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SYSTEMATIC REVIEW

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A systematic review and comparative evaluation to develop and validate a comprehensive framework for cancer surveillance systems

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Abstract

Background The increasing global burden of cancer necessitates robust cancer surveillance systems to generate accurate and comprehensive data for effective public health interventions. Despite advancements, significant gaps remain in data standardization, interoperability, and adaptability to diverse healthcare settings. This study aims to develop and validate a comprehensive framework for cancer surveillance systems that addresses these gaps, ensuring enhanced global applicability and regional relevance.

Methods A systematic review was conducted following PRISMA guidelines, analyzing 13 studies selected from an initial pool of 1,085 articles retrieved from five major databases: PubMed, Embase, Scopus, Web of Science, and IEEE. Additionally, a comparative evaluation of 13 international cancer surveillance systems was performed to identify critical data elements and practices. Key indicators were extracted. A researcher-designed checklist consolidating these elements was validated through expert consultation with a response rate of 82% ($n = 14$), achieving high reliability (Cronbach's alpha = 0.849).

Results The proposed framework addresses critical gaps in existing cancer surveillance systems by integrating a comprehensive set of epidemiological indicators, including incidence, prevalence, mortality, survival rates, years lived with disability, and years of life lost, calculated using multiple standard populations for age-standardized rates. Furthermore, the framework incorporates key demographic filters such as age, sex, and geographic location to enable stratified analyses. It also includes advanced data elements, such as cancer type classification based on ICD-O standards, ensuring precision, consistency, and enhanced comparability across diverse cancer datasets.

Conclusion The validated framework provides a structured and adaptable approach to cancer data collection and analysis, enhancing public health decision-making and resource allocation. By addressing current limitations, this study offers a significant advancement in cancer surveillance methodologies, with potential applications in diverse healthcare contexts globally.

Clinical trial registration Clinical trial number: Not applicable

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Keywords Cancer, Surveillance systems, Epidemiological indicators, Public health, Data standardization

Text box 1. Contributions to the literature

- This study enhances cancer surveillance literature by introducing a standardized framework incorporating emerging indicators (e.g., YLD, YLL), filling a methodological gap in global CSS for holistic burden assessment.
- It enriches public health data science by showcasing how advanced demographic and geographic filtering improves cancer surveillance system precision, enabling tailored interventions across diverse populations.
- The research advances cancer surveillance system interoperability knowledge, delivering a validated, adaptable model that informs global cancer control strategies with locally relevant insights.

Introduction

Cancer remains a leading cause of morbidity and mortality worldwide, accounting for approximately 10 million deaths in 2020 alone, as reported by GLOBOCAN [1]. The global burden of cancer is rising due to population growth, aging demographics, and evolving lifestyle patterns, necessitating effective cancer control strategies supported by reliable Cancer Surveillance Systems (CSS) [2, 3]. CSS are indispensable public health tools for the systematic collection, analysis, and dissemination of cancer data. They provide the foundation for evidence-based cancer control strategies, facilitating the tracking of epidemiological trends and guiding policies aimed at reducing cancer burden [4, 5].

A well-designed CSS generates reliable data on critical cancer indicators such as incidence, prevalence, survival rates, and mortality [5]. These systems provide timely and actionable insights that enable policymakers and healthcare providers to monitor cancer trends, allocate resources effectively, and evaluate the success of interventions, including screening programs and therapeutic innovations [6]. Moreover, they enable the continuous monitoring of cancer patterns and outcomes, revealing emerging trends, regional disparities, and population-specific risk factors [7, 8]. This ability to track cancer control efforts over time ensures targeted interventions, optimization of cancer care, and ultimately, reductions in cancer incidence and mortality [9, 10].

Global CSS, such as the Global Cancer Observatory (GCO), developed by the International Agency for Research on Cancer (IARC) under the World Health Organization (WHO), exemplify the potential of such systems. GCO provides comprehensive statistics on cancer incidence, prevalence, mortality, and survival across 185 countries, along with interactive visualization tools that allow for geographic and temporal analyses [1]. These functionalities make the GCO an essential resource for global cancer trend analysis, international policy guidance, and collaborative cancer control efforts.

Despite notable advancements, substantial gaps persist that limit the comparability and utility of existing CSS. One major challenge is the lack of standardization in data collection, classification, and coding practices, such as cancer morphology and topography classifications (e.g., ICD-O), which lead to inconsistencies in reporting across systems [3, 11, 12]. Similarly, variations in the adoption of standard populations for calculating Age-Standardized Rates (ASRs), including SEGI, WHO, and regional standards, further complicate cross-regional comparisons and epidemiological analyses [13–15]. While traditional metrics like incidence, prevalence, mortality, and survival rates are commonly prioritized, many systems fail to integrate disability-adjusted measures such as Years Lived with Disability (YLD) and Years of Life Lost (YLL), which are essential for capturing the societal and economic impacts of cancer [16, 17].

Additionally, technological disparities across systems impede their adaptability and utility. While advanced systems leverage visualization tools and demographic filters, many lack the infrastructure to provide region-specific granularity or real-time analytics, limiting their applicability in diverse healthcare contexts [18]. These gaps underscore the urgent need for a unified, adaptable framework that incorporates standardized data elements, advanced metrics, and technological tools to enhance data comparability, usability, and utility for cancer control at both global and regional levels.

This study addresses these critical gaps by defining and standardizing the essential data elements required for a comprehensive CSS. This research proposes a robust framework that enhances data consistency and comparability while remaining adaptable to diverse regional contexts. By bridging the gaps in standardization and adaptability, the proposed framework will support more effective cancer monitoring, enabling targeted interventions and evidence-based policymaking to mitigate the societal and economic impacts of cancer globally.

Methods

Study design

This study employed a systematic, multi-phase research design to identify essential data elements and develop a standardized framework for CSS. The methodology consisted of three primary phases: a systematic review of literature, a comparative evaluation of global CSS, and expert validation of identified data elements. This comprehensive approach ensured methodological rigor and the applicability of the findings across diverse healthcare contexts. The primary research question guiding this investigation is: What are the essential data elements and methodological practices required to design and validate a comprehensive CSS framework that ensures accurate tracking of epidemiological indicators? Secondary questions include: (1) How do demographic and geographic filters (e.g., age, sex, location) enhance the granularity and utility of cancer surveillance data for tailored public health interventions across diverse populations? (2) What gaps persist in current CSS methodologies concerning data standardization, interoperability, and adaptability, and how can these be addressed to achieve global applicability and local relevance in varied healthcare settings? (3) How do emerging indicators, such as YLD and YLL, improve the assessment of cancer burden and the effectiveness of surveillance systems in guiding resource allocation and policy development? (4) What role do standard populations (e.g., for ASRs) play in ensuring comparability of cancer indicators across regions and supporting consistent global burden assessments? (5) How does the integration of cancer type classification, such as ICD-O, contribute to precision, consistency, and comparability in cancer surveillance data across diverse datasets? This study was registered in PROSPERO (ID number: CRD420250633994).

Systematic review

Search strategy

The systematic review was conducted following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines to ensure transparency and thoroughness [19]. A preparatory phase was undertaken to refine the search strategy through expert consultations and preliminary searches. This process helped to identify relevant keywords and tailor search queries for five major academic and scientific databases: PubMed, Scopus, Web of Science, IEEE, and Embase. The search focused on essential data elements, standardization practices, and their global applicability (Table 1). Priority was given to studies meeting predefined inclusion criteria, which included relevance to CSS, peer-reviewed publication, and a focus on cancer epidemiological indicators, data standardization methodologies, or system interoperability. Only studies published in English between 01-01-2000 and 10-13-2023 were considered to ensure contemporary relevance. Exclusion criteria included studies with tangential public health topics, redundant publications, limited accessibility, or a sole focus on predictive models or machine learning approaches. The timeframe (01-01-2000 to 10-13-2023) was chosen to reflect significant post-2000 developments in information technology (e.g., web-based systems) and the release of ICD-O-3 by WHO [20], critical for modern CSS. Pre-2000 studies lack these innovations, as noted by Parkin and Bray [3].

The screening process followed a multi-stage approach. First, titles and abstracts of retrieved articles were reviewed against inclusion criteria, resulting in the exclusion of irrelevant studies. Subsequently, full-text reviews were conducted to assess alignment with the study's objectives, further narrowing the pool of articles. Finally, data extraction was performed on the selected studies to systematically analyze key data elements, standardization practices, and methodological innovations.

Clinical trial number: not applicable, as this study did not involve a clinical trial.

Risk of bias assessment

The methodological quality of studies included in this systematic review was appraised using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Cohort Studies to assess the Risk of Bias (RoB) [21]. This tool was chosen for its robust, structured approach to evaluating observational research, offering adaptability to the diverse study designs encountered (e.g., cohort, usability evaluations, cross-sectional), and its alignment with our objective of standardizing data elements across varied methodologies. The JBI Cohort Checklist consists of 11 items encompassing essential domains: participant selection (similarity of groups, recruitment processes), exposure measurement (consistency and validity), confounding factors (identification and control), outcome assessment (validity and reliability), follow-up (duration, completeness, and strategies), and statistical analysis (appropriateness). Each study was systematically evaluated across these domains to identify biases potentially impacting data reliability and comparability. Responses were classified as "Yes" (indicating low bias), "No" (high bias), or "N/A" (not applicable), culminating in an overall RoB designation of low, moderate, or high for each study.

Comparative evaluation of global cancer surveillance systems

To identify universal data elements and best practices, a comparative evaluation was conducted on 13 international CSS. These systems were chosen to represent diverse geographical regions, healthcare infrastructures, and methodological approaches to cancer data collection and reporting. Selection criteria emphasized system accessibility, availability of detailed documentation, and relevance to varied cancer epidemiology contexts. The 13 systems included in the analysis were GCO [1], European Cancer Information System (ECIS) [22], Cancer Research UK [23], Australian Cancer Data System [24], NordCan–Nordic Cancer Registry System [25], US Cancer Statistics Data Visualization Tool [26], National Children's Cancer Registry Probe (US) [27], Spanish Network of Cancer

Table 1 Search strategy for systematic review conducted across five major scientific databases

Database	Searching Query
IEEE	("Document Title": "data element*" OR "standardization" OR "global comparison" OR "epidemiological indicators") AND ("Document Title": "design" OR "designing" OR "develop" OR "developing" OR "implement" OR "creat*" OR "construct*" OR "build*" OR "Visualiz*" OR "assess*" OR "eval*") AND ("Document Title": "web-based" OR "online" OR "internet" OR "Client-Server" OR "Cloud-Based" OR "offline" OR "windows-based" OR "Distributed" OR "Enterprise" OR "Real-Time" OR "Collaborative" OR "interactive" OR "dynamic") AND ("Document Title": Cancer) AND ("Document Title": "surveillance" OR "monitor*" OR "visualize*" OR "dashboard" OR "interface" OR "system" OR "application" OR "program" OR "registry" OR "Observa*" OR "information system" OR "platform" OR "prototype"))
Scopus	(TITLE ("data element*") OR TITLE ("standardization") OR TITLE ("global comparison") OR TITLE ("epidemiological indicators")) AND (TITLE ("design*") OR TITLE("develop*") OR TITLE("implement*") OR TITLE("creat*") OR TITLE ("construct*") OR TITLE("build*") OR TITLE("Visualiz*") OR TITLE("assess*") OR TITLE ("eval*")) AND (TITLE("web-based") OR TITLE("online") OR TITLE("internet") OR TITLE ("Client-Server") OR TITLE("Cloud-Based") OR TITLE("offline") OR TITLE("windows-based") OR TITLE("Distributed") OR TITLE("Enterprise") OR TITLE("Real-Time") OR TITLE ("Collaborative") OR TITLE("interactive") OR TITLE("dynamic")) AND (TITLE ("cancer")) AND (TITLE("surveillance") OR TITLE("monitor*") OR TITLE ("visualize*") OR TITLE ("dashboard") OR TITLE("interface") OR TITLE("system") OR TITLE ("application") OR TITLE ("program") OR TITLE("registr*") OR TITLE("Observa*") OR TITLE ("information system") OR TITLE("platform")) AND (OA(ALL) AND LANGUAGE (English) AND SRCTYPE(j) AND DOCTYPE(ar))
PubMed	("data element*"[Title] OR "standardization"[Title] OR "global comparison"[Title] OR "epidemiological indicators"[Title]) AND ("design"[Title] OR "develop"[Title] OR "implement"[Title] OR "creat"[Title] OR "construct"[Title] OR "build"[Title] OR "Visualiz"[Title] OR "assess"[Title] OR "eval"[Title]) AND ("web-based"[Title] OR "online"[Title] OR "internet"[Title] OR "Client-Server"[Title] OR "Cloud-Based"[Title] OR "offline"[Title] OR "windows-based"[Title] OR "Distributed" OR "Enterprise"[Title] OR "Real-Time"[Title] OR "Collaborative"[Title] OR "interactive"[Title] OR "dynamic"[Title]) AND ("cancer"[Title]) AND ("surveillance"[Title] OR "monitor"[Title] OR "visualize"[Title] OR "dashboard"[Title] OR "interface"[Title] OR "system"[Title] OR "application"[Title] OR "program"[Title] OR "registr"[Title] OR "Observa"[Title] OR "information system"[Title] OR "platform"[Title])
Web of Science	(TI =("data element*" OR "standardization" OR "global comparison" OR "epidemiological indicators")) AND TI=(("design*" OR "develop*" OR "implement*" OR "creat*" OR "construct*" OR "build*" OR "Visualiz*" OR "assess*" OR "eval*") AND ("web-based" OR "online" OR "internet" OR "Client-Server" OR "Cloud-Based" OR "offline" OR "windows-based" OR "Distributed" OR "Enterprise" OR "Real-Time" OR "Collaborative" OR "interactive" OR "dynamic") AND (Cancer) AND ("surveillance" OR "monitor*" OR "visualize*" OR "dashboard" OR "interface" OR "system" OR "application" OR "program" OR "registr*" OR "Observa*" OR "information system" OR "platform"))
Embase	("data element*":ti OR "standardization":ti OR "global comparison":ti OR "epidemiological indicators":ti) AND (design*:ti OR develop*:ti OR implement*:ti OR creat*:ti OR construct*:ti OR build*:ti OR Visualiz*:ti OR assess*:ti OR eval*:ti) AND ("web-based":ti OR online: ti OR internet: ti OR "Client-Server":ti OR "Cloud-Based":ti OR offline: ti OR "windows-based":ti OR Distributed: ti OR Enterprise: ti OR "Real-Time":ti OR Collaborative: ti OR interactive: ti OR dynamic: ti) AND (cancer: ti) AND (surveillance: ti OR monitor*:ti OR visualize*:ti OR dashboard: ti OR interface: ti OR system: ti OR application: ti OR program: ti OR registr*:ti OR Observa*:ti OR "information system":ti OR platform: ti) AND types(Articles) AND Languages(English, Persian)

Registries (REDECAN) [28], Cancer Dimensions (Spain) [29], Finnish Cancer Registry [30], National Cancer Registry of Ireland [31], Geodes– French Public Health Agency [32], and Hamid and Christina Moghadam Program in Iran Studies Health Dashboard [33]. This evaluation extracted common data elements, assessed variations in their definitions, and examined standardization practices to enhance global comparability.

Development and validation of a standardized data checklist

Based on insights from the systematic review and comparative analysis, a standardized data checklist was developed to consolidate core elements into a comprehensive tool for CSS. This checklist aimed to balance global comparability with local relevance, capturing essential epidemiological indicators and advanced measures while incorporating filtering criteria for nuanced analyses in diverse healthcare settings. To ensure reliability and applicability, the checklist underwent a rigorous validation process. The Content Validity Ratio (CVR) was employed to evaluate the relevance of each item, with a threshold of 0.51 or higher used for retention (for 14 respondents from 17 contributors), based on established guidelines [34]. Cronbach's alpha, calculated at 0.849, indicated high internal consistency, affirming the checklist's robustness as a standardized tool for cancer data collection [35]. The CVR formula used was:

$$\mathrm{CVR} = \frac{n_e - \frac{N}{2}}{\frac{N}{2}}$$

Where n_e is the number of experts rating the item as essential and N is the total number of experts.

A simple random sampling method was employed to select participants for the validation process, ensuring a statistically valid representation of expert opinions. The panel consisted of 17 specialists, including oncologists, epidemiologists, and public health experts affiliated with Zanjan University of Medical Sciences, chosen for their expertise in cancer surveillance systems. The sample size was determined using Krejcie and Morgan's table and Cochran's formula, with a margin of error set at 0.05 for a 95% confidence level [36]. The detailed Krejcie-Morgan values for various community sizes with corresponding sample is provided in Supplementary File 1. The checklist was distributed via face-to-face meetings and email to ensure inclusivity. Feedback from the participants was systematically collected and iteratively incorporated into the checklist to refine its content. The sample size formula was:

$$n = \frac{Nz^2pq}{Nd^2 + z^2pq}$$

where N is the population size, z is the z-value for a 95% confidence interval (1.96), p and q are estimated proportions (set at 0.5 for maximum variability), and d is the margin of error (0.05).

Result

Systematic review results

The systematic review employed a rigorous search strategy, retrieving 1,085 articles from five major academic databases. During the initial screening phase, 577 articles were excluded based on predefined exclusion criteria. After removing duplicates using EndNote, 233 unique studies remained. A subsequent abstract review led to the exclusion of 210 articles that were not aligned with the study's focus on CSS and its key data elements. This narrowed the pool to 23 articles for detailed full-text evaluation. During this phase, two articles could not be retrieved, and eight were excluded for focusing solely on predictive models or machine learning applications without addressing the operational or structural aspects of CSS. Ultimately, 13 articles met the inclusion criteria and were selected for further analysis. These articles provided critical insights into CSS design and functionality, contributing directly to the development of the standardized data checklist. The PRISMA diagram (Fig. 1) outlines the detailed review process, and Table 2 summarizes the purpose, methodology, evaluated data elements, key findings, and relevance of each selected article.

The Risk of Bias assessment of the 13 included studies, conducted using JBI, revealed a generally low to moderate risk profile (Fig. 2). Most studies demonstrated low risk in domains such as confounding identification, outcome validity, and statistical appropriateness, indicating robust methodological quality. Overall, six studies were rated low RoB, six moderate, and one high, suggesting that while the majority of studies are reliable, caution is warranted when interpreting findings from those with elevated bias risks.

Comparative evaluation of international cancer surveillance systems

The comparative evaluation of 13 international CSS offered valuable insights into critical data elements, standardization practices, and innovative features. Global systems such as the GCO and ECIS demonstrated significant strengths in providing comprehensive global and regional cancer data using standardized elements and advanced visualization tools. However, limitations were observed, including variability in data quality from low- and middle-income countries and a lack of subnational granularity, restricting localized analyses.

National systems such as the Australian Cancer Data System, US Cancer Statistics Tool, and the Spanish Cancer Registry Network effectively integrated histological,

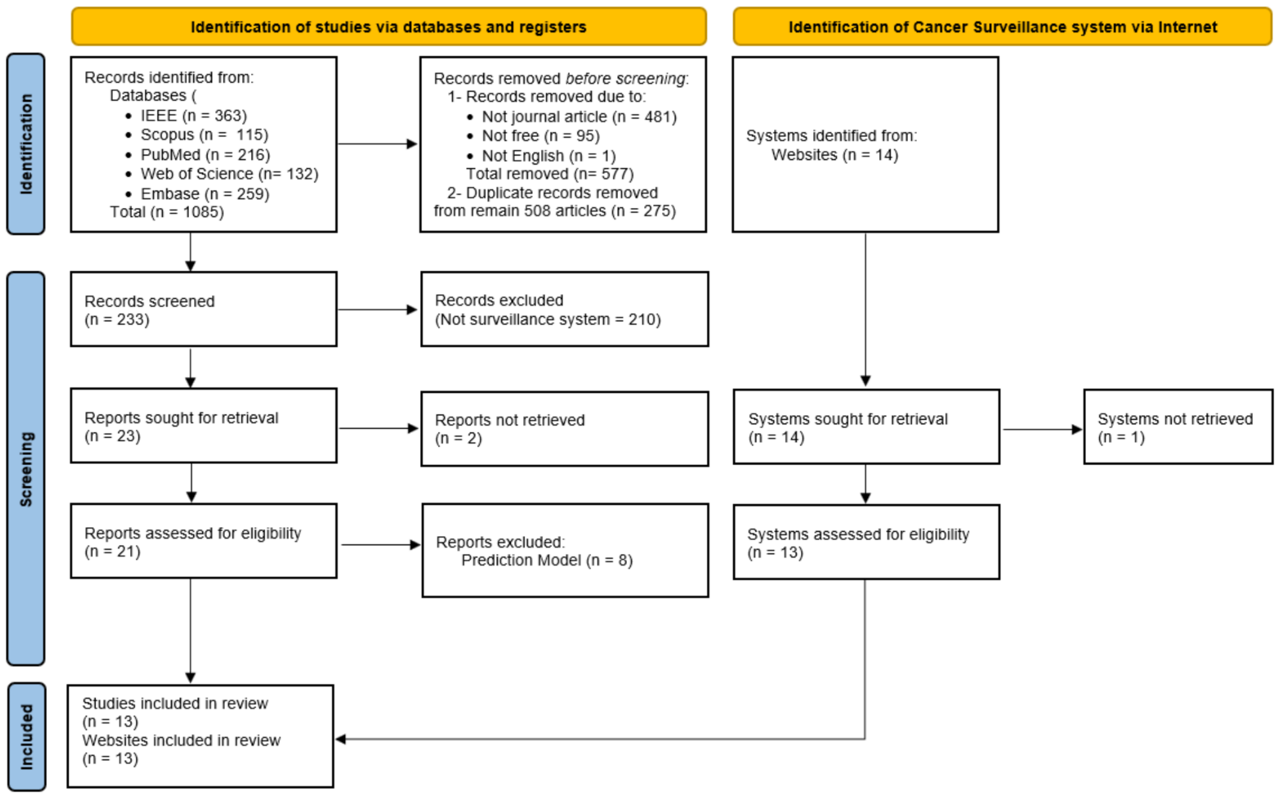

Fig. 1 PRISMA flow diagram

demographic, and geographic data, enabling detailed trend analyses and informing public health decision-making. Nonetheless, challenges such as delays in data updates and occasional gaps in completeness were noted. The Nordcan system stood out for its cross-country standardization within the Nordic region, harmonizing data from Denmark, Finland, Iceland, Norway, and Sweden. Similarly, the National Children's Cancer Registry Probe addressed a critical gap by focusing on pediatric, adolescent, and young adult cancers, providing demographic specificity and trend analyses for these populations.

These systems collectively highlighted the importance of leveraging diverse data elements, robust visualization tools, and interoperable frameworks to inform effective cancer control strategies. Common priorities across systems included key epidemiological indicators such as incidence, prevalence, mortality, and survival rates, alongside demographic filters like age, gender, and geographic location. Innovations such as advanced mapping tools and age-standardized metrics reflected the growing need for tailored solutions in cancer surveillance. A detailed assessment of each CSS is presented in Supplementary File 2.

Extraction and categorization of data elements

Building upon the systematic review and comparative evaluation, essential data elements were systematically extracted and categorized to support comprehensive cancer monitoring and evidence-based public health strategies. These elements form the basis of the standardized checklist proposed in this study, addressing critical aspects of cancer surveillance, including epidemiological, demographic, and clinical variables.

Core Epidemiological Indicators are fundamental for assessing cancer burden and include:

- Incidence: The number of new cancer cases within a specified time frame.
- Prevalence: The total number of existing cancer cases at a given point in time.
- Mortality: The number of deaths attributed to cancer within a defined period.
- Survival Rates: Metrics such as 1-year, 5-year, and 10-year survival rates, reflecting treatment outcomes and healthcare performance.
- YLL: The years lost due to premature cancer-related deaths.
- YLD: The years spent living with cancer-related disabilities, providing insights into long-term societal and economic impacts.
- Age-Standardized Populations: Use of standardized populations such as SEGI, WHO, or region-specific standards for calculating age-adjusted rates and ensuring global comparability.

Table 2 Summary of selected articles from systematic review

Reference	Purpose	Methodology	Data Elements Evaluated	Key Findings	Relevance to Study
[Benedetto et al., 2019] [37]	Design and validate SWInCaRe, a web-based application for cancer registry management	Manual vs. automated data processing; record linkage algorithms; usability evaluation	Cancer case coding, incidence, mortality, patient demographics	Automated procedures improved time and cost-efficiency. The system enhanced usability for cancer registries.	Highlights the efficiency and challenges in automation for cancer data collection, relevant for integration into cancer surveillance systems.
[Yang et al., 2021] [38]	Develop a web-based system to explore cancer risks with long-term drug use	Logistic regression on population-based datasets	Drug exposure, cancer risk factors, demographic characteristics	Identified associations between drug usage and cancer risk; provided predictive tools.	Demonstrates integration of predictive analytics in cancer surveillance, offering lessons for advanced functionality.
[Krejčí et al., 2021] [39]	Development of the Czech Childhood Cancer Information System (CCCIS)	Combined data from national cancer registries, death certificates, and clinical databases	Incidence, survival, mortality	Interactive platform enabled comprehensive epidemiological reporting for childhood cancers.	Example of integrating diverse data sources for a specialized cancer registry system.
[Henton et al., 2017] [40]	Implement SEER Cancer Survival Calculator (SEER*CSC)	Population datasets; usability testing	Survival rates, patient demographics, treatment data	Highlighted barriers in integrating tools into clinical workflows; improved communication with patients.	Useful for identifying challenges in tool adoption and integration with existing systems.
[Lundin et al., 2003] [41]	Evaluate an internet-based method for breast cancer survival estimation	Kaplan-Meier survival curves based on Finnish nationwide data	Survival probability, tumor characteristics, treatment outcomes	Demonstrated accuracy of survival estimates using web-based tools.	Validates survival prediction methodologies and underscores their utility in cancer care.
[Liang et al., 2023] [42]	Develop a visualized nomogram for small-cell lung cancer (SCLC)	Multivariable Cox regression; SEER database	Prognostic factors, survival probabilities	Visualized nomograms achieved high accuracy and usability.	Emphasizes the role of user-friendly tools in stratifying cancer risks and improving clinical decisions.
[Bianconi et al., 2012] [43]	Use IT tools for cancer registry and network integration	Web-based systems; GIS for data visualization	Incidence, mortality, survival, geographic analysis	Enabled geospatial mapping of cancer data, improving regional surveillance.	Exemplifies integration of GIS for enhancing data utility in cancer monitoring.
[Nasseh et al., 2020] [44]	Optimize oncology-related data analytics via Munich Online Comprehensive Cancer Analysis (MOCCA)	In-memory database analysis	Tumor descriptors, treatment data, demographic data	Improved data transparency and analytical capabilities for large datasets.	Highlights advanced analytics and visualization for multi-faceted oncology data.
[Mason et al., 2021] [45]	Develop a web-based calculator for metastatic progression in bladder cancer	Longitudinal dataset analysis; Markov modeling	Metastatic patterns, survival statistics, treatment pathways	Offered spatiotemporal insights into metastatic progression.	Demonstrates the importance of dynamic, real-time prediction in cancer systems.
[Jones et al., 2021] [46]	Pursue cancer data modernization with cloud-based systems	Pilot cloud computing platforms; automation analysis	Incidence, case tracking, real-time data	Automation reduced manual labor; improved timeliness and accuracy in cancer data reporting.	Supports the need for modernization and real-time data capabilities in cancer surveillance.
[Conderino et al., 2022] [10]	Assess the potential of electronic health records (EHRs) for public health surveillance of cancer prevention and control.	A scoping review of studies on EHRs for cancer surveillance, followed by a test of proposed indicators using common data models.	Indicators related to cancer prevention, early detection, treatment outcomes, and survivorship care extracted from EHRs; tested indicators for their feasibility and accuracy in public health surveillance systems.	EHR data can be a valuable resource for cancer surveillance, with indicators providing insights into prevention, early detection, and control. Challenges include data standardization, integration with existing CSS, and ensuring data quality and completeness.	Highlights the utility of advanced technological integration (EHRs) in cancer surveillance systems, aligning with this study's emphasis on technological adaptability and standardization to improve CSS effectiveness.
[Ben Ramadan et al., 2017] [47]	Usability assessment of Missouri Cancer Registry's Interactive Mapping Reports (Round 1)	Mixed-methodology usability testing; System Usability Scale (SUS)	GIS tools usability, mapping effectiveness, satisfaction metrics	Identified issues with user satisfaction and usability; recommendations for improvement.	Highlights the importance of user-centered design in GIS-based cancer surveillance tools.

Table 2 (continued)

Reference	Purpose	Methodology	Data Elements Evaluated	Key Findings	Relevance to Study
[Ben Ramadan et al., 2019] [48]	Usability assessment of Missouri Cancer Registry's Interactive Mapping Reports (Round 2)	Updated usability testing; comparison to previous round	GIS tools usability, task success rates, user satisfaction	Improved task completion rates; highlighted usability barriers specific to cancer professionals.	Reinforces the role of iterative refinement in designing effective cancer registry systems.

Key demographic variables essential for stratified analyses and identifying disparities in cancer outcomes include:

- Age: Grouped into intervals to examine age-specific risks and trends.
- Gender: To explore gender-specific patterns in cancer incidence, treatment, and outcomes.
- Geographic Location: Data stratified by region or nation to assess spatial disparities and inform targeted interventions.

Detailed cancer type data elements essential for precision monitoring include:

- Topography Codes: Based on systems such as International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3), ensuring consistent classification of cancer types and progression.
- Morphology Codes: Critical for understanding tumor characteristics, informing treatment strategies, and improving patient outcomes.

Validation of data elements

Out of 17 distributed checklists, 14 were completed and returned, yielding a response rate of 82%. The characteristics of the participants are summarized in Table 3. Expert feedback underscored the importance of core elements such as incidence, prevalence, mortality, and survival rates, all of which achieved unanimous agreement (CVR = 1.0). Additional elements, including YLL and YLD, were retained with moderate consensus (CVR = 0.71). The results of the review of essential data elements for CSS are detailed in Table 4. This validation process affirmed the relevance and applicability of the proposed checklist as a standardized tool for cancer surveillance.

Comparative analysis of cancer surveillance systems

Table 5 presents a comparative analysis of key features and data elements utilized by various cancer surveillance systems across different regions. This comparison highlights the strengths and distinct methodologies employed by these systems in cancer monitoring. The framework proposed in the current study stands out by incorporating additional indicators, such as YLL and YLD, as well as the integration of multiple standard populations. These enhancements enable a more comprehensive evaluation of cancer burden and improve the adaptability of the framework to diverse regional contexts.

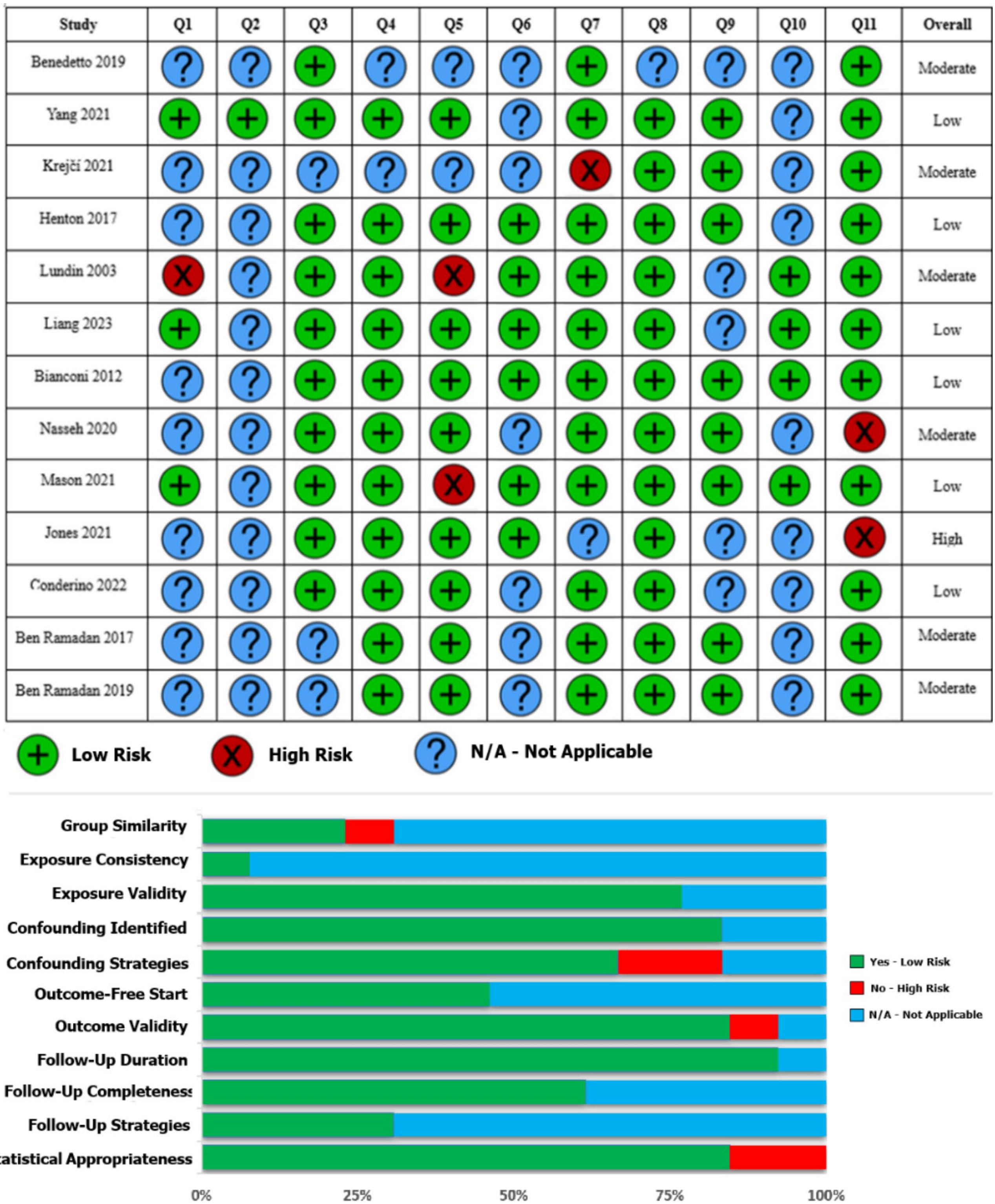

Fig. 2 Risk of bias Assessment using Joanna Briggs Institute (JBI) tool for Cohort Study

Table 3 Characteristics of participants in the data elements checklist validation process

Characteristic	Frequency (%)
Gender	
Male	12 (85%)
Female	2 (15%)
Specialization	
Health Service Management	2 (15%)
Pathology	4 (27.5%)
Epidemiology	2 (15%)
Oncology	4 (27.5%)
Professional Doctorate	2 (15%)
Work Experience	
Less Than 10 Years	3 (21%)
Between 10 And 20 Years	9 (64%)
Over 20 Years	2 (15%)

Discussion

This study aimed to define and identify the essential data elements required for a comprehensive CSS. Through a systematic review of studies and global CSS, a comparative evaluation of 13 systems, and rigorous expert validation, critical epidemiological indicators, demographic factors, and clinical data elements were identified. These findings underscore the importance of standardized data collection practices, advanced technological integration, and achieving a balance between global comparability and regional adaptability. Together, these insights lay the groundwork for developing robust and adaptable CSS frameworks that are essential for enhancing public health decision-making and addressing the escalating global cancer burden.

The systematic review of 13 studies and expert validation prioritized incidence, prevalence, mortality, survival rates, YLD, and YLL due to their unanimous (CVR = 1.0) or strong (CVR = 0.71) endorsement, reflecting their centrality to epidemiological tracking and burden assessment, unlike less critical indicators such as crude rates (CVR = 0.57), which experts deemed redundant given age-standardized alternatives. Comparative analysis showed that frameworks omitting advanced filters (e.g., county-level geography) or emerging metrics, as in some GCO implementations, were less adaptable, leading to their exclusion in favor of our multi-faceted approach. This aligns with Conderino's study [10], who similarly prioritized standardized, actionable indicators over less granular metrics in EHR-based surveillance, reinforcing our focus on precision and utility. By excluding frameworks lacking interoperability or comprehensive scope, the present study ensures a robust, prioritized CSS design tailored to diverse public health needs.

Epidemiological indicators

Epidemiological indicators such as incidence, prevalence, mortality, survival rates, YLL, and YLD provide a comprehensive understanding of cancer trends and their impact on public health. These metrics serve as the foundation for effective cancer prevention, diagnosis, treatment, and survivorship care strategies [2, 16].

Incidence is a cornerstone metric of cancer surveillance, reflecting the number of new cases diagnosed within a specific timeframe. It enables the identification of emerging trends, geographic disparities, and population-specific risk factors. Systems like SEER, GCO, and ECIS prioritize incidence data, which underpins their

Table 4 Results of the validation of essential data elements for Cancer surveillance systems

Data Element	Required	Better if Included	Not Necessary	CVR
Epidemiological Indicators				
Number Of Cases	14 (100%)	0	0	1.00
Incidence Rate	14 (100%)	0	0	1.00
Prevalence Rate	14 (100%)	0	0	1.00
Mortality Rate	14 (100%)	0	0	1.00
Survival Rate	14 (100%)	0	0	1.00
YLL	8 (57%)	2 (14%)	4 (29%)	0.71
YLD	7 (50%)	2 (14%)	4 (29%)	0.71
Crude Rate	6 (43%)	3 (21%)	5 (36%)	0.57
Age-Standardized Rate (National)	8 (57%)	2 (14%)	4 (29%)	0.71
Age-Standardized Rate (SEGI)	10 (72%)	1 (7%)	3 (21%)	0.85
Age-Standardized Rate (WHO)	12 (85%)	0	2 (15%)	1.00
Filtering Indicators				
Time	14 (100%)	0	0	1.00
Gender	14 (100%)	0	0	1.00
Age Group	14 (100%)	0	0	1.00
Geographic Area	14 (100%)	0	0	1.00
Cancer Type	14 (100%)	0	0	1.00

Table 5 Comparative analysis of data elements across Cancer surveillance systems

Cancer Surveillance System	Epidemiological Indicators	Standard Population	Cancer Classification	Geographical Location Level
Global Cancer Observatory	Incidence, Prevalence, Mortality, Survival	SEGI	38 cancer types Based on Organ Body	Global, National
United States	Incidence, Prevalence, Mortality, Survival	WHO	25 cancer types Based on Organ Body	National, State, County
Europe	Incidence, Prevalence, Mortality, Survival, Pediatric Data	1976, 2013 European Standard Population, WHO	37 cancer types Based on Organ Body	Regional, National
Australia	Incidence, Prevalence, Mortality, Survival, Screening	2001, 2023 Australian Population, SEGI, WHO	49 cancer types Based on Organ Body	National, Regional
United Kingdom	Incidence, Prevalence, Mortality, Survival, Screening, Treatment	European Standard Population	40 cancer types Based on Organ Body and Organ Type	National, Regional
Stanford Health Program	Mortality	-	-	National
This Study (Proposed Framework)	Incidence, Prevalence, Mortality, Survival, YLD, YLL	National, SEGI, WHO	All cancer types Based on Organ System, Organ Body, Organ Type	National, Provincial, County

ability to assess and compare cancer patterns globally. For example, GCO reported a 16% global rise in lung cancer incidence between 2012 and 2020, primarily driven by increased tobacco use in Asia and Eastern Europe [1, 22, 26]. SEER data highlights disparities in the U.S., where African American men exhibit the highest prostate cancer incidence, underscoring the importance of targeted screening programs [26].

Prevalence provides a holistic view of cancer burden by combining incidence, survival, and mortality data. It informs long-term planning for oncology services and survivorship care. In the U.S., the projected increase in cancer survivors from 16 million in 2020 to nearly 22 million by 2030 underscores the growing demand for integrated care models [26, 49, 50]. Similarly, ECIS projections emphasize the need for comprehensive rehabilitation and psychosocial support for Europe's increasing survivor population [22].

Mortality rates reveal cancer lethality and the efficacy of public health interventions. SEER reports that lung cancer remains the leading cause of cancer mortality in the U.S., accounting for 25% of cancer deaths [2, 26]. Globally, GCO data illustrates stark contrasts: lower-income countries face higher mortality rates due to limited early detection and treatment access, while high-income countries like Australia have achieved declining mortality rates for breast and prostate cancers, reflecting effective prevention and treatment programs [1].

Survival rates—expressed as 1-year, 5-year, and 10-year metrics—are pivotal for assessing healthcare performance and treatment effectiveness. While SEER reports a 5-year survival rate for breast cancer at 90% due to advancements in screening and therapies, pancreatic and liver cancers remain below 20%, necessitating improved diagnostic and therapeutic approaches [26]. Disparities in survival rates between low- and high-income settings further underscore the need for equitable access to cancer care [1, 51].

Emerging indicators like YLL and YLD provide nuanced insights into cancer's societal and individual impacts. GCO attributes the highest global YLL to lung cancer, particularly in Eastern Europe and Asia [2]. Early colorectal cancer screening programs in the U.S. have significantly reduced YLL, demonstrating the effectiveness of proactive interventions [26]. YLD captures the long-term impact of cancer on survivors' quality of life [1, 52].

This study highlights the critical importance of incorporating YLL and YLD into global CSS to complement traditional metrics such as incidence, prevalence, mortality, and survival. These emerging indicators provide a more comprehensive perspective on cancer's burden by capturing its broader societal and individual impacts beyond mortality statistics [2, 6]. For instance, a study by Wei et al. on the cancer surveillance system in China primarily focused on incidence and mortality data, offering valuable insights but failing to include YLL and YLD, which are essential for depicting a more complete picture of the disease's burden [53]. Consistent with findings from the Global Burden of Disease Study, these metrics align with findings from the Global Burden of Disease Study, which identified cancer as a leading contributor to disability-adjusted life years (DALYs) globally, accounting for a significant proportion of non-communicable disease burdens [54]. The integration of YLL and YLD into this study underscores their relevance in tracking the increasing survivorship challenges posed by improved cancer treatment outcomes. For example, GCO reported that cancer survivors in Europe live an average of 5.6 years with disability, underscoring the necessity for focused rehabilitation and long-term care strategies [1]. These indicators facilitate a nuanced evaluation of both immediate and extended care requirements, making them indispensable for comprehensive public health planning. By adopting YLL and YLD, global CSS can provide a holistic framework for understanding cancer's total impact, improving the capacity for evidence-based policymaking, strategic resource allocation, and targeted intervention design. These metrics collectively enrich the scope of cancer surveillance, enabling public health stakeholders to address both the acute and chronic needs of cancer patients and survivors, ultimately contributing to more effective cancer prevention, treatment, and support systems [18, 55].

The systematic review of 13 studies and expert validation prioritized incidence, prevalence, mortality, survival rates, YLD, and YLL due to their unanimous (CVR = 1.0) or strong (CVR = 0.71) endorsement, reflecting their centrality to epidemiological tracking and burden assessment, unlike less critical indicators such as crude rates (CVR = 0.57), which experts deemed redundant given age-standardized alternatives. Comparative analysis showed that frameworks omitting advanced filters (e.g., county-level geography) or emerging metrics, as in some GCO implementations, were less adaptable, leading to their exclusion in favor of our multi-faceted approach. This aligns with Conderino et al. (2022) [10], who similarly prioritized standardized, actionable indicators over less granular metrics in EHR-based surveillance, reinforcing our focus on precision and utility. By excluding frameworks lacking interoperability or comprehensive scope, our study ensures a robust, prioritized CSS design tailored to diverse public health needs.

Data filtering criteria

In addition to key epidemiological indicators, effective data filtering criteria enhance the granularity of cancer surveillance, enabling more tailored public health interventions. This study highlighted several critical filters: age-standardized populations, sex, age groups, geographical location, and cancer types.

Age-standardized populations

The inclusion of multiple standard populations—such as the national population, SEGI, and WHO—provides a critical advantage in age-standardizing cancer data, enabling more precise comparisons between regions with differing demographic structures. This approach stands in contrast to traditional systems like SEER and GCO, which typically rely on a single standard population, such as SEGI or WHO. By incorporating a variety of standard populations, this approach helps mitigate potential biases associated with age-related cancer risks, thereby ensuring more accurate and comprehensive data comparability. The flexibility to use multiple standard populations allows for more detailed analysis, particularly in regions with significant age differences, such as countries with aging populations or those with younger demographics. The importance of utilizing multiple standard populations has been underscored in studies by Anderson [56] and Mousavi [57], who highlighted the value of incorporating both national and international standards. Anderson emphasized that the choice of standard population can lead to significant variations in cancer rates, which underscores the robustness of this study's approach [56]. By including the national standard population alongside widely recognized international standards such as SEGI and WHO, this study facilitates more accurate representations of cancer trends at both the national and regional levels. This is particularly relevant for comparing cancer incidence rates across provinces, aligning with Mousavi recommendation to use national standards in conjunction with international ones to better understand cancer patterns [57]. Moreover, the ability to select between different standard populations enhances the flexibility and accuracy of cancer data comparisons. Ahmad demonstrated in a study that the choice of standard population has a significant impact on international cancer comparisons [58]. Similarly, Bray raised concerns about the biases introduced when relying on a single standard population, a limitation addressed by this study's multi-population approach [3]. Furthermore, the flexibility provided by this study aligns with the recommendations of IACR, which advocates for the use of multiple standard populations to improve the comparability of cancer data across regions and time periods. This approach ensures that cancer epidemiological indicators are accurately adjusted for demographic variations, providing a more robust and reliable framework for cancer surveillance and global health comparisons.

Sex and age group filters

Sex- and age-specific filters are essential for identifying demographic disparities in cancer trends. Systems like SEER and GCO effectively leverage these filters to highlight gender-specific patterns, such as higher rates of breast cancer in women and prostate cancer in men, and age-specific trends like the prevalence of colorectal cancer in older populations [26]. This stratification supports targeted public health interventions, ensuring that programs like mammography screening or prostate cancer awareness campaigns are appropriately tailored [59].

Geographical location filters

Geographical filters, which allow for the analysis of cancer data at county and provincial levels, are critical for understanding regional disparities in cancer incidence, survival, and treatment outcomes. Focusing on finer geographical levels, such as counties, provides a higher resolution at the national level, surpassing global systems like SEER and GCO, which primarily focus on national or provincial data. This approach allows for more detailed analysis of regional disparities in cancer incidence and outcomes, enabling more targeted and effective public health interventions. The ability to analyze data at this level enables the identification of local risk factors—such as socioeconomic conditions, environmental exposures, and healthcare access—which are often obscured in broader regional analyses. This is consistent with findings from Goovaerts [60] and Dowell [61], who emphasized the importance of detailed geographic data for targeting interventions and addressing health inequalities. Jerrett in a study demonstrated the value of fine-scale spatial data for understanding the relationship between environmental exposures and cancer risk, reinforcing the need for detailed geographic filtering in cancer surveillance [62].

Cancer types: topography and morphology codes

A refined classification of cancer types, using ICD-O-3 codes, is essential for ensuring data consistency and comparability. A multi-level classification system—comprising Organ System (e.g., C15-C26 for the gastrointestinal system), Organ Body (e.g., C16 for the stomach), and Organ Types (e.g., C16.0 for Cardia-NOS)—facilitates more detailed epidemiological analysis compared to global systems that typically use broader organ-level classifications. This refined approach allows for a more precise understanding of cancer distribution, enabling targeted public health interventions and more accurate comparisons across regions. For instance, while systems like SEER and GCO group cancers into categories like gastrointestinal or respiratory, this classification distinguishes between C16 (stomach cancer) and C16.0 (cardia cancer), allowing for more precise tracking and understanding of cancer patterns. Fritz [63] and Howlader [64] emphasized that more detailed classification enhances the identification of disease patterns and risk factors, ultimately improving targeted interventions. Additionally, Farley [2] and Gatta [65] noted the importance of precise coding for tracking rare cancers, which are often underreported in broader classifications. The ability to filter cancer data based on specific anatomical codes supports detailed analysis, further contributing to better public health outcomes and more effective treatment planning. This approach also facilitates the correlation of genomic data with specific cancer subtypes, as emphasized by Hatter enabling a more tailored and personalized approach to cancer treatment [66].

Practical implications

This study's framework advances CSS by integrating standardized data elements and advanced filtering criteria, offering significant practical implications for healthcare providers, public health officials, and policymakers. The present systematic review of 13 studies and comparative analysis of 13 CSS identified critical gaps in current knowledge, such as limited use of emerging metrics like YLD and YLL, which our framework incorporates with expert validation, enriching understanding of cancer burden beyond traditional indicators. For surveillance practices, the framework's adoption of ICD-O-3 classification and county-level geographic filters enables healthcare providers to monitor trends with precision and design targeted interventions, such as screening programs for high-incidence regions or tailored therapies for specific cancer subtypes, surpassing systems like GCO that lack such granularity. Policymakers benefit from this comprehensive data, validated with high reliability, to allocate resources effectively, prioritizing areas with elevated mortality or survivorship needs, as demonstrated by our framework's adaptability across contexts. In resource-rich settings, it supports real-time visualization tools for swift decision-making, while its incremental adaptability ensures foundational practices in resource-limited settings evolve into sophisticated metrics, bridging global comparability and regional specificity to optimize evidence-based public health strategies and patient outcomes [67, 68].

Addressing the research questions

The primary research question, which seeks to identify the essential data elements and methodological practices required to design and validate a comprehensive framework for CSS ensuring accurate epidemiological tracking, is addressed by our systematic review's findings. Through the analysis of 13 studies and expert validation, we identified incidence, prevalence, mortality, survival rates, YLD, and YLL as critical elements, achieving strong consensus, alongside practices such as ICD-O-3 coding and multiple standard populations. The comparative evaluation of 13 systems, including GCO and SEER, highlighted deficiencies in comprehensive metrics, which our framework rectifies with high reliability, ensuring precision in tracking cancer trends.

A secondary question investigates how demographic and geographic filters improve the granularity and utility of cancer surveillance data for tailored public health interventions across diverse populations. This study demonstrates that these filters, validated with unanimous expert agreement, enhance data specificity, as seen in systems like SEER where stratification supports targeted actions, such as screening in high-incidence regions. By extending this capability to county-level granularity, our framework amplifies its utility, enabling precise interventions adaptable to varied demographic contexts. Another secondary question examines the gaps in current cancer surveillance system methodologies, including data standardization, interoperability, and adaptability, and how these can be addressed for global applicability and local relevance. This analysis revealed inconsistencies in standardization (e.g., variable ICD-O adoption), limited interoperability (e.g., lack of real-time data), and poor adaptability (e.g., insufficient subnational detail). The proposed framework mitigates these through standardized elements, advanced IT integration, and flexible filters, offering a balanced solution that enhances surveillance across diverse healthcare settings.

The question of how emerging indicators like YLD and YLL enhance the evaluation of cancer burden and the effectiveness of surveillance systems in informing resource allocation and policy development is also addressed. The findings of the present study show that including these indicators, supported by expert endorsement, extends burden assessment beyond traditional metrics, unlike GCO's narrower focus. This addition, integrated into our framework, informs resource allocation, such as rehabilitation needs, and policy decisions, like screening program impacts, enhancing system effectiveness. A further secondary question explores the role of standard populations, such as those used for ASRs, in ensuring comparability of cancer indicators across regions and facilitating consistent global burden assessments. Our framework's adoption of multiple standards (SEGI, WHO, national), backed by strong expert approval, outperforms single-standard systems like SEER, reducing variability noted in this comparative analysis. This approach ensures robust, comparable global assessments of cancer burden. Finally, the question of how integrating cancer type classification, such as ICD-O, contributes to precision, consistency, and comparability in cancer surveillance data across diverse datasets is answered. The study confirms that ICD-O-3 integration, unanimously supported, resolves discrepancies observed in some CSS. Our framework's multi-level classification (organ system, body, type) enhances data precision and comparability, strengthening surveillance accuracy across datasets.

Implications for resource-limited settings

The proposed framework represents a significant advancement in cancer surveillance; however, its implementation in resource-limited settings poses unique challenges. Limited access to advanced technology, insufficient workforce training, and issues related to data quality and completeness may impede the adoption of standardized practices. Addressing these barriers will require targeted capacity-building initiatives, including the development of specialized training programs for healthcare personnel, the establishment of international collaborations to share expertise and resources, and the introduction of cost-effective technological solutions tailored to the needs of low-resource settings.

This study has limitations that should be acknowledged. The exclusion of non-English articles may have limited the diversity of perspectives and methodologies considered in the systematic review, potentially overlooking important insights from non-English-speaking regions. Additionally, while the expert validation process yielded valuable feedback, the reliance on a relatively small panel of 17 specialists introduces a risk of selection bias, as their views may not comprehensively represent the broader community of stakeholders involved in cancer surveillance. Furthermore, the focus on established CSS excluded emerging but unpublished or pilot systems, which may contain innovative practices or methodologies relevant to the study's objectives. Lastly, the applicability of the proposed framework in resource-limited settings remains to be rigorously tested. Infrastructural and technological constraints, alongside financial limitations, could pose significant challenges to its widespread implementation.

To address these limitations, future research should prioritize pilot testing the framework in diverse healthcare environments, particularly in low- and middle-income countries, to evaluate its feasibility and adaptability. Tailored strategies that integrate foundational elements of the framework incrementally could facilitate its adoption, ensuring that essential data collection practices are established before advancing to more complex metrics and analyses. These efforts will be crucial in enabling resource-limited settings to benefit from standardized cancer surveillance practices, ultimately contributing to equitable global health outcomes.

Conclusion

This study emphasizes the importance of integrating standardized epidemiological indicators and advanced data filtering criteria into CSS. By addressing gaps in global comparability, regional adaptability, and emerging metrics, the proposed framework enhances cancer surveillance capabilities. Future research should explore the integration of novel data sources such as genomic and environmental data to further enrich cancer monitoring systems. Through such advancements, CSS can better inform public health strategies, optimize resource allocation, and improve cancer outcomes globally.

Abbreviations

CSS	Cancer surveillance systems
GCO	Global cancer observatory
IARC	International agency for research on cancer
WHO	World health organization
ASRs	Age-standardized rates
YLD	Years lived with disability
YLL	Years of life lost
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
ECIS	European cancer information system
CVR	Content validity ratio
ICD-O-3	International classification of diseases for oncology, 3rd edition

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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Author contributions
M.S. conceptualized and designed the study, collected and analyzed the data, and drafted the initial manuscript. M.G.S. provided substantial guidance throughout the research process, offering valuable feedback and expertise during manuscript revisions. S.M.A. and A.J. contributed significantly to the manuscript revision, offering critical insights and substantive input to enhance the research. The authors collaborated closely to ensure the methodological rigor, analytical accuracy, and overall quality of the study, with M.S. serving as the lead researcher and primary author. All authors have reviewed and approved the final manuscript, endorsing its content and conclusions for publication.

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Data availability
No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
Ethics Approval and Consent to Participate
This study is being conducted as part of a Ph.D. thesis in Medical Informatics, which has received approval from the Tehran University of Medical Sciences. The Ethics Committee of Tehran University of Medical Sciences has carefully reviewed and evaluated the research protocol under the designated protocol number IR.TUMS.SPH.REC.1401.260. This study adhered to the ethical guidelines outlined by the institutional research committee and conformed to the principles of the 1964 Declaration of Helsinki and its subsequent amendments. As the study involved the synthesis and analysis of publicly available data from published studies, formal consent was not applicable.

Consent for publication
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Competing interests
The authors declare no competing interests.

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