

Population-Based Cancer Registries in Brazil: Relevance, Challenges and Opportunities

<https://doi.org/10.32635/2176-9745.RBC.2025v71n1.4878>

Registros de Câncer de Base Populacional no Brasil: Relevância, Desafios e Oportunidades

Registros de Cáncer de Base Poblacional en Brasil: Relevancia, Desafíos y Oportunidades

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INTRODUCTION

Cancer is the second cause of premature death by non-communicable diseases in Brazil (between 30 and 70 years of age) and the leading cause of death in very high Human Development Index (HDI) countries above cardiovascular diseases¹. Due to the rising incidence in Brazil, it is anticipated to reach 1.07 million new cases in 2050². Cancer encompasses innumerable diseases with significantly different risk factors, early diagnosis and prevention strategies, in addition to a wide spectrum of prognosis, from more favorable to highly lethal outcomes.

For a complex disease as cancer, a specific surveillance system is required to evaluate the burden of disease stratified by cancer type³. As such, it is possible to plan targeted actions for prevention, early detection and effective treatment. To prioritize coping strategies according to the emerging risks of different types of cancer on a certain territory⁴, public or private managers should know the actual incidence of the disease on the population. Cancer incidence data associated with ageing and specific behavioral, environmental and genetic risks highlight its extent as a public health problem⁵.

Population-based cancer registries (PBCR) are acknowledged worldwide as a pivotal part of any cancer monitoring program and the gold standard for disease surveillance of the population³. PBCR are specialized structures dedicated to collect, store, process, analyze and disseminate information on individuals or patients with confirmed cancer diagnosis, and they are the only source of information on cancer incidence. They allow rational action planning and provide means to evaluate the results⁴. In addition, are important sources for epidemiological studies of the disease.

In the absence of reliable and quality data from PBCR, cancer control action planning risks identifying misguided priorities. Unfortunately, this is the situation in many low-and-middle-income countries, where other health system demands are prioritized over the cancer registration in the population⁶. In this context, it is important to emphasize the importance of investing in PBCR as fundamental elements to optimize the resources and improve the outcomes for the patients⁷.

The internationally standardized methodology of cancer classification is complex and involves topography and morphology details following codification and quality control rules^{8,9}. To ensure comparability of information from different countries, criteria for registration and reporting of incident cases abide to the rules of the International Agency for Research on Cancer (IARC) and the International Association of Cancer Registries (IACR), both adopted by the National Cancer Institute (INCA)¹⁰. PBCR-based cancer world information are published periodically by IARC in the series Cancer Incidence in Five Continents initiated in 1966 and currently in its 12th edition¹¹. To be published in CI5, PBCR should meet quality standards.

Much is yet to be achieved to fill in the gaps of cancer surveillance in Latin America, although progress has been made. The implementation of PBCR is a priority in Central America while South American countries need to improve the quality of the data, wider dissemination and utilization of the information¹².

The purpose of this article is to discuss the current landscape of cancer surveillance in Brazil, focusing on the status of PBCR, with particular interest in their integration with other existing information systems, the incorporation of new technologies, and the need for a legal framework.

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DEVELOPMENT

PBCR: CURRENT STATUS AND SHORT HISTORY

Brazil has a structured cancer surveillance system that incorporates components of incidence, hospital morbidity and mortality. Incidence information are processed in 31 PBCR, covering 25% of the Brazilian population¹³.

The first major step to structure Brazilian PBCR as a national policy occurred in 1999 with the implementation of agreements with state Health Secretaries (SES) which draw resources from a national health fund to develop a program of evaluation and surveillance of cancer and risk factors (PAV)¹⁴.

With this, it was possible to implement technical units at the SES along with various courses and training programs to prepare personnel to work at and oversee the PBCR. Since 2006, targeted financial funds have been assigned monthly to PBCR within the approved budget of health surveillance directed to Municipal and State Secretaries (Directive 2,607, December 2005)¹⁵. These regular funds ensured PBCR to keep the staff with less turnover and improve their performance with dissemination of information, timeliness and pursuing international quality standards¹⁴. However, these funds ceased just a few years later.

Implementation and maintenance of PBCR are quite challenging, depending on continuous funding and governmental support. Information on the 31 available PBCR are available on INCA¹³ site with 2,277,896 cases registered between 1988 and 2020. The final years of consolidation of 17 PBCR are: five until 2017, seven until 2028, two until 2019 and three until 2020.

This scenario shows the variability of the timeliness of the consolidated bases of Brazilian PBCR. Many of them do not gather data that meet the publication schedule determined by CI5 due to outdated years of incidence. While the consolidation of the quality of the data is expected to occur in a certain period¹⁶ some PBCR present delays of more than ten years to consolidate in comparison with the calendar-year¹³. Due to the absence of a regular policy in place, many Brazilian PBCR are unable to keep their routine tasks and work timely¹⁴.

Several Brazilian PBCR have been published in CI5 (Chart 1). A good number of the registries bases have been approved, however, the participation is not continuous, reflecting the instability of many of them.

For instance, PBCR of the States of São Paulo and the cities Poços de Caldas and Florianópolis, whose quality information have already been published in CI5 are currently facing difficulties to operate, which drops the coverage of the Brazilian population from 25% to 19%, reflecting the vulnerability of some of them, in despite of their history and relevance.

If only PBCR with high quality data published in volume XII of CI5 are considered, the coverage barely reaches 4.4% of the population¹¹. Continuous funding and governmental support are required to maintain and strengthen the quality of the information of the current registries keeping the proportion of the population covered^{11,17}, even before creating new registries or expanding the present coverage.

PBCR WORKFLOW

The strategies to collect cancer cases vary among registries but overall, they consist in the identification of sources of notification, diagnostic and/or treatment centers for the population covered (pathology labs, hospitals, imaging, hematology and oncology services, radiotherapy services, etc.). Once the sources are identified, the registrars request the collection of the cases. Notwithstanding the importance of PBCR for disease surveillance, one of the main difficulties found is the access to these cases diagnosed or treated at specialized centers or private labs.

PBCR gather information allowing to describe and monitor the profile of cancer incidence for a geographically defined population, usually a municipality, but they may cover the whole state or some region or sub-region. Information are collected systematically, continuously and exhaustively ensuring the completeness of the data when searching for information in different sources of diagnosis and treatment.

Since cancer is a chronic disease, the patients attend different health services within the health system networks which makes active search in multiple data sources necessary^{8,9}. Unlike the mortality system which registers death once with complete information, PBCR data are fragmented and need to be constructed during a certain time, affecting the timeliness and completeness of the cases, requiring additional continuous effort of information integration and checking.

It is necessary to collect information about where the patient resides when the diagnosis is made to determine that the case is within the coverage area of the registry. The name of the patient, his/her mother, date of birth, identification documents are required to individualize each case and determine the exact moment of the first diagnosis (incidence). In this phase of identification, every notification of that patient is gathered, and is accounted as only one incident case for each neoplasm diagnosed³.

INCA provides Brazilian PBCR the Sisbasepop Web, a digital interface to register the cases. The platform allows the inclusion of cases (notification stage), identification and selection of final cases, further to reports related to information of incidence rates (crude and adjusted), management supervision and quality of the information, for different types of cancer. Additionally, it is possible

Chart 1. Brazil's PBCR with information published in the last five volumes of Cancer Incidence in 5 Continents

2002	2007	2014	2017	2023
Campinas	Brasília	Aracaju	Aracaju	Aracaju
Goiânia	Cuiabá	Belo Horizonte	Curitiba	Barretos
	Goiânia	Cuiabá	Florianópolis	Belo Horizonte
	São Paulo	Fortaleza	Goiânia	Campinas
		Goiânia	Jahu	Curitiba
		São Paulo	Poços de Caldas	Goiânia
				Jahu
				João Pessoa
				Recife

Source: CI5 Volumes XII a XI^{11,18-21}.

to import information about the incident cases within the PBCR coverage territory from the system of computerization of cancer register data (SisRHC), an effective integration tool of hospital and population-based registries. It is also possible to import the files from the mortality information system (SIM) for deaths of individuals living in the area covered by the registry.

Due to the rising complexity of classification of neoplasms and diversity of available treatments, a basic amount of tumor-related variables is collected, as topography, morphology, date of the diagnosis and extension of the disease.

However, significant challenges still exist to obtain and register detailed information about the extension of the disease and cancer staging either for solid tumors or hematological neoplasms which are relevant to get acquainted with the reality of early diagnosis and evaluate the overall survival²². Not so recent advances of disease characterization as the status of hormone receptors and protein HER2 for breast cancer are not incorporated yet into Brazilian registries, despite the recommendation of the American Joint Committee on Cancer (AJCC).

Brazilian PBCR do not collect treatment related information (start date, modality of treatment). In addition, Toronto²³ staging for children neoplasms is not collected as well. It is essential that Brazilian PBCR, as tools for action and for equity promotion, collect sociodemographic information of quality which is not occurring currently due to lack of resources.

Updating of the classification and staging cancer systems is delayed in comparison with other countries.

Sisbasepop, for instance, still utilizes the original version of the 3rd edition of the International Classification of Diseases for Oncology (CID-O)²⁴, although the IARC had already issued the second revision of that edition for morphology classification. Staging by the 8th edition of TNM²⁵ – Classification of Malignant Tumours, recommended by the AJCC of the Union for International Cancer Control (UICC) was translated and published only in 2022 in Brazil, but its utilization was already indicated for other countries since 2018.

RELEVANCE OF PBCR FOR CANCER SURVEILLANCE AND RELATION WITH OTHER INFORMATION SYSTEMS

The recent COVID-19 pandemic brought up the importance of information systems for health surveillance²⁶. The necessity of real-time information for these cases with daily updates possibly created a wrong expectation that cancer surveillance would require real-time information about the occurrence of cases and that it would be widely comprehensive in terms of territory. In health surveillance, it is necessary to know the difference of strategies related to acute transmissible, chronic communicable, chronic non-communicable diseases and, within the latter, the specificities of cancer for cancer surveillance³.

Several health information systems are available in Brazil whose simple enumeration is complicated, sometimes with redundant information, scarce transparency and frequently inaccessible²⁷. Some of the main cancer-related systems and their connections with PBCR are shown in Figure 1. The information from these different systems is made available by the Ministry of Health through the



computer information department of the National Health System (DATASUS) and the app Tabnet/Tabwin which was developed nearly 30 years ago. The tabulators of the PBCR and HBCR information are hosted at INCA's site that offers a panel of mortality by cancer (Atlas of Mortality)²⁸. A critical step for the surveillance as a whole and specifically for PBCR would be the integration of these different systems as will be discussed further ahead.

The main focus of cancer surveillance is to know its incidence and evaluate survival. PBCR are critical sources of information related to global goals of cancer fight. For instance, the indicator associated with the goal of the World Health Organization (WHO) Global Initiative for Childhood Cancer to increase the survival rate of children and adolescents with cancer to at least 60% until 2030²⁰ can only be measured with PBCR information^{30,31}. Similarly, the evaluation of the indicator associated with the goal to eliminate cervical cancer where every country should reach and maintain an incidence rate below 4 cases per 100,000 women depends on PBCR data^{32,33}.

PBCR¹³ together with mortality information (SIM/DATASUS)³⁴ enable the calculation of national cancer incidence estimates by INCA⁵, in addition to IARC and Global Cancer Observatory (Globocan)³⁵ estimates.

In this complex web of systems, it is worth mentioning a dashboard recently created for monitoring the 60-day Law, which regulates the time between diagnosis and treatment of confirmed malignancy³⁶. Although this monitoring could be based on Hospital-Based Cancer Registries (HBCR), the follow-up of the healthcare to the patient already diagnosed whose treatment was not initiated within the law-mandated time was not possible. The Oncology Panel is a management tool for healthcare services rather than for surveillance³⁷. It was created in 2018 to replace the cancer information system (Siscan), its mission is to "allow the monitoring of early detection actions, diagnostic confirmation and beginning of treatment of malignant neoplasms³⁸".

The implementation of Siscan as initially planned was challenging³⁹, and later it turned out to be a system restricted to cervical and breast cancer, bringing together the former Siscolo and Sismama systems. The Panel integrates data from different routine datasets (diagnostic and treatment) and register (Figure 1) with the aim of monitoring the time between diagnosis and beginning of the first treatment³⁷. Professionals of the service feed the system without the participation of the cancer registrar, a critical function to ensure the accuracy of the information on diagnosis and classification of the neoplasm.

SIM³⁴ is one of the best examples of a consolidated information system, the result of planning, investments, time, government involvement and continued efforts,

in addition to adherence to best practices of quality and monitoring of indicators.

It was implemented in the 1970s and ever since, is in continuous improvement according to international guidelines⁴⁰. Mortality data provide important epidemiologic information about the Brazilian population, being among the best systems in the world in terms of population coverage⁴¹ and percent of ill-defined causes of death (6.0% in 2022)⁴².

Vital statistics provided by SIM are essential to know cancer mortality. The integration of SIM and PBCR bases allows passive follow-up of patients with cancer, and evaluation of the population-based survival. In addition, PBCR information can qualify SIM data, especially for deaths by cancer with ill-defined location or liver, lung or brain metastases, because PBCR registers primary tumors while SIM quite often does not separate primary from metastatic cancer. Therefore, the integration of PBCR data can improve the accuracy and quality of the mortality data.

OPPORTUNITIES OF PASSIVE DATA COLLECTION AND INCLUSION OF POPULATIONAL CANCER SURVEILLANCE INTO THE STRATEGY OF DIGITAL HEALTH

The generation of population statistics is enriched in PBCR where it is possible to link information from the PBCR itself with information from other sources, often collected for different purposes, with the selection of the best available information⁴³. Nordic countries excel in this type of data linkage with exceptional quality, they are the pioneers of this practice, and world reference in quality of population-based cancer information⁴⁴. Several Brazilian PBCR utilize linkage methods to improve their databases. The PBCR of the cities of Belo Horizonte, Curitiba, Aracaju, São Paulo, Jahu, João Pessoa, for example, link their data with the state's SIM to update the vital status of the cases registered, searching cases of registered death out of the coverage area and without diagnostic of cancer at the death certificate. In another strategy, the PBCR death notifications are crossed with the bases of every HBCR in the state, looking for diagnosis of the cases and reducing the proportion of cases notified only by the death certificate.

Another databases possibly utilized by PBCR are CadSUS, SIH, SIA, BPA, Siscan, among others. Information from supplementary health databases are difficult to obtain. Health information systems data could be utilized as sources for PBCR through continuous flow and importation or exportation from or to these databases, qualifying the information of PBCR as happens in other countries⁴⁵⁻⁴⁷. Integration of PBCR with CadSUS is important to obtain information of the address of the residence and with the SIM national database to allow

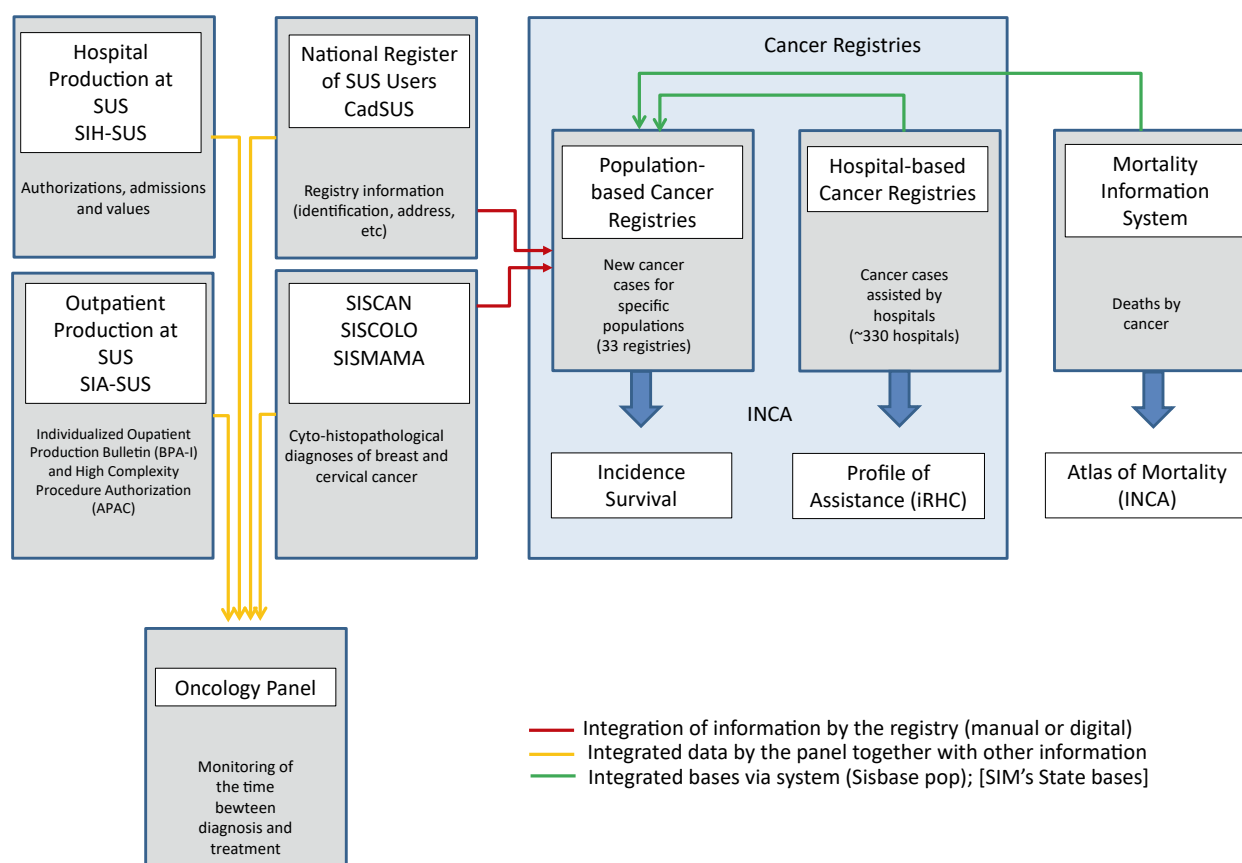


Figure 1. Main cancer-related Brazilian information systems

Note: INCA is the supervising institution in charge of the supervision of Population-based and Hospital-based Cancer Registries and hosts the respective tabulators. The institution provides information of mortality by cancer in Brazil (absolute and percent) through the Atlas of Mortality. Oncology Panel is part of CadSUS with data of the outpatient information system (SIA) through the individualized outpatient production bulletin (BPA-I) and authorization of high complexity procedures (Apac) of the hospital information system (SIH) and of the cancer information system (Siscan/Siscolo/Sismama).

passive update of cancer survival, of the patients with incidence in a certain territory who are living in another Federation Unit when they died.

The importance of passive data collection through robust electronic systems was relevant during the COVID-19 pandemic. An international survey concluded that PBCR which utilize this method were the least affected by the health crisis⁴⁵. Approximately 45% of the PBCR report that contingency measures have been adopted to mitigate the pandemic impact, including the expansion of capacity and security on information technology (IT). The rapid adoption and implementation of technologies when the pandemic began was highlighted as the positive side of the crisis⁴⁸ according to many registries.

Digital health strategy (ESD) for Brazil envisions the interoperability of systems and expansion of the national network of health data (RNDS), a potential tool for PBCR. ESD 2020-2028 estimates that until 2028, RNDS will be implemented and acknowledged as the digital platform of innovation, information and health services for the whole country bringing benefits for users, citizens, patients, communities, managers, professionals and health

organizations⁴⁹. It is important to include PBCR in ESD. Decree number 12,069 dated June 21, 2024⁵⁰ created the national strategy of digital health for 2024-2027, the 8th article mentions as a general objective the pursuit of a more inclusive, effective, proactive, participatory, and sustainable State, especially through:

- I – offer solutions that meet the society demands and acknowledge social inequalities and barriers to access public services;
- II – adjustment of the processes to the current society demands with innovation, correct utilization of technologies, safe reuse of data and improved allocation of public funds; and
- III – transparency, access to information, social participation in the formulation of public policies and promotion of sustainable development.

These topics are applicable to cancer surveillance through the utilization of existing information collecting systems, passive feeding of PBCR and the national regulation of Law number 13,685 dated June 26/2018⁵¹, which establishes the mandatory notification of cancer.

Mandatory notification *per se* does not ensure the improvement of the quality of the data nor a panacea to properly register incident cancer cases in Brazil. Additionally, in some countries, the desire to obtain so-called “national” data through automated and mandatory systems ends up overshadowing the quality of the data, which can lead to incorrect numbers and consequently to the formulation of policies based on this information^{3,52}. For instance, the comparisons of these systems with PBCR of Colômbia and Peru show underestimation of the incidence and overestimation of survival based on administrative data⁵³⁻⁵⁵.

The Federal District has successfully regulated Law number 13,685⁵¹ through Directive number 180⁵⁶ of March 21, 2019 enforced for the district, and determining formally that the Coordination of PBCR at the Federal District is the recipient of information coming from private institutions quarterly and migration of information from HBCR of the district according to the calendar established by INCA through the interfaces SisIntegradorRHC and SisBasePop.

The access to private data is critical because 26.3% of the Brazilian population in March 2024 was health insured, the State of São Paulo has the largest coverage with 43.2%⁵⁷. Patients with cancer can move from public to private institutions not exclusively, making information of one case scattered in both sectors. The city of Campinas through the municipal law number 15.371, dated January 6, 2017⁵⁸, created a PBCR, reinforcing the mandatory notification of neoplasms and ensuring the access to every information source and including them as part of the cancer surveillance, either public or private.

LEGAL FRAMEWORK

An important step for the long-term sustainability of PBCR would be a well-structured framework providing improved legal base for cancer surveillance actions developed by the registries. The most recent National Policy of Cancer Prevention and Control of the National Health System (SUS) and the national patient navigation program of the individual diagnosed with cancer created by Law number 14,758⁵⁹ of December 19, 2023, according to article 2, section I has the objective of “reducing the incidence of several types of cancer”.

In article 3, section VII, it determines that “the organization of cancer surveillance through information, identification and evaluation of the actions of disease control, its risk factors and protection” is one of its general principles and guidelines. However, it fails to describe how the surveillance will be conducted, quoting only “the integrated utilization of epidemiological and healthcare information collected through HBCR and

other available sources for planning, monitoring and evaluation of actions and services for cancer prevention and control” (article 3º, section VIII). Governments which have access to inaccurate or inadequate data or do not utilize any PBCR as source of information are unprepared to elaborate and implement cancer control policies that eventually may result in decline of incidence and survival improvement⁶⁰. In despite of this, the law fails to reference the PBCR, although it is the unique source of information on incidence.

Although Law 14,758⁵⁹, dated December 19, 2023 addresses the scope of SUS, private or complementary services have to abide to the law as defined by Law number 8,080⁶¹ dated September 19, 1990 (Health Organic Law) as disposed in article 22. “Health private services have to comply with ethical principles and rules issued by the National Health System (SUS) regarding their functioning and operation”. Health actions developed by SUS are targeted to the whole population and include promotion, protection and recovery and not only assistance, with integration of healthcare and preventive activities further to health and epidemiologic surveillance⁶¹. Therefore, to effectively provide cancer surveillance developed within PBCR, the whole population covered has to be included, either assisted by SUS or by private or complementary services.

The US National Cancer Act of 1917 signed by President Richard Nixon determined the creation of a surveillance database able to publish and evaluate cancer incidence, mortality and survival trends. The Surveillance, Epidemiology, and End Results – SEER is a coalition of PBCR in specific USA areas, concurrently with the Center of Diseases Control – CDC and US Census and publishes rates of cancer diagnosis and mortality. It also provides data for spatial studies of cancer risk and treatment patterns⁶².

This long tradition of cancer surveillance through registries as SEER offers remarkable information about the impact of the USA effort against cancer. The results of this effort are recognized. The Eighth Edition AJCC Staging Manual, for example, was dedicated to cancer registrars acknowledging their commitment, professionalism, dedication, leadership and contribution while registering and maintaining essential data to treat patients with cancer⁶³.

In 1992, the Cancer Registries Amendment Act⁶⁴ was approved to stablish CDC’s support for other state registries and collect cancer data as incidence, staging and treatment. The Act⁶⁴ created the National Program of Cancer Registries (NPCR) which allowed the USA to reach 100% of population coverage. Some non-exhaustive examples where PBCR are regulated by specific laws are

Russia⁴⁷, Switzerland⁶⁵, Japan⁶⁶, Australia⁶⁷, Uruguay⁶⁸ and China⁶⁹, the latter expanding the population coverage with 157 PBCR in CI5 XII (12.8% of the population)⁷⁰. These specific laws determine the compulsory notification of the cases directly to the PBCR for correct processing of information according to international standards.

Paradoxically, some well-established cancer registries were terminated in the last five years and others are nearly being terminated, based on the concept that collection, curatorship, analysis and interpretation of the data by epidemiologists can be replaced by artificial intelligence systems yet unvalidated⁶⁰.

PBCR depend on governmental funds to keep their activities and are subject to annual planning and approval by respective budgets, which raises concerns on sustainability, if cancer surveillance is not within a clearly established operational program⁵². As an example, the discontinuation of PBCR of São Paulo due to the interruption of the partnership with the Health Municipal Secretary since June 2020. In despite of the increase of cancer in Latin America and rising interest on cancer data, it appears that long-term planning does not exist, nor the understanding of the specificity of cancer surveillance in the region⁵⁴. Law and policy-makers should acknowledge that PBCR are effective instruments of public health, providing long-term political, legislative and financial support. Without information that only PBCR can provide, the elaboration of cancer control programs may be conducted without essential guidance⁶⁰.

Within the legal gap about the functioning of cancer surveillance in the PBCR, restrictive interpretations of the General Data of Protection Law brought more difficulty of access to cancer diagnosis information which made the General Direction of INCA-MS to reaffirm formally⁷¹ that:

The anonymity of personal data, of the individuals with neoplasms, of the professionals in charge of the assistance, of the name of the notifying institutions is ensured to each and every member of the team responsible for cancer registry by signing a confidentiality agreement. It is also guaranteed by the General Data of Protection Law (LGPD) 13.709, August 14, 2018, articles 11 and 13 where hospitals, health services and other health entities are authorized to treat sensitive data of the patients without their specific consent to ensure healthcare is provided.

As mentioned before, article 4th of Law number 13,685⁵¹, dated June 25, 2018 determined the mandatory notification and register of diseases and harms related to neoplasms by public and private services in the whole

country, still pending regulation, and remaining in a legal limbo, in despite of the example of the Federal District aforementioned.

Cancer registries are essential tools to know the disease status allowing the planning of control measures with prevention related actions (smoke cessation, HPV vaccination), screening for early detection (oncotic cytology for cervical cancer, mammograms for breast cancer diagnosis and offer of timely and proper treatment (surgery, chemotherapy, radiotherapy, target-therapy, etc.) comfort or palliative measures in cases where the goal of controlling the disease progression is no longer possible. And finally, for the evaluations of disease overall survival as an effective indicator to monitor the treatment. These information are collected by PBCR in several countries, but in Brazil they continue scattered through many public and private information systems, limiting the investigation of health inequalities among users of public and health complementary services or private insured.

It is necessary to promote cancer surveillance literacy for the numerous players involved and their role in surveillance not only in relation to registries but public and private sources from where the information is collected. Even epidemiologists and oncologists eventually publish peer-reviewed conceptually misleading articles in scientific journals^{72,73}. Public managers should acknowledge the importance of quality information to consistently deal with the disease. It is not wise to lose what has already been achieved with the implementation of cancer registries across the country. Even with the limitations and difficulties of maintaining the activities, it is not possible to think in a better strategy for cancer surveillance. Several Brazilian PBCR already have two decades of time series, showing more than resilience, persistence and dedication. On the other hand, many have been discontinued because of obstacles of continuous maintenance of activities. It is necessary to work and consolidate the registries still functioning and improve the quality and range of cancer information.

More than often specialized clinics and centers, which make the access to PBCR difficult to collect data, use statistical scenarios where the disease occurs to illustrate their presentations on cancer, recognizing the global importance of the problem. They regularly utilize maps provided by Globocan (supported by IARC) and INCA's estimates⁵.

The alleged inexistence of Brazilian's health statistics (disease) affects the awareness of PBCR, neglecting the efforts of attempting to ensure a more reliable portrait of the reality of cancer in Brazil. The work that cancer registries yields is a great step to reverse the statistical blackout and keeping them operational is a long and



tough journey, depending on local political will and commitment, however, it should be a State policy instead, inserted into cancer prevention control policies as happens in many countries.

CONCLUSION

Still, there is much to be done. It is necessary to continue working to keep what has been achieved so far and ensure the access to cancer information, allowing the collection of more comprehensive data, including treatment-related variables. A legal framework to ensure continuous functioning is required as well as rethinking the collection and consolidation of the information, incorporating techniques of automated passive collection from different bases and other tools, and eventually including surveillance strategies into the planning of actions of development of digital health. The continuous search for quality of information that meets international standards and allow comparability of the information for different populations should be prioritized.

CONTRIBUTIONS

Gil Patrus Mundim Pena and Marianna de Camargo Cancela contributed to the study design, acquisition, analysis and interpretation of the data, wording and critical review. Antonio Tadeu Cheriff dos Santos, Camila Medeiros Pezzotti, Carlos Anselmo Lima, Cristiane Bastos Daniel, Cyntia Asturian Laporte, Donaldo Botelho Veneziano, Dyego Leandro Bezerra de Souza, Flávia Nascimento de Carvalho, Helenira Fonseca de Alencar, Janira Costa Silva, Jonas Eduardo Monteiro dos Santos, Josefa Angela Pontes de Aquino, Juliana Aparecida Loro, Juliana Natívio, Julio Fernando Pinto Oliveira, Leonardo Borges Lopes de Souza, Lucrecia Aline Cabral Formigosa, Luís Felipe Leite Martins, Maria Fernanda Regueira Breda, Maria do Rosario Dias de Oliveira Latorre, Maurício Marinho dos Santos, Michele Alcântara de Almeida da Hora, Paulo Cesar Fernandes de Souza and Walmiro Ferreira Ramos Neto contributed to the analysis and interpretation of the data, wording and critical review. All the authors approved the final version to be published.

ACKNOWLEDGMENT

To Marion Piñeros for the support and invaluable suggestions.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

FUNDING SOURCES

None.

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Recebido em 15/8/2024
Aprovado em 8/10/2024



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