

Towards a national cancer information platform

Hacia una plataforma nacional de información en cáncer

Luis Eduardo Bravo^{1,2}, Mónica Lorena Quijano-Liévano³

¹ Department of Pathology, Universidad del Valle, Cali, Colombia.

² PhD Program in Health, Universidad del Valle, Cali, Colombia.

³ Student of the PhD Program in Health, Universidad del Valle, Cali, Colombia.

In recent years, Colombia has seen a surge in cancer-related regulations. New provisions, guidelines, and circulars seek to address the complexity of this disease, its increasing burden, and the need to improve care and control; however, this regulatory boom has been accompanied by technical and operational fragmentation that threatens to undermine decades of progress in epidemiological surveillance and the generation of scientific evidence (1-4).

The intention to strengthen information systems is legitimate, but recent measures often emerge without sufficient coordination with existing technical capabilities. Thus, a multiplicity of instruments coexists with different methods, causing confusion among stakeholders and heterogeneity in data quality. The outcome is a system that reports more but generates knowledge with limited utility for action.

Health regulations are necessary, but their effectiveness depends on the systems' technical coherence and continuity. Regarding cancer, this coherence can only be achieved by integrating the efforts led by the Ministry of Health and Social Protection (Ministry of Health), in conjunction with *Cuenta de Alto Costo* (CAC; High-Cost Account), regional population-based cancer registries (PBCR), the *Sistema Nacional de Vigilancia en Salud Pública* (Sivigila; National Public Health Surveillance System), and the pediatric cancer epidemiological surveillance system (*Vigicáncer*), under the technical coordination of the *Instituto Nacional de Cancerología* (INC; National Cancer Institute). Without this convergence, the country risks increasing the volume of reports without improving the quality of evidence.

The current fragmentation is not only operational but also structural. Each institution has its own definitions and workflows that do not communicate with one another, hindering joint data validation and limiting the production of consistent national indicators. At present, the system operates through parallel workflows that respond to different regulatory

Conflicts of interest

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Corresponding author

Luis Eduardo Bravo

- Department of Pathology, Universidad del Valle, Cali, Colombia.
- PhD Program in Health, Universidad del Valle, Cali, Colombia.

Email:

luis.bravo@correounivalle.edu.co

frameworks and lack a unified epidemiological validation process.

The Cali Population-Based Cancer Registry (Cali PBCR), established in 1962, marks the beginning of this story. For over sixty years, the Cali PBCR has maintained a consistent, high-quality epidemiological surveillance program, recognized by the International Agency for Research on Cancer (IARC) as one of the most comprehensive worldwide. Since its inception at the Universidad del Valle, the Cali PBCR has provided essential scientific evidence to understand the burden and trends of cancer in Colombia, to evaluate inequalities, to guide public policy, and to train generations of epidemiologists, oncologists, and public health professionals. This development occurred alongside the INC's leadership in promoting registries in the country and the systematic analysis of cancer mortality since the 1990s. The methodological consistency of the Cali PBCR, its technical independence, and its ethical commitment to data quality have established and maintained it as an international reference and as the model that has enabled the expansion of other population-based registries in Colombia, in cities such as Manizales, Bucaramanga, Pasto, Barranquilla, Medellín, and Neiva. Several of these, particularly Manizales, Pasto, and Bucaramanga, participate today in the international dissemination of cancer incidence rates through the series Cancer Incidence in Five Continents (CI5) (5-6), and of population survival rates through the CONCORD program (program for the global surveillance of cancer survival trends) (7).

The pioneering work of the Cali PBCR demonstrated that it is possible to sustain a population-based surveillance system in a Latin American context, ensuring comparability with international standards. This model, developed over sixty years, now provides the technical basis for creating a national cancer information system, integrated with healthcare institutions and the health authorities.

Colombia also participates in the international CONCORD program, led by the London School of Hygiene & Tropical Medicine (LSHTM), which compares survival rates across more than 70 countries, and in the IARC's CI5 series, where PBCR—driven by universities and supported partly and continuously by the INC and regional health secretariats—have contributed high-quality, internationally comparable data. These population-based cancer registries have enabled Colombia to be included in the world's

leading incidence and survival series, demonstrating the methodological rigor and ongoing commitment of academic institutions to public health and cancer surveillance.

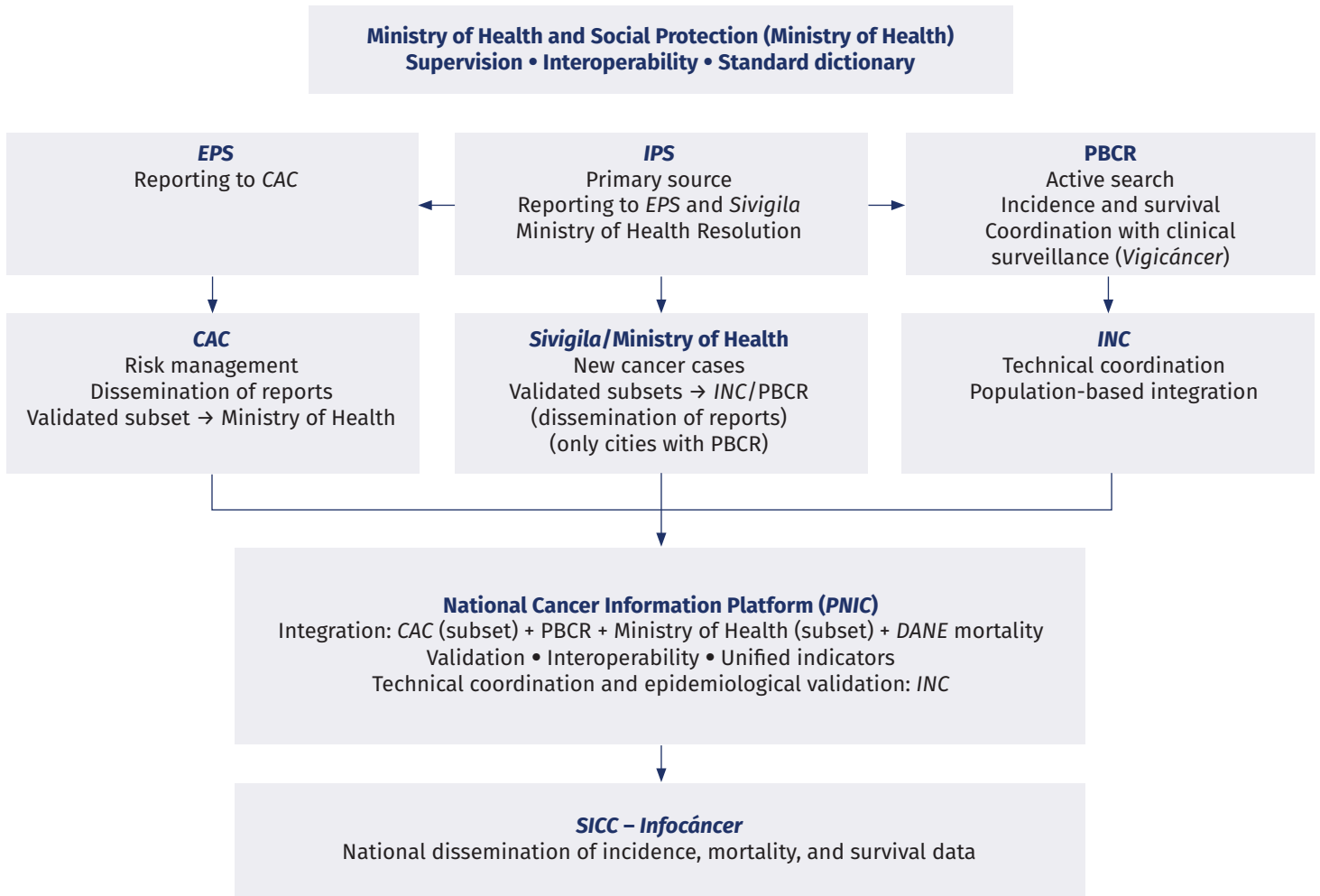
A complementary example of successful collaboration is the *Vigicáncer* system, led by pediatric hemato-oncologists in various cities across the country, with technical support from the Cali PBCR, academic backing from universities, and collaboration from health secretariats. This program has successfully standardized childhood cancer reporting, improved diagnostic timeliness, and generated reliable survival data by integrating clinical knowledge with epidemiological experience. Its development shows that cancer surveillance can and should originate from medical practice, but it must be supported by rigorous technical and methodological frameworks that ensure the quality and comparability of the information.

In geographical areas with existing regional PBCR, data integration could be implemented without new regulations by utilizing current standards for reporting high-cost diseases and recent Ministry of Health guidelines for cancer case reporting in healthcare settings. These registries could act as regional validation centers, ensuring the consistency of key variables such as tumor location, morphology, diagnostic basis, staging, initial treatment, vital status, and date of last contact. At the same time, they can offer technical support to various health service providers (*IPS*, for its acronym in Spanish) and pathology laboratories, thereby promoting accurate tumor coding and classification and enhancing data quality without interfering with the CAC's administrative duties, insurance coverage, or obligations under existing Ministry of Health regulations.

In this context, a national effort can be made to identify and integrate existing cancer information sources across the country, aiming to develop an interoperability model that facilitates data sharing among administrative, clinical, epidemiological, and population-based systems. This model would employ standard criteria for quality, timeliness, and confidentiality. The goal of this integration is to ensure that data generated by hospitals, laboratories, registries, and administrative systems are coherently integrated into a central technical hub for analysis and validation, thereby preventing duplication, filling gaps, and improving case traceability.

Figure 1 shows the proposed model for articulating the national cancer information system. This scheme integrates administrative, reporting, and population-based data flows within a unified technical framework that respects institutional roles while ensuring interoperability and cross-validation. The CAC maintains the dissemination of risk indicators, while the Ministry of Health oversees

the system, coordinates interoperability, and facilitates the transfer validated subsets to the INC and PBCR, enhancing epidemiological completeness. The National Cancer Information Platform (PNIC; *Plataforma Nacional de Información en Cáncer*) functions as the system's integrating axis, enabling the production of coherent, comparable, and technically validated national indicators.



CAC: *Cuenta de Alto Costo*; DANE: *Departamento Administrativo Nacional de Estadística* (National Administrative Department of Statistics); EPS: health promotion entities; INC: *Instituto Nacional de Cancerología* (National Cancer Institute); *Infocáncer*: *Información de Cáncer en Colombia* (Cancer Information in Colombia); IPS: health service providers; PBCR: population-based cancer registries; SICC: *Sistema de Información de Cáncer de Colombia* (Colombian Cancer Information System); *Sivigila*: *Sistema Nacional de Vigilancia en Salud Pública* (National Public Health Surveillance System); *Vigicáncer*: *sistema de vigilancia epidemiológica del cáncer pediátrico*.

Figure 1. Proposed scheme for the structure of the cancer information system in Colombia. The diagram illustrates how administrative, reporting, and population-based data sources are linked through a shared technical framework that ensures interoperability, joint validation, and integration to generate consistent national indicators.

The value of this effort lies in collaboration among institutions. Thus, the Ministry of Health takes the lead and establishes the technical guidelines; the CAC offers its capacity to consolidate clinical data and manage risk; the INC provides technical and methodological coordination; PBCR ensure the quality and comparability of epidemiological data; and *Vigicáncer*, led by pediatric hematologists and with technical support from regional population-based registries, brings a consolidated experience in active surveillance and clinical follow-up in conjunction with the National Institute of Health's *Sivigila* system, which provides public health reporting

of childhood cancer. This collaborative effort aims to develop a comprehensive information system that integrates population-based surveillance with clinical and administrative follow-up, serving both health planning and research.

[Table 1](#) summarizes the main differences between the current cancer information system structure and the proposed coordination model, focusing on how technical collaboration and interoperability could improve data quality and usefulness.

Table 1. Differences between the current system and the proposed model for the cancer information system

Axis	Current system	Ideal system ("should be")
General architecture	Fragmented: The CAC, <i>Sivigila</i> , <i>Vigicáncer</i> , PBCR, and the INC operate non-integrated mandates and systems.	Integrated: Interoperability defined by the Ministry of Health and a common technical module (PNIC) that links administrative, reporting, and population sources.
Data flow	Multiple independent flows without cross-validation or inter-institutional consistency.	Harmonized flow: IPS → EPS/CAC and <i>Sivigila</i> → Ministry of Health → INC/PBCR; <i>Vigicáncer</i> → PBCR → INC/PBCR → PNIC, with shared validations and rules.
Reporting	Partial: Only some cancers, and without population feedback; limited capacity for completeness.	Full and bidirectional reporting: all cancers; validated subsets for cities with PBCRs to ensure completeness and comparability.
CAC	It manages and disseminates risk indicators but operates in parallel, without integration with population surveillance.	It maintains risk dissemination and shares validated subsets with the Ministry of Health/INC for population analysis and technical harmonization.
INC and PBCR	Limited role to cities with PBCR: Incidence and survival only in territories with active search, without national coordination.	INC with national technical coordination + PBCR reinforced through validated subsets (Ministry of Health/CAC) to improve completeness, quality, and international comparability.
National indicators	Multiple disconnected indicators; absence of a unified national cancer surveillance scheme.	Unique indicators of incidence, mortality, survival, and population burden generated by the PNIC under common standards.

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Creating an operational tool to integrate these sources will promote true interoperability by standardizing common variables and adopting national validation protocols. This would allow Colombia to develop a population surveillance and risk management model based on verifiable, comparable, and interpretable data, capable of guiding decisions at all levels of the healthcare system.

The country now has the chance to develop a national cancer information platform without needing new legislation, through effective coordination among the Ministry of Health, the CAC, the INC, and regional PBCR. This structure would allow the National Cancer Observatory to access interoperable, reliable data that meets international standards, thereby supporting evidence-based decision-making.

Institutional coherence—not the number of regulations—is the true indicator of a health system’s maturity. A national scientific platform, with technical coordination from the INC and supported by regional PBCR and *Vigicáncer*, in close collaboration with the Ministry of Health and the CAC, would enable Colombia to take a historic step: transitioning from fragmented reporting to intelligent cancer surveillance, where information is not only collected but also understood and used to save lives.

In summary, moving toward an integrated cancer information system does not require new structures but rather technical coherence among existing systems. Interoperability, joint validation, and coordination among institutions are the key pillars that will enable the country to produce reliable, useful, and internationally comparable information. This process will involve technical, operational, and governance challenges, particularly in institutional coordination, the effective integration of sources, the strengthening of technical capacities across the system, the definition of sustainable financing mechanisms, and the transition to practices aimed at national interoperability. These aspects will need to be addressed through common validation standards and a phased implementation to ensure operational viability.

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