oncological assistance to the population" gave orders "to organize in 1945–1946:... a complete record of cancer incidence and the study of cancer mortality" (2). Starting in 1953, a system for registering and recording cancer patients was introduced throughout the Soviet Union.

Automation of the registration of cancer incidents started more than 20 years ago (1996). The P. Hertsen Moscow Oncology Research Institute – branch of the National Medical Research Radiological Centre of the Ministry of Health of the Russian Federation (P. Hertsen MORI) has been entrusted with the main functions of coordinating work on cancer-related problems (3).

The P. Hertsen MORI has developed a package of documents that includes guidelines concerning the registration, recording and follow-up monitoring of cancer patients, the format of official registration forms and how they should be completed, and the Comprehensive Classifier of Data on Cancer Patients for the Establishment of the State Cancer Registry (4–6). These documents were approved by Order No. 135 of the Russian Ministry of Health, dated 19 April 1999, "On Improvement of the National Cancer Registry System" (7).

Patients with a diagnosis code C00-D09 of the 10th revision of the International Statistical Classification of Diseases and Related Health Problems are subject to mandatory registration in the population-based cancer registry regardless of the genesis of the tumour, or the sex or age of the patient.

At present, the cancer registry of the Russian Federation is structured as a multilevel system that includes regional and national segments, and is maintained in the Cancer Register Information and Analytical System (Cancer Register IAS) being developed by the P. Hertsen MORI.

The regional segment is intended for the registration of cancer patients at regional medical institutions of the Russian Federation that keep records of cancer patients and monitor cancer cases among the population.

The regional registry is constantly updated not only as information is entered about new patients, but also as additional

information is added about previously registered cases. The data can come from primary oncology offices/departments of the general network of medical and preventive treatment facilities and hospital registries of medical institutions that provide assistance to cancer patients.

The national segment accumulates data from regional cancer registries (8). While the regional segment of the registry contains the personal data of cancer patients, the national segment contains depersonalized information.

The Cancer Register IAS can accumulate and analyse information concerning the entire spectrum of oncological care, both within a single territory (region or district of the Russian Federation) or several territories together. The registry data allows for a comparative analysis of the morbidity and mortality rates of cancer patients and other diseases and for conducting an assessment of the quality of the treatment that has been given. The registry can also monitor the status of each patient, cohort, and occupational group, and in cases involving multifocal lesions conduct a study of the clinical characteristics of each tumour process separately and as a whole with parallel current tumours and comorbidities. The Cancer Register IAS offers the ability to obtain data for a certain period and for different periods of time, ensuring the possibility of comparison over time. The survival rate of cancer patients can be calculated using various characteristics in different combinations.

When working in the cancer registry system, data quality control procedures are carried out at all stages of information compilation, including verification of the completeness, consistency and reliability of that information. The automated identity data verification procedure prevents the accidental re-entry of patient information (9–11).

The national segment of the Cancer Registry of the Russian Federation (CRRF) was launched in 2010, and as of 1 January 2018 the combined database contains information on 6 816 230 cancer patients (7 237 358 cases of cancer), including 54 947 children aged 0–14 years and 71 337 children aged 0–17 years. Information has been obtained from 64 regional population-based cancer registries of the regions of the Russian Federation (covering 78% of the population of the Russian Federation).

To illustrate the analytical capabilities of the cancer registry, Table 1 presents the 5-year adjusted survival rate of women diagnosed with C 50 breast cancer established in 2013 in several regions of the Russian Federation. The registries of regions of

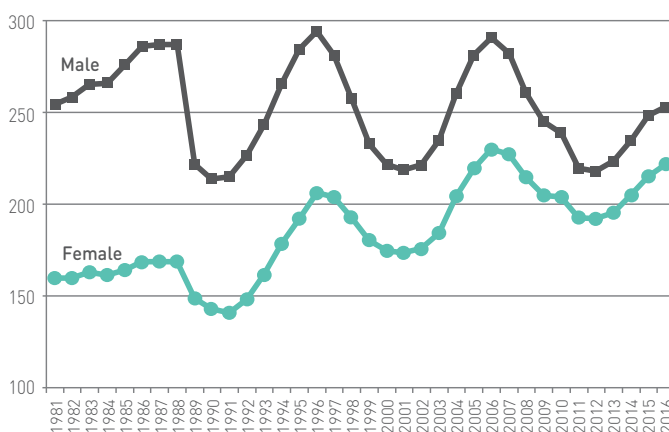
the Russian Federation that comply with IARC requirements for data quality were selected for the calculation.

**TABLE 1. 5-YEAR ADJUSTED SURVIVAL RATE OF WOMEN DIAGNOSED WITH C 50 MAMMARY GLAND MT IN 2013, DEPENDING ON STAGE (%)**

| Region         | Stage I | Stage II | Stage III | Stage IV | For all stages |
|----------------|---------|----------|-----------|----------|----------------|
| Lipetsk Region | 87.7    | 80.5     | 60.0      | 27.1     | 70.6           |
| Moscow         | 92.6    | 81.6     | 62.8      | 36.9     | 74.5           |
| Omsk Region    | 88.1    | 82.4     | 60.7      | 26.6     | 71.1           |
| Penza Region   | 90.9    | 80.8     | 57.1      | 20.0     | 72.1           |

State statistical observation forms contained in the regional cancer registries make it possible to quickly obtain information on the levels and trends of various indicators with a breakdown by individual territories, federal districts, and the Russian Federation as a whole (Figure 1) (12, 13).

**FIG. 1. DYNAMICS OF STANDARDIZED (ACCORDING TO THE WORLD STANDARD AGE DISTRIBUTION OF THE POPULATION) INCIDENCE RATE OF CANCER CASES IN MEN AND WOMEN OF THE RUSSIAN FEDERATION, PER 100,000 OF THE RELEVANT POPULATION, 1981–2016.**



The software used for the Cancer Register IAS enables it to be integrated with other medical information and analytical systems, both at the regional and national levels.

Overall, the model for recording new cases in the cancer registry system that has been implemented in the Russian Federation meets the requirements of the IARC for collecting and analysing data on the population and enables the health authorities of

the Russian Federation to obtain reliable information. The goals for the development of the CRRF system are to achieve 100% inclusion of territorial databases in the unified national database, improve information quality control procedures, and further expand its analytical capabilities.

**Acknowledgements:** None declared.

**Sources of funding:** None declared.

**Conflicts of interest:** None declared.

**Disclaimer:** The authors alone are responsible for the views expressed in this publication and they do not necessarily represent the decisions or policies of the World Health Organization.

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