

# History and current status of cancer registration in Russia

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## ARTICLE INFO

### Keywords:

Cancer registry  
Data quality  
Cancer epidemiology

## ABSTRACT

**Background:** Russia, then part of the Union of Soviet Socialist Republics (the USSR), introduced compulsory cancer registration in 1953, but a clear overall contemporary description of the cancer surveillance system in Russia is not available.

**Methods:** We summarized historical landmarks and the development of the standards of classification and coding of neoplasms in Russia and described current population-based cancer registries' (PBCR) procedures and practices.

**Results:** Cancer registration is organized according to the administrative division of the Russian Federation. More than 600,000 cases are registered annually. All medical facilities, without exception, are required to notify the PBCR about newly diagnosed cases, and each regional PBCR is responsible for registering all cancers diagnosed in citizens residing in the region. The data collection can be described as passive and exhaustive. Hematological malignancies, brain, and CNS tumors are often not referred to cancer hospitals in some regions, explaining the problems in registering these cancers.

**Conclusion:** Russia's cancer registration system is population-based, and practices seem to be generally internationally comparable. However, coding practices and national guidelines are still outdated and not up to the most recent international recommendations. Further analyses are needed to assess the comparability, validity, completeness, and timeliness of Russia's PBCRs data.

## 1. Background

Russia, then part of the Union of Soviet Socialist Republics (the USSR), introduced compulsory cancer registration in 1953. But it was not before 1963 when the USSR updated data collection and processing procedures to be comparable to those of Western cancer registries [1]. International Agency for Research on Cancer (IARC) Technical Report #35 summarized cancer registration practices in the Newly Independent States of the former Soviet Union (Belarus, the Russian Federation, and Ukraine) in 1998 [2], highlighting some important limitations. This report mentioned infrastructure for data collection, the introduction of international classifications for coding, and systemic monitoring of quality as prerequisites for obtaining data for research purposes.

Researchers and healthcare professionals can obtain cancer incidence and mortality statistics for Russia from several sources, but a clear overall description of the cancer surveillance system is not available. Systematic description of the cancer registration system is a critical step in understanding cancer statistics. For example, such a report has recently been published for the Nordic countries to explain similarities and differences despite high-quality cancer registries in all countries [3]. Here, we aimed to describe the history and current state of cancer registration procedures and practices in Russia.

## 2. History of cancer registration in modern Russia

We summarized historical landmarks and the development of the

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<https://doi.org/10.1016/j.canep.2021.101963>

Received 18 February 2021; Received in revised form 8 May 2021; Accepted 16 May 2021

Available online 2 June 2021

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standards of classification and coding of neoplasms in Russia in Fig. 1. The Ministry of Health introduced definitions for Regional and National Cancer Registries in Russia only in 1996 and IARC described cancer registration procedures in Russia in 1998 [2,4]. Although the Ministry of Health's Order #420 introduced definitions of regional and national PBCRs in 1996, in practice, the national cancer registration system was re-established in Russia in 1999 when another Order #135 was published [5]. PBCRs were established independently in all the regions, and they are obliged to follow the common framework of national legislation. Order #135 provided instructions and the classification needed for cancer registries' appropriate functioning across the country. It also introduced the ICD-O-2 morphological classification, which most of the Russian PBCRs are still using.

Several regional PBCRs had already collected incidence data before the new cancer registration system's full-scale introduction in 1999. Saint-Petersburg formally established the first PBCR in Russia in 1993. It was the only Russian cancer registry in the IARC "Cancer incidence in five continents" volumes for several decades [6]. Cancer registry data in Russia were used for national reports and rarely for other research purposes, e.g., Saint-Petersburg PBCR published survival estimates. Participation in international projects restarted in 2015: CONCORD-2 international cancer survival study [7] included data from Arkhangelsk PBCR, CONCORD-3 study included data from Arkhangelsk, Tomsk, Omsk and Karelia PBCRs [8], IARC "Cancer incidence in five continents" volume XI (2008–2012) included data from Arkhangelsk, Samara, Chelyabinsk and Karelia PBCRs [9]. IARC and World Health Organization (WHO-Europe) organized the first formal training course in cancer registration in Russia in 2015. NN Petrov National Medical Research Cancer Center completed the translation of ICD-O-3 into Russian in 2017 [10], and in 2018 the Ministry of Health recommended its use for PBCRs.

### 3. The current state of cancer registration

The cancer registration system in Russia can be formally described as passive. PBCRs collect information on all malignant and *in situ* neoplasms (according to the International Classification of Diseases, 10th revision, codes C00-96, and D00-09, respectively). More than 600,000 cases were registered annually starting from 2017 (640,391 including 83,752 non-melanoma skin cancer cases in 2019). Only new cases of invasive cancer (C00-96) are included in the national annual report. The basis of cancer registration is notification forms that physicians use to report cancer cases to the registries (Fig. 2). However, PBCRs can also

use any available medical records to add information to the database. Cancer registration is organized according to the administrative division of the Russian Federation. All medical facilities, without exception, are required to notify the PBCR about newly diagnosed cases, and each regional PBCR is responsible for registering all cancers diagnosed in citizens residing in the region. It is unclear whether all regional hospitals and clinics, especially non-cancer and private, follow these instructions. Pathology labs do not report cases directly to PBCRs but send all information to clinicians responsible for notifying PBCRs. In cases of migration or death in different areas, PBCRs do not regularly perform information transfer.

PBCRs perform linkage using personal identifiers (name, date of birth, passport number, place of residence). Physicians are required to fill in notification forms summarizing clinical records for every cancer case. Multiple notifications can be provided for a cancer case with several hospitalizations or visits. Information from pathology laboratories is included in the forms and is not reported directly to the registry except for autopsy cases. Therefore, it is impossible to separate these two sources of information explicitly. PBCRs perform linkage with mortality records regularly (within the same region), but practices vary across the country.

According to Russian regulation from 1996, PBCRs send depersonalized cancer registry data from the regions to the Research Institutes of Oncology (now National Medical Research Cancer Centers). For example, registry data from the Northwestern Federal District (NWFD) regions are collected and maintained in NN Petrov National Medical Research Cancer Center, which, according to the law, is obliged to perform epidemiological analyses for various purposes.

Hematological malignancies, brain, and CNS tumors are often not referred to cancer hospitals in some regions, meaning that the registration of these cancer types could be incomplete [11]. In some regions, surgical treatment may also take place in general hospitals.

PBCRs report preliminary data annually in February/March and perform quality checks/traceback during the next six months. Thus, the previous year's data are considered complete in October/November of the following year. The annual national report includes information on incidence (absolute number of cases, crude rates, and age-standardized rates (ASRs) per 100,000 using Segi-Doll 1960 World population standard) based on aggregated data from the registry complemented by mortality data from the Russian Federal State Statistics Service (RSSS).

We obtained additional qualitative information about cancer registration procedures through personal communication with regional PBCRs of the NWFD. According to information acquired from the

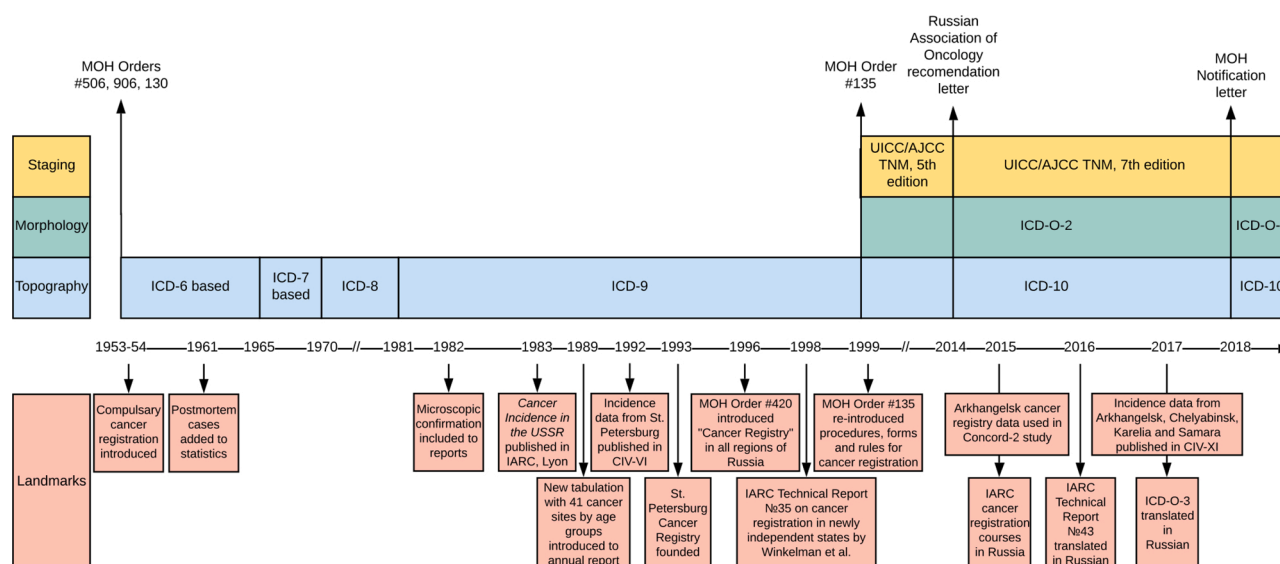


Fig. 1. Historical landmarks and development of standards of classification and coding of neoplasms in Russia, 1953–2018.

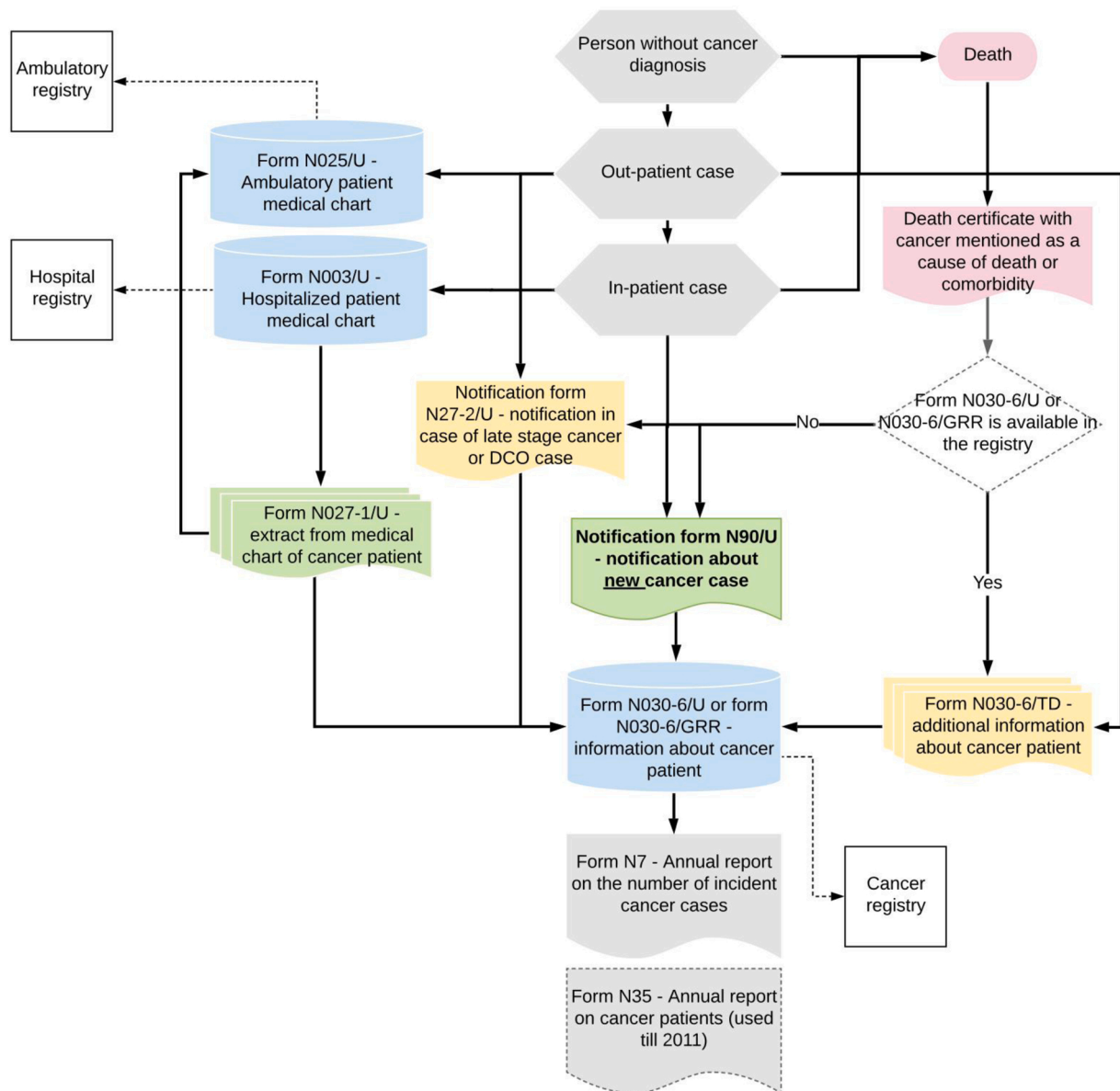


Fig. 2. Cancer registration notification system and the process of cancer registration in Russia according to the Ministry of Health Order #135 from 1999.

regions of the NWFD, PBCRs established the mortality linkage in all of them. However, it may be manual - cancer registry personnel or regional oncologists manually review death certificate records at regional civil registries to detect: 1) cancer patients from the registry who have died and 2) death certificates that mention cancer. PBCRs perform a semi-automatic procedure through manual searches in electronic databases of the state insurance system (Obligatory Medical Insurance) and civil registries. Most of the registries in the NWFD are based in the regional cancer hospitals (Oncology Dispensaries), except Saint-Petersburg and Kaliningrad, where registries are part of the regional medical statistics service. PBCRs have dedicated staff, but there is high regional heterogeneity in the number of employees in each registry. Most common software options for PBCRs have been developed in Moscow ("Cancer-register FB6") and Saint Petersburg ("NovelSPB Population-based Cancer Registry"). Some regions use their in-house software. All software tools follow national instructions but vary in the number of additional variables being processed. Trace-back procedures are not clearly described for cases initially registered with the information from death certificates (DCI), it is challenging to compare proportions of death certificate only (DCO) proportions as indicators of completeness of

registration. DCO proportions are available from the national report for all regions (all cancers combined, including non-melanoma skin cancers), and with no sex decomposition. Overall national DCO proportion in 2019 was 5.3 % (range 0–14 % in different regions). National annual reports provide additional information of DCO% and morphologically verified cases proportion (MV%) for each cancer type (Table 1).

#### 4. Comparison with international definitions and recommendations

We compared national instructions for cancer registration, listed in the corresponding national legislative document, to recommendations proposed by the European Network of Cancer Registries (ENCR) [12]. Cancer registration in Russia is consistent with some but not all ENCR recommendations (Table 2). PBCRs in Russia are coding the topography according to an adaptation of ICD-10 (4-digit version) and morphology according to ICD-O-2, with the 5th American Joint Committee on Cancer (AJCC)/Union for International Cancer Control (UICC) TNM classification used for staging; 7th AJCC/UICC TNM classification was recommended in 2014. Attempts to implement ICD-O-3 started in 2018. Some

**Table 1**

Number of cases, deaths, incidence and mortality age-standardized rates per 100,000, proportion of cases registered with information from death certificate only (DCO %), proportion of morphologically verified cases (MV%) and mortality to incidence ratios for common cancer type for which information in both incidence and mortality is available (as reported by national annual report in 2019).

Cancer type*	ICD-10	Incidence		Mortality		DCO%	MV%**	M:I ratio
		Cases	ASR per 100,000*	Deaths	ASR per 100,000*			
Lip, oral and pharynx	C00-14	17,955	7.6	9,785	4.0	3.0	95.4	0.54
Esophagus	C15	8,327	3.2	7,024	2.7	7.5	87.5	0.84
Stomach	C16	36,171	13.3	27,267	9.5	7.9	88.2	0.75
Colon	C18	45,277	16.1	23,593	7.7	7.3	88.7	0.52
Rectal and anal	C19-21	31,785	11.8	16,398	5.6	4.8	92.4	0.52
Liver	C22	9,324	3.5	10,430	3.7	31.7	50.4	1.12
Pancreas	C25	19,930	7.18	19,594	6.9	16.6	58.8	0.98
Larynx	C32	6,914	2.8	3,978	1.6	4.4	93.0	0.58
Trachea, bronchus, and lung	C33,34	60,113	22.7	50,046	18.4	11.3	73.4	0.83
Bone and cartilages	C40,41	1,418	0.9	918	0.5	7.5	84.5	0.65
Melanoma of skin	C43	11,961	4.9	3,594	1.4	1.4	97.4	0.30
Skin (non-melanoma)	C44	83,752	28.8	1,514	0.4	0.3	99.4	0.02
Female breast***	C50	73,918	53.34	21,720	13.6	0.7	97.9	0.29
Cervix uteri***	C53	17,503	15.4	6,389	5.0	1.6	97.4	0.37
Corpus uteri***	C54	27,151	18.8	6,820	3.9	2.6	96.3	0.25
Ovary***	C56	14,206	11	7,520	4.9	4.4	91.5	0.53
Prostate***	C61	45,763	43.5	13,205	12.1	2.3	94.0	0.29
Kidney	C64	24,880	10.2	8,593	3.1	5.1	83.5	0.35
Bladder	C67	17,290	6.3	6,132	2.0	4.0	91.7	0.35
Brain and CNS****	C70-72	8,776	4.3	7,801	3.4	–	–	0.90
Thyroid	C73	13,987	6.8	967	0.3	1.2	98.1	0.07
Malignant hematopoietic diseases	C81-96	31,020	14.4	16,416	6.4	6.1	93.9	0.53
All cancer types	C00-96	640,391	253.9	294,400	106.8	5.3	89.3	0.46

\* ASR per 100,000 – age standardized rates per 100,000 person-years using Segi-Doll 1960 World population standard.

\*\* MV% - annual national report provides MV% calculated for cases that do not include DCO cases, here we present MV% based on all registered cases, including DCO.

\*\*\* Rates are calculated based on separate gender categories.

\*\*\*\* DCO% and MV% are not presented for Brain and CNS category in the national report.

**Table 2**

Comparison of the ENCR recommendation and cancer registration instructions described in the Ministry of Health Order #135.

The ENCR recommendation [13]	Order #135	Comments
Minimum dataset of variables	+	–
Incidence date	+	–
Basis of diagnosis	+	In-house codes for the basis of diagnosis.
Topography, morphology, behavior	+/-	The topography is collected with ICD-10 codes.
Recording multiple primary tumors	+	Rules for registration, but not reporting.
Recording bladder tumors	–	–
Recording central nervous system tumors	–	–
Recording non-melanoma skin cancers	+	All skin cancers are recorded. It is recommended to stop follow-up for non-recurrent basal cell carcinoma (M8090-M8093) after radical treatment.
Method of detection in relation to screening	+	In-house codes without detailed instruction to the registries.
Recording and coding extent of disease	+	No clear instructions on how to record TNM are given.

definitions and recommendations are outdated or missing compared to the most recent ENCR recommendations.

## 5. Cancer statistics reports

National cancer incidence and mortality reports are published annually and also available online since 2007. Cancer incidence from

the reports is included in official state statistics. Forms with aggregated data collected every year from the regional PBCRs are the basis for the national report. There are sporadic local and international publication that use regional PBCR data [14–16].

PBCR data remain the primary source for cancer incidence, while cancer mortality statistics are based on the civil registry (Fig. 3). International reports and databases that include cancer statistics for Russia commonly acquire data from national sources (European Cancer Information System [17]), but some project or extrapolate data (e.g., GBD IHME). Comparison between all reports is warranted as both quality of primary data and model assumption may bias the estimates of cancer burden. Given the lack of full-scale quality assessment, we recommend caution in the interpretation of available national cancer statistics for Russia, especially for less common cancer types.

## 6. Conclusion

Russia has preserved a systematic approach to cancer registration at the national level. To our knowledge, cancer remains one of two disease entities registered in a population-based manner in Russia with individual-level databases (the second one is diabetes [18]). Cancer is also among only a few causes of death reported consistently across the country [19]. In 1999 new legislation introduced morphological coding, incidence date rules, and summarized processes to collect multiple variables in a population-based manner along with implementing electronic databases. However, it didn't provide an accurate description of quality control mechanisms. Lack of quality control means that apart from systemic discrepancies, we could also expect some regional heterogeneity in the data collection and processing. The other significant limitation of the current cancer registration system is that it is based on

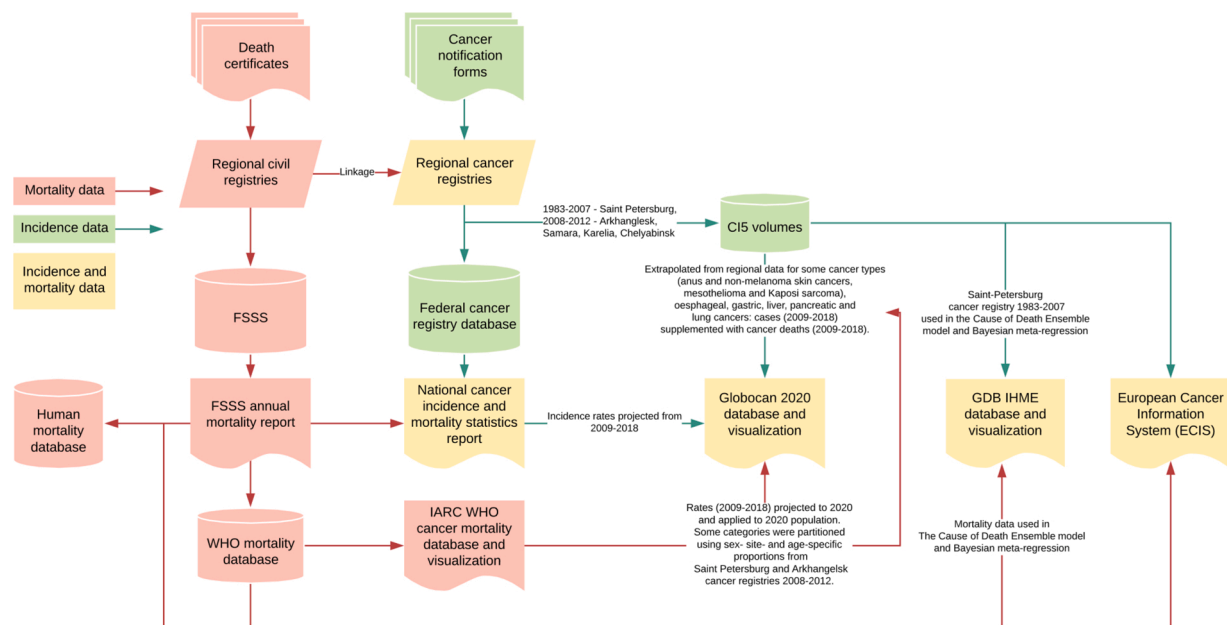


Fig. 3. Selected reports on cancer statistics in Russia and sources of cancer incidence and mortality data.

only two sources – death certificates and clinical notification. This situation is typical for some Eastern European countries [20]. Pathology laboratories are a relatively centralized and essential independent source of information that PBCRs should not ignore, but in Russia, pathology labs do not directly send reports to PBCRs.

In general, national legislation needs some updates. Full-scale implementation of ENCR/IARC recommendations, quality control procedures, and ICD-O-3 coding, along with proper training, should be prioritized for improving cancer registration in Russia. National training program for cancer registrars is not available in Russia, but it is highly recommended to improve data quality. Quality improvement requires dedication, human resources, and support from the local governing organs. However, investments in cancer registration are highly cost-effective if we account for all possible applications of cancer registry data [21]. Further analyses are needed to assess the comparability (incidence dates, multiple primaries, etc.), validity (re-abstracting and recoding, the percentage morphologically verified (MV%) and cases reported by death certificate only (DCO%), missing information, internal consistency, etc.), completeness (historic data methods, independent case ascertainment, capture-recapture methods, etc.), and timeliness (comparison of database completeness at different time points) of Russia's PBCRs individual-level data [22,23].

#### CRediT authorship contribution statement

**Anton Barchuk:** Conceptualization, Methodology, Visualization, Writing - Original draft preparation. **Alexey Belyaev:** Supervision; Data Collection, Reviewing and Editing. **Olga Gretsova:** Writing - Review & Editing. **Rustam Tursun-zade:** Writing - Review & Editing, Visualization. **Nataliia Moshina:** Writing - Review & Editing. **Ariana Znaor:** Writing - Review & Editing.

#### Authors' contributions

AB drafted the manuscript; all authors critically reviewed, edited, and approved the manuscript.

#### Declaration of Competing Interest

The authors report no conflicts of interest. The authors alone are

responsible for the content and writing of the paper. Where authors are identified as personnel of the International Agency for Research on Cancer/World Health Organization, the authors alone are responsible for the views expressed in this article, and they do not necessarily represent the decisions, policy or views of the International Agency for Research on Cancer/World Health Organization.

#### Acknowledgments

We thank doctors, registrars, and other staff at all population-based registries, oncology hospitals, and pathology labs in Russia. We thank Galina Petrova and Valery Starinsky from P. A. Hertsen Moscow Oncology Research Center, Vakhtang Merabishvili from NN Petrov National Research Medical Center of Oncology named after NN Petrov and Mati Rahu from Estonian Cancer Registry. We also thank Anssi Auvinen and Ekaterina Nazarova for insightful comments.

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