

Challenges in surveillance of all cancer cases: The Chilean National Cancer Registry

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ABSTRACT

Cancer causes millions of deaths worldwide, making its registration essential. There are clinical, hospital, and population-based registries in place. The latter is the gold standard for information on cancer incidence and survival in a defined region. Chile has five population-based registries located in specific areas of the country. The Chilean National Cancer Registry emerged with the challenge of creating a tool encompassing all three types of registries to identify the number of cancer cases by type. Its design involved a series of actions to achieve consensus among various actors regarding information, validation, and events to be registered. Four stages were identified in the care and registration process: suspected diagnosis, morphological confirmation (biopsy), clinical resolution (oncology committee, including treatment recommendations), treatment, and oncological follow-up. The platform's development (from 2018 to 2021) involved gathering information and agreements on the requirements for co-designing the registry, including a successful pilot program with over 20 public and private healthcare facilities that recorded nearly 7500 cancer cases. The deployment and use of the National Cancer Registry at a national level depends on the healthcare authority. It is an information system that continuously and systematically collects, stores, processes, and analyzes data on all cancer cases and types occurring in the country. This work presents the design and development of the tool, the challenges addressed, as well as its strengths and weaknesses.

KEYWORDS Cancer, Public Health, Digital Technology, Health Information Systems

INTRODUCTION

Cancer strongly compromises the health status of those affected and, in many cases, leads to death [1]. In 2019 in Chile, cancer ranked first among the non-transmissible chronic diseases causes of death, overtaking cardiovascular diseases [2]. Likewise, it can be noted that during 2018, 53 365 new cases of cancer, 28 443 deaths, and a prevalence of 135 618 patients were registered in Chile, this being only estimates "because no one knows exactly how many people have cancer, how many patients die from this cause or how many children and adults are diagnosed since there is no unified, updated, and detailed database." [3]. The lack of a National Cancer Registry in Chile means that information on the epidemiological situation is not available because, since such information is provided by

population-based cancer registries [4], only five registries of this kind are available in the country. These are located in certain areas (Arica and Parinacota, Antofagasta, Maule, Los Ríos, and Bío Bío) [5], with significant differences between regions [4].

However, population-based cancer registries are recognized as a "valid and reliable methodology for the systematic collection of all cancer cases diagnosed within a population" [6]. In this sense, these registries are considered by the World Health Organization and its International Agency for Research on Cancer (IARC) as the epidemiological information system that should be the basis for morbidity surveillance of this health problem [4].

En este caso, a diferencia de los estudios clínicos o registros hospitalarios, donde los resultados se refieren a grupos particulares de pacientes, los registros poblacionales del cáncer aportan información sobre las tasas de incidencia, mortalidad y supervivencia del cáncer en todos los sujetos de una población [6]. Sin embargo, un desafío mayor a dichos registros es contar con un Registro Nacional del Cáncer, porque "es muy difícil efectuar análisis epidemiológicos y programáticos con total validez mientras no se cuente con información completa sobre la incidencia de cánceres relevantes con inclusión del sector privado y sobre las interacciones entre los servicios públicos

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MAIN MESSAGES

- Cancer is one of the leading causes of death worldwide.
- In Chile, there are clinical, hospital, and population registries. The challenge with the Chilean National Cancer Registry was to design a cross-cutting platform for these three registries.
- The National Cancer Registry will allow continuous and systematic collection, storage, processing, and analysis of data on all cases and types of cancers occurring in the country from patients in the public and private health sectors.
- The platform for the National Cancer Registry will allow the storage of high-quality clinical information and the generation of knowledge from the systematic recording of variables related to the anatomopathological and clinical diagnosis of patients.

de salud" [7]. Además, en los registros de cáncer se mide la supervivencia poblacional, cuyas tasas son los indicadores más directos de la gravedad del cáncer y del impacto del tratamiento, siendo un antecedente fundamental para promover políticas públicas [8]. Por ello, se trata de un gran desafío, porque un Registro Nacional del Cáncer no puede originarse a partir de una sola fuente y la información aportada debe ser precisa y actualizada e incluir otros elementos como el seguimiento de pacientes [7]. All this implies an enormous technological effort, in addition to achieving consensus among the multitude of actors involved, which makes the task complex. This article presents the design and development of the Chilean National Cancer Registry, the challenges faced, and its strengths and weaknesses.

CHALLENGES FOR CANCER SURVEILLANCE IN CHILE

Advances aimed at improving the detection, care, and follow-up of people with cancer have gradually met certain milestones in Chile, the most recent being the National Cancer Plan in 2018 [8], which contemplates within its strategic lines the strengthening of registration, information and surveillance systems in order to have timely information that allows improving network management, conducting more cancer research, monitoring the development of the National Cancer Plan and making of decisions at the population level in cancer [8]; and subsequently the National Cancer Law (Law 21 258) [9], which stipulates that "cancer will be considered a notifiable disease. Consequently, the provisions of article 49° of the Health Code must be complied with". However, despite the existence of a mandate, the National Cancer Registry is not in use, and the information available in the population-based cancer registries at health authority sites shows figures severely outdated [5].

The National Cancer Registry [5] should be understood as an information matrix that gathers individuals with suspected, diagnosed, treated, and followed-up cancer for surveillance and data collection, thus contributing to scientific research, public health decision-making, and the healthcare of people suffering from the disease.

It was developed and tested with a successful pilot, in which more than 20 hospitals in the country participated, achieving a registry of nearly 7500 cases [10]. However, the National Cancer

Registry was not implemented nationwide after its piloting. This tool will make it possible to know the real incidence of cancer in the country by systematizing the information on cancer patients in a technological platform with national coverage when all the establishments that provide these services report information. The National Cancer Registry is a public good developed together with the Ministry of Health with the support of the Production Development Corporation to support healthcare authorities with a national information system that serves to continuously and systematically collect, store, process, and analyze information on the cases and types of cancers occurring in the country, integrating public and private health patients [3]. The National Cancer Registry's development resulted from a long and complex co-design and development process involving different relevant actors, including representatives of the national health authority, oncology, and epidemiology specialists. It results from years of research and technological innovation associated with the awarding of competitive funds.

CO-DESIGN OF THE NATIONAL CANCER REGISTRY

To design the National Cancer Registry, four stages in the care process and registry were defined: suspected diagnosis, morphological confirmation (biopsy), clinical resolution (indication for treatment), and oncological treatment and follow-up. The National Cancer Registry was developed in four phases. During Phase I (from 2018 to 2019), the first version (1.0) was achieved with the functional and non-functional characteristics outlined in the working tables. Following the piloting process, the next version (2.0) incorporated the missing aspects, including new variables, the recording events, the relevant actors, morphological confirmation, and clinical resolution. In this sense, the difference between the first and second versions was that the latter defined the system actors, the targeted groups, and the required tasks for each actor.

In phase II (year 2020), agreements were reached with the national health authority (Ministry of Health), achieving 100% acceptance of the agreed requirements in a fully functional version (2.4), which incorporated the pending aspects that were not addressed in phase I. All of the above under the current ethical and legal framework, following national and international standards, classifications, norms, and best practice guidelines [11].

In phase III (year 2020), the final version (2.4) was introduced on the Ministry of Health servers. In phase IV (year 2021), additional developments were carried out incorporating improvements and new requirements made by the Ministry of Health, generating a new version (2.7.0) available to collect data from existing national electronic clinical records at the primary, secondary, or tertiary care level. Regarding the above, registrable cases are defined by the technical standard No. 72 on population-based cancer registries of the Ministry of Health [1].

Thus, the platform for the National Cancer Registry aims to gather quality clinical information and generate knowledge from the systematic recording of variables related to the anatomopathological and clinical diagnosis of patients. Thus, the National Cancer Registry contemplates the corresponding training process for data providers, aiming to standardize the collection methodology and avoid biases. The information provided by the National Cancer Registry is presented below, according to the fields required for the registry, which have been separated into different tables for easier reading. Table 1 presents the data for patient identification and morphological conformation, and Table 2 the information on clinical resolution.

FINAL CONSIDERATIONS

Creating the Chilean National Cancer Registry resulted from continuous discussions and agreements among various stakeholders. Its design contemplated the challenge of transversally integrating clinical, hospital, and population registries. Experts point out that a National Cancer Registry is necessary to achieve valid epidemiological and programmatic analyses [7]. However, its use in practice is subject to governmental decisions, and it is not currently active, even though the health authority states it is part of the National Cancer Plan [5]. Thus, among the barriers to using national cancer registries are the associated workload, the scarce recognition of their value by the authorities, the need for a commitment in the chain of reporting actors regarding the value of the aggregated individual information, and ethical and legal aspects [6].

The National Cancer Registry is a key technological tool for healthcare management and applying public health policies in the oncological field by collecting, storing, processing, and analyzing data on all cases and types of cancer in the country, including patients in the public and private sectors. In this sense, as a whole, the National Cancer Registry information contributes to establishing priorities in allocating resources and promoting research activities in specific areas [8]. This surveillance system

Table 1. National Cancer Registry fields in patient identification and diagnostic confirmation.

Field	Description
Patient identification	
Patient's RUT	Patient's RUT entered in the system
Names, paternal and maternal surname; sex, date of birth	Data were extracted from the Civil Registry
Sector, health service, and establishment	Data obtained from the user in session
Morphological confirmation	
Region/health service; region/health service sample analysis	By default, the region or health service of the registered professional is displayed (required)
Sample source facility; sample analysis facility	Facility where the biopsy was performed. By default, the facility of the registered professional is displayed (required)
Topographic location	ICD-3 category. No rules (required)
Topographic sublocation	ICD-O-3 subcategories, according to topographic location (required)
ICD-O morphological	ICD-O-3 morphology (up to 3 can be added). No rules All morphologies are shown (required)
Metastasis histology	When activated, the option to add a new morphology is displayed. If selected, it is mandatory to enter the morphology of the metastasis. When saving the record, two cases are displayed: one of the main morphology and one of the metastases (optional)
Pathologic T	Size and extent of the main tumor. No rules (optional)
Pathologic N	Extent of cancer. No rules (optional)
Pathologic M	State presence of metastasis. No rules (optional)
Degree of differentiation	No rules (required)
Laterality	Displayed if the selected topographic site is bilateral (e.g., tonsil, breast) (required)
Date of sampling	The date on which the biopsy is performed. No rules (required)
Date sample received	Date the professional receives the biopsy. Must be greater than or equal to the date of sample collection (required)
Date of biopsy report	Date of biopsy result. Must be greater than or equal to the date of receipt (required)
Biopsy number	Biopsy identifier. No rules (required)
Complementary examination	The complementary examination is optional. The field appears by default. The practitioner should delete it if it is not required

ICD-3: International Classification of Diseases, 3rd edition. ICD-O: International Classification of Diseases. ICD-O-3: International Classification of Diseases for Oncology, 3rd edition. RUT: Individual Tax Number.

Source: Prepared by the authors.

Table 2. National Cancer Registry fields in diagnosis resolution.

Field	Description
Region/referral health service	Where the clinical resolution committee was performed, expressed according to region and health service. By default, the region or health service of the registered professional is displayed (required)
Referring facility	Facility where the morphology confirmation was performed. By default, the facility of the registered professional is displayed (required)
Region/health service of the committee	Facility where the committee resolution will be performed. By default, the region or health service of the registered professional is displayed (required)
Committee's establishment	Facility where the committee resolution will be performed. By default, the establishment of the registered professional is displayed (required)
ICD-10 category	The category is the three-character key or code corresponding to a disease or diagnostic term. No rules (required)
ICD-10	The coding of the disease with ICD-10 categories (required)
Committee date	First committee to which the patient presents. By default, this is the date on which the record was made. No rules (required)
Age at diagnosis	Age of the patient when diagnosed with cancer
Tumor origin	Establish whether it is primary, unknown, recurrence, or multiple. If recurrence is selected, the "site of recurrence" field is displayed (required)
Extent	Cancer spread location. The extent grade described in the APA report is based on ICD-O. No rules (required)
Laterality	It is registered in paired organs. Options: Right, Left, Bilateral, or Unknown (required)
ECOG scale	Scale with rating from 0 to 5 used in oncology patients. It assesses the evolution of autonomy capabilities, which is important for defining treatment. No rules (required)
Diagnosis statement	Examination and/or document confirming the presence of the neoplasm. No rules (required)
Stage level	The extent to which cancer has spread in the body. No rules (required)
Stage category	Categories that accompany the cancer according to its stage. No rules (required)
Clinical T	Size and extent of the primary tumor before treatments and surgeries. No rules (required)
Clinical N	Lymph node extension before treatments and surgeries. No rules (required)
Clinical M	Indicates whether metastases were present before treatments and surgeries. No rules (required)
Pathologic T	Size and extent of the primary tumor. No rules (required)
Pathologic N	Cancer extension. No rules (required)
Pathologic M	Indicate the presence of metastases. No rules (required)
Treatment intention	Register scheduled treatments: palliative, curative, survival, and others. There are no rules. If survival is selected, the treatment option is disabled by "Non-Oncologic Surgery"
Type of treatment	Value selection: oncologic surgery; chemotherapy; external radiation therapy; immunotherapy; hormone therapy; observation; no treatment; brachytherapy; pain relief; non-oncologic surgery; target therapy; iodine therapy; bone marrow transplantation
Comments	Record extra-committee decisions. Supports up to 200 characters, including spaces

ICD-10, International Classification of Diseases, 10th edition. ECOG, East Cooperative Oncology Group. T, size, and extent of the tumor. N, number of affected lymph nodes. M, presence of metastases. ICD-O, International Classification of Diseases. APA, American Psychiatric Association. Source: Prepared by the authors.

is oriented to cancer monitoring, making it possible to observe patterns of this disease in different populations and to identify high-risk groups. A fundamental purpose of these tools is to support decision-making, guide actions in groups with specific needs, and be useful for planning and evaluating cancer control programs.

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Desafíos en la vigilancia de todos los casos de cáncer en Chile: Registro Nacional de Cáncer

RESUMEN

El cáncer causa millones de muertes a nivel mundial por lo que su registro es fundamental, existiendo registros clínicos, hospitalarios y poblacionales. Estos últimos son el estándar de oro para la información sobre incidencia y supervivencia de cáncer en una región definida. En Chile se cuenta con cinco registros poblacionales ubicados en ciertas zonas del país. El Registro Nacional del Cáncer chileno surge como un desafío para conformar una herramienta transversal a los tres tipos de registro con la finalidad de, al menos, conocer la cantidad de casos por tipo de cáncer. Su diseño implicó un despliegue de acciones orientadas a lograr consensos entre diversos actores respecto de la información, validación y eventos necesarios de registrar. Se identificaron cuatro etapas en el proceso de atención y el registro: sospecha de diagnóstico, confirmación morfológica (biopsia), resolución clínica (comité oncológico incluyendo la indicación de tratamiento), tratamiento y seguimiento oncológico. A su vez, el desarrollo de la plataforma (años 2018 a 2021) implicó levantamiento de información y acuerdos sobre los requerimientos para el co-diseño del registro, incluyendo un exitoso pilotaje con más de 20 establecimientos de salud del sector público y privado con registro de cerca de 7500 casos de cáncer. El despliegue y uso del Registro Nacional de Cáncer a nivel nacional depende de la autoridad sanitaria. Se trata de un sistema de información que recolecta, almacena, procesa y analiza de forma continua y sistemática datos sobre todos los casos y tipos de cánceres que ocurren en el país. En este trabajo se presenta el diseño y desarrollo de la herramienta, los desafíos abordados, sus fortalezas y debilidades.



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