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RESEARCH

Design and Implementation of a Technological Platform To Establish a National Cancer Registry in Chile

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Abstract

National Cancer Registries (NCRs) are essential for monitoring cancer incidence, prevalence, and outcomes at the population level, supporting evidence-based policies and resource allocation. In Chile, fragmented health information systems and infrastructure gaps have historically hindered the establishment of a nationwide registry. In response, a technological NCR was developed under the National Cancer Plan and Cancer Act. This article presents a validation study assessing the NCR's usability from the perspective of healthcare professionals involved in cancer registration. A quasi-experimental, within-subjects design was applied, where 26 healthcare professionals from 22 institutions across Chile completed five core registry tasks using both their current systems and the NCR platform. Results show statistically significant reductions (≈40–50%) in perceived task difficulty across all tasks, with large effect sizes ($r > 0.7$), indicating improved usability and lower workload when using the NCR platform. These findings highlight the platform's potential to overcome institutional barriers to adoption and contribute to the comprehensive and sustainable implementation of a national cancer surveillance system in Chile.

Keywords Cancer · Population-based cancer registry · Latin america · National cancer registry · Software

Introduction

To build a cancer registry involves the systematically collecting, storing, and managing cancer patients` data [1]. Large repositories such as national cancer registries (NCRs) collect, store and manage key data such as cancer incidence, prevalence, mortality, survival and outcomes at a national level. Understanding the epidemiology of cancer and its dynamics may assist healthcare professionals, cancer researchers, and policymakers in making more informed decisions aiming to improve cancer prevention and control strategies, healthcare planning and allocation of resources for specific cancer types or for certain geographical areas [1, 2]. Although worldwide there are more than 700 cancer registries, as occurs with the access to healthcare, registration coverage displays marked disparities across the globe, and only a small fraction of the world population (less than 25%) is covered by population-based registries [3]. For instance, high-quality registration coverage in areas like Africa, Asia and Latin America reach to 4%, 8% and 7% of the population, respectively, while the coverage in North America and Europe is close to 83% and 32%, respectively [4].

Official figures from 2020 indicate that malignant tumors were responsible for >28,000 deaths in Chile [5]. Furthermore, projections from the International Agency for Research in Cancer (IARC) estimate more than 55,000 cases per year by 2040 [6]. Despite these grim prospects, there is no reliable information regarding cancer incidence or prevalence in Chile. This is partly explained by the absence of a unified, updated, and detailed cancer database with national coverage. Some of the obstacles for establishing a high-quality

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NCR in Chile include the existence of multiple registries that contain fragmented information. This is mainly derived from a low integration among healthcare providers; in addition, many health care centers have limited access to digital resources along with varying capacities to implement health information systems, leading to delayed or duplicated reports, restricted access to medical records of patients and discontinuity of care [7, 8].

Back in 2018, the Chilean government launched the National Cancer Plan (NCP), aiming to improve cancer prevention, early diagnosis and treatment. This plan also included establishing the first NCR via the development of a technological platform with national coverage to systematize the information of patients. Besides the abovementioned challenges, establishing a cancer registry platform requires the standardization of data, ensuring interoperability (the ability of different systems or software to work together, allowing them to exchange and use information seamlessly) and validation and the security of the information [9]. To ensure compliance with the NCP, the Chilean Congress passed the National Cancer Act (#216646) in 2020.

Previously, our research group reported the designing and the early deployment of the NCR platform, a web-based oncology electronic health record intended to consolidate the confirmation of diagnoses, staging and treatment across all chilean healthcare providers [10]. Developed through an implementation-science approach that systematically mapped barriers and enablers, the platform's specification was co-created with eight stakeholder roles—treating physicians, pathologists, oncology-committee coordinators, validators, and others—to ensure that its workflow matched real-world practices. The resulting system exposed five core use cases that are directly examined in the current study: (i) Record Morphological Confirmation, (ii) Record Clinical Resolution, (iii) Validate Cases, (iv) User Management and (v) Consult/Download Cases.

The NCR platform was previously described as a web-based oncology health record developed with an implementation-science approach to ensure interoperability, security, and reliability [10]. Thus, the goal of this article was to report the validation of our NCR platform, quantifying its usability and perceived workload reduction among healthcare professionals who perform cancer-registration tasks. Using a within-subjects, quasi-experimental design that mirrors the platform's five core use cases, we compared the new system with incumbent local solutions and demonstrate statistically significant, large-effect improvements across all tasks. These results provide an empirical base to move from technological deployment to sustainable, nationwide adoption—supporting the NCP's mandate for comprehensive, high-quality cancer surveillance in Chile.

Materials and methods

Ethics approval and consent to participate

Healthcare professionals that participated in the study signed written consent forms, ensuring their privacy. The study was approved by the research ethics committee of the Metropolitan Eastern Medical Health Service on November 2nd, 2021. All methods adhered to relevant ethical guidelines and regulations established by the Helsinki conference.

Research Design

Our study sought to evaluate some of the outcomes obtained during the development of NCR [10]. As defined by Basili and Rombach, the scope of our study was to "Analyze the NCR System for the purpose of evaluate its improvements with respect to its usability from the perspective of user, in the context of a cancer healthcare professionals performing relevant registry tasks throughout the diagnostic confirmation, staging, and treatment processes in a controlled environment." [11] We specifically focused on the system's usability for two main reasons [10]. First, the efforts of healthcare institutions are mainly focused on tracking the records of each patient to complete details on the diagnosis, staging, and treatment of the patients to provide a complete record of each registered patient. This is due to the limited time of healthcare professionals and usability issues existing health record systems. Secondly, the initial architectural design prioritized security, compatibility and reliability over other quality attributes mainly due to cost restrictions [10]. However, even under these constraints, the user interaction was designed to minimize inputs. For instance, the systems included search asistance for ICD-O topography field, which automatically filtered options to ensure consistency between ICD-O topography and morphology codes.

According to Wohlin et al., this was an explanatory-comparative, quasi-experimental and quantitative study [12]. The experiment was conceived following their guidelines, using a single-group repeated-measures design. This design was chosen over a two-group between-subjects approach due to the extremely limited availability of participants' time (healthcare professionals). The subjects were selected by convenience from healthcare professionals across Chile who participate in local cancer registries (hospitals or cancer centers) and are familiar with the clinical workflow. The main variable of the study was the subject's perception of difficulty on performing a cancer registry task, that should have been answered considering their current system and the proposed system. The variable was measured though a five-points Likert scale, where 1 means that the task was very easy to accomplish and 5 was very hard. Participants

also rated task importance (5-point scale). To summarize the overall perception of difficulty, we computed the Weighted Difficulty Score (WDS) as the product of each task's importance (1–5) and difficulty (1–5), yielding a 1–25 scale where higher values indicate greater perceived burden. WDS captures difficulty scaled by role-specific relevance, which is appropriate in heterogeneous teams (registrars, pathologists, validators, committee coordinators) where task importance legitimately varies. As a composite of two ordinal items, WDS assumes a multiplicative relation and can overweight extreme importance ratings, making it less transparent than reporting difficulty alone. To mitigate this, we also verified the results for difficulty alone. Descriptive statistics (medians, means, and standard deviations) were calculated for all variables. Given the ordinal nature of the input scales used to compute the WDS, we applied a two-tailed Wilcoxon signed-rank test to compare WDS values before and after the intervention for each task. An alpha level of $\alpha = 0.05$ was considered statistically significant. Effect sizes (r) and 95% confidence intervals for the paired differences were also reported. The effect size was calculated as $r = Z/\sqrt{n}$ where Z is the standardized Wilcoxon statistic and n is the number of non-zero paired differences. The Z value is obtained from the Wilcoxon Signed Rank Test using the normal approximation based on the ranked absolute differences.

Participants were selected through a convenience sampling strategy, recruiting volunteers from various institutions involved in cancer registration in Chile, including public health services, oncology centers, and academic units. During the data collection activities, officials from the Ministry of Health acted as neutral facilitators, supporting the logistics of implementation while ensuring an unbiased environment. The development team was present solely to provide technical support prior to the beginning of the usability tasks, and did not participate or intervene during the sessions in order to avoid influencing participants' responses or behaviors.

Each session involved a 10-minute introduction, during which the study objectives were explained and informed consent was obtained. Next, participants attended a 15-minute training session on the new NCR platform and received the login details to perform different roles within the system: Validator, Anatomical Pathologist, and Oncology Committee Coordinator, necessary to complete the experimental tasks. After this orientation, participants performed the five registry tasks on the NCR platform. Finally, subjects completed a survey, quantifying the importance, difficulty using the NCR, and difficulty when using their current system. Below, we describe each experimental task.

Experimental Task 1 – Morphological Confirmation Acting as cancer registrars, participants located a patient using national ID, reviewed pre-filled demographics, and completed the clinical form with ICD-O topography and morphology codes, sampling and report dates, and TNM (Tumor, Node, Metastasis) stage. Subsequently, the biopsy reports (in PDF format) and any ancillary test results were uploaded. The entry was then reviewed in preview mode, and the case was formally registered within the NCR platform.

Experimental Task 2 – Patient-Case Visualization With registrar or validator privileges, participants were instructed to open the *Patient Cases* window, retrieve the target record, scan the chronological list of previous entries, and inspect each one in PDF format—including stored biopsy or complementary-exam files—to verify past data before proceeding.

Experimental Task 3 – Clinical Resolution In the role of treating physicians or committee coordinators, participants registered tumors that lacked histological info. After locating the patient by ID, they filled in ICD-10 codes, committee date, tumor origin, TNM stage, and planned treatment details; then previewed the information, and confirmed the record on the system.

Experimental Task 4 – Validation of Morphological-Confirmation Cases As validators, participants reviewed each histology-based entry in the validation queue, ensuring completeness of topography, morphology, sampling dates, biopsy number, and attached reports. If every field was correct and consistent, they marked the case as *Validated*; otherwise, they requested corrections or consult the original source.

Experimental Task 5 – Validation of Clinical-Resolution Cases (8 responses) Serving again as validators, participants verified clinically registered cases by cross-checking topography with ICD-10, confirming the pathological TNM and other mandatory variables, and retaining the first committee date as the incidence date. Then they validated the case—or return it for revision—based on data completeness and consistency.

Results

A total of 26 healthcare professionals participated in the study. The activity was coordinated by the Chilean Ministry of Health and involved healthcare professionals from 22 public and private healthcare institutions. Overall, 10 out of 26 participants (≈38%) were users of hospital cancer registries, underscoring their operational role in the study.

Table 1 Descriptive statistics for the WDS of perceived difficulty with the current system and NCR

Task	System	*N*	WDS	SD	Median	Min	Max
1	Current	26	**18.6**	4.73	18	8	25
	NCR	26	**10.4**	6.01	9	5	25
2	Current	26	**18.4**	6.72	20	4	25
	NCR	26	**11.2**	5.2	10	5	25
3	Current	26	**18.9**	5.91	20	6	25
	NCR	26	**12.7**	6.45	15	3	25
4	Current	14	**19.3**	6.43	20	5	25
	NCR	14	**13.2**	6.65	12	5	25
5	Current	8	**21.9**	5.3	25	10	25
	NCR	8	**11.9**	7.53	10	5	25

improvements, independent of score weighting

General nursing staff contributed with four participants, while epidemiology and pathology units each added three heads or officers, and public-health departments provided two representatives. The remaining four posts were singletons—an oncology liaison nurse, a clinical studies unit head, an academic, and a non-communicable-disease epidemiology advisor—rounding out a profile dominated by registry personnel and supported by nursing, analytical, and public-health expertise.

The participants' answers for the survey regarding their perception of the tasks were analyzed to assess the effectiveness of the improvements. Table 1 presents the descriptive statistics for each task, expressed in terms of WDS, which represent the product of the importance and difficulty for each task. Figure 1 illustrates a boxplot comparing the differences in weighted difficulty for the five tasks.

The NCR platform consistently showed lower weighted difficulty (≈40–50% reduction in the mean WDS) across all tested tasks, indicating a clear improvement in usability. However, variability (SD) was slightly higher in NCR for some tasks, suggesting user experience is diverse. Sample sizes were reduced on Tasks 4 ($n=14$) and 5 ($n=8$) because only the relevant healthcare professionals attempted those tasks; results remain directionally consistent The Wilcoxon signed-rank test was applied to compare the WDS between the current system and the NCR platform across all five tasks and the overall average per participant. The analysis revealed statistically significant reductions in WDS for each individual task, as well as for the global score. Specifically, p-values were <0.001 for Tasks 1–3, 0.007 for Task 4, and 0.018 for Task 5, all below the pre-defined $\alpha=0.05$ threshold. These results indicate consistent improvements in perceived task difficulty when using the NCR system. The associated effect sizes (r) ranged from 0.64 to 0.83, which are considered large according to standard benchmarks. For the overall participant mean, the WDS difference was also significant ($p<1\times10^{-6}$), further supporting the robustness of the observed effect These statistical results are aligned

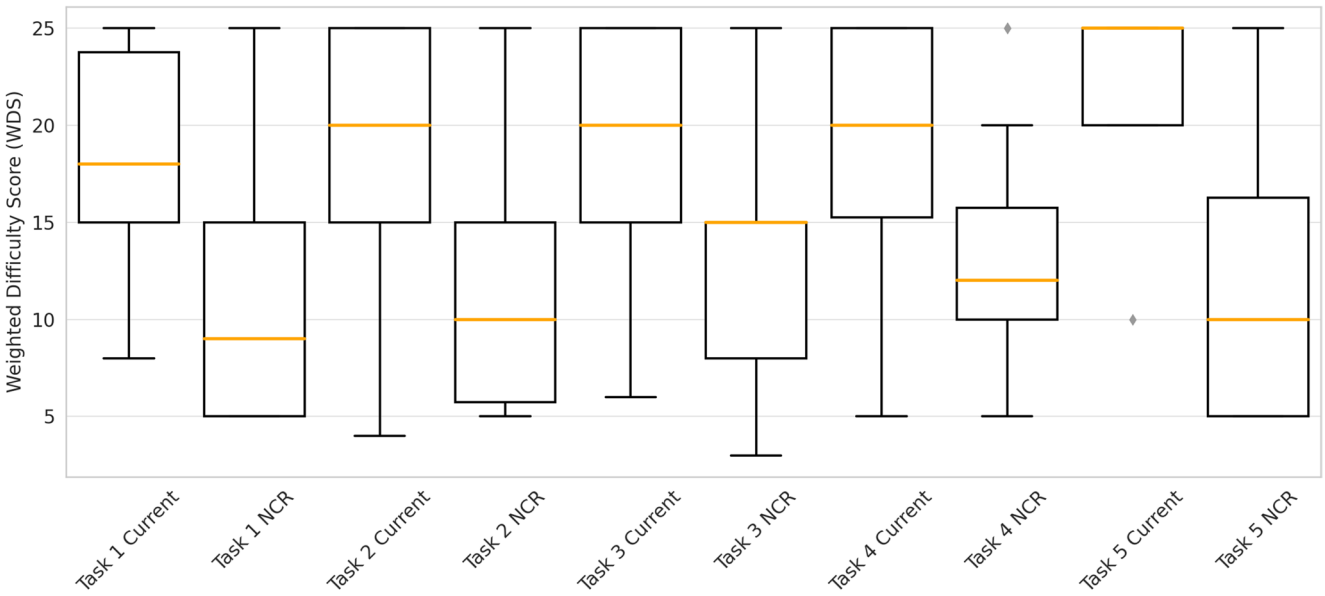

Fig. 1 Descriptive statistics for the WDS of perceived difficulty with the current system and NCR for each task

Table 2 Wilcoxon signed-rank test results for WDS across tasks comparing the current system and NCR

Task	*N*	Median Diff.	*p*-value	Effect size (*r*)	95% CI (Diff)
1	26	10.0	1.5e-04	0.83	[5.0, 12.5]
2	26	6.5	1.9e-04	0.82	[5.0, 10.0]
3	26	8.0	4.3e-04	0.79	[2.0, 10.0]
4	14	2.5	1.7e-02	0.91	[0.0, 10.0]
5	8	10.0	3.8e-02	0.95	[0.0, 20.0]

with participants' subjective perceptions: the NCR platform yielded a 40–50% reduction in difficulty scores compared to the current system. This pattern held consistently across experimental tasks, suggesting that the intervention had a substantial and generalizable effect on usability. Table 2 presents the full results of the Wilcoxon tests, including median differences, effect sizes, and bootstrapped 95% confidence intervals. To address potential limitations of the composite WDS, we also analyzed raw difficulty ratings for each task. This control analysis confirmed the main results: difficulty scores were significantly lower for the NCR platform across all tasks ($p < 0.05$), showing similar direction and magnitude of effect. These findings support the robustness of the usability

The effect size was calculated as $r = Z/\sqrt{n}$, which is appropriate for the Wilcoxon signed-rank test in within-subjects designs. Values above 0.5 are typically considered large, and those above 0.7 indicate very large effects. All tasks yielded effect sizes in the large-to-very-large range, supporting the practical relevance of the observed differences. These results, combined with narrow bootstrapped confidence intervals, confirm that the reductions in perceived difficulty with the NCR platform are not only statistically significant but also substantively meaningful.

Discussion

Practical Implications of the Findings

The very large Wilcoxon effect sizes observed correspond to a 40–50% reduction in perceived workload when using the NCR platform—an improvement users are likely to feel immediately when registering or validating cases. In Chile, such relief tackles two of the main obstacles to launching the NCR: the added workload for clinical staff and the limited institutional recognition of its value [13]. Easier workflows increase the chances that frontline healthcare professionals will consistently report cases, a prerequisite for meeting Law 21 258, which made cancer notification mandatory and is explicitly aligned with the abovementioned 2018–2028 NCP goal of strengthening registry and surveillance systems. Better usability also addresses another critical challenge highlighted by public-health experts: without complete, up-to-date data that include the private sector, high-quality epidemiological analyzes and resource planning are not feasible. By streamlining key tasks, the NCR platform lowers a major operational barrier, thereby increasing the likelihood that hospitals will adopt it beyond the successful pilot and ultimately enabling a comprehensive national picture of cancer incidence, treatment, and outcomes.

Threats To Validity

Following Wohlin's framework, the study shows strong statistical-conclusion validity for the three tasks with larger samples ($N = 26$) and acceptable power (≥ 0.99). In Tasks 4 and 5, mild departures from normality and smaller sample sizes reduce precision, yet Wilcoxon tests confirmed the same direction of effect, keeping the risk of Type-I/II error moderate. Internal validity benefits from the within-subjects design, which removes carry-over effects and controls individual variability; the short pre/post interval minimises maturation. Nevertheless, baseline difficulty was based on recall rather than live interaction, so response-shift bias and a potential "novelty halo" after the NCR tutorial remain plausible threats that could inflate perceived improvements.

Construct validity is limited by the reliance on subjective Likert ratings instead of direct performance metrics, and by the contextual difference between habitual use of the legacy system and immediate execution on the NCR. Externally, the convenience sample—motivated staff from pilot hospitals—limits generalisation to lower-resourced or private centers, a known challenge in Chile's fragmented health system. Still, the sample spans 22 institutions and multiple professional roles, providing diverse perspectives. Due to time limitations of the participants, we were able just to collect one survey (difficulty x importance). We look forward to apply other instruments (NASA TLX and SUS) during the staged deploy of the NCR. Future multicenter studies with randomised or counter-balanced designs, objective time-and-error measures, and broader hospital types are recommended to confirm that the sizable perceived gains translate into real-world efficiency improvements nationwide.

Implementation Considerations

Ensuring the efficiency, workability and data utility of a cancer registry must consider several factors. First, the involvement of clinicians. Also, establishing clear definitions and a judicious selection of variables along with strategies to improve data quality and completeness, and a comprehensive approach to ethics and patient privacy [14]. Another critical step is a proper setup of the NCR platform which also involves training and technical support for registry (data

entry) personnel, ensuring a seamless operation and maintenance. In line with the NCP, collecting the generated data on cancer prevention, diagnosis, treatment, rehabilitation, palliative care and case monitoring will demand the participation of all stakeholders. Therefore, specialized teams from the Ministry of Health, Health Services, hospitals, and clinics (with their own electronic clinical record system) will be trained in interoperability standards, specifically Clinical Document Architecture, allowing direct data contribution to the NCR. This not only implies better management but also avoid issues such as duplicate registration, improving processes associated with mandatory cancer surveillance. Furthermore, it is essential to have validators and external evaluations of the processes currently performed manually according to Technical Standard 72, which has not been updated since 2004, at each participating healthcare center. This is crucial to ensure data quality and maintain updated systems.

Currently, the database of the NCR is supplied by the National Cancer Institute located in Santiago (Chile) and is limited to six tumor types: breast, cervical, gastric, ovarian, prostate, and thyroid. Next steps involve establishing a collaboration and service provision agreement with the Chilean Ministry of Health to expand the NCR platform to the entire country. Once fully established in healthcare centers across the country, this platform will provide a valuable tool to improve the quality of data in Chile. This also opens the possibility to share the collected data building a Latin American network [15].

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Data Availability The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Consent for Publication Not applicable.

Ethics Approval and Consent To Participate The study was reviewed and approved by the Scientific Ethics Committee (CEC) of the Eastern Metropolitan Health Service (Servicio de Salud Metropolitano Oriente, SSM Oriente) on November 2nd, 2021. All participants provided informed consent prior to participating in the online interviews. Consent was obtained using a standardized script approved by the ethics committee for online studies involving individual surveys or interviews.

Competing interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Clinical trial number Not applicable.

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