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Developing a Model for the National Pediatric Cancer Registry

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Abstract

Background: A pediatric cancer registry is a crucial tool for collecting and managing health care data. The development of a national registry model for pediatric cancer is vital for organizing and overseeing data effectively. This study aimed to develop a model of the national pediatric cancer registry in Iran.

Materials and Methods: This study is an applied type. In the first phase, a systematic search was conducted across the PubMed, Web of Science, and Scopus databases. Additional grey literature was also explored through targeted Google searches. Some keywords related to pediatric cancer and registry were used to extract components for a national pediatric cancer registry model. Colombia, Denmark, China, and Indonesia were selected for a comparative study due to their comprehensive registry information, emphasis on registry processes, and geographical diversity. In the second phase, the proposed national pediatric cancer registry model was presented. In the third phase, the model was validated through a two-step Delphi technique using a questionnaire.

Results: This study identified key components of a national pediatric cancer registry. Four main components, including general information, organizational structure, content, and registry process, were identified as the main components of the national pediatric cancer registry model in Iran. Using a two-stage Delphi technique, 37 model components were systematically reviewed, and the final approval was achieved with the consensus of all the experts.

Conclusion: The proposed model establishes a robust informational infrastructure to enhance the collection, management, and oversight of pediatric cancer data nationally. It is expected to improve survival monitoring and the quality of care, although further research is essential to evaluate its real-world effectiveness in Iran.

Keywords: Data management, Information system, Neoplasms, Pediatrics, Registries

Introduction

Cancer is a major cause of morbidity and mortality among children worldwide, with leukemia, lymphoma, and central nervous system tumors being the most prevalent types (1-4). Over the past few decades, the survival rate of children with cancer has improved significantly. However, predictions indicate that, by 2030, 21 million children will be diagnosed with cancer (1, 5, 6). Effective management and control of childhood cancer requires robust information systems, such as national cancer registries, which support data collection and the sharing of the childhood cancer data extracted from multiple and heterogeneous data sources. Currently, there is no national pediatric cancer registry in Iran, and, as a result, there is no systematic collection or monitoring of incidence, mortality, and morbidity data for childhood cancers (7, 8). Considering the importance of a pediatric cancer registry in the management and control of pediatric cancer, this study was conducted to design and develop a model of the national pediatric cancer registry in Iran. The accessibility of electronic health data allows for the accurate collection of many patients' data (9). A registry is among the most vital tools in this regard, playing a crucial role in managing various diseases (10-12). Research centers, health care

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providers, and cancer care centers need a pediatric cancer registry to advance their goals (7). A well-maintained cancer registry depends on access to accurate and comprehensive data on the number of cancer patients, those undergoing treatment, survivors, and resource allocation (13).

Registries are organized information systems used to collect and manage patient data, provide systematic care, and track health outcomes in populations defined by a specific disease or condition. They are essential for understanding disease history, evaluating clinical performance, and monitoring the quality of health care. These systems serve scientific, clinical, and policy-making goals. With registries, valuable information can be provided about the incidence, prognosis, survival, and outcome of all types of cancers (14-16). A pediatric cancer registry is an essential tool for gathering health care data, assessing the performance of health care systems, and providing a valuable resource for researchers and policymakers to extract population-based data on pediatric patients with cancer (17-19). According to the International Agency for Research on Cancer (IARC), 60% of the population of Europe, 90% of the population of North America, and only 8% of the population of Asia are covered by population-based cancer registries. So, low-resource countries can use pediatric cancer registry mechanisms to cover a significant part of their deficits caused by the difference in level from high-income countries (6, 18).

Registries have a series of crucial processes and features that help identify their strengths and limitations. The processes involved offer appropriate solutions for the design and development of registries. Case finding, data collection, abstracting, follow-up, reporting, and quality control are the processes of managing and organizing registries (20). In the case-finding stage, all the diagnosed cancer cases are identified and recorded. During the data collection stage, detailed data, including demographic features, notes on diagnosis, treatment, follow-up, and patient history, are accurately gathered and stored in hospitals, treatment centers, and clinics. In the abstracting stage, patients' medical records, including demographics, tumor details, staging information, diagnostic studies, and cancer treatments, are summarized in an abstract form. During the follow-up stage, the patient's health conditions are monitored and managed after discharge. In the reporting stage, the data are analyzed and presented as reports at regular intervals. During the final stage, quality control is carried out by the registrars (21-23). Registry processes require several supporting infrastructures, including stable financial support, information technology (registry software), trained registrars, and appropriate infrastructure to implement the main registry process (22).

Today, while advanced countries increasingly use national electronic surveillance systems for disease management, leveraging their experiences can help improve such systems in low-resource settings (24). To develop the national pediatric cancer registry model, we drew on the experiences of countries with established registries. International experiences from Denmark, Colombia, China, and Indonesia, each of which has distinct registration and age-specific models for childhood cancer, were analyzed to inform the development of Iran’s national childhood cancer registry model.

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Materials and Methods

Study design

This research is an applied study that employed a mixed-methods design by combining qualitative content analysis and expert consensus via the Delphi technique. It was conducted in three distinct phases to establish a national pediatric cancer registry model. The initial phase involved a literature review and a comparative analysis of the selected countries, lasting eight months. The subsequent two phases included the presentation and validation of a National Pediatric Cancer Registry Model. They were completed in six months and four months, respectively.

Phase 1: Literature review and comparative study

To identify the components of the proposed model of the national pediatric cancer registry, the sources and articles on pediatric cancer registries in various countries were thoroughly reviewed with a concentration on the key processes of registry. Using certain keywords, some articles were identified and extracted from the PubMed, Web of Science, and Scopus databases. Additional grey literature was also explored through targeted Google searches. The search strategy is presented in Table I. The specific criteria for including the articles were as follows: they had to be in English, have the full text available, and provide detailed information about the pediatric cancer registry and its key processes.

Moreover, conference articles, letters to the editor, protocols, and articles lacking sufficient details about the pediatric cancer registry and its key processes were excluded. Based on the predetermined inclusion and exclusion criteria, A.H.D. and F.A. independently reviewed, screened and selected the studies.

The selection and review of the articles pertaining to pediatric cancer registries were in line with the objectives of the study. The required data were extracted with a specialized data extraction form developed by the research team, followed by an analysis of its content. The Ministry of Health and Medical Education (MOHME), along with universities of medical sciences, research centers, clinics, and specialized pediatric hospitals, were consulted as the custodians of the pediatric cancer data registry, and their insights and opinions were taken into consideration. This process facilitated the identification of the components of the proposed model. Colombia, Denmark, China, and Indonesia were selected due to their diverse geographic locations and registry types, as well as the availability of detailed pediatric cancer registry data. Colombia and Indonesia, as middle-income countries, share resource and infrastructure challenges similar to Iran, offering practical insights. Denmark, a high-income country with a mature population-based registry, provides a benchmark for data quality and patient follow-up. China’s hospital-based registry offers lessons on data management in emerging systems. These examples helped tailor a realistic and context-appropriate registry model for Iran.

The aforementioned four countries were selected for the comparative study based on several criteria including the availability of comprehensive and transparent information regarding their pediatric cancer registries, the diversity in registry models (both population-based and hospital-based), and their geographical representation across Asia, South America, and Europe. They also represent a range of economic and health care system contexts, allowing for the extraction of adaptable components and best practices to develop a national pediatric cancer registry model for Iran.

Denmark is a high-income country, whereas the other three are upper-income countries. The comparison shows that Denmark and Colombia have population-

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based registries, whereas China and Indonesia have hospital-based registries. The Danish Childhood Cancer Registry was launched in 1985, while Indonesia launched a childhood cancer registry in 2000, Colombia in 2009, and China in 2019. The registry in Indonesia is classified as an international initiative, whereas, in the other three countries, it is regarded as a national project. The model proposed for a pediatric cancer registry in Iran is based on a population registry and a national project.

The national model for pediatric cancer in Iran relies on a population-based registry. To develop such a model, this research incorporated elements from the population-based registries of Denmark and Colombia. Additionally, it considered components from hospital registries, like those in China and Indonesia, where certain elements, such as quality control indices, are shared with population-based registries. This comparative study also draws on the research grounded in hospital registries.

Phase 2: Presentation of the proposed model of the national pediatric cancer registry

In the second phase, the proposed model of the national pediatric cancer registry in Iran was designed based on the review of articles and information sources, a comparative study of the national registries for pediatric cancer in the selected countries, and Iran's unique climate, geography, culture, and social conditions.

This model was presented in the four main sections of general information, organizational structure, content, and registry process.

Phase 3: Validation of the proposed model and presentation of the final model of the national pediatric cancer registry

The proposed model was validated using the second-step Delphi technique. For this purpose, a closed-ended questionnaire consisting of 37 questions was designed in the four sections of general information, organizational structure, content, and registry process. In addition to those yes/no questions, an open-ended question was included at the end of the questionnaire to allow experts to provide additional comments, suggestions, or concerns that may not have been addressed by the structured items. The open-ended responses were analyzed thematically to extract the common expert insights and identify any additional components or concerns not covered by the structured questionnaire. This approach aimed to capture comprehensive feedback and ensure that all the relevant expert insights were considered in refining the final model.

The validity of the questionnaire was assessed using the content validity method, which involved distributing the questionnaire to a group of ten individuals, comprising five specialists in health information management and five pediatric cancer specialists, all of whom were faculty members. Additionally, the reliability of the questionnaire was established through retesting, resulting in a correlation coefficient of 94%.

After the reliability and validity of the questionnaire were confirmed for the first stage of the Delphi technique, the proposed model was distributed to 15 experts. These experts included five specialists in health information management, five in medical informatics, and five in pediatric cancer, none of whom were involved in validating the questionnaire. The experts were selected based on academic qualifications, relevant publications, and prior experience with cancer registry systems, ensuring diverse yet relevant perspectives.

During the first round of the Delphi technique, the experts recommended that the latest versions of this classification and naming systems, as well as the most up-to-date message and data exchange standards, be used in the final model of the national

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pediatric cancer registry in Iran. Additionally, in the first phase of the Delphi technique, the experts suggested that the following be added to the registration objectives section:

1. Analyze and compare the incidence and prevalence of childhood cancer in different geographical areas
2. Adopt effective strategies for controlling childhood cancer

The criteria for accepting or rejecting each component of the proposed model were as follows:

- The component was approved if more than 75% of the experts agreed.
- The component was moved to the second stage of the Delphi technique if the agreement was from 50% to 75%.
- The component was eliminated if less than 50% of the experts agreed.

After the analysis of the first-stage results and the incorporation of the experts' feedback, an expert panel was formed. This panel consisted of three pediatric cancer specialists and three health information management specialists, who ultimately approved the proposed model.

Ethical considerations

To ensure that ethical standards were met, the identities and responses of the experts were kept confidential during the validation of the proposed model. The participants were informed that their involvement was voluntary and that they could withdraw from the study at any time. The study was approved by Shahid Beheshti University of Medical Sciences in 2024 with the code of ethics IR.SBMU.RETECH.REC.1402.598 obtained from the National Ethics Committee in Biomedical Research.

Results

This section presents the findings from each stage of the research.

Findings from the literature review and comparative study of the pediatric cancer registry

The findings from the literature review and comparative analysis indicated that the fundamental elements crucial to the pediatric cancer registry include the establishment of the registry objectives and classification, the organization tasked with its management along with the collaborating entities, data sources, minimum dataset (MDS), standards, and the procedural framework of the registry. The comparative study results for the pediatric cancer registries in the selected countries are summarized in Table II.

Findings related to presenting the proposed model of the national pediatric cancer registry in Iran

The proposed model for the national pediatric cancer registry in Iran is structured into four main sections including general information, organizational structure, content, and registry process. The experts selected and approved the data sources for the proposed national pediatric cancer registry. These data sources included specialized children's cancer clinics, children’s hospitals, the Society to Support Children Suffering from Cancer (MAHAK), doctors’ offices, and cancer research centers.

Each section is further divided into relevant subgroups, as detailed in Table III.

Validation results of the proposed model and the final model presented for the national pediatric cancer registry in Iran

Table IV shows the results of the first stage of the Delphi technique.

Out of the 37 items, 32 (86.49%) were approved in the first round, 5 (13.51%)

were moved to the second round, and none were excluded. In the second stage of the Delphi technique, after the suggestions of the first stage were applied and a panel of experts was formed, 100% of the experts approved all the components of the model.

The final model of the national pediatric cancer registry in Iran is shown in Figure 1.

Table I: The search strategy for defined databases.

Time limitation	**Until April 2024**
Language limitation	Only full text in English
Keywords #A	“Pediatric cancer” OR “Childhood cancer”
Keywords #B	“Register,” OR “Data management,” OR “Information management,” OR “Surveillance system” OR “Information system” OR “Data system”
Search strategy	**(#A) AND (#B)**

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Table II: Results of the comparative study of the Pediatric Cancer Registry in selected countries.

Registry components	**Country**			
	Denmark	**China**	**Columbia**	**Indonesia**
Name	Danish Childhood Cancer Registry (DCCR)	National Center for Pediatric Cancer Surveillance (NCPCS)	VIGICANCER	Yogyakarta Pediatric Cancer Registry (YPCR)
Launch	1985	2019	2009	2000
Coverage	Children below 15 years of age at the time of cancer diagnosis	Chinese children aged between 0 and 19 years with cancer who are discharged from the hospital	Patients younger than 19 years of age	Children aged 0-18 years were diagnosed with cancer
Registry type	Population-based	Hospital-based	Population-based	Hospital-based
Implementation Scale	National	National	National	International Collaborative Project
Goals	-Registrations of acute toxicity of high-dose methotrexate in children with acute lymphoblastic leukemia -Monitoring the quality of childhood cancer care in Denmark -Registry of late effects of treatment Registry of complications related to the use of central venous catheters (CVCs)	-Providing data on diagnosis, treatment methods, evaluation of effects, adverse reactions, and survival information -Contribution to understanding the burden of disease and changing trends of childhood cancers in China	-Ability to access comprehensive and timely information on clinical outcomes of all children and adolescents undergoing cancer treatment in Cali -Identification of key determinants of survival will provide the basis for the development of interventions to improve long-term clinical outcomes	-Determine the prevalence of pediatric cancers in the Yogyakarta Special Region -Comparing the demographics of pediatric malignancies in the Yogyakarta Region, with those of the Saskatchewan Cancer Registry in the province of Saskatchewan
Participating Organizations\ Persons	-Department of Clinical Epidemiology -Pediatric Oncology Center -The Danish Clinical Registries (RKKP) -The Danish Regions -The Danish Childhood Cancer Foundation -University Hospitals	-Surveillance sites -Institutions & the cooperative groups -The National Health Commission of the People's Republic of China	-Pediatric oncologists -Pediatric oncologist epidemiologist -Pathologist epidemiologist -Data managers -Clinical monitors -Informatics engineer -Administrator	-University Gadjah Mada -Saskatchewan Cancer Agency -University of Saskatchewan -cancer epidemiologist -Pediatric Oncologist

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Significant features		The recording of late effect parameters related to the treatment	-NCPCS represents a comprehensive and specialized surveillance system for childhood cancer in China -It provides an important basis for key data on childhood cancer prevention and control	-VIGICANCER is an outcome monitoring system for data on childhood cancers that is embedded in a population-based registry but collects information directly from pediatric oncology unit treatment. -It can also successfully document relevant clinical events for childhood cancer patients undergoing treatment within an acceptable time frame	-An international project to create a computerized pediatric cancer registry
Standards		-ICD10 -Birch and Marsden classification -ICD-O	ICD-10	ICD-O-3 ICCC-3	ICD-O-3 ICD-10
MDS		-Clinical data -Diagnostic data -Cancer data -Treatment data -Complications data - Follow-up data	-Demographic data -Discharge data -Admission data -Diagnostic data	-Clinical data -Demographic data -Diagnostic data -Follow-up data	-Demographic data -Treatment data -Diagnostic data
Registry Process	**Case finding**	Active	Active	Active	Active
	Report	Annual reports	Annual reports	Reports	Reports
	Data Collection	Tools: Transfer data by electronic report Responsible: Research nurses Validation responsible: local pediatric oncologist	Tools: Report cards By: Manual & automatic file reporting Responsible: Staff members Validation responsible: Staff	Tools: Data form Responsible: Clinical monitors	Tools: Forms Responsible: Data manager
	Follow-up	Yearly	–	-Active: Every 3 months -Passive: Every 6 months Method: Phone	–
	Quality control Index	Completeness	-Specifically -Timeliness -Accuracy -Completeness -Comparability	-Exhaustiveness -Simplicity -Timeliness -Observation	-Consistency -Completeness
	Quality control methods	-Review -Cross-checking	–	-Checking for missing data	-Checking for duplicate -Control checks on Retrieved data

Abbreviations :MDS: Minimum Data Set, ICD: International Statistical Classification of Diseases and Related Health Problems, ICD-O: International Classification of Diseases for Oncology, ICCC: International Classification of Childhood Cancer

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Table III: Proposed Model of the National Pediatric Cancer Registry in Iran

Components	Name	"Iran National Pediatric Cancer Registry"	
General information	Coverage	Children aged 0 to 18 diagnosed with pediatric cancer	
	Goals	• Collection and management of diagnostic and treatment data related to pediatric cancer • Monitoring the quality of care for children with pediatric cancer • Identification of key factors determining survival in children with pediatric cancer • Creating an important source of information for the development of clinical outcome interventions • Access to comprehensive and up-to-date information on children with pediatric cancer • Follow-up on late effects of treatment	
Organizational structure	Responsible Organization	Ministry of Health and Medical Education	
	Participating Organizations	• National Committee for the Prevention and Control of Non-Communicable Diseases • Iranian Children's Blood and Cancer Society • Information Technology Unit of the Ministry of Health and Medical Education • Deputy of research and technology • Statistics center	
	Data Resources	• Children's Cancer Clinics • Children's Hospitals • The Society to Support Children Suffering from Cancer (MAHAK) • Cancer Research Centers • Doctors' office	
Content	Minimum Data Set	• Demographic data • Admission data • Diagnostic data • Treatment data • Complications data • Discharge data • Follow-up data	
	Standards	Terminology & classification system	ICD-O-3, ICD10, ICCC-3
		Nomenclature systems	SNOMED-CT
		Data exchange & message	HL7
Registry Process	Data Collection		Based on a manual & electronic record reporting form filled out by health care providers, epidemiologists, oncologists, pediatric oncologists, pediatric specialists, research nurses, and registrars.
	Case-finding methods		Active
	Case finding resources		Cases reported by the family of children with Pediatric cancer, medical files, pathology reports, death certificates, imaging and supporting laboratory tests, hospital logs for patient discharges, outpatient clinic health records, clinical health records, Integrated health system, and health care provider.
	Follow-up period		Monthly, Every 3 months, Every 6 months, yearly
	Follow-up methods		Communication via mobile phone, Email, Letter, Electronic communications, Text message
	Reporting approach		Providing reports in the form of monthly and annual reports, articles, and updated abstracts of pediatric cancer
	Quality Control Index		Timeliness, Accuracy, Completeness, Consistency, Simplicity, Definition
	Quality control methods		Checks on retrieved data, review the report, checks for duplication of records, review missing information, review medical records, and control checks on retrieved data.

Abbreviations :MOHME: Ministry of Health and Medical Education, HL-7: Health Level 7

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Table IV: Experts' opinions on the proposed national model for the pediatric cancer registry are based on the first stage of the Delphi technique.

Components	Agree		Disagree		Suggestions
	Frequency	Percentage	Frequency	Percentage	
General information	12	80	3	20	It was suggested that the following items be added to the objectives section of the registry: Analysis and comparison of incidence and prevalence of pediatric cancer in different geographical areas Adopting effective strategies to control pediatric cancer is essential.
Organizational Structure	15	100	0	0	-
Content	13	86.7	2	13.3	It was suggested that the latest standards related to the registry and the newest edition of classification systems be used.
Registry Process	15	100	0	0	-

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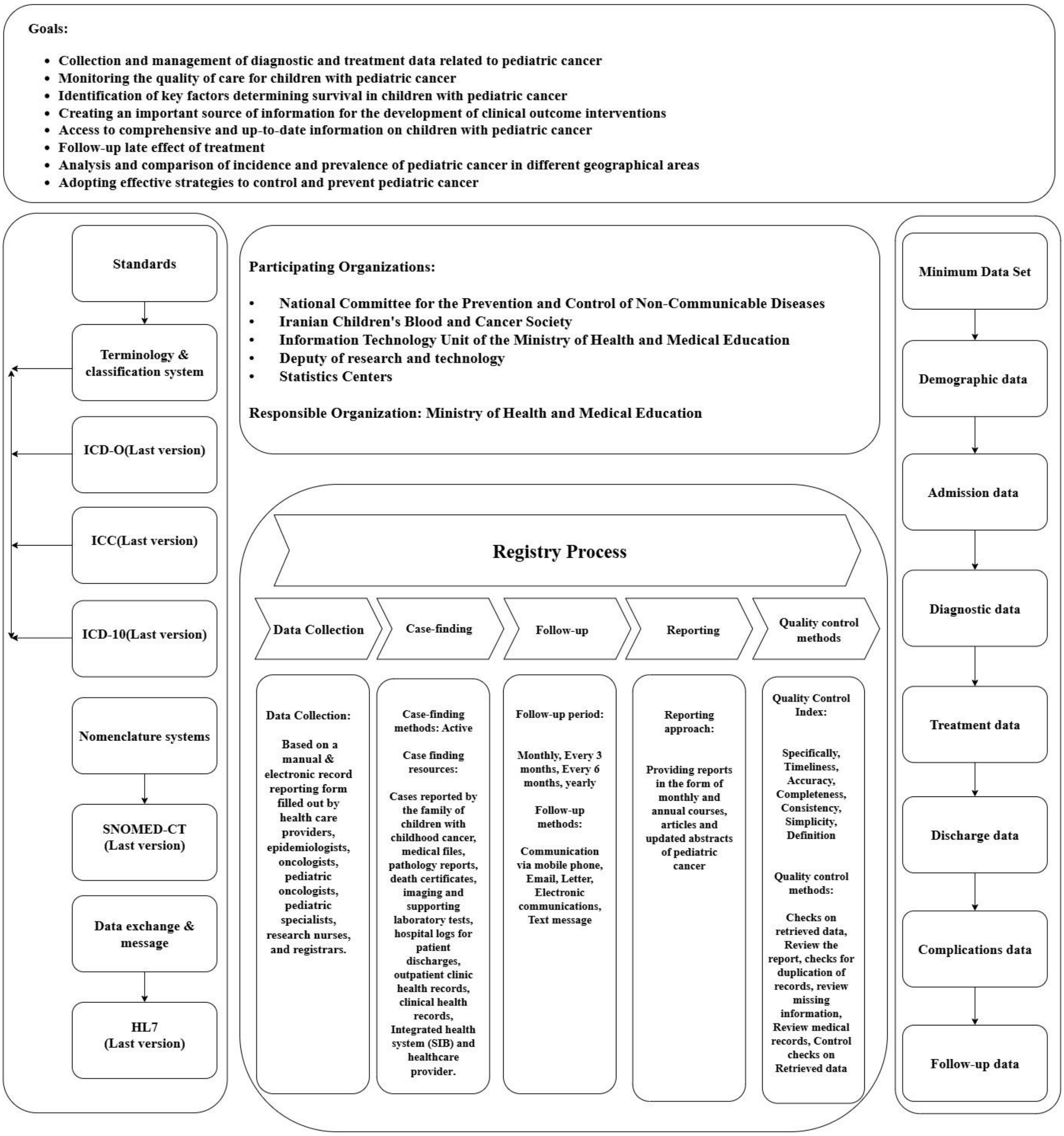

Figure 1. Final Model of the National Pediatric Cancer Registry in Iran.

Discussion

By gathering and providing crucial data, the pediatric cancer registry plays a key role in enhancing health care services, allocating resources, understanding the causes of the disease, and developing control strategies for pediatric cancer (13, 25). There are two main types of cancer registries, population-based and hospital-based. Population-based registries aim to prevent and detect cancer, while hospital-based ones aim to improve patient care and clinical research. The proposed model of the national pediatric cancer registry in Iran is based on a population-based registry (26).

In 2014, the Deputy of Research at Iran's Ministry of Health and Medical Education (MOHME) announced financial supports and issued a public call to establish registry systems for various diseases and health outcomes at both national and international levels (22). For this purpose, with the consensus of experts, the MOHME, as the main institution in charge of citizens' health in Iran, was held responsible and accountable for the proposed model of Iran's national pediatric cancer registry.

In addition to the MOHME, several other organizations and institutions have contributed to Iran's national pediatric cancer registry. They include the National Committee for the Prevention and Control of Non-Communicable Diseases, the Deputy of Research and Technology, statistical centers, the Iranian Children's Hematology and Oncology Society, and the Information Technology Unit of the MOHME. Together, they play vital roles in maintaining and supporting the registry.

The comparative study of the four selected countries, namely Indonesia, China, Denmark, and Colombia, highlighted notable differences in the age range for pediatric cancer diagnosis. In Colombia, China, and Indonesia, individuals younger than 19 years of age with cancer are classified as pediatric cancer patients, whereas, in Denmark, the classification applies to children below 15 years of age at the time of cancer diagnosis (27-29). Denmark and Colombia, with their established population-based pediatric cancer registries, provide valuable benchmarks for data quality and registry sustainability, which Iran aims to follow. Colombia shares similar challenges with Iran, such as resource limitations, while Denmark represents a high-income example with mature systems. China and Indonesia operate hospital-based registries offering practical insights into data management in resource-limited settings. Combining the lessons from both registry types helps tailor an effective population-based model suitable for Iran’s context.

The minimum dataset (MDS) serves as a crucial tool for developing surveillance programs and registry systems, ensuring accurate data collection. The MDS in this study included demographic, admission, diagnosis, treatment, discharge, complication, and follow-up data. Through comparative studies and a review of the literature, it was determined that, in pediatric cancer registries, it is essential to use nomenclature systems, classification systems, and message and data exchange standards. In the model of the national pediatric cancer registry proposed for Iran, the experts approved the use of the International Classification of Diseases for Oncology (ICD-O-3), International Statistical Classification of Diseases and Related Health Problems (ICD-10), and International Classification of Childhood Cancer (ICCC-3) as classification systems, SNOMED-CT as a nomenclature system, and Health Level 7 (HL7) as a message and data exchange standards.

The unique political, social, and health care contexts of each country influence these discrepancies in defining pediatric cancer. The national pediatric cancer registry in Iran follows the WHO definition, including children aged 0-18 years in its classification.

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Data collection, case finding, follow-up, reporting, and quality control are among the most important and indicative registry processes in the national pediatric cancer registry model in Iran (20).

One essential aspect of the pediatric cancer registry process is case finding. This involves identifying and recording the pediatric cancer cases diagnosed in both inpatient and outpatient settings. There are two methods for case finding, active and passive. In the active method, the registry expert actively searches through all the potential sources for cases. In contrast, the passive method depends on other departments to refer the reportable cases to the registry expert (30). The national pediatric cancer registry in Iran adopts an active case-finding approach, where registry experts proactively search multiple data sources, including healthcare providers, families, medical records, pathology reports, and integrated health system databases. This method improves the completeness and accuracy of case identification compared to passive reporting, which depends on external notifications. Given Iran's diverse healthcare infrastructure and the need for comprehensive surveillance, active case finding ensures thorough case capture despite its higher resource requirements, aligning well with the goals of the model for data quality and coverage.

In the proposed model of pediatric cancer registry, data collection is carried out either manually or electronically using report forms by health care providers, epidemiologists, oncologists, pediatric oncologists, pediatricians, research nurses, and registrars.

The main goal of patient follow-up is to ensure continuous monitoring to determine treatment results and monitor the patient's health status (31). In the model proposed for the national pediatric cancer registry in Iran, follow-up intervals were set at monthly, 3-month, 6-month, and yearly periods, as agreed upon by the experts. Additionally, using various communication tools such as mobile phones, letters, emails, text messages, and electronic communication methods was approved to facilitate patient follow-up in this registry model.

Publication of reports from the registry is referred to as reporting. These reports are utilized by various users for different purposes and in different formats. In the selected countries (27-29, 32), registry reports serve diverse people and organizations. Annual reporting is the most common type of reporting in these countries (27-29, 32) . In the model of national pediatric cancer registry proposed for Iran, the experts recommended and approved various reporting methods tailored to different decision-making levels and user needs. These methods include periodical reports (monthly and yearly), articles, and up-to-date abstracts on pediatric cancer.

The value and credibility of registries hinge on the quality of the data and their control methods, which are the key registry processes (33, 34). In the model proposed for the national pediatric cancer registry in Iran, several quality control methods have been suggested. These include checks on retrieved data, reviews of the report, checks for duplication of records, reviews of missing information, reviews of medical records, and control checks on retrieved data.

In addition, the model identifies key data quality indicators, specifically timeliness, accuracy, completeness, consistency, simplicity, and definitions. The experts reviewed and approved these indicators, ensuring that the registry would meet high data quality standards.

Given that many low-resource countries lack pediatric cancer registries, it is recommended that developing and implementing a national model for a pediatric cancer registry in those countries

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could serve as an initial step toward achieving universal coverage for pediatric cancer data collection.

Despite its strengths, the national pediatric cancer registry model proposed for Iran has some limitations. This study is based mainly on a literature review and expert opinion, so practical challenges may arise during implementation. Political, social, and cultural factors, along with data privacy concerns, could affect the cooperation and data sharing among the stakeholders. Therefore, careful management of these issues is necessary. Furthermore, as a theoretical framework, the model requires real-world evaluation and continuous refinement to ensure its success and sustainability.

Conclusion

A national pediatric cancer registry model establishes a structured framework for collecting and managing pediatric cancer data. This leads to access to comprehensive, up-to-date information, identification of the key survival factors in children with cancer, and monitoring of the quality of care. The pediatric cancer registry model presented in this research serves as a key roadmap for data management and offers a robust foundation for nationwide implementation and continuous enhancement of pediatric cancer data management in Iran. To ensure its effectiveness and sustainability, pilot implementation and evaluation are needed so as to identify the challenges involved and improve the system. Integrating the model into health policies and engaging stakeholders will enhance cancer surveillance and care quality for children across the country.

Data availability

Data supporting the findings of this study are available upon reasonable request from the corresponding author.

Ethical Considerations

The study was approved by the Shahid Beheshti University of Medical Sciences in 2024 with the code of ethics number IR.SBMU.RETECH.REC.1402.598 was obtained from the National Ethics Committee in Biomedical Research.

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During the preparation of this work the author(s) did not use AI.

Authors’ Contributions

F. A: Conceptualization and study design, Supervision, Review & Editing.

A.H. D: Methodology, Writing - Review & Editing.CO first Author.

N. R: Data gathering and Formal analysis.

All the authors (F. A, A.H.D, and N. R) read and approved the final manuscript.

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Conflict of Interest

The authors declare no conflict of interest.

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