Original Article

Lessons learned from setting up a hospital-based national registry for venous thromboembolic disorders in India

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Abstract

Introduction: Health registries are instrumental in tracking trends in the number of people with diseases, monitoring treatment options, and assessing health outcomes. This research examines the challenges of establishing and maintaining a venous thromboembolism (VTE) registry in the Indian context. **Methods:** A mixed-method approach with purposive sampling was conducted to capture the challenges faced by individuals playing key roles in the establishment and operation of the national registry on VTE. This study focused on 10 questions related to technological infrastructure, resource optimization, data collection and management, coordination and collaboration, regulatory compliance, and political influences and were documented using a semi-structured questionnaire and telephonic interviews. **Results:** Technological, recruitment, and follow-up challenges were prominently highlighted with issues related to data entry, system glitches, changes to the data entry forms, and potential participant reluctance. **Conclusion:** Findings from this study highlight the multifaceted challenges experienced during the establishment of a national registry on VTE. By integrating insights from our findings into suggestions, this discussion reflects the specific challenges faced by the research project and offers evidence-based strategies for mitigating these challenges.

Keywords: Challenges, India, i-RegVeD, national registry, venous thromboembolism

Introduction

Registries are generally used to describe health-oriented databases[1] and are important in providing a structured framework to compile, analyze, and distribute accurate and up-to-date information on specific health conditions. These registries, operating both at an individual and community level, serve as invaluable tools for healthcare professionals, patients, and researchers, contributing to our understanding of specific diseases over time. Patient registries, in particular, are an important tool for observing the course of the disease and examining factors that influence the prognosis and outcome of the disease, variations in treatment outcomes and its effectiveness, and disparities in care.[2,3] The importance of national health registries or large patient databases in the epidemiological context is also highlighted by their capacity to address public health effectively.[4] Implementation of a national registry involves the combination of technological systems and issues (e.g. system scalability), and the establishment and choice of accessible platforms pose significant challenges. In addition, the need for vigorous security measures to protect sensitive information and maintain the confidentiality of the participants adds another layer of complexity. Thus, balancing the needs of the investigators, patients, healthcare providers, and registries while adhering to data confidentiality and ensuring the usefulness of the data can be arduous.[5] Moreover, a well-defined governance and legal framework to ensure adequate data management

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Received: 20-02-2024 **Revised:** 21-03-2024
Accepted: 22-05-2024 **Published:** 18-11-2024

Access this article online

Quick Response Code:

Website: http://journals.lww.com/JFMPC

DOI: 10.4103/jfmpc.jfmpc_264_24

How to cite this article: Aggarwal S, Rulu P, Tabassum H. Lessons learned from setting up a hospital-based national registry for venous thromboembolic disorders in India. J Family Med Prim Care 2024;13:4901-9.

is also a prerequisite for the proper functioning of national registries.[6,7] Thus, challenges in the implementation of registries can significantly impact the overall outcome of the management and prevention of a disease.

The origin of health registries dates back to 1856 with the establishment of the National Leprosy Registry in Norway, denoting an early attempt to provide optimal healthcare and conduct epidemiological investigations of diseases that cause public health problems.[8,9] Since then, globally there have been several registries focusing on different diseases.[10-18]

Registries are maintained at the local, state, national, or international level, depending on the specific needs and goals of the project. Some registries even engage participants to sign up for clinical research,[19,20] further contributing to the advancement of the data collected. In India, the first registries consisted of cancer registries, which were established in 1981 by the Indian Council of Medical Research (ICMR). These registries include three population-based cancer registries (PBCR), and three hospital-based cancer registries (HBCR), and at present, there are 31 PBCRs and 29 HBCRs functioning across India.[21,22] Other registries in India include the Indian Clinical Trial and Education Network, the National Clinical Registry of COVID-19, the Clinical Trials Registry, the National Injury Surveillance Trauma and Capacity Building Center, Neonatal and Maturity Onset of Youth Registry India, the National Center for Disease Informatics and Research.[23-25]

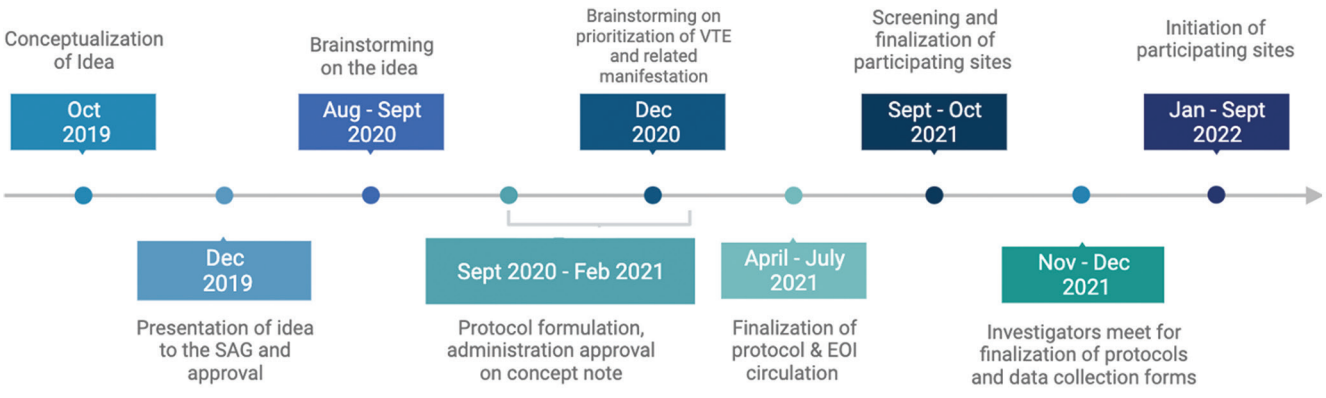
The global burden of VTE-related illness is substantial.[26,27] The focus on VTE has predominantly centered on Western populations causing a scarcity of epidemiological data from Asian countries[28] and limiting our comprehensive understanding of the topic. This knowledge gap is exacerbated by insufficient information and underreporting among developing countries[29] and Asian regions. Notably, there exists a considerable lack of clinical and foundational quality data as well as the overall incidence of VTE among Indians,[30] encompassing aspects related to both the quality of life and healthcare expenditures.[31,32] Moreover, the importance of setting up national registries in India is also highlighted,[33] and the National Health Policy of 2017[34] sets the ambitious goal of creating registries for diseases of public health importance. Against these backdrops, the current research highlights the challenges associated with the implementation, establishment, and maintenance of a hospital-based venous thromboembolism (VTE) registry (i-RegVeD) in the Indian context. Our study intends to identify the challenges associated with the establishment and implementation of a national registry, thereby aiding in the development of more effective strategies and improving the chances of successful registry adoption.

Methods

Study setting

The development of the i-RegVeD registry underwent a comprehensive multi-phase process spanning from the inception of the concept in October 2019 to the initiation of study sites between January and September 2022. The timeline depicted in Figure 1 outlines key milestones during the registry's formulation and commencement. There was a sequence of activities including brainstorming, protocol formulation, and obtaining administrative approval based on the concept note. The period from April 2021 to July 2021 saw the finalization of protocols, distribution of expression of interest (EOI) via the ICMR website and the subsequent screening and selection of participating sites. Ultimately, the activation of participating sites took place from January 2022 to September 2022 [Figure 1].

Participating sites were selected based on certain characteristics such as geographical representation, local population characteristics, VTE caseload, the strength of the local site, the adequate infrastructure of the institution, outreach, patient coverage, availability and engagement of multispecialty experts, and the scope of capacity building.[35] Out of 16 participating sites that were selected, interviews were conducted from 13 active sites. Active sites are those sites that are fully functional and have started recruiting participants.



SAG: Scientific Advising Committee, Indian Council of Medical Research; EOI: Expression of Interest

Figure 1: Timeline of formulation and initiation of the i-RegVeD registry (created using BioRender[56])

Study design

This study was conducted through a mixed-method approach to capture the challenges faced by individuals playing key roles in the establishment and operation of the national registry on VTE. The mixed method approach combines both qualitative and quantitative data to answer research questions. For instance, this research explores the types (quantitative) and context (qualitative) of the issues faced while establishing the registry. As such, the study focused on 10 key questions designed to elicit detailed responses, providing a nuanced understanding of the challenges faced by the participating sites [Figure 2]. Collective experience from 13 participating sites was documented using a semi-structured questionnaire with open-ended questions distributed through Google Forms. Additionally, telephonic interviews were conducted to supplement the responses captured through the questionnaire. The interview respondents were provided or explained the purpose of the study, depending on the mode of data collection (Google Forms or telephonic interviews), and their willingness to participate in the study was obtained through audio and/or questionnaire responses. No socio-demographic identifiers such as name, age, and gender were recorded to maintain the anonymity and confidentiality of the participants. Those participants who were unable to respond to telephonic interviews provided a scheduled time as per their convenience for their participation. Each telephonic interview lasted for about 15–30 min.

Interview respondents

Interview respondents included principal investigators (PIs) and clinical data managers (CDMs) from the 13 active sites that were selected based on purposive sampling. Principal investigators were the primary individuals responsible for conducting, regulating, and administration of the project at each site. The clinical data managers consist of research assistants and data entry operators responsible for data collection, establishing rapport and follow-up with the participants, and data entry.

Analysis

Responses from the questionnaire and telephonic interviews were compiled into a Word document to identify themes, and a detailed descriptive analysis of the responses was made to highlight the challenges encountered since the establishment of the project. For instance, a tabular representation was included, highlighting the frequency and percentage of each theme that emerged. Verbatims were also used to supplement the findings and were assigned numerical codes to maintain confidentiality.

Results

A total of 15 telephonic interviews and responses from nine semi-structured questionnaires were obtained. Based on the 15 telephonic and in-person interviews obtained from 13 participating sites and 1 coordinating site, 33% were principal investigators and 67% were data operators. The majority of the participants were males (76%) [Figure 3].

Interviews were analyzed by a thematic content analysis where four major themes emerged, which were related to administration, resources, communication, recruitment, and technological issues. As such, 56.0% of the issues raised were related to administration, 44.0% were related to both resources and communication, 76.0% were associated with recruitment, and 88.0% of the issues were related to technology [Table 1].

An in-depth descriptive analysis of responses is described below.

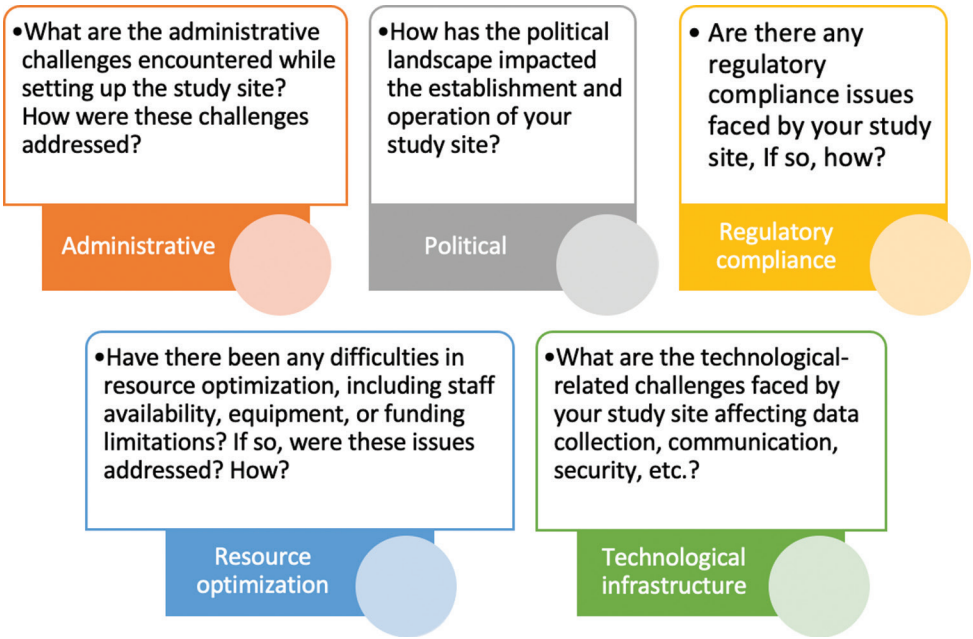


Figure 2: Domains and queries on experiences of operational challenges during formulation and implementation of VTE project.

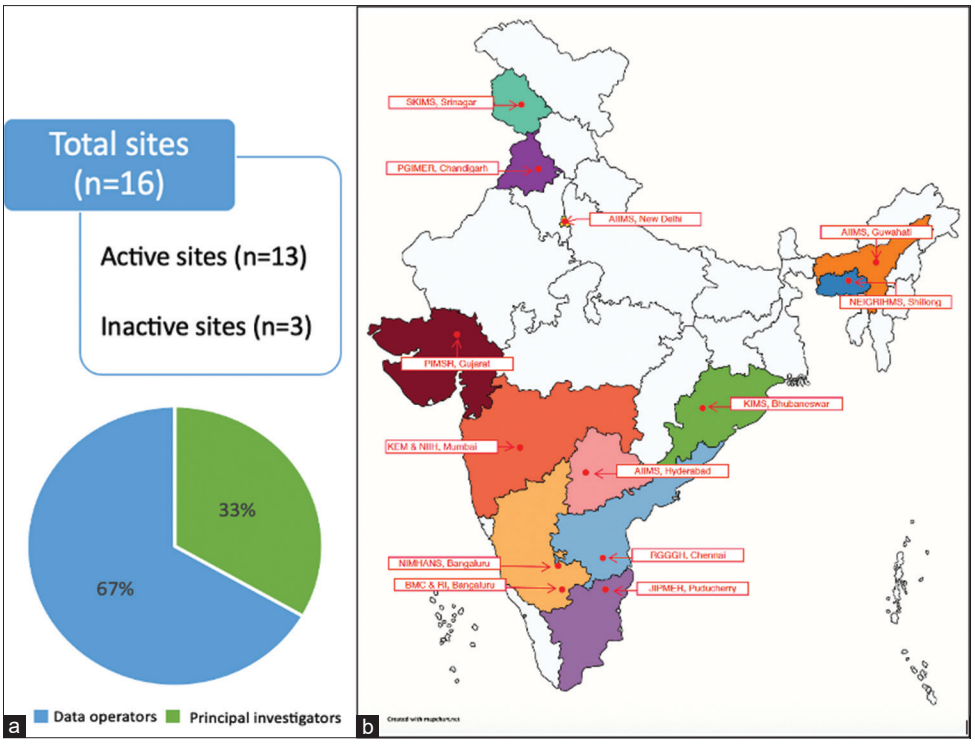


Figure 3: (a) Distribution of respondents and sites; (b) Map of India indicating VTE project study sites[57]

Table 1: Percentage distribution of themes (*n*=25)

Themes	*n* (%)
Administrative	14 (56.0)
Resources	11 (44.0)
Communication	11 (44.0)
Technology	22 (88.0)
Recruitment and follow-up	19 (76.0)

Administration-related challenges

Most institutions did not have any major challenges related to administration. As such, one of the site data managers responded:

``*There was complete support by the management and hence no major challenge encountered.*'' (Study Site Respondent 5)

From the discussion, data analysis revealed that delays in file disbursement were a common problem. They also realized that the processing of documents involves multiple departments such as the finance department and accounts department. Therefore, issues or delays at any point in the file disbursement would further impact the overall research start timeline. For instance, one respondent highlighted that,

``*In the institute, the approval process is very slow as it involves multiple steps, such as procurement, fund release, utilization certificate, or any other administrative process.*'' (Study Site Respondent 8)

In addition, the data management unit or the coordinating unit faced problems in obtaining Institutional Ethical Clearance (IEC) as the project starting time point varies for each participating institution. Thus, the different starting points may disrupt the overall flow of participant recruitment.

Resources-related challenges

Interview respondents commonly raised issues related to resources in terms of fund procurement, infrastructure, and support from the participating institution. Such instances were related to the lack of support from the hospital concerning the absence of a dedicated space and infrastructure to place the VTE project-related equipment, intense scrutiny during paperwork, and delays in financial clearance from the participating institution and coordinating site.

``*There's a shortage of space for the staff/lab of the project and other such activities. In this aspect, support from the administration [study site institution] is also not forthcoming.*'' (Study site Respondent 6)

Communication-related challenges

Communication-related challenges both at the coordinating site as well as the participating sites were observed. Initially, the data collection form was updated frequently to ensure accurate and complete data were obtained, and constant communication between the coordinating and participating sites was maintained; however, at times miscommunications are unavoidable leading to delays in uploading information at the VTE website. At the participating sites, patient recruitment involved coordinating with multiple departments (e.g. OPD, radiology, emergency department), thus, variations in practice among clinicians in different departments also caused challenges in implementing uniform guidelines.

``As most of our data entry is derived from discharge summary case sheets in our Medical Records Department (MRD), document accessibility is limited to read-only and specific timeframes. This poses a challenge in maintaining source data for auditing purposes. While lab and CT reports are downloadable, other source data rely on the Hospital Information System (HIS), requiring permissions for auditing and data verification during subsequent periods." (Study Site Respondent 7)

Technology-related challenges

Technology-related challenges were the most commonly raised issue among interview respondents. These included problems with unavailable options in the proforma, inability to proceed due to mandatory options in the forms, issues with having to save responses on the site multiple times due to system glitches, and recurrent changes to the portal causing data discrepancies in the portal. No issues related to data confidentiality or security were raised.

``Data was not saved [initially], there were about 50 missing data even after being entered in the portal. Documents [e.g. scans] were not being saved on the webpage, and technical glitches were very frequent… There was also a mismatch in the serial number that has been generated once data has been inputted." (Study Site Respondent 14)

``There are many portal-related issues, some have been cleared and others persist." (Study Site Respondent 6)

Recruitment and follow-up-related challenges

Challenges in patient recruitment and follow-up were also prominent among interview respondents. These challenges were regarding patient's reluctance to participate, especially sharing sensitive information (e.g. Aadhaar details, an individual identification card that serves as proof of identity and residence for Indian citizens), patients leaving the hospital without prior notice or providing inaccurate information, and difficulty in obtaining a correct medical history.

``Despite regular patient visits during admission, a notable challenge emerged during patient discharge, as some individuals left the hospital without prior notice. This posed difficulties in patient follow-up. Obtaining accurate patient contact details presented another obstacle, as many patients provided invalid, outdated, or expired phone numbers during admission." (Study Site Respondent 7)

``The data reporting depends upon verbal communication with patients. Many times, the patient does not want to communicate hence the data may not be complete." (Study Site Respondent 8)

Participant recruitment was also challenging as identifying potential participants involved in coordination with different departments (e.g. OPD, radiology department, and emergency department), along with local challenges (e.g. state elections), and the absence of appropriate training platforms for the CDMs, disrupted the flow of participant recruitment. In addition, distance and financial constraints experienced by the patients were additional factors that impacted the data collection process, especially for follow-up. Local public-related problems were not mentioned by interview respondents.

Discussion

The study examines the challenges associated with establishing and maintaining a VTE registry in the Indian context. Interview respondents highlighted challenges related to technology, participant recruitment and follow-ups, administration, resource, and communication-related challenges. These challenges are not distinct constructs but rather overlap with each other. Findings from this study highlight the multifaceted challenges experienced during the establishment of a national registry on VTE.

The most persistent challenge reported by interview respondents was related to technological issues. From data entry problems, redundancy in information, website crashes, and format changes to slow data acquisition, challenges in this regard highlight the importance of a robust data management system in clinical research. Although it is imperative for research projects to anticipate technological hurdles, addressing potential issues promptly can lead to quality research outcomes. As such, studies have emphasized the importance of adopting health information technology, including maintaining healthcare records and patient registries for transforming healthcare systems to be more efficient and safer and deliver higher quality care.[36-41] Suggestions such as hiring a dedicated technology person and the presence of a clinician during the portal establishment and overseeing the data collection forms are well-founded and emphasize the need for user-friendly and clinically validated data collection and entry systems. This suggestion also aligns with the importance of interdisciplinary collaboration in research technology design.[42]

Recruitment and follow-up presented a huge challenge to the research process, which is a common occurrence in research.[19,43-46] Reluctance among potential participants, especially concerning sensitive information, and logistical issues in identifying and coordinating with participants within the hospital setting contributed to delays. Therefore, finding reliable and sustainable solutions to this issue is imperative as the quality of healthcare research depends on the integrity, reliability, and accuracy of health information.[47] Efforts such as conducting telephonic reminders and establishing rapport have been implemented by participating sites to ensure accurate and reliable data are obtained.

Administrative and resource-related challenges were, to some extent, less prevalent but impactful. As such, delays in the administrative process due to changes in administrative rules and leadership created bottlenecks for file processing. Site-specific administrative hindrances and lack of dedicated space from the participating institute also added complexities to the research timeline. A study using the African Surgical Outcomes Study (ASOS), a large, multinational African collaborative study,

highlighted that the lack of adequate resources and regulatory requirements among others, presented a major barrier to clinical research in Africa.[48] In another study, administrative delays beyond the first 2 weeks were found to be significantly associated with increased odds of developing chronic disability.[39] Moreover, red tape, a concept where regulations or conformity to formal rules that are claimed to be excessive, rigid, or redundant,[49] has been studied in the context of organizational effectiveness,[50] and indicated that administrative delay is associated with red tape.[51] Thus, the administrative and resources-related challenges highlighted in our study emphasize the need for streamlined and efficient administrative procedures.

Communication-related challenges were also evident between the coordination center and participating sites, leading to multiple iterations of communication to ensure accurate data were being recorded. Variations in clinical practices among different departments at the participating sites emphasize the need for enhanced coordination and uniformity in implementing research guidelines. As such, communication-related challenges can be mitigated by establishing standardized guidelines such as conducting regular training, providing direct communication with dedicated nodal persons at the coordinating site, and conducting regular or need-basis meetings with the sites for smooth functioning. Numerous studies highlight the importance of efficient communication between various stakeholders.[52-54] For instance, a study from the National Registry for Transfusion and Hemotherapy Practice highlighted that miscommunication or incomplete information transfer is a major source of errors that lead to wrong or incomplete datasets of patients.[55] The interview respondents did not report significant challenges related to local public issues.

Based on the responses and experiences of the participating sites and the coordinating site, suggestions have been made to address the challenges faced while setting up and running a national registry on VTE in the Indian context [Figure 4]. We propose regular user feedback to ensure the usability of the

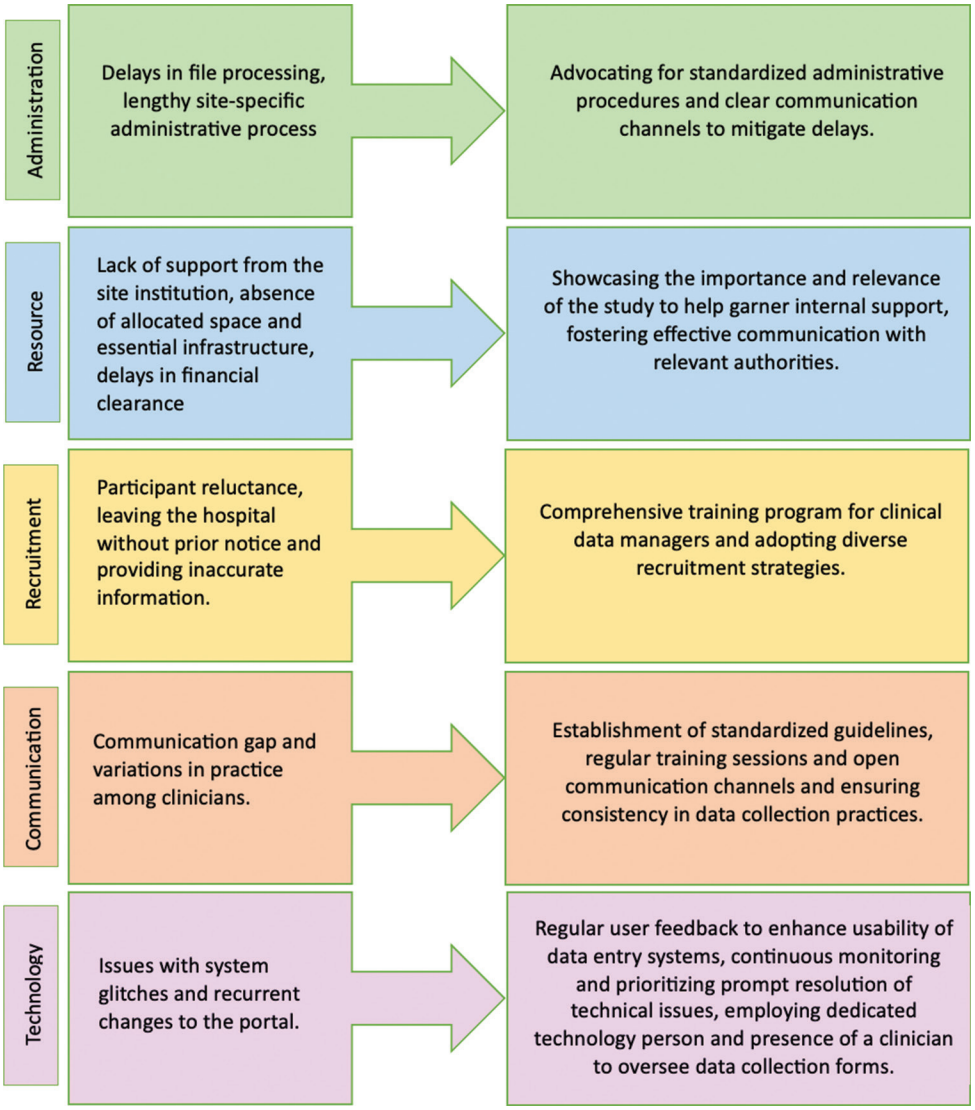


Figure 4: Challenges and suggestions related to setting up a national registry on VTE from an Indian context

VTE portal, continuous monitoring and prioritizing prompt resolution of technical issues, advocating for standardized administrative procedures and clear communication channels to mitigate administrative delays, and a comprehensive training program for CMS and adopting diverse recruitment strategies for efficient and timely data collection.

Conclusion

The challenges identified through responses from participating sites and coordinating sites align with existing literature on healthcare research, emphasizing the universality of certain issues faced by research teams. By integrating insights from our findings into the suggestions, this discussion not only reflects the specific challenges faced by the individuals involved but also offers evidence-based strategies and capacity-building for mitigating these challenges. As the research community continues to grapple with the complexities of conducting multicentric studies, the adaptability, and resilience demonstrated in addressing these challenges will be crucial for the success of such registries. The experiences and insights shared by the respondents contribute to a comprehensive understanding of the intricacies involved in executing healthcare research effectively. It is imperative for research teams to collaborate and communicate effectively, maintain flexibility, reduce administrative and resource-related barriers, and foster innovation.

Acknowledgments

The authors would like to thank all the interview respondents for participating in this study, and the Indian Council of Medical Research, New Delhi, for providing the necessary financial assistance.

Ethics

The study protocol was approved by the Institutional Ethics Committee (IEC), Indian Council of Medical Research-Central Ethics Committee on Human Research and each of the participating sites obtained ethical approval from their respective IECs. Verbal informed consent was taken from all participants before the start of the study.

Financial support and sponsorship

Indian Council of Medical Research, New Delhi (Grant No. i-RegVed/Site10/BMS-2022).

Conflicts of interest

There are no conflicts of interest.

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