

ORIGINAL RESEARCH OPEN ACCESS

Rationale and Methods of a Surveillance System for Hematopoietic Stem Cell Transplantation in Patients With Hematological Malignancies: A Qualitative Participatory Action Research Approach in Middle-Income Countries—The Experience in Iran

Sima Oshnouei¹  | Mohamad Jebraeily²  | Mohsen Asadi-Lari³  | Babak Eshrati⁴  | Rahim Asghari⁵  | Masoumeh Nabivandrezai⁶  | Ali Arash Anoushirvani⁷ | Aarefeh Jafarzadeh-Kohneloo⁸ 

¹Department of Epidemiology, School of Public Health, Iran University of Medical Sciences, Tehran, Iran | ²Department of Health Information Technology, School of Allied Medical Sciences, Urmia University of Medical Sciences, Urmia, Iran | ³Department of Epidemiology, School of Public Health, Oncopathology Research Center, Iran University of Medical Sciences, Tehran, Iran | ⁴Preventive Medicine and Public Health Research Center, Psychosocial Health Research Institute, Iran University of Medical Sciences, Tehran, Iran | ⁵Department of Internal Medicine, School of Medicine, Imam Khomeini Hospital, Urmia University of Medical Sciences, Urmia, Iran | ⁶Imam Khomeini Hospital, Urmia University of Medical Sciences, Urmia, Iran | ⁷Department of Internal Medicine, School of Medicine, Firoozgar General Hospital, Iran University of Medical Sciences, Tehran, Iran | ⁸Department of Epidemiology and Biostatistics, School of Health, Tabriz University of Medical Sciences, Tabriz, Iran

Correspondence: Babak Eshrati (babak.eshrati@gmail.com) | Rahim Asghari (Rahimasghari@gmail.com)

Received: 10 February 2025 | **Revised:** 17 July 2026 | **Accepted:** 24 July 2026

Funding: Oncopathology Research Center.

Keywords: hematological malignancies | hematopoietic stem cell transplantation | middle-income countries | participatory action research | surveillance development

ABSTRACT

Background and Aims: Hematopoietic Stem Cell Transplantation (HSCT) represents a cornerstone in the therapeutic management of hematological malignancies, aimed at achieving durable remission and enhancing survival. Optimal post-transplant care, however, necessitates access to near-real-time, actionable clinical data. Iran currently lacks a dedicated national surveillance framework for HSCT recipients. This study aims to develop and pilot a comprehensive surveillance system tailored to the complexities of HSCT within the Iranian healthcare context.

Methods: This qualitative Participatory Action Research (PAR) study was conducted at a tertiary HSCT center in Iran (2024–2025). Using purposive sampling, 15 stakeholders (hematologists, nurses, informaticians, and registry experts) with 5 years of experience were recruited. Data comprised 46 iterative, semi-structured interviews (face-to-face and telephone) conducted until data saturation was reached. Thematic analysis with independent double coding and triangulation (methodological, data source, and theoretical triangulation against EBMT/CIBMTR standards) ensured credibility. A pilot phase tested feasibility, followed by iterative refinement based on stakeholder feedback prior to institutional integration.

Results: Qualitative synthesis identified three pivotal domains for establishing a national HSCT surveillance system: transplant-specific clinical challenges, systemic barriers to development, and essential implementation phases. Primary impediments included regulatory and policy gaps, acute resource constraints, and technological deficits. Key developmental steps involved the standardization of case definitions, the design of robust data acquisition protocols, and the selection of

Abbreviations: ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia; CSS, cancer surveillance system; HL, hodgkin lymphoma; HLA, human leukocyte antigen; HSCT, hematopoietic stem cell transplantation; MM, multiple myeloma; NHL, non-hodgkin lymphoma; SEER, surveillance, epidemiology, and end results.

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evidence-based performance indicators. The pilot implementation highlighted critical operational hurdles, such as increased clinician workload and data entry burdens, which subsequently informed the development of tailored technical and structural solutions for the hospital-based rollout.

Conclusions: This study provides a replicable methodological roadmap for establishing standardized HSCT monitoring systems in middle-income countries. By identifying longitudinal data gaps and treatment deficiencies, this framework fosters multi-level collaboration with policymakers and advocates for evidence-based clinical practices to ultimately improve patient outcomes.

1 | Introduction

Hematological malignancies (HMs) comprise a broad spectrum of aggressive, life-threatening disorders that necessitate complex, multidisciplinary therapeutic interventions. Hematopoietic Stem Cell Transplantation (HSCT) remains a cornerstone treatment modality for various conditions, including leukemias, lymphomas, multiple myeloma, aplastic anemia, and solid tumors such as breast and ovarian cancer [1, 2]. Critically, the long-term follow-up of transplanted patients requires a reliable system for data collection and patient monitoring at predefined intervals. Such sustained surveillance is essential for assessing complications, detecting disease recurrence, and guiding overall health maintenance, ultimately influencing survival outcomes [3].

The effectiveness of cancer surveillance varies considerably across healthcare systems worldwide, primarily due to differences in data collection infrastructure, registry quality, and population coverage. In developed nations such as the United States, well-established cancer registries enable the collection of comprehensive longitudinal data—from initial diagnosis and staging to long-term treatment outcomes [4–6]. In contrast, resource-limited settings like Iran face underdeveloped surveillance frameworks, which contribute to poorer survival outcomes. The lack of robust registries often prevents the implementation of targeted screening programs, resulting in a higher proportion of late-stage diagnoses where curative interventions are less effective. Moreover, without data-driven insights to inform resource allocation, healthcare systems struggle to address local barriers to care quality—a disparity that highlights the urgent need for enhanced monitoring systems within the Eastern Mediterranean Region (EMR) [7, 8].

International registries such as the European Society for Blood and Marrow Transplantation (EBMT) and the Center for International Blood and Marrow Transplant Research (CIBMTR) provide gold-standard frameworks for assessing HSCT outcomes [9, 10]. However, their high-intensity documentation requirements, specialized staffing needs, and advanced IT infrastructure often render them impractical for resource-constrained settings such as Iran [11, 12]. Despite significant clinical advances in transplantation within the country, Iran still lacks a unified and comprehensive surveillance system for HMs and HSCT. In a resource-limited country such as Iran, where complete genetic, cytogenetic, and molecular testing is often unaffordable, the core question driving this surveillance system is: how successful can therapeutic interventions be when evaluated through functional outcome indicators?

In response to this challenge, this study aims to develop and evaluate a pragmatic, hospital-based surveillance system tailored to the Iranian context. The system is designed to integrate seamlessly with existing clinical workflows, capturing essential transplant data during routine follow-up visits without imposing additional resource burdens. A key innovation of this model is its use of PAR, which actively engages frontline clinicians in the dual processes of data collection and quality improvement [13]. By addressing the fragmented landscape of national cancer registries and providing near-real-time clinical insights, this hospital-based model offers a scalable template for other middle-income countries seeking to establish foundational registries before adopting more complex global standards.

2 | Materials and Methods

2.1 | Study Setting and Design

This study was conducted in Urmia County, West Azerbaijan Province, Iran, focusing on Urmia Imam Khomeini Hospital as the primary center for hematological malignancies and HSCT. The development of the surveillance system took place between 2024 and 2025 using a PAR approach. The PAR process was carried out in distinct phases: a thorough situation analysis to understand the current context, identification of gaps, and subsequent development of the surveillance system to meet stakeholder needs. This study was grounded in a constructivist paradigm, recognizing that realities of the surveillance system are socially constructed through the experiences and interactions of stakeholders. PAR was chosen as the framework to collaboratively generate actionable knowledge with clinicians and administrators.

2.2 | Expert Panel and Stakeholder Engagement

An expert panel committee was established to guide the system's development, including defining cases, identifying data sources through medical informatics, establishing minimum data sets (MDS), and setting objectives for evaluating therapeutic effectiveness. To ensure high-level expertise, members were required to have at least 5 years of professional or research experience, with a minimum of 3 years directly related to the project's focus.

The panel and key stakeholders—including the hospital registry director, data specialists, and HSCT unit staff (comprising secretaries and the head nurse)—were actively involved in an iterative design process. This collaboration ensured that feedback was continuously used to refine decisions regarding case definitions, pilot testing, analytical approaches, and dissemination mechanisms.

2.3 | Data Collection and Interviews

To identify precise operational challenges and clinical requirements, semi-structured in-depth interviews were conducted with 15 participants over a 9-month period. Participants were selected using purposive sampling to ensure high-level expertise; all clinical and administrative experts had a minimum of 5 years of professional experience in their respective fields (mean = 10 years). The cohort comprised four adult hematologists/oncologists, three transplant unit nurses, three disease surveillance and health experts, two key environmental and intermediate stakeholders, one health and medical informatics specialist, one hospital registry director, and one hematology-pathology specialist (detailed in Table 1).

A total of 46 interview sessions were performed. Interviews were primarily conducted face-to-face in the transplant unit; however, for specialists outside the unit or those with workload constraints, telephone interviews (30–40 min) were used. With participants' permission, sessions were audio-recorded; otherwise, verbatim notes were meticulously taken and transcribed immediately. This process continued until theoretical saturation was reached, focusing on HSCT treatment challenges, system requirements, and data infrastructure in resource-limited settings.

2.4 | Researcher Characteristics and Reflexivity

The lead researcher (a PhD candidate in epidemiology with 8 years of experience in HSCT data management and registry development) had no prior clinical or administrative relationship with the participants, which helped reduce potential response bias. The research team assumed that the primary barriers to establishing a surveillance system in this setting were infrastructural and financial constraints rather than a lack of willingness or competence among healthcare providers. To prevent these presuppositions from unduly influencing data collection and analysis, regular debriefing sessions were held among the research team, during which emergent findings were critically examined, and the researchers' prior assumptions were explicitly bracketed. Additionally, field notes and reflexive memos were maintained throughout the study to document how the researchers' backgrounds and evolving interpretations shaped the analytical process.

2.5 | Ethical Approval

This study received approval from the Ethics Committee of Iran University of Medical Sciences (IR. IUMS. REC.1402.763). Prior to

interviews, all participants were provided with comprehensive information about the research design and interview guidelines. Verbal informed consent was obtained, and participants retained the right to decline participation in both the interviews and the overall research at any point. During the entire data extraction and analysis process, stringent principles of patient confidentiality and data protection were consistently upheld. Audio files, handwritten notes, and other documentation were anonymized using numerical codes, with no personal identifiers recorded. Crucially, during the pilot testing phase, no patient-identifiable data were utilized. All information collected and analyzed during all steps of the study was recorded and processed anonymously, completely devoid of any identifying characteristics, thereby ensuring full confidentiality. Patient data were solely derived from routine clinical care records, without any additional interventions beyond standard treatment procedures; consequently, obtaining supporting informed consent from patients for data extraction was deemed unnecessary.

2.6 | Ensuring Validity and Reliability

We ensured the validity and reliability of our findings through a multi-faceted approach. First, an expert panel comprising both internal and external HSCT and healthcare surveillance system specialists was assembled to maximize diverse perspectives and enhance credibility. To mitigate bias, we employed a comprehensive triangulation strategy, including methodological triangulation—combining interviews with internal and external stakeholders at various levels—and data source triangulation, cross-verifying insights from HSCT specialists with external analysts [14, 15]. Furthermore, theoretical triangulation involved benchmarking interview findings against international standards (EBMT guidelines) to identify implementation gaps in resource-constrained settings. To further enhance credibility, findings were shared with three participants (member checking), who confirmed that the identified themes resonated with their experiences.

2.7 | Essential Data Elements for the Surveillance System

The selection of a minimum essential dataset resulted from a multi-step, expert-panel decision-making process. The primary goal was to collect data that validly reflects the effectiveness of HSCT and supports future analyses. To achieve this, the panel balanced international standardization—drawing on criteria from the EBMT, CIBMTR, and APBMT registries—with

TABLE 1 | Professional background of participants and frequency of interviews.

Participant category	No. of participants	Total no. of interviews
Adult hematologists and oncologists	4	13
Transplant unit nurses	3	15
Disease surveillance and health experts	3	2
Key environmental and intermediate stakeholders	2	2
Health and medical informatics specialist	1	10
Hospital registry director	1	2
Hematology–pathology specialist	1	2
Total	15	46

TABLE 2 | Minimum essential data elements approved for the HSCT surveillance system at Urmia Imam Khomeini Hospital, Iran.

Compatibility with EBMT/CIBMTR	Variables	Time of report
Identical	Center identification: hospital, university	Day 0
Identical	Patient data: national code, age, gender, blood group, rhesus factors, performance status at initiation of HSCT (ECOG), weight, height, date of initial diagnosis	Day 0
Identical	Primary disease diagnosis: lymphomas, acute leukemia, multiple myeloma and their sub-classifications	Day 0
Identical	Comorbidity index, including past medical history	Day 0
Compatible	Preparative regimen drugs and total prescribed cumulative dose (instead of daily dosing per protocol)	Day 0
Identical	Type of HSCT: autologous/allogeneic (with donor and product characteristics)	Day 0
Omitted	Chromosome analysis at diagnosis	Day 0
Omitted	Molecular markers at diagnosis	Day 0
Identical	Acute leukemias: status at HSCT (primary induction failure, complete hematological remission, relapse), type of remission, organs involved, pre-exposure status	Day 0
Identical	Lymphomas: technique for disease assessment, international prognostic indices parameters, immunophenotyping, previous therapies before HSCT (line, regimen, start date, response, response date)	Day 0
Identical	Multiple myeloma: extramedullary disease (EMD)	Day 0
Identical	In hospitalization: neutrophil engraftment, platelet engraftment, graft failure	During hospitalization
Identical	Follow-up (15, 30, 60 and 90 days): complete remission (CR), continued complete remission (CCR), no response/stable disease, partial remission, not evaluated, progression, graft failure, relapse, death	Follow-up (first 100 days)
Identical	Allogeneic complications: acute GVHD occurrence	Follow-up
Compatible	Immunosuppressive treatment and its duration (duration recorded; daily dose variation not captured)	Follow-up
Identical	Additional cell infusions, cell therapy, additional disease treatment (with reason)	Follow-up
Identical	Main cause of death, contributory cause of death	Follow-up

Note: Omitted items (cytogenetics, molecular markers, MRD) are not collected due to > 95% missingness in historical records and lack of laboratory infrastructure. All identical items follow EBMT/CIBMTR definitions exactly. Compatible items have minor modifications (e.g., cumulative total dose instead of daily dosing) but remain conceptually aligned.

prioritized customization to accommodate local infrastructure and resource limitations at Imam Khomeini Hospital. The resulting compatibility of the finalized Minimum Data Set with EBMT/CIBMTR definitions is detailed in Table 2 and summarized below.

The attending oncologist and the thesis student first reviewed the standard data-collection forms of the three leading registries: EBMT (MED-A form), CIBMTR (TED form), and APBMT (TRUMP form). The review confirmed considerable overlap in core data elements, reflecting a global effort toward standardization. However, the CIBMTR forms were found to be excessively detailed, requiring cytogenetic analyses, molecular markers, and minimal residual disease (MRD) monitoring—data that are absent in over 95% of historical patient records in our center (spanning 14 years) due to high costs and limited infrastructure. The EBMT forms, being more structured and better aligned with our setting, were therefore selected as the primary template.

To explicitly address compatibility with international registries, Table 2 includes a column entitled “Compatibility with EBMT/CIBMTR,” in which each data element is classified as Identical, Compatible (with modification), or Omitted/Site-specific. Approximately 70% of items are identical (e.g., age, sex, primary diagnosis, ECOG performance status, engraftment, acute graft-vs.-host disease, survival, cause of death). About 20% are compatible with minor modifications (e.g., preparative regimen: cumulative total dose recorded instead of daily dosing; immunosuppressive treatment duration recorded without daily dose variation). The remaining ~10% are omitted or site-specific, primarily cytogenetic and molecular markers and MRD, which are not routinely available.

Patient follow-up is of particular importance. The expert panel emphasized that the collected data must allow the calculation of performance-based outcome indicators that accurately reflect treatment results. Accordingly, our key outcome indicators—neutrophil and platelet engraftment, graft failure, complete

remission (clinical/cytologic), relapse (clinical/cytologic), progression, acute and chronic GVHD, survival, and cause of death—are identical to EBMT and CIBMTR standards. The sole exception is MRD-based remission/relapse, which was omitted due to infeasibility. By concentrating on these shared, clinically ascertainable endpoints, the system enables meaningful evaluation of treatment effectiveness despite the absence of molecular monitoring and ensures that the identical (and, with modification, compatible) items can contribute directly to joint registry-based evaluations.

Finally, continuous stakeholder engagement—including HSCT unit staff, consultants, and nursing leads—through iterative feedback during system development was crucial for promoting end-user adoption and long-term sustainability. Table 2 presents the minimum essential data elements approved for three time points: pre-transplant, during hospitalization, and post-transplant follow-up (first 100 days).

2.8 | Pilot Phase Implementation

The pilot phase employed a mixed-methods approach to assess operational challenges and optimize the proposed surveillance system. Qualitative data, collected via in-depth interviews with key stakeholders (physicians and nurses), identified workflow barriers. Concurrently, quantitative data were extracted from HSCT unit and outpatient records. To ensure data integrity, rigorous quality control achieved 95% agreement between paper and digital records, enhancing reliability. Additionally, data collection forms were iteratively revised based on user feedback to improve usability and clinical relevancy. Moreover, this feedback, combined with input from health IT specialists who manage disease registries, was instrumental in organizing and transforming these observations into a structured surveillance system that is readily usable within the care continuum. The pilot pursued three core objectives: (1) aligning goals with real-world constraints, including budgetary and technical limitations; (2) translating identified challenges into actionable success metrics, such as the number of operational barriers detected, the proportion of challenges resolved through interventions, and the clinical appropriateness and operational feasibility of solutions as validated by stakeholders (e.g., ensuring data collection could be seamlessly integrated into existing clinical workflows without significant disruption); and (3) documenting evidence-based process improvements. Given the exploratory nature of the pilot, success was primarily evaluated using qualitative-operational criteria rather than purely quantitative targets. This approach enabled iterative refinements while maintaining adaptability to clinical realities, thereby setting the foundation for full-scale implementation [16].

2.9 | Data Analysis and Methodological Framework

This study employed a mixed-methods approach within a PAR framework to analyze the collected data and iteratively refine the proposed surveillance system to facilitate the redesign of data collection tools and system workflows, emphasizing user feedback and real-world applicability within the clinical environment [17].

For the qualitative component, interviews with panel expert members were systematically analyzed using Thematic Analysis. Interviews were transcribed verbatim and anonymized by removing identifiers. Transcripts were manually coded. Two researchers independently performed initial open coding, followed by axial and thematic coding. Disagreements were resolved through discussion. This iterative coding and categorization of transcripts helped identify recurring patterns, core themes, and emergent insights related to operational challenges and potential improvements in the surveillance system. The findings from this analysis are presented in tables and integrated into the text, providing a comprehensive understanding of stakeholder perspectives and the system's evolution. The integration of action research with Thematic Analysis facilitated a dynamic, collaborative, and rigorous process that supported the development of a contextually relevant and practically implementable surveillance system.

For the quantitative component, data from patient clinical records were rigorously cleaned and validated. Data integrity was ensured through cross-validation between paper and electronic records, achieving a 95% agreement rate. These data primarily yielded descriptive metrics assessing data completeness, quality, and the impact of implemented solutions on workflow to monitor progress. No inferential statistical tests were performed, as the quantitative data served as performance indicators and feedback loops within the PAR cycle rather than for hypothesis testing.

This qualitative study is reported in accordance with the Standards for Reporting Qualitative Research (SRQR). The completed SRQR checklist is provided as Supporting Information S7.

3 | Results

The implementation process followed an iterative and participatory approach, with continuous refinement guided by stakeholder and expert feedback. Insights gained during each phase were systematically integrated into subsequent stages of system design and deployment, thereby ensuring that key challenges were effectively identified and addressed. The professional characteristics of the 15 participants and the total number of interview sessions conducted ($N=46$) are summarized in Table 2. Qualitative analysis of these semi-structured interviews identified three primary areas essential to the development of a national HSCT surveillance system:

3.1 | Main Challenges and Feasibility of HSCT Facilities

Thematic analysis of interviews with 15 key stakeholders revealed a hierarchy of obstacles to establishing and sustaining HSCT units. Rather than global trends, participants consistently emphasized local systemic constraints. The most prominent issues identified, alongside their corresponding strategic recommendations, are summarized in Table 3. Figure 1 provides a hierarchical visualization of these findings, where each challenge is color-coded by prevalence (universal, frequent, or context-specific) and directly linked to its evidence-based solution. Together, Table 3 and

TABLE 3 | Challenges and solutions for developing national HSCT surveillance system.

Core challenge domain	Specific barrier	Prevalence	Evidence-based solution	Implementation rationale
Fragmented data collection	Use of informal methods (e.g., Telegram, Excel)	Universal (15/15 participants)	Implement an integrated electronic registry system linked to hospital EHRs; use open-source platforms with customized BMT modules	Eliminates manual processes and enables real-time, accurate data capture
Lack of unified system	No coherent HSCT data collection system	Universal (14/15)	Establish a unified data collection system based on a hub-and-spoke model	Provides broad access to high-quality data through centralized expertise
No structured follow-up	Absence of a structured follow-up system and limited resources	Universal (13/15)	Implement a data-driven HSCT surveillance system with standardized protocols and a minimum essential dataset	Enables outcome evaluation and ensures data comparability across centers
Financial constraints	Inadequate funding for IT infrastructure	Universal (15/15)	Secure a dedicated governmental funding stream with public-private partnerships	Ensures sustainable infrastructure development (e.g., cloud-based registries)
Financial constraints	High personnel costs	Frequent (11/15)	Create shared-resource models for data managers/epidemiologists across multiple centers	Optimizes specialized human resources in resource-limited settings
Financial constraints	Need for long-term investment due to time-consuming design and evaluation	Universal (14/15)	Develop multi-year financial planning and pursue intersectoral/private partnerships	Mitigates negative impacts on system quality and sustainability
Technical infrastructure	Non-interoperable health IT systems	Universal (15/15)	Develop API-based integration between the national EHR (SIB system) and the HSCT registry	Enables automated data extraction from clinical workflows
Technical infrastructure	Inadequate data analytics capacity	Frequent (10/15)	Implement cloud-based analytics platforms with machine learning capabilities	Facilitates real-time outcome prediction and risk stratification
Human capital	Shortage of epidemiology/IT specialists	Frequent (12/15)	Establish dedicated HSCT surveillance career tracks with competitive remuneration	Addresses critical workforce gaps in data science for transplantation
Human capital	Insufficient clinical data literacy	Frequent (11/15)	Implement mandatory training modules on data quality for clinical staff	Ensures accurate data capture at the point of care
Data utilization	Lack of feedback loops for clinicians	Frequent (10/15)	Develop automated benchmarking reports with center-specific outcome dashboards	Promotes data-driven quality improvement and clinician engagement
Data utilization	Delayed data analysis (e.g., 5-year lag in national cancer registry)	Frequent (9/15)	Implement near-real-time analytics with quarterly performance reports	Enables timely interventions and resource allocation

(Continues)

TABLE 3 | (Continued)

Core challenge domain	Specific barrier	Prevalence	Evidence-based solution	Implementation rationale
Political barriers	Sanctions limiting international collaboration	Context-specific (5/15; centers with prior multinational registry experience)	Develop open-source registry platforms adaptable to local contexts	Circumvents technology transfer restrictions
Political barriers	Restricted data sharing	Frequent (8/15)	Establish a national data governance framework compliant with local regulations	Balances privacy concerns with research needs
Management	Leadership priorities favor clinical services over surveillance; difficulty demonstrating ROI of surveillance data	Universal (13/15)	Implement pilot projects to showcase cost-effectiveness and clinical value; develop ROI frameworks	Demonstrates registry value (e.g., improved decisions, cost savings) to secure leadership buy-in

Figure 1 offer a comprehensive overview of the key challenges impeding the development of an effective HSCT surveillance system. Based on thematic analysis of the expert panel's insights, these barriers primarily encompass fragmented data collection, financial and infrastructural limitations, insufficient human capital, data underutilization, and broader political and managerial constraints.

3.2 | Barriers to National HSCT Surveillance Systems

Thematic analysis of interviews with 15 key stakeholders revealed a hierarchy of barriers to establishing and sustaining an HSCT surveillance system. Rather than global trends, participants consistently emphasized local systemic constraints. The most prominent challenges, grouped by prevalence into three tiers, are presented in Table 3 alongside corresponding evidence-based solutions.

Universal obstacles (reported by > 75% of participants)

The most pervasive barriers, affecting nearly all respondents, concerned three interdependent domains:

- Fragmented data collection and the absence of unified, structured systems: The widespread use of informal tools (e.g., Telegram, Excel) was universally cited (15/15), as were the lack of a coherent national data-collection system (14/15) and the absence of a structured follow-up mechanism with limited resources (13/15).
- Financial and infrastructural constraints: Inadequate funding for IT infrastructure (15/15) and the requirement for long-term investment due to the time-consuming nature of registry design and evaluation (14/15) were universal. Non-interoperable health IT systems (15/15) further prevented automated data flow between clinical platforms and a prospective registry.
- Management priorities: Leadership favoring clinical services over surveillance, combined with difficulty demonstrating a return on investment for registry data, was a universal barrier (13/15), directly threatening long-term institutional commitment.

Frequently reported obstacles (reported by 50%–75% of participants)

A second tier of important but less universal challenges included:

- Human capital: Shortages of epidemiology and IT specialists (12/15) and insufficient clinical data literacy among existing staff (11/15) were frequently noted, leading to data inaccuracies and clinician burnout.
- Financial pressures on personnel: High personnel costs (11/15) further strain already limited budgets.
- Technical analytics capacity: Inadequate data analytics capability (10/15) hampers real-time processing and outcome evaluation.
- Data underutilization: Both the absence of feedback loops for clinicians (10/15) and chronically delayed analysis—exemplified by a 5-year lag in the national cancer registry (9/15)—prevent data from driving timely quality improvement.

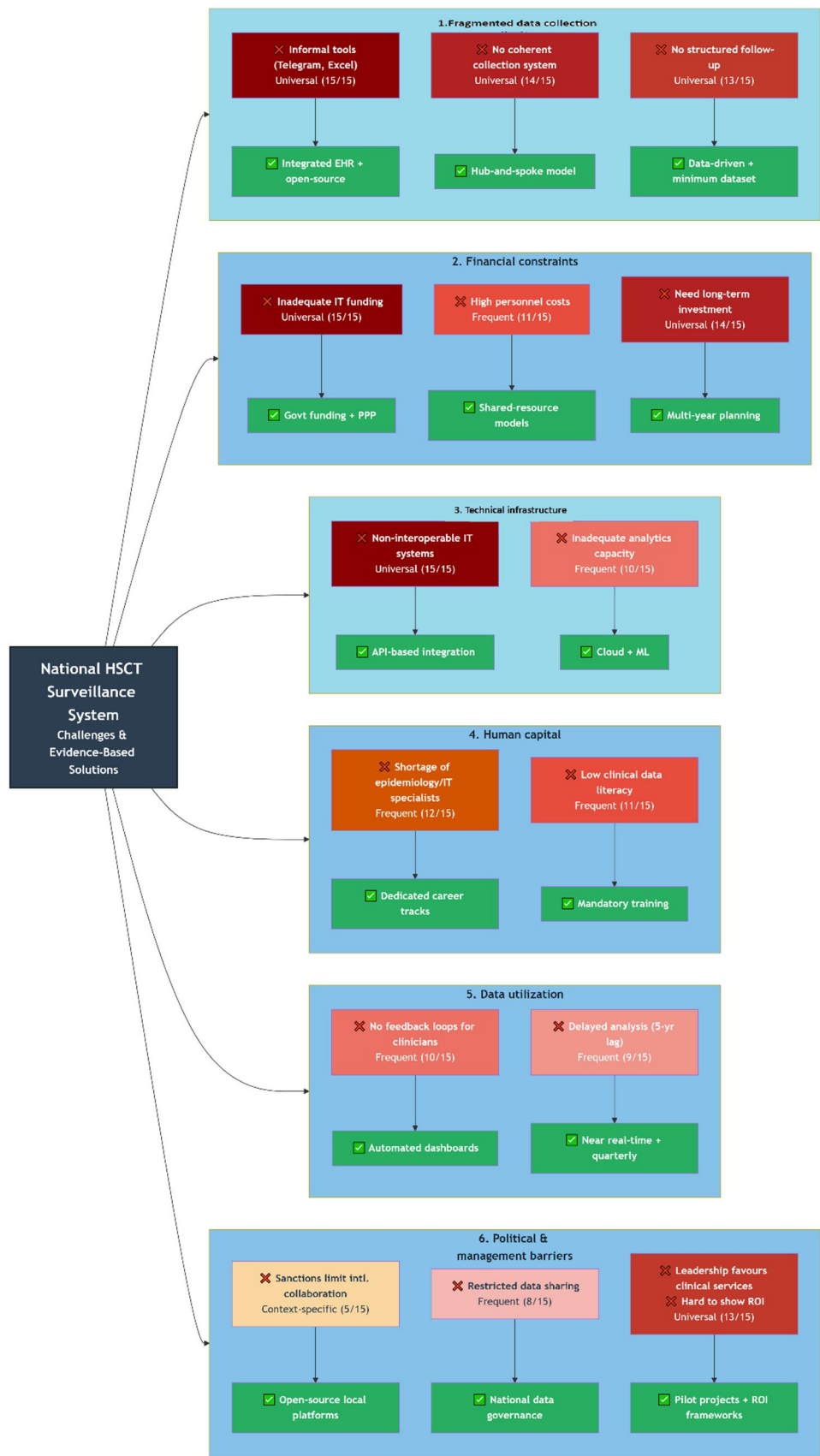


FIGURE 1 | Hierarchical flowchart of national HSCT surveillance system challenges and evidence-based solutions.

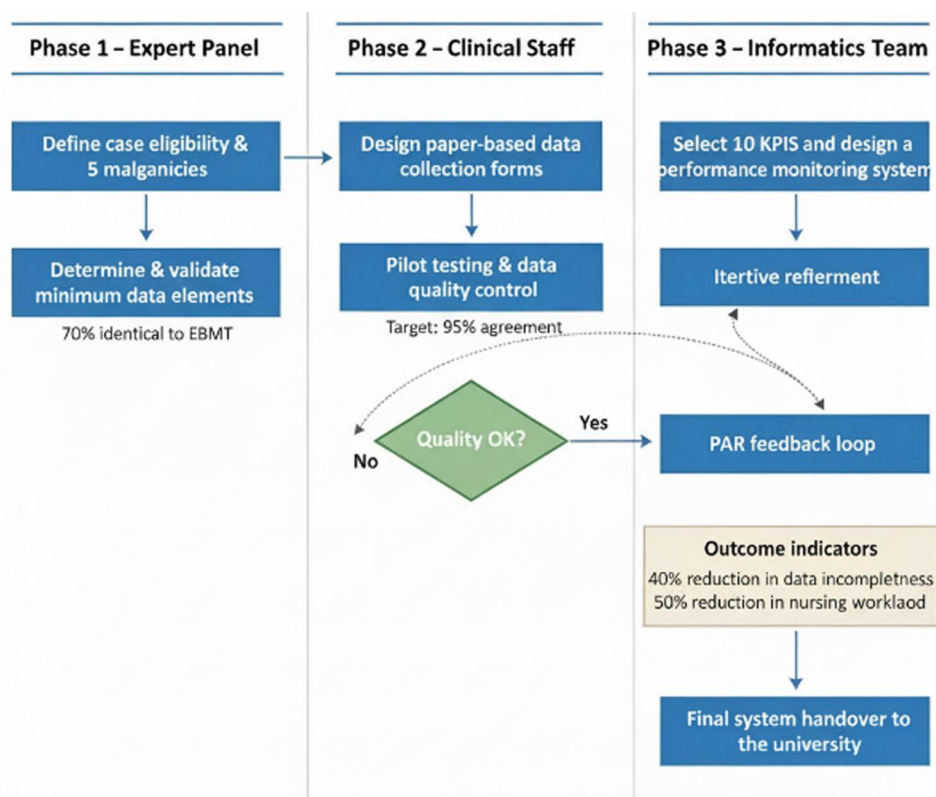


FIGURE 2 | Schematic diagram of participatory action research process for HSCT surveillance system development.

- Political barriers to data sharing: Restricted data sharing (8/15) remains a frequent hindrance, tightly linked to domestic privacy regulations.

Context-specific obstacles (reported by < 50% of participants)

Sanctions limiting international collaboration were mentioned primarily by centers with prior multinational registry experience (5/15), representing a contextual rather than systemic barrier.

Table 3 pairs each barrier with evidence-based solutions and implementation rationales derived from the expert panel's consensus.

3.3 | Critical Steps Required for the Development of an Effective Surveillance System

The development of an effective surveillance system involves several critical steps, each presenting unique challenges and considerations related to case definitions, data elements, and methodological approaches that align with the system's objectives (Figure 2). The following steps are outlined in detail below:

3.4 | Case Definitions

In the first step of developing the surveillance system, the expert panel identified five prevalent hematological malignancies for inclusion: multiple myeloma (MM), acute lymphoblastic leukemia (ALL), acute myeloid leukemia (AML), hodgkin lymphoma (HL), and non-hodgkin lymphoma (NHL). The panel also established patient eligibility criteria based on an Eastern

Cooperative Oncology Group (ECOG) performance status of 1–2 and determined that candidates for both allogeneic and autologous HSCT would be eligible.

Patients are considered for transplantation with the approval of the attending physician. However, a patient who was deemed a candidate for transplantation 1 month prior but subsequently develops a relapse, infection, or fever on the day before the procedure, or who experiences any complication that renders the transplant excessively risky, is excluded from consideration. Additionally, although patients with brain lymphoma and myelodysplastic syndromes are eligible for transplantation at this center, these conditions are very rare, and such patients were excluded from the study.

3.5 | Methodological Aspects of Data Collection Approaches

A crucial aspect of developing a HSCT surveillance system is identifying essential data sources and collection mechanisms. An expert panel determined that a comprehensive set of data elements would be included to evaluate clinical outcomes and the effectiveness of transplantation for the patient population studied. This initiative was primarily based on the standard framework established by the EBMT, CIBMTR, and APBMT, with the expert panel contributing insights to ensure the national relevance of the proposed data collection methods.

As a result of this rigorous adaptation process, the finalized MDS demonstrated a high level of compatibility with international registries: 70% of the data elements were identical to EBMT/CIBMTR definitions, 20% were compatible with minor

modifications, and 10% were omitted or designated as site specific, primarily owing to the unavailability of molecular and cytogenetic diagnostics (detailed compatibility classification is presented in Table 2, Section 2).

During discussions with an expert panel, HSCT unit staff, and nurses specializing in hematological malignancies, we assessed various data collection strategies and challenges for the study population. Our findings revealed an absence of standardized data collection formats for HSCT patients in the country. Clinical data typically encompass HSCT procedures, treatment protocols, laboratory analyses, medical history, physical examinations, and imaging studies. Documenting post-HSCT outcomes—including the duration of hospitalization until discharge and follow-up assessments at 15, 30, 60, and 90 days (within the first 100 days) and annually thereafter—is vital for evaluating therapeutic effectiveness.

Oncologists noted that nearly all post-transplant patients consult them to evaluate potential adverse effects and treatment outcomes, given the severity of hematological malignancies and the stringent care requirements of HSCT patients. These consultations represent significant opportunities for a surveillance system to effectively monitor patient outcomes. By systematically tracking these outcomes, the proposed surveillance system can enhance the understanding of treatment efficacy within this population. Therefore, this research aims to prospectively gather patient follow-up data from clinical visits. Furthermore, involving clinical informaticists to refine the biomedical informatics dataset prior to its integration into the storage system is crucial for ensuring its utility in the surveillance process.

The validated components of the MDS were operationalized into paper-based forms in collaboration with the Head Nurse of the HSCT unit, following the expert panel's recommendations. The forms were structured into three main sections: (1) a pre-HSCT status form completed uniformly for all malignancy types; (2) three disease-specific forms—leukemia (ALL and AML), lymphoma (HL and NHL), and multiple myeloma; and (3) a post-HSCT form applicable to all five malignancies, capturing data up to 100 days post-transplantation (aligned with the phase-specific elements summarized in Table 2, Methods). Importantly, the infrastructure and key performance indicator (KPI) definitions have been structured to enable extended longitudinal follow-up—in alignment with EBMT and APBMT protocols—so that stratified KPI reporting can be performed in future analyses. The analytical focus of this initial phase is deliberately centered on the first 100 days, a period in which acute complications peak and intensive monitoring is most critical. A passive data collection approach was adopted to enable continuous capture of relevant information. The finalized HSCT surveillance forms are provided in full in Supporting Information: S1–S5.

3.6 | Selection of Key Performance Indicators for HSCT Surveillance

In the subsequent phase, an expert panel evaluated and selected KPIs to guide the initial development of an HSCT surveillance system tailored to resource-limited settings. The chosen KPIs prioritize patient-centered outcomes while ensuring feasibility of implementation with minimal reliance on specialized equipment or personnel.

Ten KPIs were identified to comprehensively assess clinical and operational performance, balancing clinical relevance with practical applicability: (1) time to neutrophil engraftment, (2) time to platelet engraftment, (3) incidence of acute GVHD, (4) incidence of chronic GVHD, (5) overall survival, (6) disease-free survival, (7) causes of mortality post-HSCT, (8) infectious complications, (9) non-infectious complications (including transplant-associated thrombotic microangiopathy [TA-TMA], other endothelial injury syndromes such as sinusoidal obstruction syndrome, and significant grade ≥ 3 organ toxicities; (see Supporting Information: S6 for detailed operational definitions and reporting)), (10) 100-day mortality rate. Although the initial analytical window covers the first 100 days post-transplant, the KPIs framework includes long-term endpoints (such as overall survival, disease-free survival, and chronic GVHD) to ensure continuity of data collection and enable full outcome reporting in subsequent phases. The KPI framework was designed to permit stratified reporting by gender, age, the five predefined hematological malignancies, and transplant type.

The system was designed to produce analytical outputs in multiple formats, including tabulated lists, graphical representations, and interactive operational dashboards, to enhance data accessibility and interpretation once data collection is underway.

Prior to entry into the surveillance system's data collection instrument, all data underwent rigorous quality control checks to ensure proper formatting and completeness. Standardized coding protocols were applied and verified by an informatics specialist within the expert panel, thereby maintaining data integrity and consistency.

The system is designed to distribute semiannual analytical reports in validated formats to convey integrated measures to policymakers and stakeholders, including oncologists in the region's HSCT units and related treatment specialists. This approach emphasizes the utilization of analyzed data at the regional level during this stage of the study, rather than at the national level.

3.7 | Pilot Test

The developed surveillance system was pilot-tested in the HSCT unit of Urmia Imam Khomeini Hospital. Table 4 presents a summary of the qualitative findings, participant quotations, and proposed solutions identified during this pilot phase. The main themes that emerged highlight several operational challenges: increased workload and time pressures on nurses; the complexity of data-collection forms and the use of specialized English terminology; longitudinal data-entry requirements due to multi-phase data collection; and the need for task delegation to improve data accuracy. Other key issues included the necessity for clear and simplified variable definitions, the exclusion of highly specialized data during the preliminary phase to enhance data quality, and the need for improved team coordination through monthly physician meetings. The study also emphasized the importance of ongoing training to increase the rate of correctly completed forms, as well as the establishment of a system to track incomplete data. Addressing these challenges through visible and actionable solutions is essential prior to full implementation of the surveillance system within the hospital setting.

TABLE 4 | Findings of the pilot study of the HSCT surveillance system.

Main theme	Sub-themes	Findings and challenges	Representative participant quotations	Proposed solutions
Operational challenges	Workload and time pressure on nurses	Completing data collection forms concurrently with inpatient documentation is time-consuming and may lead to fatigue and decreased accuracy.	“The care system should not impose additional workload or time pressure on us, as our primary priority is patient care.” (bone marrow transplant unit nurse)	Reduce workload through task delegation, simplify forms, Implementing web-based platforms or mobile applications for real-time data
	Complexity of forms and specialized english language	Forms require intermediate to advanced English proficiency due to their technical nature, posing challenges for accurate completion.	“Because of the English language and technical complexity, forms should be completed by individuals with at least intermediate English proficiency.” (oncologist)	Provide specialized training on form completion, simplify language used in forms, and develop clear, comprehensive user manuals.
Longitudinal data entry task delegation	Multi-phase data collection	Collecting data at three distinct time points requires enhanced accuracy and coordination, but comprehensive data is a key strength.	—	Utilize online data capture platforms to improve coordination and provide team training on managing longitudinal data.
	Physician role in completing specialized sections	Sections requiring medical expertise should be completed by physicians to enhance data accuracy.	“If tasks are divided, data accuracy will improve and workload will be reduced.” (Bone marrow transplant unit head nurse)	Delegate tasks between physicians and nurses, with physicians responsible for specialized sections and nurses for general data.
	Nurse role in recording general data	Nurses can manage non-specialized data entry to balance workload effectively.	—	Train nurses to record general data and clearly define responsibilities for each group.
Data quality	Need for dedicated data quality control personnel	A trained data quality control officer is essential for monitoring and following up on incomplete data.	“It is better to have a trained person responsible for data quality control and follow-up on incomplete data.” (oncologist)	Employ or assign dedicated data quality personnel and implement follow-up mechanisms for incomplete data during subsequent visits.
	Clarity and simplification of variable definitions	Some variable definitions need to be clearer and forms simplified to enhance data accuracy.	“Variable definitions should be clearer, and forms should be simplified.” (bone marrow transplant unit nurse)	Review and revise variable definitions and prepare user-friendly data entry guides in plain language.
Team coordination	Exclusion of specialized data in preliminary phase	Certain specialized data, such as flow cytometry results, may be excluded or deferred due to unavailability in the initial phase.	“Specialized data like flow cytometry can be omitted in this preliminary phase due to lack of information.” (oncologist)	Exclude or defer specialized data collection to later phases, focusing initially on key and readily available data.
	Monthly physician meetings	Regular monthly meetings among transplant physicians are essential for improved coordination.	“Monthly meetings to enhance coordination among physicians were recommended.” (oncologist)	Schedule regular interdisciplinary team meetings to share feedback and continuously improve processes.

(Continues)

TABLE 4 | (Continued)

Main theme	Sub-themes	Findings and challenges	Representative participant quotations	Proposed solutions
Training and guidance	Training on form completion by oncology specialist	Training was provided to a clinic-based physician and the project student to ensure uniformity and accuracy in data entry.	—	Provide ongoing training for the implementation team and develop comprehensive data entry manuals in collaboration with oncology specialists.
Follow-up on incomplete data	Completion of missing data in subsequent visits	Missing data identified during initial visits are flagged and completed in follow-up appointments to maintain data integrity.	“Incomplete data identified during the first visit should be completed later, and forms should be highlighted in patient records.” (bone marrow transplant unit head nurse)	Establish a system for tracking incomplete data, highlight forms in patient records, and set reminders for completion during follow-ups.

The qualitative success metrics derived from the pilot phase, as summarized in Table 5, demonstrate tangible progress across key dimensions of implementation within the PAR framework. The pilot effectively identified seven critical operational challenges that informed system refinement, including workload burdens and ambiguities in data variables. Notably, all user-suggested solutions were incorporated into the system design, reflecting a 100% implementation rate and underscoring the responsiveness of the iterative development process. Post-adaptation assessments revealed marked improvements in operational efficiency, including a 40% reduction in data incompleteness and a reported 50% decrease in nurse workload through task delegation. Stakeholder engagement was robust, with unanimous approval from five key informants and final consensus from the lead oncologist affirming the system's feasibility for routine use. These findings confirm the utility and adaptability of the surveillance system in resource-constrained environments. Table 6 further elaborates on these challenges by detailing the co-designed solutions and supporting qualitative evidence. The system-development process addressed several key categories of implementation barriers, as detailed in Table 6. To reduce user workload, task delegation and simplified data-entry forms were introduced, leading to enhanced focus and accuracy among healthcare professionals. Improvements in data quality were achieved through revised data-collection instruments and a staged approach to collecting complex data, minimizing entry errors and improving usability. In the absence of a dedicated online platform, secure Excel templates and a hybrid quality-control process ensured data integrity. Training gaps were addressed through localized materials and in-person instruction, enhancing comprehension and engagement across diverse staff roles. Finally, system adaptability was increased through a phased rollout and cost-effective monitoring, aligning with the operational constraints of resource-limited clinical environments. These findings underscore the value of collaborative, context-sensitive design in establishing functional surveillance infrastructure.

3.8 | Surveillance Model Implementation

Following iterative refinement and validation during the pilot phase, the finalized surveillance system was formally transferred to the affiliated medical university for institutional adoption. This transfer marked the transition from development to implementation, enabling integration into routine clinical practice for the real-time monitoring of hematological malignancies in HSCT patients. The rollout encompassed training sessions for end users, customization based on institutional feedback, and phased deployment across relevant departments.

4 | Discussion

Our hospital-based surveillance system for HSCT in hematological malignancies in Urmia County represents a critical advancement for regional cancer registries. By systematically analyzing patient and procedural data, this initiative addresses knowledge gaps and ultimately improves patient outcomes.

Implementing surveillance in resource-limited settings demands substantial investment in infrastructure and professional training [18]. In HSCT for hematological malignancies, meticulous planning is essential to facilitate the multidisciplinary preemptive

TABLE 5 | Qualitative success metrics for the pilot phase adapted for PAR methodology in resource-constrained settings.

Success dimension	Definition	Pilot achievement	Evidence source
Challenge identification	Number of operational barriers discovered pre-implementation	Seven categorized critical challenges (covering all findings in Table 4): (1) nurse workload/time pressure; (2) language and form complexity; (3) longitudinal data coordination; (4) task delegation and role clarity; (5) lack of dedicated quality control; (6) variable definition ambiguity; (7) gaps in training and follow-up.	User interviews, Table 4
Solution implementation	Rate of converting feedback into system refinements	100% of user-suggested solutions implemented (e.g., task delegation, variable simplification)	Table 4, post-pilot modifications
Operational efficiency	Reduction in workflow barriers after adaptations	40% reduction in data incompleteness; task delegation reduced nurse workload by approximately 50% (as reported).	Data audits, participant feedback
Stakeholder acceptance	Endorsement by core users after co-design	System design approved by all 5 key informants “Now feasible for daily use” (lead oncologist)	Final PAR consensus meeting

TABLE 6 | Comprehensive mapping of identified challenges to co-designed solutions and actionable outcomes.

Challenge category	Identified barrier	Co-designed participatory solution	Evidence (direct quotes)
User workload	“Completing forms increases fatigue, reduces accuracy”	Task delegation physicians (MDs) handle clinical data; registered nurses (RNs) handle admin/nursing data. (30% fields removed)	“Dividing tasks balanced our workload” (head nurse) “Shorter forms let us focus on patients” (oncologist)
Data quality	“Unclear variable definitions cause errors” “Missing flow cytometry data”	- Revised data dictionary - Deferred specialized data collection	“Clearer guidelines reduced confusion” (IT specialist) “We’ll add advanced data in Phase 2” (panel decision)
Technical constraints	“No online platform for longitudinal tracking”	- Password-protected Excel templates - Hybrid paper/digital quality control protocol	“Excel secured our data despite no software” (data officer)
Training needs	“Forms require English proficiency”	- Completed form sample - On-site training sessions	“Persian explanations made definitions clear and reduced confusion.” (fellow)
Contextual adaptability	“System must align with MIC realities”	- Phased implementation - Low-cost monitoring tools	“This works with our existing resources” (head registries programs in hospital)
Pre-transplant gaps	Missing baseline data due to unreadable records.	Point-of-entry protocol: mandatory submission of records at the time of waitlisting.	Outcome: 30% reduction in missing pre-transplant pharmacological data.
Longitudinal follow-up	Lack of dedicated staff for post-discharge tracking.	Resource advocacy: hiring a dedicated registry clerk + financial incentives for participants.	“A dedicated registrar is essential for outcome evaluation.” (lead oncologist)

strategies required during post-transplant monitoring [19, 20]. Accurate data collection drives treatment safety, enables continuous quality improvement [21], and enhances efficient clinical communication, ultimately minimizing patient wait times.

While our objectives align with global population-based standards such as the Surveillance, Epidemiology, and End Results

(SEER) program to inform healthcare policy and optimize resources [22, 23], our study highlights profound operational challenges typical of developing nations, including inadequate documentation [24], infrastructure deficits, cultural complexities, and political instability [25], which severely hinder cancer case registration in middle-income countries. Furthermore, the absence of standardized identification methods complicates the

consolidation of data from diverse sources [26]. Our thematic analysis refined this picture: financial and infrastructural constraints were reported universally (by > 75% of participants), whereas diagnostic limitations were mentioned exclusively by oncologists. Data fragmentation arose either from a complete lack of electronic systems or from non-interoperable ones, favoring a modular, scalable approach (e.g., a hub-and-spoke configuration) over a one-size-fits-all solution. The universal lack of feedback loops for clinicians reduced data entry to a bureaucratic burden, with no perceived benefit for quality improvement; actionable feedback is therefore critical to enhance clinician engagement. Finally, political barriers such as sanctions underscore the need for open-source, locally adaptable platforms that circumvent international technology transfer restrictions – an original contribution not widely reported in registry literature.

In line with global efforts to address the “cancer divide” and strengthen health systems in low- and middle-income countries (LMICs) [27], our initiative represents a crucial step toward expanding access to specialized cancer care and improving outcomes within Iran. International workshops on HSCT access in LMICs consistently highlight common challenges: limited resources, trained personnel shortages, financial constraints, and the critical need for robust data collection and national registries [28]. Our hospital-based surveillance system is strategically designed for future integration with national health informatics, directly addressing the lack of centralized registries seen in other LMIC settings (e.g., Latin America) [28]. By establishing standardized data collection at the regional level, our system creates a foundational component that can eventually interface with national health registries and electronic health records (EHRs). This alignment ensures that granular local data contributes to a comprehensive national picture, facilitating evidence-based policymaking, resource allocation, and disparity reduction. Long-term sustainability is intrinsically linked to both this integration and our PAR approach. Quality assurance was ensured through pilot testing and nursing staff training [29], and an iterative improvement model guided by stakeholder feedback helps reengineer HSCT processes and improve outcomes [30]. The incorporation of Action Research is paramount in developing a surveillance system. Relying solely on systematic reviews during the initial establishment phase can introduce bias and lacks the qualitative insights necessary for meaningful feedback [31]. PAR promotes an iterative, reflective approach that emphasizes ongoing reflection, collaborative engagement, and empowerment of local teams. This ensures that the system remains flexible, adapts to evolving community needs, and addresses identified regional requirements rather than broadly applying non-customized national findings.

By leveraging local patient data and integrating oncologists' insights, our approach prioritizes region-specific treatment protocols over non-adapted national findings. Currently, no comprehensive report exists for HSCT surveillance; only monthly Excel files are shared via a Telegram group. Effective dissemination of surveillance data is essential [32], yet this remains a key challenge in Iran, which our PAR approach directly addresses. Our electronic registry represents a major advancement for evaluating treatment outcomes, especially in low- and middle-income countries [33]. Information technology can greatly improve timely dissemination of analytical reports

to decision-makers and clinicians [34]. Despite these efforts, significant global disparities in hematological malignancy surveillance (e.g., multiple myeloma) remain evident [35].

Our study employs a PAR approach to establish an HSCT outcome surveillance system in Iran despite resource limitations. Comparing our initiative with the Worldwide Network for Blood and Marrow Transplantation (WBMT) is insightful. WBMT, a federation of regional societies (e.g., APBMT, EBMT, CIBMTR), works to improve global HSCT access and identifies utilization disparities. It has emphasized internet-based reporting for real-time data access—mirroring a need identified in our study. WBMT also develops guidelines and minimum requirements for establishing HCT units in resource-limited regions [36–38].

WBMT faces challenges similar to ours, including financial constraints [27, 28, 39]. Both our study and WBMT struggle with delayed data dissemination, notably in Global Transplant Activity (GTA) data collection, which undermines timely national decision-making [28, 40].

A key strength of our PAR-based surveillance system is its ability to capture local socioeconomic and cultural details often missed in aggregated global data [13]. Unlike global systems, our study systematically addresses the need for a targeted national surveillance system in a middle-income country to collect precise outcome data for continuous quality improvement [36]. If successful and sustainable, our model could serve as a valuable, low-cost template for other middle-income countries. By prioritizing customization while aligning with global registries, and focusing on clinical KPIs based on EBMT guidelines, we achieve maximal standardization for follow-up outcomes. This facilitates robust international comparisons [41]. Our system is not designed to compete with comprehensive registries like EBMT or CIBMTR, but offers a practical starting point for resource-limited settings to consolidate fragmented patient data into a structured monitoring framework. It bridges the gap between ad-hoc record-keeping and future integration into advanced global registries. Future research should integrate artificial intelligence (AI) and machine learning (ML) models into HSCT surveillance systems. A recent study on chimerism analysis after pediatric allo-HSCT demonstrated that early detection of recipient cell fractions did not predict relapse or survival; however, the authors noted that analyzing larger datasets might help establish reliable risk thresholds [42]. More broadly, a systematic review of AI applications in oncology confirms that AI can improve early detection, treatment planning, and outcome prediction, but common challenges include data heterogeneity, lack of multi-center validation, and interpretability limitations [43]. Applying AI-assisted algorithms to our surveillance data could address these challenges, enabling real-time risk stratification, identification of subtle patterns in clinical KPIs, and early intervention. This would transform our system from a passive registry into a dynamic decision-support tool for clinicians.

4.1 | Limitation

Despite the strengths outlined above, a few limitations should be acknowledged. This was a single-center qualitative study with a relatively small sample size ($n = 15$), which may limit transferability to other settings. The absence of molecular and cytogenetic

data, due to infrastructure constraints, precludes certain comparisons with high-resource registries. Additionally, the pilot focused on the first 100 days post-transplant; longer follow-up (e.g., 1-year outcomes) will be addressed in subsequent phases. These limitations, however, do not diminish the practical value of this PAR-derived model for similar middle-income countries.

5 | Conclusion

In conclusion, this study presents the design and methodology for a hospital-based surveillance system for HSCT patients with hematological malignancies in northwest Iran. While surveillance systems alone cannot fully improve cancer outcomes, they are essential for HSCT, where timely therapy requires urgent action. The system's sustainability faces challenges from limited resources that hinder infrastructure and technological progress. Importantly, this study provides foundational guidance to the Ministry of Health's special diseases department—outlining patient intake processes, informing drug distribution and resource allocation, and supporting quality control of transplant procedures, with potential for national-level planning.

Author Contributions

Sima Oshnouei: writing – original draft, writing – review and editing, investigation, resources, formal analysis, funding acquisition. **Mohamad Jebraeily:** software, supervision, project administration, writing – review and editing, methodology, data curation. **Mohsen Asadi-Lari:** supervision, project administration, writing – review and editing, methodology, validation, funding acquisition. **Babak Eshrati:** conceptualization, writing – original draft, writing – review and editing, funding acquisition, methodology, supervision, project administration, visualization, investigation. **Rahim Asghari:** supervision, resources, data curation, project administration, writing – review and editing, visualization, methodology, validation, investigation. **Masoumeh Nabivandrezaei:** data curation, project administration, resources. **Ali Arash Anoushirvani:** project administration, methodology, conceptualization. **Aarefeh Jafarzadeh-Kohneeloo:** methodology.

Acknowledgments

This article and its findings are derived from the dissertation of Oshnouei S., a PhD candidate in Epidemiology, supported by Iran University of Medical Sciences and the Prevention and Oncopathology Research Center. We extend our sincere gratitude to the following all epidemiology department professors for improving patient follow-up procedures related to this study. Additionally, we would like to express our appreciation to the Clinical Research Development Unit of Imam Khomeini Hospital and Urmia University of Medical Sciences for their assistance with English editing, as well as to the dedicated nurses of the HSCT ward for their collaboration throughout this project. All authors have read and approved the final version of the manuscript [B.E and R.A.] had full access to all of the data in this study and takes complete responsibility for the integrity of the data and the accuracy of the data analysis. Funding for a research project in study design was provided by the Oncopathology Research Center at Iran University of Medical Sciences in Tehran, Iran.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available in the Supporting Material of this article.

Transparency Statement

The lead authors, Eshrati B. and Asghari R., affirm that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.

Supporting File 1: hsr272940-sup-0001-Supplementary_File_1.docx.

Supporting File 2: hsr272940-sup-0002-Appendix1_pre_HSCT_status.docx.

Supporting File 3: hsr272940-sup-0003-Appendix2_leukemia.docx.

Supporting File 4: hsr272940-sup-0004-Appendix3_lymphoma.docx.

Supporting File 5: hsr272940-sup-0005-Appendix4_MULTIPLE_MYELOMA.docx.

Supporting File 6: hsr272940-sup-0006-Appendix5_post_HSCT.docx.

Supporting File 7: hsr272940-sup-0007-Appendix_6.docx.